Fear of Cancer Recurrence and the Relationship to Quality of Life, Risk Perception and Demographics in Female Breast Cancer Survivors in the Netherlands

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Abstract

Background: Fear of cancer recurrence (FOCR) is very common in breast cancer patients. Prior research examined the determinants and consequences of FOCR at different stages of breast cancer treatment. Yet, it is important to explore these findings consistently among breast cancer survivors. Thus, the aim of this study was to measure the extent to which FOCR is a problem in breast cancer survivors and to assess the relationship of FOCR with various consequences (excessive physical examination; QoL) as well as various determinants (demographics (age, marital status, occupation, education, health literacy); risk perception). **The Method:** A cross-sectional design was adopted. The sample consisted of 252 participants and FOCR was assessed through the 6-item Cancer Worry Scale (CWS; Custers et al., 2018). Excessive physical examination was measured with a single item. Moreover, QoL was measured with the Sf-12 (Ware et al., 1996). Health literacy was assessed through the SBSQ (Fransen et al., 2011). For the various types of risk perception, self-constructed questions were used. Pearson correlations for the variables FOCR, excessive physical examination, QoL and demographics were conducted. Through a multiple regression analysis, it was measured which type of risk perception (absolute risk perception, risk appraisal or comparative risk appraisal) was most strongly associated with FOCR. **Results:** 76% of the women reported severe FOCR. Women with higher FOCR showed more excessive physical examination ($r=0.28$, $p<0.01$), less physical QoL ($r = -0.17$, $p<0.01$) and less mental QoL ($r=-0.48$, $p<0.01$). Besides, older participants ($r=-0.31$, $p<0.05$) and participants with higher health literacy ($r=-0.13$, $p<0.05$) reported less FOCR. No association between marital status, occupation, education and FOCR was found. A multiple regression revealed that both, risk appraisal ($\beta = 1.123$, $p<0.01$) and comparative risk ($\beta= 0.786$, $p<0.01$) showed to have a significant independent effect on cancer worry, while risk appraisal had the most impact. **Conclusion:** For practice, it is advised to focus on the at-risk group of patients with lower health literacy by enhancing their health literacy and to educate the participants about physical (self-)examination and strategies for reducing the risk of excessive physical self examination. Moreover, the participants should be educated about their risk for recurrence with a verbal statement and in comparison to other breast cancer survivors. By focusing on these factors FOCR might possibly prevented to some extent or reduced.

Introduction

Cancer is a serious disease, which affects people from all over the world. According to Bray et al. (2018), breast cancer is the most common type of cancer for women. Every year, more than 1.5 million women are diagnosed with breast cancer accounting for 570,000 deaths in 2015 (Sun et al., 2017). In highly developed countries, breast cancer prevalence is expected to increase in the future (World Health Organisation, 2020).

Fear of cancer recurrence (FOCR)

After the treatment for breast cancer has finished, patients enter the so-called follow up phase, as women who have had breast cancer once are at risk of getting breast cancer again (Yoon et al., 2015). Aims of follow-up care are to evaluate hidden physical side-effects of the therapy, monitoring breast cancer recurrence as well as to examine the psychological needs of the patients (Page & Adler, 2008). The latter is necessary as cancer survivors have a high risk for negative psychological consequences after their treatment. (Ewertz & Jensen, 2011). One of the most common negative psychological consequences of breast cancer patients is the fear of cancer recurrence (FOCR), which is often a life-long concern. (Freeman-Gibb et al. 2017; Vickberg, 2001). According to Custers et al. (2014), FOCR can be described as “fear or worry that the disease will return or progress in the same organ or another part of the body” (p. E44). Between 25% and 97% of breast cancer survivors are suffering from FOCR (Koch et al., 2013). To be more precise, the prevalence rate of moderate or even higher rates of FOCR among Dutch breast cancer survivors ranges between 31% and 56% (Custers et al., 2020). This wide range of prevalence rates can be explained by the usage of different instruments measuring FOCR (Koch et al., 2013). Since the prevalence rates indicate that FOCR is common in breast cancer survivors, it is important to understand the fears by identifying the potential consequences and determinants of FOCR.

Consequences of FOCR

Generally, the diagnosis of cancer goes along with psychological consequences and thus, FOCR is to some extent normal and compared to anxiety disorders not necessarily an irrational response (Crist & Grunfeld, 2013; Koch et al., 2013). However, FOCR can also cause dysfunctional behaviours like excessively checking symptoms, inability to plan the future, increased fear response, prevention behaviour or anxious daydreaming (Crist & Grunfeld, 2013;

Custers et al., 2014; Simard et al., 2013). Additionally, extreme cases of FOCR are associated with depression, anxiety disorders and post-traumatic stress syndromes (Crist & Grunfeld, 2013; Ziner et al., 2012). Furthermore, FOCR also interferes negatively with the Quality of Life (QoL) up to 6 years post-treatment of breast cancer patients and their overall well-being (Cho & Park, 2017; Freeman-Gibb et al., 2017; Yang et al., 2019; Ziner et al., 2012).

Excessive physical examination

One consequence of FOCR is excessive physical examination. Physical self-examination is an important factor of risk surveillance for potential breast cancer for all women aged above 20 (Pardi & Romli, 2017).

Specifically for breast cancer survivors, it is recommended to examine their breast themselves monthly as half of the cancer recurrences are detected by women themselves between routine check-ups (van der Sangen et al., 2013; Witteveen et al., 2018). In general, approximately 71% of the breast cancer survivors are actually monitoring their breast for signs of recurrence (Tarsk et al., 2008). Prior research found that breast cancer survivors display more frequent self-examination (Thewes et al., 2012; Soriano et al., 2018). It is important to note that there is currently no concrete empirically based definition of the concept of excessive self-examination from a psychological perspective (Soriano et al., 2008). However, since monthly self-examination is recommended, excessive physical examination is considered to be as more frequently as monthly self-examination. Accordingly, excessive physical examination would not improve early detection of any recurrence. As regular physical examination is important and decreases the FOCR in breast cancer survivors, excessive physical examination might even increase FOCR and goes along with more uncertainty (Soriano et al., 2008). In the past, physical examination has been conceptualized as a strategy for reducing distress and is theorized as similar to a compulsion in breast cancer survivors with high levels of FOCR (Soriano et al., 2008). Thus, the concept of excessive physical self-examination is viewed as a consequence of FOCR. To date, little is known about excessive self-examination, especially among breast cancer survivors. However, it is important to study this topic, as FOCR interventions that are targeting physical examination behaviour are more effective if there is more empirical knowledge about the association between FOCR and excessive physical examination. Moreover, a better understanding of this association is also needed when aiming for adequate information provision and educating the breast cancer patients about the strategy of self-examination (Soriano et al., 2008).

Quality of life (QoL)

Another potential consequence of FOCR is decreased QoL. Generally, the concept of QoL is difficult to conceptualize, as it can be described as the subjective measure of how good one's life is. It is often referred to as well-being and varies from person to person (Theofilou, 2013). According to Theofilou (2013), the evaluation of one's QoL is a multidimensional construct and encompasses “one’s emotional reactions to life occurrences, disposition, sense of life fulfilment and satisfaction, and satisfaction with work and personal relationships” (Theofilou, 2013, p. 151). Other than that, QoL is also conceptualised as ‘a multidimensional construct that includes physical health status, psychological well-being, social’ (Rabin et al., 2008, p. 54).

Two components of QoL are physical and mental QoL. Physical QoL is known as the management or relief of symptoms and therefore the maintenance of performance and independence (Bloom et al., 2004). Breast cancer patients are often facing various physical QoL challenges, such as complaints during the menopause, sexual issues, weight gain, pain, sleep issues, hot flashes or lymphedema activities (Ferell et al., 1997; Schmidt et al., 2018). In the post-treatment phase, issues such as low levels of energy, issues with physical activities, concerns about the usage of hormone replacement therapy and diet recommendations as well as issues related to breast reconstruction are common (Ganz et al., 1996). Mental QoL is defined as the effort to retain control when facing a life-threatening illness marked by emotional distress, shifted life goals and fear of the unknown as well as optimistic life shifts (Bloom et al., 2004). Often, breast cancer patients face concerns about their future as well as their diagnosis and treatment. Even patients with a low risk of cancer recurrence, display high levels of fears which are severely affecting their QoL (Lee et al., 2018). Prior research revealed that physical effects are commonly interrelated with mental QoL. Furthermore, breast cancer patients at a young age are more prone to receive multi-modal treatment, which is often more toxic, and accordingly display less physical QoL (Bloom et al., 2004).

Although in the past studies have examined the relation between FOCR and QoL, according to the researchers’ knowledge, no recent studies have examined the association of FOCR and QoL in breast cancer patients who are in the post-treatment phase. Yet, up-to-date research is needed in order to close the gap of knowledge about the understudied topic of the post-treatment phase in breast cancer patients and the corresponding association between FOCR and QoL. Only if there is comprehensive knowledge about FOCR and its consequences like QoL, it is possible to be able to provide adequate support and care, not only at a certain point in time. Thus, this research paper will investigate the association between FOCR and QoL in breast cancer survivors.

Determinants of FOCR

Next to the consequences, there are also several factors that determine FOCR.

Demographic influence

One determinant for FOCR are the demographics of breast cancer patients. Prior research already examined to some extent demographic variables in association to FOCR in breast cancer patients. Several studies revealed that characteristics of being younger and being less educated are related to more FOCR (Aghdam et al., 2014; Crist & Grunfeld, 2013; Custers et al., 2015; Freeman-Gibb, 2017; Ziner et al., 2012). Contrary, other studies have found no relationship between FOCR and age, marital status, and education or that the demographic impact is not that high (Crist & Grunfeld, 2013; Custers et al., 2015; Freeman-Gibb, 2017; Starreveld et al., 2017). Besides age, occupation and marital status, health literacy is also part of the demographics. Health literacy is conceptualized as the ability to process health-related information in order to be able to make appropriate decisions resultantly (Stacey et al., 2017). In the past, only a few studies have examined health literacy among cancer patients (Koay, et al., 2012). Especially, the association between health literacy and fear of cancer recurrence in breast cancer survivors has not been examined yet. Likewise, the association of the occupation status with FOCR were not examined among breast cancer survivors. Additionally, the other mentioned demographic characteristics (i.e. age, occupation, marital status, and education) were rarely examined in breast cancer survivors. More detailed research is necessary in order to select the right target group in order to tackle the issue of FOCR in breast cancer patients.

Risk Perception

It seems evident that a women's FOCR may be associated with her knowledge and appraisal of her personal risk for recurrence. Accordingly, several studies have examined the relationship between the patients’ risk perception and FOCR. Research has shown that a higher perceived risk of cancer recurrence, in general, is associated with more cancer worries (Lipkus et al., 2005; Phillips et al., 2013). However, there is little consistency in the way risk perception is measured (Levy et al., 2006). Thus, there are three main types of risk perceptions distinguished. First, there is the absolute risk perception, which means the assessment of one's own probability of cancer recurrence, which is often measured numerically, either as a number or a per cent (Freeman-Gibb et al., 2016; Lipkus et al., 2000). The second component is one’s risk appraisal, in terms of high or low. For some women, a risk of 1 in 100 may be perceived as high, whereas for other women the same risk may be perceived as low. For this study, the risk appraisal is conceptualized as one's evaluation of breast cancer recurrence verbally, like very low or very high. The third component is the comparative risk perception, which means the perceived risk of one's own compared to other people with similar circumstances and characteristics measured verbally (Lipkus et al., 2000). Although some studies have examined breast cancer patients' risk perception and FOCR, there is currently little consensus about the way risk perception is measured. Often, studies did not take the multiple components into account and are varying in the scale options (Lipkus et al., 2000; Phillips et al., 2013). However, it is known that absolute risk and comparative risk, for instance, are independent constructs (Lipkus et al., 2005). Yet, further research is needed in order to adequately be able to conceptualize the determinants of FOCR. Even though prior research confirmed an association between risk perception and FOCR, it is important to examine whether there are different associations with different risk perception types. Accordingly, more precise predictions can be made based on a more precise distinction. Consequently, interventions regarding FOCR, or support opportunities can be better tailored to the patients that are displaying more at-risk characteristics.

Purpose of this Study

Bases on these background information, the following research questions were formulated:

1. To what extent is FOCR prevalent in breast cancer survivors ?
2. To what extent is high FOCR associated with excessive physical examination and reduced (physical and mental) Qol?

3. To what extent is FOCR associated with demographic characteristics (age, marital status, occupation and education) and health literacy levels?
4. Which of the three types of risk perceptions (absolute risk, risk appraisal and comparative risk) is more predictive regarding FOCR in breast cancer survivors?

Methods

Design

This study was part of the larger PhD study by Jet Ankersmid. For this larger study, data were collected using a Multiple Interrupted Time Series (mITS) design. This current research paper investigated only research questions referring to the pre-implementation (baseline) data. A cross-sectional, correlational design was adopted to examine the role of the variables FOCR, excessive physical examination, QoL, age, marital status, occupation, education as well as health literacy and for predicting FOCR based on the risk perceptions.

Participants and procedures

Ethical approval for the research was obtained from all seven Santeon hospitals according to ethical principles of the declaration of Helsinki (World Medical Association, 2001).

Inclusion criteria for participating in this study were: (1) The participants faced the decision for the organization of follow-up care after receiving curative treatment for their invasive breast cancer, (2) the patients had to be at least 18 years old, (3) be able to read and speak Dutch, (4) they had to be treated in a Santeon hospital, and (5) the participants had to be able to provide informed consent and to access (and use) a device with internet (possibly with assistance by a caregiver). Breast cancer patients, who were (1) diagnosed with non-invasive breast cancer, or (2) who have received either palliative treatment or neoadjuvant therapy were excluded from this study. Additionally, (3) male patients were also excluded from this study.

Participants were selected through consecutive sampling by asking the health care professionals of the Santeon hospitals to screen all patients. Eligible breast cancer patients were invited to participate in this study by the healthcare professional. If the participant agreed to be contacted in person, by phone or via eMail, the healthcare professional handed out the patient information letter as well as the informed consent form. After that, the coordinating research investigator (or the representative) contacted the participant and asked again to participate in this study and to answer any remaining questions. If the participant was still willing to take part in the study, they was asked to sign two informed consents in the presence of the health care professional. In case of exceptions, the informed consents were returned via mail. The informed consent of the participants was stored in the corresponding Santeon hospital. Then, the participants were asked to fill in the questionnaire of the pre-implementation phase, with possible assistance by a caregiver.

For this study, 266 women who were in the post-treatment phase after suffering from breast cancer took part in this study. However, since 14 participants did not fill out the survey, only data from 252 participants could be analyzed for the demographics. For the other variables, the sample consisted of 247 participants, as some participants did not fill in the entire questionaire.

Instruments

Personal Background variables

For demographic variables, self-constructed questions regarding age, marital status, educational background and occupation were measured. First, the patients had to indicate their birth year.

Next, for marital status, five answer options could be selected. These options were 'widow (= 1)', 'divorced (= 2)', 'single (= 3)', 'living together/married (= 5)', 'different' (with the option to specification). For further analyses, some answers of the option different could be assigned to the other categories. Furthermore, since some participants indicated to be in a relationship (= 4), this category was added to omit the category 'different'. Moreover, the participants had to indicate their occupational status on the basis of seven answer options. These were reduced to the following two categories: having a paid job ('being paid for … hours per week') and not having a paid job ('WAO/disabled', 'AIW/VUT/ pension', 'voluntary/ unpaid job', 'household tasks', 'studying/training'). The answers for the option 'different' were assigned to the other categories. Next, the education level of the participants was assessed bases on one question with 9 answer options. These 9 options were reduced into the following three categories: 1= low ('no education', 'primary education' and 'primary or preparatory vocational education'), 2 = middle ('secondary general education', 'secondary vocational education and vocational guidance', 'higher general and preparatory scientific education') and 3 = high ('higher vocational education', and 'scientific education'). The category 'different' was assigned to the other categories based on the specific answer options. Moreover, health literacy was assessed with the aid of three items of the Set of

Brief Screening Questions (SBSQ) (Fransen et al., 2011). The patients had to answer the first and third question on a 5-point Likert scale (0 = never, 4 = always). The second item also ranged on a 5-point Likert scale, but from 0 = ‘not sure at all’ to 5 = ‘very sure’. The items were averaged and a cut-off score of above 2 was adopted for indicating adequate health literacy (Fransen et al., 2011). The scale showed low reliability in the current study (α =0.54). Despite this low alpha, it was decided to combine the three items into a scale score, as the alpha could not be increased by omitting one item and since the scale has been proven reliable in a number of previous studies (Fransen et al., 2011; Vreugdenhil et al., 2018).

Constructs of the larger study

For the larger study, the questionnaire entailed various constructs, which were not analysed in the current study. Namely, the organization of hormone therapy, the organization of the aftercare as well as the organization of the follow-up. Furthermore, shared decision making, patients’ needs for outcome information, patients’ and the actually received outcome information were examined, as well as their illness perceptions. Below, the variables that were relevant for the current study are described.

Constructs of the current study

For the current study, the following constructs were examined.

FOCR. For assessing fear of cancer recurrence, the Cancer Worry Scale (CWS), with six items was used (Custers et al., 2018). The patients had to answer questions about possible worries that people have after the diagnosis (e.g., How often have you thought about your risk of developing or relieving breast cancer?) on a four-point Likert Scale (1 = Never, 4 = Almost always). The score was summed (ranging from 6 to 24) and a higher score indicating more worries about their cancer (Custers et al., 2018). Therefore, the cut-off score >11 for severe levels of cancer worries was adopted (Custers et al., 2018). The scale showed good reliability in the current study (α = 0.884).

Excessive physical examination. For assessing the variable excessive physical examination, one item of the Fear of Cancer Recurrence Questionnaire-7 was used (Humphris et al., 2018). The participants had to answer a question about their physical examination check for cancer (I examine my body for signs of cancer) on a five-point Likert Scale (1= Never, 5= very often).

QoL. QoL was measured with the Short-Form health index SF-12, which encompasses 12 items and two summary measures, which are divided into 8 subscales in total (Ware et al., 1996). The *general health* (GH) scale encompasses one item about the general health perception of the participant on a 5-Point Likert scale (5 = Excellent, 1= bad). Besides, the *physical functioning* scale (PF) includes two items about the restrictions of doing moderate activities and climbing stairs on a 3-Point Likert scale (1 = Yes, severely restricted, 3 = no, not at all restricted). Moreover, the *role-physical* (RP) scale includes two items about achieving less accomplishment than wanted and limitations at work or other activities due to physical health on a bivariate scale (yes, no). Two further items about achieving fewer accomplishments than wanted and being less careful as usual in doing things due to the emotional state refer to the *role emotional* (RE) scale, which had to be answered on a bivariate scale (1 = yes, 2 = no). The next item about how pain interferes with the occupation refers to the *bodily pain* (BP) scale, which has to be answered on a 5-Point Likert scale (5 = not at all, 1 = very much). Furthermore, there are two items about feeling calm/peaceful and sad/blue relating to the *mental health scale* (MH). Next to that, the *vitality* (VT) *scale* encompasses one item about having energy. The latter three items were measured on a 6-Point Likert scale (1 = Always, 6 = Never). Last but not least, the *social functioning scale* (SF) consists of one item about the restriction of social activities due to physical health or emotional problems on a 5-Point Likert scale (1 = Always, 5 = Never). The scales PF, RP, BP and GH were combined for the summary measure ‘physical health’. The other scales (VT, SF, RE, MH) were combined for the summary measure ‘mental health’. A higher score, indicating better health. The exact scoring procedure can be found in the corresponding scoring manual of Ware et al. (1996). Overall, the entire questionnaire showed good reliability in the current study (α = 0.90). The physical health scale displayed good reliability in this study (α = 0.87). Also, the mental health scale displayed good reliability in the current study (α =0.83).

Risk Perception. The variable risk perception was measured with a self-constructed three-item questionnaire. One item intended to measure the *absolute risk* of breast cancer in women

(How high do you rate your risk for recurrence of breast cancer in the same or the other breast?). This item was measured on a six-point Likert scale (1=1 out of 5, 6= 1 out of 1000), with a higher score indicating a higher absolute risk evaluation of breast cancer recurrence. Furthermore, one item assessed the *risk appraisal* (How do you assess your risk of recurrence of breast cancer in the same or the other breast?). This item was measured with a five-point Likert scale (1 = very low, 5 = very high), with a higher score indicating a higher risk appraisal. Lastly, one item measured the *comparative risk* (How do you rate your own risk of recurrence of breast cancer in the same or the other breast, compared to the average risk of women who have had breast cancer.). This item was measured on a five-point Likert scale (1 = much lower, 5 = Much higher).

Data Analysis

All analyses were computed with the statistical software SPSS IBM 25 (Wagner III, 2019). First of all, all data screened for valid cases and missing responses were deleted. Then they were recoded and properly scored according to the manuals.

In order to select appropriate measurement tools for further analysis, the data were checked in terms of their normality. Accordingly, the data were checked by using the psychometric properties Skewness and Kurtosis. A reasonable cut-off for Skewness between values of -2 to +2 and Kurtosis values of -7 to +7 were adopted (Byrne, 2016; Curran et al., 1996). Correspondingly, all variables were found to be normally distributed (see Appendix 1).

Subsequently, demographic variables were analyzed using descriptive analyses (means (M), standard deviations(SD) and frequencies). Correspondingly, the descriptives of the variables of interest (excessive physical examination, physical QoL, mental QoL, absolute risk, risk appraisal and comparative risk) were analyzed using descriptive analyses (means (M), standard deviation (SD)) to get insights about the responses. Further, for the variables exccessive physical examination, absolute risk, risk appraisal and comparative risk, the frequencies of the answer options were analyzed.

To examine to what extent FOCR is a problem in breast cancer survivors, the descriptives of FOCR in terms of their means (*M*) and standard deviations (*SD*) as well frequencies of the levels of FOCR were examined.

For answering the second and third research question a bivariate correlation analysis with Pearson's *r* test with the variables FOCR and excessive physical examination, physical QoL, mental QoL, age, marital status, occupation, education, and health literacy was executed to examine the associations between the variables. The interpretation of the scores was based on the following ranges: a correlation coefficient of 0.00 to 0.29 was assumed to be weak, a correlation coefficient of 0.30 to 0.59 was interpreted as moderate and a coefficient of 0.60 to 1 indicated a strong correlation (Schober et al., 2018).

In order to answer the fourth question, again bivariate Pearson's *r* correlation was executed with the dependent variable FOCR and the independent variables absolute risk, risk appraisal and comparative risk. This was done to get some first impressions about the associations between the variables before going into a further analysis for predicting the most influential type of risk perception, which was assessed with a multiple regression analysis.

Results

Descriptives of the study group

The age of the participants ranged from 31 to 85 and the average participant was 62 years old (see Table 1). The majority of the participants were married and/or living together with their partner. More than half of the participants did not have a job and approximately half of the participants have a middle-high education level (51.3%). Overall, 93% of the participants had a high health literacy level.

Table 1

Demographics (N=252)

Characteristic	Range	Mean (SD)	N	%
1. Patients age in years	31--85	62 (10.11)		
2. Marital status				
Widow			22	8.7
Divorced			13	5.2
Single			27	11.1
In a relationship			3	1.2
Living together/married			187	73.8
3. Occupation				
Not having a job			142	56.3
Having a job			110	43.7
4. Education				
Low			33	13.1
Middle			129	51.2
High			90	35.7
5. Health literacy	1.3-4	3.6 (0.4)		
Low			4	1.6
High			248	98.4

Descriptives of the main variables

Excessive physical examination

The participants occassionally examined their body for cancer recurrence (49.4%) (see Table 2). However, when looking at all answer options it is noticeable, that the participants displayed a tendency to rather excessive levels of self examination.

Quality of life

Compared to the average female American population, the participants had a similar physical health (M = 49.97, SD = 8.92; M^{USA}=49.11, SD^{USA} = 9.92) and mental health (M = 50.4680, SD = 8.86; M^{USA}= 49.92, SD^{USA} = 9.80) (see Table 2). This means that they overall have an average QoL.

Table 2

Descriptives of the Variables FOCR, Excessive Physical Examination, Risk Perception (Absolute Risk, Risk Appraisal, Comparative Risk) and QoL (Physical QoL, Mental QoL) (N = 247)

Variable		Mean	SD	N	%
1.	**FOCR**	13.99	3.60		
2.	**Excessive physical examination**[a]	3.03	0.908		
	Never			19	7.7
	Rarely			34	13.8
	Occasionally			122	49.4
	Often			65	26.3
	Very often			7	2.8
3.	**Risk perception**				
	Absolute risk[b]				
	Risk appraisal[c]				
	Comparative risk[d]				
4.	**QoL**				
	Physical QoL [0-100]	49.97	8.92		
	Mental QoL [0-100]	50,47	8.86		

Note. [a]5-point Likert scale (1 = never, 5 = very often), [b]6-point Likert scale (1 = 1out of 1000, 6 = 1 out of 5), [c]5-point Likert scale (1 = very low, 5 = very high), [d]5-point Likert scale (1 = much lower, 5 = much higher)

Risk perception

Generally, the participants rated their chance of cancer recurrence in terms of their absolute risk as relatively low (see Table 2). Most (34.4%) participants rated their absolute risk as '1 out of 1000', which was the lowest option (see Table 3). Overall, the participants selected rather low answer options regarding their absolute risk estimation.

Moreover, the breast cancer patients rated their risk appraisal as low with a tendency to neutral, so neither low nor high (see Table 2). Actually, almost half (46.6%) of the participants rated their risk appraisal as neither high nor low (see Table 3). However, when looking at all possible answer options, a tendency to a rather lower risk appraisal is noticeable.

In comparison to other women who had breast cancer, the participant viewed their risk as similar (see Table 2). When looking at the frequencies, more than half (57.1 %) of the participants actually indicated their comparative risk estimation as similar (see Table 3). In total, the answer options are relatively centered with no tendencies to low nor high risk appraisals.

Table 3

Frequencies of the Answer Options of Three Risk Perceptions (Absolute Risk, Risk Appraisal, Comparative Risk) (N=247)

Variable	Answer option	N	%
1. Absolute risk	1 out of 1000	86	34.4
	1 out of 100	75	30.4
	1 out of 50	40	16.2
	1 out of 25	14	5.7
	1 out of 10	24	9.7
	1 out of 5	9	3.6
2. Risk appraisal	Very low	32	13.0
	Low	73	29.6
	Not high, not low	115	46.6
	High	25	10.1
	Very high	2	0.8
3. Comparative risk	Much lower	15	6.1
	Lower	38	15.4
	Similar	141	57.1
	Higher	52	21.1
	Much higher	1	0.4

FOCR

To answer the first research question (To what extent is FOCR prevalent in breast cancer survivors?) the descriptives were analyzed (Table 2 and Table 3). Overall, the results revealed that the participants had severe FOCR (see Table 2). Thereby roughly 75% of the participants scored above the cut-off score for severe FOCR (see Table 3).

Table 4

Frequencies of the Level FOCR (N = 247)

Level of FOCR	N	%
No severe FOCR	64	24.1
Severe FOCR	183	75.9

Association between excessive physical examination, QoL and FOCR

To answer the second research question, to what extent excessive physical examination, QoL and the demographics (age, marital status, occupation, education and health literacy) are associated with FOCR, a Pearson's r test was computed (see Table 5). The test revealed that there was a weak association between cancer worry and excessive physical examination, meaning that women with more FOCR also indicated more excessive physical examination ($r = 0.28$).

Regarding QoL, the results showed a weak negative association between the fear of recurrence and physical health ($r = -0.17$). This means that women with more FOCR reported worse physical health. Moreover, there was a moderate negative association between fear of recurrence and mental health meaning that more FOCR was associated with worse mental health ($r = -0.48$).

Association between demographic variables (age, marital status, occupation, education), health literacy and FOCR

To answer the third research question, to what extent the demographic variables and levels of health literacy are associated with FOCR, again a Pearson's r test was computed (see Table 5). The results revealed that there is a moderate negative association between fear of recurrence and age ($r = -0.31$, $p<0.01$). This indicates that older women reported less FOCR. Further, health literacy was weakly associated with FOCR ($r = -0.13$). Accordingly, women with better health literacy reported less FOCR. Nonetheless, no significant associations between marital status, occupation, education and FOCR were found.

Table 5

Bivariate Correlations of the Variable´s Excessive Physical Examination, QoL (Physical QoL, Mental QoL), Age, Marital Status, Occupation, Education, Health Literacy and FOCR (N=247)

Variable	1	2	3	4	5	6	7	8
1. Excessive physical examination	-							
2. Physical QoL	-0.06	-						
3. Mental QoL	-0.09	**0.17****	-					
4. Age	**0.13***	0.04	**0.24****	-				
5. Marital status	0.12	-0.06	0.09	**-0.23****	-			
6. Occupation	0.54	0.00	-0.12	-0.56	0.05	-		
7. Education	- 0.02	- 0.03	-0.07	**-0.23****	-0.05	**0.24****	-	
8. Health literacy	- 0.12	**- 0.19****	0.03	**-1.4***	0.06	0.12	**0.31****	-
9. FOCR	**0.28****	**-0.17****	**-0.48****	**-0.31****	0.08	0.9	0.4	**-0.13**

Note. significant correlations are in boldface; *Correlation is significant at the 0.05 level (2-tailed); **Correlation is significant at the 0.01 level (2-tailed)

Prediction of FOCR based on the different types of risk perceptions

In order to answer the fourth research question, which types of risk perception are most predictive regarding FOCR a multiple regression has been performed (see Table 7). First, a Pearson's *r* test was computed to examine the correlations of the separate risk perceptions and FOCR (see Table 6). The results revealed that there is a moderate association between the absolute risk and FOCR (r = 0.30), risk appraisal (r = 0.41) as well as comparative risk (*r* = 0.33). This means that women with a higher perceived absolute risk, risk appraisal as well as comparative risk, reported higher FOCR. Besides, a weak association between absolute risk and risk appraisal (r = 0.28) and moderate associations between absolute risk and risk appraisal (r = 0.54) as well as risk appraisal and comparative risk (r = 0.48) were found.

Table 6

Bivariate Correlations of the Variables Risk Perception (Absolute Risk, Risk Appraisal and Comparative Risk) and FOCR (N=247)

Variable	FOCR	Absolute risk	Risk appraisal
Absolute risk	0.30**	-	
Risk appraisal	0.41**	0.54**	-
Comparative risk	0.33**	0.28**	0.48**

Note. Significant correlations are in boldface; **Correlation is significant at the 0.01 level (2-tailed)

Then, a multiple linear regression was performed to ascertain the prediction of FOCR from the variables absolute risk, risk appraisal and comparative risk (see Table 7). A significant model was observed [$F(3,243)=20.342$; $p<0.05$], with an adjusted R^2 of 0.191, meaning that all predictors together can explain 19% of the variance in the dependent variable, which is rather little. The results revealed that the variable absolute risk was found to have zero effect on FOCR. However, risk appraisal and comparative risk significantly affected FOCR, with risk appraisal contributing to the greatest prediction.

Table 7

Multiple Regression Analysis of the Role of Absolute Risk, Risk Appraisal and Comparative Risk in Predicting FOR (N=247)

Variable	B	SE	β	CI (95% lower)	CI (95% upper)	t	p
Constant	8.177	0.841		6.521	9.833	9.728	0.000
Absolute risk	0.261	0.171	0.104	-0.076	0.597	1.524	0.129
Risk appraisal	1.123	0.309	0.272	0.514	1.732	3.634	0.000
Comparative risk	0.786	0.299	0.172	0.198	0.1375	2.631	0.009

Note. Dependent variable: FOCR;

Discussion

Overall, the main purpose of this study was to examine the prevalence of FOCR in cancer survivors and to examine the relationships with several consequences (excessive physical examination and Qol) and determinants (demographics and risk perceptions).

The first aim of this study was to examine the extent to which fear of cancer recurrence is a problem in breast cancer survivors. Severe fear of cancer recurrence was reported in 76% of the participants. This is quite high, in comparison with the findings of Custers et al. (2020) who revealed that between 31% and 56% of breast cancer survivors suffer from at least moderate FOCR in the Netherlands. However, the study by Custers et al. (2020) revealed that FOCR is not stable over time, and that more than half of the scores of the CWS are fluctuating above as well as below the cut-off score for high FOCR. As this study only investigated one time point, namely approximately one year after treatment at the beginning of the follow-up care, the scores might differ when examining multiple time points. However, the results of 75% reporting FOCR is in line with the study of Koch et al. (2013), who reported FOCR levels ranging from 25% to 97%. It might be the case that other studies have used different instruments to assess FOCR, which might lead to different results (Koch et al., 2013). To validate these high levels of prevalence of FOCR in breast cancer women in their post-treatment phase, it is generally advised to assess FOCR on multiple occasions in future studies. Furthermore, the cut-off score of the CWS might need to be reconsidered. Lower levels of at least severe levels of FOCR were expected, if the fears are beyond the regular extent of worries in breast cancer survivors. Still, these results support prior findings that FOCR is prominent in breast cancer patients. Correspondingly, FOCR it is important to consider in clinical practice. It is important to prevent FOCR as best as possible with the aid of health education or workshops. On the other hand, if breast cancer women do display FOCR it is necessary to provide adequate support like interventions encompassing psychological support.

The second aim of this study was to examine the associations between excessive physical examination and QoL (physical and mental QoL), with FOCR. Generally, 29.1% of the participants reported to examine their body for signs of cancer recurrence on an at least often level. As expected, our results revealed that participants with more FOCR reported more excessive physical examination. This association can be supported by prior research that indicated excessive physical examination as a consequence of FOCR in breast cancer patients (Crist & Grunfeld, 2013; Yang et al., 2019). However, prior research also indicates that physical examination might cause increased tension, fear and anxiety (Allen et al., 2010; Lechner et al., 2004). On the basis of those results, FOCR can cause more excessive physical examination. At the same time excessive physical examination can also cause FOCR. Consequently, FOCR and excessive physical examination might cause a vicious cycle. This means that more FOCR might lead to more excessive physical examination, which in turn can increase FOCR. For future research, it is important to examine whether the vicious cycle can be approved in order to be able to better understand the relationship of FOCR and excessive physical examination. As this study was able to prove that there is a relationship between those variables, for practical implications it can be noted that it is important to include the factor of excessive physical examination in interventions that tackle the issue of FOCR. Thereby, health education could offer a possibility to educate participants about the strategy of physical self-examination in general. According to Lechener et al. (2004), monthly self-examination is recommended for breast cancer patients. Thus, it is important to communicate the need for physical examination without causing the patients to do excessive physical examination. Therefore, health care professionals could conduct an action plan together with their patients in order to schedule the physical examination checks. Moreover, the patients could get advised to keep a logbook in which they can monitor their attitude and feelings when they examine theirselves or when having the urge to do so.

Besides, women with more FOCR indicated worse physical as well as mental QoL. This finding corresponds with the results of previous research that revealed that QoL and FOCR are negatively associated with each other (Cho & Park, 2017; Freeman-Gibb et al., 2017; Yang et al., 2019; Ziner et al., 2012). Both, physical and mental QoL were found to negatively impact FOCR (Koch et al., 2013). To be precise, the negative and low association between physical QoL and a negative moderate association between mental QoL and FOCR reported in this study is comparable to the findings of van den Beuken-van Everdingen et al. (2008). For practice, workshops for enhancing the QoL in breast cancer patients might be beneficial when aiming at reducing FOCR. Concrete workshops about mindfulness have been proven to be effective in improving the QoL among cancer patients (Rosen et al., 2018). Other than that, enhancing engagement in physical activity in breast cancer was proven to be linked to better QoL (Shin et al., 2017). Thus, such workshops might be useful to include in interventions aiming at specifically reducing FOCR in breast cancer patients.

The third aim of this study was to assess the relationship of the demographic characteristics (age, marital status, occupation and education) and levels of health literacy with FOCR. Marital status, occupation and education were not associated with FOCR, which is similar to the findings of previous research (Crist & Grunfeld, 2013; Custers et al., 2015; Freeman-Gibb, 2017; Starreveld et al., 2017). Moreover, older women and women with better health literacy reported less FOCR. Accordingly, this is in line with prior findings that state that age and FOCR are associated (Crist & Grunfeld, 2013; Freeman-Gibb, 2017; Ziener et al., 2012). Since health literacy was not measured to be associated with FOCR beforehand, this association is a unique finding which cannot be compared to other studies. Based on the results of this study, it can be noted that participants with higher levels of health literacy reported less FOCR. Consequently, for practice it can be stated that it is useful to take the factor of health literacy into account. For increasing the level of health literacy, personalized written information like leaflets or websites have shown to be effective when aiming at reducing anxiety and enhancing self-management (Coulter & Ellins, 2007). However, a combination of oral as well as written information was shown to be most effective (Coulter & Ellins, 2007). Hence, it is recommended to offer such personalised written and oral information for breast cancer patients for instance about their condition as well as their risk of recurrence. For the practical implication of the association between age and FOCR, this study aids in terms of identifying a potential at-risk group for interventions that aim at tackling the issue of FOCR in breast cancer patients. Consequently, as younger women seem to be more prone to display FOCR, the focus of interventions should be on younger patients. However, future research is needed to develop adequate age ranges, in which the female breast cancer patients are displaying the highest levels of FOCR.

Further, the goal was to predict which type of risk perception is most predictive concerning FOCR. It can be concluded that both, risk appraisal and comparative risk were significant predictors of FOCR. However, risk appraisal had the most influence on FOCR. Contrary, absolute risk found to have no effect on FOCR. These results are quite novel, as no current available research paper supports these findings. Consequently, these results highlighted that it is important to further validate these findings and take the risk appraisal and comparative risk estimation of breast cancer patients into account when trying to predict the variable FOCR. For practical implication, the health care professionals should inform and educate their patients in terms of their actual risk communicated with a verbal statement as well as their risk compared to other women who had breast cancer. Consequently, it might be possible that adequately communicating the actual risk of a patient in terms of choosing a verbal estimation and compare these estimations to other women with breast cancer, might also influence the breast cancer patients' own perspective with regards to accuracy. If women with high levels of perceived risk appraisal and comparative risk display FOCR, but have actually a low risk of recurrence, education about their actual risk provided by their health care professional could reduce their FOCR. However, this strategy has not been tested to be effective yet and could be important to examine in future studies.

Besides the aims of this study, it was figured out that the participants overall reported similar physical as well as mental QoL as the average female population. This is surprising as research found that women diagnosed with breast cancer reported worse QoL (Trentham-Dietz et al., 2008). In line, research has also shown that breast cancer survivors display worse QoL compared to individuals without cancer (Li et al., 2016) However, other research suggests that QoL in post-treatment patients improves compared to the mid-treatment phase (Costanzo et al., 2007). Since this study exclusively focused on women in their post-treatment phase, it might explain why the participants do not display worse levels of QoL. According to Cho and Park (2017) cancer might also positively influence life, like perceived growth in terms of appreciation of life or consciousness about personal strengths, which might also explain the average QoL in this sample. Further, it has to be noted that the QoL of this sample was compared to the average American female population. However, close resemblance of the Dutch and US norm population was found (Mols et al., 2009).

Strength and Limitations

Generally, a strong point of this study is the focus on breast cancer survivors in the Netherlands. According to the researchers' knowledge, prior research has focused on breast cancer patients that were newly diagnosed or still in treatment. Thus, this paper contributes in terms of the investigation of getting more insights into breast cancer survivors and their FOCR. Specifically, in terms of the prevalence of FOCR in breast cancer survivors as well as association with potential consequences (excessive physical examination and QoL) as well as determinants (demographics and risk perception). This study was able to uniquely assess the association of health literacy and FOCR. Further, this study shed more light on the understudied issue of excessive physical examination in post-treatment patients. Moreover, this paper uniquely contributes to evaluating the impact of the different risk perceptions (absolute risk, risk appraisal, comparative risk) on FOCR concerning breast cancer survivors. Consequently, this paper aids in terms of addressing new topics that require further research.

Furthermore, an asset of this study is an adequate number of participants filled in the survey, despite the sensitive nature of the topic and despite the onset of the COVID-19 pandemic, during which some participants were added to this study.

A major weakness of this study is the cross-sectional study design. Accordingly, all data were measured on one occasion, compared to longitudinal studies in which the variables can change. As indicated above, some variables were found to be changing over time. Thus, it is important to assess the variables at multiple points in time in future research. Furthermore, due to the cross-sectional design, no causal relationship can be established (Freeman-Gibb et al., 2017). Also, no confounding variables could be taken into account. However, for practice it is needed to understand the complexity of the construct of FOCR to adequately be able to tackle the issue. Even though the larger PhD study by Jet Ankersmid included multiple measurement occasions, only one time point was examined in this study. Consequently, for future research it is recommended to adopt another study design like a longitudinal study or randomized controlled trials (RCT) in order to assess the stability of the results and in order to be able to state cause and effect of the variables.

Furthermore, it has to be noted that some of the participants did take part after the COVID-19 pandemic started. Evidence was found that some breast cancer patients reported a decrease in emotional functioning and social functioning and an increase in loneliness due to COVID-19 (Bargon et al., 2020). Accordingly, this variable might be of interest to consider as a confounding variable in the future.

Moreover, the sample is relatively homogenous with regards to the high health literacy without purpose. Thus, the results have a narrower generalizability than purposefully established lower generalizability due to the specific inclusion criteria. This might be due to the fact that the corresponding instrument (SBSQ) displays a low reliability. Based on that, it is recommended for future research to opt for a more heterogeneous sample concerning health literacy by using another instrument.

Conclusion

To conclude, it can be stated that breast cancer women in their post-treatment phase reported severely high levels of FOCR. FOCR was associated with more excessive physical examination and lower QoL. Moreover, higher age and health was related to less FOCR. Furthermore, comparative risk and risk appraisal showed to be predictors for FOCR, while the latter one displayed the most influential predictor. For future research, the direction of the relation of excessive physical examination and FOCR should be tested, to examine whether a vicious cycle can be detected. For practice it can be stated that education and about self-examination as well as advice regarding planning and self-monitoring might help to not let self-examination become obsessive. This in turn might decrease FOCR. Moreover, participants with lower health literacy levels were identified to be at risk for FOCR. Therefore, health literacy providing strategies like personalized written and oral information, might help reducing FOCR in that particular risk group. Moreover, health professionals should educate their patients about their risk verbally and in comparison to other women, in order to enhance proper perceived risk of the participants for decreasing FOCR.

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Appendix 1

Table 1

Skewness and Kurtosis (N=252)

Variable	Skewness Statistic	SE	Kurtosis Statistic	SE
1. Cancer worry	-0.01	0.15	-0.27	0.31
2. Excessive physical examination	-0.45	0.15	0.17	0.31
3. Physical QoL	-0.94	0.15	-0.09	0.31
4. Mental QoL	1.18	0.15	0.78	0.31
5. Absolute risk	0.99	0.15	0.02	0.31
6. Risk appraisal	-0.14	0.15	-0.29	0.31
7. Comparative risk	-0.60	0.15	0.47	0.31
8. Age	-0.19	0.15	-0.27	0.31
9. Marital status	-1.52	0.15	0.77	0.31
10. Occupation	0.26	0.15	-1.95	0.31
11. Education	-0.29	0.15	-0.76	0.31
12. Health literacy	-1.58	0.15	3.04	0.31