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Research Article

Significant Increase of Patient Information and Satisfaction with Longer Initial Consultation Duration in Breast Cancer - First Results of the WAVES Study

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Abstract

Aim of the study: The "WAVES" study (Widening Aims and giving patients a Voice for Expanded Structures in breast cancer care developed jointly by patients and physicians) aims to illuminate current breast cancer care structures with special focus on physician-patient-communication.

Methods: The study is conducted within and funded by the BZKF (Bavarian Center for Cancer Research). Here, we present the results of the first preplanned analysis of the survey designed together with patients and patient advocates with the aim of adequately reflecting patients concerns. It is based on the evaluation of the first 1.000 patients who participated between 05/2022 and 08/2023, focusing on the duration of the first diagnosis consultation.

Results: The participants were between 23 and 89 years old (mean: 59.18 years). There was a significant association between longer initial consultation duration and higher patient satisfaction ($p < 0.001$). When the first consultation lasted 30 minutes or more, patients stated more frequently that they felt better informed ($p < 0.001$) and had fully or substantially understood the content ($p < 0.001$).

Conclusion: These results demonstrate a significantly higher satisfaction and better preparation of patients with initial breast cancer diagnosis if physicians' communication lasted 30 minutes or more. Therefore the WAVES study clearly demonstrates the need for improved communication structures in terms of an appropriate time frame for breast cancer patients, which is not reflected in the current reimbursement structures.

Keywords: Early Breast cancer, Metastatic Breast Cancer, survey, physician-patient communication, Current Care Structure.

Introduction

The diagnosis of breast cancer is associated with physical restriction and a heavy psychological burden [1]. Diagnosis, treatment and aftercare therefore require long-term cooperation between the patient and different medical disciplines [2]. However, even if the cancer is overcome, some people still suffer from health restrictions, anxiety or social consequences [3]. This indicates the importance of good clinical care and aftercare. The physician-patient-relationship forms the basis of any disease-related treatment [4-6]. Targeted support from medical staff and self-help

groups can help patients to cope with physical and mental stress. Non-directive and evidence-based communication focusing on current needs, values, problems, resources, and preferences exerts beneficial effects [7, 8]. However, the impact of adequate communication is often underestimated and therefore in Germany currently not reflected in planned consultation times or appropriate reimbursement. On the other hand, huge sums are spent on imaging procedures even with exposition to radiation, despite unproven benefits. Therefore, integrating communication as a quality indicator in structured education, treatment and aftercare is the worldwide approach [9]. Nevertheless, this is often difficult in everyday clinical practice, given the scarcity of time and personnel resources.

Evidence-based guideline recommendations for diagnosis, treatment and aftercare often do not consider the real-world setting. In particular, communication over the entire treatment period and beyond is usually only poorly considered as one of the most important prerequisites for successful therapy. To our knowledge, there are also no nationally established communication training standards for physicians. This is precisely where the WAVES study (Widening Aims and giving patients a Voice for Expanded Structures in breast cancer care jointly developed by patients and physicians) comes in. The idea for the study was developed in collaboration with patient advocates. The study focuses on evaluation of the current state of breast cancer care in Germany from the perspective of both patients and physicians. The first survey for patients has the aim of adequately reflecting patients' concerns especially with regard to physician-patient communication with the initial diagnosis of breast cancer. The second questionnaire for patients focuses on topics related to side effects, artificial intelligence and communication during treatment and aftercare. The questionnaire for treating physicians, again designed with patient representatives, focuses on the current care situation of breast cancer patients, based on their communication behaviors. In the long term, the study aims to develop an improved Patient-Centered Communication-Care-Concept (PCCCC) for breast cancer that also takes into account physicians' time management.

Materials and Methods

The study is conducted within and funded by the BZKF (Bavarian Center for Cancer Research). The active involvement and participation of patient and caregiver representatives is unique about WAVES - from conceptualization of the study, the development of the questionnaire to the recruitment as well as the publication and elaboration of the resulting consequences. The study is structured as a two-part questionnaire for breast cancer patients and a corresponding questionnaire for physicians.

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The first part of the patient questionnaire requests information on: general patient and anamnestic information, initial disclosure of breast cancer diagnosis, second opinion and self-study, treatment period with focus on communication, experience as male breast cancer patient, support from non-physician medical personnel, patient advocacy and support groups, characteristics, diagnosis and treatment of the disease and aftercare. The precise questions' wording chosen for this publication are listed in the Appendix.

Patients from German certified breast centers (university* and non-university**) and patient advocate networks*** were invited to participate in the WAVES study. Furthermore, the study was promoted online. The study is still recruiting. This article presents the first cross-sectional preplanned analysis of the first part of the survey after reaching n=1.000 and is based on those patients who completed the first part questionnaire by the cut-off date (10 August 2023). All participants gave written informed consent and have received or are still receiving treatment for breast cancer, proven by means of a document (e.g. physician's letter). Women and men aged 18 years and older were eligible to participate, regardless of disease stage or time of treatment. The questionnaire could be answered either online or in paper form. Descriptive data and distribution characteristics of the items were calculated for evaluation. Categorical variables were compared by using Chi-Squared tests and continuous variables by using Wilcoxon-Mann-Whitney or Kruskal-Wallis test. The Bonferroni adjustment was used for multiple comparisons. All statistical analyses were performed with R (Version 4.3.1). The WAVES study was approved by the ethics committee of the Ludwig-Maximilian-University Munich, Germany (Approval 22-0040) and was performed in compliance with German law and according to the standards set in the Declaration of Helsinki 2013. The trial is registered at ClinicalTrial.gov (NCT06416293).

Results

Cohort description

The majority (723 participants) was treated at one of the six Bavarian university hospitals, 228 patients came from other non-university hospitals in Bavaria, 41 from other federal German states; 8 did not give any information. The vast majority (98%) of participants were women, 2% men; diverse was not selected as an answer option. The mean age was 59.18 years (1st and 3rd quartiles: 51–68) and ranged from 23 to 89 years. 224 (23%) patients were undergoing treatment for primary breast cancer at the time of the survey, 645 (66.1%) were in follow-up care, 107 (10.1%) were undergoing treatment for metastatic or locally progressive disease (a detailed overview of the tumor characteristics is reported in appendix table 1). High school graduates were represented slightly above average in the cohort compared to the national average of 34% in 2022 (for details see Table 1).

Patient characteristics and emotions impacting overall satisfaction with first consultation

Overall satisfaction (feeling of being well informed) with the consultation at initial diagnosis showed no association with the age of the patient (≤ 50 vs. > 50 years) ($\text{Chi}^2(1) = 0.22, p=0.642$) or metastatic disease ($\text{Chi}^2(1)=1.30, p=0.255$). Patient satisfaction was highest when the initial consultation was conducted by gynecologists ($\text{Chi}^2(4) = 16.85, p = 0.002$). Patients with a high school diploma were more likely to be dissatisfied with the explanatory discussion compared to patients with lower school leaving certificate (Fig. 1).

Predominant feelings in connection with the announcement of the diagnosis were shock (54.8%), fear (39.7%) and helplessness (27.7%), with no significant difference between patients with a shorter or longer period of counseling (example fear: $\text{Chi}^2(4) = 7.94; p = 0.094$).

Table 1: Overview of Age, Sex and School Education of the Participants

Variable	Mean	1 st and 3 rd quartile	Minimum - Maximum
Age	59.18	51, 68	23 – 89
	Category	Number	Percent
Sex	Female	980	98
	male	20	2
School education	High school ("Abitur")	410	41.4
	Secondary School	393	39.7
	Middle School	179	18.1
	No School Diploma	8	0.8

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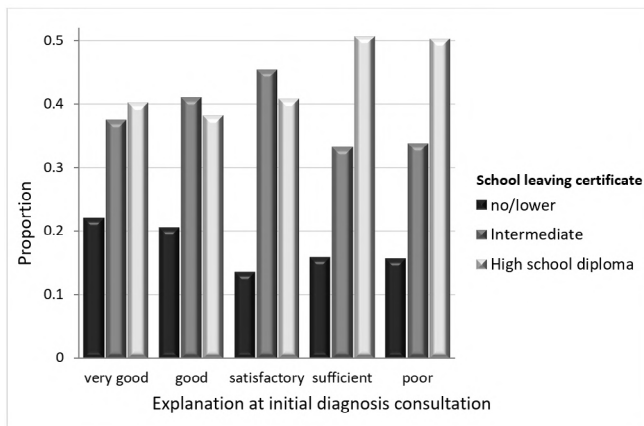


Figure 1: Association between overall satisfaction at first consultation and school graduate

Duration and satisfaction with timeframe of first consultation at initial breast cancer diagnosis

The duration of the first consultation was assessed and the consultation could be rated via a categorical rating scale, ranging from very good (1) to poor (5). The first information about the diagnosis of breast cancer was most frequently provided by the gynecologist (34.8% in private practice, 16.7% in hospital), and second most frequently by the radiologist (37.5%). Others had their first consultation with an oncologist (7.5%) or their general practitioner (3.5%); 0.2% made no statement. The duration of the first consultation varied widely according between 10 minutes (23.0%), 15 minutes (20.5%), 20 minutes (19.9%), 30 minutes (16.1%) and >30 minutes (13.4%). 7.1% did not specify the duration.

The proportion of patients who reported the duration of the consultation as being "just right" increased with longer duration of the first consultation (s. Figure 2). Whilst only 12.7% of the patients felt the duration of the consultation was "just right" at 10 minutes, with 20 minutes duration 57,7% of the patients felt that this was "just right". If the conversation

lasted more than 30 minutes, 90.1% of the patients rated the duration as "just right". This difference in satisfaction was highly significant compared to 10 or 20 minutes, respectively (both $p < 0.001$).

Differences between the groups are statistically significant (10 min vs. >30 min: $\text{Chi}^2(1) = 195.48$, adjusted $p < 0.001$, Cramers $V = 0.763$; 20 Min vs. >30 Min: $\text{Chi}^2(1) = 39.41$, adjusted $p < 0.001$, Cramers $V = 0.351$). The length of consultation had a significant impact on the patients' ratings of the consultation as well ($\text{Chi}^2(1) = 101.70$, $p < 0.001$, Cramers $V = 0.332$). Patients who reported longer consultation times (≥ 30 minutes) evaluated the quality of information in these consultations more positively than patients who reported shorter consultations (see Table 2).

Table 2: Association between evaluation of the first consultation and duration of the conversation Patients who did not provide any information here are excluded in this table.

	10–20 minutes, N = 634	30 minutes or more, N = 295	p-value
Feeling of being informed with first breast cancer diagnosis			<0.001
Very good or good (1 and 2)	318 (50.6%)	250 (85.3%)	
Satisfactory, Sufficient or insufficient (3, 4 and 5)	310 (49.4%)	43 (14.7%)	

Understanding the content of the conversation

Patients who were counselled for 30 minutes or longer were significantly more likely to say that they understood more during the consultation than those who had a consultation of 10-20 minutes ($\text{Chi}^2(1) = 16.04$, $p < 0.001$, Cramers $V = 0.132$) as shown in Table 3. Notwithstanding the significant differences in the understanding, 73% of all patients stated that they were able to make a treatment decision afterwards.

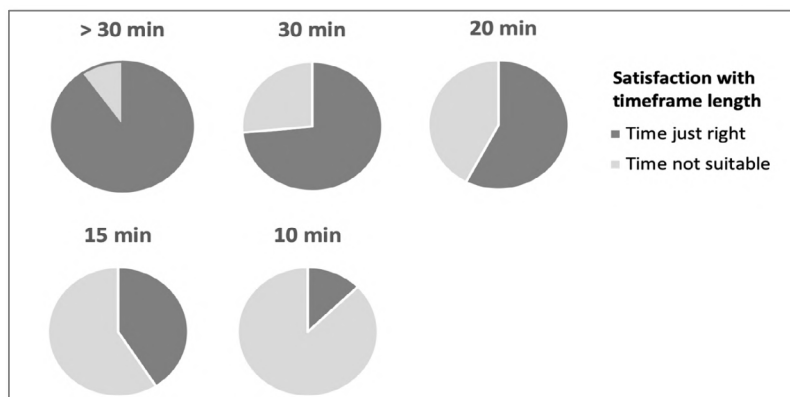


Figure 2: Overview of the relation between first consultation duration and satisfaction with timeframe length.

Table 3: Association between duration of the first consultation and perceived informedness Patients who did not provide any information here are excluded in this table.

Duration of first consultation	Understood everything/ all essentials	Did not understand everything/ unsure	p-value
	30 minutes or more	269 (91.8%)	24 (8.2%)
10-20 minutes	512 (81.7%)	115 (18.3%)	

Discussion

To the best of our knowledge, this is the first study investigating the current care structure in breast cancer focusing on physician-patient communication. Although Physician-patient communication can be defined as the most important aspect of psychosocial care [10] and known significant associations between communication skills and quality of life [11], there has still been no implementation of these insights in everyday clinical practice. A further German survey summarized that physicians should take more time for explanations [12]. It is therefore incomprehensible that there are no PCCCC or adequate billing codes available, while, on the other hand, expensive diagnostics are paid for. All this in the knowledge that good communication could avoid over-diagnostics triggered by excessive anxiety [13]. There is a lot of data on shared decision making, but so far only limited studies [14, 15] have considered the time factor. The WAVES study was conducted to assess the current status of communication during the initial consultation for breast cancer. The results of this preplanned analysis confirm the assumption that the quality of communication (indicated by a predominantly good understanding of the content) is associated with a longer duration of the first consultation and thus with a better understanding of the disease. A long first consultation is not necessarily a synonym for a high-quality consultation [16]. Nevertheless, these data show that with longer duration of the consultation both the content was significantly better understood and overall satisfaction was significantly higher.

These results support previous data that trust – which takes time - is the basis of physician-patient communication. Therefore physicians should be aware of the impact of the time spend together with the patient, not only the content of the conversation itself. It is now recognized that patient motivation is also crucial to treatment success and adherence, therefore shared decision making is increasingly practiced [17]. Basic principles of patient-centered communication include: providing information truthfully, listening actively, showing empathy, capture the need for information, using understandable language and comprehensible information material, identifying individual stressors, problems and

needs, motivating self-determination and personal activities ("empowerment"), giving hope and offering further assistance [18, 19]. When one tries to implement these many points in everyday clinical practice, it quickly becomes clear that there should be enough time to do so. Several studies have already confirmed the importance of 'taking time' and having an empathic conversation during diagnosis notification, treatment [20] and also in the aftercare [5]. In the real world, however, the system provides for fast processing in favor of increased patient case numbers and economic efficiency. The results show that different specialists conduct the initial diagnostic consultation. According to the patients, they were most satisfied when the consultation for the first confirmed diagnosis of breast cancer was conducted by a gynecologist. This shows the importance of developing a clear process in the future to guarantee a prompt presentation at a certified breast center for those affected.

Starting from this, the WAVES study aims to evaluate the resulting needs and work towards an improved system that meets the needs of both patients and physicians. Ideally, the results will be reflected in an adjustment of reimbursement and lift physician-patient-communication up to the same level such as examinations and diagnostics. One advantage of this study is the large number of patients, which suggests that it is a representative sample of breast cancer patients in Bavaria/Germany. Furthermore, the questions were co-developed not only by physicians but also by patients and patient representatives to ensure that the questions that best reflect patients' concerns are addressed. Despite the proof of breast cancer diagnosis, a limitation of the study might be the lack of verifiability of the data, as the patients themselves entered all data. Thus, it cannot be ruled out that there may only be a subjectively perceived high understanding, especially regarding medical facts – a discrepancy that has already been shown before [21]. A bias cannot be ruled out regarding the evaluation of the questionnaire based on the current state of mind and mood. In general, this bias can be considered normal, as memories are also evaluated more positively when being in a better state of mind [22]. As the evaluation of the time shows no significant association with the current state of mind it seems that it is not an unreflected positive evaluation

of the interview just because of a good mood. Follow-up studies should test the effect of specific personal and digital communication strategies on patient outcomes, to counter potential negative effects of information provision, especially in uncertain situations. Ultimately, specific communication strategies could be harnessed in clinical care to improve patient outcomes [23, 24]. Further evaluations of the WAVES study are being planned.

Conclusions

First results from the WAVES study show significantly higher patient satisfaction with physician-patient communication at the initial disclosure of breast cancer diagnosis when the physician takes time for it (≥ 30 min). This was also applied to a substantially higher understanding of the content. The latter seems to be particularly important for patients with High School diploma. As this need for sufficient patient-physician-time is yet not reflected in the current reimbursement structures, these data provide the basis for a potential restructuring of the treatment and care of breast cancer patients.

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Other

Competing Interests

No conflicts of interests regarding this study from any author.

Author Contributions

All authors contributed to the study conceptualization. Material preparation, data collection and formal analysis were performed by Nina Ditsch, Melitta B. Köpke and Stefan Schiele. The original draft of the manuscript was written by Nina Ditsch and Melitta B. Köpke. All authors participated in the Review and Editing of the Draft and approved the final manuscript.

Participating certified breast centres and patient organisations

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Augsburg, Erlangen, TUM and LMU Munich, Regensburg, Wuerzburg

** further certified Breast centres:

Rotkreuz Hospital Munich (Michael Braun, Anne Andrulat),

Hospital Dritter Orden (Isabelle Himsl, Franz von Koch), Hospital Fürstenfeldbruck (Moritz Schwörer, Constanze Türpe)

***Patient organisations and advocates:

mamazone e.V, Brustkrebs Deutschland e.V, BRCA-Netzwerk e.V, Mamma MIA – Die Krebsmagazine, Frauenselbsthilfe nach Krebs e.V, th!nk pink club e.V, Netzwerk Männer mit Brustkrebs e.V, Nicole Kultau (online blog), Allianz gegen Brustkrebs e.V.

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**Appendix Table 1 –
Overview of the tumor characteristics**

Data in absolute and relative numbers. Since 20 patients had bilateral disease, a total of 1020 tumors are listed.

Tumor size		
cT1a (<0.5cm)	37	3.60%
cT1b (>0.5-1cm)	153	15.00%
cT1c (>1-2cm)	327	32.10%
cT2 (>2-5cm)	269	26.40%
cT3 (>5cm)	68	6.70%
cT4	20	2.00%
I don't know	88	8.60%
Not specified	58	5.70%
Histopathological type		
'in situ'	33	3.20%
Other typ	46	4.50%
Ductal carcinoma in situ	57	5.60%
invasive ductal with in situ component	70	6.90%
Invasive lobular	132	12.90%
Invasive mucinous	9	0.90%
Invasive tubular	5	0.50%
medullar	5	0.50%
NST (Non special type)	438	42.90%
Not specified	225	22.10%
Estrogene receptor status (ER)		
Negative	149	14.60%
Positive	626	61.40%
Not specified	245	24.00%
Progesterone Receptor status (PR)		
negative	221	21.70%
positive	511	50.10%
Not specified	288	28.20%
HER2		
negative	561	55.00%
positive	214	21.00%
Not specified	245	24.00%
Grading		
G1	112	11.00%
G2	457	44.80%
G3	247	24.20%
GX	3	0.30%
Not specified	201	19.70%
Lymph node involvement		
Yes	186	18.20%
no	758	74.30%
Not specified	76	7.50%

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Appendix 2 - Excerpt from the Questionnaire

The questions included in the analysis from the first part of the patient questionnaire are listed here. As the survey was conducted in German, the questions listed have been translated into English.

Age _____

Gender male
 female
 diverse

Current condition very good
 good
 satisfactory
 sufficient
 poor

Marital status single
 married
 Partnership, but not married
 Widowed
 Divorced

School-leaving certificate A-levels
 Secondary school
 leaving certificate
 No school leaving certificate

What was your first reaction to the findings?
 I was shocked
 I felt helpless
 I had suspected/ feared it I was afraid
 I was angry
 I felt overwhelmed and left alone I can do it, no matter what
 I was not receptive
 Other predominant feeling not specified

What were your most important questions about the therapy and breast/breasts? their impact on your life situation? Will I lose my
 Will I still see myself as a woman?
 Will I lose my hair? What about my desire to have children?
 What will happen to my child/children now?
 How will my partner deal with the situation?
 Will my partner leave me? Do I have to die now?
 What about my work?
 Will the disease be passed on to my children? Open answer
 Not specified

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How well informed were you in general felt at the initial diagnosis?

- very well
- Good
- satisfactory
- sufficient
- inadequate
- not specified

How long did the initial interview take approximately?

- 10 min
- 15 min
- 20 min
- 30 min
- more than 30 min
- no information

How do you rate the time taken for the time was rather limited, but I was able to clarify all my questions?

- just right
- I would have liked a little more time, but all questions were answered
- I would have liked a little more time, not all questions were clarified
- I would have liked a lot more time No details

Was the attending physician able to comprehendible manner?

- explain the findings to you in a
- yes, I understood the essentials
- no, I could only partially understand the findings no,
- I didn't understand anything
- I was unsure whether I had understood everything
- no information

How did you find the communication within the Initial diagnosis generally perceived?

- very positive
- positive
- neutral
- negative
- very negative no information

Who was the first person to tell you about your breast diagnosis?

- cancer
- Radiologist
- Gynecologist in private practice
- Gynecologist in a clinic Oncologist in private practice
- clinic

Did you already have a Metastasis present?

- yes
- no
- not specified

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