

INVITED REVIEW

Experiences of children and adolescents with attention-deficit/hyperactivity disorder taking methylphenidate

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Abstract

To improve clinical counselling for adolescents about the use of stimulant medication, it is crucial to understand the experiences of young people diagnosed with attention-deficit/hyperactivity disorder (ADHD) who are taking such treatment. For this narrative review, five databases were searched for studies investigating the personal experiences of control issues in adolescents diagnosed with ADHD taking methylphenidate. We extracted the data using NVivo 12 and interpretatively synthesized them according to the procedures of thematic analysis. Interviewed youngsters spontaneously put forward self-experiences about self-esteem and sense of control, although these issues were rarely explicitly addressed in the research question. The overarching theme in these studies was 'improving the self'. Two subthemes emerged: (1) medication sometimes delivered on its promise to improve the self, but regularly it did not; and (2) youngsters felt pressurized to conform to behavioural norms and comply with the medication use that adults had decided on. To genuinely involve youngsters diagnosed with ADHD for whom stimulant medication is prescribed in the shared decision-making process, we recommend to specifically involve them in a dialogue on the medication's potential effects on their self-experiences. This will allow them to feel at least partly in control of their body and life, and less pressurized to conform to others' norms.

Attention-deficit/hyperactivity disorder (ADHD) is the most commonly diagnosed neurodevelopmental condition. The criteria listed in the DSM-5 for a diagnosis of ADHD include hyperactivity, impulsivity, and difficulties maintaining attention, and the requirement that these criteria significantly interfere with functioning in at least two everyday contexts.¹ The worldwide prevalence of ADHD is estimated to be 5.29%.² A common topic both in the clinical and in the philosophical literature on ADHD (in which several models are used to look at disability, mainly the medical model and the social model. The medical or individual model holds that ADHD is a neurodevelopmental disorder in the individual which needs behavioural and medical intervention. The social model advocates a distinction between the physical 'impairment' and the 'disability' caused by societal attitudes and infrastructures, and guards against individualizing and medicalizing personal features.^{3–5}) is the (lack of) control or agency a person with a diagnosis of ADHD has over their behaviour.^{6–8} Indeed, a diagnosis of ADHD seems to imply

that the person's behaviour and the challenges they experience are not entirely under their conscious control.

There is substantial evidence on the efficacy of pharmacological and, for non-core symptoms, some non-pharmacological treatments for ADHD in children and adolescents, with considerable consensus across guidelines.^{9,10} Symptoms of ADHD are commonly treated with stimulant drugs such as methylphenidate. However, suggested pharmacological treatments have a less than optimal effect in day-to-day clinical practice, especially beyond 2 years of treatment and in associated domains such as social skills and achievement.^{10–12} Moreover, the most commonly prescribed drugs do not show a safe profile for mood and emotional symptoms,¹³ and adherence to these medications is variable.¹⁴ Therefore, some studies argue for developing more effective interventions for children and adolescents with ADHD.¹⁵ To develop clinically practical interventions and increase patients' adherence to them, researchers emphasize the need for knowledge about youngsters' own

experiences and understanding of their ADHD diagnosis and their concomitant use of stimulant medication.^{16,17} Therefore, investigating young people's values and experiences has high methodological value, as it adds first-hand information about their personal experiences.¹⁸ This information might inform effective counselling strategies that address adolescents' feelings about, and views on, their ADHD diagnosis and medication.

A meta-analysis by Ringer of 16 qualitative studies of adolescents' experiences of their diagnosis of ADHD described four overarching themes. One theme concerns relationships. Adolescents report that they feel others regard them as different and consider them to be outsiders. They may struggle to feel integrated and not to be singled out.¹⁵ The three other themes concern self-experiences: the formation of a personal identity, ambivalence about their psychological needs, and experiences related to their body and psychological abilities. On the basis of Erikson's theory of psychosocial development, Ringer hypothesizes that, in the case of ADHD, adolescents' central task of forming a stable personal identity might be related to the encountered ambivalence about psychosocial needs, and to their experiences of lack of control. For this last theme, Ringer found that adolescents feel that, because of their ADHD, they lack control over their body, behaviours, emotions, and cognitions. As in other studies, they attribute this lack of control to their being 'biologically determined by' ADHD.^{15,19,20} In line with neurological concepts of ADHD, they perceive their control-lacking behaviour as uncontrollable, as the result of a compulsive biological trait. Such perception can have an exculpating effect and so, arguably, a beneficial effect on their self-esteem. Indeed, some research has shown that adolescents' self-esteem might not be affected by a diagnosis of ADHD.^{21,22} However, most research suggests that a diagnosis of ADHD negatively affects adolescents' self-esteem and identity formation: they may feel 'bad' and 'out of control'.²³ In this regard, the concept of 'internalized ableism' is introduced in disability studies, meaning that disabled persons internalize the negative images and the low expectations reflected to them in an ableist social climate.^{24,25} Disability scholars argue that adolescents diagnosed with ADHD are made to believe that they have to get rid of these bad/wrong things about them.^{25,26}

In the research on adolescents' experiences of taking stimulant medication, similar issues about relationships and self-esteem are found. Adolescents with ADHD seem to implement different behavioural strategies to control emotions and behaviours to 'calm' themselves.²³ For example, the use of stimulant medication may increase adolescents' sense of control because it can strengthen their sense of agency and directly affect their 'biological' challenges with regard to control.²⁷ Other adolescents, however, view medication as an external agent controlling them,¹⁹ and as undermining their self-esteem and sense of control.²⁸ Thus, like the ADHD diagnosis itself, the use of stimulant medication may affect adolescents' self-esteem and sense of control in different ways.

In summary, to assess for whom and under which circumstances stimulant medication can be a helpful clinical

What this paper adds

- Youngsters diagnosed with attention-deficit/hyperactivity disorder and taking methylphenidate wish to improve the self.
- Pressure to conform to norms may make youngsters comply reluctantly with medication.
- Medication regularly did not deliver on its perceived promise to improve the self.

intervention and improve counselling for ADHD medication, it is essential that we know how youngsters understand and experience this medication, and to have their needs and wishes heard and recognized.²⁹ During adolescence, constructing a positive self-esteem and identity in mutuality with the social environment, and developing an increasing sense of regulation and control over one's body, emotions, and actions, take centre stage.^{30–32} Stimulant medication for ADHD seems to intervene, either positively or negatively, with adolescents' sense of control. However, no synthesis or review of empirical studies is available yet on how adolescents understand and experience the medication's regulation of, and control over, their bodies and lives. Therefore, we reviewed empirical studies addressing experiences related to regulation and control in adolescents with a diagnosis of ADHD taking methylphenidate.

METHOD

In April 2023, we searched five databases for studies on how adolescents with a diagnosis of ADHD taking stimulant medication experience regulation and control issues. Databases queried were PubMed, Embase, ERIC, CINAHL, and Scopus. Search terms used to retrieve articles were adolescents AND ADHD AND medication AND qualitative AND control, and variations of these terms (Table 1). Articles were limited to search terms in titles, keywords, and abstracts, and to journal articles and dissertations with an English abstract. To retrieve all relevant papers, we also used several rounds of reference and citation tracking until we could not find any additional studies.^{33,34} After the removal of duplicate articles and an unpublished manuscript, we screened all titles and abstracts. Full-text articles were then read for inclusion eligibility. We used a Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) flow diagram to visualize included and excluded papers (Figure S1).³³

We included articles that reported a qualitative study of the experiences of children and adolescents (<18 years old) with a diagnosis of ADHD who were taking stimulant medication related to the concept of control. We appraised the quality of the articles using the Critical Appraisal Skills Programme (CASP) checklist. This checklist considers three broad issues when appraising a qualitative study: Are the results valid? What are the results? Will the results help locally?

TABLE 1 Search terms for sample, focus, and methodology.

Domain	Search terms
Sample	Child* OR Teenager* OR Adolescen* OR Youth OR Teens OR Minor*
Focus	ADHD OR 'Attention deficit hyperactivity disorder' OR 'Attention deficit' OR 'Hyperactivity disorder' OR Medication OR Drug* OR Self-control OR Responsib* OR Self-regulat* OR Blame OR Identity
Methodology	Qualitative OR 'Focus group' OR Interview* OR Ethnography

Abbreviation: ADHD, attention-deficit/hyperactivity disorder.

Ten questions help researchers to consider these issues systematically. They are answered by 'yes', 'no', or 'cannot tell' but no formal scoring system is proposed³⁵ (available at <https://casp-uk.net/casp-tools-checklists>; accessed 13th July 2022). All the eligible articles scored 'yes' at least 7 times out of 10, so they were all included (Table 2). We did not apply any criteria for exclusion in addition to those for inclusion.

We performed a thematic analysis of both the primary interview data in the study and the interpretations authors gave to these data, the secondary data.^{36,37} Primary data have less potential for noise while secondary data run the risk of losing integrity because of the data's amplification by the authors' interpretation.³⁴ We used a qualitative method, rather than a quantitative one, as we wanted to investigate how people experience and view a phenomenon and what it means to them. This implied, however, that the findings could not be generalized. We followed a two-step approach, which was a combination of deductive and inductive approaches. During the deductive and theory-driven phase, the author extracted the data with the use of NVivo 12 (QSR International Pty Ltd.; <https://lumivero.com/products/nvivo/>) by inductively identifying all primary and secondary data related to the research question about the adolescents' experiences of regulation and control over their body, emotions, and actions. The resulting pieces of text were checked by a fellow researcher for relevance. Second, the author analysed the pieces of text in an inductive way, applying the procedures of thematic analysis. This meant themes and categories were 'discovered' rather than resulting from the application of a preconceived framework used by the researchers.³⁴ This analysis was done in three steps. First, codes were assigned to chunks of text in NVivo, staying relatively close to the literal meaning of the text. Subsequently, we interpretatively combined these first-level codes into categories (or subthemes) and then into synthesized findings (or themes)³⁶ that allowed a comprehensive understanding of how the categories might be related to each other.¹⁵ Finally, we arrived at an understanding of the phenomenon of control in the context of ADHD medication that would say more than the sum of the studies' results.³⁸ We synthesized the extracted themes under the overarching theme of needing to improve the self, and two subthemes: (1) medication sometimes delivered on its promise to improve

TABLE 2 Appraisal of the quality of the articles using the Critical Appraisal Skills Programme checklist.

	Clear aim?	Method appropriate?	Design appropriate?	Recruitment appropriate?	Collection data?	Relationship?	Ethical issues?	Analysis rigorous?	Findings clear?	Results helpful?
Avisar and Lavie-Ajayi ⁴⁵	Yes	Yes	Yes	No/Yes ^a	Yes	No	Yes	Yes	Yes	Yes
Brady ⁴⁶	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes
Brinkman et al. ⁴⁸	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Charach et al. ⁴²	Yes	Yes	Yes	No/Yes ^a	Yes	No	Yes	Yes	Yes	Yes
Knipp ⁴³	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes
Leggett and Hotham ⁴⁷	Yes	Yes	Yes	Yes	Yes	No	Yes	No	Yes	Yes
Sibeoni et al. ⁴¹	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Singh ⁴⁴	Yes	Yes	Yes	Not mentioned	Yes	No	Yes	Yes	Yes	Yes
Travell and Visser ²⁸	Yes	Yes	Yes	Not mentioned	Yes	No	No	Yes	Yes	Yes

^aNo/Yes, cannot tell.

the self, but regularly it did not; and (2) youngsters felt pressurized to conform to behavioural norms and to comply with the medication use that their parents and doctor had decided on. Some adjacent codes were not included in the overarching narratives because they did not contribute to understanding the researched phenomenon of control: for example youngsters' understanding of ADHD not being in line with that of their parents, or interviewees emphasizing the positive effect of ADHD of their personality.

To ensure credibility and trustworthiness, the author worked collaboratively and reflexively on this analytical process with three other researchers, either expert in qualitative research or a clinician. This peer debriefing opened up the analytical process to alternative interpretations and potentially competing explanations.³⁷ The multidisciplinary discussion helped to refine the coding tree, specifically in fine tuning the formulation of the themes and subthemes. However, as our approach was fully qualitative in nature, our aim was not to find 'accurate' and 'reliable' coding revealing the 'true' meaning of the data. Rather, following Braun and Clarke, we considered the analysis to be a situated interpretative reflexive process, and coding open and organic, with no use of any coding framework. Themes should be the final 'outcome' of data coding and iterative theme development. Therefore, we did not quantify agreements between researchers.³⁹

RESULTS

The literature search on experiences of adolescents with a diagnosis of ADHD taking stimulant medication, related to the topic of control, revealed nine studies published in peer-reviewed journals (Table 3). Seven of the nine peer-reviewed journals had a medical or psychological focus; two had a social sciences focus. However, the question about control experiences was addressed in one paper's research question. In the other papers, youngsters spontaneously came up with the issue.

The included studies recruited children and adolescents in community settings, at mainstream and specialized schools, and in clinical settings. Their ages ranged from 6 to 18 years, with a predominance of children older than 12 years. The included studies on both children and adolescents did not differentiate their results according to the age of the included youngsters (e.g. below or above 12 years). The participants' sex was often mentioned, and in the studies where it was, more males were included than females. This is in line with the fact that ADHD is diagnosed twice as often in male children than in females.^{2,40} (This seems to be due to sex differences in the behavioural expression of the difficulties related to ADHD, leading to a recent review's recommendation of 'pursuing research to refine the profile of girls with ADHD and to develop diagnostic criteria adapted to each sex'.⁴⁰) Most of the studies took place in the USA and the UK. One study was conducted in Australia, one in France, and one in Israel. We did not incorporate this cultural factor in our analysis because the authors of the articles did not report how

such factors might influence the participants' experiences (except for the French study⁴¹). Cultural aspects and appreciations may nevertheless have influenced the original data. The studies were published between 2006 and 2023.

We present our interpretative work of narratively summarizing the extracted results. Since we specifically extracted results that concerned our research question on control experiences of youngsters using methylphenidate – as a subgroup of their more general personal experiences – some articles provided more useful results than others. Indeed, some of the included articles addressed this specific issue to a larger extent than others. We synthesized the extracted themes under the overarching one of youngsters' feeling the 'need to improve the self'. Two subthemes ranging under this overarching theme emerged: (1) medication sometimes delivered on its promise to improve the self, but regularly it did not; and (2) youngsters felt pressurized to conform to behavioural norms and to comply with the medication use that their parents and doctor had decided on.

The overarching theme of the need to improve the self relates to participants wanting to get closer to the image of whom they would like to be.⁴² The young people in the interviews talked about how they did 'bad' things when they were not taking their medication, and that medication made them 'good' or 'normal',²⁸ as was apparent from the following quote: 'It makes me feel more like a normal student'.⁴²

For the theme of improving the self, we identified three major domains: improving control, improving academic achievement, and improving relationships with others. First, some participants felt that medication enabled them to control and regulate their behaviours, emotions, life, and body, and to have more decision-making power.^{41–44} The normative capacities of the 'I' were felt to be strengthened when taking medication:⁴⁴ 'Out of control till I get my meds right'⁴³ and 'I have a problem controlling my reactions when I am without Ritalin'.⁴⁵ Second, participants often thought medication was necessary to improve academic achievement:^{41–43,45,47,48} 'Higher test scores, I don't wander off'⁴³ and 'I was really focused and the teachers saw this'.⁴⁵ Third, participants considered medication necessary to reduce interpersonal problems and help others around them:^{41–43,45,46,48} 'I should use it to help everybody around me',⁴³ 'I fight more when I'm not on medication',⁴⁶ and 'The ambiance at home was not good'.⁴¹

However, in all three domains, participants regularly felt that medication did not deliver on its promise (first sub-theme).⁴⁵ First, the relation between medication and control itself was experienced as complicated. Some youngsters felt that they maintained decision-making power and final responsibility for behavioural outcomes.⁴⁴ Other youngsters described losing control over themselves when taking medication,^{28,45,47,48} leading to feelings of identity loss and decreased self-esteem: 'I hated taking it. It changed who I was ... it was controlling me instead of me controlling myself'⁴⁷ and 'It suppresses my true self'.⁴⁵ Second, in all included studies but one,⁴¹ interviewed youngsters often expressed how the medication was not helpful academically or even disrupted their efforts to study:^{42,43,45,48} 'I didn't have enough strength to take out the exercise books'⁴⁵

TABLE 3 Parameters of the included studies.

Reference	Phenomena	Participants and sampling	Recruitment setting and country	Data gathering	Analysis	Conclusions	Quality assessment	Pharmaceutical funding
Avisar and Lavie-Ajayi ⁴⁵	Experiences of ADHD diagnosis and stimulant medication	14 adolescents (8 males) 12 years 6 months–16 years 6 months with ADHD and stimulant medication	Private psychology centre and through acquaintances	Semi-structured interviews	Interpretative phenomenological analysis	Passive actors in diagnostic process, psycho-relational side effects, medication stopped in high school	85	No
Brady ⁴⁶	Lived experiences on taking responsibility for managing their well-being	7 children (6 males) 6–15 years with ADHD	English city child and adolescent mental health ADHD specialist service	Three times over 6–12 months: mixture of oral, written, and artistic contributions	?	Children desire to maintain some sense of control over their lives and take responsibility	90	No
Brinkman et al. ⁴⁸	Understanding of how young people contribute to medication decisions	44 adolescents (24 males) 13–18 years with ADHD	10 community-based pediatric practices in Cincinnati/northern Kentucky, USA	Focus groups	Inductive approach	Strategies to exert autonomy, frequent negative side effects, selective taking of medication	100	Yes
Charach et al. ⁴²	Young people's and parents' beliefs and attitudes about medication	12 adolescents (6 males) 12–15 years with ADHD	?	Interviews	Interpretative interactionist framework	Young people can have different attitudes towards medication use from their parents	85	No
Knipp ⁴³	Teens' perceptions about ADHD and medications	15 teens (10 males) 14–17 years with ADHD	Upper middle-class high school in Arizona, USA	Interviews	Content analysis	Role function: 'I do better in school when I take the meds'	90	No
Leggett and Hotham ⁴⁷	Treatment experiences of children and adolescents with ADHD	7 adolescents with ADHD	Pediatric clinics in South Australia	Interviews	?	Nonchalant, positive for school and behaviour, side effects ('controlling me')	80	No
Sibeoni et al. ⁴¹	Adolescents' and psychiatrists' perspectives on methylphenidate	15 adolescents (11 males) 12–18 years ADHD and methylphenidate	Two French child and adolescent psychiatry departments	Semi-structured interviews	Inductive process to analyse the structure of lived experience	Epistemic position, social representation, self-awareness, perception of adolescents: avoid epistemic injustice and stigmatization	100	No
Singh ⁴⁴	Discourses about self, brain, and behaviours	151 children (70% male) 9–14 years with ADHD, with ADHD and medication, without psychiatric diagnosis	US and UK families, white and lower middle-class	Interview, pictures, drawing, sentence completion task, ordering task, vignette	Thematic analysis plus discourse analysis	Evidence of agency and responsibility	80	No
Travell and Visser ²⁸	Young people and parents' perceptions of and views on medication	17 young people 11–16 years with ADHD and medication	One English local education authority	Semi-structured interviews	Constant comparative process (Glaser and Strauss)	Value and validity of ADHD diagnosis? Voice of young people. Negative side effects	70	No

Abbreviation: ADHD, attention-deficit/hyperactivity disorder.

and 'Meds make me sleepy and grades go down'.⁴³ Third, some youngsters experienced the medication's relational effects as beneficial, while others expressed unwanted feelings of being less sociable and outgoing.^{19,28,41–43,45,46,48} 'I noted that I was fighting less, I was becoming more friendly with people'⁴¹ and 'But most of my friends recommend that I stop with this, since they see me on days that I am without and days that I am with, and say that without it I have more joy of life and all of that, and with it, I seem more depressed'.⁴⁵ Besides, many participants described their negative experiences with the medication's undesirable physical effects:^{42,43,45,47,48} 'I was less hungry and tired with no desire to do anything'.⁴⁵

Apart from the medication not always delivering on its promise of improving self-control, academic achievement, and relations with others, the second subtheme revealed that young people in the studies often felt pressurized to accept the adults' decision that they needed medication to function 'properly'. These participants felt that they did not have the possibility of not accepting the adults' decision.^{28,41,46,48} 'I was passive. My parents, they are really stubborn. They profoundly believe that if there's a medication to take, you buy it, and you take it'.⁴¹ They felt obliged to continue taking the medication despite their negative experiences: 'In Grade 3, 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'.⁴⁵ Travell and Visser interviewed youngsters who had been presented with an ultimatum: 'Either they agreed to take medication, or they would continue to get into trouble and continue to be responsible for their parents' stress'.²⁸ Some youngsters did not even feel that their inner experiences were acknowledged in relation to the medication decision: 'I always told my mother—try to take it and feel what I feel'.⁴⁵ They said that, unlike their parents, they received little or no information.⁴⁸ Nevertheless, when some interviewed youngsters got older, taking medication little by little became the result of a shared decision between the youngsters, their parents, and their treating physician.^{28,41,42,45} In some cases, young people were able to negotiate how and when medication was used, for example only when attending school.⁴² Most older adolescents had stopped taking medication or had started taking it in a selective way.^{41,42,45,46,48} 'depending on perceived need to complete daily tasks (e.g. tests, team sports)'.⁴⁸

DISCUSSION

Interviewed youngsters spontaneously put forward self-experiences about self-esteem and sense of control, although these issues were rarely explicitly addressed in the research question of the included studies. Our synthesis of the included articles revealed that many interviewed youngsters with a diagnosis of ADHD wanted to take medication to 'improve the self'. Typically, stimulant medication is seen as a treatment of behavioural symptoms that are diagnosed as ADHD. However, youngsters who were interviewed in the included studies expressed their wish to improve the self in the sense of becoming both 'normal' and 'good'. They talked

about their medication as a remedy to normalize and to improve an unsatisfying self, an 'I' in need of an increase of its capacity to control its behaviours, emotions, life, and body, of its academic achievement, and of its relationships with others. The included papers did not provide us with any insight into why these youngsters considered themselves in need of remediation: because of their diagnosis, of others' opinions (teachers, parents), and/or of their own view on themselves.

In the biomedical literature, this desire of becoming 'good' resonates with the concept of 'cognitive enhancement', which is defined as the use of substances (e.g. stimulant drugs) to improve cognitive or behavioural functioning where it is not judged to be impaired.⁴⁹ Several American neurology associations have stated in a position paper that 'neuroenhancement in children and adolescents without a diagnosis of a neurological disorder is not justifiable'.⁵⁰ Thus, a diagnosis of a medical disorder is judged to be necessary to justify the use of whatever medication to improve cognitive or behavioural functioning; that is, medication is only indicated when it is meant to 'normalize' a disorder. However, the ADHD diagnosis is controversial, with critics denying that it is a valid medical disorder, and framing it as an example of 'medicalization' defined as a process in which a previously non-medical problem comes to be seen as medical.^{51,52} Consequently, this scientific debate raises the question of whether stimulant medication for ADHD is prescribed and taken (1) either with the aim of treating a 'true' medical disorder, for patients to become 'normal' or (2) rather with the aim of enhancing or, as the interviewed youngsters expressed it, of becoming 'good', a better version of themselves. For critics, indeed, the use of stimulant medication is not seen as a treatment of a neurological disorder; thus it is not seen as justified as stated in the neurologists' position above. They consider stimulant medication to be administered to youngsters to conform and to be 'good',^{53,54} rather than to become 'normal' by treating the youngsters' medical disorder. The current review seems to confirm that, in some youngsters' understanding, the medication is not only meant to 'normalize' them but also for them to become good: a better version of themselves, a version that is valued more by themselves and others around them.

Scholars of disability take the argument one step further and would question the interviewed youngsters' wish to become 'normal' by advancing the notion of ableist normativity. An ableist society devalues disability as inherently negative, equates able-bodiedness (or mind-ness) to normalcy, and views impairment as necessarily in need of improvement, cure, and elimination. The concept of internalized ableism points at the process by which the ableist norm is internalized, making a person believe that there is something wrong with themselves and that they have to become something else by getting rid of the bad things about themselves.^{24,25}

Within this perspective, some interviewed youngsters' wish to become 'normal' might be interpreted as a sign of other people's gaze and judgement having become their own self-conscious disapproval of who they are. These others might be peers, teachers, or doctors; however, in general, parents mainly have a major effect on how a child sees and values themselves.⁵⁵ In this regard, Ruddick speaks of the societal demand on

parents of socializing their child so that it can be accepted by their community.⁵⁶ Kittay also notices that parents of a disabled child have to socialize their community to accept their ('abnormal') child as a worthy and equal individual.²⁹

For many interviewed youngsters, an essential way of becoming 'good' and 'normal', of enhancing the 'self', was by gaining control over their behaviour, emotions, and life. Indeed, in present-day Western society, behavioural self-control and rational agency are generally considered to be of great value. Local social and performance norms value self-control as opposed to weakness of will.⁴⁹ Already in ancient philosophy, self-control was seen as a sign of mental strength, whereas lack of it was attributed to a weakness of will.⁵⁷ Also, modern theories of ethics talk about independent autonomous individuals in rational pursuit of their own good.²⁹ Likewise, many youngsters in the included studies valued self-control as opposed to being out of control. In contrast, ethics of care focuses on interconnected and embodied selves who are regarded as intrinsically vulnerable unlike the idealized selves in other ethical theories, among other things because of their (dis)abilities and relationships.²⁹

Childhood is a crucial period for developing an identity through interaction with the environment and developing positive self-esteem through approval from parents or peers.⁵⁸ Specifically for adolescents, Erikson argued that feelings of independence and of being true to one's beliefs and values, and thus arguably of control over one's body, emotions, and actions, take centre stage in the developmental task during adolescence of constructing a strong sense of self and a stable identity, along with the creation of a social environment to which the young person can belong.^{30,31} In line with an ethics of care perspective, youngsters thus seem to need space to develop a positive identity and self-esteem by constructing beliefs and values both in interconnectedness with important others and in accordance with what they experience to be their authentic self.⁵⁹ In the included articles, the control issue as implicated in both the ADHD diagnosis and the stimulant medication seemed to preoccupy several of the interviewed adolescents. The theme of control applied both to their body (who is controlling my body's actions?) and to their life (who is deciding about my medication use?). This preoccupation with the control issue might be related to the importance and delicacy of finding a just balance between their own and important others' contributions to who they are and how they lead their lives.

When exploring the issue of control of a youngster's body, research shows that a diagnosis of ADHD may be a double-edged sword: on the one hand, its predominantly biological understanding might de-blame an adolescent for their less-normative behaviours such as difficulties attending to demands and inhibiting impulsive responses;^{60–62} on the other, an almost exclusively biological understanding of a youngster's challenging behaviour might reduce their belief in being able to self-control.²⁸ Our review shows that not only might a diagnosis of ADHD be experienced as a double-edged sword, but also stimulant ADHD medication. On the one hand, some interviewed adolescents in the included studies felt relieved because methylphenidate improved their schoolwork and relationships

with teachers, parents, and peers; on the other hand, the same adolescents worried about losing control over themselves.

Indeed, significantly, the improved 'self' was often not attained by the interviewed youngsters in the way they wished. The self-control enhancing effect of stimulant medication, leading to a greater capacity to regulate behaviour and emotions, was seen as coming with the cost of losing control over oneself, and was experienced as alienating and negatively affecting self-esteem. A recent review on adverse effects of stimulant medication related to mood and emotions did not include data on identity and self-esteem. However, it showed high rates of sadness, apathy, anxiety, and irritability.¹³ Also, both academically and relationally, many interviewed youngsters did not positively evaluate the effects of stimulant medication. This is in line with the finding of a recent review of 30 years of literature that academic improvement resulting from stimulant medication is small and selective.¹² We did not find any research on the relational side effects of stimulant medication.

When it came to the issue of control in their lives, many interviewed youngsters did not feel acknowledged in the decision making around their stimulant medication, or they even felt pressurized to comply with the adults' decision. This is the second source of youngsters not feeling in control as, in the decision about how to lead their life, they are not involved. When they became older, most interviewed adolescents stopped taking their medication entirely or turned to taking it selectively. Some of them said that with age they finally became involved in the decision making and acquired a voice in their stimulant use.

Our review has several limitations. We could only include a limited number of studies, which were only conducted in Western countries where the medical model of ADHD is often dominant. The selection of papers was not standardized by a protocol. The question about control experiences was addressed only in one paper's research question; in the other papers, youngsters spontaneously came up with the issue. Moreover, in line with the research question, we only included qualitative studies, which made it impossible to quantify the results. Finally, a review of qualitative studies is inevitably influenced by the reflexive interpretation of the findings, both by the authors of the studies and by us; so we countered our potential bias by using the procedures of peer debriefing.³⁷ We recommend future research on the side effects of methylphenidate in adolescents includes self and control issues to substantiate our preliminary findings and to better understand adolescents' experiences of the drug. In our research team, we are currently interviewing youngsters diagnosed with ADHD, autism spectrum disorder, and Tourette syndrome within the framework of an empirical qualitative study in which control issues are included in the broader research question focused on their experiences.

CONCLUSIONS

In clinical practice it is known that, when growing up from a child to an adolescent, many youngsters diagnosed with

ADHD stop taking their medication, entirely or partly.¹⁴ This review supports the argument that these adolescents may not simply be acting irresponsibly when declining to take medication (regularly) but may 'have their own very valid reasons which do not often come to light during the traditional clinic consultation with their parents'.⁴⁶ These youngsters might want to improve the self through medication use but the promises to that effect are not always felt to be fulfilled. They might also not really feel involved but rather pressurized to use medication. Paediatric regulatory organizations indeed recommend a better implementation of shared decision making in paediatric healthcare.^{63,64} Surprisingly, however, a recent review on strategies for improving ADHD medication adherence did not mention any child-directed strategies.⁶⁵ Our review emphasizes that, with the aim of avoiding unfounded expectations and feelings of pressure, clinicians and caregivers could do more to involve youngsters in discussing desirable and unwelcome effects, and in the decision-making process. More specifically, our study suggests that clinicians should explicitly invite children and adolescents to express their wishes and hopes about medical intervention and address the degree to which medication might respond to their wishes. Overall, there is a relative scarcity of studies investigating the opinions and experiences of young people with the use of stimulants for ADHD. We hope to have demonstrated that such insights are needed to provide the best ADHD care.

DATA AVAILABILITY STATEMENT

Data sharing is not applicable to this article as no new data were created or analyzed in this study.

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SUPPORTING INFORMATION

The following additional material may be found online:

Figure S1. PRISMA flow diagram.

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