

Taylor & Francis
Taylor & Francis Group

Journal of Psychosomatic Obstetrics & Gynecology

ISSN: (Print) (Online) Journal homepage: https://www.tandfonline.com/loi/ipob20

Experiences of young girls and women undergoing ovarian tissue cryopreservation: a systematic review and thematic synthesis

Hajra Khattak, Hannah Woodman, Yousri Afifi, Christiani A. Amorim, Simon Fishel, Ioannis Gallos, Arri Coomarasamy & Annie Topping

To cite this article: Hajra Khattak, Hannah Woodman, Yousri Afifi, Christiani A. Amorim, Simon Fishel, Ioannis Gallos, Arri Coomarasamy & Annie Topping (2022): Experiences of young girls and women undergoing ovarian tissue cryopreservation: a systematic review and thematic synthesis, Journal of Psychosomatic Obstetrics & Gynecology, DOI: 10.1080/0167482X.2022.2084376

To link to this article: https://doi.org/10.1080/0167482X.2022.2084376

View supplementary material

Published online: 04 Jul 2022.

Submit your article to this journal

Article views: 5

View related articles

View Crossmark data

Full Terms & Conditions of access and use can be found at
https://www.tandfonline.com/action/journalInformation?journalCode=ipob20

JOURNAL OF PSYCHOSOMATIC OBSTETRICS & GYNECOLOGY
https://doi.org/10.1080/0167482X.2022.2084376

Taylor & Francis
Taylor & Francis Group

REVIEW ARTICLE

Check for updates

Experiences of young girls and women undergoing ovarian tissue cryopreservation: a systematic review and thematic synthesis

Hajra Khattak[a], Hannah Woodman[b], Yousri Afifi[c], Christiani A. Amorim[d], Simon Fishel[e,f], Ioannis Gallos[a], Arri Coomarasamy[a] and Annie Topping[g,h]

[a]Tommy's National Centre for Miscarriage Research, Institute of Metabolism and Systems Research, University of Birmingham, Birmingham, UK; [b]Birmingham Medical School, College of Medical and Dental Sciences, University of Birmingham, Birmingham, UK; [c]Birmingham Women's and Children's NHS Foundation Trust, Birmingham, UK; [d]Pôle de Recherche en Gynécologie, Institut de Recherche Expérimentale et Clinique, Université Catholique de Louvain, Bruxelles, Belgium; [e]John Webster House, CARE Fertility Group, Nottingham, United Kingdom; [f]School of Pharmacy and Biomolecular Sciences, Liverpool John Moores University, Liverpool, UK; [g]Institute of Clinical Sciences, School of Nursing, University of Birmingham, Birmingham, UK; [h]University Hospitals Birmingham NHS Foundation Trust, Birmingham, UK

ABSTRACT

The aim of this study was to explore the experiences of young girls and women who underwent or considered ovarian tissue cryopreservation (OTC) using a systematic review of qualitative studies with thematic synthesis framework. Major electronic databases: MEDLINE, EMBASE, the Cochrane Library, CINAHL and PsycINFO were searched from 1946 to May 2020 and reference lists of relevant articles were hand searched. Any studies that described a qualitative inquiry and highlighted the experiences of women with regards to OTC were included. Two independent reviewers screened the title and abstracts and made a selection against inclusion criteria. Main outcomes measures were experiences of women who have considered and/or undergone OTC, decision making in women who underwent or considered OTC and patient education. Nineteen studies were assessed for full text eligibility and four were included in analysis. 144 verbatim quotations from 85 participants in high income countries (UK, USA and Denmark) were included. Two studies adopted grounded theory approach, one phenomenology and one inductive content analysis. Four themes were generated; participants described their experiences as emotional, involving complex decision-making, helping them prepare for the long-term consequences of potentially losing their fertility and hormonal function, as well as their experience being educational. Additionally, the more practical aspects of the procedure such as OTC being invasive as well as costs implications were highlighted. Women and young girls are often involved in making time-sensitive decisions whether or not to undergo OTC. Healthcare professionals involved in the care of young girls and women undergoing this method need to also take into consideration the emotional wellbeing of the patients as well as the time and expertise it requires to help them make an informed decision.

ARTICLE HISTORY
Received 2 February 2022
Revised 13 May 2022
Accepted 26 May 2022

KEYWORDS
Female fertility preservation; ovarian tissue cryopreservation; experiences; qualitative research; thematic analysis

Introduction

Ovarian tissue cryopreservation (OTC) is an emerging approach for fertility preservation and thousands of young girls and women whether treated for cancer or benign gynecological conditions, have undergone this procedure worldwide [1–3]. The most common and established method of female fertility preservation is oocyte cryopreservation [4]. Oocyte cryopreservation has limitations, such as not being suitable for prepubescent females or those who require immediate anti-cancer treatment [5]. The restrictions with oocyte cryopreservation however do not apply to OTC. Although meticulously developed, some experts in the field still consider OTC experimental [4,6]. In the recent years, many stakeholders and policy makers are exploring the possibility of routine use of this procedure with women and prepubertal girls [6,7]. Despite technical developments over the last 20 years, there remains limited information on patient experience of this procedure.

Originally developed as a fertility preservation method for young girls and women suffering with cancer, OTC has since been applied in women with

CONTACT Hajra Khattak h.khattak@doctors.org.uk Tommy's National Centre for Miscarriage Research, Institute of Metabolism and Systems Research, University of Birmingham, Birmingham B15 2TT, UK

Supplemental data for this article is can be accessed online at https://doi.org/10.1080/0167482X.2022.2084376.

© 2022 Informa UK Limited, trading as Taylor & Francis Group

nonmalignant diseases who are at risk of premature menopause [3,8–10]. OTC involves retrieving part of the ovary and freezing it in liquid or vapor nitrogen. This tissue is usually retrieved before commencing gonadotoxic anti-cancer therapy and transplanted once treatment is complete. The first live birth from OTC and transplantation was reported in 2004 [11]. Since then, around 200 live births have been reported worldwide [1,7,8,12]. OTC has provided hope to many young girls and women especially as it remains the only option of fertility preservation for prepubertal girls.

Recent advances in treatment, improved prognosis and quality of life post cancer treatment have generated a greater interest in post treatment fertility. Many seek information from their clinicians as a first port of call for primary information while others from online resources [13]. The adequacy of information provided to young girls and women to make an informed choice has been criticized and there seems to be a need for improvements when discussing fertility preservation [13]. OTC is a newer alternative method of fertility preservation when compared to embryo and oocyte cryopreservation and warrants further examination in order to understand how women and young girls make decisions about undergoing OTC. Many studies have been conducted to provide success rates of the procedure, the technique itself, patient satisfaction surveys and views of healthcare providers on the topics [1,2,10–22]. Although quantitative methods make an important contribution to evidence-based research, to be able to acquire more depth about a topic in isolation, they prove insufficient. Qualitative methods are grounded in the social and behavioral sciences where they aim to understand lifestyle, systems, policies and human environments. These methods seek information through human interaction rather than the analysis of numbers and statistical figures [23]. Syntheses of qualitative research allows the amalgamation of data across a variety of contexts. Ultimately the joining and comparison of this data allows researchers to generate new theoretical or conceptual models, identify research gaps, inform primary studies, and provide evidence for the development, implementation and evaluation of health interventions [23] The scientific potential of OTC is well developed yet the qualitative evidence is limited. This review was therefore undertaken to shed light on the experiences of women and young girls undergoing OTC for fertility preservation and their interactions with healthcare professionals.

Methods

The protocol was registered on the International Prospective Register of Systematic Reviews (PROSPERO) Database (registration number: CRD42020192882). The review was guided by recommendations to enhance transparency in reporting the synthesis of qualitative research (ENTREQ) as described in Supplementary Data as Table S1 [24,25]. The ENTREQ statement aids researchers to report aspects of the steps which structure the synthesis of qualitative health research. These include; searching and selecting qualitative research, quality appraisal, and methods for synthesizing qualitative findings [24,25].

Systematic search of the literature

A search strategy was developed in consultation with an information specialist (Supplementary Figure 1). The eligibility criteria for inclusion of studies were devised using the population, indicator or phenomenon of interest, context and study design organizing framework, as shown in Table 1 [26].

Major electronic databases: MEDLINE, EMBASE, the Cochrane Library, CINAHL and PsycINFO were sought and reference lists of relevant articles were hand searched. Any studies that described a qualitative inquiry and highlighted the experiences of women with regards to OTC were included. Abstracts retrieved through the search were first screened to remove duplicates. Subsequently, two independent reviewers screened the title and abstracts and made a selection against inclusion criteria. This was followed by the screening of full text articles by two reviewers. Any further articles identified through hand searching and that were deemed relevant by either or both of the

Table 1. PICoS framework to develop eligibility criteria.

PICoS Indicator	Eligibility criteria
Population/Participants	Young girls or women who considered or underwent ovarian tissue cryopreservation
Indicators/phenomenon of Interest	Experiences relating to ovarian tissue cryopreservation
Context	Any women or young girls who considered or underwent ovarian tissue cryopreservation as a method of fertility or hormonal preservation
Study design	Qualitative research designs including (but not limited to) thematic analysis, grounded theory, phenomenological analysis and mixed method studies with qualitative components.
Exclusion criteria	Women who underwent other fertility preservation methods such as oocyte and embryo cryopreservation

reviewers were also included in the full-text review. Disagreements were resolved with the help of a third reviewer until consensus was reached.

Quality assessment and appraisal

All included studies were critically appraised using "The Critical Appraisal Skills Programme" CASP qualitative checklist [27] and are displayed as Supplementary Data (Table S2). All the studies were appraised for their validity, evaluation of the methodological quality and an assessment of external validity. Critical appraisal was conducted independently by two reviewers (H.K. and H.W.). The findings from the two reviewers were compared and any disagreements were discussed and re-reviewed. The studies included were assessed as high quality. All included studies had clearly described aims and the qualitative methods employed in all the studies were appropriate. Although the data were collected to address the stated research questions, the relationship between researcher and participants was not described and only two studies discussed recruitment details such as data saturation [28,29]. One study reported that ethical approval was not required (as per their national legislation) however the study was attested by their Regional Committee on Health Research [30].

Data extraction

A data extraction form was developed *a priori* in Microsoft Excel to facilitate data extraction. One review author (H.K.) extracted and charted all the data, the second author (H.W.) then verified the extracted data. Any differences were resolved through discussion until consensus was reached. If differences were not resolved by discussion, a third reviewer (A.T.) was approached. Extracted materials were based on the inclusion criteria and a framework of predefined outcomes of interest. Information gathered from the selected studies included: author; year of publication; country of study; study type; setting; relevant background and impetus for the study; methodological approach and specified methods; patient characteristics and demographics; main findings including themes and narratives relating to the experience of OTC and key relevant discussion points. Data were mainly analyzed (coded) by one reviewer, but regular meetings were held with the review team to ensure that the extracted data appropriately reflected the original data.

Data synthesis

The process of thematic analysis and meta-synthesis process as described by Thomas and Harden (2008) was used and involved the following steps [31].

Step 1: Coding

Data from primary studies were coded line by line and examined for meaning. This helped identify the translation of codes between studies. An Excel spread sheet was used to organize the extracted descriptive and qualitative data.

Step 2: Theme development

The codes generated in step 1 were assessed for meanings. These meanings were further organized into categories. The properties of these categories were then analyzed.

Step 3: Theme generation

Categories generated were compared between studies and any similarities or difference was examined. Similar categories were merged such that substantive themes were generated merging higher-level constructs. This enabled the development of higher order abstractions of the phenomena.

Researcher's position

The lead researcher is a trainee in Obstetrics and Gynecology, who is undertaking a doctoral study on the topic of ovarian tissue cryopreservation and transplantation. She is also trained in OTC and has a keen interest in this method of female fertility preservation.

Results

Included studies

Through our literature search, we found 17 potential studies, but only two studies were eligible for inclusion in the analysis. Two further studies, including an unpublished doctoral thesis, were found through hand searching. Four studies were included in the thematic analysis, representing experiences of 85 females in the form of 144 verbatim quotes. The included studies were conducted in Denmark, UK and two in USA. The age range of the participants at the time of interview was 13–42 years, with all participants undergoing the procedure as a fertility preservation option due to cancer. The study design included two studies that adopted the grounded theory, one phenomenology

Table 2. Study characteristics table for included studies.

Author Year Country	Aim(s)	Sample/Population	Study design/methods	Findings/Themes	Specific outcomes	Quality appraisal score
Mitchel et al. 2020 USA	To determine patients' knowledge and feelings about their cryopreserved ovarian tissue	8 females Mean age at the time of interview = 25.8 ± 6.1 (Range 19–37 years) Mean age at OTC = 20.4 ± 7.5 (range 13–35 years)	Qualitative interview study, inductive content analysis (generation of themes)	• Lack of understanding • Fertility intentions • Hormonal function • Feelings about OTC (positive and negative)	Identification of significant knowledge gap among patients with cryopreserved ovarian tissue, about its uses, benefits as well as a strong desire for improved patient education.	High
Hershberger et al. 2013 USA	To provide an in-depth description of the decision-making process that women who are diagnosed with cancer undergo as they decide whether to accept or decline fertility cryopreservation.	27 females Mean age at the time of interview = 28.7 (Range 19–40)	Qualitative grounded theory approach	Four phases of decision-making process • Identity • Contemplate • Resolve • Engage	• Clarification of underlying process that women with cancer undergo about fertility cryopreservation • To improve quality of care for women with cancer by implementing appropriately times information and tailored developmental and contextual counseling to support decision making.	High
Tennyson et al. 2017 (unpublished thesis) UK	To explore the lived experiences of teenagers and young adults with cancer who have been offered ovarian tissue cryopreservation.	8 females Mean age at the time if interview = 17.5 (Range 13–22)	Interpretative phenomenological qualitative study	• Small procedure, big meaning • Improving adjustment to cancer • Reducing the impact of cancer	To explore the lived experiences of teenagers and young adults with cancer who have been offered ovarian tissue cryopreservation	High
Bach et al. 2020 Denmark	Futures and fears in the freezer: Danish women's experiences with ovarian tissue cryopreservation and transplantation	42 females Age range at the time of interview = 15–42 years	Qualitative semi structured in-depth interviews, grounded theory analytical approach	• Decision-making: OTC as a hope in the dark • Storage: opportunities in the freezer • Transplantation: navigating risk, chances and outcomes • Surplus tissue: having "something in the bank" for the future	Experiences with OTC and transplantation, including their reflections on long-term storage of tissue and the use of surplus tissue	High

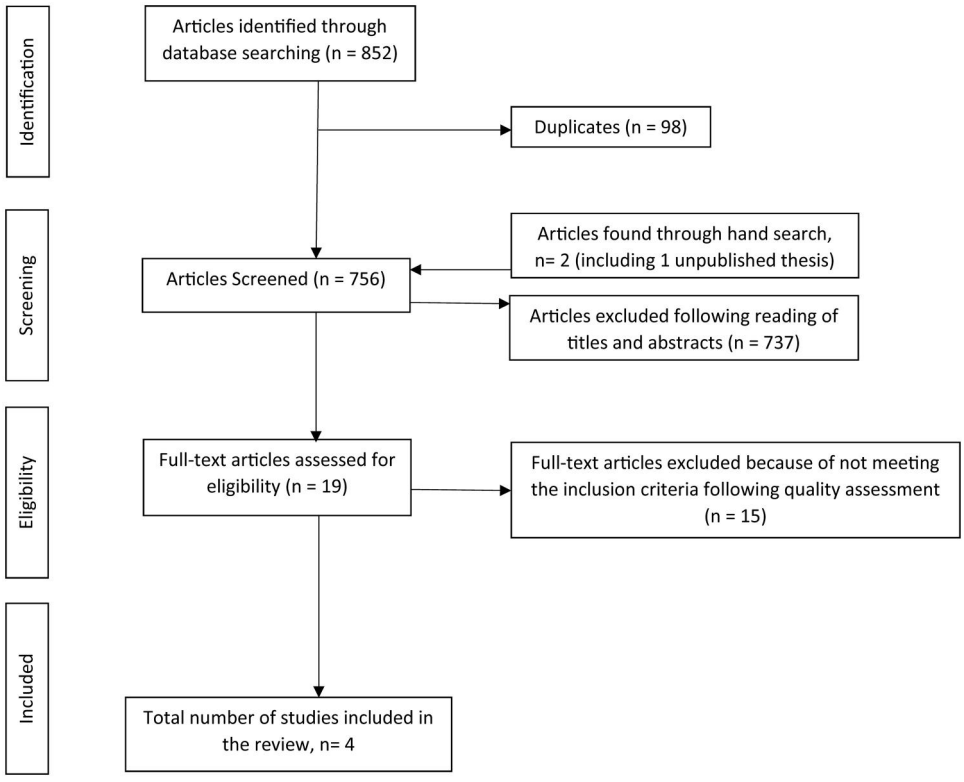


Figure 1. PRISMA flow diagram of search and selection strategy.

and one inductive content analysis. The characteristics of included studies are given in Table 2.

A Preferred Reporting Items for Systematic Reviews and Meta- Analyses (PRISMA) diagram of the search and study selection is presented in Figure 1.

Results of meta-synthesis

We identified four themes associated with experiences of young girls and women who underwent or considered having OTC. Participants described their experiences as emotional, involving complex decision-making, educational and helping them prepare for the long-term consequences of potentially losing their fertility and hormonal function. Additionally, the more practical aspects of the procedure such as cost implications and the invasive nature were also highlighted. Full quotes can be viewed in Table 3 and a schematic representation of the generated themes is shown in Figure 2.

An emotional experience

Participants described the process of undergoing fertility preservation as very emotional. There was a great deal of overwhelm, but the idea of "banking" something for the future formed part of a sense of hope for the future, about survival and was reassuring.

Overwhelmed by diagnosis and future fertility prospects. For women of childbearing age, the diagnosis of cancer can come with bad news about losing their potential for motherhood. Women described this as very challenging and an added burden to their disease.

> Everything was happening in a whirlwind. (Mitchell, Whiting-Collings, & Christianson, 2020, p. 2)

> … it was devastating, absolutely devastating. (Hershberger et al., 2013, p. 63)

Emotional resilience, being pragmatic and survivorship. Some participants dealt with the situation pragmatically, thinking of the next steps and sometimes making difficult choices.

> Then comes cancer. Alright, you know what, we can handle this. We're educated enough, that, you know what, this is not all dead set. This is a bump in the road and we will face it head on and we'll ficanc and years from now we'll look back and it'll be a memory. And that's okay. But then you tell us on top of it, that we can't have children. We can't have a family … you know, as tears rolled down my cheeks–which was not me what-so-ever–I can deal with the cancer, but throw this [loss of fertility] on top of it and it was devastating, absolutely devastating. (Hershberger et al., 2013, p. 63)

Table 3. Results of meta-synthesis.

Themes	Subthemes	Quotes
Emotional experience	Overwhelmed by diagnosis and future fertility prospects	'***Everything was happening in a whirlwind'.*** (Mitchell, Whiting-Collings, & Christianson, 2020, p. 2)
		'***I can deal with the cancer, but throw this [loss of fertility] on top of it and it was devastating, absolutely devastating'.*** (Hershberger et al., 2013, p. 63)
		'***… never thought I would have to make decisions about whether or not to have children at this point in my life'.*** (Hershberger et al., 2013, p. 64)
		'***one of the hardest things to deal with'.*** (Tennyson, 2017, p. 85)
		'***… hearing about fertility was the biggest shock of having chemo'*** (Tennyson, 2017, p. 80)
	Emotional resilience, being pragmatic and survivorship	'***It was strange because you were sitting there and "You also need to have x-rays to check if there is anything in the lungs and you need blood samples for your liver" and that sort of thing. "And then you need to go to the fertility clinic". I found that to be… strangely out of place because… well, okay, I'm also going to do that. I thought I was going to die, right? But in a way, it was also life-affirming because indirectly she was telling me that "We don't believe you are going to die. So therefore, we want to give you a chance to have children later", right?***' (Bach, Macklon, & Kristensen, 2020, p. 558)
		'***That's when I made my decision because I spoke with the nurse and she explained everything to me [about cryopreservation], you know, that "there's no guarantee that, you know, you won't be able to have children, but there is a chance that you may not, so you know, we just want to cover everything'.*** Hershberger et al., 2013, p. 65)
		'***Then comes cancer. Alright, you know what, we can handle this. We're educated enough, that, you know what, this is not all dead set. This is a bump in the road and we will face it head on and we'll fight, and years from now we'll look back and it'll be a memory. And that's okay. But then you tell us on top of it, that we can't have children. We can't have a family … you know, as tears rolled down my cheeks–which was not me what-so-ever–I can deal with the cancer, but throw this [loss of fertility] on top of it and it was devastating, absolutely devastating'.*** (Hershberger et al., 2013, p. 63)
		'***like having cancer is enough I don't want that to hinder me having children***' (Tennyson, 2017, p. 80)
	Optimism and being grateful for having the option	'***gave me one less thing to worry about with everything else going on***' (Tennyson, 2017, p. 86)
		'***It really was a salvation back then. It was the good news in the middle of everything that happened'.*** (Bach, Macklon, & Kristensen, 2020, p. 560)
	Pessimistic about OTC procedure	***I think that I could have tried another route. Yeah, I don't think I should have went that extreme because I think that's something like you're removing something. You know, removing a part of my reproductive system. I feel like it's a drastic procedure too.*** (Mitchell, Whiting-Collings, & Christianson, 2020, p. 3)
		I were to go back, I'm not sure if I would have said yes… because I know of many stories of women who received chemotherapy and didn't have any problems reproducing after that. (Mitchell, Whiting-Collings, & Christianson, 2020, p. 3)
		But where I am today, it's like… the air has gone out of the balloon. It hasn't really been seen through… you get the feeling that it was a good intention back then, but it has become a bit fluffy for me today'. (Bach, Macklon, & Kristensen, 2020, p. 560)
	Attitudes of young adults toward fertility preservation	'***I was a little mad about having to do it when I didn't have any interest in having kids'.*** (Mitchell, Whiting-Collings, & Christianson, 2020, p. 3)
		'***but my parents were very adamant like 'maybe you'll change your mind in the future', but I didn't really care'.*** (Mitchell, Whiting-Collings, & Christianson, 2020, p. 3)
		'***I do think that there is something different about being in, a teenage or young adult specifically in the fertility experience because you're it, it's so far outside your frame of reference that you're coming up with your opinion of things at the same time as you're making your decisions on them… especially if you didn't know if you wanted to have kids or something you're making the decision of whether or not it's a possibility at the same time as you're making the decision of whether or not you want it to be'.*** (Tennyson, 2017, p. 81

(*continued*)

Table 3. Continued.

Themes	Subthemes	Quotes
Complex decision-making Preparing for the long-term consequences	Autonomy	'***[it] let me have some control***' (Mitchell, Whiting-Collings, & Christianson, 2020, p. 2)
		'***It was about having the option. That I regained a bit of free will or something like that'.*** (Bach, Macklon, & Kristensen, 2020, p. 558)
		'***It was like "Do you have a child?" "No, I do not". "Okay, you have to go to the fertility clinic". I actually didn't have a lot of influence on that. And today, I mean, I'm really happy about that, because I think if I had to think about it … the pros and cons, then I don't know what I would have done'.*** (Bach, Macklon, & Kristensen, 2020, p. 558)
		'***You know, because, if it had been, my oncologist and just me, maybe I would have talked to her [oncologist] about it a little bit more and I think maybe [I would have] felt a little bit more comfortable expressing my feelings'.*** (Hershberger et al., 2013, p. 65)
		'***you're just told like you don't really have an option***' (Tennyson, 2017, p. 87)
		'***My mom said I should do it, because I had to survive. So, I had to get it out, so I would have, in some way, a future'.*** (Bach, Macklon, & Kristensen, 2020, p. 558
	Support network in decision making	'***She (my mother) was the one – her and my dad – were the ones who helped me make a lot of the big decisions'.*** (Hershberger et al., 2013, p. 64)
		'***[Being offered OTC showed] how kind of how important you are to the medical team and how much they care for you'.*** (Tennyson, 2017, p. 84)
	Time sensitive decisions	'***It's tough to make this decision under the gun'.*** (Hershberger et al., 2013, p. 64)
		'***wasn't comfortable [being told about OTC two days before her procedure]'.*** (Tennyson, 2017, p. 87)
		'***I mean, the doctor said he understood, but that he also had to restore my health again. So, he couldn't wait for weeks'.*** (Bach, Macklon, & Kristensen, 2020, p. 559)
	Female reproductive identity	'***It was like having the possibility of reclaiming my body or reclaiming my life including all the choices I had. So, it was not tied to a specific wish to have another child in that way'.*** (Bach, Macklon, & Kristensen, 2020, p. 558)
		'***If I simply had eggs retrieved, then there was the whole thing about, well, the leftover ovary I still have, what if it never started functioning again? I mean, I would go into menopause then. Boom. And I was, you know, I was not really ready for that at the age of 34. I couldn't really relate to that. But, all in all, I will return; It (OTC) is the way I am going to get back to the closest to normal. Or be most like myself again'.*** (Bach, Macklon, & Kristensen, 2020, p. 559)
		'***I was pretty insistent about wanting the last part of my tissue implanted. And if they couldn't find room, apparently my ovary is pretty small, which they always grumble about … then they could put it wherever, because I had, you know, a feeling like I had to have my body assembled again. I mean, that it had to be whole again in some way'.*** (Bach, Macklon, & Kristensen, 2020, p. 562)
		'***I mean it is kind of a drastic procedure, I feel. You know you're removing like a piece of woman's you know reproductive or hormonal system down there'.*** (Mitchell, Whiting-Collings, & Christianson, 2020, p. 3)
		'***One of those things that you take for granted'.*** (Tennyson, 2017, p. 82)
		'***During the cancer treatment, it meant everything to me that I could hope for a child. It meant so much. Also, because we were right there in our life. If they had said to me "too bad". I wouldn't have been able to keep up my spirits. And I think it would have hit me harder psychologically than it did. You have something to fight for. I mean, there always is, I guess, but something extra. And when I had done all this (freezing), and I really wanted it then … I have to come out on the other side. And I will live life again. So, it kept me going'.*** (Bach, Macklon, & Kristensen, 2020, p. 559)
		I think that people need to recognize that when you are dealing with women in my age range, having a baby is like – it is almost the same level for most women is as getting married. (Hershberger et al., 2013, p. 64).
	Concerns (or lack thereof) regarding future fertility prospects	'***That … has been a paralyzing fear of mine – not getting pregnant'.*** (Mitchell, Whiting-Collings, & Christianson, 2020, p. 3)
		'***Anxiety … because you don't know if it's going to work, you don't know if you're going to be able to use that tissue, you don't know if financially you will have resources***' (Mitchell, Whiting-Collings, & Christianson, 2020, p. 2)

(*continued*)

Table 3. Continued.

Themes	Subthemes	Quotes
		'One of the things that startled me the most when I was diagnosed was how it might affect my fertility. Not because I may never be able to bear a child, which I want to do, but because it made me realize how this diagnosis was going to be truly life changing and could affect me the rest of my life'. (Hershberger et al., 2013, p. 62)
		'But then you tell us on top of it, that we can't have children. We can't have a family … you know, as tears rolled down my cheeks – which was not me what-so-ever – I can deal with the cancer, but throw this [loss of fertility] on top of it and it was devastating, absolutely devastating'. (Hershberger et al., 2013, p. 63)
		'is this even what I should be worrying about. [?] … should I just be focusing on getting better?' (Tennyson, 2017, p. 86)
		'I think at the time it wasn't [a priority] like at all but I think more in the future like the more I think about it, it is, because after the treatment's finished and if it's like a few years in the future when everything's completely done and it's clear then that'll definitely be more of a priority so I think it might just change with time'. (Tennyson, 2017, p. 82)
Patient education	Lack of information and limited knowledge	***'Before I tried artificial conception … wow, was I naive and thought that it was just 'boop' and then you take something here, 'boop' and connect it here and then 'ding' and you implant and that's that. But all the insecurities and all, I mean … in the media and on the news, it's like the doctors can do it in a production line … kind of way and there is no … and I didn't really have a good sense of biology and how, I mean, how delicate and sensitive and unpredictable it is.*** (Bach, Macklon, & Kristensen, 2020, p. 561)
		I think they (froze) eggs … Oh, they didn't freeze eggs? (Mitchell, Whiting-Collings, & Christianson, 2020, p.3)
		'I don't even know what that means!' (Hershberger et al., 2013, p. 62)
		'I was talking to doctors and they were using a lot of jargon' (Hershberger et al., 2013, p. 62)
	Active information seeking and need for follow up	***'You were sick and had all this ahead of you. And you receive a lot of input and all that. It has been a bit hard to, how do you say, process or whatever the word is. I could have used more tangible material. To have been handed a pamphlet (laughs), you know. I mean, I could have used that back then, because … I have probably been given a lot of information which I have forgotten. And afterwards, you suffer from chemo brain and things like that … sometimes you are told about something and then it is just phhhhh (windy sound)'.*** (Bach, Macklon, & Kristensen, 2020, p. 559)
		'It would be helpful if there was patient follow-up-whether that be something as simple as a newsletter, or a quarterly email, or just something biannual that patients could know about what is happening'. (Mitchell, Whiting-Collings, & Christianson, 2020, p.3)
		'I think I just assumed growing up that everyone can have kids'. (Tennyson, 2017, p. 80)
		'Maybe they need someone to break it down in a way that I can understand for people who are younger'. (Mitchell, Whiting-Collings, & Christianson, 2020, p. 3)

Optimism and being grateful for having the option. Participants described the feelings of having undergone OTC as something that had provided hope, reassurance and an opportunity to "save" their future.

> Gave me one less thing to worry about with everything else going on. (Tennyson, 2017, p. 86)

Pessimistic about OTC procedure. Ovarian tissue cryopreservation is an invasive procedure requiring surgery and some participants felt this might impact their already deteriorating health. Participants found it to be an aggressive cure for preserving fertility. Also, the fact that they heard "stories" of women who had conceived despite having chemotherapy somewhat challenged their view about the necessity for fertility preserving intervention.

> If I were to go back, I'm not sure if I would have said yes … because I know of many stories of women who received chemotherapy and didn't have any problems reproducing after that. (Mitchell, Whiting-Collings, & Christianson, 2020, p. 3)

Attitudes of young adults toward fertility preservation. The analysis included young participants, most of whom described being coerced into having the OTC procedure. They felt they were too young to make these decisions and something they had not thought about before.

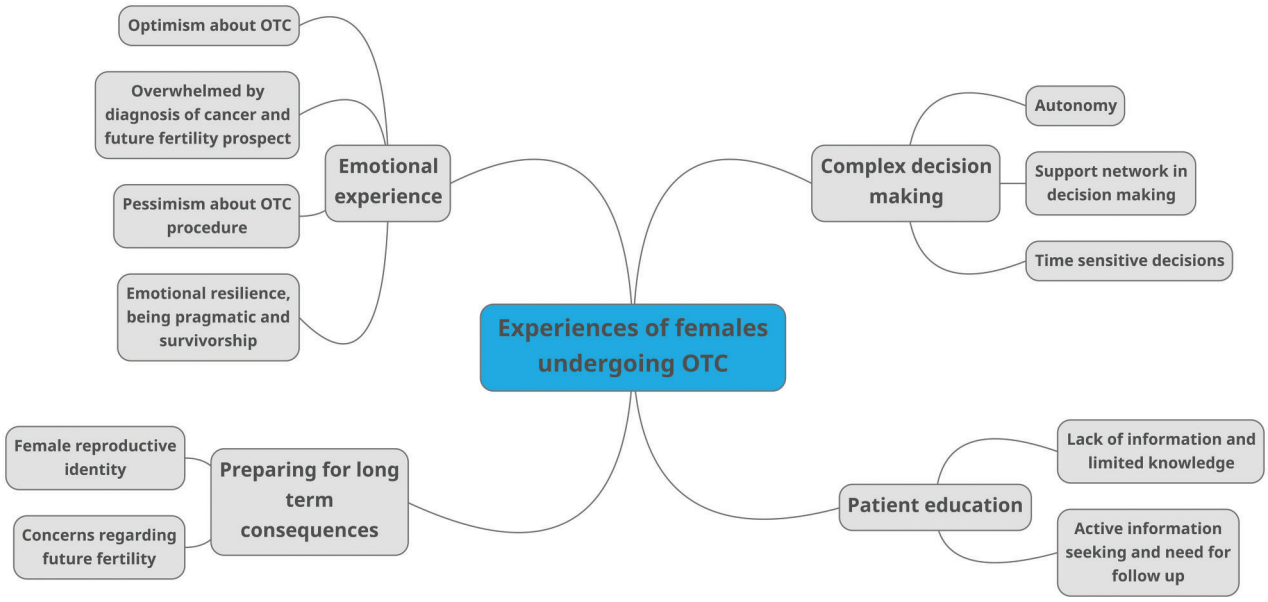


Figure 2. Schematic representation of generated themes.

> I was a little mad about having to do it when I didn't have any interest in having kids. (Mitchell, Whiting-Collings, & Christianson, 2020, p. 3)

> but my parents were very adamant like 'maybe you'll change your mind in the future', but I didn't really care. (Mitchell, Whiting-Collings, & Christianson, 2020, p. 3)

Complex decision-making

Participants appeared to find decision making about fertility and dealing with the news of a cancer diagnosis complex. Although their diagnosis was something they did not have control over, a decision about fertility preservation, provided a sense of being in charge of their destiny. Ovarian tissue cryopreservation was therefore seen as autonomous although it meant making time-sensitive decisions often with the support of family, friends and input from healthcare professionals.

Autonomy. Participants felt that the option of preserving fertility gave them a sense of control over their body. This was described in various ways as some participants felt empowered whilst others felt some coercion that the decision was made for them and they had to conform.

> [it] let me have some control. (Mitchell, Whiting-Collings, & Christianson, 2020, p. 2)

> It was about having the option. That I regained a bit of free will. (Bach, Macklon, & Kristensen, 2020, p. 558)

In contrast another participant described how she perceived that the decision was determined by whether she already had children and she just complied but ultimately was appreciative:

> It was like "Do you have a child?" "No, I do not". "Okay, you have to go to the fertility clinic". I actually didn't have a lot of influence on that. And today, I mean, I'm really happy about that, because I think if I had to think about it… the pros and cons, then I don't know what I would have done. (Bach, Macklon, & Kristensen, 2020, p. 558)

Many of the young girls in the included studies that were diagnosed with cancer had not considered the consequences of their illness or made a connection between cancer treatment and threat to future fertility. Often the decision to preserve fertility was taken by their parents or guardians and made some feel that their autonomy was taken away.

> you're just told like you don't really have an option. (Tennyson, 2017, p. 87)

Support network in decision making. The complex decision-making involved support from family, friends and advice of the health care professional. Some participants felt if it was not for this support network, they might have not made the decision to go for OTC.

> She (my mother) was the one – her and my dad – were the ones who helped me make a lot of the big decisions. (Hershberger et al., 2013, p. 64)

> [Being offered OTC showed] how kind of how important you are to the medical team and how much they care for you. (Tennyson, 2017, p. 84)

Time sensitive decisions. Participants also felt that they were making decisions sometimes under immense pressure. This was primarily due to the urgency of starting anti-cancer treatments.

> It's tough to make this decision under the gun. (Hershberger et al., 2013, p. 64)

Preparing for the long-term consequences

Women saw ovarian tissue freezing as something that gave them a future, which involved surviving cancer and leading a "normal" life. It also meant exploring what fertility meant and how they defined themselves as having, or not, a reproductive identity. For most participants, this was something they had not previously considered. It was evident that to some participants, fertility seemed to form a significant part of womanhood.

Female reproductive identity. Some participants regarded fertility as an important characteristic of being a female. It was not something they considered might be endangered as a result of a cancer diagnosis and anti-cancer therapies. Ovarian tissue cryopreservation gave these participants the option of preserving this aspect of "femaleness" after they became aware that it was at risk. Undergoing OTC meant making a choice that would have consequences beyond the here and now.

> It was like having the possibility of reclaiming my body or reclaiming my life including all the choices I had. So, it was not tied to a specific wish to have another child in that way. (Bach, Macklon, & Kristensen, 2020, p. 558)

Participants recognized that banking ovarian tissue might help long term with symptoms caused by hormonal imbalance and not just fertility. Many expressed concerns about developing treatment related early onset of menopause and the ovarian tissue provided security, hope for the future, a future that might involve living a "normal life" with children.

> I was pretty insistent about wanting the last part of my tissue implanted. And if they couldn't find room, apparently my ovary is pretty small, which they always grumble about… then they could put it wherever, because I had, you know, a feeling like I had to have my body assembled again. I mean, that it had to be whole again in some way. (Bach, Macklon, & Kristensen, 2020, p. 562)

In the account above, women conceptualized wholeness or intactness closely with fertility and normality. Whereas in contrast some focused on the assault of the removal and transplant of the ovarian tissue as an invasive procedure, removal of what constituted a woman and how in retrospect she should not have opted for it.

> I mean it is kind of a drastic procedure, I feel. You know you're removing like a piece of woman's you know reproductive or hormonal system down there. (Mitchell, Whiting-Collings, & Christianson, 2020, p. 3)

Fertility was seen as precious and now threatened "*One of those things that you take for granted*". (Tennyson, 2017, p. 82), and the option of OTC offered a consolation that softened the cancer diagnosis. Although fertility preservation was a small part of dealing with cancer, it nevertheless contributed to the wellbeing of women after treatment.

Concerns regarding future fertility prospects. The potential for loss of fertility was concerning and causing further anxiety in addition to dealing with a cancer diagnosis.

> That… has been a paralyzing fear of mine – not getting pregnant. (Mitchell, Whiting-Collings, & Christianson, 2020, p. 3)

Other anxieties were related to costs associated with restoring the tissue.

> Anxiety… because you don't know if it's going to work, you don't know if you're going to be able to use that tissue, you don't know if financially you will have resources. (Mitchell, Whiting-Collings, & Christianson, 2020, p. 2)

It also reinforced the damaged identity brought by cancer, causing further disruption with life-long consequences and unexpected losses.

> One of the things that startled me the most when I was diagnosed was how it might affect my fertility. Not because I may never be able to bear a child, which I want to do, but because it made me realize how this diagnosis was going to be truly life changing and could affect me the rest of my life. (Hershberger et al., 2013, p. 62)

Whereas others could reconcile future loss by getting through the cancer journey and surviving. Fertility preservation was secondary, put away temporarily and thought about in the future (especially for younger participants).

> is this even what I should be worrying about. [?]… should I just be focusing on getting better? (Tennyson, 2017, p. 86)

Patient education

Ovarian tissue cryopreservation is a relatively new fertility preservation method and only offered by a

limited number of centers. Our analysis highlighted the lack of information provided about this new technique to the participants. A number of study participants felt they had received limited information about follow up, specifically what they needed to do when ready to consider re-implantation of the preserved ovarian tissue.

Lack of information and limited knowledge. Many participants reported an overall lack of understanding about OTC as a fertility preservation technique. This was highlighted as lack of information provided to the participants during fertility preservation counseling. It is unclear whether this was due to the fact that these young girls and women had discussions about OTC immediately prior to commencing gonadotoxic anticancer treatment, and that there was often an imperative to make decisions quickly.

> Before I tried artificial conception … wow, was I naïve … (Bach, Macklon, & Kristensen, 2020, p. 561)

Participants also did not seem to recall the details of the procedure. Some participants mistook ovarian tissue freezing for freezing of oocytes due to the complex jargon used by healthcare professionals.

> I think they (froze) eggs … Oh, they didn't freeze eggs? (Mitchell, Whiting-Collings, & Christianson, 2020, p.3)

> I was talking to doctors and they were using a lot of jargon. (Hershberger et al., 2013, p. 62)

Active information seeking and need for follow up. Participants were keen for health care professionals to follow them up to discuss the future of their tissue. At the time of OTC, women were facing a cancer diagnosis, a barrage of information and potential decisions about treatment for cancer that included risks to fertility. However, their primary concern was the current treatment and not their future fertility. After completion of cancer treatment, women started to think more about a future that included having biological children and therefore wanted information about OTC and its implications at that point.

> I have probably been given a lot of information which I have forgotten … .(Bach, Macklon, & Kristensen, 2020, p. 559)

> It would be helpful if there was patient follow-up-whether that be something as simple as a newsletter, or a quarterly email, or just something biannual that patients could know about what is happening. (Mitchell, Whiting-Collings, & Christianson, 2020, p.3)

The included studies represented the perspectives of a wide range of female participants of different ages. Lack of knowledge appeared more pronounced in the younger group. This seemed to be related to fertility and risks of infertility not imagined.

> I think I just assumed growing up that everyone can have kids. (Tennyson, 2017, p. 80)

And a second issue was the complexity of the information presented.

> Maybe they need someone to break it down in a way that I can understand, for people who are younger. (Mitchell, Whiting-Collings, & Christianson, 2020, p. 3)

Participants therefore expected healthcare professionals to follow them up meticulously as most of the information provided before the OTC procedure was forgotten.

Discussion

In this review, we included four studies that highlighted the experiences of young girls and women undergoing OTC. The results were analyzed using 144 verbatim quotes from 85 participants. We identified four themes associated with experiences of young girls and women who underwent or considered OTC. The experiences were described as emotional, involving complex decision-making, educational and helping them prepare for the long-term consequences of potentially losing their fertility and hormonal function.

Evidence suggests that there is a great variability across studies when it comes to patient satisfaction in relation to receiving infertility related information associated with cancer [32]. Our results echo these findings as most participants would have liked more information before making a decision to undergo OTC. We found that overall, participants did not understand the technical aspects of the OTC procedure. They also did not seem to remember much of the information provided, mostly because they were under pressure and had to make other decisions in relation to cancer treatment. The European Society of Human Reproduction and Embryology (ESHRE) in their recent guideline on fertility preservation makes a strong recommendation for clinicians to provide patients with clear information on the impact of their disease (cancer or benign) and treatments on fertility [4]. This must also include decisional aids where required. Previous systematic reviews highlight the need for the provision of decision aids as early on as a week after diagnosis in the fertility preservation process [33]. There is evidence to suggest that participants preferred written information in addition to oral information such as leaflets that they can take home. Relevant

websites dedicated to fertility preservation have also shown to help patients understand the procedure better [32–34]. Furthermore Anazodo *et al.* stipulated that having more than one form of decision aid helps patients compare fertility preservation options [35]. Through this study, we found that the information provided to participants at the time of fertility preservation needs to be accessible and perhaps in more than one format so it can be easily comprehended by all age groups. Most participants were making decisions under pressure and so a healthcare professional trained to conduct these consultations is required to have these discussions. We also found that there was a discrepancy in how these young girls and women were followed up. Participants felt the need to have a longer follow up because they may forget they have a tissue "banked" for future use.

Furthermore, younger participants expressed frustration toward how the information was provided and the use of medical jargon. Through this review we found that lack of knowledge and information was more pronounced in the younger patients. The ESHRE guideline on fertility preservation also stressed the need for providing age-specific information, although this has only been considered as a "good practice point" [4]. Another study that examined the provision of oncofertility care globally, recommended age-specific information as being useful for young adolescents. We however suggest providing clear, age-specific information to young adolescents as absolutely necessary. Furthermore, since younger participants were unable to fully understand the impact of their disease on fertility, their parents or guardians were having to make these decisions on their behalf. Most young participants therefore felt frustrated with being infantilized, as if their autonomy was taken away. Interestingly, none of the included studies mention the use of Gillick competence or equivalent fitness and whether these were considered in participants before making fertility preservation decisions [36,37].

Overall, participants felt grateful for having the option of OTC especially since oocyte cryopreservation was not a feasible option for them. Participants also highlighted how making decisions under pressure was not always possible without the support of family and friends. Healthcare professionals in particular played an important role in the decision-making process. All the studies included, stated how input from the clinician and nurses as well as how the information about the procedure was provided, were key factors in accepting OTC as a fertility preservation option. Evidence suggests that patients find the decision-making process more manageable if they have adequate knowledge about fertility preservation options [38].

The psychological impact of a cancer diagnosis is substantial and necessitates the management of individuals' complicated emotional state [39,40]. This is further complicated by concerns regarding future fertility. There is evidence to suggest that women presenting for fertility preservation around the time of cancer diagnosis suffer with poorer mental health as compared to infertile patients [41]. There is further evidence to suggest that women with gynaecological conditions requiring fertility preservation need special psychological support [42]. Some patients may therefore benefit from psychological counseling in addition to fertility preservation counseling since extreme emotional states causing distress, anxiety and depression can alter decision-making [4]. The notion of overwhelm both with the cancer diagnosis as well as worries about future fertility are also highlighted in our review where participants discuss the whirlwind of a cancer diagnosis, as well as the possibility of losing fertility. Psychological support for women undergoing OTC is therefore warranted both at the time of diagnosis, as well as when making decisions about preserving future fertility.

Women saw OTC as an opportunity for the future. Young girls and women and who had not considered becoming mothers, were suddenly faced with the dilemma of being deprived off this right. Being offered OTC was therefore seen as a salvation. Some participants however did comment on the invasive nature of the procedure and something they would have reconsidered had they had more time and information. We also found that OTC was provided free of charge in two settings [30,43], whereas some participants had to pay either through their insurance or fund it themselves [28,29]. The latter were worried whether spending all this money will help them in the future since there was no guarantee they will be able to conceive after transplantation.

Strengths

To the best of our knowledge, this is the first systematic review that gathers qualitative evidence on the experiences of women undergoing OTC. Through a robust systematic search and hand searching of gray literature, we included four studies in the thematic analysis. Although OTC is being offered widely in specialized centers, patient experience has been limited to survey questionnaires only. This review captures

various aspects of patient experience as well as provides recommendations for future research and guidance that can be applied by clinicians in routine practice.

Limitations

There was a lack of true qualitative research on the topic of OTC and this limited our analysis to only four studies. Through our literature search we found that researchers deemed patient surveys as qualitative research and if there were any true qualitative studies, they mainly focused on the views of health care professionals rather than women that opt for OTC. This limited us in providing a complete picture of patient experience. Furthermore, although the age range of participants at the time of interview was given (13–42 years), age at cryopreservation was not always provided. It is therefore difficult to ascertain whether younger participants were truly adolescents at the time of cryopreservation (had started menstruation at the time of cryopreservation or even interview). There were also gaps in the information available about financial help for these women. Although free of charge in two settings (UK and Denmark), there was no information about whether it was free for all that require it or those in particular parts of the country. Participants from the US stated that they had to pay through their insurance. In the studies included, all participants interviewed were suffering with cancer. These women were primarily focusing on survivorship, with fertility preservation playing a small role in cancer survival. Lastly, the possibility of hormonal preservation from this method was only mentioned in one study. It is therefore not possible to comment on whether participants were, or not informed about this. If they were provided with information about hormonal function, we cannot ascertain whether participants simply could not recall this information or return of hormonal function was not important to them.

Implications for practice

Ovarian tissue cryopreservation should be provided by specialized centers only, with healthcare professionals particularly trained in carrying out consultations related to fertility preservation. The decision to undergo this method of fertility preservation for both cancer and benign reasons should be taken by a multidisciplinary team of reproductive endocrinologists, oncologists, surgeons, psychologists, and nurses. The centers that provide this novel technique, should provide participants with written material as well as online visual aids (websites and e-learning). There needs to be a robust policy in place for follow up of these patients. This may be complex for young girls as they are likely to have had their ovarian tissue cryopreserved when much younger. Policy makers need to reach a consensus regarding a time frame for follow up for girls who have had their tissue retrieved before puberty.

Furthermore, there is an urgent unmet need for a universal guideline for health care professionals involved in the care of women requiring OTC. Various fertility preservation societies have provided guidance on who to offer this procedure to, however there is a significant discrepancy in how this procedure is provided globally.

Young adolescents who wish to undergo this procedure pose a challenge for health care professionals. This cohort requires particular attention when it comes to the provision of information. Additionally, clinicians need to consider capacity and competence in these young girls as well as guidance on when to involve parents in the decision-making process. There is currently no robust guidance on assessing capacity and competence in young adolescent girls when it comes to considering OTC as a fertility preservation method.

Lastly, there is a need to establish a global registry and research database to generate evidence-based information regarding the return of hormonal and reproductive function from transplantation of the cryopreserved ovarian tissue.

Conclusion

This study addresses the experiences of young girls and women regarding a new fertility preservation method. Ovarian tissue cryopreservation is gaining popularity due to not requiring ovarian stimulation and therefore preventing a delay in starting anticancer treatment. Women who have considered or undergone this procedure have described their experiences as emotional, requiring complex decision making and having to make time sensitive decisions. Healthcare professionals involved in the care of young girls and women undergoing this method therefore need to take into consideration the emotional wellbeing of the patients as well as the time and expertise it requires to help them make an informed decision. Furthermore, given the novel nature of this procedure, young girls or women undergoing this method of fertility preservation should be given clear information

about what the procedure entails and followed up meticulously.

Acknowledgements

We thank Mr Derick Yates (Library & Knowledge Service, Birmingham Women's Hospital) for his assistance in designing the search strategy and literature search. The author would also like to thank Wellbeing of Women for their entry-level scholarship (award reference ELS904, Registered Charity No.: 239281) that eventually led to securing a PhD position and conducting of this study.

Disclosure statement

CAA, SF and YA are shareholders in a private company that offers ovarian tissue cryopreservation and transplantation service.

ORCID

Hajra Khattak http://orcid.org/0000-0002-7330-3825
Annie Topping http://orcid.org/0000-0002-0111-2341

References

[1] Gellert SE, Pors SE, Kristensen SG, et al. Transplantation of frozen-thawed ovarian tissue: an update on worldwide activity published in peer-reviewed papers and on the danish cohort. J Assist Reprod Genet. 2018;35(4):561–570.
[2] Sheshpari S, Shahnazi M, Mobarak H, et al. Ovarian function and reproductive outcome after ovarian tissue transplantation: a systematic review. J Transl Med. 2019;17(1):396.
[3] Dolmans MM, Donnez J. Fertility preservation in women for medical and social reasons: Oocytes vs ovarian tissue. Best Pract Res Clin Obstet Gynaecol. 2021;70:63–80.
[4] Anderson RA, Amant F, Braat D, et al. ESHRE guideline: female fertility preservation. Hum Reprod Open. 2020;2020(4):hoaa052.
[5] Donnez J, Dolmans MM. Fertility preservation in women. N Engl J Med. 2017;377(17):1657–1665.
[6] Yasmin E, Balachandren N, Davies MC, et al. Fertility preservation for medical reasons in girls and women: British fertility society policy and practice guideline. Hum Fertil. 2018;21(1):3–26.
[7] American Society of Reproductive Medicine (ASRM). Fertility preservation in patients undergoing gonadotoxic therapy or gonadectomy: a committee opinion. Fertil Steril. 2019;112(6):1022–1033.
[8] Yding Andersen C, Mamsen LS, Kristensen SG. Fertility preservation: freezing of ovarian tissue and clinical opportunities. Reproduction. 2019;158(5):F27–34.
[9] Kristensen SG, Andersen CY. Cryopreservation of Ovarian tissue: opportunities beyond fertility preservation and a positive view into the future. Front Endocrinol. 2018;9:347.
[10] Almodin CG, Almodin PM, Radaelli MRM, et al. The frst ovarian tissue transplant between monozygotic twin sisters discordant for ovarian function in Latin America. J Bras Reprod Assist. 2015;19(1):29–32.
[11] Donnez PJ, Dolmans MM, Demylle D, et al. Livebirth after orthotopic transplantation of cryopreserved ovarian tissue. Lancet. 2004;364(9443):1405–1410.
[12] Khattak H, Malhas R, Craciunas L, et al. Fresh and cryopreserved ovarian tissue transplantation for preserving reproductive and endocrine function: a systematic review and individual patient data meta-analysis. 2022. 1–17.
[13] Schover L. Psychosocial aspects of infertility and decisions about reproduction in young cancer survivors: a review. Med Pediatr Oncol. 1999;33(1):53–59.
[14] Dolmans MM, von Wolff M, Poirot C, et al. Transplantation of cryopreserved ovarian tissue in a series of 285 women: a review of five leading European centers. Fertil Steril. 2021;115(5):1102–1115.
[15] Lotz L, Barbosa PR, Knorr C, et al. The safety and satisfaction of ovarian tissue cryopreservation in prepubertal and adolescent girls. Reprod Biomed Online. 2020;40(4):547–554.
[16] Sullivan-Pyke CS, Carlson CA, Prewitt M, et al. Ovarian tissue cryopreservation (OTC) in prepubertal girls and young women: an analysis of parents' and patients' decision-making. J Assist Reprod Genet. 2018;35(4):593–600.
[17] Forman EJ, Anders CK, Behera MA. A nationwide survey of oncologists regarding treatment-related infertility and fertility preservation in female cancer patients. Fertil Steril. 2010;94(5):1652–1656.
[18] Vesali S, Navid B, Mohammadi M, et al. Little information about fertility preservation is provided for cancer patients: a survey of oncologists' knowledge, attitude and current practice. Eur J Cancer Care. 2019;28(1):e12947–8.
[19] Quinn GP, Vadaparampil ST, King L, et al. Impact of physicians' personal discomfort and patient prognosis on discussion of fertility preservation with young cancer patients. Patient Educ Couns. 2009;77(3):338–343.
[20] Shapira M, Dolmans M-M, Silber S, et al. Evaluation of ovarian tissue transplantation: results from three clinical centers. Fertil Steril. 2020;114(2):388–397.
[21] Partridge AH, Gelber S, Peppercorn J, et al. Web-based survey of fertility issues in young women with breast cancer. JCO. 2004;22(20):4174–4183.
[22] Shin S, Kim J, Kim D, et al. The importance of education regarding the effects of anticancer treatment on fertility and ovarian function in the female patients with breast cancer. J Menopausal Med. 2019;25(3):142–148.
[23] Watkins DC. Qualitative research: the importance of conducting research that doesn't "count". Health Promot Pract. 2012;13(2):153–158.
[24] Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. Int J Qual Health Care. 2007;19(6):349–357.
[25] Tong A, Flemming K, McInnes E, et al. Enhancing transparency in reporting the synthesis of qualitative

research: ENTREQ. BMC Med Res Methodol. 2012; 12(1):181.
[26] Stern C, Jordan Z, Mcarthur A. Developing the review question and inclusion criteria: the first steps in conducting a systematic review. Am J Nurs. 2014;114(4): 53–56.
[27] Critical Appraisal Skills Programme. 2018. CASP (Qualitative) Checklist. [online]; [cited 2021 Nov 30]. Available from: https://casp-uk.net/wp-content/uploads/2018/03/CASP-Qualitative-Checklist-2018_fillable_form.pdf.
[28] Hershberger PE, Finnegan L, Pierce PF, et al. The decision-making process of young adult women with cancer who considered fertility cryopreservation. J Obstet Gynecol Neonatal Nurs. 2013;42(1):59–69.
[29] Mitchel C, Whiting-Collings L, Christianson M. Understanding patients' knowledge and feelings regarding their cryopreserved ovarian tissue: a qualitative interviewing study. J Adolesc Young Adult Oncol. 2020;9(4):502–507.
[30] Bach AS, Macklon KT, Kristensen SG. Futures and fears in the freezer: Danish women's experiences with ovarian tissue cryopreservation and transplantation. Reprod Biomed Online. 2020;41(3):555–565.
[31] Thomas J, Harden A. Methods for the thematic synthesis of qualitative research in systematic reviews. BMC Med Res Methodol. 2008;8(1):45.
[32] Goossens J, Delbaere I, Lancker A, et al. Cancer patients' and professional caregivers' needs, preferences and factors associated with receiving and providing fertility-related information: a mixed-methods systematic review. Int J Nurs Stud. 2014;51(2): 300–319.
[33] Shen S, Zelkowitz P, Rosberger Z. Cancer and fertility: optimizing communication between patients and healthcare providers. Curr Opin Support Palliat Care. 2019;13(1):53–58.
[34] Ehrbar V, Urech C, Alder J, et al. Decision-making about fertility preservation-qualitative data on young cancer patients' attitudes and needs. Arch Womens Ment Health. 2016;19(4):695–699.
[35] Anazodo A, Laws P, Logan S, et al. How can we improve oncofertility care for patients? A systematic scoping review of current international practice and models of care. Hum Reprod Update. 2019;25(2): 159–179.
[36] Taylor JF, Ott MA. Fertility preservation after a cancer diagnosis: a systematic review of adolescents', parents', and providers' perspectives, experiences, and preferences. J Pediatr Adolesc Gynecol. 2016;29(6): 585–598.
[37] Quinn GP, Murphy D, Knapp C, et al. Who decides? Decision making and fertility preservation in teens with cancer: a review of the literature. J Adolesc Health. 2011;49(4):337–346.
[38] Peate M, Meiser B, Friedlander M, et al. It's now or never: fertility-related knowledge, decision-making preferences, and treatment intentions in young women with breast cancer–an australian fertility decision aid collaborative group study. J Clin Oncol. 2011; 29(13):1670–1677.
[39] Armuand GM, Wettergren L, Rodriguez-Wallberg KA, et al. Desire for children, difficulties achieving a pregnancy, and infertility distress 3 to 7 years after cancer diagnosis. Support Care Cancer. 2014;22(10): 2805–2812.
[40] Logan S, Perz J, Ussher JM, et al. Systematic review of fertility-related psychological distress in cancer patients: Informing on an improved model of care. Psychooncology. 2019;28(1):22–30.
[41] Logan S, Anazodo A. The psychological importance of fertility preservation counseling and support for cancer patients. Acta Obstet Gynecol Scand. 2019;98(5): 583–597.
[42] La Rosa VL, Shah M, Kahramanoglu I, et al. Quality of life and fertility preservation counseling for women with gynecological cancer: an integrated psychological and clinical perspective. J Psychosom Obstet Gynaecol. 2020;41(2):86–92.
[43] Tennyson R, Paper B. An interpretative phenomenological analysis study into the experience of teenagers and young adults offered ovarian tissue cryopreservation following a cancer diagnosis.Doctoral thesis. University of Oxford; 2017.