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Struggling to be heard: A scoping review of user participation in ADHD mental healthcare for children and adolescents

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Abstract

Background: Growing emphasis is placed on supporting children and adolescents with attention deficit hyperactivity disorder (ADHD) in participating in their own healthcare; however, more knowledge is needed to guide practice.
Objective: To review the scientific literature on user participation and opportunities for shared decision-making involving younger people referred for ADHD in mental healthcare services, to provide recommendations for clinical practice and future research.
Method: A systematic scoping review was performed. Eligibility was determined in two steps by two and three independent researchers, respectively. Data were extracted and analyzed using qualitative content analysis. The findings were synthesized across the various contexts and participation groups represented in the included studies. In all, the analysis involved three phases: preparation, organization, and reporting.
Results: Of the thirty full-text papers identified, five met the inclusion criteria. Four categories and seven subcategories related to user participation and opportunities for shared decision-making involving children and adolescents with ADHD were identified. The four categories were: (1) sidelined from the start, (2) lack of information, (3) trapped in medication, and (4) growing into active decision-makers; these indicate that children with ADHD feel excluded from the diagnostic process, may have limited treatment choices, and may not be heard. This review also discovers a bias in the existing literature on user participation, with a tendency to emphasize caregivers' or clinicians' perspectives over those of the young people.
Conclusions: Young people with ADHD experience they have limited opportunities to participate in their mental healthcare services. User participation and shared decision-making by young people with ADHD should be promoted in clinical practice. Accordingly, future research should explore ways to implement user participation among young people themselves when assessing and treating ADHD, not only among clinicians and caregivers.

Keywords: User participation; Shared decision-making; Children; Adolescents; ADHD; Scoping review.

Introduction

Attention deficit hyperactivity disorder (ADHD) is a neurodevelopmental disorder that often manifests in childhood. ADHD is characterized by symptoms of inattention, hyperactivity, and impulsivity that interfere with functioning (1). Problems associated with social skills and emotional dysregulation may also be of significant concern (2). To meet the criteria for ADHD, the core symptoms must impair functioning in academic, social, or occupational activities (3). The prevalence of ADHD has been reported to be approximately 3–5% among children and adolescents (4,5); however, more recent reports suggest an increase in ADHD prevalence in these life stages (1,6,7), making it one of the most common childhood diseases.

Treatment guidelines recommend a multimodal, stepwise care model for managing ADHD (8,9). The recommended treatment for children entails stimulant medication in combination with psychosocial interventions, including psychoeducation (8–10). However, medications are not effective for everyone; in addition, many experience side effects, and many stop taking their medications (10). Among young people, problems with adherence to medication are common (11) and often increase during the transition from adolescence to adulthood (12,13).

The current scoping review is part of a larger participatory action research project (14,15) that was initiated in response to concerns from healthcare professionals in child and adolescent mental health services (CAMHS) about whether children and adolescents receive sufficient information and support to make them qualified to be involved in diagnosis and treatment decisions. Those concerns stem from consideration of various aspects of the United Nations Convention on the Rights of the Child (UNCRC) (16); particularly relevant is the UNCRC's declaration that children and adolescents have the right to express their views on matters that affect them and that their views must be given weight in accordance with their age and maturity (16). To this end, in Norway, the right of minor patients to receive proper information and participate in their own treatment is included in health legislation (17) and in governmental strategies to promote youth health (18).

Furthermore, given the evolving focus on neurodiversity in understanding patients with neurodevelopmental disorders (19)—including ADHD—focusing on young patients' participation in treatment may be desirable (20). The perspective of neurodiversity has come to challenge the traditional view that there is a "normal" versus dysfunctional way of functioning mentally. This perspective entails a new way of understanding people with conditions such as autism, ADHD, dyslexia, Tourette's syndrome, and other cognitive difficulties (19,20): rather than seeing these conditions as disorders or faults that need to be fixed, the perspective sees these conditions as natural variations in the human spectrum of mental functioning. Consequently, the focus in both clinical work and research changes from a drive to identify the sources of dysfunction to a drive to identify which environments promote affirmative experiences and positive outcomes for people with neurodivergence (20). In this perspective, the involvement of neurodivergent individuals in both research and clinical practice is essential (20,21).

The literature presents various models covering different aspects of patient involvement (22). Specifically, patient-centered medicine (23,24), patient-centered care (25–27), shared decision-making (28–30), and recovery models (31,32) all incorporate user involvement and patients' perspectives. Service user involvement, along with user participation, is often aligned with mental healthcare policies (22,33) and can occur at different levels of healthcare services. At the individual level, the patient is involved in activities around planning, delivering, or reviewing mental healthcare services for their own healthcare. Beyond this, at the clinic-based level, patients participate in councils and committees at clinics by providing input and advice from their perspective as users. Broadly, at the systemic level, patients plan, deliver, or review healthcare services for the general population (34–36).

Despite these contributions, some literature concerning user involvement and participation has been criticized for lacking theoretical clarity (37) or for containing vague and inconsistent definitions of concepts and practices (38,39). In this scoping review, we chose to draw on works that specifically address the involvement of children and adolescents, namely Arnstein's (40) works on conceptualizing user involvement and user participation and Hart's (41) and Shier's (42) extensions of those works to include children and adolescents. In conceptualizing the "ladder of citizen participation," Arnstein differentiates among no participation (e.g., manipulation and therapy), symbolic participation or tokenism (e.g., informing and consulting), and real participation (e.g., partnership, delegated power, and citizen control) (40). Hart's adaptation of Arnstein's ladder emphasizes children's participation (41,43). In addition, Shier (42) delineates five levels of participation: (1) being listened to, (2) being encouraged to express their views, (3) their views being taken into account, (4) being involved in decision-making processes, and (5) sharing decision-making power and responsibility. In Shier's conceptualization of participation, passive information exchange or communication between young people and health personnel does not qualify as user participation; for participation that is more than symbolic, young people should at least be heard and have their views considered (40,44,45). Building on the works of these scientists (40–42), we conceptualize user participation as taking part in decision-making processes that affect one's treatment and health issues, specifically by being listened to, being allowed to express their views, and having those views taken into account (41,46). Because the terms user participation and user involvement are often used interchangeably, in this study we exclusively use user participation for clarity.

A look at the literature on user participation reveals that children and adolescents are underrepresented (39). Furthermore, most studies addressing user participation among children and adolescents also seem to have been conducted in somatic healthcare service settings (47–50). Although interest in user participation by young people in mental healthcare has increased (51–54), to our knowledge, few if any studies have specifically examined young people's perspectives on user participation in the assessment and treatment of ADHD; instead, much of the research seems to be centered around the roles and

perspectives of parents and healthcare professionals in these processes (52–54).

Therefore, we sought to conduct a systematic scoping review of the literature on user participation, with a focus on young people's perspectives in participatory processes related to ADHD assessment and treatment.

Method

Scoping reviews have been increasingly used in recent years to review topics in healthcare that have rarely been studied as well as in cases where the results and conclusions of conducted research have been mixed (55–58). Systematic scoping reviews require formal methods but differ from other reviews in certain ways. First, a scoping review aims to examine the extent, range, and nature of the body of literature on a specific topic from a broad perspective, and it does not necessarily assess the quality of the reviewed studies. Second, scoping reviews are especially suitable to identifying research gaps, and they may provide a means to summarize and disseminate research findings to policymakers and healthcare providers (57,59).

Given a perceived lack of knowledge on user participation among young people with ADHD, and given that the literature may be too disparate for a systematic review, we deemed the broad mapping capacity of a systematic scoping review to be suitable to providing an overview of the current knowledge on this topic. In this study, we applied the five-stage scoping review framework of Arksey and O'Malley (55,56) along with the principles and guidelines of the Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) (60). No protocol for this scoping review was registered.

Stage 1: Identifying the research question

The first stage in Arksey and O'Malley's (55,56) framework involves identifying the research questions (RQs). The central RQs of this study were:

- RQ1: What does the literature reveal about children's and adolescents' participation in the assessment and treatment of ADHD in mental healthcare services?
- RQ2: What are the experiences of children and adolescents with ADHD regarding user participation in mental healthcare services, based on the reviewed literature?

Stage 2: Identifying relevant studies

We describe the sources and strategies used to identify relevant studies in the second stage. In collaboration with an experienced librarian trained in healthcare research, we developed a search strategy that covered five databases: PubMed®, Embase (Ovid), PsycInfo® (Ovid), CINAHL Plus with Full-Text, and Ovid Nursing. Systematic electronic searches were conducted in December 2020. We performed an additional search in April 2024 to obtain newer results.

The search strategy involved specifying the context (here, ADHD diagnosis), participants (here, children and adolescents), and concepts (here, user participation) (56–59). From there, the search terms were identified. The context-related terms consisted of "attention deficit disorder" and "attention deficit disorder with hyperactivity," with subgroups searched in different combinations. The participant-related terms consisted of "preschool," "child," "adolescent," "juvenile," "youth," and "minors," also with subgroups, and in different combinations for searches. The concept-related terms consisted of "patient participation," "patient compliance," "decision-making," "choice behavior," and "patient preference", with subgroups, and in different combinations for searches. Appendix 1 describes the search strategy used for the five databases.

In addition to the systematic searches, the reference lists from the retrieved full-text articles were individually reviewed and scrutinized in order to identify additional articles that were not obtained through the computerized literature search. We also examined systematic reviews on similar topics to determine whether we had overlooked any relevant primary studies, and we consulted colleagues and experts for advice on the literature for review.

Stage 3: Study selection

The third stage involves developing inclusion and exclusion criteria based on the specific research questions.

Inclusion criteria

The key concept examined was user participation. Accordingly, we considered all studies that addressed the user participation of children and adolescents undergoing assessment and treatment for ADHD. Additionally, we assessed studies addressing the experiences of young people with ADHD in accessing treatment and services, managing medication, and coping with their impairments, to see whether user participation was addressed in relation to these topics. Another inclusion criterion was the status of peer-reviewed primary studies; we also included book chapters from edited books due to the scarcity of peer-reviewed articles on this topic. There were no restrictions regarding the study design. The publication languages were limited to English, German, Norwegian, Swedish, and Danish, and the search was limited to articles published between 2000 and 2024.

Participants were children or adolescents (8–18 years) with ADHD, or young adults (< 25 years) with ADHD if they reported experiences when they were minors. Since few studies addressed those under 18 years old, we extended the age range to also capture retrospective accounts. Studies involving the entire family were included if they specifically included young people with ADHD. Studies reporting on both young people and adults were included if the data for children and adolescents could be extracted and analyzed separately.

The context was outpatient CAMHS or community-based outpatient mental healthcare units for children and adolescents, including school-based healthcare units, outpatient pediatric units, and outpatient community-based pediatric units.

Exclusion criteria

Papers dealing with user participation among parents and healthcare personnel for young people with ADHD were excluded. Review articles, study protocols, conference papers, posters, and editorials were also excluded.

Selection process

The results of the literature search are presented in the PRISMA-ScR flow diagram (Figure 1). As shown, the database search resulted in 1,280 articles, after the librarian performing the search removed duplicates. After the searches of additional sources (such as reference lists and personal recommendations) were conducted, 26 articles were added for further scrutiny. All titles and abstracts (n = 1,306) were screened by two authors (EHM and AF) who independently evaluated each article in light of the inclusion and exclusion criteria. At this step, 1,276 articles were excluded from the analysis. In cases in which the authors evaluated articles differently, they each read the article in full to reach an agreement, and if needed, they consulted a third author (i.e., NHM) to reach a consensus. This process resulted in 30 full-text articles for assessment of eligibility.

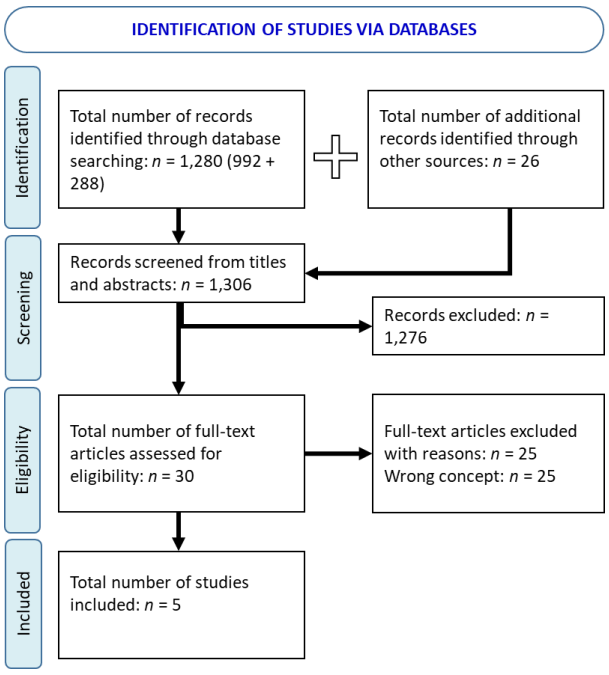

FIGURE 1. PRISMA-ScR flow diagram

The first author (EHM) examined all 30 articles, while AF and NHM independently read and evaluated each half of the articles to assess eligibility for inclusion. In eight cases (27%), the authors' evaluations conflicted, and all three authors discussed their evaluations until consensus was reached. Ultimately, five articles were included in the study, all of which were qualitative studies on the participation of children and adolescents in ADHD assessment and treatment (no quantitative articles fulfilled the inclusion criteria).

Stage 4: Charting the data

The fourth stage involves key information items obtained from the primary research reports under review. The first author (EHM) extracted data from all eligible articles and entered them into Microsoft® Excel, after which AF and NHM reviewed the extracted data. The characteristics of the studies addressing user participation were tabulated in order to provide information about the aims of the studies, participant characteristics, sample size, settings, and methods employed (Table 1).

We performed a qualitative content analysis of the organized data, guided by the RQs (61). Content analysis can be applied to both qualitative and quantitative data, and it is a suitable method for analyzing verbal, written, or visible communication (61). The content analysis involved three phases: preparation, organization, and reporting (61). In the preparation phase, we selected the unit of analysis as all texts labeled as "results" or "findings" in the articles, including "findings" mentioned in abstracts. We also included the appendices of the articles. Thereafter, we repeatedly read the articles, whereby we identified and selected meaning units—defined as one or more sentences or sentence fragments that conveyed a meaningful connection to descriptions of children's and adolescents' participation. The organization phase was performed using an inductive approach involving open coding, developing categories, and abstractions. Meaning units with similar meanings were grouped into mutually exclusive categories. The lists of categories were then grouped together to generate the main categories and subcategories through the process of abstraction. In the reporting phase, the analysis process and its results were reported. Our analysis resulted in four categories and

TABLE 1. Studies addressing user participation among young people with attention deficit hyperactivity disorder (ADHD)

Reference	Aim	Participant characteristics	Study setting	Methods[1]
Avisar and Lavie-Ajayi (2014) (62), Israel	To explore experiences of stimulant medication and treatment trajectories among adolescents with ADHD	Age: 12.5–16.5 years 14 adolescents using stimulant medication for ADHD for ≥ 6 months 8 males, 6 females	Private psychology center	Qualitative design using individual semistructured interviews Data analysis: Interpretative phenomenological analysis
Brinkman et al. (2012) (63), US	To elucidate how adolescents with ADHD contribute to medication treatment decisions	Age: 13–18 years 44 adolescents, diagnosed with ADHD 8.7 years on average prior to participation 24 males, 20 females	Community-based pediatric practices	Qualitative design using focus group interviews with open-ended, semistructured questions Recruitment stratified by sex and age Data analysis: Inductive coding
Cheung et al. (2015) (64), China	To explore experiences of adolescents and young adults with ADHD in Hong Kong in accessing treatment and services and coping with ADHD-related impairment, along with their expectations of future treatment	Age: ≥ 16 years 20 patients 16–17 years, 20 patients ≥ 18 years 27 males, 13 females	Specialist health care services	Mixed-methods design using qualitative semistructured interviews, field notes, Adult ADHD Self-Report Scale (ASRS) to assess severity of ADHD symptoms, and questionnaires on demographics, current medication, symptoms, and severity of impairment Data analysis of semi-structured interviews: Grounded theory
Mikesell et al. (2020), (65), US	To explore children's real-time participation in stimulant medication decisions	Age: 5–11 years 16 children with ADHD, who had received a first-time stimulant medication prescription, and their parents The families were English-speaking	Two community mental health clinics	Analysis of video-recordings of three follow-up visits of medication titration with emphasis on identifying the clinician's Treatment Recommendation inspired by conversation analytic research
Travell and Visser (2006) (66), UK	To explore the experiences, perceptions, and views of young people with ADHD and their parents	Age: 11–16 years 17 adolescents and their parents	Local health education authority	Qualitative semistructured interviews Data analysis: Grounded theory

Note. [1]*The methods include research design, data collection, and analytical methods.*

seven subcategories (see Results). Since we conducted a scoping review, the quality of the included studies was not evaluated (55–57).

Stage 5: Collating, summarizing, and reporting the results

The fifth stage involves collating, summarizing, and reporting the results. A scoping study seeks to present an overview of all reviewed material; consequently, issues of how best to present this potentially large body of material are critical (55). For the current study, this stage is presented in the Results section below.

Results

The results of this study were drawn from five selected scientific articles that the authors considered relevant to the purpose of the study (62–66). The main characteristics of the included studies are presented in Table 1. The selected studies were published between 2006 and 2020; all were qualitative studies that used data gathered through interviewing children, adolescents, and young adults (62–64,66) and through video-recording clinical consultations with young people, their parents, and clinicians (65). No quantitative studies were included. With respect to context, the included studies were conducted at specialist healthcare services and community-based pediatric services, including school healthcare services. The studies were conducted in Israel, England, China, and the USA. All five studies addressed user participation among young people at the individual level, addressing the challenges experienced by children and adolescents themselves in a clinical setting.

As an incidental finding, we identified eight primary studies that addressed caregiver participation in the assessment and treatment of ADHD in children and adolescents (67–73), and five studies that discussed clinicians' involvement and interaction with caregivers in processes related to user participation and shared decision-making, without including young people themselves (74–78). These articles were excluded from the review due to the inclusion and exclusion criteria.

Qualitative content analysis

The qualitative content analysis revealed four categories and seven subcategories (Figure 2). The first category, "sidelined from the start," encompassed the subcategories "admission recommended by others" and "external observers in the process of assessment." In the "lack of information" category, the subcategories included "little information for young people" and "knowledge needs." The third category, "trapped in medication," comprised the subcategories "no choice" and "struggling to be heard." Finally, the category of "growing into active decision-makers" contained the subcategory of "putting medication on hold." A detailed table of the analysis process outlining the codes, subcategories, and categories is available in Appendix 2.

Sidelined from the start

Admission recommended by others

From the beginning to the end of their treatment trajectories, children and adolescents described themselves as occupying a sidelined position, as "silent bystanders" (63) or "external observers" (66) to their difficulties while others around them recommended that they undergo assessment and diagnosis. These others were usually teachers, doctors, or parents. Teachers, in collaboration with parents, often initiated the young person's admission to mental healthcare services: "The teachers have recommended to my parents to take me to diagnosis, that I needed a diagnosis" (62, p. 40). Often, young people did not know why they had been admitted:

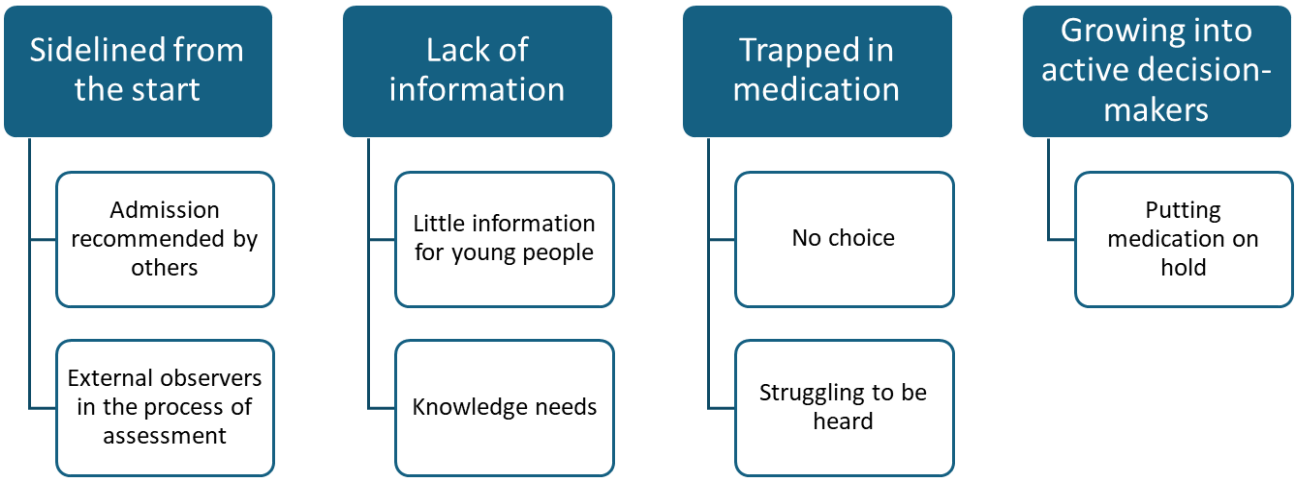

FIGURE 2. Categories and subcategories

"My parents brought me to child psychiatry, and I had no idea why…perhaps they wanted me to have better concentration" (64, p. 5).

External observers in the process of assessment

During assessment as patients at medical facilities, young people experienced the sense of being "external observers of processes, which were to bring significant effects upon their lives" (66, p. 213). The main actors in these processes were parents and doctors (62). Young people described the process of diagnosis as one in which their parents did most of the talking: "I didn't say nothing to the doctor. Mom was just doing all the talking" (63, p. 15). They also described how they initially felt that they were included in the process of diagnosis, but then it turned out to be a false inclusion that was at "the level of being told about the need for, and possible effects of, medication, together with some attempts to gain their consent to take it" (66, p. 212).

Lack of information

Little information for young people

The lack of information tailored to children and adolescents was an overall theme in four of the studies (62–64,66), which underscores how the parents—not the children or adolescents—are the primary receivers of explanations about the assessment, diagnosis, and treatment of the condition. Often, the therapists spoke directly with the parents, without involving the young person in the information exchange: "They did not say anything to me. They told me that I had attention deficit hyperactivity disorder. I found it hard to concentrate; I thought they referred to that" (62, p. 40). The information was seldom adapted for the children or adolescents, and it focused mostly on medication dosage: "They told me when I should take my tablets, why I should take my tablets and the dose, it'll go from a small dose up to a bigger dose the doctor said" (66, p. 209).

Knowledge needs

Young people expressed a need for more information about the condition and on alternative treatment options (64,66), which was considered to be valuable not only in terms of providing choice regarding medical treatment but also in terms of self-understanding: "Let the children know more about this disorder…if I know what is happening to myself, the attitude, even the effect of the treatment will be different" (64, p. 7). Some of the children or adolescents interviewed in the studies worried about side effects of the medication and requested more information about potential negative outcomes: "I worry that it will cause harm to body, but doctor said it won't" (64, p. 6).

Trapped in medication

No choice

Many of the young people in the included studies described feeling trapped in the process of medication trials, where they felt compelled to follow the decisions of their parents and physicians. They expressed a sense of having no real choice but to begin taking medication: "I don't want to take it now. I just don't like it. They won't let me stop" (63, p. 15). Some young people felt that, despite negative side effects, they were pushed to continue taking the medication at the request of adults because of the possible positive effects. One argument that parents often made was that medication would help them at school:

"I don't think no one has a choice cos like they can't just say, 'no, I don't want to have tablets, no that's it, they can't just go and say that, they've got to have them to help you know, I have got to have them to help me at school" (66, p. 212).

Some described pressure from parents as an "unspoken ultimatum" between agreeing to take the medication or continuing to get into trouble and thus cause stress for their parents (66). Moreover, the parents and physicians were the main decision-makers who decided that young people should continue medication despite negative side effects: "I was too drowsy, with loss of appetite; I felt like I was in a dream. I told my parents, and they said it was a pill that helped; I just had to get used to it" (62, p. 44). This was confirmed in analyses of video recordings of medical trial consultations with children or adolescents with ADHD, parents, and physicians, which revealed a process in which the parents made decisions in partnership with the physician regarding medication, in spite of disagreement from the child or adolescent (65). These consultations show how the parents, not the young people, were treated as the primary decision-makers regarding the latter's medication (65): "Clinicians initiated medication discussions with parents or delivered the treatment recommendation to parents, thereby treating parents as the primary decision-makers" (65, p. 75).

Struggling to be heard

Young people reported the experience of not being listened to and that their experiences were not acknowledged or understood by clinicians or their parents. They described their "struggle to be heard" about their negative experiences associated with medication (62). They shared that they tried to speak out clearly and loudly but were not listened to by either parents or physicians (62):

"I don't think [my doctor] really cares at all about what I'm saying. He makes decisions anyway. If I tell him I really don't want to be on medicine, he says, "Well, you are gonna stay on it because you need to stay on it"" (63, p. 15).

The experience of young people struggling to be heard during consultations with parents and physicians is also visible in the video recordings of medical consultations involving children and adolescents, parents, and physicians (65). These recordings show how physicians favor the parents' voice in medical decisions at the expense of the child's voice most of the time, and how the children's rejections are not considered. Often, the clinician sought the young person's perspective on treatment after it had already been agreed to by the parent (65).

Doc: The one thing I would like to do though is try a higher dose, just to make sure we are not missing if she's gonna do better at a higher dose. Would you guys wanna try that? Trying the twenty seven?
Child: No.
Child: Yes?
Doc: heh heh heh
Child: No yes, mom.
Child: No?
Doc: [shifts gaze to mom]
Mom: huh huh huh
Doc: heh heh
Doc: Well, I...the reason I would wanna try it is just to see. So, we would try the twenty-seven and you say...if the teacher says wow she's doing so much better even... and there's not any side effects; then we say okay maybe we should try this dose. 'Cause um if you're saying no: there's not improvement and there's more side effects? We would go back down. To the other one. We would know in a couple of days.
Doc: I think that would be the smart thing to try.
Mom: Okay
(65, p. 82).

The child's initial rejection response in this sequence was not taken seriously but rather treated as laughable and unserious; the child's contribution was minimized compared to that of the mother, from whom the doctor sought acceptance to raise the dose. This behavior by the physician and the parent seems to negatively influence the child's further responses in communication: "Upon no uptake of the child's rejection, the child backs down, modifying her initial rejection that was delivered with conviction to a tentatively produced (i.e., rising intoned) acceptance" (65, p. 83). In the papers included in our scoping review, it seems that medication is often continued despite the vocal protests of young people (62,63). Nevertheless, the papers also pointed out that children and adolescents seemed to be content with their level of involvement (63) and that "they felt they had been listened to and had had some choice" (66, p. 212).

Growing into active decision-makers.

As children grew older, they became more involved in discussions and decision-making regarding their medications. Evolving from external observers or silent bystanders to more active participants in the medication process, they assumed increasing autonomy over medication-related decisions and management (63). To this end, adolescents described an involvement in discussions and decision-making with their parents and doctors that increased over time (63).

Putting medication on hold

Often, this transition to taking on more responsibility led to the covert disposal of medication or to trials on and off medication before the eventually decision to quit taking the medication (62, 63): "When the control over him was slacker, the withdrawal process was gradual: First, he changed to selective use and then stopped completely" (62, p. 44). When the pressure from parents and teachers decreased and young people were able to act on their own wishes, they often chose to stop taking medication (62).

Discussion

By focusing on the perspectives of young people with ADHD with respect to user participation, this study offers new insights into potential barriers to their involvement in their own treatment. The results identified challenges that include feeling sidelined in interactions with healthcare providers from the start, lacking sufficient information, and facing communicative biases—especially in medication discussions, where parents are expected to have the final say. Such factors not only hinder meaningful participation but also foster a sense of powerlessness among young people. The findings also confirmed that research on user participation by young people with ADHD is limited and rarely incorporates the young people's perspectives: only five studies addressed user participation involving children and adolescents, most of which were related to testing ADHD medications. In addition, we identified a gap in the research literature, as the majority of work targeted parents' or clinicians' perspectives in interventions developed to improve shared decision-making involving young people with ADHD (67–78). These articles were excluded from our review based on our inclusion and exclusion criteria. This tendency to target parents—not children or adolescents—is also observable in pediatrics (50) and in recent studies on child and adolescent mental health outside of ADHD (52,54,79–81).

Nevertheless, the findings from our study underscore the importance of prioritizing the perspectives of children and adolescents in these processes, highlighting how a perceived lack of involvement can be experienced as burdensome by young people; they reported being sidelined, not receiving any information, having no choice, and not being heard. All these experiences are important to address in pursuit of improving user participation among young people. Our findings resonate with previous similar findings: the systematic review by Viksveen et al. (36) and the clinical studies by Bjønness et al. (51) and Ådnanes and Steihaug (82) demonstrate how adolescents with mental health issues in general may not feel heard or may feel that they are excluded from meetings, not asked for their opinions, pushed into treatment that they did not initiate or control, or labeled with a diagnosis. However, none of these studies referred to ADHD specifically, merely addressing mental health issues among young people in general.

The finding that children and adolescents with ADHD lack information about their diagnosis and the treatment possibilities specifically meant for them may represent an important barrier to their participation and shared decision-making. This finding indicates a violation of existing recommendations and clinical guidelines, which emphasize a carefully planned feedback process after ADHD assessment and targeted psychoeducation as the first-line treatment intervention (8,9). At the same time, the literature also reveals a lack of studies on psychoeducation programs meant for young people (83,84).

The finding of young people feeling trapped in medication describes how they are not often heard in the adolescent–parent–clinician interaction. This is in line with Coyne and Harder (47), who—based on previous research—argue that in such a "three-way relationship", the young person is often handled in an exclusionary manner that does not promote their opportunity for self-determination (47, p. 314). This is confirmed in our study, which shows how the communication related to participation processes may be too poorly organized for young people to be able to participate. Our findings also illuminate how such processes may unfold. In particular, the situation that occurs during a drug trial with central stimulants is a unique setting: here, the child or adolescent, together with their parents and clinicians, must jointly determine whether the dose should be increased or decreased and whether the medication should be replaced or discontinued. This decision is not based on blood tests or other objective standards but on the child's experience of change, possible improvement, or side effects, along with others' observations and objective assessments of the child. Few studies have illuminated this perspective on communication, although Pillen et al. (85) attempted to highlight such interactions in a study on how creating a space for opinion-sharing and collaboration in the adolescent–parent–clinician triad may be crucial to participation and shared decision-making. The Medication Integration Protocol as described by Hogue et al. (86), may also represent a fruitful framework for such collaboration.

Our last finding concerns growing into an active decision-maker. This finding elucidates how adolescents, who experienced having little influence on their situations as children, attain more autonomy and decide more for themselves as they grow older—not necessarily by taking additional responsibility for their treatment but rather by distancing themselves from the diagnosis, discontinuing their medication, and quitting treatment. In ADHD cases, the occurrence of a transition gap (87)—characterized by discontinuity between CAMHS and adult mental health services (AMHS)—represents a professional concern around follow-up with young patients with ADHD (12,88–90). Studies have discussed organizational challenges (12,89) and clinical factors (13,87,91) in relation to this problem. According to Buitelaar (87), a key factor in preventing a transition gap is to ensure that "adolescents become to feel responsible and take responsibility for dealing with ADHD" (87, p. 450). In a study on willingness to use ADHD treatments, Bussing et al. (92) found significant discrepancies between teenagers and adults (i.e., parents, healthcare professionals, and teachers) in the willingness to use psychosocial and pharmacological interventions. They stressed the need to develop better "treatment engagement practices" for adolescents with ADHD (92, p. 1), because "un-expressed adult–adolescent discrepancies in treatment willingness may contribute to adolescent treatment dropout" (92, p. 10). Although these authors do not refer to the concept of user participation, they highlight the importance of more actively engaging and communicating with adolescents in clinical encounters to prevent their dropout. This leads to an important question regarding the challenges of transitioning to AMHS: Can strategies and interventions that integrate young people's voices in their ADHD treatment planning prior to the transition—such as tailored psychoeducation programs, structured participation frameworks, or clinician training on adolescent-centered communication—benefit the management of up-coming changes?

Integrating young people's voices in both treatment and research is essential, not only to understand how they can actively participate in their own care but also to identify effective support and health-promoting measures. This is particularly important for those with neurodevelopmental conditions (like ADHD, autism, and Tourette's syndrome) who, in

line with the understanding of neurodiversity, do not have curative treatments (19,20). Instead, such care focuses on creating supportive environments that foster their well-being, coping, and active participation in their own lives (20). The findings of this study emphasize the importance of ensuring that young people with ADHD are included, properly informed, and heard—insights that may be equally relevant for children and adolescents with other neurodevelopmental conditions (93,94). Moreover, the study highlights the need to involve these young people in research—for instance, as part of participatory action research—so as to enhance its relevance and practical impact (21,95). Participatory research in child and adolescent psychiatry has gained increasing attention in recent years and is now increasingly recognized as enhancing the relevance of human research more broadly (96).

Recommendations for future research and clinical practice

By focusing on young people's perspectives concerning user participation, this study offers new insights into potential barriers to their involvement in their ADHD treatment. We identified a knowledge gap regarding user participation and shared decision-making among children and adolescents with ADHD, and we found that young people were underrepresented as research informants. Therefore, there is a need for future research that uses participatory research methods involving children and adolescents in investigations of how to better facilitate the participation and shared decision-making of young people with ADHD in CAMHS, not only regarding medication, but also in diagnostic assessment and negotiations about school accommodations and possible lifestyle changes. An interesting research question may also be whether user participation among young people with ADHD varies across treatments settings; like primary care or community pediatrics versus CAMHS?

Furthermore, to gain better knowledge on the position of young people and on how they can be better included and supported during decision-making processes, we argue that there is a need for more targeted studies examining the specific setting and processes that unfold within the three-way relationship between patients, parents, and clinicians in a medication trial.

Research on the effectiveness of user participation by young people with ADHD must also answer a range of questions, such as: How might better participation frameworks mitigate treatment dropout rates? Could participatory approaches reduce the transition gap to AMHS? Will they enhance young patients' sense of responsibility for their health and empower them? Alternatively, would this result in unfortunate decisions and place excessive responsibility on them?

User participation and shared decision-making involving young people with ADHD should be promoted in clinical practice. There is a need for a better clinical understanding of what may be involved in user participation by children and adolescents with ADHD in the interaction between children, adolescents, parents, caregivers, and therapists; how young people can involve themselves in these processes; what children and adolescents think of cooperating with their parents and clinicians; and how clinicians facilitate participation-friendly communication when meeting young patients.

Limitations and strengths of the study

The selections of databases and of search terms may have influenced the scope of the findings. Although our literature search was conducted using five major databases, it was not exhaustive, which may be a limitation. It might have been beneficial to include additional databases, such as Web of Science and SocINDEX, which may contain relevant papers for our assessment.

A strength of our study is that systematic searches were conducted in collaboration with an experienced librarian and using major databases. Titles and abstracts were thoroughly and systematically screened by two authors, and full-text studies were screened by three authors. Reference lists were screened to ensure that relevant studies were not overlooked.

The inclusion of studies in English, German, and Scandinavian languages was another strength, especially considering the growing focus on user participation in mental healthcare in Scandinavian countries.

Conclusion

This scoping review reveals how children and adolescents with ADHD often feel deprived of agency in their interactions with healthcare services. Many reports receiving little information about their condition and treatment, with limited opportunities to participate in decision-making. They also describe experiences of lacking choice regarding treatment and not being adequately heard. While existing research has explored the involvement of parents and clinicians in clinical decisions, studies focusing on young people's direct engagement in their own care remain scarce. The findings highlight a critical gap in the literature, revealing the need for greater emphasis on user participation by children and adolescents in ADHD treatment. Future research should explore participatory approaches that actively involve young people with ADHD in healthcare decisions and that consider strategies promoting shared decision-

making between patients, families, and healthcare providers.

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Conflicts of interest
The authors have no conflicts of interest to declare.

References

1. Chan E. Attention deficit hyperactivity disorder in children and adolescents: Epidemiology and pathogenesis. In: Connor RF, editor. UpToDate. Wolters Kluwer. [Accessed on 9 January, 2025].

2. Barkley RA. Emotional dysregulation is a core component of ADHD. In: Barkley RA, editor. Attention deficit hyperactivity disorder: A handbook for diagnosis and treatment. New York: Guilford Press; 2015. pp. 81-115.

3. American Psychiatric Association. Diagnostic and statistical manual of mental disorders: DSM-5. 5th ed. Arlington, VA: American Psychiatric Association; 2013.

4. Barican JL, Yung D, Schwartz C, Zheng Y, Georgiades K, Waddell C. Prevalence of childhood mental disorders in high-income countries: a systematic review and meta-analysis to inform policymaking. BMJ Ment Health. 2022;25(1):36–44. https://doi.org/10.1136/ebmental-2021-300277

5. Sacco R, Camilleri N, Eberhardt J, Umla-Runge K, Newbury-Birch D. A systematic review and meta-analysis on the prevalence of mental disorders among children and adolescents in Europe. Eur Child Adolesc Psychiatry. 2024;33(9):2877–94. https://doi.org/10.1007/s00787-022-02131-2

6. Chaulagain A, Lyhmann I, Halmoy A, Widding-Havneraas T, Nyttingnes O, Bjelland I, et al. A systematic meta-review of systematic reviews on attention deficit hyperactivity disorder. Eur Psychiatry. 2023;66(1):e90. doi: 10.1192/j.eurpsy.2023.2451

7. Salari N, Ghasemi H, Abdoli N, Rahmani A, Shiri MH, Hashemian AH, et al. The global prevalence of ADHD in children and adolescents: a systematic review and meta-analysis. Ital J Pediatr. 2023;49(1):48. https://doi.org/10.1186/s13052-023-01456-1

8. The Norwegian Directorate of Health. ADHD/Hyperkinetic disorder – National professional guideline for assessment, treatment and follow up [web page]. Oslo: The Norwegian Directorate of Health; 29 February 2016 [last updated 4 May 2022; accessed on 9 March 2025]. Available from: https://www.helsedirektoratet.no/retningslinjer/adhd

9. National Institute for Health and Care Excellence (NICE). Attention deficit hyperactivity disorder: diagnosis and management [web page]. London, Manchester: National Institute for Health and Care Excellence; 14 March 2018 [last updated 13 September 2019; accessed on 9 March 2025]. Available from: https://www.nice.org.uk/guidance/ng87/chapter/Recommendations

10. Chan E, Fogler JM, Hammerness PG. Treatment of Attention-Deficit/Hyperactivity Disorder in Adolescents: A Systematic Review. JAMA. 2016;315(18):1997-2008. doi: 10.1001/jama.2016.5453.

11. Titheradge D, Godfrey J, Eke H, Price A, Ford T, Janssens A. Why young people stop taking their attention deficit hyperactivity disorder medication: A thematic analysis of interviews with young people. Child Care Health Dev. 2022;48(5):724-35. doi: 10.1111/cch.12978.

12. Hall CL, Newell K, Taylor J, Sayal K, Swift KD, Hollis C. 'Mind the gap'--mapping services for young people with ADHD transitioning from child to adult mental health services. BMC Psychiatry. 2013;13:186. doi: 10.1186/1471-244X-13-186.

13. Price A, Mitchell S, Janssens A, Eke H, Ford T, Newlove-Delgado T. In transition with attention deficit hyperactivity disorder (ADHD): children's services clinicians' perspectives on the role of information in healthcare transitions for young people with ADHD. BMC Psychiatry. 2022;22(1):251. doi: 10.1186/s12888-022-03813-6.

14. Pain R, Whitman G, Milledge D. Participatory Action Research Toolkit: An Introduction to Using PAR as an Approach to Learning, Research and Action. Durham: Durham University & Lune Rivers Trust; 2012.

15. Whyte WF, editor. Participatory Action Research. London: SAGE Publications; 1991.

16. United Nations. Convention on the Rights of the Child. New York: United Nations; 1989.

17. Norway. Pasient og brukerrettighetsloven [The Patient and User Rights Act]. 1999. Act on patient and user rights, by 1999-07-02 no. 63 [cited 14 March 2025]. Available from: https://lovdata.no/dokument/NL/lov/1999-07-02-63

18. The Ministry of Health and Care Services. [#Youth health – The Government's strategy for youth health]. Oslo: The Ministry of Health and Care Services; 2016.

19. Sonuga-Barke EJS, Thapar A. The neurodiversity concept: is it helpful for clinicians and scientists? Lancet Psychiatry. 2021;8(7):559-61. doi: 10.1016/S2215-0366(21)00167-X.

20. Sonuga-Barke EJS. Paradigm 'flipping' to reinvigorate translational science: Outlining a neurodevelopmental science framework from a 'neurodiversity' perspective. J Child Psychol Psychiatry. 2023;64(10):1405-08. https://doi.org/10.1111/jcpp.13886

21. Sonuga-Barke EJS, Chandler S, Lukito S, Kakoulidou M, Moore G, Cooper N, et al. Participatory translational science of neurodivergence: model for attention-deficit/hyperactivity disorder and autism research. Br J Psychiatry. 2024;224(4):127-31. doi: 10.1192/bjp.2023.151

22. Storm M, Edwards A. Models of user involvement in the mental health context: intentions and implementation challenges. Psychiatr Q. 2013;84(3):313-27. doi: 10.1007/s11126-012-9247-x.

23. Balint M. The doctor, his patient and the illness. 2nd ed. Edinburgh: Churchill Livingstone; 2000.

24. Meland E, Schei E, Bærheim A. [Patient centered medicine-a review with emphasis on the background and documentation]. Tidsskr Nor Laegeforen. 2000;120(19):2253-6.

25. Ahmad N, Ellins J, Krelle H, Lawrie M. Person-centred care: from ideas to action. Bringing together the evidence on shared decision making and self-management support. London: The Health Foundation; 2014.

26. Harding E, Wait S, Scrutton J. The state of play in person-centred care: A pragmatic review of how person-centred care is defined, applied and measured, featuring selected key contributors and case

studies across the field. London: The Health Policy Partnership; 2015.

27. Mead N, Bower P. Patient-centredness: a conceptual framework and review of the empirical literature. Soc Sci Med. 2000;51(7):1087-110. doi: 10.1016/s0277-9536(00)00098-8.

28. Wills CE. Sharing decisions with patients: Moving beyond patient-centered care. J Psychosoc Nurs Ment Health Serv. 2010;48(3):4-5. doi: 10.3928/02793695-20100202-03.

29. Coulter A, Collins A. Making shared decision-making a reality. No decision about me, without me. London: The King's Fund; 2011.

30. Langer DA, Jensen-Doss A. Shared decision-making in youth mental health care: Using the evidence to plan treatments collaboratively. J Clin Child Adolesc Psychol. 2018;47(5):821-31. doi: 10.1080/15374416.2016.1247358.

31. Borg M, Davidson L. The nature of recovery as lived in everyday experience. Journal of Mental Health. 2008;17(2):129-40. https://doi.org/10.1080/09638230701498382

32. Karlsson B, Borg M. [Recovery: traditions, renewal and practices]. Oslo: Gyldendal akademisk; 2017.

33. Millar SL, Chambers M, Giles M. Service user involvement in mental health care: an evolutionary concept analysis. Health Expect. 2016;19(2):209-21. doi: 10.1111/hex.12353. Epub 2015 Feb 13.

34. Bahus M. [User participation in the health services]. In: Bolstad E, editor. The Great Norwegian Encyclopedia on snl.no. [last updated 16 September 2024; accessed on 12 January 2025]. Available from: https://snl.no/brukermedvirkning_i_helsetjenesten

35. Norwegian Directorate of Health. User participation [web page]. Oslo: Center for user participation, Norwegian Directorate of Health; 17 October 2017 [updated 15 December 2022; accessed 12 January 2025]. Available from: https://www.helsedirektoratet.no/tema/brukermedvirkning.

36. Viksveen P, Bjønness SE, Cardenas NE, Game JR, Berg SH, Salamonsen A, et al. User involvement in adolescents' mental healthcare: a systematic review. Eur Child Adolesc Psychiatry. 2022;31(11):1765-88. doi: 10.1007/s00787-021-01818-2.

37. Castro EM, Van Regenmortel T, Vanhaecht K, Sermeus W, Van Hecke A. Patient empowerment, patient participation and patient-centeredness in hospital care: A concept analysis based on a literature review. Patient Educ Couns. 2016;99(12):1923-39. https://doi.org/10.1016/j.pec.2016.07.026

38. Jørgensen K, Rendtorff JD. Patient participation in mental health care - perspectives of healthcare professionals: an integrative review. Scand J Caring Sci. 2018;32(2):490-501. doi: 10.1111/scs.12531.

39. Tambuyzer E, Pieters G, Van Audenhove C. Patient involvement in mental health care: one size does not fit all. Health Expect. 2014;17(1):138-50. doi: 10.1111/j.1369-7625.2011.00743.x.

40. Arnstein SR. A ladder of citizen participation. Journal of the American Institute of Planners. 1969;35(4):216-24. https://doi.org/10.1080/01944366908977225

41. Hart R. Children's participation: From tokenism to citizenship. Florence: UNICEF International Child Development Centre; 1992.

42. Shier H. Pathways to participation: Openings, opportunities and obligations. Children & Society. 2006;15(2):107-17. https://doi.org/10.1002/chi.617

43. Olsen T, Tesfai A, Lorentsson A. [Young people and participation. Use of power for beginners]. Oslo: Universitetsforlaget; 2019.

44. Mjøsund NH, Vinje HF, Eriksson M, Haaland-Øverby M, Jensen SL, Kjus S, et al. Salutogenic service user involvement in nursing research: A case study. J Adv Nurs. 2018;74(9):2145-56. doi: 10.1111/jan.13708.

45. Sweeney A, Morgan L. Levels and stages. In: Wallcraft J, Schrank B, Amering M, editors. Handbook of service user involvement in mental health research. Chichester, UK: Wiley-Blackwell; 2009. pp. 25-35.

46. Lansdown G. Every child's right to be heard. A resource guide on the UN Committee on the Rights of the Child, general comment no. 12. Save the Children, UK; 2011.

47. Coyne I, Harder M. Children's participation in decision-making: balancing protection with shared decision-making using a situational perspective. J Child Health Care. 2011;15(4):312-9. doi: 10.1177/1367493511406570.

48. Feenstra B, Boland L, Lawson ML, Harrison D, Kryworuchko J, Leblanc M, et al. Interventions to support children's engagement in health-related decisions: a systematic review. BMC Pediatr. 2014;14:109. doi: 10.1186/1471-2431-14-109.

49. Fiks AG, Localio AR, Alessandrini EA, Asch DA, Guevara JP. Shared decision-making in pediatrics: a national perspective. Pediatrics. 2010;126(2):306-14. doi: 10.1542/peds.2010-0526.

50. Wyatt KD, List B, Brinkman WB, Prutsky Lopez G, Asi N, Erwin P, et al. Shared Decision Making in Pediatrics: A systematic review and meta-analysis. Acad Pediatr. 2015;15(6):573-83. doi: 10.1016/j.acap.2015.03.011.

51. Bjønness S, Grønnestad T, Storm M. I'm not a diagnosis: Adolescents' perspectives on user participation and shared decision-making in mental healthcare. Scand J Child Adolesc Psychiatr Psychol. 2020;8:139-48. doi: 10.21307/sjcapp-2020-014

52. Cheng H, Hayes D, Edbrooke-Childs J, Martin K, Chapman L, Wolpert M. What approaches for promoting shared decision-making are used in child mental health? A scoping review. Clin Psychol Psychother. 2017;24(6):O1495-O511. doi: 10.1002/cpp.2106.

53. Gondek D, Edbrooke-Childs J, Velikonja T, Chapman L, Saunders F, Hayes D, et al. Facilitators and barriers to person-centred care in child and young people mental health services: A systematic review. Clin Psychol Psychother. 2016;24(4):870-86. doi: 10.1002/cpp.2052.

54. Liverpool S, Pereira B, Hayes D, Wolpert M, Edbrooke-Childs J. A scoping review and assessment of essential elements of shared decision-making of parent-involved interventions in child and adolescent mental health. Eur Child Adolesc Psychiatry. 2021;30(9):1319-38. doi: 10.1007/s00787-020-01530-7.

55. Arksey H, O'Malley L. Scoping studies: towards a methodological framework. Int J Soc Res Methodol. 2005;8(1):19-32. https://doi.org/10.1080/1364557032000119616

56. Levac D, Colquhoun H, O'Brien KK. Scoping studies: advancing the methodology. Implement Sci. 2010;5:69. https://doi.org/10.1186/1748-5908-5-69

57. Peters MDJ, Godfrey CM, Khalil H, McInerney P, Parker D, Soares CB. Guidance for conducting systematic scoping reviews. Int J Evid Based Healthc. 2015;13(3):141-6. doi: 10.1097/XEB.0000000000000050.

58. Peters MDJ, Godfrey C, McInerney P, Munn Z, Tricco AC, Khalil H. Scoping Reviews. 2020. In: Aromataris E, Lockwood C, Porritt K, Pilla B, Jordan Z, editors. JBI Manual for Evidence Synthesis [last updated 26 March 2024; accessed on 12 March 2025]. Available from: https://doi.org/10.46658/JBIMES-24-09

59. Birkeland B, Foster K, Selbekk AS, Høie MM, Ruud T, Weimand B. The quality of life when a partner has substance use problems: a scoping review. Health Qual Life Outcomes. 2018;16(1):219. doi: 10.1186/s12955-018-1042-4.

60. Tricco AC, Lillie E, Zarin W, O'Brien KK, Colquhoun H, Levac D, et al. PRISMA Extension for Scoping Reviews (PRISMA-ScR): Checklist and Explanation. Ann Intern Med. 2018;169(7):467-73. doi: 10.7326/M18-0850.

61. Elo S, Kyngäs H. The qualitative content analysis process. J Adv Nurs. 2008;62(1):107-15. doi: 10.1111/j.1365-2648.2007.04569.x.

62. Avisar A, Lavie-Ajayi M. The burden of treatment: Listening to stories of adolescents with ADHD about stimulant medication use. Ethical Hum Psychol Psychiatry. 2014;16(1):37-50. DOI: 10.1891/1559-4343.16.1.37

63. Brinkman WB, Sherman SN, Zmitrovich AR, Visscher MO, Crosby LE, Phelan KJ, et al. In their own words: adolescent views on ADHD and their evolving role managing medication. Acad Pediatr. 2012;12(1):53-61. doi: 10.1016/j.acap.2011.10.003.

64. Cheung KK, Wong IC, Ip P, Chan PK, Lin CH, Wong LY, et al. Experiences of adolescents and young adults with ADHD in Hong Kong: treatment services and clinical management. BMC Psychiatry. 2015;15:95. https://doi.org/10.1186/s12888-015-0478-x

65. Mikesell L, Marti FA, Guzman JR, McCreary M, Zima BT. Attending to parent and child rights to make medication decisions during pediatric psychiatry visits. In: Lindholm C, Stevanovic M, Weiste E, editors. Joint decision making in mental health: An interactional approach. New York: Palgrave Macmillan/Springer Nature; 2020. pp. 69-94. DOI:10.1007/978-3-030-43531-8_3

66. Travell C, Visser J. 'ADHD does bad stuff to you': young people's and parents' experiences and perceptions of Attention Deficit Hyperactivity Disorder (ADHD). Emot Behav Diffic. 2006;11(3):205-16. DOI:10.1080/13632750600833924

67. Brinkman WB, Hartl Majcher J, Poling LM, Shi G, Zender M, Sucharew H, et al. Shared decision-making to improve attention-deficit hyperactivity disorder care. Patient Educ Couns. 2013;93(1):95-101. DOI: 10.1016/j.pec.2013.04.009

68. Coletti DJ, Pappadopulos E, Katsiotas NJ, Berest A, Jensen PS, Kafantaris V. Parent perspectives on the decision to initiate medication treatment of attention-deficit/hyperactivity disorder. J Child Adolesc Psychopharmacol. 2012;22(3):226-37. doi: 10.1089/cap.2011.0090.

69. Davis CC, Claudius M, Palinkas LA, Wong JB, Leslie LK. Putting families in the center: family perspectives on decision making and ADHD and implications for ADHD care. J Atten Disord. 2012;16(8):675-84. doi: 10.1177/1087054711413077

70. Lipstein EA, Lindly OJ, Anixt JS, Britto MT, Zuckerman KE. Shared decision making in the care of children with developmental and behavioral disorders. Matern Child Health J. 2016;20(3):665-73. doi: 10.1007/s10995-015-1866-z.

71. McGuinness TM. Helping parents decide on ADHD treatment for their children. J Psychosoc Nurs Ment Health Serv. 2008;46(8):23-7. doi: 10.3928/02793695-20080801-08.

72. Tan D, King TR. Finding the "Sweet Spot": Sharing the decision-making in ADHD treatment selection. Ann Gen Psychiatry. 2022;21:14. https://doi.org/10.1186/s12991-022-00394-2

73. Spencer AE, Sikov J, Loubeau JK, Zolli N, Baul T, Rabin M, et al. Six Stages of Engagement in ADHD Treatment Described by Diverse, Urban Parents. Pediatrics. 2021;148(4):e2021051261. doi: 10.1542/peds.2021-051261.

74. Brinkman WB, Hartl J, Rawe LM, Sucharew H, Britto MT, Epstein JN. Physicians' shared decision-making behaviors in attention-deficit/hyperactivity disorder care. Arch Pediatr Adolesc Med. 2011;165(11):1013-9. doi: 10.1001/archpediatrics.2011.154.

75. Fiks AG, Gafen A, Hughes CC, Hunter KF, Barg FK. Using freelisting to understand shared decision making in ADHD: parents' and pediatricians' perspectives. Patient Educ Couns. 2011;84(2):236-44. doi: 10.1016/j.pec.2010.07.035.

76. Fiks AG, Hughes CC, Gafen A, Guevara JP, Barg FK. Contrasting parents' and pediatricians' perspectives on shared decision-making in ADHD. Pediatrics. 2011;127(1):e188-96. doi: 10.1542/peds.2010-1510.

77. Honeycutt C, Sleath B, Bush PJ, Campbell W, Tudor G. Physician use of a participatory decision-making style with children with ADHD and their parents. Patient Educ Couns. 2005;57(3):327-32. doi: 10.1016/j.pec.2004.09.004.

78. Bjønness S, Viksveen P, Johannessen JO, Storm M. User participation and shared decision-making in adolescent mental healthcare: a qualitative study of healthcare professionals' perspectives. Child Adolesc Psychiatry Ment Health. 2020;14:2. https://doi.org/10.1186/s13034-020-0310-3

79. Hayes D, Edbrooke-Childs J, Town R, Wolpert M, Midgley N. Barriers and facilitators to shared decision making in child and youth mental health: clinician perspectives using the Theoretical Domains Framework. Eur Child Adolesc Psychiatry. 2019;28(5):655-66. doi: 10.1007/s00787-018-1230-0.

80. Hayes D, Edbrooke-Childs J, Town R, Wolpert M, Midgley N. A systematic review of shared decision making interventions in child and youth mental health: synthesising the use of theory, intervention functions, and behaviour change techniques. Eur Child Adolesc Psychiatry. 2023;32(2):209-22. doi: 10.1007/s00787-021-01782-x

81. Crickard EL, O'Brien MS, Rapp CA, Holmes CL. Developing a framework to support shared decision making for youth mental health medication treatment. Community Ment Health J. 2010;46:474-81. doi: 10.1007/s10597-010-9327-z.

82. Ådnanes M, Steihaug S. "You never know what happens next" - young adult service users' experience with mental health care and treatment through one year. Int J Integr Care. 2016;16(3):5. doi: 10.5334/ijic.2435

83. Montoya A, Colom F, Ferrin M. Is psychoeducation for parents and teachers of children and adolescents with ADHD efficacious? A systematic literature review. Eur Psychiatry. 2011;26(3):166-75. doi: 10.1016/j.eurpsy.2010.10.005.

84. Dahl V, Ramakrishnan A, Spears AP, Jorge A, Lu J, Bigio NA, et al. Psychoeducation interventions for parents and teachers of children and adolescents with ADHD: A systematic review of the literature. J Dev Phys Disabil. 2020;32:257-92. https://doi.org/10.1007/s10882-019-09691-3

85. Pillen S, Glazemakers I, Bal S. [A qualitative study of shared decision making related to psychotropic drugs in adolescence]. Tijdschr Psychiatr. 2024:66(3):125-29.

86. Hogue A, Fisher JH, Dauber S. Assessing Support for Medicine Decision Making for Youth with ADHD Who Receive Therapy [Internet]. Washington (DC): Patient-Centered Outcomes Research Institute (PCORI); 2020 Sep. Available from: https://www.ncbi.nlm.nih.gov/books/NBK594605/ doi: 10.25302/09.2020.CER.140313704

87. Buitelaar JK. Optimising treatment strategies for ADHD in adolescence to minimise 'lost in transition' to adulthood. Epidemiol Psychiatr Sci. 2017;26(5):448-52. doi: 10.1017/S2045796017000154.

88. Coghill DR. Organisation of services for managing ADHD. Epidemiol Psychiatr Sci. 2017;26(5):453-8. doi: 10.1017/S2045796016000937.

89. McCarthy S, Asherson P, Coghill D, Hollis C, Murray M, Potts L, et al. Attention-deficit hyperactivity disorder: treatment discontinuation in adolescents and young adults. Br J Psychiatry. 2009;194(3):273-7. doi: 10.1192/bjp.bp.107.045245.

90. Price A, Newlove-Delgado T, Eke H, Paul M, Young S, Ford T, et al. In transition with ADHD: the role of information, in facilitating or impeding young people's transition into adult services. BMC Psychiatry. 2019;19:404. doi: 10.1186/s12888-019-2284-3.

91. Young S, Murphy CM, Coghill D. Avoiding the 'twilight zone': recommendations for the transition of services from adolescence to adulthood for young people with ADHD. BMC Psychiatry. 2011;11:174. https://doi.org/10.1186/1471-244X-11-174

92. Bussing R, Koro-Ljungberg M, Noguchi K, Mason D, Mayerson G, Garvan CW. Willingness to use ADHD treatments: a mixed methods study of perceptions by adolescents, parents, health professionals and teachers. Soc Sci Med. 2012;74(1):92-100. doi: 10.1016/j.socscimed.2011.10.009.

93. Eagle T. ADHD Communities Online: Understanding Collective Medical Knowledge and Healthcare Tensions [dissertation]. Santa Cruz: University of California Santa Cruz; 2024.

94. Connor TK. Participatory autism research: How consultation benefits everyone. Front. Psychol. 2021;12. doi: 10.3389/fpsyg.2021.713982

95. Kakoulidou M, Pavlopoulou G, Chandler S, Lukito S, Matejko M, Jackson I, et al. Deepening the participation of neurodivergent youth in qualitative mental health research: Co-development of a general approach and the evaluation of its implementation in a study on emotion. JCPP Advances. 2024;4(4):e12287. https://doi.org/10.1002/jcv2.12287

96. MacLeod A, Manitsa I, De Brito S. Participatory research in child psychology and psychiatry: Embracing untidiness to break new ground. JCPP Advances. 2024; 4(4): e12284. https://doi.org/10.1002/jcv2.12284