Social Participation in the Development of the National Palliative Care Policy in Brazil: the Frente PaliATIVISTAS Movement

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Participação Social na Construção da Política Nacional de Cuidados Paliativos no Brasil: o Movimento da Frente PaliATIVISTAS

Participación Social en la Elaboración de la Política Nacional de Cuidados Paliativos en el Brasil: el Movimiento del Frente de Cuidados Paliativos

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INTRODUCTION

The mapping of the global development of palliative care placed Brazil at an intermediate level based on overall services provision, a few funding sources, availability of morphine, non-integrated specialized services to mainstream health care systems and some initiatives of capacity building[1]. According to an 81 countries rank about the quality of life and death, Brazil was listed in the 79th position, revealing what still needs to be done to move forward in that area[2].

Organized actions by committed communities can contribute to reverse this reality in the country[3-5]. Efforts to educate the society and policy makers about this global health inequality are more impactful whether voices of those who offer, receive and manage these essential services are included and, therefore, are able to advocate on behalf of the urgency in providing palliative care to those in suffering.

The objective of this article is to report the trajectory of the social participation in pursue of the approval of the National Palliative Care Policy (PNCP) in Brazil through a social movement called *Frente PaliATIVISTAS*.

DEVELOPMENT

Creation of Frente PaliATIVISTAS

The *Frente PaliATIVISTAS* was created in February 2023 as a response to the high demand for palliative care. The movement endorses the Brazilian legal-historical backbone that advocates the participation of the society in the formulation of public policies[6-11]. Its principles are described in Chart 1[12,13].

The *Frente PaliATIVISTAS* was formed by users, health professionals, service providers and managers of the National Health System (SUS) country-wide. Social media (WhatsApp® and Instagram®) were utilized to stimulate the involvement and articulation of the community for the construction and dissemination of ideas, open, participative and democratic dialogue reuniting more than one thousand members in less than one month.

Whereas small changes of a dynamic system can cause large effects in time[14-17], it is possible to state that when *Frente PaliATIVISTAS* was created, just like a butterfly (symbol of palliative care and of this social movement), it flapped her wings, unchaining a cascade of actions across the country and expressive involvement of the community[18].

Frente PaliATIVISTAS conducted some strategic actions through the forums of popular participation and SUS guiding principles (Figure 1).

Frente PaliATIVISTAS at Health Conferences and Brasil Participativo

Frente PaliATIVISTAS endeavored to include palliative care in the agenda of the Health Conferences and *Brasil Participativo* (Figure 2).

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Chart 1. Guiding principles of *Frente PaliATIVISTAS*

Ensure visibility to the urgency of offering palliative care to those in suffering through wide disclosure of the alarming rates of severe diseases and low quality of death in the country – **The Brazil we have**
It is justified and motivated through the defense of the access to palliative care across every level of health attention since diagnosis and through the evolution of a severe disease, ensuring the right to life with dignity until death and support to the bereaved – **The Brazil we want**
In order to **ensure rights and defend SUS, life and democracy,** it advocates the inclusion of palliative care as a State Policy with assigned funds, de-bureaucratization and availability of essential medicines to control pain and other symptoms
Defense of the access to palliative care as a human right having valorization of life and human dignity as indisputable principles according to the Alma-Ata Declaration[12], where everyone matters and can't be left behind: **Tomorrow will be another day for everyone!**
Break the chronic SUS underfunding to meet the constitutional right to health properly and with sustainability, valuing health professionals

Source: The authors, based on the 1st Free National Conference of Palliative Care[13].
Caption: SUS = National Health System.

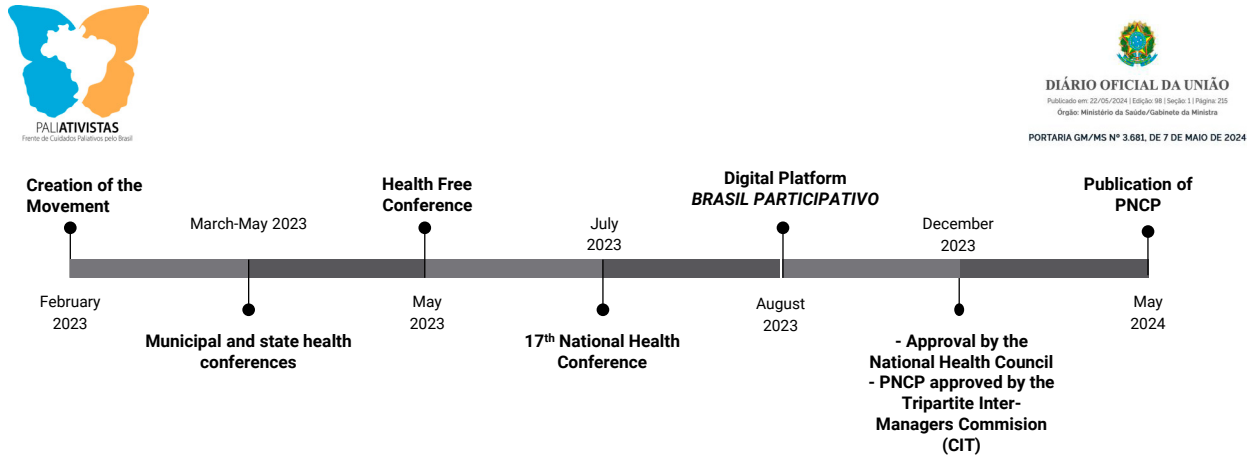

Figure 1. Strategic actions of *Frente PaliATIVISTAS* for publication of the National Palliative Care Policy

The movement summoned users and supporters from the whole country to join synchronized and organized actions under the motto "Palliative Care, Public Policies Now!". Digital activism was encouraged through hashtags #CuidadosPaliativosPolíticasPúblicasJá, #CuidadosPaliativosparaTodos and #PalliativeCareforAll, further to the creation of a logo (the form of a butterfly containing the map of Brazil) and a visual identity (orange color tee shirts). At the same time, the defense of a single guideline of palliative care at the health conferences aimed to include it in the quadrennial plan 2024-2027 for SUS as follows: Implement PNCP, with assigned funding integrated to the Health Attention Networks and as a component of the Health Primary Attention through Family Health Strategy.

The participants of this movement, mobilized by the defense of access to palliative care, attended the conferences at 78 municipalities and 19 states, and ten states and the Federal District succeeded to elect 11 *PaliATIVISTAS* delegates and approval of a single guideline.

The I Free National Conference of Palliative Care, titled "Palliative Care: a human right – public policies now", was held in May 2023 in 20 poles at the five Brazilian regions in person and online on YouTube®, being considered as the most expressive (more than six thousand participants and 168 sponsoring institutions) and the second in number of synchronous participants (n=2,688). The election of more delegates and strengthening the approval of the single guideline and other proposals of palliative care was the outcome compiled in a final report sent to the 17th National Health Conference (CNS) held in July 2023 in Brasília.

3,526 delegates attended the CNS, 30 of them *PaliATIVISTAS*, making it one of the biggest thematic delegations ever. The theme of the 17th CNS was to *Ensure*

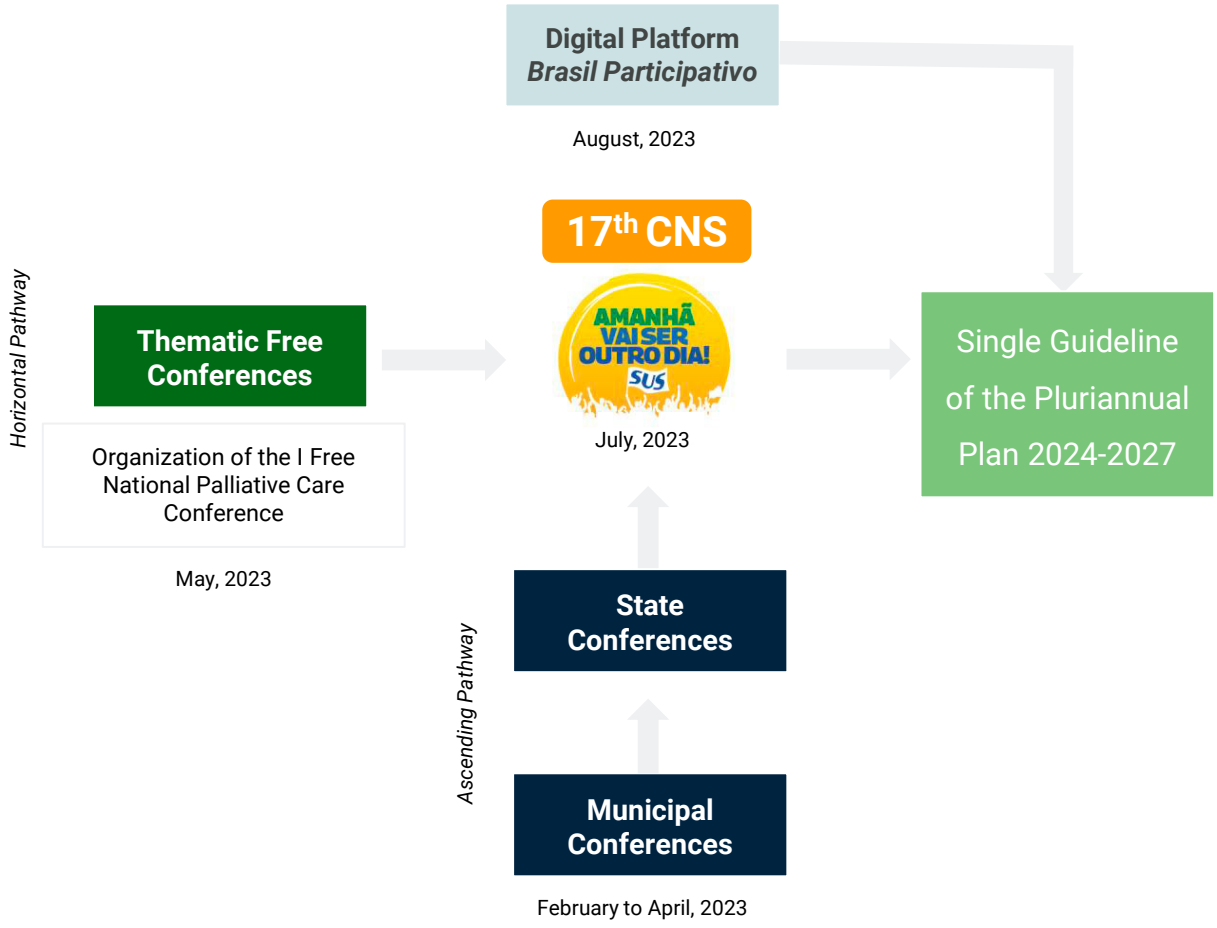

Figure 2. *Frente PaliATIVISTAS* in the Health Conferences and *Brasil Participativo*

rights and defend SUS, life and democracy – Tomorrow will be another day, paraphrasing the song by Chico Buarque de Hollanda. The four thematic axles were: 1. *The Brazil we have, the Brazil we want*; 2. *The role of social control and social movements to save lives*; 3. *Ensure rights and defend SUS, life and democracy*; and 4. *Tomorrow will be another day to everyone*[19,20].

During the CNS, further to joining the workgroups of the four axis, the delegates of *Frente PaliATIVISTAS* performed self-managed activities at a thematic space, disseminating knowledge about palliative care. At the public act *Ensure Rights and Defend SUS, Life and Democracy,* they stood out using the visual identity of the movement and made themselves heard through posters of palliative care[21,22].

More than 5,800 individuals were involved at the 17th CNS, where the Brazilian people at this moment emerged with full strength as a political subject[19] after a murky antidemocratic, anti-environmentalist, radical neoliberal, antagonist of the human rights and anti-science period re-enacted in the former government[21,22]. The guidelines and proposals of palliative care presented by *Frente PaliATIVISTAS* at that conference were approved as priority for SUS and the society as a whole.

Another strategy the movement has utilized was the inclusion of the same single guideline for consideration and voting by *Brasil Participativo*. Countering the strategy of use of social media for mass manipulation and dissemination of fake news[23], the movement utilized these resources to summon the society for free and coordinated participation to vote the proposal. As outcome, the single guideline was the fourth more voted in the area of health (11,419 votes), among other 1,297 proposals and consequently, incorporated into the Pluriannual Plan of the Federal Government for SUS. These data suggest that digital democracy platforms can potentialize the level of direct and personal participation of the individuals in the process of formation of public policies[24,25].

A key aspect of the process was the interaction of several players (users, health professionals and managers) pursuing a consensual agenda to achieve compatible and interchangeable goals.

The *Frente PaliATIVISTAS* has also adopted many strategies[2,5,24,26] of multiprofessional and intersectoral engagement based on life sciences, humanity and arts (manuals, audiovisual materials, music, etc.) that were instrumental to canvass more public engagement with eclectic profile.

National Palliative Care Policy

The *Frente PaliATIVISTAS* brought the theme of palliative care for community debate and democratized the access to information about quality of life, of death and of dying. Its engagement was pivotal to approve the PNCP at the CNS and further ratification by the Tripartite Inter-managers Committee.

Eventually, the guidelines and proposals of *Frente PaliATIVISTAS* at the 17th CNS were reflected in the publication of the PCNP by the Ministry of Health integrated to Health Attention Network and component of the Primary Health Care Attention with assigned funding on May 22, 2024[27].

Upon the publication of PNCP, the efforts of *Frente PaliATIVISTAS* are focused on its implementation and challenges to achieve a more compassionate, effective and culturally flexible health system. It is engaged in fostering care equity to meet the individuals' needs in view of their vulnerabilities, promoting health access especially for those who are suffering now.

CONCLUSION

The *Frente PaliATIVISTAS* contributed to overcome the absence of a specific public policy, an important barrier for the development of palliative care in Brazil. Eventually, it is expected that this experience leads to fresh engagement to the palliative cause and inspires the creation of other social movements.

CONTRIBUTIONS

All the authors contributed substantially to the study design, acquisition, analysis and interpretation of the data, writing and critical review. They approved the final version for publication.

DECLARATION OF CONFLICT OF INTERESTS

There is no conflict of interests to declare.

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