

Breast cancer patients' most important quality of life themes for a radiotherapy decision aid

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ABSTRACT

Background and aim: The BRASA patient decision aid (BRASA-PtDA) facilitates shared decision making for breast cancer patients (BCPs) facing a radiotherapy treatment decision. During evaluations, patients indicated the wish for quantitative information on side effects. Therefore, this study assessed BCPs opinion on which and how information on side effects should be incorporated in the BRASA-PtDA.

Methods: A workshop was organized with BCPs (n = 9), researchers (n = 5) and clinicians (n = 3). Subsequently, a survey was sent to BCPs (n = 744) investigating the generalisability of the workshop findings, and posing additional questions. The survey entailed multiple choice questions on quality of life themes, the use of a decision aid and risk communication.

Results: The workshop revealed BCPs wish for a layered, all encompassing information system. Information on the impact of side effects on daily life was preferred above the risk of these side effects. The survey revealed that important quality of life (QoL) themes were having energy (81%; n = 605), arm function (61%; n = 452), pain (55%; n = 410). Despite the focus on qualitative effects in the workshop, 89% of the survey respondents also wanted to be informed on individualized risks of side effects. 54% Of the survey respondents had never heard of a PtDA.

Conclusions: BCPs preferred information on the impact of side effects, but also their individualized risks on side effects. Most important QoL themes were having enough energy, arm function and pain. Consequently, the BRASA-PtDA should be reshaped, starting with quality of life themes, rather than side effects.

1. Introduction

In recent years, personalized medicine has become the cornerstone for oncological treatment by tailoring the best medically available treatment to the individual needs and preferences of the patient. In selected early breast cancer patients (BCPs) (stage 0–2), radiotherapy (RT) lowers the local recurrence rate but does not impact the overall

survival [1], such that the choice for adjuvant RT is considered to be a so-called “preference sensitive decision”. Especially in these preference-sensitive situations, shared decision making (SDM) is important, e.g. where the health care professional and the patient make a joint decision. In SDM, recurrence risks of treatment with and without RT are weighed against the possible side effects and treatment burden [1]. Such a decision talk can be supported by the use of patient decision

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aids (PtDA), which help patients feel more knowledgeable, better informed and clearer about their values [2] as well as decrease their decisional conflict [3,4].

In order to support a selected group of early stage BCPs in their choice for (additional) RT, we developed and evaluated the BRASA-PtDA [5] (www.beslissamen.nl). In the BRASA-PtDA, local recurrence rates (LR) were indicated in percentages with visual support, but the risk of side effects was only indicated as “very common”, “sometimes” or “rare”. The BRASA-PtDA led to better informed choices and a tendency to refrain from additional RT but it did not affect decisional conflict, nor experienced SDM [6].

Prior to developing the BRASA-PtDA, interviews were held with patients and professionals, revealing a large variation in patient needs on how and in what way information on side effects should be communicated and a large variation in how many and how detailed radiation oncologists communicate on side effects [1]. After using the BRASA-PtDA, these findings were confirmed when several patients asked for more specific information on the risk of side effects. Since developing prognostic models for all relevant side effects is not possible, we needed to know which side effects were considered most important to patients to be quantified and mentioned in the BRASA-PtDA. Also, it was unclear how to best refer to the side effects [1], how to relate them to quality of life (QoL), e.g. grade, duration or short-versus long-term, and how and when this information should be provided. Therefore, the aim of this study was to assess BCPs’ opinion on which and how information on side effects and impact on QoL should be incorporated in the BRASA-PtDA, a PtDA to support the choice for (additional) RT.

2. Methods

This was a mixed methodology study consisting of a qualitative methodology by using a workshop and followed by a quantitative methodology by sending out a survey. We first conducted a two-day workshop with 24 participants in August 2020 using the 2KNOWHOW LearningChain as a framework [7] (Table 1; Appendix 1). Secondly, we performed a nationwide survey amongst Dutch BCPs to validate the results from the workshop and to pose additional questions.

Table 1

Participant characteristics of the EMBRACES workshop (n = 24). Abbreviation: HVE = Higher Vocational Education.

| Role | Relevant Expertise | N | Age (yr) | Education level | Work experience (yr) | Time since treatment |
|--------------------------------------|--|---|----------|-----------------|----------------------|----------------------|
| Clinicians | Shared Decision Making, Breast cancer, Radiation therapy | 3 | 54 | PhD | 30 | n/a |
| | | | 60 | PhD | 37 | |
| | | | 48 | PhD | 22 | |
| Senior Researchers | Artificial Intelligence, Shared Decision Making | 2 | 46 | PhD | 19 | n/a |
| | | | 48 | PhD | 24 | |
| Junior Researchers | Artificial Intelligence, Shared Decision Making, Innovation implementation | 3 | 33 | Msc. | 7 | n/a |
| | | | 23 | Msc. | 1 | |
| | | | 36 | Msc. | 7 | |
| Patient organisation representatives | Breast cancer, Shared Decision Making, Long-term effects | 3 | 45 | HVE | 21 | n/a |
| | | | 42 | MSc. | 16 | |
| | | | 56 | HVE | 34 | |
| Project Leader | Multidisciplinary events, Breast cancer, Research professional | 1 | 40 | PhD | 16 | n/a |
| Process Supervisor | Health care events, journalism | 1 | 64 | MSc. | 40 | n/a |
| Cartoon-drawer | Visually capturing the essence of information provided | 1 | 48 | HVE | 25 | n/a |
| Photographer | Capturing the process and interaction, Innovation implementation | 1 | 36 | MSc. | 6 | n/a |
| Former BCPs | Long term effects (n = 3), Young women expertise (n = 1). Fellow sufferers contact (n = 1), Online self-aid programs (n = 1), Shared Decision Making (n = 1), Self-direction (n = 1), Digital support team (n = 1) | 9 | 57 | HVE | n/a | 9 |
| | | | 57 | HVE | | 4 |
| | | | 60 | HVE | | 9 |
| | | | 50 | HVE | | 5 |
| | | | 50 | HVE | | 9 |
| | | | 32 | MSc. | | 3 |
| | | | 66 | HVE | | 7 |
| | | | 67 | HVE | | 5 |
| 53 | HVE | | 16 | | | |

2.1. Workshop

Patients were recruited through the Dutch Breast Cancer Association (BVN). Purposive sampling was used to obtain a heterogeneous group with respect to diversity in age, interest and education. No specific exclusion criteria were used. Professionals were approached based on their involvement in the earlier BRASA study (NCT03375801) or other SDM studies. The workshop goal was to obtain the patients’ perspectives on: 1) The most important side effects; 2) The best way to refer to these side effects; 3) How to relate them to QoL; and 4) How and when this information should be provided.

Before the workshop, (former) BCPs were asked to look into their medical records and consider: (i) experienced side-effects of RT, (ii) the consequences of treatment choices on their life, (iii) the information they received, (iv) if the odds for survival were ever discussed, (v) which visualization for presenting risks they would find appealing and (vi) when a decision aid (DA) would be useful. The workshop consisted of a short introduction of the goal, research questions and interactive part allowing participants to describe what motivates them in life. A participant shared her story of side effects to ensure participants would not limit themselves to theoretical frameworks. The patients’ perspective was recorded and presented via an open-ended speech bubble mentimeter for transparency and ideation purposes.

In focus groups, possible side-effects of RT were summarized, validated by clinicians and via consensus clustered into major categories. The clusters were enriched with consequences for QoL by the former BCPs. Finally, the side effects were prioritized, by clinicians, researchers and former patients using red, yellow and green labels respectively and presented to the whole group. Furthermore, groups of two or three people, one clinician or researcher and one patient, discussed patients’ visualization preference and when the PtDA should be offered. To reach a draft for a research proposal, the opinions from the focus groups were integrated in two mixed groups. Common denominators among the proposals were identified following the discussion and the main conclusions were presented.

2.2. Survey

In December 2020, a digital survey was developed consisting of ten multiple choice questions related to demographics, QoL themes, use of

DA and risk communication, including the option to elaborate (Appendix 3). This survey was sent to the 3000 participating BCPs taking part in the BVN b-force panel [8]. Participants of the BVN b-force panel take part in surveys on a voluntary basis. Characteristics of participants are gathered per survey.

2.3. Data analyses

Patient-, treatment characteristics and patient preferences were described using the number of patients per category. Differences in characteristics between groups were assessed using Chi-square test or fisher exact test where appropriate for categorical variables. All analyses were performed using IBM SPSS Statistics for Windows (version 25; Armonk, NY, USA, IBM Corp.). A two-sided p-value ≤ 0.05 was considered statistically significant.

3. Results

3.1. Results from the workshop

3.1.1. Participant characteristics

In total, the workshop was attended by 24 participants, 2 men and 22 women. A balanced representation was sought between clinicians, researchers, (former) patients, patient representatives and facilitating participants (Table 1). The expertise of the former patients was diverse ensuring different views. Average time after diagnosis was 7.4 years and 8 of the BCPs had a higher vocational education.

3.1.2. Side effects and impact on QoL

The side effects mentioned are displayed in Table 2. BCPs stressed that the risk of side effects in itself was not as important as the limitations of a particular side effect on the day-to-day activities like sports,

Table 2

All side effects mentioned and the frequency of priority given per target group during the EMBRACES workshop.

| Major categories | Named side-effects | Priority |
|----------------------|--|---|
| FUNCTIONALITY | Primarily, limitations in shoulder/arm, stiffness: | Clinician n = 3 Patient n = 15 Researcher n = 4 |
| | - Connective tissue problems | |
| | - Fibrosis | |
| | - Muscle problems | |
| | - Hard chest | |
| | And to a lesser extent: | |
| | - Problems with swallowing | |
| | - Heart damage | |
| | - Lung damage and pneumonitis | |
| | - Bone damage and fracture | |
| PAIN | Pain, e.g. caused by stiffness: | Clinician n = 1 Patient n = 7 Researcher n = 2 |
| | - Aching | |
| | - Burning | |
| | - Stinging | |
| | - Scar-pain | |
| FATIGUE | Fatigue | Clinician n = 2 Patient n = 4 Researcher n = 2 |
| SKIN | - Itching | Clinician n = 1 Patient n = 4 Researcher n = 2 |
| | - Irritation | |
| | - Redness | |
| | - Discoloration | |
| | - Burning branderig | |
| | - Broken skin | |
| | - Edema | |
| | - Burn | |
| | - Molting | |
| | - Red skin | |
| | - Blood Vessel problems | |
| | - Shape change (bigger and smaller) | Clinician n = 1 Patient n = 2 Researcher n = 1 |
| | - Unsatisfactory cosmetics | |
| - Edema | | |

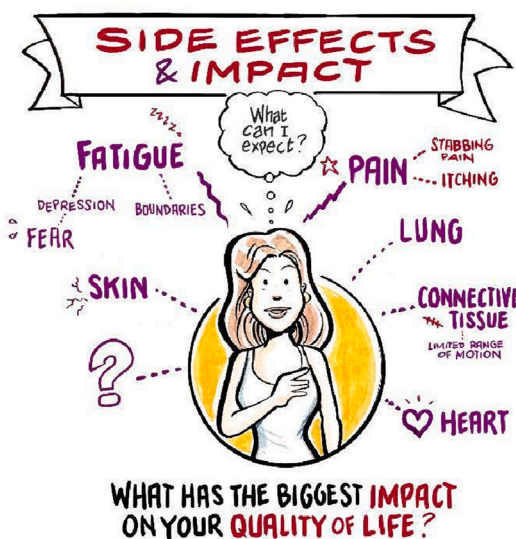


Fig. 1. Cartoon created during the workshop, illustrating the most important side-effects mentioned by former breast cancer patients, their impact on daily life as well as a major question breast cancer patients are struggling with at the time of diagnosis, namely “What can I expect?” (Cartoon Gert-Jan Kleijne from ComicHouse).

being an active grandparent, or being independent in work (Fig. 1). One BCP expressed: “I can feel [the pain] the whole day, someone else does not notice it.” “If I would have known that I would not be able to cycle anymore, I would have thought twice about it.” To give an example of information relevant to day-to-day activities: “What exactly is a minor skin burn and a major skin burn?” The implications are daily wound dressing changes by a nurse for a certain amount of time and in case of severe skin burns an intolerance to wearing a bra. Both are of immediate consequence for social activities and may impact how a person can lead their life. Of all side effects mentioned, fatigue, limitations on function retention and pain were unanimously the most important for doctors, patients and researchers.

3.1.3. Translation to a research proposal

BCPs did not have a clear preference for one specific visualization. The personal bar chart and the pictograph using female symbols tended to receive the most votes.

BCPs preferred access to all high quality information during the complete course of breast cancer treatment, in one place, where they could determine themselves when to access what kind of information. BCPs preferred information to be divided into parts, enabling more detailed information with a click. Essential was the incorporation of impact on the QoL for a BCP, which is highly patient-dependent. All information (including risks) should be incorporated in the PtDA, but the patient should choose the level of detail themselves, e.g. with regard to the frequency and severity as well as the personal risk of a side effect. Also, easy access to information like testimonials and expert panels was desired in the PtDA, along with the demarcation between evidence based information and personal experiences (appendix 2).

For a broad implementation, the workshop participants unanimously agreed that besides a layered DA, time for a patient to (re)think and ask questions, as well as interest of the clinician in the patient preferences are crucial to facilitate SDM as standard high quality care.

3.2. Results of the survey

3.2.1. Participant characteristics

Of all 3000 BCPs receiving the b-force survey, 744 women responded of which 89% (n = 664) had invasive breast cancer, 3% (n = 23) had

Table 3
Participant characteristics of the b-force survey (n = 744).

| Characteristic | Total group | Subgroups | No. in group |
|-----------------------|------------------|-----------------------------|--------------|
| Age | 57.8 ± 9.3 years | <50 years | 152 |
| | | 51–65 years | 435 |
| | | >65 missing | 156 |
| | | | 1 |
| Cancer diagnosis | N = 744 | Past invasive breast cancer | 664 |
| | | Breast cancer in situ | 23 |
| | | Metastasized breast cancer | 57 |
| | | | 1 |
| Time since diagnosis | N = 744 | <3 years | 175 |
| | | 3–5 years | 246 |
| | | >5 years missing | 322 |
| | | | 1 |
| Received radiotherapy | N = 744 | yes | 561 |
| | | no | 182 |
| | | missing | 1 |
| | | | 1 |
| Education level | N = 744 | Low | 86 |
| | | Average | 233 |
| | | High | 410 |
| | | Missing | 15 |
| | | | 1 |
| Paid job | N = 744 | yes | 401 |
| | | no | 285 |
| | | missing | 58 |
| | | | 1 |

breast cancer in situ and 8% (n = 57) had stage IV metastasized breast cancer. Mean age was 57.8 ± 9.3 years and average years since diagnosis was 6.9 ± 4.6 years. Education level distribution was low, middle and high in 12%, 31% and 55% of the women, respectively (2% would not say) (Table 3).

3.2.2. Quality of life themes

In the survey, QoL themes BCPs most valued were having energy (81%; n = 605), arm function (61%; n = 452), pain (55%; n = 410) and the ability to concentrate (48%; n = 356). Reasons were primarily related to being independent (69%), being able to do hobbies and sports (55%) and being able to work (53%) (Fig. 2). There was no significant difference between patients with former breast cancer and patients with metastatic breast cancer, except for sports which were higher valued by former breast cancer patients (p = 0.04).

3.2.3. Personal risk

In the workshop, BCPs unanimously agreed that the impact of side effects was most important to them, implying less interest in quantified

risks on side effects. For generalization purposes, we also explored that theme in the survey. 89% (n = 662) of respondents indicated that they wanted to know their personal risk of a side effect before starting treatment, with 64% indicating wanting the physician to explain consequences to daily life and 52% indicating wanting to know the impact on daily life (Fig. 3). This result indicated that although impact on daily life is considered the most important aspect to be communicated with regard to side effects, personal risks should also be mentioned.

We explored whether former BCPs were familiar with a PtDA. 54% (n = 403) BCPs had never heard of a DA before, 16% had heard of it but never used it, 23% knew what it was, but had never used it. Only 7% had in fact used a DA. Women aged >65yrs were less likely to have heard of a DA or have used it compared to women <50yrs (Pearson’s Chi-Square p < 0.01). Women aged 51–65 years tended to have heard of a DA more than those aged 65 years and older (not sig.). If respondents would now face a treatment decision, 88% (n = 654) (29% likely and 59% very likely) would use a DA to gain insight into the side effects of treatment. A digital DA was preferred (71%; n = 525) over a paper version (11%; n = 80), of which 72% (n = 380) preferred the option to print results.

4. Discussion

This study shows that former BCPs consider having energy, usability of the arm and pain, as the most important QoL themes due to their influence on daily life. They want to be informed on the impact and risk of side effects. Most of them wanted all information about the entire breast cancer treatment in one central place and preferably via a layered system. In this way, patients can choose when to access what kind of information, meeting their personal needs and allowing for a structured way of presenting evidence-based information and patient experiences.

4.1. Side-effects and impact on QoL

In line with research by Raphael et al. [1], our study indicated that emphasis should be placed on the severity and impact of side effects on daily activities instead of risk only. They found that professionals primarily discussed skin reaction, pain, fatigue and change in breast shape [1]. In our workshop, fatigue and pain were also predominantly mentioned, while skin reactions and change in breast shape were lower ranked. An explanation can be the impact of fatigue, pain and arm mobility on daily function.

Results from a Danish oncology survey on chemotherapy side effects also revealed that we still use a non-complete list of side effects [9]. Our results indicate that merely naming symptoms is not enough. Therefore,

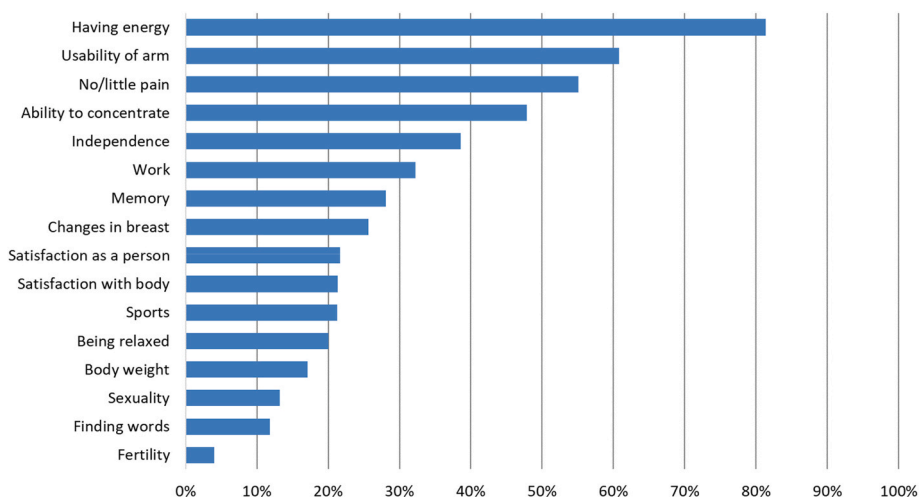


Fig. 2. Most important quality of life themes mentioned by former breast cancer patients in the b-force survey, with a mean time after diagnosis of seven years (n = 744).

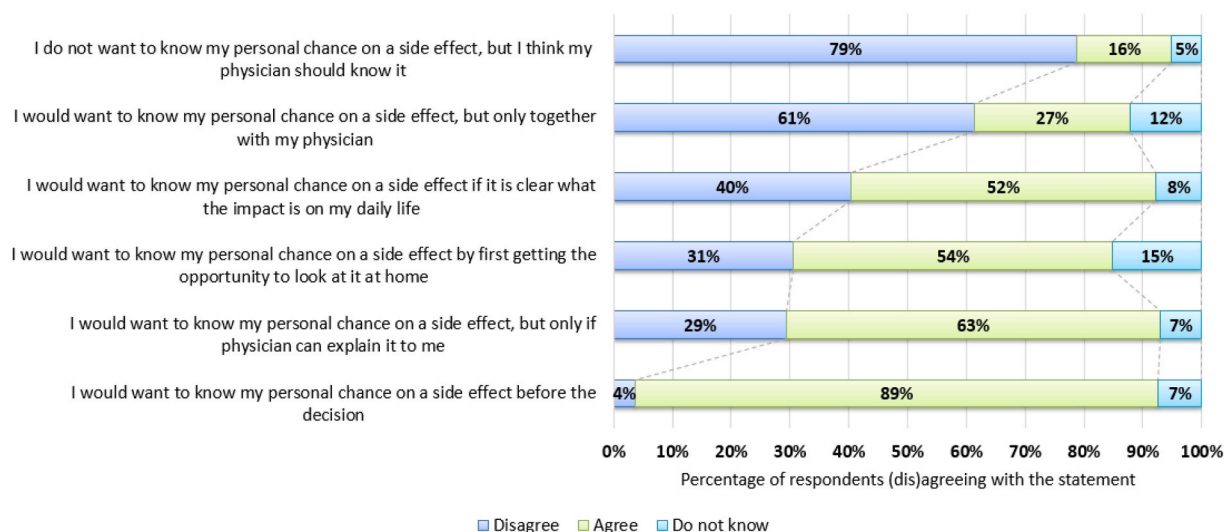


Fig. 3. Preferences of former breast cancer patients to know their personal risk of a side effect and their preferences regarding several preconditions (Obtained via the b-force survey; $n = 744$).

we propose a patient-centered methodology in a PtDA, starting from what is important to patients in their daily lives, guiding them towards the best possible treatment that makes this possible with the least impact on their personal life. Therefore, our results on QoL will pave the way to personalized treatment options, since patient centeredness is especially experienced by patients when health care professionals can empathize [10] and know personal details [11]. Knowledge on QoL themes will support the physician to tailor side effects information and their impact to the patient. In example, knowing the most important QoL themes for the patient can help steer the radiation treatment plan, e.g. balancing the trade-off between radiation coverage and the risk of side effects such as impaired shoulder function. Consequently, patients will feel better informed, which will increase their trust in their clinician [12,13]. The patient's voice in our results highlight the need for more frequent and extensive elicitation of preferences than is currently the case [11] and to include the impact of side effects in the risk communication and value elicitation during the SDM conversation stage 'team talk' [14].

4.2. Personal risk information

The interest to know personal risks on side effects and disease recurrence is ambivalent. In our survey most patients wanted to know their personal risk [15]. In patients with chronic lung disease, the interest in predicting mortality was high [16]. Therefore, the use of prognostic models for mortality risks should not be disregarded when developing a DA. Promising web-based DAs [17] should focus on predicting the chance of a specific grade of toxicity, since merely a dichotomous yes/no result for a specific side effect is not informative enough. Although former BCPs have indicated the need for qualitative data, patients may understand risks more accurately when probabilistic information is presented in numbers rather than words [18]. Therefore, information should be made easy to interpret by people from various socio-demographic backgrounds, avoiding currently applied ambiguous labels as "common", "rare" [18–21].

4.3. Access to care path information

To have one central place of information is challenging, both technologically and in terms of information because of 1) the complexity of patients and multidisciplinary treatments 2) the treatments given and explained by different disciplines (surgeons, medical oncologists, radiation oncologists) and 3) alignment between different hospitals. This results in fragmented information given to the patient, influencing

subsequent treatment choices. Therefore, there is a need to indicate dependency between treatment options as well as give patients the opportunity to absorb information in the quantity they can handle, and at the moment they feel is most appropriate. Such an all-encompassing DA would provide patients with reliable information rather than what they find on the internet [24–26] as over 70% of BCPs still seek information about their diagnosis online [24]. Upon achieving a tailored DA with reliable risk information, the DA could help clinician relational and risk communication skills [27,28]. The first step towards such a DA could be an overview of the current DAs and their dependencies.

4.4. Strengths and limitations

This study has limitations. Mean time between diagnosis and time of the survey and workshop was seven years, which may have affected the ability of former BCPs to recapitulate their feelings and needs at the time of diagnosis. Also, despite collaboration with BVN for a balanced recruitment, selection bias may have occurred concerning patients most willing to participate. Secondly, the number of patients, clinicians and researchers in our workshop was small, enabling us to receive motivated opinions and interactive discussions. Since the results of the workshop were largely in agreement with the survey, we believe that the results are generalizable to the general population.

4.5. Practical implications and further studies

Aspects related to positive health [29], such as QoL, wellbeing and participation are important starting points for professionals and patients for SDM. Using these alternative starting points will enable a different angle towards the health of the patient in which the possibilities and meaning in their life are highlighted. Positive health may also help to increase job satisfaction of professionals, as was shown in primary care professionals [30]. Therefore, it is warranted to apply positive health and QoL as a starting point in a DA (Appendix 2). In this way, a PtDA connects QoL with side effects and will help engagement between clinicians and patients which is utterly important for SDM [31]. Furthermore, clinicians can take on a more active role in SDM, thereby increasing perceived autonomy for patients, without influencing the patient's preferred and perceived decision making roles [32].

Our study indicates BCPs preference to have information available relating to the whole multimodality treatment journey with a clear demarcation between evidence-based information and personal experiences. Reliability and communication are important issues, since

perceived misconceptions can influence the choice [33]. Therefore, we suggest developing a layered system with tailored, reliable information according to individual preferences. Furthermore, we stress the need for time for decision making since insufficient time is related to a higher chance of discordance between preferred and perceived involvement in the decision [34].

Apart from incorporating the QoL themes in the PtDA, professionals should explain the impact of the side-effects on QoL themes most important for a patient.

5. Conclusions

We showed that limitations patients encounter because of the side effects is more important than merely information on side effects. We therefore conclude that this should be incorporated in the SDM process, by adding it to the PtDA by starting with the positive health motivator and connecting that to QoL themes and information resources on impact of side effects. This provides the patient with a comprehensive overview of what a treatment choice entails. We also found that the patients' preferences when to access what kind of information vary greatly, with a common denominator that high quality information on the whole treatment course of breast cancer in one spot is preferred. We therefore conclude that PtDA's should be placed in the context of the complete care path, in which it is clear which choices may affect other choices later on in the treatment course.

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Ethical approval

For the workshop all participants gave consent to use the data. The survey was part of the Breast Cancer Foundation Netherlands bforce 'share your experience' questionnaire for which patients give consent.

Declaration of competing interest

The other authors report no conflicts of interest.

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Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.breast.2022.06.002>.

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