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Evolving role of patient associations in shaping healthcare policies in Brazil

Maira Caleffi[1,2] and Gabriele Luise Neves Alves[1]

[1]Brazilian Federation of Philanthropic Institutions for Breast Health Support - FEMAMA, Dr. Vale Street, 157, Porto Alegre, RS, 90560-010, Brazil.
[2]Hospital Moinhos de Vento Breast Center, Ramiro Barcelos Street, 850, Porto Alegre, RS, 90035-001, Brazil.

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ABSTRACT

Patient associations are civil society organizations that play a key role in supporting individuals undergoing long-term health treatments, particularly in developing countries. Most of them are also actively involved in defending patients' rights through initiatives that aim to develop and implement public policies focused on supporting care. Patient associations have grown increasingly professionalized, driven by serious issues regarding healthcare access and outcomes, especially in critical areas like oncology. In this article, we explore the evolving role of patient associations in the formulation of national health policies based on advocacy actions promoted by the Brazilian Federation of Philanthropic Institutions for the Support of Breast Health (FEMAMA), a civil society organization with over 19 years of experience and the biggest network of patient associations in the country, with more than 70 associates. FEMAMA is aligned with national medical societies and international guidelines, such as the World Health Organization's Global Breast Cancer Initiative and the Union for International Cancer Control, which aims to reduce the global burden of breast cancer through collaboration and strengthened health systems. Civil society mobilizations promoted by FEMAMA over the years have contributed to the implementation of structural public health policies, both for public and private health systems in Brazil. Initially focused on breast cancer, some of these achievements were later expanded to oncology as a whole, particularly benefiting patients relying on the public health system, which is the only healthcare access option for 71.5% of Brazilians. Over the years, patient associations have significantly influenced advances in oncology and general health public policy. However, advocacy is a continuous work, with goals that evolve alongside clinical, systemic, and socio-political developments.

Introduction

Patient associations are civil society organizations (CSOs) that play a fundamental role in supporting individuals undergoing long-term health treatments, particularly in developing countries, such as Brazil[1]. Most of them are also actively involved in defending patients' rights through initiatives that aim to develop and implement public policies focused on supporting care[2]. Brazilian patient associations emerged from civil society demands in the 1990s, the same period when the Unified Health System, a free, public healthcare system, was implemented in the country[3]. Since then, the role and impact of the patient associations have grown increasingly professionalized, driven by serious issues regarding healthcare access and outcomes, especially in critical areas like oncology[4].

Cancer patient associations are key players in promoting equitable treatment by advocating for transformative policy changes, incorporating patient perspectives into public policy development, encouraging stakeholder collaboration, supporting evidence-based health policies, and shaping sustainable, inclusive healthcare systems[1]. These organizations achieve such goals through political education, patient empowerment for advocacy, and the creation of aligned advocacy networks focused on monitoring public health indicators[2].

In this article, we explore the evolving role of patient associations in the formulation of health policies in Brazil based on advocacy actions promoted by the Brazilian Federation of Philanthropic Institutions for the Support of Breast Health (FEMAMA), a civil society organization with over 19 years of experience and the biggest network of patient associations in Brazil, with more than 70 oncology-focused associates[5].

FEMAMA is aligned with national medical societies and international guidelines, such as the World Health Organization's Global Breast Cancer Initiative (GBCI/WHO), which aims to reduce the global burden of breast cancer through collaboration and strengthened health systems[6]. It is also a member of the Union for International Cancer Control (UICC)[7], which, in collaboration with WHO[8], provides courses and materials to support the implementation of GBCI and the development of breast cancer control policies and programs.

The GBCI is based on three pillars: (1) health promotion and early detection, (2) timely diagnosis, and (3) comprehensive treatment and supportive care. The goal is to reduce breast cancer mortality by 2.5% per year by 2040, saving 2.5 million lives. Major advocacy goals include: over 60% of invasive cancers diagnosed at stages I or II; cancer diagnosis within 60 days of the first clinical evaluation; and more than 80% of breast cancer patients receiving multimodal treatment without abandonment[6].

Advocacy

Patient associations can significantly contribute to the development of structural public health policies. Civil society mobilizations promoted by FEMAMA over the years have contributed to the implementation of national laws and regulations, both for public and private health systems in Brazil. Initially focused on breast cancer, some of these achievements were later expanded to oncology as a whole, particularly benefiting patients relying on the public health system, which is the only healthcare access option for 71.5% of Brazilians[9].

FEMAMA's advocacy was key to securing the first national law on the prevention, detection, treatment, and follow-up of breast and cervical cancers within the public health system (Federal Law 11664/2008)[10]; the 30-day deadline for diagnostic tests and the 60-day deadline to start treatment after diagnosis (Federal Law 12732/2012)[11]; and mandatory cancer reporting both in the public and the private healthcare system (Federal Law 13685/2018)[12].

Patient associations led by FEMAMA also conduct a range of initiatives in partnership with other CSOs and political leaders, such as public hearings, national events, forums, conferences, awareness campaigns, and the empowerment of patients as advocacy spokespersons[5]. For example, in 2017, the organization mobilized nationally for the inclusion of the drugs trastuzumab and pertuzumab in the public health system for the treatment of metastatic HER2+ breast cancer, showing how well-informed and organized patients can transform public health policies[13].

More recently, FEMAMA, alongside other civil society representatives, influenced the creation of the National Policy for Cancer Prevention and Control (PNPCC) and the National Navigation Program for People Diagnosed with Cancer (Federal Law 14758/2023), which represent major milestones in Brazilian health legislation[14]. The PNPCC is key for incorporating intersectoral actions to address cancer determinants through joint government and civil society efforts[14]. Regarding patient navigation, FEMAMA was a pioneer in educating associations about the topic and advancing discussions on its regulation in Brazil[2].

Moreover, during October Pink 2024, FEMAMA led an advocacy campaign for the publication of the Breast Cancer Clinical Protocol and Therapeutic Guidelines (PCDT) within the public health system, the "PCDT Pink"[15]. The document provides standardized diagnostic and therapeutic guidelines for breast cancer based on scientific evidence, ensuring safety and effectiveness in clinical management[16]. The campaign reached millions of shares on social media, and the protocol was officially published in December of the same year[16]. Following its publication, funding regulation and treatment availability became mandatory.

The FEMAMA network of associations also fosters patient participation in public health consultations. In 2021, it launched the campaign "Pay More Attention #SheNeedsIt" advocating for the inclusion of cyclin-dependent kinase inhibitors (CDK4/6i) in the Brazilian health system, first in the private and later in the public health system[17]. The advocacy reversed an initial negative recommendation by the National Commission for the Incorporation of Health Technologies (CONITEC), leading to approval of CDK4/6i as treatment for metastatic HR+/HER2- breast cancer (Ordinance SCTIE/MS 73/2021)[18].

Furthermore, alongside medical societies[19], FEMAMA achieved another major win in Public Consultation N°. 144 by the National Supplementary Health Agency, held from 12/10/2024 to 01/24/2025[20]. The goal was to establish a quality seal for oncology in the supplementary health system that included annual screening mammograms for women aged 40 to 74, replacing the previously proposed biennial screening for women aged 50 to 69[19]. Over 63,000 contributions were submitted, one of the largest mobilizations in the agency's history, resulting in a major advocacy achievement[20].

Discussion

Despite important progress, breast cancer control in Brazil remains a major challenge. Incidence has steadily increased over the past decades, with around 74,000 new cases annually[21]. Breast cancer ranks first in cancer-related mortality among Brazilian women, causing 19,000 deaths per year[21]. Mammography coverage is below 30% for women in the target age group[22]. Diagnosis at stages III and IV occurs in 40% of cases[22]. Additionally, 43.9% of women are diagnosed before age 50, and 16.3% before age 40[23]. Moreover, 15% of patients experience treatment delays of 30 to 60 days, increasing mortality by 6% to 8%, while 35% face delays exceeding 60 days, raising mortality by 12% to 16%[21].

Scientific advances in oncology diagnosis and treatment are constant, but they are not automatically made available in the Brazilian public health system. Technology incorporation is handled by CONITEC through evidence review and public consultation, but many high-cost treatments and procedures remain inaccessible due to financial barriers. While legal frameworks are critical for implementing health access policies in Brazil, they have not yet significantly improved the breast cancer landscape in alignment with GBCI goals. More needs to be done in terms of screening, diagnosis, treatment, and control in underserved settings.

There are various opportunities to build upon advocacy achievements aligned with GBCI goals and indicators. One key strategy includes building relationships behind the scenes of national policy making to understand and align the interests of different stakeholders around patient-centered action. Another promising area, without losing the focus on data and evidence-based advocacy[24], is to incorporate patient testimonials into campaigns, finding a balance between presenting scientific evidence and evoking emotional engagement to mobilize civil society. Brazilians have a strong culture of solidarity, which can be further harnessed for health advocacy engagement.

Currently, health advocacy associations face challenges transitioning initiatives across different administrations and political contexts, especially in developing countries like Brazil. Many approved laws and commitments achieved through advocacy do not always translate into tangible action and results. This is a real challenge, though not insurmountable. Recognizing this factor is vital to understanding advocacy as a continuous effort, with progress and achievements requiring constant documentation, monitoring, and revision.

One of the major challenges for patient associations conducting advocacy in Brazil is limited financial resources[25] and, often, a lack of specific training[26]. Institutions often compete for scarce advocacy funding and rely heavily on volunteers and patients who, while motivated and willing, may lack formal training in advocacy. More than half of the CSOs that joined FEMAMA had little training in advocacy initially, as they were support groups for cancer patients, which was crucial for the further development of empathetic advocacy actions. Ongoing training is essential to align the organization's advocacy purposes. In recent years, these organizations have become increasingly professionalized to meet higher demands from funders regarding results and performance indicators.

What differentiates FEMAMA's advocacy from that of other institutions and serves as a potential institutional model is its nationwide, network-based social mobilization strategy. Femama works by educating, training and listening to local CSOs, which operate in cities and states, so that they can share their knowledge with the community and local managers to raise awareness among legislators and executive committees to support patients' interests. The goal is to keep cancer on the political agenda of governments at all three levels (national, state and municipal). Moreover, all its actions are evidence-based, carried out with strategic partners, and grounded in patients' lived experiences, voices, and demands, who are given space to lead advocacy efforts themselves.

Conclusion

Over the past decades, patient associations like those within FEMAMA have been central to advocacy efforts in support of the right to health in Brazil. These organizations play an active role in uniting stakeholders to identify and overcome challenges, always based on evidence, international best practices, and with space for patients' perspectives to support the design of structural public health policies. Over the years, patient advocacy has significantly influenced advances in oncology and general health public policy in Brazil. However, this is a continuous work, with goals that evolve alongside clinical, systemic, and socio-political developments.

Conflicts of Interest Statement:

Maira Caleffi, MD PhD, declares participation the following initiatives: External Advisory Committee for Roche International Experience Exchange with Patient Organizations (IEEPO); Advisory Expert for AstraZeneca Global Breast Cancer Care Council; Member of the Breast Cancer Coalition in the public health system promoted by Novartis; Technical Consultant of the Policy Paper Implementation of public policy for access to genetic testing in the detection of pathogenic variants in BRCA in the public health system; presidency of The Brazilian Federation of Philanthropic Institutions Supporting Breast Health (FEMAMA).

Gabriele Luise Neves Alves, MSc, is Coordinator of Research and Health Information at The Brazilian Federation of Philanthropic Institutions Supporting Breast Health (FEMAMA).

References:

1. Azenha G, Bass LP, Caleffi M, Smith R, Pretorius L, Durstine A, Perez CP. The role of breast cancer civil society in different resource settings. *Breast.* 2011;20(Suppl 2)\:S81-S87. https://doi.org/10.1016/j.breast.2011.02.005.

2. Caleffi M, Hobold EA, Johnson G. The Relevant Work of Breast Cancer Patient Associations in the Search for Quality Access to Care and Guarantee of Rights in Brazil. *Curr Breast Cancer Rep.* 2023; 15:1-6. https://doi.org/10.1007/s12609-023-00496-0.

3. Albuquerque A, Soares Neto JAR. Patient organizations and their role in implementing health care rights. *Ibero-American Health Law Notebooks.* 2022;11(1):144-162. https://doi.org/10.17566/ciads.v11i1.811.

4. Caleffi M, et al. Breast cancer survival in Brazil: How much does health care access impact cancer outcomes? *Breast.* 2020;54:155-159. https://doi.org/10.1016/j.breast.2020.10.001.

5. Brazilian Federation of Philanthropic Institutions Supporting Breast Health (FEMAMA). Available at: https://femama.org.br/. Accessed May 2025.

6. World Health Organization (WHO). *Global Breast Cancer Initiative Implementation Framework: Assessing, Strengthening and Scaling-Up of Services for the Early Detection and Management of Breast Cancer.* Geneva: WHO; 2023. Available at: https://www.who.int/initiatives/global-breast-cancer-initiative/. Accessed May 2025.

7. Union for International Cancer Control (UICC). *Breast Cancer Advocacy Handbook: A Handbook to Support and Inspire Cancer Advocates.* Geneva; 2024. Available at: https://www.uicc.org/news-and-updates/resources/breast-cancer-advocacy-handbook. Accessed May 2025.

8. World Health Organization (WHO). *Breast Cancer.* Available at: https://www.who.int/news-room/fact-sheets/detail/breast-cancer. Accessed May 2025.

9. Brazilian Institute of Geography and Statistics (IBGE). *National Health Survey: 2019: Life Cycles.* Rio de Janeiro: IBGE; 2021.

10. Brazil. Federal Law 11664, April 29, 2008. Provides for health actions to ensure prevention, detection, treatment, and follow-up of cervical and breast cancers within the Unified Health System (SUS). Brasília, 2008.

11. Brazil. Federal Law 12732, November 22, 2012. Provides for the first treatment of patients with confirmed malignant neoplasia and establishes a timeframe for its initiation. Brasília, 2012.

12. Brazil. Federal Law 13685, June 25, 2018. Provides for mandatory reporting of health conditions and events related to neoplasms and congenital malformations. Brasília, 2018.

13. Gomes AL et al. Inclusion of Metastatic Breast Cancer Treatments in SUS (Public Health Care System): Strategic Actions. Journal of Global Oncology. 2018; 4(2): 151. https://doi.org/10.1200/jgo.18.71300.

14. Brazil. Federal Law 14758, December 19, 2023. Establishes the National Policy for Cancer Prevention and Control and the National Navigation Program for People Diagnosed with Cancer within the SUS. Brasília, 2023.

15. FEMAMA. *PCDT Rosa.* Available at: https://femama.org.br/site/pcdt-rosa/. Accessed May 2025.

16. Ministry of Health (Brazil). National Committee for Health Technology Incorporation (Conitec). Clinical Protocol and Therapeutic Guidelines: Breast Cancer. 2024.

17. FEMAMA. *Pay More Attention, She Needs It (#elaprecisa).* Available at: https://demaisatencao.femama.org.br/. Accessed May 2025.

18. Ministry of Health (Brazil). Ordinance SCTIE/MS No. 73, December 6, 2021. Establishes the incorporation of medications (abemaciclib, palbociclib, and ribociclib succinate) for the treatment of advanced or metastatic hormone receptor-positive (HR+) and HER2-negative breast cancer within SUS. *Diário Oficial da União*, Section 1. December 7, 2021.

19. Brazilian College of Radiology and Diagnostic Imaging (CBR), Brazilian Society of Mastology (SBM),

the Brazilian Federation of Gynecology and Obstetrics Associations (FEBRASGO), Brazilian Society of Clinical Oncology (SBOC), the Brazilian Society of Radiotherapy (SBRT), the Federal Council of Medicine (CFM), Brazilian Federation of Philanthropic Institutions Supporting Breast Health (FEMAMA), Oncoguia. Technical Scientific Opinion on the importance of starting mammographic screening at age 40 and over 70 for early detection of breast cancer. Available at: https://cbr.org.br/wp-content/uploads/2025/02/Parecer_reuniao_ANS_contribuicoes_-CBR-SBM-FEBRASGO-FEMAMA_v-final.pdf. Accessed May 2025.

20. Ministry of Health (Brazil). National Health Supplement Agency. Public Consultation - CP N. 144, which institutes the Certification Program for Good Practices in Health Care for Private Health Care Plan Operators, containing the Certification Manual for Good Practices in Oncological Care - OncoRede. Available at: https://www.gov.br/ans/pt-br/acesso-a-informacao/participacao-da-sociedade/consultas-publicas/consulta-publica-144. Accessed May 2025.

21. National Cancer Institute (INCA). *Breast Cancer Control in Brazil: Data and Numbers.* Rio de Janeiro: INCA; 2024. Available at: https://www.inca.gov.br/publicacoes/livros/controle-do-cancer-de-mama-no-brasil-dados-e-numeros-2024. Accessed May 2025.

22. Almeida, A, Rosenburg, J. Overview of breast cancer care in the Brazilian Unified Health System (SUS). *Observatório de Oncologia.* 2023. Available at: https://observatoriodeoncologia.com.br/estudos/outros/cancer-de-mama/2023/panorama-da-atencao-ao-cancer-de-mama-no-sus-2/. Accessed May 2025.

23. Rosa DD, et al. The impact of sociodemographic factors and health insurance coverage on the diagnosis and clinicopathological characteristics of breast cancer in Brazil: AMAZONA III study (GBECAM 0115). *Breast Cancer Res Treat.* 2020. https://doi.org/10.1007/s10549-020-05831-y.

24. Chhetri D, Zacarias F. Advocacy for Evidence-Based Policy-Making in Public Health: Experiences and the Way Forward. *J Health Manag.* 2021; 23(1): 85-94. https://doi.org/10.1177/0972063421994948.

25. Dall'Agnol CF, et al. Transparency and accountability in resource mobilization in the third sector: a multiple case study conducted in Southern Brazil. *Universo Contábil.* 2017;13(2):187-203. Available at: https://www.redalyc.org/pdf/1170/117051921011.pdf. Accessed May 2025.

26. Mutebi M, et al. Breast cancer treatment: A phased approach to implementation. *Cancer.* 2020; 126:2365-2378. https://doi.org/10.1002/cncr.32910.