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CARE FOR THE TRANSGENDER PATIENTS (C FERRANDO, SECTION EDITOR)

Clinical Ethics Support for Gender-Affirming Care Teams: Reflections from a Scoping Review

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Abstract

Purpose of Review This review aims to provide gender-affirming providers and ethics practitioners with up-to-date knowledge regarding the models of clinical ethics support (CES) available in the transgender care setting, the activities of CES services, and the benefits and limitations of CES in this context.

Recent Findings Literature related to CES in transgender care is limited at present but will likely expand as the number of both transgender care centers and CES services continues to grow internationally. All literature substantively addressing the review question derives from the USA or the Netherlands and describes an "integrative" or "embedded" model of CES, in which ethics practitioners work regularly and collaboratively with multidisciplinary transgender care teams to provide preventive and responsive ethics support.

Summary A scoping review of the literature shows that, at some transgender care programs in the USA and the Netherlands, embedded or integrative CES is available to highlight the ethics issues in everyday practice and to help clinicians navigate ethically complex cases. Other forms of CES available to gender-affirming providers include ethics consultation services and ethics committees. CES in transgender care can involve ethics consultation or moral case deliberation for particular cases; participation in clinical meetings to draw attention to and clarify ethical issues at play; and input into treatment protocol development. To further illustrate how ethics practitioners can contribute to a multidisciplinary approach to gender-affirming care, the authors also provide examples of embedded ethics support in one transgender care center in the USA based on their experiences. Clinicians working in transgender care may benefit from engaging with their organization's CES service or reaching out to local and regional healthcare ethics organizations for support.

Keywords Transgender care · Gender-affirming care · Clinical ethics · Ethicist · Ethics committee

Introduction

Optimal gender-affirming care, like all good healthcare, involves attention to the ethical dimensions of practice. A growing body of literature highlights the kinds of ethical issues faced by clinicians who provide transgender care [1•, 2]. A more limited body of literature discusses the kinds of clinical ethics supports those clinicians can draw upon when faced with ethical issues. As an increasing number of transgender care programs emerge, we sought to understand the scope and nature of clinical ethics support services available to address the unique ethics issues in this area of healthcare. Our review addresses the following question: What kinds of clinical ethics support (CES) are available in the context of gender-affirming care?

A scoping review was conducted to identify the available evidence on CES in transgender care and to provide an

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overview of its content. Our aims were twofold: (1) to provide gender-affirming providers with an overview of the types of CES that may be, or become, available to them and (2) to allow ethics practitioners to consider various models for providing ethics support to transgender patients and gender-affirming teams. We sought to capture any kind of CES in the transgender care context including ethics consultation, embedded ethicists, and ethics committees. A scoping review was considered an appropriate approach to address this broad enquiry and gain a clear understanding of the volume and nature of literature related to the provision of CES in transgender care [3, 4]. In addition to reporting the findings from our scoping review, we also reflect upon our own experiences providing ethical guidance to adult and pediatric transgender care teams, and describe common ethical issues that arise.

Methods

The process used to identify the papers included in the scoping review is detailed in Fig. 1. A literature search was conducted on December 20, 2021, in PubMed, MEDLINE (Ovid), CINAHL, and Google Scholar. These databases were chosen to capture a broad range of clinical ethics publications in the biomedical literature. First, a narrow search was conducted in each of the databases to pinpoint papers related to clinical ethics in transgender care, rather than the broader category of papers related to or touching on ethical issues in transgender care. For this narrower search, the following terms were used in PubMed, with equivalent terms used in the other databases:

("ethicist" OR "bioethicist" OR "bioethics consultant" OR "clinical ethicist" OR "ethics consultant") AND ("transgender").

Though a significant percentage of these results were considered relevant to the review question, due to the limited number of returned results, it was decided to conduct a search that would return a larger pool of literature for greater coverage. For this broader search, the following search was conducted in all databases:

("ethics") AND ("transgender").

These search terms were applied to all fields across the databases. Results were limited to English language publications from the year 2000 onward, and books were excluded. In Google Scholar, only the first 100 results were considered.

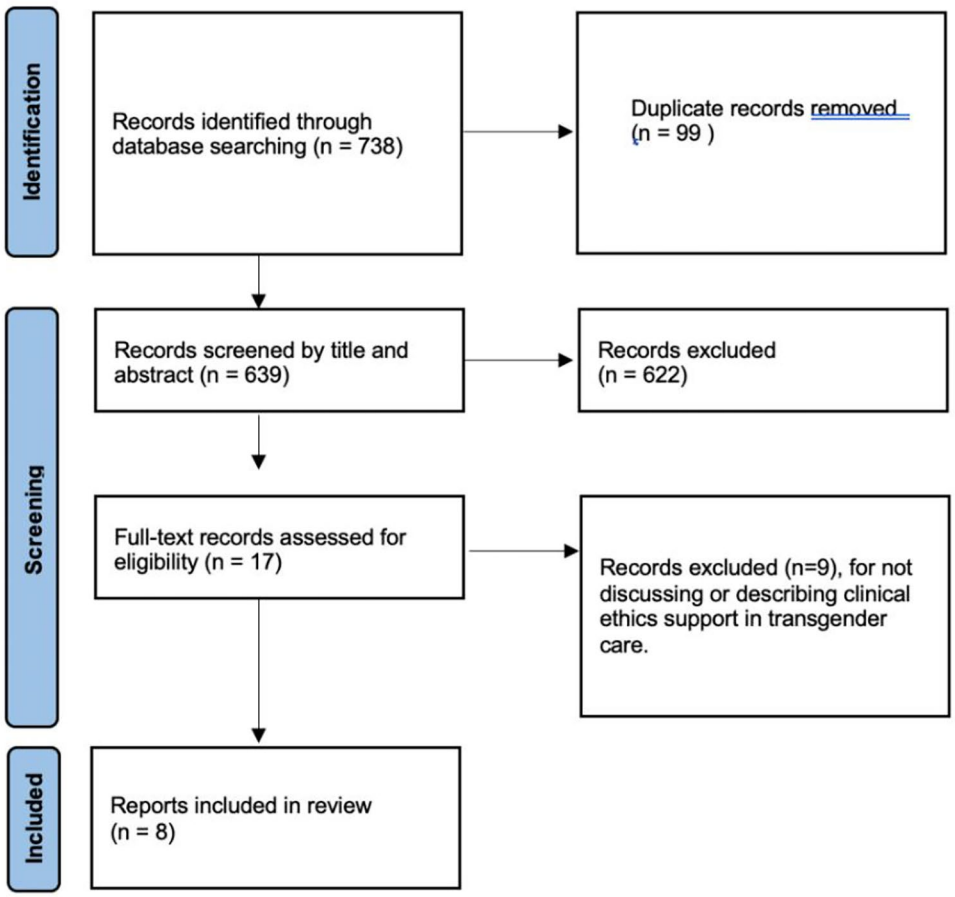

Fig. 1 PRISMA table

This decision was made given the impracticability of reviewing all 97,100 returned results, and the apparent waning relevance of titles by this point. Notably, all results returned from the initial narrow search were captured in the broader search. The searches were repeated on January 10, 2022, to capture any additional publications from the period December 21, 2021–January 10, 2022.

The database searches returned 738 results, of which 99 were duplicates. Title and abstract screening were performed by one author (SF) for the remaining 639 results. Titles were considered relevant if they mentioned, or it was considered possible that the full text may mention, clinical ethics in transgender care. There was a low threshold for inclusion of borderline papers, which then underwent full-text review for inclusion. For instance, titles or abstracts of papers that included case studies of ethically complex cases in transgender care were included on the basis that there may be mention of CES in the full text. Seventeen results were considered possibly relevant.

Full-text review was subsequently performed by two authors (SF and HM) against the following inclusion criteria:

- Conceptual or empirical work that discusses or describes CES in transgender care.
- Published after the year 2000.
- Access to English language version.

Given the sparse nature of literature on the subject, any publication that mentioned CES in transgender care, even if only in a few sentences, was included. Similarly, all publication types apart from books were included. The decision to exclude books was a pragmatic one, given the work that would be involved in full-text review for any mention of CES. Eight publications, as detailed in Table 1, were ultimately included in the review.

Two authors (SF and HM) independently extracted data from the publications using an extraction table that captured (among other things) model of CES; ethics activities; benefits and risks/limitations; and core themes. For each article, SF and HM completed the table and then compared and discussed findings to achieve consensus. Given the lack of empirical literature returned that met the inclusion criteria, formal quality assessment was not performed. However, all included articles derive from peer-reviewed journals.

Nature of Available Literature

Ultimately, only eight articles met the inclusion criteria for this scoping review. Five discussed CES only peripherally, with just three addressing the topic in a substantive way [5••, 6••, 7••]. Of these three substantively relevant publications, two are narrative reviews, and the third includes empirical evidence regarding CES in transgender care. The narrative reviews relate to experiences developing ethics programs at interdisciplinary transgender care centers [5••, 6••]. The empirical work evaluates the usefulness of moral case deliberation (MCD) as a CES activity in multidisciplinary transgender care for adolescents [7••].

All eight publications included in this review present experiences from either the USA or the Netherlands. Among the three papers from the Netherlands, two relate to experiences at one transgender care center (the Center of Expertise on Gender Dysphoria (CEGD) of the Amsterdam University Medical Center) [1•, 6••]. The third [7••] relates to CES at CEGD of the Amsterdam University Medical Center along with one other center, the transgender clinic at Curium-Leiden University Medical Center in Leiden. Accordingly, the findings from this review relate to a narrow field of experience.

Of note, this scoping review will not have captured reports of CES in transgender care in languages other than English. There may be additional work taking place in this space that has not been published in English or has not been published at all. This body of literature is likely to grow as the fields of transgender care and clinical ethics continue to develop internationally.

Results: Clinical Ethics Support in the Literature

Table 1 highlights the models of CES in transgender care identified in the literature, and their key activities, benefits, and risks. The publications that substantively addressed the research question all described an "embedded" or "integrative" model of CES in transgender care. The US literature refers to the embedded approach, and the Dutch to the integrative approach. Both the embedded and integrative models function as part of a broader CES service [9]. In these models, rather than providing ad hoc advice on challenging cases when consulted, ethicists work regularly and collaboratively with transgender care teams to provide specialized CES through a variety of activities, discussed below. Both the Dutch and US literature emphasize the collaborative nature of these models, in which clinicians become increasingly able to independently identify and address ethics issues in their everyday work, and ethicists strengthen their own expertise in transgender care. The Dutch integrative model emphasizes the dynamic and collaborative nature of ethics programming. Hartman et al. [6••] note that "… the CEGD professionals were continuously involved in both the implementation and further development of CES, in part by participating in and co-creating the evaluation of CES activities. The types of CES services offered were not planned out or decided in advance, but evolved during the process …

Table 1 Clinical ethics support findings from publications included in analysis

Author & Year	Article Type	Purpose	Ethics activities	Model of clinical ethics support	Benefits of model	Risks/Limitations of model
Chen et al. [18]	Narrative Review	To describe a model of clinical practice and its development at one pediatric gender program	- Ethics consultation	Clinical ethicist	- Helpful in navigating disagreements between parents	- None described
Gerritse et al. [1]	Empirical research: Focused Ethnography	To systematically map the moral and ethical challenges faced by healthcare professionals working in one transgender care center	- Moral case deliberation (MCD) - Ethics research	Integrative clinical ethics support (CES)	- Increases transparency in clinical decision making by making normative assumptions explicit - Helps clinicians reach and substantiate decisions by "facilitating self-awareness and sensitivity to context and ethical issues - Makes clinicians more aware of, and responsive to, the moral dimensions of their work	- Tension between building trust with team and maintaining critical distance
Harris and Frader [19]	Commentary responding to published case study	To propose an ethically supportable approach to care in a case presented by another set of authors, as part of a set of commentaries on the subject case	- Helping patients and families clarify their values - Helping clinicians understand the moral implications of different courses of action	Clinical ethicist	- Facilitates decision making that takes into account relevant values	- None described

Table 1 (continued)

Author & Year	Article Type	Purpose	Ethics activities	Model of clinical ethics support	Benefits of model	Risks/Limitations of model
Hartman et al. [6••]	Narrative Review	To describe and promote a specific, integrative model of CES based on the experience of one transgender care center	- MCD - Attending weekly multidisciplinary meetings - Collaborating with transgender care providers in education activities - Ethics research - Ethics logbook activity, followed by workshops on identified ethics issues - Discussion of ethics issues at regular policy meetings - Interactive workshops at international conferences to address ethical issues in gender-affirming care - Steering committee meetings to guide ethics activities and develop follow-up actions to address issues that emerge from MCD	Integrative CES	- Increases transparency in clinical decision making by making normative assumptions explicit - Makes clinicians more aware of the moral dimensions of their work - Increases clinicians' awareness of various perspectives on clinical scenarios - Helps clarify ethical dilemmas and improves clinicians' ability to respond to moral issues in their practice	- Responsibility for follow-up on insights and identified action strategies is a challenge - Tension between building trust with team and maintaining critical distance - Not always enough time to thoroughly discuss moral issues beyond merely raising them - Overdependence by clinicians on ethicist for addressing ethical issues

Table 1 (continued)

Author & Year	Article Type	Purpose	Ethics activities	Model of clinical ethics support	Benefits of model	Risks/Limitations of model
Mabel et al. [5]	Narrative Review	To describe how interdisciplinary transgender healthcare teams can benefit from the support of an ethicist	- Ethics consultation - Supporting patients' decision-making processes - Attending patient case conferences - Supporting clinicians' decision-making processes, for example by helping: (a) weigh the risks and potential benefits of interventions to determine what is ethically appropriate; (b) support deliberation about what constitutes the best interests of a pediatric patient in a particular case; (c) identify possible value judgments inappropriately impacting decision-making; and/or (d) provide process and communications guidance for exploring sensitive concerns - Contributing to the development of guidelines or treatment protocols - Contributing to research design and scholarship	Embedded clinical ethicist	- Helps foster "culturally competent care and an affirming patient experience." - Addresses ethical issues proactively, before they escalate into more serious ethical challenges - Enables ethicists to cultivate specialty expertise in transgender care that translates into more effective ethical guidance - Brings a unique perspective to team's research and scholarship	- Ethicist can be perceived by patients as an additional gatekeeper - Tension between building trust with team and maintaining critical distance - Overdependence on ethicist for addressing ethical issues - Clinicians may feel their authority is being usurped - With an embedded model, only receiving the perspective of one ethicist

Table 1 (continued)

Author & Year	Article Type	Purpose	Ethics activities	Model of clinical ethics support	Benefits of model	Risks/Limitations of model
Mabel et al. [12•]	Narrative Review	To outline strategies for managing different types of moral distress in pediatric gender-affirming care	- Ethics consultation, including: (a) supporting clinicians in thinking through ethically supportable courses of action and (b) providing input about optimal decision-making processes - Moral distress interventions, including: (a) unit-based ethics discussions and (b) moral distress reflective debriefs	- Ethics consultation service - Ethics committee	- Clinical ethics support can mitigate different types of moral distress in pediatric transgender care	- None identified
Vrouenraets et al. [7••]	Empirical Research: Mixed Methods	To evaluate the usefulness of Moral Case Deliberation in multidisciplinary transgender care for adolescents	- MCD, including: (a) policy changes and development as a result of deliberation in a particular case; and (b) structurally embedded MCD in regular interdisciplinary meetings	Integrative CES	- Increases clinicians' awareness of others' perspectives on clinical scenarios - Increased attention to the moral dimensions of practice - Improves clinicians' ability to respond to similar ethical issues in future cases - Improvement in quality of treatment decisions - MCD led to increases in mutual respect and open communication among team members	- Slowing down the process of developing a treatment plan - Creating fatigue if too many cases are discussed or a saturation point for ethics learning is reached
Wolf-Gould et al. [11]	Case Commentary	To discuss the ethical implications of treating BRCA + trans-feminine youth	- Ethics committee review [not undertaken in this case as ethics committee declined review, citing lack of training in gender-affirming care]	Ethics committee	- None described	- Lack of training leading to uninformed recommendations

to continuously respond to the changing CES needs of the CEGD team." The remaining publications identified individual clinical ethicists, ethics consultation services, and ethics committees as CES mechanisms that may be available to transgender care providers.

The CES activities identified in the literature included ethics consultation; MCD; ethics research and scholarship; participation in multidisciplinary meetings and patient case conferences; education; identification of frequently encountered ethical issues, including through systematic processes such as an ethics logbook [6••]; contributions to policy changes and development of guidelines and treatment protocols; and delivering moral distress interventions. In descriptions of both the embedded and integrative models, participation in regular clinical meetings was highlighted as an "opportunity for the ethicist to apply an ethical lens to a patient's case and (re)orient the team's thinking by identifying the ethical considerations in play" [5••]. Hartman et al. [6••] detailed how ethicists asked clarifying questions during weekly clinical meetings. For instance, "'Why did you choose to not treat this patient?' or 'How does this relate to argument X which was just mentioned?' … Through asking these questions, [the ethicists] aimed to make the existing implicit moral frameworks more explicit and thereby visible and subject of discussion for the team" [6••].

In the Dutch context, MCD is a key CES activity in transgender care (and in clinical ethics work more broadly). MCD consists of a structured discussion, facilitated by a specifically trained individual, in which clinicians collectively reflect on an ethics question related to a clinical case [8••]. The aim of MCD is to facilitate better ethical decision making by encouraging healthcare providers to engage with different perspectives on the ethics challenges they experience in their everyday work [6••]. The comparable ethics activity reported in the US context is ethics consultation. Ethics consultation, performed according to the American Society for Bioethics and Humanities "ethics facilitation" approach, involves clarifying the ethics issues that need to be addressed, gathering relevant information, performing ethical analysis, and identifying the ethically acceptable options in a specific patient case [10]. Ethics consultation is generally performed independently by a clinical ethicist, including an embedded ethicist, or by an ethics committee or other ethics response group. A key feature of ethics consultation, which distinguishes it from MCD, is that the ethicist incorporates relevant ethical and legal norms to provide recommendations to the clinical team. The ethicist strives to integrate stakeholder perspectives into the ethical analysis, but the recommendations that are provided to the team are always based upon the relevant ethical and legal norms, and not upon stakeholder perspectives. This means that there are times that the stakeholders may not personally agree with the recommendations provided. This highlights one central difference between ethics consultation and MCD, which does not aim to provide a team with normative recommendations to utilize within their clinical care.

Some of the benefits of CES identified in the literature include making clinicians more aware of the moral dimensions of their work; improving clinicians' ability to respond to similar ethical issues in future cases; addressing ethical issues proactively, before they escalate into more serious ethical challenges; and promoting mutual respect and open communication among team members, among other perceived benefits. For example, Hartman et al. [6••] share the following experience: "We found that [CES]... can be valuable since it urges [ethics] professionals to help the team in revealing the ethical dimension of everyday issues that were previously interpreted as merely factual, medical or were even completely unnoticed by the team." Mabel et al. also note that having an ethicist "identifying the ethical considerations in play... represents a form of preventative ethics insofar as it may limit serious ethical dilemmas from developing down the road" [5••].

Some of the risks and limitations of CES identified in the literature include the tension between building trust with a team while also needing to maintain critical distance; the fact that there is not always time to thoroughly discuss ethics issues in the clinical context, beyond merely raising them; overdependence on an ethicist for addressing ethical issues; patients perceiving CES as an additional gatekeeper; and slowing down the development of a treatment plan because of the steps involved in addressing ethical issues, among others. The most cited limitation was the tension between building trust with a team and being sufficiently critical and/or maintaining the necessary distance to provide an "outsider" perspective. As Gerrtise et al. [1•] put it, CES practitioners must "employ a delicate balance between taking care for the relationship and win[ning] the trust of clinicians on the one hand and being critical and explicitly normative on the other." Mabel et al. comment that "an ethicist may consciously or unconsciously attempt to align their perspective with those of other members of the transgender health care team to preserve relationships" [5••]. Notably, this limitation is specific to the embedded or integrative model of CES support highlighted in the literature. While not commented upon in the literature, ad hoc CES may not result in the same concern.

One publication included in the scoping review highlights that available CES services may not always be equipped to provide the guidance sought by transgender care providers. In a case study, a transgender care team referred a pediatric case to a hospital's ethics committee, but the ethics committee declined review, citing a lack of training in gender-affirming care [10]. As noted by other publications, utilizing ethics professionals who have a requisite understanding of

transgender care is crucial to optimal CES in the transgender care space [5••].

Of note, some of the CES happening in the US centers on mitigating moral distress among care providers [12]. The Dutch literature is also cognizant of the role that CES may play in reducing moral distress among clinicians [6••]. However, literature substantively discussing the subject was not retrieved in this scoping review.

Our Experiences Providing CES in Transgender Care

Given that this scoping review revealed limited literature on the subject, we also share our experiences as ethicists contributing to pediatric and adult transgender care through an embedded ethicist model.[1] In order to highlight the types of ethical issues in which CES may be helpful to gender-affirming clinicians, we limit the experiences described in this section to a few examples of ethics consultation and describe the ways in which ethics practitioners can provide support through this particular CES activity. Upon reviewing the types of ethical issues that prompted requests for ethics consultation in our embedded model, LS and GM identified a few key challenges in transgender care that we think are worth highlighting. Elsewhere, Gerritse et al. provide a robust and empirical account of the scope of ethical issues encountered in the Dutch integrative model [1•].

A common issue prompting requests for ethics guidance in pediatric gender care is parental disagreement or lack of support from one parent for gender-affirming care. Clinicians with whom we have worked on the Cleveland Clinic pediatric gender care team frequently seek support from both parents before commencing treatment since data suggest that support of both parents optimizes clinical outcomes [13•]. In these cases, the clinical ethicist often provides guidance to the team regarding navigating parental disagreement and optimizing social support, and ultimately makes recommendations regarding the circumstances under which it would be ethically supportable to proceed with pubertal suppression or hormone therapy in the absence of agreement from both parents. These recommendations are conveyed verbally to the team as well as in the electronic medical record. The ethicist also provides validation to the clinical team during multidisciplinary meetings when these cases are ongoing.

With regard to adult transgender care, we highlight three additional types of ethics challenges that often prompt requests for consultation. The first relates to the appropriateness of surgical or medical intervention where there is increased risk due to a patient's medical comorbidities. For example, in one case, an ethics consultation was performed as part of a multidisciplinary evaluation of a patient's surgical candidacy for vulvoplasty in the setting of advanced cancer. The patient's life-limiting prognosis raised questions about the balance of risks and burdens associated with a surgical intervention that posed a significant risk of blood clot during the postoperative recovery period due to her cancer and increased immobility. In this case, the embedded ethicist met with the patient to support the gender care team's assessment of the patient's understanding and appreciation of surgical and perioperative risks, as well as alternative treatment options. The ethicist also supported the team's consideration of information relevant to their decision to offer surgery, including justice concerns arising from delays in the patient's access to gender care related to her psychosocial history.

Another common ethical challenge relates to questions about the authenticity of treatment preferences in light of concerns about potential coercion. For example, in one case, an ethics consultation was prompted by a patient's sudden decision to discontinue estrogen therapy and start testosterone after seven years of hormone therapy, vaginoplasty, and breast surgery. The patient was in a new relationship and had made statements suggesting that this decision was based on a partner's preferences. In cases for which there is concern that decision making is subject to undue influence from close others, the ethicist's practice generally consists of meeting with the patient to understand their decision through a deeper exploration of goals and preferences related to gender care. Being transparent about the reason for involvement is crucial to both maintaining trust and fostering conversations that help uncover a patient's authentic preferences. The ethicist also typically recommends the involvement of a psychiatrist. In the case described, the ethicist provided guidance through formal recommendations in chart notes, as well as multidisciplinary team discussions, to inform the plan of care.

Finally, ethics guidance is often sought to clarify the scope of clinician obligations, including when barriers to therapeutic alliance arise. In one example, a patient stated they felt they were being "subject to an inquisition" by the gender care team. This individual then behaved in a way that was perceived as threatening by two members of the team. The team questioned whether they could ensure a therapeutic alliance with the patient going forward. The ethicist met with the clinicians and discussed the various ethically supportable options. The ethicist suggested setting clear and appropriate boundaries with the patient regarding required standards for interaction before discontinuing the relationship. Alternatively, the team could inform the patient they were no longer comfortable working with them and refer

[1] All authors have, at various points, had experience providing embedded ethics support to the Transgender Surgery & Medicine Program at Cleveland Clinic.

them to another provider to ensure continued access to care. Both of these pathways require upholding clinician obligations of non-abandonment and transparency.

Of note, when there are few or no other gender care providers in an area, a clinicians' obligations may be different, as discontinuing a patient–provider relationship can result in harms to a patient who may be unable to access care elsewhere. Although the ethicist met only with the healthcare team in this specific case, we note that there could be utility to meeting separately with the patient to identify any misunderstanding about goals, concerns, or communication styles. As highlighted in Table 1, there is a risk that the patient would perceive the ethicist as another gatekeeper, but the ethicist might also be perceived as a neutral third party who is well-positioned to help repair the therapeutic alliance.

How Clinicians and Transgender Care Teams Can Find CES

Many healthcare organizations have ethics consultation services or ethics committees. The quality of these services can vary, as some individuals performing this work have little to no training or knowledge of recognized standards [14]. In the USA, as part of a push for continued professionalization of the field of clinical ethics, ASBH launched a certification process for healthcare ethics consultants in 2018, [15] the aim of which is to certify whether an individual is minimally competent to perform ethics consultations [16]. We recommend soliciting CES from ethics professionals who have experience regularly performing ethics consultations (as opposed to doing so only occasionally) and are trained in this work. Clinical ethicists who provide CES full-time and clinicians in other specialties for whom CES is a component of their paid professional work would be well-suited. Volunteer ethics committee members who do not regularly provide CES or who lack appropriate training in recognized standards may not be.

Clinicians may benefit from inquiring with their organization's ethics consultation service or ethics committee as to whether such an individual exists, or reaching out to local and regional healthcare ethics organizations for support. For example, in Ohio where some of us work, the Bioethics Network of Ohio is an organization composed of individuals working in healthcare ethics [17]. The leadership of such an organization may be able to connect interested clinicians and gender care teams to competent ethics practitioners who can provide CES. As noted elsewhere in the literature, we also recommend that individuals providing CES in the context of transgender care be gender-affirming, familiar with the clinical aspects of transgender care, and free of anti-transgender bias [5••].

Conclusion

This scoping review reveals that little has been published regarding CES in transgender care. Based on the existing literature, we have summarized the common models, ethics activities, benefits, risks and limitations of CES in this context. We highlighted a number of different models of CES provided to gender-affirming care teams in both pediatric and adult settings. Integrative and embedded models are presently the most common form of CES in transgender care described in the literature. Where there are CES services available, the literature describes benefits such as helping gender-affirming clinicians become more aware of, and better able to respond to, the moral dimensions of their work. Given the lack of literature on this topic, in order for ethics practitioners to continue developing expertise, we would encourage ethicists to share their experiences (either through publication or at professional conferences), to continue conducting empirical research to inform their work, and importantly, to explore the ways in which the quality of CES can be assessed and improved.

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Declarations

Conflict of Interest The authors declare that they have no conflict of interest.

Human and Animal Rights and Informed Consent This article does not contain any studies with human or animal subjects performed by any of the authors.

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•• Of major importance

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