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ORIGINAL ARTICLE

After initial treatment for primary breast cancer: information needs, health literacy, and the role of health care workers

Anna Schmidt[1] · **Nicole Ernstmann**[1] · **Simone Wesselmann**[2] · **Holger Pfaff**[1] ·
Markus Wirtz[3] · **Christoph Kowalski**[2]

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Abstract

Purpose After a short hospital stay of just some days follows long-term outpatient care for breast cancer patients. The aim of the study is to describe the information needs of breast cancer outpatients and to get in touch with aspects of health literacy, as well as contact various health care workers.

Methods In a multicenter study, patients were asked about their information needs 10 weeks after surgery. The analysis on hand includes data about 1248 female patients. In addition to descriptive analyses identifying the most prevalent information needs, logistic regression analyses were calculated to identify factors associated with these.

Results The results show that information needs of breast cancer outpatients are mainly in "follow-up after acute treatment", "coping with long-term side effects", and "heredity of breast cancer". In addition to sociodemographic patient characteristics, perceived helpful contacts with various health care workers as well as a satisfactory patient's level of health literacy reduced the probability of unmet information needs.

Conclusions Breast cancer outpatients have numerous information needs. In addition to provide information at the right time regarding a specific disease phase, it is important that health professionals' support affected breast cancer patients in coping with the new situation.

Keywords Information needs · Breast cancer outpatient · Health literacy · Health care workers

Purpose

According to a report by the World Health Organization, breast cancer is the most common cancer that women get, accounting for 28 % of all women in the European region [1]. New incidence is predicted for 2014, involving 600 men and 75,200 women [2]. The formation of certified breast cancer centers and the average of even earlier-confirmed diagnosis of breast cancer through early detection measures and guideline compliant therapy contribute to the 5-year survival rate, currently 86 % having improved significantly in the last decade in Germany [3]. More than 85 % of breast cancer patients are treated in certified breast cancer centers. The average length of hospital stay in Germany is 6.4 days after breast cancer surgery [4]. The required hospitalization, to remove the malignant tumor with possible subsequent adjuvant treatment (chemotherapy or radiation therapy), is largely standardized by the evidence-based guidelines. This also applies in principle when conveying information. Each patient must be fully informed and elucidated, for each patient, there are social workers and psycho-oncologists available. So far, however, only little is examined regarding how patients receive information after initial surgical treatment in the outpatient setting and what questions patients have regarding coping with their "new everyday life".

Note right at the start that after extensive research, few studies were found that contain information needs of ambulatory patients about 10 weeks after diagnosis, i.e., queried at the

✉ Anna Schmidt
anna.schmidt@uk-koeln.de

[1] Institute for Medical Sociology, Health Services Research and Rehabilitation Science (IMVR), Faculty of Human Science and Faculty of Medicine, University of Cologne, Eupener Strasse 129, 50933 Cologne, Germany

[2] German Cancer Society, Kuno-Fischer-Strasse 8, 14057 Berlin, Germany

[3] Institute for Psychology, University of Education, Kunzenweg 21, 79117 Freiburg, Germany

same time of therapeutic measures. In a qualitative study, information needs of breast cancer outpatients are identified. Deficits were shown in the discharge management and regarding the continuous contact person during the course of disease. The provision of information by the nurses in the inpatient and outpatient sectors was considered as particularly important [5]. Breast cancer patients are especially satisfied with the information and emotional support provided by their oncology nurse during their treatment period [6]. Furthermore, cancer patients find interaction with other patients in a social support group that can provide the group members with opportunities to give and receive informational support [7].

In a postal survey of cancer outpatients, affected individuals expressed in particular unanswered questions regarding medical treatment, as well as health information they have received from health care professionals [8]. In a longitudinal survey, patient characteristics were identified by oncology patients who are linked with information needs. The authors found evidence that the younger married patients with higher educational background search more actively for information than patients who are older or not married. Furthermore, it appears that patients who are diagnosed with breast cancer actively look for information than patients with other tumor entities [9].

Empirical results show that the care with patient-relevant information in the outpatient setting is insufficient [8]. The various health care workers are of particular importance in this matter. While the treatment in the post-hospital phase is usually clearly defined [10], the ambulatory care often lacks fixed contacts for the patients. The contact person available to hospitalized patients, to reduce their specially perceived lack of information, is not necessarily the same individuals in ambulatory care. This begs the question who of the contacts is the most important ones for patients, so that their information needs during follow-up care are as little as possible. So far, little is known about how patients perceive the dissemination of information through the various (outpatient and inpatient) contact.

In a qualitative study about information needs from the UK, breast cancer patients as well as the corresponding provision of information by the treating surgeon are examined. The results of the study provide evidence that the provision of bio-medical information (side effects, prognosis) by the patients' physicians is often difficult to understand [11]. In a randomized control study by Beaver et al. [12], breast care nurses provided additional information via phone for cancer patients in the intervention group. This additional measure within the follow-up care had a positive influence on women with breast cancer (less anxiety, higher patient satisfaction, fewer hospital visits). After an extensive research, no study could be found that compares various health care workers with each other regarding the exchange of information.

One important aspect to be taken into account is the sociodemographic background and other personal characteristics of each individual patient [11]. Another important aspect in this context appears to be the extent of the patient's health literacy. According to Sørensen et al. [13; page 3], health literacy is "linked to literacy and encompasses people's knowledge, motivation, and competences to access, understand, appraise, and apply health information in order to make judgments and make decisions in everyday life regarding health care, disease prevention, and health promotion to maintain or improve the quality of life during one's life course". Many empirical studies have shown that a low level of health literacy is linked with poorer health outcomes [14–16].

Aim of the study

Using the data of the Breast cancer Patients' Information And Training needs (PIAT) study, the information needs of breast cancer outpatients have to be worked out 10 weeks after discharge of the initial surgery. It should also be verified whether information needs are linked with different patient characteristics (working age, educational background, health literacy, etc.). In addition, it should be described which health care workers patients consider as helpful regarding replying unanswered questions.

Methods

Study design and participants

The data used were collected within the PIAT study, a multicenter prospective cohort study with three assessment time points. The aim of the study is to determine the need for health literacy-oriented information and training measures for women and men who recently were diagnosed with breast cancer. Approval for the study has been obtained from the Ethics Committee at the Cologne University Hospital (UHC). For this paper, we investigated data at the second assessment point, i.e., 10 weeks after the initial surgery, during follow-up care.

While preparing the study—and in addition to the literature research—ten certified breast cancer centers all over Germany were asked to send the information leaflets they currently use to the authors' institution. To ensure that the inquiry was oriented toward the needs of the patients, a qualitative preliminary study was carried out initially. Interviews and focus groups were held at two breast cancer centers with patients and staff (breast care nurses, psycho-oncologist, and quality management representatives). The patient questionnaire as well as the questionnaire for the breast cancer centers were developed and refined (details of these questionnaires are beyond the scope of the current paper, but can be requested from the author). The choice of these two centers took regional differences between patient groups in a large city (Cologne, with a population of approximately 1,008,000) and a mediumsized town (Datteln, with a population of approximately 35, 000) into account. Patients were recruited through the support group “Frauenselbsthilfe nach Krebs” (Post-Cancer Self-Help for Women), so that an overview of the system could also be incorporated. The interviews and focus groups were based on the same assessment time points used for the main study.

At the start of the quantitative main study, the participating hospitals received post document folders for the research study, each including a consent declaration form and a questionnaire with a postage-paid return envelope, a patient information leaflet, and further information on the PIAT study. During the period from February to August 2013, all patients with recently diagnosed breast cancer, who had signed the consent form, were included in the PIAT study by the nursing or medical staff. The initial (T1) questionnaire was completed by the patients during their hospital stay and returned to the Institute of Medical Sociology, Health Services Research, and Rehabilitation Science (IMVR), separately from the consent declaration form. The T2 questionnaires were sent 10 weeks after the initial treatment to the home address of each patient and returned directly to the IMVR.

Out of 247 German breast care center operating sites, all certified according to the requirements of the German Cancer Society (May 2012), a random sample of 98 certificated breast care centers were asked to participate in the PIAT study. Sixty breast care operating sites participated in the study and send at least five of the T1 questionnaires back. One thousand four hundred forty patients were asked to fill out the T2 questionnaire, of whom 1248 responded (87 %).

Measures

T2 data were used for the analysis on hand. Sociodemographic and disease characteristics of the patients were collected at the first time point in the T1 questionnaire. In order to assess the information needs on various topics, which were identified as being the most relevant after initial treatment in the qualitative stage, the patients were asked to answer 12 items (Table 2). The possible answers are “Yes” and “No”. For the dependent variable “heredity”, the variable own children (yes/no) was incorporated as well.

In addition, the affected individuals were asked, in general, how helpful they considered the information they received from the following groups: physician, nurses, social workers, psycho-oncologists, physiotherapists, pastoral workers, breast care nurses, representatives of self-help groups, gynecologist, family/partner, friends, or fellow patients. The response categories are (helpful): 1 = not at all; 2 = hardly; 3 = partly/partly; 4 = most of the time; 5 = very much; 6 = I had no contact with this person; 7 = I did not want any information from this person. The categorical variable were recoded and included in the analyses with the following response categories (helpful): 1 = not at all; 2 = hardly; 3 = partly/partly; 4 = most of the time; 5 = very much. For the analysis, the response categories “6” and “7” were excluded. Subsequently, the variables on providers most often mentioned as being helpful (physicians, gynecologist, social services worker) were used in the regression analysis as an interval scale.

The extent of the patients’ health literacy was calculated by using the German short form of the Measurement of Health Literacy in Europe (HLS-EU-Q16) [17]. The questions were about ways of coping with health and disease in general, not specifically with breast cancer. The item “… taking decisions that improve your health” was supplemented to ensure that every aspect was covered (access, understanding, assessment, and application). The response categories were 4 = “very easy”, 3 = “quite easy”, 2 = “quite difficult”, 1 = “very difficult”, and 5 = “I do not know”. Higher values on the scale thus show higher health literacy. Details about the psychometric properties of the instrument can be found elsewhere [18].

The variable “age” was dichotomized into “working age under 65 years” and “age over 65 years”. The variable “school education” was dichotomized into “no graduation/ elementary school” and “middle-school/vocational training or university degree”. Vocational training (1 = no training; 2 = training; 3 = university), gender, patient’s native language (German vs. other), and if they have children or not were additionally inquired in the analyses. Additionally, living with a partner (yes/no) and information if multi-morbidity exists (0 = no more disease; 1 = one–two disease(s); 2 = more than three diseases) were requested. Clinical details were provided by hospital staff along with the consent declaration form. The clinical details were included as the categorical variable “UICC stage (0 = UICC 0; 1 = UICC 1; 2 = UICC 2; 3 = UICC 3; 4 = UICC 4)”. The variable is calculated from the tumor size, the existing number of lymph nodes, and the presence of metastases. The more pronounced the findings are, the higher is the UICC stage [19].

Data analysis

Prior to the calculation, we considered the frequency distribution from the study sample. Bivariate links between the patient’s characteristics and the dependent variables were calculated by using logistic regressions. All predictors (independent variables) were then included in the logistic regression model with the selected information needs (three most frequently mentioned) as the dependent variables. The inclusion of the independent variables is systematically done backwards (likelihood ratio). The results of the null model (not adjusted model) and the final model (adjusted model) are shown in Table 4. Cases with over 70 % missing data were deleted. No imputations were performed for missing data.

Results

Descriptive findings

The distributions of the sociodemographic data and other variables are shown in Table 1. The mean value from the health literacy scale is 2.94 on a range from 1 (difficult) to 4 (easy). Table 2 shows the descriptive results on "information needs", and Table 3 shows the data about "helpful individuals".

Multivariate analysis

Table 4 shows the results of the null model and the final model of the logistic regression analysis. We calculated for each specific information need a separate, systematic logistic regression. We report about the statistics significant adjusted odds ratios (OR) from the final model.

Higher information needs on follow-up care were linked with lower health literacy (adjusted OR = 0.297***; 95 % CI 0.163–0.542) and with UICC stages I–III (adjusted OR = 4.031**–4.409**; 95 % CI 1.469–11.772) than patients on stage 0. Information needs on follow-up care were lower, if patients reported that information from social service workers (adjusted OR = 0.741**; 95 % CI 0.583–0.941) and gynecologists (adjusted OR = 0.714**; 95 % CI 0.549–0.928) were useful. Higher information needs on long-term side effects were linked with a higher educational background (adjusted OR = 2.512**; 95 % CI 1.379–4.575), with lower health literacy (adjusted OR = 0.207***; 95 % CI 0.105–0.408) and with participants who are at a working age (adjusted OR = 2.564***; 95 % CI 1.472–4.467). Participants with breast cancer UICC stage IV (adjusted OR = 12.209*; 95 % CI 1.513–98.538) have the highest information needs than patients on stage 0. Information needs on long-term side effects were lower when breast cancer patients reported that information from physicians (adjusted OR = 0.701*; 95 % CI 0.494–0.995) and social service workers (adjusted OR = 0.652**; 95 % CI 0.483–0.880) were helpful. Patients who are at a working age (adjusted OR = 2.200; 95 % CI 1.312–3.691), with children (adjusted OR = 6.319***; 95 % CI 2.990–13.352) and with lower health literacy (adjusted OR = 0.479**; 95 % CI 0.270–0.849) had higher information needs on inheritability. If the information from social service workers (adjusted OR = 0.767*; 95 % CI 0.606–0.970) and gynecologists (adjusted OR = 0.745*; 95 % CI 0.575–0.965) were helpful, the information needs from the participants were lower.

Table 1 Patient characteristics in the study sample (PIAT-T2, *n* = 1248)

Variable	Coding	Breast cancer patients		Missing values (from T1 + T2)	
		n	%	*n*	%
Sex	Male	5	0.4	132	10.6
	Female	1111	89.0		
Age	Working Age	776	62.2	111	8.9
	Not Working Age	361	28.9		
Living with a partner	Yes	906	72.6	41	3.3
	No	301	24.1		
Native language	German	1094	87.7	105	8.4
	Other	49	3.9		
School education	No graduation	6	0.5	119	9.6
	Elementary school	311	24.9		
	Middle-school	480	38.5		
	Vocational training/University degree	332	26.6		
Multi-morbidity	No other disease	87	7.0	97	7.8
	One to two other disease(s)	955	76.5		
	Three or more other diseases	109	8.7		
Vocational training	No vocational training	84	6.7	166	13.3
	Vocational training	759	60,8		
	University	239	19.2		
UICC stage	Stage 0	71	5.7	229	18.3
	Stage I	443	35.5		
	Stage II	362	29.0		
	Stage III	122	9.8		
	Stage IV	21	1.7		

Table 2 Information needs from breast cancer outpatients (PIAT-T2, n = 1.248)

Variables Do you have unanswered questions about:	Yes (%)	No (%)	Missing value (%)
"How will I tell my family?"	1.8	96.4	1.8
Retirement Insurance	26.9	71.4	1.7
Working age	21.9	75.8	2.3
Severe disability	29.2	68.6	2.2
Measures of rehabilitation	36.9	61.0	2.2
Coping with health insurance	23.7	74.0	2.2
Port catheter	12.5	83.6	3.9
Fatigue	36.3	62.3	1.4
Coping with fears	34.1	64.1	1.8
Follow-up care after Breast cancer therapy	55.8	42.6	1.6
Coping with long-term side effects	65.7	32.9	1.4
Heredity of breast cancer	44.9	53.6	1.5

The Nagelkerke's pseudo R-square for the adjusted models were 0.221 (dependent variable follow-up care), 0.319 (dependent variable long-term side effects), and 0.221 (dependent variable inheritability).

Discussion

Main findings

About 10 weeks after the diagnoses of breast cancer, questions about follow-up care after the acute treatment, the coping of long-term side effects, and about the topic heredity of breast cancer were the most prevalent. Due to the short inpatient stay, it can be assumed that many patient concerns are transferred to the outpatient sector. Numerous studies have shown that information needs of stationary breast cancer patients are remarkable, among others on topics regarding psychological support, nutrition, health promotion, and rehabilitation [11, 20, 21]. These needs are shifting during follow-up care toward the ongoing treatment and inheritability. The results provide evidence that respondents had less unanswered questions relating to these areas, if they considered that the physician, the gynecologists, or social service workers were helpful in supplying information. The results show that contact with people from the treatment team was perceived as helpful and, thus, may play a role in ensuring that the respondents' unmet information needs are reduced.

Table 3 Helpful information from different health care workers (PIAT-T2, n = 1248)

Variables Is the information you receive form the following individuals helpful?	Not at all helpful (%)	Hardly helpful (%)	Partly/ partly (%)	For the most part helpful (%)	Very much helpful (%)	I had no contact to this person. (%)	I did not want any information from this person. (%)	Missing value (%)
Physicians	1.0	4.4	20.1	39.6	31.8	1.9	0.2	1.0
Nurses	1.4	4.7	15.1	32.5	27.3	14.7	1.8	2.5
Social service workers	3.0	5.4	13.0	24.0	22.7	26.1	3.5	2.2
Psycho-oncologists	2.2	3.6	7.9	13.5	10.7	45.4	13.9	2.9
Physiotherapists	2.3	4.1	8.3	15.1	17.1	42.1	8.3	2.7
Pastoral Workers	2.5	1.7	3.9	3.0	3.5	59.3	24.0	2.2
Breast care nurses	1.9	3.4	6.7	15.8	17.5	46.7	5.4	2.6
Representative of self-help groups	1.9	1.9	4.6	3.9	2.5	64.5	18.3	2.3
Gynecologists	2.1	4.9	14.7	29.5	38.0	8.3	1.4	1.2
Family/partner	1.8	6.4	15.6	20.8	49.8	1.3	2.3	1.9
Friends	2.5	7.4	21.2	23.5	38.2	2.0	3.4	1.8
Fellow patients	3.0	8.7	26.1	21.0	17.9	15.5	5.4	2.3

Table 4 The results of the logistic regression analysis: unmet information needs in specific areas (null model and final model) (PIAT-T2, $n = 1248$)

Independent variables (null model)	Follow-up care (OR)	CI	Long-term side effect (OR)	CI	Hereditary (OR)	CI
Education (no graduation/elementary school[a])	1.246	0.716–0.608	2.518**	1.379–4.600	0.877	0.498–1.543
Working age (not working age[a])	1.529	0.907–2.578	2.421**	1.370–4.277	2.260**	1.317–3.879
Living with a partner (no[a])	1.217	0.685–2.164	1.376	0.738–2.566	1.025	0.555–1.892
Native language (German native speaker[a])	8.353	0.865–80.662	2.151	0.324–14.304	2.476	0.464–13.227
Multi-morbidity (no other disease[a])						
One to two other disease(s)	1.379	0.265–2.643	1.855	0.655–5.253	1.003	0.396–2.543
Three or more other diseases	1.196	0.536–2.484	1.212	0.348–4.213	0.927	0.291–2.953
Health literacy	0.327***	0.176–0.608	0.196***	0.098–0.393	0.482*	0.259–0.897
Helpfulness of information from physicians (inpatient)	0.778	0.555–1.090	0.712	0.485–1.044	0.937	0.665–1.319
Helpfulness of information from gynecologist (outpatient)	0.765	0.576–1.017	0.951	0.692–1.306	0.743*	0.558–0.989
Helpfulness of information from social service workers	0.778	0.602–1.007	0.638**	0.469–0.866	0.766*	0.593–0.988
UICC stage (stage 0[a])						
Stage I	4.505**	1.673–12.133	6.672***	2.496–17.829	1.444	0.561–3.718
Stage II	4.104**	1.488–11.318	5.657***	2.063–15.513	1.147	0.433–3.041
Stage III	4.256**	1.355–13.371	3.450*	1.113–10.696	0.949	0.309–2.915
Stage IV	6.608	0.852–51.260	14.365*	1.742–118.476	6.499	0.746–56.658
Children (none[a])	–		–		6.635***	3.083–14.280
Nagelkerke's pseudo-R^2		0.232		0.331		0.240
Independent variables (final model)						
Education (no graduation/elementary school[a)])	–		2.512**	1.379–4.575	–	
Working age (not working age[a])	1.537	0.927–2.549	2.564***	1.472–4.467	2.200**	1.312–3.691
Living with a partner (no[a])	–		–		–	
Native language (German native speaker[a])	8.538	0.902–80.800	–		–	
Multi-morbidity (no other disease[a])						
One to two other disease(s)	–		–		–	
Three or more other diseases	–		–		–	
Health literacy	0.297***	0.163–0.542	0.207***	0.105–0.408	0.479**	0.270–0.849
Helpfulness of information from physicians (inpatient)	–		0.701*	0.494–0.995	–	
Helpfulness of information from gynecologist (outpatient)	0.714**	0.549–0.928	–		0.745*	0.575–0.965
Helpfulness of information from social service workers	0.741**	0.583–0.941	0.652**	0.483–0.880	0.767*	0.606–0.970
UICC-stage (stage 0[a])						
Stage I	4.409**	1.651–11.772	5.891***	2.233–15.543	–	
Stage II	4.031**	1.469–11.057	5.337***	1.961–14.527	–	
Stage III	4.057*	1.295–12.716	3.283*	1.066–10.116	–	
Stage IV	6.085	0.784–47.248	12.209*	1.513–98.538	–	
Children (none[a])	–		–		6.319***	2.990–13.352
Nagelkerke's pseudo-R^2		0.221		0.319		0.221

[a] Reference response: *CI* 95 % Confidence interval, *OR* odds ratio

$*P \leq 0.05$, $**P \leq 0.01$, $***P \leq 0.001$

Helpful information from social service workers seems to reduce the probability of unanswered questions regarding long-term side effects and inheritability. As aforementioned in the study by Beaver et al. [12], an individual follow-up care plan with the right contacts, geared to the patient's needs, represents a good starting point for tackling the new everyday life [8, 22]. As empirical studies show, the satisfaction of the affected individuals increases when they are provided with individualized information on routine follow-up visits [22, 23].

Respondents who have an advanced tumor (UICC stage I–III) have more information needs than participants with smaller, non-spreading tumors. The results lead to the assumption that participants with higher health literacy have less information needs regarding questions about follow-up care after the acute treatment, questions about the use of long-term side effects and about heredity of breast cancer. Furthermore, a lower level of health literacy is linked with inadequate patient-physician communication [24–26]. Regarding questions about the subject heredity of breast cancer, it seems hardly surprising that respondents with children have a significantly increased likelihood of unmet information needs [27].

However, the question remains, why do more than 50 % of patients have unmet information needs, despite the perceived contact with physicians, gynecologists, and social service workers? As already mentioned, it could be that no contact was made with various health care workers. In this survey, most of the participants say, however, that these contacts were made. It remains unclear whether the individuals thought that the respective contact person was the right one and that they did not ask their questions. Likewise, the way in which patients communicate with physicians is one reason why patients do not dare to ask their questions [28]. In addition, there is the possibility that it is difficult for the affected individuals to put their lack of information in "proper" words. This may be a reason for participants reporting that they did not want information from different providers. Important considerations can be explained due to the inclusion of the patients' characteristics. It seems, in addition to the level of health literacy, school education, age, and language skills of the respondents, that the kind of realized information deficiency and the demanded offers also play a vital role in this matter [24, 29]. A single follow-up care plan that provides appropriate patient-centered information for the patient can contribute at best to reduce the unmet information needs [30]. The accessibility and continuity of a trusted person in the care process are thereby recognized as an important predictor [31]. The way of presenting information should be tailored into the best case to each need of the affected individuals.

Implications for practice

Certified breast cancer centers are, according to their understanding, not merely responsible for inpatient care. A routine, standardized query of the information needs—both at centers as well as at resident practitioners—makes it possible for the affected individuals to express their lack of knowledge. If not already included as standard, providing assistance in coping with their new everyday life should be included in patient-centered care. Assuming that the social services should expand its offerings in the outpatient sector, this could play a key role [25]. The role of a specialized cancer or breast nurse in the outpatient sector could also be extended [26].

As mentioned in the discussion, patients reported that they had no contact with many health care workers. It may be possible that a low-threshold service range, with the telephone number or email of social workers or breast care nurses, would reduce the barrier to contacting these providers after the hospital stay. The increase health literacy of the affected individuals linked with fewer unmet information needs should be the effort of all who are employed in care for breast cancer. It would be desirable if information materials, geared to the needs of breast cancer patients, were accessible in the outpatient sector. In this regard, written, oral, or mediation via phone by various outpatient facilities (physician's office, breast cancer center, counseling services) is conceivable. For women and their families to set up so-called centers for familial breast cancer, in which the risk of heredity is analyzed and discussed with affected women, could be a conceivable solution for questions around the topic heredity of breast cancer [27].

Limitations of the study

In reference to other study results, it is important to take into account that these raise the information needs of ambulatory patients usually after the first half year after diagnosis. Thus, it may be that the unanswered questions differ at the time of treatment than the ones upon completion of the therapeutic measures. As the study involved a written questionnaire, patients with dyslexia, a native language other than German, and those with lower levels of health literacy are most likely underrepresented in the sample as is true for most other studies. Various preliminary tests using the "think aloud" method were carried out to adapt the questionnaire as closely as possible to the patients' needs. Despite this, the formulation of answered questions with preset answers might lead to the fact that patients are not able to clearly classify themselves and consequently ticking something that was not fully applicable to them [32]. Distortions in response behavior can always arise in this way when quantitative methods are used. Another limitation could be the selection bias; patients who answer the questions are probably more motivated patients, so the information needs of the greater population may be underestimated by this study. Considerations of social desirability [33] should be taken into account when interpreting the results; it is possible that patients did not always make accurate statements regarding their understanding of medical matters such as the health literacy scale. Other interesting questions, such as how the contact with social service workers in the outpatient setting has been established, cannot be answered using the data of the PIAT study.

Future research

Future studies could investigate other aspects that identify the reasons for unmet information needs. Are lacks of contacts due to the outpatient sector or the preferences of breast cancer patients not adequately taken into account regarding the manner in which information is conveyed? The numerous given information needs increase the presumption that there is a gap of provisions in the transition from inpatient to outpatient care. Further research should analyze these interface problems. Future studies aimed at improving patients' health literacy will also have to determine whether providing an information leaflet is the method of choice, whether spoken word is better, or if patients prefer newer media. An interesting question is how a situation could be created, which is registered in the health literacy, but is not patient-perceived knowledge as a query and thus stigmatizing.

In addition to research on breast cancer, other tumor entities would also be of major interest in connection with the provision of information about ways of coping with new conditions in everyday life.

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Conflict of interest The authors declare that they have no competing interests.

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