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Unmet information needs concerning nutrition experienced by female breast cancer patients treated for primary breast carcinoma in breast care centres in North-Rhine Westphalia, Germany - an evaluation of an intervention study using a fact sheet with basic information regarding nutrition.

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Die dieser Arbeit zugrunde liegenden Datensätze wurden ohne meine Mitarbeit im Rahmen der jährlichen Brustkrebsstudie des Instituts für Medizinsoziologie, Versorgungsforschung und Rehabilitationswissenschaft (IMVR) der Universität zu Köln unter der Leitung von Herrn Prof. Dr. Holger Pfaff zur Verfügung gestellt.

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Die Ergebnisse dieser Auswertungen wurden von mir auf dem jährlichen Benchmark Workshop, der vom IMVR organisiert wird, am 28.11.2017 in Dortmund vorgestellt und ein 90-minütiger Workshop für Vertreter und Vertreterinnen der Kliniken, die an dieser Interventionsstudie teilgenommen haben, geleitet.

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List of Abbreviations

ICC	Intraclass correlation coefficient
DGE	German Nutrition Society (Deutsche Gesellschaft für Ernährung)
IMVR	Institute for Medical Sociology, Health Services Research and Rehabilitation Science
QOL	Quality of life
Ref.	Reference category
SE	Standard error

1. Introduction

1.1 Cancer in general

With globally 17.2 million cancer incidents in 2016 and 24.5 million cancer incidents in 2017, cancer is a socially relevant topic and becomes even more important as incidence rates have been increasing affecting people all over the world[1,2]. In contrast to infectious diseases affecting humanity, such as HIV, tuberculosis or malaria, cancer diseases show a greater variance and require different approaches in terms of prevention, diagnosis, and treatment[1]. The studies of Fitzmaurice et al. describe the global burden of cancer, estimating the number of cancer incidences worldwide with the help of the International Classification of Diseases[1-3]. When it comes to the chance of developing cancer, there are differences by gender: Globally, one in three men and one in four women is likely to experience a cancer diagnosis during their lifetime[2]. Female cancer patients most commonly suffer from nonmelanoma skin cancer, breast cancer and colorectal cancer, while most cancer deaths in female patients occur in breast, TBL (tracheal, bronchus, and lung) and colorectal cancer patients[1,2]. From 2007 to 2017, cancer incidence rates increased while death rates decreased[2]. Data from 2018 shows a shift in the cancer incidences and mortality rates of female patients: The most commonly cancer diagnoses as well as the highest mortality rates are in breast cancer, colorectal cancer, and lung cancer[4].

1.2 Breast cancer

Globally, breast cancer is the most common cause of cancer deaths in women in the years 2015, 2016 and 2017 and the odds of females developing breast cancer during their lifetime is one in 20 in 2016 and one in 18 in 2017[1-3]. On the one hand, the chances of developing breast cancer are higher in high sociodemographic index countries than in middle or low sociodemographic index countries[1,3,5]. On the other hand, mortality rates are higher in low-income-countries[4-6].

As far as new incidences are concerned, breast cancer is the most common cancer cause in German women. Around 69,000 women are diagnosed with breast cancer in Germany every year[7]. In Germany, one in eight women is likely to suffer from breast cancer in her lifetime. One in six women is younger than 50 years at the time of diagnosis[7]. The recent study of Hübner et. al. investigates long-term related incidence and mortality trends in Germany from 1995 to 2016, finding out that breast cancer incidence rates increased while mortality rates decreased[8]. Breast cancer treatment is associated with high healthcare costs that need to be covered by the health insurance institutions in Germany[9]. An early detection of breast cancer leads to an improved prognosis and better chances of survival[10].

A screening programme including mammography screenings of the breast in women aged between 50 and 69 years was started in Germany in 2005[11,12]. After the implementation of the new screening programme, the breast cancer incidence rates showed a typical development: incidence rates quickly increased and slowly decreased over time. Furthermore, screening has led to more women being diagnosed with earlier stages of breast cancer, while diagnoses of late-stage breast cancer decreased[7,8,11-13]. Whether screening programmes for breast cancer, including mammography screenings of the breast, not merely decrease the mortality of breast cancer but lead to overdiagnosis, false-positive results and unnecessary biopsies is debated in the literature controversially[8,10,14,15]. The review of Marmot et al. focuses on literature about the benefits on mortality rates and the chances of overdiagnosis by a breast cancer screening programme implemented in in the United Kingdom, stating that the mortality in women invited to the screening programme can be reduced by 20%[10]. The current calculations of Zielonke et al. show that nearly 21,700 breast cancer deaths per year are prevented in Europe by breast cancer screening programmes. The number of prevented breast cancer related deaths in Europe could be increased significantly, if the screening coverage is optimised[15]. In Germany, the number of detected early-stage breast cancer cases increased by 48.1% in the screening age group from 2005 to 2016 while advanced-stage breast cancer incidence declined by 31.6%[8].

Risk factors for developing breast cancer are a young age at the menarche and a high age at the menopause as well as a higher age at the first birth, childlessness, hormone replacement therapy while and after menopause and a high density of the breast[7,16-18]. Further risk factors are obesity, a small amount of physical activity, ethnicity and the consumption of alcohol or cigarettes[7,16,18,19].

The national cancer institute defines a cancer survivor as a person who has been diagnosed with cancer from the time of cancer diagnosis until the end of life[20]. Globally, a change in the population age structure, an increase in age-specific incidence rates and population growth itself have resulted in an overall increase of breast cancer incidence rates by 35%[2]. On account of improved treatment options and the development of new treatment strategies, the chances of surviving breast cancer have increased remarkably while breast cancer mortality rates have decreased over the years in Germany[8]. The relative five-year survival rate for women with breast cancer in Germany is 88%, the relative ten-year survival rate measures 83%[7]. Taking into consideration the prolonged time a breast cancer patient survives after diagnosis and the fact that incidence rates increased over the past years, the importance of educating patients not only about treatment options and therapy but also about life with breast cancer becomes clear.

1.3 Information needs in cancer patients

Schlegel et al. define an information need as a conscious expression, which can be verbal or nonverbal, of a desire for knowledge to answer clinical questions[21]. Accessing unmet information needs in cancer patients is essential to be able to understand and meet patients' needs, which is a key aspect to guarantee improved care and effective treatment-related decision making[22]. Prioritised ways of receiving information are personal consultations with medical stuff, self-help groups and brochures[23,24]. Personal consultation is valued more by older cancer patients than by younger cancer patients[23]. As individual access to expert knowledge is limited by the resources of the healthcare system, other supporting information tools and sources should be offered[23,24]. Information seeking styles differ, depending on whether the patient is pre- or posttreatment, leading to the idea that in order to meet the unmet needs of cancer patients, their individual situation needs to be kept in mind, so that versatile approaches might be necessary[25].

1.3.1. Unmet information needs in cancer patients in general

Patients diagnosed with cancer have high cancer-related information needs depending on the type of cancer they have been diagnosed with[23,26]. In contrast to these findings, Watanabe et al. state, that unmet needs of cancer survivors are more influenced by their backgrounds, meaning age, gender, treatment course and presence of symptoms than they are influenced by the cancer type[27].

Unmet information needs differ between male and female cancer patients, as the multicentre, epidemiological cross-sectional study of Faller et al. shows: Female patients experience more unmet information needs than male patients and they are more likely to be dissatisfied with the information they receive[23,28]. Furthermore, sociodemographic factors like age, insurance status, financial support and the fact of living alone or with other people influence the information needs of cancer patients[28-32]. Younger cancer patients experience higher levels of cancer-specific distress than older cancer patients, when their needs focusing on information, psychological needs and physical and daily living needs are not met[29]. Unmet information needs, combined with other needs, can contribute to the occurrence of anxiety and depression in younger cancer patients[30].

Unmet information needs in cancer patients focus on general information about the cancer and disease characteristics, schedule and logistics, lifestyle and things you can do to help yourself get well (for example nutrition, supplements, physical activity), costs and epidemiology, heritability, likelihood of a cure, symptoms and available treatments and their side effects[24,31,32].

1.3.2. Unmet information needs in breast cancer patients

Breast cancer patients experience breast cancer-specific information needs. It is undisputed that breast cancer-specific information needs overlap with general cancer-specific information needs. Unmet breast cancer-specific needs cover the fields of information about things you can do to help yourself get well, having access to professional counselling and receiving information about symptoms and side-effects at home[33]. Recognising a recurrence and needing help in coping with the fear of recurrence, chances of cure, breast cancer family risk and antioestrogen therapy are the most commonly fields of female breast cancer information needs[22,34,35]. According to Halbach et al., the most frequently occurring information needs in breast cancer patients focus on side effects and medication, health promotion, medical examination results, treatment options and social issues[36]. Qualitative interviews show that patients have the desire to be informed about self-management of their health, specifically the modification of their lifestyle in terms of nutrition, exercise, and breast self-examination[37]. The current survey of Loeliger et al. comes to similar results concerning nutrition, stating that breast cancer patients as well as carers value nutrition as an important element in their cancer path[38].

Information needs in breast cancer survivors differ from the needs of breast cancer patients at the point of diagnosis: Unmet information needs in breast cancer survivors focus on posttreatment and follow-up consultation coordination, follow-up care, information about local health care services and emotional support provided, return to work and late effects of the treatment[39,40]. The study of Herbert et al. focuses on unmet information needs of breast cancer survivors five years after diagnosis, concluding that unmet information needs concentrate on places of care and things you can do to help yourself. It is suggested that written information might be helpful to meet unmet needs of breast cancer survivors[41]. The multicentre, prospective observational study of Lo-Fo-Wong et al. concentrates on risk factors of breast cancer survivors for experiencing unmet needs on different domains, for example the physical and daily living domain or the psychological domain. Higher age, comorbidities, having had chemotherapy or a mastectomy and the level of distress are significant risk factors for unmet information needs of breast cancer survivors[42].

There are specific sociodemographic factors, such as age, education, cultural factors, native language, and place of residence (rural or urban setting) influencing the prioritisation of information needs experienced by breast cancer patients[22,35,43-49]. As far as the information needs of young breast cancer patients are concerned, fertility and family planning as well as sexual dysfunction due to treatment and menopausal-related concerns are further information needs as women are often diagnosed before they have completed their families[45-47]. Younger age is significantly associated with posttreatment sexual dysfunction in female breast cancer patients regardless of whether they received endocrine therapy or had already been treated for sexual dysfunction[45,50]. 49% of breast cancer patients of all ages surveyed by Reese at al. using web-based baseline self-report surveys, experience unmet information needs concerning sexuality and seek help for their sexual concerns. Reese et al. conclude from their findings that it is essential to give accurate and timely sexual health information to women treated for breast cancer[51]. In addition to sociodemographic characteristics, clinicopathological characteristics such as cancer stage, family history of breast cancer, HER2-receptor-positivity, target therapy or palliative care as well as the psychological status, meaning the level of stress, thoughts of suicide or quality of life (QOL), influence the prioritization of unmet information needs in breast cancer patients[22].

Attempts to survey satisfaction of breast cancer patients with the information provided and to find predictors of patient satisfaction is part of research studies[52,53]. The cross-sectional descriptive survey of Miyashita et al., focuses on the information breast cancer patients receive and on whether the patients are satisfied with that information. Receiving information about topics like follow-up tests, possible symptoms after hospital discharge or lymphedema, does not imply satisfaction with the information provided[53]. Higher levels of satisfaction are observed in patients diagnosed with advanced breast cancer[52]. The cross-sectional study of Ellegaard et al. surveys Danish breast cancer survivors and discovers that all women included in the survey experience at least one unmet need. Receiving understandable up-to-date information is one of the most important unmet needs[39]. Furthermore, culturally sensitive information resources concerning breast cancer as well as a preference for information in the native language of the patients are demanded by breast cancer patients[49].

1.4 Nutrition

The systematic review by Zhang et al. aims to give an overview of the current studies on the connection between lifestyle factors, cancer incidence rates and cancer mortality rates[54]. Studies show that there is a connection between the risk of developing cancer and certain lifestyle factors, such as alcohol consumption, body weight, diet, physical activity, and smoking[54,55]. The metanalysis of Naja et al., gives an overview over the published literature about the connection between dietary patterns in general, the consumption of alcohol, red and processed meat, fruits, vegetables and breast cancer risk, stating that a particular nutrition can help to prevent breast cancer[56]. Six dietary factors that are associated with either a higher risk of breast cancer incidence (alcohol, beer/cider, wine) or a lower risk of breast cancer incidence (fibre, apple/pear, carbohydrates) are identified in a survey of Heath et al., using dietary questionnaires[57]. A connection between adherence to a low carbohydrate diet and increasing odds of breast cancer in postmenopausal women is shown in a hospital-based case-control study[58]. Dietary patterns such as eating out for breakfast and lunch have a significant impact on developing breast cancer[59]. Other studies focus on biochemical nutrient pathways, finding a connection between glycaemic control, insulin levels and breast cancer incidence rates[60,61]. The consumption of sweet foods, especially desserts is positively associated with the breast cancer risk of female patients[61]. Further factors associated with an influence on endogenous insulin levels are physical activity, body size, adult weight gain and alcohol consumption[61]. In the population-based study of Arnold et al., the global burden of cancer attributable to excess BMI is estimated, stating that two thirds of the total cancer burden in female post-menopausal breast cancer and corpus uteri cancer patients are attributed to excess BMI[62]. The study of Harris et al. analyses the usefulness of the eight nutrition-related recommendations for the prevention of cancer published by the World Cancer Research Fund concerning the incidence of breast cancer in Swedish women[63]. A positive association between following nutrition-related recommendations and a decreased risk of developing breast cancer is demonstrated[63]. The current study of Ghosn et al. shows similar results: lifestyle can affect the breast cancer incidence and following certain eating recommendations leads to a significant lower odd of breast cancer occurrence[64]. The nutrition recommendations that are used in the cited studies all correspond to the criteria of a healthy nutrition, recommended by the German Nutrition Society (DGE)[65]. The DGE is an independent association in Germany that pursues the goal of showing the need for research on nutrition and educating the German population regarding nutrition and diet[66].

Not only in connection with prevention of breast cancer but also in connection with decreasing the risk of death as a result of breast cancer, research studies indicate that a low-fat dietary pattern that includes increased vegetable, fruit and grain consumption might be helpful[67,68]. Another prospective cohort study does not show associations between whole grain intake or total dairy products and breast cancer prognosis, but finds that the consumption of oatmeal or muesli might be a protective factor influencing the mortality positively after diagnosis[69]. An increased post-diagnostic diet quality in female breast cancer survivors shows a significant inverse association with mortality rates[70]. There are many different articles focusing on the pros and cons of vitamins and supplement use, such as antioxidant intake or vitamins B, C, D and E with inconsistent results concerning cancer incidence, mortality, and survival[71-75].

1.5 Aim of the study

The results of the annual breast cancer patients survey in North Rhine-Westphalia, Germany, show that breast cancer patients experience an unmet information need concerning nutrition. In 2016, 39.9% of the female breast cancer patients would have liked to receive more information about nutrition (n=4,489)[76].

This intervention study aims to improve the unmet information need concerning nutrition experienced by female breast cancer patients in North Rhine-Westphalia, Germany, by using a fact sheet with basic information about nutrition. The fact sheet does not focus on a specific breast cancer diet or supplement use but includes basic knowledge about a wholefood, balanced diet. Earlier studies attempting to decrease unmet information needs and distress in breast cancer patients and to increase their QOL using information-based, breast cancer specific websites or programmes, showed inconsistent results[77-80]. As far as we know, this is the first intervention study at this point in time which tries to decrease unmet information needs in female breast cancer patients concerning nutrition using a fact sheet with basic information about nutrition.

2. Material and method

2.1 Material

The Institute of Medical Sociology, Health Services Research and Rehabilitation Science (IMVR) of the University of Cologne conducts an annual survey that depicts the situation of breast cancer patients in North Rhine-Westphalia and allows a standardised summary of the quality of care. Patients included in the annual survey are diagnosed with primary breast carcinoma and undergo surgery in a breast care centre in North Rhine-Westphalia during the survey period[81]. The medical association of Westphalia-Lippe accredits breast care centres in North Rhine-Westphalia that are participating in the survey of the IMVR in order to observe whether the criteria for breast care centre accreditation are met from the patients' points of view[81].

Since 2006, the study has been carried out annually between 1st February to 31st July. The Cologne Patients Questionnaire for Breast Cancer (CPQ-BC) was designed to address the specific needs of breast cancer patients. It was edited and changed in 2012 (Cologne Patients Questionnaire for Breast Cancer 2.0 (CPQ-BC 2.0)) to reduce ceiling effects and to be able to derive information with greater practical relevance. The aim is to enable the participating breast care centres to compare themselves with other breast care centres and to improve their quality of care[81]. Additionally to an annual benchmark workshop, each breast care centre receives written feedback from the IMVR after a survey period, that shows the results of each breast care centre and allows their comparison[81]. Sociodemographic information as well as the subjective perception of treatment, hospital stay, communication and convalescence are included in the questionnaire. Furthermore, the medical staff passes on the clinical data such as cancer staging, grading, type of procedure or operation that is performed and further treatment to the IMVR[81]. Scales that are included are hospital organisation, hospital services, quality of the patient's interactions with physicians or the nursing staff, psychosocial information needs, involvement in treatment and discharge[81]. In 2017 the Cologne Patients Questionnaire for Breast Cancer 3.0 (CPQ-BC 3.0) was used.

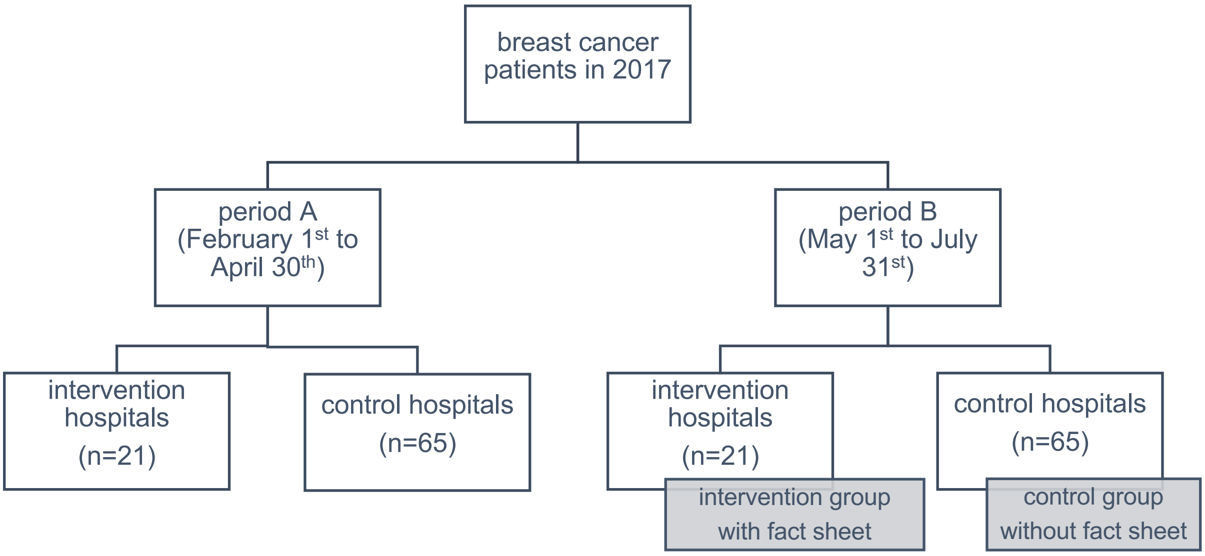
The survey of 2016 shows that there is unmet information need regarding nutrition in female breast cancer patients treated in a breast care centre in North Rhine-Westphalia[76]. An intervention to improve the unmet information need of breast cancer patients concerning nutrition was planned for the survey period of 2017. The idea of developing a nutrition fact sheet was formed at the benchmark workshop in 2016, where representatives of the breast care centres were invited to discuss the most relevant findings of that years' survey.

The fact sheet was developed in cooperation with the CIO, the Centre of Integrated Oncology Aachen, Bonn, Cologne, Düsseldorf (ABCD). With the kind help of Carmen Strauch, leading nutritionist at the CIO, a two-page fact sheet was designed, including basic knowledge about a wholefood, balanced diet. Furthermore, the ten rules of a healthy diet published by the DGE were included[82]. The aim was to develop a fact sheet that is understood by many people of different ages, cultural backgrounds and native or non-native speakers. Therefore, no technical terms or foreign words were used, and the fact sheet was written in simple language. Please see the fact sheet in the appendix.

To compare the quality of care in one hospital in the same year, taking into consideration the intervention, an experimental study design is required, in which the distribution of the fact sheet is cluster-randomised. As cluster-randomisation is not possible, due to organisational processes in the breast care centres, a quasi-experimental study design is created to reduce variations such as employee changes, management or clinic restructuring. This quasi-experimental study design allows the comparison of the quality of care in one hospital in the same year, making it possible to compare the unmet information need concerning nutrition of patients who are treated in the same hospital and who possibly receive and do not receive the fact sheet. The whole survey period of 2017 stretches from 1 February to 31 July. It is divided into two periods: Period A, stretching from 1 February to 30 April, is called the control period because no fact sheets are distributed. Period B, stretching from 1 May to 31 July, is called intervention period because the fact sheets are distributed in the intervention hospitals. The breast cancer patients treated in the intervention period can be clustered into two groups: the control group, including patients that are treated in hospitals that do not distribute fact sheets, and the intervention group in which fact sheets are distributed in the respective hospitals. Please see figure 1: Quasi experimental study design of the intervention study.

As the distribution of the fact sheet is organised by the hospitals themselves, it cannot be guaranteed that every breast cancer patient who is treated in an intervention hospital in the intervention period (= intervention group) receives the fact sheet. In the following, the term “possibly receiving the fact sheet” refers to patients in the intervention group.

Figure 1: Quasi experimental study design of the intervention study.



2.2 Method

The dichotomised item: “Would you have liked to receive more information regarding nutrition from your breast care centre”, is used to measure the unmet information need in female breast cancer patients in the survey period of 2016 (n=4489) and 2017 (n=4626) and the answers are compared. Moreover, sociodemographic information such as age, highest educational attainment and native language are reported by the breast cancer patients themselves. This sociodemographic information is associated with the unmet information need concerning nutrition experienced by the breast cancer patients. Only answers from female breast cancer patients are taken into consideration, as the number of cases of male breast cancer patients in this intervention study does not allow reliable statements about gender-specific differences in information needs.

In order to analyse unmet information need regarding nutrition experienced in female breast cancer patients descriptively, the IBM SPSS Statistics version 25 is used. Intercorrelations are checked by calculating either Pearson or Spearman correlation coefficients and chi-square tests are conducted. Due to listwise deletion, cases with missing data for the dependent and independent variables are excluded.

With the kind support of Dr. Sophie E. Groß, a multilevel analysis is carried out using Stata version MP15. The multilevel analysis takes into consideration the clustering of patients in the individual breast care centres in North Rhine-Westphalia. This is an attempt to explain the information need experienced at an organisational level. The null model does not include the self-reported sociodemographic characteristics recorded in the survey and tries to explain the variance in information need that is attributed to the hospitals themselves. It consists of data from all female breast cancer patients in the whole survey period (period A and B). Model I takes into consideration sociodemographic characteristics such as age, education and native language and tries to explain the variance in information need under control of these characteristics, not taking into account the intervention variable (possibly receiving the fact sheet). The full model takes into consideration the intervention variable (possibly receiving the fact sheet) when trying to explain the variation in unmet information need, also controlling for the sociodemographic characteristics age, education, and native language. Model I and the full model only include patients that are treated during the intervention period (period B) of the survey period of 2017.

3. Results

3.1 Descriptive results

The response rate of returned questionnaires is 86.9% in 2016 and 89% in 2017. The unmet information need experienced by female breast cancer patients concerning nutrition is 39.9% in 2016 and 39.4% in 2017.

3.1.1. Study population

Answers of 4,626 female breast cancer patients are analysed. Table 1 shows the demographic characteristics of the study population (sample) as well as the demographic characteristics of the patients clustered in the intervention group and control group in 2017.

When looking at the age of the study population, the majority of patients is aged between 50-59 years (28.9%) and 60-69 years (28.0%). Only 0.5% of the patients are aged between 18-29 years, 3.1% are aged between 30-39 years and 7.5% of the patients are aged 80 years or older. The median age is 61 years, the maximum age is 97 years, and the minimum age is 24 years. There are no identifiable group differences, tested via chi-square tests, comparing the intervention group to the sample concerning age (p=0.41).

As regards the highest educational attainment, 2.0% of the patients do not have a school graduation certificate. 23.0% achieved a lower secondary school certificate, 16.3% achieved an intermediate secondary school certificate and 28.1% successfully completed junior high school. 11.9% graduated from an upper secondary school and 18.7% achieved A levels. Trying to identify significant group differences in terms of the highest educational attainment, chi-square tests are conducted. The chi-square tests do not show significant group differences between the intervention group and the sample (p=0.467).

When looking at the native language of breast cancer patients in this study, 92.3% are German native speakers, while 7.7% are non-native German speakers. When comparing the intervention group with the sample chi-square tests do not show any group differences (p=0.097).

All in all, the intervention group does not differ from the whole sample of 2017 concerning age, educational attainment achieved and native language, as shown by the conducted chi-square tests. This means that a bias of the data due to differences in the intervention group compared with the whole sample is not expected.

Table 1: The demographic characteristics of 4,626 female breast cancer patients who are included in the intervention study.

	Sample (overall data from 2017) (n)	**Intervention group** (possibly receiving the fact sheet) (n)	**Control group** (not receiving the fact sheet) (n)
Age			
Median	61 years	61years	60 years
18-29 years	0.5% (21)	0.9% (5)	0.5% (8)
30-39 years	3.1% (144)	4.3% (24)	3.4% (58)
40-49 years	13.3% (608)	13.7% (76)	13.2% (225)
50-59 years	28.9% (1324)	29.7% (165)	28.2% (482)
60-69 years	28.0% (1283)	26.8% (149)	27.7% (474)
70-79 years	18.8% (863)	17.6% (98)	18.9% (323)
80 years or older	7.5% (342)	7.0% (39)	8.2% (141)
Total	100% (4585)	100%[a] (556)[a]	100% (1711)
Highest graduation certificate achieved			
Without school graduation certificate	2.0% (90)	2.4% (13)	1.4% (24)
Lower secondary school	23.0% (1035)	20.6% (113)	24.3% (406)
Intermediate secondary school	16.3% (733)	16.1% (88)	14.8% (248)
Junior high school	28.1% (1263)	27.0% (148)	28.1% (471)
Upper secondary school	11.9% (533)	13.3% (73)	11.5% (193)
A levels	18.7% (842)	20.6% (113)	19.8% (332)
Total	100% (4496)	100%[b] (548)[b]	100% (1711)
Native Language			
German	92.3% (4179)	94.0% (519)	92.6% (1565)
Another native language	7.7% (351)	6.0% (33)	7.4% (125)
Total	100% (4530)	100%[c] (552)[c]	100% (1711)

[a] Group differences comparing the intervention group with the overall data of 2017: Chi-square test (Pearson) p=0.41

[b] Group differences comparing the intervention group with the overall data of 2017: Chi-square test (Pearson) p=0.467

[c] Group differences comparing the intervention group with the overall data of 2017: Chi-square test (Pearson) p=0.097

3.1.2. Unmet information need concerning nutrition

Out of 4,475 valid responses in 2017, 39.4% (n=1,762) of the female breast cancer patients experience an unmet information need concerning nutrition. When looking at the patients' characteristics taking into account the unmet information needs experienced, the following trends are identifiable.

Age seems to be a demographic factor influencing the unmet information need experienced, as can be seen in table 2. Table 2 compares the overall data from 2017 to the intervention group and the control group in 2017 regarding information need experienced.
Increased unmet information need concerning nutrition is shown in the age cohorts 18-29 years (42.9%), 30-39 years (50.0%), 40-49 years (44.6%) and 50-59 years (43.5%). The older the breast cancer patient, the less information need is experienced, as can be seen in the age cohorts 60-69 years (36.5%), 70-79 years (35.2%) and 80 years and older (29.3%). Looking at the connection between age and unmet information need concerning nutrition, significant group differences are identified in the sample of 2017 ($p\leq0.001$).

The connection between the unmet information need experienced concerning nutrition and the highest educational attainment of the breast cancer patients is shown in table 3. Table 3 compares the overall data from 2017 to the intervention group and the control group in 2017 regarding information need experienced. The highest unmet information need concerning nutrition shows in patients achieving an upper secondary school graduation (47.1%) or A levels (43.8%) and in patients that did not achieve any graduation certificate (41.6%). The lowest unmet information need is experienced by patients with a lower secondary school graduation (32.4%). 37.3% of patients that achieved an intermediate secondary school certificate and 40.0% of patients that successfully completed junior high school experience unmet information needs concerning nutrition. Looking at the highest educational attainment and unmet information need concerning nutrition, significant group differences are identified in the sample of 2017 ($p\leq0.001$).

Native language is a sociodemographic factor affecting the unmet information need concerning nutrition that is experienced by breast cancer patients (see table 4). Table 4 compares the overall data from 2017 to the intervention group and the control group in 2017 regarding information need experienced. 38.6% of German native speakers and 49.9% of non-native German speakers experience an unmet information need concerning nutrition. As well in terms of native language and unmet information need concerning nutrition, significant group differences are identified in the sample of 2017 ($p\leq0.001$).

Table 2: Comparing the overall data from 2017 to the intervention group and the control group in 2017 regarding information need experienced concerning nutrition.
Looking at female breast cancer patients; separated into seven age-groups.

	Information need?	*18-29 years % (n)*	*30-39 years % (n)*	*40-49 years % (n)*	*50-59 years % (n)*	*60-69 years % (n)*	*70-79 years % (n)*	*80 + years % (n)*	*Missing age-group (n)*	*All age-groups % (n)*	*Total % (n)*
Overall data in 2017	Yes	42.9% (9)	50.0% (72)	44.6% (269)	43.5% (568)	36.5% (456)	35.2% (284)	29.3% (90)	- (3)	39.4%[a] (1748)	100% (1751)
	No	57.1% (12)	50.0% (72)	55.4% (334)	56.5% (739)	63.5% (792)	64.8% (522)	70.7% (217)	- (1)	60.6% (2688)	100% (2689)
Intervention group (possibly receiving the fact sheet)	Yes	20.0% (1)	29.2% (7)	32.9% (25)	39.6% (65)	25.7% (37)	29.7% (27)	24.2% (8)	- (0)	31,7%[b] (170)	100% (170)
	No	80.0% (4)	70.8% (17)	67.1% (51)	60.4% (99)	74.3% (107)	70.3% (64)	75.8% (25)	- (1)	68.3% (367)	100% (368)
Control group (not receiving the fact sheet)	Yes	50.0% (4)	60.3% (35)	46.6% (103)	42.5% (203)	35.9% (165)	36.7% (110)	31.0% (40)	- (-)	39.9%[c] (660)	100% (660)
	No	50.0% (4)	39.7% (23)	53.4% (118)	57.5% (275)	64.1% (295)	63.3% (190)	69.0% (89)	- (-)	60.1% (994)	100% (994)

[a] Group differences within the overall data from 2017: Chi-square test (Pearson) p≤0.001

[b] Group differences within the intervention group (possibly receiving the fact sheet): Chi-square test (Pearson) p=0.195

[c] Group differences within the control group (not receiving the fact sheet): Chi-square test (Pearson) p≤0.001

Table 3: Comparing the overall data from 2017 to the intervention group and the control group in 2017 regarding information need experienced concerning nutrition. Looking at female breast cancer patients; separated into groups according to the highest educational attainment achieved.

	Information need?	*Without school graduation certificate* *%* *(n)*	*Lower secondary school* *%* *(n)*	*Intermediate secondary school* *%* *(n)*	*Junior high school* *%* *(n)*	*Upper secondary school* *%* *(n)*	*A levels* *%* *(n)*	*Missing graduation certificate* *%* *(n)*	*All groups* *%* *(n)*	*Total* *%* *(n)*
Overall data in 2017	Yes	41.6% (37)	32.4% (314)	37.3% (265)	40.0% (494)	47.1% (248)	43.8% (363)	- (30)	39.5%[a] (1721)	100% (1751)
	No	58.4% (52)	67.6% (655)	62.7% (446)	60.0% (741)	52.9% (278)	56.2% (466)	- (51)	60.5% (2638)	100% (2689)
Intervention group (possibly receiving the fact sheet)	Yes	46.2% (6)	24.0% (25)	34.5% (29)	33.6% (49)	31.5% (23)	33.6% (37)	- (1)	31.9%[b] (169)	100% (170)
	No	53.8% (7)	76.0% (79)	65.5% (55)	66.4% (97)	68.5% (50)	66.4% (73)	- (7)	69.1% (361)	100% (368)
Control group (not receiving the fact sheet)	Yes	37.5% (9)	35.4% (135)	38.0% (93)	40.5% (185)	49.5% (94)	40.8% (133)	- (11)	39.9%[c] (649)	100% (660)
	No	62.5% (15)	64.6% (246)	62.0% (152)	59.5% (272)	50.5% (96)	59.2% (193)	- (20)	60.1% (974)	100% (994)

[a] Group differences within the overall data from 2017: Chi-square test (Pearson) p≤0.001

[b] Group differences within the intervention group after May (possibly receiving the fact sheet): Chi-square test (Pearson) p=0.443

[c] Group differences within the control group (not receiving the fact sheet): Chi-square test (Pearson) p=0.051

Table 4: Comparing the overall data from 2017 to the intervention group and the control group in 2017 regarding information need experienced concerning nutrition. Looking at female breast cancer patients; separated into groups according to the patient's native language.

	Informaiton need?	*Native speaker (German)* *%* *(n)*	*Non-native German speaker* *%* *(n)*	*Missing native language* *%* *(n)*	*All groups* *%* *(n)*	*Total* *%* *(n)*
Overall data in 2017	Yes	38.6% (1560)	49.9% (171)	- (20)	39.5%[a] (1731)	100% (1751)
	No	61.4% (2484)	50.1% (172)	- (33)	60.5% (2656)	100% (2689)
Intervention group (possibly receiving the fact sheet)	Yes	31.6% (158)	36.4% (12)	- (5)	31.9%[b] (170)	100% (175)
	No	68.4% (342)	63.6% (21)	- (2)	68.1% (363)	100% (365)
Control group (not receiving the fact sheet)	Yes	38.9% (589)	50.0% (61)	- (10)	39.8%[c] (650)	100% (660)
	No	61.1% (924)	50.0% (61)	- (9)	60.2% (985)	100% (994)

[a]Group differences within the overall data of 2017: Chi-square test (Pearson) p≤0.001
[b]Group differences within the intervention group (possibly receiving the fact sheet): Chi-square test (Pearson) p=0.570
[c]Group differences within the control group (not receiving the fact sheet): Chi-square test (Pearson) p=0.016

3.1.3. Intervention effect on subgroups

Comparing the control group with the intervention group, the unmet information need experienced is reduced significantly by 8.3 percentage points from 39.9% in the control group to 31.6% in the intervention group, as calculated via a chi-square test (p≤0.01).

The unmet information need concerning nutrition decreases most in breast cancer patients aged 30-39 years: from 60.3% in the control group to 29.2% in the intervention group. The second highest decrease is recorded in the age cohort 18-29 years where a total reduction of 30 percentage points is recorded (from 50.0% in the control group to 20.0% in the intervention group). Breast cancer patients aged between 50-59 years experience the smallest decrease with a reduction of 2.9 percentage points in unmet information need (from 42.5% in the control group to 39.6% in the intervention group, see table 2).

The highest decrease in unmet information need concerning nutrition is found in patients who had achieved upper secondary school graduation certificates (by 18 percentage points from 49.5% in the control group to 31.5% in the intervention group), A levels (by 7.2 percentage points from 40.8% in the control group to 33.6% in the intervention group) and junior high school graduation certificates (by 6.9 percentage points from 40.5% in the control group to 33.6% in the intervention group). Breast cancer patients in the intervention group who had not achieved any school graduation certificate experience higher levels of unmet information need concerning nutrition in comparison to breast cancer patients being in the control group (see table 3).

With a decreased unmet information need by 13.6 percentage points from 50.0% in the control group to 36.4% in the intervention group non-native German speakers benefit more from the distribution of the fact sheet than native German speakers (reduction by 7.3 percentage points from 38.9% in the control group to 31.6% in the intervention group, see table 4).

No significant group differences in terms of age (p=0.195), education (p=0.443) and native language (p=0.570) are identified, comparing patients with unmet or met information needs within the intervention group (see tables 2,3 and 4).

3.2 Multilevel analysis

The hierarchical structure of the data with patients nested within hospitals requires multilevel modelling to account for clustering[83]. Table 5 shows the models, that are used for the multilevel analysis. The null model that is used to calculate the interclass correlation coefficient (ICC), does not include any predictors. The ICC allows a diversion of the variation of the dependent variable (information need) between the different hospitals. Model I includes patients' characteristics such as age, education and native language and does not take into accout the intervention variable (possibly receiving the fact sheet). The intervention variable (possibly receiving the fact sheet) is added to the predictors in the full model. Listwise deletion reduces the number of female breast cancer patients to 2,192 patients in the null model, clustered in 86 hospitals. Model I consists of 2,181 female breast cancer patients and the full model consists of 2,168 female breast cancer patients, clustered in 84 hospitals each.

As already mentioned above, descriptive results show a statistically significant relationship between the unmet information need concerning nutrition and patients' characteristics such as age, education and native language (see tables 2, 3 and 4). When taking into consideration patients' characteristics (age, education, and native language) (model I), education and native language are no longer significantly associated with the unmet information need regarding nutrition, while age remains a significant predictor explaining the unmet information need experienced (table 5). Even with the addition of the intervention variable in the full model (possibly receiving the fact sheet), age is still significantly associated with a higher unmet information need concerning nutrition.

Possibly receiving the fact sheet (intervention variable) is significantly associated with a higher chance of a met information need (OR = 1.45; p≤0.05) under the control of sociodemographic variables (full model). A higher age is also significantly associated with a higher chance of a met information need (OR 1.02; p≤0.05) (full model) (see table 5).

Table 5: Results from the multilevel logistic regression analysis; odds ratios (95% confidence intervals). Taking into account female breast cancer patients that are treated in the intervention period.

	nullmodel	**model I**	**full model**
Possibly receiving the fact sheet (intervention variable)	**-**	**-**	**1.45 (1.09 – 1.92)**
Ref. no fact sheet			
Age	**-**	**1.02 (1.01 – 1.02)**	**1.02 (1.01 – 1.02)**
Highest graduation certificate achieved			
Without school graduation certificate	-	0.93 (0.46 – 1.88)	0.85 (0.42 – 1.73)
Lower secondary school	-	1.04 (0.76 – 1.42)	1.03 (0.75 – 1.41)
Intermediate secondary school	**-**	1.06 (0.78 – 1.44)	1.04 (0.77 – 1.41)
Junior high school	-	0.99 (0.77 – 1.28)	0.97 (0.75 – 1.26)
Upper secondary school ***Ref. Abitur***	-	0.80 (0.59 – 1.06)	0.79 (0.57 – 1.08)
Native language German ***Ref. foreign speaker***		0.75 (0.53 -1.06)	0.75 (0.53 – 1.05)
***n* patient**	2192	2181	2168
***n* hospitals**	86	84	84
ICC	0.04	0.04	0.03
Random-effects parameters hospital level estimate (SE)	0.35 (0.07)	0.35 (0.05)	0.32 (0.08)

statistically significant odds ratios are in boldface;
abbreviation: Ref.: reference category; ICC: Intra-class correlation coefficient, SE: standard error

4. Discussion

4.1 Unmet information need concerning nutrition

This intervention study shows that possibly receiving a fact sheet with basic information about nutrition significantly reduces the information need concerning nutrition experienced by female breast cancer patients treated for primary breast carcinoma in a breast care centre in North Rhine-Westphalia, Germany. In this intervention study the unmet information need concerning nutrition is reduced significantly by 8.3 percentage points from 39.9% in the control group to 31.7% in the intervention group. The multilevel analysis comes to the same result: possibly receiving the fact sheet leads to a significantly higher chance of a covered information need concerning nutrition. The latest research of Loeliger et al. supports our findings: Nutrition is an important topic for breast cancer patients. However, accessibility of information concerning nutrition is described as worthy of improvement by Australian breast cancer patients[38].

4.2 Sociodemographic factors influencing unmet information need

Descriptively, sociodemographic factors as age, education and native language seem to have an influence on the unmet information need experienced by female breast cancer patients in this intervention study.

4.2.1. Age

Younger breast cancer patients (age cohorts 18-29, 30-39, 40-49 and 50-59 years) experience higher unmet information needs than older breast cancer patients (age cohorts 60-69, 70-79 and 80 years and older). Moreover, younger breast cancer patients in the intervention group, possibly receiving the fact sheet, experience the highest reduction in unmet information need (30 percentage points in the age cohort 18-29 years and 31.1 percentage points in the age cohort 30-39 years). The multilevel analysis reveals that the demographic factor age is already significantly associated with unmet information need, without considering the intervention variable (possibly receiving the fact sheet). This means that younger breast cancer patients experience higher unmet information needs concerning nutrition independently of the intervention. That age is a demographic characteristic influencing the prioritisation of unmet information needs has been shown in many other studies, focusing on fertility and family planning as well as sexual dysfunction due to treatment and menopausal-related concerns[43,45-47].

This intervention study shows that not only fertility and family planning as well as sexual dysfunction are important topics for breast cancer patients, but that nutrition is another important aspect, younger breast cancer patients specifically are interested in. The importance of meeting unmet information needs in younger cancer patients becomes clear, knowing that higher levels of cancer-specific distress are reported in younger cancer patients when their information needs are not met[29]. Furthermore, unmet information needs can contribute to the occurrence of anxiety and depression in younger cancer patients[30].

4.2.2. Education

In this study, education is a sociodemographic factor that influences unmet information need concerning nutrition on the descriptive level as well: Breast cancer patients that had achieved an upper secondary school graduation certificate or A levels experience higher information needs than patients with other school graduation certificates. Besides, breast cancer patients that had not achieved any school graduation certificate experience high information needs concerning nutrition as well.

Looking at the intervention group, breast cancer patients with higher school graduation certificates (A levels, upper secondary school, and junior high school) experience a higher reduction in unmet information need than patients with lower school graduation certificates. The findings of this intervention study go along with other research studies that show that education is a sociodemographic factor that does not only influence the prioritisation of information needs but does associate with a high thirst of knowledge about the cancer disease[25,43].

4.2.3. Native language

The importance of linguistically appropriate information and the need experienced by breast cancer patients to receive understandable and up-to-date information is surveyed in different studies[35,39,49]. Being able to understand the information breast cancer patients receive in form of written information, is essential to enable women to look at the big picture and understand the scale and consequences of their decision making[35]. Culturally sensitive information resources as well as information in the native language are demanded by breast cancer patients[49]. Therefore, cultural aspects need to be kept in mind when focusing on meeting information needs of breast cancer patients.

The descriptive results of this intervention study show that, above all, non-native German speakers experience higher levels of unmet information need concerning nutrition. Finding understandable and culturally sensitive information seems to be a problem of breast cancer patients in Germany. Furthermore, non-native German speakers benefit more than native German speakers from a fact sheet that is written in easy-to-understand language and that does not include technical terms or foreign words. Taking into consideration our findings and the existing literature regarding information needs in breast cancer patients, one can conclude that information needs should be covered in a conscientious and comprehensive manner to decrease the variety of unmet information needs experienced in breast cancer patients.

4.3 Information seeking styles

Breast cancer patients in general tend to be active in their information seeking, meaning they search more actively for information than patients diagnosed with other cancer types[25]. The study of Eheman et al. analyses information seeking preferences of cancer patients at different points of their cancer diagnosis (pre- and posttreatment) and relates them to sociodemographic characteristics. Younger age and higher levels of education are associated with more active styles of seeking information[25]. Higher education is associated with an increased enthusiasm for being informed about different treatment options[43]. Furthermore, younger age and higher education lead to breast cancer patients feeling well-informed as well as being able to use active decision making[43]. These findings could be an explanation why younger and higher educated breast cancer patients benefit more from being in the intervention group and therefore possibly receiving the fact sheet than older and less educated patients as shown in the descriptive results of this intervention study. It also supports our finding from the multilevel analysis that younger age in general is significantly associated with a higher information need concerning nutrition.

Patients that have completed their treatment are more likely to develop passive information seeking styles[25]. The favourable timepoints when information should be provided are at early stages of diagnosis and treatment as well as post-treatment[38]. As the breast cancer patients that are included in the survey of the IMVR are diagnosed with primary breast carcinoma in a breast care centre in North Rhine-Westphalia within the survey period, they can be categorised as active information seeking patients, according to the findings of Eheman et al[25]. Furthermore, the information is provided at an early stage of diagnosis, which is a favourable time for providing information to a breast cancer patient according to Loeliger et al[38].

Recalling that the unmet information need concerning nutrition is reduced by 8.3 percentage points from 39.9% in the control group to 31.7% in the intervention group, a fact sheet seems to be a feasible instrument to reduce unmet information need significantly as it seems to meet the information seeking strategies of the breast cancer patients included in this study.

4.4 Meeting unmet information needs

Previous studies, aiming to decrease unmet information needs in breast cancer patients and to increase the QOL show inconsistent results[77-80]. The QOL is linked directly to unmet information needs in young breast cancer patients, when comparing their QOL-scales to their satisfaction with the breast cancer related information they receive[53]. The psychological morbidity is reported more distinctively in younger female breast cancer patients than in older ones after diagnosis leading to the assumption that younger women are affected more negatively by a breast cancer diagnosis which leaves them with significant QOL issues that may last past diagnosis[79]. The randomised controlled trial of White et al. surveys whether access to an information-based, breast cancer specific website reduces distress, specifically anxiety and depression, and increases the QOL in young breast cancer patients. The website is subdivided into 3 stages of breast cancer therapy: diagnosis, treatment, and survivorship. Furthermore, emotional responses, support services, family responses and life after cancer are addressed[77]. White et al. could not establish proof of an intervention effect, finding no statistically significant difference between unmet information needs, depression, anxiety or QOL in the intervention group and the Usual Care Group. It is indicated that there might be a positive effect on the time needed until the QOL improves after diagnosis and that the intervention study increases the awareness of other available internet resources. Nevertheless, access to an information based, breast cancer specific website does not reduce the number of consultations with health professionals[77]. The randomised controlled trial of Ryhänen et al. reveals similar results: An intervention effect on QOL, anxiety and management of treatment-related side effects using an internet-based breast cancer patient pathway programme, which is a patient education website with the main goal of empowering breast cancer patients, could not be shown[80]. An intervention study trying to find out whether a 16-week web-based self-management programme in comparison to care as usual has positive effects on the reduction of distress and fears of cancer recurrence, fatigue and general cancer-related distress is conducted by Van den Berg et al. In the beginning, breast cancer patients seem to experience a reduction in distress with a statistical significance. Over the time of breast cancer treatment and survivorship (6 to 10 months) the intervention effect vanishes[78].

To conclude, the mentioned research studies above show inconsistent results and are not able to show an intervention effect, as it is shown in our intervention study, reducing unmet information need concerning nutrition in female breast cancer patients significantly. What needs to be kept in mind, when comparing the previous literature mentioned to the intervention study conducted, is that the intervention study of the IMVR does not give information about unmet information needs of breast cancer patients at different points in their cancer journey, only focuses on unmet information need concerning nutrition and does not take into account QOL, distress or anxiety of the breast cancer patients.

Current research focuses on implementing smartphone apps to keep up with the rapid development of information science and technology and improve person-centred care for patients diagnosed with cancer[84-87]. The study of Richards et al. focuses on cancer patients' needs and wishes concerning app features, anticipated benefits and barriers and potential disadvantages of an app in order to design an app tailored to the special needs of cancer patients[85]. Self-management support in the form of information about treatment-related side effects, cancer support service and lifestyle changes such as diet, exercise and smoking are topics cancer patients categorise as important information[85]. A smartphone app designed by Livingston et al., provides information, support services, clinical trials information and allied health resources with the aim to reduce distress and unmet needs of newly diagnosed cancer patients during treatment and into survivorship[84]. Significant differences in unmet needs among newly diagnosed cancer patients, comparing the intervention group and the control group, could not be shown but there might be improvements in the overall distress in patients using the smartphone app[84]. Although this study focuses on cancer patients newly diagnosed with all forms of cancer, over half of the study population is diagnosed with breast cancer. This allows the assumption that the findings of Livingston et al. are applicable to breast cancer specific outcomes. Sociodemographic factors such as age or education seem to have an influence on the acceptance and evaluation of a smartphone app as well as on the effort that is needed to understand how to use a smartphone app designed for breast cancer patients[86]. The blind, noninferiority randomised controlled trial of Bibault et al. aims to find out whether a difference concerning the satisfaction to breast cancer-related answers given by chatbots versus answers given by health care professionals is reported by French breast cancer patients[87]. A chatbot potentially helps with minor health problems by answering the breast cancer patient's question in a personalised text message. Therefore, the amount of doctor's appointments due to minor health concerns might be reduced. As individual access to expert knowledge is limited by the resources of the healthcare system, this might have a positive effect on the quality of care as health care professionals spend more time treating patients who need a consultation the most[23,24,87].

Looking at the studies mentioned above, what needs to be kept in mind is that often QOL, distress, anxiety and depression are evaluated, not only looking at the unmet information need experienced. The intervention study of the IMVR only focuses on meeting the unmet information need of female breast cancer patients concerning nutrition measured by a dichotomised item and does not consider patient-reported outcomes and does not measure QOL, distress, anxiety, or depression. Furthermore, this intervention study does not take into consideration the different stages of breast cancer diagnosis and treatment as the breast cancer patients included in the study are diagnosed with primary breast cancer in a breast care centre in North Rhine-Westphalia in the study period of 2017. A fact sheet, as it is used in this intervention study, is a printed sheet that is handed out to the breast cancer patient directly and does not require internet access, technical requirements such as a computer, tablet or a smartphone in order to download a certain app. Considering the median age of 61 years of the female breast cancer patients in this intervention study, a written fact sheet that is printed and handed out to the patient directly seems to be advantageous in comparison to an online programme, or a smartphone app in order to decrease unmet information needs concerning nutrition in breast cancer patients.

4.5 Nutrition and breast cancer

The fact sheet that is used in this intervention study was developed in cooperation with the Centre of Integrated Oncology Aachen, Bonn, Cologne, Düsseldorf with the kind help of the leading nutritionist Carmen Strauch. As our literature research shows, there is a quantity of literature about the connection between nutrition and breast cancer risks or mortality rates with inconsistent results[54-64,67-75]. One can draw the conclusion that more research is needed to make a reliable statement of favourable dietary patterns and nutrition for female breast cancer patients when it comes to improvement of mortality rates. Therefore, the fact sheet with written information about nutrition focuses on basic knowledge about a wholefood, balanced diet. The ten rules of a healthy diet, published by the DGE, are included. These ten rules include advice like eating five portions of fruits and vegetables a day, choosing whole grains, drinking unsweetened tea or water instead of sodas, reducing sugar and salt intake and leading an active lifestyle[82]. It is important to emphasise that no cancer diet or specific supplement intake is advised as there is, to our knowledge at the point of this intervention study, no scientifically consistent data.

There are other studies trying to evaluate the functionality of nutrition-related rules concerning breast cancer risk or mortality. Harris et al. evaluate the usefulness of the eight nutrition-related recommendations for the prevention of cancer, published by the World Cancer Research Fund[63]. Concerning the incidence of breast cancer in Swedish women, a positive association between following the nutrition-related recommendations and a decreased risk of developing breast cancer is shown[63]. The current research of Ghosn et al. focuses on evaluating whether lifestyle has an effect on the breast cancer incidence in the Iranian population. Their findings support the findings of Harris et al. giving evidence of a positive association between following eating recommendations and a decreased breast cancer incidence[64]. The findings of Harris et al. and Ghosn et al. cannot be related to our intervention study directly as the patients included had already been diagnosed with breast cancer. Nevertheless, they support the idea of using nutrition-related recommendations to give a guideline to breast cancer patients. In the intervention survey of the IMVR the ten rules of the DGE are used to educate female breast cancer patients on a wholefood, balanced diet.

Concerning the mortality rates in female breast and gynaecological cancer survivors, a statistically significant inverse association between the post-diagnostic diet quality in female cancer survivors and the mortality rate is assessed[70]. The post-diagnostic diet quality in the study of Karavasiloglou et al. is assessed with the Healthy Eating Index, comprised of the recommendations of the Food Pyramid, blood parameters, sodium dietary intake and diet variety[70]. Again, what needs to be emphasised is that the intervention study of the IMVR does not evaluate mortality rates after diagnosis but focuses on unmet information need of female breast cancer patients concerning nutrition. Nevertheless, the study of Karavasiloglou et al. addresses the fact, that post-diagnostic diet quality influences the outcomes of breast cancer survivors and therefore educating patients diagnosed with breast cancer about diet quality and a balanced diet after diagnosis might have a positive influence on the breast cancer survivors' unmet information need as well as on mortality.

To conclude, this intervention study shows that female breast cancer patients experience unmet information needs concerning nutrition. A fact sheet with written information concerning nutrition is a feasible instrument to meet unmet information needs in female breast cancer patients in Germany, as shown in this intervention study. Furthermore, risk factors that might lead to an increased unmet information need as well as factors leading to an increased benefit concerning the unmet information need experienced when receiving a fact sheet are identified. Individualised cancer care, as in the means of identifying risk groups with higher unmet information needs and providing them with information, becomes more and more important as there is more research and knowledge about unmet information needs and the factors leading to it[27,42]. Identified risk factors of unmet information needs could be used in the clinical context to individualise cancer care[27,42]. As individual access to expert knowledge is limited by the resources of the healthcare system, other supporting information tools and sources could potentially fill a gap between information needs and resources[23,24].

4.6 Limitations

An experimental study design is needed to compare the quality of care in one hospital in the same year. As the organisational processes in the breast care centres in North Rhine-Westphalia do not allow for a randomisation of the distribution of the fact sheet on a patient or organisational level, a quasi-experimental study design is created. It is debatable whether a patient-level randomisation or a cluster randomisation is more suitable for this intervention study, because of spill over effects that can be expected from a randomisation on a patient's level. The quasi-experimental study design is created by splitting the survey period of 2017 into two periods: Period A, stretching from 01 February to 30 April, is called the control period because no fact sheets are distributed. Period B, stretching from 01 May to 31 July, is called intervention period because the fact sheets are distributed in the intervention hospitals. This quasi-experimental study design allows the comparison of the quality of care in one hospital in the same year and reduces variations such as employee changes, management or clinic restructuring. Nevertheless, the intervention is not randomised on a patient's level.

Furthermore, the intervention hospitals voluntarily agreed to distribute the fact sheets and they were not randomised as well. This might have led to a bias, thinking that hospitals that engage more in patients' care might be more interested in taking part in an intervention study. Hierarchical multi-level models are used to correct the effects of the hospital level. As the distribution of the fact sheet is organised by the hospitals themselves, it cannot be guaranteed that every breast cancer patient being treated in an intervention hospital in the intervention period (= intervention group) actually receives the fact sheet. Therefore, the term "possibly receiving the fact sheet" is used in the analysis of the results of this intervention study. As this intervention study shows, unmet information need concerning nutrition can be reduced significantly, even higher effects might be achieved if the receipt of the fact sheet could be ensured. Self-reported information always involves the risk of social desirability bias and common method bias. In this intervention study, sociodemographic information such as age, highest educational attainment and native language is self-reported. Receiving assistance in completing the questionnaire, as it is indicated by patients with disabilities in this study, always bears the risk of participation bias.

5. Summary

5.1 Summary

The annual survey of the IMVR of the University of Cologne reveals that breast cancer patients that are treated for primary breast carcinoma in a breast care centre in North-Rhine Westphalia, Germany, experience unmet information needs concerning nutrition. This intervention study shows that possibly receiving a fact sheet with basic nutritional information reduces the information need concerning nutrition experienced by female breast cancer patients in Germany in 2017 significantly. Age is a sociodemographic factor that influences unmet information need concerning nutrition despite the intervention: younger breast cancer patients experience higher unmet information needs concerning nutrition than older breast cancer patients. In this intervention study, younger and higher educated female breast cancer patients benefit more from possibly receiving the fact sheet than older and less educated female breast cancer patients. Identifying groups that benefit most from an intervention might help hospitals in Germany to improve their quality of care concerning meeting the information needs of their patients.

The aim of this study - to improve the unmet information need concerning nutrition experienced by female breast cancer patients in North Rhine-Westphalia, Germany, using a fact sheet with basic information regarding nutrition - is achieved. A fact sheet focusing on basic nutritional information seems to be a feasible instrument to reduce unmet information need in female breast cancer patients significantly. Concerning instruments used to decrease unmet information need in cancer patients, inconsistent results are shown in the literature. Smartphone apps as well as online programmes or information-based websites require access to the internet and a technical device, such as a tablet or a smartphone. Considering that the median age of this study population is 61 years, a written fact sheet that is provided by the breast care centre and handed to the breast cancer patient directly, might be advantageous in comparison to an online programme or a smartphone app.

This intervention study design can be applied to other topics of unmet information need, as a fact sheet is an instrument that is easy to implement and does not need certain technical requirements. The amount of research that is conducted while and after the survey period of this intervention study shows that meeting unmet needs of cancer patients is an important topic and that information needs should be covered in a conscientious and comprehensive manner to improve the quality of care. To our knowledge, this intervention study is the first study at this point in time that aims to decrease the unmet information need of female breast cancer patients concerning nutrition by using a fact sheet with basic information regarding nutrition.

5.2 Zusammenfassung in deutscher Sprache

Die jährliche Routinebefragung des IMVR zeigt, dass Frauen, die 2016 in Nordrhein-Westphalen in einem Brustkrebszentrum behandelt werden, ein ungedecktes Informationsbedürfnis zum Thema Ernährung empfinden. Diese Interventionsstudie zeigt, dass ein ungedeckter Informationsbedarf hinsichtlich der Ernährung von Brustkrebspatientinnen, die 2017 in einem Brustzentrum in Nordrhein-Westphalen auf Grund einer primären Brustkrebserkrankung behandelt werden, durch die Aushändigung eines Informationsblattes zum Thema Ernährung adressiert werden kann. Das in dieser Interventionsstudie ausgehändigte Informationsblatt enthält grundsätzliche Informationen zu einer gesunden Ernährung. Es wird keine bestimmte Ernährungsform empfohlen, insbesondere keine „Krebsdiät“.

Soziodemographische Merkmale wie Alter, Bildungsabschluss oder Muttersprache beeinflussen den ungedeckten Informationsbedarf hinsichtlich der Ernährung bei Brustkrebspatientinnen, sowie den Nutzen eines Informationsblattes mit grundsätzlichen Informationen zum Thema Ernährung für Brustkrebspatientinnen. Alter ist ein soziodemographisches Merkmal, das den ungedeckten Informationsbedarf zum Thema Ernährung während einer Brustkrebsdiagnose und -therapie unabhängig von der hier durchgeführten Intervention beeinflusst: Brustkrebspatientinnen jüngeren Alters empfinden einen größeren ungedeckten Informationsbedarf zum Thema Ernährung als ältere Brustkrebspatientinnen. Zusätzlich profitieren jüngere Brustkrebspatientinnen eher als ältere Brustkrebspatientinnen von einem Informationsblatt mit allgemeinen Informationen zu einer gesunden Ernährung. In dieser Interventionsstudie zeigt sich außerdem, dass Bildung und die Muttersprache einen Einfluss auf die Senkung des Informationsbedürfnisses zum Thema Ernährung haben: Patientinnen, die einen höheren Bildungsgrad erreichten oder eine andere Muttersprache als Deutsch sprechen, profitierten mehr von einem Informationsblatt zum Thema Ernährung als Patientinnen mit niedrigerem Bildungsabschluss und Deutsch als Muttersprache.

Brustkrebszentren in Deutschland könnten durch die Erkenntnisse dieser Interventionsstudie profitieren, da Risikogruppen mit erhöhtem Informationsbedarf identifiziert wurden (jüngeres Alter und höherer Bildungsabschluss) und diese Gruppen gezielten Zugang zu Informationsmaterial erhalten könnten. Somit könnte die Qualität der Patientenversorgung in deutschen Brustkrebszentren gesteigert werden.

Das Ziel dieser Interventionsstudie - das ungedeckte Informationsbedürfnis von Brustkrebspatientinnen, die in einem Brustzentrum in Nordrhein-Westphalen mit einer primären Brustkrebsdiagnose behandelt werden zu adressieren - ist erreicht. Ein Informationsblatt, das allgemeine Informationen zum Thema Ernährung enthält und in einfacher Sprache und ohne Fremd- sowie Fachwörter verfasst ist, scheint ein geeignetes Instrument zu sein, um dem ungedeckten Informationsbedarf von Brustkrebspatientinnen entgegenzuwirken. Andere Instrumente, um ungedeckten Informationsbedarf zu senken, wie beispielsweise Smartphone Apps, Onlineprogramme oder informationsbasierte Internetseiten, zeigten widersprüchliche Ergebnisse in der Literatur und waren nicht in der Lage in Studien signifikante Verbesserungen des Informationsbedürfnisses zu erzielen. Für die Verwendung von Apps und Onlineprogrammen ist zum einen ein internetfähiges Gerät, zum anderen aber auch die Fähigkeit sich mit Apps und Onlineprogrammen zurechtzufinden, notwendig. Ein Informationsblatt hingegen wird den Patientinnen direkt ausgehändigt, ohne dass Zugang zum Internet oder ein internetfähiges Gerät notwendig ist. Wenn man das mittlere Alter von 61 Jahren der Brustkrebspatientinnen bedenkt, die in dieser Interventionsstudie eingeschlossen wurden, könnte dies ein entscheidender Vorteil sein.

Das Studiendesign dieser Interventionsstudie kann auf weitere Themengebiete ausgedehnt werden. Ein Informationsblatt erfordert keine technischen Voraussetzungen von den Empfängern und Empfängerinnen und ist somit ein leicht zu implementierendes Instrument. Die Menge an Studien, die während und nach der Studienperiode dieser Interventionsstudie durchgeführt und publiziert wurde zeigt, dass das Adressieren von ungedecktem Informationsbedarf von Krebspatienten und Krebspatientinnen ein aktuelles und wichtiges Thema ist.

Unseres Wissens nach ist diese Interventionsstudie die erste Studie zum Durchführungszeitpunkt, die das Informationsbedürfnis von Brustkrebspatientinnen zum Thema Ernährung mit einem Informationsblatt mit grundsätzlichen Informationen zu einer gesunden Ernährung adressiert.

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7. Premature Publication

Groß SE, Weidner D, Cecon N, Pfaff H, Strauch C, Scholten N. Does basic information concerning nutrition improve the information needs of breast cancer patients? An evaluation. Support Care Cancer. 2020 Nov;28(11):5419-5427. doi: 10.1007/s00520-020-05385-1. Epub 2020 Mar 7. PMID: 32146546; PMCID: PMC7546988.

8. Appendix

8.1 Fact sheet

Ernährung bei Brustkrebs

1 Das ist wichtig!

Sogenannte „Krebsdiäten“ sind nicht sinnvoll oder teilweise sogar gefährlich. Solche Wunderdiäten sind wissenschaftlich nicht belegt und bewirken keine Heilung. Lassen Sie sich von Krebsdiäten nicht verwirren oder verunsichern.

Frauen mit Brustkrebs sollten 3 Punkte umsetzen:

- Normalgewicht anstreben bzw. halten
- vollwertig essen und trinken
- körperliche Aktivität

2 Was ist eine vollwertige Ernährung?

Vollwertige Ernährung heißt, sich aus allen Lebensmittelgruppen zu bedienen. So ist man optimal mit Energie und Nährstoffen versorgt und fördert seine Gesundheit. Zur Umsetzung einer vollwertigen Ernährung hat die Deutsche Gesellschaft für Ernährung (DGE) 10 Regeln zusammengestellt.

Die 10 Regeln der DGE

1. Die Lebensmittelvielfalt genießen
2. Reichlich Getreideprodukte sowie Kartoffeln
3. Gemüse und Obst – Nimm „5 am Tag“
4. Milch- und Milchprodukte täglich, Fisch ein- bis zweimal in der Woche, Fleisch, Wurstwaren sowie Eier in Maßen
5. Wenig Fett und fettreiche Lebensmittel
6. Zucker und Salz in Maßen
7. Reichlich Flüssigkeit
8. Schonend zubereiten
9. Sich Zeit nehmen und genießen
10. Auf das Gewicht achten und in Bewegung bleiben

Zum Nachlesen:

https://www.dge.de/ernaehrungspraxis/vollwertige-ernaehrung/10-regeln-der-dge/

Essen und trinken Sie ausreichend, abwechslungsreich und ausgewogen.

Brustkrebs ist nach aktuellem Wissensstand ein Krebs, der den Energiestoffwechsel des Körpers nicht beeinflusst. Eine besondere Ernährungsform ist nur in ganz wenigen Ausnahmefällen notwendig.

Essen Sie vorwiegend pflanzliche Lebensmittel. Wählen Sie frisches Gemüse, Obst, Hülsenfrüchte und Vollkorn- statt Weißmehlprodukte. Vollkornprodukte enthalten wesentlich mehr Nähr- und Ballaststoffe als Weißmehlprodukte. Ballaststoffe haben ein größeres Sättigungsvermögen, dadurch essen Sie insgesamt weniger, sind aber schneller und länger gesättigt. Sie sollten **30g Ballaststoffe täglich** zu sich nehmen. Durch die Auswahl von Vollkornprodukten und reichlich frischem Gemüse und Obst (**„5 am Tag“**) können Sie diese Menge mühelos erreichen. Fünf Portionen Gemüse und Obst entsprechen etwa **400g Gemüse** (z.B. 200g gegart, 200g als Rohkost/ Salat) und etwa **250g Obst**. Als Portionsmaß kann die eigene Hand verwendet werden.

Ein hoher Konsum von Gemüse und Obst fördert nicht nur das allgemeine Wohlbefinden, sondern senkt nachweislich das Risiko für Krebserkrankungen.

Der Grund dafür ist der Gehalt an **sekundären Pflanzenstoffen**, die bis auf einige Ausnahmen vorwiegend in Gemüse und Obst enthalten sind. Es wird aber dringend davon abgeraten, diese (z.B. Phytoöstrogene) in Form von Nahrungsergänzungsmitteln wie Pillen oder Pulver einzunehmen, da die Wirkung noch nicht ausreichend erforscht ist.

Tierische Lebensmittel gehören zu einer vollwertigen Ernährung und sollten maßvoll in den Speiseplan eingebaut werden. Sie liefern neben wichtigem Eiweiß auch viele Nährstoffe, die in Pflanzen nicht oder nicht ausreichend enthalten sind (z.B. Vitamin B12).

Essen Sie **insgesamt maximal 600g Fleisch und Wurstwaren pro Woche**. Verzehren Sie **maximal 300g rotes Fleisch pro Woche** (entspricht etwa 2 Portionen). Reduzieren Sie den Verzehr von industriell verarbeitetem, gepökeltem, geräuchertem und gesalzenem Fleisch. Zu viel Fleisch erhöht das Risiko, an Darmkrebs zu erkranken und verursacht Krankheiten wie Übergewicht und Gicht.

Calciumhaltige Produkte, wie **Milch und Milchprodukte**, sollten täglich verzehrt werden. Sie beugen gemeinsam mit Vitamin D Osteoporose (Knochenschwund) vor. Wählen Sie eine fettarme und naturbelassene Variante der Produkte.

Vitamin D kann durch UV-Strahlung (20 Minuten Sonnenbaden) vom Körper selbst produziert werden oder wird über die Nahrung aufgenommen (z.B. Lachs, Sardine, Avocado, Käse, Milchprodukte, Eier). Ein Vitamin D-Mangel ist nicht nur schädlich für die Knochen, er könnte sich sogar negativ auf den Verlauf einer Krebserkrankung auswirken.

Essen Sie **Fisch ein bis zwei Mal in der Woche**. Fisch enthält Jod und wichtige Omega-3-Fettsäuren, die nicht vom Körper hergestellt werden können. Omega-3-Fettsäuren sind bspw. auch in Leinsamen, Leinöl oder Walnüssen enthalten.

Achten Sie besonders bei Lebensmitteln tierischer Herkunft wenn möglich auf eine gute Qualität (biologische Haltung, Nachhaltigkeit). Die Kosten gleichen sich aus, wenn man den Konsum auf die empfohlenen Mengen reduziert.
Bevorzugen Sie frische oder selbstverarbeitete Lebensmittel gegenüber Fertigprodukten. Letztere enthalten zu viele Zusatzstoffe (z.B. Geschmacksverstärker), Fett, Zucker und Salz. Die Produkte werden dadurch besonders geschmackvoll, so dass sie sich gut verkaufen. Dabei wird aber nicht auf eine sinnvolle Kombination von Nährstoffen geachtet, die für eine gesunde Ernährung notwendig ist.

Achten Sie bei der Zubereitung und beim Verzehr darauf, dass die Lebensmittel einwandfrei sind. Entsorgen Sie schimmelige Lebensmittel. Besonders schimmeliges Getreide, Hülsenfrüchte und Nüsse können Aflatoxine (Schimmelpilzgift) enthalten, die leberschädigend wirken und Krebs verursachen können.

Verordnen Sie sich niemals selbst Nahrungsergänzungsmittel oder Ähnliches. Sollten Sie den Verdacht haben, an einem Nährstoffmangel zu leiden, lassen Sie dies immer bei einem Arzt abklären. Nährstoffmängel lassen sich in der Regel über die Ernährung regulieren. Sollte jedoch eine Erkrankung hinter einer Mangelerscheinung stehen, wird von ärztlicher Seite eingegriffen.

4 Alkoholische Getränke

Verzichten Sie auf alkoholische Getränke.
Alkohol ist sehr kalorienreich, aber sehr nährstoffarm. Außerdem greift er Zellen an, wodurch zahlreiche Krankheiten verursacht oder begünstigt werden (z.B. Gicht, Leberzirrhose, verschiedene Krebsarten). Es besteht ein starker Zusammenhang zwischen Alkoholkonsum und Brustkrebs. Je mehr konsumiert wird, desto höher ist das Risiko, an einem Brustkrebs zu erkranken oder ein Rezidiv zu bekommen.

Da für viele Menschen der Genuss von Alkohol einfach dazu gehört, wird empfohlen, den Genuss stark zu beschränken. Ein Glas eines Getränks pro Tag gilt als maximale Verzehrmenge.

Wer bisher keinen Alkohol konsumiert, sollte nicht damit anfangen.

5 Körpergewicht

Ein Normalgewicht vermindert das Risiko eines Rezidivs und verbessert die Überlebenschancen. Normalgewicht bedeutet einen BMI von 18,5 bis 24,9 und einen Taillenumfang von max. 88cm. Der BMI (Body Mass Index) beschreibt das Verhältnis von Körpergewicht zu Körpergröße:

$$\text{Körpergewicht (kg)}/\text{ Körpergröße (m)}^2$$

In verschiedenen Studien wurde ein Zusammenhang zwischen Übergewicht und Brustkrebs nachgewiesen. Zudem ist Übergewicht ein Risikofaktor für Herz-Kreislauf-Erkrankungen, Alters-Diabetes (Diabetes mellitus Typ 2) und andere Krebsarten. Daher ist es immer sinnvoll, Übergewicht zu reduzieren und langfristig ein Gewicht im Normalbereich zu halten. Senken Sie Ihr Gewicht langsam.

Radikaldiäten versorgen den Körper nicht ausreichend mit Energie und Nährstoffen und bewirken nachfolgend den Jojo-Effekt. Durch eine Umstellung auf eine vollwertige Ernährung und etwas körperlicher Aktivität werden Sie automatisch abnehmen. Bei Fragen und Hilfestellungen zum Thema Abnehmen kontaktieren Sie Ihren Arzt oder Ernährungsberater.

6 Sport und Bewegung

In den letzten Jahren haben zahlreiche Studien belegt, dass das Sitzen bzw. ein Mangel an Bewegung das Risiko für Herz-Kreislauf-Erkrankungen, Krebs und weitere Erkrankungen erheblich steigert.

Machen Sie Bewegung zu einem festen Bestandteil Ihres Alltags!

7 Wer kann helfen?

Weitere Informationen können Sie bei den folgenden Stellen erhalten:

- Ernährungsberatung
- Deutsche Krebshilfe
- Deutsche Gesellschaft für Ernährung

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9. Curriculum vitae

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