Asian Bioethics Review
https://doi.org/10.1007/s41649-024-00303-7

ORIGINAL PAPER

The Current State and Challenges of Clinical Ethics Consultation for Prenatal Diagnosis: A Qualitative Study of Committee Employee Perspectives in China

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Received: 28 February 2024 / Revised: 2 June 2024 / Accepted: 4 June 2024

Abstract

Clinical ethics consultations (CECs) play an important role in resolving ethical issues in clinical practice worldwide. The government has encouraged the development of CECs in China to address the ethical challenges arising in prenatal diagnosis. So far, the current state and challenges facing CEC remain understudied. This study aimed to explore the perspectives of employees on ethics committees for prenatal diagnosis in 13 medical institutions in Hunan Province, China. Twenty-eight employees participated in interviews. Our qualitative approach employed content analysis to identify major themes in interviewees' responses, which covered the composition and vision of their prenatal diagnosis ethics committee, as well as the challenges they faced. The results show that CEC in China is in an exploratory stage, with models for CEC composition, and workflow varying significantly. Therefore, we propose the future direction of efforts to improve CECs, including improving CEC working mechanisms and operating procedures, strengthening ethical training for healthcare workers and ethics committee employees, and developing more specific ethical guidance based on the accumulated experiences of ethics committee employees in the early development of CEC for prenatal diagnosis.

Keywords Clinical ethics consultation · Ethics committee · Prenatal diagnosis · Clinical ethics

Abbreviation

CEC Clinical ethics consultation

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Published online: 05 September 2024

Introduction

In hospitals, clinical ethics as an organised activity has developed more slowly than research ethics (Saunders 2004). During the 1960 to 1980s, the USA began to establish clinical ethics committees, mainly kidney-dialysis selection committees, abortion review committees, and infant care review committees (McGee et al. 2002). After that, many other countries started to establish similar committees (Orzechowski et al. 2020; Dörries et al. 2011). A hospital in the UK established an informal clinical ethics committee in 1995 to provide advisory opinions on ethical issues in prenatal diagnosis (Thornton et al. 1995). In accordance with the Universal Declaration on Bioethics and Human Rights, an ethics committee should be established to advise on ethical issues in clinical practice and stimulate debate, education, public awareness, and participation in bioethics (UNESCO 2005). However, few studies describe clinical ethics consultation (CECs) in developing countries (Moodley et al. 2020).

Medical ethics committees were first established in China's hospitals in 1994, with the main function of providing ethics consultations (Zhang et al. 2017). After 1997, their role shifted towards primarily overseeing ethical reviews of biomedical research involving human subjects, with the provision of ethics consultation decreasing significantly, even to the point of disappearance (Zhang et al. 2017). China's medical institutions have no universal mechanism for conducting CECs, and few institutions provide such consultations (Zhang et al. 2018). Only in cities like Beijing and Shanghai are there ethics committees that spontaneously carry out informal ethical consultations (Liang 2019). China's National Health Commission (2019) promulgated "The Measures for the Administration of Prenatal Diagnostic Techniques" in 2002, which recommended that healthcare institutions applying for prenatal diagnostic techniques should establish ethics committee; in the event of the discovery of foetal anomalies, cases involving ethical issues should be referred to ethics committee for discussion. Prenatal diagnoses inform decisions about whether to continue with a pregnancy, which raises ethical issues that require consulting with experts in prenatal diagnosis. Currently, some high-level tertiary hospitals in China have voluntarily established specialised ethics committees for prenatal diagnosis (Affiliated Hospital of Guangdong Medical University 2023; The Second Xiangya Hospital OF Central South University 2023). In addition to referencing the composition standards of medical ethics committees, prenatal diagnosis ethics committees also need genetic counsellors, obstetricians and gynaecologists, neurologists and neurosurgeons, and other related professionals. These committees handle CECs and ethical reviews of research projects and techniques. CEC remains in the exploratory stage in China. The common practice among hospitals in China is to establish a prenatal diagnosis ethics committee to conduct ethics consultations on related ethical issues. The ideal model would be to have a comprehensive ethics committee to handle all clinical issues.

Asian countries have generally been slower than other countries in developing CEC, and some developing countries have not yet universally established CEC

mechanisms. A survey in Turkey showed that physicians need ethics consultation, but the institutional basis for providing such services is lacking (Kadioğlu et al. 2011). Likewise, medical institutions in China have not yet established a unified CEC mechanism. Conversely, Singapore was relatively early in incorporating CEC into its healthcare system. Its Ministry of Health established a centre (then known as the Clinical Ethics Training, Research and Support Network) in 2009 to establish a network of hospital ethics committees and develop local CEC capacity (NUS Centre for Biomedical Ethics n.d.).

Interestingly, the ethics committees in some Asian countries often handle CECs and ethical reviews of biomedical research. In many hospitals in Japan, CECs are carried out by the hospital ethics committees, which are responsible for conducting ethics reviews of research on human subjects and providing consultation on individual ethical issues that arise in clinical practice (Nagao and Takimoto 2023). In South Korea, as exemplified by Seoul National University Hospital, in addition to the hospital ethics committee, an institutional ethics committee was established in 2018 to conduct ethical reviews of all research involving human subjects. This committee is also tasked with providing CECs (Yoo et al. 2023). The situation in China is similar to those in South Korea and Japan, with a number of prenatal diagnostic ethics committees now carrying out CECs and ethical reviews of research projects.

Prenatal diagnosis is used to assess the presence of disease or potential disease in the foetus (HKU Department of Obstetrics and Gynaecology 2023). The incidence of congenital abnormalities in China is about 5.6%, close to the level of middle-income countries worldwide (National Health Commission 2012). China promulgated the "Law on Maternal and Infant Health Care" in 1994 (revised for the second time in 2017) to protect the health of mothers and babies and improve their quality of life. It mentions that termination of pregnancy is permitted under the following circumstances after prenatal diagnosis, and the physician should explain the situation to both husband and wife: if the foetus suffers from a serious hereditary disease; if the foetus has serious defects; or if the continuation of the pregnancy is likely to jeopardise the life and safety of the pregnant woman or to seriously jeopardise the health of the pregnant woman due to the presence of a serious disease (National People's Congress 2017). However, in clinical practice, the situation regarding pregnancy termination is very diverse and complex, and sometimes, some patients request termination if the foetus has minor defects, which is similar to the situation in France (Garel et al. 2002). In this process, the incapacity of society to properly care for disabled children and the risk of eugenic pressure have been identified (Garel et al. 2002). In addition, researchers from China and the USA have reported a lack of a robust, evidence-based informed consent procedure in prenatal diagnosis (Johnston et al. 2017; Sui 2012). Further refining the informed consent procedure is necessary for respecting women's autonomy.

However, there are significant cross-cultural differences in the practice of prenatal diagnosis and termination of pregnancy (Geller et al. 1993), particularly in terms of maternal autonomy. Although Chinese law regarding maternal and infant health care stipulates that termination of pregnancy should be entirely the choice of the pregnant individual (National People's Congress 2017), in the context of traditional Chinese culture, the family plays an important role in medical decision-making

and may even make decisions on behalf of the patient under some circumstances (Raposo 2019). Findings from a study in Turkey suggest that the entire families of pregnant women have the right to decide whether to terminate a pregnancy (Long et al. 2018). In Spain, a woman's partner may influence the decision to continue or terminate a pregnancy, and family and friends also play a role in decision-making (Ferrer Serret and Solsona Pairó 2018). In cultures where the family plays a central role in decision-making, appropriate family involvement in medical decisions should not be overlooked (Lin et al. 2013).

Moreover, the welfare system for disabled children requires further refinement to alleviate family burdens (Dong et al. 2023). Despite the rapidly increasing amount and coverage of social security for disabled families, these measures do not offset the income gap between families with and without disabilities (Loyalka et al. 2014). China's welfare system for children with disabilities is actively being improved. For instance, the General Office of State Council has issued the "Fourteenth Five-Year Plan for the Development and Improvement of Special Education", which outlines the main goal of establishing a high-quality special education system by 2025 (General Office of the State Council 2021). Lastly, public attitudes towards disability can influence the choice to terminate pregnancy after prenatal diagnosis. Research has shown that the general public typically holds negative implicit attitudes towards disabled people (Wilson and Scior 2015). Due to these circumstances, ordinary families fear giving birth to children with defects and often request termination of pregnancy in cases of minor abnormalities.

The importance of CECs for prenatal diagnosis in China is increasingly prominent in policy and practice when dealing with ethical issues related to birth defects. However, the current status and existing problems of its operation have not been deeply researched and understood. Therefore, this study aims to explore the views of the prenatal diagnosis ethics committee employees on the current situation of CEC in China, including the composition and vision of prenatal diagnosis ethics committee. By analysing and discussing the challenges faced by prenatal diagnosis CEC, we hope to provide empirical insights for the future development of CEC in China and new ideas for dealing with clinical ethical issues.

Methods

Hunan Province is in central China. The prevention and treatment of congenital disabilities in Hunan Province are representative of the national situation. The incidence of congenital disabilities in Hunan Province is higher than the national average (Hunan Daily 2016), so various measures have been taken to strengthen the prevention and treatment of congenital disabilities. For example, Hunan Province enacted Measures for "the Prevention and Control of Birth Defects", which has provided legal support for preventing and controlling congenital disabilities. Moreover, its congenital disabilities prevention and treatment network has been constantly improved, and the three levels of preventive measures have been strengthened. Premarital medical examination, pre-pregnancy eugenic examination, and folic acid supplementation have been incorporated into basic public services, and

the free maternal prenatal screening programme has subsequently been incorporated into the provincial government's key livelihood projects to promote. The province's prevention and treatment of congenital disabilities have progressed, with the incidence of congenital disabilities declining year-on-year for two consecutive years: 221.87 per 10,000 in 2014; 218.39 per 10,000 in 2015; and 1803 per 10,000 in 2016, finally curbing a trend that has been on the rise since 1996 (Hunan Provincial Health Commission 2017).

Recruitment and Sampling

As of June 30, 2022, 498 medical institutions in 30 provincial-level administrative districts across the country were approved to carry out prenatal diagnostic techniques. Among them, Hunan Province has 27, the fifth most nationally (National Health Commission 2022). We conducted in-depth semi-structured interviews with employees of prenatal diagnosis ethics committees at 13 medical institutions in Hunan Province, including those from the regions of Changsha ($n=9$), Zhuzhou ($n=1$), Chenzhou ($n=1$), Huaihua ($n=1$), and Zhangjiajie ($n=1$). Because prenatal diagnostic facilities (mostly those with higher levels of maternal and child health care) are mostly concentrated in Changsha, the capital city of Hunan Province, and the ethics committees of these facilities face more complex ethical issues, target sampling was used to select 28 participants from the five regions. Participants were selected based on the following criteria: (1) qualified employees, including members and staff who worked for ethics committees for prenatal diagnosis, and (2) at least one year of experience working on an ethics committee. All 28 physicians contacted agreed to participate (100%). We recruited participants until data saturation was reached.

Data Collection

This study collected data from November 2022 to February 2023. XXW and YW, Ph.D. bioethicists trained in social science research methodologies, conducted 20–50-min interviews via telephone or face-to-face. Table 1 lists all questions in the interview guide.

Data Analysis

All participants provided written or electronic informed consent. YW led analysis in collaboration with the research team. All transcripts were de-identified using these codes prior to analysis. We used content analysis to analyse the main themes in the data (Krippendorff 2019). YW analysed the interview transcripts using qualitative data analysis software (NVivo. 12) and iteratively discussed and refined the coding structure with XXW and DL. Subsequently, TCH conducted a secondary analysis of the main themes, examining the transcripts for different themes. Based on the interview outline, we derived a codebook with 6 codes and 34 sub-codes. Content that emerged through coding was organised through team

Table 1 Semi-structured interview guide

1. When was your prenatal diagnosis ethics committee established? Can you introduce the clinical ethics consultation (CEC) of your committee?
2. How many members does your prenatal diagnosis ethics committee have? What is your opinion about the composition of its membership?
3. How would you describe the scope and function of your prenatal diagnosis ethics committee? Have there been any subsequent changes in its functions?
4. Since the establishment of your prenatal diagnosis ethics committee, what is its workflow like? Have there been any subsequent changes in the workflow?
5. Has your prenatal diagnosis ethics committee been self-evaluated and externally evaluated? Do you think it is necessary to evaluate its performance?
6. Have you encountered any challenges in conducting prenatal diagnosis CEC?
7. Can you describe the strengths and possible weaknesses of the current prenatal diagnosis ethics committee?
8. For services related to prenatal screening and prenatal diagnosis, how do you think ethics committees should currently work to provide ethical support for such services?
9. Is there anything else you would like to share about the prenatal diagnosis ethics committee?

discussion into three main categories: the member composition of prenatal diagnosis ethics committees, the vision of prenatal diagnosis ethics committees, and the challenges they faced in prenatal diagnosis ethics committees. Participants' responses were initially identified using two criteria: the participant's serial number (1–28) and their professional background. For example, "Participant 1, ethics" refers to the first participant, indicating that they have a professional background in ethics. These categories and the subcategories from which they were aggregated are shown in Table 2 and further explained in the results narrative below.

Results

Themes reached saturation after interviewing 28 participants. Most participants ($n=15$) were members, and the rest were chairs/vice chairs ($n=5$) or ethics office directors/secretaries ($n=8$) (Table 3). The participants' professional backgrounds were mainly ethics/law, obstetrics/gynaecology/paediatrics, genetics, nursing, and reproductive medicine. Most participants ($n=20$) were female. Four participants had over 10 years of ethics-related work experience.

At present, ethics committees in China do not provide CEC on a wide scale; CEC is relatively concentrated on ethics committees related to prenatal diagnosis. A few ethics committee members who have provided CEC services felt that committees needed to be diverse and representative to safeguard patients' rights and develop optimal decision-making mechanisms. Most participants believed that the purpose of CEC was to make suggestions to help patients and their families make informed decisions. Working mechanisms and procedures must be standardised for Chinese CEC, and consistent ethics training is urgently needed.

Table 2 Main study findings

Main categories	Subcategories	Connotation of relationship
Composition of prenatal diagnosis ethics committees—diversity and representation	Each prenatal diagnosis ethics committee should have multidisciplinary membership	A diverse membership can provide more professional and comprehensive information from different perspectives, making the discussion on ethical issues more thorough
	Each committee should appoint members who are representative professionals in their fields	Choosing representative members is important to ensure the reliability and accuracy of the committee's decision-making
The vision of prenatal diagnosis ethics committees—suggestion oriented	Patients' and families' decisions should be fully respected	Each patient's condition and family situation are different, and the reasons for making decisions vary as well
	When the patient disagrees with the committee's conclusion, the committee will continue to collect information and further explain the relevant content to the patient	The committee makes suggestions to help patients and their families make informed decisions, but the final decision-making authority lies with the patients and their families
Challenges faced in prenatal diagnosis ethics committees—procedures and training	There is a lack of relevant regulations to guide the working mechanisms and operating procedures of clinical ethics consultation (CEC)	Prenatal diagnosis CEC remains in the exploratory stage, and refining relevant mechanisms and procedures would be beneficial for standardising consultations
	Lacking clinical ethics training, especially in the field of prenatal diagnosis	Ethical training is beneficial in cultivating the sensitivity and awareness of healthcare workers and ethics committee employees regarding clinical ethical issues

Table 3 Characteristics of 28 study participants

Characteristics	*N* (%)
Participants' role in ethics committee	
Chairman/Vice Chairman	5 (17.9)
Member	15 (53.6)
Others (director/secretary/administrator of the Office of the Ethics Committee)	8 (28.6)
Gender	
Female	20 (71.4)
Male	8 (28.6)
Professional fields	
Ethics/Law	5 (17.9)
Obstetrics and Gynaecology/Paediatrics	6 (21.4)
Genetics	4 (14.3)
Nursing	5 (17.9)
Reproductive Medicine	3 (10.7)
Others (Public Health, Analytical Chemistry, Ultrasound Medicine, Biostatistics, Stem Cells and Regenerative Medicine)	5 (17.9)
Work experience (years)	
1–5	15 (53.6)
6–10	9 (32.1)
> 10	4 (14.3)
Categories of medical institutions	
General hospital	10 (35.7)
Special hospital (maternal and child health, genetic)	18 (64.3)
Education level	
Bachelor's degree	8 (28.6)
Master's degree	13 (46.4)
Doctoral degree	7 (25.0)
Professional titles	
Primary professional	2 (7.1)
Intermediate professional	7 (25.00)
Senior professional	18 (64.3)
Not applicable	1 (3.6)

Composition of Prenatal Diagnosis Ethics Committee—Diversity and Representation

The membership of CEC for prenatal diagnosis must be diverse and representative to safeguard the rights of patients and develop the best decision-making options for them.

A diverse membership provides more professional and comprehensive information from different perspectives, making the discussion on ethical issues more thorough:

> The committee must include experts in obstetrics and gynaecology, as well as other medical experts. Such diverse expertise is needed because of the numerous genetic diseases that can be revealed through prenatal diagnosis. Moreover, the committee should also incorporate sociologists, as well as ethics or legal experts from external institutions. (Participant 3, clinical medicine and ethics).

> There are too many committee members with medical backgrounds, which might lead to insufficient protection for patients. The committee encountered a case (we have simplified this case) in which, after prenatal diagnosis, the couple requested the termination of pregnancy. The committee members with a medical background, due to medical considerations, immediately agreed to this decision. However, after discussion with a lawyer, the committee began to consider other factors and gained a more comprehensive understanding of the case before making a final decision. If decisions are made blindly before fully understanding these circumstances, mistakes could occur. (Participant 4, paediatrics).

Still, having members from external parties is important to avoid conflicts of interest and ensure the impartiality and objectivity of decision-making:

> The members are all from one medical organisation, and I don't think that's good. There must be members from outside hospitals and organisations. (Participant 3, clinical medicine and bioethics).

> Since the positions and backgrounds of committee members differ, they consider the matter from different perspectives, which can make the solution more well-rounded. (Participant 20, genetics; Participant 22, stem cells and regenerative medicine).

However, choosing representative members is important to ensure the reliability and accuracy of the committee's decision-making:

> The members should have some expertise or authority in their field so that the committee's decision-making is more secure. (Participant 3, clinical medicine and bioethics).

In particular, those members who represent the perspective of the public and understand the actual situation of patients and families can provide clinicians with more intuitive perspectives and more acceptable and implementable recommendations:

> Community members mainly analyse the issues from the patient's point of view based on the patient's specific situation, so that the patient may be more receptive. (Participants 5, obstetrics and gynaecology; Participants 17, genetics).

Members from non-medical backgrounds must undergo recruiting processes to ensure members who are passionate about ethical contribution are selected:

> When choosing a member from a non-medical background, you can't just find anyone. There must be a level of professionalism; look for experts in humanities, such as sociology or ethics, who understand ethics and the relevant requirements of ethics and the country. Non-medical members hold an important value because ethical counselling is not just a medical judgment – it involves many factors. (Participant 25, law).

The Vision of Prenatal Diagnosis Ethics Committee—Suggestion Oriented

The function of CEC for prenatal diagnosis currently lacks unified and specific guidance, with various medical institutions currently determining how to unify practices.

Some participants reported that patients' and families' decisions should be fully respected:

> The CEC for prenatal diagnosis only advise patients and their families based on the patient's preferences, leaving them with the final decision. However, patients' choices are generally consistent with the committee, so they typically respect the committee's recommendations. (Participant 1, ethics; Participant 6, genetics).

During the discussion process, CEC respect for patients' diverse backgrounds is emphasised:

> In addition to medical and economic reasons, cultural reasons need to be fully considered. For example, patients' and families' traditional customs and cultures often profoundly impact patients' perceptions and must be respected. However, young patients' values may change as times change. (Participant 15, law).

When the patient disagrees with the committee's conclusion, the committee will continue to collect information and further explain the relevant content to the patient to ensure they are fully informed and choose autonomously:

> If the patient disagrees, the committee will continue to review relevant information to achieve fully informed consent as much as possible. The ultimate principle is to fully synthesise the views of the patient and their family, with the patient having the greatest autonomy. (Participant 7, genetics).

However, a few participants felt that the ethical consultation synthesised the views of many parties and considered the legitimacy and reasonableness of the decision-making. They reported that not implementing the ethical consultation would weaken the role and credibility of ethics committee:

> The committee synthesised the views of many parties and spent significant workforce and resources to conduct the discussion. Not implementing recommendations will weaken the role of the committee. (Participants 9 and 18, reproductive medicine).

Challenges Faced by Prenatal Diagnosis Ethics Committee—Procedures and Training

CEC for prenatal diagnosis is in the development stage:

> There is no document to standardise how the committee operates, the composition of its members, their responsibilities, etc. (Participant 8, nursing; Participant 16, ultrasonic medicine).

Some participants reported that the government should introduce relevant laws and regulations to standardise the construction and development of prenatal diagnosis CEC:

> Many committees have not established standardised operation practice. (Participants 24, reproductive medicine).

Apart from prenatal diagnosis, many areas in clinical practice require the intervention of CEC; however, healthcare professionals currently lack sufficient awareness of ethics and guidance from ethics professionals:

> Many areas of clinical work require the help of CEC, for example, whether to cease treatment for some critically ill patients. However, people don't view this as an ethical issue. (Participant 5, obstetrics and gynaecology; Participant 17, genetics).

Similarly, authorities must improve relevant regulations to promote the integration of ethics into clinical practice and protect the rights and interests of patients and doctors:

> Sometimes, very special problems are encountered in clinical practice, and the government lacks an enforcement standard for handling these problems. I think it should introduce CEC to promote the standardisation of clinical ethics. It should regulate medical behavior and protect the rights and interests of our doctors, as well as safeguard the rights and interests of patients. (Participant 5, obstetrics and gynaecology; Participant 17, genetics).

Regarding training, ethics training specific to prenatal diagnosis is relatively rare but necessary. A specific ethics training programme is needed to improve the ethical awareness of healthcare professionals and the professionalism of CEC members:

> General ethics training is also needed, and ethics training specific to prenatal diagnosis would be better; training specific to prenatal diagnosis ethics is currently lacking. (Participants 2, ethics; Participants 20, genetics).

Therefore, training methods must be diversified to increase the attractiveness of the training, which could include, for example, using a case study:

> A typical case to explain how to do ethical counselling can make the training more effective, as long as it is done once everyone will know it. (Participant 25, law).

Simultaneously, a refined training plan is needed:

> Committee members should be professionally trained, and the committee should offer precise training. Training should be conducted according to the operation, and the responsibility and division of labour of each member should be clear. (Participant 25, law).

Discussion

Empirical research focused on CEC in China is lacking. Our study is the first to use in-depth interviews to provide a preliminary understanding of the status of CEC. The findings reveal the challenges faced by ethics committees and that CEC in China are currently in the early developmental stage. In China, CEC for prenatal diagnosis currently has a preliminary development. Most previous studies focused on discussing CEC in general. A few have focused on CEC that specialise in serving a particular medical field. CEC frequently occurs in acute care hospitals (Fox et al. 2022), with some programmes focused on providing services in specific contexts, such as intensive care units (Picozzi and Gasparetto 2020), psychiatry (Bruun et al. 2018), paediatrics (Leland et al. 2020), and end-of-life situations (Haltaufderheide et al. 2020). No studies have specifically discussed CEC for prenatal diagnosis, and only a few mentioned that obstetricians should seek professional consultation, which may provide a useful forum for discussion and, thereby, resolution (Women's Health Issues 1990). Chinese medical institutions have not established a CEC system similar to that for research ethics review, and medical staff and patients have no access to expert consultation when they encounter difficult clinical ethics issues (Liang 2017). Prenatal diagnostics raise several important ethical issues, some related to diagnostic testing in general and others to the specific circumstances of pregnancy (Gates 1993). Therefore, ethics consultation is necessary to deal with these ethical issues. Therefore, neither the existing Chinese regulations nor previous studies have clearly proposed the development mode of CEC for prenatal diagnosis.

In our study, participants described the need for diversity and representativeness in the composition of CEC for prenatal diagnosis. Indeed, calls for multidisciplinary membership have existed throughout the history of clinical ethics committees, and the value of diverse membership is generally recognised (Prince and Davis 2015). Participants emphasised the importance of selecting professionals with a high level of expertise and authority in the field as committee members. Clinical ethics experts must cover a variety of relevant areas of knowledge, requiring special analytical skills, and should have expertise in counselling, including conflict mediation or crisis intervention (Reiter-Theil 2001). Members of CEC should be increasingly professionalised, including the introduction of standards of competence, quality review, and ethical guidance on the practice of ethics counselling (Prince and Davis 2015). Professionalisation aims to ensure that ethics counsellors are adequately trained, competent, and legitimate (Prince and Davis 2015). Diverse and representative membership facilitates the ethical advisory capacity of CEC.

Clinical ethics committees have been slower to develop than research ethics committees, and many clinical ethical dilemmas are arguably more complex than research ethical dilemmas (Szeremeta et al. 2001). A Canadian study found that "hybrid committees" that serve as clinical and research ethics committees are rare (Racine 2007). Healthcare professionals initially confused research ethics committees with clinical ethics committees (Moodley et al. 2020). Ethics counselling activities differ significantly from ethics review activities. According to Silverman, the purpose of counselling is not to make determinations or even recommendations but rather to enhance action-taking by gaining consensus from all parties involved in a case (e.g. the healthcare team, the patient, and the family) (Silverman 1994). Therefore, the core aim of ethical counselling is to listen to multiple opinions, be patient-centred, and assist in informed patient decision-making (Silverman 1994). Perhaps the most valuable role of CEC is to emphasise the difficulties inherent in clinical ethical dilemmas, not just provide simple answers (Gillon 1997). CEC should focus on providing advice to enhance patient decision-making.

Currently, the biggest challenge facing CEC for prenatal diagnosis in China is the lack of standardised procedures. A Norwegian study found that committee members recognise a need to improve their routines and procedures, clarify their profile and field of responsibility, increase awareness of the committee, secure adequate operating conditions, and develop organisational integration and support (Pedersen et al. 2009). Similarly, participants in our study felt that many areas of clinical practice other than prenatal diagnosis require the intervention of a clinical ethics committee, but ethical awareness among healthcare professionals and guidance from ethics professionals were lacking. Committee members in the Norwegian study reported that when health personnel are faced with ethical dilemmas, they usually do not consider consulting a committee (Pedersen et al. 2009). A US study found that physicians who believe in shared decision-making are more likely to use ethical counselling (Orlowski et al. 2006). China must prioritise the formulation of CEC norms and standardise CEC operating procedures.

Participants in our study mentioned that some committee members were not motivated by ethics training due to their busy clinical schedules and demanding professional duties. Clinicians in a Norwegian study similarly mentioned that finding time to be present during deliberations may be difficult (Førde et al. 2008). In particular, prenatal diagnosis usually involves abortion-related issues that require advice within a relatively short period, requiring a high degree of timeliness. Clinicians may have various time constraints, priorities, and thresholds, suggesting the need for flexible routines for submissions and deliberations (Pedersen et al. 2009). A study in the UK found that persuading staff, particularly the junior medical staff, that education on ethical issues matters as much as purely didactic clinical teaching has been a challenge. In addition, no systematic approach to training CEC members exists, and many programmes fail to provide CEC trainees with sufficient knowledge, skills, and experience to develop the required competencies (Ong et al. 2020). Currently, CEC in China remains in the early stages of development. Therefore, the clinical ethics training of healthcare professionals and CEC members must be urgently strengthened.

Conclusion

This study provides a preliminary understanding of the state of CEC in China and provides insight into the challenges to committee counselling services as perceived by committee members. Our study highlights directions for future improvement, including improving the working mechanism and operational procedures of prenatal diagnosis CEC, strengthening ethics training for healthcare professionals and EC members, conducting refined training through case studies, and constructing patient case-centred CEC. The policy of building ethics committee for prenatal diagnosis in China has been adequately explored, but the ethical cases and problems encountered in actual scenarios are often more complex. Therefore, more detailed guidance should be developed based on accumulated experience in the early development of ethics committees.

Limitations

First, CEC is still in the preliminary exploration stage in China, and the prenatal diagnosis ethics committee employees may not be aware of the differences in their respective ideas and practices. Uniform norms are needed for future CECs in China to reduce practice variation. Second, some prenatal diagnosis ethics committee employees had not received ethical training in the three years before being interviewed. Thus, their understanding and handling of ethical issues in prenatal diagnosis might differ from those who had recently received ethical training, potentially impacting the interview results. Follow-up studies should reduce the variability of the participants to increase the stability of the findings. Third, the interviews were mainly conducted in one province, so our findings may not represent ethics committees in other regions of China. In addition, future research could extend to other groups and regions to better understand the current situation, while further exploration of ethical dilemmas faced in CEC is needed.

Author Contribution XMW was responsible for the concept and study design. YW conducted the interviews and coded the data. TCH and YQZ had oversight of the coding of the data. The data were interpreted by all authors. YW wrote the original draft while XMW reviewed and edited the draft. All authors critically revised the manuscript for important intellectual content. XL, XZ, and DL supervised the study. All authors gave final approval of the work to be published.

Funding This study was funded by National Social Science Fund of China, Research on Moral Issues in the Field of Contemporary Science and Technology (grant number 22&ZD044); the China Postdoctoral Science Foundation (grant number 2023M733977); Changsha Science and Technology Plan Project (grant number kh2302018); Major Scientific and Technological Projects for collaborative prevention and control of birth defects in Hunan Province (grant number 2019SK1010).

Data Availability The data that support the findings of this study are available from the corresponding author, upon reasonable request. All data are in Chinese.

Code Availability Not applicable.

Declarations

Ethics Approval and Consent to Participate All methods were carried out in accordance with relevant guidelines and regulations stated in the Helsinki Declaration. Local ethical approval was obtained from the Institutional Review Board (IRB) of Xiangya School of Public Health at Central South University (XYGW-2022–97) in Changsha, China. Informed consent was obtained from all participants. Respondents in this study were informed that participation was voluntary. We explained that the participants were providing their consent to take part in the study.

Consent for Publication The data obtained would be published in academic communities.

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