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## The self-reported perceptions of the repercussions of the disease and its treatments on daily life for young women with breast cancer and their partners

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### ABSTRACT

**Purpose:** This study aimed to compare the self-reported perceptions of the repercussions of the disease and its treatments and emotional distress in young women with breast cancer and their partners.

**Design:** Cross-sectional study using self-reported questionnaires.

**Sample:** 491 couples in which women were aged <45 years when diagnosed with non-metastatic breast cancer in four different groups of treatment: during chemotherapy with or without Trastuzumab; under Trastuzumab with or without hormone therapy; during hormone therapy; and during the follow-up period.

**Methods:** Patients and partners completed a questionnaire assessing their self-reported perceptions of the disease and treatments (Patient YW-BCI and Partner YW-BCI for the partners) and their emotional distress (CESD; STAI).

**Findings:** Patients reported more difficulties than partners in the *management of child(ren) and everyday life, body image and sexuality, negative affectivity about the disease and apprehension about the future, career management, and finances*. While the difficulties were generally more marked in the chemotherapy and Trastuzumab groups than in the hormone therapy and follow-up groups, the *negative affectivity about the disease and apprehension about the future* was high in all four groups,

### KEYWORDS

breast cancer; couple;  
emotional distress; partner;  
quality of life;  
young women

especially in patients. The partners reported more difficulties in *sharing with close relatives*, and even more in those groups reflecting the latest treatment phases. No difference appeared between patients and partners in *couple cohesion* and *deterioration of relationships with relatives*. Partners were less anxious than patients but as depressed as them.

**Conclusions:** Difficulties of patients and partners seem particularly severe in the early care pathway, maybe reflecting better adjustment in women under surveillance and their partners. A longitudinal study will substantiate this finding and enable a better identification of some explanatory processes of these differences and similarities in the daily self-reported repercussions of the disease throughout the cancer care pathway.

**Implications for psychosocial oncology:** It seems important to support young women with breast cancer and their partners, as our results evidence distress in both and differences according to the type of treatment the woman is currently receiving. Healthcare providers need consistent methods to identify and respond to couples' distress and reduce significant disparities in support.

## Introduction

Treatments of breast cancer lead to significant side effects that decrease the physical and psychological quality of life of patients, from diagnosis to follow-up.<sup>1-3</sup> Even several years after their diagnosis, women with breast cancer (WBC) present a lower quality of life than women in the general population and this is even more marked when women are young (< 45/50 years).<sup>1,2,4</sup> For instance, young women tend to present lower functioning (e.g. emotional, cognitive, and sexual functioning) and more symptoms (e.g. fatigue, pain, anxiety, depression) than older WBC, especially early in the care pathway.<sup>2,3</sup> Their higher level of distress and poorer quality of life may be due to the greater impact of the disease and the aggressive treatments as well as daily age-related issues.<sup>5-8</sup> It therefore seems important to focus attention on young WBC. Despite the special features of their self-reported perceptions, few studies have focused on the way their experience may differ depending on the type of treatment they are receiving. Most young WBC receive loco-regional treatment (surgery and radiotherapy) and chemotherapy with hormone therapy (for a hormone-sensitive tumor) and immunotherapy with Trastuzumab (for a tumor overexpressing *HER2* protein).

Cancer affects the patients as well as their relatives, especially the partner, throughout the care pathway.<sup>9-11</sup> The partner is often the main caregiver and his/her support is important for the adjustment of the WBC, especially for the young woman.<sup>12-14</sup> Although few studies have examined the impact of a breast cancer diagnosis on partners, the latter seem to be affected by the disease in their everyday life.<sup>9,15</sup> They report more anxiety, depression, and a lower quality of life and mental health than partners of

healthy women.<sup>16,17</sup> The young age of partners impacts their quality of life,<sup>18</sup> predicts a better physical quality of life but more negative effects,<sup>15</sup> with more distress related to cancer and general distress.<sup>19</sup> The partners also have to cope with specific age-related concerns and difficulties. However, few studies, to our knowledge, have focused on their daily self-reported perceptions of the way the cancer and its treatments influence their own life.

The difficulties of young WBC and their partners particularly concern the feeling of couple cohesion, negative affectivity and apprehension about the future, body image and sexuality, career management, deterioration of relationships with close relatives, management of children and everyday life, financial difficulties, and sharing with close relatives.<sup>20,21</sup> To date, few studies have taken into account the young WBC's perspective *and* that of her partner; most have focused on either the patient's *or* the partner's self-reported perceptions.<sup>22</sup> Thus, this study aimed to understand better the daily preoccupations and emotional distress of young women affected by non-metastatic breast cancer and of their partner, in four different groups of medical treatment received and depending on the tumor's characteristics (i.e. Trastuzumab for *HER2*-positive breast cancer, and/or hormone therapy for a hormone-dependent tumor). The objectives were to identify, according to the type of treatment targeted in this study, differences and similarities in patients' and partners' self-reported repercussions of the disease and treatments on their daily life (objective 1) and their emotional distress (objective 2).

## Participants and methods

### *Study participants and recruitment*

The study was led in 27 French cancer treatment centers from January 2010 to June 2012. It was proposed to early WBC who had received or were receiving chemotherapy at the time of the study and were aged 18–45 years at the time of their initial diagnosis, and to their spousal partners. Only patients and partners living as a couple for at least six months at the time of the study, not suffering from psychiatric disorders, and fluent French speakers were included. The study was conducted in accordance with regulatory and ethical approvals (*Committee of Protection of Persons; Consultative Committee for Data Processing in Research in the Field of Health; National Committee of Data Processing for Data Protection*).

Based on the type of treatment received, four independent groups of patients (and thus partners) were formed: (1) patients under chemotherapy with or without Trastuzumab (group C); (2) patients under Trastuzumab with or without hormone therapy (group T); (3) patients during hormone therapy alone (no other overlapping treatment) (group H); and (4) patients under surveillance (after the end of all treatments, including no longer

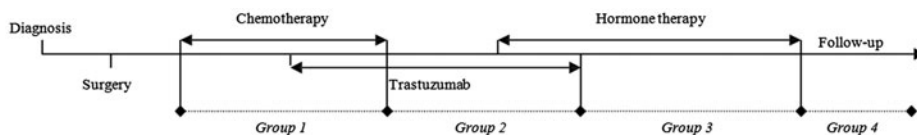
receiving hormone therapy) (group F). For purposes of clarity, group C is called the “chemotherapy group” (even though some patients were also receiving Trastuzumab), group T is called the “Trastuzumab group” (even though some patients were still under chemotherapy when receiving Trastuzumab), and group F is called the “follow-up group”. Data from 491 couples who completed full questionnaires were retained: 141 in group C; 50 in group T; 162 in group H; 138 in group F (Figure 1).

### Procedures and instruments

The study was explained to the patient during a consultation, with or without her partner. After the agreement of the patient about her participation and the one of her partner, the investigator provided a letter of information and a consent form, the questionnaire and a socio-demographic data form for each member of the couple. The participants completed these documents alone at home and then returned them to the treatment center carrying out the study, in the pre-stamped envelope provided. The patient’s medical data were collected by the investigator and conditions of anonymity and confidentiality were guaranteed to all participants.

The data shown in the present study are part of a larger project in which all participants were asked to complete the YW-BCI, but not necessarily the emotional distress measures (CESD, STAI). Participants were randomly allocated to one of four groups at the time of their inclusion: (1) completion of the YW-BCI only, (2) completion of the YW-BCI and quality of life scale (to test concurrent validity), (3) completion of the YW-BCI twice (for reliability analysis), and (4) completion of the YW-BCI, CESD, and STAI. Data from the first three groups have been published.<sup>20,21</sup> In the last group, there were 112 couples in which the patient and the partner fully completed the YW-BCI, CESD, and STAI scales, hence the present sample.

*Self-reported perceptions of the disease and its treatments.* Patients were asked to complete the YW-BCI<sup>20</sup> and partners its corresponding version (Partner YW-BCI<sup>21</sup>). These scales assess the patient’s and the partner’s self-reported perceptions of the impact of the cancer and its treatment on different areas of their life, taking into account their young age (36 items and 8 dimensions) and in terms of their difficulties: (1) *feeling of couple*



**Figure 1.** Groups of young women with breast cancer in the present study (all patients having had or still having chemotherapy).

*cohesion* -  $\alpha$  Patients = .91,  $\alpha$  Partners = .81 - (e.g. problems in communication, cohesion, and social support within the couple, example item: "I feel close to my partner", same reversed item for patient and for partner), (2) *negative affectivity and apprehension about the future* -  $\alpha$  Patients = .84,  $\alpha$  Partners = .81 - (e.g. negative emotions felt, perception of the future, fear for the child(ren); example item for patient and for partner: "I feel worried"), (3) *management of child(ren) and everyday life* -  $\alpha$  Patients = .81,  $\alpha$  Partners = .84 - (e.g. problems in managing housework, daily life and the education of the child(ren), example item for patient and for partner: "I have problems managing daily life with my child(ren)"), (4) *sharing with close relatives* -  $\alpha$  Patients = .82,  $\alpha$  Partners = .75 - (e.g. problems with help, communication, social support, example item for the patient: "I talk about my disease with those around me", example item for the partner: "I talk about the disease with those around me" - reversed item), (5) *body image and sexuality* -  $\alpha$  Patients = .82,  $\alpha$  Partners = .79 - (e.g. body image perception of the woman and perception of partner's difficulties with the body image of their wife, problems with sexuality and desire, example item for the patient: "I have some sexual problems because of my disease", example item for the partner: "I have some sexual problems because of the disease"), (6) *financial difficulties* -  $\alpha$  Patients = .80,  $\alpha$  Partners = .79 - (e.g. income decrease, problems in getting a loan, additional costs, example item for the patient: "I have problems dealing with the costs incurred by my disease," example item for the partner: "I have problems dealing with the costs incurred by the disease"), (7) *deterioration of relationships with close relatives* -  $\alpha$  Patients = .80,  $\alpha$  Partners = .75 - (e.g. problems in communication, feeling neglected, tensions with relatives, example item for the patient: "My disease creates tensions with the people around me," example item for the partner: "The disease creates tensions with the people around me"), and (8) *career management* -  $\alpha$  Patients = .85,  $\alpha$  Partners = .70 - (e.g. sick leave, personal investment in job, effectiveness at work, example item for patient and partner: "I have problems doing my job"). Patients and partners were instructed to indicate to what extent each assertion corresponded to their current state ("at this moment, currently"), using a 5-point Likert scale, from 1: "strongly disagree" to 5: "strongly agree". The two scales are constructed in order that each item of the questionnaire for the patient matches an item in the questionnaire for the partner, enabling comparisons between the self-reported perceived difficulties of patients and partners.

*Anxiety assessment.* The State-Trait Anxiety Inventory (STAI-trait<sup>23,24</sup>) was used to measure anxiety. Participants rated self-descriptive statements (20 items) on a four-point Likert-like scale, ranging from 1 = "does not describe me at all" to 4 = "accurately describes me". The participant's anxiety level corresponds to his/her response sum, with possible scores ranging from 20 to 80. In the current sample,  $\alpha$  Patients = .95,  $\alpha$  Partners = .96.

*Depression inventory.* Couples answered the CESD,<sup>25,26</sup> consisting of 20 items about the frequency (*never, rarely/occasionally/quite often/often, all the time*) with which they had subjectively experienced symptoms or behaviors associated with depression during the past week. The overall score ranges from 0 to 60. In the present sample,  $\alpha$  Patients = .82,  $\alpha$  Partners = .84.

### **Statistical methods**

Descriptive statistics were calculated for all the variables measuring the self-reported perceptions of the disease and its treatments (YW-BCI; Partner YW-BCI), anxiety (STAI), and depression (CESD). The purpose of these analyses was to understand better and compare the self-reported perceptions and the emotional distress of young patients and their partners in the four groups of patients (C, T, H, F). To study the combined effects of the different treatment groups and the fact of being the patient or the partner, average comparisons and Generalized Linear Models (GLMs) were estimated on the groups of 491 patients and 491 partners who completed the (Partner) YW-BCI. Four GLM models were tested and compared with each other by ANOVA and the model with the best AIC (Akaike Information Criterion) with a significant explanatory contribution was retained.<sup>27</sup> The first model tested was one without Independent Variables (IVs) that provided a starting AIC. If the initial AIC decreased when an explanatory variable was added, it meant that this variable contributed something interesting to the explanation of the phenomenon. Explanatory variables were added gradually. If the AIC was stabilized by adding a variable, this variable explained nothing about the Dependent Variable (DV). Table 3 describes the final AIC and the explanatory indices of each of the IV on the DV added progressively to the model. Thus, the second model tested in this research integrated the four groups (types of treatment). The third model also integrated the patient/partner distinction. The fourth model finally tested the interaction between the four treatment groups and the patient/partner distinction. All analyses were conducted using R (version 3.2.2). The power analysis was calculated for GLM with the R “pwr” package.

The analyses for the (Partner) YW-BCI on the 491 couples with degrees of freedom of 981 and 978, respectively, and the choice of a medium effect size showed a power analysis of .99. The power analysis on CESD and STAI with the 112 couples who also completed these questionnaires with degrees of freedom of 223 and 220, respectively, and the choice of a medium effect size showed a power analysis of .62 and of .99 if we expected a wide effect size.



## Results

### Participant characteristics

The final sample consisted of 491 couples in which the woman was aged under 45 years when diagnosed with a non-metastatic breast cancer (Table 1). All the partners were male and most couples was married ( $n = 358$ , 72.9%) with children ( $n = 438$ , 89.2%). The patients (age:  $M = 40.73$ ,  $SD = 6.28$ ) and partners (age:  $M = 43.28$ ,  $SD = 7.46$ ) had been in a couple for a mean period of 13.87 years at the time of the study ( $SD = 8.53$ ). As indicated in Table 1, there were significant differences between patients and partners related to age (respectively,  $F(3, 486) = 21.89$ ,  $p < .001$ ;  $F(3, 483) = 14.87$ ,  $p < .001$ ), educational level ( $\chi^2(21) = 51.96$ ,  $p < .001$ ;  $\chi^2(12) = 37.58$ ,  $p < .05$ ), employment ( $\chi^2(12) = 22.20$ ,  $p < .05$ ;  $\chi^2(21) = 21.27$ ,  $p < .05$ ), the length of the couple relationship ( $F(3, 464) = 15.85$ ,  $p < .001$ ), and the presence of child(ren) ( $\chi^2(3) = 8.49$ ,  $p < .05$ ). For patients, significant differences were found related to the time since diagnosis ( $F(3, 487) = 143.35$ ,  $p < .001$ ) and the treatment received (surgery:  $\chi^2(3) = 77.73$ ,  $p < .001$ ; radiation therapy:  $\chi^2(3) = 237.81$ ,  $p < .001$ ; Trastuzumab:  $\chi^2(3) = 168.00$ ,  $p < .001$ ; hormone therapy:  $\chi^2(3) = 285.01$ ,  $p < .001$ ), reflecting the differences in the cancer care depending on the tumor characteristics.

Means and standard deviations for each dimension of the self-reported repercussions of the disease and treatment and emotional distress (anxiety, depression) in patients and partners are shown in Table 2. Overall, patients reported more difficulties in the dimensions of *Negative affectivity and apprehension about the future*, *Body image and sexuality*, *Career management*, and *Finances* but fewer difficulties in *Sharing with close relatives* than partners.

The results of the GLM models testing the effect of the treatment groups (IVs), of being a patient or a partner (IV), and the interaction between these two variables on the self-reported perceptions and emotional distress (DVs) is presented in Table 3.

### Self-perception of the repercussions of the disease and its treatments

Figure 2 illustrates the daily preoccupations and experience of the disease of patients and of their partner, in the four different treatment groups. For the *management of child(ren) and everyday life*, the self-reported perception of the patients was generally more negative than that of their partners ( $\beta = .20$ ,  $p < .01$ ), and these difficulties were more marked in the group of patients still under chemotherapy. Partners experienced more difficulties in *sharing with their close relatives* about the disease than patients ( $\beta = -.60$ ,  $p < .01$ ) and this difficulty tended to be more substantial in the “chemotherapy” than

**Table 1.** Sample characteristics.

	Chemotherapy		Trastuzumab		Hormone therapy		Follow-up	
	Patients (n = 141)	Partners (n = 141)	Patients (n = 50)	Partners (n = 50)	Patients (n = 162)	Partners (n = 162)	Patients (n = 138)	Partners (n = 138)
<b>Demographics</b>								
Age (M, SD)	38.08 (5.55)	40.31 (6.80)	38.08 (5.59)	41.56 (7.88)	41.90 (5.54)	44.50 (6.83)	43.04 (6.76)	45.50 (7.63)
Length of the relationship (in years: M, SD)	10.51 (6.70)		10.79 (7.20)		15.27 (8.09)		16.52 (9.65)	
Presence of child(ren) (n, %)	119 (84.4)		41 (82.0)		150 (92.6)		124 (90.0)	
Education (n, %)								
No qualification	3 (2.1)	8 (5.7)	2 (4.0)	6 (12.0)	13 (8.0)	8 (4.9)	14 (10.1)	13 (9.4)
Secondary education diploma – below baccalaureate	29 (20.6)	44 (31.2)	10 (20.0)	14 (28.0)	38 (23.5)	59 (36.4)	41 (29.7)	41 (29.7)
Baccalaureate or equivalent diploma	24 (17.0)	28 (19.9)	15 (30.0)	8 (16.0)	38 (23.4)	36 (22.2)	24 (17.4)	21 (15.2)
First undergraduate cycle degree / equivalent diploma	36 (25.5)	20 (14.2)	12 (24.0)	16 (32.0)	33 (20.4)	23 (14.2)	28 (20.3)	30 (21.7)
Second university cycle degree / doctorate equivalent diploma	48 (34.0)	40 (28.4)	9 (18.0)	6 (12.0)	39 (24.1)	35 (21.6)	31 (22.5)	33 (23.9)
Missing	1 (0.7)	1 (0.7)	2 (4.0)	0	1 (0.6)	1 (0.6)	0	0
<b>Employment (n, %)</b>								
Employment	0	2 (1.4)	1 (2.0)	1 (2.0)	3 (1.9)	4 (2.5)	0	3 (2.2)
Farmers	6 (4.3)	8 (5.7)	2 (4.0)	7 (14.0)	12 (7.4)	20 (12.3)	5 (3.6)	11 (8.0)
Craftspeople, shopkeepers, company managers	23 (16.3)	33 (23.4)	3 (6.0)	3 (6.0)	22 (13.6)	25 (15.4)	12 (8.7)	33 (23.9)
Executives and intellectual professions	25 (17.7)	34 (24.1)	7 (14.0)	11 (22.0)	37 (22.8)	46 (28.4)	26 (18.8)	31 (22.5)
Intermediate professions	69 (48.9)	38 (27.0)	26 (52.0)	15 (30.0)	66 (40.7)	27 (16.7)	71 (51.4)	22 (15.9)
Manual workers	0	20 (14.2)	8 (16.0)	9 (18.0)	4 (2.5)	35 (21.6)	5 (3.6)	25 (18.1)
Retired	15 (10.7)	1 (0.7)	0	0	0	3 (1.9)	2 (1.4)	6 (4.3)
Unemployed	3 (2.1)	4 (2.8)	3 (6.0)	4 (8.0)	14 (8.6)	2 (1.2)	17 (12.3)	7 (5.1)
Missing		1 (0.7)	0	0	4 (2.5)	0	0	0
<b>Disease and treatment characteristics</b>								
Time since diagnosis (in years): Mean (SD)	.40 (.20)		.84 (.39)		2.68(1.71)		5.47(3.58)	
Treatment received (n, %)								
Surgery	106 (75.2)		48 (96.0)		161 (99.4)		137 (99.3)	
Chemotherapy	140 (99.3)		50 (100)		158 (97.5)		134 (97.1)	
Radiation therapy	19 (14.3)		31 (66.0)		139 (85.8)		127 (92.0)	
Trastuzumab	17 (12.2)		49 (98)		33 (20.5)		20 (14.6)	
Hormone therapy	0		15 (30.0)		155 (95.7)		62 (44.9)	

**Table 2.** Descriptive statistics and paired t-test.

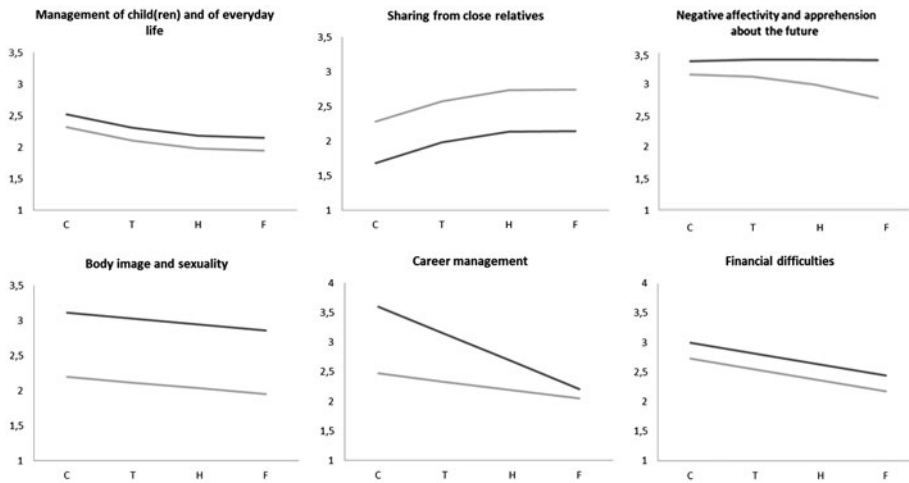
	Chemotherapy			Trastuzumab			Hormone therapy			Follow-up			
	Patients M (SD)	Partners M (SD)	t	d	Patients M (SD)	Partners M (SD)	t	d	Patients M (SD)	Partners M (SD)	t	d	
<i>Self-reported perceptions of the repercussions of the disease and its treatments (BCI)</i>													
Management of child(ren) and everyday life	2.51 (.97)	2.31 (.88)	-2.17*	.22	2.47 (.89)	2.25 (.92)	-0.99	.24	2.15 (.87)	1.92 (.83)	-3.56**	.27	2.15 (.92)
Feeling of couple cohesion	1.71 (.88)	1.78 (.71)	1.30	-.09	1.76 (.89)	1.70 (.73)	-0.85	.07	1.77 (.81)	1.75 (.71)	-0.86	.03	1.77 (.83)
Deterioration of relationships with close relatives	2.04 (.72)	2.15 (.79)	1.35	-.15	2.08 (.93)	2.02 (.78)	-0.06	.07	2.19 (.87)	2.11 (.75)	-1.16	.10	2.16 (.86)
Sharing with close relatives	1.66 (.58)	2.31 (.77)	8.34**	-.96	1.92 (.79)	2.54 (.85)	4.05**	-.76	2.11 (.79)	2.78 (.88)	7.33**	-.80	2.22 (.92)
Negative affectivity and apprehension about the future	3.37 (.98)	3.16 (.89)	-1.99*	-.03	3.42 (.92)	3.1 (1.13)	-1.20	.22	3.39 (1.02)	3.00 (.86)	-4.49**	.41	3.39 (.90)
Body image and sexuality	3.13 (1.13)	2.18 (.90)	-9.47**	.94	3.10 (1.06)	2.33 (.99)	-4.79**	.75	2.86 (1.14)	1.91 (.84)	-10.49**	.96	2.89 (1.17)
Career management	3.59 (.99)	2.44 (.87)	-8.65**	1.24	3.37 (1.14)	2.46 (.95)	-3.93**	.87	2.58 (1.15)	2.18 (.89)	-4.08**	.39	2.26 (.91)
Financial difficulties	2.98 (1.02)	2.68 (.98)	-3.68**	.30	3.00 (1.08)	2.77 (1.09)	-0.96	.21	2.62 (1.04)	2.31 (.92)	-4.53**	.30	2.42 (1.01)
<i>Emotional state</i>													
STAI	45.16 (13.65)	44.57 (12.04)	.19	.05	45.18 (11.95)	48.13 (15.10)	-0.57	-.22	44.90 (14.05)	45.49 (13.33)	-.22	-.04	46.77 (13.98)
CESD	18.23 (6.60)	17.28 (6.37)	.56	.15	20.00 (6.91)	19.82 (10.35)	.05	.02	17.70 (8.12)	18.75 (9.21)	-.71	-.12	18.94 (9.31)

Note: \*p < .05, \*\*p < .001.

**Table 3.** GLM parameter estimates for the self-reported perceptions and emotional distress measures shown in Figures 2 and 3.

	Management of child(ren) and everyday life	Feeling of couple cohesion	Deterioration of relationships with close relatives	Sharing with close relatives	Negative affectivity and apprehension about the future	Body image and sexuality	Career management	Financial difficulties	STAI	CESD
(Intercept)	2.42**	.08	.05	.05	.12	.22*	.10	.30**	50.52**	3.23**
Treatment course	-.13**	.03	.02	.16**	-.12*	-.08**	-.14**	-.18**	-3.00*	.04
Patients/partners	.20**	.12	-.09	-.60**	.06	.91**	1.45**	.26**	-6.28	.11
Course*Person	.01	.06	.03	.06	.12*	.01	-.32**	-.02	3.50*	.06
AIC	2755	2794	2793	2618	2744	2608	2311	2733	1807	2713

Note: \* $p < 0.05$ , \*\* $p < 0.01$ , AIC = Akaike Information Criterion.

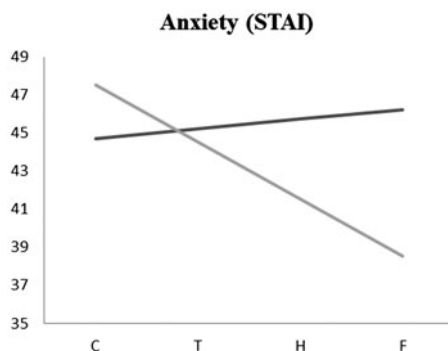


**Figure 2.** Modeling differences in the self-reported perceptions of the repercussions of the disease in the daily life of young women with breast cancer and their partners according to the type of medical treatment received. *Note.* C: Chemotherapy with or without Trastuzumab, T: Trastuzumab with or without hormone therapy, H: Hormone therapy with no other treatment, F: Follow-up. The black lines represent models of patients and the gray lines those of partners.

in the “Trastuzumab” group ( $\beta = .13, p < .01$ ). However, it did not deteriorate in the “hormone therapy” and “follow-up” groups and was equivalent in patients and partners. Patients and partners differed only slightly in the *negative affectivity about the disease and apprehension about the future* scores in the “chemotherapy” group (both had a high level of distress) ( $\beta = -.12, p < .01$ ). The negative affectivity of partners was less substantial in the “Trastuzumab”, “hormone therapy”, and “follow-up” groups but remained high and similar in women in each treatment group ( $\beta = .12, p < .05$ ). Patients also reported more difficulties than their partners in their *professional life* ( $\beta = 1.45, p < .01$ ) but this was higher in the groups reflecting the early treatment phases ( $\beta = -.14, p < .05$ ), with the curve tending to return to that of the partners in the “follow-up” group. Concerning the difficulties in *body image and sexuality*, partners were less affected than patients ( $\beta = -.91, p < .01$ ) and these difficulties gradually decreased for both patient and partner groups (in the order of C, T, H, F) ( $\beta = -.08, p < .01$ ). Finally, partners were less affected by *financial difficulties* than patients ( $\beta = .26, p < .01$ ), with more difficulties in the “chemotherapy” group compared to the “follow up” group. No effect was found for *feeling of couple cohesion* and *deterioration of relationships with close relatives*.

### **Anxiety and depression**

The levels of emotional distress (CESD, STAI) of patients and partners were also compared. Concerning emotional distress, 22.31% of patients and



**Figure 3.** Modeling differences in anxiety of young women with breast cancer and their partners according to the type of medical treatment received. *Note.* C: Chemotherapy with or without Trastuzumab, T: Trastuzumab with or without hormone therapy, H: Hormone therapy with no other treatment, F: Follow-up. The black lines represent models of patients and the gray lines those of partners.

20.53% of partners reported high to very high anxiety levels, and nearly 28% of patients and 47% of spouses had significant depressive symptoms. While partners were more anxious in the “chemotherapy” group, their anxiety was lower in the “Trastuzumab”, “hormone therapy”, and “follow-up” groups, respectively ( $\beta = 3.50$ ,  $p < .05$ ). In contrast, patients’ anxiety tended to be more substantial in the first phases of treatment (in the order of C, T, H, F). Concerning depression, there was no significant effect (Figure 3).

## Discussion

This study aimed to assess the shared or different perceptions of the repercussions of the disease and treatments and emotional distress of young WBC and their partners, using tools specifically created for them.<sup>20,21</sup> This assessment was performed according to the type of treatment received (i.e. chemotherapy with or without Trastuzumab; Trastuzumab with or without hormone therapy; hormone therapy only; follow-up). Young WBC reported more difficulties than their partners in the *management of children and everyday life, negative affectivity and apprehension about the future, body image and sexuality, career management, and the financial field* (objective 1). These difficulties were greater in the first groups corresponding to the early stages of care, when patients were under chemotherapy with or without Trastuzumab and under Trastuzumab with or without hormone therapy. This could be explained by physical complaints after the initial stress of the diagnosis and early treatment phase that decrease later after further treatments. Young women could tend to have a greater capacity to recover and more physical flexibility. They could use more active coping strategies during the cancer pathway and the basis of their self-evaluations may change according to the stage of the cancer pathway.<sup>3</sup>

Difficulties in *sharing with close relatives* appear to be relatively scarce (especially in patients) in the early stages of their cancer care pathway (i.e. in the chemotherapy and Trastuzumab groups). This may suggest that patients benefit from strong social support when under these types of treatment. Relatives may be more available to help them face the disease repercussions and the treatment side effects during these stages. This is consistent with previous studies revealing that support from relatives is more evident at diagnosis and during the treatment period (surgery, chemotherapy, and radiotherapy) than during hormone therapy and remission.<sup>13,28,29</sup> Relatives want to return to a normal life and see the side effects of hormone therapy less.<sup>13,29</sup> In addition, for partners, these difficulties are more substantial in the hormone therapy and follow-up stages and are greater at every treatment time because relatives and health professionals are focused on the patient.<sup>10,30</sup>

Interestingly, the patients and their partners report comparable scores in the four treatment groups for difficulties in *couple cohesion* and *deterioration of relationships with close relatives*. Difficulties in sharing with relatives and the deterioration of relationships with relatives may refer to a frequent feeling among young women of being different and 'out of sync' with those of their age.<sup>7</sup> Difficulties of couples seem to be less substantial at the end of the pathway but emotional distress remains constant for patients, as previously shown for young women.<sup>31</sup> These results could reveal an effect of time rather than an effect of treatment type, particularly given that the present study design consists of four independent groups in which time since diagnosis and type of treatment overlap. Each active treatment (chemotherapy with or without Trastuzumab; Trastuzumab with or without hormone therapy; hormone therapy only), due to the specific side effects it entails, has daily repercussions for patients and partners, particularly chemotherapy.<sup>28,32</sup> Overall, emotional distress was more pronounced in the patients under chemotherapy and their partners than in the post-chemotherapy groups, in accordance with previous studies showing a decline in emotional distress in the year following the start of active treatment.<sup>32</sup> The way women cope with the disease in its early stages, according to their personal and social resources, appears decisive for their later adjustment. The similarities in the perceptions of patients and partners support the results of previous studies that demonstrate interdependence in the self-reported perceptions of cancer patients and their main caregivers.<sup>33</sup> There are correlations between the adjustments of WBC and their partners.<sup>9,18,19,34</sup>

The results confirm the significant impact of the cancer on partners, who are as depressed as patients and show less sharing and more anxiety during chemotherapy (objective 2).<sup>9,15-17</sup> In our sample, young women and partners report similar scores for depression according to the treatment group.

Nevertheless, partners seem to recover more quickly for negative affectivity and anxiety, even though this result should be considered with caution because of the cross-sectional study design. Although patients overall report more *negative affectivity and apprehension about the future* than partners when under chemotherapy, patients and partners show the same level of negative affectivity. This could suggest a shared apprehension about this type of treatment phase, marking the beginning of treatments, and their fear of its side effects. Even more surprisingly, partners of patients under chemotherapy present more anxiety than patients, maybe reflecting their limited sharing with – and potential support from – their relatives. While patients reveal the same level of *negative affectivity and apprehension about the future* and anxiety scores in the different groups, partners report less *negative affectivity and apprehension about the future* when patients are under hormone therapy or in the reentry period. These results could be explained by: (1) the fear of recurrence and psychosocial difficulties during hormone therapy and follow-up in young WBC, (2) their tendency to report cancer-related thoughts and a search for meaning in the self-reported perceptions of cancer even years after diagnosis, and (3) the belief and desire of partners that the disease and treatments are over.<sup>13,29</sup>

An interesting approach suggested by these results would be to study the effect of the disparity/concordance of the perceptions of each member of the couple in their adjustment to the disease. However, further investigation from a dyadic and longitudinal perspective, as carried out by Kim et al.,<sup>35</sup> for example, is needed to know whether disparities such as the woman's anxiety remaining high during the follow-up period while the partner's significantly decreases are a recipe for greater difficulty in couple adjustment.

### **Study limitations**

Despite some limitations (e.g. the sample may not be representative of all couples facing disease because they were sufficiently well adjusted as a couple to participate, cross-sectional design, all heterosexual couples even though the study was offered to every couple, need to collect more data for CESD and STAI to improve power analyses), this study provides encouraging findings with implications for practical applications. The results will be verified in further studies using a longitudinal and dyadic design.

### **Clinical implications**

It seems important to inform the patients and partners better about the supportive services available according to their needs and to anticipate



problems, as soon as the cancer is diagnosed.<sup>36</sup> Indeed, young patients and their partner seem to report more difficulties in the early stages of the cancer pathway, especially for patients. In addition, health professionals can help patients to reduce the physical limitations and negative consequences caused by the disease and treatments on professional activity and daily management. Encouraging the maintenance of links between the couple and their relatives could improve the instrumental support. This concrete help in daily life is important for patients to reduce their difficulties in managing their career and daily tasks.<sup>37</sup> Providing psychological support is essential for young WBC and their partner. In fact, patients report high anxiety, negative affectivity and apprehension about the future in the different groups of active treatments (chemotherapy, Trastuzumab, hormone therapy), and even in follow-up. Partners are particularly distressed when the patients are under chemotherapy and seem to be reassured after this period. This difference between the anxiety of women and partners can cause a lag in the self-reported perceptions of both partners and make partners less supportive, leading to problems in couples. The difficulties in sharing with relatives, especially during the follow-up and for partners, could lead to social isolation and weak social support. Health professionals should facilitate the integration of relatives in supportive care and be vigilant about the relationships between partners, professional caregivers and patients. Thus, it seems important to support young WBC and their partners at two main times. First, the beginning of the care pathway, here represented by the chemotherapy and Trastuzumab groups, is the step with the most difficulties for couples: they may need help to cope with the diagnosis and the first treatments. During this period, professionals can identify couples experiencing major difficulties and at higher risk of serious repercussions in the long term. Second, it seems important to monitor patients and couples during hormone therapy and follow-up because of their anxiety and apprehension about the future and less social support. Healthcare providers need consistent methods to identify and respond to couples' distress and reduce significant disparities in support.

For the practice of oncology professionals, intervention regarding negative affectivity for both members of the couple is important. During the first stages of the treatment, a focus on the partner's feelings should be developed. The patient must be supported during all phases of treatment for their negative affectivity and apprehension of the future. It is necessary to support the couple in the management of children and everyday life and in the regulation of problems (or the apprehension of problems) of finances as well as the de-dramatization of career management. During chemotherapy and Trastuzumab treatment, the patient needs support for her

body image and sexuality. The partner, who seems less affected by this dimension, can value his partner and put her at ease with her body.

## Conclusions

This research is interesting in that it offers suggestions for supporting young women with breast cancer and their partner. It shows that the partner also needs support for his negative affectivity and his feelings in different quality of life registers. He must be helped to maintain his good relationships with his entourage, which may deteriorate during the treatment phases. Patients in the chemotherapy and Trastuzumab groups seem more vulnerable and should be treated with more care. A reflection on interventions that could regulate the different quality of life registers in patients and partners seems a very valuable perspective.

Future interventional research should be implemented to respond in real time to the needs of patients and their partners throughout the care pathway. Clearly, the use of supportive care devices to reduce the emotional distress and difficulties of these couples and increase their quality of life is of utmost importance.

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The study obtained all the necessary legal and ethical authorizations (Consultative Committee for Data Processing in Research in the Field of Health; National Commission for Data Protection) and was carried out in accordance with the Code of Ethics of the World Medical Association (Declaration of Helsinki: CP°09910).

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