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Does lack of deeper understanding of shared decision making explains the suboptimal performance on crucial parts of it? An example from breast cancer care

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ABSTRACT

Purpose: Although most of the clinicians in breast cancer care seem to approve of shared decision making (SDM), actual implementation is limited. The aim of this study was to explore the experiences, issues and concerns of early-adopter professionals with regards to shared decision making.

Methods: This qualitative descriptive study was part of a pilot study aimed at implementing SDM in breast cancer teams. We interviewed 27 clinicians; 9 breast cancer surgeons, 11 nurse practitioners and 7 nurses. The teams were exposed to a multifaceted implementation programme, among others: a patient decision aid (PtDA), a procedure to disseminate the PtDA and advice on redesigning the clinical pathway.

Results: Participants considered SDM, including the delivery of the PtDA, to be a team effort, in which every professional should take responsibility. Most clinicians primarily focused on the first steps of SDM ignoring preference and decision talk. The remaining steps, like the uptake of the PtDA in the clinical pathway, were regarded as challenging, with surgeons, intentionally or unconsciously, delegating this responsibility to nurses. One barrier to successfully implementing SDM seems to lie in the fact that clinicians were unaware of their lack of competency regarding SDM.

Conclusions: A deeper understanding is needed among clinicians of what SDM actually is and how a PtDA contributes to this process. Nurses play an important role in the delivery of the PtDA, but their role is not clearly defined. Teams should consider a clear realignment of tasks between surgeons and nurses, which implies re-design of the pathway.

1. Introduction

Women diagnosed with early stage breast cancer can often be given the choice between breast conserving therapy (BCT) or mastectomy. Both options have identical prognosis with regard to survival, but each patient may value the advantages and disadvantages of these therapies differently (Fisher et al., 2002), indicating that the patient's preference may determine the decision. Patients vary in their personal preferences, influenced by issues such as level of fear and anxiety, body image values and attitudes towards radiotherapy (Legare et al., 2016; Hershman et al., 2009; Caldon et al., 2011).

Several studies have shown that involving patients in the decision-making process improves their knowledge about treatment risks and benefits, and their satisfaction with the decision made (Barry and Edgman-Levitan, 2012). There is also increasing evidence that most patients want to take an active part in treatment decisions (Coulter,

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2003). Shared decision making (SDM) is the process in which clinician and patient discuss treatment options, to determine the treatment option that best fits the individual patient. First, the clinician needs to invite the patient to work together as part of a team to make a decision between two relevant options (choice talk). This is followed by information on the pros and cons of the options (option talk), and, once the patient has digested the information, elaborating with the patient to elicit the preference (preference talk), and finally, to make the treatment decision (decision talk) with the patient (Elwyn et al., 2013b, 2017).

Tools to support SDM, like a patient decision aid (PtDA), seem to improve the process of patients' involvement in the decision making process, with patients showing more knowledge about the options and more accurate risk perceptions, and decisions being more consistent with patients' values (Stacey et al., 2014; Sivell et al., 2012; Livaudais et al., 2013).

Although support for the wide-scale adoption of SDM and the development of PtDAs is growing, actual implementation is slow and faces many challenges. Implementation of SDM is suffering from lack of knowledge and self-efficacy, and negative attitudes among clinicians towards SDM in general or to the content of PtDAs (Legare et al., 2008, Elwyn et al., 2013a,b). Although interventions to implement SDM adjusted to clinical schedules, including the use of PtDAs in a time-saving manner, evoke less resistance, the best timing and procedures for integrating a PtDA in the clinical pathway are still unknown (Legare et al., 2014; Feibelmann et al., 2011; Belkora et al., 2009).

To close the gap between the principles of SDM and the actual implementation, we developed a SDM implementation programme for breast cancer care teams, including a PtDA, a motivational 5-min video for patients, a 10-min educational video for professionals and tailored advice on when and how to indicate and disseminate the PtDA. The objective of this study was to explore the experiences, issues and concerns of professionals in teams that were exposed to the implementation programme, and the specific lessons on the implementation of a PtDA within an oncological clinical pathway. Various studies have generated insights into relevant barriers and facilitators for the implementation of SDM (Elwyn et al., 2013a; Legare et al., 2008; Legare and Witteman, 2013; Feibelmann et al., 2011). We seek to validate these findings for the situation in the Netherlands. We believe we add to the existing body of knowledge as we conducted our research with early-adopter teams that were already dedicated to implementing SDM. We considered these teams as early-adopters because they showed special interest in SDM and the use of the PtDA. They showed this by volunteering for participation in this study during the development of the PtDA. We exposed them to an implementation programme we developed. We assumed this would provide more knowledge on successful implementation strategies, which can help scale up the use of PtDAs among breast cancer teams also willing to adopt SDM.

2. Methods

2.1. Design

The study focused on implementing a PtDA in daily clinical practice. This was a qualitative study, part of a pilot study aimed at the implementation of SDM in the surgical treatment process of early stage breast cancer. The study lasted two years, from July 2015 until June 2017.

2.2. Population and setting

Dedicated breast cancer teams, known for their positive attitude towards SDM and willingness to improve the process of SDM, from eight hospitals in the west and south of the Netherlands were invited to participate in this study. Seven teams decided to participate. The teams gained free access to a web-based PtDA, for which they had to pay a subscription fee if they decided to continue to use it after the pilot. All team members were invited to join an introduction meeting to explain the implementation programme. To generate meaningful input for the interviews, the clinicians were asked to audiotape some patient contacts during the course of the implementation period. From each participating hospital a minimum of two clinicians, at least one breast cancer nurse and one breast cancer surgeon, were purposefully included in this study. Participating clinicians had to be fully exposed to the programme.

2.3. Ethical considerations

The Maastricht University Medical Centre (MUMC+) ethics committee declared that this study does not fall under the scope of the Medical Research Involving Human Subjects Act (METC 14-5-042). Handling of personal data was in accordance with the Dutch Personal Data Protection Act and Medical Research (Human Subjects) Act.

2.4. Implementation programme

The research team organised a meeting in each hospital for the breast cancer team to explain the implementation programme and discuss the tailored advise on when and how to indicate and disseminate the PtDA. The programme consisted of offering recommendations (tailored to the specific needs of the team and to the hospital's specific workflow) on: 1. a procedure on how to present the PtDA to the patient, 2. minor adjustments in the pathway, 3. watching both a 10-min educational lecture and a 5-min motivational video on SDM (role modelling). The 5 min motivational video shows how to perform the core processes of SDM according to the three-talk model. The model consists of three conversational steps: 1. choice talk in which the clinician makes it clear that there are two relevant options, 2. followed by option talk in which information on the pros and cons of the options is given 3. and finally, performing decision talk to make the treatment decision with the patient. This model somewhat simplifies the complex process of SDM and helps clinicians to systematically achieve a dialogue with patients (Elwyn et al., 2017). The programme was built around a personalised PtDA for patients. The preferred procedure for presenting and using the PtDA was described as follows:

- The personal login code is printed on a paper prescription pad, which is available on the clinician's desk in the consultation room. Each sheet contains the various treatment choices to remind the professional about presenting the PtDA, and a unique personal login code; see Fig. 1.
- The clinician hands out the prescription pad sheet with the personal login code to 'prescribe' the PtDA. The clinician personalises the sheet by ticking the treatment options that are relevant for the patient in addition to breast conserving treatment and mastectomy, such as adjuvant or neo-adjuvant chemotherapy, and/or reconstructive surgery during or after the curative surgery.
- The web-based PtDA can be read at home, when the patient logs in. After first reading the general information, the patient is invited to tick the options that had been marked on the prescription pad sheet, so only the treatment options that are available to the individual patient are shown on the screen. Thus, each patient can personalise the PtDA to prevent an overload of information.
- The PtDA includes a 5-min video, aimed at both patients and professionals, in which a clinician and a patient talk about the importance of SDM and how the PtDA can be used to support this process. The purpose is to raise the team's awareness regarding the SDM process and the positive impact of SDM.

2.5. Data collection

A total of 34 clinicians, surgeons, nurses and nurse practitioners

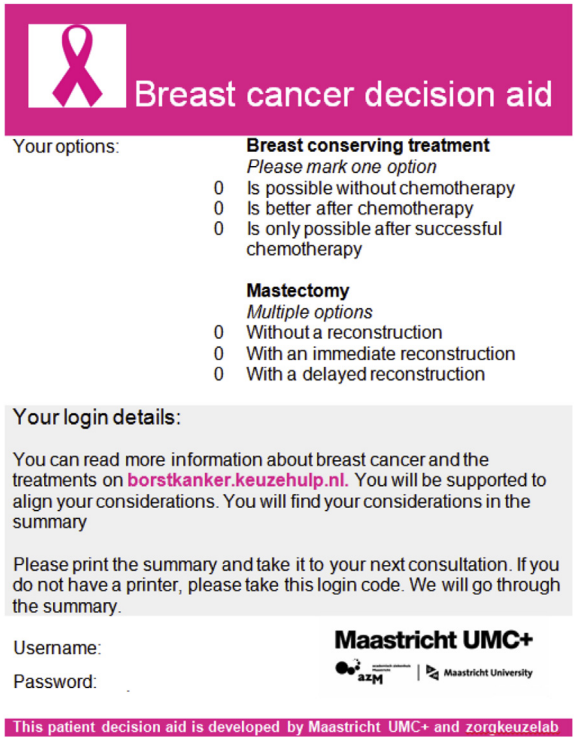

Fig. 1. The prescription pad.

from seven hospitals were invited to participate in a semi-structured face-to-face interview. The interview systematically addressed the following topics: 1. their attitude and behaviour with respect to SDM, 2. their knowledge about SDM and the PtDA, 3. the use of the PtDA within the process of SDM. The interviews were recorded on audiotape, the interviewer also took field notes. See Appendix 1 for the interview guide.

Many clinicians feel they involve patients in an appropriate way in decision making, but seem to lack knowledge on what SDM is really about (Dunning et al., 2003; Gulbrandsen et al., 2014; Joseph-Williams et al., 2017). After the clinicians were exposed to the main questions, approximately halfway through the course of the interview, the researcher showed Elwyn's model of SDM as it was used in the educational video, thus making the clinicians aware of the different steps in the process (Elwyn et al., 2012). The clinicians also received a brief feedback on 1. the previously collected process data in this pilot study (the results of SDMQ9 and CollaboRATE), 2. the actual uptake of the PtDA, 3. the results of the Observer OPTION^5 on previously made audio tapes in the consultation room. The audiotaped consultations (N = 33) were rated with Observer OPTION^5 and the scores were compared with earlier research results (Elwyn et al., 2013b; Barr et al., 2015). Observer OPTION^5 aims to measure to what extent the patient is involved in the decision about the treatment. The instrument consists of a set of competences, including problem definition and alternating options (item 1), expressing support and forming a partnership (item 2), portraying options and communicating risk (item 3), and eliciting preferences and conducting the decision process (item 4 and 5). Showing Elwyn's model and the data we helped professionals to compare their own perceived performance with what SDM actually consist of and the objective results.

2.6. Data analysis

The interviews were transcribed verbatim and processed anonymously. Each interview was independently coded by two authors applying thematic content analysis, using NVivo software to organise the data. Differences in opinion between the coders were solved by discussion until agreement was reached. We identified key themes by grouping the codes into larger themes, which were further explored, restructured, refined and reduced in number (Vaismoradi et al., 2013).

The previously recorded audio tapes were evaluated using Observer OPTION^5. The measurement level is ordinal on a five point scale where "0" indicates the non-performance of a behaviour and "4" indicates the performance of a behaviour at high competency (Elwyn et al., 2013a,b). Two members of the research team assessed the recordings independently (Stubenrouch et al., 2016). The scores were compared and differences were discussed until consensus was reached. The overall inter-rater reliability, measured by Cohen's Kappa, was substantial (0.71). SPSS was used to calculate descriptive statistics to assess the extent to which clinicians involved their patients in SDM. We determined means, SDs, medians and ranges for each item. An overall score was obtained by adding the scores of each item and recalculate this to obtain a value between 0 and 100. Higher scores represent higher level of which clinicians involve patients in the SDM process (Elwyn et al., 2013a,b).

3. Results

3.1. Study population

Of the 34 invited, 27 professionals from 7 different breast cancer teams were willing to participate. Participants included 9 breast cancer surgeons, 11 nurse practitioners and 7 breast cancer nurses. The average duration of the interviews was 23 min (SD 6.5, range 14–43 min).

The main themes that emerged from the data analyses were: (1) Diverging attitudes of clinicians towards SDM and the PtDA. (2) Facilitating delivery of the PtDA. (3) Barriers in the implementation of SDM behaviour. Within each theme there were a number of subthemes.

3.1.1. Diverging attitudes among clinicians towards SDM and the PtDA

3.1.1.1. Team effort. The attitudes of individual clinicians towards SDM and the PtDA seemed to depend on there being a shared vision within the breast cancer team regarding SDM and working experience. Most clinicians felt positive towards SDM and considered SDM to be a team process in which every professional has a responsibility to achieve appropriate implementation. In this process the nurses were often considered to be the case manager, with an important contribution in low-key communication with the patient and the execution of several steps in the SDM process. As nurses, in general, see or talk to the patients after they had time to use the PtDA and to discuss the options with their family, they play an important role in the preference and decision talk steps. Although clinicians indicated they understand the SDM model, elicitation of preferences was not common and patients' decisions seemed somewhat influenced by the preferences of the clinician.

> *"You know, I think that the nurse is a very important person. We, surgeons, don't have the time to extensively explain the PtDA, talk about psychosocial aspects of a treatment. So, that is when the nurses take over, they support the patients to make a decision, they guide them through the whole process, explain the PtDA". ID5,surgeon*

3.1.1.2. Critical attitudes. Some clinicians reported (not speaking for themselves) a rather critical attitude in their teams towards SDM and the PtDA. It was felt to be too disruptive with regard to the prevailing routines. In their opinion, the best possible treatment was already chosen in the Multi-disciplinary Tumour board (MDT), and involving the patient might lead to inferior medical treatment. Other clinicians doubted the applicability of SDM as it might increase the complexity of care and confuse patients.

"That's [SDM] one of those new things they introduce, and if you're already close to your retirement, and then you suddenly have to go about your diagnostic interviews in an entirely new way, that … uhm … takes some getting used to". ID8, surgeon

"I sometimes wonder whether all of this [SDM] really is necessary. I mean, patients are satisfied, so are we not asking too much from them?" ID15 Nurse

"Sometimes there are patients who really have a very small tumour, less than 8 mm. We discuss this in the MDT, because if the patient really wants to have a mastectomy, the extensive surgery does more harm to the body than the radiotherapy, according to the radiotherapist. Then of course patients will be offered the choice, but we are inclined to say; "Gosh, this could very easily be a breast conserving therapy, why would you choose such a heavy intervention?" ID4, Nurse practitioner

3.1.2. Facilitating delivery of the PtDA

3.1.2.1. Delivering the PtDA. Clinicians were positive about the PtDA, as it provides easily accessible information, facilitates more conscious treatment choices and more active patient participation. Many clinicians struggled to establish an appropriate method for indicating the PtDA and to determine the best timing in the routine clinical pathway to deliver the PtDA to the patient. However, it was believed by some that in the course of our project this clearly improved, as it became part of the normal work routine. This was indeed illustrated by increased distribution rates in some hospitals. According to the clinicians this was mostly due to the breast cancer nurses, who acted as an important link in the delivery of the PtDA and promoting its use to patients. However, breast cancer nurses often felt that they were the only ones who made an effort to deliver the PtDA. Despite improved distribution rates, the quality of integration and the use of the PtDA varied between hospitals.

3.1.2.2. Clinician experiences with regard to the PtDA. Clinicians who used the PtDA correctly were enthusiastic and reported they experienced its benefits. Yet, many clinicians lacked knowledge on the content of the PtDA, and why or how they should use it. This led to inaccurate expectations regarding the PtDA, incorrect or limited use and limited implementation of SDM. Some clinicians regarded the PtDA as a purpose in itself, instead as a means to support SDM, which seems to have resulted in the limitation of the SDM process to choice talk and option talk only. These clinicians erroneously believed that announcing that a choice was going to be made, the invitation to the patient to be involved and just providing the PtDA to the patient was sufficient and thus to have fully complied with the principles of SDM. These clinicians erroneously believed that the PtDA provided sufficient information and thus to have fully complied with the principles of SDM.

Most of the clinicians who actually delivered the PtDA to patients had high expectations about the eagerness with which patients would use it, and were disappointed about the rather moderate uptake. These clinicians reflected on the huge amount of information patients often receive, such as written materials on treatments, patient associations and study invitations.

" I think that I had expected more enthusiasm. I had expected people to say: "Oh, it's great and it was very clear what my choices were", and … something like that. And, in practice, I think … uhm … whether this is down to patients or not, I don't know, it's disappointing how we, how much the patient is using it."ID1, surgeon

3.1.2.3. Extra costs. Finally, some clinicians reported that the actual implementation of a PtDA would generate extra costs, without creating more income. Patient associations and authorities like insurance companies are more or less forcing hospitals to use several of these PtDAs, in order to preserve their quality certificates. The costs, after the implementation period, to gain access to the patient decision aids are equal for each hospital without consideration of the size of the patient group. This worries clinicians of low-volume breast cancer sites, as this price tag could create a serious barrier.

"No, you see … uhm … the health insurance provider more or less requires us to use decision aids. And if this price is just as expensive as for standard, for big hospitals, then this really is a serious problem for us. So, the question is; more and more is being added, costs are on the increase and the budgets that hospitals have aren't getting any bigger. You can only spend what you've got once, so that's got to be an … uhm … issue that needs to be addressed." ID3, surgeon

3.1.3. Barriers in the implementation of SDM behaviour

3.1.3.1. SDM performance. While most clinicians perceived SDM as being well implemented in their daily workflow, the actual behaviour as assessed through the audiotapes ranged from above average to very limited or non-existent. A minority of the clinicians appeared to have an adequate view on how to perform SDM. They reported they actively explore patients' preferences, context and specific characteristics during the consultation. These clinicians were aware of the different values patients find important. However, most clinicians only used a limited part of the SDM process, primarily focusing on the explanation of the treatment choice (choice talk), and options in general (option talk). The elicitation of preferences, concerns or values were not spontaneously considered to be important by these clinicians. This also applied to the last step in the SDM process, as there seems to be too little room for considering and discussing the final decision (decision talk). In some hospitals, patients were given a PtDA without planning a face-to-face follow-up appointment for the decision talk, thus failing to make it self-evident to patients that they can express their considerations and preferences. Most of the clinicians stated that the treatment decision is still influenced by the opinion of individual clinicians and the advice of the MDT especially if the MDT recommends one treatment option only.

Some of the clinicians questioned the applicability of SDM, because decision making in cancer care is of such high complexity. Clinicians also considered their patients to be vulnerable, e.g. patients with low intellectual skills or frail elderly patients, and felt the inclination to protect them. They noticed they were consciously more paternalistic in consultations with such vulnerable patients, urging patients towards a certain treatment, instead of exercising SDM.

Confronted with feedback on the actual process of SDM, the results on Observer OPTION[5] (see Table 1), some clinicians acknowledged they were unconsciously incompetent, and reported a lack of a deeper understanding of what SDM actually is. To improve their understanding of SDM clinicians mentioned a need for coaching, training or face-to-face 'on the job' instructions.

"I was convinced that we really involved patients in making a treatment decision, but it seems that what we think is not the reality. Apparently we need to reconsider our way of discussing with patients". ID18 Nurse practitioner.

3.1.3.2. Conflicting interests. In addition, clinicians mentioned the conflict of the consequences of SDM with the quality requirements of the National Breast Cancer Audit (NBCA). According to these quality requirements, patients diagnosed with breast cancer should start treatment within five weeks, thus limiting the time for deliberation and planning extra consultation to achieve a well-considered decision.

"The advantages and disadvantages will then be outlined, very briefly, and the patient will then be given the decision aid. And then … uhm … ultimately, the patient will receive a phone call, two or three days later. The truth is that treatment will then already have been set in motion from a medical point of view, so the treatment proposal will already have been set in motion. But the patient can always … uhm … we will always check

Table 1
Observer OPTION[5] Topics and Mean Scores (SD) for the breast cancer teams (N = 33), compared to performance of other clinicians (N = 101) in a comparable setting of implementation.

	Breast cancer	Chest pain*
Option[5] Overall score		
Mean (SD)	42.0 (10.8)	44.9 (10.8)
Median (range)	41.3 (20–60)	42.5 (17.5–72.5)
Item 1 Alternate Options		
Mean (SD)	2.5 (0.7)	2.2 (0.4)
Median (range)	2.3 (1–3.5)	2 (0–3)
Item 2 Support deliberation/forming a partnership		
Mean (SD)	1.3 (0.7)	1.0 (0.6)
Median (range)	1 (0–3)	1 (0–3)
Item 3 Information about options		
Mean (SD)	2.0 (0.7)	1.9 (0.6)
Median (range)	2 (0–3)	2 (0–4)
Item 4 Eliciting preferences		
Mean (SD)	1.4 (0.9)	1.8 (0.6)
Median (range)	2 (0–4)	2 (1–4)
Item 5 Integrating preferences in decision		
Mean (SD)	1.3 (1.0)	1.99 (0.53)
Median (range)	1 (0–3)	2 (1–3)

Scores on each item ranged from 0 "No effort" to 4 "exemplary effort." Overall scores are recalculated to a 0 to 100 point scale.
*Results Barr, P et all (Barr et al., 2015). (at the time of writing there were no breast cancer study using Observer OPTION[5] available).

> *which choice a patient wants to make in a telephone call. Something like; "well, did you use the decision aid, and … uhm … are you happy with the proposal and can we now go ahead with your treatment? Like that really … uhm." ID9, nurse*

4. Discussion

This study explored the experiences, issues and concerns of early-adopter professionals with regard to SDM. The study met our aims as results show that the breast cancer teams proved to be early-adopters demonstrating glimpses of true SDM behaviour. Result also show that clinicians consider SDM, including the provision of the PtDA, to be a challenging team effort in which team members each have their own responsibility, with an important role for breast cancer nurses. Nevertheless, even in such best practice examples, misconceptions, paternalism and scepticism, as well as a limited implementation of SDM appeared. Most clinicians seemed to lack a deeper understanding of what SDM is actually about, as they primarily focused on the first steps of SDM, the team/choice talk and option talk, neglecting preference and decision talk. Important barriers mentioned were the rather fixed treatment recommendations set by the MDT, and the conflict between the time that is needed for the SDM process and the benchmarks for timely treatment required for quality of care indicators from the National Breast Cancer Audit.

In line with earlier research, the results of this study show that most clinicians are apparently unaware of the substantial deviance of their actual behaviour from the SDM process (Stiggelbout et al., 2012; Pass et al., 2012; Hoffmann et al., 2014). In particular, the preference and decision talk is often neglected or incorrect, apparently caused by a lack of understanding on how patients construct preferences with regard to certain treatments (Blair and Legare, 2015; Sevdalis and Harvey, 2006).

What this study contributes is the finding that the attitude towards SDM among clinicians also often depends on the attitude of their teams. Earlier studies regarding the implementation of SDM primarily focused on the isolated patient–professional interaction. In the current study, clinicians reported that implementation of SDM depends on the team's understanding of SDM within the limits set by the organisation of the local clinical pathways. Teams willing to explore the role of each team member and motivated to alternate tasks could improve the SDM process. As almost every clinician mentioned that the breast cancer nurses are crucial for the delivery of the PtDA and the SDM process as a whole, it is evident that they should obtain more and perhaps different responsibilities in this process. Earlier research suggests that the engagement of nurses, when well positioned and provided with the necessary expertise, could lead to important quality improvements in SDM (Stacey et al., 2008).

Our results suggest that even if patients have the required knowledge it is difficult to decide against an advice formulated by multiple clinicians during the MDT. Therefore, the treatment advice given by the MDT, especially when clinicians communicate the preference of the MDT during the clinical encounter, seems to contribute to maintaining an uneven power balance between professionals and patients where the patient's preference gets easily overruled (Joseph-Williams et al., 2014). This imbalance may be an important factor of which clinicians should be aware, and which they should try to minimise.

Some clinicians felt frustrated in their expectations of the use of the PtDA and enthusiasm of patients, which could partially be caused by a lack of awareness and understanding with regard to the use of the PtDA (Caldon et al., 2011). The results also reveal the difficulties encountered in altering routine workflow in order to implement the PtDA as a part of SDM (Elwyn et al., 2016). Clinicians need more support on the use and delivery of a PtDA, and need to be made aware that implementing a PtDA is not the same as implementing SDM.

Some clinicians questioned the limits to implementing SDM, given the vulnerability of patients, a barrier that is also found in other countries (Lloyd et al., 2013). For them, SDM does not seem suitable for every patient in every situation, depending on the patient's intellectual capacity, older age or lack of motivation for SDM. This means that even in early-adopter breast cancer teams willing to invest in SDM, we found there is a prejudice about what patients want rather than asking them about their preferred level of involvement (Joseph-Williams et al., 2014, 2017). This prejudice seems persistent and will not simply be solved by introducing a PtDA. Clinicians were also concerned that too many tools and too much information will lead to an information overload, which limits the use of the PtDA among patients (Lin et al., 2013).

Finally, the more or less forced implementation of PtDAs by patient associations and health insurance companies may also lead to extra costs. The prospect of implementing several of these PtDAs in the future is worrisome for the clinicians in smaller hospitals. The price tags could create serious limitations in the future.

4.1. Strengths and limitations

The qualitative design of this study allowed us to learn about the experiences and concerns of dedicated clinicians who recently started to implement SDM in daily clinical practice, as well as about the barriers and facilitators they encountered. The interviews were held with the clinicians who were still trying to implement SDM; therefore, recall bias was minimised. The sample size of this study (N = 27) was sufficient to reach data saturation; no new themes emerged from the data after 23 interviews. We interviewed early-adopters who favour SDM. This conscious selection bias strengthens the relevance of the findings that are most likely underestimating the critical attitudes and barriers and complexity among the total group of breast cancer clinicians. The process of SDM is increasingly considered to be a team effort. Our sample consisted of individual surgeons, nurse practitioners and nurses. Therefore, the results do not represent the opinion of the whole breast cancer teams. Although the surgeons and nurses are viewed as the primary partners in SDM for breast cancer, a limitation is that we did not involve radiotherapists and medical oncologists.

5. Conclusion

In our early-adopter teams, the clinicians were generally willing to

implement SDM and the PtDA. Actual implementation in clinical practice, however, was still limited. The implementation of essential parts of the SDM process, preference and decision talk, seemed inadequate, which could partially be explained by a lack of deeper understanding of SDM among clinicians. We need to convince clinicians that using a PtDA in the clinical pathway will not indisputably lead to more awareness and higher performance in SDM. Breast cancer teams that want to apply SDM should not only focus on the patient–doctor communication during clinical encounters but should also consider the role of the breast cancer nurse, a task reallocation and the reorganisation of the clinical pathway, in order to create an environment where SDM is seen as the usual care. Additionally, we suggest that the MDT in its current form is a potential barrier to implementing SDM, as quite often, despite the preference-sensitive decisions, only one treatment option was recommended.

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Appendix A. Supplementary data

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References

Barr, P.J., O'malley, A.J., Tsulukidze, M., Gionfriddo, M.R., Montori, V., Elwyn, G., 2015. The psychometric properties of Observer OPTION(5), an observer measure of shared decision making. Patient Educ. Counsel. 98, 970–976.

Barry, M.J., Edgman-Levitan, S., 2012. Shared decision making–pinnacle of patient-centered care. N. Engl. J. Med. 366, 780–781.

Belkora, J.K., Loth, M.K., Volz, S., Rugo, H.S., 2009. Implementing decision and communication aids to facilitate patient-centered care in breast cancer: a case study. Patient Educ. Counsel. 77, 360–368.

Blair, L., Legare, F., 2015. Is shared decision making a utopian dream or an achievable goal? Patient 8, 471–476.

Caldon, L.J., Collins, K.A., Reed, M.W., Sivell, S., Austoker, J., Clements, A.M., Patnick, J., Elwyn, G., Bresdex, G., 2011. Clinicians' concerns about decision support interventions for patients facing breast cancer surgery options: understanding the challenge of implementing shared decision-making. Health Expect. 14, 133–146.

Coulter, A., 2003. Patient information and shared decision-making in cancer care. Br. J. Canc. 89, S15–S16.

Dunning, D., Johnson, K., Ehrlinger, J., Kruger, J., 2003. Why people fail to recognize their own incompetence. Curr. Dir. Psychol. Sci. 12, 83–87.

Elwyn, G., Durand, M.A., Song, J., Aarts, J., Barr, P.J., Berger, Z., Cochran, N., Frosch, D., Galasinski, D., Gulbrandsen, P., Han, P.K.J., Harter, M., Kinnersley, P., Lloyd, A., Mishra, M., Perestelo-Perez, L., Scholl, I., Tomori, K., Trevena, L., Witteman, H.O., Van Der Weijden, T., 2017. A three-talk model for shared decision making: multistage consultation process. Br. Med. J. 359 j4891.

Elwyn, G., Frosch, D., Thomson, R., Joseph-Williams, N., Lloyd, A., Kinnersley, P., Cording, E., Tomson, D., Dodd, C., Rollnick, S., Edwards, A., Barry, M., 2012. Shared decision making: a model for clinical practice. J. Gen. Intern. Med. 27, 1361–1367.

Elwyn, G., Frosch, D.L., Kobrin, S., 2016. Implementing shared decision-making: consider all the consequences. Implement. Sci. 11, 114.

Elwyn, G., Scholl, I., Tietbohl, C., Mann, M., Edwards, A.G., Clay, C., Legare, F., Van Der Weijden, T., Lewis, C.L., Wexler, R.M., Frosch, D.L., 2013a. Many miles to go ...": a systematic review of the implementation of patient decision support interventions into routine clinical practice. BMC Med. Inf. Decis. Mak. 13 (Suppl. 2), S14.

Elwyn, G., Tsulukidze, M., Edwards, A., Légaré, F., Newcombe, R., 2013b. Using a 'talk' model of shared decision making to propose an observation-based measure: Observer OPTION 5 Item. Patient Educ. Counsel. 93, 265–271.

Feibelmann, S., Yang, T.S., Uzogara, E.E., Sepucha, K., 2011. What does it take to have sustained use of decision aids? a programme evaluation for the breast cancer initiative. Health Expect. 14 (Suppl. 1), 85–95.

Fisher, B., Anderson, S., Bryant, J., Margolese, R.G., Deutsch, M., Fisher, E.R., Jeong, J.H., Wolmark, N., 2002. Twenty-year follow-up of a randomized trial comparing total mastectomy, lumpectomy, and lumpectomy plus irradiation for the treatment of invasive breast cancer. N. Engl. J. Med. 347, 1233–1241.

Gulbrandsen, P., Dalby, A.M.L., Ofstad, E.H., Gerwing, J., 2014. Confusion in and about shared decision making in hospital outpatient encounters. Patient Educ. Counsel. 96, 287–294.

Hershman, D.L., Buono, D., Jacobson, J.S., Mcbride, R.B., Tsai, W.Y., Joseph, K.A., Neugut, A.I., 2009. Surgeon characteristics and use of breast conservation surgery in women with early stage breast cancer. Ann. Surg. 249. https://doi.org/10.1097/SLA.0b013e3181a38f6f.

Hoffmann, T.C., Legare, F., Simmons, M.B., Mcnamara, K., Mccaffery, K., Trevena, L.J., Hudson, B., Glasziou, P.P., Del Mar, C.B., 2014. Shared decision making: what do clinicians need to know and why should they bother? Med. J. Aust. 201, 35–39.

Joseph-Williams, N., Elwyn, G., Edwards, A., 2014. Knowledge is not power for patients: a systematic review and thematic synthesis of patient-reported barriers and facilitators to shared decision making. Patient Educ. Counsel. 94, 291–309.

Joseph-Williams, N., Lloyd, A., Edwards, A., Stobbart, L., Tomson, D., Macphail, S., Dodd, C., Brain, K., Elwyn, G., Thomson, R., 2017. Implementing shared decision making in the NHS: lessons from the MAGIC programme. Br. Med. J 357 j1744.

Legare, F., Briere, N., Stacey, D., Lacroix, G., Desroches, S., Dumont, S., Fraser, K.D., Rivest, L.P., Durand, P.J., Turcotte, S., Taljaard, M., Bourassa, H., Roy, L., Painchaud Guerard, G., 2016. Implementing shared decision-making in interprofessional home care teams (the IPSDM-SW study): protocol for a stepped wedge cluster randomised trial. BMJ Open 6 e014023.

Legare, F., Ratte, S., Gravel, K., Graham, I.D., 2008. Barriers and facilitators to implementing shared decision-making in clinical practice: update of a systematic review of health professionals' perceptions. Patient Educ. Counsel. 73, 526–535.

Legare, F., Stacey, D., Turcotte, S., Cossi, M.J., Kryworuchko, J., Graham, I.D., Lyddiatt, A., Politi, M.C., Thomson, R., Elwyn, G., Donner-Banzhoff, N., 2014. Interventions for Improving the Adoption of Shared Decision Making by Healthcare Professionals. Cochrane Database Syst Rev. CD006732.

Legare, F., Witteman, H.O., 2013. Shared decision making: examining key elements and barriers to adoption into routine clinical practice. Health Aff (Millwood) 32, 276–284.

Lin, G.A., Halley, M., Rendle, K.A., Tietbohl, C., May, S.G., Trujillo, L., Frosch, D.L., 2013. An effort to spread decision aids in five California primary care practices yielded low distribution, highlighting hurdles. Health Aff (Millwood) 32, 311–320.

Livaudais, J.C., Franco, R., Fei, K., Bickell, N.A., 2013. Breast cancer treatment decision-making: are we asking too much of patients? J. Gen. Intern. Med. 28, 630–636.

Lloyd, A., Joseph-Williams, N., Edwards, A., Rix, A., Elwyn, G., 2013. Patchy 'coherence': using normalization process theory to evaluate a multi-faceted shared decision making implementation program (MAGIC). Implement. Sci. 8.

Pass, M., Volz, S., Teng, A., Esserman, L., Belkora, J., 2012. Physician behaviors surrounding the implementation of decision and communication AIDS in a breast cancer clinic: a qualitative analysis of staff intern perceptions. J. Canc. Educ. 27, 764–769.

Sevdalis, N., Harvey, N., 2006. Predicting preferences: a neglected aspect of shared decision-making. Health Expect. 9, 245–251.

Sivell, S., Edwards, A., Manstead, A.S., Reed, M.W., Caldon, L., Collins, K., Clements, A., Elwyn, G., Bresdex, G., 2012. Increasing readiness to decide and strengthening behavioral intentions: evaluating the impact of a web-based patient decision aid for breast cancer treatment options (BresDex. Patient Educ. Counsel. 88, 209–217. www.bresdex.com.

Stacey, D., Legare, F., Col, N.F., Bennett, C.L., Barry, M.J., Eden, K.B., Holmes-Rovner, M., Llewellyn-Thomas, H., Lyddiatt, A., Thomson, R., Trevena, L., Wu, J.H., 2014. Decision Aids for People Facing Health Treatment or Screening Decisions. Cochrane Database Syst Rev CD001431.

Stacey, D., Murray, M.A., Legare, F., Sandy, D., Menard, P., O'connor, A., 2008. Decision coaching to support shared decision making: a framework, evidence, and implications for nursing practice, education, and policy. Worldviews Evidence-Based Nurs. 5, 25–35.

Stiggelbout, A.M., Van Der Weijden, T., De Wit, M.P., Frosch, D., Legare, F., Montori, V.M., Trevena, L., Elwyn, G., 2012. Shared decision making: really putting patients at the centre of healthcare. Br. Med. J 344, e256.

Stubenrouch, F.E., Pieterse, A.H., Falkenberg, R., Santema, T.K., Stiggelbout, A.M., Van Der Weijden, T., Aarts, J.A., Ubbink, D.T., 2016. OPTION(5) versus OPTION(12) instruments to appreciate the extent to which healthcare providers involve patients in decision-making. Patient Educ. Counsel. 99, 1062–1068.

Vaismoradi, M., Turunen, H., Bondas, T., 2013. Content analysis and thematic analysis: implications for conducting a qualitative descriptive study. Nurs. Health Sci. 15, 398–405.