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Capacity to consent: a scoping review of youth decision-making capacity for gender-affirming care

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Abstract

Background Transgender and gender expansive (TGE) youth often seek a variety of gender-affirming healthcare services, including pubertal suppression and hormone therapy requiring that TGE youth and their parents participate in informed consent and decision making. While youth must demonstrate the ability to understand and appreciate treatment options, risks, benefits, and alternatives as well as make and express a treatment choice, standardized approaches to assess the capacity of TGE youth to consent or assent in clinical practice are not routinely used. This scoping review identified the currently available data regarding adolescent capacity to consent to gender-affirming medical treatments.

Methods Articles relevant to assessing adolescent capacity for clinical decision-making were identified using OVID Medline, Web of Science, and PubMed. Articles were reviewed and thematically analyzed.

Results Eight relevant articles were identified using three tools for measuring adolescent clinical decision-making capacity: Measure of Understanding, Measure of Competence, and MacArthur Competence Assessment Tool (MacCAT). These studies explored hypothetical treatment decisions, mental health treatment decisions, HIV treatment decisions, genetic testing decisions, and gender-affirming medical decisions. Only one study specifically examines the capacity of TGE youth to consent to medical treatments. Age was correlated with capacity in most, but not all studies. Other studies found cognitive measures (IQ, literacy, numeracy) may impact important aspects of capacity (understanding and reasoning).

Conclusions For clinicians caring for TGE youth, tools such as the MacArthur Competence Assessment Tool for Treatment (MacCAT-T) may prove useful, in conjunction with consideration of youth developmental abilities and utilization of shared decision-making practices. A standardized, collaborative approach to assessing TGE youth capacity would benefit TGE youth and their parents, and allow clinicians to more easily resolve ethical concerns.

Keywords Transgender persons, Sexual and gender minorities, Adolescent, Minors, Decision making, Informed consent, Delivery of healthcare, Clinical ethics

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Background

Transgender and gender expansive (TGE) persons are individuals whose experience or expression of gender differs from their sex assigned at birth [34]. TGE youth may experience gender dysphoria, or feelings of discomfort or distress because of the incongruence between their gender identity and their physical characteristics, which may require medical intervention [34]. TGE youth experiencing dysphoria benefit from social, family, and psychological support, and many also seek gender-affirming medical interventions that are associated with improved mental health [5, 14, 42]. In the early stages of puberty, TGE youth may pursue pubertal suppression with gonadotropin-releasing hormone (GnRH) to pause the development of secondary sex characteristics. Older adolescents may also consider gender-affirming hormone medical treatments, including the use of hormones such as testosterone or estrogen [34]. Gender-affirming medical treatment can refer to either pubertal suppression and/or hormone therapies that support a youth's gender identity. Current clinical guidelines acknowledge the complexity of the decision to start gender affirming medical treatments during adolescence and prioritize a thorough informed consent process.

Clinicians providing gender affirming treatments to TGE youth face increasing scrutiny and legislative barriers to caring for TGE youth [59], and typically rely on a multi-step informed consent process and shared decision-making involving youth and their families [11]. Youth (and their legal guardians if under the age of legal majority) must be fully informed about the benefits, risks, and alternatives to the proposed treatment. The clinician providing treatment must assess the youth's capacity for decision making. Lastly, the youth and their guardian(s) must make a decision about pursuing the proposed treatment and provide consent/assent. An essential element in that process includes determining that a youth starting gender-affirming medical treatment demonstrates a sufficient level of decision-making capacity, which is defined as consisting of the following: (1) understanding of information regarding the condition and available treatments, (2) appreciation in the context of one's life and values, (3) reasoning among choices with consideration of risks and benefits, and (4) expression of a clear, consistent choice [11, 43, 62]. Decision-making capacity is distinguished in this review from competence, which typically refers to the legal status of an individual to make decisions, with legal policies varying considerably based on geographic location [26].

There are currently no standardized or uniform approaches to assessing decision-making capacity in TGE youth despite clinical recommendations for incorporating this into clinical care for TGE youth. Given the emerging nature of gender-affirming treatment in youth, uncertainty and disagreements in the field, and current socio-political climate around gender-affirming treatments, it is critical that clinicians have a reliable way of ensuring youth capacity is accurately and consistently assessed [1, 10, 35, 36]. Previous reviews conducted in 2004 [40] and 2008 [38] explored youth capacity, but did not focus solely on treatment decisions. They included studies focusing on consent for research, participation in decision making, parent and provider perspectives, and observations of adult and youth behavior in medical encounters [38, 40]. Additionally, no studies identified in these reviews included gender identities beyond male and female [38, 40]. This scoping review was conducted to identify the most recent relevant research on assessing medical decision-making capacity in youth across various diagnoses and clinical conditions, to better understand TGE youth capacity to consent to gender affirming medical treatments.

Methods

Using the PRISMA-ScR checklist [52], a scoping review of current literature surrounding clinical decision-making capacity with a focus on TGE youth was performed. Our protocol was developed after a preliminary review of the literature (noting reviews on youth competency and capacity from 2004 [40] and 2008 [38] that did not include TGE youth) and discussion with the research team and key stakeholders (including a TGE youth advisory board). Primary databases that were searched include OVID, PubMed, and Web of Science. Several articles were also obtained through thorough searches of the citations of other relevant articles. Key search terms for the databases included: informed consent, youth consent, informed consent by minors, parental consent, decision making, capacity, competence, comprehension, adolescent, adolescence, youth, transgender persons, transgender, transsexualism, gender expansive, health care, health services, treatment, therapeutics, and delivery of health care. These terms were chosen for their relevance to the literature review objectives and were combined to generate an expansive list of articles to review.

Exclusion criteria included articles that were not written in English, published prior to 2010, did not reach a final publication, were not relevant to the topic of youth decision-making capacity in clinical scenarios, and articles focused on other aspects of gender-affirming care (social transitioning, mental health therapy, hair removal, voice training, surgery etc.) as this review is limited to non-surgical medical treatments requiring a prescribing clinician.

A total of 880 articles were obtained (Fig. 1). Seven additional articles were identified through citation review. Manuscripts were screened based on title and abstract with redundant articles removed. 30 potentially

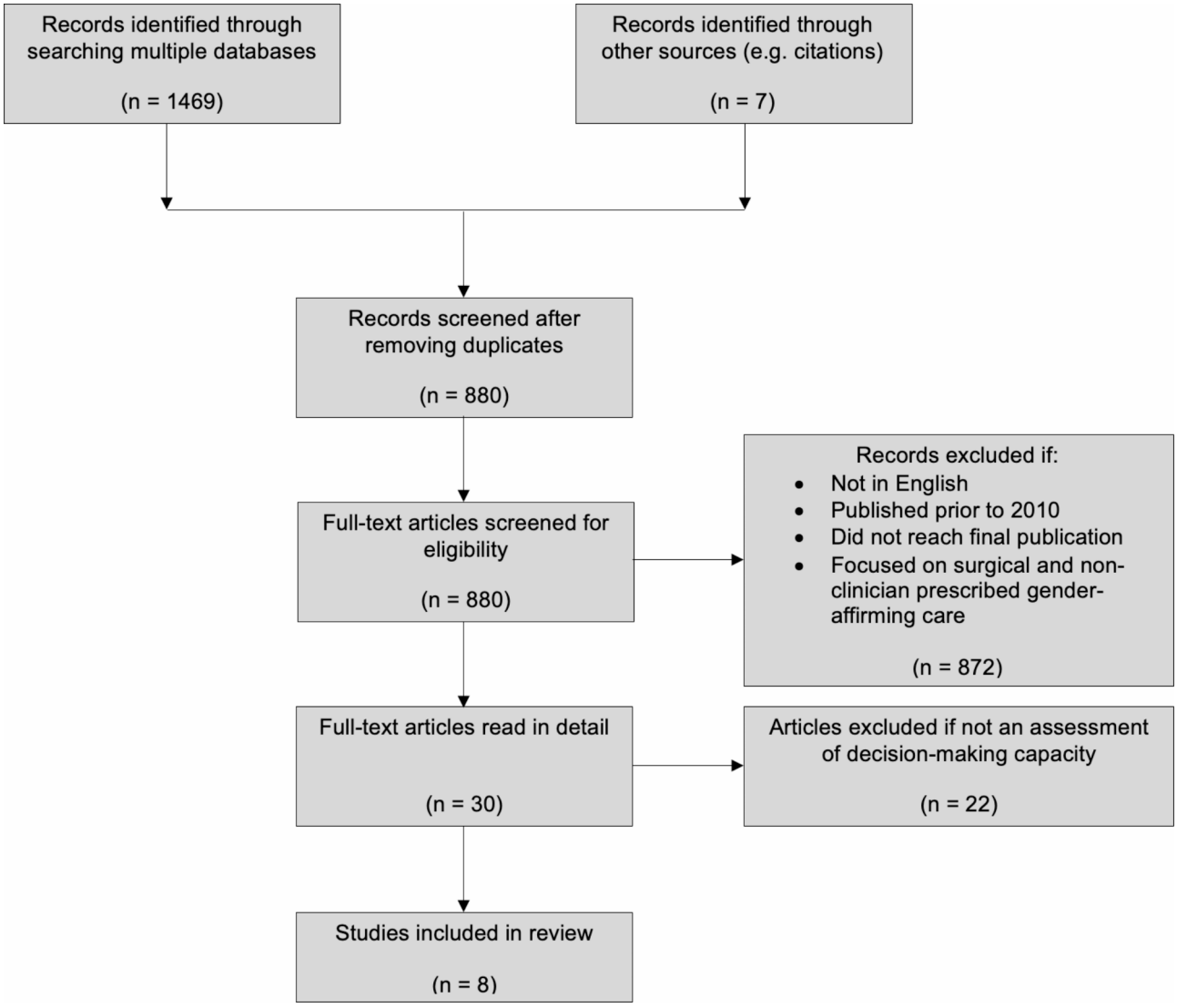

Fig. 1 Selection of Articles for Review

relevant studies were selected for full-text review and a total of eight articles were included in the final review (see Appendix – Table S1).

Data abstraction was initially performed by one researcher (LGM) and adjusted based on a second reviewer of each article (KEB, HFS, JFT). Each article was read in full and analyzed by 3–4 members of the research team. Data was abstracted into a standardized form including the following: title, authors, publication date, design/methods, country of origin, sample characteristics, results, summary, strengths, and weaknesses. Given the small number of studies with heterogeneous measures and populations, we used a narrative/thematic synthesis approach which allows quantitative data to be examined in a textual manner and is well suited to informing clinical guidelines [29]. The research team met over a series of months to discuss results, ensure consistency in extraction, and identify key themes. Disagreements were resolved through discussion and consensus was reached.

Results

Eight articles evaluating adolescent decision-making capacity since 2010 were evaluated in the literature, and only one involved TGE youth. The three decision-making capacity assessment tools evaluated in these articles include: Measure of Understanding, Measure of Competence, and MacArthur Competence Assessment Tool. Studies originated from 5 countries and included a total of 532 youth (age 6–24 years). The tools used have similarities (flexibility for disease specificity, measuring understanding), as well as important differences (subscales, scoring, etc.) (see Table 1). Populations of youth evaluated for capacity for medical treatment decisions

Table 1 Comparison of tools to assess decision-making capacity

Tool	Development	Administration	Subscales	Scoring
Measure of Understanding (MUA) (Schachter et al. 2011)	Developed by physicians, bioethicists, adolescents with ADHD, and adolescents' parents	Patients provided information about stimulant medication, then interviewed with 8 open ended questions modeled after the MacCAT-T, followed by 42 multiple choice questions, to assess understanding of ADHD, ADHD treatment, medication benefits, side effects, alternatives	Understanding	Total composite score of interview and multiple choice questions with maximum attainable score of 100.
Measure of Competence (MOC) (Weithorn et al. 1982)	Developed by clinicians and attorneys	Patients provided with a series of four clinical vignettes with hypothetical treatment dilemmas, then interviewed to assess their understanding of the clinical dilemma, ability to provide rational reasons for their choices, and create a reasonable outcome.	Scale of Reasonable Outcome, Scale of Rational Reasons, Understanding (Rote Recall – measures understanding of facts, and Inference – measures appreciation)	Understanding scored from 0–2, Scale of Reasonable Outcome scored from 1–5, Scale of Rational Reasons scored variably based on clinical vignette with points allocated for degree of thought behind decisions.
MacArthur Competence Assessment Tool for Treatment (MacCAT-T) (Grisso et al. 1997)	Developed by Grisso et al. based on previous studies of decision-making competence	Semi-structured interview with patients, starting with disclosure of the patient's conduction, followed by questions pertaining to the benefits and risks of, and alternatives to the recommended treatment. Questions are designed to assess the four elements of capacity. Finally, the patient expresses a choice.	Understanding, reasoning, appreciation	Understanding scored from 0–6, reasoning from 0–8, and appreciation from 0–4. No cut-offs provided for determination of decision-making capacity.

included healthy populations responding to hypothetical scenarios as well as youth making clinical decisions about their own health condition (attention deficit hyperactivity disorder (ADHD), anorexia nervosa (AN), psychiatric medications, human immunodeficiency virus (HIV), genetic testing, and pubertal suppression).

Measure of Understanding (MUA)

A Toronto study from 2011 examined the ability of adolescents (12–16 years) with ADHD to understand information related to ADHD treatment in the informed consent process [47]. The study included four groups: 58 adolescents with attention deficit hyperactivity disorder (ADHD), parents of the adolescents with ADHD, 64 healthy control adolescents, and parents of the healthy controls. Researchers developed the Measure of Understanding (MUA) tool based on the MacArthur Competence Assessment Understanding of Treatment Disclosures [2] and includes both open ended interview questions and multiple-choice questions. All adolescent participants also took the Wide Range Achievement Test Revision 3, which assesses for reading, spelling and math skills, along with the Wechsler Intelligence Scale for Children-IV (WISC-IV) and Youth Self Report (YSR). Adolescents with ADHD had significantly lower estimated IQ, as well as reading, spelling, and math scores, compared to control adolescents. 78% of ADHD adolescents had a final understanding score within two standard deviations (SD) from the mean of ADHD parent scores. Of adolescent participants (both those with ADHD and controls), approximately 89% were within two standard deviations of the parental mean understanding score. While the MUA measures understanding, only one aspect of capacity, it does assess understanding of the condition being treated, treatment options, and risks and benefits of the treatment. This study highlights adequate understanding among most youth both with and without ADHD as well as potential factors (low numeracy, low literacy) that may impact understanding for adolescents.

Measure of Competence (MOC)

In 2020, the Weithorn and Campbell Measure of Competence (MOC) [60] tool was utilized in a study of decisional capacity of healthy South African youth using hypothetical scenarios [23]. The MOC consists of four clinical scenarios (diabetes, epilepsy, depression, and enuresis) with questions regarding evaluating four central competencies of decision-making capacity defined by the authors (Understanding, Choice, Reasonable Outcome, and Rational Reasons). Researchers administered the tool to 100 participants (10–17 years) and 25 adult controls (>17 years, the standard for comparison). Notably, exclusion criteria included having one of the four clinical conditions (diabetes, epilepsy, depression, enuresis) or having a family member with the condition. Age was the only variable that was significantly correlated with competence, with children less than 12 years of age having poor correlation with adult responses on all subscales. Youth less than 14 years were also less likely to present abstract factors on the providing rational reasons subscale. The authors conclude that youth 12 years and older are capable of providing informed consent, as they were able to reliably score similarly (within the margin

of error) as adults on each of the Scales (Understanding, Choice, Reasonable Outcome, and Rational Reasons).

MacArthur Competence Assessment Tool (MacCAT)

Several studies used the MacArthur Competence Assessment Tool (MacCAT) in children and adolescents to assess capacity to consent to research or treatment decisions. This tool assesses four areas: (1) understanding relevant information and recommended treatment (2), reasoning about the potential risks and benefits (3), appreciating the nature of the situation and the consequences of the choices, and (4) expressing a choice. No overall score for the MacCAT-T is intended to represent capacity or the lack thereof. The original intent of this tool was to determine the degree of capacity or a deficiency in specific abilities which can then be used alongside other clinical supports in judgments about how to proceed with decision making.

While the MacCAT-CR has been validated as a way to assess capacity for adults [13, 17] and youth [24, 25] to consent to clinical research (CR), the capacity to consent to clinical care differs from research in important ways. Acknowledging the difference between choices to participate in research and treatment decisions, the MacCAT-T [20] was developed to evaluate capacity to make clinical treatment decisions. It has been used in adult populations with potentially reduced capacity such as people with psychiatric concerns [57, 58], cognitive impairment, and dementia [44]. The MacCAT-T has been studied in clinical settings with youth making choices about HIV treatment, mental health treatment, predictive genetic testing, and pubertal suppression.

A 2010 study included 50 youth (7–17 years), 25 with HIV and 25 without, who were matched for age and gender [6]. In addition to collecting Kaufman Brief Intelligence Test, Second Edition (KBIT-2) and Behavior Assessment Scale for Children, Second Edition (BASC-2) data, MacCAT-T scores were obtained. HIV positive youth responded to a treatment scenario about HIV/AIDS, while youth without HIV responded to a scenario about strep throat. Scores on the MacCAT-T were different based on age, with 7–11 year-olds scoring lower than those older than 12 years. However, there was no difference between those with or without HIV. Scores in both groups were lower on understanding and reasoning compared to appreciation and expression of a choice. There was no significant relationship between KBIT-2 or BASC-2 scores and MacCAT-T scores. This study did provide some qualitative assessment of responses to MacCAT-T testing noting doubt and skepticism about an HIV diagnosis may have impacted scoring.

In 2011, researchers used the MacCAT-T to assess the decision-making capacity of adolescents with anorexia nervosa (AN) [53]. The study included two groups: 35 adolescents with AN at an inpatient university hospital, and 40 healthy adolescents recruited via community posting for comparison. All adolescents were of female gender and less than 17 years. This study assessed the impact of cognitive, emotional, and behavioral functioning on decision-making capacity by administering the following additional tests: Youth Self Report (YSR) for emotional and behavioral functioning, Wechsler Abbreviated Scale of Intelligence (WASI) for estimated IQ, and Immediate Verbal Memory and Attention/Concentration subscales of the Children's Memory Scale (CMS) for memory and attention. There were no group differences found for understanding or expressing a choice, however, healthy adolescents significantly outperformed adolescents with AN in every reasoning subscale component of the MacCAT-T, except comparative reasoning. These differences between the control adolescents and adolescents with AN were present despite all participants having a similar IQ, verbal memory, and attention skills.

In a 2014 study, researchers recruited 72 participants (13–24 years) with HIV from a pediatric/adolescent infectious disease program [7]. All participants had been in the program for at least one year, were aware of their positive HIV diagnosis, and were taking antiviral medication. Demographic variables including gender, ethnicity, illness characteristics (e.g. mode of transmission, T cell count, viral load), and disease management characteristics (e.g. appointment adherence, determined by the percentage of appointments kept over the 12 month period preceding enrollment) were also collected. The researchers expanded upon the MacCAT-T script developed by Chenneville and colleagues as described above [6]. The scoring rubric featured a scale with no credit, partial credit, or full credit, and was developed in accordance with Grisso's and Appelbaum's guide for scoring the MacCAT-T [19]. The script and scoring rubric were validated by HIV experts, including infectious disease physicians, nurses, outreach coordinators, and those in academics. The MacCAT-T was administered to youth in interviews lasting 20–60 min. Each interview was scored by at least two independent examiners to minimize reliability issues, and internal consistency was measured as well. Cutoff scores for determining capacity were derived from recommendations by Aydin and Sehiralti, though these cutoff scores were specifically assessed in adults [3]. Results of the MacCAT-T interviews demonstrated that participants had the 100% competencies in appreciation and expression of a choice subscales, while understanding and reasoning scores were lower, at 61.76% and 60.29%, respectively. While the sample size was too small to detect statistically significant differences based on demographic characteristics, participants 18 years and older had higher scores in understanding, reasoning, expression of a choice, and total MacCAT-T.

A 2015 study from the Netherlands included 17 youth (6–18 years), at risk for a specific cardiac disease to determine if the MacCAT-T could be used to determine capacity to consent to predictive genetic testing [28]. All participants were recruited from the clinical genetics department of one hospital after their clinicians recommended predictive genetic testing. In order to be clinically relevant, the MacCAT-T was adapted to pertain to predictive genetic testing with specifics such as the influence of genetic testing on social relationships and how parents and friends would feel if the youth chose to do predictive genetic testing. The reference standard was a video-taped counseling session including all of the information needed for a participant to consent to genetic testing, which was then reviewed by a panel of experts. Three panelists each rated the reference standard and MacCAT-T interviews. Results of the reference standard classified 71% of youth as competent, while the MacCAT-T classified 94% as competent. The mean age of youth classified as incompetent and competent by the reference standard were 9.3 years and 12.1 years, respectively. Notably, there was high inter-rater agreement for total MacCAT-T scores, at 0.95. There was 76% agreement between MacCAT-T and reference standard competence classifications. However, inter-rater agreement for the reference standard classifications overall was lower, with only 47% of cases having agreement among all three panelists, compared to 65% of cases for the MacCAT-T. Importantly, when the MacCAT-T was used, agreement increased overall, suggesting that use of a standardized tool in conjunction with clinical assessment may be beneficial.

A 2017 study used the MacCAT-T to assess decision-making capacity for psychiatric treatment in 22 youth (11–18 years) hospitalized for acute psychiatric disorders [37]. These disorders included bipolar and related disorders, depressive disorders, schizophrenia and other psychotic disorders, and personality disorders. The MacCAT-T was administered in 20–35 min semi-structured interviews and focused on participants' current treatment regimens, which included antipsychotic medications, antiepileptic mood stabilizing medications, selective serotonin reuptake inhibitors (SSRIs), or benzodiazepines. Cognitive functioning was assessed using the Wechsler Intelligence Scale for Children III (WISC-III). Psychiatric symptomatology and emotional and behavioral functioning were assessed with the Brief Psychiatric Rating Scale v4.0 (BPRS) and a youth self-report (YSR), respectively. All participants in the study were able to successfully complete the MacCAT-T; however, 36% were not able to express a choice, almost half scored less than 5 (range 0–8) on the reasoning subscale, and 41% of participants had impairment in the appreciation subscale. While there were no significant correlations between psychiatric diagnoses and MacCAT-T scores, the presence of excitement/mania was significantly negatively correlated with understanding subscale cores and higher emotional and behavioral challenges overall correlated to lower expression of choice scores.

Finally, the MacCAT-T has been used to assess medical decision-making capacity of TGE youth in a Dutch study published in 2021 [55]. 74 out of 280 eligible TGE adolescents (10–18 years), the majority assigned female at birth (AFAB), were recruited from two Dutch gender clinics. Cognitive, emotional, and behavioral functioning were also assessed using the Dutch Wechsler Intelligence Scale for Children or Adults and the Child Behavior Checklist completed by parents. A reference standard similar to the study involving predictive genetic testing was used which involved an interview scored by experts who were blinded to both youth demographics and characteristics and the results of other expert judgments. Experts also judged the MacCAT-T interviews, which were based on the choice to undergo pubertal suppression and included key questions such as "what would be possible consequences if you would choose to undergo this intervention, and what if you would not?" Notably, one clinician involved in the diagnostic trajectory of each youth was included as an expert. In this study, 89.2% of participants (over 10 years of age) were found to have capacity by the MacCAT-T, and 93.2% by the reference standard. Interrater agreements between panelists were 89.2% for the reference standard, and 86.5% for the MacCAT-T. Of note, female sex assigned at birth and higher total IQ scores were correlated with higher MacCAT-T scores, while age, family status, clinic location, duration of diagnostic trajectory, and presence of emotional and behavioral difficulties were not. Age was not significantly correlated with total MacCAT-T score and only eleven participants (ages 11–17) were judged to lack capacity. The researchers note that a requirement for starting pubertal suppression at these Dutch clinics is "having no interfering psychosocial difficulties," and that, in the Netherlands, transgender adolescents undergo a psycho-diagnostic assessment and several monthly sessions with a mental health clinician that usually take place over 6 months which may contribute to the rates of capacity seen in their sample.

Discussion

This scoping review has identified the current data regarding assessments of youth capacity to consent to gender-affirming treatments, finding only one study to date that has assessed the capacity of TGE youth making treatment decisions. Similar to two previous reviews conducted in 2004 [40] and 2008 [38], the included studies demonstrate that variables such as gender, psychiatric conditions, and cognitive measures are inconsistently associated with adolescent performance on capacity

measures and should not be used as proxy measures for capacity.

While age cut offs (e.g. 14 years for consent to research, 18 years for legal majority) are often used as a proxy for decisional capacity, early research by Weithorn and Campbell examining medical decision-making in youth aged 8–21 revealed that age alone does not fully determine capacity [60]. Age was correlated to performance on some or all aspects of capacity assessments in two studies of youth capacity included in this review, but importantly, not in all studies. Of 16 studies identified across the 2004 [40] and 2008 [38] reviews, only one study found a positive correlation between age and understanding, six had mixed results, and nine found no relationship between age and capacity. This review adds to the mounting evidence that age is an inadequate marker of decisional capacity for youth. Many potential correlates with decisional capacity, including some identified in adolescent brain development research [15], have not yet been systematically examined and could include social determinants of health, family support and economic status, individual agency, self-directed information seeking, and ability for abstract thought [18]. Most studies of capacity have also failed to incorporate elements that have been identified as important in adolescent decision making, such as setting, difficulty of decision, degree of emotional response, and relationship to the treating clinician [30, 49].

Previous reviews [38, 40] have noted significant differences in methodologies in research on capacity prior to 2008, including sampling, design, and measurements. Only three studies included in those reviews used standardized measurement tools [38, 40]. Standardized capacity assessments for youth making treatment decisions may have several potential benefits for TGE youth. While only one study specifically examined the capacity of TGE youth, taken together, the studies in this review demonstrate the feasibility of utilizing a standardized assessment tool when capacity is in question. Importantly, multiple studies included youth with mental health diagnoses and demonstrated that these youth, with the exception of those hospitalized for psychiatric conditions, are also generally capable. Given that clinicians of gender-affirming medical treatments have expressed concern about co-occurring mental health diagnoses [56], this review highlights that capacity evaluation is possible in youth with mental health conditions.

Additionally, clinicians may judge capacity differently based on the likely prognosis or outcome of a youth's decision [39] and the use of a standardized tool may reduce bias especially in light of the high inter-rater agreement (0.865–0.95) of the MacCAT-T total scores [28, 56]. Of note, Hein et al.'s study on capacity to consent to predictive genetic testing demonstrated that the use of the MacCAT-T increased overall agreement among panelists. However, in Vrouenraets et al.'s study on capacity to consent to gender-affirming care, interrater agreement among clinicians using the reference standard was also high. This suggests that different clinicians may have different ways of assessing capacity, and when there is inconsistency or particular difficulty assessing a youth's capacity, the use of the MacCAT-T may be especially helpful [55].

Similar to other authors calling for a more nuanced understanding of capacity, the data in this review emphasize the need to consider cognitive and developmental factors when assessing decision-making capacity in youth, rather than utilizing strict age cut-offs to determine capacity [21, 26, 27, 37, 47]. This is also in keeping with calls for greater adolescent participation in healthcare from multiple youth-focused organizations. The United Nations Convention on the Rights of the Child states in Article 12 that youth have the right to "participation/right to have one's views expressed freely (in accordance with the age and maturity of the child)" [46]. The World Health Organization (WHO) has developed a clinical tool for supporting youth participation in healthcare that highlights "joint exploration of the situation and options… [and] common synthesis of the situation" as a way of promoting youth participation [61]. The National Academies of Sciences, Engineering, and Medicine, Health and Medicine Division, in the recently published The Promise of Adolescence: Realizing Opportunity for All Youth, emphasizes the responsibility of clinicians to empower youth to participate in their healthcare in accordance with their maturity level [41].

While the MacCAT-T is feasible and potentially useful in TGE youth, it may prioritize rational reasoning and be oriented toward cognitive functions [54], potentially overly relying on memory for its assessment of understanding [22]. Studies that include adult responses as the "reference standard" may also unknowingly prioritize certain ways of making decisions or valuing certain outcomes. The use of adults presumes a "correct decision" which is not the case in most value and preference-sensitive clinical treatment decisions, such as the choice to pursue gender-affirming medical treatment. The alternative, using a recorded or observed informed consent discussion (already occurring in the clinical care of the patient) may be feasible, but is time and personnel intensive, especially if attempting to ensure inter-rater reliability with multiple evaluators both scoring of the MacCAT-T and the reference standard.

Assessing capacity is only one aspect of informed consent, and a youth's ability to make decisions is dependent, at least in part, on the quality of information provided. It is also imperative that information is developmentally appropriate [21]. This importance is highlighted

in Mandarelli et al.'s study of decision-making capacity in youth hospitalized with acute psychiatric disorders, which demonstrated that cognitive functioning was significantly correlated with understanding and reasoning subscale scores on the MacCAT-T, as well as Schachter et al.'s study, which demonstrated that among youth with ADHD, follow-up understanding was significantly correlated with baseline understanding [37, 47]. Other authors have called for cognitively and developmentally appropriate delivery of information to TGE youth [21, 33, 39]. This may include providing youth with separate informational handouts and offering oral explanations when needed, as well as employing teach-back methods, to ensure adequate understanding before a decision is made [21, 39]. Informational materials should be adapted to the health literacy of the youth and developed in conjunction with input from the TGE community [33]. For TGE youth, this may include using a tablet to present videos and figures at a developmentally appropriate level to better educate youth about risks, benefits, alternatives to hormone therapy, and fertility preservation [33].

While there are multiple models of care for TGE individuals [16], given the potential for individual variability in capacity for TGE youth and ongoing debate about potential harms or regret, a dual consent model [21, 56] has been proposed. This dual consent procedure would require that youth and parents get separate versions of information and sign a consent form. Based on research indicating that by approximately age 12, youth have decision-making capacity, Hein et al. recommend a dual consent procedure for youth aged 12 and up, regardless of the treatment decision under consideration, until they reach the age of legal consent. For TGE youth presenting for gender affirming medical treatment however, youth and parents often do not present to medical attention at the same point in the decision-making process, with youth typically being farther along in their decision [8, 12], making information provision to parents a priority. Critical reflections on models of care, including informed consent, highlight that providing information and assessing capacity are necessary, but not sufficient for ensuring respect for autonomy, or emerging autonomy in the case of youth [16].

Limitations and Future Research

This review included eight studies with relatively small sample sizes, potentially limiting the generalizability of the findings. Identified studies also employed slightly different procedures for administering and scoring the capacity tools, limiting aggregation of the data. However, this review is the most recent attempt to summarize the available literature on youth capacity to consent to medical treatments since 2008.

Further research that focuses on TGE youth decision-making capacity is needed as only one study thus far has utilized the MacCAT-T in TGE youth [55]. Future research should include more diverse populations and clinical settings. It should also include youth accessing pubertal suppression at a younger age, as well as youth with cognitive impairments or differences, such as those with ASD [31, 51] or psychiatric conditions [32]. In addition, a greater understanding of what role parents and clinicians should take when a TGE youth is deemed as not having decision-making capacity is needed [55]. Shared decision-making practices are likely to complement standardized capacity assessments [8, 9, 12], but more empiric data is needed. Parents often provide a supportive role and provide perspective for youth, in terms of social or family concerns [9]. Future research could also include developing a shared decision-making tool designed specifically for TGE youth, and evaluating its consistency, barriers to usage, and effects on decision satisfaction and youth-parent relationships [9]. Future research of how legislation limiting access to gender-affirming medical treatment impacts decision-making practices among TGE youth, parents, and clinicians is also needed as legal policies are changing access and availability of gender affirming care [50].

Conclusions

This review adds to the empiric evidence available of youth capacity to consent to treatment decisions across a variety of clinical contexts, including gender affirming care, improving our understanding of TGE youths' capacity to consent to gender affirming treatment. The use of a standardized tool to assess capacity, such as the MacCAT-T, shows promise in multiple studies of youth making treatment decisions. The use of a tool for capacity assessment may allow parents and clinicians to more reliably understand the growing decision-making capabilities of TGE youth and allow youth to participate meaningfully in their own healthcare decisions during the informed consent process. Due to stigmatization of this patient population and potential mistrust in the healthcare system, it is imperative that clinicians provide a safe, empathetic, "cold cognition" environment, with establishment of rapport prior to such assessments [9, 21, 33, 48]. The dual process model of cognition suggests that humans use both "hot" (in the moment, intuitive, automatic) as well as "cold" (deliberate and rational) modes of thinking and decision making [49]. For adolescents, providing appropriate time, structure, information, and support allows for more deliberative or "cold" decision making [45]. Clinicians should facilitate discussions with the youth to better understand any vulnerabilities that may impact decision-making abilities, such as housing instability, financial instability, or mental health

conditions [4, 61]. Rather than prevent the youth from meaningfully taking part in the decision-making process, these vulnerabilities should be addressed collaboratively between youth and clinicians so that conditions are more conducive to optimal decision-making. Creating a supportive, trusting environment also includes ensuring a youth's chosen name and pronouns are in their medical records, and that the limits of confidentiality are explained [48].

Proxy measures, such as age, should be avoided as they do not adequately reflect the individual and developmental considerations required of clinicians caring for youth. Capacity assessments should ideally be performed by the same clinician over several visits. This allows the clinician to further establish rapport with the youth to build a safe environment. It also respects the developing capabilities of youth, accounts for contextual factors that can potentially impact the capacity of youth during any one visit, provides more time for the youth and family to reflect, and ensures that decision-making needs are continuously being met [4, 33, 39, 46, 61]. Additionally, when there is ambiguity during capacity assessment, clinicians may benefit from consulting individuals in the youth's life who are more familiar with the youth's abilities, such as family members and mental health clinicians.

This scoping review is the first to identify the currently available data regarding assessments of youth capacity to consent to gender-affirming treatments, finding only one study to date that has assessed the capacity of TGE youth making treatment decisions. This highlights the critical need for additional research into the capacity of TGE youth making treatment decisions. The MacCAT-T has considerable potential for use as a standardized tool for assessing adolescent capacity; however, it is not intended to be used as a standalone measure and would therefore be most beneficial if embedded in a process of shared decision-making.

Abbreviations

AFAB	Assigned Female At Birth
ADHD	Attention Deficit Hyperactivity Disorder
AN	Anorexia Nervosa
ASD	Autism Spectrum Disorder
BASC-2	Behavior Assessment Scale for Children, Second Edition
BPRS	Brief Psychiatric Rating Scale v4.0 (BPRS)
CMS	Children's Memory Scale
GnRH	Gonadotropin-Releasing Hormone
HIV	Human Immunodeficiency Virus
KBIT-2	Kaufman Brief Intelligence Test
MacCAT	MacArthur Competence Assessment Tool
MacCAT-CR	MacArthur Competence Assessment Tool for Clinical Research
MacCAT-T	MacArthur Competence Assessment Tool for Treatment
MOC	Measure of Competence
MUA	Measure of Understanding
SD	Standard Deviations
SSRI	Selective Serotonin Reuptake Inhibitor
TGE	Transgender and Gender Expansive
WASI	Wechsler Abbreviated Scale of Intelligence
WHO	World Health Organization
WISC-III	Wechsler Intelligence Scale for Children III (WISC-III)
YSR	Youth Self-Report

Supplementary Information

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Supplementary Material 1

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Author contributions
LGM performed the initial search of literature and selected the articles. All selected articles were read in full by at least 3-4 members of the team. LGM wrote the main manuscript text and created all figures, JFT provided extensive revisions, and KEB and HFS provided suggestions for revisions. All authors read and approved the final manuscript.

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Declarations

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Not applicable.

Consent for publication
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The authors declare no competing interests.

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