


## ORIGINAL ARTICLE

# The experience of female oncological patients and fertility preservation: A phenomenology study

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## Abstract

**Objective:** The aim of this study is to analyse the experience of fertility preservation among female oncological patients.

**Methods:** A phenomenological study was conducted in an Assisted Human Reproduction Unit. The sample was composed of 14 females of reproductive age diagnosed with a cancer that may affect reproductive function, who had undergone a fertility preservation procedure. In-depth interviews were carried out, and the transcripts were entered into the Atlas.ti.v.8.2.3 qualitative analysis software package. The steps proposed by Taylor–Bogdan were followed in the analysis of the data.

**Results:** Four thematic categories emerged in relation to the experience with the fertility preservation process: interruption of life plans and changes in the person; knowledge about fertility preservation options, reproductive capacity and impact because of the possible loss; dyadic relationships and social representations of fertility.

**Conclusions:** Patients suffer from difficulties when making decisions about fertility whilst dealing with a cancer diagnosis. They need adequate information and support from health professionals. Despite increasing awareness of fertility preservation, there is a lack of knowledge regarding patients' experiences and needs related to this process.

## KEYWORDS

cancer, experiences, female, fertility preservation, phenomenology, qualitative research

## 1 | INTRODUCTION

Cancer is one of the leading causes of morbidity and mortality worldwide, with nearly 10 million deaths in 2020 (Ferlay et al., 2020; WHO, 2022). More than 14 million people are diagnosed with cancer around the world each year, and its incidence is increasing (Ferlay et al., 2020). The most common cancers are currently breast, lung and colon–rectum cancers, with 2.26, 2.21 and 1.93 million newly

diagnosed cases, respectively in 2020 (Ferlay et al., 2020; WHO, 2022). The data suggest that one out of two males and one out of three females will develop cancer during their lives (SEOM, 2017; WHO, 2022).

Many cancers can be overcome if they are detected early and cured effectively. In recent decades, breakthroughs in antineoplastic treatments have led to a significant increase in survival rates (Aguar Junior et al., 2020; Ellison et al., 2021). Indeed, several scientific

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societies and researchers maintain that cancer chronicity will increase in the future (Aguar Junior et al., 2020; Del Pozo-Lérída et al., 2019). Due to this progressive increase in cancer survival, it is necessary to consider the patients' long-term quality of life and to minimise the side effects of the treatments they must undergo.

It is important to bear in mind that many cancer treatments compromise reproductive function, leading to premature ovarian failure in females as well as infertility or subfertility in adults (Abdul et al., 2021; Del Pozo-Lérída et al., 2019; Wang et al., 2020). According to numerous studies, the reproductive capacity in humans is clearly related to quality of life, feelings of well-being and personal autonomy (Anazodo et al., 2019; Wang et al., 2020). Its loss could therefore have a major impact on cancer survivors, with considerable problems involved in accepting the *impossibility* of having offspring as a result of the treatments received.

Although the incidence of cancer increases with age, a significant number of cases appear in childhood, adolescence and reproductive age (15–44 years) (Fidler et al., 2017; WHO, 2022). Considering the overall developments in modern medicine and the growing global trend for delaying parenthood, an increasing number of cases of people diagnosed and treated for cancer have not yet completed their family (Abdul et al., 2021; Anazodo et al., 2019; Vuković et al., 2019).

Incorporating fertility issues in the treatment and care of patients diagnosed with cancer at a reproductive age has therefore become an increasingly important topic in clinical and research contexts (Abdul et al., 2021; Anazodo et al., 2019; Chen et al., 2022; Harada & Osuga, 2019). Fertility emerged as an integral component of quality of life for cancer survivors receiving gonadotoxic treatments, and it is considered an essential component of the comprehensive approach to cancer patients' care (Hoffman et al., 2021; Vuković et al., 2019; Zaami et al., 2021).

Fertility preservation is defined as the application of medical, surgical and laboratory procedures to preserve fertility in young adults or adults who are at risk of losing it before the natural end of their reproductive life (Arecco et al., 2022; Harada & Osuga, 2019; Zaami et al., 2021). Two of the most commonly used techniques for fertility preservation in women oncological patients are the vitrification of ova and/or embryos, and the freezing of ovarian tissue (Chen et al., 2022; Harada & Osuga, 2019).

Making decisions about fertility preservation at the time of diagnosis and before starting chemotherapy treatments may be difficult and complex for the patient, because medical, bioethical, legal and psychological issues converge (Lambertini et al., 2020; Van den Berg et al., 2021; Wan et al., 2021; Zaami et al., 2021). In addition, cancer is a threatening disease. It is presented as a risk of premature death, interrupting the path of life and changing the worldview of the patient and their relatives. These aspects, together with a lack of information and the urgency involved in starting the cancer treatment, are reasons behind limited uptake of the fertility preservation process among oncology patients (Lambertini et al., 2020; Torres-Castaño et al., 2020; Van den Berg et al., 2021; Wan et al., 2021; Zaami et al., 2021).

In view of the above, there is a need to move from a biomedical model of health care to a holistic approach, that is, a shift from a

biomedical approach of cancer treatment towards a holistic understanding of the impact of cancer on the individual's quality of life, taking into account both the physical and the psychosocial dimensions of this experience. Nevertheless, research indicates substantial gaps in our knowledge of cancer patients' experiences (Dahhan et al., 2021; Mollica et al., 2017; Vesali et al., 2018).

As regards fertility preservation in oncology patients, there is an increasing number of studies describing the techniques and the success rates of the different options (Arecco et al., 2022; Chen et al., 2022). However, there is a lack of knowledge about patients' specific needs, fears or feelings about the procedure for fertility preservation when they are diagnosed with cancer (Dahhan et al., 2021; Hoffman et al., 2021). Nursing professionals should base their care on an understanding of what people feel or experience when they are facing an event that destabilises their daily life, as cancer does (Errasti Ibarrodo et al., 2018; Guerrero-Castañeda et al., 2017).

This research therefore aims to fill the gap identified in knowledge of patients' specific needs and experiences regarding fertility preservation by understanding those of women cancer patients of reproductive age. Gaining in-depth knowledge from their perspective will contribute to raising awareness among health-care professionals about these issues in order to be able to provide optimum counselling and to define tailored and individualised strategies to improve the quality of care for cancer patients.

## 2 | METHODS

### 2.1 | Study design

A phenomenological study was conducted. In this paradigm, a social phenomenon is analysed through the meaning of the experiences and behaviours of the people who live through it in a specific context (Maykut & Morehouse, 1994; Rapport & Wainwright, 2006; Zahavi & Martiny, 2019).

The phenomenology approach provides an understanding of the situation and the experiences of oncological patients as regards the process of fertility preservation. This approach is focussed on intense and deep knowledge rather than extensive and generalisable knowledge, contributing a different perspective to the existing bibliography on the area of study (Zahavi & Martiny, 2019). In specific terms, this study followed Husserl's philosophical approach to descriptive phenomenology that emphasises the 'pure' description of people's experiences (Husserl, 1992; Kim et al., 2020; Matua & Van Der Wal, 2015). It gives an understanding of the phenomenon being observed by describing the living experience as perceived by the participants (Kim et al., 2020).

### 2.2 | Context of study

The study was carried out in the Assisted Human Reproduction Unit (AHRU) of the La Fe University and Polytechnic Hospital (Valencia).

This public hospital is the leading institution for many specialties in the Community of Valencia and beyond. Moreover, it is responsible for the health-care of 300,000 inhabitants.

### 2.3 | Study population: Characteristics and selection of participants

The participants were selected based on a purposeful sampling, by retrospectively reviewing the registry of the AHRU for the 3 years prior to the data collection (2017–2019) (108 patients). The subjects included in the study were females of reproductive age (18–44 years), diagnosed with a cancer that could affect reproductive function due to the need to receive gonadotoxic treatments, who had undergone treatment for fertility preservation. The patients in the acute phase of chemotherapy or with cognitive, neurological or mental impairment that could restrain communication were excluded. There were 24 eligible women in the registry who met the inclusion criteria.

Data saturation was achieved with 13 interviews. One more interview was conducted afterwards to confirm saturation, and the final sample size was 14 participants. To ensure the confidentiality of the interviewees' data, they were assigned a letter depending on the type of their fertility preservation treatment: vitrification of oocytes and/or embryos (V) or freezing of the ovarian tissue (F), as well as a number which referred to their order of participation in the study (Table 1).

### 2.4 | Data collection

The AHRU nurses contacted the 24 eligible patients to explain the study to them, and asked for their consent to provide the research

team with their telephone numbers. The researchers then contacted the possible participants in the study. All of them had undergone fertility preservation treatments between 20 and 8 months previously. At this point, 20 women accepted, and they were informed that the interview would be recorded. The reasons for not participating were not explored at this point. Not all of those who volunteered to participate were interviewed, as data saturation was achieved. The criteria followed when deciding who to contact first was their proximity to the place where the interviews were conducted. The research team thanked the volunteers who did not participate in a telephone call. Fourteen semi-structured personal interviews were carried out using a script of open questions based on the researchers' experience and the literature review to ensure that the research objectives were met (Table 2). This script elicited information about the oncological patients' experiences, beliefs, motivations, attitudes and behaviours related to the process of fertility preservation, facilitating the free flow of the participants' discourse and narratives, following the philosophy that guides phenomenology. The field work was carried out from March to May 2019 in classroom at Nursing School La Fe (Valencia), because this location was considered a neutral place, away from the hospital environment, enabling better interaction. Hospital facilities were avoided to control the symbolic effect that this could have on the participants and therefore on the data. The duration of the interviews ranged between 60 and 120 min, and they were recorded in audio format (MP3) with an Evistr L57 recorder to facilitate the data transcription process.

The same researcher conducted all the interviews to ensure homogeneity in the data collection process. She was a nurse with 4 years of experience of working in oncology, who had studied a master's degree in Oncology Nursing, and a person with experience and knowledge of the issue studied.

**TABLE 1** Sociodemographic characteristics of patients and cancer diagnosis

Participants	Age	Civil status	Level of studies	Job	Cancer diagnosis
V1 <sup>†</sup>	34 years	Married	University	Inactive	Appendix tumour
V2	29 years	Couple	University	Active	Ovary tumour
V3	29 years	Married	University	Inactive	Breast cancer
V4	33 years	Single	Secondary	Active	Breast cancer
V5	37 years	Couple	Primary	Inactive	T-cell lymphoma
V6	27 years	Single	University	Active	Neck sarcoma
V7	28 years	Single	University	Inactive	Breast cancer
F1 <sup>‡</sup>	36 years	Married	University	Active	Breast cancer
F2	37 years	Married	Secondary	Inactive	Medulloblastoma
F3	21 years	Couple	University	Student	Breast cancer
F4	34 years	Single	Primary	Inactive	Hodgkin's lymphoma
F5	34 years	Couple	University	Inactive	Breast cancer
F6	34 years	Married	Secondary	Active	Breast cancer
F7	34 years	Married	No studies	Active	Breast cancer

<sup>†</sup>V: Vitrification of oocytes and/of embryos.

<sup>‡</sup>F: Freezing of the ovarian tissue.

## 2.5 | Data analysis

First, the textual corpus was prepared for reading, by literally transcribing the recordings. All the interviews and the subsequent data transcription were carried out by the same person to minimise possible biases and/or confusing variables, following the steps proposed by

Taylor–Bogdan: data preparation, discovery of topics, coding and relativisation (Figure 1) (Taylor & Borgdan, 1998). The transcripts were entered in the Atlas.ti.v.8.2.3 qualitative analysis software package in order to perform the analysis process. This software is a tool for content and discourse analysis of qualitative data that facilitates management, organisation and interpretation (Soratto et al., 2020).

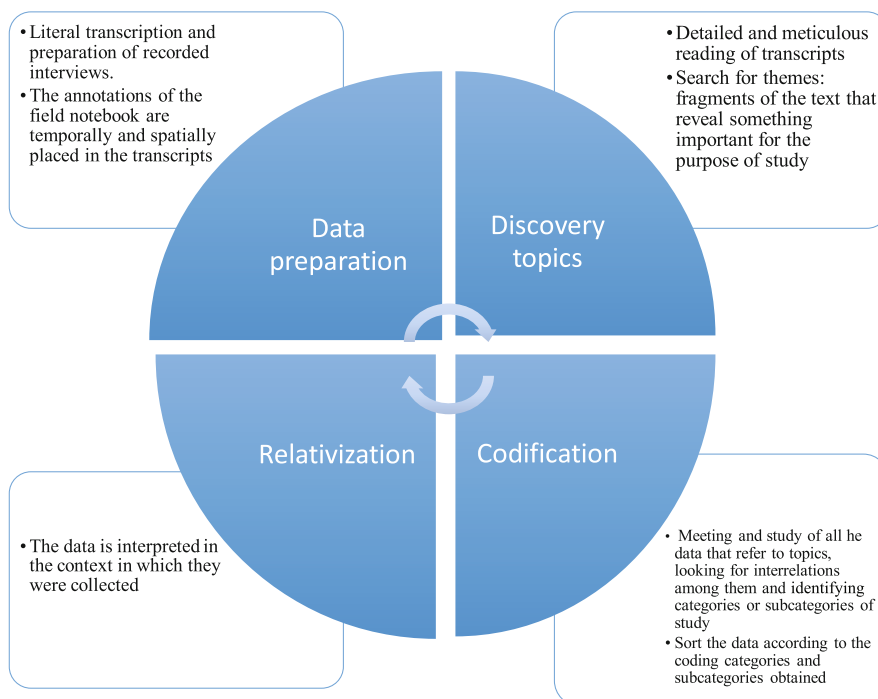
The data analysis process began during its collection. The information was analysed as it was generated. This sequential analysis made it possible to continuously adapt the method of collecting and analysing information for further exploration of new and emerging topics.

Two researchers pre-analysed the texts. The pre-analyses were performed through several readings of the primary documents, and the first list of topics was created. At this stage, the researchers tried to set aside their own thoughts and feelings about fertility preservation in order to attempt to explore the phenomenon from the participants' perspective without any preconceived ideas. The quotations were then generated, and the most relevant text segments were highlighted and coded. Relationships were then established, and code categories and themes were created to interpret the phenomenon being studied based on the informants' discourses.

The coding was carried out inductively, that is, topics and codes emerged as the analysis was carried out (Pope et al., 2000). The content analysis included triangulation of researchers to increase the rigour of the analyses and to avoid the potential bias caused by the researchers' expectations. Two researchers therefore analysed the data independently. The analysis of all the interviews was also reviewed by the lead researcher. For the correct interpretation of data, when consensus was not achieved, a third researcher reviewed the transcription and participated in the decision.

**TABLE 2** Study dimensions and thematic questions

Study dimensions	Thematic questions
Feelings and emotions	<p>Did you know that cancer treatments could produce fertility problems? What doubts did you have about this?</p> <p>What options did health professionals give you? What did they say? Did you understand the received information?</p> <p>What feelings did you have? How did you experience all this?</p> <p>How did you live the whole issue about fertility? Did you worry about it at different/or the same level as the diagnosis of cancer? Why?</p> <p>Do you think there is some aspect that, if it had changed, would have made it easier for you to understand/adapt better to the situation? Why?</p>
Couple and society	<p>Did you comment aspects related to fertility with your partner? What reaction did she/he have? Do you think that aspects related to fertility could affect your relationship?</p> <p>Do you think that in society there is still a kind of 'stigma' around infertility?</p>



**FIGURE 1** Phases of the qualitative analysis in progress proposed by Taylor–Bogdan

### 2.5.1 | Researchers' reflexivity

The researchers involved in data analysis were nurses with training in qualitative research achieved through Masters or PhD courses, who had previous experience carrying out qualitative studies through focus groups and interviews. They had between 5 and 7 years of clinical experience in the field.

## 2.6 | Ethical considerations

The study was approved by the Clinical Research Ethics Committee of the Research Institute of The University Hospital La Fe (Register number: 2018/0013). All the females participated voluntarily after receiving the patient information sheet (which included the objectives of the study, what their participation consisted of, and data protection in accordance with Spanish Organic Law (15/1999) and signing the informed consent form.

All the written and audio materials were locked away, with access restricted to the research team, ensuring the confidentiality of the information. All references to individuals or institutions that could identify the interviewee were removed from the transcripts.

## 3 | RESULTS

Fourteen patients participated in the study (Table 1). All of them were female, and their mean age was 31.93 years (SD: 4.53). Ten of them were living with their partner, and four were single. Nine out of 14 had gynaecological cancer (eight patients had breast cancer and one had ovarian cancer), and all of them had received gonadotoxic treatment.

The results were presented according to the thematic categories identified by the research team. Initially, the proposal was to analyse the data for the two types of treatments separately, based on the idea that the participants' experience could change in different processes. However, they were finally analysed together since the experience was found to be similar. The only difference observed was that in the ovarian tissue freezing group, the feelings, emotions, stress, and impact of the diagnosis were more intense due the fact that this process has to be carried out more quickly and more traumatically. One main theme with four categories, called 'Experience with the fertility

preservation process', emerged from the data and will be explained in the following section.

### 3.1 | Experience with the fertility preservation process

Four categories were identified within this theme: Interruption of life plans and changes in the person, knowledge about fertility preservation options, reproductive capacity and impact due to the possible loss, and dyadic relationships and social representations of fertility (Figure 2).

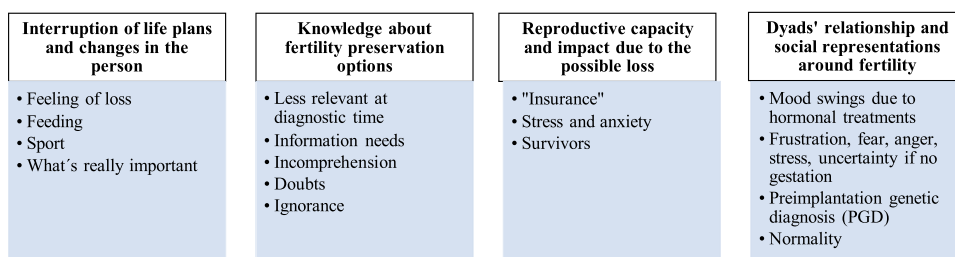
#### 3.1.1 | Interruption of life plans and changes in the person

Cancer is a threatening phenomenon that comes into the individual's life without warning and upturns their established plans, both regarding motherhood and in general (work, studies, etc.). They talked about a 'pause' in life:

*'That year, after Christmas, I was going to try to become a mother, and now I'm not... and I said: and now I'm not going to become a mother?' (F6, 34 years old, married). 'I was reading some information about maternity issues... Although I knew it wasn't for me this year, and that had moved completely to the background' (V6, 27 years old, single). 'Now I'm on hold, before I had my life, I've put it on hold, and when I finish all this I'll take it back and start living again' (F3, 21 years old, with a partner).*

They also experienced a feeling of loss due to the oncological process and had the idea that they would never be able to return to their pre-sickness condition:

*'When it happened to me, I just wanted this to end even though I thought that afterwards everything would go back to how it was before. And no...That does not happen' (F1, 36 years old, married). 'I do not feel normal, and I do not know if I'll recover 100%' (F5, 34 years old, with a partner).*



**FIGURE 2** Experience of the process of fertility preservation

Experiencing a disease of this type led to changes in lifestyles in terms of healthier eating, exercising routinely, and avoiding certain contaminants among most of the participants:

*'Do sport, now I will not leave it as I left it to study or work. That's over! Now I do not want extra hours or stress...'* (F5, 34 years old, with a partner), *'For example, I did not take good care of myself, but since this happened, food for me is...'* (V3, 29 years old, married).

The interviewees said that this process had changed their way of living, of understanding life and in some cases, their character and personality:

*'Although these things teach you to value other things...It teaches you to think and to value things more'* (V2, 29 years old, with a partner). *'It's sad because sometimes you have to go through these situations to make those small changes'* (V6, 27 years old, single). *'Life is limited and you have to live it'* (F5, 34 years old, with a partner).

### 3.1.2 | Knowledge about fertility preservation options

Most of the interviewees received information about the option of carrying out the fertility preservation process when they were informed of their diagnosis. However, they stated that they were in shock and did not focus their attention on this issue:

*'Besides, at that moment I only thought of my life and that I was going to die'* (V6, 27 years old, single). *'Well, at that moment I cared more about the cancer'* (V7, 28 years old, single).

Two of them were informed about fertility preservation options in the following appointment with the oncologist. However, all of them said that they specifically understood what the process consisted of in their first appointment at the AHRU:

*'I understood it better when they explained it to me in assisted reproduction'* (V7, 28 years old, single).

Above all, they experienced feelings of misunderstanding and doubts. Many of the participants did not know that the treatment could affect their reproductive function. They therefore requested more information since they did not understand why they were asked about if they wanted to become mothers when they were given the news that they had cancer:

*'At the beginning I did not understand. I thought: this does not matter to me, I mean, I do not want to have*

*children and I do not know if I'll be alive in two years'* (V6, 27 years old, single). *'And at the beginning I did not understand anything at all. I did not understand anything! Because I was there because of cancer and I did not know why they were asking me about children...'* (V5, 37 years old, with a partner).

Information was a double-edged sword. On the one hand, the interviewees sometimes perceived a lack of information about the process, and they requested more explanations about some hormone therapy treatments:

*'They could have explained to me that it was because of the chemo treatment so that I understood it but... I do not know'* (F5, 34 years old, with a partner). *'In that respect, the worst thing is the issue of hormonal medication because they give you a sheet and they explain it briefly, but you have a lot of doubts. I did not know and because I have a friend who's a nurse...'* (V4, 33 years old, single).

However, on the other hand, too much information overwhelmed them and created more anxiety:

*'OK, that's it. I do not want to know anymore. I know it's aggressive, do not tell me a forecast or anything, just tell me the treatment'* (V6, 27 years old, single).

The lack of empathy on the part of health professionals was also mentioned by interviewees:

*'But sometimes they do not even ask you how you are?'* (V1, 34 years old, married). *'In medicine sometimes they treat you like a piece of meat, a young girl... At the clinical level it's very interesting, or something like that'* (V7, 28 years old, single).

### 3.1.3 | Reproductive capacity and impact due to the possible loss

The possible loss of reproductive capacity was experienced very differently depending on the patients' age and plans. For instance, young females who had not yet considered becoming mothers saw the fertility preservation as 'insurance' for the future:

*'For me it was very secondary, it was more my doctor's insistence'* (F4, 34 years old, single). *'No, no ... The preservation was secondary'* (V2, 29 years old, with a partner).

On the other hand, among the females who wanted to have children in the near future, the possible loss of fertility created considerable stress and anxiety:

*'I already have two children, but it's important for me because I'd like to have more, and it's part of my plans' (F7, 34 years old, married). 'I just finished the chemo and I wanted to have a family... In fact, well I told you before, that I wanted to have a family before I was sick. Then I was in a hurry...'* (V1, 34 years old, married).

Moreover, there were some interviewees who initially did not consider motherhood as important, but when they overcame the oncological process and treatment, it became their centre of interest:

*'To give you an idea of the whole process, everything about reproduction was more difficult for me than the cancer. For me, cancer was like saying: well, this has happened to me... I'll make some changes in my life, personal relationships that do not interest me and all right! It was a gift, on my birthday as well, in addition. But the other thing was worse...'* (V1, 34 years old, married).

### 3.1.4 | Dyadic relationships and social representations of fertility

As for relationships with their partners, there were two opposite situations: on one hand, there was the possibility that the relationship was reinforced, and the partner provided more fundamental support, and on the other, the patient expected support or an attitude that did not exist, and the relationship broke down.

All the participants mentioned how difficult the treatments were due to the adverse effects, which made them aware that they were sick. For them, the worst aspects were the changes in their body image (loss of hair, breast removal, etc.):

*'At 21 days I lost all my hair, everything. And every time I looked at myself in the mirror I would say: is that me?' (V5, 37 years old, with a partner). 'I remember the subject of the breast with my partner... At the beginning I was very embarrassed, and I covered myself up, I did not want him to see me naked... But I do not know, he's taken it quite well. It's a blow! And I also thought that my partner would leave me' (F5, 34 years old, with a partner). 'At first I did not want to be with my husband or him to look at me, but then I accepted him' (F7, 34 years old, married).*

At the beginning, the issue of fertility did not seem to affect the couple's relationship. The most problematic aspect was the changes of mood caused by the hormonal treatment:

*'What my partner has taken very badly is my mood swings due to the treatment. He lives with it and he endures it, but he does not understand it' (F1, 36 years old, married).*

After the treatment was over, if they were considering having children and complications arose, they felt great frustration, stress, fear, anger and uncertainty. These reactions were mainly observed in women around 35 years old:

*'At the time, when you have cancer you do not place a great deal of importance on it, but now... Always, always, always, whenever I went to the oncologist my question was always the same: when can I have a child?' (F1, 36 years old, married). 'I think the relationship is stronger, but it's true that when I was a little more obsessed... He was fed up with me and the subject. He also wants to become a father but I was like very annoying... Not really annoying... But well, yes, I was very confused about the subject' (V1, 34 years old, married).*

Another issue that emerged during the interviews was preimplantation genetic diagnosis (PGD). This is a prevention technique used in assisted reproduction to detect anomalies in the genetic material of embryos. In some cases, the express authorisation of the appropriate health authority is required after a favourable report from a National Commission, which is a factor that implies an additional difficulty in achieving motherhood:

*'Because I have already spent a lot and I want to at least try... So that those who come later do not have to go through the same thing...'* (F1, 36 years old, married).

The interviewees believed that the possible handicap of infertility problems was becoming a more well-known issue. Nevertheless, they noticed a kind of social stigma around this issue, mainly among older people who were less aware because it was a problem of modern society:

*'I believe that people are very ignorant, but they are gradually becoming more aware. Many people cannot have babies and resort to these things' (V4, 33 years old, single). 'I believe that younger people think of it as a normal thing. It's more difficult for older people... Just like the issue of adoption and all that, they see it as weird. We have come a long way but maybe society is not yet fully aware of it' (F7, 34 years old, married).*

## 4 | DISCUSSION

To our knowledge, this is one of the few studies to have explored oncological patients' experiences related to the fertility preservation process, showing that it is unique and unrepeatable for each person.

As widely described in the related literature, this study stresses that cancer is a threatening element that interrupts people's lives, leading to them experiencing feelings of fear and loss (Van den Berg et al., 2021; Wan et al., 2021; Zaami et al., 2021). Specifically, it points

out that patients have the perception that the illness changed them, including their lifestyles, their way of looking at life and even their personality. These feelings seem to be more marked among young patients, like those in the population of this study. These results are consistent with previous studies that highlighted that having cancer is a stressful and potentially traumatic event, and that the individual's response to this situation could be determined by the patient's personal characteristics, such as age (Dahhan et al., 2021; Zaami et al., 2021). Young adults with cancer present high rates of psychological distress and unmet support needs (Nilsson et al., 2021; Sisk et al., 2019).

There was no clear consensus in this study regarding knowledge of fertility treatments and the various options available. Whilst some participants asked for more detailed information about the fertility process and the range of possibilities, other patients found it overwhelming. Moreover, the appropriate time for providing information about these options was not clearly determined. Receiving this information at the same time as the cancer diagnosis, according to the usual practice, seems not to be the best option, as the patients were still in shock whilst attempting to accept their diagnosis. Previous studies also found that when the diagnosis was confirmed, the patients experienced a great emotional impact with negative thoughts, including fear of death (Dahhan et al., 2021; Nilsson et al., 2021; Sisk et al., 2019). Dahhan et al. (2021) also identified this in a phenomenological study conducted with women with breast cancer. The participants emphasised their difficulties with accepting both the diagnosis and the threat to their fertility. Moreover, women with hormone-sensitive cancer experienced a threat of possible cancer growth due to fertility preservation (Dahhan et al., 2021).

Previous research has already indicated the need for adequate and acute information to enable oncology patients to make informed decisions about their treatment, understanding the benefits, harm and uncertainties (Kim et al., 2019; Torres-Castaño et al., 2020; Van den Berg et al., 2021; Zaami et al., 2021). This becomes critically important as regards fertility preservation to ensure that patients genuinely understand the process and can make an informed decision with realistic expectations at the right time. The findings of this study, as well as previous research, suggest that the implementation of decision support interventions involving health-care professionals in both oncology and fertility services may be beneficial within the clinical care pathway of fertility preservation and cancer (Anazodo et al., 2019; Dahhan et al., 2021; Di Mattei et al., 2021; Jones et al., 2017). Moreover, it is necessary to implement training programmes and educational tools targeted at improving professionals' communication skills for collaborative decision-making and delivering care that is patient-centred (Anazodo et al., 2019; Jones et al., 2017; La Rosa et al., 2020; Vesali et al., 2018). Further research regarding the development of these decision support interventions for young adult oncology patients is required.

As has been highlighted in this study, the risk of losing their reproductive capacity had varying degrees of impact on the patients' emotions depending on several aspects, such as their age and specific plans. The patients who had already thought about motherhood

before the cancer diagnosis felt more anxious and worried about the issue than the younger participants who were not ready for it. Nevertheless, in some cases, regardless of the patient's desire to have children, fertility preservation became essential for them, and an even more important issue than having cancer. Previous research has emphasised the importance of fertility among young adult cancer patients (Anazodo et al., 2019; Hoffman et al., 2021; Jones et al., 2017; Vuković et al., 2019; Zaami et al., 2021) and how this could vary according to patients' sociodemographic characteristics, such as already having children at time of diagnosis (Dahhan et al., 2021; Di Mattei et al., 2021). Previous maternity is an aspect that was not considered in this study, and it should be explored in future research.

As regards dyadic relationships during the process, two possible situations were identified in this research: reinforcement, unifying or a weakening of the relationship that could even lead to its breakdown. Previous studies have also shown that cancer clearly impacts on couples' relationships (Acquati & Kayser, 2019; Chen et al., 2021; Kayser & Acquati, 2019) and identified two critical moments for the couple: during the acute treatment of cancer and in the post-treatment stage.

The participants in this study found that the side effects of hormonal treatment, which included changes of mood, had a negative impact on the dyadic relationship. On the other hand, once the treatment was over and patients started to focus on fertility issues, other negative feelings affecting the couple arose, such as frustration, stress, fear, anger and uncertainty. Several studies that have focussed on the dyads' coping have shown that younger couples are at greater risk of poor coping because of less collaborative behaviours and higher vulnerability to stress (Kayser & Acquati, 2019). This is the case of the study conducted by Acquati and Kayser (2019) with couples in which a woman had breast cancer, highlighting the important negative impact of cancer on the quality of life of younger patients and their partners.

Another aspect that arose in this study is the important role played by health professionals. The patients sometimes felt that they did not receive the empathy and support they expected from professionals. The evidence suggests that many women with cancer do not feel they receive sufficient support from health professionals when making decisions regarding fertility preservation (Anazodo et al., 2019; Jones et al., 2017; Torres-Castaño et al., 2020). This situation could lead them to fail to take up fertility care at this crucial time.

Most published studies focus on recognising the factors that make fertility preservation techniques appropriate (the patient's age, situation, type of cancer, type of treatment and urgency), the types of treatments and the success rates (Arecco et al., 2022; Chen et al., 2022; Cho et al., 2020). In other words, they are based on the clinical and medical aspects of this issue. However, there is a lack of research that explores the patients' needs, feelings and experiences with this process (Dahhan et al., 2021; Hoffman et al., 2021). More research needs to be done on the experience of cancer patients undergoing fertility preservation treatments, which is becoming an important issue due to the high survival rates achieved by



antineoplastic treatments. Addressing this shortcoming may be helpful to those managing patients struggling to make difficult decisions in an often brief period before potentially sterilising cancer treatment is started (Errasti Ibarrondo et al., 2018; Guerrero-Castañeda et al., 2017; Jones et al., 2017).

This study has some limitations. First, the sample size is small, although data saturation was achieved. Second, the participants were selected from a specific organisation and their profile might not represent all oncological patients undergoing fertility preservation treatments. Moreover, the participants were all in a similar phase of the disease, as they had already finished their oncological treatment and all of them had decided to undergo fertility preservation procedures. Accordingly, there is a lack of information about those who rejected this option. Another limitation of this research is that the aspect of previous motherhood or the number of children was not explored, and this is an issue that could be interesting to include in further studies, as well as possible gender differences. This research studied women's experiences, and exploring men's experiences could be also of interest. A more heterogeneous sample of participants at different stages of the process focussing on individual characteristics such as gender and previous motherhood could therefore be recommended for future studies. The results of this study are not generalisable to all oncological patients. However, the objective of a phenomenology study is to obtain in-depth knowledge about the experience lived by individuals as regards one phenomenon, and this was achieved in this study.

Our phenomenological approach enabled health professionals' understanding of the 'phenomenon' of fertility preservation after a cancer diagnosis to be enhanced through the eyes of those experiencing it. There is a need to further explore the individual's characteristics (age, whether they are single or live in couple, previous motherhood, type and stage of the cancer) and their impact on the experience regarding the fertility process. Based on this knowledge, person-centred interventions could be developed to improve care for patients and families, considering not only the physical aspects but also addressing their psychological and social needs.

## 4.1 | Implications for practice

These findings suggest important implications for practice. The results provide relevant knowledge about patients' experiences of fertility preservation that could help professionals informing and advising them. There is a need for holistic care, considering the person affected by the disorder and the specific characteristics. Current evidence suggests that there is a need for comprehensive policies that reflect the individual's needs (Mollica et al., 2017). This seems to be even more important among young adults, a population in which the illness clearly interrupts their life at an especially critical point in the lifespan. Holistic and multidimensional approaches to the design and implementation of tailored interventions to promote well-being are critical in addressing the complexity of the care recipient as biopsychosocial and spiritual beings.

In conclusion, this study suggests that within a wide range of individual experiences in the cancer care process, there are repeated patterns and trajectories:

1. Cancer is a threatening element that interrupts people's lives and creates emotional distress. Each person deals with the situation in a different way, and it seems that the patient's individual characteristics (age, marital status and previous motherhood) have an impact on their experience.
2. The increase in cancer survival rates among young adults of reproductive age justifies the need to develop techniques to preserve patients' fertility. Fertility has emerged as an integral component of quality of life for cancer survivors, and it is considered an essential component of the comprehensive approach to cancer patients' care.
3. Cancer affects not only at the person but also their partner. It is necessary to look at the dyad and to study effective dyadic coping strategies for this population.
4. The patients experience difficulties when making decisions about fertility whilst almost simultaneously coping with their cancer diagnosis. They need adequate information and support from health professionals.
5. Despite the advances and the increasing awareness about the importance of the integral treatment of cancer and fertility preservation, there is a lack of knowledge regarding patients' experiences and needs in this process.

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## CONFLICT OF INTEREST

The authors declare that they have no conflicts of interest.

## DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

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