

Survey on the Necessity, Sensibility, and Timing of Psycho-Oncological Counseling and the Willingness to Discuss Various Topics During the Inpatient Stay in the Case of Breast Cancer

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Abstract

After the diagnosis of cancer patients require a lot of information because the disease affects all aspects of life. Some important issues regarding optimal counseling remain to be determined. This includes the time-related relevance of various topics and questions regarding who and when to consult on the topics. We analyzed the answers of 155 women with non-metastatic breast cancer undergoing primary surgery, primary chemotherapy, and having completed adjuvant treatment regarding the above-mentioned issues. We found that counseling must consider the treatment situation. Breast cancer patients in the follow-up phase reported that they preferred being counseled by female consultants. Our results largely support a counseling concept which puts the breast care nurse at the center of interest rather than psychologists and social service workers. A breast care nurse centered counseling system for women with non-metastatic breast cancer appears to meet patients' needs best.

Keywords

counseling, cancer, oncology, clinical research areas, breast care, nurse

Introduction

When confronted with the diagnosis of cancer, it is a requirement that patients are thoroughly informed about their situation in order to consent to surgery, chemotherapy, radiotherapy, endocrine treatment, or immunological treatments. As shown by Kovač et al. (2014), patients experience fear and worry with almost every facet of cancer treatment. The fear of chemotherapy and radiotherapy (67%), the horror of losing hair (59%), and the fear of relapse or disease progression (57%) represent the most important ones (Kovač et al., 2014). However, patients' problems are not only related to the disease itself. Since cancer has an impact on almost every situation of the patients' lives, the patients also require information on several other aspects. The most common needs are psychological and the need for information (Puts et al., 2012). Other relevant issues include:

- Consequences of cancer treatment (e.g., loss of hair, nausea, fatigue, climacteric problems)
- Emotional problems (e.g., worries, fears, sadness, nervousness, feeling of helplessness, restlessness, brooding)

- Economic problems due to inability to work and social benefits (e.g., severely handicapped ID card, follow-up treatment)
- Spiritual/religious concerns (e.g., relationship with God, loss of faith, meaning of life)
- Importance of diet, physical activity (sport)
- Patients' desire to make an own contribution to improve the situation
- Complementary and alternative medicine (CAM)
- Practical questions (e.g., living situation, insurance, work/school, transportation, transport)
- Family problems (e.g., in dealing with the partner or with the children)
- Current physical problems (e.g., pain, nausea, exhaustion, sleep, exercise/mobility)

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- Sexuality
- Changes in everyday life (e.g., childcare, caring for relatives)

A systematic review confirms that the level of unmet needs in newly diagnosed cancer patients after the start of treatment is high, which seems to be especially true for older patients (Puts et al., 2012). The findings of Kovač et al. (2014) suggest that psychological support is important in the early period after breast surgery due to the vulnerability of the patients, and because it can diminish the risk of a potential escalation of distress. High levels of distress were found in younger patients and patients with more extensive surgery (bilateral mastectomy vs. unilateral mastectomy vs. lumpectomy) (Schubart et al., 2014).

A systematic review regarding the delivery of information showed that delivery of postoperative patient education through the individualization of content, use of combined media for delivery, provision of education on a one-on-one basis, and in multiple sessions is associated with improvement in educational/health outcomes (Fredericks et al., 2010). Another systematic review found scarce and conflicting evidence of benefits to gynecologic patients of healthcare professional use of video- or computer-based patient education (Thygesen et al., 2015). It was concluded that the referred interventions might be best suited to the highest educated with coping skills beyond the average (Thygesen et al., 2015). However, precautions should be taken before recommending interventions which have not been evaluated. In all situations and at every stage of the disease, open, honest, and timely communication seems to be important. It was shown that discussions of life expectancy and prognosis led to a reduction in anxiety when they were included in the consultations (Rodin, Mackay, et al., 2009; Rodin, Zimmermann, et al., 2009). Increasing patient participation in decision-making was associated with greater satisfaction but did not necessarily decrease distress (Rodin, Mackay, et al., 2009; Rodin, Zimmermann, et al., 2009).

In Germany, oncological treatment and care is largely provided by cancer centers which are certified by a process initiated and controlled by the Deutsche Krebsgesellschaft e. V. (German Cancer Society). The cancer centers are visited by experts in the field to evaluate the treatment quality and certify that the treatment standards are fulfilled. The catalog of requirements for cancer centers of the German Cancer Society can be found on the homepage of Onkozert (Retrieved September 24, 2021, from <https://www.onkozert.de/en/organ/breast>). Among many other parameters the rates of patients who are counseled by psycho-oncologists and social workers are specified. However, since health insurance companies urge hospitals to reduce the duration of patients' hospital stay to a minimum, time constraints make it difficult to deliver all cancer-relevant information to the patient during the patient's hospital stay.

A recent study from Germany shows that a considerable amount of the required information needed is unmet and that there is a bidirectional relationship between satisfaction with the given information and anxiety symptoms after 6 months (Goerling et al., 2020). This study also points out that satisfaction with the information received is an important precondition of adherence to treatment in cancer patients. As stated in numerous publications and systematic reviews, many aspects regarding counseling and educating patients on the important topics in oncology are unclear. In order to be able to deliver the necessary information based on patients' needs, we initiated this prospective study. Our main goal was to find out:

1. Which issues are the most important ones?
2. Who is considered to be best suited to counsel patient on a specific topic?
3. At what time should the consultation take place, and
4. If and in how far have the needs of the patients been met during the hospital stay?

Patients, Materials, and Methods

We developed an assessment form which, apart from demographic data, assessed patients' individual ranking of the topics stated above. They could choose from a list of health professionals (physician, nurse, breast care nurse), members of their family, clerics, social service staff, but could also supply their own answer. They were asked to complete this assessment form every day during their hospital stay in order to find out which day would be best suited to providing the required information. The assessment form is based on prior work by Okamoto et al. (2012) and Puts et al. (2012). The assessment form was pretested in 10 patients for readability and face validity.

Furthermore, we assessed the dimensions of personality according to the Five-Factor Model, the predominant model for describing personality, using the ultra-short 10 Item Big Five Inventory (BFI-10) (Rammstedt et al., 2013). A copy of the assessment form can be obtained from the corresponding author.

Assuming that there may be differences between women with breast cancer who started with neoadjuvant chemotherapy (Group 1) and those who started with surgery (Group 2) we intended to recruit 50 patients for each group. The two groups were formed in order to find out whether psychological support is needed after breast surgery as described by Kovač et al. (2014) or if psychological support and information is needed directly after diagnosis. Patients undergoing primary chemotherapy would then receive psychological support and information some months after diagnosis since psychological support is usually made available during a patients' hospital stay. Additionally, 50 patients who had

already undergone a completed treatment and who belonged to self-help groups were asked to complete an abbreviated version of the assessment forms. These patients were to be compared (Group 3).

Inclusion and exclusion criteria:

Inclusion criteria: histologically confirmed breast cancer, ability to understand German and the informed consent form, age > 18 years

Exclusion criteria: metastases from any primary tumor

Ethics

The study protocol was approved by an Ethics Committee on November 19th, 2019. Afterward the study was approved by the Study Committee of our Clinic on February 3rd, 2020.

Recruitment Measures

When it was decided that the patients would undergo surgery, they were then informed about the planned operation and this study. They were given a detailed information sheet which described the planned study. All patients were given the opportunity to ask questions. An informed written consent was given before participation. Patients were asked to complete the questionnaire after surgery on the days 1 through 5 during hospitalization except for Group 3 who received an abbreviated version.

Statistics

All data were collected and documented in Excel version 16.58 and then transferred in PSPP version 1.4.1, a free statistical software application (www.gnu.org), intended as a free alternative to IBM SPSS Statistics. We used descriptive statistics, cross-tabulation, and correlation analyses.

Results

Recruitment started on February 6th, 2020. Unfortunately, the study had to be interrupted several times because of the COVID-19 pandemic. We faced several problems during the pandemic (e.g., restricted surgical capacities) and because it was almost impossible to determine when normal treatment conditions would be reestablished, the study was closed on March 31st, 2021.

Within the given study period, 179 patients were treated surgically for primary breast cancer, among them 126 patients who received primary surgery and 53 patients who received primary chemotherapy followed by a surgical intervention. 105 of these patients completed the study. The other 74 patients were not willing to participate for various reasons, did not complete the assessment form, lost assessment form, or did not return it. This left 105 patients for the evaluation. Additionally, 50 patients from the self-help groups

were asked to complete an abbreviated version of the assessment form. All 50 of the patients from the self-help groups accepted the invitation and returned the forms. Table 1 displays the characteristics of the three groups.

Importance of the Various Topics

Figure 1 shows the relative importance of various topics to the patients in the entire group. The comparison between the group of patients undergoing primary surgery and those undergoing surgery after primary chemotherapy shows no differences regarding the perceived importance of all topics with the exception of “recommendations on therapy” and “consequences of treatment.” Here, patients undergoing primary surgery were significantly more interested receiving information during the days after surgery ($\chi^2_{\text{recommendations}} = 15.4$; $df = 3$; $p = .002$; $\chi^2_{\text{consequences}} = 9.4$; $df = 3$; $p = .024$). The reluctance of patients to receive information during the stay in hospital decreased over time regarding most issues except for “current physical problems,” “sexuality,” and “changes in everyday life,” as shown in Figure 2.

Characteristics of the Ideal Counseling Circumstances

Patients were asked what they considered to be the best time for counseling on the various topics. Figure 3 depicts the answers of the entire group. However, the answers significantly differed between patients who underwent primary surgery and those who underwent primary chemotherapy. Patients who received primary chemotherapy were more interested in receiving the information after diagnoses rather than after surgery except for family problems ($\chi^2 > 13.8$; $df = 6$; $p < .031$). These differences were most pronounced regarding “practical problems” ($\chi^2 = 40.6$; $df = 6$; $p < .001$).

Furthermore, we assessed whether patients would prefer a female or a male consultant. The results are shown in Figure 4. It shows that most patients are indifferent regarding the issue of gender. A closer look at the three groups shows that both patients with primary surgery and those with primary chemotherapy had no preference for female consultants. The preference toward female consultants was primarily found in the group of patients in the Follow-up group. They were less pronounced and not statistically significant with respect to “social benefits,” “complementary medicine,” and “practical aspects,” “spiritual, religious aspects,” “possible own contributions,” and “changes in everyday life.” Regarding all other topics, χ^2 -Test revealed values greater than > 11.6 ; $df = 4$; $p < .020$. The preference for female consultants was most pronounced regarding “consequences of treatment” ($\chi^2 = 29.3$; $df = 6$; $p < .001$). 50% of the patients in the follow-up group preferred a female consultant compared to 10.9% or 11.1% in the groups of patients with primary surgery and primary chemotherapy.

Table 1. Patients' Characteristics.

	Entire group N = 155	Primary surgery N=70	Primary chemotherapy N=35	Follow-up N=50
Age [mean (SD)]	60.3 (12.2)	62.5 (11.4)	54.9 (13.1)	61.0 (11.6)
Year of diagnosis [N (%)]				
<2015	30 (19.4)	1 (1.4)	1 (2.9)	28 (56.0)
2016–2017	8 (5.2)	0 (0.0)	0 (0.0)	8 (16.0)
2018–2019	26 (16.8)	1 (1.4)	12 (34.3)	13 (26.0)
2020–2021	91 (58.7)	68 (97.1)	22 (62.9)	1 (2.0)
Use of psychotropic drugs [N (%)]	24 (15.5)	8 (11.4)	5 (14.3)	11 (22.0)
School leaving certificate [N (%)]				
None	3 (1.9)	3 (4.3)	0 (0)	0 (0)
Elementary school	5 (3.2)	2 (2.9)	2 (5.9)	1 (2.0)
Lower Secondary School (Hauptschule)	34 (22.1)	16 (22.9)	8 (23.5)	10 (20.0)
Intermediate Secondary School (Realschule)	61 (39.6)	31 (44.3)	9 (26.5)	21 (42.0)
Vocational Diploma	12 (7.8)	5 (7.1)	2 (5.9)	5 (10.0)
Grammar School Certificate/ University Entrance Diploma	12 (7.8)	2 (2.9)	4 (11.8)	6 (12.0)
Tertiary Education/University Degree	23 (14.8)	10 (14.3)	8 (23.5)	5 (10.0)
Other	4 (2.6)	1 (1.4)	1 (2.9)	2 (4.0)

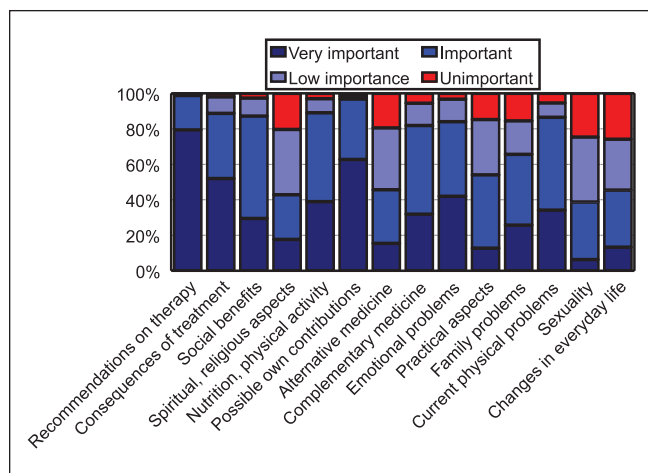


Figure 1. Patients ratings on the importance of various topics related to cancer and breast cancer.

Finally, we analyzed what profession should counsel the various topics. The answers are summarized in Table 2. The figures show that most patients are indifferent about the consultants' primary profession. Physician, breast care nurse, psychologist, and social service worker are considered to be the most important people. However, if patients want a specific consultant, it is the one who should be assumed to be as competent as possible for this specific issue, for example physician for treatment recommendation or social service worker for social benefits.

In the second part of our analysis, we investigated in how far aspects of personality influenced the perception of the importance of the various topics. After Bonferroni correction, we found no significant correlations. Also, no significant

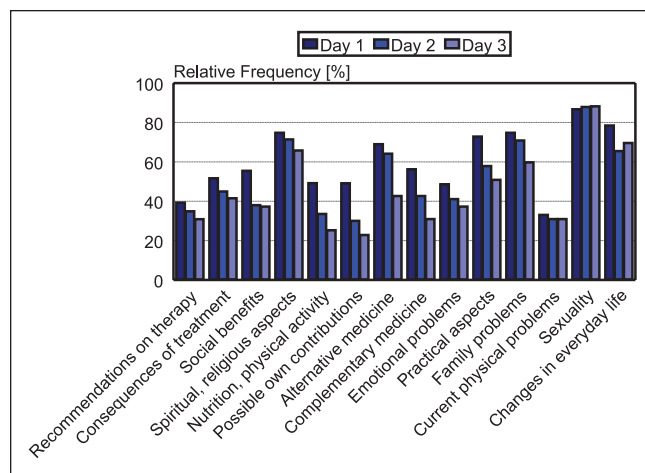


Figure 2. Percentage of patients who responded that they would be reluctant or very reluctant to receive information on various topics (n = 105).

correlations were found between aspects of personality and preferences regarding the gender of the consulting person.

Discussion

This study analyzed the information needs of breast cancer patients with a particular interest in which information should be given, when and by whom.

Better tailoring of patients' informational needs can improve patient well-being. It shows that "spiritual, religious aspects," "alternative medicine," "practical aspects," "sexuality," and "changes in everyday life" are topics which patients do not consider to be important. Interestingly,

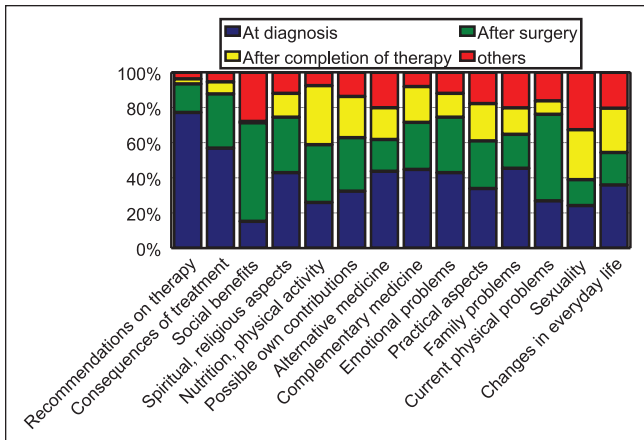


Figure 3. Percentage of patients on what they considered would be the best time for counseling on the various topics.

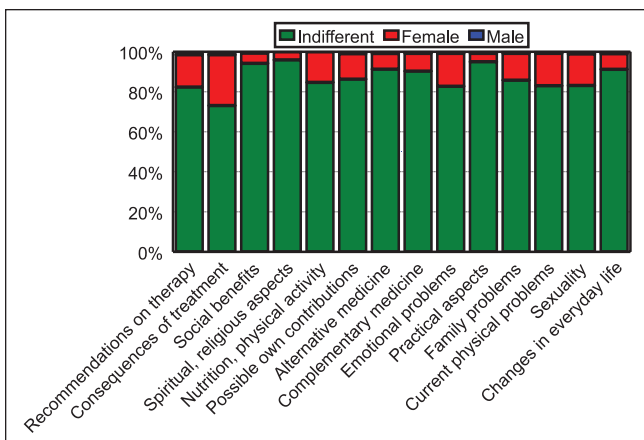


Figure 4. Patients' preference for a female or a male consultant.

although “nutrition and physical activity” is considered to be an important topic, most patients report that information on it should be delivered after completion of therapy. Regarding patients' preferences, it was found that gender preferences were mainly found in the follow-up group. They do not seem to be important in the acute treatment situation. The patients also reported some preferences when asked what profession should counsel. According to our data, physicians, breast care nurses, psychologists, and social service workers are the most important people in this field.

Counseling of oncological patients does not only entail providing information. Appropriate counseling may help patients cope better with the disease. This has been shown in low-risk prostate cancer patients who underwent radical prostatectomy and had better long-term patient satisfaction ratings after perioperative patient education (Kretschmer et al., 2017). As shown here, recommendations on therapy and the consequences of treatment are the topics which the patient required/needed to know at diagnosis. Appropriate counseling will also lead to better chances for cancer patients

to return to work (De Boer et al., 2015). Studies on type 1 diabetes care also highlight the importance of self-care. Patients' background, motivation, relationships with health-care staff, and patient counseling were found to influence whether or not they fulfilled those duties, which are all crucial elements in type 1 diabetes care and a long-term positive outcome (Hirjaba et al., 2015). Such elements can be important in avoiding the side effects of treatment, for example oral mucositis. Regular oral care, oral cryotherapy, low-level-laser therapy, and honey are part of a concept which can minimize the problem but the efficacy depends on the patient's cooperation (Münstedt & Männle, 2019).

The necessity of appropriate counseling is based on the concepts of Antonovsky who referred to the ability to comprehend the whole situation, and the capacity to use the resources available, as the sense of coherence (SOC). The SOC reflects people's ability to assess and understand the situation they are in. Its key elements are comprehensibility, meaningfulness, and the manageability. Modeling and adjusting consultation offers to patients' needs will thus help the patients' SOC. Thus, people can find a reason to move in a health promoting direction, also have the capacity to do so. The sense of coherence reflects a person's view of life and their capacity to respond to stressful situations. If a person considers life as structured, manageable, and meaningful, the person can identify, benefit, use, and re-use the resources at his or her disposal. Recent studies have identified the importance of the SOC with respect to disease progression and mortality due to breast cancer and other causes (all-cause mortality) indicating a favorable influence (Lindblad et al., 2018). The perceived manageability of life circumstances as a part of SOC can help to identify and implement meaning-oriented interventions which are effective in distressed cancer patients (Winger et al., 2016). As a result, a strong SOC seems to be associated with a more positive subjective state of health. As shown in a trial, women with strong SOC reported less fatigue, lower symptom burden, and a higher quality of life (Hiensch et al., 2020). In this respect adequate counseling of patients can have a tremendous impact on the patients' well-being. An important issue is that the information is delivered to the patients according to their preferences. So far, it has been shown that cognitive behavioral therapy produced some favorable effects on anxiety, depression, and mood disturbance but the evidence for survival improvement is still lacking for breast cancer patients (Jassim et al., 2015). However, appropriate counseling can help avoid patients' refusal of adjuvant treatment or premature termination of treatment. Both factors have been found to be clearly associated with worse survival (Männle, Münstedt, et al., 2021; Männle, Siebers, et al., 2021).

In the oncological setting, there are different counseling possibilities. Two examples are depicted in Figure 5a and b. Figure 5a shows the currently practiced situation as required by the German certification process. The patient is counseled by various experts who will have to assess the patients' informational needs and counsel them accordingly. Consequently,

Table 2. Patients' Wishes As to Which Professional Group Should Advise on the Various Issues.

	Sexuality	Complementary medicine	Bodily issues	Alternative medicine	Practical issues	Family problems	Treatment recommendations	Therapy consequences	Emotional problems	Change in everyday life	Nutrition and physical activity	What can I do myself?	Social benefits	Spiritual, religious aspects
No preferences	51.6	55.3	52.6	58.3	58.5	58	50	51.5	51.9	55.3	54.2	58.8	53.7	51
Physician	6.4	36.5	24.6	27	2.5	1.6	50	75.4	6.3	2	16.1	20.3	2.2	—
Breast care nurse	9.5	10.5	22.3	11.3	5.1	4.2	5.1	34.6	12.9	5.9	29.8	24.5	2.2	2
Psychologist	12.7	1.6	2.4	1.8	—	23.4	1.9	1.5	36	3	0.8	4.8	0.7	7.1
Clergyman	—	—	—	—	—	0.8	—	—	0.6	—	—	—	—	12
Nurse	—	1.6	6.9	—	0.6	—	—	0.8	0.8	1	2.6	2.8	—	—
Social service worker	—	—	—	—	26.2	1.6	0.6	—	1.6	25.3	—	—	41.8	—
Family	8.5	0.8	—	0.9	1.7	8.4	1.9	—	8.7	6.8	—	1	—	11.2
Others	—	0.8	0.8	—	2.5	—	50	51.5	0.8	—	5.2	1.3	53.7	19.4
No interest	16.8	2.4	3.1	11.3	7.6	8.4	50	75.4	0.8	11.7	0.8	1	2.2	11.7

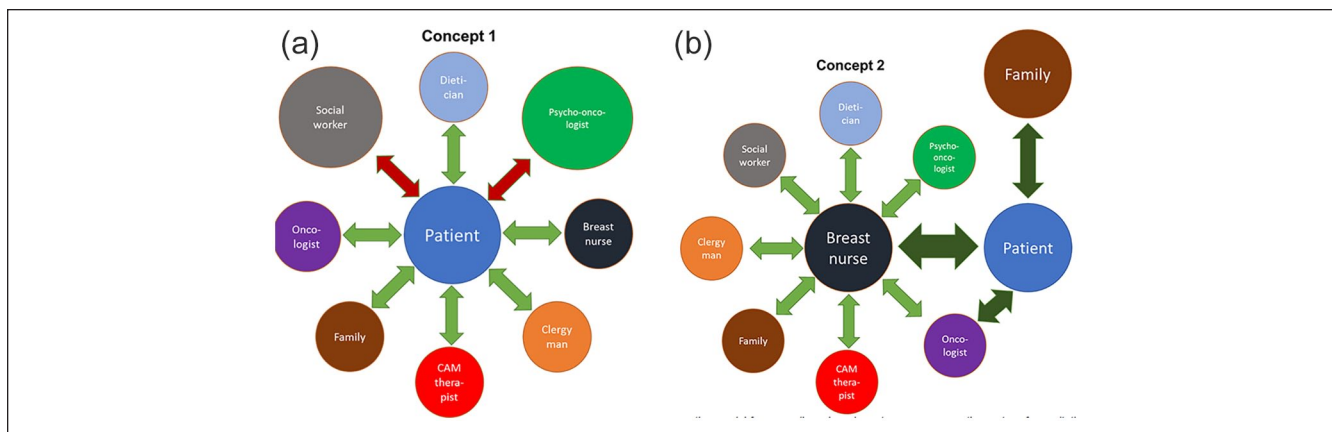


Figure 5. (a) Currently practiced concept for counseling patients as required by the German certification process and (b) alternative model for counseling where breast care nurses are the center of consultation.

the patients will be contacted by many different people. According to the German S3-Guideline on psycho-oncological diagnosis, counseling and treatment of adult cancer patients and the concept of psychosocial counseling by the German federal ministry of health, psychosocial counseling centers are to be established in order to improve cancer patients' well-being (Bundesgesundheitsministerium (Federal Ministry of Health), 2021; German S3-Guideline, 2021). However, their counseling only refers to psychosocial topics. The implementation of counseling centers for outpatient counseling is reasonable. As shown in this study there is a great reluctance shown by patients regarding counseling during the first few days after the operation regarding most topics except for information on treatment recommendation and treatment consequences. This is apparent even though there is a huge demand for information on many other topics. We assume that patients who want a specific consultant, would choose someone who they consider to be the most competent regarding their specific issue. It is questionable whether the people involved in psychosocial counseling will be able to counsel on all topics. For example, if they would counsel on complementary and alternative medicine, six relevant categories of information have been identified: role of the advisor, evaluation of evidence, assessment of efficacy, assessment of toxicity, monitoring parameters, and provision for a closure (De Lemos et al., 2004). It will be difficult for them to be informed on all these topics and to keep up to date with the advances in these fields. As shown here, regarding many issues, patients seem to appreciate the services offered by breast care nurses to a greater extent than the services provided by psychologists and social service workers. Preferences for breast care nurses can be found in every aspect assessed in this study. The breast care nurses will build up contact to the patients, assess the patients' informational and spiritual needs, consult with the various experts and inform the patients in situations where there are problems which can be easily solved. Clearly, they will not be experts in all the fields

but they can find out the relevant answers to the cancer patients' questions after consulting with experts and communicate them back to the patient. Figure 5b depicts an alternative model for patient counseling where breast care nurses are the center of consultation. The patients' clear preferences for being counseled by physicians on treatment recommendations and therapy consequences as well as for legal issues indicate that the counseling should be done by physicians on these topics. As our study has shown that the patients surveyed here seem to feel very comfortable being counseled by breast care nurses, this has resulted in questions being raised about the current model of psychosocial counseling in Germany. This does not mean that patients should not have contact to psycho-oncologists, social workers, and the others involved in counseling. On the contrary, it is the breast care nurses' task to assess the patients' needs and to prepare the other professions for the patients' individual needs which ensures effective support. The problem with the current system is illustrated by an example of plastic surgery. Patient-tailored information was given more frequently by plastic surgeons whereas patient-related risk factors were provided more often for wound healing problems and oncological contra-indications and were those highlighted by surgical oncologists (Van Bommel et al., 2018). This emphasizes the importance of avoiding patients' uncontrolled direct contact with stakeholders. It seems crucial in order to achieve a reasonable consensus to optimize patient counseling and shared decision-making to ensure that patients will not regret earlier treatment decisions (Van Bommel et al., 2018).

However, our hypothesis that a breast care nurse centered model could be more satisfactory in comparison to the current model for psychosocial counseling in Germany must be investigated more specifically in future research. Naturally, psychologists can apply the general interaction skills important for successful communication decision-making more easily, however, the search for different strategies seems justified since Andreis et al. (2018) reported that patients

considered psycho-education an important intervention for their life (Andreis et al., 2018; see also Rodin, Mackay, et al., 2009; Rodin, Zimmermann, et al., 2009). This however, did not show a significant effect on anxiety and body image perception. Our concept is well in line with the findings of Galway et al. (2012) who found that nurse-delivered interventions comprising information combined with supportive attention may have a beneficial impact on mood in an undifferentiated population of newly diagnosed cancer patients. Another key issue seems to be the records or the written results of the consultations that are provided to the patients. Here, a Cochrane review found that the majority of the studies reported better recall of information for those receiving recordings or summaries (Pitkethly et al., 2008). Interestingly, the role of multimedia is controversial. It seems to depend on the patient and topic whether multimedia tools may or may not enhance patient counseling (Pandya et al., 2020).

However, poor educational status can limit patients' ability to seek and act on the counseling provided by the health care professionals (Jyoti et al., 2022). Perhaps proactive breast care nurses, who determine the patients' specific needs, could be particularly useful and adjust the information to patients' capabilities.

Limitations

Our study faced significant problems due to the Covid-19 pandemic which did not allow us to recruit all eligible patients in our hospital. Thus, there may be a selection bias. The anxiety due to the corona pandemic played some role regarding the recruitment. Furthermore, the results may not be valid for other countries. As shown by Rodin, Mackay, et al. (2009) and Rodin, Zimmermann, et al. (2009) preferences of cancer patients regarding communication exhibit individual and cultural variability. Also, our results cannot be transferred to other tumor entities especially those which affect both male and female patients or only male patients. Here, it may be assumed that male patients could have other preferences regarding the gender of the consulting person.

Conclusions

This study shows that there should be a continuous assessment regarding patients' needs during all phases of treatment for breast cancer. The counseling must consider the treatment situation (primary surgery vs. primary chemotherapy). For reasons which should be elucidated in future research, it would perhaps be better if breast cancer patients were counseled by females in the follow-up phase. Our results largely support a counseling concept which puts the breast care nurse at the center of interest rather than psychologists and social services workers, who are currently the main actors in the psychosocial counseling system in Germany. Future research must determine whether a breast care nurse centered counseling system could be a means of improving the

situation. If this is the case, this concept could be transferred to other tumor entities with nurses acquiring the relevant qualifications to become experts in colon cancer, prostate cancer, and so on.

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