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## **Evaluate the subjective experience of the disease and its treatment in the partners of young women with non-metastatic breast cancer**

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CHRISTOPHE V., DUPREZ C., CONGARD A., FOURNIER E., LESUR A., ANTOINE P. & VANLEMMENS L. (2016) *European Journal of Cancer Care* 25, 734–743  
Evaluate the subjective experience of the disease and its treatment in the partners of young women with non-metastatic breast cancer

### Abstract:

The impact of the disease experience on the quality of life of the relatives of patients with cancer is now well documented. However, few scales specifically address the partners' subjective quality of life. This study aims to validate a questionnaire assessing the impact of cancer on the quality of life of the partners of young women with breast cancer. Partners (n = 499) of women aged <45 when diagnosed with a non-metastatic breast cancer completed a self-reported questionnaire generated from non-directive interviews led in an initial study. The structure of the scale was examined by exploratory and confirmatory factor analyses. Internal consistency, test-retest reliability and concurrent validity were assessed. The final Partner-YW-BCI contained 36 items and assessed eight dimensions of the subjective experience of partners:

(1) feeling of couple cohesion, (2) negative affectivity and apprehension about the future, (3) body image and sexuality, (4) career management, (5) deterioration of the relationships with close relatives, (6) management of child(ren) and of everyday life, (7) financial difficulties, and (8) sharing and support from close relatives. The scale showed adequate psychometric properties, and will help clinicians to identify the problems of partners and to respond to them by an optimal care management.

Keywords: Breast Cancer Inventory, partner, caregiving, quality of life, young women.

## INTRODUCTION

Cancer has psychosocial consequences not only on patients but also on their close relatives (for a review, see Hodges et al. 2005; Given et al. 2012), particularly their partners (Hagedoorn et al. 2000; Hasson-Ohayon et al. 2010; Zwahlen et al. 2011). In breast cancer, the partners report negative emotional reactions, changes in their career plans and in the organisation of their home life, worries about their child(ren) and changes in their couple relationship (Fitch & Allard 2007; Harrow et al. 2008).

Although the quality of life and the unmet needs of care-givers of cancer patients are well documented (e.g. Soothill et al. 2001; Wen & Gustafson 2004; Campbell et al. 2009; Shin et al. 2011; Minaya et al. 2012), those of their partners, facing the disease and its repercussions on a daily basis, are less known. Early research works listed the specific need for information about the disease and its treatment (e.g. Kilpatrick et al. 1998; Hodgkinson et al. 2007). Others highlighted not only the role of the partner's support, but also the processes of interdependence between the two partners in the adjustment within the couple (e.g. Ben-Zur et al. 2001; Dorros et al. 2010; Kraemer et al. 2011). Clinicians are increasingly aware of the concerns of the partner, which partially mirror those of the patient, particularly when she is young (under 45–50 years old at the time of the initial diagnosis): the wish to become a parent, which is sometimes incompatible with the treatment offered, problems in managing the education of their sometimes still very young child(ren), deterioration in their marital relationship and sexuality, and a break on their professional career (for a review, see Roche 2006; Anders et al. 2009; Gabriel & Domchek 2010; Narod 2012; Partridge et al. 2012).

Despite these recent works, to the best of our knowledge, there is no tool available to understand the subjective experience of the disease and its repercussions in the partners of young women with breast cancer. Having such a tool will thus help clinicians identify the specific problems of partners, in order to guide them towards suitable support care, as is already done for patients (e.g. Velikova et al. 2004; Carlson et al. 2012).

Based on these observations, the present study aims to validate an inventory to measure the subjective experience of the disease and its treatment in the partners of young patients (<45 years at the initial diagnosis) with non-metastatic breast cancer: the 'Partner-of Young Women with Breast Cancer Inventory' ('Partner-YW-BCI').

## PARTICIPANTS AND METHODS

### Study population

The sample consisted of 499 partners of young patients with non-metastatic breast cancer (497 men, 2 women), aged 26–68 years ( $M = 43.29$ ,  $SD = 7.45$ ). They agreed to participate in the study between January 2010 and June 2012 in 27 French cancer treatment centres. The inclusion criteria were to be the partner of a young patient (<45 years at the initial diagnosis) with non-metastatic breast cancer who was or has been treated by chemotherapy. Only those partners who had been living as a couple for at least 6 months at the time of the study, had no known psychiatric disorders (delirium, psychotic problems, etc.) and were fluent in French, were included.

The study obtained all the necessary legal and ethical authorisations (Committee of Protection of Persons; 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).

## Procedure

The objectives and procedure of the study were explained to the patients, accompanied or not by their partner, during an outpatient appointment. No partner could participate without the explicit agreement of the patient. Following this agreement, the investigating doctor gave the patient, or her partner if present, a letter of information and a consent form for each member of the couple, the questionnaire and a socio-demographic data form. The participants completed these documents alone at home and then returned them in the pre-stamped envelope provided to the treatment centre carrying out the study. At the same time, the patient's medical data were collected by each investigator in the participating centres. Conditions of anonymity and confidentiality were guaranteed to all participants.

## Questionnaires

All the partners replied to the Partner-YW-BCI. In order to test the concurrent validity of the questionnaire, 105 of them also completed a quality-of-life questionnaire already validated and commonly used: the SF-36 (Ware & Sherbourne 1992; French validation by Lep'lege et al. 1998). Another group of partners ( $n = 84$ ) answered the Partner-YW-BCI twice with an interval of 1 month so as to test the reliability of the questionnaire.

## Partner-YW-BCI

This is a self-reported questionnaire composed of 77 items resulting from a previous qualitative study carried out with 69 couples in which the young woman (<45 years at the initial diagnosis) was living with non-metastatic breast cancer (Vanlemmens et al. 2012a, 2012b). These items were chosen to assess specifically the impact of the disease and treatment of the patient on their partner. They were organised into different dimensions: (1) psychological and affective experience concerning the present and the future (14 items, e.g. emotions felt, perception of the future), (2) physical (6 items, e.g. impact of the patient's disease on one's own physical health, acceptance of the patient's physical changes), (3) management of daily/ home life (4 items, e.g. new sharing of household tasks, changes in life habits), (4) questions about the child(ren) (8 items assessing the impact of the disease and its treatment on their child(ren), i.e. management of daily life with their child(ren), emotional problems experienced by the child(ren), being available for them), (5) professional life (4 items, e.g. personal investment in the job, effectiveness at work), (6) financial difficulties (4 items, e.g. fall in income and lifestyle, additional costs), (7) familial and social relationships (16 items, e.g. communication, cohesion, social support, perception of the impact of the disease on relatives and on social activities) and (8) couple relationship (21 items, e.g. communication, cohesion and support within the couple, social activities, sexuality).

The partners were asked to assess to what extent each item corresponded to their current state ('at this moment, currently') by indicating their degree of agreement for each item on a 5-point Likert scale (from 1 = 'strongly disagree' to 5 = 'strongly agree').

## Medical outcome study health survey short form-36 items (SF-36)

In order to test the concurrent validity of the Partner-YW-BCI, the participants were asked to complete the SF-36 (Ware & Sherbourne 1992; French validation by Lep'lege et al. 1998). This generic quality of life self-reported questionnaire is composed of 36 items related to the 4 weeks before the interview, and divided into nine dimensions: mental health (5 items), vitality (4 items), physical activity (10 items), limitations due to physical state (4 items), physical pain (2 items), perceived health (5 items), social life/relationships with others (2 items), limitations due to psychological state (4 items) and perceived changes in health during the previous year (1 item). For each dimension, the scores were coded then added before being linearly transformed on a scale from 0 (worst health) to 100 (best health possible).

## Statistical analyses

### *Analyses to identify the factorial structure of the scale/construct validity*

Descriptive analyses (examination of the distribution of the answers to items and correlation matrices between items) were first carried out to remove poorly discriminative items.

An exploratory factorial analysis using principal axes with Promax rotation was then carried out with the Statistical Package for the Social Sciences (IBM SPSS Statistics, France) version 18 software to identify the factorial structure of the scale. Exploratory factorial analyses were conducted on a population of 379 partners randomly chosen from the 499 partners. Confirmatory analyses were carried out on the other 120 partners of this sample. Classic criteria were used to extract the factors: the scree test (Cattell 1966), and representativeness of the components as a function of the number of items and their coherence with the constructs. At this stage, items showing cross-loadings or loadings less than 0.30 on the factors were eliminated. Another point also guided the removal of items; we wanted to construct an equivalent structure for these partners and their spouses, which will be the subject of another publication (thus 35 items were eliminated). Items related to physical feeling were also not retained at this stage as they did not load a unique factor and showed numerous cross-loadings (6 items removed).

A confirmatory factorial analysis, based on structural equation modelling, was then applied to the answers to the retained items, using LISREL 8.8 software (Joreskog & Sorbom 2001). The indices used to assess the adjustment of the model were: Chi-squared goodness-of-fit test, Root Mean Square Error of Approximation (RMSEA), Normed Fit Index (NFI), Standardized Root Mean Square Residual (SRMR) and Adjusted Goodness of Fit Index (AGFI).

### *Analysis of internal consistency and test-retest reliability*

The internal consistency of each sub-scale of the questionnaire was examined using Cronbach's alpha coefficients ( $>0.70$ ). Test-retest reliability was investigated using the Bravais-Pearson correlation coefficient between the scores of 84 partners who completed the questionnaire twice with a mean interval of 17 days (Min = 8 days, Max = 30 days, M = 16.99, SD = 5.22).

## Analysis of concurrent validity

Concurrent validity was assessed via the Bravais–Pearson correlation coefficients between the scores of participants in the Partner-YW-BCI and their scores in the SF-36.

## RESULTS

### Sample characteristics

The majority of the participants had a job at the time of the study (94.37%). Concerning their educational level, most of the participants had a secondary (31.79%) or a graduate qualification (23.54%). Almost all the participants were already living in a couple with the patients at the time of the diagnosis (96.99%, mean duration of the couple relationship = 13.91 years, SD = 8.51) and had children (90.30%). Concerning the situation of the patients at the time of the study, they had suffered from breast cancer for 2.59 years on average (SD = 2.86), 143 were undergoing chemotherapy with or without Trastuzumab, 50 were undergoing Trastuzumab with or without hormone therapy, 166 patients were undergoing hormone therapy only and 140 were under follow-up.

### Factorial structure of the questionnaire

#### *Exploratory analyses*

Exploratory factorial analyses of the principal factors were carried out on a random sample of 436 partners, and revealed a structure of 8 factors explaining 58.02% of the total variance (Table 1): F1: Management of child (ren) and of everyday life (5 items, 21.76% of the total variance), F2: Negative affectivity and apprehension about the future (6 items, 8.53%), F3: Feeling of couple cohesion (5 items, 6.04%), F4: Financial difficulties (4 items, 5.64%), F5: Body image and sexuality (4 items, 4.48%), F6: Deterioration of relationships with close relatives (5 items, 4%), F7: Sharing and support from close relatives (4 items, 3.96%), and F8: Career management (3 items, 3.52%).

The final inventory thus consisted of 36 items ('YW-BCI36'). The previously identified dimensions were thus found: psychological and affective experience and apprehension about the future, management of daily life – with items linked to children, professional life and financial difficulties. The dimension related to social and familial relationships was divided into two parts, depending on the positive or negative valence of the interpersonal relationships: the first was linked to the feeling of support and the second to the deterioration of relationships with close relatives. Similarly, two dimensions emerged related to the couple: cohesion – with items linked to support and closeness, and body image and sexuality – with items linked more to couple intimacy.

These eight dimensions were quite strongly linked, as shown by the correlations presented in Table 2. In particular, the dimension 'negative affectivity and apprehension about the future' was quite strongly and positively correlated with all the subscales about problems (concerning the management of child(ren) and of everyday life, body image and sexuality, finances, and relationships with close relatives), like the deterioration of relationships with close relatives.

#### *Confirmatory analyses*

The indices of confirmatory factorial analyses carried out on a random sample of 108 partners suggested a good adjustment of the model overall ( $\chi^2(566) = 802.18$ ;  $P < 0.001$ ;  $\chi^2/df = 1.41$ ; RMSEA = 0.055; NFI = 0.80, SRMR = 0.075; AGFI = 0.78).

#### Internal consistency of the scale

Internal consistency was acceptable with Cronbach's alphas going from 0.70 (for the dimensions 'sharing and support from close relatives' and 'career management') to 0.84 (for the dimension 'management of child(ren) and of everyday life') (Table 3).

#### Test-retest reliability

Overall, the test-retest reliability of the questionnaire (mean interval in days between two completions:  $M = 16.99$ ,  $SD = 5.22$ ) was acceptable (Table 3). Only the test-retest correlation coefficient of the dimension 'career management' was lower than the expected threshold ( $r = 0.496$ ).

#### Concurrent validity

As expected, the correlations between the dimensions of the two scales were moderate (from -0.211 to -0.456), Table 4. The strongest correlations were observed between the dimensions 'negative affectivity and apprehension about the future' of the Partner-YW-BCI and the scales of social functioning and physical pain of the SF-36 ( $r = -0.456$ ,  $P < 0.001$  and  $r = -0.439$ ,  $P < 0.001$ , respectively). Consistent with the clinical observations, the dimension 'negative affectivity and apprehension about the future' of the Partner-YW-BCI scale was also negatively correlated with the dimensions 'vitality', 'social functioning', and 'perceived general health' of the SF-36.

## DISCUSSION

The aim of the present work was to validate a new tool, in the French language, to assess the repercussions of the disease and its treatment on the daily life of partners of young patients with non-metastatic breast cancer, based on the results from a qualitative study (Vanlemmens et al.

Table 1. Factorial structure of the questionnaire (loadings)

Items	Management of child(ren) and of everyday life	Negative affectivity and apprehension about the future	Feeling of couple cohesion	Financial difficulties	Body image and sexuality	Deterioration of relationships with close relatives	Sharing and support from close relatives	Career management
<i>I have problems managing the education of my child(ren)</i> (J'ai des difficultés à gérer l'éducation de mon (mes) enfant(s))	0.809			0.376		0.375		
<i>I have problems doing some domestic tasks</i> (J'ai des difficultés pour assurer certaines tâches domestiques)	0.799	0.348		0.543	0.335			0.354
<i>I have problems managing daily life with my child(ren)</i> (J'ai des difficultés dans la gestion du quotidien avec mon (mes) enfant(s))	0.798			0.364		0.352		
<i>I have problems managing daily life</i> (J'ai des difficultés dans la gestion du quotidien)	0.760	0.430		0.554	0.394	0.404		0.386
<i>I'm overwhelmed by domestic tasks</i> (Je suis débordé(e) par la gestion des tâches domestiques)	0.760							0.312
<i>I'm concerned about the future</i> (L'avenir me préoccupe)		0.742						
<i>I feel worried</i> (Je me sens inquiet(e))		0.731						
<i>I have anxieties</i> (J'ai des angoisses)	0.314	0.714		0.383				0.362
<i>I am calm</i> (Je suis serein(e)) (R)		-0.670	0.340	-0.302				-0.437
<i>I am afraid for my child(ren)</i> (J'ai peur pour mon (mes) enfant(s))		0.664						
<i>I think about my disease every day</i> (Je pense tous les jours à la maladie)		0.647						0.328
<i>My couple is strong</i> (Mon couple est uni)			0.803					
<i>I feel close to my partner</i> (Je me sens proche de ma partenaire)			0.787					
<i>I feel that I support my partner</i> (J'ai le sentiment de soutenir ma partenaire)			0.758					
<i>I am attentive toward my partner</i> (Je suis attentif(-ve) à ma partenaire)			0.740					



Table 1. Continued

Items	Management of child(ren) and of everyday life	Negative affectivity and apprehension about the future	Feeling of couple cohesion	Financial difficulties	Body image and sexuality	Deterioration of relationships with close relatives	Sharing and support from close relatives	Career management
<i>I can confide in my partner (Je peux me confier à ma partenaire)</i>	-0.323		0.708					
<i>I have problems dealing with the costs incurred by the disease (J'ai des difficultés pour faire face aux frais engendrés par la maladie)</i>	0.360			0.852				
<i>I have financial difficulties (J'ai des difficultés financières)</i>	0.354			0.832				
<i>The disease causes additional costs (La maladie occasionne des frais supplémentaires)</i>	0.342			0.713				
<i>I have to reduce my lifestyle (Je dois diminuer mon train de vie)</i>	0.395	0.301		0.704	0.318			
<i>I no longer dare touch my partner physically (Je n'ose plus toucher physiquement ma partenaire)</i>					0.723			0.382
<i>I feel less sexual desire (Je ressens moins de désir sexuel)</i>		0.314			0.717			0.320
<i>I no longer recognize my partner physically (Je ne reconnais plus ma partenaire physiquement)</i>	0.381	0.324			0.678			
<i>I have some sexual problems because of the disease (Je rencontre des difficultés sexuelles à cause de la maladie)</i>					0.669			
<i>I feel neglected by some of my close relatives (Je me sens délaissé(e) par certains de mes proches)</i>	0.302					0.769		
<i>I can count on those around me (Je peux compter sur ceux qui m'entourent) (R)</i>						-0.736	0.385	
<i>The disease creates tensions with the people around me (La maladie crée des tensions avec les personnes qui m'entourent)</i>	0.441	0.351		0.325		0.679		0.429

Table 1. Continued

Items	Management of child(ren) and of everyday life	Negative affectivity and apprehension about the future	Feeling of couple cohesion	Financial difficulties	Body image and sexuality	Deterioration of relationships with close relatives	Sharing and support from close relatives	Career management
<i>I have problems communicating with some of my close relatives (J'ai des problèmes de communication avec certains de mes proches)</i>	0.385	0.348		0.398		0.648		
<i>The disease has a negative impact on my close relatives (La maladie a un impact négatif sur mes proches)</i>		0.330				0.599		
<i>I talk about the disease with those around me (Je discute de la maladie avec mon entourage)</i>							0.758	
<i>I talk about how I feel with some of my close relatives (Je parle de ce que je ressens à certains de mes proches)</i>							0.748	
<i>I can confide in some people (Je peux me confier à certaines personnes)</i>							0.670	
<i>Some people around me help me a lot (Certaines personnes de mon entourage m'aident beaucoup)</i>							0.584	
<i>I feel that I'm effective at work (Je me sens efficace dans mon activité professionnelle) (R)</i>		-0.312						-0.790
<i>I put a lot into my work (Je m'investis dans mon travail) (R)</i>								-0.712
<i>I have problems doing my job (J'ai des difficultés à exercer mon activité professionnelle)</i>	0.547	0.407		0.314				0.680
% of variance before rotation	8.05	3.15	2.24	2.09	1.66	1.51	1.47	1.30
% of variance after rotation	21.76	8.53	6.04	5.64	4.48	4.09	3.96	3.52
% added up after rotation	21.76	30.29	36.33	41.97	46.45	50.54	54.50	58.02

Extraction: principal axis factoring method. Rotation: Promax method. For the sake of readability, loadings below 0.20 are not shown.

Table 2. Correlations between the dimensions of the factorial structure of the questionnaire

	1	2	3	4	5	6	7	8
Management of child(ren) and of everyday life (1)	–							
Negative affectivity and apprehension about the future (2)	0.364**	–						
Feeling of couple cohesion (3)	–0.202	–0.288*	–					
Financial difficulties (4)	0.502**	0.541**	–0.136	–				
Body image and sexuality (5)	0.413**	0.353**	–0.285*	0.403**	–			
Deterioration of relationships with close relatives (6)	0.507**	0.564**	–0.332**	0.550**	0.497**	–		
Sharing and support from close relatives (7)	–0.079	–0.071	0.237	–0.059	0.006	–0.266*	–	
Career management (8)	0.000	–0.042	0.138	–0.112	0.005	–0.039	–0.025	–

Bravais–Pearson's  $r$  ( $N = 436$ ).\* $P < 0.05$ , \*\* $P < 0.001$ .

Table 3. Internal consistency and test–retest reliability of the questionnaire

	Number of items	$\alpha$	$r$
Management of child(ren) and of everyday life	5	0.84	0.824
Negative affectivity and apprehension about the future	6	0.81	0.804
Feeling of couple cohesion	5	0.81	0.661
Financial difficulties	4	0.79	0.795
Body image and sexuality	4	0.75	0.725
Deterioration of relationships with close relatives	5	0.75	0.776
Sharing and support from close relatives	4	0.70	0.690
Career management	3	0.70	0.496

All the correlations are significant at  $P < 0.01$ ,  $N = 84$ .

2012a, 2012b). Although some scales are available to evaluate the unmet needs of partners of cancer patients (e.g. FIN-H, Kilpatrick et al. 1998), or the overall quality of life of caregivers (e.g. CarGOQoL, Minaya et al. 2012), to our knowledge, there is no specific tool to assess the subjective experience of spouses faced with the patient's cancer. Yet, in a systemic approach, the repercussions of the disease on the spouses and the way in which they deal with it clearly impact the adjustment of the patient towards the disease (e.g. Hagedoorn et al. 2000; Ben-Zur et al. 2001; Manne et al. 2009; Dorros et al. 2010; Kraemer et al. 2011). Moreover, caregivers often express their need to be able to rely on health professionals to learn how to help the patient (e.g. Hoga et al. 2008). A better understanding of the partner's experience is therefore an undeniable asset in the overall understanding of the patient's own experience, the couple's experience and how they deal together with the disease.

The 'Partner-YW-BCI36' inventory is composed of 36 items, shows good psychometric qualities and enables the specific problems of partners of young patients with non-metastatic breast cancer to be assessed. It has been validated as a structure of eight factors: (1) management of child(ren) and of everyday life (5 items), (2) negative affectivity and apprehension about the future (6 items), (3) feeling of couple cohesion (5 items), (4) financial difficulties (4 items), (5) body image and sexuality (4 items), (6) deterioration of relationships with close relatives (5 items), (7) sharing and support from close relatives (4 items) and (8) career management (3 items). This inventory shows good construct validity, as well as good internal and external consistency according to the analyses of items carried out. The concurrent validity indicates correlations in agreement with our hypotheses and with a comparable and already validated quality of life tool (SF-36).

The Partner-YW-BCI36, by its structure and the items composing it, is also particularly valuable in identifying not only the daily problems of coping with the disease but also the positive aspects and resources of the partner, especially in terms of cohesion within the couple, and sharing and support from close relatives. Reducing difficulties, lightening the potential burden, limiting negative emo-

tional repercussions, and reinforcing positive affective relationships with partners can only be beneficial for the treatment of patients.

Eventually, future research should focus on a longitudinal approach of the experience of partners in order to determine which phases of treatment are the most problematic. Similarly, few studies have investigated the experience of spouses in homosexual couples. For example, it would be interesting to see if the subjective experience of female partners of breast cancer patients, who potentially could have or have had the disease themselves, is the same as that of a male partner. It is also important to develop dyadic protocols that simultaneously take into account the problems and resources of the patient and their partner at each step of the care pathway. Clearly, a better understanding of the subjective experience of the partner

Table 4. Concurrent validity/correlations between the dimensions of the PARTNER-BCI and those of the SF-36

	Physical functioning	Limitations due to physical state	Limitations due to emotional state	Vitality	Emotional well-being	Social functioning	Physical pain	Perceived health	Health transition
Management of child(ren) and of everyday life	-0.308**	-0.283**	-0.376**	-0.410**	0.017	-0.334**	-0.316**	-0.366**	-0.350**
Negative affectivity and apprehension about the future	-0.180	-0.125	-0.216*	-0.340**	-0.015	-0.456**	-0.439**	-0.313**	-0.233*
Feeling of couple cohesion	0.185	0.076	0.152	0.185	0.029	0.237*	0.173	0.170	0.192
Financial difficulties	-0.099	-0.233*	-0.339**	-0.197	-0.058	-0.223*	-0.145	-0.177	-0.202
Body image and sexuality	0.049	-0.120	-0.239*	-0.158	0.019	-0.179	-0.035	-0.181	-0.159
Deterioration of relationships with close relatives	-0.211*	-0.153	-0.278*	-0.176	0.004	-0.347**	-0.225*	-0.207	-0.082
Sharing and support from close relatives	0.081	0.040	-0.035	0.184	-0.025	0.147	0.121	0.220*	0.08
Career management	-0.062	0.149	0.183	0.108	0.157	0.030	0.026	-0.003	0.045

*N* = 105.

\**P* < 0.01, \*\**P* < 0.001.

alongside that of the patient, including the convergences/divergences in the perceptions of the dyad, will enable a better appreciation of the processes of adjustment to the disease (Romero et al. 2008), and improve the overall treatment of these couples via appropriate and personalised support care.

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