



## Attitudes toward motherhood and social support as predictors of emotional distress in recently diagnosed young women with cancer undergoing fertility preservation

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**Abstract: Objective.** Young women with cancer can benefit from various treatment options for fertility preservation. More work is needed to discern which factors affect psychological outcomes and the decision to undergo fertility preservation for female cancer survivors. The purpose of this study was to examine the relationship between attitudes toward motherhood, concerns about fertility, satisfaction with information received, social support and emotional distress among young women with cancer undergoing fertility preservation treatment. **Method.** Cross-sectional administration of instruments (semi-structured interview, Scale of Perceived Social Support, BSI-18) to 115 young women (average age 31 years) newly diagnosed with cancer. Assessment was done on the same day or day after undergoing Ovarian Tissue Cryopreservation (OTC). **Results.** The degree of concern reported by the women when they knew that cancer treatment might affect their reproductive capacity was high. Almost half stated that they would change the treatment-related information they received. Factors influencing their decision to receive OTC include the importance of having a child and maintaining hormonal function. Higher emotional distress was significantly associated with increase desire to have children, belief that having children is necessary for couple's fulfillment, desire to change the information received, higher degree of concern about the possible loss of fertility, and less perceived social support. **Conclusions.** Both attitudes to motherhood and social support are factors that determine the emotional distress experienced by young women with cancer when faced with the possible loss of infertility. There is a need to offer fertility preservation counseling to these women.

**Keywords :** cancer, fertility preservation, oncofertility, distress, attitudes.

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## [es] Actitudes hacia la maternidad y el apoyo social como predictores de trastornos emocionales en mujeres jóvenes con cáncer recientemente diagnosticadas que se someten a la preservación de la fertilidad

**Resumen: Objetivo.** Mujeres jóvenes con cáncer pueden beneficiarse de opciones para la preservación de su fertilidad. Se necesitan estudios que determinen las implicaciones psicológicas de someterse a estas técnicas y de la propia decisión de recibirlos. Este estudio analiza el distres emocional, las preocupaciones sobre la fertilidad, las actitudes ante la maternidad, la satisfacción con la información recibida y el apoyo social en mujeres con cáncer que reciben un tratamiento de preservación de la fertilidad. **Método.** Una muestra de 115 mujeres (edad media 31 años) recién diagnosticadas de cáncer fueron evaluadas (Entrevista semiestructurada, Escala de apoyo social percibido, BSI-18) el mismo día o día después de someterse a una criopreservación de tejido ovárico. **Resultados.** El grado de preocupación manifestado por las mujeres cuando supieron que el tratamiento del cáncer podría afectar su capacidad reproductiva fue alto. Casi la mitad declaró que cambiarían la información recibida sobre el tratamiento de preservación de la fertilidad. Un mayor distrés se asoció significativamente con mayor deseo de tener hijos, la creencia de que tener hijos es necesario para la relación de pareja, el deseo de cambiar la información recibida, mayor grado de preocupación por la posible pérdida de fertilidad y menor apoyo social. **Conclusiones.** Tanto las actitudes hacia la maternidad como el apoyo social son factores que determinan el distrés emocional que experimentan las mujeres jóvenes con cáncer cuando se enfrentan a la posible pérdida de infertilidad. Es necesario ofrecer asesoramiento sobre la preservación de la fertilidad a estas mujeres.

**Palabras clave:** cáncer, preservación de la fertilidad, oncofertilidad, distrés emocional, actitudes.

**Sumario.** 1. Introduction 2. Methods 3. Results 4. Discussion 5. Acknowledgements 6. References.

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### 1. Introduction

The number of young women surviving beyond a cancer diagnosis is increasing<sup>(1)</sup>. Alongside this increasing prevalence of survivorship are women delaying childbearing or experiencing difficulty conceiving a child<sup>(2)</sup>. The context in which survivors opt to bear children is closely related to the cancer treatment they receive, as chemotherapy, radiotherapy, and/or surgical removal of reproductive organs can cause premature ovarian failure and infertility in these women<sup>(3)</sup>.

Studies examining the psychological impact of female infertility caused by cancer treatment show significant adverse consequences in socioemotional well-being and quality of life, indicating that survivors' infertility is associated with sadness, anger, and clinically significant distress and anxiety<sup>(4-7)</sup>. Women's emotional functioning prior to treatment can also intensify across time, adversely affecting quality of life in this population<sup>(4,7-9)</sup>. Some retrospective studies have examined how young women diagnosed with cancer react when they were informed of the potential for infertility<sup>(10,11)</sup>. Results showed that the disclosure of this information may be as distressing as the cancer itself and can impact treatment decisions.

Female cancer survivors without children and those who may be interested in childbearing require specific clinical and psychological care to cope with the

possible loss of fertility. Women can benefit from various treatment options for fertility preservation such as cryopreservation (e.g., embryos, oocytes, and ovarian tissue), *in vitro* maturation of immature oocytes, and ovarian suppression with gonadotropin-releasing hormone<sup>(12)</sup>. Professional organizations recommend that all women of reproductive age be counseled at the time of their cancer diagnosis about the possible effects of treatment on their future reproductive health and have access to fertility preservation options<sup>(12-14)</sup>.

Studies have examined the effectiveness of infertility educational materials offered to women recently diagnosed with cancer, attitudes towards fertility preservation techniques, and psychological consequences of decision making. Studies conducted in the U.S. and European countries demonstrate that a majority of women with cancer have a strong desire to be informed about fertility preservation<sup>(15,16)</sup>. However, nearly half of young women recently diagnosed are not given information about the impact of cancer treatment on their future fertility and reproductive capacity<sup>(17-19)</sup>. Fewer still typically proceed with fertility preservation<sup>(20-21)</sup>. Recent work indicates women with access to fertility preservation treatment had elevated well-being<sup>(22)</sup>. Another review examined the effect of counseling (alone, and with fertility preservation) and concluded that there is evidence to support the psychological benefit of intervention for this population<sup>(23)</sup>.

Despite these initially positive findings, the empirical literature on this topic remains thin: more work is needed to help discern which factors affect psychological outcomes and the decision to undergo fertility preservation for female cancer survivors. Preliminary results point to three domains of inquiry. The first includes demographic variables (i.e., age, relationship status) and the number of children at the time of diagnosis<sup>(24-27)</sup>. Second, the role that information supports play; for instance, work in this area demonstrates that patients who did not feel supported via counseling and information on fertility preservation options were more likely to experience decisional conflict and lower quality of life following treatment<sup>(24,27)</sup>. Lastly, attitudes toward motherhood, and specifically the desire to have children in the future which increased concern about the loss of fertility and was associated with higher emotional distress<sup>(10,28-30)</sup>. The majority of these prior works utilized retrospective designs, analyzed relatively small samples sizes, and included large variability in fertility preservation treatment uptake. There is a gap in understanding the needs of women recently diagnosed by cancer who are currently choosing to undergo specific preservation techniques.

The primary purpose of this study was to examine psychological functioning among young women recently diagnosed with cancer; specifically, their attitudes toward motherhood, concerns about fertility, and satisfaction with information received. We were interested in the relationship between fertility attitudes and emotional distress experienced when undergoing fertility preservation treatment. A second objective was to understand the contribution of social support in managing these women's emotional distress.

## 2. Methods

### Setting and Participants

This study was conducted at the Hospital Peset of Valencia and at the Hospital La Fe of Valencia in Spain. The study was approved by the Ethical Committee of both

medical centers. These two sites have clinical expertise in fertility preservation, including cryopreservation of ovarian tissue. The study sample included women recently diagnosed with cancer who were scheduled to undergo ovarian tissue cryopreservation (OTC) between 2007 and 2015 before receiving cancer treatment. Women were approached by the team's psychologist to take part in the study and provide informed consent. A total of 122 women were initially invited to participate in the study; 6 refused to participate (95% consent rate). Women enrolled in the study completed in-person self-report surveys (N= 115; 99% study completion rate among those enrolled) the same day or the next day undergoing OTC. Women were identified only with a study number; the list pairing study number and names was kept confidential and destroyed after completion of data collection.

The demographic and clinical characteristics of the final sample are shown in Table 1. The average age of the sample was 31 years (SD = 5.2): women tended to be married or in a stable relationship (56%) and with a high socioeconomic status. For instance, almost all were employed (80%) and had completed education from a university or college (52%). The majority of women had no biological children (88%): 12% had at least one biological child. Roughly two-thirds of the sample (68%) had breast cancer, while others had Hodgkins's Lymphoma, Non-Hodgkins's Lymphoma, or other types of cancer.

Table 1. Demographic and Clinical Characteristics (N=115)

<b>Variable</b>	<i>N</i> (%) or <i>M</i> ± <i>SD</i>
Average Age	30.55 ± 5.24
Relationship/Living Situation Status	
Married/with stable partner	64 (55.65)
Single	47 (40.87)
Divorced/Separated	4 (3.48)
Highest level of education	
Primary Education	12 (10.43)
Secondary or High School	43 (37.39)
University Studies	60 (52.17)
Employment Status	
Employed	92 (80.00)
Student	13 (11.30)
Unemployed	6 (5.22)
Other	4 (3.48)
Mother of Biological children	
Yes	14 (12.17)
No	101 (87.83)

<b>Variable</b>	<b>N (%) or M ± SD</b>
<b>Cancer Diagnosis</b>	
Breast Cancer	78 (67.83)
Hodgkin's Lymphoma	22 (19.13)
Non-Hodgkin's Lymphoma	5 (4.35)
Ovarian Tumor	1 (0.87)
Intestinal Cancer	2 (1.74)
Osteosarcoma	1 (0.87)
Adrenal Cancer	1 (0.87)
Leukemia	1 (0.87)
Other	4 (3.48)

### **Instruments and Variables**

A semi-structured interview was developed for this study based on the literature<sup>(31,32)</sup>. The self-report measures assessed attitudes toward motherhood and fertility preservation (see Table 2). Perceived social support was assessed by the Multidimensional Scale of Perceived Social Support (EMASP)<sup>(33)</sup>. This measure is comprised of 12 Likert-scale items that yield a Global Social Support score. Cronbach's alpha in this study was 0.76. Emotional distress was assessed by the Brief Symptoms Inventory-18 (BSI-18)<sup>(34)</sup>. This is a widely-used self-report instrument assessing psychological distress with 18 Likert-scale items that yield a total score for emotional distress (Global Severity Index; GSI), with three subscales (Depression, Anxiety, and Somatization). Only the total score was considered in this study showing a Cronbach's alpha of 0.88.

Table 2. Attitudes towards Fertility and Motherhood (N=115)

<b>Variable</b>	<b>n (%) or M ± SD</b>
Satisfaction with information received about reproductive side effects	7.64 ± 2.45
Would change information received	
Yes	47 (40.87)
No	68 (59.13)
Degree of concern about treatment affecting reproductive capacity	8.1 ± 2.08
Importance of having a child in decision to have surgery	8.6 ± 1.75

<b>Variable</b>	<b>n (%) or M ± SD</b>
Importance of hormonal function in decision to have surgery	8.0 ± 2.24
Extent to which decision to have surgery was woman's own	9.4 ± 1.25
Desire for child in the future n (%)*	
Not sure	5 (4.35)
Probably	33 (28.70)
Certainly	77 (66.96)
Attitudes towards motherhood n (%)	
Had not thought about it	12 (10.43)
Did not want to have children	1 (0.87)
Wanted to have children	82 (71.30)
Other	3 (2.61)
No response	17 (14.78)
Effect of cancer on desire for children	
Diminished desire	5 (4.35)
No effect	77 (66.96)
Increased desire	33 (28.70)
Woman is unfulfilled without child(ren)	
Yes	32 (27.83)
No	83 (72.17)
Couple is unfulfilled without child(ren)	
Yes	24 (20.87)
No	91 (79.13)

### Statistical Analysis

Descriptive statistics were generated for all demographic and clinical characteristics, as well as for key variables assessing psychological constructs. Bivariate analyses were conducted to assess the relationship between emotional distress and all other variables. Based on the results of these analyses, an ordinary least squares (OLS) linear regression was performed with the Global Severity Index score as the dependent variable. Analyses were conducted using Stata 14 statistical software.

### 3. Results

#### Attitudes toward Fertility and Motherhood

Table 2 shows descriptive results for attitudes toward fertility and motherhood. The degree of concern reported by the women when they knew that cancer treatment might affect their reproductive capacity reached an average of 8.1 out of 10. Satisfaction with the information received about cancer treatment was valued at an average of 7.6 out of 10, although 40% of the sample (N= 47) said that they would change some of the information they had received. For instance, in an open-ended item, participants indicated that they would like to receive more information about side effects of cancer treatment and have more time to discuss it with their providers. Women also stated they would like to receive more in-depth explanations about all the options to preserve fertility, particularly with coordination between their oncologist and gynecologist. Considering women in the sample had already received a referral for infertility treatment, they demonstrated relatively high autonomy in their choice to receive OTC ( $M = 9.4$  out of 10). Factors influencing their decision included the importance of having a child ( $M = 8.6$  out 10) and maintaining hormonal function ( $M = 8.0$  out 10).

Most women noted their desire to have children in the future (67%), and an additional 29% indicated that they would probably want to have a child in the future (4% were uncertain). The majority (71%) noted they had wanted to have children prior to being diagnosed with cancer. However, almost a third of the sample noted that knowing the effect(s) of cancer treatment on their fertility had increased their desire to have children (N=33, 28%): 67% (N=77) stated that knowing the effects of cancer had not altered their desire to have children, and 4% (N= 5) believed that the disease had decreased their desire for children. Finally, almost 28% (N= 32) believed that women without children were somehow incomplete, and 21% (N=24) considered that a couple without children was unfulfilled.

#### Predictors of Emotional Distress

Bivariate associations between independent variables and the GSI scale are displayed in Tables 3 and 4. Higher emotional distress was significantly associated with the following: an increased desire for children after knowing the possible effects on fertility of cancer treatment ( $p < .01$ ), higher consideration that children are necessary for couple's fulfillment ( $p < .05$ ), the desire to change the information received about fertility after cancer and about preservation options ( $p = .05$ ), and higher degree of concern about the possible loss of fertility after cancer treatment ( $p < .01$ ). Also, higher perceived social support was associated with less emotional distress ( $p < .01$ ). Meanwhile, a higher degree of concern about the possible loss of fertility after cancer treatment was positively associated with placing greater importance on restoring hormonal function ( $p < .05$ ) and having a child after cancer treatment ( $p < .001$ ). Moreover, greater emphasis on having child after cancer treatment was positively associated with the extent to which a women felt more autonomous in deciding to undergo OTC ( $p < .001$ ).

Table 3. Bivariate Associations with Emotional Distress

Variable	M (SD)	N	T
Marital status			
Unmarried	7.24 (8.37)	51	-1.78*
Married	10.16 (9.18)	64	
Education			
< College	9.45 (10.12)	55	0.67
>= Degree	8.32 (7.69)	60	
Children			
1+	6.93 (6.74)	14	-1.09
0	9.13 (9.17)	101	
Desire to change information received			
Yes	10.91 (10.08)	47	1.99*
No	7.44 (7.78)	68	
Children necessary to woman's fulfillment			
Agree	11.15 (10.48)	32	1.55
Disagree	7.98 (8.13)	83	
Children necessary for couple's fulfillment			
Agree	13.54 (12.19)	24	2.27**
Disagree	7.63 (7.44)	91	
Cancer has increased desire for children			
Yes	13.58 (11.81)	33	-3.03***
No	6.96 (6.64)	82	
Previous attitude toward motherhood			
Wanted children	9.06 (8.87)	82	-0.38
Neutral/Did not want children	8.00 (10.60)	16	
Desire for future children			
Certainly	9.08 (8.38)	77	-0.35
Probably	8.42 (10.01)	38	

\* $p < .10$ , \*\* $p < .05$ , \*\*\* $p < .01$ 

Table 5 shows the results of the OLS multivariate regression model with GSI scores provided by the BSI-18 as the dependent variable, including significant independent variables observed in bivariate analyses. Two models were estimated. Model 1

Table 4. Correlations with Emotional Distress (N=115)

<b>Variable</b>	BSI-18 Global Severity Index (Distress)	EMASP Total Score (Social Support)	Age	Satisfaction	Concern	Importance of Childbearing	Importance of Hormonal Function	Decision Autonomy
Distress	1.00							
Social Support	-0.29**	1.00						
Age	0.02	-0.12	1.00					
Satisfaction	-0.14	0.05	-0.08	1.00				
Concern	0.27**	0.05	-0.06	-0.15	1.00			
Importance of Childbearing	0.16	0.11	0.10	-0.02	0.46***	1.00		
Importance of Hormonal Function	-0.06	-0.05	-0.08	0.05	0.19*	0.03	1.00	
Decision Autonomy	0.18	-0.15	0.09	-0.03	0.10	0.33***	0.02	1.00

\* $p < .05$ , \*\* $p < .01$ , \*\*\* $p < .001$

excludes social support as a predictor: it revealed that two variables contributed significantly to the emotional distress. These were women's cancer experience (for those who reported an increased desire to have children) and their belief that having children is necessary for couple's fulfillment, both of which were related to increased distress. These variables accounted for 20% of variation in GSI score (Adj. R-squared = 0.20). Model 2 includes social support as a predictor and the resulting model accounts for one-quarter of the variation in distress (Adj. R-squared = 0.25). This model showed that women with higher levels of social support experienced lower levels of distress. Moreover, being married, having a higher level of concern about reproductive capacity, and reporting that one's cancer experience has increased the desire to have children were also associated with higher levels of distress.

Table 5. Multivariate Regression

Variables	Model 1	Model 2
Married	2.149 (1.529)	3.180* (1.511)
Child Necessary for Couple's Fulfillment	4.507* (1.877)	2.452 (1.928)
Would Change Info Received	2.599 (1.549)	2.147 (1.500)
Cancer has Increased Desire to Have Children	5.128** (1.708)	4.935** (1.647)
Degree of Concern	0.653 (0.378)	0.741* (0.365)
Social Support		-0.483** (0.157)
Constant	-1.070 (3.011)	31.14** (10.88)
Observations	115	115
R-squared	0.232	0.294
Adj. R-squared	0.197	0.255

Note. Standard Errors are in ( )'s.

\*\*\* p<0.001, \*\* p<0.01, \* p<0.05

#### 4. Discussion

International organizations<sup>(12-14)</sup> have recommended that the impact of cancer treatment on fertility should be discussed with all cancer patients of reproductive age and options for fertility preservation should be routinely addressed. Many centers throughout Europe and the United States have followed these recommendations and cancer patients have greater access to reproductive medicine<sup>(17)</sup>. However, studies show that many patients do not receive all available information<sup>(17-19)</sup>. In our study, conducted with the first population of women recently diagnosed with cancer who underwent OTC in Spain, almost half (40.87%) stated that they would change the treatment-related information they received. This was despite the fact that participants had been informed about the possibility of loss their fertility after cancer treatment and proceeded with OTC. Women detailed several information needs, including needing: to receive more information about effects of cancer treatment on fertility, the options of fertility preservation, and more time to discuss preservation options, as well as more coordination between their oncologist and gynecologist. The desire to receive more information was associated, at the bivariate level, with higher emotional distress. This supports previous studies and emphasizes that counseling and information regarding fertility preservation options is one important way to help young cancer patients to cope psychologically with a cancer diagnosis and enhance quality of life<sup>(23,27,35,36)</sup>.

The emotional impact of knowing the possible loss of fertility is well documented<sup>(10,11)</sup>. Knowing the factors that impact emotional distress could help to detect vulnerable patients who may need psychological intervention. Attitudes toward motherhood are particularly salient in their association with emotional distress<sup>(10,28-30)</sup>. This work adds contextual information to the factors that impact emotional distress as they relate to values on motherhood for cancer survivors. Specifically, results from this sample indicate elevated emotional distress for those whose cancer experience increases the desire to have children paired with the belief that having children is necessary for couple's fulfillment. Although the group of individuals who aligned with these beliefs was not a large portion of the sample, it is critical to be able to identify these women at high risk who are susceptible to experience greater distress at the news of the possible loss of infertility and offer them the psychological assistance.

A higher degree of concern about how cancer treatment will affect reproductive capacity was also associated with higher levels of distress in this study. This concern was associated, in turn, with values of restoring hormonal function and having a child after OTC cancer treatment. One of the advantages of cryopreservation of ovarian tissue compared to other alternatives for preserving fertility is that it not only allows for the capacity for childbearing, including the potential for restored hormonal ovarian function. In our study we evaluated separately the importance attached to having a child, and the importance of restoring hormonal function after cancer treatment. The results demonstrated high mean scores on both issues indicating high importance for women. The cessation of hormone function is associated with vasomotor, skeletal, genitourinary and cardiovascular problems, and may be accompanied by specific symptoms such as hot flashes, vaginal dryness, sexual dysfunction, weight gain, psychological distress and possible cognitive impairment affecting quality of life<sup>(12,37)</sup>. This could explain why women endorsed

importance for this issue and it was associated with greater emotional distress.

The adequacy of social support resources for patients have been associated with psychological adaptation to cancer<sup>(38,39)</sup>, to fertility problems in general population<sup>(40,41)</sup>, and to fertility problems derived from cancer treatment<sup>(4)</sup>. In our sample, higher levels of social support were similarly associated with lower levels of emotional distress. Furthermore, when social support was included in the multivariate analysis together with other variables, the belief that children are necessary for couple's fulfillment ceases to be a predictor of distress. For instance, having greater social support seems to decrease emotional distress regardless of the belief that children are necessary for couple's fulfillment. Yet, being married increased emotional distress when social support was considered. Therefore, it seems social support is more relevant to decrease emotional distress in the case of married women than in single women. This result can also be understood from a cultural perspective. In Spain, due to the social structure and prominent collectivistic values, the family is the main source of social support. Therefore, not being married, and not receiving culturally-relevant social support, can be a source of additional stress relating to infertility problems.

Limitations to the study include a relatively small sample, recruited from a specific geographical and cultural background. However, the study presents positive aspects compared to previous studies including a prospective follow-up assessment at the time of fertility preservation treatment. Moreover, eligibility focused on women undergoing a specific technique (OTC) that, although is still considered experimental, is convenient in most cases of young women with cancer<sup>(15,42)</sup>. Therefore, the study provides a deeper understanding of the psychological implications of this specific population of women with cancer in a Spanish sample.

Our study shows that both attitudes to motherhood and social support are factors that determine the emotional distress experienced by female cancer survivors when faced with the possible loss of infertility. It provides evidence for a need to offer fertility preservation counseling to young women with cancer of reproductive age while considering their needs, values, sociocultural environment and availability of resources for fertility preservation. As scientific organizations have recommend, this counseling must be offer through an interdisciplinary perspective that must include a variety of health care<sup>(12)</sup>. This multidisciplinary approach has already enabled the progress of the oncofertility for survivors in recent years (3). As the discipline grows and women delay childbearing, there will be an increased demand to screen for infertility risk and emotional distress. Support resources should be further developed and tested in order to enhance quality of life in this population.

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