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Cover Page Footnote

Authors would like to express their thanks to the project team members and PFM Stalmeier, Radboud University Medical Center Nijmegen for the effort they put in this project.

Preference-sensitive decisions of patients with metastatic breast cancer: The need for decision support

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Abstract

Because of disease progression and the increasing number of treatment options, patients with metastatic breast cancer face multiple decisions over time. Our aim was to identify the multiple decisions patients with metastatic breast cancer face in order to decide which decision aids will be developed. First, we analyzed the clinical practice guidelines to identify decisions encountered by patients with metastatic breast cancer and healthcare professionals. Furthermore, an online questionnaire for patients, a focus group interview with patients and interviews with healthcare professionals were performed. In addition, we performed a systematic literature research and internet search to identify relevant decision support tools and we assessed their quality. Finally, all results were discussed with a mixed group of eight experts, consisting of researchers, patients and healthcare professionals and a comprehensive advice was given which decision aid to develop. It turned out that patients with metastatic breast cancer and healthcare professionals are confronted with eight major decision points regarding treatment and examinations during the care process. We identified four decision aids. These tools partially overlap with some of the identified decision points. Experts advised to develop a decision aid for patients with metastatic breast cancer that would address all mentioned decision points. We concluded patients with metastatic breast cancer and healthcare professionals will benefit from a personalized decision aid in which all eight major decision points are addressed. This decision aid would help patients and healthcare professionals to explore patients' personal values and preferences in order to make a well-informed decision.

Keywords

Shared decision making, breast cancer, decision aids, patient-centred care, healthcare

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Authors would like to express their thanks to the project team members and PFM Stalmeier, Radboud University Medical Center Nijmegen for the effort they put in this project.

Introduction

The World Health Organisation reports breast cancer as the most common cancer in women worldwide. Breast cancer is also the principle cause of death from cancer among women¹. Metastatic breast cancer means that the cancer has spread from the breast to a location outside the breast and surrounding lymph nodes. Metastases occur in bones (85%), liver (40-50%), lungs (15-25%) and brain (6-16%).^{2,3} The median survival of patients with metastatic breast cancer is approximately two years. However, survival can vary from several months to multiple years.⁴ Metastatic breast cancer is considered as a non-curable disease, but the growth of the metastases can be controlled for months to years. Treatment is focused on slowing disease progression, maintaining well-being and preventing and relieving symptoms and complaints.⁴

Medical treatment options have increased over the last years; different types of chemotherapy, hormone therapy, targeted therapy and palliative procedures such as surgery and radiotherapy are available.^{5,6} The treatment plan for an individual patient will depend on tumour type, location and size of the metastasis and/or tumour, treatment history, co-morbidity, age and health of the patient and on the patient's personal preferences and values.⁴

Because of disease progression and the increasing number of treatment options, patients with metastatic breast cancer face multiple decisions over time. For example, decisions about treatments with similar or unclear outcomes, treatments with different procedures and potential complications. Furthermore, they also have to decide whether or not to undergo examinations that offer little or no new insights in disease progression. Ideally,

these decisions should be made after patients have received enough information to make an informed choice and after patients' personal values and preferences have been shared in partnership with the caregiver(s).⁷ In this process of shared decision making, healthcare professionals and patients share the best available evidence and healthcare professionals support patients to consider options, to deliberate and express their preferences in order to achieve an informed decision.^{8,9}

Decision support tools - such as decision aids and option grids - facilitate the process of shared decision making. These tools can take many different forms and vary in content and level of complexity.¹⁰ The effect of decision aids is shown by a systematic review of 86 randomized trials. When patients use decision aids, they improve their knowledge of the options, feel more informed and more clear about what matters most to them, have more realistic expectations of benefits and harms of the options and participate more actively in decision making. Moreover, decision aids help patients to feel more satisfied with their decisions and, in many situations, informed patients elect for more conservative treatment options.¹⁰ Despite the obvious beneficial effects of decision aids for patients, there is limited decision support available for patients with metastatic breast cancer. There has been a plea for decision aids that have been developed by means of a well-documented and systematically applied development process, have been user-tested and are open to scrutiny.¹¹ Our aim was to identify the multiple decisions patients with metastatic breast cancer face in order to decide which decision aids to develop. To achieve this, our study focused on the following three questions:

1. Which preference-sensitive decisions do patients with metastatic breast cancer and healthcare professionals encounter during the care process?
2. Which decision support tools are available for patients with metastatic breast cancer and what is their quality?
3. Which decision aid(s) should be developed?

Methods

1. Which preference-sensitive decisions do patients with metastatic breast cancer and healthcare professionals encounter during the care process?

To identify preference-sensitive decisions encountered by patients with metastatic breast cancer and healthcare professionals, we studied the care process and analysed the clinical practice guidelines on breast cancer and metastatic breast cancer¹²⁻¹⁵ by using the 'HARING tool-8' (<http://www.ha-ring.nl/en/tool-8>).¹⁶ This is a tool which aims to support the integration of shared decision making into the development to clinical practice guidelines. Furthermore, we performed an online questionnaire for patients, a focus group interview with patients and individual interviews with healthcare professionals.

Online questionnaire

Patients were approached via the online forum of the Dutch Breast Cancer Association (B-force) to gather information on their experiences with preference-sensitive decision points in the care process. Patients were asked to describe which important decision points they had faced, their experiences with these decision points, whether and what treatment options they were given and how the consequences of these options were discussed with them. The questionnaire was online for four weeks and a qualitative thematic analysis¹⁷ by three team members was performed to categorize important decision points.

Focus group interview

A focus group interview with patients was organized: patients were selected from the sixty-nine patients that responded to the online questionnaire. Selection criteria of patients for the interview were 'willingness to participate' and 'diversity in decision points'. Fifteen patients were invited, nine participated. The focus group interview lasted 90 minutes and was moderated by two team members. Patients were asked to elaborate on their experiences with the important decision points identified from the online questionnaire and with additional decision points that were raised during the focus group. Furthermore, they were asked which values were important for their decision making process. The focus group was audio recorded. Again a qualitative thematic analysis of the results was performed by the project team. The summary of the focus group meeting was crosschecked with all participating patients.

Interviews with healthcare professionals

Two medical oncologists were interviewed by two members of the project team in order to assess what preference sensitive decision points they experience in the treatment of patients with metastatic breast cancer. The topic list for the interview was based on collected information on the care process and treatment options from guidelines, literature and the patient association. The medical oncologists were asked questions about their experiences with shared decision making, decision points, use of decision aids, patient values, the healthcare process and treatment guidelines. Both interviews were audio recorded and transcribed verbatim. Two researchers independently performed a qualitative thematic analysis. Themes were allocated to all important fragments of the transcript. Results were cross-checked with the oncologists and frequently occurring themes were selected.

2. Which decision support tools are available for patients with metastatic breast cancer and what is their quality?

We performed a systematic literature and internet search to identify decision support tools for patients with

metastatic breast cancer and we assessed their quality and usefulness.

Consensus was searched for and unanimously one advice on what decision aid should be developed was formulated.

Figure 1. PICO strategy

PICO	Definition
• Population	• Patients with metastatic or advanced breast cancer, male and female, and of all ages
• Intervention	• Decision aids or decision supportive tools or decision support or shared decision making
• Comparison	• Usual care
• Outcome	• All reported outcome measures for shared decision making

Systematic literature and internet search

In order to identify existing decision support tools for patients with metastatic breast cancer, the databases Medline, Embase and the internet were searched. The PICO method - a common technique used in evidence-based medicine to frame and answer a clinical question - was used as search strategy (Figure 1). Abstracts of selected articles were screened for eligibility by two researchers. Inclusion criteria were: metastatic or advanced breast cancer, decision support tool, information on the development, evaluation or use of the decision aid. In addition, an internet search was performed with the same search terms, using the snowballing method and reference tracking: scanning the reference list of full text papers and links to other resources and using judgment to decide whether to pursue this further. Specific websites with an inventory of decision aids, such as the website of the Ottawa Hospital Research Institute (OHRI) and Med-Decs were consulted.^{18,19} Furthermore, an international network of experts and organisations on shared decision making and experts on breast cancer care were contacted to receive more specific information on articles or decision aids.

Assessment of quality of available decision aids on metastatic breast cancer

The quality of the decision aids was assessed by two researchers using the International Patient Decision Aid Standards (IPDAS) criteria.¹⁹ The IPDAS criteria are divided into three categories: content (28 criteria), development process (29 criteria), effectiveness (7 criteria). If a decision aid complies with all criteria, it receives the maximum quality score of 100%.

3. Which decision aid(s) should be developed?

All results were summarized and discussed with a mixed team of experts: one caregiver, two patient representatives, two experts on decision aids and shared decision making and four researchers. Every member was asked to express their opinion and advice on which decision aid should be developed. Criteria for selection were 'relevant for the majority of patients', 'meeting information needs' and 'available information on benefits and risks of options'.

Results

1. Which preference-sensitive decisions do patients with metastatic breast cancer and healthcare professionals encounter during the care process?

Clinical practice guidelines

None of the relevant clinical practice guidelines contained explicit information on preference-sensitive decisions during the care process.

Online questionnaire

In total, 69 patients with metastatic breast cancer completed the online questionnaire on their experiences with preference-sensitive decision points in the care process. Fourteen respondents stated they did not receive enough information from their healthcare professionals. They missed information on the various treatment options, medical information on the disease and the medication (side-effects, prognosis) and options for end of life care. Seven respondents stated they did not mind not being able to choose; they trusted their caregiver to make the best choice for them. Patients named seven general categories of decision points: 'participating in a scientific trial', 'dosing schedule' and 'method of administration', 'starting a treatment', 'stopping a treatment', 'proceeding treatment', 'transferring to another treatment, caregiver or hospital' (Figure 2). Five patients also mentioned that they faced non-medical decisions, related to their work and home situation.

Focus group interview

To receive more in depth information on decision points and values involved in decision making, a focus group interview was organized. All focus group participants confirmed 'starting with a treatment', 'dosing schedule' and 'method of administration', and 'transferring to another caregiver' as important medical decision points (Figure 2). In addition, they mentioned 'undergoing diagnostic procedures and check-ups for monitoring' as a decision point. Values and preferences that are important for decision making were related to work, social participation, role in the family, quality of life, hobbies, leisure, social and psychological support. Patients also state

that they need to consider their own role in the decision making process. Patients stated they would like to receive support from healthcare professionals in getting insight into their own values and preferences.

Interviews with healthcare professionals

Both oncologists had experience with shared decision making with patients. Oncologists confirmed the following general decision points: ‘initiating treatment’, ‘stopping treatment’ or ‘proceeding with treatment’. Furthermore, they mentioned ‘starting with palliative chemotherapy’, ‘proceeding to second or third line chemotherapy’, ‘stopping with third line chemotherapy’, ‘choosing between different types of chemotherapy’ and ‘dosing schedule’ (Figure 2). Both oncologists experienced difficulties in the shared decision making process, since the number of administrations for each chemotherapy is limited to a maximum according to treatment protocols and guidelines, which narrows down the treatment options. According to the oncologists, most patients’ values or preferences within the deliberation process are related to aspects of quality of life and the home and work situation. Side-effects of a treatment, especially hair loss, age and expectations of others are important arguments for patients to reject a treatment.

2. Which decision support tools are available for patients with metastatic breast cancer and what is their quality?

To identify decision support tools for patients with metastatic breast cancer, we performed a systematic literature and internet search.

Systematic literature and internet search

The systematic literature search in Embase and Pubmed resulted in 133 articles. Only papers that concerned metastatic or advanced breast cancer, decision support tools, information on the development, evaluation or use of the decision aid were included. After applying the selection criteria, three articles remained. Two of these referred to the same decision aid. The internet search resulted in two additional decision aids (Figure 3). Consulting the international network of experts on shared decision making and experts of advanced breast cancer provided no additional relevant decision aids.

Assessment of quality of available decision aids on metastatic breast cancer

The quality of the four decision aids was assessed with the IPDAS criteria (Figure 2) by two independent researchers. Decision aid number 1 (Facing a treatment decision: Decision aid for patients with metastatic breast cancer considering chemotherapy) scored 60.4% on 53 criteria. The decision aid compares chemotherapy in addition to supportive care versus supportive care alone. The quality of the content and the effectiveness scored good (16 out of 23 resp. 6 out of 7 criteria). However, the decision aid does not provide any information or references regarding the development process and therefore scores low on the section ‘development process’ (10 out of 23 criteria). It contains a worksheet for patients to gain insight into their personal values and preferences. However, the decision aid contains a lot of text and the overall readability, scored with the SMOG criteria, is low.

The second decision aid (Living with metastatic breast cancer: making the journey your own) scored 56.6% on 53 criteria. It gives a general description of all treatment

Figure 2. Overview of important decision points for patients with metastatic breast cancer

Decision points	Online questionnaire Patients	Focus-group Patients	Interviews Caregivers
Should I participate in a scientific trial?	x		
Should I change the dosing schedule of the medication?	x	x	x
Should I change the method of administration of the medication?	x	x	
Should I start a treatment?	x	x	x
Should I stop a treatment?	x		x
Should I proceed with the treatment?	x		x
Should I transfer to another treatment, caregiver or hospital?	x	x	
Non-medical decisions, related to their work and home situation	x		
Should I undergo diagnostic procedures and check-ups for monitoring?		x	
Should I start with palliative chemotherapy?			x
Should I proceed to second- or third line chemotherapy?			x
Should I stop with third line chemotherapy?			x
Which type of chemotherapy do I prefer?			x

Figure 3. Decision aids for patients with metastatic breast cancer and the scoring on the IPDAS criteria

Decision aid	Decision points	IPDAS criteria			
		Content	Development process†	Effectiveness	Total score (%)
Facing a treatment decision: Decision aid for patients with metastatic breast cancer considering chemotherapy (English) Chiew et al. ²⁰	Chemotherapy (yes or no) for patients who are resistant for hormone therapy	16/23	10/23	6/7	60.4
Living with metastatic breast cancer: Making the journey your own (English) – Dartmouth-Hitchcock Medical Center ^{21,22}	All treatment options	8/23	18/23	4/7	56.6
Decision aid palliative chemotherapy for mamma carcinoma (Dutch) – RadboudUMC ²³	Chemotherapy (yes or no)	10/23	9/20	2/7	42.0
Mayoclinic: Interactive Breast Cancer Decision Tool (English) (http://www.mayoclinic.com) [not available anymore]	General overview of breast cancer regarding for example anatomy, stage, type and treatment options	4/23	3/20	1/7	16.0

† Depending on the format and content of the decision aid, additional criteria were applied, causing the total number of criteria to vary between different decision aids.

options. This tool rates high on the criteria of the development process (18 out of 23 criteria). The decision aid does not provide data regarding survival, side-effects and associated risks specific for those treatment options, or more preferably, their subtypes. This decision aid scored sufficiently on readability, but due to the large amount of text, overall readability might be low. This tool provides examples of patients' experiences with treatments to give more insight into which personal values and considerations are associated with the decision. However, the decision aid does not stimulate the patient to reflect on the meaning of this information for personal consideration (value clarification).

The third decision aid, called palliative chemotherapy for mamma carcinoma, scored 42.0% on 50 criteria. The decision aid compares chemotherapy with the option of watchful waiting and provides information on survival, benefits and risks. However, the decision aid does not help the patient to gain insight into their own preferences regarding treatment options and outcomes. In addition, the decision aid scored low on development process (9 out of 20 criteria) and readability.

The fourth decision aid, a video of the Mayo Clinic Interactive Breast Cancer Decision Tool, scored 16.0% on 50 criteria. The video gives a general overview of breast cancer; such as anatomy, stage of disease and treatment options. This information, however, is too general in order to support patients and healthcare professionals in a

shared decision making process. No information on benefits and risks of treatment options and no checklist to elicit values and preferences is presented.

3. Which decision aid(s) should be developed?

Important decision points that could be addressed in a decision aid according to patients and oncologist are:

1. participating in a scientific trial
2. dosing schedule and method of administering medication
3. starting a treatment, stopping or proceeding treatment
4. transferring to another treatment, caregiver or hospital
5. non-medical decisions, related to work- and home situation
6. undergoing diagnostic procedures and check-ups for monitoring, for example CT-scans
7. starting with palliative chemotherapy
8. changing type of, stopping or proceeding second or third line chemotherapy (i.e. a new variant of chemotherapy when the previous type causes for example too many side-effects, or the disease progresses) (Figure 2).

The existing decision aids address medical decisions; two describe the choice between chemotherapy in addition to supportive care versus supportive care alone, one decision aid gives a description of all general treatment options and the option of 'watchful waiting' for patients with metastatic breast cancer and one gives a general overview

of breast cancer, regarding for example disease stage, anatomy and general treatment options for all stages. Therefore, only a fraction of the mentioned decision points is covered in these decision support tools. Finally, after discussing all results, the project team and experts advise to develop a decision aid for patients with metastatic breast cancer that addresses all mentioned decision points.

Discussion

From our study, we conclude that patients with metastatic breast cancer and their healthcare professionals face eight major preference-sensitive decision points during the care process. Furthermore, since available decision aids do not cover all these decision points, there is a need for a decision aid that addresses all identified decision points.

Guidelines on breast cancer contain no explicit information on the advantages and disadvantages of the various treatment and care options for patients with metastatic breast cancer and their healthcare professionals. However, our study shows that patients with metastatic breast cancer and their healthcare professionals face eight major preference-sensitive decision points during the care process. For some of the mentioned decision points, decision support tools are available. However, none of the identified decision support tools covers all eight major decision points, due to the limited focus or the moderate quality of the decision aids. Therefore, the project team and experts decided to start the development of a decision aid that addresses the eight decision points and provides a personal value worksheet to help patients and healthcare professionals to explore the patient's personal preferences and values. This decision aid will employ the relevant parts of the identified decision aids and correspond with the content of the Dutch guideline on breast cancer, in line with the advice of experts.^{12, 24, 25}

In 1995, a study by McQuellon²⁶ emphasized that patients have clear preferences for specific treatments for metastatic disease. However, their preferred role in the decision making process varies among patients. In addition, individual patients' preferences often change in the course of the disease. In particular, in the last phase of life, patients often put more emphasis on weighing length of life against quality of life. For instance, in the decision whether or not to start treatment aimed at life prolongation, the possibility of side effects play an important role. Evidence suggests that informed patients elect for more conservative treatment options associated with more quality of life.²⁷ Therefore, communication about patients' expectations, wishes and preferences for participation in treatment decisions is of great importance.²⁸ In our study, both patients and healthcare professionals indicated the importance of communication on options and values for eight major decision points.

In our study only two oncologists were interviewed and only one focus group with patients was held. This resulted in valuable qualitative data for considering the focus of the decision aid to be developed and the information needs of patients and their healthcare professionals. Preferably, more interviews and multiple focus groups should be conducted until no new answers were given (saturation). Although both oncologists and patients mentioned predominantly similar decision points, it might be possible that other patients, nurses, radiologists, surgeons and general practitioners express other decision points as well. Another limitation is the recruitment of patients; the patients interviewed, were contacted through the website of the Dutch Breast Cancer Association. Patients that responded to the questionnaire are active members within the metastatic breast cancer community and might have a different opinion about the major decision points than other patients. Third, all participants of the focus group were diagnosed with earlier stage breast cancer several years before receiving the diagnosis of metastatic breast cancer. There were no patients who did not have any history with early stage breast cancer in the focus group. Results of the focus group therefore might not completely reflect all decisions patients within the whole community of metastatic breast cancer face after diagnosis. Despite these limitations, this is the first study to give insight into the major decision points patients with metastatic breast cancer and healthcare professionals are facing during the care process. It is also one of the fewer studies that comprehensively describes the process of starting the development of a decision aid.

This explorative study provides useful results which can be used in further research or the development of a decision aid for patients with metastatic breast cancer. Both patients and healthcare professionals were interviewed to obtain more in-depth knowledge about the decision points that patients with metastatic breast cancer encounter. Their responses and the analysis of available decision aids showed that there is a strong need for the development of a decision tool to support the decision making process relating to eight different decision points, in which the patient's values and preferences are taken into account as well.

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