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Paediatric and adolescent fertility preservation procedural training and service provision: a qualitative study exploring views of clinicians in Australia and New Zealand

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Abstract

Background Remarkable progress in paediatric and adolescent fertility preservation (FP) has led to growing demand for services. However, best practice for gamete and gonadal tissue in paediatric and adolescent patients remains ill-defined. We explored the views of FP clinicians and laboratory staff on training needs for paediatric and adolescent FP procedures and services, the barriers across the FP pathway, and suggestions for improving service delivery.

Methods Semi-structured interviews were conducted with multidisciplinary oncofertility experts from Australia and New Zealand. Data analysis of interview transcripts used the Framework Method. Results are reported with straight descriptions consistent with Qualitative Descriptive methods.

Results Eighteen oncofertility clinicians and reproductive laboratory staff were interviewed. Paediatric surgeons viewed ovarian and testicular tissue harvesting within their scope of practice, though not gonadal tissue grafting. Education through direct observation and videos, and incorporation of oncofertility care into formalised surgical training programs was deemed important. Reproductive laboratory staff recommended that surgical training should include gonadal tissue harvesting techniques and guidance regarding adequate tissue volume removal. Reproductive laboratory staff requested bereavement training to better prepare them to support discussions with families. Oncofertility counselling and follow-up was not considered within scope of surgical practice by some surgeons and highlighted an unmet educational need by others.

Conclusions As FP procedures become more widespread, building of a surgical and laboratory workforce with the skills to implement care is important. A multidisciplinary approach, supported by clear governance frameworks outlining roles, responsibilities and best practice before, during, and after FP procedures, is essential to delivering high-quality, coordinated care.

Key words: Paediatric, Adolescent, Fertility preservation, Surgery, Oncofertility, Qualitative

Highlights:

- Best surgical practice guidelines for paediatric FP are unclear despite increasing demand.
- Surgical training in gonadal tissue harvesting was recommended by reproductive clinicians.
- Bereavement care and counselling training were identified as unmet educational needs.

1. Background

Remarkable progress has been made in the area of fertility preservation (FP), which has resulted in increasing demands from various patient groups, including paediatric and adolescent patients. Children and adolescent young adults (CAYA) diagnosed with cancer in Australia now have five-year survival rates of 84% and 89%, respectively, due to advances in cancer treatment (1). Improved survival rates now allow parents/carers to consider the long-term aspects of their child's health, including future parenthood. Fertility preservation services may also be offered to other patient groups at risk of developing gonadal failure (e.g., premature ovarian insufficiency, Turner syndrome) and transgender individuals receiving gender-affirming treatments (2-4). Fertility preservation is increasingly recognised as an essential service for all patients at risk of infertility (5).

The science of FP is rapidly evolving. In paediatric and adolescent patients, FP techniques include ovarian or testicular cryopreservation. Ovarian tissue cryopreservation (OTCP) typically requires laparoscopy to extract ovarian tissue which is cryopreserved and later grafted back into the body when the patient desires biological parenthood. OTCP is now considered a standard procedure for females at any age however long-term outcomes monitoring in children is required (6-8). Over 200 births have been reported in adult women following OTCP who underwent the procedure post-menarche (9). Meta-analyses report that the chance of live birth per woman who has her tissue grafted is around 28% (7). However, only three births have been reported in women who have had their tissue stored in childhood (5, 10-12). Denominator data are not available for those who have had their tissue stored in childhood as published reports are limited to isolated case studies. Trials of human testicular tissue grafting have just begun, and currently no births have been reported in humans (13), thus, it is still considered experimental. The surgical procedures to collect gonadal tissue have been shown to have low complication rates in children (0-5%) (14-16), and a recent systematic review had shown laparoscopy to be low risk for infants less than 1 year (17). However, there is no gold standard method for selection, harvesting, tissue processing, or grafting of gonadal tissue from children, with significant heterogeneity of surgical management reported worldwide (18-20). Optimal techniques for detection of malignant cells within the tissue prior to grafting have not been determined, particularly for blood borne malignancy (21).

Further challenges to surgical care include the fact that fertility preservation services require rapid mobilisation of multidisciplinary teams across paediatric and adult healthcare services. A single patient may receive preoperative, intraoperative, and postoperative assessment and care from a variety of clinicians or departments. Preoperative care may involve various oncofertility clinicians, including clinical nurse specialists, oncofertility care coordinators, oncologists, gynaecologists, endocrinologists, and clinical ethicists (22). Paediatric surgeons, paediatric gynaecologists, urologists, or reproductive endocrinologists may undertake FP surgery. Post-surgical processing of tissue is generally performed

by reproductive scientists and pathologists. FP has reinforced the collaboration needed between disciplines and services to provide prompt and effective care, however best practice programs for paediatric and adolescent FP remain variable across settings (23). Furthermore, FP surgical experience for many specialists is limited, and there is a lack of there specific credentialing criteria. Understanding the experiences of multidisciplinary clinicians involved in FP may help elucidate best practice goals and identify barriers to timely and equitable access to FP services.

The objective of this study was to explore the views of multidisciplinary experts (such as paediatric gynaecologists, paediatric surgeons, oncologists, endocrinologist, reproductive medicine clinicians, and ethics and legal experts) working in paediatric and adolescent FP in Australia and New Zealand, regarding their perceptions of training, challenges across the FP surgical pathway, and to identify ways to improve practice in this specialist clinical area.

2. Methods

The standards for qualitative research reporting guidelines were used for reporting the results of this study (24).

2.1 Recruitment

This qualitative exploratory study was conducted in Victoria, Australia and recruited leading multidisciplinary paediatric and adolescent oncofertility experts working in Australia and New Zealand. Potential participants from the Australian and New Zealand Consortium in Oncofertility (ANZCO) and the Fertility Preservation Taskforce Victoria (Australia) were invited to participate via email with a participant information sheet and consent form. ANZCO was developed in 2019 and comprises health providers and scientists from the eleven Australian and New Zealand Children's Haematology Oncology (ANZCHOG) centres (22). FP Taskforce Victoria comprises experts from a range of disciplines such as paediatric gynaecology, paediatric surgery, oncology, endocrinology, reproductive medicine, and ethics and legal department from The University of Melbourne, The Royal Children's Hospital Melbourne, the Royal Women's Hospital Melbourne, Peter MacCallum Cancer Centre, and Monash Medical Centre (25). Clinicians were eligible for inclusion if they were involved in clinical care of paediatric and adolescent patients undergoing surgical FP. Twenty-eight clinicians were invited to participate. Ethical approval for the study was received from the [removed for blinding].

2.2 Data collection

Structured qualitative interviews were conducted via a videoconference platform (with or without video function, as per participants' preference) by author [removed for blinding], a Biomedicine Honours student supervised by senior author [removed for blinding], conducting this study to fulfil the

requirements of an Honours degree. The student was supported before, during, and after interviews, and possessed the skills to conduct structured interviews. Data collection occurred August-September 2021 and was planned to be conducted in the field however due to restrictions related to the COVID pandemic interviews were conducted by distance mode. The additional strain on the healthcare system at that time may have impacted availability of clinicians for interview. FP procedures were considered an emergency and oncofertility care continued during the pandemic and was prioritised according to institutional resourcing (ASRM, ESHRE & IFFS 2020) (26). Participants completed the consent form, and provided verbal consent prior to the interview, and provided demographic information (Table 1). Interviews were guided by a structured topic guide focused on training, barriers, and ethical issues related to FP that lasted between 15-30 minutes duration (determined by participants' responses and time). Digital recordings were transcribed verbatim, de-identified, and entered into NVivo 12 (QSR International 2019) for collation, data management, and analysis.

2.3 Data analysis

Interview transcripts were analysed using the Framework Method (27), a matrix-style analytic approach, which involves: data familiarisation; initial coding framework construction; indexing and sorting; reviewing data extracts, coding revision; data summary and display; and category construction and description (27). The data within the matrices were interrogated and synthesised into domain summaries. To ensure researchers kept a reliable link to the source data, direct quotations were retained within the matrix (27). Coding of data was completed in NVivo 12 and summarised onto a coding matrix using Excel. Emergent domains were discussed regularly by authors [removed for blinding] to ensure the analysis was strongly linked to the data source. Given the exploratory nature of the study, we chose to report results with straight descriptions consistent with Qualitative Descriptive methods (28). In this paper, the quotations that support the development of the domains are presented in tables underneath the explanatory text.

2.4 Study setting

Participants recruited for this study represent all 11 ANZHCOG centres. At the time of the study, OTCP was considered innovative and TTCP was considered experimental in prepubertal children. Only one of the 11 ANZCHOG centres offered oncofertility care governed within a novel technologies and clinical ethics framework, as previously reported (22). This was the only centre to offer TTCP, and eight centres offered OTCP to prepubertal patients. FP referral pathways were present in seven centres.

3. Results

Twenty-eight oncofertility experts from ANZCO and the Fertility Preservations Taskforce were invited and eighteen agreed to participate; the majority practised in Australia, and almost two-thirds were women (Table 1). Over half of the participants worked in surgical roles (n=10, 55%) and those in non-surgical roles represented a range of disciplines including oncologists, scientists, clinical nurse consultants (CNC), and non-clinical roles.

Table 1: Participant characteristics

Variable	Responses	n = 18
Gender	Women	11 (61%)
	Men	7 (39%)
Surgical discipline/role* (total proportion 55%)	Paediatric surgeon	4 (22%)
	Reproductive consultant, Paediatric adolescent gynaecologist, and Reproductive Fellow	6 (33%)
Non-surgical discipline/role* (total proportion 45%)	Scientist	2 (11%)
	Paediatric adolescent oncologist, Clinical nurse consultant, Clinical ethicist, Research manager	6 (34%)

*Individual role responses not provided to avoid re-identification of participants

Analysis of interview transcripts have been collated into three broad domains: FP surgery skills, remit and training; Barriers and challenges in accessing and providing FP services; and Ethical challenges related to paediatric and adolescent FP care.

3.1 Surgical background and study context

Before presenting the qualitative results, we provide information regarding the approach surgeons interviewed in this study undertake to provide readers with contextual information.

For procedures involving TTCP, surgeons report:

- Midline scrotal approach (for cosmesis).
- Diathermy a 5mm longitudinal ellipse shape through the tunica albuginea to minimise bleeding and future look and feel of testis. Testicular tissue comes up with it and can be removed with sharp dissection.
- Coagulation of vessels at margins of tunica albuginea for haemostasis.

- Closure in layers with an absorbable suture.

For procedures involving OTCP surgeons report:

- Central port 5mm and two 5mm working ports.
- Visualise both ovaries to ensure they are normal.
- Partial oophorectomy (raise cortical flap) using scissors of at least ½ of the cortex.
- If undertaking a partial decortication, choose an area of smooth cortex and avoid cystic areas if possible (to maximise follicle density) in the collected sample.
- Sometimes complete oophorectomy is undertaken in the context of high-risk treatment, pelvic or total body irradiation.
- Bipolar diathermy for haemostasis.

3.2 Fertility preservation surgery skills, remit and training needs

Surgery skills and remit

Participants expressed mixed opinions when asked about the need for credentialling or special training in FP surgery (Table 2). Some participants reflected on their own profession and reported that additional credentialling was unnecessary because technical training was a component of their specialist training (albeit for other indications). Most surgeons believed gonadal tissue harvesting for FP was within the scope of clinical practice for paediatric surgeons (ovarian and testicular), gynaecologists (ovarian), and urologists (testicular). However, three surgeons expressed that gonadal tissue grafting after thawing required advanced skills, and proctorship by an experienced surgeon was essential. Another participant thought that credentialling requirements across the oncofertility pathway (consent, surgery, tissue collection, and storage) would depend on the centre providing the care. At one paediatric centre, preoperative assessment for OTCP was undertaken by the gynaecology team, where decisions were made regarding fertility risk, pre- and post-op supportive care, nature of surgery (complete versus partial oophorectomy) and laterality of procedures (in the context of pelvic radiation). One participant reflected that the hardest aspect of care was not the surgery but the discussion beforehand and relied on gynaecological assessment prior to the decision for OTCP surgery. Specialists' skill development associated with access to surgical experience was sometimes impacted by the hospital's clinical protocols/arrangement. That is, when FP surgery was conducted in conjunction with another procedure (for the purposes of efficiency) paediatric surgeons rather than gynaecologists lead the FP surgery, impacting on the amount of surgical experience obtained over time by gynaecologists.

Scientists interviewed suggested upskilling for centres with low exposure/volume of FP surgery, to ensure optimal size of tissue collection and laboratory quality control to protect the quality of tissue

processing. It was thought that laboratory accreditation could result in more laboratories being able to undertake the processing of harvested tissue.

Table 2. Paediatric FP surgery skills and remit
Ovarian tissue biopsies don't need a separate pathway because if you can do a Level 3 laparoscopy as per AGES, which any gynaecologist who has done a FRANZCOG should be able to do it. That's minimum standards. (P7 – surgeon)
I think the biggest thing is grafting, not the tissue extraction … having the knowledge of how to perform it, where to locate the graft, and what fashion to insert the graft. (P18 - surgeon)
If the patients had other procedures done, the surgical team was doing it because it was on their theatre list instead of the gynaecology team. (P7 – surgeon)
The answer to [whether there should be a credentialing protocol for FP surgery] – that would really depend on the centre. Not just in the surgery, but in the whole process, where you're collecting tissue, the quality of the tissue, the storage of the tissue and the consent and storage. (P2 – oncologist)
At the moment, there is no test code for tissue preparations. So, the tissue manipulation isn't a registered or recognised test, and I think there should be quality control and quality assurance. (P17 - scientist)
If there was scope for accreditation for [tissue preparation], then more labs may undertake to do the process, not just specifically embryology labs. (P17 - scientist)

FP service education and training needs

Many participants suggested opportunities for upskilling in FP surgery, reporting that education sessions or instructional videos may be helpful for those in clinical practice. Formal incorporation of oncofertility into surgical training programs was considered important for future workforce development and planning with the expectation that fertility preservation procedures would become more widely accessible in 5-10 years. Non-surgical education and training needs were identified at both micro and macro levels (Table 3). Non-clinical participants identified counselling training for non-clinical staff who interact with patients during gamete/tissue retrieval discussions. Further, non-clinical participants identified the need for bereavement training as a key area for upskilling, particularly in the context of liaising with families about the management of stored gonadal tissue in

the event of a child's death. At a macro level, education to improve medical specialists' understanding of FP services was raised. Scientists interviewed suggested upskilling for centres with low exposure/volume of FP surgery, to ensure optimal size of tissue collection and laboratory quality control to protect the quality of tissue processing. It was thought that laboratory accreditation could result in more laboratories being able to undertake the processing of harvested tissue. Further, the scientist participants identified a need for greater awareness of the National Ovarian and Testicular Tissue Transport and Cryopreservation Service (NOTTCS) (which offers transport processing and storage of gonadal tissue from around Australia for centres that do not have access to a tissue cryopreservation laboratory), and a targeted laboratory patient information system to better track patient information (29).

Table 3. FP service education and training needs
Bereavement training is definitely missing from our training. We're trained to be scientists, but we're not really told how to kind of counsel the patients on their fertility preservation journey. I think it's important that we do get some more training in patient contacts and dealing with patients. (P17 – scientist)
Community knowledge, that is the medical specialists are not fully aware of the services, not fully aware of successes, not fully aware where science is at. (P16 – clinical nurse consultant)
[Some surgeons] have said, 'surely you can't do this on really small children', and so I think in Australasia, it would be helpful to have more education around [FP surgery]. (P15 – oncologist)
I think training videos are the most practical approach. So, I would suggest some sort of training module that could either be done online with certification rather than a particular qualification. (P4 - oncologist)
Although we've got a national service setup where we could transport tissue from other states to Victoria, many don't know that that's available or how to access that. I think we need to look at better education of those other centres, so they know what is available. (P11 – scientist)
There isn't a custom-made laboratory or patient information management system for these patients, and I think that is slightly missing. We need a system to [keep track of patient Information]. (P17 – scientist)
It's often the issue about the surgeon not taking sufficient tissue for [lab processing]. I think we need to look at better education of centres around Australia that don't get a [large] level of experience and knowledge. (P11 - scientist)

3.3 Barriers and challenges in accessing and providing fertility preservation services

Participants cited a variety of challenges to accessing FP (Table 4). A lack of clinical ethical frameworks resulted in both testicular and ovarian tissue harvesting not being conducted or not prioritised consistently across the centres. Some participants reported that a lack of guidance on patient selection, contraindications, inconsistent referral pathways, and late referrals were issues that may jeopardise access to FP. Paediatric surgeons reported feeling competent about counselling regarding the FP surgical procedure, the surgical implications, and the surgical complications that could occur. Six surgeons felt that there were few absolute contraindications to FP surgery, however, other surgeons and non-surgeons discussed detailed assessment of co-morbidities to facilitate safe selection of patients for surgery. A number of participants reported a lack of skills in oncofertility consultation, and not being up to date with the latest evidence with regards to FP outcomes as a challenge when caring for paediatric and adolescent patients.

Surgeons and oncologist participants reported concern that there might be inconsistent information provision to patients due to involvement of multiple clinicians and siloed work of clinical specialties. These concerns were not expressed by clinicians who had oversight for the patient across the FP journey continuum (such as oncofertility clinicians/coordinators).

A major barrier at paediatric institutions lacking dedicated oncofertility operating lists included the time-sensitive nature of referrals for fertility preservation, which created uncertainty regarding operating theatre planning and resultant distress for staff and families. This was exacerbated in some regions due to inconsistent funding arrangements, which meant that in some centres, patients required referral to private practice for FP care, creating a financial burden for families. This was not the case in New Zealand (NZ) where federal funding is provided that allows equitable access.

Early referrals were considered instrumental in allowing time to determine patient eligibility and assist families with informed decision making. A strict eligibility protocol for OTCP in NZ was reported to mitigate inequity of access across cultural groups.

Challenges with tissue processing were reported by participants related to logistical issues arising from offsite processing locations. Key concerns identified included timely and appropriate transportation and consistency in tissue processing procedures. It was suggested that more FP coordinators throughout Australia and a greater awareness of NOTTCS may alleviate some of these challenges.

Table 4. Barriers and challenges in accessing and providing FP
I think the only barrier is that people who don't know what [FP] is. For example, with testicular biopsy people were somewhat uncomfortable doing it because it was experimental. (P5 - surgeon)

The only reason that [the patient was referred] was because one of the registrars had been to a talk and so they thought of FP whereas the consultant didn't. (P6 - surgeon)
Certain hospitals charge $2000 for ovarian tissue retrieval process because there's not enough funding. So someone has to pay privately. And then the barriers are the patients miss out or they have to get referred to the public system. (P13 - surgeon)
Our protocol is 0 to 18 year and we've been comfortable with the safety side of that. We're comfortable with the equity side of it and that different cultural groups in New Zealand have gone ahead with [FP]. (P8 - researcher manager)
I would hope that when you're taking the history and the family history, you'll be able to factor in those other risk factors for infertility. But I would say most cancer specialists aren't doing that and then just solely taking the risk based on the treatment and going ok, low risk, I don't have to refer them. And I think it can be quite paternalistic. (P2 - oncologist)
"I look at the other comorbidities, for example risk of bleeding. I'll work through what the risk of doing FP in that setting, or if the patient is immunocompromised. (P2 – oncologist)
"I don't think there's any real contraindication to doing [FP surgery] ... well, I've been doing this FP for a while, and I've never seen a complication from it." (P1 – surgeon)
I know freezing is proven but I'm not up to date with all the latest evidence of use of those products down the track. (P4 - oncologist)
I'm not privy to what surgeons are saying to families, nor are they privy to what I'm saying to the families. So there's potential for contradiction in messaging and potential confusion for the family and the patient making the decision. (P4 – oncologist)
It's issues of getting the IVF media to [retrieval sites] and transport containers being properly prepared at a recordable temperature for the duration, that tissue isn't in transit for too long, and it's arriving at the destination at an optimum time to process it. (P16 – clinical nurse consultant)

3.4 Ethical challenges related to paediatric and adolescent FP care

Ethical issues were raised by participants primarily related to consent and the use of unused FP tissue (Table 5). In relation to consent, the challenge of FP information provision and consultations was raised by a number of participants. Challenges included ensuring parents had an unambiguous understanding of the procedure, were aware that outcomes are currently uncertain, and knew they were under no obligation to proceed. One participant advocated for being transparent about technique

efficacy and the probability of achieving future fertility (and the procedures involved to achieve this). Decision discordance between child and parent was raised as a challenge, as too was a concern when parents are not at all worried about their child's future fertility. Some participants described a tension in the consent process where the patient, being a minor, was unable to consent and there were some occasions where parents did not wish to discuss the procedure with their child at an age where they could reasonably understand.

Views on the hypothetical use of unused tissue for research were explored with three surgeon and three non-surgeon participants. Five (of these six) participants thought it would be unethical to *not* use the tissue for research if it would make advancements in fertility preservation. One participant reported that the option to discard or donate tissue should be available for patients and their families.

Table 5. Ethical challenges related to FP care
They also need to think about what preserving fertility would actually mean. They need to have some sense this is not a magic fix, and there would be other interventions down the track. (P10 – ethicist)
I've had issues where the individual who was a minor has really wanted FP but the parents haven't wanted it. (P14 - surgeon)
We had patient who was old enough to understand and the parents didn't want to talk to him about fertility preservation. (P2 - oncologist)
My main concern is [parents are] not really worried about their child's fertility, even though we counsel that their child may very well survive the cancer treatment. (P13 - surgeon)
I think that FP surgery is fairly ethically sound. It's whether you're giving false hope because we don't know whether there's possible use for the tissue [in the future]. (P14 – surgeon)
I think that research [on unused FP tissue] would definitely benefit future fertility aspects and advancements in fertility preservation. (P18 - surgeon)
I'm not sure about the use of unused tissue for research…. I'm still trying to make up my mind. When it's a child, I think it's different. (P17 - scientist)
Parents have wanted their deceased child's tissue used for research but we can't. I would like it to be used for research if that is the patients' or families' wishes. (P16 - clinical nurse consultant)

4. Discussion

Introduction of new medical technologies has implications for training and certification of medical practitioners and allied staff. This cross-sectional, exploratory study provides insights into the attitudes of FP providers from ANZ regarding FP surgery skills and remit, training needs, perceived barriers to providing FP, and ethical challenges. To our knowledge, attitudes of FP providers to training and credentialling in FP has not previously been explored.

Credentialling is a process whereby an organisation verifies training, experience, and professional standing to determine competence and suitability to provide safe and high quality healthcare (30). Of note, *credentialling* was not defined during interviews with clinicians, allowing them to reflect on different aspects of their scope of practice and training. Most surgeons (paediatric gynaecologists and paediatric surgeons) in this study reported their fertility preservation surgical caseloads were low due to the uncommon nature of paediatric and adolescent FP surgery or due to cases being diverted to high volume surgeons. Thus, surgeon participants suggested training through surgical videos with teaching instructions, proctorship, and direct observation of procedural skills (DOPS). Ghiasian et al. found there is value in all modes to educate and assess surgeons' knowledge; however, DOPS had an advantage as it did not compromise visualisation of surgery and has been shown to provide rapid progression of learning (31, 32).

The surgeon participants indicated that despite the novelty of ovarian and testicular tissue biopsy, their current practice and training (including general gynaecology training) provided them with transferrable skills to competently perform the procedures and therefore separate credentialing for tissue harvesting was reported to be unnecessary. Paediatric FP surgery has been reported to have low risk of complications in appropriately selected patients (0-4% for ovarian tissue biopsy and 0-3% for testicular tissue biopsy) (13-15, 33, 34) which is reflected in surgeons' reports of uncomplicated FP surgery in this study; concerns were more related to institutional and ethical issues. For adult gynaecology patients surgery would usually be in the remit of a fertility surgeon, but for children this could be a general surgeon, paediatric and adolescent gynaecologist (for ovarian tissue harvest) and a general surgeon or urologist (for testicular tissue harvest). However, surgeon participants suggested that credentialing may have a role in ovarian tissue grafting, due to the additional knowledge and advanced skills required that may be outside that scope of generalists (35, 36). Of note the first human trials of testicular tissue grafting are underway. Unlike ovarian tissue grafting which occurs around the time of desired parenthood, pre-clinical studies have suggested that testicular grafting prior to adulthood provides better outcomes possibly due to the hormonal milieu around puberty. If transition of testicular tissue grafting into clinical practice occurs in the future, it is possible that paediatric surgery/urology may play a role, having implications for the paediatric workforce.

Scientists in this study raised the importance of quality tissue extraction (i.e., amount of tissue for processing) to ensure a realistic potential to achieve fertility and optimal quality of tissue for future usage. Techniques for optimal cryopreservation of tissue for children are still being published (34). Inexperience in the extraction and cryopreservation process could further reduce the efficacy of OTCP (37). Inadequate ovarian biopsy size or poor selection of the biopsy site (for example targeting areas with visible follicular cysts and corporeal lutea rather than smooth cortex) can reduce prospects for parenthood (38). Oophorectomy is the preferred option in very small infants where ovarian biopsy alone may not retrieve sufficient tissue (33, 34). Longitudinal studies are required to shed more light on the volume of paediatric tissue required for future fertility, and the long-term impact of oophorectomy in the context of cancer therapy. Clearer protocols and evidence summaries around oophorectomy versus ovarian biopsy would be beneficial for surgeons.

Standardised protocols for non-surgical components of FP surgery, such as the technical aspects of handling, transporting, and storing tissue to ensure maximised biopsy quality were suggested by some participants in this study. Mishandling samples, improper storage, and delayed tissue processing are factors that can compromise tissue quality (39, 40). In contrast to the techniques required for cryopreservation of eggs, embryos, and sperm which most assisted reproduction laboratories are capable of performing, techniques for OTCP and TTCP are biophysically different and require that they be undertaken in experienced, specialised assisted reproduction laboratories (38). Raising awareness of the National Ovarian and Testicular Transportation and Cryopreservation Service (NOTTCS) based in Melbourne, Australia was suggested by participants because this service offers a centralised establishment with the facilities, expertise, and regulations to process gonadal tissue and standardised tissue preparation (38). Centralised referral models (such as those suggested by NOTTCS) play a very important role given the limited outcome data from childhood tissue transplantation. This concept of central cryobanking has resulted in high reproducible success rates from international models (41).

A lack of standardised referral pathways and inconsistent information provision regarding fertility care across ANZCO centres created challenges for patients to access fertility preservation, which is consistent with existing literature (42, 43). A recent study by Lau et al. demonstrated that 64% of ANZCHOG centres did not have standard pathways of referral for oncofertility patients, exacerbating disparities in care (22). This is consistent with findings from systematic reviews, citing lack of referral pathways as the most common barrier to implementation of care (43, 44). International guidelines suggest that rather than identifying a particular discipline to deliver FP consultations, knowledgeable and experienced oncofertility providers are essential. The clinician/s responsible for this care should be clearly designated (8). Robust referral pathways may alleviate issues of delayed referrals, which was reported by participants to limit decision-making time for families and increase pressures downstream on scheduling of FP surgery. Not all patients require referral, especially if they have had

consultation with a knowledgeable oncologist, however for those who are high risk for infertility, delays in referral to experienced oncofertility providers are known to result in patients deciding to decline FP surgery in order to proceed with their cancer treatment, or else to start treatment prior to FP (45, 46). Inconsistent information provision to patients and families was reported as a concern by some participants in this study. Development of referral pathways and defined organisational structures may promote consistent information between clinical teams and patients/families and thereby reduce the risk of patients/families receiving contradictory information and avoid confusion (6, 44). The use of FP-specific decision aids may assist in the amelioration of this issue. Further, the implementation of a nurse coordinator and multidisciplinary meeting can improve awareness and information flow between teams (47).

In addition to referral pathways, ethical frameworks are important to protect patients when introducing novel treatments (48). The lack of clinical ethical guidance at some hospitals resulted in FP procedures not being performed, even though OTCP and TTCP often have low surgical risks. Developing clear ethical guidelines may provide hospitals with clarity and confidence regarding paediatric and adolescent FP services (49). Our study participants identified that a lack of funding and ethical framework were significant barriers to patients accessing FP care. This also results in barriers to clinicians obtaining surgical experience. In Victoria, a governed oncofertility program exists, with publicly funded surgeries and established ethical frameworks, providing surgeons with a landscape of certainty within which to practice FP (49). In New Zealand, OTCP is financially supported by the government, facilitating equitable access for eligible patients. A study in Canada found that implementing a publicly funded program for reproductive care was associated with a rise in FP uptake, highlighting how costs may affect how FP services are delivered (50).

Table 6: Proposed recommendations to address barriers to FP surgery and improve FP services and access (based on study results and expert opinion of the authorship group)
Access
Establish robust oncofertility referral pathways to connect paediatric, adult, and laboratory services.
Implement guidelines for infertility risk assessment (inclusive of risk related to cancer treatments and other potential reproductive risk factors) to improve appropriateness of referrals.
Consider developing national standards for FP eligibility criteria to improve consistency and equity in referrals.
Multidisciplinary teams

Establish communication guidelines for shared information between teams to facilitate consistent information-provision to patients and families.
Consider enhancing surgical training through use of videos with teaching instructions, observation of surgery, and surgical proctorship.
Oncofertility counselling pathways
Oncofertility counselling should be conducted by clinicians who are knowledgeable, experienced, clearly designated, and work within a multidisciplinary team (Mulder et al., 2021). Clinicians with technical expertise such as paediatric urologists and/or endocrinologists for males, and paediatric gynaecologists or fertility specialists for females should provide oversight, notwithstanding overlapping procedural skills with other clinicians for tissue harvesting.
Ongoing counselling and monitoring for long-term or late effects is required. Pubertal onset, progression, sexual, menstrual health and body image concerns are monitored long-term by a gynaecologist, while uterine factor infertility, and fertility impacts are managed by fertility specialists. Males also need endocrinologic and urologic follow-up for late effects.
Technical cryobanking
Develop guidelines for tissue biopsy surgical techniques, which include standardised protocols for tissue removal, processing, freezing, and histopathology reporting.
Raise awareness of centralised biobanking facilities to improve access and tissue processing for centres without well experienced FP reproductive laboratories.
Ethics
Development of updated evidence summaries around FP technology.
Develop an ethics framework document that outlines ethical aspects of paediatric and adolescent FP surgery (e.g., how to manage situations where FP cannot be offered, important aspects of consent).
Advocate for changes to assistive reproductive technology laws to allow research on unused paediatric and adolescent gonadal tissue.
Bereavement
Provide deceased pathway and training for staff who liaise with families.
Provide bereavement training to staff.

Addressing the identified gaps in training, standardisation, and referral pathways is essential for enhancing paediatric and adolescent oncofertility care and ensuring equitable access to fertility preservation services. Implementing robust ethical frameworks and funding mechanisms can further support clinicians in providing high-quality, consistent care for young people and their families. The authors provide recommendations to address barriers to FP surgery and improve services and access in Table 6.

5. Limitations

This study focused on the experiences of clinicians from Australia and New Zealand, and we acknowledge that specialty access and FP practice varies significantly across different geographical areas and healthcare systems. A broader inclusion of specialties and centres, from diverse global regions, would be valuable to comprehensively understand the gaps in access and technical aspects of FP worldwide. This study was undertaken in 2021 during the COVID pandemic lock-down period in Melbourne, Australia impacting availability of clinicians for interviews. Whilst data collection occurred four years in the past, this time lag between conducting interviews and manuscript publication is not inconsistent with much qualitative research due to the time-intensive nature of qualitative data analysis and researcher capacity for investigator-led studies. We acknowledge that while there was a large proportion of non-surgeon participants, it was important to obtain insights across the full multidisciplinary spectrum involved in paediatric fertility preservation surgery care pathways. Further the authors acknowledge that the inclusion of specific data regarding the number of surgeries undertaken by the surgeons interviewed would have provided additional context to the perspectives provided.

This exploratory study lays the groundwork for future research with a view to recruit a broader range of disciplines and/or a greater number of participants using, for example, a qualitative study focusing on targeted topics, targeted professions, or a quantitative survey. Further, future research should aim to capture more diverse international perspectives.

6. Conclusion

This study explores the views of multidisciplinary paediatric and adolescent FP clinicians, scientists, and staff to identify needs and service gaps of FP care across institutions in ANZ. We provide a range of recommendations (Table 6) based on the results of the study, together with expert opinions of the authors who have extensive clinical experience in paediatric and adolescent FP. Recommendations consider ways in which teams can improve care and consistency of FP service surgery offered to prepubertal children across the FP pathway. There is a long latency before reproductive outcomes can be assessed when interventions involve young children. Therefore, identifying training, technical, and ethical barriers now is important to ensure the field is prepared with robust frameworks as more patients reach reproductive age.

Authors' contributions

[removed for blinding].

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Conflict of interest

The authors' report no conflict of interest.

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Table 1: Participant characteristics

Variable	Responses	n = 18
Gender	Women	11 (61%)
	Men	7 (39%)
Surgical discipline/role* (total proportion 55%)	Paediatric surgeon	4 (22%)
	Reproductive consultant, Paediatric adolescent gynaecologist, and Reproductive Fellow	6 (33%)
Non-surgical discipline/role* (total proportion 45%)	Scientist	2 (11%)
	Paediatric adolescent oncologist, Clinical nurse consultant, Clinical ethicist, Research manager	6 (34%)

*Individual role responses not provided to avoid re-identification of participants

Table 2. Paediatric FP surgery skills and remit
Ovarian tissue biopsies don't need a separate pathway because if you can do a Level 3 laparoscopy as per AGES, which any gynaecologist who has done a FRANZCOG should be able to do it. That's minimum standards. (P7 – surgeon)
I think the biggest thing is grafting, not the tissue extraction … having the knowledge of how to perform it, where to locate the graft, and what fashion to insert the graft. (P18 - surgeon)
If the patients had other procedures done, the surgical team was doing it because it was on their theatre list instead of the gynaecology team. (P7 – surgeon)
The answer to [whether there should be a credentialing protocol for FP surgery] – that would really depend on the centre. Not just in the surgery, but in the whole process, where you're collecting tissue, the quality of the tissue, the storage of the tissue and the consent and storage. (P2 – oncologist)
At the moment, there is no test code for tissue preparations. So, the tissue manipulation isn't a registered or recognised test, and I think there should be quality control and quality assurance. (P17 - scientist)
If there was scope for accreditation for [tissue preparation], then more labs may undertake to do the process, not just specifically embryology labs. (P17 - scientist)

Table 3. FP service education and training needs
Bereavement training is definitely missing from our training. We're trained to be scientists, but we're not really told how to kind of counsel the patients on their fertility preservation journey. I think it's important that we do get some more training in patient contacts and dealing with patients. (P17 – scientist)
Community knowledge, that is the medical specialists are not fully aware of the services, not fully aware of successes, not fully aware where science is at. (P16 – clinical nurse consultant)
[Some surgeons] have said, 'surely you can't do this on really small children', and so I think in Australasia, it would be helpful to have more education around [FP surgery]. (P15 – oncologist)
I think training videos are the most practical approach. So, I would suggest some sort of training module that could either be done online with certification rather than a particular qualification. (P4 - oncologist)
Although we've got a national service setup where we could transport tissue from other states to Victoria, many don't know that that's available or how to access that. I think we need to look at better education of those other centres, so they know what is available. (P11 – scientist)
There isn't a custom-made laboratory or patient information management system for these patients, and I think that is slightly missing. We need a system to [keep track of patient Information]. (P17 – scientist)
It's often the issue about the surgeon not taking sufficient tissue for [lab processing]. I think we need to look at better education of centres around Australia that don't get a [large] level of experience and knowledge. (P11 - scientist)

Table 4. Barriers and challenges in accessing and providing FP
I think the only barrier is that people who don't know what [FP] is. For example, with testicular biopsy people were somewhat uncomfortable doing it because it was experimental. (P5 - surgeon)
The only reason that [the patient was referred] was because one of the registrars had been to a talk and so they thought of FP whereas the consultant didn't. (P6 - surgeon)
Certain hospitals charge $2000 for ovarian tissue retrieval process because there's not enough funding. So someone has to pay privately. And then the barriers are the patients miss out or they have to get referred to the public system. (P13 - surgeon)
Our protocol is 0 to 18 year and we've been comfortable with the safety side of that. We're comfortable with the equity side of it and that different cultural groups in New Zealand have gone ahead with [FP]. (P8 - researcher manager)
I would hope that when you're taking the history and the family history, you'll be able to factor in those other risk factors for infertility. But I would say most cancer specialists aren't doing that and then just solely taking the risk based on the treatment and going ok, low risk, I don't have to refer them. And I think it can be quite paternalistic. (P2 - oncologist)
"I look at the other comorbidities, for example risk of bleeding. I'll work through what the risk of doing FP in that setting, or if the patient is immunocompromised. (P2 – oncologist)
"I don't think there's any real contraindication to doing [FP surgery] … well, I've been doing this FP for a while, and I've never seen a complication from it." (P1 – surgeon)
I know freezing is proven but I'm not up to date with all the latest evidence of use of those products down the track. (P4 - oncologist)
I'm not privy to what surgeons are saying to families, nor are they privy to what I'm saying to the families. So there's potential for contradiction in messaging and potential confusion for the family and the patient making the decision. (P4 – oncologist)
It's issues of getting the IVF media to [retrieval sites] and transport containers being properly prepared at a recordable temperature for the duration, that tissue isn't in transit for too long, and it's arriving at the destination at an optimum time to process it. (P16 – clinical nurse consultant)

Table 5. Ethical challenges related to FP care
They also need to think about what preserving fertility would actually mean. They need to have some sense this is not a magic fix, and there would be other interventions down the track. (P10 – ethicist)
I've had issues where the individual who was a minor has really wanted FP but the parents haven't wanted it. (P14 - surgeon)
We had patient who was old enough to understand and the parents didn't want to talk to him about fertility preservation. (P2 - oncologist)
My main concern is [parents are] not really worried about their child's fertility, even though we counsel that their child may very well survive the cancer treatment. (P13 - surgeon)
I think that FP surgery is fairly ethically sound. It's whether you're giving false hope because we don't know whether there's possible use for the tissue [in the future]. (P14 – surgeon)
I think that research [on unused FP tissue] would definitely benefit future fertility aspects and advancements in fertility preservation. (P18 - surgeon)
I'm not sure about the use of unused tissue for research…. I'm still trying to make up my mind. When it's a child, I think it's different. (P17 - scientist)
Parents have wanted their deceased child's tissue used for research but we can't. I would like it to be used for research if that is the patients' or families' wishes. (P16 - clinical nurse consultant)

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Bereavement
Provide deceased pathway and training for staff who liaise with families.
Provide bereavement training to staff.

Declaration of interests

☐ The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

☒ The authors declare the following financial interests/personal relationships which may be considered as potential competing interests:

Camille Paynter reports financial support was provided by Australian Government Medical Research Future Fund. Yasmin Jayasinghe reports financial support was provided by The University of Melbourne. Debra Gook reports financial support was provided by Cancer Council Victoria. Zobaida Edib reports financial support was provided by Australian Government Medical Research Future Fund. Michael Assis reports financial support was provided by Australian Government Medical Research Future Fund. If there are other authors, they declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.