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Addressing Ethical Challenges in Assessing Decision-Making Capacity in Transgender Adolescent Care: Creation of an Ethics Support Tool

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Abstract

Assessing decision-making competence in transgender and gender-diverse adolescents is a complex task, as care in this area involves supporting a developing gender identity and making decisions about treatments that often lack international agreement. Even when competence assessments are performed, moral dilemmas can arise during the decision-making process. Traditional clinical ethics support approaches, such as moral case deliberation, may be insufficient because they do not provide thematic guidance tailored to these situations. This study therefore sought to create a practical ethics support tool to aid care providers in navigating moral challenges related to decision-making competence in transgender adolescent care. A participatory design approach was used, involving care providers in all stages of the tool's development and dissemination. Initially, nine care providers were interviewed to explore their experiences with moral challenges and identify their ethics support needs. These insights informed the tool's structure and content, which were refined through two focus group discussions. Subsequently, four care providers tested the tool, and feedback was collected from the development team and an advisory board. The finalized tool was then presented to all Dutch providers working in transgender adolescent care. Care providers highlighted the need for guidance in defining and assessing decision-making competence. Key moral challenges included conversations about fertility options, addressing co-occurring mental health conditions, and clarifying the role of parents in decision-making. The resulting tool, named the Competence Consultant, is an interactive PDF composed of four sections: (1) Clarifying information, (2) Identifying doubts and moral questions, (3) Guidance for conversations, and (4) Overview and conclusions. Developing an ethics support tool for a contentious area of care is crucial, as it helps providers navigate real-world moral challenges, enhancing their moral awareness and competence. The Competence Consultant offers a practical example of an innovative, thematic ethics support instrument tailored to the needs of transgender care providers.

Keywords: Ethical challenges, Care, Transgender Adolescent, Capacity

Introduction

Informed consent and shared decision-making are central principles in contemporary healthcare, requiring both comprehensive disclosure of information by healthcare professionals and active engagement of patients in consenting to and co-deciding on medical interventions [1, 2]. To participate meaningfully, patients must demonstrate decision-making competence, typically assessed through four key abilities: communicating a choice, understanding relevant information, appreciating the situation and its consequences, and reasoning about treatment options [3]. Assessing competence, sometimes referred to as "Gillick" competence in certain countries, is distinct from the legal age of consent, which varies internationally [4].

In the context of transgender and gender-diverse adolescents, evaluating decision-making competence is particularly sensitive. Decisions pertain to a developing gender identity—an inherently self-determined aspect of identity—while also having potentially lifelong

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consequences, often made during adolescence [5, 6]. Treatments can include puberty suppression, gender-affirming hormone therapy, and, upon reaching adulthood, surgical interventions [7]. Clinical guidelines emphasize that a key criterion for initiating such interventions is the adolescent's capacity to provide informed consent [8, 9].

Decision-making in transgender adolescent care involves numerous ethical questions and ongoing debates, including minimum age for treatment, parental involvement, and the impact of societal contexts [6, 10–14]. Given that the cognitive capacities underlying competence are still developing in children and young adolescents [13], care providers may question the adolescent's ability to fully understand treatment options and potential long-term consequences [15]. There are concerns that adolescents may not yet have a stable sense of gender identity. Providers must balance protecting adolescents from making poorly informed decisions with respecting their autonomy and supporting self-development [13]. International consensus on the age at which adolescents can be considered decision-making competent in this context remains lacking [13]. Transgender adolescents themselves have also reflected on the ethical challenges of determining the appropriate age for participating in medical decision-making [16].

Recently, the UK High Court ruled that minors are generally unlikely to provide informed consent for puberty suppression treatment [17], requiring court involvement for such decisions and creating additional barriers to gender-affirming care for transgender adolescents. This ruling was widely regarded as harmful to a vulnerable group experiencing incongruence between their assigned sex at birth and gender identity, and it raised broader concerns about the interpretation of informed consent [18, 19]. Delays in puberty suppression could prolong suffering and necessitate more invasive interventions later, such as mastectomy, though this ruling has since been overturned in a higher court [20]. Empirical research using the MacArthur Competence Assessment Tool for Treatment (MacCAT-T) has shown that most adolescents are competent to consent to puberty suppression during routine informed consent procedures, indicating that providers generally do not question their decision-making capacity [21]. Nevertheless, ongoing debates in both empirical research and public discourse highlight the complexities surrounding competence in young transgender individuals. A recent editorial in The Lancet Child and Adolescent Health noted that "…disproportionate emphasis is given to young people's inability to provide medical consent," linking the lack of consensus on puberty suppression to concerns about minors' decision-making capacity [22–24].

Beyond debates over competence, numerous moral challenges arise in clinical practice when working with transgender adolescents. These challenges are distinct from uncertainties about gender dysphoria itself, access to care, or the technical assessment of competence [25]. They often involve concerns about the stability of gender identity development, long-term impacts on fertility [26], or managing co-occurring psychiatric conditions such as autism [27]. Providers may also face ethical questions regarding parental involvement and their own professional responsibilities in the decision-making process [6, 12, 28].

These moral issues emerge around assessing and navigating adolescents' decision-making capacity. They are frequently unresolved at the moment they arise, or may remain inherently unsolvable, due to uncertainty about future identity development or treatment preferences. Transgender care inherently involves unpredictability about long-term outcomes and identity evolution, which complicates competence assessment for informed consent. At the same time, adolescents experience immediate stress and suffering, and delaying intervention is not always feasible [18, 19]. Consequently, care providers, adolescents, and other stakeholders need strategies to discuss and address dilemmas even when ideal solutions are unattainable, as moral dilemmas always carry some degree of harm [29]. Structured ethics support can help care providers navigate these challenges [6, 12, 30]. Empirical studies in healthcare broadly [31, 32] and in transgender care specifically [33] indicate that ethics support can enhance constructive handling of moral dilemmas. For instance, moral case deliberation offers a structured group discussion guided by a trained facilitator [34], but it can be time-intensive and mainly supports general ethical reflection. To provide more individualized, flexible, and theme-specific support, ethics support tools have been developed [33, 35], allowing integration of ethical guidance into daily practice [36, 37].

In response, we conducted a practice-oriented study to develop an ethics support tool to aid providers in managing moral challenges related to decision-making competence in transgender adolescent care. The tool aims to help understand and weigh ethical dilemmas surrounding competence when initiating puberty-

blocking treatment. Our objectives were twofold: (1) to describe the moral dilemmas and specific ethics support needs identified by care providers, and (2) to co-create a practical, hands-on tool to support the decision-making process and address these dilemmas.

Materials and Methods

Study setting and context

The research team brought together professionals from multiple backgrounds: clinicians from the Child and Adolescent Psychiatry Department and the Amsterdam Center of Expertise on Gender Dysphoria (CEDG) (AV and IH), and researchers specializing in ethics support from the Department of Ethics, Law, and Humanities at Amsterdam UMC (JS and BM). The ethics team has maintained a long-standing collaboration with CEDG spanning over ten years [36]. As a nationally and internationally recognized center, CEDG has extensive experience in both delivering gender-affirming care and conducting research on transgender health [38]. Traditionally, care for transgender minors in the Netherlands has been centralized at CEDG, although three newer centers have recently started offering partial services for smaller patient groups: Zaandam in the north, Genderteam Zuid in the south, and RadboudUMC as another academic center. Professionals from these emerging centers were also included in this project. The study received financial support from the Janivo Stichting, which funds social, research, or cultural initiatives involving children and adolescents.

Participatory co-creation approach

The tool was developed using a participatory, co-creation methodology, engaging care providers of transgender and gender-diverse youth throughout the project. This approach, also referred to as "collective making" [39], emphasizes knowledge co-generation between researchers and stakeholders, highlighting personal experiences, contextual factors, relationship quality, and innovative problem-solving, which together are believed to enhance the practical impact of research [39, 40]. Care providers contributed via interviews and focus group discussions, and a dedicated working group collaborated intensively on the tool's content, design, and usability.

To inform development, the research team incorporated findings from six previous studies exploring both adolescents' and care providers' perspectives on decision-making competence regarding puberty-blocking treatments [16, 21, 37, 41, 42], as well as moral dilemmas reported by care teams across Europe [14]. In addition, an advisory board comprising experts in pediatric decision-making competence, medical ethics, and transgender care provided periodic input and guidance. The full co-creation process is illustrated in **Figure 1**.

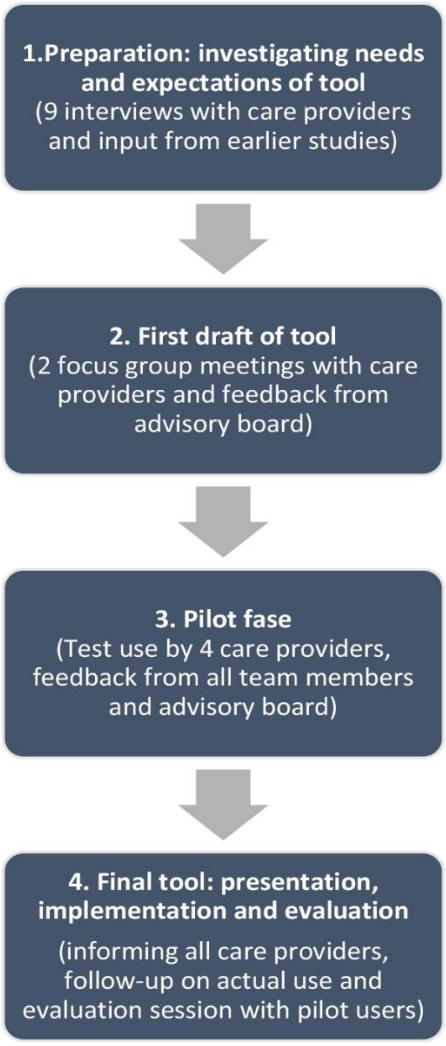

Figure 1. Co-creation process

Phase 1: interviews

The first step in developing the tool involved in-depth interviews conducted by JS with care providers from diverse professional backgrounds across multiple transgender clinics in the Netherlands. Participants were deliberately chosen to reflect both well-established and newly formed gender care teams, ensuring that a wide range of perspectives on the use and design of an ethics support tool were captured **(Table 1)**.

All interviews were audio-recorded and transcribed word-for-word. Analysis followed a framework approach [43]: after gaining an overall understanding of the data, JS and at least one additional researcher (AV, IH, or BM) independently examined the transcripts to identify passages related to decision-making competence, clinical decision processes, ethical dilemmas encountered, strategies for managing these dilemmas, and preferences or ideas regarding ethics support. Other relevant insights emerging during the review were also noted. The independent analyses were then compared and discussed to generate a unified, comprehensive set of themes. From this thematic overview, JS synthesized summaries and selected illustrative quotes, which formed the basis for creating the first draft of the tool.

Table 1. Profiles of the 9 interviewed care providers

Characteristic	Number of Participants
Profession	
Child endocrinologists	2
Child and adolescent psychiatrists	2
Child psychologists	4
Nurse specialist	1
Work Setting / Location	
Center of Expertise on Gender Dysphoria (CEDG), Amsterdam UMC	4
Gender team, Radboudumc Nijmegen	2
Peripheral clinics providing partial transgender care	3

Phase 2: draft development and focus group review

The initial version of the tool was refined through two online focus group sessions, which involved the care providers previously interviewed. These sessions aimed to: (A) validate the interview findings by sharing a summary with participants, (B) gather any additional insights or perspectives, (C) apply the draft tool to real-life cases to test its practical relevance, and (D) collect recommendations for improving the tool's content, structure, and usability. BM facilitated the meetings, with AV and JS assisting and observing. Each session lasted approximately two hours, was conducted virtually, and audio-recorded. The recordings were later reviewed to produce detailed summaries, which informed the creation of a revised second version of the tool.

Phase 3: pilot testing and iterative feedback

A professional graphic designer converted the second version into an interactive PDF format suitable for practical use. This version was piloted over a period of three to five weeks by four care providers. Following the pilot, in-depth interviews were conducted to explore their experiences and gather additional suggestions for improvement. Beyond the pilot group, the tool was shared in team meetings and sent to the advisory board and other relevant providers to collect broader feedback.

Phase 4: finalization, implementation, and evaluation

In response to the feedback collected, the tool was finalized and distributed to all professionals involved in the assessment and care of transgender and gender-diverse adolescents. Care providers who had participated in earlier phases took a leading role in introducing the tool to their teams, promoting its use, and integrating it into practice. Six months later, an evaluation session with the four pilot participants was held to reflect on its implementation, identify potential obstacles, and discuss strategies for wider adoption.

Ethical considerations

Participation in interviews and focus groups was entirely voluntary. Participants were informed that they could withdraw at any time without explanation. Written informed consent was obtained prior to each session, including consent for audio recording. The study protocol was reviewed by the Institutional Review Board of AMC, which determined that no additional ethical approval was required under Dutch regulations (Ref. no. W20_267).

Results and Discussion

Phase 1: insights from Interviews and Prior Research

Nine care providers with diverse professional backgrounds, working in both central and peripheral transgender care settings (ranging from long-established to recently founded clinics) in the Netherlands, were interviewed **(Table 1)**. Analysis of the interviews identified five primary themes: (1) the need for guidance in assessing adolescents' decisional competence and supporting their decision-making; (2) ethical challenges surrounding fertility, co-morbid conditions, and parental involvement; (3) current strategies for addressing moral dilemmas; (4) preferred forms of ethics support; and (5)

alignment of these findings with prior interviews conducted with adolescents and their parents [42].

Need for guidance in evaluating decisional competence and decision-making processes in transgender adolescents

Healthcare providers reported uncertainty in how to properly evaluate the decision-making abilities of transgender adolescents and expressed a desire for more education and guidance on assessment methods. Some questioned the established framework of the four capacities—understanding, reasoning, weighing options, and making a choice—as well as the clinical procedures used to assess these capacities, indicating a need for clearer guidance. One participant noted, "…decision-making competence is a very vague concept. We expect a certain level of it, but I don't think we really know what exactly we are looking for. For example, being able to repeat what puberty suppression involves—does that truly indicate decision-making competence?" (R1).

Several respondents also raised doubts about the threshold for determining sufficient competence, particularly in relation to long-term consequences, and called for more consensus and guidance. One interviewee asked: "When do we consider a child competent for decision-making? To understand the consequences—yes—but which ones? For a year? Five years? Or when they want to have a child in the future? I struggle with this. I might consider someone competent for near-term consequences, but not for the very long term. But can we ever know that for any life decision?" (R5). Another highlighted the difficulty in understanding potential treatment side effects: "If a twelve-year-old has never experienced a hot flash, which is completely normal, how can they know in advance whether they can cope with it?" (R9).

This uncertainty also appeared linked to how providers perceived puberty-suppressing treatment. Some viewed it as reversible, allowing additional time to explore both the adolescent's gender identity and their decision-making capacity through education and lived experience. One participant explained: "…I feel that the decision-making moment is somewhat extended because puberty suppression can delay the process. This period allows adolescents to reflect on whether they truly want to proceed, since they haven't yet started hormonal treatment." (R6). Conversely, others considered puberty suppression as part of the broader hormonal transition, with less reversibility, and emphasized the importance of fully understanding long-term consequences and subsequent treatment steps before starting puberty suppression. As one provider stated: "Starting puberty suppression is a significant decision because it can place children on a path that is difficult to reverse, even though permanent changes haven't occurred yet." (R9). Some providers struggled with whether puberty suppression should be considered reversible, particularly in cases where adolescents might not be competent for irreversible treatments—such as surgery—due to factors like intellectual disabilities that could limit their ability to give informed consent.

When asked about the timing of assessing decision-making competence, providers reported that they did not rely on a single moment. Instead, they formed impressions over multiple interactions with the adolescent and finalized assessments collaboratively with colleagues during team discussions about treatment indications. One participant reflected: "…the fact that multiple specialists are involved gives me the reassurance that I am not assessing competence on my own." (R9). Overall, providers rarely questioned the decisional competence of their adolescent patients and seldom deemed them definitively incapable of making decisions.

Fertility, co-morbidity, and the ethical role of parents as central moral challenges

Nearly all care providers highlighted the ethical dilemmas surrounding discussions of future fertility desires and current fertility preservation options with transgender adolescents. One provider reflected: "What I struggle with most regarding decision-making competence is: how can anyone truly know this at this moment? Especially with fertility wishes, which can change completely—even independently of decision-making competence—sometimes between the ages of 30 and 35" (R1). Providers stressed the importance of informing adolescents about treatment implications for fertility, while also recognizing the difficulty in expecting children to fully respond to such questions: "…yet we are talking to a child who is not at all capable of answering these questions" (R1). The usual criterion of decision-making competence—anticipating future consequences—becomes particularly challenging: "…we are discussing fertility wishes with children who are still in the Donald Duck phase. I can provide all the information, but it's hard to know if they truly understand the consequences" (R8). The core difficulty lies in the fact that adolescents are being asked to make decisions

about experiences they have not yet encountered: "…how can we expect a child to decide on something they haven't even partially lived through?" (R6).

Co-occurring psychiatric conditions were seen as additional barriers to both engaging adolescents in decision-making and evaluating their competence for treatment. For example, one clinician noted: "…with some highly autistic patients, communication is very complex. They may fixate intensely on certain preferences—like the texture of a dress—so while they might understand an idea of who they want to become, it is much harder to judge if they grasp all the implications of hormonal changes" (R4).

Care providers also frequently faced moral tensions arising from differing perspectives between adolescents and their parents. One provider described: "Sometimes parents focus on their own perspective, like wanting to become grandparents, and emphasize fertility preservation—pushing interventions such as egg freezing. But this can be extremely invasive, intense, and traumatic for biological girls who identify as boys" (R4). At the same time, the ethical challenges around parental involvement were nuanced. Another provider explained: "These are ethically complex situations, where the child's wishes may conflict with those of the parents. A child might be competent to make decisions, but also aware that their choice could deeply clash with parental expectations…so perhaps we need to invest more in systemic support to help parents come on board. But for how long should we do that, and what if parents continue to refuse treatment?" (R8).

Addressing moral challenges in clinical practice

Care providers reported that they generally had a supportive and open team environment where they could openly reflect on ethical dilemmas, either in supervision sessions or team meetings. When concerns arose about an adolescent's ability to make informed decisions, the diagnostic and preparatory phase for treatment was often prolonged to provide additional education, strengthen the therapeutic relationship, and supply more information to help the young person better understand the treatment and its potential consequences. One clinician described this approach: "In situations of serious doubt, we discuss the matter with both the adolescent and their parents. Based on what we know at the time, we may question whether now is the right moment for treatment. Sometimes it's better to allow more time for the adolescent to develop and gain clarity before starting treatment" (R3).

Desired support tools

To navigate ethical challenges more effectively, interviewees expressed a need for a shared framework outlining definitions and criteria for assessing decision-making capacity. One provider suggested, "a reference card listing key questions and options would probably be very useful" (R6). At the same time, they were clear that they did not want rigid scoring systems or formal competence tests: "I would definitely not want a requirement that adolescents reach, say, 80 percent competence before starting treatment, because that's not the intention at all" (R1).

Providers also highlighted the importance of addressing vulnerable populations, such as adolescents with psychiatric comorbidities, and wanted a tool that could centralize and dynamically track relevant information about each adolescent's decision-making abilities over time: "…what do we know at this moment, what factors need to be considered, what can we reasonably expect at a certain age, and what cannot yet be expected?" (R1). Another clinician added that it would be valuable to monitor developmental changes over time: "If you assess a child at age 9 and then again at 13, you can see how their capacities have evolved. That would be very useful to observe their growth" (R5). They also emphasized the need for the tool to guide ethical conversations with both adolescents and their parents, helping to surface the underlying moral dilemmas that influence clinical decisions: "…I want a tool that brings the core ethical issues clearly to the table, because these are what shape my professional judgment" (R8).

Development of the preliminary tool

From the interviews, a first version of the support tool was created, organized according to five key themes that emerged during data analysis. The tool included four sequential sections: providing clarifying information, identifying doubts and moral questions, offering guidance for conversations, and summarizing conclusions with suggested next steps. Given the uncertainties expressed by providers regarding decision-making competence, the tool was designed to present clear, accessible information on this topic, explicitly address ethical challenges, and incorporate strategies already in use by clinicians. Feedback on preferred forms of support was also taken into account to ensure that the

tool would be practical and usable in everyday clinical practice.

Phase 2: focus group feedback and subsequent refinement

The draft version of the tool was presented in two focus group sessions with care providers, consisting of three and five participants, respectively (eight of the nine initially interviewed providers participated; one was unable to join due to personal reasons). Participants recognized the themes identified in the interviews and appreciated the tool's four-step structure. When discussing how the tool could be applied to real cases, several questions arose regarding clarification or expansion of content, particularly for steps 1 and 2, which were seen as both valuable and complex. Focus group members reported difficulty in interpreting the four criteria for decision-making competence within the context of transgender adolescent care and noted a lack of consensus. For example, the criterion regarding "appreciating the situation" raised questions: how should this be understood when discussing treatment options with very young children? Are providers applying this criterion consistently? Participants suggested that the criteria might need further operationalization and concretization, but also acknowledged that this remains an area of ongoing debate, making full consensus unrealistic in the current process [24, 44].

Some participants also highlighted that the tool did not sufficiently address situations where adolescents are judged decisional-incompetent. Questions were raised regarding existing guidelines on fertility preservation for minors or shared decision-making with individuals with cognitive impairments. Completing step 2, which involves identifying doubts, was described as particularly challenging. Additionally, participants expressed a desire for more guidance on reflecting upon and articulating their values in relation to their moral uncertainties.

The focus groups offered several suggestions for the tool's layout and practical use. They recommended that the tool allow follow-up over time, enabling repeated use at different stages of the treatment trajectory. They also proposed tailoring the tool for different purposes, allowing users to skip steps or questions depending on the situation. In general, the tool was considered overly extensive, containing too many questions. Participants suggested including an illustrative case to guide users through the process. Finally, they emphasized that the tool should be suitable for team use or collaborative completion, as using it individually felt one-sided for some.

Based on this feedback, several adjustments were incorporated into the final tool, summarized in **Table 2**. In step 1, a preliminary question was added to help users determine whether their doubt concerns the assessment of decision-making competence itself or how to handle a decisional (in)competent adolescent. Comprehensive information on both decisional competence and incompetence, including references to relevant guidelines, was also added. In step 2, the concept of moral doubt was clarified, and additional questions were included to prompt reflection on potentially conflicting values. The final step was revised to provide explicit space for reviewing conclusions from previous steps and forming an overall judgment. Additionally, an illustrative case highlighting moral challenges related to competency was included in each step to serve as a practical example and guide.

Table 2. Final version of the ethics support tool: the competence consultant (in Dutch: 'Wilsbekwaamheidswijzer')

Section	Content
A. Gathering and clarifying information	
1. Define your starting point: What is your doubt clear or still vague?*	I am using this tool because I am not sure what exactly bothers me, or because my main uncertainty is about: • Whether this person has decision-making competence for the specific decision at hand (→ proceed with step A and, if necessary, B, C and D) • How to properly involve a person who lacks decision-making competence in the decision-making process (→ skip step A, go directly to B, C and D) • How to properly involve a person who does have decision-making competence in the decision-making process (→ skip step A, go directly to B, C and D)

2. Describe the case in detail	• Who is the patient/client? • How confident are you about the gender dysphoria diagnosis, and does that certainty (or lack thereof) contribute to your current doubt? • What exact decision needs to be made? • Who are the key stakeholders? Briefly describe them (parents, colleagues, other professionals, etc.) • What is the current situation? • What essential information is still missing right now?
3. Assess decision-making competence for this particular decision	– Information box explaining decision-making capacity (the 4 standard criteria, how to evaluate them, influencing factors, what constitutes incompetence, alternative theoretical perspectives, external references) *– Write down your impression of the patient's ability for each of the 4 criteria – If incompetence is suspected or established: identify and describe the authorized substitute decision-maker(s)*
4. Identify factors that may affect competence	– Possible influencing factors: age, psychiatric disorders, intellectual disability, insufficient supportive environment, etc. – Which of these factors actually seem relevant in this case? – How should these factors be addressed? (e.g., adopt a wait-and-see attitude, use stepwise decision-making, invest in education or strengthen the social support system, etc.)
B. Uncovering doubts and ethical issues	
1. After section A, reflect: What do you personally find difficult? What exactly is your doubt?	
2. Does the doubt mainly concern the diagnosis/treatment itself or the competence and decision-making process? (Reminder: this tool focuses primarily on the latter)	
3. Which ethical themes emerge? Examples: future fertility wishes, openly discussing long-term consequences, vulnerability of minors, degree of parental involvement, etc.*	
4. Map the values involved and their relative weight	– Which values are at play? (Example word cloud: caution, happiness, beneficence, autonomy, non-maleficence, protection, freedom, openness, trust, tailored care, solidarity, responsibility, respect, information provision, shared decision-making, best interests of the child, togetherness, etc.) *– For each value: what specific action or norm does it demand in this situation?* – Which values conflict with each other?* – Can you rank the values from most to least important for this case?
C. Guidance for value-exploring conversations	
1. Decide with whom you need to discuss your ethical doubts/questions and what you specifically want to learn from them	
2. Practical suggestions and example questions for conversations at three levels:	**Colleagues** Options: one-on-one talk, mono- or multidisciplinary team meeting, formal moral case deliberation. Example questions: What matters most to you as a care provider? It is perfectly fine if opinions differ — if so, describe the differences clearly. **Adolescent** Refer to existing guidelines on shared decision-making, talking with youth who have intellectual disabilities, and discussing fertility wishes. Example questions: What is important to this young person? Which values can you discover? Can you explore with them how they themselves view "being competent to decide"? How does their perspective enrich your own view? **Parents / legal representatives** Possible topics: share your own doubt, explore whether parents also feel uncertain, discuss their

	view on what is best for their child. Example questions: What do parents consider most important? Which values emerge? How do they assess their child's decision-making competence? Do they believe they can (or should) decide on behalf of their child?
D. Drawing conclusions and planning next steps*	
1. Create a concise overview to support conclusions (this page can also be used to structure a team discussion about the original question)*	– What was the original question/doubt? (see section A) – Which values are most relevant and important? (see section B) – How do the involved parties (adolescent, parents, team) view the situation? (see section C)
2. Formulate your (team) conclusion or provisional answer based on the above. Describe the main considerations*	
3. Reflect critically on the conclusion*	– What concrete actions are possible? – What are potential (negative) consequences of each action for the adolescent, the parents, yourself, or the team? – How can any negative consequences be mitigated or managed?
4. Define clear next steps	Examples: draft a treatment plan together with the adolescent, work on enhancing competence, re-assess competence later, repeat (parts of) this tool, consult an ethicist, organize a formal moral case deliberation, etc.
Extra information (background resources)	Separate pages or pop-ups with detailed information on: • What is decision-making competence? • What are the four abilities/capacities of decision-making competence? • Why is it important to assess decision-making competence? • How should decision-making competence be assessed? • Which factors influence the decision-making competence of minors? • What to do when a minor lacks decision-making competence? • What alternative theoretical views on competence exist? • Where can I find additional information and resources?

* Element that was adjusted or newly added after the feedback round in phase 2

Phase 3: Pilot testing

In the third phase, a professional graphic designer converted the second draft into a polished, interactive digital PDF and the tool was officially named "Competence Consultant" (Dutch: "Wilsbekwaamheidswijzer"). Four care providers who had participated in earlier interviews or focus groups tested the tool: each applied it to at least one case individually, and one used it to guide a team discussion. During follow-up interviews, participants appreciated the clear organization, visual layout, and the centralization of information. However, several noted that completing the tool could be time-intensive and suggested simplifying it or allowing navigation to skip certain steps depending on the purpose. Step 2, which involves identifying moral doubts and values, was reported as particularly challenging. Participants also proposed including an illustrative set of values, either derived from prior interviews or specific to the department, and adapting the final step to serve as a structured guide for team conversations.

The pilot version was subsequently shared with additional study participants and the advisory board for written feedback, and presented in a departmental meeting with an explicit request for comments. Feedback was predominantly positive, with participants valuing its relevance and practical utility, though some cautioned against making its use mandatory in a way that might add administrative burden.

Feedback from both hands-on pilot users and written comments informed the third and final version of the tool, developed in collaboration with the graphic designer. Minor textual edits were made, and key changes included: adding explanatory text balloons at starting questions to indicate which steps might be most applicable, incorporating a word cloud of relevant values in step 2, and revising the final step title to "Overview and Conclusions." **Table 2** provides an English summary of steps and questions.

Phase 4: final tool presentation, implementation, and evaluation

The finalized tool takes the form of an interactive infographic with four sequential steps: (1) Clarify information; (2) Identify doubts and moral questions; (3) Guidance for conversations; and (4) Overview and Conclusions. It is designed for either individual or collaborative use, with space to make notes directly within the document.

Step 1 focuses on clarifying the context: defining the purpose of the tool, identifying the adolescent involved, and summarizing what is known about decision-making competence and relevant factors. Step 2 is designed to help users articulate moral doubts, trace the sources of uncertainty, explore ethical themes, and consider potentially conflicting values. Step 3 provides strategies for engaging in dialogue with others to clarify and investigate values, while step 4 enables users to synthesize key points from the earlier steps and structure team discussions toward shared conclusions and actionable next steps.

The tool was distributed to the gender team and discussed in meetings and emails. The recommendation was to use it as a standard aid for preparing, conducting, or reflecting on informed consent procedures, and optionally in cases involving questions or doubts about an adolescent's decisional competence. Despite repeated presentations in team meetings, actual usage remained limited. Barriers included high workload, team turnover, reduced caseloads due to the COVID-19 pandemic, and lack of integration into existing administrative workflows. Nevertheless, pilot users reported that the tool supported them in clarifying their doubts, articulating dilemmas for discussion, and defining concrete follow-up steps. To encourage broader adoption, participants suggested running a promotional campaign and incorporating the tool explicitly into future moral case deliberation sessions when relevant.

This study explored the ethical challenges faced by care providers and their perceived needs for ethics support when assessing decision-making competence in transgender adolescents. The developed ethics support tool was specifically designed for the transgender care context, though it draws on general criteria for decision-making competence, as this setting raises distinctive ethical issues—such as the connection between competence and the adolescent's gender identity and existence. Using a participatory research approach, care providers and researchers collaborated to co-create a practical ethics support tool.

The interviews revealed that care providers frequently struggled with understanding the concept of decision-making competence and sought guidance both on its definition and on how to evaluate it appropriately. The primary moral challenges identified involved: (1) discussing potential future fertility with young children, (2) managing psychiatric comorbidities, and (3) negotiating the role of parents in decision-making. In cases of substantial moral doubt, some providers extended the diagnostic process to ensure adolescents were adequately supported in understanding treatment decisions. Participants also expressed a need for structured methods to articulate their ethical concerns, facilitate discussions with colleagues, and guide conversations with adolescents and their parents. In the following discussion, we contextualize these moral challenges within existing literature, reflect on the process of co-creating the ethics support tool, and examine the tool itself, including its strengths, limitations, and implications for clinical practice and research.

Ethical challenges in assessing decision-making competence

The difficulty of evaluating decision-making capacities is well-documented across healthcare settings, not just in transgender care [3, 13, 25]. This challenge may partially stem from limited awareness of validated assessment instruments, such as the MacCAT-T [45]. Additionally, competence is inherently a morally complex concept because it involves normative judgments about what constitutes 'adequate' or 'sufficient' decision-making by minors [13]. Care providers in this study also struggled with these normative questions and highlighted the need for greater consensus within the field. Moreover, the assessment of decision-making competence is a central concern in ongoing debates about whether transgender and gender-diverse adolescents should be eligible for gender-affirming care [8, 9, 15, 18, 19, 22]. The World Health Organization recently published guidance for clinicians on assessing adolescent decision-making competence, recommending tools such as the MacCAT-T, underscoring the broader need for support in this area [46].

Participants reported that they rarely judged transgender adolescents as definitively incompetent for decision-making, which aligns with findings from previous research using validated assessment instruments [21]. Nevertheless, the study confirmed that even when

adolescents are generally competent, care providers encounter multiple ethically challenging situations related to the assessment of competence. These include discussions about long-term consequences such as fertility, balancing parental involvement, and managing psychiatric conditions such as autism. Adolescents and parents have also reported similar ethical dilemmas [16, 21]. Thus, the key ethical concern is not whether adolescents are competent per se, but how to involve them meaningfully in decisions while they are still developing cognitively and emotionally. This includes questions about the extent to which adolescents should understand long-term outcomes of current and future treatment, how to accommodate delayed cognitive development or intellectual disabilities, and when the adolescent's preferences should take precedence over parental consent—or conversely, when parental input is ethically appropriate. Ultimately, the priority should be supporting the adolescent's autonomy and ability to make and express decisions regarding their care. As Ashley [44] recently argued, regardless of formal competence, the patient is often best positioned to make decisions about medical interventions that profoundly affect their identity; thus, emphasis should be placed on supporting rather than assigning decision-making in gender-affirming care.

Co-creating an ethics support tool

Building on the input provided by care providers, an ethics support tool was developed during the second phase of this study. The tool is specifically designed for the complex realities of transgender adolescent care, making it an innovative form of ethics support, particularly as it offers thematic guidance—something that typical ethics support methods, like moral case deliberation, do not emphasize. This co-creation process aligns with approaches we have used in previous studies for developing ethics support tools [33, 35, 36, 47]. It can be described as an 'integrative ethics support' approach, since both the development process and the dissemination of content occurred directly within the transgender care practice. By involving care providers as co-creators, they became active participants and co-owners of both the process and the final product. The completed tool exemplifies what has been referred to as 'innovative clinical ethics support activities through an emerging design' [36], in which the ethicist functions primarily as a facilitator of dialogue rather than as the sole author of content. As Inguaggiato *et al*. [48] have emphasized, ethical knowledge emerges through exchange among those directly experiencing morally challenging situations.

During the co-creation process, the ethicists themselves encountered ethical considerations similar to those faced by care providers, such as determining how to balance being supportive with providing structure or direction. Questions arose about when and to what extent ethicists should guide or shape the content. Another limitation was the absence of adolescent input; while the focus was on care providers' challenges, including adolescents might have enriched both the process and the final tool. Additionally, it was sometimes difficult to distinguish whether care providers' ethical concerns related to decision-making competence specifically or more broadly to treatment decisions or gender dysphoria, which, although closely related, were not the primary focus of this study.

The competence consultant

The finalized tool, named the Competence Consultant, combines practical guidance—such as information and relevant guidelines—with a structured approach to exploring moral doubts related to decision-making competence. It offers a stepwise process that begins with gathering and clarifying relevant information, followed by defining and reflecting on moral questions. The subsequent step encourages examining the perspectives and values of the adolescent, parents, and colleagues to reach a comprehensive overview and plan for next steps in the decision-making process. These steps can be conducted individually or collaboratively within a team.

The tool is designed to enhance care providers' moral sensitivity, helping them recognize and articulate ethical challenges and providing structured ways to discuss them. Importantly, the Competence Consultant does not make judgments regarding an adolescent's competence; it neither classifies adolescents as competent or incompetent nor prescribes decisions. Evidence from care providers indicates that doubts about competence are relatively rare [21], and decision-making competence remains a dynamic and nuanced concept that cannot be fully captured by a checklist [13]. Rather than providing direct answers, the tool guides care providers in systematically exploring ethical questions, encouraging dialogue with adolescents and colleagues, and referencing existing support instruments.

While the tool does not resolve ongoing debates in transgender care, it offers a practical, case-based

framework that enables care providers to navigate moral uncertainties, clarify their ethical concerns, and make well-considered decisions in daily practice. In a field that still lacks evidence-based consensus on treatment options—as highlighted by recent critiques of current medical approaches [49]—such a tool is both highly relevant and necessary to support individual providers in making careful, ethically informed assessments.

Limitations

The co-creation of this ethics support tool had several limitations. First, its scope is primarily focused on care providers, without a direct component for adolescents or their parents. This was aligned with the project's explicit goal of developing a provider-focused tool, but it could be considered a weakness that the perspectives of adolescents and parents were not more directly incorporated, as their involvement could have enriched both the process and the final product. Second, the pilot phase included only four care providers due to time constraints, although additional feedback was gathered from larger team meetings to supplement this. Finally, uptake of the tool in the initial period after its launch was limited, influenced by the high workload, COVID-19 measures, and societal debates affecting the gender team during the study. Despite some positive initial experiences, broader implementation and feasibility evaluation are clearly needed.

Strengths

The primary strength of this study lies in the creation of a practical, user-friendly tool designed to support care providers navigating the ethically complex terrain of decision-making competence in transgender adolescent care, particularly in the context of early medical-affirming interventions. Compared with existing instruments, such as the WHO tool [46] and the MacArthur Competence Assessment Tool [45], this tool addresses specific contextual moral challenges and aids professionals in clarifying their own ethical concerns. Its design allows for ease of use, digital storage, and repeated application over time, making it readily applicable in practice. The final tool provides comprehensive information on decision-making competence, guided questions to articulate moral doubts, practical suggestions for dialogue with adolescents, parents, and colleagues, and references to relevant guidelines. Moreover, the development process serves as a model for translating general theoretical frameworks into practical tools tailored to specific clinical settings.

Implications for practice and research

The tool can support healthcare professionals in navigating ethically challenging situations related to the decision-making processes of transgender and gender-diverse adolescents. While it does not resolve ethical dilemmas, it facilitates the clarification and exploration of these issues, complementing careful clinical judgment. By analyzing patterns in tool usage, care providers may identify recurring moral questions, informing the development of normative policies and guidance. Future efforts should focus on promoting the tool's use and integrating it into routine workflows.

The tool can also be adapted for international contexts in transgender care, serving as a foundation for creating new frameworks and guidelines for shared decision-making, including guidance on diagnosing and defining gender dysphoria and involving all relevant stakeholders. In adapted forms, it could also be applied in other clinical contexts where ethical dilemmas arise around adolescent decision-making competence. As co-creation of ethics support tools is a novel and promising approach, further conceptual work is needed to refine both the co-creation process and the structure of the tool itself.

Conclusion

Given the numerous ethical dilemmas in transgender and gender-diverse adolescent care, this study mapped key moral challenges and developed a practical ethics support tool, the Competence Consultant, to assist care providers in articulating, reflecting on, and navigating these dilemmas, thereby enhancing their moral sensitivity. The tool and its development process contribute to advancing innovative methods of ethics support, demonstrating how co-creation between ethics staff and care providers can produce effective tools. Ultimately, it offers structured support for addressing ongoing and emerging ethical issues in decision-making throughout all stages of transgender care.

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References

1. Childress JF, Childress MD. What does the evolution from informed consent to shared decision making teach us about authority in health care? AMA J Ethics. 2020;22(5):423–9.
2. Barry MJ, Edgman-Levitan S. Shared decision-making: the pinnacle of patient-centered care. N Engl J Med. 2012;366(9):780–1.
3. Appelbaum PS. Assessment of patients' competence to consent to treatment. N Engl J Med. 2007;357(18):1834–40.
4. Hein IM, De Vries MC, Troost PW, Meynen G, Van Goudoever JB, Lindauer RL. Informed consent instead of assent is appropriate in children from the age of twelve: policy implications of new findings on children's competence to consent to clinical research. BMC Med Ethics. 2015;16:76. doi:10.1186/s12910-015-0067-z
5. de Vries ALC, Cohen-Kettenis PT. Clinical management of gender dysphoria in children and adolescents: the Dutch approach. J Homosex. 2012;59(3):301–20.
6. Harris RM, Tishelman AC, Quinn GP, Nahata L. Decision making and the long-term impact of puberty blockade in transgender children. Am J Bioeth. 2019;19(2):67–9.
7. de Vries ALC, Klink D, Cohen-Kettenis PT. What the primary care pediatrician needs to know about gender incongruence and gender dysphoria in children and adolescents. Pediatr Clin North Am. 2016;63(6):1121–35.
8. Coleman E, Bockting W, Botzer M, et al. Standards of care for the health of transsexual, transgender, and gender-nonconforming people, version 7. Int J Transgend. 2012;13(4):165–232. doi:10.1080/15532739.2011.700873
9. Hembree WC, Cohen-Kettenis PT, Gooren LJ, Hannema SE, Meyer WJ, Murad MH, Rosenthal SM, Safer JD, Tangpricha V, T'Sjoen GG. Endocrine treatment of gender-dysphoric/gender-incongruent persons: an Endocrine Society clinical practice guideline. J Clin Endocrinol Metab. 2017;102(11):3869–903.
10. Clark BA, Virani A, Marshall SK, Saewyc EM. Conditions for shared decision making in the care of transgender youth in Canada. Health Promot Int. 2021;36(3):570–80.
11. Clark BA, Marshall SK, Saewyc EM. Hormone therapy decision-making processes: transgender youth and parents. J Adolesc. 2020;79:136–47.
12. Gerritse K, Hartman L, Antonides MF, Wensing-Kruger A, de Vries ALC, Molewijk AC. Moral challenges in transgender care: a thematic analysis based on a focused ethnography. Arch Sex Behav. 2018;47(8):2319–33.
13. Hein IM. Children's competence to consent to medical treatment or research. Amsterdam: Amsterdam University Press; 2015.
14. Vrouenraets LJJJ, Fredriks AM, Hannema SE, Cohen-Kettenis PT, de Vries MC. Early medical treatment of children and adolescents with gender dysphoria: an empirical ethical study. J Adolesc Health. 2015;57(3):367–73.
15. Laidlaw M, Cretella M, Donovan K. The right to best care for children does not include the right to medical transition. Am J Bioeth. 2019;19(2):75–7.
16. Vrouenraets LJJJ, Fredriks AM, Hannema SE, Cohen-Kettenis PT, de Vries MC. Perceptions of sex, gender, and puberty suppression: a qualitative analysis of transgender youth. Arch Sex Behav. 2016;45(6):1697–703.
17. EWHC (Civ). Bell v Tavistock; 2020.
18. de Vries ALC, Richards C, Tishelman AC, Motmans J, Hannema SE, Green J, Rosenthal S. Bell v Tavistock and Portman NHS Foundation Trust [2020] EWHC 3274: weighing current knowledge and uncertainties in decisions about gender-related treatment for transgender adolescents. Int J Transgend Health. 2021;22(3):217–24.

19. Giordano S, Garland F, Holm S. Gender dysphoria in adolescents: can adolescents or their parents give valid consent to puberty blockers? J Med Ethics. 2021;47(5):326–32. doi:10.1136/medethics-2020-106999
20. Bell v. Tavistock, EWCA Civ 1363. 2021. Available from: https://www.judiciary.uk/judgments/bell-and-another-v-the-tavistock-and-portman-nhs-foundation-trust-and-others/
21. de Vrouenraets LJJJ, Vries ALC, de Vries MC, Van der Miesen AIR, Hein IM. Assessing medical decision-making competence in transgender youth. Pediatrics. 2021;148(6):e2020049643.
22. The Lancet Child Adolescent Health. A flawed agenda for trans youth. Lancet Child Adolesc Health. 2021;5(6):385. doi:10.1016/S2352-4642(21)00139-5
23. Armitage R. The communication of evidence to inform trans youth in health care. Lancet Child Adolesc Health. 2021;5(9):e32.
24. Riggs DW, Tollit M, Lin A. Refusing puberty blockers to trans young people is not justified by the evidence. Lancet Child Adolesc Health. 2021;5(9):35–6.
25. Dunn LB, Nowrangi MA, Palmer BW, Jeste DV, Saks ER. Assessing decisional capacity for clinical research or treatment: a review of instruments. Am J Psychiatry. 2006;163(8):1323–34.
26. Kreukels B, Cohen-Kettenis P. Puberty suppression in gender identity disorder: the Amsterdam experience. Nat Rev Endocrinol. 2011;7(8):466–72. doi:10.1038/nrendo.2011.78
27. Van der Miesen AIR. Contemporary complexities in transgender care: disentangling the intersections among gender diversity, autism, and mental health. Amsterdam: Amsterdam University Press; 2021.
28. Priest M. Transgender children and the right to transition: medical ethics when parents mean well but cause harm. Am J Bioeth. 2019;19(2):45–59.
29. Spronk B, Widdershoven G, Alma H. Addressing harm in moral case deliberation: the views and experiences of facilitators. BMC Med Ethics. 2020;21(1):1–11. doi:10.1186/s12910-020-0450-2
30. Baker LL. True autonomy/false dichotomies? Genderqueer kids and the myth of the quick fix. Am J Bioeth. 2019;19(2):63–5.
31. De Snoo-Trimp JC, Molewijk B, Ursin G, et al. Field-testing the Euro-MCD instrument: experienced outcomes of moral case deliberation. Nurs Ethics. 2020;27(2):390–406. doi:10.1177/0969733019849454
32. Haan MM, van Gurp JLP, Naber SM, Groenewoud AS. Impact of moral case deliberation in healthcare settings: a literature review. BMC Med Ethics. 2018;19(1):85. doi:10.1186/s12910-018-0325-y
33. Hartman LA, Metselaar S, Molewijk AC, Edelbroek HM, Widdershoven GAM. Developing an ethics support tool for dealing with dilemmas around client autonomy based on moral case deliberations. BMC Med Ethics. 2018;19(1):97. doi:10.1186/s12910-018-0335-9
34. Stolper M, Molewijk B, Widdershoven G. Bioethics education in clinical settings: theory and practice of the dilemma method of moral case deliberation. BMC Med Ethics. 2016;17(1):45. doi:10.1186/s12910-016-0125-1
35. De Snoo-Trimp JC, Hartman L, Molewijk B. Ethics support for the distribution of hospital beds: co-creating a map of values and norms for the allocation meetings. Studia Universitatis Babes-Bolyai Bioethica. 2021;66(1):65–6.
36. Hartman L, Inguaggiato G, Widdershoven G, Wensing-Kruger A, Molewijk B. Theory and practice of integrative clinical ethics support: a joint experience within gender affirmative care. BMC Med Ethics. 2020;21(1):79. doi:10.1186/s12910-020-00520-3
37. Vrouenraets LJJJ, Hartman LA, Hein IM, de Vries ALC, de Vries MC, Molewijk AC. Dealing with moral challenges in treatment of transgender children and adolescents: evaluating the role of moral case deliberation. Arch Sex Behav. 2020;49(7):2619–34.
38. Bakker A. Een halve eeuw transgenderzorg aan de VU. Amsterdam: Boom Uitgevers; 2020.
39. Langley J, Wolstenholme D, Cooke J. 'Collective making' as knowledge mobilisation: the contribution of participatory design in the co-creation of knowledge in healthcare. BMC Health Serv Res. 2018;18(1):585. doi:10.1186/s12913-018-3397-y
40. Greenhalgh T, Jackson C, Shaw S, Janamian T. Achieving research impact through co-creation in community-based health services: literature review and case study. Milbank Q. 2016;94(2):392–429. doi:10.1111/1468-0009.12197

41. Vrouenraets LJJJ, de Vries MC, Hein IM, Arnoldussen M, Hannema SE, de Vries ALC. Perceptions on the function of puberty suppression of transgender adolescents who continued or discontinued treatment, their parents, and clinicians. Int J Transgend Health. 2022;23(2):158–71. doi:10.1080/26895269.2021.1974324
42. Vrouenraets LJJJ, de Vries ALC, Arnoldussen M, Hannema SE, Lindauer RJL, de Vries MC, Hein IM. Stakeholders' perceptions on medical decision-making competence regarding puberty suppression in transgender adolescents (in prep).
43. Gale NK, Heath G, Cameron E, Rashid S, Redwood S. Using the framework method for the analysis of qualitative data in multi-disciplinary health research. BMC Med Res Methodol. 2013;13:117. doi:10.1186/1471-2288-13-117
44. Ashley F. Youth should decide: the principle of subsidiarity in paediatric transgender healthcare. J Med Ethics. 2021;47(2):97–100. doi:10.1136/medethics-2021-107820
45. Grisso T, Appelbaum PS, Hill-Fotouhi C. The MacCAT-T: a clinical tool to assess patients' capacities to make treatment decisions. Psychiatr Serv. 1997;48(11):1415–9.
46. World Health Organization. Assessing and supporting adolescents' capacity for autonomous decision-making in health care settings: a tool for health-care providers. Geneva: World Health Organization; 2021.
47. Hartman L, Widdershoven G, de Vries A, Wensing-Kruger A, den Heijer M, Steensma T, Molewijk B. Integrative clinical ethics support in gender affirmative care: lessons learned. HEC Forum. 2019;31(3):241–60. doi:10.1007/s10730-019-09376-6
48. Inguaggiato G, Metselaar S, Widdershoven G, Molewijk B. Clinical ethics expertise as the ability to co-create normative recommendations by guiding a dialogical process of moral learning. Am J Bioeth. 2019;19(11):3–16. doi:10.1080/15265161.2019.1665735
49. Levine SB, Abbruzzese E, Mason JW. Reconsidering informed consent for trans-identified children, adolescents, and young adults. J Sex Marital Ther. 2022;48(7):706–22. doi:10.1080/0092623X.2022.2046221