European Journal of Surgical Oncology 45 (2019) 1163–1170

Contents lists available at ScienceDirect

European Journal of Surgical Oncology

journal homepage: www.ejso.com

Implementation of Value Based Breast Cancer Care

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ARTICLE INFO

Article history:
Received 18 October 2018
Received in revised form
19 December 2018
Accepted 3 January 2019
Available online 4 January 2019

Keywords:
Breast cancer
Value-based healthcare
Patient reported outcome measures
Implementation

ABSTRACT

Purpose: Adding value of care to patients is crucial for all stakeholders. The use of both provider and patient reported outcome data was implemented in a single academic breast cancer center. We describe the development of the outcomes set, data integration within electronical health records (EHR) and clinical use.

Methods: An Integrated Practice Unit (IPU) was constructed providing the full care cycle for breast cancer patients. Provider reported outcomes and patient reported outcomes (PROs) were defined, reflecting the entire cycle of care and long-term sustainability of quality of life. Multidisciplinary provider and patient perspectives were obtained via focus groups and surveys. Patient pathways were redesigned in order to identify suitable opportunities for data collection during the entire care cycle.

Results: A Standard Set for Breast Cancer Outcomes together with case-mix variables and timelines was agreed upon within the IPU. A secure electronic platform, directly linked to the EHR, was designed to measure PROs during the outpatient phase. First year evaluation showed a decrease of response rates over time, from 83.3% at baseline to 45.2% at 12 months after surgery. Patients reacted positively to the use of PROMs in daily clinical cancer care.

Conclusion: Assessment of patient reported as well as provider reported outcomes was implemented within our standard of breast cancer care. For this, dedicated resources, change of culture and practice, and improved knowledge and awareness about Value-based healthcare (VBHC) were essential. Our proposed framework aims to serve as a blueprint for implementation of VBHC in daily care.

Introduction

Value-based healthcare (VBHC) aims to improve the quality of care delivered by measuring and improving outcomes that reflect value instead of volume [1,2]. Value of care is defined as health outcome per total costs [1]. Since value in healthcare depends on results, not inputs, value is measured by the outcomes achieved and not the volume of services delivered [1]. Ideally, these outcomes reflect patient-orientated results instead of structure or process-measures that do not always reflect the results obtained [1]. Multiple health outcomes are often used to evaluate the care for a single medical condition. In a VBHC-design outcomes are both provider reported (i.e. breast cancer survival rates, complications, hospitalization rates) and patient reported (PROs) [1]. Inherently, these outcomes are disease specific and multidimensional to reflect the total cycle of care and quality of life (QoL) and disease burden in the long run [1,3].

Specifically in the care for (early stage) breast cancer patients the importance of value is increasingly being recognized. High survival rates are achieved in early stage breast cancer patients [4,5] irrespective of the type of surgery performed [6–8]. Considering these excellent and comparable oncological outcomes and the multiple locoregional strategies available in this setting (i.e. breast conserving therapy (BCT), mastectomy, whether or not followed by breast reconstructive surgery; all with differences in outcomes and

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https://doi.org/10.1016/j.ejso.2019.01.007
0748-7983/

Abbreviations

BCT	Breast Conserving Therapy
VBHC	Value-based Healthcare
PRO(M)	Patient Reported Outcome (Measurement)
ICHOM	International Consortium for Health Outcome Measurements
ABC	Academic Breast cancer Centre
NST	Neoadjuvant Systemic Therapy
EHR	Electronical Health Record
FFS	Fee-for-service

costs), there is an increasing need for outcome measurements that accurately differentiate between treatment strategies. In the era of increasing healthcare costs and stringent measures to lower costs, these outcomes could increase breast cancer care efficacy (by improving outcomes against equal or lower costs). In addition, adequate outcome assessment could also add in future treatment decision making and/or follow-up regimens.

The Erasmus MC, a major academic healthcare institute within the Netherlands, initiated a VBHC-strategy. With commitment from both the institution and different multidisciplinary disease teams, multiple outcome sets were defined and a data collection tool was developed to capture these outcomes. Following a pilot phase the concept was gradually rolled out and is now used in daily practice for 10 medical conditions amongst which breast cancer. The International Consortium for Health Outcome Measurements (ICHOM) has initiated efforts to develop standard sets of patient-centered outcome measurements for various medical conditions amongst others breast cancer. As part of the ICHOM Working Groups, clinicians from the Erasmus MC have contributed to the development or implementation of multiple outcome sets on an international level [9–13].

Value-based breast cancer care was designed in 2014 and initiated in October 2015 by the dedicated multidisciplinary breast cancer team of the Erasmus MC Academic Breast Cancer Centre. A standardized outcomes set was created that encompassed both provider reported outcomes and PROs. Striving to implement value-based breast cancer care on a broader (inter)national scale, this article gives a step by step overview of the framework deployed for implementation of this outcome set and discusses the challenges within the implementation process. The description of our data collection tool that was linked to the electronic health records (EHRs) and the research performed during this implementation phase, is additionally aimed to serve as a guide for future implementations. Lastly, future steps are discussed needed to transform current breast cancer care towards a value-based breast cancer care.

Methods

Within the institute a breast cancer specific-strategy was developed to transform the current breast cancer care to value-based breast cancer care (Fig. 1) [2,3]. This step by step overview functions as a blueprint in the implementation process.

Institutional dedication

Recently, the executive board of the Erasmus MC initiated a 5-year VBHC-strategy to transform the institute into a true value innovator. This institutional dedication is pivotal to enable a transformation of the current healthcare systems towards a VBHC-system. This institutional leadership ensures sufficient resources needed for this transformation [14]. We consulted the Institutional Review Board, who concluded that informed consent was not needed since the VBHC-strategy is considered standard of care in Erasmus MC.

Dedicated multidisciplinary team

An integrated, and thus multidisciplinary breast cancer practice unit was already operative within our institute. The team is composed of oncological (breast)surgeons, medical oncologists, radiation oncologist, radiologists, plastic & reconstructive surgeons, pathologists, specialist breast cancer nurses (all present at

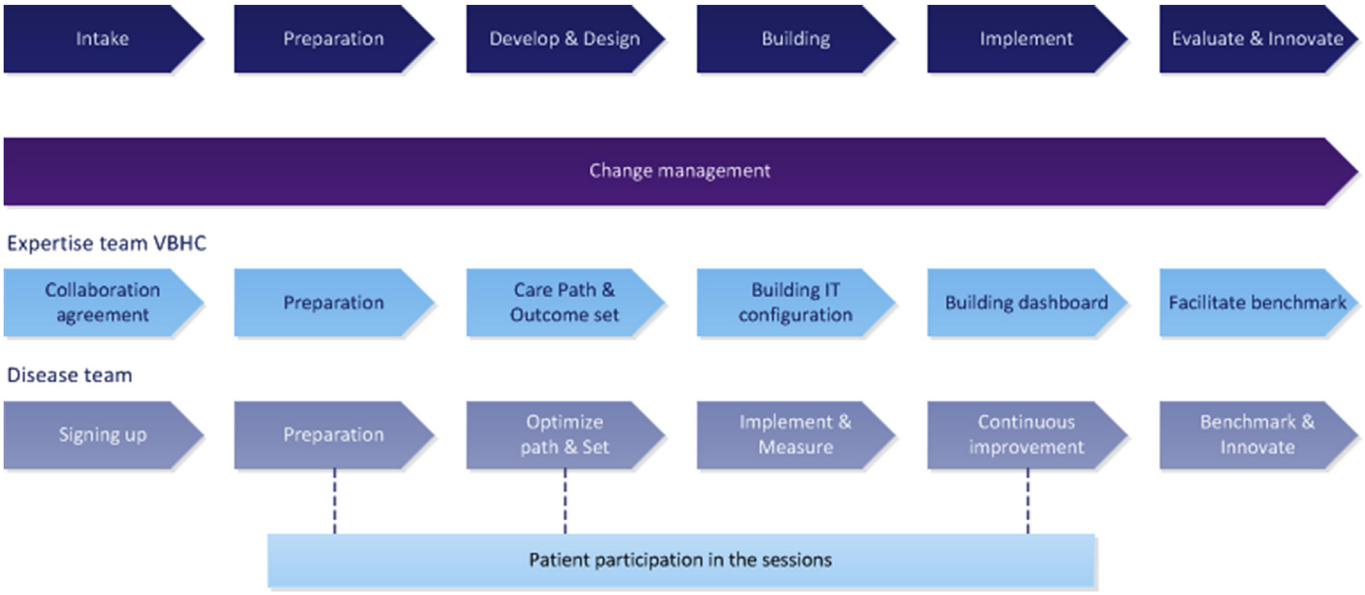

Fig. 1. Erasmus MC's blueprint, facilitate the teams on their journey towards VBHC.
VBHC, Value-based healthcare; IT, Information Technology.

multidisciplinary board meetings), clinical geneticists, psychologists, gynaecologists, and thoracic surgeons (consulted upon indication). Within breast cancer care Patient Reported Outcome Measures (PROMs) had already gained interest and participation in the institutional pilot phase was therefore seen as a unique opportunity.

Care pathway

Realigning services with patient needs is fundamental to deliver more efficient care [2]. For breast cancer, a 'complex' care pathway (involving many different disciplines), was first redesigned to serve as a starting-point for the design of other care-pathways: young women with (potentially hereditary) breast cancer who need neoadjuvant systemic treatment and afterwards undergo mastectomy with immediate (autologous) breast reconstruction. Within this redesign the time-points when to visit several different physicians and when to evaluate different outcomes were determined (eFig. 1, Supplement).

Breast cancer outcomes set

Defining an outcomes set is an essential step within any VBHC-initiative which should occur before actual implementation. A first version of the outcomes set was composed by the multidisciplinary team after five 3-h work sessions.

To ensure patients' input in the outcomes selection, interviews and surveys were performed within breast cancer patients in different treatment phases. Validated questionnaires were searched capturing the intended outcomes. PROMs incorporated in the set were the EORTC-QLQ-Core (C30) [15], EORTC-QLQ Breast Cancer (B23) [16], BREAST-Q (both preoperative and postoperative modules) [17], EQ-5D-5L [18], Distress Thermometer [19], the Reproductive Concerns Scale (RCS-NL) [20], and the CarerQoL-7D [21]. All questionnaires were available in validated Dutch versions (Fig. 2).

Outcomes such as patient, tumour and treatment characteristics, survival rates and treatment-related complications were defined by physicians considering patient input. These outcomes serve as either an outcome on its own (for example survival rates) or as a variable in multivariable or case-mix analyses used to evaluate outcome scores (eTable 1).

The determined time-points for data collection are equal to those in the, later developed, ICHOM set. Time-points determined were: baseline (prior to treatment; T0), following the last course of neoadjuvant systemic therapy (T3), 6 months after surgery (T6) and annually thereafter (T12-60) (Fig. 2). To capture the period where patients might still be on endocrine therapy, follow-up was recommended up to 5–10 years in early breast cancer patients. Annual follow-up up to age 50 years was recommended for young breast cancer patients. Annual follow-up for 10 years was recommended for patients with advance disease.

Data collection tool

An in-house developed open source electronical data collection tool was used and configured, which allowed the construction of data collection-forms and automatic distribution of PROMs. Emails are sent to the patients in order to activate the distribution of PROMs. After the right treatment pathway is selected by the physician, all the following PROMs will be sent automatically by the tool at the right time-point. The tool was linked to the EHR enabling the review of the collected data for individual patients at the (outpatient) clinic. The secure platform is build up by two software programs, LimeSurvey [22] and GemsTracker [23]. The development team simultaneously developed a user-friendly interface to display the collected data. Since the selected BREAST-Q questionnaire is surgery-specific, multiple pathways for data collection had to be build (i.e. BCT, mastectomy alone and mastectomy with breast reconstruction, either with implants or autologous). Longitudinal PRO data and data from the caregivers is collected in these pathways (Fig. 2).

Results

During the institutional pilot-phase, in which a VBHC-strategy was implemented for six medical conditions, multiple institutional and regional (breast cancer specific) symposia were organized to update and include both physicians within the hospital, primary care givers, patient advocacy groups and other stakeholders in the ongoing initiative. Currently a VBHC-strategy is being used in the daily care for ten other medical conditions other than breast cancer [10–12].

Implementing value-based breast cancer care

An initial period of 3 months was used to test and evaluate the use of the different pathways. During this phase all emails (distributing the PROMs) were sent manually to patients by specialist nurses. This enabled proper insight in the functioning of the pathways. The manual distribution consequently led to a reminder to discuss the initiative with patients or to follow-up on patients who had not responded. Currently, all postoperative modules are distributed automatically to patients (by the electronical data collection tool) 3 weeks before the scheduled consultation with two following weekly reminders. The preoperative surveys are distributed manually by specialist nurses considering their delicate timing of administration (directly following diagnosis and before surgery or start of neoadjuvant chemotherapy). An advantage of this continuous manual distribution is that it serves as a reminder to discuss the initiative with all patients (and caregivers) at the outpatient clinic. An additional change was made in the follow-up regimen, i.e. the PROs collection at the six month postoperative time-point (T6) was considered mandatory instead of optional. The collected PROs at this time-point were evaluated and discussed with the patient in the telephone consultation with the specialist nurse. A first consultation at the outpatient clinic was scheduled together with the (mammographic) follow-up visit. PRO scores were than evaluated and discussed with the patient in the consultation room.

An average of 20 min per patient was needed to complete the PROMs of the outcome set at one specific time-point [24].

First evaluation

We evaluated the first two years of our VBHC-initiative. Ethical approval for this evaluation was granted by the Institutional Review Board of the Erasmus MC (MEC-2018-1015). A total of 239 breast cancer patients, surgically treated at our institute, were enrolled between October 2015 and December 2017. A response rate of 83.3% (199/239 patients) was seen at baseline (T0), which decreased over time to 65.7% (157/239 patients) at 6 months postoperatively (T6) and 55.1% (108/196 patients) at 12 months postoperatively (T12). Looking at the different questionnaires it was found that not all questionnaires were completed at the several time-points (T0, T6, and T12). For example, only the EORTC-QLQ-C30 and −B23 were completed and the BREAST-Q not, or otherwise (Fig. 3). Moreover, some time-points were completely missed leaving all PROMs at that specific time-point empty.

The specialist nurse monitored whether patients completed the

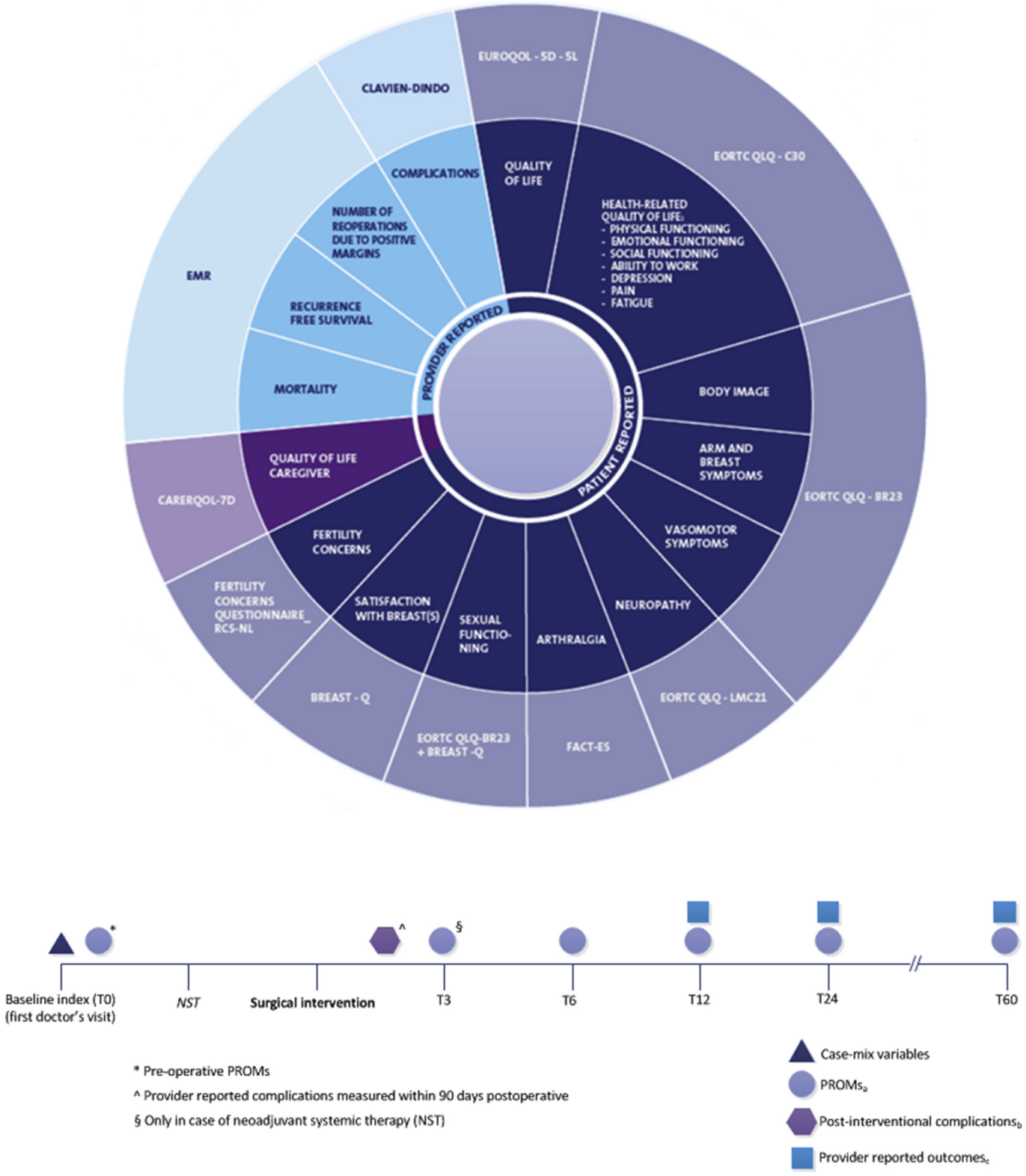

Fig. 2. Erasmus MC's standard set for breast cancer.
[a]All PROMs are collected at baseline (T0), 6 months (T6) after treatment, and then annually (T12-T60), except for the BREAST-Q-satisfaction with breast module, which is only collected at baseline (T0), 1 year (T12) and 2 years (T24) after treatment. [b]Collection of acute complications is recommended while the patient is undergoing treatment or within 90 days of treatment completion, except for complications of hormonal therapy, which are collected up to one year (T12). [c]Survival and disease control.
NST = neoadjuvant systemic therapy; PROMs = patient reported outcome measurements.

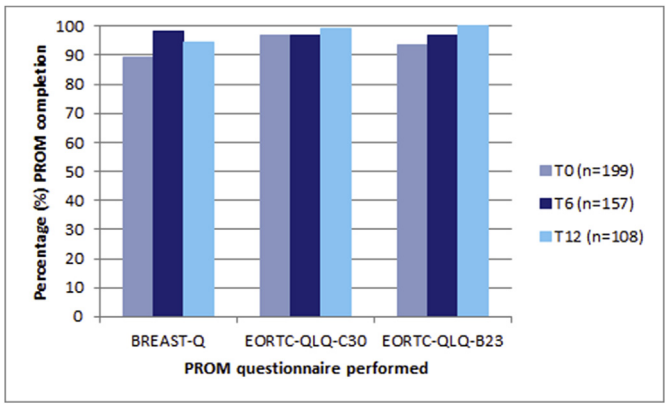

Fig. 3. Percentage of breast cancer patients filled in the PROM questionnaires (N%) per time point during the first year.
Vertical axis shows the percentage (%) of patients who completed the PROM per time point.
T0 = baseline (prior to treatment), T6 = six months after surgery, T12 = twelve months after surgery.

PROMs and asked patients about their reason not completing the questionnaire (if applicable). When no responses were received patients mostly stated that they had forgotten about the surveys (preoperatively) or had not understood that they would be administered repeatedly (postoperatively).

Ongoing efforts resulted in a user-friendly interface that directly displays the outcomes collected in a dashboard so they can be evaluated by both patients and physicians. Concerning feedback, PROs are filled in prior to outpatient clinic visits and discussed by the healthcare provider. If not filled in, the patient is asked to do so and a phone call is planned. Essential for the success of this VBHC-initiative is the (direct) feedback of the PRO scores and/or the changes in the scores according to baseline values. An adequate interpretation of these (changes in) scores enables an appropriate change in care strategy or intervention. Reference scores are additionally needed to evaluate PROs scores in a broader perspective. In order to obtain useful reference scores applicable to our patient population, we evaluated PRO scores which were retrospectively assessed within our institute (all breast cancer patients treated over the last ten years) [25] and through the regional and national patient advocacy groups [24]. In addition, we evaluated the median PROs for the different PROM modules over time during the first year. As expected PRO scores decreased between baseline (T0) and 6 months postoperatively (T6), but higher scores were seen at one year postoperatively (T12) compared to T6, Fig. 4. Graphical visualization of the trend of PRO scores over time, during treatment and/or follow-up, facilitate a quick overview of a patient's current state of health in the physiological, social, and physical areas and turn this information into a diagnostic tool.

To evaluate whether patients were satisfied with our initiative, an experience survey was composed, asking patients (n = 30) how satisfied they were with the number of PROMs, the content of the PROMs and the feedback of the PRO scores during hospital visits. Patients reported that PROMs were aligned with their treatment (86.3%), and they felt themselves more heard at T6 (64.3%) and at T12 (100%). The majority of the patients even reported that

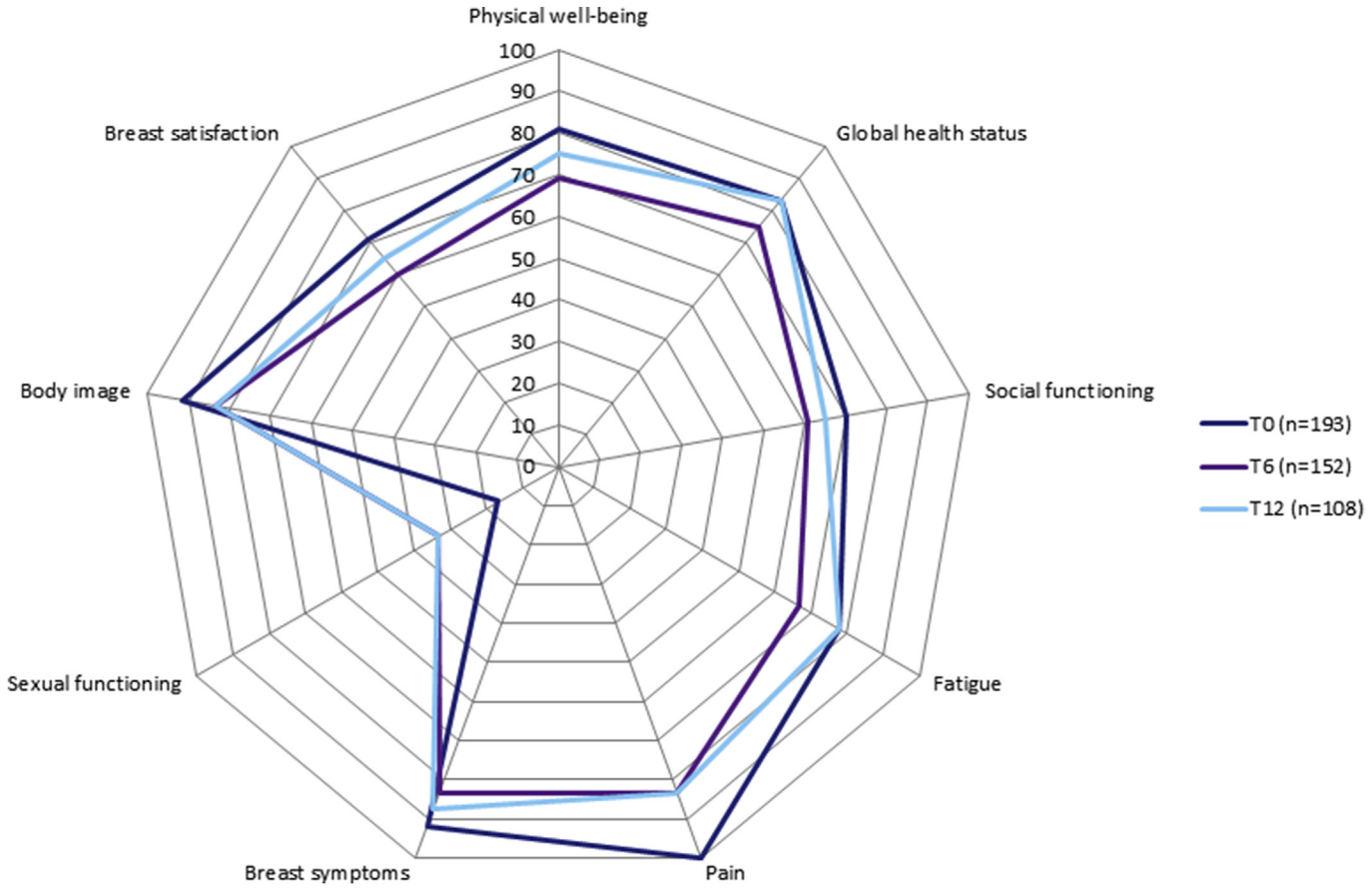

Fig. 4. Spider plot representing the different PROM scores per time point (239 patients).
T0 = baseline (prior to treatment), T6 = six months after surgery, T12 = twelve months after surgery.

completing the PROMs helped them to become more aware of their everyday functioning (60.0%), and contributed positively to their breast cancer treatment (80%) (Fig. 5).

Discussion

Value-based breast cancer care was implemented within our institution over a time-period of three years. First, standardized care pathways were developed by the dedicated multidisciplinary team. Second, a breast cancer outcomes set was developed in collaboration with breast cancer patients and regional patient advocacy groups. Third, the outcomes set was integrated in clinical practice by using a newly developed data collection tool which was linked to the electronic health records. Patients within our institute now receive PROs at baseline and at predetermined time-points throughout their care cycle to discuss these outcomes with their healthcare providers and tailor their supportive therapies were necessary.

The compliance during the first year was lower than expected. Possible explanations are patients' unawareness or misunderstanding about the repeated administration of the PROMs. False or changing e-mail addresses was another issue which explains the lower compliance rate over time. In order to tackle these difficulties, a brochure to explain the VBHC-initiative and the different time-point of survey-assessment was therefore created.

Patients who have participated with the collection tool receiving and completing the PROMs have provided positive feedback about the initiative thus far. They stated that the use of PROMs helps them to prepare for the upcoming appointment, which makes it more tailored to their needs. Care providers at our institute reported similar benefits, additionally stating that with the use of PROMs a more complete view about the provided care can be obtained. Studies evaluating the use of a similar tool reported comparable positive feedback of both patients and care providers and identified several strengths [26–28]. The ability to prioritize topics for discussion at outpatient visits, symptom monitoring and management were well documented, as well as improved patient-provider communication leading to more shared decision making. Clinicians found PRO data useful and not disruptive to their practice [29–31]. Several tools are available nowadays and successful implementations of outcomes sets by IT-systems integrated in the EHRs have been reported [28,32–34]. Also, when enquiring about the expectations of breast cancer patients through the regional and national patient advocacy groups, positive answers were collected [24]. Recently, a collaboration with eight hospitals in the Southwest region of the Netherlands aiming at the same outcomes set was started to expand the local value-based breast cancer-initiative. In this way transparency between hospitals can be driven in order to improve quality of regional breast cancer care by benchmarking outcomes. Comparing outcomes for quality monitoring requires implementation of identical outcomes sets. Regional and national, or even international, efforts to adapt an identical set creates the possibility for benchmarking and comparative effectiveness research.

Both authors LK and MM were part of the ICHOM working group that established a consensus on the breast cancer outcome set [13]. The ICHOM breast cancer set was compared to the institutional outcomes set and changes were made to obtain the highest resemblance. In addition to the ICHOM set the Erasmus MC outcomes set also includes the EQ-5D-5L-questionnaire and all modules of the BREAST-Q (i.e. not only the 'satisfaction with breast'-module). This general health questionnaire was added mid-2016 within all VBHC-initiatives at the Erasmus MC in order to evaluate the health status of all patients referred to our centre [35]. The BREAST-Q is a surgery specific questionnaire developed in 2009 with the use of modern psychometric methods [17]. It is expected to accurately differentiate satisfaction with cosmetic outcome per type of surgery performed [36,37]. An important advantage of early adaption to a value-based breast cancer care-initiative is that it generates the possibility to gain insights in the validity and applicability of PROMs used.

Internationally, current payment systems are mostly based on the volume of services (fee-for-service-model). Bundled-payment is a value-based model in which the basis for reimbursement is bundled care and value (results rather than services). Wang et al. [38], examined the correlation of outcomes and medical expenditures by comparing a bundled-payment system to a fee for services-system in 17,940 breast cancer patients. With a range of 5-year follow-up, the medical payments of the bundled-payment group remained stable, whether the fee-for-service payments steadily increased. This suggests that bundled-payment systems may lead to better adherence to quality indicators, better outcomes,

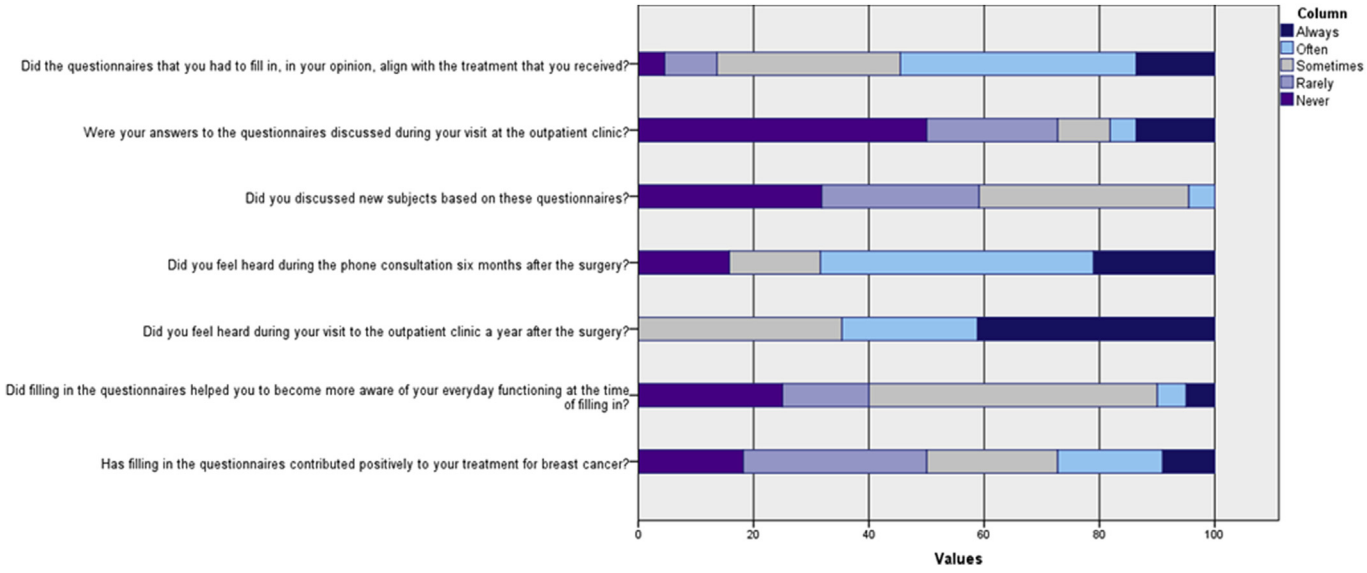

Fig. 5. Experience survey (30 patients).

and more-effective cost-control over time [38]. Healthcare systems that already have a bundle-payment system could take advantage of the transformation made by breast cancer multidisciplinary teams towards a value-based breast cancer system. Although a VBHC-initiative is hard to translate to a fee-for-service model, it is expected that all stakeholders will benefit from such a transition to longer term bundles [3]. Not only in a fee-for-service system but also in a bundled payment system sufficient research to gain insight in PROs validity and applicability is needed before PROs can be used to guide payments.

Limitations seen within the implementation process should be rephrased into key lessons. Dedicated resources (human and financial) need to be established to make outcome measurement core business. Changing culture as well as practice is a key part of the process and must be acknowledged in the attempted changes. Healthcare providers therefore need to make active efforts to secure support for VBHC in daily practice. The development of our data collection tool was a significant milestone in the implementation process. Due to IT functional problems implementation slowed down, but true progress could be made after the data collection tool was functioning well. This went hand in hand with improved knowledge and awareness about VBHC and the data collection tool. Running pilots and educating both providers and patients are therefore essential for high compliance rates with provider outcomes and PROs. Lastly, to ensure continuous adaptation and correction during the implementation process, small and incremental changes should be made instead of mass overhaul [12].

With breast cancer survival rates continuing to improve, the focus on survivorship issues and quality of life is increasingly becoming important. In the context of breast cancer care a value approach is expected to generate necessary insights in outcomes for the different surgical strategies and improve care efficiency (by improving outcomes and stabilizing or reducing costs). The VBHC-initiative is expected to pave the way [24]. Our initiative has now grown beyond its own centre to support other breast cancer centres to implement the same set of outcomes, seeding the potential for learning and improvement initiatives on a much broader scale. At the moment we analyse a large dataset in order to develop prediction models for quality of life concerning certain therapies.

Conclusion

A value-based breast cancer strategy including explicit and longitudinal PRO scores was successfully implemented within our institute. Measurement of PROs as well as provider reported outcomes was implemented within our standard care. Structured measurements will create opportunities for performance improvement, shared treatment decision making and benchmarking between different providers and healthcare systems, both on a regional and international scale. For this, dedicated resources, change of culture and practice, and improved knowledge and awareness about VBHC were essential. The outline described of both the development and implementation of this initiative is meant as a guide for future implementations.

Funding sources

Authors LVE and JH are partly funded by the Dutch Federation of University Medical Centres (NFU). No funding or other support was received for the manuscript.

Conflict of interest

All authors declare to have no potential or actual on conflict of interest.

Acknowledgements

The authors would like to thank the members of the Value-Based Healthcare expert team of the Erasmus MC as well as the specialist breast cancer nurses care of the department of Surgical Oncology, for their effort during the implementation of the value-based breast cancer-initiative.

Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.ejso.2019.01.007.

References

[1] Porter ME. What is value in health care? N Engl J Med 2010;363(26):2477–81.
[2] Porter MET EO. Redefining health care: creating value-based competition on results. Boston: Harvard Business School Press; 2006.
[3] Porter MEL TE. The Strategy that will fix health care. Harv Bus Rev 2013;91:50–70. 10.
[4] Jemal A, Bray F, Center MM, Ferlay J, Ward E, Forman D. Global cancer statistics. CA A Cancer J Clin 2011;61(2):69–90.
[5] van der Waal D, Verbeek AL, den Heeten GJ, Ripping TM, Tjan-Heijnen VC, Broeders MJ. Breast cancer diagnosis and death in The Netherlands: a changing burden. Eur J Public Health 2015;25(2):320–4.
[6] Fisher B, Anderson S, Bryant J, Margolese RG, Deutsch M, Fisher ER, et al. 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 2002;347(16):1233–41.
[7] Lagendijk M, van Maaren MC, Saadatmand S, Strobbe LJA, Poortmans PMP, Koppert LB, et al. Breast conserving therapy and mastectomy revisited: breast cancer-specific survival and the influence of prognostic factors in 129,692 patients. Int J Canc 2018;142(1):165–75.
[8] Litiere S, Werutsky G, Fentiman IS, Rutgers E, Christiaens MR, Van Limbergen E, et al. Breast conserving therapy versus mastectomy for stage I-II breast cancer: 20 year follow-up of the EORTC 10801 phase 3 randomised trial. Lancet Oncol 2012;13(4):412–9.
[9] Rodrigues IA, Sprinkhuizen SM, Barthelmes D, Blumenkranz M, Cheung G, Haller J, et al. Defining a minimum set of standardized patient-centered outcome measures for macular degeneration. Am J Ophthalmol 2016;168:1–12.
[10] Morgans AK, van Bommel AC, Stowell C, Abrahm JL, Basch E, Bekelman JE, et al. Development of a standardized set of patient-centered outcomes for advanced prostate cancer: an international effort for a unified approach. Eur Urol 2015;68(5):891–8.
[11] Salinas J, Sprinkhuizen SM, Ackerson T, Bernhardt J, Davie C, George MG, et al. An international standard set of patient-centered outcome measures after stroke. Stroke 2016;47(1):180–6.
[12] Arora J, Hai M. Implementing ICHOM's standard sets of outcomes: cleft lip and palate at Erasmus university medical centre in The Netherlands. London, UK: International Consortium for Health Outcomes Measurement (ICHOM); 2016.
[13] Ong WL, Schouwenburg MG, van Bommel ACM, Stowell C, Allison KH, Benn KE, et al. A standard set of value-based patient-centered outcomes for breast cancer: the international Consortium for health outcomes measurement (ICHOM) initiative. JAMA Oncol 2017;3(5):677–85.
[14] A blueprint for measuring health care outcomes [https://hbr.org/2016/12/a-blueprint-for-measuring-health-care-outcomes].
[15] Aaronson NK, Ahmedzai S, Bergman B, Bullinger M, Cull A, Duez NJ, et al. The European Organization for Research and Treatment of Cancer QLQ-C30: a quality-of-life instrument for use in international clinical trials in oncology. J Natl Cancer Inst 1993;85(5):365–76.
[16] Sprangers MA, Groenvold M, Arraras JI, Franklin J, te Velde A, Muller M, et al. The European Organization for Research and Treatment of Cancer breast cancer-specific quality-of-life questionnaire module: first results from a three-country field study. J Clin Oncol 1996;14(10):2756–68.
[17] Pusic AL, Klassen AF, Scott AM, Klok JA, Cordeiro PG, Cano SJ. Development of a new patient-reported outcome measure for breast surgery: the BREAST-Q. Plast Reconstr Surg 2009;124(2):345–53.
[18] MV M, MV K, MAAE S, de Wit GA, Prenger R, AS E. Dutch tariff for the five-level version of EQ-5d. Value Health 2016;19(4):343–52.
[19] Abrahams HJG, Gielissen MFM, de Lugt M, Kleijer EFW, de Roos WK, Balk E, et al. The Distress Thermometer for screening for severe fatigue in newly diagnosed breast and colorectal cancer patients. Psycho Oncol 2017;26(5):693–7.
[20] Garvelink MM, ter Kuile MM, Louwe LA, Hilders CG, Stiggelbout AM. Validation of a Dutch version of the reproductive Concerns scale (RCS) in three populations of women. Health Care Women Int 2015;36(10):1143–59.
[21] Hoefman RJ, van Exel J, Brouwer WB. Measuring the impact of caregiving on informal carers: a construct validation study of the CarerQol instrument. Health Qual Life Outcomes 2013;11:173.

[22] LimeSurvey [https://www.limesurvey.org/].
[23] GemsTracker [https://gemstracker.org/].
[24] Lagendijk M, van Egdom LSE, Richel C, van Leeuwen N, Verhoef C, Lingsma HF, et al. Patient reported outcome measures in breast cancer patients. Eur J Surg Oncol 2018;44(7):963–8. https://doi.org/10.1016/j.ejso.2018.03.009. Epub 2018 Mar 21.
[25] Lagendijk M, van Egdom LSE, van Veen FEE, Vos EL, Mureau MAM, van Leeuwen N, et al. Patient-reported outcome measures may add value in breast cancer surgery. Ann Surg Oncol 2018;25(12):3563–71. https://doi.org/10.1245/s10434-018-6729-6. Epub 2018 Sep 3.
[26] Wu AW, White SM, Blackford AL, Wolff AC, Carducci MA, Herman JM, et al. Patient Viewpoint Scientific Advisory B: improving an electronic system for measuring PROs in routine oncology practice. J Canc Surviv 2016;10(3):573–82.
[27] Jensen RE, Snyder CF, Abernethy AP, Basch E, Potosky AL, Roberts AC, et al. Review of electronic patient-reported outcomes systems used in cancer clinical care. J Oncol Pract 2014;10(4):e215–22.
[28] Kelleher SA, Somers TJ, Locklear T, Crosswell AD, Abernethy AP. Using patient reported outcomes in oncology clinical practice. Scand J Pain 2016;13:6–11.
[29] Detmar SB, Aaronson NK. Quality of life assessment in daily clinical oncology practice: a feasibility study. Eur J Cancer 1998;34(8):1181–6.
[30] Detmar SB, Muller MJ, Schornagel JH, Wever LD, Aaronson NK. Health-related quality-of-life assessments and patient-physician communication: a randomized controlled trial. JAMA 2002;288(23):3027–34.
[31] Velikova G, Booth L, Smith AB, Brown PM, Lynch P, Brown JM, et al. Measuring quality of life in routine oncology practice improves communication and patient well-being: a randomized controlled trial. J Clin Oncol : Offic J Am Soc Clin Oncol 2004;22(4):714–24.
[32] Fayanju OM, Mayo TL, Spinks TE, Lee S, Barcenas CH, Smith BD, et al. Value-based breast cancer care: a multidisciplinary approach for defining patient-centered outcomes. Ann Surg Oncol 2016;23(8):2385–90.
[33] Azad TD, Kalani M, Wolf T, Kearney A, Lee Y, Flannery L, et al. Building an electronic health record integrated quality of life outcomes registry for spine surgery. J Neurosurg Spine 2016;24(1):176–85.
[34] Carberry K, Landman Z, Xie M, Feeley T, Henderson J, Fraser Jr C. Incorporating longitudinal pediatric patient-centered outcome measurement into the clinical workflow using a commercial electronic health record: a step toward increasing value for the patient. J Am Med Inf Assoc 2016;23(1):88–93.
[35] Herdman M, Gudex C, Lloyd A, Janssen M, Kind P, Parkin D, et al. Development and preliminary testing of the new five-level version of EQ-5D (EQ-5D-5L). Qual Life Res 2011;20(10):1727–36.
[36] Javid SH, Lawrence SO, Lavallee DC. Prioritizing patient-reported outcomes in breast cancer surgery quality improvement. Breast J 2017;23(2):127–37.
[37] Reeve BB, Hays RD, Bjorner JB, Cook KF, Crane PK, Teresi JA, et al. Psychometric evaluation and calibration of health-related quality of life item banks: plans for the Patient-Reported Outcomes Measurement Information System (PROMIS). Med Care 2007;45(5 Suppl 1):S22–31.
[38] Wang CJ, Cheng SH, Wu JY, Lin YP, Kao WH, Lin CL, et al. Association of a bundled-payment program with cost and outcomes in full-cycle breast cancer care. JAMA Oncol 2017;3(3):327–34.