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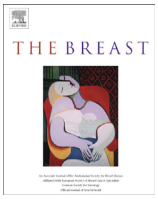

Original article

Patient participation in multidisciplinary tumor conferences

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ABSTRACT

Objectives: To identify (1) how frequently patients are invited to take part and actually do take part in multidisciplinary tumor conferences (MTCs), (2) which patient characteristics affect whether they are invited to MTCs and whether they decide to participate, (3) the extent to which invitation and participation depend on the specific hospital.
Study design: Survey data from 4146 newly-diagnosed breast cancer patients treated in 83 hospitals in North Rhine-Westphalia, Germany, were analyzed using multilevel modeling.
Results: 12% of the patients were offered participation in the MTC. More than half of these patients actually participated. Invitations to participate differed by patients' sociodemographic, disease, and treatment characteristics, whereas decisions to participate were largely independent of these characteristics. Invitation and participation are strongly dependent on the specific hospital.
Conclusion: The practice of inviting cancer patients to MTCs requires further research, particularly on benefits and disadvantages for patients and ways of organizing MTCs.

Introduction

Medical ethics emphasize the patient's right to be fully informed about and to participate in treatment decisions [1]. In addition, research has shown that many cancer patients have a strong desire to be informed about and to be involved in their own care [2–4]. A recent review [5] summarizing research on ways of meeting patient preferences and the associated health outcomes concluded that meeting patient preferences can lead to better health outcomes through two pathways: better patient adherence and therapeutic benefits associated with patient autonomy and satisfaction. Ways of involving patients in cancer care therefore need to be identified.

A large number of specialists are today involved in caring for a patient and multidisciplinary cancer care (MCC) has become standard in high-quality care. Several benefits of MCC have been described in the literature [6–8] e. g., optimized treatment planning through evidence-based decision-making, better coordination of care, better communication between health-care providers, reassuring patients that providers are working together and are considering treatment options carefully.

A widely accepted tool in MCC is the multidisciplinary tumor conference (MTC). MTCs are regular meetings of a multidisciplinary treatment team in which the diagnosis and treatment of cancer patients are discussed. In Germany, MTCs are widely established and are required in accreditation programs for cancer centers (e. g., by the German Cancer Society and the Medical Association of Westphalia-Lippe). Reviews summarized evidence on the benefits of MTCs [9,10] for treatment decision-making, and MTCs are accepted and valued by health-care providers and patients [11–13].

The ways in which MTCs are organized and regulations on whether patients should be invited to them vary widely across and within countries. To date, and to the best of our knowledge, there have been very few publications on patient involvement in MTCs. A pilot study including 30 breast cancer patients in Australia [14] assessed the feasibility and acceptability of involving patients in MTCs. The vast majority of participating patients found the involvement helpful and would recommend participation. Patients reported an improved understanding of diagnostis and treatment,

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and the meetings did not increase their anxieties. However, only half of the health-care providers interviewed supported patient involvement in the MTC. Providers expressed the following reactions: “interesting”, “worthwhile”, “I was more alert”, “more attentive during discussion”, “awkward”, “disruptive”, “It inhibited discussion”, “We had to modify the use of our jargon”. The same group of researchers surveyed health-care providers involved in breast cancer care and patient advocates regarding their views on involving breast cancer patients in MTCs [15]. Whereas the vast majority of patient advocates and breast cancer nurses were supportive of involving patients in the MTC, less than a third of the physicians supported the approach. The main reasons for supporting patient participation were that patients were better informed and empowered, and that it facilitated decision-making and improved communication between patients and providers. Concerns were that patients would feel anxious, that providers had to modify their medical language, and that it would take too much time. In another article [11], focus groups with health-care providers in Australia showed that patient attendance was opposed by most providers because of concerns about the patients' ability to cope with the information discussed and the effect of the patient's presence on the decision-making process.

Research question

The objective of the present study was to investigate the topic in a population of patients treated in breast cancer centers in North Rhine-Westphalia (NRW). NRW is Germany's most populous state (≈17,500,000 inhabitants) and approximately 20% of all breast cancer patients in Germany are treated there. To ensure a high quality of care, breast cancer patients in NRW have been treated in accredited breast cancer centers since 2005. For accreditation, the centers have to discuss the cases of at least 95% of patients with primary breast cancer in regular MTCs [16]. The requirements specify that patients should be able to participate in MTCs if they wish, disregarding the lack of evidence on benefits and harms of patient participation. So far, it is not known how often breast cancer patients are invited to participate in MTCs or how often they do so. It may be assumed that providers in breast cancer centers decide whether to invite a patient to participate on the basis of the patients' characteristics e. g., age, emotional state, severity of disease. In addition, inviting patients to MTCs is not practiced and favored in all breast cancer centers, due to the various concerns mentioned above, as well as time constraints and presumably due to different organizational cultures and management attitudes.

The aim of this study was to answer three questions: (1) How frequently are patients invited to take part in MTCs and how often do they actually do so? (2) Which patient characteristics determine whether they are invited to MTCs and whether they decide to participate? (3) To what extent do invitation and participation depend on the specific hospital?

Methods

Study design and sample

Data were collected from a postal survey of a consecutive sample of patients from 91 accredited breast cancer center hospitals in NRW. Before being discharged, eligible patients were asked to give written consent to participate in the survey. The survey was designed according to Dillman's Total Design Method, with three contact attempts being made [17]. The survey data were supplemented with clinical data provided by the hospitals. Patients were included if they: (1) had undergone in-patient surgery between February 1 and July 31, 2013 for newly diagnosed breast cancer, (2) had at least one malignancy; and (3) had at least one postoperative histological evaluation. The survey was approved by the Ethics Committee of the Medical Faculty of the University of Cologne. Further details on the survey have been reported elsewhere [18–20].

Instruments

Patients were surveyed with a breast cancer-specific version of the Cologne Patient Questionnaire (CPQ) [21]. The CPQ assesses patients' perceptions of several aspects of hospital care. Patients were asked “Were you asked if you wanted to participate in the tumor conference?”. The response options were “Yes, and I did”, “Yes, but I did not”, “No”, and “Can't remember”. A variable for “invitation to participate” was established by grouping together

Table 1
Descriptive results of the patient-level variables ($N = 4146$).

Variables	Response trait	N (%)
UICC stage	Stage 0	443 (10.7)
	Stage I	1614 (38.9)
	Stage II	1105 (26.7)
	Stage III	336 (8.1)
	Stage IV	144 (3.5)
	Missing	504 (12.2)
Grading	G1	637 (15.4)
	G2	2242 (54.1)
	G3	1028 (24.8)
	Missing	239 (5.8)
Type of surgery	Mastectomy without direct reconstruction	747 (18.0)
	Mastectomy with direct reconstruction	262 (6.3)
	Breast-conserving surgery	2987 (72.0)
	Missing	150 (3.6)
Neoadjuvant chemotherapy	Yes	410 (9.9)
	No	3699 (89.2)
	Missing	37 (0.9)
Health insurance status	Statutory	2962 (71.4)
	Statutory with additional private insurance	630 (15.2)
	Private	470 (11.3)
	Missing	84 (2.0)
Age	18–39	145 (3.5)
	40–49	659 (15.9)
	50–59	1173 (28.3)
	60–69	1127 (27.2)
	70–79	805 (19.4)
	≥80	214 (5.2)
	Missing	23 (0.6)
Highest education level achieved[a]	No lower secondary school education	76 (1.8)
	Lower secondary school education	1734 (41.8)
	Intermediate secondary school education	1136 (27.4)
	Entrance certificate for a university of applied sciences	355 (8.6)
	University entrance certificate	717 (17.3)
	Other/missing	128 (3.1)
Native language	German	3810 (91.9)
	Other	270 (6.5)
	Missing	66 (1.6)
In partnership	Yes	2922 (70.5)
	No	1154 (27.8)
	Missing	70 (1.7)
Were you asked if you wanted to participate in the tumor conference?	Yes, and I did	256 (6.2)
	Yes, but I did not	234 (5.6)
	No	3369 (81.3)
	Can't remember	201 (4.8)
	Missing	86 (2.1)

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

[a] In Germany, educational levels are named as follows in ascending order according to years of schooling: (1) *ohne Volks-und Hauptschulabschluss* (no lower secondary 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).