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Fear of cancer recurrence after breast and colorectal cancer treatment: reported optimism during treatment as a stable and resilient factor?

Thesis for obtaining the certificate of the post-academic formation 'psycho-oncology' by

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ABSTRACT

Objective: The aim of the present study was to examine the role of optimism during breast and colorectal cancer treatment in relation to fear of cancer recurrence outcome. The time course of optimism as well as the predictive value of it towards fear of cancer recurrence (FCR) was examined.

Methods: Breast and colorectal cancer patients (*n* = 11) undergoing curative treatment completed an adjusted version of the Life Orientation Test-Revised (LOT-R-NL) to measure dispositional and situated optimism as well as pessimism. Several months later, participants completed the LOT-R-NL for a second time as well as the Concerns about Recurrence Scale-questionnaire (CARS) to measure FCR. Friedman's tests were used to examine stability of optimism and pessimism. A multiple regression analysis was performed to test for predictive values of optimism and pessimism.

Results: The results confirmed the stability of dispositional and situated optimism as well as pessimism over a period of time from undergoing (T1) to after completion of curative treatment (T2). Regression analyses demonstrated that higher FCR after treatment was directly predicted by higher situated pessimism during treatment, i.e. pessimism towards illness and treatment.

Limitations: Given the small sample size, the results of the current research do not represent a heterogeneous sample. As a result, significant findings can only be considered as valuable quantitative indications and trends. Hence, future research will be needed.

Conclusion: The present study examines the role of optimism during curative treatment in relation to fear of cancer recurrence. Although dispositional and situated optimism were correlated with FCR, situated pessimism was found to be the only predictor of FCR.

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INTRODUCTION

According to the GLOBOCAN project of the International Agency for Research on Cancer, there were approximately 14.1 million new cases of cancer worldwide in 2012. The most commonly diagnosed cancers were lung (1.82 million), breast (1.67 million), and colorectal (1.36 million) (Ferlay et al., 2015). Due to global demographic transitions the incidence rate is expected to increase (Bray & Soerjomataram, 2015). Besides, a study exploring 40-year trends in cancer survival rates supported substantial increases in survival from cancer (Quaresma, Coleman, & Rachet, 2015). Because of the growing gap between cancer incidence and mortality, more and more cancer patients will become long-term survivors. As a result, the need arose for better understanding post-treatment concerns. Research identified numerous physical, emotional, and practical challenges as well as unmet needs encountered by cancer survivors (Armes et al., 2009; Beckjord et al., 2014). One of the most prevalent reported unmet needs of cancer survivors concerns dealing with fear of cancer recurrence (Armes et al., 2009; Simard et al., 2013; Thewes, Butow, Girgis, & Pendlebury, 2004).

Fear of Cancer Recurrence

Fear of cancer recurrence (FCR) is often described as "*the fear of the disease recurring or progressing in the same organ or in another area of the body*" (Vickberg, 2003). However, a universal definition is still missing. A wide variability in reported prevalence and severity rates may partly be explained by the lack of a consensual definition and the heterogeneity of the phenomenon as well as the variety of assessments (Koch, Jansen, Brenner, & Arndt, 2013; Lebel, Ozakinci, Humphris, Mutsaers, et al., 2016; Lebel, Ozakinci, Humphris, Thewes, et al., 2016; Simard et al., 2013; Simard & Savard, 2009). In a systematic review conducted by Simard et al. (2013), multiple FCR assessment methods were identified. Simard et al. concluded that the majority of the survivors reported low to moderate degrees of FCR. However, consistent with previous research, they considered FCR as one of the greatest concerns and the most prevalent unmet need. In summary, 39 – 97 % of the survivors reported some degree of FCR, 22 – 87 % reported moderate to high levels, and 0 – 15 % reported high levels of FCR. However, established criteria for clinical levels of FCR are needed to support the accuracy and reliability of such assumptions (Simard et al., 2013). In 2016, Lebel et al. invited experts in the field (e.g. expert researchers) aiming to establish a consensual definition of FCR. A Delphi method was used to identify the most relevant definition. The attendees proposed a definition reflecting the broad spectrum in which patients experience FCR, i.e. "*Fear, worry, or concern relating to the*

possibility that cancer will come back or progress". Possible characteristics of clinical FCR were established: "(1) high levels of preoccupation, worry, rumination, or intrusive thoughts; (2) maladaptive coping; (3) functional impairments; (4) excessive distress; and (5) difficulties making plans for the future". Fardell et al. (2016) reviewed theoretical frameworks used to explain FCR and to guide FCR research. They presented a novel theoretical approach, existing of a synthesis of theories, which accentuates FCR as a multidimensional construct. The role of cognitive processes and metacognitions in the development and maintenance of FCR was highlighted.

There is no clear consensus concerning the duration and stability of FCR intensity. In several quantitative studies reviewed by Koch et al. (2013), patients even reported FCR five or more years after initial diagnosis and most researchers did not find a significant association between years since diagnosis and FCR. They concluded that FCR can last for a long time and, besides, remains relatively stable over time. This is in line with suggestions of the majority of the cross-sectional and longitudinal studies reviewed by Simard et al. (2013). Likewise, none of the studies included in the review of Crist & Grunfeld (2013) showed an association between severity of FCR and time since diagnosis. However, comparison among studies is limited due to diversity in the measurements and follow-up periods. Additional longitudinal research is needed to verify the stability of FCR (Simard et al., 2013). Some researchers suggested that reported FCR findings may depend on the time at which the measurement is taken (Koch et al., 2013; McGinty, Small, Laronga, & Jacobsen, 2016). McGinty et al. (2016) described patterns of short-term changes in FCR over time, namely higher reported scores by cancer survivors a week prior to follow-up mammography, which, in turn, decreased after obtaining negative results and increased again during the month following the mammography.

Impact of FCR

In a prospective study, more than half of former breast cancer patients reported moderate to high levels of FCR. A negative correlation between FCR and quality of life (QoL) was found (van den Beuken-van Everdingen et al., 2008). Some researchers presumed that worries of recurrence do not have a dramatic impact on the QoL of most cancer survivors (Deimling, Bowman, Sterns, Wagner, & Kahana, 2006; Thewes et al., 2004). However, FCR is associated with negative consequences, such as increased anxiety and more depressive symptoms (Deimling et al., 2006; Humphris et al., 2003; Skaali T, Fossa S D, Bremnes R, & Dahl O, 2009). In a study of Thewes et al. (2012), 70 % of surveyed breast cancer patients reported clinical levels of FCR. A quarter of the respondents indicated a substantial impact of FCR on their mood. Other patients found that FCR limited their ability to make plans and goals for the future. Likewise,

positive associations between psychological factors (e.g. distress, anxiety and depression) and FCR were found in a review of Simard et al. (2013). Strong evidence emerged that poor QoL was associated with greater FCR, with moderate evidence that FCR predicted QoL. Based on several studies, Koch et al. (2013) concluded FCR to be significantly negative associated with QoL and psychosocial well-being even years after the initial diagnosis, potentially inducing anxiety and depression in long-term cancer survivors. Furthermore, FCR was associated with higher health costs and lower surveillance rates, which may compromise health outcomes (Thewes et al., 2012). Nevertheless, few assumptions about the direction of relationships can be made based on study designs found in literature. Thus, caution should be taken in interpreting the results and conclusions about causality based on prospective designs (Koch et al., 2013; Simard et al., 2013).

Factors Associated with FCR

The identification of key factors associated with high levels of FCR will help to detect groups at risk and to develop intervention strategies to enhance well-being in cancer survivors. A variety of potential determinants of FCR has been examined in the past. For many of them, findings are not consistent across studies. Furthermore, study designs didn't allow to make conclusions about directions of relationships (Crist & Grunfeld, 2013; Koch et al., 2013).

A review by Crist & Grunfeld (2013) showed strong evidence for a relationship between FCR and younger age (see also Starreveld, Markovitz, van Breukelen, & Peters, 2017; van den Beuken-van Everdingen et al., 2008; Vickberg, 2003). Moderate evidence was found for interdependency of FCR with demographic factors as ethnicity and having younger children. Weak or inconclusive evidence was shown for the contribution of socio-demographic factors (gender, education, employment), social resources (family resources and stressors, significant others), as well as cancer-related characteristics (cancer type, stage, treatment type) to levels of FCR. Experiencing pain was found to be associated with FCR (van den Beuken-van Everdingen et al., 2008). However, there are relatively few studies regarding whether and how habitual attending to and negative interpretation of pain – known as cognitive biases – influence pain experience in cancer survival (Heathcote & Eccleston, 2017). Heathcote & Eccleston (2017) concluded that symptom uncertainty can turn pain experience into a cue of threat, which may, in turn, lead to fear about disease recurrence. Based on other models used in non-cancer pain fields, the authors presented the Cancer Threat Interpretation Model, a cognitive affective model of the appraisal and experience of pain in the context of cancer survival. They suggested

that understanding the process of normal cognitive biases to prioritize threat in cancer survival can be useful to develop treatment preventing secondary anxiety after cancer. Koch et al. (2013) concluded that psychosocial factors seem to be stronger associated with FCR compared to medical or demographic factors. Data from several studies reviewed by Crist & Grunfeld (2013) suggested that depressive and active problem-orientated coping were associated with greater FCR. Furthermore, they found that denial coping and avoidance-orientated coping predicted future FCR. Other studies found distinct groups of FCR patients based on psychological factors. Simard, Savard, & Ivers (2010) found different profiles of FCR, varying according to severity and type of coping strategy, namely Mild FCR-Low Copers, Mild FCR-High Copers, Moderate FCR-High Copers, and High FCR-High Copers. McGinty et al. (2016) used the cognitive–behavioral model (CBM) of health anxiety by which they predicted a higher-FCR and a lower-FCR class. Several CBM variables were significant predictors: breast cancer survivors who reported greater perceived risk, lower coping self-efficacy, and greater reassurance-seeking behaviors were more likely to be classified in the higher-FCR than to the lower-FCR subgroup. As indicated by characteristics of FCR proposed in the study of Lebel et al. (2016), as well as by the novel theoretical approach presented by Fardell et al. (2016), coping takes a prominent role concerning FCR. Besides, Finck, Barradas, Zenger, & Hinz (2018) suggested that optimism affects patients to better cope with disease.

Optimism

Optimism is often conceptualized as a cognitive-affective personality construct, i.e. dispositional optimism. Scheier & Carver (1985) defined dispositional optimism as persons' generalized and stable expectancies that good things will happen to them. Literature has highlighted optimism as a trait-like disposition, linked to both psychological and physical health outcomes (Carver & Scheier, 2014; Carver, Scheier, & Segerstrom, 2010; Forgeard & Seligman, 2012; Matthews, Raikkonen, Sutton-Tyrrell, & Kuller, 2004; Saboonchi, Petersson, Alexanderson, Bränström, & Wennman-Larsen, 2016; Schou, Ekeberg, & Ruland, 2005). For example, studies revealed better QoL in optimistic people as well as that optimists engage in more effective coping and adopt more health-promoting behaviors than people low in optimism (for an overview, see Carver et al., 2010 and Carver & Scheier, 2014). Research has shown that cancer patients with a low level of optimism and high in pessimism are at risk for higher levels of anxiety and depression (Zenger, Brix, Borowski, Stolzenburg, & Hinz, 2010).

Two year temporal stability of optimism and pessimism was established by Saboonchi et al. (2016). However, optimism also shows evidence of some change when examining longer intervals. It was less stable in comparison with other personality traits such as neuroticism, extraversion, and conscientiousness over similar intervals (Segerstrom, 2007). Chopik, Kim, & Smith (2015) indicated that optimism generally increases in older adults before decreasing. Increases over a 4-year period were associated with increases in self-reported health. They suggested that changes in optimism contribute to changes in health. In line with this assumption, research supported the causal status of optimism towards pain (Marjolein M. Hanssen, Peters, Vlaeyen, Meevissen, & Vancleef, 2013). Given the apparently causal relationship, coping is often proposed to mediate the influence of optimism on QoL (M. M. Hanssen et al., 2015; Schou et al., 2005). Additional research is needed to better understand through which mechanisms optimism leads to outcomes such as higher levels of physical and psychological well-being and health (Forgeard & Seligman, 2012; Hanssen et al., 2015; Schou et al., 2005). Although optimism is supposed to be a relatively stable dispositional construct, some interventions have showed to be successful in enhancing optimism in persons. Researchers need to continue developing effective interventions (Forgeard & Seligman, 2012).

The literature on dispositional optimism suggests that the personality construct has largely been found to have positive effects. Independent of the level of fear and anxiety reported prior to treatment (Llewellyn, Weinman, McGurk, & Humphris, 2008), a lack of optimism was found to be a predictor of FCR (Llewellyn et al.,2008; Starreveld et al., 2017). Dispositional optimism predicted FCR stronger compared to other cognitive and emotional representations and coping strategies (Llewellyn et al., 2008). Some researchers, however, suggested that situated optimism – i.e. optimistic situation-specific expectancies – can be associated with somewhat different outcomes than general, trait-like optimism (Armor & Taylor, 1998; Benyamini & Raz, 2007; Thornton, Perez, Oh, & Crocitto, 2012). For example, dispositional optimism was a predictor of better sexual intimacy and confidence in prostate cancer patients, whereas cancer-specific expectations uniquely predicted better informed decision making. Although dispositional optimism and specific expectations were related, they contributed uniquely to prostate cancer-related QoL outcomes (Thornton et al., 2012). Kube et al. (2018) integrated the two types of expectations – situation-specific dysfunctional expectations and dispositional optimism – into the cognitive model of depression. They aimed to better understand cognitive processes as well as identify targets for intervention. In the literature on situated optimism, researchers indicated that situation-specific optimism often has an unrealistic degree, however, appears to be flexible.

This flexibility allows people to adapt their behavior in a way that maintains a positive sense of self while, at the same time, maintaining relative accuracy with respect to the demands of the environment. This provides benefits in adjustment to stressful events and persistence in coping with difficult situations (Armor & Taylor, 1998; Benyamini & Raz, 2007).

Present Study

The aim of the present study was to examine the role of optimism during cancer treatment in relation to fear of cancer recurrence outcome. A longitudinal design was used to examine reported optimism during treatment as a significant predictor in the severity of FCR in breast and colorectal cancer patients. Next to dispositional optimism, the study assesses the role of situated optimism concerning the illness and treatment in relation to FCR-outcome. During the period of treatment psychosocial support by care providers is usually provided, hence, predictors present during treatment may be used for screening.

It was assumed that optimism is a stable as well as a resilient factor concerning FCR. Therefore, it was hypnotized that there is no significant difference between reported optimism during treatment (T1) and after treatment (T2). Next to dispositional optimism, stability of situated optimism towards illness and treatment was expected. Furthermore, it was hypothesized that greater optimism during curative treatment will predict lower FCR after completion of treatment. Finally, it was assumed that there is an association between FCR and time since/till follow-up control, but that the correlation will be less strong when higher scores of optimism were reported. Most recent studies showed a bidimensional structure with optimism and pessimism as two independent factors when using the LOT-R-NL (Glaesmer et al., 2012; Hinz et al., 2017; Saboonchi et al., 2016; ten Klooster et al., 2010), hence effects of dispositional and situated pessimism were also measured.

METHODS

Procedure

Between October 2017 and February 2018 (T1), patients were screened for eligibility using medical chart review. Patients present in the hospital received the information of the questionnaire, including the informed consent, the initial questionnaires, and a stamped envelope from the onco-coach or a psychologist. Others were sent these forms to their home address. The informed consent and the information received by patients are given in Appendix 1. The initial questionnaires comprised a form to map socio-demographic characteristics as well as a survey assessing optimism. The participants were asked whether they wanted to receive

the following questionnaires by postal mail or by e-mail. Potential participants who did not replied were no longer contacted. The respondents who did return completed questionnaires, were contacted several months later in April 2018 (T2). They were asked to complete the survey assessing optimism a second time as well as another survey assessing FCR. However, if their treatment was not yet completed at T2, participants were only asked to fill in the survey assessing optimism.

Participants

Eligibility criteria. Breast cancer patients and colorectal cancer patients undergoing curative treatment in the Sint-Trudo Hospital (*n* = 46) were approached to participate. Inclusion criteria were undergoing a curative treatment for cancer or cancer in situ, without detected distant metastases. Exclusion criteria were a history of other cancers. Statistical analyses only include participants who received negative results on follow-up controls, i.e. where no signs of possible recurrence were found. The study was approved by the Medical Ethics Committee of the Sint-Trudo Hospital.

Measures

Demographic and clinical characteristics. A self-report form was used to collect following socio-demographic parameters at T1: age, gender, family status, and education. Some relevant clinical, cancer-related parameters were assessed using medical chart review: (stage at) diagnosis, time since diagnosis, treatment(s) received, and time since treatment completion. At T2, participants were also asked for the date of the latest and the next follow-up control.

Optimism. At both assessment time points, dispositional optimism was measured with the Dutch Life Orientation Test-Revised (LOT-R-NL) (ten Klooster et al., 2010; Appendix 2). The LOT is originally an American questionnaire (Scheier & Carver, 1985). Since its revision, the LOT-R is composed of 10 items (Scheier, Carver, & Bridges, 1994). Along four filler items, it contains three items each for positive and negative general life expectations. Scores are given on a 5-point Likert scale. Patients were asked to rate the extent to which they agreed with each statement ranging from strongly disagree to strongly agree. Although originally composed of a unidimensional scale with optimism and pessimism as endpoint, other studies showed and confirmed a bidimensional structure with optimism and pessimism as two independent factors (Glaesmer et al., 2012; Hinz et al., 2017; Saboonchi et al., 2016; ten Klooster et al., 2010). Both the English and Dutch versions of the test have shown adequate internal consistency (Hinz et al., 2017; Scheier et al., 1994; ten Klooster et al., 2010).

Because the LOT-R-NL only contains items about general life expectancy, five items measuring disease-related expectations were added (situated optimism; Appendix 2). Two added items assess positive and negative expectations concerning the disease itself (e.g. 'When I heard about my illness, I had a tendency to think of a bad outcome'). Two others involve positive and negative expectations concerning the treatment (e.g. 'I expect good results from the treatment I receive'). One item involves the role of experienced social support ('The support of family members and / or friends helps me to be positive in relation to my illness and treatment').

Fear of Cancer Recurrence. At T2, participants completed the Concerns About Recurrence Scale – Dutch Language Version (CARS-DLV; Appendix 2). The CARS is originally an American questionnaire assessing the extent to which patients are worried about the possibility of cancer recurrence as well as the nature of these concerns (Vickberg, 2003). The CARS does not approach FCR as one-dimensional, with the advantage that more suggestions can be made for a therapeutic intervention. Four items assess the overall fear of recurrence concerning frequency, potential for upset, consistency and intensity of fear (6-point Likert scale). Slightly different than the CARS, the CARS-DVL assesses specific domains of fear via three subscales: health worries, womanhood worries, and role worries (in total 26 items, 5-point Likert scale). The CARS-DVL was found to be valid and reliable by van den Beuken-van Everdingen et al. (2008). Hauspie and Crombez (2012) proved a high internal consistency in a Flemish population.

Although the CARS originally only assesses women's fear of breast cancer recurrence, in the current study this questionnaire is used for a broader target group (cf. discussion section). Items assessing womanhood worries were adjusted in dialogue with patients in order to make all items relevant for both breast cancer and colorectal cancer patients (cf. discussion section). Some questions regarding patients' feeling of need for support when dealing with FCR and other difficulties are added (yes or no). Participants were also asked if they consult or have consulted a psychologist (yes or no). The adjustments and additions are given in Appendix 2.

Statistical Analyses

The prevalence of fear of cancer recurrence was measured by determining the percentage of participants with a moderate (average item score 2 or 3) or high to very high (average item score 4 or 5) degree of fear on the general part of the CARS-DLV (4-item overall fear scale). The total FCR score was calculated by summing all 4 items (range = 0 – 20) with higher scores indicating greater FCR.

The statistical analysis of the data was conducted with the SPSS 20 statistical software. Due to the small sample size and the not normally distributed data, non-parametric statistics were used for associations and comparisons throughout. Associations between the CARS-DVL, optimism and pessimism (dispositional and situated), demographic characteristics (age, gender, family status, education), disease-related variables (diagnosis, stage, time since diagnosis, time since latest follow-up and till next follow-up), and variables concerning support (social support, need of help), were conducted using Spearman's rank correlation coefficient (rho) or Kruskal-Wallis Tests. Within analysis of variance (Friedman Test) was conducted to compare differences of optimism and pessimism between different assessment points (T1 and T2). Bootstrapped multivariate regression was used to predict values of the dependent variable FCR (bias-corrected, 83% bootstrapping confidence intervals with 11 bootstrapping samples). Dummy coding was used for the incorporation of nominal variables.

RESULTS

Participants

All patients scheduled for cancer treatment at Sint-Trudo Hospital between October 2017 and February 2018 (T1), were screened for eligibility. Out of these patients, 46 patients met the inclusion criteria for the study. A total of 16 patients signed the consent forms and completed the initial survey, which have led to a participation rate of 35 % of all contacted patients. Eleven patients completed the follow-up survey (T2), resulting in a response rate of 24 %. Participant characteristics are shown in Table 1 for those who completed both surveys.

Participating patients (at both T1 and T2, n = 11) were compared to non-participating patients (n = 30) on age and time since diagnosis. Data of 24 non-responders were available. The average age of the non-respondents was 63.75 years (SD = 13.84). This is not significantly different from the average age of the respondents (M = 56.55 , SD = 12.09) (U = 86.50, p = .105). There was no significant difference between respondents (M = 290.27, SD = 249.51) and non-respondents (M = 215.33, SD = 85.26) regarding time since diagnosis (U = 124.00, p = .776).

Fear of Cancer Recurrence Compared with Demographic and Clinical Characteristics

Descriptive data indicated that the mean of the overall FCR score was 7.73 (SD = 5.52). Of the 11 participants, 45.5 % reported moderate FCR and 18.2 % a high to very high degree of FCR. Bivariate relationships showed that FCR was not significantly correlated with variables regarding demographic characteristics. Furthermore, most disease-related variables did not contribute to differences in FCR (see Table 3 and 4). A significant correlation was only found between FCR and the stage of cancer. Among the participating patients, there was only stage I and II. A Mann-

Whitney test indicated that patients with stage II cancer reported a significant greater fear of cancer recurrence (Mdn = 12) than patients with stage I colon/breast cancer (Mdn = 5), $U = 3.0$, $p = .042$, $A = .89$ (i.e. large effect size; Stern, 2011). Additionally, there was no significant correlation between FCR and variables regarding social support, need for psychological help concerning dealing with FCR/others difficulties, and previous psychological help (see Table 3 and 4). 27.3 % and 36.4 % of the respondents, however, reported a need for help concerning respectively dealing with FCR and other difficulties.

Fear of Cancer Recurrence Compared with Optimism and Pessimism

Means and standard deviations of dispositional as well as situated optimism and pessimism were calculated at T1 and T2 baseline to assess whether the average levels of the participants changed systematically over the follow-up period. These descriptive statistics are shown in Table 5. Friedman's Tests showed no significant difference between T1 and T2 so all measures remained stable over the follow-up period (see Table 5).

Interrelations between FCR and variables of (dispositional and situated) optimism and pessimism were examined using Spearman's rho correlations (see Table 6). Bivariate relationships showed that FCR was negatively correlated with dispositional optimism at T2 ($\rho = -.767$, $p < .01$) and situated optimism at T2 ($\rho = -.673$, $p < .05$). In contrast, situated pessimism at T1 ($\rho = .950$, $p < .001$) as well as T2 ($\rho = .655$, $p < .05$) was positively correlated with FCR. Dispositional and situated optimism at T1 as well as dispositional pessimism at T1 and T2 were not significantly associated with FCR.

Fear of Cancer Recurrence and Predictors

Multiple regression analysis was conducted to investigate if variables, measured during treatment, can significantly predict FCR after treatment. Based on scatterplots, some variables (i.e. dispositional optimism at T1 and stage of diagnosis) were withdrawn from the analysis because threats to the assumption of linearity were revealed. The simultaneous effects of dispositional and situated optimism as well as pessimism during treatment on FCR were analyzed. The value of R^2 was .88 (adjusted R^2 was .83), indicating a significant effect ($F(3,7) = 17.76$, $MS_{residual} = 5.045$, $p = .001$). The standard error of the estimate was 2.25. Only a linear correlation was found between FCR and situated pessimism during treatment, so only situated pessimism (T1) accounted for a significant amount of unique variance of FCR following higher reported situated pessimism predicted higher FCR. A strong linear correlation was found ($\beta = .968$, $p < .001$). However, the *p*-value associated with the bootstrap model was .08, which only approaches significance.

DISCUSSION

The aim of the present study was to examine the role of optimism during breast and colorectal cancer treatment in relation to fear of cancer recurrence outcome (FCR). Via a longitudinal design, it was examined if optimism during treatment remains stable as well as if it is a predictive factor concerning FCR severity after completion of curative treatment. Furthermore, an association between FCR and time since/until follow-up control as well as the role of optimism regarding the strength of this correlation, was investigated. Next to dispositional optimism as well as pessimism, the role of situated optimism and pessimism towards illness and treatment was examined concerning all hypotheses.

The findings showed support for the first hypothesis. Dispositional and situated optimism as well as dispositional and situated pessimism remained stable over the follow-up period. This is consistent with previous research demonstrating temporal stability of optimism and pessimism (Saboonchi et al., 2016). The results were not consistent with the hypothesis that dispositional and situated optimism during treatment would be significant predictors of FCR (Llewellyn et al., 2008; Starreveld et al., 2017). Although the current findings showed an association between FCR and optimism after treatment completion, dispositional and situated optimism dúring treatment were not significantly associated with FCR. Furthermore, the current study did not show a predictive, resilient value of reported optimism during treatment towards severity of FCR. The results of the present study did, however, demonstrate that fears of cancer recurrence after treatment were directly predicted by situated pessimism, i.e. pessimism towards illness and treatment. Higher scores on situated pessimism during treatment predicted higher scores on FCR after completion of curative treatment. These results may support findings of other studies indicating a bidimensional structure of optimism and pessimism (Glaesmer et al., 2012; Hinz et al., 2017; Saboonchi et al., 2016; ten Klooster et al., 2010) as well as approaching dispositional and situated optimism/pessimism as separated factors (Armor & Taylor, 1998; Benyamini & Raz, 2007; Kube et al., 2018; Thornton et al., 2012). These results need to be interpreted with caution given the lack of significance when performing the bootstrapped model. Also the small sample size and associated limitations can affect the results (see limitations).

In contrast with findings of McGinty et al. (2016), the present study didn't support the hypothesis that time since/until follow-up control would be associated with a higher score on overall FCR. Results of the present study are in accord with recent studies indicating no association between severity of FCR and time since diagnosis (Crist & Grunfeld, 2013; Koch et

al., 2013; Simard et al., 2013). However, the current sample size may be too small to gain statistical significances concerning correlations.

In the present study, 45.5 % of the patients reported moderate FCR. This is line with the research of Vickberg (2003) (45 %) and the systematic review of Simard et al. (2013) (22 – 87 %). However, the percentage of patients reporting high to very high FCR is somewhat higher in the present study (18.2 %) in comparison with Vickberg (2003) (10 %) and Simard et al. (2013) (0 – 15). In line with suggestions of the majority of the cross-sectional and longitudinal studies reviewed by Simard et al. (2013), few associations between FCR and demographic and clinical characteristics as well as social resources were found. A significant correlation was only found between FCR and the stage of cancer. Patients with stage II cancer reported a significant greater fear of cancer recurrence than patients with stage I colon/breast cancer. Due to the lack of participants with cancer stage III, the prevalence and severity of FCR could be underestimated. Future research should represent a heterogeneous sample size, for example, by involving university hospitals.

Overall, the results suggest that affected patients with worse cancer stage at diagnosis, with higher situated pessimism during (T1) and after treatment (T2), and lower dispositional and situated optimism after treatment (T2), may be at risk of FCR. Additional findings of the current study showed a significant correlation between dispositional and situated optimism at T1 and T2. This is consistent with findings of Thornton et al. (2012). In contrary, no significant correlation between dispositional and situated pessimism was found. Dispositional and situated optimism at T1 correlated significantly with respectively dispositional and situated optimism at T2. Again, for pessimism this was not the case. More research investigating FCR in relation to optimism and pessimism as separated factors, might be useful. As described above, the findings demonstrate that fears of cancer recurrence after treatment may be directly predicted by situated pessimism during treatment, i.e. pessimism towards illness and treatment. Situated pessimism at T1 was negatively correlated with dispositional and situated optimism at T2. Future research could further invest in interpreting these results as well as investigate possible mechanisms and causalities.

Study Limitations

There are a number of limitations that need to be considered. First, results would only be generalizable to former breast and colorectal cancer patients with a history of non-metastatic cancer receiving negative follow-up results. However, the generalization could be questioned since the current sample only included Belgian cancer patients treated in one hospital.

Furthermore, the small sample size is an important limitation that must be noted. Given this size, it was not possible to represent a heterogeneous sample. Also the limited response rate of only 24 % (and 35 % concerning the first questioning) contributes to the fact that the sample can't be considered representative for the whole cancer population. For example, it is possible that more distressed or pessimistic individuals would be less likely to respond, therefore the prevalence of pessimism and the possible impact of pessimism on FCR severity may be underestimated. As a result, significant findings could only be seen as trends and future research is needed to confirm these findings. In contrary, due to lack of statistical power the current study might miss significant findings, i.e. certain findings that would be significant when investigating a larger sample.

Secondly, there are remarks concerning the assessments used. Both the LOT-R and the CARS-DVL have been psychometrically tested in multiple studies, however, in the current study some adjustments and additions have been made. These versions were not empirically validated so other studies are necessary to confirm the results as well as to validate the adjusted instruments. Given the many different instruments used to assess FCR, there is no consensus on what should be considered as the gold standard measure of FCR (Simard et al., 2013). The CARS-DVL can measure multidimensional aspects of FCR. Nevertheless, cut-off scores for clinical levels of FCR are missing for this scale and are needed to support assumptions that have been made. Additionally, it must be noted that statistical qualities have only been tested for female breast cancer patients, therefore further research is needed to confirm the usefulness of the CARS-DVL in female and male colorectal patients. Due to the small sample size in the present study, only the overall FCR was measured based on the four general items. A multidimensional conceptualization, however, would give more suggestions concerning targets of clinical interventions in patients suffering from (different levels of) FCR.

Third, the longitudinal study design incorporates a relatively short follow-up period. Originally, an additional follow-up survey was planned after several months. Due to the small sample size, this survey was annulated, limiting the assessment of the stability of the measured variables over the survivorship trajectory. The study could have contributed more if it had included enough participants to conduct longitudinal research concerning FCR. Additional longitudinal research is needed to verify the stability of FCR (Simard et al., 2013).

Clinical Implications

The current study demonstrated that the majority of patients report moderate to high fear of cancer recurrence. Also, almost a third of the questioned patients in the present study did

report a need for help in dealing with FCR. Previous research indicated that one of the most prevalent reported unmet needs of cancer survivors concerns dealing with fear of cancer recurrence (Armes et al., 2009; Simard et al., 2013; Thewes et al., 2004). Despite these findings as well as the association of heightened FCR with negative consequences such as increased anxiety and more depressive symptoms (Deimling et al., 2006; Humphris et al., 2003; Skaali T et al., 2009), clinical care for cancer patients struggling with FCR is limited (Lebel, Ozakinci, Humphris, Thewes, et al., 2016). Psychosocial support by caregivers is often provided during treatment, however, mostly is no longer present at the time FCR arises. More attention towards dealing with FCR is needed.

The development and validation of short FCR screening measures that can be used in clinical settings, may be valuable (Lebel, Ozakinci, Humphris, Thewes, et al., 2016). Nevertheless, caution should be taken as measuring FCR could unintentionally induce anxiety for recurrence. Research is needed to identify and investigate risk factors that can be detected during treatment, which can predict the development of high levels of FCR. The current study highlighted the role of situated pessimism as predictor of FCR severity, which may contribute to research concerning risk factors. Based on such findings, appropriate screening tools may be developed.

Research approaching FCR as a multidimensional concept could give more suggestions concerning targets of clinical interventions in patients suffering from FCR. Several interventions, largely based on cognitive-behavioral models, are currently being tested in randomized controlled trials to reveal evidence-based guidelines on how to reduce FCR in patients with a history of cancer (Lebel, Ozakinci, Humphris, Thewes, et al., 2016). Along these lines, modifiable characteristics related to heightened FCR may help the development of interventions. Future research is needed to further test the efficacy of CBM-informed interventions in reducing FCR as well as to explore whether changes in, for example, situated pessimistic beliefs could reduce the development or maintenance of heightened FCR. Despite the general stable nature of optimism and pessimism, some researchers assumed that changes may occur due to the use of mental simulations interventions. However, there is no indication about the efficiency and long-lasting effects of these interventions (Carver & Scheier, 2014). Simultaneous changes in variables of optimism/pessimism and FCR severity should be examined, as well as mutual causalities. To date, no universal accepted theoretical accounts of FCR can guide the development of interventions neither explain which factors are causal concerning (different levels of) FCR (Fardell et al., 2016). Finally, although a considerable number of respondents of the present

study reported high FCR scores and/or a need for help in dealing with FCR, nobody contacted the psychological service of the hospital despite multiple offers to (re)start psychosocial support. Besides the need for appropriate screening and effective interventions, efforts are needed to lower the barriers towards psychosocial services. Therefore, it is important to enhance the awareness of patients and the accessibility of psychological services. Barriers to approach psychosocial care experienced by patients, should be investigated.

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APPENDICES

Appendix 1. Information of the questionnaire and informed consent. Sint-Truiden, 5 september 2017

Titel van de studie: 'Fear of cancer recurrence after breast and intestinal cancer treatment: reported optimism during treatment as stable and resilient factor?'

Opdrachtgever: KULeuven, Cédric Hèle Instituut, in samenwerking met Sint-Trudo Ziekenhuis

Onderzoeksinstelling: Sint-Trudo Ziekenhuis, Diestersteenweg 100, 3800 Sint-Truiden

Lokale onderzoekers: Michelle Vankrunkelsven (psychologe en student postacademische opleiding psych-oncologie, michelle.vankrunkelsven@stzh.be), Prof. Geert Crombez (promotor, geert.crombez@ugent.be), Sarah Hauspie (promotor, sarah.hauspie@azmmsj.be)

Comité voor Medische Ethiek: Comité Medische Ethiek Sint-Trudo Ziekenhuis, Diestersteenweg 100, 3800 Sint-Truiden

Ombudsdienst Sint-Trudo Ziekenhuis: Veerle Pien (veerle.pien@stzh.be)

Beste,

U wordt uitgenodigd om deel te nemen aan een studie in het kader van de opleiding Psycho-Oncologie via de KULeuven en het Cédric Hèle instituut. Hoewel studies aantonen dat bij de meeste vrouwen met borstkanker en personen met darmkanker de ziekte na behandeling wegblijft, blijkt uit de praktijk en uit wetenschappelijke studies dat velen zich zorgen blijven maken over het terugkomen van de kanker. Het lijkt ons zinvol om na te gaan welke patiënten zich hieromtrent het meest zorgen maken en of zij baat blijken te hebben bij ondersteuning. Om die reden willen we de ingesteldheid van patiënten tijdens en na hun behandeling bevragen. Graag vragen we jullie medewerking door het invullen van enkele vragenlijsten. Hierbij willen we jullie vragen op dit moment een eerste vragenlijst in te vullen. Binnen enkele maanden (in april en in oktober) volgen twee korte vragenlijsten. We zouden jullie deelname erg waarderen, jullie deelname kan een meerwaarde betekenen voor toekomstige patiënten.

Het invullen van de vragenlijsten zal telkens ongeveer 15 minuten in beslag nemen. Op het einde van een vragenlijst krijgt u de mogelijkheid om opmerkingen of feedback te geven, indien u dat wenst. Wanneer u op eender welk moment het gevoel hebt psychologische moeilijkheden te ervaren of u zorgen te maken, mag u contact opnemen met de psychologische dienst van het ziekenhuis. Zowel voor reeds lang bestaande zorgen, als zorgen gestart sinds deelname aan de studie, willen we ondersteuning bieden. Er zijn geen verwachte risico's bij deelname aan de bevraging. Mocht u door uw deelname toch enig nadeel ondervinden, zal u een gepaste behandeling krijgen.

De vragenlijsten worden **anoniem** verwerkt, gegevens en antwoorden worden stikt vertrouwelijk behandeld. Er zijn geen kosten verbonden aan de deelname. U kunt het antwoordformulier terugsturen in de gefrankeerde enveloppe, samen met het toestemmingsformulier (één versie mag u in uw bezit houden). Zonder **ondertekend toestemmingsformulier** kunnen de vragenlijsten niet worden gebruikt. U mag de documenten ook gewoon terug aan de onco-coach bezorgen. De deelname is vrijwillig. U kan weigeren om deel te nemen, en u kan zich op elk ogenblik terugtrekken uit de studie zonder dat u hiervoor een reden moet opgeven en zonder dat dit de relatie met de onderzoeker of de behandelende arts schaadt.

Alvast bedankt voor uw medewerking.

Met bijkomende vragen of bezorgdheden kan u op elk ogenblik contact opnemen met:
Michelle Vankrunkelsven · 0475 58 33 84 · michelle.vankrunkelsven@gmail.com
Psychologe en studente postacademische opleiding Psycho-Oncologie

Toestemmingsformulier (versie voor de deelnemer)

Ik ondergetekende…….. verklaar dat ik geïnformeerd ben over de aard, het doel, de duur, de eventuele voordelen en risico's van de studie en dat ik weet wat van mij wordt verwacht. Ik bevestig dat ik de nodige tijd heb gehad om het informatiedocument te lezen en om met een door mij gekozen persoon, zoals een familielid of mijn huisarts, te praten.

Ik weet bij wie ik terecht kan voor vragen

Ik begrijp dat mijn deelname aan deze studie vrijwillig is en dat ik vrij ben mijn deelname aan deze studie stop te zetten zonder dat dit mijn relatie schaadt met het therapeutisch team dat instaat voor mijn gezondheid.

Ik begrijp dat er tijdens mijn deelname aan deze studie gegevens over mij zullen worden verzameld en dat de onderzoeker en de opdrachtgever de vertrouwelijkheid van deze gegevens verzekeren in overeenstemming met de Belgische wetgeving ter zake.

Ik stem in met de verwerking van mijn persoonlijke gegevens volgens de modaliteiten die zijn beschreven in het informatieformulier. Ik geef ook toestemming voor eventueel overdracht naar en verwerking van mijn gecodeerde gegevens in andere landen dan België.

Ik ben bereid op vrijwillige basis deel te nemen aan deze studie.

Ik heb een exemplaar ontvangen van het 'informatieformulier' en van het 'toestemmingsformulier'.

Naam en voornaam: ……..

Datum: …….

Handtekening:

Onderzoeker

Ik ondergetekende …….. onderzoeker verklaar de nodige informatie betreffende deze studie te hebben verstrekt evenals een exemplaar van het informatiedocument aan de deelnemer te hebben overhandigd.

Ik bevestig dat geen enkele druk op de deelnemer is uitgeoefend om hem/haar te overtuigen tot deelname aan de studie en ik ben bereid om op alle eventuele bijkomende vragen te antwoorden.

Ik bevestig dat ik werk in overeenstemming met de ethische beginselen zoals vermeld in de laatste versie van de "Verklaring van Helsinki", de "Goede klinische praktijk", en de Belgische wet van 7 mei 2004 betreffende experimenten op de menselijke persoon.

Naam, voornaam: ……..

Datum: ……
Handtekening:

Toestemmingsformulier (ondertekend terug te bezorgen)

Titel van de studie: 'Fear of cancer recurrence after breast and intestinal cancer treatment: reported optimism during treatment as stable and resilient factor?'

Opdrachtgever: KULeuven, Cédric Hèle Instituut, in samenwerking met Sint-Trudo Ziekenhuis

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Ombudsdienst Sint-Trudo Ziekenhuis: Veerle Pien (veerle.pien@stzh.be)

Ik ondergetekende…….. verklaar dat ik geïnformeerd ben over de aard, het doel, de duur, de eventuele voordelen en risico's van de studie en dat ik weet wat van mij wordt verwacht. Ik bevestig dat ik de nodige tijd heb gehad om het informatiedocument te lezen en om met een door mij gekozen persoon, zoals een familielid of mijn huisarts, te praten.

Ik weet bij wie ik terecht kan voor vragen

Ik begrijp dat mijn deelname aan deze studie vrijwillig is en dat ik vrij ben mijn deelname aan deze studie stop te zetten zonder dat dit mijn relatie schaadt met het therapeutisch team dat instaat voor mijn gezondheid.

Ik begrijp dat er tijdens mijn deelname aan deze studie gegevens over mij zullen worden verzameld en dat de onderzoeker en de opdrachtgever de vertrouwelijkheid van deze gegevens verzekeren in overeenstemming met de Belgische wetgeving ter zake.

Ik stem in met de verwerking van mijn persoonlijke gegevens volgens de modaliteiten die zijn beschreven in het informatieformulier. Ik geef ook toestemming voor eventueel overdracht naar en verwerking van mijn gecodeerde gegevens in andere landen dan België.

Ik ben bereid op vrijwillige basis deel te nemen aan deze studie.

Ik heb een exemplaar ontvangen van het 'informatieformulier' en van het 'toestemmingsformulier'.

Naam en voornaam: ……..

Datum: ……

Handtekening:

Appendix 2. Questionnaires concerning demographic characteristics, optimism, and fear of cancer recurrence.

Persoonsgegevens:
Naam en voornaam:

Geboortedatum:

Datum van invulling:

LOT-R-NL
(Nederlandse vertaling van "Life Orientation Test-Revised", MF Scheier, CS Carver, & MW Bridges, 1994)

Gelieve eerlijk en zo accuraat mogelijk te zijn. Probeer uw antwoord op de ene uitspraak niet van invloed te laten zijn op uw antwoorden op de andere uitspraken. Er zijn geen juiste of foute antwoorden. Beantwoord de vragen op basis van uw eigen gevoel, in plaats van hoe u denkt dat de 'meeste personen' zouden antwoorden.
Geef door middel van een cijfer tussen 1 en 5 aan in welke mate u het eens of oneens bent met de bewering. De betekenis van de cijfers is als volgt:

1 = helemaal oneens
2 = oneens
3 = noch eens, noch oneens
4 = eens
5 = helemaal eens

1. Bij onzekerheid verwacht ik meestal het beste.

1	2	3	4	5
Helemaal oneens				Helemaal eens

2. Ik kan me gemakkelijk ontspannen.

1	2	3	4	5
Helemaal oneens				Helemaal eens

3. Als er iets mis met mij kan gaan, zal dit ook gebeuren.

1	2	3	4	5
Helemaal oneens				Helemaal eens

4. Ik ben altijd optimistisch over mijn toekomst.

1	2	3	4	5
Helemaal oneens				Helemaal eens

5. Ik beleef plezier met mijn vrienden.

1	2	3	4	5
Helemaal oneens				Helemaal eens

6. Het is belangrijk voor mij dat ik bezig blijf.

1	2	3	4	5
Helemaal oneens				Helemaal eens

7. Ik verwacht bijna nooit dat de dingen in mijn voordeel zullen uitdraaien.

1	2	3	4	5
Helemaal oneens				Helemaal eens

8. Ik ben niet zo gemakkelijk van mijn stuk te brengen.

1	2	3	4	5
Helemaal oneens				Helemaal eens

9. Ik verwacht zelden dat mij goede dingen overkomen.

1	2	3	4	5
Helemaal oneens				Helemaal eens

10. In het algemeen verwacht ik dat mij meer goede dan slechte dingen zullen overkomen.

1	2	3	4	5
Helemaal oneens				Helemaal eens

Bijkomende vragen:

11. Ik verwacht(te) goede resultaten van de behandeling die ik onderga(/onderging).

1	2	3	4	5
Helemaal oneens				Helemaal eens

12. Bij het vernemen van mijn ziekte, had ik de neiging om te denken aan een slechte afloop.

1	2	3	4	5
Helemaal oneens				Helemaal eens

13. De steun van familieleden en/of vrienden helpt mij om positief ingesteld te zijn ten aanzien van mijn ziekte en behandeling.

1	2	3	4	5
Helemaal oneens				Helemaal eens

14. Ik verwacht(te) dat de behandeling bij mij minder goed zal(/zou) aanslaan dan verwacht zou worden.

1	2	3	4	5
Helemaal oneens				Helemaal eens

15. Ook bij de confrontatie met mijn ziekte, probeer ik uit te gaan van een goede afloop.

1	2	3	4	5
Helemaal oneens				Helemaal eens

Hartelijk dank voor uw medewerking

Met bijkomende vragen of bezorgdheden, kan u op elk ogenblik contact opnemen met:
Michelle Vankrunkelsven, 0475 58 33 84.
Wanneer u het gevoel hebt psychologische moeilijkheden te ervaren, mag u contact opnemen met de psychologische dienst van het ziekenhuis, 011 69 93 25.

Persoonsgegevens:

Naam en voornaam:

Geboortedatum:

Datum van invulling:

Wanneer was de laatste controle-afspraak i.k.v. uw kanker? . . / . . / . . . .

Wanneer is uw volgende controle-afspraak gepland? . . / . . / . . . .

Zorgen over het terugkomen van de kanker*

(Nederlandse vertaling van "The Concerns about Recurrence Scale", SM Johnson Vickberg, 2002; *aangepaste versie)

Met de volgende vragen verzoeken wij u aan te geven of u wel eens bezorgd bent dat de kanker terugkomt. Onder terugkomen bedoelen we dat de kanker terug komt op dezelfde plaats of op een andere plaats in het lichaam.

Alhoewel de meeste personen bij wie borst-, colon-, of rectumkanker in een vroeg stadium is ontdekt nooit meer een probleem met kanker zullen krijgen, weten we dat velen zich toch zorgen maken over het terugkomen van de kanker. Er zullen ook personen zijn die zich helemaal geen zorgen maken. Hoe dan ook, uw antwoorden op de volgende vragen zijn voor ons erg belangrijk. We begrijpen dat u van streek kan raken door te denken aan of antwoord te geven op vragen over de mogelijkheid van het terugkomen van de kanker. We hebben uw hulp echter nodig om te begrijpen hoe personen denken over deze mogelijkheid.

Wij vragen u bij de volgende 4 vragen het nummer te omcirkelen welke het beste aansluit bij uw gevoel. Bijvoorbeeld, bij de eerste vraag moet u "1" omcirkelen wanneer u nooit denkt aan de mogelijkheid van het terugkomen van de kanker. Omcirkel een "6" wanneer u constant denkt aan het terugkomen van de kanker, of omcirkel "2 ", "3", "4" of "5" als de tijd dat u hieraan denkt hier ergens tussenin zit.

1. Hoe vaak denkt u aan de mogelijkheid dat de kanker terug kan komen?

1	2	3	4	5	6
Ik denk er helemaal niet aan					Ik denk er de hele tijd aan

2. Hoe erg maakt de mogelijkheid dat de kanker kan terugkomen u van streek?

1	2	3	4	5	6
Ik raak er erg van streek door				helemaal niet van streek door	Ik raak er heel door

3. Hoe vaak maakt u zich zorgen over de mogelijkheid dat de kanker terug zal komen?

1	2	3	4	5	6
Ik maak mij					Ik maak mij

helemaal geen zorgen zorgen de hele tijd

4. Hoe bang bent u dat de kanker terug zal komen?

1	2	3	4	5	6
Ik ben helemaal niet bang					Ik ben ontzettend bang

Wij zijn nu geïnteresseerd in uw zorgen ten aanzien van een mogelijke terugkeer van de kanker. Wanneer u denkt aan een mogelijke terugkeer van de kanker, waar maakt u zich dan het meest zorgen over?

Alhoewel elk van de volgende beweringen het gevolg zouden kunnen zijn van het terugkomen van de kanker, willen wij specifiek weten of u zich nu hierover ook echt zorgen maakt. U zou bijvoorbeeld kunnen geloven dat wanneer de kanker terug zou komen een (nieuwe) operatie nodig is. Wij willen graag weten of u zich ook echt zorgen maakt over deze mogelijkheid.

Omcirkel bij de volgende vragen alstublieft het cijfer dat aangeeft hoeveel zorgen u zich maakt over de achtereenvolgende beweringen. Wanneer u zich geen zorgen maakt of wanneer u denkt dat een bewering niet op u van toepassing is kunt u een "0" omcirkelen voor "helemaal niet".

0= helemaal niet
1= een klein beetje
2= matig
3= veel
4= ontzettend veel

Ik maak me zorgen dat het terugkomen van de kanker:

5. mij emotioneel van streek zou maken.	0	1	2	3	4
6. mij zou afhouden van dingen die ik van plan was te doen.	0	1	2	3	4
7. mijn lichamelijke gezondheid zou bedreigen.	0	1	2	3	4
8. mij minder vrouw/man zou doen voelen.	0	1	2	3	4
9. chemotherapie nodig zou maken.	0	1	2	3	4
10. nadelig zou zijn voor mijn relaties met vrienden en familie.	0	1	2	3	4
11. mij het gevoel zou geven dat ik geen controle meer heb over mijn leven.	0	1	2	3	4
12. mijn identiteit zou bedreigen (hoe ik mijzelf zie).	0	1	2	3	4
13. in zou grijpen op mijn lichamelijk vermogen tot het uitvoeren van dagelijkse bezigheden.	0	1	2	3	4
14. mijn leven zou bedreigen.	0	1	2	3	4
15. mijn zelfvertrouwen zou beschadigen.	0	1	2	3	4

16. ernstiger zou zijn dan de eerste keer.	0	1	2	3	4
17. financiële problemen voor mij zou veroorzaken.	0	1	2	3	4
18. in zou grijpen op mijn gevoel van seksualiteit.	0	1	2	3	4
19. bestraling nodig zou maken.	0	1	2	3	4
20. mij pijn en lijden zou brengen.	0	1	2	3	4
21. zou betekenen dat ik mijn borst(en) verlies / dat een stoma moet geplaatst worden.	0	1	2	3	4
22. in zou grijpen in mijn vermogen plannen te maken voor de toekomst.	0	1	2	3	4
23. mijn spiritualiteit of geloofsovertuiging zou bedreigen.	0	1	2	3	4
24. mij ervan zou weerhouden belangrijke rollen te vervullen (op mijn werk of thuis)	0	1	2	3	4
25. er voor zou zorgen dat ik mij minder vrouwelijk /mannelijk zou voelen.	0	1	2	3	4
26. een (nieuwe) operatie nodig zou maken.	0	1	2	3	4
27. de oorzaak van mijn overlijden zou zijn.	0	1	2	3	4
28. mijn romantische relaties zou beschadigen.	0	1	2	3	4
29. mij er van zou weerhouden om mijn verantwoordelijkheden na te komen (op mijn werk of thuis).	0	1	2	3	4
30. mij een naar gevoel zou geven over hoe mijn lichaam eruit ziet of voelt.	0	1	2	3	4

Bijkomende vragen:

Hebt u het gevoel nood te hebben aan ondersteuning

- bij het omgaan met angst voor herval Ja Nee
- bij het omgaan met andere moeilijkheden Ja Nee

Bent u reeds in begeleiding bij een psycholoog (geweest)? Ja Nee

Geeft u graag feedback of opmerkingen:

Wanneer u het gevoel hebt psychologisch moeilijkheden te ervaren, mag u steeds contact opnemen met de psychologische dienst van het ziekenhuis. Zowel voor zorgen gestart sinds de deelname aan het onderzoek, als reeds lang bestaande zorgen, willen we ondersteuning bieden.
011 69 93 25 - psychologen@stzh.be

Bedankt voor uw medewerking.

Appendix 3. Tables.

Table 1. Demographic characteristics of responders (completed both surveys, n = 11).

Age	Mean (SD)	56.55 (12.09)
	Range	28-69
		Total *n* (%)
Gender		
	Male	2 (18.2)
	Female	9 (81.8)
Marital status		
	Unmarried	2 (18.2)
	Married	6 (54.5)
	Divorced	1 (9.1)
	Separated	0
	Widow	2 (18.2)
Partner		
	Yes, and live together	7 (63.6)
	Yes, but live elsewhere	1 (9.1)
	No	3 (27.3)
Children		
	Yes, and live with me	3 (27.3)
	Yes, but live elsewhere	6 (54.5)
	No	2 (18.2)
Education		
	No	0
	Primary education	0
	Secondary education	1 (9.1)
	Higher sec. education	6 (54.5)
	Higher non-university	4 (36.4)
	University	0
	Post-university	0

Table 2. Disease-related characteristics of responders (completed both surveys, n = 11).

	Mean (SD)
Time since diagnosis	236 days (109.42)
Time since follow-up	44 days (34.25)
Time till follow-up	60 days (61.40)

		Total *n* (%)
Diagnosis		
	Breast	7 (63.6)
	Colon	4 (36.4)
	Rectum	0
Stage		
	Stadium 0	0
	Stadium I	7 (63.6)
	Stadium II	4 (36.4)
	Stadium III	0
Surgery		
	No	0
	Yes	11 (100)
Chemotherapy		
	No	6 (54.5)
	Yes	5 (45.5)
Radiotherapy		
	No	6 (54.5)
	Yes	5 (45.5)
Hormonal Therapy		
	No	8 (72.7)
	Yes	3 (27.3)
Multiple treatment		
	No	4 (36.4)
	Yes	7 (63.6)

Tabel 3. Correlations between FCR (CARS-DVL) and demographic and disease-related variables : descriptive sand Spearman correlation coefficients.

	n	M	SD	ρ
Age	11	56.55	12.09	- 0.32
Education	11	3.27	0.65	- 0.20
Social support T1/T2	11/11	3.27/3.55	0.79/0.69	0.635/0.409
Stage diagnosis	11	1.36	0.51	0.657*
Time since diagnosis	11	236 days	109.42	-0.159
Time since follow-up	7	44 days	34.25	-0.036
Time till follow-up	10	60 days	61.40	0.122

**p = .05.*

Tabel 4. Associations between FCR (CARS-DVL) and demographic and disease-related variables : Kruskal-Wallis Tests.

	n	df	Chi-square	*p*[ab]
Gender	11	1	0.889	0.436
Marital status	11	3	0.955	0.879
Partner	11	2	1.662	0.527
Children	11	2	2.909	0.253
Need for help FCR/other	10/10	1/1	0.636/0.409	0.517/0.610
Psychological help	11	1	0.500	0.582
Surgery[c]	11			
Chemotherapy	11	1	0.133	0.792
Radiotherapy	11	1	0.000	1.000
Hormonal therapy	11	1	0.167	0.776

Note. There were no significant results.
[a]There are a few nonparametric effect size estimates, but they are not well-known and they are not available in the typical statistical software package.
[b]Exact Sig. [2*(1-tailed Sig.)].
[c]There is only one group so Kruskal-Wallis Test cannot be performed. All patients have undergone surgery.

Tabel 5. Temporal stability of variables optimism and pessimism (dispositional and situated) : Friedman's Tests.

	Mdn (range)	*n*	df	Chi-square	*p*[a]
Dispositional optimism		11	1	0.111	0.739
T1	6.00 (3 - 12)	11			
T2	6.82 (4- - 12)	11			
Disp. pessimism		11	1	0.143	0.705
T1	6.00 (0 - 7)	11			
T2	4.00 (0 - 9)	11			
Situated optimism		11	1	0.200	0.655
T1	6.00 (3 – 8)	11			
T2	6.00 (3 - 6)	11			
Situated pessimism		11	1	0.143	0.705
T1	3.00 (0 – 6)	11			
T2	4.00 (0 – 6)	11			

Note. There were no significant results.
[a]There are a few nonparametric effect size estimates, but they are not well-known and they are not available in the typical statistical software package.
[b]Asymp. Sig.

Tabel 6. Correlations between FCR and variables of (dispositional and situated) optimism and pessimism : Spearman correlation coefficients (*n* = 11).

	Disp opt T1	Disp pes T1	Sit opt T1	St pes T1	Dis opt T2	Dis pes T2	Sit opt T2	Sit pes T2
Overall fear	-0.100	0.285	-0.414	**0.950****	**-0.767****	0.440	**-0.673***	**0.655***
Disp opt T1	1	-0.413	0.634*	-0.203	0.646*	0.017	0.443	0.137
Disp pes T1		1	-0.099	0.205	-0.489	0.202	-0.126	0.160
Sit opt T1			1	-0.457	0.641*	-0.152	**0.908****	-0.041
Sit pes T1				1	**-0.816****	0.490	-0.670*	0.584
Dis opt T2					1	-0.350	0.696*	-0.512
Dis pes T2						1	-0.292	-0.146
Sit opt T2							1	-0.317
Sit pes T2								1

Note. Dis = dispositional, Sit = situated, opt = optimism, pes = pessimism
**p* = .05. ***p* = .01.