


BREAST CANCER OUTCOME ASSESSMENT: A STANDARD SET TO IMPROVE CARE <https://doi.org/10.56238/sevened2025.020-006>**Adrienne Prati Lucarelli¹, Maria Marta Martins², Felipe Lucarelli Carvalho³ and Gabriela Martins Vasconcelos⁴.****ABSTRACT**

Breast cancer is one of the leading causes of mortality among women worldwide. Strategies that prioritize early diagnosis, evidence-based therapeutic interventions, and patient-centered care are key to optimizing overall survival and quality of life.

A major challenge in value-based healthcare is the lack of standardized measurements of health outcomes, making it difficult to optimally monitor and compare the quality of healthcare in different settings globally.

This article aims to present a set of standards, the Standard Set, for the management of breast cancer, covering early diagnosis, effective treatment, minimization of side effects, minimal recurrence and psychosocial support, as well as the clinical outcomes essential for the follow-up of patients.

Keywords: Breast Cancer. Cancer Treatment. Quality of Life. Standard Set.

¹ Master and Dr., adjunct professor at the Faculty of Medical Sciences of Santa Casa de São Paulo; Full Professor at the São Camilo University Center.

Email: lucarelliadri@gmail.com

ORCID: <https://orcid.org/0000-0002-6566-7143>

² Master and Dr., adjunct professor at the Faculty of Medical Sciences of Santa Casa de São Paulo; Full Professor at the São Camilo University Center.

E-mail: dramariamartamartins@gmail.com

ORCID: <https://orcid.org/0000-0003-0693-8342>

³ Engineering Student at UNICAMP (State University of Campinas)

E-mail: felipelucarelli2002@gmail.com

ORCID: <https://orcid.org/0009-0007-7754-9076>

⁴ Medical student at FCM Santa Casa de São Paulo.

E-mail: gamvasconcelos@gmail.com

ORCID: <https://orcid.org/0009-0001-4448-7776>

INTRODUCTION

Despite advances in the diagnosis and treatment of breast cancer, this disease continues to pose a considerable challenge to health systems and affected women. The implementation of a standardized set of care and clinical outcomes, the *Standard Set*, seeks to ensure a more efficient and personalized approach to patient care. This model has the potential to improve treatment outcomes while providing comprehensive support to patients during all stages of the disease.¹

The *Standard Set* for Breast Cancer is an approach that organizes essential components for the care and follow-up of patients, proposing specific actions to improve the diagnosis, treatment and support offered. Implementing a *Standard Set* provides an opportunity to optimize care, promote personalization of treatment, and improve the patient experience in the healthcare system. The main components and their respective proposed actions are detailed below.^{1,2}

The various phases of the *Standard Set* are: phases of early diagnosis, effective treatment, minimization of side effects, minimal recurrence, psychosocial support, treatment outcome, overall survival, quality of life, disease progression, functionality and work capacity, patient satisfaction, and complete pathological response.^{1,2}

Phases of Early Diagnosis: Early detection of breast cancer is essential to increase survival rates. It is proposed the implementation of public campaigns for education on mammography, as well as the improvement of screening programs and access to early diagnosis.^{1,2}

Effective Treatment: Effective treatment should be based on standardized protocols for the different stages of breast cancer. The use of personalized therapies, based on the molecular characteristics of the tumor, is crucial for therapeutic success. The multidisciplinary approach, involving oncologists, surgeons, radiotherapists and psychologists, is essential to ensure an integrated and individualized treatment.^{1,2}

Minimization of Side Effects: the side effects of treatment, such as nausea, tiredness, and pain, must be properly evaluated and managed to improve the quality of life of patients. In addition, providing nutritional support and palliative care is essential to alleviate suffering and optimize the physical and psychological well-being of patients.²

Minimal Recurrence: Regular monitoring of patients after treatment is essential to detect cancer recurrence early. Preventive and therapeutic interventions, such as ongoing follow-up and adjustments to the therapeutic regimen, should be implemented to minimize the risk of relapse.³

Psychosocial Support: Psychological support plays a crucial role in patients' recovery, helping them cope with the emotional and psychosocial challenges of cancer. Psychological support programs and support groups for patients and families are essential to provide emotional well-being during and after treatment.^{2,3}

Treatment Outcomes: Clinical outcomes of breast cancer are essential parameters for assessing treatment efficacy and quality of life. Key outcomes include: overall survival, quality of life, disease progression, toxicity, side effects, functionality and work ability, time to early diagnosis, time to diagnosis, patient satisfaction, pathologic complete response.^{2,3}

Overall Survival: Increasing patient survival is the most relevant outcome. The main goal of treatment should be the cure or effective control of the disease.³

Quality of Life: ensuring the physical, emotional, and social quality of life of patients during and after treatment is essential. This includes reducing symptoms such as fatigue, pain, and emotional disturbances, as well as improving emotional and social function.^{2,3}

Disease Progression and Recurrence: Reducing the rate of disease progression and preventing relapses are important indicators of therapeutic success.^{2,3}

Toxicity and Side Effects: minimizing the adverse effects of treatment is essential to ensure adherence to the therapeutic regimen and improve tolerance to treatment.³

Functionality and Work Capacity: preserving the functional capacity of patients and helping them return to work after treatment are relevant goals to ensure quality of life.²

Patient Satisfaction: the measurement of patient satisfaction with the treatment and the support received directly reflects the quality of the care provided, impacting their adherence and confidence in the therapeutic process.^{1,2}

Pathologic Complete Response (CPR): in neoadjuvant treatments, achieving a CPR is considered a favorable indicator, suggesting a good response to treatment and a more positive prognosis^{1,2}.

OBJECTIVE

This article aims to present and discuss the relevance of a *Standard Set* for the follow-up of patients with breast cancer, highlighting the main components, expected outcomes, and the potential impact on clinical practice. In addition, it aims to explore how this approach can contribute to improving clinical outcomes, reducing inequalities in care, and providing more patient-centered support.

BREAST CANCER OUTCOMES ASSESSMENT QUESTIONNAIRE

A detailed questionnaire can be used to collect data on clinical outcomes and quality of life of patients. It should cover information about the patient, the treatment received, clinical outcomes, quality of life, satisfaction with the treatment, and any additional comments^{2,3}

The proposed questionnaire is organized into six main sections^{2,3}:

- **Patient Information:** This includes data such as age, gender, date of diagnosis, and stage of cancer. These initial data are crucial to contextualize treatments and clinical outcomes.
- **Treatment Received:** details the types of interventions performed (surgery, chemotherapy, radiotherapy, hormone therapy, among others), duration of treatment and possible side effects.
- **Clinical Outcomes:** measures the overall survival rate, disease-free survival, and disease progression, which are essential indicators for assessing therapeutic efficacy.
- **Quality of Life:** uses validated scales, such as the EORTC QLQ-C30, to assess physical, emotional, and social aspects during and after treatment. This section is essential to understand the impact of cancer on the patient's daily life.
- **Treatment Satisfaction:** explores the patient's perception of the treatment received and identifies areas for improvement.
- **Additional Comments:** allows patients to share specific observations or experiences, enriching qualitative data.

THE STANDARD SET AND ACTIONS DEVELOPED

The emphasis on early diagnosis should be carried out with public education campaigns, emphasizing the importance of mammography to promote the early detection of the disease., it is important to improve screening programs aimed at expanding access to early diagnosis, allowing interventions in the early stages of cancer^{3,4}.

Effective treatment should prioritize standardized protocols and should be developed to address different stages of breast cancer, providing evidence-based treatments, so including personalized therapies adjusted to the specific characteristics of the tumor can improve the effectiveness of interventions.³

The multidisciplinary approach is a fundamental tool and involves the entire patient treatment team, such as oncologists, surgeons, radiotherapists, and psychologists, who can offer integrated and comprehensive care^{3,4}.

Minimizing side effects consists of the appropriate management of side effects, **including strategies to reduce the adverse impacts of treatment on patients' quality of life, so nutritional support and palliative care are important, offering additional assistance to relieve symptoms and promote well-being^{1,2}.**

In order for the patient to have minimal recurrence of the disease, regular monitoring with follow-up to detect early signs of recurrence should be a fundamental factor, in addition to preventive and therapeutic interventions to reduce the chances of recurrence of the disease^{1,2}.

Psychosocial support should include psychological support programs aimed at patients and their families, helping them to cope with the emotional impact of cancer. In addition, a patient-centered approach should focus on emotional and psychosocial needs, promoting more humanized and sensitive care^{3,4}.

This model highlights the importance of integrated and multidisciplinary actions to improve clinical outcomes, quality of life, and the overall experience of breast cancer patients.

STANDARD SET AND RELEVANT ASPECTS IN QUALITY OF LIFE

The quality of life of breast cancer patients is influenced by a number of factors associated with diagnosis and treatment. Thus, the most important symptoms are fatigue and lymphedema, that is, persistent problems of tiredness and swelling that limit daily activities. Likewise, pain and mobility, as pain in treated areas and reduced arm movements compromise functionality.⁵

Changes in appearance and hormonal changes impact self-image and symptoms resulting from hormonal changes or early menopause affect quality of life.⁵

Emotional health evaluates anxiety, depression, and fear, recurrent elements in cancer patients.⁵

PROMS (PATIENT REPORTED OUTCOME MEASURES) IN THE CARE OF PATIENTS WITH BREAST CANCER

They play a central role in monitoring the patient experience. These standardized tools allow you to: monitor the effects of treatments, personalize interventions, and identify critical areas for improving quality of life.⁵

These are standardized questionnaires that must be filled out by patients to verify their opinion about their health status. Some important points are related to the patient's own perception of the level of limitation or disability generated by the disease.⁵

DISCUSSION

A mixed-method study involving observations of consultations and semi-structured interviews with patients and health professionals was conducted to identify facilitators and barriers to the use of PROMs; barriers and facilitators were structured. For each barrier, evidence-based improvement strategies were selected. Subsequently, the improvement strategies were ranked on priority and feasibility by a panel of experts, information technology professionals, and PROM implementation experts, creating an implementation improvement strategy. Barriers to implementation included that the electronic health record and PROMs did not align with the individual needs of end-users, clinicians' hesitancy to counsel patients on health-related quality of life issues, and lack of consensus among providers were the biggest challenges. Forty-one improvement strategies were identified, of which 25 remained after classification.⁶

Despite the increasing use of patient-reported outcome measures (PROMs) for self-reported data collection among hospital outpatients, physician use of these data remains suboptimal.

In 2023, a Dutch study aiming to investigate the use of clinicians' PROM data with a focus on adoption, implementation, and maintenance was conducted. Clinicians accessed PROM data for approximately 3 out of 20 (14%) patients during their outpatient visits, despite numerous strategies to improve this practice. They identified problems in adoption, implementation, and maintenance. The hospital's strategies, organically and pragmatically shaped, were related to 27 (37%) of the 73 strategies of Expert Recommendations for Implementing Change⁷. These strategies focused on enhancing clinicians' capacity, timeliness, and motivation. They found deficiencies in the quality of execution and integrity of strategies in relation to addressing all barriers and leveraging facilitators. They identified variations in the factors that influence the use of PROMs among frequent PROM users, occasional users, and non-users. Challenges to facilitating effectiveness were apparent, with certain desired strategies being unfeasible or impeded.⁷

The International Consortium for Health Outcomes Measurement (ICHOM) convened a multidisciplinary international working group, comprised of 26 healthcare providers and patient advocates, to develop a standard set of value-based, patient-centered outcomes for breast cancer. The working group met via 8 conference calls and completed a follow-up survey after each meeting⁸. Patient focus group meetings (8 breast cancer patients and anonymous online surveys of 1225 multinational breast cancer patients and survivors were also conducted to elicit input from patients. The standard set covers cancer survival and

control, and treatment non-efficacy outcomes (e.g., acute treatment complications), to be collected through administrative data and/or clinical records. A combination of multiple patient-reported outcome measurement tools is being recommended to capture the degree of long-term health outcomes. ICHOM will strive to gain broad acceptance of this set and facilitate its implementation in routine clinical practice in various settings and institutions around the world⁸.

Recent data on patient satisfaction with care has revealed positive experiences of many cancer patients, but also demonstrated persistent unmet needs for communication and coordinated supportive psychosocial care. Despite the shift to patient-centered care and numerous changes in the cancer care system, studies suggest that the quality of cancer care in some countries is still determined by patient characteristics such as age, educational background, and length of treatment

Progressive changes and effective strategies to increase patient-centered care, such as disease management programs and patient navigators, are effective cancer patient approach strategies. However, there is a need for greater implementation and promotion of new ones⁹. Physicians are encouraged to offer psychosocial support to all patients, regardless of their social characteristics, and to take into account the identified experiences and needs of patients, but this welcome is not always perceived. In particular, physicians are advised to support integrated care through greater collaboration with psychosocial care and to improve patient-centered communication to increase the quality of cancer care delivery, but often the health care provider does not know the patient's needs and shortcomings of the cancer service. Thus, it is essential that this issue be debated and new strategies developed to improve care⁹.

CONCLUSION

The implementation of a *Standard Set* in breast cancer management represents a significant advance in cancer care, providing a structured, patient-centered approach. By integrating clinical outcomes, quality of life, and satisfaction, this model promotes a more comprehensive and personalized follow-up, favoring continuous improvements in the health system. The incorporation of PROMs and the systematic evaluation of outcomes ensure a more effective response to the needs of patients, guiding evidence-based and humanized therapeutic strategies. With a focus on reducing inequalities, clinical improvement, and psychosocial support, this approach has the potential to transform clinical practice, optimizing therapeutic outcomes and promoting a better quality of life for breast cancer patients.

REFERENCES

1. Ferreira DC, vieira I, Pedro MI, Caldas P, Varela M: Patient Satisfaction with Healthcare Services and the Techniques Used for its Assessment: A Systematic Literature Review and a Bibliometric Analysis. *Healthcare (Basel)*. 2023 Feb 21;11(5):639.doi: 10.3390/healthcare11050639
2. Gavurova B, Dvorsky J, Popesko B. Patient Satisfaction Determinants of Inpatient Healthcare. *J 10.3390/ijerph182111337.Int J Environ Res Public Health*. 2021;18(21):11337. doi: 10.3390/ijerph182111337
3. van Engen V, van Lint CL, Peters IA, Ahaus K, Buljac-Samardzic M, Bonfrer I. Enhancing Patient Response to Patient-Reported Outcome Measures: Insights From a Leading Dutch University Hospital. *Value Health*. 2024 Dec;27(12):1753-1761. doi: 10.1016/j.jval.2024.09.016. Epub 2024 Oct 18. PMID: 39426515.
4. Bøhn SKH, Svendsen K, Balto A, Gjelsvik YM, Myklebust TÅ, Børøund E, Eriksen HR, Meland A, Østby K, Nes LS, Kiserud CE, Reinertsen KV, Ursin G. Health-related quality of life among women diagnosed with in situ or invasive breast cancer and age-matched controls: a population-based study. *J Patient Rep Outcomes*. 2024 Sep 17;8(1):105. doi: 10.1186/s41687-024-00781-1. PMID: 39298004; PMCID: PMC11413291.
5. Ong WL, Schouwenburg MG, van Bommel ACM, Stowell C, Allison KH, Benn KE, Browne JP, Cooter RD, Delaney GP, Duhoux FP, Ganz PA, Hancock P, Jagsi R, Knaul FM, Knip AM, Koppert LB, Kuerer HM, McLaughlin S, Mureau MAM, Partridge AH, Reid DP, Sheeran L, Smith TJ, Stoutjesdijk MJ, Vrancken Peeters MJTFD, Wengström Y, Yip CH, Saunders C. A Standard Set of Value-Based Patient-Centered Outcomes for Breast Cancer: The International Consortium for Health Outcomes Measurement (ICHOM) Initiative. *JAMA Oncol*. 2017 May 1;3(5):677-685. doi: 10.1001/jamaoncol.2016.4851. PMID: 28033439.
6. Legendijk M, Mittendorf E, King TA, Gibbons C, Pusic A, Dominici LS. Incorporating Patient-Reported Outcome Measures into Breast Surgical Oncology: Advancing Toward Value-Based Care. *Oncologist*. 2020 May;25(5):384-390. doi: 10.1634
7. Boomstra E, Walraven I, van der Ploeg IMC, Wouters MWJM, van de Kamp MW, Dirven R, Albers E, Fraterman I, Poulissen M, van de Poll-Franse LV, de Ligt KM. Moving beyond barriers: a mixed-method study to develop evidence-based strategies to improve implementation of PROMs in clinical oncology care. *Qual Life Res*. 2024 Sep 20. doi: 10.1007/s11136-024-03787-w. Epub ahead of print. PMID: 39302555. /theoncologist.2019-0355. Epub 2019 Dec 17. PMID: 31848315
8. van Engen V, Bonfrer I, Ahaus K, Den Hollander-Ardon M, Peters I, Buljac-Samardzic M. Enhancing Clinicians' Use of Electronic Patient-Reported Outcome Measures in Outpatient Care: Mixed Methods Study. *J Med Internet Res*. 2024 Oct 18;26:e60306. doi: 10.2196/60306. PMID: 39422999; PMCID: PMC11530726.
9. Ziegler E, Klein J, Kofahl C. Patient experiences and needs in cancer care- results from a nationwide cross-sectional study in Germany. *BMC Health Serv Res*. 2024 May 2;24(1):572. doi: 10.1186/s12913-024-10951-y. PMID: 38698426; PMCID: PMC11067160.