# Fear of Cancer Recurrence and need for psychological support among Dutch breast cancer survivors: prevalence and associated factors

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#### Abstract

**Background**: Fear of cancer recurrence (FCR) is a prevalent concern among women who have been diagnosed with breast cancer, and it negatively impacts their psychological well-being and quality of life and increases healthcare utilisation. Despite its significance, a substantial number of women with high FCR do not receive adequate psychological support. This study explores the relationship between FCR and the need for psychological support while considering factors such as coping styles, social support, and perceived risk of recurrence.

**Aim:** To investigate the level of FCR in breast cancer patients one year after treatment and to explore the predictors of FCR, including illness-related variables and demographics, risk perceptions, and coping styles. Additionally, to determine the number of patients needing psychological help, identify the predictors of this need, such as illness-related variables and demographics, FCR, perceived overall health, social network/support, and coping styles.

**Methods**: This cross-sectional study utilised baseline data from the NABOR study, which included women aged 30 or older who had been curatively treated for non-metastasised primary breast cancer. The study assessed FCR using the Cancer Worry Scale (CWS), coping styles with the Mental Adjustment to Cancer (MAC) scale, social networks using the Lubben Social Network Scale (LSNS), and the need for psychological support. Risk perceptions and perceived overall health were also evaluated. To answer research questions, we utilised descriptive statistics, correlation analysis between variables, and linear regression to identify predictors of FCR and the need for psychological support.

**Results**: This study found a high prevalence of FCR (36.6 %) in women with breast cancer, with younger age, poor psychological adjustment, heightened perceived risk and lower perceived overall health worsening FCR. Some women (3.6%) needing psychological support do not receive it, while a significant number of those offered (58%) help decline. Additionally, increased FCR, younger age, and lower perceived overall health increase participants' need for support.

**Conclusion**: This study enhanced our understanding of the relationship between fear of cancer recurrence (FCR) and the psychological support needs of breast cancer survivors. The findings indicated a high prevalence of FCR and identified relevant predictors. Furthermore, the study highlighted the significance of psychological support and provided insights into the factors influencing the need for such support. These findings emphasise the necessity of a personalised care approach to assist survivors in managing their fears and improving their overall well-being.

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## 1. Introduction

Breast cancer is a common disease among women. While survival rates have improved, survivors often face various unmet needs, particularly the fear of cancer recurrence (FCR), which has been widely studied. Breast cancer is the most common cancer type among women globally, with almost two million cases in 2018 (Nardin et al., 2020). Breast cancer prognosis has improved significantly over time thanks to early diagnosis and innovative treatments. Consequently, survival rates have increased over time and reached a range of 90% (5-year) and 80% (10-year), respectively (Nardin et al., 2020). Cancer survivors experience various unmet supportive care needs, deteriorating their quality of life (Fan et al., 2023). Fear of cancer recurrence (FCR) emerges among the most common unmet supportive needs among female breast cancer survivors (Fan et al., 2023). FCR is characterised by the fear or worry that cancer could return or progress in the same place or another part of the body (Lebel et al., 2016; Luigjes-Huizer et al., 2022).

FCR is a common and distressing psychological challenge for breast cancer survivors, found to be associated with various demographic, clinical, and psychosocial factors, including age, treatment type, coping mechanisms, mental health, and social support. Numerous studies have shown that approximately one in two breast cancer survivors experiences clinical FCR, with rates of 52% in the USA (Befort & Klemp, 2011), 60.6% in Thailand (Chumdaeng et al., 2020), 54.8% in Denmark (Ellegaard et al., 2017) and 67.5% in China (Yu Z Sun D, 2022). A younger age was one of the most consistently identified factors associated with higher FCR (Crist & Grunfeld, 2013). Conversely, a weak association has been found between FCR and education (Costanzo et al., 2007; Crist & Grunfeld, 2013; Oztas et al., 2022). In terms of clinical factors, higher FCR has been found to be associated with chemotherapy (Humphris et al., 2018; Mehnert et al., 2009), although this link has not been substantiated by other studies in the literature (Crist & Grunfeld, 2013). Being treated with chemotherapy and having low confidence in treatment were associated with dysfunctional FCR five to six years post-diagnosis in long-term breast cancer survivors, as reported in (Heidkamp et al., 2021). Similarly, a weak relation between cancer stage and FCR was found in the literature, as reported by (McGinty et al., 2012; Rabin et al., 2004). When it comes to psychosocial factors, coping styles were found to be associated with higher FCR. Research revealed an association between coping styles and FCR in breast cancer survivors. Maladaptive metacognition and negative coping styles positively correlate with FCR, whereas adaptive metacognition and positive coping styles negatively correlate with FCR among postmastectomy patients, as reported by (H. Zhang et al., 2023). Survivors employing positive coping strategies seek medical support, suggesting that trust in professionals aids in managing FCR (X. Zhang et al., 2022). Overall, coping orientation significantly influences FCR in survivors (Oztas et al., 2022). High baseline anxiety, depression, and life stress were predictors of higher FCR levels in studies by (Walburg et al., 2019) and (Yang et al., 2023). Less optimistic survivors reported higher FCR, as noted by (Starreveld et al., 2018). Research suggests a link between heightened risk perceptions and Fear of Cancer Recurrence (FCR). Overestimating the risk of recurrence increases FCR (Ankersmid et al., 2022; Humphris et al., 2018), while FCR was found to significantly positively correlate with risk estimations (Ankersmid et al., 2022). It was discovered by (McGinty et al., 2012) that high threat appraisal and low coping appraisal predict greater FCR. In their systematic review, (Lu et al., 2023) analysed eleven studies on the relationship between social support and FCR among Chinese breast cancer survivors. Each study included in the analysis reported that social support significantly reduced the risk of FCR, demonstrating a moderate negative correlation. Additionally, (Sawma T, 2022) concluded that the quality of communication within families was associated with a reduced FCR.

Longitudinal studies have shown that FCR is not static; it varies over time and follows various trajectories among breast cancer survivors. Several longitudinal studies have explored how FCR changes during the cancer care trajectory. For instance, (Yang et al., 2023) revealed three types of FCR trajectories (high level-decreasing – 18%, intermediate level-stable – 64% and low level-increasing – 18%) among Chinese women treated for breast cancer throughout the 18-month period after discharge. Similarly, (Schapira et al., 2022) identified five distinct FCR trajectories in young breast cancer survivors diagnosed at age 40 or younger. Most had moderate or high FCR that improved over time, but a significant subset (21.7%) maintained high FCR throughout the study period. Younger breast cancer survivors were more likely to experience fluctuating or consistently high FCR levels over a one-year monthly assessment, as reported in (J. A. Custers et al., 2020).

High FCR is consistently associated with increased healthcare utilisation, such as more frequent consultations and emergency room visits, which leads to higher healthcare costs. Elevated FCR consistently correlates with increased healthcare utilisation for reassurance purposes, including additional consultations with medical professionals, ultimately raising healthcare costs, as shown by (Carlson & Bultz, 2003; Van Beek et al., 2021), and confirmed by the systematic review of (Williams et al., 2021). Similarly, (Lebel et al., 2013) observed that higher FCR significantly predicted a higher number of emergency room visits in the past six months among cancer survivors. In addition, (Champagne et al., 2018) found that clinical levels of FCR were associated with higher consultation rates with medical and psychosocial professionals, as well as increased use of anxiolytics, hypnotics, and antidepressants among cancer patients. In their study, (Vachon

et al., 2021) revealed that younger breast cancer survivors are at higher risk of over-utilisation of healthcare services.

Despite its prevalence and significant impact on quality of life and healthcare utilisation, many women experiencing elevated FCR do not receive the necessary psychological support. Unmet supportive care needs are prevalent among breast cancer survivors, with FCR being one of the most common concerns (Ellegaard et al., 2017; Fan et al., 2023; Lebel et al., 2014; Lisy et al., 2019; Miroševič et al., 2019). Studies have found that up to 74% of breast cancer survivors experience unmet needs related to social support, daily activities, sexual/intimacy issues, and fear of cancer recurrence (Fan et al., 2023). Studies reveal a concerning trend; while FCR was associated with increased visits to both oncology and primary care providers, it did not significantly predict the use of mental health treatment, as reported by (Otto et al., 2018). In their study, (Luigjes-Huizer et al., 2022) revealed that 40% of cancer patients who experienced FCR, indicated a need for mental support. However, FCR was not associated with the utilisation of psychosocial services among Chinese cancer survivors, as reported by (Li & Cheng, 2021), indicating a significant gap between the need for and the uptake of psychological support. While numerous studies have identified various demographic, clinical and psychosocial factors associated with FCR levels, their simultaneous influence on expressed need for and the uptake of psychological support need further clarification.

There may be various reasons why women with high FCR do not seek psychological care. One reason is that they may have sufficient support in their social network. Higher levels of social support have been associated with lower levels of FCR, suggesting a protective effect (Manning-Walsh, 2005). Conversely, women who experience more FCR may have a heightened need for social support, emphasising the importance of strong social networks in managing FCR (Bloom et al., 2001). Additionally, social support was identified as one of the top unmet supportive care needs among breast cancer survivors, indicating that even those with social networks may require additional support (Fan et al., 2023).

Another reason for not seeking psychological support may be attributed to maladaptive coping styles. Coping styles significantly influence the experience of FCR (Luigies-Huizer et al., 2022). Conversely, adaptive coping mechanisms, such as a fighting spirit, are associated with lower levels of FCR and greater utilisation of support services (Watson et al., 1990). In contrast, maladaptive coping styles, like helplessness or avoidance, are linked to higher FCR levels and less engagement with available support (Greer et al., 1979; Stanton et al., 2002).

Moreover, the lack of adequate information and communication with healthcare providers

contributes to the persistence of unmet needs and FCR. Breast cancer survivors have expressed

a strong need for ongoing dialogue with healthcare providers, understandable and up-to-date

information, and reassurance that they are receiving the best medical care (Ellegaard et al., 2017;

Kim et al., 2020). The need for a constructive relationship with healthcare providers was

emphasised as a means to empower survivors and facilitate effective self-management (Kim et

al., 2020).

Improvements in breast cancer treatments have led to improved survival rates but have also led

to more significant psychological challenges for survivors, with FCR as one of the most common

challenges. Elevated FCR is linked to an increased demand for supportive care. The existing

literature extensively studies factors influencing FCR. However, there remains a significant gap in

understanding the relationship between FCR and the need for psychological support. Little is

known about how various demographic, clinical and psychosocial factors interact with FCR levels

to determine a survivor's need for psychological help. Understanding these complex relationships

is crucial in identifying breast cancer survivors who need mental health support, but are less likely

to seek help. This study addresses that gap by examining the predictors of FCR and the need for

psychological assistance. Additionally, it aims to highlight the importance of a personalised care

approach for breast cancer survivors, thereby improving their overall well-being.

Research Objectives 1.1.

This study will focus on analysing the available data to answer the following research questions.

RQ1: How high is FCR in breast cancer patients one year after treatment, and to what extent can

FCR be predicted by:

RQ1a: Illness-related variables and demographics

**RQ1b**: Risk perceptions (absolute, appraisal and relative)

**RQ1c**: Coping styles (fighting spirit and helplessness/hopelessness)

RQ2: How many patients (in total and of those with high FCR) expressed a need for psychological

help, and to what extent is this need predicted by:

**RQ2a**: Illness-related variables and demographics

**RQ2b**: Fear of cancer recurrence (FCR)

**RQ2c**: Coping styles (fighting spirit and helplessness/hopelessness)

RQ2d: Social network/social support

**RQ2e**: Reported overall health

## 2. Methods

## 2.1. Design

A study design using a cross-sectional approach was employed. The utilised data is a subset of a more extensive study called NABOR, which aims to assess the (cost-)effectiveness of personalised surveillance (PSP) and personalised aftercare plans (PAP) concerning patient-reported cancer worry, self-rated quality of life, overall quality of life, and (cost-)effectiveness (Klaassen-Dekker et al., 2023). We utilised the baseline data for the current study, which were gathered through questionnaires, sent at about 1 year after initial treatment.

## 2.2. Participants & Procedures

The NABOR study population included all new female patients who have been curatively treated for non-metastasized primary breast cancer and have begun follow-up care. Candidates had to meet the following inclusion criteria: 1) be female, 2) be 40 years or older due to a higher recurrence risk, 3) be making decisions regarding post-treatment surveillance and after-care organisation, 4) have undergone curative treatment, including breast surgery, for invasive nonmetastasized breast cancer, and 5) be proficient in understanding spoken and written Dutch. Exclusion criteria are as follows: 1) having bilateral breast cancers, 2) being a BRCA1/2 or CHEK2 carrier, 3) needing an MRI, and 4) participating in another study requiring fixed scheduled followup appointments and/or imaging (Klaassen-Dekker et al., 2023) . Patients meeting the inclusion criteria and returning to the hospital for follow-up consultations approximately one year after their initial post-treatment imaging were invited by their healthcare provider. During this consultation, patients received information and were asked to participate in the study. Patients were asked to return a signed informed consent form. If they did not return the form within two weeks, their healthcare provider contacted them to inquire whether they wished to participate and sign the informed consent. After signing the informed consent, patients received an online questionnaire three weeks following their follow-up consultation. A paper version of the questionnaire was available upon request. Automatic reminders were sent after two and four weeks. If patients still had not completed the questionnaire, a paper version was sent to them via postal mail. At the time the dataset was created, a total of 529 patients had given their consent. The estimated time to complete the questionnaire was approximately 45 minutes.

#### 2.3. Materials

This study's main focus was on the fear of cancer recurrence (FCR) and the need and fulfilment of the need for psychological support. These two variables were analysed in relation to other measured variables, namely age, education, cancer stage, chemotherapy, risk perceptions, social support, perceived overall health and coping styles. These data were integrated with another dataset from the Netherlands Cancer Registry (NCR), comprising illness-related and demographic information for each participant.

#### 2.3.1. Demographic and illness related variables

Demographic and illness related variables were obtained from the NCR-registry ?? (or In this study, we collected demographic variables, including age and education. Age was defined as a continuous variable, while we defined education levels as low, medium, and high. We also utilised illness-related variables, including cancer stage and chemotherapy. We defined two categories for the cancer stage: below or equal to stage 2 and above stage 2. Chemotherapy was defined as a binary variable, capturing whether a participant received chemotherapy (yes/no). We also measured the overall self-reported health on the visual analogue scale between 0 and 100.

#### 2.3.2. Fear of Cancer Recurrence

Fear of cancer recurrence (FCR) was measured by the 6-item Cancer Worry Scale (CWS) (J. A. E. Custers et al., 2014), a psychometric tool developed to measure one's level of worry or anxiety about developing cancer. The CWS scale's items cover the intensity of worry and how it affects one's daily life and mood. Each item is rated on a 4-point Likert scale, describing how often a person worries, ranging between 'Not at all or rarely' (scored as 1) to 'Almost all the time' (scored as 4). FCR score is computed by summing scores on individual items. Hence, the FCR score ranges between 6 and 24. If a person scores FCR higher than 13, they are considered to experience severe levels of fear of recurrence (J. A. E. Custers et al., 2014). In the current study, Cronbach's alpha for the CWS scale was 0.90, indicating excellent internal consistency.

#### 2.3.4. Need for psychological support and fulfilment of that need

In this study, the need for psychological support and fulfilment of this need was measured with an item from the Need for Support for Cancer Worry (Luigjes-Huizer et al., 2022). A complete list of questions on this scale is provided in Appendix A. The used item captures the answer to the question: "Please indicate whether you have received this support: Reference to (online) psychologist". Women selected one of the following answers:

- (1) No, I didn't need that either
- (2) No, but I did need that
- (3) Yes, it was offered, but I didn't use it
- (4) Yes, but it didn't help me much
- (5) Yes, and it did help me

The variable capturing the need for psychological support reflects both whether women in the study were offered support and whether they accepted it and found it helpful. We derived two additional variables from the original variable. The first new variable, 'needed psychological help' with 2 values: yes (options 2, 4 and 5) and no (options 1 and 3). The second new variable, 'fulfilled need for psychological help' was applied only to those women who were offered psychological help and received it, with 2 values: yes (option 4) and no (option 5).

#### 2.3.2. Coping Style

Coping style was measured with the Mental Adjustment to Cancer (MAC) scale (Braeken et al., 2010), a self-report measure designed to assess psychological adjustment to cancer. It consists of 22 items<sup>1</sup>, each rated on a 4-point Likert scale ranging from 'definitely does not apply to me' (1) to 'definitely applies to me' (4). The MAC contains 5 subscales of which only two were used for the study: fighting spirit (16 items) and helplessness/hopelessness (6 Items). The Fighting Spirit (FS) subscale measures positive coping strategies, such as active coping, positive reinterpretation, and seeking social support. Higher scores on this subscale indicate better psychological adjustment. The total score range for the FS subscale is 16 to 64, with a cut-off score of 47. A score below 47 suggests a poorer psychological adjustment (Braeken et al., 2010). The Helplessness/Hopelessness (HH) subscale measures negative coping strategies, such as avoidance, denial, and rumination. The total HH subscale score range is 6-24, with higher scores indicating poorer psychological adjustment. A score above 11 on the HH subscale suggests a poor psychological adjustment (Braeken et al., 2010)The Cronbach alphas in the current study for FS and HH were 0.77 and 0.80, respectively, indicating good internal consistency.

#### 2.3.3. Social Network

Study participants' social network was measured with the Lubben Social Network Scale (LSNS) (Lubben et al., 2006), a concise self-report measure developed to assess the size of social networks and perceived social support. It includes three items, each evaluating a different aspect of social relationships: 'How many family members or friends do you see or speak to at least once a month?', 'How many relatives or friends do you feel close enough to call on for help?' and 'How many relatives or friends do you feel comfortable discussing private matters with?'. Each item is rated on a 6-point Likert scale, ranging from 'None' (0) to 'nine or more' (5). The total score on the LSNS ranges from 0 to 15, with higher scores indicating a more extensive and supportive social network. In the current study, the internal consistency of the LSNS scale was good, with a

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<sup>&</sup>lt;sup>1</sup> In this study, women filled in items regarding only FS and HH subscales, while MAC scale contains more subscales.

Cronbach's alpha of 0.81. A score of less than 6 on the LSNS is commonly regarded as a clinical cut-off point, signalling a smaller and less supportive social network (Lubben et al., 2006).

#### 2.3.5. Risk perceptions

Our study used a custom-made, 3-item scale to measure women's perceptions of cancer recurrence (Hackert et al., 2022). The items measured **risk perception** (expressed as a percentage, with answering options ranging from 'less than 1%' (1) to 'more than 30%' (9)), **risk appreciation** (expressed qualitatively, from 'very low' (1) to 'very high' (5)), and **relative risk perception** (expressed as risk compared to other women, ranging from 'much lower' (1) to 'much higher' (5)). Among all variables, higher scores indicate higher perceived risk. In this study, we treat these items as separate variables.

#### 2.4. Data analysis

The obtained data was first imported into STATA software, for analysis. Descriptive statistics were then computed for each variable used in this study, providing insight into their main tendencies. Next, a correlation between demographics, clinical and psychosocial factors and FCR was assessed. Next, a linear regression analysis was conducted to investigate which variables might predict the fear of cancer recurrence (FCR) among the women in the study. Univariate correlation was applied to identify factors associated with the need for psychological support. Finally, logistic regression was applied to identify predictors of a study participant needing psychological help, as well as factors of finding received psychological support helpful.

## 3. Results

## 3.1. Description of the study group

Table 3.1 presents the demographic and clinical characteristics of the study participants. A comparable proportion of participants were aged between 50-64 (39%) and 65-74 (35%), while a notably lower percentage were either younger than 49 or older than 74. In terms of education, nearly half of the women in the study had completed higher education, whereas only 12% had completed only lower education. While 21 women from the study were diagnosed with breast cancer at a stage higher than two, around two in three women received chemotherapy.

Table 3.1

Demographic and Clinical Characteristics of Participants (N=511)

Variable	Category	N (%)
	Below 49 years	70 (13.21)
Ago	50-64 years	210 (39.62)
Age	65-74 years	190 (35.85)
	75 and above	60 (11.32)
	Lower	58 (12.58)
Education	Medium	185 (40.13)
	Higher	218 (47.29)
Concer store	<= 2	488 (95.87)
Cancer stage	>2	21 (4.13)
Chemotherapy	Yes	360 (67.92)
Опотновнегару	No	170 (32.08)
Overall health perception (0-100 scale)		78.5 (14.9)

*Note.* Unless otherwise indicated, values in the third column represent N(%). For general health, the value represents the Mean (Standard Deviation).

Table 3.2 presents descriptive statistics for the psychosocial variables examined in this study. Approximately one in ten women reported experiencing poorer psychological adjustment. Only three percent of participants indicated a lack of adequate social support. Furthermore, the women in the study perceived their overall health as relatively good, scoring 78 out of 100.

**Table 3.2**Descriptive Statistics of Psychosocial Variables Used in This Study

Variable name	N	Mean	SD
Fighting spirit	460	48.5	6.1
below cut-off score (179, 38.9 %)			
Hopelessness / Helplessness	469	8.1	2.5
above cut-off score (54, 11.5 %)			
Social network	469	11.6	2.6
below cut-off score (15, 3.2 %)			

Note. SD = Standard Deviation.

Score distribution of risk variables are depicted on Table 3.3. The majority of women considered their risk for breast cancer recurrence as relatively low, and approximately 12% reported a risk exceeding 30%.

Table 3.3

Distribution of Risk Appreciation, Relative Risk and Absolute Risk Perception Scores

Variable name	Response	N (%)
	Very low	79 (16.8)
	Low	129 (27.5)
Risk appreciation	Not low/not high	199 (42.4)
	High	51 (10.9)
	Very high	11 (2.3)
	Much lower	28 (6.0)
	Lower	83 (17.7)
Risk relative	The same	282 (60.1)
	Higher	69 (14.7)
	Much higher	7 (1.5)
	less than 1%	61 (13.0)
	1 - 2%	39 (8.3)
	2 - 5%	63 (13.5)
	5 - 10%	78 (16.7)
Risk perception	10 - 15%	57 (12.2)
	15 - 20%	48 (10.3)
	20 - 25%	32 (6.8)
	25 - 30%	31 (6.6)
	more than 30%	59 (12.6)

#### 3.1. Fear of Cancer Recurrence and associated factors

Approximately a third (36.6%) of women reported experiencing elevated FCR, averaging a score of 12.3 (+/-3.8), suggesting that breast cancer survivors experience significant fear even a year post-treatment. Table 3.4 displays the correlation matrix between FCR and demographics, illness-related characteristics, and psychosocial factors.

Table 3.4

Correlations Between FCR, Demographics, Illness-related and Psychosocial Factors

	Fear of cancer recurrence
Age	-0.21***
Cancer stage	0.07
Chemotherapy	0.12**
Fighting spirit	-0.07
Helplessness/Hopelessness	0.44***
Risk perception	0.50**
Risk appreciation	0.53***
Relative risk perception	0.34***
Social network	-0.16**
Overall health perception	-0.27***

Note. FCR = Fear of Cancer Recurrence.

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

We found that FCR among women in the study negatively significantly correlated with their age (r=-0.21), indicating that younger women are at a higher risk of experiencing elevated FCR. Surprisingly, no significant association was found between the cancer stage and FCR. In contrast, women who received chemotherapy were at higher risk of experiencing FCR, although the correlation strength was weak (r=0.12).

Psychosocial factors, such as coping styles, risk perceptions, social support, and overall perceived health, demonstrated a significant connection to fear of cancer recurrence (FCR). Specifically, FCR was positively correlated with feelings of hopelessness and helplessness (r=0.44), indicating that women with poorer psychological adjustment reported higher levels of FCR. Furthermore, risk perception, relative risk, and risk appreciation each exhibited statistically significant correlations with FCR, with correlation strengths of 0.50, 0.34, and 0.53, respectively. These findings suggest that the greater the risk a woman from the study perceived regarding the

possibility of experiencing cancer again, the stronger her fear of cancer recurrence became. We also identified a significant relationship between participants' social support and FCR, revealing a weak negative correlation (r=-0.16). This suggests that women with larger social networks tend to experience lower FCR, implying that a portion of their need for support may be addressed within their social network. Finally, the better women perceived their overall health, the lower the FCR they experienced (r=-0.27).

To enhance our understanding of the predictive power of the identified factors of FCR among women in the study, we conducted a linear regression analysis output with FCR as dependent and age, education, chemotherapy, helplessness/hopelessness, risk perceptions, social network and overall health as predictor variables. As depicted in Table 3.5, results revealed that FCR could be predicted to 41% with the included variables. Significant predictors were: younger age (coeff=0.07), more helplessness/hopelessness coping style (coeff = -0.07), higher risk perception (coeff=0.27) and appreciation (coeff=1.17).

Table 3.5

Linear Regression Predicting FCR

Factors	Coefficient (95% confi	Coefficient (95% confidence interval)		
Age	-0.07***	(-0.10, -0.04)		
Education				
Medium	0.11	(-0.82, 1.05)		
Higher	-0.06	(-1.00, 0.87)		
Chemotherapy	-0.07	(-0.71, 0.59)		
Helplessness/ Hopelessness	0.43***	(0.31, 0.56)		
Risk perception	0.27**	(0.10, 0.44)		
Risk relative	0.00	(-0.45, 0.45)		
Risk appreciation	1.17***	(0.69, 1.65)		
Social network	-0.05	(-1.66, 0.06)		
Overall health perception	0.00	(-0.03, 0.01)		
Constant	9.90***	(6.60, 13.20)		
N	438			
F(10, 427)	31.67			
R <sup>2</sup>	0.4258			
p	<0.001			

Note. FCR = Fear of Cancer Recurrence. The reference category for Education was Lower.

<sup>\*</sup>p<0.05, \*\*p<0.01, \*\*\*p<0.001

## 3.2. Need and fulfilment of the need for psychological support

Table 3.6 provides descriptive statistics for the variable used to measure both the need for and the fulfilment of the need for psychological support among the women in the study.

Table 3.6

Descriptive Statistics for Need Variables for Full Sample and Women with High FCR Scores

		High FCR	Full sample
		(N= 171)	(N= 466)
Variable name	Answer	n (%)	n (%)
Referral to (online)	not received, no need	73 (42.7%)	275 (59%)
psychologist	not received, did need	11 (6.4%)	17 (3.6%)
	offered, not used	34 (19.9%)	102 (21.9%)
	received, not helped	12 (7%)	13 (2.8%)
	received, did help	41 (24%)	59 (12.7%)
Needed psychlogical help <sup>1</sup>	Yes	64 (37.4%)	89 (19.1%)
	No	107 (62.6%)	377 (80.9%)
Psychological help fulfilled	Yes	41 (77.3%)	59 (81.9%)
need <sup>2</sup>	no	12 (22.6%)	13 (18.1%)

Note. FCR = Fear of Cancer Recurrence.

Approximately 40% (n=174) of women in the study were offered psychological help, with 58% of them (n=102) choosing not to accept it. The majority of women who did receive psychological support found it beneficial.

The scores on the question in Table 3.6 were transformed into two new variables. The first new variable, 'needed psychological help' with 2 values: yes (options 2, 4 and 5, 19.1%) and no (options 1 and 3, 80,9%). The second new variable, 'fulfilled need for psychological help' was applied only to those women who were offered psychological help and received it, with 2 values:

<sup>&</sup>lt;sup>1</sup> Needed psychological help: YES = options 2,4, and 5 on question 1; NO = options 1 and 3

<sup>&</sup>lt;sup>2</sup> Only computed for women who have received psychological help (n=72 for total group and 53 for high FCR group)

yes (option 5, 81.9%) and no (option 4, 18.1%). We provide a correlation between existing need, as well as fulfilment of the need and considered factors in Appendix A.

Table 3.7

Logistic Regression Predicting Needed Psychological Help

Factors	Odds Ratio (95% CI)
Age	0.95** (0.92, 0.99)
Education	
Medium	1.54 (0.47, 5.08)
Higher	2.13 (0.66, 6.87)
Cancer stadium	0.29 (0.60, 1.40)
Chemotherapy	1.80 (0.94, 3.44)
Fighting spirit	1.00 (0.95, 1.06)
Helplessness/ Hopelessness	1.03 (0.90, 1.18)
Fear of cancer recurrence	1.26*** (1.16, 1.38)
Social network	0.90 (0.81, 1.00)
Overall health perception	0.97** (0.95, 0.99)
Constant	1.31 (0.01, 151.60)
N	427
$LR \chi^2(10)$	114.48
p	<0.001
Pseudo R <sup>2</sup>	0.274

Note. CI = confidence interval, LR  $\chi^2$  = Likelihood Ratio Chi-Square. The reference category for Education was Lower.

We conducted logistic regression to identify predictors of needing psychological support among the women in the study, with age, education, cancer stadium, chemotherapy, helplessness/hopelessness, FCR, risk perceptions, social network and perceived overall health as predictor variables. Results, as depicted in Table 3.7, revealed that needed psychological help could be predicted to 27% with the included variables. Significant predictors were: younger age (odd ratio=0.95), higher FCR (odd ratio=1.26) and lower perceived overall health (odd ratio=0.97).

To identify the predictors of a fulfilled need for psychological support among the women in the study who were offered and accepted such support, we conducted a logistic regression analysis,

<sup>\*</sup>p<0.05. \*\*p<0.01. \*\*\*p<0.001

including age, education, cancer stage, chemotherapy, feelings of helplessness/hopelessness, fear of cancer recurrence (FCR), risk perceptions, social networks, and perceived overall health as predictor variables. Table 3.8 illustrates the regression outcomes. The predictors accounted for 36% of the variance in fulfilled need. Higher perceived overall health (pdd ratio=0.97) emerged as the only significant predictor.

Table 3.8

Logistic Regression Predicting Fulfilled Need

Factors	Odds ratio (95% CI)
Age	0.91 (0.81, 1.02)
Education	
Medium	0.74 (0.12, 4.50)
Cancer stadium	0.03 (0.00, 1.42)
Chemotherapy	0.41 (0.51, 1.00)
Fighting spirit	1.13 (0.95, 1.34)
Helplessness/ Hopelessness	1.27 (0.84, 1.93)
Fear of cancer recurrence	0.71 (0.50,1.00)
Social network	1.03 (0.74, 1.44)
Overall health perception	1.14** (1.03, 1.26)
Constant	0.01 (0.00, 10403.12)
N	65
$LR \chi^2(9)$	21.37
р	0.011
Pseudo R <sup>2</sup>	0.3616

Note. CI = confidence interval, LR  $\chi^2$  = Likelihood Ratio Chi-Square. The reference category for Education was Lower.

<sup>\*</sup>p<0.05, \*\*p<0.01, \*\*\*p<0.001

## 4. Discussion

Our study confirmed a relatively high prevalence of FCR, which can be predicted by younger age, feelings of helplessness and hopelessness, heightened risk perception, and increased risk appreciation. Data from the study revealed that one in five women (in the full sample, or almost two in five with elevated FCR) reported needing support from a psychologist. We found that younger women, those experiencing elevated FCR, and those with perceived lower overall health were at a greater risk of requiring psychological support. Among women who received support from a psychologist, a higher perceived overall health was a significant predictor of their needs being fulfilled.

(1) How high is FCR in breast cancer patients one year after treatment?

The study revealed that a significant portion of women who survived breast cancer experience heightened Fear of Cancer Recurrence (FCR). Specifically, 36.6% of women scored FCR values above the threshold of 13 (J. A. E. Custers et al., 2014), with an average score of 12.3 (+/-3.8). While confirming FCR as a prevalent unmet need, the obtained rate is somewhat lower than those rates reported in other studies (Befort & Klemp, 2011; Chumdaeng et al., 2020; Ellegaard et al., 2017; Yu Z Sun D, 2022). A potential explanation for this difference could be differences in sample characteristics, such as mean time since diagnosis (for example, 3.2 years in (Befort & Klemp, 2011), compared to 1 year in this study), cultural context, cancer stage at diagnosis, or methodological differences. These findings emphasize the importance of addressing FCR as a common unmet need among breast cancer survivors.

(2) To what extent can FCR be predicted by: Illness-related variables and demographics, Risk perceptions (absolute, appraisal and relative) and Coping styles (fighting spirit and helplessness/hopelessness)?

The correlation analysis revealed that younger receiving chemotherapy, age, helplessness/hopelessness coping style, higher risk perceptions, having lower social support and higher perceived overall health were significantly associated with heightened FCR. The regression analysis confirmed that younger age, feelings of helplessness/hopelessness, higher risk perception and risk appreciation were significant predictors of higher FCR among breast cancer survivors. The finding regarding younger age is strongly in line with existing literature, as one of the most commonly reported predictors of FCR (Crist & Grunfeld, 2013). Such association may exist due to the awareness of having more years ahead, leading to anxiety about how recurrence could impact their plans. Similarly, the revealed predictive power of risk perception is in line with a previous study by (Ankersmid et al., 2022). The association between helplessness and hopelessness (HH) and increased FCR highlights the negative impact of maladaptive coping, which aligns with a previous study by (Greer et al., 1979), reporting HH to be associated with lower survival-free rates, likely because maladaptive coping styles reinforce negative expectations. Future research is needed to further analyse the interplay between the identified predictors and evaluate the efficacy of interventions aimed at modifying them.

#### (3) How many patients reported needing psychological help?

One in five participants in the study indicated a need for psychological support. Yet, not everyone was provided with such assistance, although two-thirds of the women who were offered psychological help chose not to utilise it. Among those women with high FCR, almost double as much (37.4%) reported needing psychological help. Such a result is comparable with previous findings, 36% by (Baker-Glenn et al., 2011), 40% by (Luigies-Huizer et al., 2022) and 49% by (van Scheppingen et al., 2011), suggesting consistency in the proportion of breast cancer survivors experiencing FCR, who actively recognise a need for mental health support. Although revealing a significant level of reported need, these findings highlight that a majority of study participants with high FCR didn't report needing psychological support. In addition, almost 40% of women with elevated FCR, who were offered pscychological help, decided not to use it. This could be attributed to maladaptive coping styles, such as Helplessness/Hopelessness (r=0.26), already receiving support from their social network (r=-0.17), as depicted in correlation table A.1 in Appendix A, or negative expectations of psychotherapy, as concluded in (Deuning-Smit et al., 2023). Among the roughly 15% of total number of participants who did seek help from a psychologist, the perceived benefit was high; 80% of the women reported finding the help useful. This is in line with the study by (Luigjes-Huizer et al., 2024), who remarked that 69% of those who received psychological help, found it helpful. These findings highlight that psychological support plays a crucial role in aiding women with breast cancer deal with FCR. It can be concluded that relying on patients' self-reported need for psychological support may lead to an underestimation of such need among breast cancer survivors. Future research could focus on identifying and understanding the barriers preventing the uptake of psychological support. In practise, psychological help should be offered to breast cancer survivors soon after the treatment, rather than later, according to findings in (Brebach et al., 2016).

(4) To what extent is this need predicted by: Illness-related variables and demographics, FCR, perceived overall health, social network and coping styles?

Younger women, experiencing elevated FCR and perceiving low overall health, were identified as being at a higher risk of requiring support from a psychologist. The regression analysis confirmed that age is a common predictor of both elevated FCR and the need for psychological support, which is in line with findings by (Luigjes-Huizer et al., 2022). Although our findings confirmed the predictive power of elevated FCR in needing mental health support, a stronger effect was expected, as FCR is commonly identified as one of the most common unmet need among breast cancer survivors (Fan et al., 2023). This result highlights the importance of analysing barriers to becoming aware of this need, such as lack of FCR awareness (Deuning-Smit et al., 2023). Among those women who received psychological support, those who perceived their overall health as lower were at a greater risk of not having their needs fulfilled. From a practical standpoint, clinicians should be aware of the identified factors of needing psychological support among breast cancer survivors, aiming for a more personalised approach to communicating available resources and the importance of psychological well-being.

## 4.1 Strengths and limitations

This research has several methodological advantages that enhance the credibility and consistency of its findings. This study's main methodological strength is its large sample size (N=511), which enhanced statistical power and increased the reliability of the findings. Additionally, large sample size is especially beneficial when conducting analyses to identify complex relationships between variables, as well as when generalizing the obtained results. By using validated instruments to measure essential constructs, such as fear of cancer recurrence, coping styles, social support, and quality of life, we ensured the reliability of the findings. By applying robust statistical methods, including descriptive statistics, correlation analysis, linear and logistic regression, we were able to understand the relationships between the studied variables.

On the other hand, there exist several limitations when analysing the findings. The main limitation of the study lies in its cross-sectional design, which prevents an analysis of how the fear of cancer recurrence and the need for psychological support change over time. Utilisation of self-reported measures may lead to biases, such as social desirability bias. The generalisability of the results is also constrained by the study's inclusion criteria, which targeted women who had undergone curative treatment for non-metastatic primary breast cancer and were fluent in Dutch. Lastly, while the study accounted for numerous relevant predictors, the possibility of unmeasured variables influencing fear of cancer recurrence and the need for psychological support remained.

## 5. Conclusion

This study aimed to improve our understanding of the relationship between fear of cancer recurrence and the need for psychological support, among breast cancer survivors. The findings revealed a high FCR prevalence, as well as younger age, maladaptive coping, and high-risk perceptions being significant predictors. In addition, this study revealed that supportive care needs are common among breast cancer survivors and identified younger age, higher FCR and lower perceived overall health as significant predictors. These findings emphasize the importance of utilising a personalised care approach aimed at helping breast cancer survivors cope with their psychological challenges and improving their overall well-being.

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## Appendix A: Associated factors of the need for psychological support

Table A.1

Correlations Between Needed Psychological Help, Fulfilled Need, FCR, Demographics, Illness-Related and Psychosocial Factors

	Existing need		Fulfilled	l need
	r	$\chi^2$	r	$\chi^2$
FCR	0.38***		-0.27*	
Age	-0.29***		-0.01	
Education		3.45		0.28
Cancer stage		0.02		1.48
Chemotherapy		13.36***		0.65
Fighting Spirit	-0.02		0.25*	
Helplessness/Hopelessness	0.26***		-0.35**	
Risk perception	0.20*** -0.20			
Risk appreciation	0.23***		-0.08	
Relative risk perception	0.26***		0.05	
Social network	-0.17**		0.06	
Overall health perception	-0.34***		0.34**	

Note. Pearson's r correlations are reported for associations involving continuous variables [FCR, Age, Fighting Spirit, Helplessness/Hopelessness, Risk perception, Risk appreciation, Relative risk perception, Social network, Perceived overall health];  $\chi^2$  values are reported for associations involving categorical variables [i.e., education, cancer stage and chemotherapy]. p<0.05, \*\*p<0.01, \*\*\*p<0.001

Table A.2

Distribution of Needed Psychological Help and Fulfilled Need by Education Level,

Chemotherapy Status and Cancer Stage

		Existin	Existing need		d need
		Yes	No	Yes	No
Variable name	Answer	n (%)	n (%)	n (%)	n (%)
Education	Lower	6 (1.3%)	51 (11.2%)	3 (4.2%)	1 (1.4%)
	Medium	34 (7.4%)	150 (32.8%)	23 (32.4%)	4 (5.6%)
	Higher	46 (10.1%)	170 (37.2%)	33 (46.5%)	7 (9.9%)
Chemotherapy	Yes	44 (9.4%)	45 (9.7%)	29 (40.3%)	8 (11.1%)
	No	45 (9.7%)	267 (57.3%)	30 (41.7%)	5 (6.9%)
Cancer stage	<=2	81 (18.2%)	347 (78%)	55 (80.9%)	11 (16.2%)
	>2	3 (0.7%)	14 (3.1%)	1 (1.5%)	1 (1.47%)