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# **Barriers to procreational intentions among cancer survivors**

## **2 years after diagnosis: a French national cross-sectional survey**

**Short title:** Parenting intentions among fertile cancer survivors

**Julien Mancini<sup>1,2,3</sup>, Dominique Rey<sup>1,4</sup>, Marie Préau<sup>1,4,5</sup>, Anne Gaëlle Le Corroller-Soriano<sup>1</sup>, and Jean-Paul Moatti<sup>1,4,6</sup>**

<sup>1</sup> INSERM, UMR912, Epidemiology and Social Sciences Unit, Paoli-Calmettes Institute, Marseille, F-13273 France;

<sup>2</sup> Aix Marseille Université, School of Medicine, Teaching and Research Laboratory of Medical Information (LERTIM), Marseille, F-13385 France;

<sup>3</sup> Assistance Publique - Hôpitaux de Marseille, La Timone Hospital, Public Health and Medical Information Department (SSPIM), Marseille, F-13385 France;

<sup>4</sup> South-Eastern Health Regional Observatory (ORS PACA), Marseille, F-13006 France;

<sup>5</sup> Université de Nantes, Laboratory of Psychology LABCD, Nantes, F-44312 France

<sup>6</sup> Aix Marseille Université, School of Economics, Marseille, F-13231 France

**Corresponding Author:** Dr Julien Mancini

Laboratoire d'Enseignement et de Recherche sur le Traitement de l'Information Médicale (LERTIM EA 3283)

Faculté de Médecine, 27 Bd Jean Moulin, 13385 Marseille Cedex 05

Tel: +33: 491 324 600, Fax: +33 491 324 639

E-mail: [julien.mancini@univmed.fr](mailto:julien.mancini@univmed.fr)

## **Abstract**

**Objectives** – To determine the procreational intention rates among cancer survivors whose fertility was unimpaired and to identify the factors associated with their procreational intentions.

**Methods** – 6957 adult cancer patients treated between September and October 2002 were randomly selected from the French National Health Insurance Fund's Chronic Disease File. 4270 responded to a cross-sectional questionnaire 2 years after diagnosis, of whom 959 reported being fertile and responded to a question about their procreational intentions.

**Results** – 33.5% of the 257 male and female survivors aged 20-44 had procreational intentions. After adjusting for age, gender, and already having children, only a high educational level (adjusted odds ratio: 3.1, 95% confidence interval 1.3 to 7.8) and stable or increasing financial resources (2.4, 1.0 to 5.7) were independently associated with the respondents' procreational intentions. Neither cancer stage at diagnosis nor the present stage significantly affected their plans in this respect.

**Conclusions** –Two years after cancer diagnosis, the reasons why some survivors who are still fertile have no parenthood projects were similar to those previously given by members of the general population.

**Keywords:** cancer, oncology, cancer survivors; parenthood; procreational intentions; socio-economic status; national survey

## INTRODUCTION

Since the childbearing age is occurring increasingly late in life in industrialized countries, many adult cancer survivors have not yet had children, or as many children as they intend to. Previous studies on the psychosocial consequences of cancer occurring before or during the reproductive years have shown that parenthood is a major concern among young survivors [1]. Parenthood after cancer is not exceptional, but according to a recent survey, it drops by about 25% in the case of a first child and by 36% in that of higher-order births in comparison with the general population [2]. Although cancer itself and/or its treatment can of course cause sterility [3], this may not be the only barrier to parenthood after cancer. Cancer survivors may fear that pregnancy will result in the recurrence of cancer, that the child will not be healthy, or that they will not live long enough to see their child grow up [4-6]. Financial difficulties, a family history of cancer or fear of responsibility may also affect the desire for a child [1]. On the other hand, experience of cancer can enhance the skills and pleasures of parenthood, help to regain health and femininity, and decrease the fear of death [7]. Surveys on cancer survivors have suggested that having cancer does not generally affect the wish to have a child [1], and can even strengthen this wish in childless survivors [4]. However, previous research has mainly focused on cancer survivors' rates of parenthood [2,8-10] and on women's motivations for childbearing after breast cancer [1]; whereas little is known so far about the procreational intentions of survivors with other types of cancer [4,5], and no surveys have been conducted to our knowledge on the parenting intentions of a representative population of fertile cancer survivors.

The aim of this study was therefore first to determine the procreational intention rates in a representative sample of French cancer survivors of both sexes, who claimed to be still fertile two years after cancer was diagnosed. The second aim was to identify the factors contributing to these survivors' procreational intentions and to compare the cancer-related factors with the socio-demographic factors usually involved in procreational decisions in healthy individuals.

## METHODS

### *Study population*

A French national cross-sectional survey on the living conditions of adult cancer patients two years after cancer diagnosis was launched in 2004 [11, 12]. Patients were randomly selected from the National Health Insurance Fund's Long Duration Disease File. Eligible patients were all those included in this file between September and October 2002 at the diagnosis of biopsy-proven primary cancer, aged over 18 years at diagnosis, still alive two years after diagnosis, not hospitalised at the time of the survey and with a valid address. Among the 6,957 eligible cancer patients, 4,270 agreed to participate (response rate: 64.1%). Comparisons between respondents and non-respondents based on the patients' characteristics recorded in the Long Duration Disease File showed that both groups were similar in terms of gender. Respondents were younger, however, than non-respondents (66.6% < 70 years vs. 53.5%;  $P<0.001$ ) and had skin cancer or colorectal cancer less frequently (9.7% vs. 11.7%;  $P=0.009$ , and 2.9% vs. 4.7%;  $P<0.001$ , respectively).

### *Data collection*

Telephone interviews were conducted with consenting patients between November 2004 and January 2005 to collect their sociodemographic data and data on their disease history and health status at the time of the interview. For ethical reasons, the question about parenting intentions ("*Do you plan to have a first child or more children?*") was asked only to patients who reported that they were still fertile. This question therefore mainly measured real procreational intentions, i.e. the desire to have biological children. Medical characteristics (cancer site, stage at diagnosis and present status) were collected by advisory physicians from the National Health Insurance Fund. Coping with cancer was assessed using the 'Mental Adjustment to Cancer' scale (MAC), a 21-item self-report questionnaire measuring three possible responses to cancer: fighting spirit, hopelessness/helplessness, and anxious preoccupation [13]. Health-related quality of life was assessed using the Medical Outcomes Study 36-Item Short-Form Health Survey (SF-36) [14].

### *Patients (Figure 1)*

Since the questionnaire focused on reproductive issues, the upper age limit was set at 44 years for women and 70 years for men. However, the main analyses focused on the 20-44 year-old men and women combined. Men and women were both asked about their fertility ("*Are you sterile?*") and women were asked about their menopausal status ("*Are you post-menopausal?*"). People who declared that they were sterile and/or post-menopausal were taken to be infertile and excluded from the study. Our initial study sample consisted of 969 two-year cancer survivors who declared that they were fertile. Self-declared infertile women had genital cancer and underwent chemotherapy more frequently than self-declared fertile

women; self-declared infertile men had prostate cancer and underwent surgical treatment, radiotherapy, and brachytherapy more frequently than self-declared fertile men (further details about this sample are given in a previous paper [12]). Among the self-declared fertile survivors, the 959 (99%) who responded to the question about their parenthood projects were studied here: there were 175 women and 784 men.

### ***Statistical analyses***

Since the topic of parenthood involves different age-groups between males and females, the procreational intention rates recorded in the various age-groups were first stratified depending on gender.

Secondly, as the plan to have a child was a rare event among older men, and as the sample studied here was not very large (the group consisting of young survivors was particularly small), the factors associated with this plan were assessed in 20-44 year-old men and women combined. The respondents' main socio-demographic factors (sex, age, and present number of children) were first fed into a multiple logistic regression model. The contribution of each factor potentially associated with procreational intentions was tested in several logistic regression models and assessed using odds ratios adjusted for sex, age, and present number of children).

## RESULTS

### *Procreational intentions depending on gender*

Among the 175 fertile women under 45 years of age, 46 (26.3%) planned to have a first child or more children. This project was more frequent in younger women (71.1% of women in the 20-34 age-group vs. 18.5% of those in the 35-39 age-group, and 5.3% of those in the 40-44 age-group;  $p<0.001$ ), but was still envisaged by the oldest women (up to 43 years of age). Childless women more frequently declared that they had childbearing intentions (56.8%) than women with children (18.1%;  $p<0.001$ ).

Among the 784 fertile men less than 71 years old, 48 (6.1%) planned to have a first child or another child. The frequency of this plan decreased with age (77.8% of men in the 20-34 age-group vs. 45.5% of those in the 35-39 age-group, 8.3% of those in the 40-44 age-group, 2.9% of those in the 45-49 age-group, and 0.9% of those >49 years of age;  $p<0.001$ ) but it was still envisaged by some of the oldest cancer survivors (up to the age of 70). In the 20-44 male age-group, childless respondents declared that they had procreational intentions (83.9%) more frequently than those who already had children (27.5%;  $p<0.001$ ).

### *Factors associated with procreational intentions in 20-44 year-old survivors (men and women combined)*

Eighty-six (33.5%) of the 257 fertile cancer survivors aged 20-44 years (mean age = 36.7 +/- 5.8 years) declared that they had procreational intentions. These intentions were more frequent in males and in the youngest childless patients (table 1).

After adjusting for age, gender, and already having children, only a lower education level and reduced financial resources were found to be independently associated with having no procreational intentions. Survivors whose financial resources had decreased mostly claimed that this situation had resulted directly from the occurrence of cancer (78.7%). In addition, a stable relationship with one's partner, a fighting spirit and a low feeling of hopelessness/helplessness were slightly associated with procreational intentions. No correlations were found to exist between the respondents' declared procreational intentions and their current employment status ( $p=0.14$ ), family financial resources ( $p=0.24$ ), or the negative sexual consequences of cancer ( $p=0.33$ ). Currently having a partner was found in the univariate analysis to be negatively associated with the respondents' procreational intentions. After stratification for already having children (table 2) and adjusting for age, gender and already having children, it was positively although not significantly associated with these intentions (odds ratio=1.8; 95% confidence interval (0.8 to 4.8);  $p=0.240$ ).

The respondents' procreational intentions were not found to depend on the cancer site, cancer prognostic index, or troublesome sequelae (table 3). Nor did they depend on cancer stage at diagnosis (localised, regional, or distant tumour;  $p=0.92$ ), treatment (surgery, radiotherapy, chemotherapy, hormone therapy:  $p=0.26$ ;  $p=0.52$ ;  $p=0.59$ ;  $p=0.14$ ,

respectively), or disease status 2 years later (remission, stability, relapse;  $p=0.94$ ) (detailed results are available to the authors at their request). In addition, the procreational intention rates of survivors who stated that their family members had an increased risk of cancer were similar to the rates of to those who did not think that this was the case (odds ratio=0.6; 95% confidence interval (0.3 to 1.4);  $p=0.242$ ).

## DISCUSSION

The desire for children among cancer survivors has not yet been properly documented. Many of the present cancer survivors whose fertility had been spared had procreational intentions, but these intentions were thwarted by reduced financial resources.

One third of the 20-44 year-old fertile French cancer survivors questioned in the present survey 2 years after cancer was diagnosed declared that they had procreational intentions. Schover *et al* [4] recorded similar rates of procreational intentions in a small sample of American cancer survivors. The first part of the “Gender and Generation Survey” carried out in 2005 on a sample of the general French population aged 18-45 also predicted similar rates of procreational intentions during the next three years (51.8% and 47.7% among childless women and men, respectively, and 22.3% and 23.8% among women and men with one or more children, respectively [15]). The procreational intentions declared by the childless male survivors surveyed here were even higher (83.9%), but these were lifetime predictions and did not only focus on the subsequent three years.

As was to be expected, procreational intentions were declared more frequently by younger cancer survivors. However, the results obtained in the present survey showed that older cancer survivors still had procreational intentions, which suggests that all patients treated for cancer, irrespective of their age, should be given detailed information about the risk of infertility associated with cancer treatment [12]. For example, premenopausal women with localised breast cancer should be informed that early conception, six months after completing their treatment, will not reduce their chances of survival [16]. These results are in agreement with those obtained in a study in which even older pre-menopausal breast cancer patients and those who already had children at diagnosis expressed interest in receiving fertility-related information [17]. The frequent persistence of parenthood projects in fertile cancer survivors suggests that the much lower rates of parenthood recorded in cancer survivors in comparison with the general population [2,9,10] may be mainly attributable to impaired fertility. In addition, pregnancy is often delayed for years in premenopausal women who undergo long-term hormone therapy until childbearing becomes impossible, although they are still fertile and have a strong desire to have children. Closer attention should be paid in general to preserving cancer patients’ fertility. Applying new methods of protecting patients’ fertility and making appropriate changes in their treatment can help to preserve their fertility without reducing the efficacy of the care [18].

The main predictors of patients’ procreational intentions were age, gender and already having children, as previously described in studies on fertility rates [2,8,19]. However, although post cancer reproduction rates are known to be strongly associated with the type, extent and treatment of the malignancy [8], none of the variables measuring objective or perceived health status were found in our survey to be associated with the patients’ parenthood projects. This low impact of the clinical conditions on patients’ desire for children

is consistent with the results of previous surveys on HIV patients [20] and breast cancer patients [1]. The only major negative cancer-related factor affecting the respondents' procreational intentions was an indirect factor, namely a decreased income. This setback was reported by those it had affected to have resulted directly from having cancer. This finding is in agreement with a Norwegian population-based study, in which patients' earnings were found to decrease after cancer [21]. This link between financial resources and parenthood projects is not specific to cancer, however. Financial restraints are common arguments against parenthood in the general population [22,23]. Family resources were not found to be directly associated here with respondents' procreational intentions, as they are among people having to adjust to a new financial situation. During times of increased financial uncertainty due to occupational insecurity, for instance, it may be advisable for individuals to postpone childbearing [15,24].

Having a partner was not found to be significantly associated with the respondents' procreational intentions, although the statistical analysis may have lacked power in this case because relatively few of the patients had no partner ( $n=45$ ). The latter subgroup included some of the youngest adult cancer survivors, who had not yet found a partner but may have declared long-term procreational intentions. Although our results were systematically adjusted for age-group, some residual confusion may have persisted. Young adult cancer survivors who have not yet found a partner may experience some difficulty in doing so, as previously described in the case of childhood cancer patients [25], and these respondents' parenthood projects may therefore not come to fruition for lack of a partner. Future studies on larger samples of young adult cancer survivors should shed light on this question.

Our study has a few limitations. First, the fertility assessments were based on patients' own reports. Misclassification biases probably occurred [12], but self-perception of fertility may be as relevant as real fertility for assessing parenthood plans. The procreational intention rates obtained here were not representative of all cancer survivors, as sterility results only from some particular types of cancer and treatment. For ethical reasons, the parenting intentions of self-declared infertile patients were not assessed, although these survivors may have intended to have children, in which case they may have to resort to adoption or third-party reproductive strategies [26]. Secondly, our sample included only a few survivors with forms of cancer such as leukaemia, lymphoma or testicular cancer. The under-representation of these types of cancer was not due to a selection bias but resulted directly from the effects of cancer treatment on the patients' fertility. Our sample was therefore representative of fertile French cancer survivors 2 years after diagnosis, but our results might not be extrapolated to other countries, as fertility rates and explanatory variables are liable to differ from one country to another [15]. Lastly, as our sample was rather small in the case of the fertile 20-44-year old survivors, we did not analyze the survivors separately depending on gender, age and whether they already had children.

In conclusion, the results of this study show that the cancer-related factors analyzed do not deeply affect the procreational intentions of fertile survivors, and that 2 years after cancer diagnosis, cancer survivors' reasons for not intending to procreate tended to be similar to those expressed by the general population, although no direct comparisons were performed on this point. Further efforts are obviously required to spare cancer patients' fertility, but once 'patients' have become 'survivors', providing more targeted support could help French cancer survivors whose income levels have dropped as the result of the disease to adjust to their new financial situation.

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### \* The ALD Cancer Study Group (“Groupe d'étude ALD Cancer”)

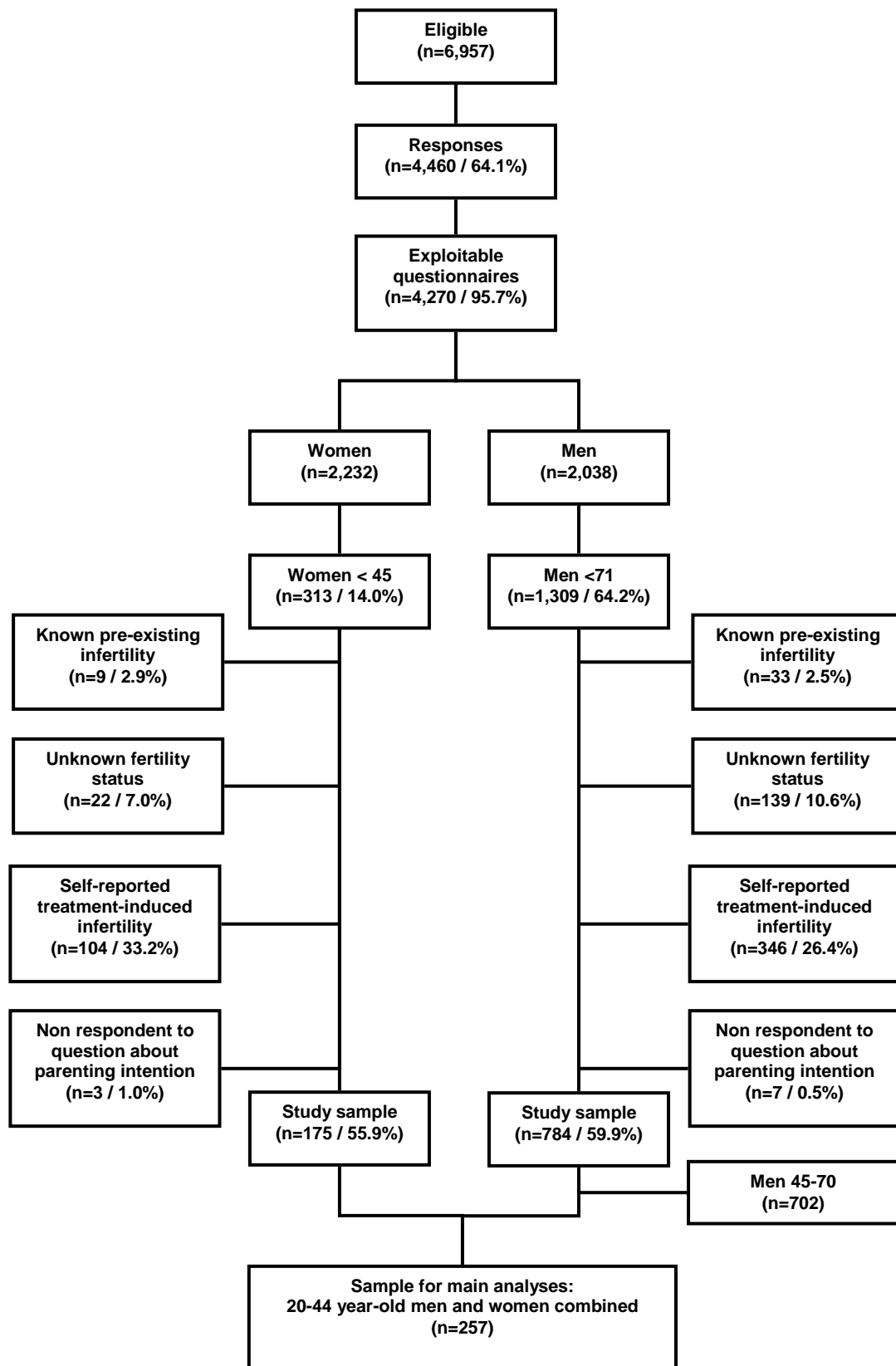
Guy-Robert AULELEY (Caisse Nationale du RSI, Paris), Pascal AUQUIER (Université de la Méditerranée, Marseille), Philippe BATAILLE (Université Lille 3, Lille), Nicole BERTIN (CNAMTS, Paris), Frédéric BOUSQUET (HAS, Paris), Anne-Chantal BRAUD† (Institut Paoli-Calmettes, Marseille), Chantal CASES (IRDES, Paris), Sandrine CAYROU (Psychologist, Toulouse), Claire COMPAGNON (Health consultant, Paris), Paul DICKES (Université Nancy 2 - GRAPCO - LABPSYLOR, Nancy), Pascale GROSCLAUDE (Tarn Region cancer records, Albi), Anne-Gaëlle LE CORROLLER-SORIANO (Inserm U379, Marseille), Laëtitia MALAVOLTI (Inserm U379, Marseille), Catherine MERMILLIOD (DREES, Paris), Jean-Paul MOATTI (Université de la Méditerranée - Inserm U379, Marseille), Nora MOUMJID-FERDJAOUI (GRESAC - Université Lyon 1, Lyon), Marie-Claude MOUQUET (DREES, Paris), Lucile OLIER (DREES, Paris), Frédérique ROUSSEAU (Institut Paoli-Calmettes, Marseille), Gérard SALEM (INCa, Boulogne-Billancourt), Christine SCARAMOZZINO (Ligue Nationale contre le Cancer, Paris), Florence SUZAN (Institut de veille sanitaire, Saint-Maurice), Vincent VAN BOCKSTAEL (CCMSA, Paris), Alain WEILL (CNAMTS, Paris).

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**Figure 1: Participants' flowchart**



**Table 1:** Socio-demographic factors associated with procreational intentions in French adult cancer survivors.

	Procreational intentions				Adjusted OR*	Adjusted (95%CI)	Adjusted <i>p</i> -value
	No		Yes				
	n	%	n	%			
<b>Gender</b>							
Male	42	51.2	40	48.8	2.32 (1.04 to 5.16)		0.039
Female	129	73.7	46	26.3	1		
<b>Age</b>							<0.001
20-34	21	25.9	60	74.1	25.30 (8.98 to 71.30)		<0.001
35-39	56	73.7	20	26.3	5.97 (2.05 to 17.37)		0.001
40-44	94	94.0	6	6.0	1		
<b>Previous children</b>							<0.001
0	21	30.9	47	69.1	12.88 (5.13 to 32.35)		<0.001
1	27	50.9	26	49.1	8.09 (3.21 to 20.39)		<0.001
2 and more	123	90.4	13	9.6	1		
<b>Education</b>							0.048
< high school	81	77.1	24	22.9	1		
high school graduate	40	64.5	22	35.5	1.46 (0.55 to 3.90)		0.451
> high school	50	55.6	40	44.4	3.13 (1.25 to 7.82)		0.015
<b>Financial resources</b>							
Stable/increased	117	64.6	64	35.4	2.38 (1.00 to 5.69)		0.050
Reduced	54	72.0	21	28.0	1		
<b>Partnership</b>							0.306
No	22	48.9	23	51.1	1		
Stable	116	72.5	44	27.5	2.96 (0.87 to 10.12)		0.083
Deteriorated/separated	28	70.0	12	30.0	2.92 (0.65 to 13.26)		0.163
New	5	41.7	7	58.3	4.16 (0.65 to 26.75)		0.134

CI = confidence interval.

\*adjusted odds ratio (adjustment for gender, age and already having a child).

**Table 2:** Association between current partnership and procreational intentions stratified on already having a child.

	Rate of procreational intentions (%)		<i>p</i>
	Currently with a partner	Currently without partners	
<b>Previous children</b>			
0 ( <i>n</i> =68)	67.9	70.0	0.851
1 ( <i>n</i> =53)	56.1	25.0	0.058
2 and more ( <i>n</i> = 136)	10.5	0.0	0.605
<b>Total</b>	28.5	48.4	0.003

**Table 3:** Cancer-related factors associated with procreational intentions in French adult cancer survivors.

	Procreational intentions				Adjusted OR*	(95%CI)	Adjusted <i>p</i> -value
	No		Yes				
	n	%	n	%			
<b>Cancer site</b>							0.324
<i>Breast</i>	63	87.5	9	12.5	0.60	(0.17 to 2.19)	0.440
<i>Thyroid</i>	26	54.2	22	45.8	2.44	(0.77 to 7.76)	0.130
<i>Melanoma</i>	15	62.5	9	37.5	1.83	(0.42 to 7.99)	0.422
<i>Testicular</i>	8	40.0	12	60.0	1.40	(0.28 to 7.00)	0.679
<i>Lymphoma</i>	9	42.9	12	57.1	2.63	(0.62 to 11.13)	0.190
<i>Leukaemia</i>	8	57.1	6	42.9	1.29	(0.24 to 7.05)	0.768
<i>Other**</i>	42	72.4	16	27.6	1		
<b>Troublesome sequelae</b>							
<i>Yes</i>	26	83.9	5	16.1	0.42	(0.11 to 1.59)	0.199
<i>No</i>	143	63.8	81	36.2	1		
<b>Specialized psychological support at time of survey</b>							0.316
<i>No, not wanted</i>	133	65.2	71	34.8	1		
<i>No, regrettably</i>	23	79.3	6	20.7	0.37	(0.10 to 1.34)	0.129
<i>Yes</i>	15	62.5	9	37.5	0.93	(0.24 to 3.63)	0.915
	<b>Mean</b>	<b>SD</b>	<b>Mean</b>	<b>SD</b>			
<b>Prognosis index***</b>	62.1	20.2	58.8	21.1	1.00	(0.98 to 1.02)	0.751
<b>SF-36 Physical Component Summary</b>	47.3	9.0	48.8	8.6	1.02	(0.98 to 1.07)	0.287
<b>SF-36 Mental Component Summary</b>	42.6	11.0	45.8	9.8	1.02	(0.99 to 1.06)	0.175
<b>MAC21 Fighting Spirit (FS)</b>	54.4	9.7	55.9	9.5	1.04	(1.00 to 1.08)	0.069
<b>MAC21 Hopelessness/Helplessness (HH)</b>	50.4	13.4	46.9	9.3	0.97	(0.93 to 1.00)	0.067
<b>MAC21 Anxious Preoccupation (AP)</b>	46.4	8.8	44.3	8.5	0.97	(0.93 to 1.01)	0.165

*CI* = confidence interval.

\*adjusted odds ratio (adjustment for gender, age and already having children).

\*\*upper aerodigestive tract (10), renal (9), digestive (8), genital (7), sarcoma (6), brain (5), connective and soft tissue (4), lung (3), eye (3), endocrine (1), multiple myeloma (1), skin (1).

\*\*\*based on national 5-year relative survival weighted by stage (solid tumours), spread (Hodgkin's disease), or grade (other lymphomas) at diagnosis (range: 0-100).