# Communication and Interaction in Multidisciplinary Tumor Conferences

**Doctoral thesis** 

to obtain a doctorate (PhD)

from the Faculty of Medicine

of the University of Bonn

Barbara Schellenberger, née Giller

from Bottrop 2023

Written with authorization of the Faculty of Medicine of				
First reviewer:	Prof. Dr. Nicole Ernstmann			
Second reviewer:	Prof. Dr. Lena Ansmann			
Day of oral examination: 1	1.01.2023			
	chosomatic Medicine and Psychotherapy			
Director: Prof. Dr. Franziska Geiser				

# **Table of contents**

List of abbreviations	4
1. Abstract	5
2. Introduction and Aims	6
2.1 Theoretical Framework	6
2.2 Empirical Background	8
2.3 Aims	9
2.4 References	10
3. Publications	13
3.1 Publication 1: Opportunities and limitations of shared decision multidisciplinary tumor conferences with patient participation – A qualitative inte with providers	rview study
3.2 Publication 2: Questions and emotional expressions from patients and confidence while participating in multidisciplinary tumor conferences in breast and gy cancer centers	necological
3.3 Publication 3: Patient participation in multidisciplinary tumor conferences in gynecological cancer care: How patient-centered is the communication?	
4. Discussion	44
4.1 Limitations and Strengths	45
4.2 Implications	46
4.3 References	47
5. Acknowledgements	49

# List of abbreviations

HCP Healthcare professional

MTC Multidisciplinary tumor conference

PINTU Patient involvement in multidisciplinary tumor conferences in

breast cancer care

SDM Shared decision making

# 1. Abstract

In some cancer centers in North Rhine-Westphalia, oncology patients are invited to participate in their case discussions in multidisciplinary tumor conferences (MTCs). Few studies have examined MTC communication with patient participation from the participant perspective, while an examination of specific aspects of communication is lacking. This work aims to generate insights into communication in MTC case discussions with patient participation and answer the following questions: 1) How do healthcare professionals (HCPs) assess opportunities and limitations of person-centered communication, specifically shared decision making (SDM) in MTCs with patient participation?; 2) How do patients communicate in MTCs with patient participation?; 3) How person-centered do HCPs communicate in MTCs with patient participation? Data for the three publications were collected between November 2018 and February 2020 at six breast and gynecologic cancer centers within the PINTU project (Patient involvement in multidisciplinary tumor conferences in breast cancer care). To answer the questions, different methods were used: (1) Conduct of semi-structured, guideline-based expert interviews followed by qualitative content analyses, and (2)/(3) survey data collection from patients and audio recordings of case discussions in MTCs with patient participation followed by analyses of patients', companions', and HCPs' expressions in anonymized transcripts of audio recordings. Multiple regression analyses determined associations between communicative behavior, patient- and context-related characteristics, and patients' trust in the treatment team after case discussion. Results showed that (1) from the HCPs' point of view, single steps of SDM can be implemented in a limited way in MTCs with patient participation; (2) patients and companions tend to express emotions indirectly; question number was significantly associated with the hospital, and patients' need for psychological support led to a rise in questions asked; and (3) most questions of the HCPs were polar (yes/no). Patients' trust in the treatment team was associated with the nature of HCPs' responses to emotions. Functions of MTC communication with patient participation could be analyzed; however, further research needs to address functions to fulfill and endpoints to achieve to use patients' MTC participation effectively to actively engage patients in the MTC.

# 2. Introduction and Aims

In Germany, about 92,500 women are diagnosed with gynecologic cancer every year, including tumors of the female breast and genital organs (Robert Koch-Institut 2021). For patients, a diagnosis marks the beginning of a long treatment journey, during which they meet many HCPs in different settings, because multidisciplinary care is an essential principle of cancer treatment (Ansmann et al. 2014). Patients are normally treated in breast and in gynecologic cancer centers. As part of the care, the cases of oncology patients are usually discussed in an MTC, in which members of different professional groups talk about diagnosis and therapy of patients with cancer and decide on treatment recommendations (Ansmann et al. 2014). In North Rhine-Westphalia, some patients are invited to participate in their own case discussion in the MTC (Ansmann et al. 2014). This expands the group of people present at the MTC to include the patient and, if appropriate, companions. Although MTCs with patient participation seem to be rather an exception, they are regularly performed in some breast and gynecologic cancer centers in Germany.

While there are numerous studies on MTCs without patient participation (e. g. Soukup et al. 2018), there is evidence on MTCs with patient participation, so far mainly from Australia and Germany (e. g. Butow et al. 2007; Diekmann et al. 2020). Previous research highlighted both advantages and disadvantages of participation for HCPs and patients (Butow et al. 2007; Diekmann et al. 2020). Communication with patients in other oncology settings has also been well studied (see 2.2 Empirical Background), but evidence on communication with patients in MTCs is lacking.

# 2.1 Theoretical Framework

Through person-centered HCP-patient communication, a diagnosis can be made and a treatment plan can be developed (Haes and Bensing 2009). According to the six function model of medical communication (Haes and Bensing 2009), communication can have different functions in the medical context: (1) fostering the relationship, (2) gathering information (3) providing information (4) decision making (5) enabling disease and treatment related behavior, and (6) responding to emotions. These functions can be interrelated (Haes and Bensing 2009). A trustful relationship as a basis supports the other functions, e. g., by

helping to obtain relevant information for diagnosis. Since a physician has approximately 160,000-300,000 patient conversations over the course of his or her professional life (Morris et al. 2013), communication is an essential part of a HCP's daily care routine.

In health services research, health services structures and processes are investigated from a patient and population perspective, taking into account complex context conditions (Pfaff and Schrappe 2011). The throughput model (Pfaff and Schrappe 2011) is often used to represent processes in healthcare and classify objects of study. In this work, the throughput model (Pfaff and Schrappe 2011) and the six function model of medical communication (Haes and Bensing 2009) are merged to examine the communication in MTCs with patient participation (see 2.3 Aims, Figure 1).

In terms of the MTCs, patients, HCPs, and resources are counted as input in the throughput model (Pfaff and Schrappe 2011). Medical communication should fulfill certain functions to achieve the goals that HCPs but also patients have. The MTC itself can be included in the throughput as a health service and is performed under the influence of various context factors. This initially results in the provided health service (output). Communicative behavior, such as exploratory behavior or the provision of information, can be located in the output and considered as immediate endpoints with regard to the functions of medical communication. While different possible outcomes (e. g., physical, psychological, social) are summarized in the throughput model, the six function model of medical communication (Haes and Bensing 2009) additionally distinguishes between intermediate and long-term endpoints that can be influenced by communicative behavior. Shortly after the encounter, the intermediate endpoints are relevant; for example, an HCP can strengthen the patient's trust by establishing a close relationship. On the one hand, health can be considered an objective endpoint, such as cure or survival; on the other hand, subjective health or quality of life may also be considered. This may include, e. g., physical functioning or psychological complaints. Depending on the research question, communicative behavior can thus be the focus of medical communication research as an immediate endpoint and/or as an intermediateand/or long-term endpoint (Haes and Bensing 2009).

# 2.2 Empirical Background

At least since the 1970s, with the shift from HCP-centered to patient-centered medicine, communication between the HCP and the patient has become the focus of the encounter (Koerfer and Koerfer 2018). Meanwhile, the focus has shifted further toward person-centered healthcare, where the patient is no longer viewed solely in terms of health and illness, but as a person with needs and preferences (American Geriatrics Society Expert Panel on Person-Centered Care 2016). There are numerous study findings on patient-/person-centered communication in the oncology context (National Cancer Institute 2022). The following section describes a selection of study results that relate to the functions outlined in the model that conversations with patients can and must have during the course of a cancer disease.

Communication and trust: When HCPs communicate with patients showing they are listening to them and care for them, patients are more likely to trust HCPs. This may lead them to feel less anxious, more likely to adhere to treatment recommendations, and less likely to regret treatment decisions (Hillen et al. 2011; Vries et al. 2014).

*Information:* Patients can better understand the disease if they are given information. Being informed can also lead to patients being better able to manage emotions and take responsibility for their situation (Blödt et al. 2018).

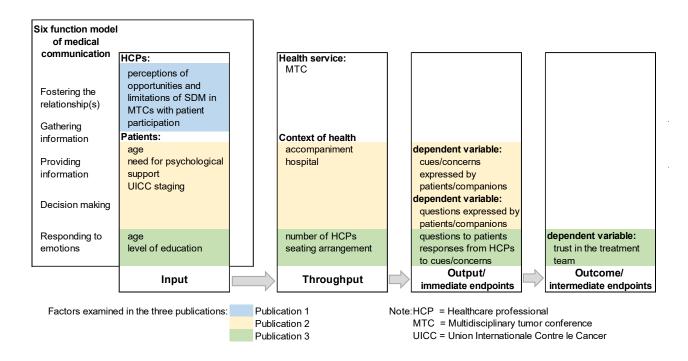
Expression of emotions and responding to them: Emotions tend to be expressed indirectly by patients with cancer (Del Piccolo et al. 2019). Context factors such as environment may influence the number of negative emotional expressions (Del Piccolo et al. 2019). In a study by Butow et al. (2002), associations were found between the number of emotional expressions and the patient's age and gender, claiming that female and younger patients show more expressions. HCPs' responses to patients' emotions can vary as well, consisting in giving patients room to express themselves further or limiting them, for example (Del Piccolo et al. 2011). If HCPs express empathy, patient recall will be positively affected in clinical practice (Westendorp et al. 2021).

Decision making: In patients with prostate cancer, significant associations were found between SDM and prostate-specific health-related quality of life (Ernstmann et al. 2019). It is

known from study results that differences in decision making processes in different oncology settings—MTCs, ward rounds, and outpatient clinics—correlate with the presence or absence of patients (Salloch et al. 2014).

# **2.3 Aims**

While there is already a large body of research on HCP-patient communication in various oncology settings, studies on communication in MTCs with patient participation are still scarce. Taking into account the throughput model (Pfaff and Schrappe 2011) and the six function model of medical communication (Haes and Bensing 2009), the present work aims to generate insights into communication in case discussions in MTCs with patient participation (Figure 1).



**Figure 1:** Research model based on the throughput model (Pfaff and Schrappe 2011) and the six function model of medical communication (Haes and Bensing 2009)

The focus lies on an in-depth look at five functions that cannot be seen independently of each other, because when HCPs ask questions, they receive information that in turn can be important for decision making. The work aims to capture HCPs' views on the possibility of

person-centered communication (specifically SDM) to analyze communication (HCPs' and patients'/companions' utterances—questions, emotions, and responses to them) and to investigate whether there are associations with certain patient characteristics (input) and/or context factors (throughput) and/or outcomes/endpoints.

The following research questions were addressed:

- 1) How do HCPs perceive the opportunities and limitations of person-centered communication, specifically SDM in MTCs with patient participation?
- 2) How do patients communicate in case discussions in MTCs with patient participation?
- 3) How person-centered do HCPs communicate in MTCs with patient participation?

To answer the questions, questions 2 and 3 were answered with three sub-questions each, which can be found on pages 25 and 36, respectively.

# 2.4 References

American Geriatrics Society Expert Panel on Person-Centered Care. Person-Centered Care: A Definition and Essential Elements. J Am Geriatr Soc. 2016;64(1):15–8. doi:10.1111/jgs.13866

Ansmann L, Kowalski C, Pfaff H, Wuerstlein R, Wirtz MA, Ernstmann N. Patient participation in multidisciplinary tumor conferences. Breast. 2014;23(6):865–9. doi:10.1016/j.breast.2014.09.004

Blödt S, Kaiser M, Adam Y, Adami S, Schultze M, Müller-Nordhorn J, Holmberg C. Understanding the role of health information in patients' experiences: secondary analysis of qualitative narrative interviews with people diagnosed with cancer in Germany. BMJ Open. 2018;8(3):e019576. doi:10.1136/bmjopen-2017-019576

Butow P, Harrison JD, Choy ET, Young JM, Spillane A, Evans A. Health professional and consumer views on involving breast cancer patients in the multidisciplinary discussion of their disease and treatment plan. Cancer. 2007;110(9):1937–44. doi:10.1002/cncr.23007

Butow PN, Brown RF, Cogar S, Tattersall MHN, Dunn SM. Oncologists' reactions to cancer patients' verbal cues. Psychooncology. 2002;11(1):47–58. doi:10.1002/pon.556

Del Piccolo L, Haes H de, Heaven C, Jansen J, Verheul W, Bensing J, et al. Development of the Verona coding definitions of emotional sequences to code health providers' responses (VR-CoDES-P) to patient cues and concerns. Patient Educ Couns. 2011;82(2):149–55. doi:10.1016/j.pec.2010.02.024

Del Piccolo L, Mazzi MA, Mascanzoni A, Lonardi M, Felice M de, Danzi OP, et al. Factors related to the expression of emotions by early-stage breast cancer patients. Patient Educ Couns. 2019;102(10):1767–73. doi:10.1016/j.pec.2019.04.002

Diekmann A, Heuser C, Schellenberger B, Bohmeier B, Holmberg C, Ansmann L, Ernstmann N. Patient participation in multidisciplinary tumor conferences: Providers' perceptions of patients' need satisfaction and emotional experiences. Psychooncology. 2020;29(8):1263–71. doi:10.1002/pon.5413

Ernstmann N, Herden J, Weissbach L, Karger A, Hower K, Ansmann L. Prostate-specific health-related quality of life and patient-physician communication - A 3.5-year follow-up. Patient Educ Couns. 2019;102(11):2114–21. doi:10.1016/j.pec.2019.07.030

Haes H de, Bensing J. Endpoints in medical communication research, proposing a framework of functions and outcomes. Patient Educ Couns. 2009;74(3):287–94. doi:10.1016/j.pec.2008.12.006

Hillen MA, Haes HCJM de, Smets EMA. Cancer patients' trust in their physician-a review. Psychooncology. 2011;20(3):227–41. doi:10.1002/pon.1745

Koerfer A, Koerfer K. Dialogische Kommunikation und Medizin. In: Koerfer A, Albus C, eds. Kommunikative Kompetenz in der Medizin: Ein Lehrbuch zur Theorie, Didaktik, Praxis und Evaluation der ärztlichen Gesprächsführung. Göttingen: Verlag für Gesprächsforschung; 2018. p. 262–365

Morris M, Donohoe G, Hennessy M, O Ciardha C. Pro forma: impact on communication skills? Clin Teach. 2013;10(5):318–22. doi:10.1111/tct.12062

National Cancer Institute. Communication in Cancer Care (PDQ®)–Health Professional Version. 2022. Accessed 3 Sep 2022

Pfaff H, Schrappe M. Einführung in die Versorgungsforschung. In: Pfaff H, Neugebauer, E. A. M., Glaeske, G., Schrappe M, eds. Lehrbuch Versorgungsforschung: Systematik - Methodik - Anwendung. Stuttgart: Schattauer; 2011. p. 2–41

Robert Koch-Institut. Zentrum für Krebsregisterdaten. 2021. https://www.krebsdaten.de/Krebs/DE/Content/Krebsarten/krebsarten\_node.html. Accessed 30 Aug 2022

Salloch S, Ritter P, Wäscher S, Vollmann J, Schildmann J. Medical expertise and patient involvement: a multiperspective qualitative observation study of the patient's role in oncological decision making. Oncologist. 2014;19(6):654–60. doi:10.1634/theoncologist.2013-0268

Soukup T, Lamb BW, Arora S, Darzi A, Sevdalis N, Green JS. Successful strategies in implementing a multidisciplinary team working in the care of patients with cancer: an overview and synthesis of the available literature. J Multidiscip Healthc. 2018;11:49–61. doi:10.2147/JMDH.S117945

Vries AMM de, Roten Y de, Meystre C, Passchier J, Despland J-N, Stiefel F. Clinician characteristics, communication, and patient outcome in oncology: a systematic review. Psychooncology. 2014;23(4):375–81. doi:10.1002/pon.3445

Westendorp J, Stouthard J, Meijers MC, Neyrinck BAM, Jong P de, van Dulmen S, van Vliet LM. The power of clinician-expressed empathy to increase information recall in advanced breast cancer care: an observational study in clinical care, exploring the mediating role of anxiety. Patient Educ Couns. 2021;104(5):1109–15. doi:10.1016/j.pec.2020.10.025

# 3. Publications

The three publications were based on data from the PINTU project, which was funded by the German Cancer Aid.

The goal of the first original article was to generate insights into how HCPs assess the limitations and opportunities of SDM in MTCs with patient participation. The second and the third original articles aimed to generate insights into HCP-patient communication and possible associations with patient characteristics and/or context factors, and/or patients' trust as an outcome.

- 1) Data from n = 30 semi-structured interviews with HCPs, who regularly attend MTCs with and without patient participation, were analyzed. A qualitative content analysis was carried out to examine opportunities and limitations of SDM in MTCs with patient participation from the HCPs' perspective in breast and gynecologic cancer centers.
- 2) Data of the observations (transcripts of the audio data and field notes) from 82 case discussions in MTCs in three breast and gynecologic cancer centers and questionnaire data were used. Patients' and companions' expressions were analyzed in terms of questions and emotions. Qualitative analysis was performed to determine themes linked with negative emotions. Two multiple linear regressions were performed to capture if input and/or throughput factors determine the patients' communicative behavior.
- 3) Again, the data of the observations were analyzed. HCPs' questions to patients and responses to patients'/companions' emotional expressions were coded. Multiple linear regression analysis was used to determine associations between HCPs' responses, patient-and context-related characteristics, and patients' trust in the treatment team as an outcome after the case discussion.

3.1 Publication 1: Opportunities and limitations of shared decision making in multidisciplinary tumor conferences with patient participation – A qualitative interview study with providers

Bohmeier B, Schellenberger B, Diekmann A, Ernstmann N, Ansmann L, Heuser C. Opportunities and limitations of shared decision making in multidisciplinary tumor conferences with patient participation – A qualitative interview study with providers. Patient Educ Couns. 2021;104(4):792–799. doi:10.1016/j.pec.2020.09.007

Patient Education and Counseling 104 (2021) 792-799

ELSEVIER

Contents lists available at ScienceDirect

# Patient Education and Counseling

journal homepage: www.elsevier.com/locate/pateducou



# Opportunities and limitations of shared decision making in multidisciplinary tumor conferences with patient participation – A qualitative interview study with providers



Barbara Bohmeier<sup>a,b,\*</sup>, Barbara Schellenberger<sup>a,b</sup>, Annika Diekmann<sup>a,b</sup>, Nicole Ernstmann<sup>a,b,c</sup>, Lena Ansmann<sup>d</sup>, Christian Heuser<sup>a,b</sup>

- <sup>a</sup> Center for Health Communication and Health Services Research (CHSR), Department for Psychosomatic Medicine and Psychotherapy, University Hospital Bonn, Germany
- <sup>b</sup> Center for Integrated Oncology (CIO), University Hospital Bonn, Germany
- <sup>c</sup> Institute for Patient Safety, University Hospital Bonn, Germany
- <sup>d</sup> Division for Organizational Health Services Research, Department of Health Services Research, School of Medicine and Health Sciences, Carl von Ossietzky University Oldenburg, Germany

#### ARTICLE INFO

Article history: Received 15 May 2020 Received in revised form 1 September 2020 Accepted 6 September 2020

Keywords:
Breast cancer
Gynecological cancer
Patient physician communication
Shared decision making
Multidisciplinary tumor conference
Patient participation
Patient involvement
Patient-centered care in oncology
Providers' perspective

#### ABSTRACT

*Objective*: The aim of this study was to examine opportunities and limitations of shared decision making in multidisciplinary tumor conferences with patient participation from the providers' perspective in breast and gynecological cancer centers.

Methods: Semi-structured guideline-based expert interviews were conducted with providers from breast and gynecological cancer centers with and without patient participation in multidisciplinary tumor conferences. Interviews were transcribed, anonymized and analyzed using qualitative content analysis. Results: The providers (n = 30) reported that some process steps of shared decision making can be implemented in limited form and under certain conditions in multidisciplinary tumor conferences with patient participation. Above all, patients can potentially ask questions and contribute individual additional information and their preferences.

Conclusion: This study contributes first insights into the implementation of shared decision making in multidisciplinary tumor conferences with patient participation. From the providers' perspective, the implementation of shared decision making seems difficult under the current circumstances. Further studies, using patient experiences, participative observations or interventional designs, are required. Practice Implications: Despite the limited implementation of shared decision making in tumor conferences, patient participation can be advantageous as it can allow patients to ask questions and contribute individual additional information as well as their preferences.

© 2020 The Authors. Published by Elsevier B.V. This is an open access article under the CC BY-NC-ND license (http://creativecommons.org/licenses/by-nc-nd/4.0/).

#### 1. Introduction

A total of 68,950 women in Germany were diagnosed with breast cancer and 26,150 with a gynecological tumor<sup>1</sup> in 2016 [1]. For most oncological disorders S3 guidelines exist that describe the different evidence-based treatment options, including their risks and benefits. Many of these treatments are associated with a meaningful impact on the patient's quality of life [2]. Various decisions must be made in order to specify the treatment. In oncology, the concept of shared

E-mail address: barbara.bohmeier@stud-mail.uni-wuerzburg.de (B. Bohmeier).

decision-making (SDM) plays an important role. SDM means that the physician and the patient actively participate in making the decision on an equal footing and on the basis of shared information [3,4]. SDM is considered a key element of high-quality health care [5,6]. It is associated with positive effects, including more patient knowledge about various treatment options and their risks and benefits, greater satisfaction with the decision-making and treatment processes, higher quality of life, greater compliance, and decreased fear [7–10]. Both national and international studies show that the majority of oncology patients and the majority of providers in oncology prefer making decisions in a shared manner [11–18].

Nevertheless, studies show that SDM has not been systematically implemented in oncology for various reasons, most of them systemic [19–26]. Research indicates that multidisciplinary tumor conferences (MTCs) might be a barrier to the implementation of SDM in oncology since patient preferences receive very little attention in the

<sup>\*</sup> Corresponding author at: Center for Health Communication and Health Services Research (CHSR), Department for Psychosomatic Medicine and Psychotherapy, University Hospital Bonn, Venusberg-Campus 1, 53127 Bonn, Germany.

<sup>&</sup>lt;sup>1</sup> Including: Cervical, womb, vulval and ovarian cancer.

development of the treatment recommendation in MTCs [27,28]. MTCs are regular meetings within a multidisciplinary treatment team in which the diagnosis and treatment of cancer patients are discussed and evidence-based, guideline-compliant treatment recommendations are developed [29,30]. Treatment recommendations made in MTCs are primarily developed on the basis of medical information. Further patient-related information, such as sociodemographic characteristics, psychosocial factors, comorbidities, and patient preferences, are considered to a lesser extent [24,25,27,28,31-42]. Studies show that the vast majority of MTC recommendations is implemented. But there are regularly cases in which either no decision on the treatment recommendation is made during the MTC or the recommendation cannot be implemented in this way afterward [43–46]. Reasons include insufficient consideration of non-medical, patient-based information as well as the need for further conversations with the patient [32,42,47– 49]. This may lead to a repeated case presentation in an MTC, which might delay treatment [35,37,43,50]. Studies also show that where treatment alternatives are available, providers preselect the treatment in the MTC and then discuss this treatment with the patient after the MTC [27,28,39]. All mentioned studies point out that it is important to investigate how patient preferences can be better taken into account in

In this regard, studies report a rare patient participation in MTCs in various countries [14,51–54], with hitherto unexplored advantages and disadvantages for patients and providers. Provider concerns regarding patient participation in MTCs are based on potential interference with objective case consideration, about patients' ability to cope, and about impairment of the decision-making process [33,55]. In addition, providers associate patient participation with greater time requirements, a modification of their medical terminology, and limiting the discussion among providers [14,33,56]. From the patient perspective, a German and an Australian study report that participation was perceived as empowering, helpful, and informative but also caused emotional reactions during and after participation and was associated with difficult experiences such as fear and overstrain [56,57]. Potential benefits of patient participation in MTCs discussed in the literature are greater provider attentiveness, reinforcement of team approach, familiarization with the patient before treatment, patients being more informed and empowered and improvement of compliance [14,56]. Studies also report that patients who were present during the MTC or in other decision-making situations were able to directly contribute their preferences and better participate in decision making [39,58].

However, the effects of patient participation in MTCs on the implementation of SDM in oncology have not yet been studied. Therefore, this study investigated providers' perceptions of the opportunities and limitations of SDM in MTCs with patient participation.

# 2. Methods

# 2.1. Study design

This multicenter, exploratory qualitative expert interview study investigated the opportunities and limitations of SDM in MTCs with patient participation from the providers' perspective. The study was conducted as part of the three-year (06/2017 through 05/2020) PINTU study $^2$ . The PINTU study aims to explore differences between MTCs with and without patient participation in breast and gynecological cancer centers in terms

of their organization, interaction, and decision making as well as provider and patient assessments of patient participation [59].

### 2.2. Inclusion criteria and participants

Providers were recruited in breast and gynecological cancer centers in North Rhine-Westphalia, Germany (3 with and 3 without patient participation in MTCs, n = 6 centers). Providers from centers with and without patient participation were included to collect the subjective experiences as well as the hypothetical opinion regarding SDM in MTC with patient participation. Using purposeful sampling [60], providers from medical, nursing and psychological disciplines who regularly attend MTCs as well as staff organizing and documenting the MTC were invited to participate in the study in an effort to survey heterogeneous experiences. N = 116 providers were contacted by email, phone, and personally. Providers who gave written informed consent were included in the analysis.

#### 2.3. Data collection

The interdisciplinary research team consisted of two psychologists (AD, NE), one sociologist (CH), a health scientist/public health researcher (LA), a rehabilitation scientist (BB), and a health services researcher (BS). All researchers have prior experience with conducting and analyzing qualitative interviews. An interview guideline for providers from cancer centers with and without patient participation in MTCs was developed by the interdisciplinary research team. The interview guideline was modified in the context of two pretests. The guideline was structured on the basis of criteria related to its content (organization, interaction, decision making) and timing (before, during, after the MTC). In the interviews, provider experiences, opinions, and concerns regarding the feasibility of patient participation and the quality of decision making in MTCs were discussed. In addition, differences between MTCs with and without patient participation and the advantages and disadvantages of patient participation were addressed. The guiding questions on the topics were as open as possible, and interviewers were able to pose follow-up questions. For the research question of this study, the questions listed in Table 1 were of particular importance. These questions were developed on the basis of the Shared Decision Making Ouestionnaire – Physician Version (SDM-Q-Doc) by Scholl et al. [61] and the SDM process steps according to Elwyn et al. [62] and Härter [4].

**Table 1**For the research question relevant questions in the interview guideline.

or the research question relevant questions in the interview guideline.				
MTC without patient participation	If patients would participate, which topics could already be discussed during the MTC? Which rather not?			
MTC with patient participation	To what extent are different treatment options, their risks and benefits discussed with patients during the tumor conference?			
	How is it checked whether the patients have understood all the information?			
	To what extent are patients given the opportunity to express their treatment preferences and needs?			
	What influence do patients have on treatment recommendations and decisions?			
	Does the decision regarding the treatment with the patient already take place during the tumor conference?			

Is the further procedure already discussed with the

patient during the tumor conference?

<sup>&</sup>lt;sup>2</sup> PINTU: "Patient involvement in multidisciplinary tumor conferences – an exploratory study"; conducted by: a) Center for Health Communication and Health Services Research, University Hospital Bonn; b) Institute of Medical Sociology, Health Services Research, and Rehabilitation Science, University of

The semi-structured expert interviews were conducted between April and November 2018 by four researchers (AD, BB, CH, BS) until no new aspects emerged. Based on provider preference, the interviews were conducted either by phone or in person at the centers. Excepting the pretests, all interviews were to be held by one researcher with one interviewee. Upon interviewee request, one interview was conducted with two interviewees and without audio recording. Instead, the researcher prepared memory protocols immediately after the interview. All other interviews were documented by audio recording. After each interview, initial impressions and interpretations were also recorded in writing in field notes.

Alongside the interviews, a standardized written questionnaire collected personal data of the providers for the sample description. It was completed either during the interview or mailed afterward. The questionnaire included information on sociodemographics and the provider's position at the cancer center (Table 3).

#### 2.4. Data analysis

The audio-recorded interviews were transcribed in accordance with defined standards [63] and anonymized. Transcripts and notes were entered in MAXQDA. The interviews were analyzed with qualitative content analysis according to Mayring [64]. Categories were deductively assigned. The interviews were coded by two researchers (BB, CH) who were in regular communication with one another to validate the categories.

First, a category system was developed which was broken down into opportunities and limitations of SDM in MTCs with patient participation. The categories represent the SDM process steps known from the literature in a slightly modified form [4,61,62] (Table 2). Then, all transcripts and notes were analyzed in a first pass regarding the SDM process steps, and important text passages were marked. Afterward, the coding guide was generated with the deductively defined categories, associated category definitions, key examples, and coding rules. Next, the text passages pertaining to the defined categories were coded, extracted, and paraphrased. For each category, a summary of sources was provided.

**Table 2** Process steps of shared decision making [4,61,62].

Process steps of shared decision making
1. Disclosure that a decision needs to be made
2. Formulation of equality of partners
3. Presentation of treatment options
4. Informing on the benefits and risks of the options
5. Investigation of the patient's understanding and expectations
6. Identification of both parties' preferences
7. Negotiation
8. Reaching a shared decision
9. Arrangement of follow-up

# 3. Results

# 3.1. Sample description

From among 116 invited providers, n=32 from the six cancer centers were willing to participate in the interview-based study (response rate of 27.6 %). A pretest was conducted with n=2 of these 32 providers. N=30 interviews were included in the analysis. Providers who declined to participate in the interviews reported doing so because they rarely or never participated in MTCs, lacked

time, lacked interest, had left the cancer center, or preferred answering interview questions in writing. The sample consisted of providers from cancer centers with (16 providers) or without patient participation (14 providers) in MTCs. The organization of the MTCs with patient participation is very different in the included cancer centers. For instance, patients may participate in the medical discussion or enter the MTC after the discussion. Within the PINTU study these feasibility and organization aspects of patient participation in MTC will be analyzed. Table 3 presents sociodemographic characteristics. The majority of the interviews took about 30 min. The interview duration ranged between 14 and 81 min.

### 3.2. SDM process steps in MTCs with patient participation

The first two SDM process steps of "disclosure that a decision needs to be made" and "formulation of equality of partners" were not covered by the interviews. In most cases patients are informed about the (potential) cancer diagnosis before the MTC. Therefore, the researchers assumed that these two topics are already discussed with the patients prior to the MTC. For the other SDM process steps, Table 4 presents interview quotes that are representative of the individual categories.

#### 3.2.1. Presentation of treatment options

The majority of providers from centers with patient participation reported that patients are presented one treatment option in MTCs. Several treatment options are briefly presented in cases

**Table 3** Participant characteristics (n = 30).

· · · · · ·	
Characteristic	n (%)
MTC with patient participation experience	
Yes	16 (53.3 %)
No	14 (46.7 %)
Gender	
Women	19 (63.3 %)
Men	11 (36.7 %)
Age (years)	
Range	25-61
Mean	49
Categories	
25–37	3 (10 %)
38-49	10 (33.3 %)
50-61	16 (53.3 %)
missing	1 (3.3 %)
Profession	
Gynecologist	12 (40.0 %)
Breast Care Nurse	4 (13.3 %)
Radiation Oncologist	4 (13.3 %)
Psycho-Oncologist	4 (13.3 %)
Oncologist	2 (6.7 %)
Pathologist	1 (3.3 %)
Quality Manager	1 (3.3 %)
Diet-Assistant	1 (3.3 %)
MTC Documentalist	1 (3.3 %)
Dueforsional comparisons (sugars)	
Professional experience (years) Range	<1-38
Mean	<1-36 15.4
Mean	15.4
Frequency of MTC participation per month	
Range	1-20
Mean	4
Time of MTC experience (years)	
Range	<1-14
Mean	8.7

**Table 4**Key examples from the providers' interviews.

Category SDM process steps	Key examples
Presentation of treatment options	"And, er, er, the different professional groups would say: 'Well (-) that is what WE can offer. We could do this, we could do that. And er (-) um (-) we have come to the realization that, well, there are (-) three options [ ]." (Psycho-oncologist, no participation, I. 011, A. 53)
	"But she is, um, actually, IF there are different choices, she is always told the choices." (Gynecologist, participation, I. 019, A. 33)
	"No, that s/, em, would be beyond the scope. That is to say, we simply say, we have recommended that as the best treatment on the basis of the GUIDElines. That's our recommendation. They just have to see whether they FOLLOW the recommendation. [] And THEN, as part of the one-to-one consultation, you talk about the alternatives again. But the, the/ our RECOMMENDATION is first of all our recommendation, without alternatives." (Radiation therapist, participation, I. 024, A. 27)
Informing on the benefits and risks of the options	"Which effect, which side effects? Which EFFECT em (-) do you even mean? Well, am I among the patients who are very LIKELY to benefit from chemotherapy or only MAYBE? All of these details are then, em, (-) (clicks tongue) not talked about at all during the tumor conference." (Psycho-oncologist, participation, I. 12, A. 77)
	"We can/ it's not the tumor conference's purpose to go through ALL side/possible side effects of chemotherapy. They HAVE a detailed conversation with every specialist, eh, mentioned in the recommendation anyway before starting therapy." (Breast care nurse, participation, I. 034, A. 150)
Investigation of the patient's understanding and expectations	"Well, advantages are, as mentioned before, (-) that (-) the patient's INDIVIDUAL particularities (-) are immediately revealed, right? That a patient can also (-) interject: 'Yes, but I, eh, (-) did not tolerate that well in the past.' Or something like that, which might not have come out so well in the medical history. [ ] Having this information IMMEDIATELY, so to speak, that would be a big advantage." (Gynecologist, no participation, I. 008, A. 95)
	"But most of the time, eh, it is simply, eh, (-) compact. So, there's not all that much room for questions. So, I usually tell them they should already go downstairs for an appointment for the one-to-one consultation." (Radiation therapist, participation, I. 024, A. 11)
	"She can, at any time, yeah, ask questions there, too. But she can also say that she has other things. She can also present other concepts from other uni entities [author's note: university medical centers are meant]." (Breast care nurse, participation, I. 031, A. 125)
Identification of both parties' preferences	"Well, the fact that you can make the decision with even more information about patient preferences. As a result, the following conversations are such that all tumor board decisions, of course, can be implemented one-to-one, one HUNDRED percent." (Radiation therapist, no participation, I. 015, A. 55)
	"Em, (4) well, if, if there's an alternative, if you don't know or aren't really sure, eh, according to the (-) findings, according to the guidelines, according to the treatment concept, em, then it helps, em (-), if the patient then contributes his statement, eh, his opinion. But he would, in MY opinion, be much better off doing that in a one-on-one conversation with the treating physician. Than in front of a tumor conference." (Pathologist, participation, I. 021, A. 109)
Negotiation	"Of course, there are also patients who have problems with the standard case (-). And it's not rare to have patients with whom we are done in two minutes or in one minute because we say it's a clear case. The guideline recommendation is TOTALLY clear, without any alternative worth mentioning. And then you discuss this decision with the patient for an hour or longer, that happens all the time. It's not like this need for discussion is reserved for the SEVERE cases, the cases that are severe from our perspective. And now imagine moving this patient conversation to the tumor conference, that doesn't work." (Gynecologist, no participation, I. 008, A. 111)
	"There can be discussions sometimes. If the patient asks again if that's really the best therapy, for example, or whatever." (Radiologist, participation, I. 027, A. 43)
Reaching a shared decision	"If, if there's agreement, right, between, between the treatment recommendation and the patient's treatment PREFERENCE, it can be defined during the tumor, eh, conference." (Medical psycho-oncologist, participation, I. 018, A. 49)
Arrangement of follow-up	"THAT is usually done in a one-on-one conversation, right? Then the patients are/ are told, so to speak: 'Well, you now have an appointment', for example in the oncology PRACTICE, right, and everything else, right, we'll talk about THERE and, right, that's where you'll get the further appointments, prescriptions, etc." (Medical psycho-oncologist, participation, I. 018, A. 51)

where the providers see alternatives or have no clear treatment preference or where the patient rejects the recommended treatment. However, providers reported that guidelines limit their options anyway. Other providers from centers with and without patient participation stated that treatment alternatives are discussed in a one-to-one conversation with the patient before or after the MTC. Few providers from centers without patient participation could imagine that it is possible to discuss various treatment options in MTCs with patient participation.

# 3.2.2. Informing on the benefits and risks of the options

Some providers from centers with patient participation reported that the benefits and risks of the presented treatment recommendation are regularly discussed briefly, while other providers reported that benefits and risks are presented upon patient request. Further, providers reported that benefits and risks are discussed with the patient in MTCs if there is a choice between

different treatment options. The majority of providers from centers with and without patient participation stated, however, that the side effects of treatment are discussed in more detail during a one-to-one consultation after the MTC.

## 3.2.3. Investigation of the patient's understanding and expectations

Most providers from centers with patient participation reported that the patient has the opportunity to ask questions and contribute her personal thoughts and additional information at the end of the case presentation. Providers from centers without patient participation could well imagine implementing this SDM process step as well. However, some providers from centers with and without patient participation believed that the patient should listen and write down questions for the follow-up conversation. In addition, after the MTC, additional questions are reportedly clarified and detailed explanations given. Further, some providers said that questions are already answered and information provided before the MTC.

### 3.2.4. Identification of both parties' preferences

Most providers from centers with patient participation reported that both parties inform one another of their preferences during the MTC. First, the providers' treatment recommendation is presented and explained to the patient. Then, the patient has the opportunity to state her preferences regarding the presented treatment recommendation and possible alternatives. Providers from centers without patient participation concurred that in case of participation, the patient could directly contribute her preferences. According to some interviewees from centers without patient participation, this would improve decision quality and lead to "one-to-one" implementation of most treatment recommendations, thereby obviating the need for presenting the case a second time. Preferences are reportedly discussed both before the MTC and afterward. One of the interviewees from a center without patient participation added that it makes sense to know the patient's preferences before the providers discuss the treatment recommendation so that it can be taken into account. Few providers from centers with and without patient participation argued that it is impossible to discuss preferences in the MTC or that this is not an appropriate place to do so.

### 3.2.5. Negotiation

This SDM process step involves weighing different treatment options regarding their benefits and risks together with the patient. However, the providers from centers with patient participation reported that discussions with the patient cover the recommended treatment, but not other treatment options. The majority of providers reported that during the MTC, the treatment recommendation is given to the patient, and there is rarely any further interaction in this setting. Most providers without patient participation believed that the patient should discuss the decision about the further treatment with her treating physician in a one-on-one follow-up conversation. Most providers with patient participation reported that this is the way it is done.

# 3.2.6. Reaching a shared decision

Providers from centers with patient participation reported that patients can accept or reject the presented treatment recommendation during the MTC if she already has a clear preference. The majority of providers stated that the treatment decision is typically made in the MTC. Cases in which the treatment decision is made afterward are reportedly those in which the patient needs a reflection period, wants to get a second opinion, or the providers' treatment recommendation does not coincide with the patient's treatment preference. Therefore, it has to be discussed in detail in a follow-up conversation. Few providers from centers with patient participation reported that the decision is made only later, in the follow-up conversation. In some cases, the treatment has already been decided upon before the MTC since the patients are prepared for the MTC.

### 3.2.7. Arrangement of follow-up

According to the providers from centers with patient participation, the follow-up is not discussed in detail in the MTC. Instead, an appointment is scheduled for the follow-up conversation or an encounter with the treating physician. Most providers from centers with patient participation reported that the further procedure is agreed in a personal conversation with the patient after the MTC. During this conversation, further appointments are made, a schedule is defined, and the specific implementation of the treatment is discussed. Few providers from centers with patient participation stated that organizational matters or the procedure are discussed already with the patient before the MTC. Providers from centers without patient participation believed that it would not be possible to implement this SDM process step in MTCs with patient participation.

#### 4. Discussion and conclusion

#### 4.1. Discussion

In this study, the opportunities and limitations of SDM in the context of MTCs with patient participation were investigated from the providers' perspective. For this purpose, n = 30 guided expert interviews were analyzed using qualitative content analysis. Providers reported that in MTCs, patients are typically presented one treatment option together with its benefits and risks. Most of the time, the patient subsequently has the opportunity to ask questions, provide additional specific information, and state her preferences regarding the providers' presented treatment recommendation. According to the providers, discussions with the patient cover the recommended treatment, but not alternative treatment options. They added that if the patient has already stated her preference, the treatment decision may be made together with the patient during the MTC. According to the providers, however, the only options available to the patient are to either accept or reject the presented treatment recommendation. Providers reported that in cases where the patient's treatment preference deviates from the providers' treatment recommendation, this is discussed in detail with her once again after the MTC. According to the providers, the further procedure is not discussed in detail but agreed outside the MTC.

The providers' reports demonstrate that the implementation of SDM in MTCs with patient participation is ambivalent. As it has been found for other decision-making situations in oncology, the systematic implementation of SDM in MTCs seems difficult at this time [19-22,24,65,66]. Nevertheless, many providers reported that they apply some steps of the SDM process. Other steps, in contrast, can be implemented only in limited form and under certain conditions. The interviews suggest some reasons for the limited implementation of SDM process steps in MTCs with patient participation. They include, for instance, lack of time, guidelines, comprehension problems, and patient overstrain. Feasibility aspects and further barriers of patient participation in MTCs are currently being researched by the PINTU team. In view of these systemic barriers, providers at times practice the informed consent concept, which is considered a paternalistic form of the physician-patient interaction [67]. In conformity with our results, other studies on decision-making situations in oncology have shown that patients are presented only one treatment option including its risks and benefits [22,25,68,69] since from the provider perspective, no alternatives are available [25]. In contrast, a German observational study by Hahlweg et al. (2015) on various MTCs revealed that in many of the presented cancer cases, several treatment options were available, but only one treatment recommendation was documented [27]. In this context, the question arises which cases of illness ("standard case" according to guideline vs. complex case) providers have in mind when reporting that there are few or no treatment alternatives. In a study by Hahlweg et al., physicians rarely reported engaging in patient conversations about treatment options before the MTC [27]. In deviation from these results, providers from centers with patient participation in the MTC reported that they have already talked with the patient about different treatment options and worked out a treatment recommendation before the MTC. These discrepancies may be due to different procedures being used at the centers, center size, different indications, and the option of patient participation. A U.S. study on breast and prostate cancer [66,70] and an Australian study on breast cancer and other cancer types [66,70] have shown that physicians in various decision-making situations rarely exhibit behaviors exploring patient concerns, expectations, and preferences [66,70]. In our interviews, in contrast, providers reported asking patients about their thoughts and preferences during the MTC and patients having an opportunity to ask questions and contribute

additional information in the end. In addition, even providers from centers without patient participation in MTCs concurred with Butow et al. and Choy et al. that patient participation is associated with consideration of the patient perspective [14,56]. In a German study by Diekmann et al. (2019), breast cancer patients reported that in the MTC, they were able to state their opinions on further treatment and to therefore more intensively contribute to decision making [57,58]. This can be considered a benefit of patient participation since failure to consider patient preferences and other patient-based factors is among the reasons for treatment recommendations not being implemented and represents a barrier to effective decision making regarding the treatment recommendation in MTCs [32,42,47,48]. Often, this requires another case presentation in the MTC, which can delay treatment [35,37,43,50]. In conformity with these results, interviewed providers from centers without patient participation in MTCs believed that if patient preferences are considered in the MTC, treatment recommendations made in the MTC can be implemented, thereby eliminating a repeat presentation of the patient case. A current French study by Massoubre et al., in contrast, did not find any influence of the presence of head and neck cancer patients on decision making in the MTC [71]. In this context, it is important to bear in mind that the patient's influence on decision making may differ depending on whether the patient takes an active or passive role in the MTC or how the MTC is organized.

### 4.1.1. Strengths and limitations

This study has limitations to be taken into account in the interpretation of results. Firstly, collecting the provider perspective without simultaneously collecting the patient perspective represents a limitation. However, the patient perspective is currently intensively being studied within the PINTU study and results are to be expected soon. Secondly, the first two SDM process steps were not explicitly queried, as the researchers assumed that these topics are already discussed with the patient prior to the MTC. In addition, only providers from breast or gynecological cancer centers were surveyed, which limits the generalizability of results to other tumor entities and might bias the results in general. The conclusions consider this important limitation. The study also has several strengths. One of its main strengths is the fact that it examines a largely unexplored topic. So far, SDM has been investigated only in MTCs without patient participation [27]. Another advantage is its exploratory approach since it provides comprehensive and unbiased insights into the new topic. The collection of the provider perspective represents another strength since providers in particular can facilitate or hinder the implementation of SDM. In addition, this study might contribute to further supporting efforts to implement SDM in oncology.

# 4.2. Conclusion

This study contributes first insights into the implementation of SDM in MTCs with patient participation by interviewing providers about their experiences and opinions using guided expert interviews. The providers' statements show that the implementation of SDM in MTCs with patient participation seems difficult under the current circumstances. However, patient participation in MTCs can give patients an opportunity to ask questions in the MTC and contribute additional information about themselves and their preferences. This may influence the implementation of SDM in oncological care in general. Further studies, for instance using patient experiences and in the form of participative observations or interventional designs, are required in order to draw definitive conclusions about the advantages or disadvantages of patient participation in MTCs. After that the implementation of SDM in MTCs with patient participation can further be evaluated.

### 4.3. Practical implications

The study shows that despite the limited implementation of SDM in MTCs, patient participation can be advantageous as it can allow patients to ask questions and contribute individual additional information as well as their preferences. This represents an important aspect of patient-centered oncological care. However, according to the SDM model, it is important to not only take into account treatment preferences in relation to a single treatment option, but also define the optimal treatment with the aid of the patient and her preferences. Of course, the patient's individual desire to participate in decision making always has to be taken into account. In view of provider concerns about the implementation of SDM in MTCs with patient participation, it is worth considering how patient preferences and other patient-based information can be better taken into account in MTCs without patient participation in an effort to ensure that the treatment recommendation is established in a patient-centered manner. An alternative to patient participation in MTCs could be to discuss various treatment options and their risks and benefits with the patient and to explore their preferences prior to the MTC. Another option could be the use of representatives, for instance the treating physician, the breast care nurse, or the psychooncologist, who could then report patients' preferences in the MTC [32,72].

### Ethics approval and consent to participate

All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. This study was approved by the ethics committee of the Medical Faculty of the University of Cologne, Germany (Reference number for the approval: 17–405). Written informed consent was obtained from all individual participants included in the study.

# Funding

This study was supported by the German Cancer Aid (DKH, grant number 70112286).

# Availability of data

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

# **CRediT authorship contribution statement**

Barbara Bohmeier: Conceptualization, Data curation, Formal analysis, Investigation, Methodology, Writing - original draft, Writing - review & editing. Barbara Schellenberger: Investigation, Methodology, Writing - review & editing. Annika Diekmann: Investigation, Methodology, Writing - review & editing. Nicole Ernstmann: Funding acquisition, Methodology, Writing - review & editing. Lena Ansmann: Funding acquisition, Methodology, Writing - review & editing. Christian Heuser: Conceptualization, Data curation, Formal analysis, Investigation, Methodology, Supervision, Writing - review & editing.

# **Declaration of Competing Interest**

The authors report no declarations of interest.

# Acknowledgements

We would like to thank all breast and gynecological cancer centers and providers who participated in this study. We are grateful to the German Cancer Aid for funding this research.

#### References

- [1] Robert Koch-Institut, Krebs in Deutschland für 2015/2016. [Cancer in Germany in 2015/2016], twelfth, Ausgabe, Berlin, 2019.
- [2] Office des Leitlinienprogrammes Onkologie c/o Deutsche Krebsgesellschaft e. V., Onkologische Leitlinien. [Oncological guidelines], (2017). (Accessed 23 June 2019) https://www.leitlinienprogramm-onkologie.de/leitlinien/.
- June 2019) https://www.leitlinienprogramm-onkologie.de/leitlinien/.
  [3] C. Charles, A. Gafni, T. Whelan, Shared decision-making in the medical encounter: what does it mean? (or it takes at least two to tango), Soc. Sci. Med. 44 (1997) 681–692, doi:http://dx.doi.org/10.1016/s0277-9536(96) 00221-3.
- [4] M. Härter, Partizipative Entscheidungsfindung (Shared Decision Making) Ein von Patienten, Ärzten und der Gesundheitspolitik geforderter Ansatz setzt sich durch. [Shared decision making- an approach demanded by patients, physicians and the health policy prevails], Z. Arztl. Fortbild. Qualitatssich. 98 (2004) 89–92.
- [5] C. Bergelt, I. Scholl, M. Härter, Chancen und Barrieren partizipativer Entscheidungsfindung in der Onkologie. [Chances and barriers of shared decision-making in oncology], Forum 31 (2016) 140–143, doi:http://dx.doi. org/10.1007/s12312-016-0036-6.
- [6] Institute of Medicine, Crossing the Quality Chasm: A New Health System for the 21st Century Washington (DC), (2001).
- [7] S.J. Katz, S. Hawley, The value of sharing treatment decision making with patients: Expecting too much? JAMA 310 (2013) 1559–1560, doi:http://dx.doi. org/10.1001/jama.2013.278944.
- [8] D. Stacey, F. Légaré, K. Lewis, M.J. Barry, C.L. Bennett, K.B. Eden, M. Holmes-Rovner, H. Llewellyn-Thomas, A. Lyddiatt, R. Thomson, L. Trevena, Decision aids for people facing health treatment or screening decisions, Cochrane Database Syst. Rev. (2017)CD001431, doi:http://dx.doi.org/10.1002/14651858. CD001431.pub5.
- [9] L.B. Wenzel, D.B. Mukamel, K. Osann, L. Sparks, L.J. Havrilesky, A.A. Wright, J.L. Walker, K. Robison, R.D. Alvarez, L. van Le, M.T. Wakabayashi, L.M. Randall, A. Wahi, S. Hsieh, J. Lipscomb, D.E. Cohn, Shared decision-making in ovarian cancer, JCO 35 (2017) 5549, doi:http://dx.doi.org/10.1200/JCO.2017.35.15\_suppl.5549.
- [10] S. Vahdat, L. Hamzehgardeshi, S. Hessam, Z. Hamzehgardeshi, Patient involvement in health care decision making: a review, Iran, Red Crescent Med. J. 16 (2014) e12454, doi:http://dx.doi.org/10.5812/ircmj.12454.
- [11] B. Chewning, C.L. Bylund, B. Shah, N.K. Arora, J.A. Gueguen, G. Makoul, Patient preferences for shared decisions: a systematic review, Patient Educ. Couns. 86 (2012) 9–18, doi:http://dx.doi.org/10.1016/j.pec.2011.02.004.
- [12] C. Bieber, J. Nicolai, K. Gschwendtner, N. Müller, K. Reuter, A. Buchholz, B. Kallinowski, M. Härter, W. Eich, How does a shared decision-making (SDM) intervention for oncologists affect participation style and preference matching in patients with breast and colon cancer? J. Cancer Educ. 33 (2018) 708–715, doi:http://dx.doi.org/10.1007/s13187-016-1146-7.
- [13] V.C. Hamelinck, E. Bastiaannet, A.H. Pieterse, C.J.H. van de Velde, G.-J. Liefers, A. M. Stiggelbout, Preferred and perceived participation of younger and older patients in decision making about treatment for early breast cancer: a prospective study, Clin. Breast Cancer 18 (2018) e245–e253, doi:http://dx.doi.org/10.1016/j.clbc.2017.11.013.
- [14] P. Butow, J.D. Harrison, E.T. Choy, J.M. Young, A. Spillane, A. Evans, Health professional and consumer views on involving breast cancer patients in the multidisciplinary discussion of their disease and treatment plan, Cancer 110 (2007) 1937–1944, doi:http://dx.doi.org/10.1002/cncr.23007.
- [15] C. Charles, A. Gafni, T. Whelan, Self-reported use of shared decision-making among breast cancer specialists and perceived barriers and facilitators to implementing this approach, Health Expect. 7 (2004) 338–348, doi:http://dx. doi.org/10.1111/j.1369-7625.2004.00299.x.
- [16] H.L. Kane, M.T. Halpern, L.B. Squiers, K.A. Treiman, L.A. McCormack, Implementing and evaluating shared decision making in oncology practice, CA Cancer J. Clin. 64 (2014) 377–388, doi:http://dx.doi.org/10.3322/ caac.21245.
- [17] M. Kunneman, A.H. Pieterse, A.M. Stiggelbout, R.A. Nout, M. Kamps, L.C.H.W. Lutgens, J. Paulissen, O.J.A. Mattheussens, R.F.P.M. Kruitwagen, C.L. Creutzberg, Treatment preferences and involvement in treatment decision making of patients with endometrial cancer and clinicians, Br. J. Cancer 111 (2014) 674–679, doi:http://dx.doi.org/10.1038/bjc.2014.322.
- [18] J.C. de Snoo-Trimp, L. Brom, H.R.W. Pasman, B.D. Onwuteaka-Philipsen, G.A.M. Widdershoven, Perspectives of medical specialists on sharing decisions in Cancer care: a qualitative study concerning chemotherapy decisions with patients with recurrent glioblastoma, Oncologist 20 (2015) 1182–1188, doi: http://dx.doi.org/10.1634/theoncologist.2015-0095.
- [19] A. Amundsen, T. Nordøy, K.E. Lingen, T. Sørlie, S. Bergvik, Is patient behavior during consultation associated with shared decision-making?: a study of patients' questions, cues and concerns in relation to observed shared decisionmaking in a cancer outpatient clinic, Patient Educ. Couns. 101 (2018) 399–405, doi:http://dx.doi.org/10.1016/j.pec.2017.10.001.

- [20] N. Padilla-Garrido, F. Aguado-Correa, M. Ortega-Moreno, J. Bayo-Calero, E. Bayo-Lozano, La toma de decisiones compartidas desde la perspectiva del paciente oncológico: roles de participación y valoración del proceso. [Shared decision making from the perspective of the cancer patient: participatory roles and evaluation of the process], An. Sist. Sanit. Navar. 40 (2017) 25–33, doi: http://dx.doi.org/10.23938/ASSN.0003.
- [21] S.K. Smith, D. Nathan, J. Taylor, E. van Gelder, A. Dixon, G.K.B. Halkett, C. Milross, H.M. Dhillon, Patients' experience of decision-making and receiving information during radiation therapy: a qualitative study, Eur. J. Oncol. Nurs. 30 (2017) 97–106, doi:http://dx.doi.org/10.1016/j.ejon.2017.08.007.
- [22] L. Brom, J.C. de Snoo-Trimp, B.D. Onwuteaka-Philipsen, G.A.M. Widdershoven, A.M. Stiggelbout, H.R.W. Pasman, Challenges in shared decision making in advanced cancer care: a qualitative longitudinal observational and interview study, Health Expect. 20 (2017) 69–84, doi:http://dx.doi.org/10.1111/ hex.12434.
- [23] E.G. Engelhardt, A.H. Pieterse, A. van der Hout, H.J.C.J.M. de Haes, J.R. Kroep, P. van Quarles Ufford-Mannesse, J.E.A. Portielje, E.M.A. Smets, A.M. Stiggelbout, Use of implicit persuasion in decision making about adjuvant cancer treatment: a potential barrier to shared decision making, Eur. J. Cancer 66 (2016) 55–66, doi:http://dx.doi.org/10.1016/j.ejca.2016.07.011.
- [24] P. Hahlweg, S. Didi, L. Kriston, M. Härter, Y. Nestoriuc, I. Scholl, Process quality of decision-making in multidisciplinary cancer team meetings: a structured observational study, BMC Cancer 17 (2017) 772, doi:http://dx.doi.org/10.1186/ s12.885-017-3768-5.
- [25] W. Frerichs, P. Hahlweg, E. Müller, C. Adis, I. Scholl, Shared decision-making in oncology - a qualitative analysis of healthcare providers' views on current practice, PLoS One 11 (2016)e0149789, doi:http://dx.doi.org/10.1371/journal. pone.0149789.
- [26] J.R. Covvey, K.M. Kamal, E.E. Gorse, Z. Mehta, T. Dhumal, E. Heidari, D. Rao, C. Zacker, Barriers and facilitators to shared decision-making in oncology: a systematic review of the literature, Support. Care Cancer 27 (2019) 1613–1637, doi:http://dx.doi.org/10.1007/s00520-019-04675-7.
- [27] P. Hahlweg, J. Hoffmann, M. Härter, D.L. Frosch, G. Elwyn, I. Scholl, In absentia: an exploratory study of how patients are considered in multidisciplinary cancer team meetings, PLoS One 10 (2015)e0139921, doi:http://dx.doi.org/ 10.1371/journal.pone.0139921.
- [28] D.W. Hamilton, B. Heaven, R.G. Thomson, J.A. Wilson, C. Exley, Multidisciplinary team decision-making in cancer and the absent patient: a qualitative study, BMJ Open 6 (2016)e012559, doi:http://dx.doi.org/10.1136/ bmjopen-2016-012559.
- [29] S.S. Brar, C. Provvidenza, A. Hunter, J.C. Victor, J.C. Irish, R.S. McLeod, F.C. Wright, Improving multidisciplinary cancer conferences: a population-based intervention, Ann. Surg. Oncol. 21 (2014) 16–21, doi:http://dx.doi.org/10.1245/s10434-013-3296-8.
- [30] A. Fleissig, V. Jenkins, S. Catt, L. Fallowfield, Multidisciplinary teams in cancer care: Are they effective in the UK? Lancet Oncol. 7 (2006) 935–943, doi:http:// dx.doi.org/10.1016/S1470-2045(06)70940-8.
- [31] T.A.K. Gandamihardja, T. Soukup, S. McInerney, J.S.A. Green, N. Sevdalis, Analysing breast Cancer Multidisciplinary patient management: a prospective observational evaluation of team clinical decision-making, World J. Surg. 43 (2019) 559–566, doi:http://dx.doi.org/10.1007/s00268-018-4815-3.
- [32] B.W. Lamb, K.F. Brown, K. Nagpal, C. Vincent, J.S.A. Green, N. Sevdalis, Quality of care management decisions by multidisciplinary cancer teams: a systematic review, Ann. Surg. Oncol. 18 (2011) 2116–2125, doi:http://dx.doi.org/10.1245/ s10434-011-1675-6.
- [33] B. Devitt, J. Philip, S.-A. McLachlan, Team dynamics, decision making, and attitudes toward multidisciplinary cancer meetings: health professionals' perspectives, J. Oncol. Pract. 6 (2010) e17–20, doi:http://dx.doi.org/10.1200/JOP.2010.000023.
- [34] J.D. Harrison, E.T. Choy, A. Spillane, P. Butow, J.M. Young, A. Evans, Australian breast cancer specialists' involvement in multidisciplinary treatment planning meetings, Breast 17 (2008) 335–340, doi:http://dx.doi.org/10.1016/j. breast.2008.03.001.
- [35] J. Kidger, J. Murdoch, J.L. Donovan, J.M. Blazeby, Clinical decision-making in a multidisciplinary gynaecological cancer team: a qualitative study, BJOG 116 (2009) 511–517, doi:http://dx.doi.org/10.1111/j.1471-0528.2008.02066.x.
- [36] B.W. Lamb, J.S.A. Green, J. Benn, K.F. Brown, C.A. Vincent, N. Sevdalis, Improving decision making in multidisciplinary tumor boards: prospective longitudinal evaluation of a multicomponent intervention for 1,421 patients, J. Am. Coll. Surg. 217 (2013) 412–420, doi:http://dx.doi.org/10.1016/j. jamcollsurg.2013.04.035.
- [37] A. Lanceley, J. Savage, U. Menon, I. Jacobs, Influences on multidisciplinary team decision-making, Int. J. Gynecol. Cancer 18 (2008) 215–222, doi:http://dx.doi. org/10.1111/j.1525-1438.2007.00991.x.
- [38] L. Restivo, T. Apostolidis, A.-D. Bouhnik, S. Garciaz, T. Aurran, C. Julian-Reynier, Patients' non-medical characteristics contribute to collective medical decision-making at multidisciplinary oncological team meetings, PLoS One 11 (2016)e0154969, doi:http://dx.doi.org/10.1371/journal.pone.0154969.
- [39] S. Salloch, P. Ritter, S. Wäscher, J. Vollmann, J. Schildmann, Medical expertise and patient involvement: a multiperspective qualitative observation study of the patient's role in oncological decision making, Oncologist 19 (2014) 654–660, doi:http://dx.doi.org/10.1634/theoncologist.2013-0268.
- [40] N.P. Tamirisa, J.S. Goodwin, A. Kandalam, S.K. Linder, S. Weller, S. Turrubiate, C. Silva, T.S. Riall, Patient and physician views of shared decision making in cancer, Health Expect. 20 (2017) 1248–1253, doi:http://dx.doi.org/10.1111/hex.12564.

- [41] C. Taylor, L. Atkins, A. Richardson, R. Tarrant, A.-J. Ramirez, Measuring the quality of MDT working: an observational approach, BMC Cancer 12 (2012) 202, doi:http://dx.doi.org/10.1186/1471-2407-12-202.
- [42] C. Taylor, J. Finnegan-John, J.S.A. Green, No decision about me without me" in the context of cancer multidisciplinary team meetings: a qualitative interview study, BMC Health Serv. Res. 14 (2014) 488, doi:http://dx.doi.org/10.1186/ s12913-014-0488-2.
- [43] J.M. Blazeby, L. Wilson, C. Metcalfe, J. Nicklin, R. English, J.L. Donovan, Analysis of clinical decision-making in multi-disciplinary cancer teams, Ann. Oncol. 17 (2006) 457–460, doi:http://dx.doi.org/10.1093/annonc/mdj102.
- [44] R. English, C. Metcalfe, J. Day, Z. Rayter, J.M. Blazeby, A prospective analysis of implementation of multi-disciplinary team decisions in breast cancer, Breast J. 18 (2012) 459–463, doi:http://dx.doi.org/10.1111/j.1524-4741.2012.01270.x.
- [45] C. Großmann, A. Cramer, O. Torres, D. Kranzfelder, Akzeptanz der Tumorkonferenzentscheidung – eine retrospektive Analyse. [Acceptance of the tumor conference decision – a retrospective analysis], (2012) . https:// www.thieme-connect.com/products/ejournals/abstract/10.1055/s-0032-1318528.
- [46] S. Rajan, J. Foreman, M.G. Wallis, C. Caldas, P. Britton, Multidisciplinary decisions in breast cancer: does the patient receive what the team has recommended? Br. J. Cancer 108 (2013) 2442–2447, doi:http://dx.doi.org/ 10.1038/bjc.2013.267.
- [47] A.F. van Leeuwen, E. Voogt, A. Visser, C.C.D. van der Rijt, A. van der Heide, Considerations of healthcare professionals in medical decision-making about treatment for clinical end-stage cancer patients, J. Pain Symptom Manage. 28 (2004) 351–355, doi:http://dx.doi.org/10.1016/j.jpainsymman.2004.01.005.
- [48] B.W. Lamb, C. Taylor, J.N. Lamb, S.L. Strickland, C. Vincent, J.S.A. Green, N. Sevdalis, Facilitators and barriers to teamworking and patient centeredness in multidisciplinary cancer teams: findings of a national study, Ann. Surg. Oncol. 20 (2013) 1408–1416, doi:http://dx.doi.org/10.1245/s10434-012-2676-9.
- 20 (2013) 1408–1416, doi:http://dx.doi.org/10.1245/s10434-012-2676-9.
  [49] S. Hollunder, U. Herrlinger, M. Zipfel, J. Schmolders, V. Janzen, T. Thiesler, E. Güresir, A. Schröck, F. Far, T. Pietsch, D. Pantelis, D. Thomas, S. Vornholt, N. Ernstmann, T. Manser, M. Neumann, B. Funke, I.G.H. Schmidt-Wolf, Cross-sectional increase of adherence to multidisciplinary tumor board decisions, BMC Cancer 18 (2018) 936, doi:http://dx.doi.org/10.1186/s12885-018-4841-4.
- [50] J.J. Wood, C. Metcalfe, A. Paes, P. Sylvester, P. Durdey, M.G. Thomas, J.M. Blazeby, An evaluation of treatment decisions at a colorectal cancer multi-disciplinary team, Colorectal Dis. 10 (2008) 769–772, doi:http://dx.doi.org/10.1111/j.1463-1318.2007.01464.x.
- [51] C. Heuser, A. Diekmann, C. Kowalski, A. Enders, R. Conrad, H. Pfaff, L. Ansmann, N. Ernstmann, Health literacy and patient participation in multidisciplinary tumor conferences in breast cancer care: a multilevel modeling approach, BMC Cancer 19 (2019) 330, doi:http://dx.doi.org/10.1186/s12885-019-5546-z.
- [52] L. Ansmann, C. Kowalski, H. Pfaff, R. Wuerstlein, M.A. Wirtz, N. Ernstmann, Patient participation in multidisciplinary tumor conferences, Breast 23 (2014) 865–869, doi:http://dx.doi.org/10.1016/j.breast.2014.09.004.
- [53] N.M. Rankin, M. Lai, D. Miller, P. Beale, A. Spigelman, G. Prest, K. Turley, J. Simes, Cancer multidisciplinary team meetings in practice: results from a multiinstitutional quantitative survey and implications for policy change, Asia. J. Clin. Oncol. 14 (2018) 74–83, doi:http://dx.doi.org/10.1111/ajco.12765.
- [54] K.S. Saini, C. Taylor, A.-J. Ramirez, C. Palmieri, U. Gunnarsson, H.J. Schmoll, S.M. Dolci, C. Ghenne, O. Metzger-Filho, M. Skrzypski, M. Paesmans, L. Ameye, M.J. Piccart-Gebhart, E. de Azambuja, Role of the multidisciplinary team in breast cancer management: results from a large international survey involving 39 countries, Ann. Oncol. 23 (2012) 853–859, doi:http://dx.doi.org/10.1093/annonc/mdr352.
- [55] F.C. Wright, C. de Vito, B. Langer, A. Hunter, Multidisciplinary cancer conferences: a systematic review and development of practice standards, Eur. J. Cancer 43 (2007) 1002–1010, doi:http://dx.doi.org/10.1016/j. eica.2007.01.025.
- [56] E.T. Choy, A. Chiu, P. Butow, J. Young, A. Spillane, A pilot study to evaluate the impact of involving breast cancer patients in the multidisciplinary discussion

- of their disease and treatment plan, Breast 16 (2007) 178–189, doi:http://dx.doi.org/10.1016/j.breast.2006.10.002.
- [57] A. Diekmann, C. Heuser, N. Ernstmann, F. Geiser, S.E. Groß, E. Midding, H. Pfaff, L. Ansmann, How do breast cancer patients experience multidisciplinary tumor conferences? - A description from the patient perspective, Breast 44 (2019) 66–72, doi:http://dx.doi.org/10.1016/j.breast.2018.12.012.
- [58] L. Ansmann, N. Ernstmann, Patientinnenteilnahme an Tumorboards die Sicht teilnehmender Patientinnen. [Patient participation in tumor boards – the perspective of participating patients], Gesundheitswesen 77 (2015), doi: http://dx.doi.org/10.1055/s-0035-1563083.
- [59] C. Heuser, A. Diekmann, N. Ernstmann, L. Ansmann, Patient participation in multidisciplinary tumour conferences in breast cancer care (PINTU): a mixedmethods study protocol, BMJ Open 9 (2019) e024621, doi:http://dx.doi.org/ 10.1136/bmjopen-2018-024621.
- [60] L.A. Palinkas, S.M. Horwitz, C.A. Green, J.P. Wisdom, N. Duan, K. Hoagwood, Purposeful sampling for qualitative data collection and analysis in mixed method implementation research, Adm. Policy Ment. Health 42 (2015) 533– 544, doi:http://dx.doi.org/10.1007/s10488-013-0528-y.
- [61] I. Scholl, L. Kriston, J. Dirmaier, A. Buchholz, M. Härter, Development and psychometric properties of the shared Decision making Questionnaire – physician version (SDM-Q-Doc), Patient Educ. Couns. 88 (2012) 284–290, doi: http://dx.doi.org/10.1016/j.pec.2012.03.005.
- [62] G. Elwyn, A. Edwards, P. Kinnersley, R. Grol, Shared decision making and the concept of equipoise: the competences of involving patients in healthcare choices, Br. J. Gen. Pract. 50 (2000) 892–899. https://www.ncbi.nlm.nih.gov/ pmc/articles/PMC1313854/.
- [63] S. Fuß, U. Karbach, Grundlagen der Transkription: Eine praktische Einführung. [Basics of transcription: A practical introduction], Budrich; UTB, Opladen, Stuttgart, (2014)
- [64] P. Mayring, Qualitative Inhaltsanalyse: Grundlagen und Techniken. [Qualitative content analysis], twelfth, überarb. Aufl., Beltz, Weinheim (2015).
- [65] N. Paraskeva, E. Guest, H. Lewis-Smith, D. Harcourt, Assessing the effectiveness of interventions to support patient decision making about breast reconstruction: a systematic review, Breast 40 (2018) 97–105, doi:http://dx. doi.org/10.1016/j.breast.2018.04.020.
- [66] K.D. Woodhouse, K. Tremont, A. Vachani, M.M. Schapira, N. Vapiwala, C.B. Simone, A.T. Berman, A review of shared decision-making and patient decision aids in radiation oncology, J. Cancer Educ. 32 (2017) 238–245, doi:http://dx.doi.org/10.1007/s13187-017-1169-8.
- [67] N. Weis, Zwischen Anspruch und Wirklichkeit: Patientenkompetenz und Leitlinien-orientierte Medizin – ein Plädoyer. [Expectations and reality: Patient competence and guideline-oriented medicine – a plea for humane and integrative medicine], DZO 48 (2016) 48–54, doi:http://dx.doi.org/10.1055/s-0042-108141.
- [68] P. Hahlweg, M. Härter, Y. Nestoriuc, I. Scholl, How are decisions made in cancer care? A qualitative study using participant observation of current practice, BMJ Open 7 (2017)e016360, doi:http://dx.doi.org/10.1136/bmjopen-2017-016360.
- [69] D. Stacey, L. Paquet, R. Samant, Exploring cancer treatment decision-making by patients: a descriptive study, Curr. Oncol. 17 (2010) 85–93, doi:http://dx.doi. org/10.3747/co.v17i4.527.
- [70] S. Singh, P. Butow, M. Charles, M.H.N. Tattersall, Shared decision making in oncology: assessing oncologist behaviour in consultations in which adjuvant therapy is considered after primary surgical treatment, Health Expect. 13 (2010) 244–257, doi:http://dx.doi.org/10.1111/j.1369-7625.2009.00587.x.
- [71] J. Massoubre, M. Lapeyre, R. Pastourel, V. Dupuch, J. Biau, A.-F. Dillies, T. Mom, B. Pereira, L. Gilain, N. Saroul, Will the presence of the patient at multidisciplinary meetings influence the decision in head and neck oncology management? Acta Otolaryngol. 138 (2018) 185–189, doi:http://dx.doi.org/10.1080/00016489.2017.1384059.
- [72] R.A. Sharma, K. Shah, E. Glatstein, Multidisciplinary team meetings: what does the future hold for the flies raised in Wittgenstein's bottle? Lancet Oncol. 10 (2009) 98–99, doi:http://dx.doi.org/10.1016/S1470-2045(09)70006-3.

3.2 Publication 2: Questions and emotional expressions from patients and companions while participating in multidisciplinary tumor conferences in breast and gynecological cancer centers

Schellenberger B, Heuser C, Diekmann A, Ansmann L, Krüger E, Schreiber L, Schnettler B, Geiser F, Schmidt-Wolf IGH, Ernstmann N. Questions and emotional expressions from patients and companions while participating in multidisciplinary tumor conferences in breast and gynecological cancer centers. Patient Educ Couns. 2022;105(7):2058–2066. doi:10.1016/j.pec.2021.12.010

Patient Education and Counseling 105 (2022) 2058-2066



Contents lists available at ScienceDirect

# Patient Education and Counseling

journal homepage: www.elsevier.com/locate/pec



# Questions and emotional expressions from patients and companions while participating in multidisciplinary tumor conferences in breast and gynecological cancer centers



Barbara Schellenberger<sup>a,b,\*</sup>, Christian Heuser<sup>a,b</sup>, Annika Diekmann<sup>a,b</sup>, Lena Ansmann<sup>c</sup>, Emily Krüger<sup>a,b</sup>, Leonie Schreiber<sup>a,b</sup>, Bernt Schnettler<sup>d</sup>, Franziska Geiser<sup>b,e</sup>, Ingo G.H. Schmidt-Wolf<sup>b,f</sup>, Nicole Ernstmann<sup>a,b</sup>

- <sup>a</sup> Center for Health Communication and Health Services Research (CHSR), Department for Psychosomatic Medicine and Psychotherapy, University Hospital Bonn, Germany
- <sup>b</sup> Center for Integrated Oncology (CIO), University Hospital Bonn, Germany
- <sup>c</sup> Division for Organizational Health Services Research, Department of Health Services Research, School of Medicine and Health Sciences, Carl von Ossietzky University Oldenburg, Germany
- <sup>d</sup> Department of Sociology, University of Bayreuth, Germany
- <sup>e</sup> Department for Psychosomatic Medicine and Psychotherapy, Faculty of Medicine, University Hospital Bonn, Germany
- f Department of Integrated Oncology, University Hospital, Bonn, Germany

# ARTICLE INFO

Article history:
Received 13 September 2021
Received in revised form 18 November 2021
Accepted 15 December 2021

Keywords:
Breast cancer
Gynecological cancer
Multidisciplinary tumor conference
Multidisciplinary tumor board
Oncology
Patient-centered communication

#### ABSTRACT

Objective: To investigate (a) how many questions and negative emotions (cues/concerns) breast and/or gynecologic cancer patients and companions express during their case discussion in multidisciplinary tumor conferences (MTCs), (b) with which topics the emotions are linked, and (c) which patient- and context-related characteristics determine patients' communicative behavior.

Methods: This observational study included audio/video recordings of MTCs with patient participation in three breast and gynecological cancer centers. Using the Verona Coding Definitions of Emotional Sequences, patients' and companions' questions and negative emotions expressed were analyzed. Multiple regression analyses were used to determine associations between communicative behavior and patient- and context-related characteristics.

Results: We identified 607 questions and 230 cues/concerns expressed by patients/companions in 82 case discussions in MTCs. The number of questions was significantly associated with the hospital. In case discussions with patients who had need for psychological support and who were accompanied, more questions were asked by patients/companions.

*Conclusion:* The results show that active patient participation does not depend only on patient characteristics, but also on the hospital setting.

*Practice implications:* If cancer centers want to enable patient participation in MTCs, they must define the role of the patient before. Subsequently, conditions must be created to enable this role expectation.

© 2021 The Authors. Published by Elsevier B.V. CC\_BY\_NC\_ND\_4.0

#### 1. Introduction

1.1. Patient participation in multidisciplinary tumor conferences

Multidisciplinary tumor conferences (MTCs) are well established in oncological care and typically take place weekly [1,2]. During the MTCs, members of different professions discuss the diagnosis and therapy of cancer patients and decide on treatment recommendations [3]. In this context, biomedical information is often more incorporated into the discussion than psychosocial information is

E-mail address: barbara.schellenberger@ukbonn.de (B. Schellenberger).

<sup>\*</sup> Correspondence to: Center for Health Communication and Health Services Research (CHSR), Department for Psychosomatic Medicine and Psychotherapy, University Hospital Bonn, Venusberg-Campus 1, 53127 Bonn, Germany.

[4–8], and decision-making can be influenced by factors such as time pressure and excessive case load [4]. Because a lack of patient-centered information can hinder both decision-making and the implementation of the treatment plan [9–11], some studies suggest that patients should be represented by appropriate representatives [4,12]. Another possibility is patient participation, which is recommended in other medical contexts when there is a stable doctorpatient relationship and medical and lay language is used in a balanced way [13].

One way for including patients' preferences and views is inviting the patients themselves to participate in their case discussion in the MTC, which is practiced in some cancer centers in North Rhine-Westphalia, Germany. Study evidence on patient participation in MTCs has been generated, primarily in Australia [5,14-16] and Germany, where between 5% and 7% of patients in breast cancer care participate [3,17,18]. To date, there are no clear findings in the literature regarding the advantages and disadvantages of patients participating in MTCs. Based on interview and survey results, physicians are more reluctant than breast care nurses to allow patients to participate in MTCs [5,15], whereas patient representatives and breast care nurses mostly support the idea [15]. Advantages of participation are seen in patients being better informed, and thus gaining a better understanding of the disease [15,19,20]. On the other hand, however, healthcare providers caution that if patients are overloaded with medical information about diagnosis or therapy, they may react emotionally in the form of anxiety or stress, and the doctor-patient relationship may be disturbed [5,15,19,20]. They also object that participation requires more time and organization, healthcare providers must adapt their professional language, and discussion is inhibited [15,20]. Patients perceive participation in the MTC as helpful and informative [16,18], with some patients also reporting difficult experiences and negative emotional reactions [18].

Whether patients are invited at all and whether they participate are associated with patient characteristics such as socio-demographics and health literacy and can differ between cancer centers themselves [3,17]. When participation in MTCs does take place, initial findings have revealed that it is implemented in very different ways. For example, seating arrangements vary, such that patients and healthcare providers sit at a round table, theater style, or in a U-shape [21]. It is known from MTCs without patient participation that the seating arrangement plays a role in discussion, and 62% of healthcare providers would prefer a round table discussion; however, this was not feasible with larger teams [22].

### 1.2. Active patient participation in medical encounters

Patients are often initially emotionally unstable after a cancer diagnosis [23], and may experience many anxious moments throughout their cancer treatment [24]. There is an increased need for information after receiving the diagnosis and throughout treatment [25,26]. From the perspective of breast cancer patients, patients require support in coping with uncertainty after symptom recognition and should be provided with information on practical and emotional disease-related topics and treatment options at the time of diagnosis and treatment decision [27]. In this regard, information can help increase treatment adherence, improve the patient's understanding of the disease, manage the patient's emotions, and thus ultimately help the patient gain control in a difficult situation [26,28].

Asking questions allows patients to gain information and clarify uncertainties and, along with the expression of emotions, is an essential feature of patient participation in medical encounters [29]. Allowing patients to ask questions at MTC as a building block in oncology care could lead to better informed patients. At the same time, it could make it easier for patients to participate in decision

making [15]. On the part of the healthcare providers, recognizing emotions [30] and leaving room for patients to ask questions [31] are features of patient-centered communication, which is a core clinical skill for healthcare providers [32] and part of high-quality care [30].

Communication between healthcare providers and patients is influenced, on one hand, by context factors but also on the other hand by their skills, needs, and emotions [33]. To assess the communication of patients in outpatient oncological care, the questions of the patients were counted. Patients asked a median of 11 questions per consultation [34,35], predominantly about potential therapy [34]. In this setting, patients with high uncertainty asked more questions [36].

Patients can express negative emotions through concerns and cues, whereby a concern is defined "as a clear and unambiguous expression of an unpleasant current or recent emotion" [37] and a cue "as a verbal or non-verbal hint which suggests an underlying unpleasant emotion and would need a clarification" [37]. In addition, in the oncological setting, emotions are more likely to be indirectly expressed, averaging 1.9-3.4 cues and concerns per consultation [34,35,38,39], with only 24% of consultations lacking the expression of negative emotions [36]. Contextual factors such as setting had an influence on the number of cues/concerns expressed [39]. In terms of content, the following topics were identified among the cues/ concerns in adolescents and young adults, when they received their cancer diagnosis and a treatment recommendation: "side effects/late effects" (39%), "what will happen in the near future/practical aspects" (16%), "fear" (27%), and "sadness" (17%) [40]. Associations were found between the number of emotional cues and age and gender of the patient, so that female and younger patients expressed more cues [35]. In addition, the duration of the consultation was related to the number of informational cues, indicating unmet information needs, or the number of questions expressed by patients but not to the number of emotional cues [35,41]. MTC is about deciding on a treatment recommendation. In order to be able to decide on a treatment recommendation for patients in MTC with patient participation, personal and social aspects, i.e. also the emotions, wishes and questions of the patients, must be taken into account [20]. For patients, therefore, MTC could be the place to bring in these aspects.

# 1.3. Aim

To date, there are no study results regarding the extent to which patients, when present in MTCs, take part in the communication. This study aims to fill this research gap and generate preliminary findings on patient communicative behavior in MTCs. This study answers the following research questions: a) How many questions and negative emotions do breast and/or gynecologic cancer patients and their companions express during participation in their case discussion in MTCs? b) Which topics are linked with the emotions? c) Which patient characteristics and context factors determine the patients' communicative behavior?

#### 2. Methods

# 2.1. Sample and setting

Data were collected between November 2018 and February 2020 within the multicenter, non-interventional study 'Patient involvement in multidisciplinary tumor conferences in breast cancer care' (PINTU [42]), which was conducted in six breast and gynecological cancer centers in Germany's most populated state of North Rhine-Westphalia. Patients whose case was to be discussed in an MTC were recruited by the medical staff on the wards. In the hospitals with regular patient participation, all eligible patients (i.e. having a breast cancer or gynecologic cancer) were invited to attend the tumor

conference. Those who chose to participate were then invited to participate in our study. Data for the multicenter study were collected in six cancer centers, one of which comprised two hospitals. The data analyzed here constitute a PINTU subsample of case discussions with patient participation in three breast and gynecological cancer centers (n=4 hospitals), which was taken to analyze the communication in MTCs when the patient is present. Eligible patients had to be at least 18 years old and were diagnosed with breast and/or gynecological cancer (ICD codes C50.xx-C58.xx, D05.xx-D07.xx). MTC participants and recruited patients provided written informed consent. The passive participatory observations during MTCs were conducted by AD, BS and CH, each in pairs. Field notes were taken, including, among others, the duration of the case discussions and the seating arrangement. Audio data of the case discussions were transcribed verbatim and anonymized.

#### 2.2. Patient characteristics and clinical data

Patients received questionnaires at three points in time: before the MTC (T0), immediately after the MTC (T1), and 4 weeks after the MTC as a postal survey (T2) with two reminders according to Dillman's total design method [43]. The questionnaires consisted of validated instruments and self-developed items and were pretested before their use in three cognitive interviews according to established methods [44]. We included data from the TO questionnaire in this study. Sociodemographic data included age, marital status, having children, level of professional education, and employment status. The need for psychological support was measured with a single item ("Do you need psychological support?"), differentiating three options. The patients could choose "Yes, I'm in need for psychological support and I'm already receiving treatment", "Yes, I'm in need for psychological care and I'm waiting for treatment", or "No, I'm not in need for psychological care". Response options were converted to a binary variable (yes-no) for analysis. Cancer entity (breast and/or gynecological) and UICC staging were obtained from the case discussion and/or tumor documentation.

# 2.3. Analysis of communication

We used a mixed-methods approach (see Fig. 1 for the methods used). A total of four researchers examined the transcripts, including video and audio recordings. Each of two researchers coded the expressed questions and cues/concerns of patients and companions. For validation, the identified questions and cues/concerns were discussed and consented in regular consultations within the research team. The mean was calculated from the total number of categories of the two coders to the questions and the cues/concerns.

#### 2.3.1. Questions from patients and companions

Patients' and companions' questions were coded by function (e.g., request information, request confirmation) following the methods of Stivers and Enfield [45]. We list the classification in the results section with explanation and examples.

# 2.3.2. Emotional expressions from patients and companions

To capture the negative emotions of patients and their companions, we used the validated Verona Coding Definitions of Emotional Sequences (VR-CoDES) [46]. Patients or their companions may indicate unpleasant feelings (cues) or explicitly express concerns verbally (concerns). These expressions can either be elicited by healthcare providers or elicited independently by a patient. The cues were divided into seven subcategories depending on their expression (see results section).

While previous data were often collected from dyadic patient/ healthcare provider-conversations (e.g. [39]), in this study the cues/ concerns were summarized by patients and companions, as described by Korsvold et al. [47]. Four coders performed VR-CoDES coding independently in two teams. Interrater reliability was based on Cohen's Kappa calculation for a random sample of 10 case discussions (77 cues/concerns). The agreement was substantial (Cohen's Kappa = 0.74). Moreover, we used a summarizing qualitative content analysis to capture topics linked to the cues/concerns.

#### 2.4. Statistical analyses

We used descriptive statistics to illustrate the sociodemographic and clinical data and to describe the settings of the case discussions in the MTCs (e.g., the seating arrangement). Two multiple linear regression analyses with (a) the number of questions from patients/companions and (b) the number of cues/concerns fom patients/companions as dependent variables were performed to explore associations between patient characteristics, clinical data, and context factors (including age, need for psychological support, disease stage, accompaniment of patients, and hospital) and patient verbal behavior using SPSS version 27. The selection of independent variables was based on the literature and an exploratory approach. Missing data were handled using pairwise deletion.

#### 3. Results

### 3.1. Sample

Patients from seven hospitals participated in the study (N = 317; n = 95 with and n = 222 without patient participation). Audio data from the case discussions were available for n = 82 patients (see Fig. 2 for the flow of participants from which data were used). Since additional video recordings were only available from n = 5 case discussions, only the audio recordings were included in the further analysis.

### 3.1.1. Sociodemographic and clinical characteristics of the patients

The average age of the 82 patients was 59 years. A total of 39 (48%) patients were accompanied, and 43 (52%) were not. Table 1 presents the sample characteristics of the participating patients.

#### 3.1.2. Case discussions in the MTCs

We analyzed 82 case discussions. The MTCs took place either in a theater style (n = 5), in a U-shape (n = 17), or at a round table (n = 60). Audio data had a total length of 10:09:12 h, and individual case discussions lasted an average of 07:26 min (range: 01:25–20:54 min). There was an average of eight healthcare providers present (range: 3–19). In the MTCs, patients and their companions were integrated into the respective seating arrangements, although a pattern was not always discernible. While in the centers that conferred at a round table or in a U-shape, a fixed place was provided for patients/companions, this could not be observed in the theater style.

# 3.2. Communication analysis

# 3.2.1. Questions, cues and concerns

Questions: Patients asked 460 questions (76%) and companions 147 questions (24%), for a total of 607 questions. The questions were divided into 391 informational questions, 180 confirmatory questions, 18 repair questions, and 18 rhetorical questions. On average, seven questions were expressed per case discussion (range: 0–26, median: 6). Table 2.

Cues and concerns: A total of 230 cues/concerns (average 2.8 per case, median: 2, range: 0–24) were identified in the case discussions: 198 (86%) expressed by patients and 32 (14%) by companions. Most of the cues/concerns were patient elicited (209, 91%). No cues/

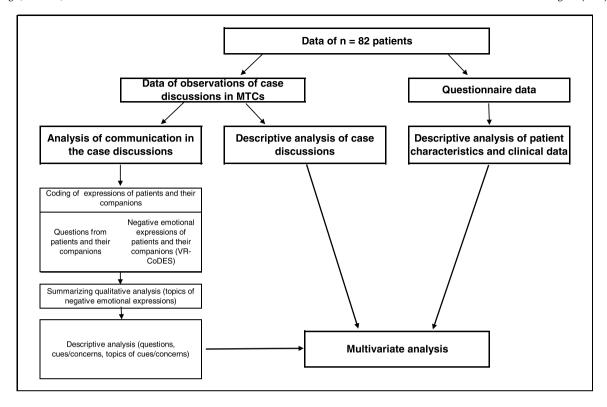


Fig. 1. Methods used for data analysis.

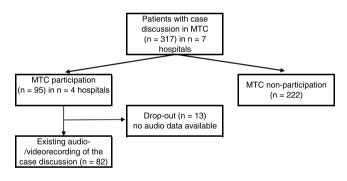


Fig. 2. Flow of participants from which data were used.

concerns were expressed in 11 case discussions (13%). Among the cues, neutral, salient expressions occurred most frequently (73%). Table. 3.

# 3.2.2. Topics linked to cues/concerns

To capture the topics linked to the cues, we analyzed the content of the cues/concerns in the context of the conversation. These were most frequently expressed when discussing the treatment in general (64 cues/concerns, 28%), followed by cues/concerns linked to the diagnosis (46 cues/concerns, 20%) and cues/concerns linked to possible side effects of the treatment (43, 19%). Fear of progression/fear of recurrence was linked to 12% of cues/concerns (28 cues/concerns) and comorbidities to 11% (25 cues/concerns). Only 10 of the 230 cues/concerns (4%) were linked to general uncertainty/doubt and self-reproach, and 9 (4%) were linked to the burden/risk for relatives. With regard to the ability to work, 5 cues/concerns were expressed (2%). Fig. 3 illustrates the occurrence of the different topics.

# 3.3. Multivariate analyses

Two independent multivariate linear regression models with dependent variables "questions expressed" (model 1) and "number

of cues/concerns expressed" (model 2) were performed (see Table 4). Because the probability of expressing questions and emotions is higher for longer case discussions [39], we did not include the duration of the case discussion in the multivariate regression models.

In model 1, significant patient and context predictors were found for the number of questions expressed. Table 4 presents the final two models. Because of multicollinearity, we excluded the seating arrangement in the models. Significantly more questions during case discussion were expressed by patients and companions in case of need for psychological support (4.259 with p = 0.001) and of being accompanied (3.398 with p = 0.006). In addition, patients expressed fewer questions in hospital 2 (compared with hospital 1: -5.027, p = 0.001) and in hospital 4 (compared with hospital 1: -5.728, p = 0.023). In model 2, no significant predictors could be found for the number of cues/concerns expressed.

# 4. Discussion and conclusion

# 4.1. Discussion

The aim of this study was to gain information on verbal and emotional communication by patients and companions in MTCs with patient participation. For this purpose, we analyzed the case discussions with participating patients in breast and gynecological cancer centers using a mixed-methods approach. We were able to describe the expressions of questions and negative emotions as well as their content and to show that more questions were asked by patients/companions in case discussions with patients who had need for psychological support and who were accompanied. In addition, there were significant differences between the hospitals, which are most likely to be related to different implementation of the MTC.

Most of the questions expressed requested information or confirmation of information. This result reflects the finding that cancer patients have a great need for information and uncertainties around

**Table 1**Patient characteristics (*n* = 82) retrieved from questionnaire data (T0). Cancer entity and UICC stage were extracted from the observation and the MTC documentation.

	n	%
Age (years)		
Mean (SD)	59 (11.2)	
Marital status	55 (11.2)	
Married	49	60
Widowed	9	11
Single	9	11
Divorced	8	10
Missing	7	9
Children		
Yes	61	74
No	15	18
Missing	6	7
Professional education		
None	3	4
Vocational training	42	51
Master craftsmen	5	6
University of Applied Sciences	3	4
University	17	21
Other	2	2
Missing	10	12
Currently employed		
Yes	22	27
No	41	50
Missing	19	23
Need for psychological support		
Yes	24	29
No	50	61
Missing	8	10
Cancer entity		
Breast cancer	77	94
Breast and gynecological cancer	5	6
UICC stage		
0	10	12
I	38	46
II	16	20
III	3	4
IV	10	12
Missing	5	6

Note: Due to rounding, percentages may not add up to exactly 100%.

receiving a diagnosis [25,26]. Patient participation in their own case discussion could provide patients with increased information during the important phase of diagnosis and treatment recommendation, as would be the desire of many patients [27].

Different from interactions that include communication about diagnosis and treatment recommendation outside of MTCs, in our study the patients themselves asked more questions than the companions, with fewer patients being accompanied at all [41,48]. Furthermore, in our study fewer questions per case discussion were asked by patients and/or companions at all than in oncological outpatient initial consultations [34,35]. It could be due to the fact that, from the perspective of healthcare providers, the MTC serves more as a discussion forum for themselves, and biomedical information is primarily exchanged [4–8]. This raises the question as to which role patients should take during their case discussion: Should they be informed only about the recommendation in this setting, or should they also be given the opportunity to contribute themselves?

The results in terms of the number of cues/concerns expressed, other than questions, were similar to those of other studies [34,35,38,39]. Compared with interactions that include communication about histological results and treatment recommendation outside of MTC [39], we found fewer case discussions in our study in which no negative emotions occurred at all. Patients also tend to express their emotions in indirect ways in MTCs, as they do in other oncological settings [34,39]. Unlike in dyadic settings with only the patient and the oncologist, the MTC is usually attended by the healthcare providers who are subsequently involved in the specific therapy (e.g., radiation therapy, chemotherapy). Thereby, patients

**Table 2** Questions from patients and companions in n = 82 case discussions.

	Definition	Total (%)	Mean per case discussion (SD)	Example
Questions by patients and relatives Request for information	Questions for information	607 (100%) 7.4 (5.8) 391 (64%) 4.8 (4.1)	7.4 (5.8) 4.8 (4.1)	S4: Um, (-) IS there no way, as to the bone metastases, to somehow (-) monitor or (639) \$4; [Do/] the medications have SIDE effects?
Request confirmation	Questions that require confirmation	180 (30%)	2.2 (2.1)	(039) S2: Well, you can, but you just always have the risk of capsular contracture quickly developing, too. Well.   it can also   S9:   Tevallar the fact? (402) C1: Well sixteon times then. (402) radiation
Other initiation of repair	Questions inviting repair, including repair initiators (e.g., "Huh?").	18 (3%)	0.2 (0.6)	51. Wen, state it times trein (1977) fudination S9: Gynecologist? (516) S7: The radiation takes three weeks. S3: How long?
Rhetorical	Questions that do not require an answer	18 (3%)	0.2 (0.5)	S7: Three weeks (524) S1: Now I have that too. Right? (518) S3: Preferably not at all, but in for a penny, in for a pound, right? (638)

**Table 3** Cues/concerns from patients and companions in n = 82 case discussions.

Cues/concerns total	230 (100%)	Examples
Concern	15 (7%)	S11: I would tend be more scared of the RADIATION. That this um/ (-) I mean, you read it, it's all on the Internet today, you read that it can do this and that. (742)
Cue A Vague words to describe emotions	4 (2%)	S8: Yes, thank God. It's also / (-) WELL, because I had mentally, I think, again, it's only been 14 days ago, right? But (-) so then, that's not necessary. (401)
Cue B Hidden concerns that are verbally pointed out	21 (9%)	S4: Nobody gets out of here alive anyway, right? (Laughs) That's for SURE. (639)
Cue C Reference to emotion (physiological or cognitive)	7 (3%)	S5: Well, I / I didn't sleep at all some nights. (527)
Cue D  Neutral statements that stand out	168 (73%)	S8: I was here Tuesday of last week, and the doctor, she told me that I had to have, um, SURGERY again. (401)
Cue E repeated, previous neutral expression	7 (3%)	S5 (Healthcare provider): // Yes, that// will be 28 radiation sessions. S2 (Patient): Yes, that's // a long time. S5: //So, after// six weeks S2: Mhm. (-) That's a long time. (513)
Cue F Non-verbal cue	5 (2%)	S2: Yes. That's only right. I see that too. (Sighs) I had thought this would pass me by. Oh man. Okay. (559)
Cue G unpleasant emotion in the past	5 (2%)	S13: It was kind of a shock for me. (507)

Note: Due to rounding, percentages might not add up to exactly 100%.

have the opportunity to address their possible concerns about therapy and possible side effects in a direct discussion with the appropriate specialist. The multitude of cues that concern this topic underlines this assumption.

Topics were captured in the context of cues/concerns through content analysis. The expressed cues/concerns in the case discussions were mostly linked to the diagnosis and treatment and their possible side effects, similar to conversations with adolescents receiving diagnosis [40].

When patients participate in case discussions, healthcare providers should be prepared that patients can react emotionally, which has been reported from the perspectives of healthcare providers and patients [5,15,18–20].

For the total number of expressions of cues/concerns, no significant associations with patient characteristics were found, unlike Butow et al. [35], who found that younger patients expressed more cues. However, significant associations were found for the total number of questions at both the patient and context levels. Whereas in the study by Beach et al. [36], patients with high uncertainty asked more questions, patients in our study with need for psychological support asked more questions. By reviewing this need, it might be possible that patients with psychological need are more likely to benefit from participation in settings with several healthcare providers, like MTCs. The benefit to patients of having a

companion present [49] led to more questions being asked during the case discussion, and at least one-quarter of the questions were asked by companions. Perhaps the social support leads to patients being more confident and asking questions, especially because studies show that companions sometimes ask more questions in oncological conversations outside of MTC [41]. In addition, fewer patients were accompanied than in oncological interactions outside of MTC [41,48].

The number of expressed questions from patients/companions was dependent on the hospital, just like the invitation to the case discussion itself depends on the cancer center [17]. It should be noted that significantly fewer questions were asked in hospitals where the MTCs did not take place at a round table, and on average more healthcare providers were present. Thus, the number of healthcare providers and the seating arrangement as context factors seem to be associated with communicative behavior, as already reported by healthcare providers for MTCs without participation of patients for the team communication [22].

The data used in this study were derived from surveys and from passive-participant observations of case discussions during MTCs. To the best of our knowledge, this is the first study to observe MTCs with patient participation. Although this study had a small number of cases and therefore a low power in calculations, it is still the largest prospective study in this research field to date. Because

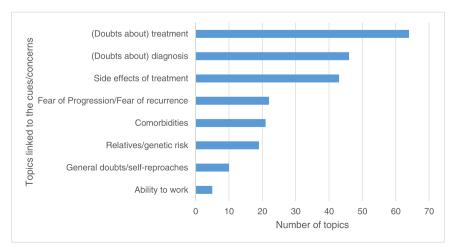


Fig. 3. Distribution of topics linked to the n = 230 cues/concerns expressed by patients/companions during n = 82 case discussions in the MTCs.

**Table 4**Multiple linear regression modelling with two independent models 1) number of questions expressed by patients and companions during case discussions as dependent variable and 2) number of cues/concerns expressed by patients and companions during case discussions as dependent variable; Unstandardized regression coefficients (b).

		Model 1: number of questions expressed by patients and companions during the case discussions ( $n = 82$ ) as dependent variable		Model 2: number of cues/concerns expressed by patients and companions during the case discussions ( $n = 82$ ) as dependent variable		
Variable	b	p value	95% CI	b	p value	95% CI
Constant						
	3.320	0.371	-4.047-10.686	3.326	0.211	-1.931-8.584
Age	0.027	0.623	-0.083-0.137	-0.028	0.482	-0.106-0.051
Need for psychological support						
No		Ref			Ref	
Yes	4.259	0.001	1.704-6.813	1.731	0.062	-0.092-3.555
UICC staging <sup>a</sup> Accompaniment	0.631	0.215	-0.376-1.639	0.279	0.440	-0.440-0.998
No		Ref			Ref	
Yes <b>Hospital</b>	3.398	0.006	1.036-5.761	0.304	0.720	-1.382-1.990
Hospital 1		Ref			Ref	
Hospital 2	-5.027	0.001	-7.9562.098	-0.217	0.836	-2.308-1.873
Hospital 3	-0.969	0.599	-4.637-2.699	1.075	0.415	-1.543-3.693
Hospital 4 Adjusted R <sup>2</sup>	-5.728	<b>0.023</b> 34%	-10.6290.827	-1.727	0.327 1%	-5.225-1.771

<sup>&</sup>lt;sup>a</sup> Higher scores indicate a higher stage of disease.

recruitment was done on the wards by medical staff, we cannot comment on the extent to which selection bias may be present. As in many health services research studies a selection bias towards native German speaking, higher educated, and higher motivated patients can be assumed. To mitigate the potentially disruptive factors of the presence of observers and the technical equipment for audio-/ videotaping, the researchers visited the hospitals and the MTCs before data collection and explained the planned method [50]. The regularity of observations over an extended period of time enabled the MTC members to become familiar with the presence of the observers. The observation is also a major strength, because it provided insights into the MTC and not purely from the point of view of participants. For the analysis we used the VR-CoDES, which is widely used to analyze emotional communication in healthcare providerpatient encounters [51], and we achieved a substantial interrater reliability through discussion [37].

Despite the relatively small sample of this study, we were able to determine the significant associations between patient- and context-related variables and patients' communicative behavior in case discussions in MTCs. The distribution across the four hospitals was not even, in part because participation is practiced in very different ways across hospitals [21]. On one hand, the spatial conditions (e.g., seating arrangement) differ, and on the other hand, there is also a difference in the extent to which the patient is already present at the entire case discussion or takes part only after the discussion between the healthcare providers.

Our first analyses made it clear that a large number of other research questions have not yet been answered in connection with communication in the MTCs. We found that in case discussions, patients ask more questions than express emotions. The literature suggests that asking questions satisfies the need for information and improves adherence [29,52]. However, the extent to which this actually occurred in our sample was not investigated at this point. Likewise, we did not investigate the extent, if any, to which expressed emotions influence treatment recommendations, which may well be reasonable, as it is known from the literature that such information is weighted less in case discussions [4–8].

Further research should investigate how patient-centered healthcare providers communicate in case discussions that include patient participation and how to facilitate it. Because contextual factors seem to be the main determinant of the extent to which patients obtain information during the MTCs, these aspects should

be considered when enabling patients to participate in cancer centers

#### 4.2. Conclusion

When patients participate in case discussions in MTCs, health-care providers should be clear in advance as to what role the patient should take: should she or he be informed only about the diagnosis and further treatment, or is there space for questions and emotions in the MTC? If the patient is to take an active role for the purpose of patient-centeredness, the results show initial indications of the factors that facilitate patient involvement.

# 4.3. Practice implications

Cancer centers willing to allow patients to participate in the case discussion in the MTC should define the patient's role beforehand. Therefore, they must create conditions to fulfill this role expectation; for example, if patients should be active participants in the communication, they should be encouraged in advance to bring a companion. Since the number of health care providers and the seating arrangement as contextual factors also seem to be related to communicative behavior, consideration should be given to which providers should be present at the meeting and whether there is a possibility of having the meeting take place at a round table.

### Ethics approval and consent to participate

All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki Declaration and its later amendments or comparable ethical standards. This study was approved by the ethics committee of the Medical Faculty of the University of Cologne, Germany (reference number for the approval: 17–405). Written informed consent was obtained from all individual participants included in the study.

#### **Funding**

This study was funded by the German Cancer Aid (DKH, grant number 70112286).

#### **CRediT authorship contribution statement**

Barbara Schellenberger: Conceptualization, Data curation, Formal analysis, Investigation, Methodology, Writing – original draft, Writing – review & editing, Christian Heuser: Investigation, Methodology, Writing – review & editing. Annika Diekmann: Formal analysis, Investigation, Methodology, Writing – review & editing, Lena Ansmann: Funding acquisition, Investigation, Methodology, Writing – review & editing, Emily Krüger: Formal analysis, Writing – review & editing, Leonie Schreiber: Formal analysis, Writing – review & editing, Bernt Schnettler: Methodology, Writing – review & editing. Franziska Geiser: Methodology, Writing – review & editing. Ingo G. H. Schmidt-Wolf: Methodology, Writing – review & editing. Nicole Ernstmann: Funding acquisition, Conceptualization, Investigation, Methodology, Supervision, Writing – review & editing.

#### **Data Availability**

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

#### Acknowledgments

We would like to thank all participating hospitals, healthcare providers, and patients who made this study possible. We are grateful to the German Cancer Aid for funding this research.

#### References

- [1] Saini KS, Taylor C, Ramirez A-J, Palmieri C, Gunnarsson U, Schmoll HJ, et al. Role of the multidisciplinary team in breast cancer management: results from a large international survey involving 39 countries. Ann Oncol 2012;23:853–9. https:// doi.org/10.1093/annonc/mdr352
- [2] Prades J, Remue E, van Hoof E, Borras JM. Is it worth reorganising cancer services on the basis of multidisciplinary teams (MDTs)? A systematic review of the objectives and organisation of MDTs and their impact on patient outcomes. Health Policy 2015;119:464–74. https://doi.org/10.1016/j.healthpol. 2014.09.006
- [3] Ansmann L, Kowalski C, Pfaff H, Wuerstlein R, Wirtz MA, Ernstmann N. Patient participation in multidisciplinary tumor conferences. Breast 2014;23:865–9. https://doi.org/10.1016/j.breast.2014.09.004
- [4] Lamb BW, Brown KF, Nagpal K, Vincent C, Green JSA, Sevdalis N. Quality of care management decisions by multidisciplinary cancer teams: a systematic review. Ann Surg Oncol 2011;18:2116–25. https://doi.org/10.1245/s10434-011-1675-6
- [5] Devitt B, Philip J, McLachlan S-A. Team dynamics, decision making, and attitudes toward multidisciplinary cancer meetings: health professionals' perspectives. J Oncol Pr 2010;6:e17–20. https://doi.org/10.1200/JOP.2010.000023
- [6] Hahlweg P, Hoffmann J, Härter M, Frosch DL, Elwyn G, Scholl I. In absentia: an exploratory study of how patients are considered in multidisciplinary cancer team meetings. PLoS One 2015;10:0139921https://doi.org/10.1371/journal.pone. 0139921
- [7] Dew K, Stubbe M, Signal L, Stairmand J, Dennett E, Koea J, et al. Cancer care decision making in multidisciplinary meetings. Qual Health Res 2015;25:397–407. https://doi.org/10.1177/1049732314553010
- [8] Horlait M, Baes S, Dhaene S, van Belle S, Leys M. How multidisciplinary are multidisciplinary team meetings in cancer care? An observational study in oncology departments in Flanders. Belg, J Multidiscip Healthc 2019;12:159–67. https://doi.org/10.2147/IMDH.S196660
- [9] Soukup T, Lamb BW, Sarkar S, Arora S, Shah S, Darzi A, et al. Predictors of treatment decisions in multidisciplinary oncology meetings: a quantitative observational study. Ann Surg Oncol 2016;23:4410-7. https://doi.org/10.1245/ s10434-016-5347-4
- [10] Soukup T, Petrides KV, Lamb BW, Sarkar S, Arora S, Shah S, et al. The anatomy of clinical decision-making in multidisciplinary cancer meetings: a cross-sectional observational study of teams in a natural context. Medicine 2016;95:3885. https://doi.org/10.1097/MD.0000000000003885
- [11] Hollunder S, Herrlinger U, Zipfel M, Schmolders J, Janzen V, Thiesler T, et al. Cross-sectional increase of adherence to multidisciplinary tumor board decisions. BMC Cancer 2018;18:936. https://doi.org/10.1186/s12885-018-4841-4
- [12] Lamb BW, Taylor C, Lamb JN, Strickland SL, Vincent C, Green JSA, et al. Facilitators and barriers to teamworking and patient centeredness in multidisciplinary cancer teams: findings of a national study. Ann Surg Oncol 2013;20:1408–16. https://doi.org/10.1245/s10434-012-2676-9

- [13] Myren BJ, Hermen RPMJ, Koksma JJ, Bastiaans S, de Hullu JA, Zusterzeel PLM. Openness to new perspectives created by patient participation at the morbidity and mortality meeting. Patient Educ Couns 2021;104:343–51.
- [14] Rankin NM, Lai M, Miller D, Beale P, Spigelman A, Prest G, et al. Cancer multidisciplinary team meetings in practice: results from a multi-institutional quantitative survey and implications for policy change. Asia PacJ Clin Oncol 2018;14:74–83. https://doi.org/10.1111/ajco.12765
- [15] Butow P, Harrison JD, Choy ET, Young JM, Spillane A, Evans A. Health professional and consumer views on involving breast cancer patients in the multidisciplinary discussion of their disease and treatment plan. Cancer 2007;110:1937–44. https://doi.org/10.1002/cncr.23007
- [16] Choy ET, Chiu A, Butow P, Young J, Spillane A. A pilot study to evaluate the impact of involving breast cancer patients in the multidisciplinary discussion of their disease and treatment plan. Breast 2007;16:178–89. https://doi.org/10. 1016/j.breast 2006.10.002
- [17] Heuser C, Diekmann A, Kowalski C, Enders A, Conrad R, Pfaff H, et al. Health literacy and patient participation in multidisciplinary tumor conferences in breast cancer care: a multilevel modeling approach. BMC Cancer 2019;19:330. https://doi.org/10.1186/s12885-019-5546-z
- [18] Diekmann A, Heuser C, Ernstmann N, Geiser F, Groß SE, Midding E, et al. How do breast cancer patients experience multidisciplinary tumor conferences? - a description from the patient perspective. Breast 2019;44:66–72. https://doi.org/10. 1016/i.breast 2018 12 012
- [19] Diekmann A, Heuser C, Schellenberger B, Bohmeier B, Holmberg C, Ansmann L, et al. Patient participation in multidisciplinary tumor conferences: providers' perceptions of patients' need satisfaction and emotional experiences. Psychooncology 2020;29:1263–71. https://doi.org/10.1002/pon.5413
- [20] Heuser C, Diekmann A, Schellenberger B, Bohmeier B, Kuhn W, Karbach U, et al. Patient participation in multidisciplinary tumor conferences from the providers' perspective: is it feasible in routine cancer care? J Multidiscip Health 2020;13:1729–39. https://doi.org/10.2147/JMDH.S283166
- [21] Ansmann L, Heuser C, Diekmann A, Schellenberger B, Biehl C, Danaei M, et al., Patient participation in multidisciplinary tumor conferences: how is it implemented? What is the patients' role? What are patients' experiences? Cancer Med 2021. https://doi.org/10.1002/cam4.4213
- [22] C. Taylor, A.J. Ramirez, Multidisciplinary team members'views about MDT working: Results from a survey commissioned by the NationalCancer Action Team, 2009 (Accessed 10 March 2021).
- [23] Härter M, Reuter K, Aschenbrenner A, Schretzmann B, Marschner N, Hasenburg A, et al. Psychiatric disorders and associated factors in cancer. Eur J Cancer 2001;37:1385–93. https://doi.org/10.1016/S0959-8049(01)00136-8
   [24] Parker PA, Aaron J, Baile WF. Breast cancer: unique communication challenges
- [24] Parker PA, Aaron J, Baile WF. Breast cancer: unique communication challenges and strategies to address them. Breast J 2009;15:69–75. https://doi.org/10.1111/j. 1524-4741.2008.00673.x
- [25] Matsuyama RK, Kuhn LA, Molisani A, Wilson-Genderson MC. Cancer patients' information needs the first nine months after diagnosis. Patient Educ Couns 2013;90:96–102. https://doi.org/10.1016/j.pec.2012.09.009
- [26] Halbach SM, Ernstmann N, Kowalski C, Pfaff H, Pförtner T-K, Wesselmann S, et al. Unmet information needs and limited health literacy in newly diagnosed breast cancer patients over the course of cancer treatment. Patient Educ Couns 2016;99:1511–8. https://doi.org/10.1016/j.pec.2016.06.028
- [27] Prades J, Ferro T, Gil F, Borras JM. Core communication components along the cancer care process: the perspective of breast cancer patients. Breast 2014;23:617–22. https://doi.org/10.1016/j.breast.2014.06.001
- [28] Blödt S, Kaiser M, Adam Y, Adami S, Schultze M, Müller-Nordhorn J, et al. Understanding the role of health information in patients' experiences: secondary analysis of qualitative narrative interviews with people diagnosed with cancer in Germany. BMJ Open 2018;8:019576https://doi.org/10.1136/bmjopen-2017-019576
- [29] Street RL, Millay B. Analyzing patient participation in medical encounters. Health Commun 2001;13:61-73. https://doi.org/10.1207/S15327027HC1301\_06
   [30] Epstein RM, Franks P, Fiscella K, Shields CG, Meldrum SC, Kravitz RL, et al.
- [30] Epstein RM, Franks P, Fiscella K, Shields CG, Meldrum SC, Kravitz RL, et al. Measuring patient-centered communication in patient-physician consultations: theoretical and practical issues. Soc Sci Med 2005;61:1516–28. https://doi.org/ 10.1016/j.socscimed.2005.02.001
- [31] Stewart MA. What is a successful doctor-patient interview? a study of interactions and outcomes. Soc Sci Med 1984;19:167–75. https://doi.org/10.1016/0277-9536(84)90784-3
- [32] Fallowfield L, Jenkins V. Effective communication skills are the key to good cancer care. Eur J Cancer 1999;35:1592-7. https://doi.org/10.1016/S0959-8049(99)00212-9
- [33] Feldman-Stewart D, Brundage MD, Tishelman C. A conceptual framework for patient-professional communication: an application to the cancer context. 801-9; discussion 810-1 Psychooncology 2005;14. https://doi.org/10.1002/pon.950
- [34] Amundsen A, Nordøy T, Lingen KE, Sørlie T, Bergvik S. Is patient behavior during consultation associated with shared decision-making? A study of patients' questions, cues and concerns in relation to observed shared decision-making in a cancer outpatient clinic. Patient Educ Couns 2018;101:399–405. https://doi. org/10.1016/j.j.pec.2017.10.001
- [35] Butow PN, Brown RF, Cogar S, Tattersall MHN, Dunn SM. Oncologists' reactions to cancer patients' verbal cues. Psychooncology 2002;11:47–58. https://doi.org/ 10.1002/pop.556
- [36] Beach WA, Dozier DM. Fears, uncertainties, and hopes: patient-initiated actions and doctors' responses during oncology interviews. J Health Commun 2015;20:1243–54. https://doi.org/10.1080/10810730.2015.1018644

- [37] L. Del Piccolo, A. Finset, C. Zimmermann, Verona coding definitions of emotional sequences (VR-CoDES). Manual, International Association for Communication in Healthcare; 2016.
- [38] Finset A, Heyn L, Ruland C. Patterns in clinicians' responses to patient emotion in cancer care. Patient Educ Couns 2013;93:80–5. https://doi.org/10.1016/j.pec. 2013.04.023
- [39] Del Piccolo L, Mazzi MA, Mascanzoni A, Lonardi M, de Felice M, Danzi OP, et al. Factors related to the expression of emotions by early-stage breast cancer patients. Patient Educ Couns 2019;102:1767–73. https://doi.org/10.1016/j.pec.2019.04.002
- [40] Korsvold L, Mellblom AV, Finset A, Ruud E, Lie HC. A content analysis of emotional concerns expressed at the time of receiving a cancer diagnosis: an observational study of consultations with adolescent and young adult patients and their family members, Eur. J Oncol Nurs 2017;26:1–8. https://doi.org/10.1016/j.eion.2016.10.005
- [41] S. Eggly, L.A. Penner, M. Greene, F.W.K. Harper, J.C. Ruckdeschel, T.L. Albrecht, Information seeking during "bad news" oncology interactions: Question asking by patients and their companions, Soc. Sci. Med. 63; 2006, 2974–2985. https:// doi.org/10.1016/j.socscimed.2006.07.012.
- [42] Heuser C, Diekmann A, Ernstmann N, Ansmann L. Patient participation in multidisciplinary tumour conferences in breast cancer care (PINTU): a mixedmethods study protocol. BMJ Open 2019;9:024621https://doi.org/10.1136/ bmjopen-2018-024621
- [43] Dillman DA. Mail and telephone surveys: the total design method. Wiley; 1978.
- [44] Prüfer P, Rexroth M. Zwei-phasen-pretesting. DEU Mannh 2000.
- [45] Stivers T, Enfield NJ. A coding scheme for question-response sequences in conversation. J Pragmat 2010;42:2620-6. https://doi.org/10.1016/j.pragma.2010. 04.002

- [46] Zimmermann C, Del Piccolo L, Bensing J, Bergvik S, de Haes H, Eide H, et al. Coding patient emotional cues and concerns in medical consultations: the Verona coding definitions of emotional sequences (VR-CoDES). Patient Educ Couns 2011;82:141–8. https://doi.org/10.1016/j.pec.2010.03.017
- [47] Korsvold L, Mellblom AV, Lie HC, Ruud E, Loge JH, Finset A. Patient-provider communication about the emotional cues and concerns of adolescent and young adult patients and their family members when receiving a diagnosis of cancer. Patient Educ Couns 2016;99:1576–83. https://doi.org/10.1016/ji.pec. 2016.03.028
- [48] Del Piccolo L, Goss C, Bottacini A, Rigoni V, Mazzi MA, Deledda G, et al. Asking questions during breast cancer consultations: does being alone or being accompanied make a difference? Eur J Oncol Nurs 2014;18:299–304. https://doi. org/10.1016/j.ejon.2014.02.001
- [49] Laidsaar-Powell R, Butow P, Bu S, Fisher A, Juraskova I. Attitudes and experiences of family involvement in cancer consultations: a qualitative exploration of patient and family member perspectives. Support Care Cancer 2016;24:4131–40. https://doi.org/10.1007/s00520-016-3237-8
- [50] Heath C, Hindmarsh J, Luff P. Video in qualitative research: analysing social interaction in everyday life. SAGE Publications, Inc; 2010. 1 Oliver's Yard, 55 City Road London EC1Y 1SP.
- [51] L. Del Piccolo, A. Finset, A.V. Mellblom, M. Figueiredo-Braga, L. Korsvold, Y. Zhou, et al., Verona Coding Definitions of Emotional Sequences (VR-CoDES): Conceptual framework and future directions, Patient Educ. Couns. 100; 2017, 2303–2311. Doi: 10.1016/j.pec.2017.06.026.
- [52] Harrington J. Improving patients' communication with doctors: a systematic review of intervention studies. Patient Educ Couns 2004;52:7–16. https://doi. org/10.1016/S0738-3991(03)00017-X

3.3 Publication 3: Patient participation in multidisciplinary tumor conferences in breast and gynecological cancer care: How patient-centered is the communication?

Schellenberger B, Heuser C, Diekmann A, Ansmann L, Krüger E, Schreiber L, Geiser F, Karger A, Schmidt-Wolf IGH, Milz K, Peisker U, Ernstmann N. Patient participation in multidisciplinary tumor conferences in breast and gynecological cancer care: How patient-centered is the communication? Psychooncology 2022. doi:10.1002/pon.5999

DOI: 10.1002/pon.5999

#### **ORIGINAL ARTICLE**

# Patient participation in multidisciplinary tumor conferences in breast and gynecological cancer care: How patient-centered is the communication?

Barbara Schellenberger<sup>1,2</sup> | Christian Heuser<sup>1,2</sup> | Annika Diekmann<sup>1,2</sup> | Lena Ansmann<sup>3</sup> | Emily Krüger<sup>1,2</sup> | Leonie Schreiber<sup>1,2</sup> | Franziska Geiser<sup>2,4</sup> | André Karger<sup>5</sup> | Ingo G. H. Schmidt-Wolf<sup>2,6</sup> | Katrin Milz<sup>7</sup> | Uwe Peisker<sup>8</sup> | Nicole Ernstmann<sup>1,2</sup>

Barbara Schellenberger, Center for Health Communication and Health Services Research (CHSR) Department for Psychosomatic Medicine and Psychotherapy, University Hospital Bonn, Bonn 53127, Germany. Email: barbara.schellenberger@ukbonn.de

#### **Funding information**

German Cancer Aid DKH, Grant/Award Number: 70112286 Open Access funding enabled and organized by Projekt DEAL.

#### Abstract

Objective: Patients' participation is part of patient-centeredness, but it is so far unclear whether providers in multidisciplinary tumor conferences (MTCs) with patient participation communicate in a patient-centered way. Our aim is to explore (a) to what extent providers ask questions to breast and gynecological cancer patients during case discussion in MTCs, (b) how providers respond to patients' expressions of emotions during case discussions, and (c) which patient- and context-related characteristics and responses are associated with patients' trust in the treatment team after the case discussion.

Methods: This observational study included survey data and audio recordings of MTCs with patient participation at three breast and gynecological cancer centers. Providers' questions to patients and responses to patients' emotional expressions were coded using the Verona Coding Definitions of Emotional Sequences. The response can be explicitly or non-explicitly related to the emotion and spacereducing or space-providing. Multiple linear regression analysis was used to determine associations between providers' responses, patient- and context-related characteristics, and patients' trust in the treatment team after the case discussion.

This is an open access article under the terms of the Creative Commons Attribution-NonCommercial-NoDerivs License, which permits use and distribution in any medium, provided the original work is properly cited, the use is non-commercial and no modifications or adaptations are made. © 2022 The Authors. Psycho-Oncology published by John Wiley & Sons Ltd.

<sup>&</sup>lt;sup>1</sup>Center for Health Communication and Health Services Research (CHSR), Department for Psychosomatic Medicine and Psychotherapy, University Hospital Bonn, Bonn, Germany

<sup>&</sup>lt;sup>2</sup>Center for Integrated Oncology (CIO), University Hospital Bonn, Bonn, Germany

<sup>&</sup>lt;sup>3</sup>Division for Organizational Health Services Research, Department of Health Services Research, School of Medicine and Health Sciences, Carl von Ossietzky University Oldenburg, Oldenburg, Germany

<sup>&</sup>lt;sup>4</sup>Department for Psychosomatic Medicine and Psychotherapy, Faculty of Medicine, University Hospital Bonn, Bonn, Germany

<sup>&</sup>lt;sup>5</sup>Clinical Institute of Psychosomatic Medicine and Psychotherapy, Medical Faculty Heinrich-Heine-University Düsseldorf, Düsseldorf, Germany

<sup>&</sup>lt;sup>6</sup>Department of Integrated Oncology, University Hospital Bonn, Bonn, Germany

<sup>&</sup>lt;sup>7</sup>Breast Cancer Center Rhein-Sieg, GFO Clinics Troisdorf, Troisdorf, Germany

<sup>&</sup>lt;sup>8</sup>Clinic of Gynecology, Obstetrics and Senology, Breast Cancer Center Aachen-District of Heinsberg, Hermann-Josef-Hospital Erkelenz, Erkelenz, Germany

1598 SCHELLENBERGER ET AL.

Results: We analyzed 82 case discussions (77 breast, 5 breast and gynecological cancer patients). Providers asked a total of 646 questions, of which 86% were polar (yes/no). Providers gave 303 responses to a total of 230 emotional expressions by patients. Non-explicit responses were associated with more trust when they were space-providing, but with less trust when space-reducing.

**Conclusions:** The frequency of providers' closed questions and space-reducing responses to emotions shows that patient-centered communication rarely takes place in MTCs with patient participation.

#### **KEYWORDS**

breast cancer, cancer, gynecological cancer, multidisciplinary tumor board, multidisciplinary tumor conference, oncology, patient-centered communication, trust

#### 1 | INTRODUCTION

After receiving a cancer diagnosis, patients must make complex and far-reaching decisions together with various providers during the course of multidisciplinary treatment. They often need to build relationships with providers in the short term, which makes immediate trust more important. Through relationship building, trust can develop as an intermediate endpoint according to the six function model of medical communication. When cancer patients feel that they are listened to and that their emotions are acknowledged, they are more likely to trust the provider. As a result they might have less anxiety and experience more patient empowerment. They might be more likely to accept treatment recommendations and less likely to regret treatment decisions. Trust has been shown to be stronger among older and more highly educated cancer patients.

Trust in providers can be improved through patient-centered communication, which includes asking content questions and recognizing and responding to emotions. Patients can express negative emotions verbally and clearly (concerns) or through verbal and nonverbal hints (cues). Cancer patients tend to express their concerns indirectly. In responding to a patient's emotion, a provider may explicitly or non-explicitly refer to the emotion and provide or reduce space for the patient's further expression. As a number of studies have shown, cancer patients and oncologists agree that patients' emotions should be addressed by responses that are empathic, exploratory, and acknowledging. 11,12

When considering patient cues, a distinction can be made between informative cues (indicating information needs) and emotional cues (indicating emotional support). 

In initial consultations for oncology outpatients providers tended to respond more to informational cues than to emotional cues. 

Other studies report, that oncologists responded empathically to emotional expressions only sometimes (29%) 

and emotional cues from patients resulted in space-providing responses at a rate of 58%–77%. 

A study of pediatric cancer consultations found that 85% of responses were non-explicit with regard to addressing emotions. Backchanneling, which provides space for the patient to say more through using a minimal prompt, was the most common non-explicit, space-providing

response (32%), while informational advice was the most common non-explicit, space-reducing response (28%).<sup>17</sup>

The communication process between providers and patients is reciprocal; it is influenced by the patients' and providers' characteristics and by external factors, such as the setting. 18 A multidisciplinary tumor conference (MTC) is an internationally well-established specific setting for medical encounter. 19 Usually, there is a regular discussion of a cancer patient's diagnosis and therapy, involving various professions, in which treatment recommendations are decided upon.<sup>20</sup> Decision making can be complicated when patient-centered information is lacking. 21,22 However, there are approaches that allow patients to participate in the MTC, what is practised in some cancer centers in North Rhine-Westphalia, Germany, where 5%-7% of breast cancer patients participate in their case discussions. 20,23,24 Initial findings show that participation is implemented in different ways.<sup>25</sup> There is still no clear evidence regarding the advantages and disadvantages of patient participation, both for providers and patients. On the one hand, participation may allow patients to be better informed. On the other hand, if patients are overloaded with medical information, they may react emotionally, which could disrupt the provider-patient relationship.<sup>26-28</sup> Providers object that patient participation requires more time and adjusted professional language. 26,28 Patients who participated in case discussions found them mostly helpful and informative<sup>24,29</sup> but also reported difficult situations and negative emotional reactions.<sup>24</sup> We have reported elsewhere on the expression of negative emotions of patients in MTCs.30 However, it has not yet been investigated how providers respond to patients' emotions in MTCs.

# 1.1 | Research question

There are currently few reports of patient participation in MTCs in Germany, however in some cancer centers it appears to be an established practice and in others it occurs as an exemption (e.g. due to the patient's wish). Therefore, to date, there are no recommendations on how MTCs with patient participation should be designed. One goal of our study is to contribute to this through our results. Since up to now in Germany only breast cancer patients and to a

SCHELLENBERGER et al. | 1599

lesser extent gynecological cancer patients are known to participate in MTCs in some cancer centers, we are investigating this phenomenon in this patient population. Participation in one's own care is part of patient-centeredness.<sup>31</sup> Some patients are given the opportunity to participate in their own case discussion in the MTC, but it is so far unclear whether providers in MTCs communicate in a patientcentered way (respond to emotions and ask questions, which may differ in form and function<sup>32</sup>) or whether through their communication the function of relationship building is fulfilled, which would be associated with patient trust as an intermediate endpoint.3 This study aimed to fill this research gap and generate findings regarding communication in MTCs with patient participation. Answers to the following research questions were sought: (a) To what extent do providers ask questions to breast and gynecological cancer patients during their case discussions in MTCs? (b) How do providers respond to patients' expressions of negative emotions during case discussions? (c) Which patient- and context-related characteristics and responses determine patients' trust in the treatment team after the case discussion?

# 2 | METHODS

# 2.1 | Study design and sample

This analysis is part of the German multicenter, non-interventional study 'Patient involvement in multidisciplinary tumor conferences in breast cancer care' (PINTU).33 Data were collected between November 2018 and February 2020. We used a PINTU subsample of case discussions with patient participation in three breast and gynecological cancer centers. Patients who were diagnosed with breast and/or gynecological cancer (ICD codes: C50. xx-C58. xx, D05. xx-D07. xx) and who took part in their case discussion in an MTC were recruited by medical staff on the wards. Participants provided written informed consent. Two researchers at a time conducted passive participatory observation during the MTCs. Field notes included the duration of the case discussion, the seating arrangement, and the number of providers present. Audio recording of the case discussions were transcribed verbatim and anonymized. Patients were asked to complete questionnaires: before the MTC (T0), immediately after the MTC (T1), and 4 weeks after the MTC (T2). The data was analyzed quantitatively by including survey data, coded audio data and coded observation data.

# 2.2 | Instruments

We included data from T0 and T1. The patients' sociodemographic data included age, having children, and level of education. Patients' trust in the treatment team was assessed using a subscale of the psychosocial care by physicians-index.<sup>34</sup> This subscale uses five items to measure different aspects of trusting physician-patient interactions (e.g. 'I completely trusted my physicians'). The terms

'physicians' and 'hospital' were replaced by 'treatment team' and 'cancer center.' Four answer categories were given, ranging from totally disagree to totally agree. Information regarding the cancer entity (breast and/or gynecological) and Union Internationale Contre le Cancer (UICC) staging was obtained from the case discussion and/or tumor documentation.

### 2.3 Data analysis

Four researchers coded the providers' questions to patients and their responses to cues/concerns expressed by patients and their companions. All recordings were double coded. The questions and responses identified were discussed and agreed upon in regular consultations within the research team. We calculated the mean amount, and the mean amount per subcategory of provider questions and responses, as recorded by the two coders.

# 2.3.1 | Questions from providers

Providers' questions were coded by question type (e.g., polar [yes/no] question, content question) and function (e.g., request for information, request for confirmation), following Stivers and Enfield.<sup>32</sup> This classification is shown in the Results section (see 3.2 Questions), with explanation and examples.

# 2.3.2 | Providers' responses to emotional expressions from patients and companions

To capture providers' responses to negative emotions expressed by patients and their companions, we used the validated Verona Coding Definitions of Emotional Sequences to code providers' responses (VR-CoDES-P). The coding of a provider response is dependent on coding of the patient's expression of cues/concerns. The provider's response can refer to the cue/concern either explicitly or non-explicitly; the response can be either space-reducing or space-providing. This categorization can be further subdivided into 17 subcategories. Four coders worked independently in two teams using the German translation of VR-CoDES-P. We calculated interrater reliability, based on Cohen's Kappa, for a random sample of ten case discussions (63 responses); agreement was substantial (Cohens Kappa: 0.75).

# 2.3.3 | Statistical analyses

Descriptive statistics were used to report sociodemographic and clinical data, the settings of the MTCs, and the communication behavior of the providers. We performed a multiple linear regression analysis, with trust in the treatment team as the dependent variable, to explore associations between patient- and context-

1600 SCHELLENBERGER ET AL.

related characteristics and providers' communication. IBM SPSS statistics version 27 was used for the analysis.

The selection of patient characteristics as independent variables was based on literature as trust is higher among older and more educated cancer patients<sup>5</sup>; age and educational level were included. Context-related characteristics were acquired from field notes; they included round table as seating arrangement and the average number of providers present as we assumed that these variables could have an impact on trust. Providers' responses (by function and explicitness, mean amount for each) served as independent variables. Multicollinearity of the independent variables was checked by calculating the Variance Inflation Factor. A Durbin-Watson statistic was used to assess autocorrelation.

### 3 | RESULTS

## 3.1 | Sample description

Ninety-five patients from three centers (four hospitals) participated. Audio data from case discussions were available for 82 patients. A total of 39 (48%) patients were accompanied, and 43 (52%) were not. Table 1 presents the patients' characteristics.

## 3.1.1 | Case discussions in the MTCs

We analyzed 82 case discussions. The seating arrangements for the MTCs were theater-style (n=5), U-shaped (n=17), and round table (n=60). Individual case discussions lasted an average of 07:26 min (range: 01:25–20:54 min). An average of eight providers (range: 3–19) were present. The following professionals were mostly represented: Oncologist, gynecologist, radiologist, radiation therapist, pathologist, psychooncologyist, breast care nurse.

## 3.2 | Questions

Providers asked patients a total of 646 questions. On average, each case discussion contained eight questions (range: 1–27; median: 7; Table 2).

## 3.3 | Responses

We identified 303 responses from providers (average: 3.7 per case; range: 0–29) to 230 cues/concerns from patients (Table 3).

#### 3.4 | Multivariate analyses

Table 4 shows the results of multiple linear regression analysis with the dependent variable trust in the treatment team. No significant

**TABLE 1** Patient characteristics (n = 82)

	N	%
Age (years)	59 (11.2)	
Mean (SD)		
Children		
Yes	61	74.4
No	15	18.3
Missing	6	7.3
Highest education level achieved		
No lower secondary school education	1	1.2
Lower secondary school education	18	22.0
Intermediate secondary school education	23	28.0
University entrance certificate	32	39.0
Other	1	1.2
Missing	7	8.5
Cancer entity		
Breast cancer	77	93.9
Breast and gynecological cancer	5	6.1
UICC stage		
0	10	12.2
I	38	46.3
II	16	19.5
Ш	3	3.7
IV	10	12.2
Missing	5	6.1

*Note*: Due to rounding, percentages might not total exactly 100%. Abbreviation: UICC, Union Internationale Contre le Cancer.

results were found at the patient level or for contextual factors. Significant associations were found in connection with non-explicit, space-reducing (beta = -0.372; p = 0.013), explicit, space-providing (beta = -0.361; p = 0.021), and non-explicit, space-providing (beta = 0.419; p = 0.008) responses.

## 4 DISCUSSION

This study inquired into providers' communication behavior in MTCs with patient participation and its possible association with patients' trust in the treatment team after the MTC. We analyzed case discussions with participating patients at breast and gynecological cancer centers. We described providers' questions to patients and their responses to expressions of negative emotions by patients. We found that content questions were rarely addressed to patients. The potential of patient participation, namely to not only let the patient participate in their own care, but to actively involve the patient with patient-centered communication techniques (e.g. active listening,

SCHELLENBERGER ET AL. 1601

**TABLE 2** Questions from providers in case discussions (n = 82)

		N (%)	Example	
Question type and definition	Polar question	553 (85.6%)	S2: And you've already had the follow-up here today? (518)	
	two answers are possible			
	Content question	58 (9%)	S1: What//do you do for a living?//(639)	
	Q-word'question			
	('Wh' question)			
	Alternative question	12 (1.9%)	S6: Do you want to come see us or do you want to go	
	Including a limited number of alternative answers in the question		somewhere else? (420)	
	Multi-question	23 (3.6%)	S2: (Mumbling) yes, a relatively small tumor. Right? I wanted	
	More than one question in a turn		to ask again why Ms. (name) sent you for the mammogram?//Was that, like/automatic. (516)	
Total number of questions from providers		646 (100%)		
Social action of	Rhetorical	219 (33.8%)	S1: Right? And also, a mammogram, the first mammogram on	
the question	Questions that do not require an answer		the affected side, makes sense AT THE EARLIEST six months after the/, um, end of treatment, right? (501)	
	Request for information	204 (31.6%)	S4: Who is your gynecologist? (636)	
	Questions for information			
	Request confirmation	202 (31.3%)	S7: We usually start four to six weeks after surgery. We need	
	Questions that require confirmation		a little time, including for planning. That is, you live in (name of town)? (545)	
	Other initiation of repair	13 (2%)	S5: What about therapy, when does it start or what does it even look like, then?	
	Questions inviting repair, including repair initiators (e.g., 'Huh?')		(S3: Radiotherapy?) (567)	
	Suggestion	8 (1.2%)	S2: Would you like to drink something? Some water? (640)	
	Questions that suggest or propose something			
	Assessment	1 (0.2%)	S2: Yes, yes. (–) basically, it's all very small and, and very/extremely	
	Evaluations that were formatted to seek agreement		advantageous. But nevertheless (beep), you, of course, take a loright? Young, (–) (?other situation), (–) what else can we gain in terms of knowledge in order to determine that it really/that we can really sit back and relax? (645)	
Total number of que		646 (100%)	· · ·	

Note: Due to rounding, the numbers may not add up precisely to the totals; percentages may not total exactly 100%.

open questions), is therefore not being realised. We showed that response types were associated with patients' trust in the treatment team after the MTC. If providers responded to emotions in a non-explicit, space-providing manner, patients reported higher trust in the treatment team. Non-explicit, space-reducing and explicit, space-providing responses were associated with lower levels of trust.

The majority of providers' questions were rhetorical, followed by questions that requested information or confirmation. Because rhetorical questions do not require a response, and confirmation questions simply indicate agreement or disagreement,<sup>32</sup> the majority of questions did not serve to actively involve the patient. The

most frequent responses to patients' expressions of negative emotions were space-reducing, which contrasts with other studies in which 58%–77% of providers' responses were space-providing. Space-reducing responses invited patients to participate less. A provider may have the perspective that treatment recommendations should not be influenced by patient emotions. However, the MTC is also seen as a venue for providers to address patient emotions. Perhaps providers mitigate the disadvantage they perceive in patient participation (in terms of additional time commitment) by asking and answering questions in a way that does not encourage it. 26,28 In terms of subcategories, our

1602 SCHELLENBERGER ET AL.

TABLE 3 Distribution of providers' responses to patients' expressions of negative emotions (n = 230) in MTCs (n = 82), and examples of the most frequent subcategories of responses, based on VR-CoDES-P, <sup>10</sup> Patient (PA), Provider (PR)

Distribution of responses						
Responses, N (%)	Space-providing	Space-reducing	Total			
Explicit	24 (7.9%)	88 (28.9%)	112 (36.9%)			
Non-explicit	85 (27.9%)	107 (35.2%)	191 (63.1%)			
Total	108 (35.7%)	195 (64.3%)	303 (100%)			
Most frequent subcategories and re	esponses					
Type of response	Example					
	PA: What is the general prognosis? () What will it look like, (-), um, (-) let's say, in terms of my ability to work?					
Explicit, space-providing (content exploration)	PR: What do//you//do? (639)					
	PA: But I'm not through with this issue. Well, to me, it's still an issue where I think, maybe it's better to do it, after all. Yes.					
Explicit, space-reducing (information advice)	PR: You can take as much time as you'd like to think about that. Because there's even evidence of a (xxx xxxx, #00:02:03–5#) gene mutation, no STRICT recommendation, and nobody says: 'Oh, but you have to do that, otherwise you'll get something again.' Then, I'd say, definitely schedule an appointment for a consultation. (544)					
		IOTHERAPY. That this, um/(–) I mear w, and it can do this and that. I do alr				
Non-explicit, space-providing (backchannel)	(PR: Mhm.) (742)					
	PA: Sure. (Laughs) and this hormone	e treatment, it has, um, no really majo	r side effects?			
Non-explicit, space-reducing (information advice)	PR: Well, you'll get a medication, yo	u're to receive a so-called aromatase	inhibitor (526)			

 $\textit{Note} : \ \mathsf{Due} \ to \ \mathsf{rounding}, \ \mathsf{numbers} \ \mathsf{presented} \ \mathsf{may} \ \mathsf{not} \ \mathsf{add} \ \mathsf{up} \ \mathsf{precisely} \ \mathsf{to} \ \mathsf{the} \ \mathsf{totals} \ \mathsf{provided}.$ 

results are similar to those of other studies that analyzed communication in oncology settings beyond the MTC. Answers gave information rather than addressing emotions.<sup>35</sup> The provision of clinical information by the provider may be the basis for emotional comfort in oncology care.<sup>36</sup> The proportion of information-advising responses was found to be similar in pediatric oncology settings; backchanneling was identified as the most common non-explicit, space-providing response.<sup>17</sup>

No significant associations were found between trust in the treatment team and patient characteristics, unlike other studies reporting stronger trust among older and more highly educated cancer patients.<sup>5</sup> No significant associations were found between trust in the treatment team and contextual factors either. In contrast, several significant associations were found for responses to cues/concerns: The finding that patients reported less trust with more explicit, space-providing responses may be surprising; however, it can be explained by the most frequent subcategory. The most common explicit, space-providing response was further content exploration. An important prerequisite for a trustful provider-patient relationship is the provider's familiarity with the individual case.<sup>12</sup> Less trust might result from exploration during the MTC, a venue in which

decisions about further treatment are made, because patients might believe that the provider is not sufficiently familiar with their case. The lower trust with more explicit and space-providing responses could also occur in more complex cases where patients express stronger emotions. In these situations, trust could be lower for other reasons and providers could explore the emotions more openly to manage the complexity of the situation.

We found further significant associations: While non-explicit, space-reducing responses were associated with less trust in the treatment team, non-explicit, space-providing responses were associated with more trust in the treatment team. The most common space-reducing response was providing information, both explicitly and non-explicitly. This result may be an indication that information by the provider, which can be the basis for a trusting relationship, must be considered in a differentiated way. Providing information in response to a cue/concern had no significant association with trust in the treatment team. In fact, providing general information in response to an expression of negative emotion was associated with less trust in the treatment team among patients in our study. Backchanneling as active listening technique, which shows the patients they are being listened to, <sup>37</sup> was most frequent in non-explicit, space-

SCHELLENBERGER ET AL. | 1603

TABLE 4 Multiple linear regression modeling using trust in the treatment team as the dependent variable; standardized regression coefficients (beta), *p*-values (*p*) and 95% confidence interval (CI)

	Trust in the trea	tment team as a dependent	variable
Variable	Beta	p	95% CI
Constant		0.000	2.989-6.638
Patient level			
Age	0.106	0.396	-0.009-0.022
Level of education	0.043	0.735	-0.170-0.240
Contextual factors			
Average number of providers present <sup>a</sup>	0.290	0.209	-0.029-0.130
Seating arrangement round table			
No		Ref	
Yes	0.147	0.533	-0.510-0.974
Number of responses from providers to cues/concerns			
Non-explicit, space-reducing	-0.372	0.013	-0.3300.041
Non-explicit, space-providing	0.419	0.008	0.032-0.204
Explicit, space-reducing	-0.222	0.095	-0.253-0.021
Explicit, space-providing	-0.361	0.021	-0.8890.076
Adjusted R <sup>2</sup>	27.4%		

<sup>&</sup>lt;sup>a</sup>average number of providers present per MTC.

providing answers. Thus, our study reveals that active listening techniques can engender more patient trust in providers.

## 4.1 | Study limitations

To the best of our knowledge, it is the first study to observe MTCs with patient participation. However, the distribution of the variables with regard to contextual factors is uneven because participation is practiced in different ways across hospitals<sup>25</sup> and the relatively small number of cases confers low statistical power. Furthermore, our sample was limited to patients with breast and gynecological cancer. A larger sample and additional entities are necessary to examine whether the associations found persist and/or whether further associations emerge. Before data collection, we visited the MTCs to explain the observation method<sup>38</sup> and mitigate potentially disruptive factors related to the presence of observers and technical equipment. Through regular observations, MTC members became familiar with the presence of the observers. The observation is one of our study's major strengths; it provides insights into the MTC that are not solely from the participants' points of view. We used VR-CoDES-P<sup>10</sup> coding for analysis, which is rooted in a patient-centered approach<sup>39</sup> and achieved a substantial interrater reliability. In previous studies, data were often collected from dyadic patient-provider conversations, 16 whereas we analyzed the communication between patients, their companions and several providers. Therefore, we had to adapt the VR-CoDES-P<sup>10</sup> application accordingly. The coding system has been developed for the sequential analysis of interactions. Due to the amount of observational data, we first considered the patients' expressions of emotions and the providers' responses to them individually. The analysis of dyadic sequences could follow, based on the separate analyses to analyze certain phenomena in depth dyadically. In our survey, trust was measured with a four-point Likert scale which we defined as a continuous variable for the statistical analysis, although it can be critically discussed whether treating it as an ordinally scaled variable could be more appropriate. We are unable to draw conclusions about how trust evolves over the course of treatment. However, we found significant associations between providers' communicative behaviors during case discussions and patients' trust in the treatment team, despite a relatively small sample.

#### 4.2 | Clinical implications

The aim of a case discussion in the MTC is to exchange much complex information in a short time, primarily between the treatment providers involved, in order to be able to make an evidence-based treatment recommendation. However, biomedical aspects remain in the foreground while psychosocial aspects receive less attention. Providers could use the presence of patients to obtain information about psychosocial aspects that could be important for the recommendation and to build a trustful relationship. Our results provide preliminary evidence about provider responses to expressions of emotion that are relevant for relationship-building. Therefore, we can give first recommendations with regard to communication for providers enabling patients to participate in the

1604 | SCHELLENBERGER ET AL.

MTC. Providers should be aware that patients are highly sensitive to this conversational situation and should take patient-orientation more into account. Hillen et al.<sup>2</sup> suspect that because oncology patients need to acquire trust in their providers quickly, they may have fewer demands for communication. However, our study showed that communicative behavior in the oncology team can be relevant for the process of building a trustful relationship. Although a deeper trustful relationship appears to be established only after repeated interactions,<sup>2</sup> case discussion within the MTC seems to be an opportunity to build trust. Providers should obtain information about the patient before a case discussion with patient participation, as asking for it during the case discussion can damage trust. Since an association was found between providers' responses to expressions of emotion and patients' trust in the treatment team, providers should consciously use conversational strategies such as backchanneling. Our findings raise further research questions. First, the role of the patient in the MTC should be clarified from the provider's perspective. Our study showed that even short communication sequences with the patient in the MTC can be associated with patient's trust. However, it is unclear which medical communication functions (e.g. relationship-building, gathering information, providing information, responding to emotions<sup>3</sup>) should be fulfilled in MTCs with patient participation. There is a need to clarify questions such as whether the patient should be given the opportunity to actively participate, whether the situation should be used to build a trustful relationship, and what factors can support patient-centered communication in MTCs. It is also necessary to determine what expectations patients have of participation in case discussions. Communication concepts that meet expectations can be developed in cancer centers that want to enable participation. Patients should then be informed about the process and their role prior to participation.

## 5 | CONCLUSIONS

The frequency of closed questions and space-reducing responses to expressions of emotion shows that patient-centered communication rarely takes place in MTCs with patient participation. The question here is whether a completely different form of MTC would be required for patient participation. Patients' levels of trust in the treatment team were dependent on how providers responded to their expressions of emotions. Communication strategies (e.g., back-channeling) can be applied in case discussions in MTCs with patient participation to improve patients' trust in the treatment team.

## **AUTHOR CONTRIBUTIONS**

Barbara Schellenberger interpreted the results, drafted and revised all sections of the manuscript, and is guarantor. Lena Ansmann, Nicole Ernstmann, Christian Heuser, and Annika Diekmann developed the study framework. Christian Heuser, Annika Diekmann, and Barbara Schellenberger observed the MTCs. Barbara Schellenberger, Christian Heuser, Annika Diekmann, Emily Krüger, and Leonie Schreiber planned and conducted the data analysis. Christian Heuser,

Lena Ansmann, Franziska Geiser, André Karger, Ingo G.H. Schmidt-Wolf, and Nicole Ernstmann assisted in interpretation of data and review and editing of the manuscript. Katrin Milz, and Uwe Peisker assisted in data collection and review and editing of the manuscript. All authors read and approved the final manuscript.

#### **ACKNOWLEDGEMENTS**

We would like to thank all hospitals, providers, and patients who participated in this study. We are grateful to German Cancer Aid (DKH, grant number 70112286) for funding this research.

Open Access funding enabled and organized by Projekt DEAL.

#### **CONFLICT OF INTEREST**

The authors declare that they have no competing interests.

## **CONSENT TO PARTICIPATE**

Written informed consent was obtained from all individual participants included in the study.

#### **DATA AVAILABILITY STATEMENT**

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

#### ETHICS STATEMENT AND CONSENT TO PARTICIPATE

All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. This study was approved by the ethics committee of the Medical Faculty of the University of Cologne, Germany (Reference number for the approval: 17–405).

### REFERENCES

- Hillen MA, de Haes HCJM, Stalpers LJA, et al. How can communication by oncologists enhance patients' trust? An experimental study. *Ann Oncol.* 2014;25(4):896-901. https://doi.org/10.1093/annonc/mdu027
- Hillen MA, Onderwater AT, van Zwieten MCB, de Haes HC, Smets EMA. Disentangling cancer patients' trust in their oncologist: a qualitative study. *Psycho Oncol.* 2012;21(4):392-399. https://doi.org/ 10.1002/pon.1910
- de Haes H, Bensing J. Endpoints in medical communication research, proposing a framework of functions and outcomes. *Patient Educ Counsel.* 2009;74(3):287-294. https://doi.org/10.1016/j.pec.2008. 12.006
- Vries AMM, de Roten Y, Meystre C, Passchier J, Despland J.-N, Stiefel F. Clinician characteristics, communication, and patient outcome in oncology: a systematic review. *Psycho Oncol.* 2014;23(4): 375-381. https://doi.org/10.1002/pon.3445
- Hillen MA, de Haes HC, Smets EMA. Cancer patients' trust in their physician-a review. Psycho Oncol. 2011;20(3):227-241. https://doi. org/10.1002/pon.1745
- Ernstmann N, Wirtz M, Nitzsche A, et al. Patients' trust in physician, patient enablement, and health-related quality of life during colon cancer treatment. J Cancer Educ. 2017;32(3):571-579. https://doi. org/10.1007/s13187-017-1166-y

SCHELLENBERGER ET AL. | 1605

- Henman MJ, Butow PN, Brown RF, Boyle F, Tattersall M. Lay constructions of decision-making in cancer. *Psycho Oncol.* 2002;11(4): 295-306. https://doi.org/10.1002/pon.566
- Epstein RM, Street RL. Patient-Centered Communication in Cancer Care: Promoting Healing and Reducing Suffering. MD: National Cancer Institute: 2007.
- Zimmermann C, Del Piccolo L, Finset A. Cues and concerns by patients in medical consultations: a literature review. *Psychol Bull.* 2007;133(3):438-463. https://doi.org/10.1037/0033-2909.133. 3 438
- Del Piccolo L, de Haes H, Heaven C, et al. Development of the Verona coding definitions of emotional sequences to code health providers' responses (VR-CoDES-P) to patient cues and concerns. Patient Educ Counsel. 2011;82(2):149-155. https://doi.org/10.1016/j. pec.2010.02.024
- Visser LNC, Schepers S, Tollenaar MS, de Haes HCJM, Smets EMA. Patients' and oncologists' views on how oncologists may best address patients' emotions during consultations: an interview study. Patient Educ Counsel. 2018;101(7):1223-1231. https://doi.org/10. 1016/j.pec.2018.02.012
- Mazor KM, Beard RL, Alexander GL, et al. Patients' and family members' views on patient-centered communication during cancer care. Psycho Oncol. 2013;22(11):2487-2495. https://doi.org/10. 1002/pon.3317
- Butow PN, Brown RF, Cogar S, Tattersall MHN, Dunn SM. Oncologists' reactions to cancer patients' verbal cues. *Psycho Oncol.* 2002;11(1):47-58. https://doi.org/10.1002/pon.556
- Pollak KI, Arnold R, Alexander SC, et al. Do patient attributes predict oncologist empathic responses and patient perceptions of empathy? Support Care Cancer. 2010;18(11):1405-1411. https://doi.org/10. 1007/s00520-009-0762-8
- Mellblom AV, Finset A, Korsvold L, Loge JH, Ruud E, Lie HC. Emotional concerns in follow-up consultations between paediatric oncologists and adolescent survivors: a video-based observational study. *Psycho Oncol.* 2014;23(12):1365-1372. https://doi.org/10. 1002/psp.3568
- Finset A, Heyn L, Ruland C. Patterns in clinicians' responses to patient emotion in cancer care. *Patient Educ Counsel*. 2013;93(1):80-85. https://doi.org/10.1016/j.pec.2013.04.023
- Sisk BA, Friedrich AB, DuBois J, Mack JW. Emotional communication in advanced pediatric cancer conversations. J Pain Symptom Manag. 2020;59(4):808-817. https://doi.org/10.1016/j.jpainsymman.2019. 11.005
- Feldman-Stewart D, Brundage MD, Tishelman C. A conceptual framework for patient-professional communication: an application to the cancer context. *Psycho Oncol.* 2005;14(10):801-809. https:// doi.org/10.1002/pon.950
- Prades J, Remue E, van Hoof E, Borras JM. Is it worth reorganising cancer services on the basis of multidisciplinary teams (MDTs)? A systematic review of the objectives and organisation of MDTs and their impact on patient outcomes. *Health Pol.* 2015;119(4):464-474. https://doi.org/10.1016/j.healthpol.2014.09.006
- Ansmann L, Kowalski C, Pfaff H, Wuerstlein R, Wirtz MA, Ernstmann N. Patient participation in multidisciplinary tumor conferences. *Breast.* 2014;23(6):865-869. https://doi.org/10.1016/j.breast.2014. 09 004
- Soukup T, Lamb BW, Sarkar S, et al. Predictors of treatment decisions in multidisciplinary oncology meetings: a quantitative observational study. Ann Surg Oncol. 2016;23(13):4410-4417. https://doi.org/10.1245/s10434-016-5347-4
- Hollunder S, Herrlinger U, Zipfel M, et al. Cross-sectional increase of adherence to multidisciplinary tumor board decisions. BMC Cancer. 2018;18(1):936. https://doi.org/10.1186/s12885-018-4841-4

- Heuser C, Diekmann A, Kowalski C, et al. Health literacy and patient participation in multidisciplinary tumor conferences in breast cancer care: a multilevel modeling approach. *BMC Cancer*. 2019;19(1):330. https://doi.org/10.1186/s12885-019-5546-z
- Diekmann A, Heuser C, Ernstmann N, et al. How do breast cancer patients experience multidisciplinary tumor conferences? - a description from the patient perspective. *Breast.* 2019;44:66-72. https://doi.org/10.1016/j.breast.2018.12.012
- Ansmann L, Heuser C, Diekmann A, et al. Patient participation in multidisciplinary tumor conferences: how is it implemented? What is the patients' role? What are patients' experiences? Cancer Med 2021;10(19):6714-6724. https://doi.org/10.1002/cam4.4213
- Butow P, Harrison JD, Choy ET, Young JM, Spillane A, Evans A. Health professional and consumer views on involving breast cancer patients in the multidisciplinary discussion of their disease and treatment plan. *Cancer*. 2007;110(9):1937-1944. https://doi.org/10. 1002/cncr.23007
- Diekmann A, Heuser C, Schellenberger B, et al. Patient participation in multidisciplinary tumor conferences: providers' perceptions of patients' need satisfaction and emotional experiences. *Psycho Oncol.* 2020;29(8):1263-1271. https://doi.org/10.1002/pon. 5413
- Heuser C, Diekmann A, Schellenberger B, et al. Patient participation in multidisciplinary tumor conferences from the providers' perspective: is it feasible in routine cancer care? *J Multidiscip Healthc.* 2020;13:1729-1739. https://doi.org/10.2147/JMDH.S28 3166
- Choy ET, Chiu A, Butow P, Young J, Spillane A. A pilot study to evaluate the impact of involving breast cancer patients in the multidisciplinary discussion of their disease and treatment plan. *Breast.* 2007; 16(2):178-189. https://doi.org/10.1016/j.breast.2006.10.002
- Schellenberger B, Heuser C, Diekmann A, et al. Questions and emotional expressions from patients and companions while participating in multidisciplinary tumor conferences in breast and gynecological cancer centers. *Patient Educ Counsel*. 2021;105(7): 2058-2066. https://doi.org/10.1016/j.pec.2021.12.010
- Scholl I, Zill JM, Härter M, Dirmaier J. An integrative model of patient-centeredness - a systematic review and concept analysis. PLOS ONE. 2014;9(9):e107828. https://doi.org/10.1371/journal. pone.0107828
- Stivers T, Enfield NJ. A coding scheme for question-response sequences in conversation. *J Pragmat*. 2010;42(10):2620-2626. https://doi.org/10.1016/j.pragma.2010.04.002
- Heuser C, Diekmann A, Ernstmann N, Ansmann L. Patient participation in multidisciplinary tumour conferences in breast cancer care (PINTU): a mixed-methods study protocol. *BMJ Open.* 2019;9(4): e024621. https://doi.org/10.1136/bmjopen-2018-024621
- Ommen O, Wirtz M, Janssen C, Neumann M, Ernstmann N, Pfaff H. Validation of a theory-based instrument measuring patient-reported psychosocial care by physicians using a multiple indicators and multiple causes model. *Patient Educ Counsel*. 2010;80(1):100-106. https://doi.org/10.1016/j.pec.2009.09.017
- Korsvold L, Mellblom AV, Lie HC, Ruud E, Loge JH, Finset A. Patient-provider communication about the emotional cues and concerns of adolescent and young adult patients and their family members when receiving a diagnosis of cancer. *Patient Educ Counsel*. 2016;99(10):1576-1583. https://doi.org/10.1016/j.pec.20 16.03.028
- Salmon P, Young B. The inseparability of emotional and instrumental care in cancer: towards a more powerful science of clinical communication. *Patient Educ Counsel*. 2017;100(11):2138-2140. https://doi.org/10.1016/j.pec.2017.05.019
- Ryan H, Schofield P, Cockburn J, et al. How to recognize and manage psychological distress in cancer patients. Eur J Cancer

1606 | SCHELLENBERGER ET AL.

- 38. Heath C, Hindmarsh J, Luff P. Video in Qualitative Research: Analysing Social Interaction in Everyday Life. SAGE Publications, Inc: 1 Oliver's Yard, 55 City Road London EC1Y 1SP; 2010.
- Del Piccolo L, Finset A, Mellblom AV, et al. Verona coding definitions of emotional sequences (VR-CoDES): conceptual framework and future directions. *Patient Educ Counsel*. 2017;100(12):2303-2311. https://doi.org/10.1016/j.pec.2017.06.026
- 40. Horlait M, Baes S, Dhaene S, van Belle S, Leys M. How multidisciplinary are multidisciplinary team meetings in cancer care? An observational study in oncology departments in Flanders,

Belgium. J Multidiscip Healthc. 2019;12:159-167. https://doi.org/ 10.2147/JMDH.S196660

How to cite this article: Schellenberger B, Heuser C, Diekmann A, et al. Patient participation in multidisciplinary tumor conferences in breast and gynecological cancer care: how patient-centered is the communication? *Psychooncology*. 2022;31(9):1597-1606. https://doi.org/10.1002/pon.5999

## 4. Discussion

The aim of this work was to gain insight into the communication and interaction in MTCs with patient participation. For this purpose, opportunities and limitations of SDM from the HCP perspective were presented on the one hand, and on the other hand, the communication was examined based on observation, audio recordings, and survey data. Through this approach, for the first time, the communication that takes place in the MTCs with patient participation was captured.

This work is based on two models, the throughput model (Pfaff and Schrappe 2011), which helps to classify the MTC as an object of study, and the six function model of medical communication (Haes and Bensing 2009), which can be used in the study of communication and the effectiveness of communication. The results showed that communication in case discussions in MTC with patient participation appears to serve specific functions, namely relationship building, information reception, information giving, decision making, and responding to emotions, at least in a limited way. HCPs reported that implementing SDM as part of person-centered communication in case discussions with patients in MTCs can be difficult (Bohmeier et al. 2021). Furthermore, it was shown that person-centered communication techniques tend to be used less in case discussions with patient participation in MTCs (Schellenberger et al. 2022 b). Thus, the potential of patient participation in individual case discussions to involve the patient actively is not realized. But this work has also shown that the MTC seems to be a place where patients have the opportunity to ask questions and express their emotions (Schellenberger et al. 2022 a). The communicative behavior of patients and HCPs was associated to input and throughput factors on the one hand but also to the outcome for patients on the other hand.

To date, it does not appear to be clarified which functions the communication with the patient in the case discussion should serve. Since multiple HCPs are involved in MTCs conversations, the functions should be important for the whole team to achieve the goals of the communication together. If person-centered communication is to take place in case discussions with patient participation, the question arises to what extent context factors, such

as the seating arrangement or the number of HCPs present, can be adjusted accordingly to facilitate person-centered communication and improve the outcome for the patient.

## 4.1 Limitations and Strengths

The present work has several limitations. First, all data are from a study examining MTCs in the context of care for patients with breast and/or gynecologic cancers and included only women, so these results cannot be generalized to other cancer entities or male patients with breast cancer or other cancers. In addition, the patient perspective was not considered in this work; i. e., it was not investigated which functions the communication in the MTC case discussions should have from the patient perspective and how patients experienced the MTC communication. Therefore, the object of investigation could not yet be fully covered. The presence of observers and technical equipment for recording may have been potentially confounding factors during data collection. To mitigate these, the research team visited hospitals and MTCs to explain the observation method (Heath et al. 2010). In addition, MTC members were familiarized with the presence of observers and technical equipment for recording through regular observations over an extended period of time. However, the results were generated by analyzing a variety of data—transcripts of HCP-interviews, observations, transcripts of audio recordings, and questionnaire data. This mixed-methods approach, i. e., the combination of qualitative and quantitative research methods, allowed for a better understanding of the object of study (O'Cathain et al. 2007). At the same time, the exploratory approach of the study, which provides an unbiased insight into the subject, is a major strength.

In addition, it is important to note that the data were collected in an environment that is constantly changing and evolving. The HCP interviews took place in 2018, and observations were conducted from 2018 until February 2020, so data collection was not affected by the COVID-19 pandemic. In conversations during the project, HCPs expressed that the format of the MTC changed with the onset of the pandemic: Patients initially did not participate at all, and HCPs met via videoconference. The extent to which MTCs have changed overall as a result of the pandemic, or how MTCs with patient participation currently proceed, is not known.

## 4.2 Implications

*Implications for research:* This work has used an exploratory approach to gain initial insights into communication in MTCs with patient participation. A larger sample size and a study in additional centers, also with other entities and male patients, would be necessary to investigate whether the initial evidence of the found phenomena and associations persist and/or whether additional associations emerge.

In particular, immediate and intermediate endpoints were examined using the six function model of medical communication (Haes and Bensing 2009). In terms of endpoints and functions, the model used offers many more opportunities to investigate the communication in MTCs with patient participation further. By examining communication in detail, it became apparent what functions case discussions with patient participation can serve in MTCs. However, which functions of medical communication should be fulfilled in MTCs with patient participation is still unclear. Only after clarifying which functions communication in MTCs should (primarily) have, HCPs could be trained in the targeted use of conversational techniques, and interventions could follow.

However, the model describes the functions more from the HCP perspective (Deledda et al. 2013). In research findings on the quality of communication from the patient perspective that use this model as a basis, the functions of giving information and fostering relationship are strongly represented (Bensing et al. 2013). Nevertheless, the extent to which medical communication should serve the same functions for patients as it does for HCPs would first need to be explored if the patient perspective is to be considered. It may be that the model would need to be adapted accordingly.

Practical implications: The goal of an MTC case discussion is to exchange information between the involved HCPs in order to make an evidence-based treatment recommendation. When patients participate in the case discussion, communication inevitably changes. A detailed look at the data helps provide initial recommendations about how to better achieve potential goals of communication in MTCs with patient participation. This work shows that patient participation in MTC case discussions can be beneficial because patients have the

opportunity to ask questions, express emotions, and contribute their preferences. Thus, HCPs could use patient presence to gather information as much as to build a trusting relationship. If cancer centers want to allow patients to participate in case discussion in the MTC, the goals of patient participation in case discussion should be clarified in advance, as well as the functions of the communication.

The present work offers insights into HCPs' assessment of SDM, into patient characteristics and context factors conducive to active patient participation, and into HCPs' responses to patient emotions associated with trust in the treatment team. When cancer centers support MTC patient participation, it should be considered that, in addition to context factors, HCPs' communicative behavior may also contribute to achieving specific goals. For example, the presence of a companion seems to support patients' active participation, as does the seating arrangement or the number of HCPs present. Furthermore, HCPs could consciously use conversational strategies such as backchanneling to strengthen the relationship.

In continuation, based on these results, research could develop a (communication) guide for MTCs with patient participation in order to continue to improve the care of patients with cancer.

## 4.3 References

Bensing J, Rimondini M, Visser A. What patients want. Patient Educ Couns. 2013;90(3):287–90. doi:10.1016/j.pec.2013.01.005

Bohmeier B, Schellenberger B, Diekmann A, Ernstmann N, Ansmann L, Heuser C. Opportunities and limitations of shared decision making in multidisciplinary tumor conferences with patient participation - A qualitative interview study with providers. Patient Educ Couns. 2021;104(4):792–9. doi:10.1016/j.pec.2020.09.007

Deledda G, Moretti F, Rimondini M, Zimmermann C. How patients want their doctor to communicate. A literature review on primary care patients' perspective. Patient Educ Couns. 2013;90(3):297–306. doi:10.1016/j.pec.2012.05.005

Haes H de, Bensing J. Endpoints in medical communication research, proposing a framework of functions and outcomes. Patient Educ Couns. 2009;74(3):287–94. doi:10.1016/j.pec.2008.12.006

Heath C, Hindmarsh J, Luff P. Video in Qualitative Research: Analysing Social Interaction in Everyday Life. London: Sage; 2010

O'Cathain A, Murphy E, Nicholl J. Why, and how, mixed methods research is undertaken in health services research in England: a mixed methods study. BMC Health Serv Res. 2007;7:85. doi:10.1186/1472-6963-7-85

Pfaff H, Schrappe M. Einführung in die Versorgungsforschung. In: Pfaff H, Neugebauer, E. A. M., Glaeske, G., Schrappe M, eds. Lehrbuch Versorgungsforschung: Systematik - Methodik - Anwendung. Stuttgart: Schattauer; 2011. p. 2–41

Schellenberger B, Heuser C, Diekmann A, Ansmann L, Krüger E, Schreiber L, et al. Patient participation in multidisciplinary tumor conferences in breast and gynecological cancer care: How patient-centered is the communication? Psychooncology 2022 b. doi:10.1002/pon.5999

Schellenberger B, Heuser C, Diekmann A, Ansmann L, Krüger E, Schreiber L, et al. Questions and emotional expressions from patients and companions while participating in multidisciplinary tumor conferences in breast and gynecological cancer centers. Patient Educ Couns. 2022 a;105(7):2058–66. doi:10.1016/j.pec.2021.12.010

# 5. Acknowledgements

My special thanks go to my supervisor, Prof. Dr. Nicole Ernstmann, who supported me throughout the entire period of my doctorate. Without her helpful suggestions, the regular exchange and her always open ear, this dissertation would not have been possible.

Furthermore, I would like to thank my second supervisor, Prof. Dr. Lena Ansmann, who has supported me on my way since my job interview for the PINTU project. Thanks especially for the feedback on the manuscript drafts.

I would like to thank the other committee members, Prof. Dr. Franziska Geiser and Prof. Dr. Ingo Schmidt-Wolf, for their support and participation in the publications as co-authors and for reviewing this dissertation.

Thanks should also go to the other co-authors of the publications, Dr. Annika Diekmann, Dr. Christian Heuser, Barbara Bohmeier, Emily Krüger, Leonie Schreiber, Dr. André Karger, Katrin Milz, Dr. Uwe Peisker, and Prof. Dr. Bernt Schnettler, for their cooperation and comments.

I am also grateful to my colleagues at the Center for Health Communication and Health Services Research, whom I could always turn to if I had any questions.

Many thanks to all participants of the PINTU project, as this project, which is the basis of this thesis, could not have taken place without their participation.

Finally, I thank my husband and my two children for the support they have given me.