

# **Individual and organizational determinants of patient participation in multidisciplinary tumor conferences**

Doctoral thesis

to obtain a doctorate (PhD)

from the Faculty of Medicine

of the University of Bonn

**Christian Heuser**

from Bonn

2021

Written with authorization of  
the Faculty of Medicine of the University of Bonn

First reviewer: Prof. Dr. Nicole Ernstmann

Second reviewer: Prof. Dr. Lena Ansmann

Day of oral examination: 25.06.2021

For the clinic and polyclinic for psychosomatic medicine and psychotherapy  
Director: Prof. Dr. Franziska Geiser

## Table of Contents

	<b>List of Abbreviations</b>	<b>4</b>
<b>1.</b>	<b>Abstract</b>	<b>5</b>
<b>2.</b>	<b>Introduction &amp; Aims</b>	<b>6</b>
	2.1 Oncological healthcare: current situation and background	6
	2.2 Theoretical background	7
	2.2.1 Medical sociology: individual and organizational determinants in healthcare	8
	2.2.2 Health services research: provision of healthcare services	8
	2.3 Empirical background: individual and organizational determinants of patient participation in multidisciplinary tumor conferences	9
	2.4 Aims	11
	2.5 References	11
<b>3.</b>	<b>Publications</b>	<b>15</b>
	3.1 Publication 1: Patient participation in multidisciplinary tumour conferences in breast cancer care (PINTU): a mixed-methods study protocol	16
	3.2 Publication 2: Health literacy and patient participation in multidisciplinary tumor conferences in breast cancer care: a multilevel modeling approach	24
	3.3 Publication 3: Participation in Multidisciplinary Tumor Conferences from the Providers' Perspective: Is It Feasible in Routine Cancer Care?	33
	3.4 Publication 4: How do breast cancer patients experience multidisciplinary tumor conferences? A description from the patient perspective	45
<b>4.</b>	<b>Discussion</b>	<b>53</b>
	4.1 Limitations and strengths	55
	4.2 Implications for research and practice	56
	4.3 References	57
<b>5.</b>	<b>Acknowledgements</b>	<b>59</b>

## List of Abbreviations

HL: Health literacy

HSR: Health services research

MCC: Multidisciplinary cancer care

MTC: Multidisciplinary tumor conference

MTCs: Multidisciplinary tumor conferences

MTCpp: Multidisciplinary tumor conference patient participation

PIAT: Strengthening patient competence: Breast cancer patients' information and training needs

PINTU: Patient involvement in multidisciplinary tumor conferences in breast cancer care – an exploratory study

## 1. Abstract

**Background:** Patient participation in multidisciplinary tumor conferences (MTCpp) is a new healthcare reality. Initial knowledge exists concerning risks and benefits for patients and providers. It is also known that MTCpp rates differ between cancer centers, but no details are available on which patient groups participate. In this context, the theories and models of medical sociology and health services research help to explain individual and organizational determinants in healthcare and the provision of healthcare services.

**Aims:** The aims of this cumulative dissertation are to analyze the use and determinants of MTCpp as well as to explore the provision of MTCpp. Thus, the four publications answer the following research questions: Which individual and organizational determinants of MTCpp can be explored? How do providers experience the feasibility and the provision of MTCpp? How do patients experience MTCpp?

**Methods:** Within the four publications, data from three different research projects conducted in Germany between 2013 and 2020 is used. (1) The study protocol describes the methodological principles of the mixed-methods research on MTCpp followed here. In the three following original publications, (2) multilevel logistic regression analysis of survey data from 863 patients and 43 breast cancer centers, (3) content analysis of 30 provider interviews with inductive and deductive coding, (4) and descriptive analysis and content analysis of survey data from 8893 patients and 86 centers have been performed.

**Results:** (1) After describing mixed-methods research on MTCpp, (2) the second publication revealed significant differences between patients participating in MTCs and between cancer centers themselves in MTCpp. (3) In the third publication, a mixed picture regarding providers' experiences fostering or hindering the provision of MTCpp in the respective cancer centers was found. These results help explain differences between cancer centers in MTCpp that were analyzed in the second publication. (4) In the fourth publication, a wide range of patient experiences concerning decision-making, communication, and their emotional and cognitive situation during participation were found. These results help explain differences found in MTCpp between patient groups in the second publication.

**Discussion & conclusion:** Using the throughput model, individual and organizational determinants for behavior, such as the use of MTCpp and the providers' and patients' experiences regarding the provision and use of the healthcare service MTCpp, were analyzed. Future research should focus on immediate, intermediate, and long-term outcomes by studying a wide range of psychosocial and medical outcomes of MTCpp. In terms of healthcare practice, an update of certification catalogs might be discussed if findings of an interventional phase-III study define risks and benefits associated with MTCpp.

## 2. Introduction & aims

### 2.1. Oncological healthcare: current situation and background

Oncological healthcare is a complex field due to increasing diagnostic and treatment options and a holistic treatment approach in cancer care (Rabinowitz 2004). Higher patient survival rates also create new challenges that can be met only by a multidisciplinary team. Consequently, multidisciplinary cancer care (MCC) is an important element of modern cancer care worldwide (Tattersall 2006) and one of the central certification criteria for German certified cancer centers. Cancer centers specialize in a specific cancer entity, e.g. breast or gynecological tumors, which are of special interest in this dissertation. MCC ensures the collaboration of relevant professionals from different disciplines in an effort to support patients through their cancer treatment. MCC is multifactorial and involves a number of characteristics, including increased coordination of care, better communication between health care providers, comprehensive and integrated treatment decisions, cost reduction, enhanced access to clinical trials, improved patient satisfaction, and higher survival rates (Chang et al. 2001; Hahlweg et al. 2017; Houssami and Sainsbury 2006; Prades et al. 2015). For many years, cancer patients in Germany have been treated in centers implementing MCC.

MCC has mainly been implemented through multidisciplinary tumor conferences (MTCs), which are a central instrument of MCC and have been internationally established (Wright et al. 2007). MTCs are regular weekly meetings of a multidisciplinary treatment team in which the diagnosis and treatment recommendations of cancer patients are discussed. In Germany, two different certification programs exist for cancer centers: one from the German Cancer Society (Germany-wide) and another from the Medical Association of Westphalia-Lippe (for the state of North Rhine-Westphalia) (Ärzttekammer Westfalen-Lippe 2020; Deutsche Krebsgesellschaft 2020). Both certification catalogs require MTCs and regulate the attendance of specific medical and nursing professions (Haier 2016). Evidence is available on the benefits of MTCs for treatment decision-making and treatment outcomes (Choy et al. 2007; Croke and El-Sayed 2012; Wright et al. 2007). Hence, MTCs are widely valued by healthcare providers and patients (Butow et al. 2007; Devitt et al. 2010; Harrison et al. 2008; Komatsu et al. 2011; Morement et al. 2017).

Current international research on MTCs focuses on the questions of whether and how patient-centeredness is achieved. Research has shown that the consideration of patient preferences differs significantly between MTCs and that treatment recommendations are mainly made on the basis of clinical information (Hahlweg et al. 2017; Taylor et al. 2012). At the same time, studies examining aspects of patient-centered care have revealed that giving patients access to healthcare services and involving patients and their preferences in processes can have positive effects for patients (Hubbard et al. 2008; Scholl et al. 2014). For example, the consideration of patient preferences in MTCs can lead to better patient outcomes, e.g. a higher quality of life (Street et al. 2012). Treatment recommendations from MTCs that take patient preferences, patient information and the patient's health status into account are more likely to be implemented because they are more acceptable to patients (Lamb et al. 2013; Raine et al. 2014; Taylor et al. 2014). In addition, adherence to MTC recommendations decreases significantly if patient information and preferences are incorrect or unknown (Hollunder et al. 2018).

In an effort to ensure the consideration of individual patient information and preferences, the participation of patients in MTCs has been discussed nationally and internationally for about ten years, but this has been done only sporadically and not in the form of a systematic research project investigating all relevant perspectives. In Germany, MTC patient participation (MTCpp) is allowed if patients wish to attend, regardless of the cancer center's certification program. Patient participation is explicitly incorporated in the requirements catalog of the Medical Association Westphalia-Lippe. Although access to MTCs is potentially offered to all patients, there is no knowledge on the provision and actual use of the healthcare service of MTCpp.

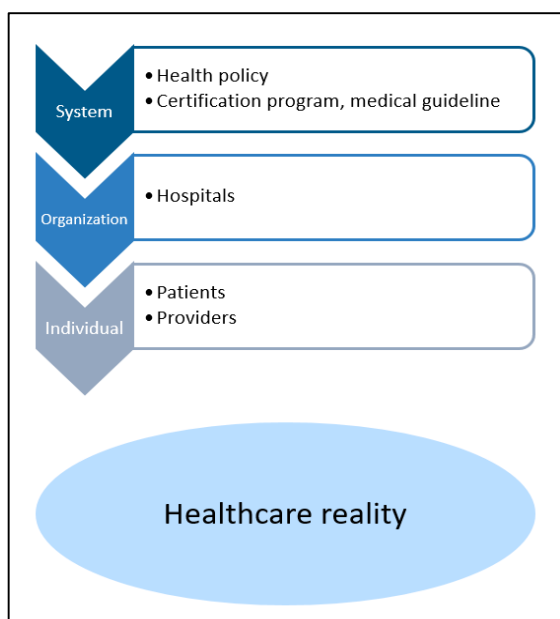
## 2.2. Theoretical background

In this context, the theories and models of medical sociology and health services research help to explain individual and organizational determinants in healthcare as well as the use and provision of healthcare services.

### 2.2.1. Medical sociology: individual and organizational determinants in healthcare

Medical sociology analyzes either the social determinants of the development and course of diseases (social epidemiology) or the social determinants of the structure and function of the healthcare system and their use by patients as well as the provision of healthcare (health services research) (Faller and Lang 2010; Knesebeck et al. 2009; Siegrist 2005). Social determinants can be located at different levels of the healthcare system, as shown by the macro-meso-micro model (Figure 1) (Mielck 2005).

**Figure 1: Macro-meso-micro model**



System-level characteristics (macro level) influence the healthcare reality through health policies and regulations, e.g. certification programs. Organization-level characteristics (meso level) influence the healthcare reality through hospital characteristics like ownership form or teaching status. Individual-level characteristics (micro level) influence the healthcare reality through patient and provider characteristics and their communication with each other.

### 2.2.2. Health services research: the provision of healthcare services

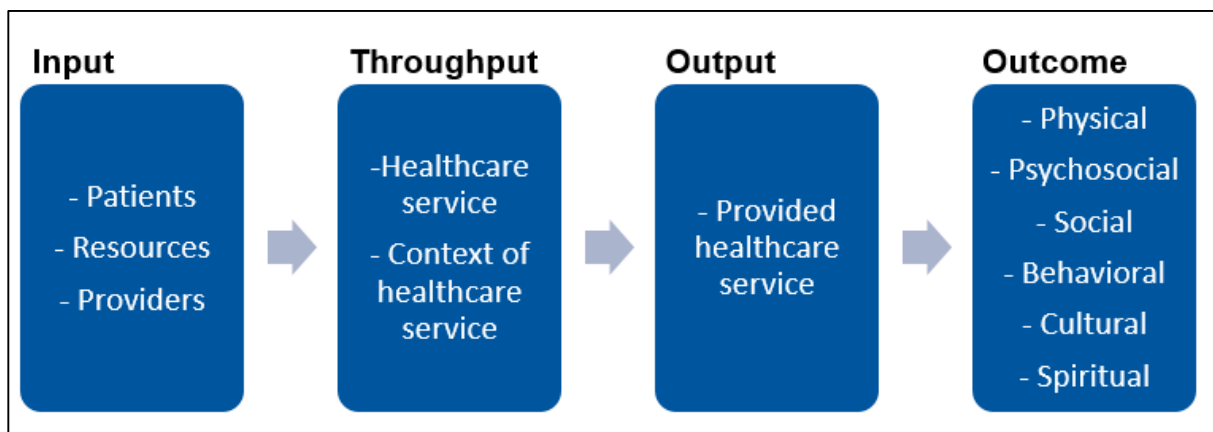
To answer the questions concerning MTCpp, the second research field concerned with social determinants of the structure and function of the healthcare system (health services research, HSR), helps model the healthcare reality of MTCpp. In HSR models as well as in this study, the focus of analysis is on the providers' and patients' experiences regarding the provision and use of the healthcare service of MTCpp. Furthermore, individual and organizational determinants of behavior, such as the use of MTCpp, can be analyzed. The use of these models makes it necessary to take a closer look at the above-mentioned field of HSR, which is defined by Pfaff et al. as



*“...an interdisciplinary research field that examines structures and processes of healthcare provision, with special emphasis on the patient and population perspective, focusing on the appropriateness of treatment, the improvement of care and the complexity of context and intervention.” (Pfaff et al. 2011).*

According to this definition, a core element is the examination of healthcare services under everyday conditions. For a systematic investigation of a healthcare service like an MTC, the theoretical framework of the **throughput model** from Pfaff et al. (Figure 2) was used (Pfaff et al. 2011). Accordingly, HSR focuses on the following: (1) the exploration of patient characteristics, resources for providing health services and the characteristics of providers (input); (2) healthcare services and their context, such as the provider-patient relationship or the process organization (throughput); (3) the provided healthcare service (output); and (4) the resulting physical, psychological or social outcomes (outcome).

**Figure 2: Throughput model**



Adapted from Pfaff et al. 2011 (Pfaff et al. 2011).<sup>1</sup>

### 2.3. Empirical background: individual and organizational determinants of patient participation in multidisciplinary tumor conferences

Since patients rarely participate in MTCs, few studies have investigated the advantages and disadvantages of MTCpp (Komatsu et al. 2011; Taylor et al. 2013; Vahdat et al. 2014). Thus, there is only initial evidence showing that patient participation is associated with

<sup>1</sup> The author is aware that there is a revised model from 2017 (2<sup>nd</sup> edition). However, reference is made to the original model of 2011 (1<sup>st</sup> edition), as it more clearly conceptualizes the theoretical foundations used in this doctoral thesis.

stronger involvement in decision-making and more satisfactory outcomes due to potentially improved variables such as treatment adherence and patient satisfaction (Dew et al. 2015; Taylor et al. 2010). Further benefits for patients can be improved understanding of the diagnosis and treatment as well as patient empowerment (Choy et al. 2007). However, authors also point out risks for patients, such as uncertainty and anxiety. Among the benefits from the providers' point of view, support in recommendation development and better patient-provider communication have been mentioned (Butow et al. 2007). In addition, the discussion of high-risk treatment options seems to contribute to their professional self-image (Salloch et al. 2014). As possible challenges for providers, the longer duration of MTCs, the need to adjust to lay language, and the discussion being restrained in the presence of patients have been discussed (Devitt et al. 2010).

In summary, initial hypotheses regarding the risks and benefits of MTCpp are available from international research, but none of these studies have systematically examined MTCpp. It is unknown which patient groups participate and which factors might determine participation. Only one study suggests that patient participation varies by patient characteristics and between the breast cancer centers themselves (Ansmann et al. 2014), but no explanations for the variation by individual and cancer center characteristics are available. None of these initial insights in this research field have been confirmed by rigorous observational studies. No knowledge is available on individual and organizational determinants of MTCpp in the international context and on patients' and providers' experiences with the provision and use of MTCpp in the German context.

Therefore, in this cumulative dissertation, the above-described HSR model is used to close the mentioned gaps in research and gain knowledge on the individual and organizational determinants as well as patients' and providers' experiences with the provision and use of MTCpp. As research on MTCpp is multidimensional and requires the use and combination of different (quantitative and qualitative) methods and data, a mixed-methods approach is followed here (O'Cathain et al. 2010). The combination of the described theoretical, methodological and empirical background is presented in Table 1.

**Table 1: Combination of theoretical, methodological and empirical background**

<b>Gap in research</b>	<b>HSR model</b>	<b>Study in this dissertation</b>	<b>Publication</b>
Mixed-methods research on MTCpp	-	PINTU (2017-2020)	Publication 1: study protocol
Individual patient and organizational center determinants of MTCpp	Input: patient and provider characteristics	PIAT (2013-2014)	Publication 2: original publication
Providers' perceived feasibility and required context of MTCpp	Throughput: provision of healthcare services and their context	PINTU (2017-2020)	Publication 3: original publication
Patient experiences in MTCs	Input and throughput: use and patient experiences	Annual patient survey in breast centers (2015-2016)	Publication 4: original publication

#### 2.4. Aims

The presented theories and models from medical sociology and health services research seem to help explain determinants of healthcare reality and perspectives in the use and provision of healthcare services. This cumulative dissertation aims to analyze the use and determinants of MTCpp (input) and explore the provision and required context of MTCpp (throughput). Following this, the four publications answer the following research questions: Which individual and organizational determinants of MTCpp can be explored? How do providers experience the feasibility and required context of the provision of MTCpp? How do patients experience MTCpp?

#### 2.5. References

- Ansmann, L., Kowalski, C., Pfaff, H., Wuerstlein, R., Wirtz, M. A. & Ernstmann, N. (2014). Patient participation in multidisciplinary tumor conferences. *Breast* 23 (6), 865–869. doi:10.1016/j.breast.2014.09.004
- Ärzttekammer Westfalen-Lippe. (2020). Certification of breast cancer centers in North-Rhine Westphalia. Requirement catalogue breast cancer centers. [Verfahren zur Zertifizierung von Brustzentren in NRW. Anforderungskatalog-Brustzentren].

[https://www.aekwl.de/fileadmin/user\\_upload/aekwl/aekzert/Anforderungskatalog\\_fuer\\_Brustzentren\\_NRW.pdf](https://www.aekwl.de/fileadmin/user_upload/aekwl/aekzert/Anforderungskatalog_fuer_Brustzentren_NRW.pdf). Zugegriffen: 13. Januar 2021

- Butow, P., Harrison, J. D., Choy, E. T., Young, J. M., Spillane, A. & Evans, A. (2007). Health professional and consumer views on involving breast cancer patients in the multidisciplinary discussion of their disease and treatment plan. *Cancer* 110 (9), 1937–1944. doi:10.1002/cncr.23007
- Chang, J. H., Vines, E., Bertsch, H., Fraker, D. L., Czerniecki, B. J., Rosato, E. F., Lawton, T., Conant, E. F., Orel, S. G., Schuchter, L., Fox, K. R., Zieber, N., Glick, J. H. & Solin, L. J. (2001). The impact of a multidisciplinary breast cancer center on recommendations for patient management. *Cancer* 91 (7), 1231–1237
- Choy, E. T., Chiu, A., Butow, P., Young, J. & Spillane, A. (2007). A pilot study to evaluate the impact of involving breast cancer patients in the multidisciplinary discussion of their disease and treatment plan. *Breast* 16 (2), 178–189. doi:10.1016/j.breast.2006.10.002
- Croke, J. M. & El-Sayed, S. (2012). Multidisciplinary management of cancer patients. Chasing a shadow or real value? An overview of the literature. *Current Oncology* 19 (4), 232–238. <http://currentoncology.com/index.php/oncology/article/download/944/953>
- Deutsche Krebsgesellschaft. (2020). S3-Guideline for the Early Detection, Diagnosis, Therapy and Follow-up of Breast Cancer (Version 4.3) [S3-Leitlinie Früherkennung, Diagnostik, Therapie und Nachsorge des Mammakarzinoms (Version 4.3)]. [https://www.leitlinienprogramm-onkologie.de/fileadmin/user\\_upload/Downloads/Leitlinien/Mammakarzinom\\_4\\_0/Version\\_4.3/LL\\_Mammakarzinom\\_Langversion\\_4.3.pdf](https://www.leitlinienprogramm-onkologie.de/fileadmin/user_upload/Downloads/Leitlinien/Mammakarzinom_4_0/Version_4.3/LL_Mammakarzinom_Langversion_4.3.pdf). Zugegriffen: 13. Januar 2021
- Devitt, B., Philip, J. & McLachlan, S.-A. (2010). Team dynamics, decision making, and attitudes toward multidisciplinary cancer meetings. Health professionals' perspectives. *Journal of oncology practice* 6 (6), e17-20. doi:10.1200/JOP.2010.000023
- Dew, K., Stubbe, M., Signal, L., Stairmand, J., Dennett, E., Koea, J., Simpson, A., Sarfati, D., Cunningham, C., Batten, L., Ellison-Loschmann, L., Barton, J. & Holdaway, M. (2015). Cancer care decision making in multidisciplinary meetings. *Qualitative health research* 25 (3), 397–407. doi:10.1177/1049732314553010
- Faller, H. & Lang, H. (2010). *Medical Psychology and Sociology [Medizinische Psychologie und Soziologie]* (Springer-Lehrbuch, 3., vollständig neu bearbeitete Auflage). Berlin, Heidelberg: Springer-Verlag Berlin Heidelberg
- Hahlweg, P., Didi, S., Kriston, L., Härter, M., Nestoriuc, Y. & Scholl, I. (2017). Process quality of decision-making in multidisciplinary cancer team meetings. A structured observational study. *BMC cancer* 17 (1), 772. doi:10.1186/s12885-017-3768-5
- Haier, J. (2016). Tasks and limits of tumor conferences [Aufgaben und Grenzen von Tumorkonferenzen]. *Der Onkologe* 22 (3), 184–191. doi:10.1007/s00761-015-2939-8
- Harrison, J. D., Choy, E. T., Spillane, A., Butow, P., Young, J. M. & Evans, A. (2008). Australian breast cancer specialists' involvement in multidisciplinary treatment planning meetings. *The Breast* 17 (4), 335–340. doi:10.1016/j.breast.2008.03.001
- Hollunder, S., Herrlinger, U., Zipfel, M., Schmolders, J., Janzen, V., Thiesler, T., Güresir, E., Schröck, A., Far, F., Pietsch, T., Pantelis, D., Thomas, D., Vornholt, S., Ernstmann,

- N., Manser, T., Neumann, M., Funke, B. & Schmidt-Wolf, I. G. H. (2018). Cross-sectional increase of adherence to multidisciplinary tumor board decisions. *BMC cancer* 18 (1), 936. doi:10.1186/s12885-018-4841-4
- Houssami, N. & Sainsbury, R. (2006). Breast cancer. Multidisciplinary care and clinical outcomes. *European Journal of Cancer* 42 (15), 2480–2491. doi:10.1016/j.ejca.2006.05.023
- Hubbard, G., Kidd, L. & Donaghy, E. (2008). Preferences for involvement in treatment decision making of patients with cancer. A review of the literature. *European Journal of Oncology Nursing* 12 (4), 299–318. doi:10.1016/j.ejon.2008.03.004
- Knesebeck, O. v. d., Bauer, U., Geyer, S. & Mielck, A. (2009). Social inequalities in health care - A plea for systematic research. [Soziale Ungleichheit in der gesundheitlichen Versorgung - Ein Plädoyer für systematische Forschung]. *Das Gesundheitswesen* 71 (2), 59-64. doi:10.1055/s-0028-1119371
- Komatsu, H., Nakayama, K., Togari, T., Suzuki, K., Hayashi, N., Murakami, Y., Iioka, Y., Osaka, W., Yagasaki, K., Nakamura, S., Neumann, J. & Ueno, N. T. (2011). Information Sharing and Case Conference Among the Multidisciplinary Team Improve Patients' Perceptions of Care. *The Open Nursing Journal* 5 (1), 79–85
- Lamb, B. W., Taylor, C., Lamb, J. N., Strickland, S. L., Vincent, C., Green, J. S. A. & Sevdalis, N. (2013). Facilitators and barriers to teamworking and patient centeredness in multidisciplinary cancer teams. Findings of a national study. *Annals of surgical oncology* 20 (5), 1408–1416. doi:10.1245/s10434-012-2676-9
- Mielck, A. (2005). *Social Inequality and Health - Introduction to the Current Discussion*. [Soziale Ungleichheit und Gesundheit - Einführung in die aktuelle Diskussion] (1. Auflage). Bern: Verlag Hans Huber
- Morement, H., Harrison, R. & Taylor-Robinson, S. D. (2017). The multidisciplinary team meeting in the UK from the patients' perspective. Comments and observations from cholangiocarcinoma patients and their families. *International Journal of General Medicine* 10, 305–310. doi:10.2147/IJGM.S145029
- O'Cathain, A., Murphy, E. & Nicholl, J. (2010). Three techniques for integrating data in mixed methods studies. *BMJ (Clinical research ed.)* 341, c4587. doi:10.1136/bmj.c4587
- Pfaff, H., Neugebauer, E. A. M., Glaeske, G. & Schrappe, M. (Hrsg.). (2011). *Health Services Research. Systematics - Methodology - Application*. [Lehrbuch Versorgungsforschung. Systematik - Methodik - Anwendung]. Stuttgart: Schattauer
- Prades, J., Remue, E., van Hoof, E. & Borrás, J. M. (2015). 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 (Amsterdam, Netherlands)* 119 (4), 464–474. doi:10.1016/j.healthpol.2014.09.006
- Rabinowitz, B. (2004). Interdisciplinary breast cancer care. Declaring and improving the standard. *Oncology (Williston Park, N.Y.)* 18 (10), 1263-1270
- Raine, R., Wallace, I., Nic a' Bhaird, C., Xanthopoulou, P., Lanceley, A., Clarke, A., Prentice, A., Ardron, D., Harris, M., Gibbs, J. S. R., Ferlie, E., King, M., Blazeby, J. M.,

- Michie, S., Livingston, G. & Barber, J. (2014). Improving the effectiveness of multidisciplinary team meetings for patients with chronic diseases: a prospective observational study. *Health Services and Delivery Research* 37 (2). doi:10.3310/hsdr02370
- Salloch, S., Ritter, P., Wascher, S., Vollmann, J. & Schildmann, J. (2014). Medical expertise and patient involvement. A multiperspective qualitative observation study of the patient's role in oncological decision making. *The oncologist* 19 (6), 654–660. doi:10.1634/theoncologist.2013-0268
- Scholl, I., Zill, J. M., Härter, M. & Dirmaier, J. (2014). An integrative model of patient-centeredness - a systematic review and concept analysis. *PloS one* 9 (9), e107828. doi:10.1371/journal.pone.0107828
- Siegrist, J. (2005). *Medical Sociology [Medizinische Soziologie]* (6. Aufl.). München: Elsevier Urban & Fischer
- Street, R. L., Elwyn, G. & Epstein, R. M. (2012). Patient preferences and healthcare outcomes. An ecological perspective. *Expert Review of Pharmacoeconomics & Outcomes Research* 12 (2), 167–180. doi:10.1586/erp.12.3
- Tattersall, M. H. N. (2006). Multidisciplinary team meetings. Where is the value? *The Lancet Oncology* 7 (11), 886–888. doi:10.1016/S1470-2045(06)70916-0
- Taylor, C., Atkins, L., Richardson, A., Tarrant, R. & Ramirez, A.-J. (2012). Measuring the quality of MDT working. An observational approach. *BMC cancer* 12, 202. doi:10.1186/1471-2407-12-202
- Taylor, C., Finnegan-John, J. & Green, J. S. A. (2014). "No decision about me without me" in the context of cancer multidisciplinary team meetings. A qualitative interview study. *BMC health services research* 14, 488. doi:10.1186/s12913-014-0488-2
- Taylor, C., Munro, A. J., Glynne-Jones, R., Griffith, C., Trevatt, P., Richards, M. & Ramirez, A. J. (2010). Multidisciplinary team working in cancer. What is the evidence? *BMJ (Clinical research ed.)* 340, c951. doi:10.1136/bmj.c951
- Taylor, C., Shewbridge, A., Harris, J. & Green, J. S. (2013). Benefits of multidisciplinary teamwork in the management of breast cancer. *Breast cancer (Dove Medical Press)* 5, 79–85. doi:10.2147/BCTT.S35581
- Vahdat, S., Hamzehgardeshi, L., Hessam, S. & Hamzehgardeshi, Z. (2014). Patient involvement in health care decision making. A review. *Iranian Red Crescent medical journal* 16 (1), e12454. doi:10.5812/ircmj.12454
- Wright, F. C., Vito, C. de, Langer, B. & Hunter, A. (2007). Multidisciplinary cancer conferences. A systematic review and development of practice standards. *European Journal of Cancer* 43 (6), 1002–1010. doi:10.1016/j.ejca.2007.01.025

### **3. Publications**

This cumulative dissertation comprises one study protocol and three original articles published in international peer-reviewed journals indexed in Web of Science.

(1) The study protocol describes the methodological principles of the mixed-methods research on MTCpp (Heuser et al. 2019a). As research on MTCpp is multidimensional and requires the use and combination of different (quantitative and qualitative) methods and data, a mixed-methods approach is followed here.

(2) In the second publication, data from a standardized nationwide postal survey of 863 breast cancer patients and 43 centers in Germany was used. The survey was part of the larger PIAT study. A multilevel logistic regression analysis of patient and center data was performed in order to explore individual and organizational determinants of MTCpp (Heuser et al. 2019b).

(3) In the third publication, semi-structured, cross-sectional interview data from 30 providers in six breast and gynecological cancer centers in North-Rhine Westphalia were analyzed. Inductive and deductive content analysis was performed to explore feasibility and context factors of MTCpp (Heuser et al. 2020). In this publication the reasons for the significant organizational differences (see publication 2) and the fostering or hindering required context of MTCpp were analyzed. The data was part of the larger PINTU study (Heuser et al. 2019a).

(4) In the fourth publication, a descriptive quantitative analysis and a qualitative content analysis of open-ended questions from an annual postal survey of 8893 breast cancer patients in North Rhine Westphalia were performed. Patients' experiences and their possible reasons for (non)participation in MTCs were examined (Diekmann et al. 2019) as this might help explaining differences found in MTCpp between patient groups in the second publication.

3.1. Publication 1: Patient participation in multidisciplinary tumour conferences in breast cancer care (PINTU): a mixed-methods study protocol

**Heuser, C.**, Diekmann, A., Ernstmann, N. & Ansmann, L. (2019a). Patient participation in multidisciplinary tumour conferences in breast cancer care (PINTU): a mixed-methods study protocol. *BMJ open* 9 (4), e024621. doi:10.1136/bmjopen-2018-024621. Impact Factor: 2,496 (2019).



# BMJ Open Patient participation in multidisciplinary tumour conferences in breast cancer care (PINTU): a mixed-methods study protocol

Christian Heuser,<sup>1,2</sup> Annika Diekmann,<sup>1,2</sup> Nicole Ernstmann,<sup>1,2</sup> Lena Ansmann<sup>3,4</sup>

**To cite:** Heuser C, Diekmann A, Ernstmann N, *et al*. Patient participation in multidisciplinary tumour conferences in breast cancer care (PINTU): a mixed-methods study protocol. *BMJ Open* 2019;**9**:e024621. doi:10.1136/bmjopen-2018-024621

► Prepublication history for this paper is available online. To view these files, please visit the journal online (<http://dx.doi.org/10.1136/bmjopen-2018-024621>).

Received 12 June 2018  
Revised 21 January 2019  
Accepted 13 March 2019



© Author(s) (or their employer(s)) 2019. Re-use permitted under CC BY-NC. No commercial re-use. See rights and permissions. Published by BMJ.

For numbered affiliations see end of article.

## Correspondence to

Mr Christian Heuser;  
[christian.heuser@ukbonn.de](mailto:christian.heuser@ukbonn.de)

## ABSTRACT

**Introduction** A central instrument of multidisciplinary care is the multidisciplinary tumour conference (MTC). In MTCs, diagnosis and treatment of cancer patients are discussed, and therapy recommendations are worked out. As we found previously, patients participate in MTCs in some breast cancer centres in the state of North Rhine-Westphalia, Germany. However, studies on risks and benefits of patient participation have not provided substantiated findings. Therefore, the study's objective is to analyse differences between MTCs with and without patient participation.

**Methods and analysis** This is an exploratory mixed-methods study. MTCs in six breast and gynaecological cancer centres in North Rhine-Westphalia, Germany, are examined. MTCs will be conducted with and without patient participation. First, interviews with providers concentrating on the feasibility of patient participation and quality of decision-making will be carried out, transcribed and analysed by means of content analysis. Second, videotaped or audiotaped participatory observations in MTCs will be executed. Video data or transcribed audio data from video and audio recordings will be coded using the established "Observational Assessment Rating Scale" for MTCs and analysed by comparing centres with and without patient participation. Third, all patients will fill out a questionnaire before and after MTC, including questions on psychosocial situation, decision-making and expectations before and experiences after MTC. The questionnaire data will be analysed by means of descriptive and multivariate statistics and pre-post-differences within and between groups.

**Ethics and dissemination** Consultation and a positive vote from the ethics committee of the Medical Faculty of the University of Cologne have been obtained. For all collected data, relevant data protection regulations will be adhered to. All personal identifiers from patients and providers will be pseudonymised, except video recordings. Dissemination strategies include a discussion with patients and providers in workshops about topics such as feasibility, risks and benefits of patient participation in MTCs.

**Trial registration number** DRKS00012552.

## INTRODUCTION

Many developments in oncological healthcare have taken place over recent years: among them multidisciplinary care and patient-centred care. In oncology, multidisciplinary

## Strengths and limitations of this study

- One of the first studies on patient participation in multidisciplinary tumour conferences (MTCs).
- Mixed-methods study triangulating qualitative interviews of healthcare providers (eg, organisational aspects of MTCs), qualitative observations of MTCs (eg, decision-making) and a quantitative survey of patients with and without patient participation (eg, individual psychosocial situation, needs and experiences).
- Observational design with potential methodological problems like Hawthorne effect and observer-expectancy bias.
- Future research on this topic would benefit from interviews with patients and a survey with providers as well as an interventional study design.
- Limited number of breast and gynaecological cancer centres and surveyed patients, but detailed analyses.

care is implemented in the form of multidisciplinary tumour conferences (MTCs) as a central instrument of treatment decision-making.<sup>1</sup> MTCs are defined as regular meetings of a multidisciplinary team in which the diagnosis and treatment of cancer patients are discussed. In Germany, MTCs are widely established and are required by accreditation programmes for cancer centres.<sup>2,3</sup> Usually, patients do not participate in MTCs.

The international research on MTCs without patient participation reveals that treatment decisions are often made without considering patient information and preferences.<sup>4-7</sup> Therapy recommendations in MTCs are in fact often developed solely on the basis of clinical information. However, the need for further discussions and conversations with the patients and their relatives is one of the most common reasons for postponing decisions in the MTC.<sup>8,9</sup> Patient preferences are not considered comprehensively in MTCs although in



many MTCs, patients are supposedly represented by nurses or by the patients' most frequently attending doctor.<sup>9 10</sup> Furthermore, studies prove that MTC recommendations which consider patient information and preferences (health condition, comorbidity) are more likely to be implemented, as they are clinically more appropriate and accepted by the patients.<sup>11</sup> In addition, for decision-making processes in different oncological contexts, observations in a large German university hospital demonstrate that patient preferences might be better included in decision-making if patients are present during the process of developing recommendations.<sup>12</sup>

But so far, very few studies on patient participation in MTCs exist, not least because it is seldom practised in healthcare. Until now, only a few publications have explored the attitudes of patients and other MTC participants with regard to patient participation.<sup>13–15</sup> As potential benefits for patients, a better understanding of diagnosis and treatment, stronger involvement in decision-making, patient empowerment and better treatment adherence and confidence have been named. But authors also point out risks, such as uncertainty, excessive burden and anxiety. Among the benefits from the providers' point of view (eg, physicians, psycho-oncologists, nurses), the support in recommendation development and better patient-physician communication have been mentioned. The possible disadvantages or challenges discussed are the longer duration of MTCs, the need to adjust to lay language and the discussion being restrained in the presence of patients. However, these assumptions have not been proven in rigorous observational studies.

It still remains unclear how patient participation changes the organisation, interaction and decision-making in MTCs. Especially the question whether patient participation is feasible and which benefits and risks the patients and providers can expect seems to be relevant.

### Aims of the study

In our study 'Patient Participation in Multidisciplinary Tumour Conferences in Breast Cancer Care' (PINTU), information about the organisation of and interaction in MTCs with and without patient participation will be generated and the perspectives and experiences of participating patients and providers will be revealed. We aim to answer the following research questions: (1) How do the providers participating in MTCs perceive the participation of patients in the MTC with regard to the feasibility of participation and the quality of decision-making? (2) How do MTCs with and without patient participation differ with regard to organisation, interaction and patient orientation? (3) How do patients experience the participation and what direct cognitive and emotional effects does the participation have on the patients?

## METHODS AND ANALYSIS

### Study design

PINTU is a multicentre non-interventional study using a mixed-methods approach. The combination of qualitative and quantitative research methods and the use of mixed-methods study designs can frequently be observed in health services research.<sup>16–19</sup> Since a mixed-methods study approach combines elements of quantitative and qualitative scientific theory and methodology, new opportunities arise for using and combining sources of data, leading to new findings in social sciences and therefore also in health services research.<sup>20</sup> In addition to the theoretical benefits of combining methods,<sup>21</sup> there are relevant practical implications for this study:

- ▶ Information from quantitative data might not be identified in qualitative data and vice versa.
- ▶ Non-sampling errors might be reduced since data from different sources are used (eg, interview and observation).
- ▶ Common method bias (eg, resulting from only using self-reported items in questionnaires) might be reduced.

As combining both approaches is the key element of mixed-methods studies, but their execution and reporting has not been finally clarified,<sup>22 23</sup> we will use the well-described triangulation technique from O' Cathain *et al.*<sup>24</sup>

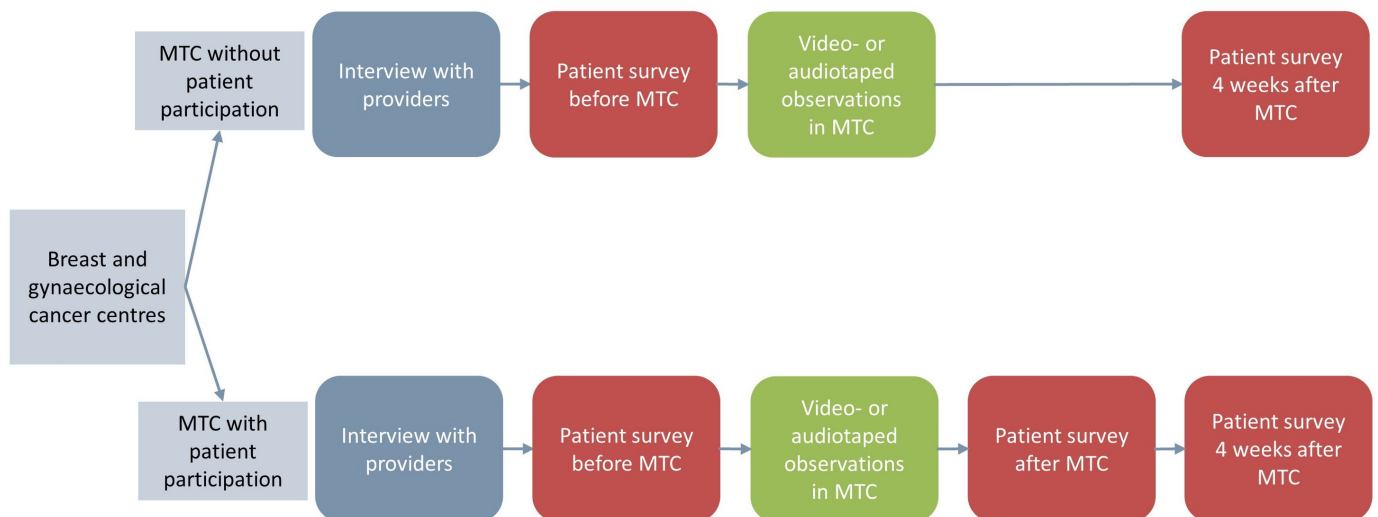
The mixed-methods design of our study (see figure 1) includes, in the qualitative part, (a) an interview invitation to providers participating in MTCs and (b) participatory observations in MTCs with and without patient participation, which are videotaped or audiotaped. In the quantitative part of the study, (c) a standardised questionnaire will be given to all patients—MTC participants and non-participants alike—before and after the MTC.

### Sample

The study is conducted in breast and gynaecological cancer centres in North Rhine-Westphalia, Germany, the most populous German state. Study hospitals were selected following purposeful sampling criteria,<sup>25</sup> varying the size of the centre (case volume) and the teaching status (teaching hospital vs non-teaching hospital). These centre structures can have an impact on the organisation of MTCs because in larger breast and gynaecological cancer centres, more cases are discussed, and in teaching hospitals, more employees, especially assistant doctors, participate in MTCs.<sup>26</sup>

Inclusion criterion for providers is frequent participation in MTCs. With regard to the above-mentioned purposeful sampling, participants shall represent a large variety of disciplines (medical, nursing, psychological) involved in the MTCs.

The inclusion criteria for participating patients are a minimum age of 18 years, at least one breast or gynaecological cancer diagnosis (C50.xx - C58.xx, D05.xx - D07.xx), sufficient German language skills to understand the written informed consent and the survey questions and the physical, psychological and cognitive ability to



**Figure 1** PINTU mixed-methods study design. MTC, multidisciplinary tumour conference; PINTU, Patient participation in multidisciplinary tumour conferences in breast cancer care - an exploratory study.

participate. An average of 10 discussed patients per MTC meeting can be expected (n=180 patients in total).<sup>12</sup> Three MTC meetings will be studied in each of the three breast and gynaecological cancer centres that do not invite any patients to MTCs (n=90 non-participating patients). Three MTCs will be analysed in each of the three breast and gynaecological cancer centres where patients are invited to the MTCs (n=90 participating patients). If less than 90 patients participate in the MTCs, more observations will be conducted.

### Recruitment

The recruitment of the breast and gynaecological cancer centres was started with the aid of the search engine Oncomap. From our former studies, we were able to identify suitable breast and gynaecological cancer centres where some patients participate in MTCs.<sup>27 28</sup> Next, the managers of the centres (usually chief physicians) will be contacted, and the research team will personally introduce the study at the centres. The staff council in the centres will be informed about the research project. All participating providers in the MTCs and all participating and non-participating patients will be informed in written and oral form about the purpose, conduct and data protection aspects of the study.

### Interviews

To capture the perspective of different providers, approximately five interviews will be conducted in each of the six breast and gynaecological cancer centres (n=30). Therefore, different providers (eg, oncology, gynaecology/senology, radiotherapy, psycho-oncology and nursing) will be selected to gain a comprehensive perspective on MTCs in each centre. The purposeful sampling strategy aims at including all professional groups and different hierarchical levels involved in MTCs in breast and gynaecological cancer centres. The interviews with providers

will take place a few weeks before the participatory observation of the MTCs.

### Participatory observation and video or audio recordings

Experience from other studies, in which the group interaction in institutions was recorded on video or audio, has shown that it is important to build trust in the research team. Two observations in MTCs without data collection will help to get used to the organisational processes in the breast and gynaecological cancer centres and to build the participants' trust in order to agree to and become accustomed to the video or audio recordings.

### Patient survey

Participating and non-participating patients will be screened by hospital staff for inclusion criteria. If patients meet the inclusion criteria, they will be informed by hospital staff verbally and with written material provided by the research team. Patients who give their informed written consent will be included in the study.

### Measures

#### Interviews

Semistructured interviews will be conducted to capture the experiences, opinions and concerns of the providers participating in MTCs. The interview guideline will include the following topics:

- ▶ Organisation before, during and after the MTC (eg, setting the agenda, documentation of decisions, technical aids, invitation of providers and patients, seating arrangement).
- ▶ Interaction before, during and after the MTC (eg, interaction between providers and between providers and patients).
- ▶ Decision-making before, during and after the MTC.
- ▶ Perceived or expected differences between MTCs held with and without patient participation.





- ▶ Perceived or expected differences in patient participation (dis-)advantages regarding organisation, patient-provider communication and decision-making.

#### Participatory observation and video or audio recordings

The database will consist of video or audio (transcribed) recordings, observation protocols and clinical protocols of the MTCs. Observations by means of video or audio recordings are planned in at least 18 MTC meetings in six breast and gynaecological cancer centres within a given time period of approximately 12 weeks. If the respective MTC team agrees to video recordings, video recording can take place after patients give their informed written consent. If the team does not agree to video recordings, audio recordings will take place after patients give their informed written consent. In contrast to audio recordings, videography provides the opportunity to observe all interaction modalities, ie, nonverbal communication, gestures and facial expressions, as well as other relevant aspects, such as the locations of the persons in the room, the use of technology and the physical environment. The use of observation protocols will also provide information about the mentioned aspects, especially if MTCs are audio recorded. Clinical protocols contain clinical information on grading, comorbidities, metastasis and type of surgery. In reference to a study on MTCs by Taylor *et al*<sup>6</sup> in which they developed the 'Observational Assessment Rating Scale for multidisciplinary tumour conferences (MDT-OARS)', our observation categories are the following:

- ▶ Organisation and infrastructure of the MTC.
- ▶ Interaction between team members (eg, hierarchy).
- ▶ Interaction between the team and the patients.
- ▶ Patient orientation and the decision-making process during the MTC.

For the comparison of patient orientation in MTCs with and without patient participation, the observation criteria for the category 'patient orientation' will be differentiated more strongly. As the MDT-OARS was developed only in MTCs without patient participation, this differentiation is necessary for an adequate measurement of MTCs with patient participation in the research project.

#### Patient survey

In order to explore the feasibility, risks and benefits as well as the differences between patients participating and not participating in MTCs, all patients will fill out standardised survey questions directly before the MTC (T0, all patients), directly after the MTC (T1, MTC participating patients) and 4 weeks after the MTC (T2, all patients). Not all scales will be used in all three points of measurement. The main reason for the differences between time points is the scales' sensitivity to change. Psychological scales might be affected more strongly during MTC and/or treatment than more stable moderators like health literacy. Thus, some scales which we believe to change through the MTC patient participation will have to be

asked repeatedly, while other stable concepts and characteristics only need to be asked at baseline. Thereby, we also tried to reduce the survey length. With very few exceptions, validated scales are used as survey questions, and author agreement was obtained. Standards of survey development<sup>29 30</sup> will be followed concerning self-developed scales (information need before MTC, interruptions during MTC). Because of the exploratory design, primary and secondary outcomes are not differentiated. Outcomes, moderators/baseline characteristics and process measures in T0, T1 and T2 are shown in [table 1](#).

#### Data collection

##### Interviews

Each interview can take up to 1 hour and will be pretested with providers concerning the duration and comprehension of questions. The interviews will take place at the breast and gynaecological cancer centres. All interviews will be recorded by means of an audio device for future transcription and analyses, according to established standards.<sup>31</sup> Additionally, field notes will be used. The interview guideline can be adjusted after each interview if relevant new aspects are mentioned.

##### Participatory observation and video or audio recordings

For the video or audio recording, one or more cameras or audio recorders will be set up in the MTC room, depending on the room and the seating arrangement. They will be positioned to ensure that they can preferably capture the entire room and all interactions between the participants. The camera set-up and angle and the recording quality of image and audio will be tested in advance. In order to ensure the quality of the recordings and to enable the participants to become accustomed to the cameras and recordings, we will pretest the organisation in all breast and gynaecological cancer centres. Additional observation protocols will serve as an instrument through which peculiarities and important background information can be documented directly.

##### Patient survey

The practicability of the surveys and the potential burden on patients will be pilot-tested prior to the study using cognitive pretest interviews following established methods, especially using the 'think aloud' method.<sup>32</sup> Pretest participants will be recruited with the help of a cancer information centre and self-help groups (eg, breast cancer self-help group), which are cooperation partners in this study. Pretested patients will be inpatients or recently discharged from hospital. After patients have signed the written informed consent, T0 surveys can be filled out during hospitalisation and sent back to the research team. T1 will be filled out by participating patients after MTC and sent back to the research team. Two personalised reminders<sup>33</sup> will be provided according to Dillman's Total Design Method. T2 is a postal survey conducted 4 weeks after the MTC using the method

**Table 1** Survey instruments used in T0, T1 and T2

T0	T1	T2
<b>Baseline characteristics/Moderators</b>		<b>Moderators</b>
Sociodemographic characteristics <sup>40</sup>		Support from family <sup>40</sup>
Health literacy <sup>41</sup>		Health literacy <sup>41</sup>
Need for participation <sup>42</sup>		
Need for informational education <sup>42</sup>		Need for informational education <sup>42</sup>
Preference for paternalism <sup>42</sup>		
Preference for self-help <sup>42</sup>		
Information need before MTC (self-developed)		
	<b>Process measures</b>	<b>Process measures</b>
	Shared decision-making <sup>43</sup>	Shared decision-making <sup>43</sup>
	Experience during MTC <sup>15</sup>	Decision regret scale <sup>44</sup>
	Interruptions during MTC (self-developed)	Health literacy communication <sup>45</sup>
<b>Outcomes</b>	<b>Outcomes</b>	<b>Outcomes</b>
Health related quality of life <sup>46</sup>		Health related quality of life <sup>46</sup>
Therapy confidence <sup>40</sup>	Therapy confidence <sup>40</sup>	Therapy confidence <sup>40</sup>
Trust in providers <sup>42</sup>	Trust in providers <sup>42</sup>	Trust in providers <sup>42</sup>
Need for psychological support <sup>40</sup>	Need for psychological support <sup>40</sup>	Need for psychological support <sup>40</sup>
Fear of cancer progression <sup>40</sup>	Fear of cancer progression <sup>40</sup>	Fear of cancer progression <sup>40</sup>

mentioned above. Moreover, several strategies which increase response rates will be applied.<sup>34</sup>

### Triangulation

The different data sources will be matched during data collection in the form of a mixed-methods matrix<sup>23 24</sup> to obtain comprehensive information with the help of quantitative and qualitative data. Because of pseudonymisation, we will be able to match data, for instance, from provider interviews conducted in one centre with observations in the MTCs of the same centre and survey data of patients treated in this centre. From a methodological perspective, this might also reduce common limitations like ‘Hawthorne effect’ (participants act differently because of the observation), ‘observer-expectancy bias’ (observer reactivity causing problems with internal validity) and ‘common method bias’ (potential systematic error in the variance of a variable owing to the use of only one measurement method). However, it should be noted that interviews will be held exclusively with providers and surveys conducted exclusively with patients. No patient interviews will be conducted as the questionnaire bases on qualitative data analysis of patients’ experiences during MTCs. As participating and non-participating patients will fill out the questionnaire we will be able to explore differences in the consideration of patient preferences. No provider questionnaire will be conducted as the number of cases per breast or gynaecological cancer centre would be low (five per centre).

### Data analysis

#### Interviews

The audiotaped interviews will be transcribed verbatim and analysed by at least two independent researchers from different disciplines in accordance with the well-established methods of content analysis.<sup>35 36</sup> Subsequently the analysis will be interpreted by a group of researchers. In this process, inductively identified categories can complement and modify the deductively derived categories from previous international research.<sup>6 10 37 38</sup> The results will be used to inform patient survey development in this study. This might include questions regarding the positive and negative effects of patient participation in MTCs and to further explore how patient preferences are considered in decision-making in MTCs from the patients’ perspective.

#### Participatory observation and video or audio recordings

Audio data will be transcribed and analysed. Video recordings will be analysed directly, and their audio track will be transcribed and analysed. In the first instance, quantitative descriptive structural parameters can be gathered from the recorded observation and video data, on which basis descriptive comparisons between the MTCs with and without patients can already be made. Here, the key variables are the qualification and number of participants, duration of the MTCs, seating arrangements, length of conversations for each participant and technical support. The processes taking place in the



MTCs will furthermore be analysed with the aid of the videos, transcripts and observation protocols. In addition, the above-mentioned MDT-OARS by Taylor *et al*<sup>5 6</sup> will be used for quantitative evaluation of the video-based or audio-based observations. The tool was used by them to capture the quality of the MTCs in observations. The tool, including the criterion ‘patient orientation’, will be differentiated more strongly in the research project for the comparison of patient orientation in MTCs with and without patient participation. To increase inter-rater reliability, the material will be coded by two researchers independently from one another, and the preliminary results will be discussed in the work group consisting of patient representatives, clinicians as well as social scientists who were not directly involved in the data collection. Data from clinical protocols will be analysed descriptively, comparing participating and non-participating patients, and as independent variables and covariables in regression models.

#### Patient survey

Data will be electronically recorded and processed with the Teleform data capturing software. Afterwards, plausibility tests will be run. Data from validated scales in the survey will be constructed according to the coding manuals after demonstrating the psychometric properties. Data from self-developed instruments on measured constructs will be psychometrically analysed. The survey data will be analysed by means of the statistics programme IBM SPSS V.25. Open-ended questions will be evaluated content-analytically. The next step is to conduct multivariate analyses (regression models) for differences between the patients with versus patients without MTC participation, between time points and between patient subgroups.

#### Triangulation

In addition to the above description of triangulation, the qualitative results will be used for explaining the quantitative results by applying the triangulation method. Consequently, it will be possible to match, for example, the providers’ perspective on shared decision-making with observations in MTCs and patients’ assessments of shared decision-making in the survey.

#### Patient and public involvement

Healthcare providers, patients and self-help groups are involved in the planning of the study design, recruitment and instrument development. Data and results will be discussed in yearly workshops. PINTU explicitly involves researchers, providers and patients in a community-based participatory research design.

## ETHICS AND DISSEMINATION

### Ethical considerations

For all collected data, the relevant data protection regulations will be adhered to. Video recordings are an especially sensitive field. In order to adequately consider

ethical and data protection aspects, consultation and a positive vote has been obtained from the ethics committee of the Medical Faculty of the University of Cologne. The British General Medical Council created ethical and data protection guidelines for audio and video recordings of patients, which underlie the research project.<sup>39</sup> All participants in this study will receive written information about the aims and procedures of the study. Furthermore, all patients and providers will be asked for informed written consent to collect their data in interviews (providers), MTCs (patients and providers) and surveys (patients) as well as to analyse and save their data. All personal identifiers will be pseudonymised. By request, all personal data can be deleted immediately without stating reasons.

### Dissemination plan

The results can provide guidance on the feasibility, risks and benefits of the participation of patients in MTCs. Patients will be invited to a workshop in order to discuss the study results (eg, on the Patients Day of the German Cancer Congress). In a transfer workshop, the results will be discussed with the providers in the breast and gynaecological cancer centres to plan and arrange subsequent intervention studies. On the one hand, the workshops will supply providers with feedback regarding the research results, and on the other hand, they will serve as a platform for the exchange between providers for mutual organisational learning. With the publication of the results in national and international scientific journals and at conferences, the applicants additionally expect a nationwide and international impetus for the patient-oriented treatment of cancer patients.

### Author affiliations

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

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

<sup>3</sup>Department of Health Services Research, Faculty of Medicine and Health Sciences, Carl von Ossietzky University Oldenburg, Oldenburg, Germany

<sup>4</sup>Institute of Medical Sociology, Health Services Research and Rehabilitation Science (IMVR), Faculty of Human Sciences and Faculty of Medicine, University of Cologne, Cologne, Germany

**Acknowledgements** The authors want to thank all patients and providers who will participate in the study, the cooperation partners (centres) and the scientific advisory council of this study.

**Contributors** All authors designed the study. CH drafted and revised all sections of the paper and is guarantor. AD, LA and NE revised the paper. CH, AD, LA and NE designed data collection tools.

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

**Competing interests** None declared.

**Patient consent for publication** Obtained.

**Ethics approval** Ethics Committee of the Medical Faculty of the University of Cologne, Germany.

**Provenance and peer review** Not commissioned; externally peer reviewed.

**Open access** This is an open access article distributed in accordance with the Creative Commons Attribution Non Commercial (CC BY-NC 4.0) license, which



permits others to distribute, remix, adapt, build upon this work non-commercially, and license their derivative works on different terms, provided the original work is properly cited, appropriate credit is given, any changes made indicated, and the use is non-commercial. See: <http://creativecommons.org/licenses/by-nc/4.0/>.

## REFERENCES

- National Cancer Action Team. The Characteristics of an Effective Multidisciplinary Team (MDT). London 2010.
- Medical Association Westfalen-Lippe. *Certification of breast cancer centers in North-Rhine Westphalia. Requirement catalogue breast cancer centers [Verfahren zur Zertifizierung von Brustzentren in NRW. Anforderungskatalog Brustzentren]*. 2018.
- German Cancer Aid. *Interdisciplinary S3-guideline for diagnostic, therapy, and rehabilitation of breast cancer [Interdisziplinäre S3-Leitlinie für die Diagnostik, Therapie und Nachsorge des Mammakarzinoms]*. 2012.
- Lamb BW, Brown KF, Nagpal K, et al. Quality of care management decisions by multidisciplinary cancer teams: a systematic review. *Ann Surg Oncol* 2011;18:2116–25.
- Taylor C, Finnegan-John J, Green JS. "No decision about me without me" in the context of cancer multidisciplinary team meetings: a qualitative interview study. *BMC Health Serv Res* 2014;14:488.
- Taylor C, Atkins L, Richardson A, et al. Measuring the quality of MDT working: an observational approach. *BMC Cancer* 2012;12:202.
- Hahlweg P, Hoffmann J, Härter M, et al. In absentia: an exploratory study of how patients are considered in multidisciplinary cancer team meetings. *PLoS One* 2015;10:e0139921.
- van Leeuwen AF, Voogt E, Visser A, et al. Considerations of healthcare professionals in medical decision-making about treatment for clinical end-stage cancer patients. *J Pain Symptom Manage* 2004;28:351–5.
- Lamb BW, Taylor C, Lamb JN, 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.
- Hahlweg P, Didi S, Kriston L, et al. Process quality of decision-making in multidisciplinary cancer team meetings: a structured observational study. *BMC Cancer* 2017;17:772.
- Blazey JM, Wilson L, Metcalfe C, et al. Analysis of clinical decision-making in multi-disciplinary cancer teams. *Ann Oncol* 2006;17:457–60.
- Salloch S, Ritter P, Wäscher S, et al. Medical expertise and patient involvement: a multiperspective qualitative observation study of the patient's role in oncological decision making. *Oncologist* 2014;19:654–60.
- Butow P, Harrison JD, Choy ET, et al. 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.
- Devitt B, Philip J, McLachlan SA. Team dynamics, decision making, and attitudes toward multidisciplinary cancer meetings: health professionals' perspectives. *J Oncol Pract* 2010;6:e17–20.
- Choy ET, Chiu A, Butow P, et al. 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.
- 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.
- Curry LA, Krumholz HM, O'Cathain A, et al. Mixed methods in biomedical and health services research. *Circ Cardiovasc Qual Outcomes* 2013;6:119–23.
- Palinkas LA. Qualitative and mixed methods in mental health services and implementation research. *J Clin Child Adolesc Psychol* 2014;43:851–61.
- Palinkas LA, Arons GA, Horwitz S, et al. Mixed method designs in implementation research. *Adm Policy Ment Health* 2011;38:44–53.
- Klassen AC, Creswell J, Plano Clark VL, et al. Best practices in mixed methods for quality of life research. *Qual Life Res* 2012;21:377–80.
- Axinn WG, Pearce LD. *Mixed method data collection strategies*. Cambridge: Cambridge University Press, 2006.
- Wisdom JP, Cavaleri MA, Onwuegbuzie AJ, et al. Methodological reporting in qualitative, quantitative, and mixed methods health services research articles. *Health Serv Res* 2012;47:721–45.
- O'Cathain A, Murphy E, Nicholl J. The quality of mixed methods studies in health services research. *J Health Serv Res Policy* 2008;13:92–8.
- O'Cathain A, Murphy E, Nicholl J. Three techniques for integrating data in mixed methods studies. *BMJ* 2010;341:c4587.
- Patton MQ. Enhancing the quality and credibility of qualitative analysis. *Health Serv Res* 1999;34(5 Pt 2):1189–208.
- Radecki SE, Nyquist JG, Gates JD, et al. Educational characteristics of tumor conferences in teaching and non-teaching hospitals. *J Cancer Educ* 1995;9:204–16.
- Ansmann L, Kowalski C, Pfaff H, et al. Patient participation in multidisciplinary tumor conferences. *Breast* 2014;23:865–9.
- Ansmann L, Ernstmann N. Patient participation in tumor conferences in breast cancer centers in North-Rhine Westphalia – the perspective of participating patients [Patientinnenteilnahme an Tumorboards in NRW-Brustzentren – die Sicht teilnehmender Patientinnen]. *Senologie - Zeitschrift für Mammadiagnostik und -therapie* 2015;12.
- Schaeffer NC, Dykema J. Questions for surveys: current trends and future directions. *Public Opin Q* 2011;75:909–61.
- Bradburn NM, Sudman S, Wansink B. *Asking questions: the definitive guide to questionnaire design - for market research, political polls, and social and health questionnaires*. Hoboken: John Wiley & Sons Inc, 2004.
- Flick U, Kvale S, Angrosino MV, eds. *The Sage qualitative research kit*. London: SAGE, 2007.
- Prüfer P, Rexroth M. Two-Phases-Pretesting [Zwei-Phasen-Pretesting]. *ZUMA-Arbeitsbericht* 2000;08.
- Dillman DA. *Mail and telephone surveys: the total design method*. New York, 1978.
- Edwards PJ, Roberts I, Clarke MJ, et al. Methods to increase response to postal and electronic questionnaires. *Cochrane Database Syst Rev* 2009;3:MR000008.
- Miles MB, Huberman AM, Saldaña J. *Qualitative data analysis: a methods sourcebook*. 3rd edn. Los Angeles, London, New Delhi, Singapore, Washington DC: SAGE, 2014.
- Mayring P. *Qualitative content analysis [Qualitative Inhaltsanalyse]*. 11th edn. Weinheim u.a: Beltz, 2010.
- van Dongen JJJ, Habets IGJ, Beurskens A, et al. Successful participation of patients in interprofessional team meetings: A qualitative study. *Health Expect* 2017;20:724–33.
- Soukup T, Lamb BW, Sarkar S, et al. Predictors of Treatment Decisions in Multidisciplinary Oncology Meetings: A Quantitative Observational Study. *Ann Surg Oncol* 2016;23:4410–7.
- General Medical Council. Making and using visual and audio recordings of patients. 2013. Available at: [https://www.gmc-uk.org/-/media/documents/making-and-using-visual-and-audio-recordings-of-patients\\_pdf-58838365.pdf](https://www.gmc-uk.org/-/media/documents/making-and-using-visual-and-audio-recordings-of-patients_pdf-58838365.pdf) (accessed 9 March 2018).
- Ansmann L, Hower K, Pfaff H. The Cologne Patient Questionnaire for Breast Cancer 2.0 [Der Kölner Patientenfragebogen für Brustkrebs 2.0]. 2015. Available at: [http://www.imvr.de/uploads/Kennzahlen/Kennzahlenhandbuch%20KPF-BK%202\\_0.pdf](http://www.imvr.de/uploads/Kennzahlen/Kennzahlenhandbuch%20KPF-BK%202_0.pdf) (accessed 9 March 2018).
- Sørensen K, Van den Broecke S, Fullam J, et al. Health literacy and public health: a systematic review and integration of definitions and models. *BMC Public Health* 2012;12:80.
- Pfaff H, ed. *The Cologne Patient Questionnaire. Development and validation of a questionnaire of the involvement of patients as co-therapist [Der Kölner Patientenfragebogen (KPF): Entwicklung und Validierung eines Fragebogens zur Erfassung der Einbindung des Patienten als Kotherapeuten]*. Sankt Augustin: Asgard-Verl, 2003.
- Scholl I, Koelewijn-van Loon M, Sepucha K, et al. Measurement of shared decision making - a review of instruments. *Z Evid Fortbild Qual Gesundhwes* 2011;105:313–24.
- Brehaut JC, O'Connor AM, Wood TJ, et al. Validation of a decision regret scale. *Med Decis Making* 2003;23:281–92.
- Ernstmann N, Halbach S, Kowalski C, et al. Measuring attributes of health literate health care organizations from the patients' perspective: Development and validation of a questionnaire to assess health literacy-sensitive communication (HL-COM). *Z Evid Fortbild Qual Gesundhwes* 2017;121:58–63.
- Groenvold M, Klee MC, Sprangers MA, et al. Validation of the EORTC QLQ-C30 quality of life questionnaire through combined qualitative and quantitative assessment of patient-observer agreement. *J Clin Epidemiol* 1997;50:441–50.

3.2. Publication 2: Health literacy and patient participation in multidisciplinary tumor conferences in breast cancer care: a multilevel modeling approach

**Heuser, C.**, Diekmann, A., Kowalski, C., Enders, A., Conrad, R., Pfaff, H., Ansmann, L. & Ernstmann, N. (2019b). Health literacy and patient participation in multidisciplinary tumor conferences in breast cancer care: a multilevel modeling approach. *BMC cancer* 19 (1), 330. doi:10.1186/s12885-019-5546-z. Impact Factor: 3,15 (2019).




## RESEARCH ARTICLE

## Open Access



# Health literacy and patient participation in multidisciplinary tumor conferences in breast cancer care: a multilevel modeling approach

Christian Heuser<sup>1,2\*</sup> , Annika Diekmann<sup>1,2</sup>, Christoph Kowalski<sup>3</sup>, Anna Enders<sup>4</sup>, Rupert Conrad<sup>5</sup>, Holger Pfaff<sup>6</sup>, Lena Ansmann<sup>7</sup> and Nicole Ernstmann<sup>1,2</sup>

## Abstract

**Background:** Decisions made in multidisciplinary tumor conferences (MTC) that consider patient preferences result in better patient outcomes. Furthermore, it has been shown that in some breast cancer centers in Germany, patients participate in MTCs and that participation is associated with sociodemographic and breast cancer center-related factors. Health literacy (HL) has been shown to be predictive for individual health behavior and is an important prerequisite for patient participation in healthcare. However, so far nothing is known about the association between HL and MTC patient participation. To close this gap in research, we analyzed which patient characteristics affect participation in MTCs and whether participation varies between breast cancer centers.

**Methods:** In a prospective, multicenter cohort study, newly diagnosed breast cancer patients were surveyed directly after surgery (T1) as well as 10 weeks (T2) and 40 weeks (T3) after surgery. After descriptive analysis, t-tests were conducted, correlations for independent variables were run, and logistic multilevel regression analysis was applied to estimate the association between patient participation in MTCs at T1 and HL (HLS-EU-Q16 [1]), sociodemographic and disease-related characteristics ( $n = 863$  patients) and the variation between breast cancer centers ( $n = 43$  centers).

**Results:** Descriptive results show that 6.8% of breast cancer patients took part in a MTC. The logistic multilevel regression model revealed that patients with an inadequately HL are less likely to participate in MTCs (OR = 0.31, 95%-CI = 0.1–0.9, Pseudo- $R^2 = 0.06$ ), and participation is dependent on the breast cancer center (ICC = 0.161).

**Conclusions:** These findings are the first to show significant differences in HL and patient participation in MTCs in a large sample of breast cancer patients. In future research on patient participation in MTCs and HL, questions concerning the organization, communication and decision-making in MTCs with and without patient participation have to be addressed, and patient and provider perspectives must be equally considered.

**Trial registration:** Database Health Services Research, [VFD\\_PIAT\\_12\\_001630](https://www.clinicaltrials.gov/ct2/show/study?term=VFD_PIAT_12_001630), registered prospectively on 01.03.2012.

**Keywords:** Health literacy, Multidisciplinary tumor conference, Tumor board, Patient participation, Breast Cancer, Health services research, Multilevel regression analysis

\* Correspondence: [christian.heuser@ukbonn.de](mailto:christian.heuser@ukbonn.de)

<sup>1</sup>Center for Health Communication and Health Services Research (CHSR), Department of Psychosomatic Medicine and Psychotherapy, University Hospital Bonn, Sigmund-Freud-Str. 25, 53127 Bonn, Germany

<sup>2</sup>Center for Integrated Oncology (CIO Bonn), University Hospital Bonn, Sigmund-Freud-Str. 25, 53127 Bonn, Germany

Full list of author information is available at the end of the article



## Background

Oncological healthcare has been faced with many developments in recent years. Among them are *multidisciplinary care* as a process aiming to foster cooperation between professionals from a range of disciplines [2] as well as *patient centered care* as a healthcare process aiming to achieve socially and psychologically integrated care [3]. Multidisciplinary tumor conferences (MTCs) mainly represent the first development as a regular exchange between healthcare professionals [4, 5]. It remains unclear if MTCs could as well incorporate processes and structures of patient centeredness to foster decisions that explicitly consider patient preferences [6, 7]. International studies have revealed that decisions in MTCs that consider patient preferences result in better patient outcomes [8–10]. However, it has been shown that patient preferences concerning decision-making are not considered systematically in MTCs and treatment recommendations are mainly based on clinical information [11–13]. Many decisions in breast cancer care are preference-sensitive, especially in metastatic breast cancer treatment [14]. Therefore, incorporating patient preferences in MTCs is a central factor in treatment decision-making to achieve higher-quality decisions [15] and to possibly optimize adherence efficiency of MTC decisions [16].

In an effort to better take patient preferences into account, the participation of patients in MTCs has been widely discussed recently. In Germany, MTCs are part of the certification criteria of the German Cancer Society and the Medical Council of North Rhine-Westphalia [17]. The requirements of the Medical Council of North Rhine-Westphalia demand that patients should be allowed to participate in MTCs for the discussion of their own case [18]. Initial findings indicate that the active participation of patients in MTCs, e.g. concerning decision-making, is important [19, 20] because it may increase patient compliance and satisfaction [21–23]. Participating patients define themselves as collaborating actors who are able to state their preferences in the process of decision-making [24]. From the healthcare providers' perspective, discussing therapy options with patients in the context of MTCs might be seen as a challenging part of their profession [25]. Besides potential benefits of patient participation in MTCs, studies indicate possible negative consequences for patients and providers. Patients may not fully understand the complexity of clinical information, which may increase fear regarding therapy and prognosis [26]. Moreover, the discussion between providers might be restricted. Medical experts may find it difficult to discuss a complex medical case in the presence of patients due to the need to adjust their language and to think about possible misinterpretations of their medical evaluations by the patient [27]. Further challenges might include organizational barriers, e.g. time pressure and difficult management of the patient invitation [28].

All in all, first hints concerning risks and benefits of MTC patient participation exist. To better understand how to make patient participation in MTCs beneficial, we need to know which patient subgroups are participating in MTCs in the first place, especially because we know that in some breast cancer centers in Germany, patients participate in MTCs [29]. As patients do not regularly participate in MTCs, however, little is known about the associated benefits and risks as well as participating patient subgroups. Therefore, it is important to understand which patient subgroups are likely to participate in MTCs to get a better knowledge on which patients might be more likely to find MTCs beneficial or detrimental.

In this context, one prior research shows that patients' invitation to and participation in MTCs depends on individual sociodemographic and disease-related characteristics [30]. However, little is known about further patient characteristics. As health literacy (HL) has been shown to be predictive for individual health behavior and to be an important prerequisite for patient participation in healthcare [31, 32], it can be assumed that patients with sufficient HL are more likely to participate in MTCs. According to Sorensen et al., HL is defined as the knowledge, motivation and competence to access, understand, appraise and apply health information [33]. HL is an important factor in responding to the complex demands of modern healthcare systems, e.g., concerning the use of healthcare services, patient-provider communication, better health outcomes or disease prevention [32–36]. Previous studies found an increased prevalence of low HL especially among people with low education, older age, chronic disease or an ethnic background [1, 37]. In addition, HL does not depend on individual characteristics alone, but at the same time is a product of individuals' capacities in an organizational setting and demands of the healthcare system, which make up organizational HL [38–40]. So far, nothing is known about the association between individual HL and patient participation in MTCs.

## Research aim

This is the first study analyzing the possible association between HL and patient participation in MTCs. The aim is to analyze the impact of individual HL, sociodemographic and disease-related characteristics as well as the impact of the variation between breast cancer centers on patient participation in MTCs.

## Methods

### Study design and sample

In a prospective, multicenter cohort study,<sup>1</sup> newly diagnosed breast cancer patients were surveyed directly after (T1), 10 weeks after (T2) and 40 weeks after (T3) surgery, with three reminders sent according to Dillman's Total Design Method [41]. Patients needed to give written informed consent to take part in the survey. The survey was approved by the

Ethics Committee of the Medical Faculty of the University of Cologne. Data were collected from 2013 to 2014 using standardized self-report measures in written questionnaires. Breast cancer centers were recruited by randomly sampling 98 out of 247 German breast cancer centers meeting the criteria of the German Cancer Society and the German Society for Senology. In total  $n = 56$  breast cancer centers took part in the study and  $n = 43$  were included in the analysis of the study; this discrepancy is due to missing or insufficient patient data in some centers. Patient inclusion criteria were in-patient surgery for newly diagnosed breast cancer (C50.xx, D05.xx) performed between February 01 and August 31, 2013, at least one malignancy and at least one postoperative histological evaluation. In total, 1395 patients took part in the study (response rate = 87.7%), with  $n = 863$  (61.9%) patients included in the analysis, with the discrepancy due to missing data in dependent and independent variables.

### Instruments and variables

All measures and instruments used in the questionnaires were pre-tested in a pilot study as described elsewhere [42, 43]. All items used in this manuscript were measured in T1. Patients who filled out the item “Have you been offered the opportunity to participate in a tumor conference?”, (1 = Yes and I took it; 2 = Yes and I did not take it; 3 = No) were considered. The item was used as dependent variable in order to measure the participation in MTC (0 = “No” and “Yes and I did not take it”; 1 = “Yes and I took it”). HL was measured with the validated HLS-EU-Q16 questionnaire. HLS-EU-Q16 was categorized into ‘sufficient’, ‘problematic’ and ‘inadequate’ categories according to common standards [1] (Cronbach’s Alpha 0.90). Data on sociodemographic patient characteristics were assessed in the patient survey with the help of self-reported items (formal education, age, health literacy, living with partner, native language, health insurance status). Data on clinical patient characteristics were provided by the clinical personnel (UICC stage). Table 1 shows the descriptive results of the 863 patients and 43 breast cancer centers included in the model.

### Analysis

Firstly, the data were analyzed descriptively. Secondly, inter-correlations among the independent variables were checked for multicollinearity. Lastly, the associations between patient participation in MTCs and HL, sociodemographic and disease-related characteristics were analyzed using two-level random intercept hierarchical logistic models. As the data were hierarchically structured, i.e., individual patient data were nested in breast cancer center clusters, multilevel modeling was used to account for clustering [44, 45]. In a first step, a two-level model without predictors (null model) was fitted in order to calculate the intraclass correlation coefficient (ICC null model). The ICC indicates the proportion of variance in the dependent variable that is attributable to

differences between breast cancer centers. In a second step, patient characteristics were added as predictors at the patient level. The resulting odds ratios (OR) and 95% confidence intervals (95%-CI) were standardized via standard deviations to allow comparisons of effect sizes. No imputations were performed for missing data. Due to listwise deletion for the dependent variable and all independent variables, individual data of  $n = 863$  patients and organizational data of  $n = 43$  centers were included in the model. All analyses were conducted with STATA version 15.

## Results

### Descriptive analyses

According to the survey, 59 patients (6.8%) took part in MTCs. For detailed descriptive results of the sample see Table 1.

**Table 1** Descriptive results of the  $n = 863$  patients

Variables	Response trait	<i>n</i> (%)
Dependent variable: participation in MTC	No	804 (93.2)
	Yes	59 (6.8)
Highest education level achieved	No school education	62 (7.2)
	Lower secondary school education	503 (58.3)
	Intermediate secondary school education	101 (11.7)
	Entrance certificate for a university of applied sciences / University entrance certificate	197 (22.8)
Age	18–39	36 (4.2)
	40–49	193 (22.4)
	50–59	273 (31.6)
	60–69	204 (23.6)
	≥70	157 (18.2)
Health literacy	Inadequate	139 (16.1)
	Problematic	287 (33.3)
	Sufficient	437 (50.6)
Living with partner	No	222 (25.7)
	Yes	641 (73.2)
Native language	German	827 (95.8)
	Other	36 (4.2)
Health insurance status	Statutory	659 (76.4)
	Private	89 (10.3)
	Statutory with additional private insurance	115 (13.3)
UICC stage	Stage 0 / I	441 (51.1)
	Stage II	300 (34.8)
	Stage III / IV	122 (14.1)
<i>n</i> patients		863
<i>n</i> breast cancer centers		43

**Table 2** T-test results with HL status and MTC patient participation

HL	Participating patients	Non-participating patients
Inadequate	6.8%	16.8%
Problematic	32.3%	33.3%
Sufficient	61.0%	49.9%
	Mean: 2.54 SD: 0.62 95%-CI: 2.38–2.70	Mean: 2.33 SD: 0.75 95%-CI: 2.28–2.38

Sufficient HL scores were found in 61% of the participating patients, whereas 32.3% exhibited problematic and 6.8% inadequate HL. Of the non-participating patients, 49.9% had sufficient HL, 33.3% problematic HL and 16.8% inadequate HL. T-tests revealed that the HL status of participating patients (mean 2.54) and non-participating patients (mean 2.33) significantly differed ( $t = -2.12$ ,  $p = .05$ ). T-test results are shown in Table 2. The

proportion of patients participating in MTCs in the 43 breast cancer centers ranged from 0 to 75%.

### Multivariate analyses

No multicollinearity was found between the independent variables. The logistic multilevel regression model revealed that HL is significantly associated with the participation of breast cancer patients in MTCs (Pseudo- $R^2 = 0.06$ ). Patients with inadequately HL are less likely to participate in MTCs (OR = 0.31, 95%-CI = 0.1–0.9) than patients with sufficient HL. Concerning other sociodemographic or disease-related characteristics, no significant associations were found in the model. The ICC shows a value of 0.161 (16.1%) and the ICC null model of 0.149 (14.9%) indicating that 14.9% of the variance in the dependent variable (patient participation on MTC) is associated to differences only between breast cancer centers (level 2). All results are shown in Table 3.

**Table 3** Logistic multilevel hierarchical regression model with participation in the MTC as the dependent variable

Variables	Response trait	OR <sup>1</sup>	95%-CI <sup>2</sup>
Highest education level achieved	No school education	1.93	0.74–5.31
	Lower secondary school education (Ref.)	1.00	
	Intermediate secondary school education	1.74	0.75–3.97
	Entrance certificate for a university of applied sciences / University entrance certificate	1.12	0.54–2.34
Age	18–39	0.39	0.10–3.15
	40–49	0.69	0.30–1.56
	50–59 (Ref.)	1.00	
	60–69	0.80	0.38–1.69
	≥70	0.93	0.42–2.08
Health literacy	Inadequate	<b>0.31</b>	<b>0.11–0.93</b>
	Problematic	0.85	0.47–1.56
	Sufficient (Ref.)	1.00	
Living with partner	No	1.00	
	Yes	0.92	0.48–1.75
Native language	German	1.00	
	Other	1.89	0.49–7.23
Health insurance status	Statutory (Ref.)	1.00	
	Private	0.74	0.26–2.12
	Statutory with additional private insurance	0.95	0.39–2.27
UICC stage	Stage 0 / I (Ref.)	1.00	
	Stage II	0.83	0.45–1.53
	Stage III / IV	0.39	0.13–1.18
<i>n</i> patients		863	
<i>n</i> breast cancer centers		43	
ICC <sup>3</sup> (ICC null model)		<b>0.161 (0.149)</b>	

<sup>1</sup>Standardized odds ratios (OR)<sup>2</sup>95%-confidence intervals (95%-CI)<sup>3</sup>Intraclass correlation coefficient (ICC)Significant results in bold ( $p < 0.05$ )

## Discussion

The aim of the study was to examine how HL, sociodemographic patient characteristics and disease-related patient characteristics are associated with patient participation in MTCs and to what extent patient participation in MTCs varies between breast cancer centers. The logistic multilevel regression model showed that significant differences in participation exist between HL level groups and between breast cancer centers. To the best of our knowledge, our findings show this association for the first time. In the following sections, specific aspects of these results are discussed in detail.

### Patient characteristics

Descriptive results show that 6.8% of breast cancer patients in German breast cancer centers took part in MTCs, which is a slightly lower percentage than in other studies based on data from North Rhine-Westphalia [30]. This may be due to the two different requirement catalogues of breast cancer centers in Germany: The Medical Council of North Rhine-Westphalia demands that patients should be allowed to participate in MTCs for the discussion of their own case, which led to a call for invitation to MTCs. In contrast, the German Cancer Society (Germany-wide) does not demand patient participation in MTCs.

The descriptive and multivariate results of our analyses reveal that patients with an inadequately HL are less likely to participate in MTCs. Our results are in line with research on the implications of individual HL on health-related behavior [32, 34]. Higher HL enables patients to better communicate with healthcare professionals and to be more involved in diagnosis and treatment [36, 46]. This may ultimately lead to better health process measures and health outcomes [1, 33, 35].

As patients' formal education, age, native language, partner status and health insurance showed no significant association in the model, it can be concluded that in the here presented sample of breast cancer survivors sociodemographic characteristics are not associated with patient participation in MTCs. This might be seen as contradictory to common findings as highly educated and/or younger patients would be more likely to participate in MTC due to greater HL, greater coping skills and stronger preferred involvement in decision-making [47, 48]. Prior findings from Ansmann et al. on patient participation in MTCs show opposite findings as well [30]. One explanation might be the lack of a definition of "MTC" given in the questionnaire potentially leading to a misunderstanding of the questionnaire item "participation in MTC". This might indicate that patients with lower education possibly have a greater tendency to respond socially desirable (MTC participation "yes"). Another reason might be an inconsistent invitation of patients from healthcare providers as patients might be

selected based on sociodemographic and/or disease-related characteristics. Lastly, missing data has to be taken into account: patients with lower education, higher age, inadequately health literacy, native language not "German" and statutory health insurance status descriptively show a greater amount of missing data.

The model shows no significant associations for the UICC stage. This result stands in contrast to prior findings [30] and to the hypothesis that patients with a UICC stage III/IV take part more frequently in MTCs because in advanced disease stages, more treatment options can be discussed and therefore patients may think that they can benefit more from stating their preferences in the decision-making process. The absence of differences in our study might be explained, on the one hand, by the small number of patients in the categories UICC stage III/IV. On the other hand, from the perspective of severely compromised patients with UICC stage III/IV, the physical and emotional effort associated with participating in MTCs may outweigh potential benefits of their involvement in the decision-making process.

### Breast cancer center variation

Prior findings showed that invitations extended to patients to take part in a MTC and actual participation rates vary significantly between breast cancer centers [30]. The ICC for the null model implies that 14.9% of the variance in participation in MTCs is attributable to the breast cancer center. The rather high ICC underlines the fact that providers' attitudes towards patient participation in MTCs as well as the associated processes before, during and after MTCs differ quite strongly between breast cancer centers. This leads to research implications regarding the examination of specific risks and benefits emerging from patient participation in MTCs for patients and providers across various centers. After this examination the question can be raised whether MTC participation and the processes to ensure participation might be one aspect of organizational HL [49] in the sense of patient centeredness.

### Limitations and strengths

When interpreting these findings, some limitations, strengths as well as future research and practice implications have to be considered. As a *limitation*, the observational design with mainly self-reported items has to be taken into account; it might contain a possible systematic error in the variance of the dependent variable. Furthermore, three patient selection processes might have taken place: firstly, only women were included in the analysis, secondly, although we are not able to test it, we suggest that healthier patients might have filled out the questionnaire more often and lastly, the characteristics of patients with missing data (see "Patient characteristics"). Another



source of overestimation of associations might be the common method bias. Overall, no causal effects can be formulated due to the observational design. A *strength* of the study is the nationwide random sample of breast cancer centers and patients. Furthermore, we considered the nested data structure with the multilevel modelling approach. Additionally, the multilevel regression model can be seen as an advanced statistical method combining many patient variables in one model.

### Implications

As *research implications* for this study, four main aspects have to be taken into account. (1) In general, our results supply no evidence regarding the risks and benefits of patient participation in MTCs for patients and providers. Concerning future study designs, a triangulation [50] of different qualitative and quantitative methods is needed to better equally address the perspectives of patients and providers on MTC participation. Such a mixed-methods study [51] on risks and benefits might include patient experiences of MTC participation and their psychosocial situation as well as provider perspectives of possible opportunities associated with and barriers to patient participation in MTCs. In addition, a future study might be able to clarify the association between the sociodemographic characteristics included here and the likelihood of participation. Ideally, future research would benefit from an interventional study design. (2) Research on patient participation in MTCs and HL differences has to give greater consideration to healthcare processes. Patient-provider communication and decision-making in MTCs have to be additionally addressed with the help of different concepts [46]. This might include, e.g. the patients' perspective on organizational patient-centred efforts in MTCs in order to analyze healthcare organizations' responsiveness to patients' individual needs in decision-making and patient-provider communication during MTC. This seems to be an important aspect of HL for future research as communicational processes and skills are considered increasingly important in healthcare. A research-guiding hypothesis in this context is the above-mentioned question of whether MTCs in their common form represent processes and structures of patient centeredness, because they mainly consist of decisions which consider patient preferences [6, 52]. This might include the question of whether the participation of patients in MTCs is an effective tool to realize patient centeredness. Therefore, relevant aspects (see (1)) have to be compared in MTCs with and without patient participation. (3) The interesting interaction between HL and sociodemographic characteristics, which is increasingly discussed in Germany [37, 53], should be considered more strongly in MTC research. (4) As the missing data

contains patient subgroups which represent potential vulnerable groups in healthcare (low education, higher age, low health literacy) it is important for future studies to follow strategies reaching these patients. This might include the adjustment of survey instruments in simple language, the use of qualitative research approaches instead of using standardized quantitative instruments which are potentially difficult to fill out, and the cooperation with organized patient groups (e.g. self-help groups) in order to integrate research questions focusing on specific (information) needs or (emotional) concerns, e.g. the procedures of a MTC.

As *practical implications* for level 2 (organization and providers), it is worth considering factors that may possibly encourage or hinder the adoption of patient participation in MTCs. This may include the following aspects concerning the organization of MTCs: the selection and the consistent or inconsistent invitation of patients, a verbally and written definition of and invitation to the MTC which is easily understandable for all patients, the duration of the MTC per patient, the number of discussed cases in one MTC, interruptions during MTCs, or documents and technical aids. Furthermore, processes in the MTCs like the interaction between the providers as well as the interaction between providers and patients must be studied. Lastly, to include provider and breast cancer center manager attitudes towards patient-centered approaches, the provider experiences concerning the involvement of patients in the decision-making process is important. For level 1 (patients), the subjective experiences of patients in MTCs are important in order to explore the potential risks and benefits of participation. This may include patient expectations, concerns, and fears before and after the MTC and patient experiences concerning the decision-making.

### Conclusions

This study has highlighted a significant research gap concerning the individual and organizational determinants of patient participation in MTCs among breast cancer patients. The findings show that significant differences in MTC patient participation exist between patient groups (individual HL) and between breast cancer centers, and hence demonstrate the necessity of more research in this field. Overall, future research and practice should answer the questions regarding risks and benefits of patient participation in MTCs. Deeper insight into the feasibility of patient participation in MTCs, possible subgroups of patients that might benefit from participation as well as the quality of the decision-making process would be beneficial in the development of specific recommendations for patients and providers in MTCs.

## Endnotes

<sup>1</sup>PIAT: Strengthening patient competence: Breast cancer patients' information and training needs (Funding: The German Federal Ministry of Health; Carried out by: Institute for Medical Sociology, Health Services Research, and Rehabilitation Science (IMVR))

## Acknowledgements

We would like to thank all of the patients and breast cancer centers participating in the study.

## Funding

This study was funded by The German Federal Ministry of Health.

## Availability of data and materials

Data and all other materials for this study are kept at the Institute of Medical Sociology, Health Services Research and Rehabilitation Science, University of Cologne, Germany. The datasets generated and analysed during the current study are not publicly available due to terms of written informed consent to which the participants agreed but are available from the corresponding author on reasonable request.

## Authors' contributions

CH planned and conducted data analyses, drafted and revised all sections of the paper and is guarantor. AD, RC and LA assisted in data analysis, interpretation of the results and editing the manuscript. HP, CK, AE and NE developed the study framework and patient survey and assisted in data analyses, interpretation of the results and editing the manuscript. All authors read and approved the final manuscript.

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

## Consent for publication

Not applicable.

## Competing interests

The authors declare that they have no competing interests.

## Publisher's Note

Springer Nature remains neutral with regard to jurisdictional claims in published maps and institutional affiliations.

## Author details

<sup>1</sup>Center for Health Communication and Health Services Research (CHSR), Department of Psychosomatic Medicine and Psychotherapy, University Hospital Bonn, Sigmund-Freud-Str. 25, 53127 Bonn, Germany. <sup>2</sup>Center for Integrated Oncology (CIO Bonn), University Hospital Bonn, Sigmund-Freud-Str. 25, 53127 Bonn, Germany. <sup>3</sup>German Cancer Society e.V. (DKG), Department for Certification, Kuno-Fischer-Straße 8, 14057 Berlin, Germany. <sup>4</sup>Department for Research and Quality Management, The Federal Centre for Health Education (BZgA), Maarweg 149-161, 50825 Cologne, Germany. <sup>5</sup>Department of Psychosomatic Medicine and Psychotherapy, University Hospital Bonn, Sigmund-Freud-Str. 25, 53127 Bonn, Germany. <sup>6</sup>Institute of Medical Sociology, Health Services Research, and Rehabilitation Science (IMVR), Faculty of Human Sciences and Faculty of Medicine, University of Cologne, Eupener Str. 129, 50933 Cologne, Germany. <sup>7</sup>Organizational Health Services Research, Department for Health Services Research, Carl von Ossietzky University of Oldenburg, Ammerlaender Heerstraße 140, 26129 Oldenburg, Germany.

Received: 9 October 2018 Accepted: 28 March 2019

Published online: 08 April 2019

## References

- HLS-EU Consortium. Comparative report of health literacy in eight EU member states. The European Health Literacy Survey HLS-EU. 2012.
- Prades J, Remue E, van Hoof E, Borrás 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>.
- Stewart M. Patient-centered medicine: transforming the clinical method. 4th ed. Thousand Oaks: SAGE Publ; 1997.
- Taylor C, Atkins L, Richardson A, Tarrant R, Ramirez A-J. Measuring the quality of MDT working: an observational approach. *BMC Cancer*. 2012;12:202. <https://doi.org/10.1186/1471-2407-12-202>.
- Croke JM, El-Sayed S. Multidisciplinary management of cancer patients: chasing a shadow or real value? An overview of the literature. *Curr Oncol*. 2012;19:232–8. <https://doi.org/10.3747/co.19.944>.
- Scholl I, Zill JM, Härter M, Dirmaier J. An integrative model of patient-centeredness - a systematic review and concept analysis. *PLoS One*. 2014;9:e107828. <https://doi.org/10.1371/journal.pone.0107828>.
- Hahlweg P, Didi S, Kriston L, Härter M, Nestoriuc Y, Scholl I. Process quality of decision-making in multidisciplinary cancer team meetings: a structured observational study. *BMC Cancer*. 2017;17:772. <https://doi.org/10.1186/s12885-017-3768-5>.
- Raine R, Wallace I, Nic a' Bhaird C, Xanthopoulou P, Lanceley A, Clarke A, et al. Improving the effectiveness of multidisciplinary team meetings for patients with chronic diseases: a prospective observational study. *Health Services and Delivery Research* 2014. doi:<https://doi.org/10.3310/hsdr02370>.
- Taylor C, Finnegan-John J, Green JSA. "No decision about me without me" in the context of cancer multidisciplinary team meetings: a qualitative interview study. *BMC Health Serv Res*. 2014;14:488. <https://doi.org/10.1186/s12913-014-0488-2>.
- Lamb BW, Taylor C, Lamb JN, Strickland SL, Vincent C, Green JSA, Sevdalis N. 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>.
- Hahlweg P, Hoffmann J, Harter 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:e0139921. <https://doi.org/10.1371/journal.pone.0139921>.
- 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>.
- Street RL, Elwyn G, Epstein RM. Patient preferences and healthcare outcomes: an ecological perspective. *Expert Review of Pharmacoeconomics & Outcomes Research*. 2012;12:167–80. <https://doi.org/10.1586/erp.12.3>.
- van de Haterd J, Voogdt-Pruis H, Raats I, van den Brink R, van Veenendaal H. Preference-sensitive decisions of patients with metastatic breast cancer: the need for decision support. *Patient Experience J*. 2016;3:50–6.
- Stacey D, Samant R, Bennett C. Decision making in oncology: a review of patient decision aids to support patient participation. *CA Cancer J Clin*. 2008;58:293–304. <https://doi.org/10.3322/CA.2008.0006>.
- 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>.
- Haier J. Tasks and limitations of tumor boards [Aufgaben und Grenzen von Tumorkonferenzen]. *Onkologie*. 2016;22:184–91. <https://doi.org/10.1007/s00761-015-2939-8>.
- Medical Association Westfalen-Lippe. Certification of breast cancer centers in North-Rhine Westphalia. Requirement catalogue breast cancer centers: [Verfahren zur Zertifizierung von Brustzentren in NRW. Anforderungskatalog-Brustzentren]; 2018.
- 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>.

20. Vahdat S, Hamzehgardeshi L, Hessam S, Hamzehgardeshi Z. Patient involvement in health care decision making: a review. *Iran Red Crescent Med J*. 2014;16:e12454. <https://doi.org/10.5812/ircmj.12454>.
21. Komatsu H, Nakayama K, Togari T, Suzuki K, Hayashi N, Murakami Y, et al. Information sharing and case conference among the multidisciplinary team improve patients' perceptions of care. *Open Nurs J*. 2011;5:79–85. <https://doi.org/10.2174/1874434601105010079>.
22. 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>.
23. Taylor C, Munro AJ, Glynne-Jones R, Griffith C, Trevatt P, Richards M, Ramirez AJ. Multidisciplinary team working in cancer: what is the evidence? *BMJ*. 2010;340:c951. <https://doi.org/10.1136/bmj.c951>.
24. Hubbard G, Kidd L, Donaghy E. Preferences for involvement in treatment decision making of patients with cancer: a review of the literature. *Eur J Oncol Nurs*. 2008;12:299–318. <https://doi.org/10.1016/j.ejon.2008.03.004>.
25. Salloch S, Ritter P, Wascher 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;19:654–60. <https://doi.org/10.1634/theoncologist.2013-0268>.
26. Devitt B, Philip J, McLachlan S-A. Team dynamics, decision making, and attitudes toward multidisciplinary cancer meetings: health professionals' perspectives. *J Oncol Pract*. 2010;6:e17–20. <https://doi.org/10.1200/JOP.2010.000023>.
27. O'Brien MA, Ellis PM, Whelan TJ, Charles C, Gafni A, Lovrics P, et al. Physician-related facilitators and barriers to patient involvement in treatment decision making in early stage breast cancer: perspectives of physicians and patients. *Health Expect*. 2013;16:373–84. <https://doi.org/10.1111/j.1369-7625.2011.00712.x>.
28. 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>.
29. Ansmann L, Ernstmann N. Patient participation in tumor conferences in breast cancer centers in North-Rhine Westphalia – the perspective of participating patients: [Patientinnenteilnahme an Tumorboards in NRW-Brustzentren – die Sicht teilnehmender Patientinnen]. *Senologie - Zeitschrift für Mammadiagnostik und -therapie*. 2015. <https://doi.org/10.1055/s-0035-1550449>.
30. 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>.
31. Bauer U, Bittlingmayer UH, Richter M, editors. *Health Inequalities: determinants and mechanisms [Determinanten und Mechanismen gesundheitlicher Ungleichheit]*. 1st ed. Wiesbaden: VS Verlag für Sozialwissenschaften; 2008.
32. von Wagner C, Steptoe A, Wolf MS, Wardle J. Health literacy and health actions: a review and a framework from health psychology. *Health Educ Behav*. 2009;36:860–77. <https://doi.org/10.1177/1090198108322819>.
33. Sørensen K, van den Broucke S, Fullam J, Doyle G, Pelikan J, Slonska Z, Brand H. Health literacy and public health: a systematic review and integration of definitions and models. *BMC Public Health*. 2012;12:80. <https://doi.org/10.1186/1471-2458-12-80>.
34. Nutbeam D. The evolving concept of health literacy. *Soc Sci Med*. 2008;67:2072–8. <https://doi.org/10.1016/j.socscimed.2008.09.050>.
35. Berkman ND, Sheridan SL, Donahue KE, Halpern DJ, Viera A, Crotty K, et al. *Health Literacy Interventions and Outcomes: An Updated Systematic Review 2011*: Agency for Healthcare Research and Quality (US).
36. Nouri SS, Rudd RE. Health literacy in the "oral exchange": an important element of patient-provider communication. *Patient Educ Couns*. 2015;98:565–71. <https://doi.org/10.1016/j.pec.2014.12.002>.
37. Schaeffer D, Hurrelmann K, Bauer U, Kolpatzik K. *National Action Plan on Health Literacy. Strengthen the Health Literacy in Germany [Nationaler Aktionsplan Gesundheitskompetenz. Die Gesundheitskompetenz in Deutschland stärken]*. Berlin: KomPart; 2018.
38. Pelikan JM, Dietscher C. Why should and how can hospitals improve their organizational health literacy? [Warum sollten und wie können Krankenhäuser ihre organisationale Gesundheitskompetenz verbessern?] *Bundesgesundheitsblatt Gesundheitsforschung Gesundheitsschutz*. 2015;58:989–95. <https://doi.org/10.1007/s00103-015-2206-6>.
39. Kowalski C, Lee S-YD, Schmidt A, Wesselmann S, Wirtz MA, Pfaff H, Ernstmann N. The health literate health care organization 10 item questionnaire (HLHO-10): development and validation. *BMC Health Serv Res*. 2015;15:47. <https://doi.org/10.1186/s12913-015-0707-5>.
40. Brach C, Keller D, Hernandez LM, Baur C, Parker R, Dreyer B, et al. *Ten attributes of health literate health care organizations*. Washington, DC: Institute of Medicine of the National Academies; 2012. p. 1–27.
41. Dillman DA. *Mail and Telephone Surveys: The Total Design Method*. New York: Wiley; 1978.
42. Halbach SM, Ernstmann N, Kowalski C, Pfaff H, Pfortner T-K, Wesselmann S, Enders A. 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>.
43. Schmidt A, Ernstmann N, Wesselmann S, Pfaff H, Wirtz M, Kowalski C. After initial treatment for primary breast cancer: information needs, health literacy, and the role of health care workers. *Support Care Cancer*. 2016;24:563–71. <https://doi.org/10.1007/s00520-015-2814-6>.
44. Hox JJ. *Multilevel analysis: techniques and applications*. 2nd ed New York NY u.a.: Routledge; 2010.
45. Snijders TAB, Bosker RJ. *Multilevel analysis: an introduction to basic and advanced multilevel modeling*. 2nd ed Los Angeles Calif. u.a.: SAGE Publ; 2012.
46. Ernstmann N, Halbach S, Kowalski C, Pfaff H, Ansmann L. Measuring attributes of health literate health care organizations from the patients' perspective: development and validation of a questionnaire to assess health literacy-sensitive communication (HL-COM). *Z Evid Fortbild Qual Gesundheitswes*. 2017;121:58–63. <https://doi.org/10.1016/j.zefq.2016.12.008>.
47. Say R, Murtagh M, Thomson R. Patients' preference for involvement in medical decision making: a narrative review. *Patient Educ Couns*. 2006;60:102–14. <https://doi.org/10.1016/j.pec.2005.02.003>.
48. Paasche-Orlow MK, Parker RM, Gazmararian JA, Nielsen-Bohman LT, Rudd RR. The prevalence of limited health literacy. *J Gen Intern Med*. 2005;20:175–84. <https://doi.org/10.1111/j.1525-1497.2005.40245.x>.
49. Farmanova E, Bonneville L, Bouchard L. Organizational health literacy: review of theories, frameworks, guides, and implementation issues. *Inquiry*. 2018;55:46958018757848. <https://doi.org/10.1177/0046958018757848>.
50. O' Cathain A, Murphy E, Nicholl J. Three techniques for integrating data in mixed methods studies. *BMJ*. 2010;341:c4587. <https://doi.org/10.1136/bmj.c4587>.
51. Axinn WG, Pearce LD. *Mixed method data collection strategies*. Cambridge: Cambridge University Press; 2006.
52. Scholl I, LaRussa A, Hahlweg P, Kobrin S, Elwyn G. Organizational- and system-level characteristics that influence implementation of shared decision-making and strategies to address them - a scoping review. *Implement Sci*. 2018;13:40. <https://doi.org/10.1186/s13012-018-0731-z>.
53. Siegrist J, editor. *Social inequalities in health: New evidence and policy implications*. 1st ed. Oxford: Oxford Univ. Press; 2010.

**Ready to submit your research? Choose BMC and benefit from:**

- fast, convenient online submission
- thorough peer review by experienced researchers in your field
- rapid publication on acceptance
- support for research data, including large and complex data types
- gold Open Access which fosters wider collaboration and increased citations
- maximum visibility for your research: over 100M website views per year

**At BMC, research is always in progress.**

Learn more [biomedcentral.com/submissions](https://biomedcentral.com/submissions)





3.3. Publication 3: Patient participation in multidisciplinary tumor conferences from the providers' perspective: is it feasible in routine cancer care?

**Heuser, C.**, Diekmann, A., Schellenberger, B., Bohmeier, B., Kuhn, W., Karbach, U., Ernstmann, N. & Ansmann, L. (2020). Patient Participation in Multidisciplinary Tumor Conferences from the Providers' Perspective: Is It Feasible in Routine Cancer Care?. *Journal of multidisciplinary healthcare* (13), 1729–1739. doi:10.2147/JMDH.S283166. Impact Factor: 1,913 (2019).

# Patient Participation in Multidisciplinary Tumor Conferences from the Providers' Perspective: Is It Feasible in Routine Cancer Care?

This article was published in the following Dove Press journal:  
*Journal of Multidisciplinary Healthcare*

Christian Heuser <sup>1</sup>  
Annika Diekmann <sup>1</sup>  
Barbara Schellenberger<sup>1</sup>  
Barbara Bohmeier<sup>1</sup>  
Walther Kuhn<sup>2</sup>  
Ute Karbach<sup>3</sup>  
Nicole Ernstmann<sup>1</sup>  
Lena Ansmann <sup>4</sup>

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

<sup>2</sup>Gynecological Cancer Center Deggendorf, DONAUISAR Hospital, Deggendorf, Germany; <sup>3</sup>Sociology in Rehabilitation, Faculty of Rehabilitation Sciences, Technical University Dortmund, Dortmund, Germany; <sup>4</sup>Division for Organizational Health Services Research, School of Medicine and Health Sciences, Carl von Ossietzky University Oldenburg, Oldenburg, Germany

**Objective:** Recent studies from Germany show that a small amount of breast and gynecological cancer patients participate in multidisciplinary tumor conferences (MTCs) at some cancer centers. One reason for the variation by center might be the providers' attitudes about and experiences with MTC patient participation (MTCpp), which has not been analyzed before. Therefore, it is the aim of this study to analyze the providers' expected or experienced feasibility concerning MTCpp at breast and gynecological cancer centers in Germany.

**Methods:** This paper presents cross-sectional qualitative interview data from the PINTU study. From April to December 2018, n=30 health-care providers from n=6 breast and gynecological cancer centers in North-Rhine-Westphalia, Germany, were interviewed. One-half of the providers had no experience and the other half had experience with MTCpp. Inductive and deductive coding was performed in order to capture the feasibility aspects of participation.

**Results:** MTCpp seems not to be feasible in routine cancer care following providers' expected barriers and negative experiences. However, MTCpp seems to be feasible for selected cancer patients following providers' expected opportunities and positive experiences. Our results show that both provider groups report positive and negative experiences or expectations.

**Conclusion:** The mixed findings regarding expected or experienced feasibility of MTCpp provide first insights into differences concerning MTCpp between organizations. Our results suggest that the providers' perceptions (expectations and experiences) influence the possibility for patients to participate in an MTC in a cancer center.

**Keywords:** multidisciplinary tumor conference, multidisciplinary tumor board, multidisciplinary team meeting, patient participation, health-care provider, content analysis

## Introduction

Multidisciplinary tumor conferences (MTCs) are a well-established structure for decision-making in oncological healthcare worldwide.<sup>1-3</sup> Research done on MTCs has revealed benefits and limitations for providers and patients.<sup>4</sup> Among providers, more effective coordination of healthcare and decision-making was found, which can be explained by a more efficient diagnostic discussion within a multidisciplinary team.<sup>5-9</sup> From the providers' perspective, making recommendations in MTCs is seen as part of physicians' professional self-concept.<sup>10,11</sup> Weekly meetings enable team-based decision-making and better communication between providers of different professions.<sup>12-14</sup> Among patients, MTCs were shown to improve health-related quality of life,<sup>15,16</sup> and

Correspondence: Christian Heuser  
University Hospital Bonn, Venusberg-Campus I, Building 02, Bonn 53127, Germany  
Tel +49 228 287 11545  
Fax +49 228 287 9011545  
Email christian.heuser@ukbonn.de

a positive effect on patient's overall survival has been suggested.<sup>17,18</sup> Prior studies show that patients have a positive opinion of multidisciplinary teams.<sup>19</sup> However, international studies have found that patients perceive a lack of communication about and representation in MTCs.<sup>20–22</sup> Furthermore, a lack of patient information within MTCs, especially about their preferences, can decrease the adherence and effectiveness of MTC decisions significantly.<sup>23–26</sup> This has led to the question how patient characteristics and preferences can be included in MTC decision-making.<sup>27,28</sup> In this context, the question of patient participation in MTCs (MTCpp) has been discussed.

In Germany, different certification programs with their own requirement catalogues exist for breast and gynecological cancer centers: eg by the German Cancer Society (Germany-wide) and by the Medical Association of Westphalia-Lippe (for the state of North Rhine-Westphalia).<sup>29,30</sup> In both requirement catalogues MTCs are mandatory for all certified cancer centers. MTCpp is allowed if patients wish to attend but this is only mentioned in the Medical Association Westphalia's requirement catalog. Previous studies have shown that in Germany, participation is a rare but constant reality in healthcare, with 5–7% of breast cancer patients participating in MTCs, regardless of the certification program.<sup>31–33</sup> The results of these studies also suggest that MTCpp varies by patient characteristics and between the breast cancer centers themselves.<sup>31,33</sup> So far, no explanations for the variation between organizations as well as the feasibility of MTCpp from the providers' perspective exist.

Few studies have explored the attitudes of providers toward MTCpp as well as its potential benefits and risks.<sup>34–38</sup> Still, the question if and how MTCpp is feasible in routine cancer care remains unanswered. Analyzing the providers' perspective is important since their expectations or experiences might influence the possibility for patients to participate in an MTC in a cancer center. To take providers' expectations or experiences into account the conceptual framework for patient-provider communication in cancer care from Feldman-Stewart et al<sup>39</sup> can be used. According to the model, providers' expected or experienced external factors, their attitudes and goals, can be analyzed – in this case regarding the feasibility of MTCpp. External factors can be defined as organizational and system-level factors influencing the providers' communication in MTCs through their impact on provider attitudes. Attitudes, including the providers' needs, skills, values, beliefs and emotions affect the content and form of MTC communication.

Providers' goals are defined as the objective of the providers' communication.

The aim of this study was to analyze the providers' expected or experienced feasibility of patient participation in MTCs in breast and gynecological cancer centers in order to explain differences in MTCpp between organizations.

## Materials and Methods

### Study Design and Sample

The methods section is based on the consolidated criteria for reporting qualitative research, a 32-item checklist for interviews and focus groups.<sup>40</sup> The presented data is part of the multicenter, non-interventional mixed-methods PINTU study conducted at six breast and gynecological cancer centers in Germany's most populous state of North Rhine-Westphalia. PINTU stands for "patient involvement in multidisciplinary tumor conferences in breast cancer care – an exploratory study" and aimed to answer three main research questions: 1) How do MTC with and without patient participation differ in terms of organization, interaction and patient orientation? 2) How do patients experience participation and what are the immediate effects of participation? 3) How do health-care providers evaluate patient participation in MTC in terms of feasibility and quality of decision-making?<sup>41</sup> The study has been approved by the Ethics Committee of the Medical Faculty of the University of Cologne. At three centers, patients regularly participate in MTCs, and at the other three centers, patients do not participate in MTCs. Cancer centers were selected using purposeful sampling criteria,<sup>42,43</sup> varying the size of the center (case volume) and the teaching status (teaching hospital vs non-teaching hospital) because center structures can have an impact on the organization of MTCs.<sup>44</sup>

This paper presents data from qualitative interviews with health-care providers conducted as part of the larger PINTU study. The inclusion criterion for health-care providers was frequent participation in MTCs. With regard to the above-mentioned purposeful sampling, participants are to represent all professional (medical and non-medical) groups and different hierarchical levels involved in MTCs at breast and gynecological cancer centers. Providers with and without experiences with MTCpp were included in the sample in order to capture expected and experienced feasibility of MTCpp at the same time.

## Data Collection

To capture these different perspectives, n=116 providers were invited by e-mail and telephone to participate in the study, and approximately five interviews were conducted at each of the six breast and gynecological cancer centers (n=30, see Table 1). Data were collected from April 2018 until December 2018 by four different researchers (CH, AD, BS, BB) experienced with qualitative research in their field of expertise (sociology, psychology, health services research). Written informed consent was obtained from all participants. The interviews took place at the breast and gynecological cancer centers or were conducted via telephone, they took between 24 and 81 minutes, and no other person was present besides the researcher and the participant. All interviews were recorded by means of an audio

device for future transcription and analyses, according to established standards.<sup>45</sup> Two interviews were not recorded due to lack of participant consent. Instead, memory protocols were obtained. In all cases, field notes were used as additional data. The interview guideline was adjusted after each interview if relevant new aspects were mentioned. When no new aspects emerged in the interviews, data collection was stopped.

## Measures

Semi-structured interviews were conducted to capture the experiences, opinions and concerns of the providers participating in MTCs, especially concerning their external factors, attitudes and goals concerning MTCpp. In general, the interview guideline included the topics of MTC

**Table 1** Description of the Sample (n=30 Providers)

	All Providers (n=30)	Providers with Experiences (n=16)	Providers without Experiences (n=14)
Gender			
Women	19 (63.3%)	11 (68.8%)	8 (57.1%)
Men	11 (36.7%)	5 (31.2%)	6 (42.9%)
Age (years)			
Range	25–61	39–61	25–60
Mean	49	51	46
Categories			
25–37	3 (10%)	0 (0.0%)	3 (21.4%)
38–49	10 (33.3%)	7 (43.8%)	3 (21.4%)
50–61	16 (53.3%)	9 (56.2%)	7 (50.0%)
Missing	1 (3.3%)	0 (0.0%)	1 (7.1%)
Profession			
Gynecologist	12 (40.0%)	6 (37.5%)	6 (42.9%)
Breast Care Nurse	4 (13.3%)	3 (18.8%)	1 (7.1%)
Radiation Oncologist	4 (13.3%)	3 (18.8%)	1 (7.1%)
Psycho-Oncologist	4 (13.3%)	2 (12.5%)	2 (14.3%)
Oncologist	2 (6.7%)	1 (6.3%)	1 (7.1%)
Pathologist	1 (3.3%)	1 (6.3%)	0 (0.0%)
Quality Manager	1 (3.3%)	0 (0.0%)	1 (7.1%)
Diet-Assistant	1 (3.3%)	0 (0.0%)	1 (7.1%)
MTC Documentarist	1 (3.3%)	0 (0.0%)	1 (7.1%)
Professional experience (years)	<1–38	7–33	<1–38
Frequency of MTC participation per month			
Range	1–20	<1–20	1–4
Mean	4	5	3
Time of MTC experience (years)			
Range	<1–20	2–20	<1–14
Mean	8.8	10.0	7.3

organization, interaction and decision-making. Furthermore, providers were asked for the differences they expected or experienced between MTCs with and without patient participation in order to capture expected and experienced feasibility of MTCpp at the same time. Further details of the interview guideline have been reported in the study protocol.<sup>41</sup>

## Data Analysis

The audiotaped interviews were transcribed verbatim, pseudonymized, entered into the software program MAXQDA and analyzed by two independent researchers (CH, AD) from different disciplines (sociology, psychology) in accordance with the well-established methods of content analysis<sup>46,47</sup> in order to increase inter-rater reliability. First, inductively identified codes were modified by deductively derived codes from previous international research on MTCpp.<sup>37,48–50</sup> These codes were used as a coding system for the whole material. Next, categories were inductively developed throughout the material, modified by derived categories from the above-mentioned Feldman-Stewart conceptual framework and compiled by CH and AD. Last, the entire material was coded using the differentiated coding system. Subsequently, the analysis was interpreted and consented within the research team (CH, AD, BS, NE, LA) and the findings were discussed in a group consisting of 8 former interview participants with and without MTCpp experiences and the research team.

## Results

### Sample

The sample consisted of n=19 women and n=11 men from different professional disciplines (Table 1). One-half of the providers (n=16) had experience with MTCpp (see experienced feasibility), whereas the other half of the providers (n=14) had no experience (see expected feasibility). There was a wide range of ages (25–61 years) and work experience (<1–38 years).

### Expected Feasibility of MTC Patient Participation

The coding of the n=14 provider interviews without experience in MTCpp revealed the following possible barriers: greater time requirements and organizational effort, interference with discussion and with the use of medical terminology, lack of own communication skills, lack of patient comprehension of clinical information, emotional reactions

of patients and data protection issues. As potential benefits, these providers expected patients' increased involvement in the MTC decision-making process, patients' better understanding of their own clinical data and competitive advantages for the cancer center. There was a uniform opinion concerning possible barriers and benefits across all three cancer centers without MTCpp. No major differences between the medical and non-medical professions or hierarchical levels could be observed, even if Breast Care Nurses (BCN) were slightly more open for the idea of MTCpp.

### Experienced Feasibility of MTC Patient Participation

The coding of the n=16 providers with experience in MTCpp revealed greater time requirements and organizational effort for some providers, interference with discussion and with the use of medical terminology, lack of patient comprehension as well as emotional reactions of patients during the MTC as negative experiences. Patients' emotional reactions were often addressed directly after the MTC since many providers reported that a BCN or a familiar doctor accompanies patients before and after the MTC. The argument of increased time requirements and organizational effort was not relevant for all MTCpp experienced providers compared to non-experienced providers because only 1–2 patients participate per MTC weekly. The argument of interference with discussion varied among the providers since some reported not adjusting their use of medical terminology in the presence of patients. As positive experiences, providers reported a more effective decision-making process since the goal of the treatment can be defined immediately together with the patients. Furthermore, faster appointments with specialists, a more patient-oriented communication climate and more patient-centered decisions because patients' preferences are included earlier in the treatment process were mentioned. To ensure the success of MTCpp, the providers suggested a small setting and the preselection of informed and interested patients. Overall, there were no major differences between the different professions' opinions. Characteristic quotes of the providers with and without MTCpp experiences are presented in Table 2.

### External Factors of MTCpp

Providers with MTCpp experience reported that the requirement catalog for cancer center accreditation, center self-image, clinical guideline and awareness of patients and their related information are highly important for

**Table 2** Characteristic Quotes of the Providers

	<b>Barriers</b>	<b>Benefits</b>
Providers' expectations	Well, the main argument is actually the time factor. And the related organizational EFFORT. (-) (I: Yes.) (-) Yes, and, um, I believe, (-) when talking with colleagues WITHOUT the patient (-) we talk, (—) well, not more OPENLY, but (-) ARE maybe a little less focused on our choice of words, than WOULD be the case if the patient were present.	I would definitely, um, well, see it as an advantage because the patient could also contribute and have a say (I: Yes.) or ask why (I: Yes.) is that the best decision now, right? Or if he has arguments, um (-) that he has a TOTALLY different opinion, that he could definitely, um, talk about that with the physicians there.
	And (-) well, that is sometimes difficult with the foreign words and with the SPEED at which patients are discussed, too. (-) So that is the question, whether the patient, um, gains anything from that, or even understands any of it? (I: Yes.)	But for patients who, um, (-), well, are take a lot of responsibility for their own health and want to know as much as possible, for them, it's certainly of benefit.
	<b>Negative experiences</b>	<b>Positive experiences</b>
Providers' experiences	But also, they OFTEN said, it's like you are sitting at a tribunal (I: Yes.) and receive your sentence.	So, as I said, ultimately, that tends to be the exception. As an offer, I think, it's important, for the patient to theoretically have this, um, option [...] AND I believe the ad ... /the advantage, um, is that the patient is simply involved in the treatment decision, feels taken SERIOUSLY and maybe simply sees how seriously we take him and, well, um, the CASE. And that it's not simply one person alone DECIDING, but that it's really a group decision, which might give him piece of mind, too. AND, um, they, as a result also get the feeling that they are taking over the reins again themselves. Right, it's not us deciding what they will do, but they decide what we SHOULD do. (I: Yes, yes, yes.)
	And, um, then you just notice that your colleagues generally are more cautious in the discussion. (-) Right, and (-) often, you then might postpone decisions, or you tell patients [...] that this might be discussed in detail directly with the specific physician.	One thing is, I get to know/see (-) the physicians who in some way have to do with my (-) case. AND I, um, might find out um (-) my recommendation a few days BEFORE, that is, EXACTLY at the time when the decision is made (I: Yes.) and not only at the time when the, um, the, um, detailed consultation is scheduled. In case of any questions, she can also directly ask the other partners. Some things (-) can be clarified very directly. They are usually simple things, well/or simple things TO US, right?

MTCpp. The different requirement catalogs for cancer center accreditation were often mentioned. With regard to patient participation, multidisciplinary was regarded as helpful for patients since it allows discussing the diagnostic information in the presence of different professionals. Some providers mentioned that the chief physician was trained at a center where MTCpp was practiced and transferred this practice to the present center. Consequently, the self-image of the whole center is affected, and MTCpp is implemented at the center in question. The content of clinical guidelines was described as strongly guiding the MTC recommendation. Concerning patient participation, on the one hand, it was emphasized that the recommendation must be based on the clinical guideline, and patient preferences were not

allowed to change the recommendation. As a result, MTCpp was not regarded as helpful. On the other hand, providers also described that they discussed the clinical-guideline-based recommendation with patients to arrive at a shared decision. Deviation of the final treatment decision from the clinical-guideline-based MTC recommendation was regarded as highly important by some providers since those deviations are often based on patient preferences. In this context, the criterion of providers' awareness of patient personality and patient-related information becomes important because all of the providers believe that patients and their preferences must be known and diagnostics must be completed before the MTC. These aspects can be summarized as external factors as they possibly affect providers' attitudes concerning MTCpp.



### Attitudes Concerning MTCpp Including Needs, Skills, Values, Beliefs and Emotions

Across all interviews, the providers' central need was to find the best recommendation ("need for truth"). For the providers, the best recommendation should be found on the basis of objectivity, facts and clinical guidelines through a multidisciplinary discussion. Patient or provider emotions should not play any role in the recommendation process. Providers' MTCpp-related skills largely involve aspects of communication and organization. Concerning communication, some providers reported that the patients' presence and the switch to lay language interfered with the discussion. Adequately discussing medical information in the multidisciplinary team but at the same time keeping it understandable for patients is perceived as a challenge. In this context, MTC organization becomes relevant because in some centers, patients enter the MTC after the medical discussion between providers. In this setting, providers did not report conflicts between expert and lay language and discussion. Furthermore, in the view of many providers, patients must be accompanied before, during and after the MTC, for example, by a breast care nurse. Some providers implemented an additional MTCpp setting with fewer providers present. Others described a "natural" preselection of patients since only 5-10% of patients were willing to participate. The providers' values concerning MTCpp may be shaped by the above-mentioned external factor of "center self-image." Two types of values can be differentiated, of which the first one was mentioned by every provider and the second one seen as an add-on. Firstly, MTCs are a professional instrument to make treatment decisions (medical logic). Secondly, MTCs are an instrument for considering patient information, preferences and emotions and involving patients in the decision-making process (social logic). MTC-related beliefs are reflected by the providers' understanding of patient-provider roles in the MTC. Making treatment recommendations was seen as part of the physician's expertise; thus, patients might experience MTCs as a tribunal and therefore should not enter this "field of expertise." Other providers believe that patients should be allowed to enter this "field of expertise" because of transparency reasons and in order to better understand the treatment decision. Furthermore, patient involvement in decision-making was generally regarded as positive, but since this involvement is not ensured by patient participation for some providers, MTCpp was not supported. Several providers mentioned that the patient's sociodemographic background has an immense impact on

the quality and efficiency of the MTC discussion, thereby making participation more or less helpful for different patients. Providers' emotions were hardly addressed in the interviews. Very few situations of uncertainty were mentioned, in which medical information had to be explained to the patient in lay language in front of all colleagues, although providers wanted to be seen as professional.

### Goals Concerning MTCpp

Across all interviews, the main goal was to discuss and establish the best recommendation in accordance with clinical guidelines in a multidisciplinary manner. With regard to MTCpp, potential goal conflicts can be described. MTCs without patients are an important instrument to establish the guideline-based recommendation as the "best decision" in the view of the medical specialists and can be seen as a tool for advanced education in teaching hospitals. Some providers experienced MTCs with patient participation to have a different character: MTCs with patients are seen as a place to ask for information that is not always important for decision-making or treatment. Other providers reported that patient participation leads to decisions that are more congruent with the patients' goals because the jointly defined treatment goal incorporates patient preferences. In the first case, MTCpp was regarded as possibly conflicting with the providers' goal, and in the second case, as supporting the providers' goal.

### Discussion

The aim of the study was to analyze the providers' expected or experienced feasibility of patient participation in MTCs at breast and gynecological cancer centers in order to explain why MTCpp differs between cancer centers. Inductive coding revealed feasibility aspects in the form of opportunities and barriers expressed by providers without MTCpp experience as well as positive and negative experiences from providers experienced with MTCpp. Deductive coding added important themes of the feasibility of MTCpp. These findings suggest that providers' experienced external factors, attitudes and goals can hinder or foster MTCpp. In the following sections, specific aspects of these results are discussed in detail.

### Feasibility of MTC Patient Participation

MTCpp seems not to be feasible in routine cancer care following the providers' anticipated barriers and negative

experiences. However, MTCpp seems to be feasible for selected cancer patients following the providers' perceived opportunities and positive experiences. Our results confirm previous findings from international research concerning providers' views on MTCpp.<sup>34–37,51</sup> Butow et al 2007 reported providers mentioning potential patient anxiety during and after the MTC as well as a conflict between medical and lay language.<sup>35</sup> We can expand Butow's findings concerning the management of patient involvement by describing variations of MTCpp: Patients may enter the MTC after the medical discussion, a smaller MTC setting may be implemented, and patients may be supported by a breast care nurse before, during and after the meeting. Support by a breast care nurse seemed to be an important aspect that was also described by O'Brien et al<sup>51</sup> Whereas providers and patients shared some views of a good MTCpp, physicians "may underestimate the importance [for patients] of feeling comfortable" during the MTC. Our findings from providers experienced with MTCpp show that significant changes in organization and setting are made if patients take part during the discussion of their own case. Furthermore, communication skills to address patients' emotional reactions were seen as highly important by providers experienced with MTCpp which we analyzed more detailed in a different publication on MTCpp.<sup>52</sup> Van Dongen et al and Choy et al recommend adequate support and preparation for the meeting, eg paying attention to patients' willingness and ability to participate, which were also mentioned by providers in this present study. In addition, it seems important for all necessary information to be shared with patients before the MTC.<sup>34,37</sup> The main remaining barrier is increased time requirements, which might be surprising since in Germany, only 5–10% of patients actually participate in an MTC. Concerning decision-making, no hard facts can be presented with this data, but providers reported that MTCpp leads to earlier consideration of patient preferences in the treatment process, potentially leading to more patient-oriented treatment decisions.

### Differences in MTC Patient Participation Between Organizations

Furthermore, our results expand the findings from previous international research concerning the reasons for differences in MTCpp between cancer centers. Previous German studies have shown significant differences in the frequency of MTCpp between breast cancer centers<sup>31,33</sup> but could not

explain them. We were able to explain potential reasons for these differences by studying the providers' experienced external factors, attitudes and goals concerning the feasibility of MTCpp. Importantly, the main MTC goal of defining the best recommendation remains unchanged in MTCs with patients but in a slightly different manner: On the one hand, a medical recommendation must be made and MTCs without patients being perceived as a medical recommendation-issuing committee free from interference by patients' emotions, wishes or questions. On the other hand, the decision-making process with patients' personal and social aspects has to be discussed and MTCs with patient participation are regarded as medical recommendation-issuing committees that need to address patients' emotions, wishes, preferences, questions and social characteristics. These conflicts might be reflected by differences in the possibility for patients to participate in an MTC. These results suggest that providers' expectations and experiences with MTCpp feasibility explain why patient participation in MTCs differs between organizations (cancer centers). Nevertheless, it has to be discussed why on the one hand no major differences between the professions' perceptions in all six cancer centers exist, but on the other hand differences in MTCpp between these centers exist. One hypothesis is that MTCpp is more frequently in non-university hospitals and centers with a lower case volume. As sampling intended to take this variation into account there must be further explanations, eg the degree of patient-centeredness<sup>22</sup> in the center.

### Limitations and Strengths

Our sample consists exclusively of providers from breast and gynecological cancer centers. Therefore, the providers' experiences are based only on MTC communication with women as none of the providers remembered a male breast cancer patient participating in an MTC. Our conclusions consider this important limitation. In general, breast and gynecological cancers are solid tumors, which means that our sample does not include non-solid tumors, eg those of hematological cancer patients, and providers have no experience with non-solid cancer patients. Furthermore, feasibility aspects are based on subjective experiences from providers who might have participated in the interviews because they were more supportive of MTCpp. However, with data from 30 interviews, we have obtained a wide range of detailed expectations and experiences. Nevertheless, we have no comprehensive picture of MTCs in general since observations are not matched to interview data and no patient data or patient interview data



concerning their experiences in MTCs has been analyzed. No patient interview data, eg concerning their reasons for and experiences with MTCpp were included in this study. Patient interview data are also not a part of the PINTU study and a limitation of the project. Instead, patient survey data on their experiences with MTCpp is analyzed in a different study of the PINTU project. Lastly, the study used an observational design as a first step to analyze existing MTC processes, but future research would benefit from interventional study designs.

However, this is one of the first studies analyzing providers' experiences and their external factors, attitudes and goals concerning MTCpp and if MTCpp is feasible in routine cancer care. The interviews are not biased by hierarchies or other professional groups, which is a common problem while conducting focus groups with providers. The presented results are the first explanation of differences in MTCpp between cancer centers. This is an important step for getting deeper insights into determinants of MTCpp evolving from providers' perceptions. Lastly, this is the first use and adaption of the well-established Feldman-Stewart framework of communication in cancer care for MTC and MTCpp.

## Implications

The findings can help explain differences concerning MTCpp between German breast and gynecological cancer centers as external factors, attitudes and goals of providers take important feasibility aspects into account. However, we only analyzed the providers' characteristics within the framework. Thus, future research should firstly address patients' external factors, attitudes and goals influencing their MTC communication with providers with the help of patient interview data, eg concerning their reasons for and experiences with MTCpp. Secondly, the feasibility analyzed for providers at breast and gynecological cancer centers should be transferred to other cancer entities, eg non-solid tumors or cancer entities that affect mainly men. Thirdly, for research on MTCs, a time dimension could be added to the framework in order to analyze communication processes before, during and after the MTC or other healthcare processes in general. Lastly, our analysis revealed an important difference between the guideline-based recommendation that must be established during MTCs and decision-making with patients during or after MTC. For future research, we strongly recommend defining and differentiating the unit of analysis by breaking it down into the recommendation or decision. This might

explain divergent results concerning the need for MTCpp: While Massoubre et al<sup>36</sup> found that 97% of MTC recommendations without patient participation were followed and concluded that MTCpp is not essential, Hollunder et al found a great lack of MTC decision adherence caused by missing patient information and failure to consider their preferences<sup>23</sup> which might increase the need for MTCpp, even in the case of limited clinical evidence<sup>53</sup> or limited multidisciplinary discussion.<sup>54,55</sup> For future research, this should firstly mean that patient outcomes have to be analyzed as they are an important part of general MTC outcome quality.<sup>49,50,56–59</sup> Some patient outcomes will be analyzed in the quantitative part of the PINTU study. Secondly, this underlines the need for a patient-centered approach in oncological healthcare taking into account patients' preferences regardless of whether patients participate in MTC or not. As shared-decision-making in MTCs seems to be challenging<sup>60</sup> different ways of involving patient preferences in MTCs have to be discussed in the future.

## Conclusions

This study has contributed to filling the research gap on providers' experiences of and expectations for the feasibility of MTCpp. The providers' perceptions of feasibility are one influencing factor for MTCpp and therefore provide first insights into differences concerning MTCpp between cancer centers. Overall, future research and practice should focus on processes in MTCs, eg by considering differences in communication between MTCs with and without patient participation and their impact on the quality of decision-making and on patient outcomes (eg anxiety, quality of life) and patient-reported experiences (eg experienced patient-centered care). These questions must be answered before any specific recommendations for patients, providers and cancer centers concerning MTCs can be developed.

## Data Sharing Statement

Data and all other materials for this study are kept at the Center for Health Communication and Health Services Research, University of Bonn, University Hospital Bonn, Germany. The datasets generated and analyzed during the current study are not publicly available due to terms of written informed consent to which the participants agreed but are available from the corresponding author on reasonable request.

## Ethics Approval and Informed Consent

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

## Trial Registration

German Clinical Trials Register (DRKS), DRKS00012552, registered prospectively on 16.06.2017, [https://www.drks.de/drks\\_web/navigate.do?navigationId=trial.HTML&TRIAL\\_ID=DRKS00012552](https://www.drks.de/drks_web/navigate.do?navigationId=trial.HTML&TRIAL_ID=DRKS00012552).

## Acknowledgments

We would like to thank all of the providers and all breast and gynecological cancer centers for participating in this study.

## Author Contributions

All authors made a significant contribution to the work reported, whether that is in the conception, study design, execution, acquisition of data, analysis and interpretation, or in all these areas; took part in drafting, revising or critically reviewing the article; gave final approval of the version to be published; have agreed on the journal to which the article has been submitted; and agree to be accountable for all aspects of the work.

## Funding

This study was funded by The German Cancer Aid (Grant number: 70112286).

## Disclosure

Prof. Dr. Lena Ansmann report grants from German Cancer Aid, during the conduct of the study. The authors report no other conflicts of interest in this work.

## References

- Fleissig A, Jenkins V, Catt S, Fallowfield L. Multidisciplinary teams in cancer care: are they effective in the UK? *Lancet Oncol*. 2006;7(11):935–943. doi:10.1016/S1470-2045(06)70940-8
- Saini KS, Taylor C, Ramirez A-J, et al. Role of the multidisciplinary team in breast cancer management: results from a large international survey involving 39 countries. *Ann Oncol*. 2012;23(4):853–859. doi:10.1093/annonc/mdr352
- Taylor C, Munro AJ, Glynne-Jones R, et al. Multidisciplinary team working in cancer: what is the evidence? *BMJ*. 2010;340(mar23 2):c951. doi:10.1136/bmj.c951
- 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
- Raine R, Wallace I, Nic A' Bhairst C, et al. Improving the effectiveness of multidisciplinary team meetings for patients with chronic diseases: a prospective observational study. *Health Ser Deliv Res*. 2014;37(2). doi:10.3310/hsdr02370
- National Cancer Action Team. *The Characteristics of an Effective Multidisciplinary Team (MDT)*. London; 2010.
- Chang JH, Vines E, Bertsch H, et al. The impact of a multidisciplinary breast cancer center on recommendations for patient management. *Cancer*. 2001;91(7):1231–1237. doi:10.1002/1097-0142(20010401)91:7<1231:AID-CNCR1123>3.0.CO;2-K
- Cianfrocca ME, Shelby M, Birdi S, et al. A multidisciplinary team approach to efficient breast cancer diagnosis. *JCO*. 2016;34(7\_suppl):88. doi:10.1200/jco.2016.34.7\_suppl.88
- Rosell L, Wihl J, Nilbert M, Malmström M. Health professionals' views on key enabling factors and barriers of national multidisciplinary team meetings in cancer care: a qualitative study. *J Multidiscip Healthc*. 2020;13:179–186. doi:10.2147/JMDH.S240140
- Salloch S, Ritter P, Wascher 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):654–660. doi:10.1634/theoncologist.2013-0268
- National Cancer Action Team. *Multidisciplinary Team Members' Views About MDT Working: Results from a Survey Commissioned by the National Cancer Action Team*. London; 2009.
- Harrison JD, Choy ET, Spillane A, Butow P, Young JM, Evans A. Australian breast cancer specialists' involvement in multidisciplinary treatment planning meetings. *Breast*. 2008;17(4):335–340. doi:10.1016/j.breast.2008.03.001
- Macaskill EJ, Thrush S, Walker EM, Dixon JM. Surgeons' views on multi-disciplinary breast meetings. *Eur J Cancer*. 2006;42(7):905–908. doi:10.1016/j.ejca.2005.12.014
- Devitt B, Philip J, McLachlan S-A. Team dynamics, decision making, and attitudes toward multidisciplinary cancer meetings: health professionals' perspectives. *J Oncol Pract*. 2010;6(6):e17–20. doi:10.1200/JOP.2010.000023
- Croke JM, El-Sayed S. Multidisciplinary management of cancer patients: chasing a shadow or real value? An overview of the literature. *Curr Oncol*. 2012;19(4):232–238. doi:10.3747/co.19.944
- Street RL, Elwyn G, Epstein RM. Patient preferences and healthcare outcomes: an ecological perspective. *Expert Rev Pharmacoecon Outcomes Res*. 2012;12(2):167–180. doi:10.1586/erp.12.3
- Hong NJL, Wright FC, Gagliardi AR, Paszat LF. Examining the potential relationship between multidisciplinary cancer care and patient survival: an international literature review. *J Surg Oncol*. 2010;102(2):125–134. doi:10.1002/jso.21589
- Kesson EM, Allardice GM, George WD, Burns HJG, Morrison DS. Effects of multidisciplinary team working on breast cancer survival: retrospective, comparative, interventional cohort study of 13 722 women. *BMJ*. 2012;344(apr26 1):e2718. doi:10.1136/bmj.e2718
- Lamb BW, Jalil RT, Shah S, et al. Cancer patients' perspectives on multidisciplinary team working: an exploratory focus group study. *Urol Nurs*. 2014;34(2):83–91. doi:10.7257/1053-816X.2014.34.2.83
- Taylor C, Finnegan-John J, Green JSA. "No decision about me without me" in the context of cancer multidisciplinary team meetings: a qualitative interview study. *BMC Health Serv Res*. 2014;14:488. doi:10.1186/s12913-014-0488-2

21. Hamilton DW, Heaven B, Thomson RG, Wilson JA, Exley C. Multidisciplinary team decision-making in cancer and the absent patient: a qualitative study. *BMJ Open*. 2016;6(7):e012559. doi:10.1136/bmjopen-2016-012559
22. Hahlweg P, Hoffmann J, Harter 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(10):e0139921. doi:10.1371/journal.pone.0139921
23. Hollunder S, Herrlinger U, Zipfel M, et al. Cross-sectional increase of adherence to multidisciplinary tumor board decisions. *BMC Cancer*. 2018;18(1):936. doi:10.1186/s12885-018-4841-4
24. Rajan S, Foreman J, Wallis MG, Caldas C, Britton P. Multidisciplinary decisions in breast cancer: does the patient receive what the team has recommended? *Br J Cancer*. 2013;108(12):2442–2447. doi:10.1038/bjc.2013.267
25. Morement H, Harrison R, Taylor-Robinson SD. The multidisciplinary team meeting in the UK from the patients' perspective: comments and observations from cholangiocarcinoma patients and their families. *Int J Gen Med*. 2017;10:305–310. doi:10.2147/IJGM.S145029
26. Hoinville L, Taylor C, Zasada M, Warner R, Pottle E, Green J. Improving the effectiveness of cancer multidisciplinary team meetings: analysis of a national survey of MDT members' opinions about streamlining patient discussions. *BMJ Open Qual*. 2019;8(2):e000631. doi:10.1136/bmjopen-2019-000631
27. Lamb BW, Taylor C, Lamb JN, et al. Facilitators and barriers to teamworking and patient centeredness in multidisciplinary cancer teams: findings of a national study. *Ann Surg Oncol*. 2013;20(5):1408–1416. doi:10.1245/s10434-012-2676-9
28. Bate J, Wingrove J, Donkin A, Taylor R, Whelan J. Patient perspectives on a national multidisciplinary team meeting for a rare cancer. *Eur J Cancer Care (Engl)*. 2019;28(2):e12971. doi:10.1111/ecc.12971
29. German Cancer Aid. *Interdisciplinary S3-Guideline for Diagnostic, Therapy, and Rehabilitation of Breast Cancer: [Interdisziplinäre S3-Leitlinie Für Die Diagnostik, Therapie Und Nachsorge Des Mammakarzinoms]*. 2012.
30. Ärztekammer W-L. *Certification of breast cancer centers in North-Rhine Westphalia. Requirement catalogue breast cancer centers: [Verfahren zur Zertifizierung von Brustzentren in NRW. Anforderungskatalog-Brustzentren]*. 2018.
31. 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. doi:10.1186/s12885-019-5546-z
32. 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. doi:10.1016/j.breast.2018.12.012
33. Ansmann L, Kowalski C, Pfaff H, Wuerstlein R, Wirtz MA, Ernstmann N. Patient participation in multidisciplinary tumor conferences. *Breast*. 2014;23(6):865–869. doi:10.1016/j.breast.2014.09.004
34. 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. doi:10.1016/j.breast.2006.10.002
35. 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. doi:10.1002/cncr.23007
36. Massoubre J, Lapeyre M, Pastourel R, et al. Will the presence of the patient at multidisciplinary meetings influence the decision in head and neck oncology management? *Acta Otolaryngol*. 2018;138(2):185–189. doi:10.1080/00016489.2017.1384059
37. van Dongen JJJ, Habets IGJ, Beurskens A, van Bokhoven MA. Successful participation of patients in interprofessional team meetings: a qualitative study. *Health Expect*. 2017;20(4):724–733. doi:10.1111/hex.12511
38. van Dongen JJJ, de Wit M, Smeets HWH, Stoffers E, van Bokhoven MA, Daniëls R. "They are talking about me, but not with me": a focus group study to explore the patient perspective on interprofessional team meetings in primary care. *Patient*. 2017;10(4):429–438. doi:10.1007/s40271-017-0214-3
39. Feldman-Stewart D, Brundage MD, Tishelman C. A conceptual framework for patient-professional communication: an application to the cancer context. *Psychooncology*. 2005;14(10):801–809. doi:10.1002/pon.950
40. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *Int J Qual Health Care*. 2007;19(6):349–357. doi:10.1093/intqhc/mzm042
41. 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. doi:10.1136/bmjopen-2018-024621
42. Patton MQ. Enhancing the quality and credibility of qualitative analysis. *Health Serv Res*. 1999;34(5 Pt 2):1189–1208.
43. Palinkas LA, Aarons GA, Horwitz S, Chamberlain P, Hurlburt M, Landsverk J. Mixed method designs in implementation research. *Adm Policy Ment Health*. 2011;38(1):44–53. doi:10.1007/s10488-010-0314-z
44. Radecki SE, Nyquist JG, Gates JD, Abrahamson S, Henson DE. Educational characteristics of tumor conferences in teaching and non-teaching hospitals. *J Cancer Educ*. 2009;9(4):204–216.
45. Flick U, Kvale S, Angrosino MV, et al. eds. *The Sage Qualitative Research Kit*. London: SAGE; 2007.
46. Kuckartz U. *Qualitative Inhaltsanalyse: Methoden, Praxis, Computerunterstützung*. 4 ed. Weinheim: Beltz Juventa; 2018.
47. Kuckartz U. *Analyzing Qualitative Data with MAXQDA: Text, Audio, and Video*. [Place of Publication Not Identified]. SPRINGER; 2019.
48. 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. doi:10.1245/s10434-016-5347-4
49. Taylor C, Atkins L, Richardson A, Tarrant R, Ramirez A-J. Measuring the quality of MDT working: an observational approach. *BMC Cancer*. 2012;12(1):202. doi:10.1186/1471-2407-12-202
50. Hahlweg P, Didi S, Kriston L, Härter M, Nestoriuc Y, Scholl I. Process quality of decision-making in multidisciplinary cancer team meetings: a structured observational study. *BMC Cancer*. 2017;17(1):772. doi:10.1186/s12885-017-3768-5
51. O'Brien MA, Ellis PM, Whelan TJ, et al. Physician-related facilitators and barriers to patient involvement in treatment decision making in early stage breast cancer: perspectives of physicians and patients. *Health Expect*. 2013;16(4):373–384. doi:10.1111/j.1369-7625.2011.00712.x
52. Diekmann A, Heuser C, Schellenberger B, et al. Patient participation in multidisciplinary tumor conferences: providers' perceptions of patients' need satisfaction and emotional experiences. *Psychooncology*. 2020;29(8):1263–1271. doi:10.1002/pon.5413
53. Lassalle R, Marold J, Schöbel M, et al. Entscheidungsprozesse im Tumorboard bei eingeschränkter Evidenzlage. *Laryngorhinotologie*. [Decision process in a multidisciplinary cancer team with limited evidence]. 2014;93(4):237–243. doi:10.1055/s-0033-1353199
54. Soukup T, Murtagh G, Lamb BW, Green J, Sevdalis N. *How Multidisciplinary are Multidisciplinary Case Reviews in Cancer Care? Analysis of Team Decision-Making Fidelity*. 2019.
55. 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. doi:10.2147/jmdh.s196660
56. Offermanns G, Koldzic E, Schweiger A. Qualitätsentwicklung in der onkologischen Versorgung durch multiprofessionelle Teamarbeit am Beispiel von Tumorboards: ein Überblick. *Public Health Forum*. 2019;27(3):205–207. doi:10.1515/pubhef-2019-0050

57. 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(8):2116–2125. doi:10.1245/s10434-011-1675-6
58. Evans L, Donovan B, Liu Y, Shaw T, Harnett P. A tool to improve the performance of multidisciplinary teams in cancer care. *BMJ Open Qual*. 2019;8(2):e000435. doi:10.1136/bmj-oq-2018-000435
59. Houssami N, Sainsbury R. Breast cancer: multidisciplinary care and clinical outcomes. *Eur J Cancer*. 2006;42(15):2480–2491. doi:10.1016/j.ejca.2006.05.023
60. 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*. 2020. doi:10.1016/j.pec.2020.09.007

### Journal of Multidisciplinary Healthcare

Dovepress

### Publish your work in this journal

The Journal of Multidisciplinary Healthcare is an international, peer-reviewed open-access journal that aims to represent and publish research in healthcare areas delivered by practitioners of different disciplines. This includes studies and reviews conducted by multidisciplinary teams as well as research which evaluates the results or conduct of such teams or healthcare processes in general. The journal

covers a very wide range of areas and welcomes submissions from practitioners at all levels, from all over the world. The manuscript management system is completely online and includes a very quick and fair peer-review system. Visit <http://www.dovepress.com/testimonials.php> to read real quotes from published authors.

Submit your manuscript here: <https://www.dovepress.com/journal-of-inflammation-research-journal>

3.4. Publication 4: How do breast cancer patients experience multidisciplinary tumor conferences? - A description from the patient perspective

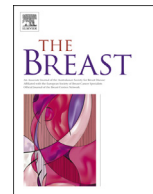
Diekmann, A., **Heuser, C.**, Ernstmann, N., Geiser, F., Groß, S. E., Midding, E., Pfaff, H. & Ansmann, L. (2019). How do breast cancer patients experience multidisciplinary tumor conferences? - A description from the patient perspective. *Breast* 44, 66–72. doi:10.1016/j.breast.2018.12.012. Impact Factor: 3,754 (2019).





Contents lists available at ScienceDirect

The Breast

journal homepage: [www.elsevier.com/brst](http://www.elsevier.com/brst)

## Original article

## How do breast cancer patients experience multidisciplinary tumor conferences? – A description from the patient perspective



Annika Diekmann<sup>a, b, c, \*</sup>, Christian Heuser<sup>a, b, c</sup>, Nicole Ernstmann<sup>a, b, c</sup>,  
 Franziska Geiser<sup>b, c</sup>, Sophie Elisabeth Groß<sup>d, e</sup>, Evamarie Midding<sup>a, b, c</sup>, Holger Pfaff<sup>d</sup>,  
 Lena Ansmann<sup>f</sup>

<sup>a</sup> Center for Health Communication and Health Services Research (CHSR), University Hospital Bonn, Sigmund-Freud Straße 25, 53127 Bonn, Germany

<sup>b</sup> Department for Psychosomatic Medicine and Psychotherapy, Faculty of Medicine, University Hospital Bonn, Sigmund-Freud Straße 25, 53127 Bonn, Germany

<sup>c</sup> Center for Integrated Oncology Bonn (CIO), University Hospital Bonn, Sigmund-Freud Straße 25, 53127 Bonn, Germany

<sup>d</sup> Institute of Medical Sociology, Health Services Research and Rehabilitation Science (IMVR), Faculty of Human Sciences and Faculty of Medicine, University of Cologne, Eupener Straße 129, 50933 Cologne, Germany

<sup>e</sup> Institute of Health Services Research, LVR-Clinics, Wilhelm-Griesinger-Straße 23, 51109 Cologne, Germany

<sup>f</sup> Department of Health Services Research, Faculty of Medicine and Health Sciences, Carl von Ossietzky University Oldenburg, Ammerländer Heerstraße 140, 26129 Oldenburg, Germany

## ARTICLE INFO

## Article history:

Received 17 October 2018

Received in revised form

4 December 2018

Accepted 26 December 2018

Available online 4 January 2019

## Keywords:

Breast cancer

Multidisciplinary tumor conference

Patient involvement

Patient participation

Tumor board

## ABSTRACT

**Objectives:** Aim of this study was to investigate the experiences of breast cancer patients who participated in multidisciplinary tumor conferences (MTCs).

**Study design:** Data from two consecutive years of an annual postal survey of patients with primary breast cancer were combined. Data was collected between February and July 2015 (response rate 72%) and 2016 (response rate 73%) from N = 8893 patients (ICD-10 C50) after hospital discharge from 86 breast cancer center hospitals in North Rhine-Westphalia, Germany. The study used a mixed-methods design. Standardized quantitative survey questions were analyzed descriptively and an open-ended question was analyzed using qualitative content analysis.

**Results:** Around 9% of the patients were invited to participate in a multidisciplinary tumor conference (MTC) and 49% of the invited patients reported actual participation in a MTC. Approximately 87% of those patients did not regret their participation in the MTC. The qualitative analysis from the open-ended question indicated that MTC participation was perceived by patients as being both supportive and informative ( $n = 109$  expressions). However, some patients reported difficult experiences and emotional reactions during and after participation ( $n = 37$  expressions). Altogether, the patients' perception was divided into positive and negative, cognitive and emotional experiences following participation in a MTC. **Conclusion:** The perception of the MTCs varies between the participating patients. Further research on advantages and disadvantages for patients and particularly on the feasibility from the provider's perspective is necessary.

© 2019 The Authors. Published by Elsevier Ltd. This is an open access article under the CC BY-NC-ND license (<http://creativecommons.org/licenses/by-nc-nd/4.0/>).

## 1. Introduction

With around 71,000 new cases diagnosed every year in Germany, breast cancer is the most commonly diagnosed cancer in women [1]. Currently, one out of eight women in Germany are

diagnosed with breast cancer during her lifetime, and 17,850 women become deceased as a result of this disease annually [2]. The experience of breast cancer influences the patients' psychological condition and frequently leads to anxiety or depressive disorders [3,4]. The global impact of this disease on the woman's body and mind requires the need for holistic treatments [5].

Progress in cancer research has given rise to new diagnostic and treatment options for breast cancer patients [6]. Therefore, oncological care is becoming more complex and requires the cooperation of a multidisciplinary team of specialists [7]. In recent years, a

\* Corresponding author. Center for Health Communication and Health Services Research (CHSR), University Hospital Bonn, Sigmund-Freud Straße 25, 53127 Bonn, Germany.

E-mail address: [Annika.Diekmann@ukbonn.de](mailto:Annika.Diekmann@ukbonn.de) (A. Diekmann).

multidisciplinary approach to managing breast cancer has become the standard of care [6–9]. Multidisciplinary cancer care (MCC) describes the collaborative work of relevant professionals from different disciplines working together to support a patient through their cancer treatment journey [5]. This type of care is multifactorial and involves a number of factors which include: increased coordination of care, better communication between health care providers, comprehensive and integrated treatment decisions as well as enhanced access to clinical trials [8,10–13]. Several studies have reported an association between improved patient satisfaction and survival rates [8,11,12].

A common process for implementing MCC involves the organization of multidisciplinary tumor conferences (MTCs). MTCs are regular meetings comprising of a multidisciplinary treatment team of health care specialists who are involved at differing stages of a cancer patient's management plan [11,12,14]. The treatment team consists of various medical specialists who are involved in breast cancer care [6,13,15]. MTCs are internationally established and are a requirement in Germany by the certification catalogue for breast centers of the German Cancer Society and the Medical Council Westphalia-Lippe, Germany [16,17]. According to a patient survey, conducted in breast cancer centers in North-Rhine Westphalia, patients are invited to participate in tumor conferences at some breast cancer centers. The invitation depends on a number of patient characteristics [14]. Typically, only few patients take part in MTCs, resulting in a dearth of available data on the distribution, risks and benefits of patient participation in MTCs [14,18]. The provider perspective on patient participation in MTCs are largely unexplored. An Australian study reported on the provider perspective of breast cancer patient's attending MTCs and highlighted that surgeons, medical oncologists and radiation oncologists were not supportive of the idea of patient participation in treatment planning meetings, predominantly due to the psychosocial concerns they felt were experienced during and following the meeting attended by the patient. In addition, health care providers found that they had to adapt the use of medical terminology to describe the patient's condition, which at times restricted communication and discussion with other health professionals at the multidisciplinary tumor conference (MTC). In contrast, the majority of nurses and patient advocates supported the involvement of breast cancer patients in the MTC as they felt that the patient could be encouraged and empowered. Moreover, they observed that the interactive establishment of the management plan resulted in better informed and supported patients through their cancer treatment journey as compared with standard routine care. Furthermore, the participation would facilitate a collaborative decision-making model in order to enhance communication between providers and patients [18]. Another Australian study reporting on outcomes generated from focus groups with health-care providers, report provider's rejection of patient participation in MTCs. Providers were concerned about a patient's ability to deal with the information being discussed [9].

A pilot study of 30 breast cancer patients explored the acceptability and feasibility of involving these patients in MTCs. The majority of the patients recommended the participation and valued the involvement as being helpful. However, some patients reported negative experiences regarding participation, including increased anxiety, being overwhelmed by the information discussed or experiencing difficulties interacting with the providers during the MTC [19]. This Australian pilot study is an intervention study. It combined both quantitative and qualitative data by using questionnaires the patients filled out before and after the MTC as well as qualitative interviews with the breast care nurses after the MTC. Compared to the Australian pilot study our study is not based on an intervention but is an exploratory study and observes how the

patient's experience participation in a MTC by using an open-ended question about how the patient's experienced the MTC. Since answering this question was completely optional it can be assumed that the responding patients had a particular need to communicate their experiences. This study builds on intuitive, unfiltered data that can serve as a starting point for future qualitative studies, which can review the issues that patient's mentioned in our study in-depth.

To date, there have been few studies investigating the patient's experience regarding participation in a MTC. Further benefits and risks of patient participation in a MTC are widely unexplored. The aim of this study was to bridge the gap regarding 'How do patient's experience their participation in MTCs?'

## 2. Materials and methods

### 2.1. Study design and sample

Data from two consecutive years of an annual postal survey were conducted at 86 breast cancer center hospitals in North Rhine-Westphalia, Germany. Data were collected between February and July of the years 2015 and 2016 and from patients, who (1) were newly diagnosed with breast cancer (ICD-10 C50), (2) had undergone primary breast cancer surgery during their current hospital stay, (3) had at least one malignancy and (4) had at least one postoperative histology. Patient recruitment took place in the breast cancer centers. The hospital staff provided the research team with patient clinical characteristics, which included: stage and grade of tumor. Before being discharged, patients provided written consent to take part in the survey. The patient survey was designed utilizing the Dillman Total Design Method [20]. Further details of the survey have been reported elsewhere [21,22]. The study received the approval from the ethics committee of the Faculty of Medicine of the University of Cologne, Germany.

### 2.2. Instruments

For the survey, the Cologne Patient Questionnaire – Breast Cancer (KPF-BK) was used [23]. This breast cancer-specific version of the Cologne Patient Questionnaire included: aspects of hospital organization, patient information and satisfaction as well as interaction between healthcare providers and patients. For the following investigation, the question: "Were you asked if you wanted to participate in the tumor conference?" was analyzed. The response options were: (1) "Yes, and I did", (2) "Yes, but I did not", (3) "No", and (4) "I do not remember."

A variable for "invitation to participate" was established by grouping together patients who received an invitation, regardless of their actual participation, versus patients who reported that they had not been invited. A variable for "participation in the MTC" was established for patients who reported that they had participated in the MTC [14]. Patients who indicated that they participated in a MTC were asked the subsequent open-ended question: "Please briefly describe how you experienced the MTC." In addition, socio-demographic information was also collected and included: age, type of health insurance, native language, partnership status and highest level of school education.

### 2.3. Analysis

The study used a mixed methods approach with a sequential explanatory design, which included both quantitative and qualitative analysis [24]. We conducted descriptive analysis using SPSS version 25 (IBM SPSS Statistics, 2017). Differences between patients, who participated in a MTC, vs. patients, who did not participate in a MTC as well as differences between patients, who

**Table 1**  
Descriptive results of the patients' characteristics of the whole sample (N = 8893), the participating patients' in the MTC (n = 408), the non-participating patients' (n = 8032) and the patients who answered the open-ended question (n = 188).

Variables	Response trait	Total (%)	Non-participation (%)	Participation (%)	p-value	Participation (%)	Open-ended question (%)	p-value
UICC Stage	Stage 0	553 (7.5)	498 (7.5)	29 (8.6)	0.778	29 (8.6)	16 (10.4)	0.789
	Stage I	3371 (45.7)	3053 (45.8)	161 (47.8)		161 (47.8)	67 (43.5)	
	Stage II	2551 (34.6)	2302 (34.6)	106 (31.5)		106 (31.5)	53 (34.4)	
	Stage III	645 (8.7)	575 (8.6)	30 (8.9)		30 (8.9)	11 (7.1)	
	Stage IV	262 (3.5)	231 (3.5)	11 (3.3)		11 (3.3)	7 (4.5)	
	Missing	1511 (–)	1373 (–)	71 (–)		71 (–)	34 (–)	
Grading	G1	1207 (14.6)	1108 (14.9)	47 (12.5)	0.308	47 (12.5)	27 (15.8)	0.920
	G2	4768 (57.8)	4284 (57.4)	230 (61.0)		230 (61.0)	88 (51.5)	
	G3	2281 (27.6)	2065 (27.7)	100 (26.5)		100 (26.5)	56 (32.7)	
	Missing	637 (–)	575 (–)	31 (–)		31 (–)	17 (–)	
	Age	18–29	33 (0.4)	31 (0.4)		2 (0.5)	2 (0.5)	
30–39	275 (3.1)	247 (3.1)	20 (4.9)	20 (4.9)	8 (4.3)			
40–49	1271 (14.3)	1165 (14.5)	46 (11.3)	46 (11.3)	27 (14.4)			
50–59	2506 (28.3)	2282 (28.5)	115 (28.3)	115 (28.3)	49 (26.2)			
60–69	2423 (27.3)	2188 (27.3)	119 (29.2)	119 (29.2)	46 (24.6)			
70–79	1741 (19.6)	1553 (19.4)	88 (21.6)	88 (21.6)	45 (24.1)			
>80	612 (6.9)	541 (6.8)	17 (4.2)	17 (4.2)	12 (6.4)			
Type of health insurance	Statutory	6401 (72.7)	5800 (72.8)	286 (70.8)	0.001	286 (70.8)	144 (76.6)	0.156
	Statutory with additional private insurance	1368 (15.6)	1232 (15.5)	74 (18.3)		74 (18.3)	26 (13.8)	
	Private	995 (11.3)	900 (11.3)	42 (10.4)		42 (10.4)	17 (9.0)	
	Other	24 (0.3)	37 (0.5)	2 (0.4)		2 (0.4)	1 (0.5)	
	Missing	89 (–)	63 (–)	4 (–)		4 (–)	0 (–)	
	Native language	German	8137 (92.8)	7379 (93.0)		356 (88.8)	0.001	
Other	628 (7.2)	554 (7.0)	45 (11.2)	45 (11.2)	13 (7.0)			
Missing	128 (–)	99 (–)	7 (–)	7 (–)	3 (–)			
Living with partner	Yes	6201 (71.3)	5639 (71.5)	283 (71.3)	0.918	283 (71.3)	135 (72.2)	0.679
	No	2497 (28.7)	2245 (28.5)	114 (28.7)		114 (28.7)	52 (27.8)	
	Missing	195 (–)	148 (–)	11 (–)		11 (–)	1 (–)	
Having Children	Yes	6883 (80.9)	6241 (81.1)	300 (76.1)	0.016	300 (76.1)	145 (78.0)	0.376
	No	1628 (19.1)	1459 (18.9)	94 (23.9)		94 (23.9)	41 (22.0)	
	Missing	382 (–)	332 (–)	14 (–)		14 (–)	2 (–)	
Highest level of school education <sup>a</sup>	No lower secondary school education	164 (1.9)	138 (1.7)	14 (3.5)	0.044	14 (3.5)	4 (2.2)	0.061
	Lower secondary school education	3622 (41.6)	3264 (41.4)	159 (40.1)		159 (40.1)	76 (40.8)	
	Intermediate secondary school education	2307 (26.5)	2121 (26.9)	91 (22.9)		91 (22.9)	41 (22.0)	
	Entrance certificate for a university of applied sciences	953 (10.9)	863 (10.9)	49 (12.3)		49 (12.3)	22 (11.8)	
	University entrance certificate	1559 (17.9)	1405 (17.8)	76 (19.1)		76 (19.1)	39 (21.0)	
	Other	109 (1.3)	96 (1.2)	8 (2.0)		8 (2.0)	4 (2.2)	
	Missing	179 (–)	145 (–)	11 (–)		11 (–)	2 (–)	

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

<sup>a</sup> In Germany, educational levels are named as follows in ascending order according to years of schooling: (1) ohne Volks- und Hauptschulabschluss (no lower school education), (2) Volks- und Hauptschulabschluss (lower secondary education), (3) Realschule/Polytechnische Oberschule 10. Klasse (intermediate secondary school education), (4) Fachhochschulreife (entrance certificate for a university of applied sciences), (5) Hochschulreife (university entrance certificate).

participated in a MTC, vs. patients, who completed the open-ended question were analyzed by calculating chi-square. For qualitative analysis, data was transcribed and analyzed using qualitative content analysis according to Miles, Huberman and Saldaña [25]. For managing the data, MAXQDA software version 12.2.1 was used. Coding was deductive and inductive. Inductively identified codes were complemented and modified by deductively derived frames. The coding process was conducted by two researchers separately, and regular consultations were carried out within the research team for validation.

### 3. Results

#### 3.1. Descriptive results

The sample consisted of N = 8893 patients. The response rate of

the survey was 72% (2015) and 73% (2016). **Table 1** highlights patient characteristics. Around 87% (n = 7773) of the patients reported that their case was discussed in a MTC, and approximately 84% (n = 7496) of the patients specified that they were informed about the outcome regarding their cancer management plan following the MTC. Approximately 9% (n = 760) of patients were invited to participate in a MTC. About 49% (n = 373) of the invited patients reported participation, and overall, 5% (n = 408) of the whole sample took part in a MTC. About 41% (n = 3048) of non-invited patients reported that they would have liked to participate in a MTC. In total, 87% (n = 356) of the patients did not regret their participation in the tumor conference at the time of the survey. **Table 2** reports on survey items representing patient's experience with participation in a MTC.



**Table 2**  
Descriptive results of the patients' participation in MTCs (N = 408).

Variables	Response trait	N (%)
For how many minutes did you participate in the MTC?		N <sub>Valid</sub> : 367 (90.0) N <sub>Missing</sub> : 41 (10.0) Min: 2 min Max: 60 min Median: 15.0 min Std. Deviation: 10.4
How many persons were sitting in the MTC except you?		N <sub>Valid</sub> : 364 (89.2) N <sub>Missing</sub> : 44 (10.8) Min: 1 person Max: 17 persons Median: 4 persons Std. Deviation: 3.1
Were you accompanied by someone? (e.g. partner, spouse, relative)	Yes No Missing	283 (69.4) 99 (24.3) 26 (6.4)
Did you have the opportunity to express your opinion referring to the subsequent treatment?	Yes No Missing	350 (85.8) 24 (5.9) 34 (8.3)
Were you involved in the decision making process referring to the subsequent treatment?	Yes No Missing	315 (77.2) 58 (14.2) 35 (8.6)
Did you regret the participation in the MTC?	Yes Partly No Missing	13 (3.2) 8 (2.0) 356 (87.2) 31 (7.6)

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

### 3.2. Results of qualitative data analysis

Around half of the patients who participated in the MTC (N = 188) responded to the following open-ended question: "Please briefly explain how you experienced the MTC." Qualitative analysis was performed on the open-ended responses provided by patients and included: (1) situational context, (2) personal context and (3) decision making. Under each of the three main categories, further subcategories were developed. The main categories of "decision-making" and "personal context" as well as the subcategories "classification of experiences as negative or positive" evolved deductively out of examining the literature [10,19,26]. The other main category and the other subcategories evolved from data analysis. Fig. 1 details the categorization tree. The categories as well as their subcategories are described below.

**Situational context.** The situational context focused on how the MTC appeared to the patients. It describes the psychosocial

influence of the atmosphere of the MTC on the patient. The analysis resulted in three subcategories in relation to the *situational context* category, namely *positive experience*, *neutral experience* and *negative experience*. The *positive* and *negative experience* can be specified as *cognitive experiences* and *emotional experiences*, whereas the *neutral experience* only represents *no new information received* (n = 9 expressions). The cognitive experience describes how the patients perceived the MTC on a cognitive level without expressing their experiences emotionally. Examples of positive cognitive experiences included (n = 79 expressions) the following:

"Helpful concerning the subsequent treatment" or "Very informative"

Comparatively, examples of negative cognitive experiences (n = 15 expressions) included:

"Like an assembly line. Cases were discussed too fast." or "The group was under time pressure – this made for a negative impression" or "the [...] oncologist used foreign words concerning chemotherapy that neither my companion nor I could understand".

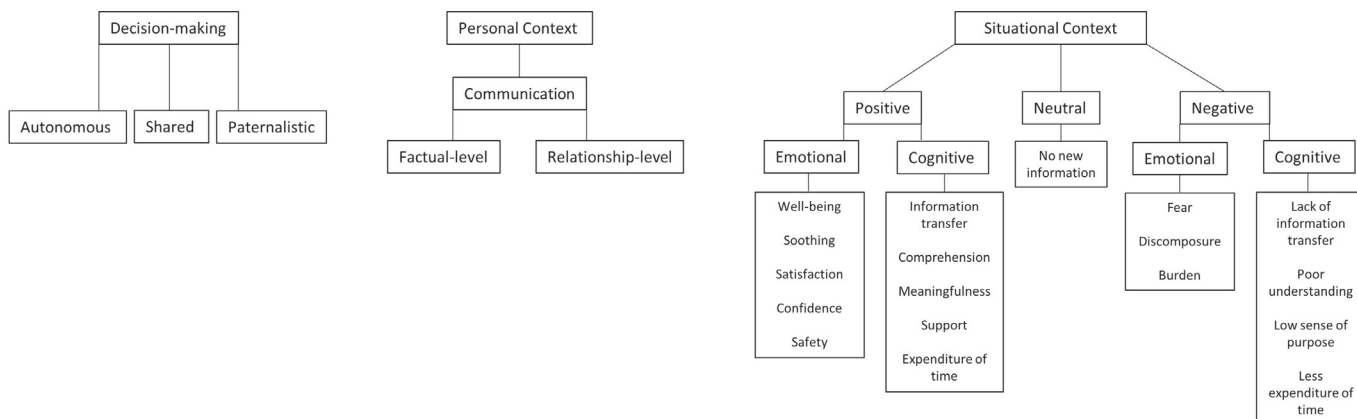
In contrast, an emotional experience described how the patient perceived the MTC on an emotional level, which excluded cognitive interpretations. The following are examples of a positive emotional experience (n = 30 expressions) of the MTC:

"For my mind very reassuring" or "I left the MTC soothed, with a positive outlook for the future" or "encouraging."

In contrast, examples of a negative emotional experience (n = 22 expressions) included:

"Very stressful – the label 'MTC alone ...', "Like a tribunal" or "Very frightening"

**Personal context.** The category "personal context" described the patient's perception of the communication skills demonstrated by the healthcare providers during the MTC. This category differentiates from the category "situational context" as follows: the category "personal context" referred to the social component of the MTC by focusing specifically on the communication between patients and health care providers of the MTC, while the category "situational context" related to the psychosocial influence of the atmosphere of the MTC on the patients. The perceived competence of the provider's communication skills was categorized into two



**Fig. 1.** Categorization-tree of the patient experiences in the multidisciplinary tumor conference (MTC).

subcategories, which included: *factual-level* and *relationship-level* of communication. *Factual-level* ( $n = 76$  expressions) referred to the objective and factual communication of the patient's information and professional appearance during the MTC:

*"Very qualified", "Factual, targeted [...]" or "Competent, factual [...]"*

In contrast, the *relationship level* ( $n = 41$  expressions) of healthcare provider communication referred to caring behaviors exhibited during the MTC and sensitive communication of the patient information:

*"Friendly, calm, understanding", "The doctors were very nice and personal" or "sensitive"*

*Decision-making.* The decision-making category referred to how the final decision in association with a treatment recommendation was made in the MTC and who (providers and/or patient) significantly contributed to the decision. The subcategory *autonomous decision-making* ( $n = 3$  expressions) applied to when the decision was predominantly made by the patient:

*"Presentation of the facts, further treatment options [...] and then my decision"*

The subcategory *shared decision-making* ( $n = 7$  expressions) reflected a decision which was made together with the health care providers and patient:

*"I was advised about the further treatment and was given time to think about the possible options" or "My wishes were considered"*

The last subcategory explored *paternalistic decision-making* ( $n = 22$  expressions) and related to the decisions made exclusively by the healthcare providers without consideration of the patient perspective:

*"I was presented with a fait accompli (duration of chemo) without being involved and without any explanation ... !!!"*

Altogether the qualitative analysis provided an ambiguous picture of the participants' perceptions. There were not only inter-individual differences between the patient's reporting negative and positive impressions, but also intra-individual discrepancies within the same patient. Thus some patients exhibited a cross-categorical reaction pattern ( $n = 35$  expressions), such as a negative emotional, but a positive cognitive reaction.

#### 4. Discussion

The aim of the study was to investigate the experiences of breast cancer patients who participated in MTCs. The study used a mixed methods approach of both quantitative and qualitative data analysis. Descriptive findings indicated poor patient involvement in MTCs, indicating that it is not yet an established process within the healthcare system. However, patient involvement in MTCs is currently being practiced in some breast cancer centers in Germany. Half of the invited patients were not interested in participating in a MTC. This may indicate that patients may have had no preference or may face fears regarding participation in a MTC meeting given the nature of the information being discussed and the patient's health at the time of the MTC taking place [14,26]. Conceivably, the term MTC may have been unknown to some of the

surveyed patients, although a definition had been provided in the survey. Further investigation regarding reasons for non-participation would be required.

In Table 1 chi-square tests indicated that patients whose native language was not German were more likely to participate in the MTC. Moreover, patients who do not have children and patients who have an additional private health insurance were more likely to participate in the MTC. To date, and to the best of our knowledge, these patient characteristics have not been considered in prior publications. However, these results need to be interpreted with caution, as tests did not adjust for other covariates and the findings are based on a relatively small sample size.

The majority (87%) of participating patients did not regret their participation in a MTC. Results of the descriptive analysis seem to be in contrast with the ambivalent findings of negative and positive perceptions of participation represented by the outcome generated from the qualitative analysis.

Patients did experience positive aspects of participation, such as being informed about their illness, which was the most frequent response to the open-ended question. In addition, participation in a MTC was reported to have positively influenced the well-being of many patients. This may be associated with a positive experience of involvement in a meeting where the patient is receiving information around their diagnosis and treatment from a multidisciplinary group of supportive health care professionals involved with their care. This can make patient's feel cared about and gives the impression of being well supported. Other international studies report similar findings experienced by patients in attendance at a MTC [18,19].

Comparatively, patients also reported feelings regarded being overwhelmed by the information, as they felt that they were overloaded with information received as well as medical terminology used in discussions at the MTCs. In addition, the sensitive mental condition of many patients explains a patient's inability to follow the content of the MTC. The fact that some patients indicated a cross-categorical reaction pattern, highlights the difficult situation faced. Many patients feel overwhelmed by their diagnosis, particularly after hearing different views from a multi-disciplinary team of clinicians, whilst in discussion about different aspects of a patient's treatment plan. This could in turn lead to a patient's increased psychological distress and further cause anxiety. Patients want to be informed about their cancer progression and treatment recommendations, but facing the facts about their illness may also evoke negative emotional reactions [19]. The vast majority of patients indicated that they had no regrets in their decision to participate at one of these meetings. As both negative and positive experiences have been highlighted by patients, it makes it difficult to determine or recommend whether the benefits associated with MTC outweigh the negative emotions following the experience with attendance. Clinicians need to be mindful of a number of issues when offering the opportunity to participate in a MTC to a patient, which would include: coping strategies of the individual patient, age and cultural appropriation of the information provided and discussed, patient participation preferences and health literacy of the individual patient.

In terms of patient-provider communication, some patients reported about their perception on a relationship level of communication. These patients focused on 'how' the caregivers talked to and cared about them. In contrast, a second group of patients focused on the factual ('what') level of communication [27]. They emphasized the professional appearance of the health care providers and gave little consideration to their social communication skills. A better understanding of the relationship between the different feelings expressed by patients in relation to the category *personal context* requires further exploration in order

to better support and enhance clinician and patient communication.

With regards to the decision-making category, patients presented differing views. The level of involvement in decision-making depended on the individual patient as well as on the participation preference, the attitude of the health care providers toward shared decision-making with the patient, the temporal aspect of the MTC and the information of cancer treatment recommendations being provided by the health care provider and processed by the patient [9,18,19].

Overall, 50% of patients ( $N = 188$ ) responded to the open-ended question. Hence, our qualitative findings need to be interpreted cautiously as we are unable to determine the experiences of those patients that participated in a MTC, but did not respond to this survey question. Sometimes, patients' responses to the open-ended question were brief, making it difficult to thematically categorize a patient's response into one of the three main categories or further subcategories. Furthermore, responses were at times ambiguous. In addition, there were no nonverbal or paraverbal information that could contribute to a better understanding of patients' actual emotional perception. Patient interviews would be a positive step in assisting with ameliorating some of these issues, in order to provide a holistic picture of the patients' experiences in a MTC. As the sample represented patients receiving treatment at local breast cancer centers in NRW, we are unable to generalize these findings and experiences to an international breast cancer population, even though the sample size for this population was significant in size ( $N = 8893$ ) [28]. A mixed methods approach of using both quantitative and qualitative methods assists with explaining and providing a greater understanding of the quantitative results presented through a detailed explanation provided using qualitative analysis [29].

#### 4.1. Implication for practice and research

These preliminary findings do not support recommendations for or against patient participation in a MTC. A positive experience associated with attendance at a MTC depends on communication, which should be respectful and sensitive on an emotional level as well as informative on a cognitive level. The success of participation further depends on how much information a patient actually wants to receive and to the degree of which a patient wants to be involved in the management of their cancer treatment journey. Hence, the level of information provided at a MTC should be individually assessed. For practical advice, an individual assessment of the patients' information needs, decision-making preferences (autonomous, shared, paternalistic) and psycho-social assessment (e.g. anxiety) would be critical in assisting with identifying patients that may benefit from attendance and participation in a MTC. Additionally, studies with a controlled design would be a preferential methodology in providing a deeper insight into the circumstances faced by the patients when participating in MTCs, e.g. by observing MTCs with patient participation.

## 5. Conclusion

The study indicated mixed experiences for patients that attended and participated in a MTC at different breast cancer centers. The quantitative analysis revealed mainly positive experiences concerning patient participation, however the open-ended question indicated a mixed response of both positive and negative patient experiences.

Several further questions remain unanswered: (1) Which patients benefit from participation? (2) How do caregivers experience patient participation? (3) How is shared decision-making

implemented in the process of MTC and how do patients and providers experience it? (4) Is MTC participation beneficial or harmful for patients in terms of psychological health? (5) How are these patients followed up after a MTC and what kind of (psychological) support do they receive after the meeting?

These mentioned questions should be addressed in studies using suitable quantitative and qualitative designs. A subsequent study on the patient, provider and organizational perspective regarding patient involvement in MTCs is currently being conducted.

## Acknowledgement

We would like to thank all of the participating patients and hospitals. The patient survey was financed by the participating hospitals. We are grateful to German Cancer Aid (Deutsche Krebshilfe e. V., grant nr. 110239) and Köln Fortune for funding the data analysis.

## References

- [1] Robert Koch-Institut. Bericht zum Krebsgeschehen in Deutschland 2016. RKI-Bib1. Robert Koch-Institut; 2016.
- [2] Robert Koch-Institut. Wie steht es um unsere Gesundheit? RKI-Bib1. Robert Koch-Institut; 2015.
- [3] Burgess C, Cornelius V, Love S, Graham J, Richards M, Ramirez A. Depression and anxiety in women with early breast cancer: five year observational cohort study. *BMJ* 2005;330(7493):702.
- [4] İzci F, Sarsanov D, Erdogan Zİ, İlgün AS, Çelebi E, Alço G, et al. Impact of personality traits, anxiety, depression and hopelessness levels on quality of life in the patients with breast cancer. *Eur J Breast Health* 2018;14(2):105–11.
- [5] Rabinowitz B. Interdisciplinary breast cancer care: declaring and improving the standard. *Oncology (Williston Park, N Y)* 2004;18(10):1263–8. discussion 1268–70, 1275.
- [6] Croke JM, El-Sayed S. Multidisciplinary management of cancer patients: chasing a shadow or real value? An overview of the literature. *Curr Oncol* 2012;19(4):232–8.
- [7] Fleissig A, Jenkins V, Catt S, Fallowfield L. Multidisciplinary teams in cancer care: are they effective in the UK? *Lancet Oncol* 2006;7(11):935–43.
- [8] Houssami N, Sainsbury R. Breast cancer: multidisciplinary care and clinical outcomes. *Euro J Canc* 2006;42(15):2480–91.
- [9] Devitt B, Philip J, McLachlan S-A. Team dynamics, decision making, and attitudes toward multidisciplinary cancer meetings: health professionals' perspectives. *J Oncol Pract* 2010;6(6):e17–20.
- [10] Hahlweg P, Didi S, Kriston L, Härter M, Nestoriuc Y, Scholl I. Process quality of decision-making in multidisciplinary cancer team meetings: a structured observational study. *BMC Canc* 2017;17(1):772.
- [11] Prades J, Remue E, van Hoof E, Borrás 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(4):464–74.
- [12] Wright FC, Vito C de, Langer B, Hunter A. Multidisciplinary cancer conferences: a systematic review and development of practice standards. *Euro J Canc* 2007;43(6):1002–10.
- [13] Chang JH, Vines E, Bertsch H, Fraker DL, Czerniecki BJ, Rosato EF, et al. The impact of a multidisciplinary breast cancer center on recommendations for patient management. *Cancer* 2001;91(7):1231–7.
- [14] Ansmann L, Kowalski C, Pfaff H, Wuerstlein R, Wirtz MA, Ernstmann N. Patient participation in multidisciplinary tumor conferences. *Breast* 2014;23(6):865–9.
- [15] Gabel M, Hilton NE, Nathanson SD. Multidisciplinary breast cancer clinics. Do they work? *Cancer* 1997;79(12):2380–4.
- [16] Haier J. Aufgaben und Grenzen von Tumorkonferenzen. *Onkologie* 2016;22(3):184–91.
- [17] Westfalen-Lippe Ärztekammer. Certification of breast cancer centers in North-Rhine Westphalia. Requirement catalogue breast cancer centers: [Verfahren zur Zertifizierung von Brustzentren in NRW. Anforderungskatalog-Brustzentren; 2018.
- [18] 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.
- [19] 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):178–89.
- [20] Dillman DA. Mail and telephone surveys: the total design method. 1978. New York.
- [21] Ansmann L, Kowalski C, Ernstmann N, Ommen O, Jung J, Visser A, et al. Do

- breast cancer patients receive less support from physicians in German hospitals with high physician workload? A multilevel analysis. *Patient Educ Counsel* 2013;93(2):327–34.
- [22] Ansmann L, Kowalski C, Ernstmann N, Ommen O, Pfaff H. Patients' perceived support from physicians and the role of hospital characteristics. *Int J Qual Health Care* 2012;24(5):501–8.
- [23] Pfaff H, editor. *The Cologne Patient Questionnaire. Development and validation of a questionnaire of the involvement of patients as co-therapist: [Der Kölner Patientenfragebogen (KPF): Entwicklung und Validierung eines Fragebogens zur Erfassung der Einbindung des Patienten als Kotherapeuten]*. Sankt Augustin: Asgard-Verl; 2003.
- [24] Creswell John W, Clark Vicki L Plano, editors. *Designing and conducting mixed methods research*. second ed. Sage publications; 2017.
- [25] Miles MB, Huberman AM, Saldaña J. *Qualitative data analysis: a methods sourcebook*. third ed. Los Angeles, London, New Delhi, Singapore, Washington DC: SAGE; 2014.
- [26] Hubbard G, Kidd L, Donaghy E. Preferences for involvement in treatment decision making of patients with cancer: a review of the literature. *Eur J Oncol Nurs* 2008;12(4):299–318.
- [27] von Thun Friedemann Schulz, editor. *Miteinander reden: 3: Das "Innere Team" und situationsgerechte Kommunikation. Kommunikation, Person, Situation*. Rowohlt Verlag GmbH; 2013.
- [28] Ansmann L, Kowalski C, Pfaff H. Ten years of patient surveys in accredited breast centers in North Rhine-Westphalia. *Geburtshilfe Frauenheilkd* 2016;76(1):37–45.
- [29] O' Cathain A, Murphy E, Nicholl J. Three techniques for integrating data in mixed methods studies. *BMJ* 2010;341:c4587.

## 4. Discussion

The aims of this cumulative dissertation were to analyze the use and determinants of MTCpp (input) as well as to explore the provision and required context factors of MTCpp (throughput). Accordingly, the research questions of the four publications were the following: Which individual and organizational determinants of MTCpp can be explored? How do providers experience the feasibility and required context of the provision of MTCpp? How do patients experience MTCpp?

(1) After describing mixed-methods research on MTCpp in the study protocol of the PINTU study (Heuser et al. 2019a), (2) the second publication using multilevel logistic regression modeling revealed significant differences between individual characteristics as well as between cancer centers in terms of MTCpp (Heuser et al. 2019b). This contributes to the analysis of input in the HSR throughput model of MTCpp. (3) In the third publication, content analysis of provider interviews with inductive and deductive coding showed a mixed picture of providers' experiences concerning the provision of MTCpp in their cancer centers as well as required context factors fostering MTCpp (Heuser et al. 2020). These results in part explain the between-center differences found in the second publication regarding the provision of MTCpp. This contributes to the analysis of throughput in the HSR throughput model. (4) Finally, in the fourth publication, descriptive and content analysis revealed a mixed picture of patients' experiences concerning decision-making, communication, and their emotional and cognitive situation during participation (Diekmann et al. 2019). These results in part explain the differences in participation between patient groups found in the second publication. This contributes to the analysis of input and throughput factors in the HSR throughput model. In the following sections, specific aspects of the results from the original publications are discussed in detail.

Concerning the second publication, three important findings should be discussed: (i) For Germany, only one previous study analyzed the prevalence of MTCpp (Ansmann et al. 2014). According to the second and fourth publication, we can conclude that MTCpp is a rare but constant reality in healthcare, with 5-7% of breast cancer patients participating in MTCs (Diekmann et al. 2019; Heuser et al. 2019b). (ii) Only one previous study has suggested that participation varies by individual patient characteristics. This result can be extended by this study: Health literacy (HL) as an individual patient characteristic was

significantly associated with MTCpp. Patients with higher HL participated more often in the discussion of their own case. This result is in line with international and national HL studies, which have shown that high HL is predictive of individual health behavior and an important prerequisite for patient participation in healthcare (Berkman et al. 2011; Nutbeam 2008; Sørensen et al. 2012; Wagner et al. 2009). In light of these results, it can be noted that MTCpp requires patients to respond to the complex demands of our modern healthcare system in order to use the healthcare service of MTCpp and communicate with providers during the MTC (see also publication 4). As low HL is associated with low education levels, older age, and chronic disease and varies by ethnic background (Paasche-Orlow et al. 2005; Sørensen et al. 2015), social differences in the use of MTCpp exist. (iii) This publication also found significant differences in MTCpp between cancer centers, with 15% of the variance of the dependent variable being due to differences between breast cancer centers. Thus, it was for the first time revealed for MTCpp that organizational (meso level) characteristics and individual (micro level) characteristics determine the use (input) and provision (throughput) of a healthcare service that has been theoretically described above within the micro-meso-macro and HSR throughput models. The reasons for organizational differences were unclear at that point.

The third publication then explored the reasons for organizational differences through an analysis of providers' experiences in the provision of MTCpp in their cancer centers as well as important contextual factors fostering MTCpp. Importantly, the providers' MTC goal of "determining the best treatment recommendation" remains unchanged by patient participation. This means that even in the presence of patients in MTCs, the recommendation made is solely based on medical guidelines. In addition to this recommendation process, the MTC then includes a decision-making process that takes into account patients' personal and social situation. This extended function of MTCs might conflict with the context of the provision of MTCpp, e.g. the limited MTC timeframe, or with providers' attitudes. These conflicts firstly reflect differences between cancer centers concerning MTCpp (see publication 2) and secondly are an example of what Pfaff et al. 2011 described with regard to the throughput and the provision of a healthcare service. On the example of MTCpp, the HSR throughput model and the importance of organizational effects in oncological healthcare were analyzed in this dissertation. All

things considered, MTCpp seems not to be feasible for all patients in routine care, but does seem feasible for selected patients.

In the fourth publication, patients' experiences with MTCpp were analyzed. The perception of MTCs varies between participating patients. Approximately 87% did not regret their participation in the MTC. The qualitative analysis of the answers to the open-ended question indicated that MTC participation was perceived as being both supportive and informative (n=109 expressions). However, some patients reported difficult experiences and emotional reactions during and after participation (n=37 expressions). These mixed experiences reflect differences in MTC organization and in individual patient characteristics. Furthermore, they are an example of the use of a healthcare service (input) and the experiences with a specific healthcare service (throughput), in this case concerning MTCpp. This first analysis of patients' experiences shows the need for a systematic inclusion of patient-reported experiences (PREMs) in the evaluation of (new) healthcare services as well as for further research on the important factors of patient experiences and outcomes.

#### 4.1. Limitations and strengths

A limitation of this PhD work is that it cannot be fully generalized for several reasons. All presented data are part of non-interventional phase II studies. No causal effects can be defined for any of the publications. Furthermore, some patient selection took place, with the samples containing mainly women and patients with solid breast and gynecological tumors. The third and fourth publication are in part based on qualitative research methodology, which focuses on individual experiences and is not intended to provide the same type of generalization as quantitative research methodology. With regard to the theoretical HSR model, it must be noted that the categories of output and outcome were not analyzed in this cumulative dissertation.

The following strengths apply to all three original publications: The presented findings represent the first analysis of providers' and patients' experiences with MTCpp in Germany and the first explanations of between-center differences concerning MTCpp internationally. This was possible, firstly, due to the use of a wide range of methods and



analyses in the sense of a mixed-methods methodology in health services research (see publication 1) and, secondly, due to the integration of this new research field in well-established theories of medical sociology and health services research.

#### 4.2. Implications for research and practice

Embedded in the medical sociology and HSR model, some research implications can be summarized. As the categories of output and outcome were not analyzed in this cumulative dissertation, future research on MTCpp should analyze these aspects of the HSR model. In accordance with de Haes and Bensing 2009 (Haes and Bensing 2009), immediate, intermediate, and long-term endpoints of communication should be taken into account by studying a wide range of (psychosocial and medical) outcomes of MTCpp in future research, e.g. fear of cancer progression, trust in providers, or quality of life. Furthermore, future throughput research should focus on processes taking place during MTCs that can be analyzed with the help of standardized observations of MTCs, e.g. concerning communication and decision-making. In addition, the research on women with breast and gynecological cancer presented here must be transferred to other samples like male cancer patients and patients with non-solid tumors. Lastly, future research would benefit from interventional phase-III studies in order to clarify risks and benefits of MTCpp for patients and providers. After that, recommendations for oncological healthcare practice can be formulated, especially whether and, if so, for whom MTCpp is useful.

This dissertation summarizes some initial practical implications for breast and gynecological cancer care in Germany: Providers' experiences suggest that MTCpp seems not feasible for all patients in routine care but does seem feasible for selected patients. At the same time, mixed patient experiences indicate more positive experiences than expected by providers. Good preparation and follow-up of participating patients, e.g. by a breast care nurse, seem especially important. Communication skills training for providers in MTCpp might help achieve positive patient experiences. This should include the communication of "bad news" as well as skills for patient empowerment. Furthermore, providers need to explain to patients the difference between *standardization* and *individualization* in oncological healthcare. This means clarifying the possible difference

between solely guideline-based recommendations in MTCs and the actual decision-making with the patients in consideration of their preferences. Before, during, and after MTCs, providers face the complex task of transferring evidence-based recommendations to individual patients in the form of “personalized” medicine and “customized” psychosocial, social, and cultural characteristics (Ansmann and Pfaff 2018). Shared decision-making could therefore be included in communication skills training for oncological healthcare practitioners. Finally, in the long term, an update of certification catalogs might be discussed after determining the risks and benefits of MTCpp in an interventional phase III study (Campbell et al. 2000).

#### 4.3. References

- Ansmann, L., Kowalski, C., Pfaff, H., Wuerstlein, R., Wirtz, M. A. & Ernstmann, N. (2014). Patient participation in multidisciplinary tumor conferences. *Breast* 23 (6), 865–869. doi:10.1016/j.breast.2014.09.004
- Ansmann, L. & Pfaff, H. (2018). Providers and Patients Caught Between Standardization and Individualization: Individualized Standardization as a Solution Comment on "(Re) Making the Procrustean Bed? Standardization and Customization as Competing Logics in Healthcare". *International journal of health policy and management* 7 (4), 349–352. doi:10.15171/ijhpm.2017.95
- Berkman, N. D., Sheridan, S. L., Donahue, K. E., Halpern, D. J., Viera, A., Crotty, K., Holland, A., Brasure, M., Lohr, K. N., Harden, E., Tant, E., Wallace, I. & Viswanathan, M. (2011). *Health Literacy Interventions and Outcomes. An Updated Systematic Review: Agency for Healthcare Research and Quality (US)*
- Campbell, M., Fitzpatrick, R., Haines, A., Kinmonth, A. L., Sandercock, P., Spiegelhalter, D. & Tyrer, P. (2000). Framework for design and evaluation of complex interventions to improve health. *BMJ* 321 (7262), 694–696. doi:10.1136/bmj.321.7262.694
- Diekmann, A., Heuser, C., Ernstmann, N., Geiser, F., Groß, S. E., Midding, E., Pfaff, H. & Ansmann, L. (2019). How do breast cancer patients experience multidisciplinary tumor conferences? - A description from the patient perspective. *Breast* 44, 66–72. doi:10.1016/j.breast.2018.12.012
- Haes, H. de & Bensing, J. (2009). Endpoints in medical communication research, proposing a framework of functions and outcomes. *Patient education and counseling* 74 (3), 287–294. doi:10.1016/j.pec.2008.12.006
- Heuser, C., Diekmann, A., Ernstmann, N. & Ansmann, L. (2019a). Patient participation in multidisciplinary tumour conferences in breast cancer care (PINTU): a mixed-methods study protocol. *BMJ open* 9 (4), e024621. doi:10.1136/bmjopen-2018-024621

- Heuser, C., Diekmann, A., Kowalski, C., Enders, A., Conrad, R., Pfaff, H., Ansmann, L. & Ernstmann, N. (2019b). Health literacy and patient participation in multidisciplinary tumor conferences in breast cancer care: a multilevel modeling approach. *BMC cancer* 19 (1), 330. doi:10.1186/s12885-019-5546-z
- Heuser, C., Diekmann, A., Schellenberger, B., Bohmeier, B., Kuhn, W., Karbach, U., Ernstmann, N. & Ansmann, L. (2020). Patient Participation in Multidisciplinary Tumor Conferences from the Providers' Perspective: Is It Feasible in Routine Cancer Care?. *Journal of multidisciplinary healthcare* (13), 1729–1739. doi:10.2147/JMDH.S283166
- Nutbeam, D. (2008). The evolving concept of health literacy. *Social Science & Medicine* 67 (12), 2072–2078. doi:10.1016/j.socscimed.2008.09.050
- Paasche-Orlow, M. K., Parker, R. M., Gazmararian, J. A., Nielsen-Bohlman, L. T. & Rudd, R. R. (2005). The prevalence of limited health literacy. *Journal of general internal medicine* 20 (2), 175–184. doi:10.1111/j.1525-1497.2005.40245.x
- Sørensen, K., Pelikan, J. M., Röthlin, F., Ganahl, K., Slonska, Z., Doyle, G., Fullam, J., Kondilis, B., Agrafiotis, D., Ueters, E., Falcon, M., Mensing, M., Tchamov, K., van den Broucke, S. & Brand, H. (2015). Health literacy in Europe: comparative results of the European health literacy survey (HLS-EU). *The European Journal of Public Health* 25 (6), 1053–1058. doi:10.1093/eurpub/ckv043
- Sørensen, K., van den Broucke, S., Fullam, J., Doyle, G., Pelikan, J., Slonska, Z. & Brand, H. (2012). Health literacy and public health. A systematic review and integration of definitions and models. *BMC public health* 12, 80. doi:10.1186/1471-2458-12-80
- Wagner, C. von, Steptoe, A., Wolf, M. S. & Wardle, J. (2009). Health literacy and health actions. A review and a framework from health psychology. *Health education & behavior* 36 (5), 860–877. doi:10.1177/1090198108322819

## 5. Acknowledgement

I would like to take this opportunity to thank some people for their valuable support during my dissertation journey.

Particularly, I would like to thank my doctoral mother Prof. Dr. Nicole Ernstmann for your right sense of giving content and personal related support on the one hand, and encouraging own decisions and autonomously research on the other hand. Furthermore, your expertise in health services research helped me a lot to write the umbrella of this dissertation.

Many thanks to my second supervisor Prof. Dr. Lena Ansmann for your always helpful advices and discussions concerning methods and theories of medical sociology and health services research, your forward-looking questions with regard to journal selection and manuscript submission and your detailed editing of my manuscripts.

I would like to thank Prof. Dr. Rupert Conrad and Prof. Dr. Walther Kuhn for your expertise in clinical oncology which helped me a lot to understand the discussions in tumor conferences and your (realistic) clinical perspective on patient participation in tumor boards in North-Rhine Westphalia and Bavaria.

Many thanks to my PINTU colleagues Annika Diekmann, Barbara Schellenberger, Barbara Bohmeier, Sebastian Reck, Theresa Frick, Emily Krüger and Leonie Schreiber for the excellent cooperation and project management.

Furthermore, I would like to thank all participants of the CHSR PhD seminar and the PhD seminar of the German Society of Medical Sociology (DGMS) for your valuable and helpful feedback especially concerning my presentations.

Over 10.000 patients, nearly 100 cancer centers and many healthcare providers were included in the studies of this dissertation. Without your data und support this dissertation would not have been possible.

I want to thank all of my coauthors – namely Prof. Dr. Lena Ansmann, Barbara Bohmeier, Prof. Dr. Rupert Conrad, Annika Diekmann, Dr. Anna Enders, Prof. Dr. Nicole Ernstmann, Prof. Dr. Franziska Geiser, Dr. Sophie Groß, Prof. Dr. Ute Karbach, Dr. Christoph Kowalski, Prof. Dr. Walther Kuhn, Dr. Evamarie Brock-Midding, Prof. Dr. Holger Pfaff, Barbara Schellenberger – for your constructive and helpful comments, which made every manuscript more stringent.

Last but not least, I want to thank my wife Andrea for your many-sided support, “keeping my back free” during writing periods, your critical editing of long sentences and giving me new motivation after manuscript rejections as well as my daughter Charlotte for letting me use parts of my parental time for writing on this dissertation.