

PARTICIPAÇÃO E CONTROLE SOCIAL NO CONTEXTO POLÍTICO DOS CUIDADOS PALIATIVOS NO BRASIL: UMA REFLEXÃO TEÓRICA

PARTICIPATION AND SOCIAL CONTROL IN THE POLITIC CONTEXT OF PALLIATIVE CARE: A THEORETICAL REFLECTION

PARTICIPACIÓN Y CONTROL SOCIAL EN EL CONTEXTO POLÍTICO DE LOS CUIDADOS PALIATIVOS: UNA REFLEXIÓN TEÓRICA

Jacqueline Resende Boaventura¹, Juliana Dias Reis Pessalacia², Tatiana Carvalho Reis Martins³, Alexandre Ernesto da Silva⁴, Maristela Rodrigues Marinho⁵, Priscila Kelly da Silva Neto⁶.

RESUMO

Objetivo: Refletir acerca da efetivação do princípio da participação e controle social no contexto dos cuidados paliativos. **Métodos:** Reflexão teórica, fundamentada no princípio organizativo da 'participação popular', à luz da Lei nº 8142 de 1990, que dispõe sobre a atuação da comunidade na gestão do Sistema Único de Saúde (SUS) brasileiro e em publicações nacionais e internacionais na temática. **Resultados:** Experiências referentes à presença popular, na formulação e gestão de políticas de saúde, para os cuidados paliativos nos países, são escassas. O envolvimento social em cuidados paliativos ocorre de forma limitada, em diferentes contextos, contemplando-se condições específicas, tais como avaliação da qualidade dos serviços, acesso a fármacos e decisões envolvendo terminalidade. No Brasil, a inserção dos cuidados paliativos, nas políticas públicas de saúde, é recente, porém deve contemplar os princípios estabelecidos pelo SUS. Acredita-se que o envolvimento popular proporcione ao paciente em cuidados paliativos e seus familiares voz ativa e autonomia e maior controle nas políticas públicas. **Conclusão:** Torna-se relevante o aprofundamento da discussão acerca da participação e controle social voltados a pacientes em CP e seus familiares, no âmbito da formulação e gestão de políticas públicas, para esses cuidados no Brasil e do papel da enfermagem no fortalecimento desse direito. **Descritores:** Cuidados paliativos. Participação do paciente. Controle social formal. Políticas de saúde. Enfermagem.

ABSTRACT

Objective: To reflect on the implementation of the principle of participation and social control in the context of palliative care (PC). **Methods:** Theoretical reflection based on the organizational principle of 'popular participation', in the light of Law 8142 of 1990, which provides for community participation in the management of the Brazilian Unified Health System and in national and international publications. **Results:** Experiences regarding popular participation in the formulation and management of health policies for PC in countries are scarce. Social involvement in PC occurs in a limited way in different contexts, considering specific conditions, such as quality of service assessment, access to drugs, and decisions involving terminality. In Brazil, the insertion of PC in public health policies is recent, but it should include the principles established in the unified health system. Popular involvement is believed to provide patients in PC and their families with active voice and autonomy, as well as greater control over public policies. **Conclusion:** It is relevant to deepen the discussion about participation and social control aimed at patients in PC and their families, in the context of the formulation and management of public policies for this care in Brazil and the role of nursing in strengthening this right. **Descriptors:** Palliative care; Patient Participation; Social control formal; Health policy; Nursing.

RESUMEN

Objetivo: Reflexionar sobre la implementación del principio de participación y control social en el contexto de los cuidados paliativos. **Métodos:** reflexión teórica, basada en el principio organizativo de 'participación popular', al amparo de la Ley N ° 8142 de 1990, que prevé la participación comunitaria en la gestión del Sistema Único de Salud (SUS) de Brasil y en publicaciones nacionales e internacionales sobre esta temática. **Resultados:** las experiencias con respecto a la participación popular en la formulación y gestión de políticas de salud para cuidados paliativos en los países son escasas. La participación social en los cuidados paliativos se produce de forma limitada en diferentes contextos, considerando condiciones específicas, como la evaluación de la calidad del servicio, el acceso a los medicamentos y las decisiones que involucran la fase terminal. En Brasil, la inserción de los cuidados paliativos en las políticas de salud pública es reciente, pero debe incluir los principios establecidos en el SUS. Se cree que la participación popular brinda a los pacientes en cuidados paliativos y a sus familias, voz activa y autonomía, y un mayor control sobre las políticas públicas. **Conclusión:** es relevante profundizar la discusión sobre participación y control social dirigida a pacientes en PC y sus familias, en el contexto de la formulación y gestión de políticas públicas para esta atención en Brasil y el papel de la enfermería en el fortalecimiento de este derecho.

Descritores: Cuidados paliativos; Participación del paciente; Control social formal; Políticas de salud; Enfermería.

¹Enfermeira, Especialista. Aluna do Programa de Pós-Graduação - Mestrado em Enfermagem UFMS. ²Enfermeira, Pós Doutora em Enfermagem. ³Enfermeira, Doutora em Ciências da Saúde. ⁴Enfermeiro, Doutor em Enfermagem. ⁵Enfermeira, Especialista pela Universidade Federal de Mato Grosso do Sul. ⁶Enfermeira, Especialista pela Universidade Federal de Mato Grosso do Sul.

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INTRODUCTION

Traditionally, Palliative Care (PC) has been defined according to the concept proposed in 1990 and revised in 2002 by the World Health Organization (WHO) as “assistance promoted by a multidisciplinary team which aims to improve the quality of life of patients and their families who are facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual”⁽¹⁾.

However, an even broader concept of PC has recently been proposed with basis on the Lancet Commission on Global Access to Palliative Care and Pain Relief in 2017. According to the report of this committee, PC is defined as active holistic care of individuals across all ages with serious health-related suffering due to severe illness, and especially of those near the end of life, with the aim to improve the quality of life of patients, their families and their caregivers⁽²⁾.

The scenario of PC is still in the process of political structuring in Brazil; organization strategies so far are challenging, because its approach does not only contemplate patient care, but a commitment to care, and requires integration and dedication of a multidisciplinary team⁽³⁾.

Thus, a resolution was adopted in 2014 whereby the World Health Assembly (WHA) challenges all governments to include PC in health plans and policies. Moreover, the World Health Organization (WHO) was assigned to monitor these actions⁽⁴⁾.

In Brazil, however, PC is very fragile, a set of isolated measures, and almost always dependent on donations, besides limited in terms of access to pain control medications. In this context, it is evident that patients with severe diseases usually have to live with uncontrolled pain and do not have access to quality PC in the country⁽⁵⁾.

This problem is due to the fact that there is still no specific public health policy in the country for the implementation and organization of PC at the three levels of complexity of the health system. Thus, the current organization of PC is based on ordinances related to cancer patient care and the Ordinance on the Health Care Network of People with Chronic Diseases within the Unified Health System (SUS)⁽⁵⁾.

Thus, based on several discussions of the Tripartite Intergovernmental Commission (TIC) of

the Brazilian Ministry of Health (MOH) published in November 2018 in the Official Gazette (DOU), Resolution n^o. 41 which “Provides for the guidelines, organization of palliative care, in the light of integrated continuous care measures, within the Unified Health System (SUS)”⁽⁶⁾. This resolution defines in its Art. 2 the following: “Art. 2 Palliative care consists of the assistance promoted by a multidisciplinary team which aims to improve the quality of life of patients and their families who are facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual”⁽⁶⁾.

Thus, TIC Resolution n^o. 41 is a reference to the future creation of a policy and ordinances with strategies that ensure the implementation of the objective proposed in the resolution⁽⁵⁾.

Popular participation in the context of public health policies is a foundation strongly respected by governments and health managers. Including the patients in the decisions, understanding their values and preferences, is paramount for conducting an individualized practice and formulating clinical guidelines. However, few studies have addressed the best way to understand and obtain user perception in the formulation and updating of health policies for PC⁽⁷⁾.

That said, it is considered necessary to seek experiences in the organization and social involvement in the implementation of public health policies aimed at PC. Thus, we seek to reflect on the implementation of the principle of participation and social control in the context of PC in the Brazilian SUS.

METHODS

This is a theoretical reflection based on the principle of Popular Participation in the light of Law number 8142 of December 28, 1990⁽⁸⁾. The Brazilian Unified Health System (SUS) foresees a system with doctrinal and organizational principles that is constantly updated through laws, rules and regulations that are being promulgated, due to adjustments to new needs of the population. Normative principles guide how the system should function, having doctrinal principles as its guide⁽⁹⁾. The discussion was based on national and international articles that discuss Popular Participation in health policies related to PC. However it is noteworthy that the concept of

Popular Participation in Brazil differs from that in other countries. In Brazil, Popular Participation is a principle of the SUS and comprises the multiple actions that different social forces develop to influence the formulation, execution, supervision and evaluation of public policies and/or basic services (health, education, housing, transportation, sanitation and others), according to Health Sciences Descriptors (DeCS). In the international context, such a concept is described in Medical Subject Headings (MeSH) only as the involvement of community members in community affairs, not pointing this concept as related to public health policies. Such conceptual differences hinder the search for scientific articles in the databases through the combination of the descriptors 'Popular Participation' and 'Palliative Care', because several publications unrelated to the concept of Popular Participation put in the Brazilian SUS legislation result from this combination. Thus, we opted for a work of theoretical reflection; after the exhaustive search of experiences in international databases, some similar practices were identified in the international context, and this gave support for the reflection on a possible policy contemplating Popular Participation in the context of PC. Thus, national and international articles that addressed Popular Participation, regarding the population to participate in the formulation, planning, implementation or evaluation of public health policies and services related to PC were preferred.

RESULTS AND DISCUSSION

In a context of population aging and increased use of technologies to maintain life, the need to seek strategies to ensure that patients' preferences be respected is increasingly urgent⁽¹⁰⁾.

The goal is to provide quality, systematized care that covers a large portion of the population. However, this objective only becomes tangible when popular participation is inserted in the development and implementation of guidelines for clinical practice. However, ensuring user involvement is a complex issue, despite being strongly defended by managers⁽¹¹⁾.

The assessment of the participation of patients and families in decisions related to death and PC becomes an important tool for guiding and implementing more ethical public health policies⁽¹⁰⁾ and it is up to managers involved in PC services to try to develop ways to include patients

and family members in dialogues about end-of-life care⁽⁷⁾.

A systematic review⁽¹²⁾ aiming to determine the impact of community participation in public health, in end-of-life care, showed that services that involve the community in actions aimed at the terminality in these patients have a positive impact on the formulation of policies and research, meeting goals that are perceived as complex. It is also emphasized that it is impracticable to discuss end-of-life issues out of the social, political and economic context of communities.

A qualitative research⁽¹³⁾ conducted in the Netherlands sought to understand the influence and participation of patients and their representatives in policy making and decision-making in PC. In that country, the existence of PC networks is a reality that aims to ensure the availability and variety of quality PC and constantly adjust the service according to the needs of patients and families through popular participation. Popular involvement is believed to provide PC patients with an active voice and to guarantee the principles of autonomy and social control during their treatment. In the analysis of the data, social participation was remarkable in the formulation and implementation of policies, but during the evaluation processes, the involvement decreased and, in the phase of adjustment of the offered services, there was no satisfactory influence of users. It is noted that the participation of representatives of society in the evaluation and adjustment phases was neglected by health professionals, because users a lay people and community members, their capacity to collaborate with health planning actions is underestimated⁽¹³⁾.

Thus, it is shown that popular participation in an organized manner, in the context of health policies, is a user right and feedback of the care provided to the population. However, there are divergences between the values of behavioral actions resulting from popular manifestations in the issues, involving practical processes and long-term processes. Attitudes that require quick decision-making appear to be more important in relation to more bureaucratic processes, such as public health policies⁽¹³⁾.

Thus, a European⁽⁷⁾ systematic review conducted in Australia confirmed the little information demonstrating the impact of popular participation on health, especially when directly related to PC, and that community involvement in

PC occurs within specific policies such as pharmaceutical policies.

Thus, it is noted that the experiences of countries regarding popular participation in the formulation and management of health policies are scarce. When articles approach the social involvement in PC, they address specific conditions such as the quality of services provided⁽¹³⁾, availability of drugs⁽⁷⁾, and terminality⁽¹²⁾.

Comparing the findings with the Brazilian reality, it is noted that social participation in health in Brazil has been structured on the conception of social control, to allow civil community to collaborate since the creation of strategies to the definition of allocation of resources, so that they may meet the interests of the community. Therefore, the main places for the manifestation of participation and social control, for the implementation of health policies in the spheres of the Brazilian government, are the Health Councils and Conferences⁽¹⁴⁾. However, in the international context, it is observed in the publications explored that there are no discussions about the organization regarding the participation of users in councils, conferences or meetings that stimulate and ensure the state-society relationship in practices of surveillance and control over existing norms.

In Brazil, the publication and insertion of PC in public health policies is recent and there is no specific policy so far for the standardization and organization of this care in the country. Therefore, it is necessary to use the doctrinal and organizational principles of SUS in the implementation of PC in the country. By guaranteeing the principle of participation and social control, the process of building, implementing and managing health policies becomes democratic. Furthermore, attention is drawn to a reality that meets the real needs of the community in question.

Because terminality is a dilemmatic subject that requires interdisciplinary assessment, studies on this theme involve the population in decision making and strategy formulation in PC, mainly, at the heart of the manifestations of wills at the end of life and their legal and social implications.

An example that has a close similarity with the Brazilian Health Councils is the one of the Maryland Advisory Committee in the United States (USA), which focuses on advising on state policy making for PC, consisting of a group of interdisciplinary experts and advocates for

citizens. The Maryland State Advisory Council on Quality of Care at the End of Life (MSAC) combines strategic planning, public engagement, and scheduled meetings to allow comments on state proposals and policies. The MSAC was created by a legislation that considers it a permanent organ of Maryland government. The work of the MSAC over eight years has shown that the model can be an effective catalyst for a positive change in the creation of policies related to the end of life⁽¹⁵⁾.

In Canada, the Canadian Strategy for Cancer Control (CSCC) is also an interesting mechanism of popular participation that began in January 1999 and involved more than 130 health professionals and community representatives. A crucial aspect of the successful implementation of the strategy was the early involvement of provincial/territorial ministries of health in the planning process. Several working groups and two stakeholder conferences were proposed to develop recommendations and priorities for cancer control in the country. In the council report, the participation of patients, who they call 'survivors', in the development and implementation of the CSCC was highlighted as priority, as a balanced approach to cancer control should include the perspective and experience of the patient. The voice of patients and survivors is brought to the Board by the Canadian Cancer Action Network (CCAN), a coalition of patient/survivor support groups representing a wide range of cancer types⁽¹⁶⁾.

The initial pages of the current 'Canadian Strategy for Cancer Control: 2017–2022' describe the testimony of a patient counselor of the National Survivorship Working Group. It is noted that 700 Canadians - researchers, health professionals, academics, system-leading health professionals, and patient advocates - met through the CSCC to address the growing number of cancer cases and deaths in the country⁽¹⁷⁾.

In Spain, a 'modified citizen jury' model was organized with the participation of 30 members and four experts as witnesses. The objective of this jury was to evaluate the quality of cancer treatment through the patient's opinions, experiences and perceptions, seeking recommendations to improve cancer treatment in the country. For one day, judges representing 13 of 17 Spanish Autonomous Communities were attended to make recommendations to improve the quality of cancer treatment. Concerns about care fragmentation, testing delays, duplication,

and poor social and emotional support were identified. Some strategies proposed by the jury included a 24-hour care center, PC continuity, and appropriate follow-up and support after therapy ended. It was highlighted by this study that, although holding a jury with a small number of judges may seem to be a limitation when compared to other methodologies, the citizen jury is a unique mechanism of public democracy that can yield rich data on patient perceptions and recommendations on political issues, as patient organizations and patient leadership in Spain are generally not invited to participate in the political decision-making process⁽¹⁸⁾.

In a different way, popular participation is an organizational guideline of the Brazilian SUS and, therefore, strategies should be foreseen so that patients and their families can actively participate in the construction, evaluation and improvement of public policies on PC.

In Brazil, an informal social movement has been started, driven by patients, aiming at greater visibility of the needs of people suffering from life-threatening diseases. Recently, a patient undergoing treatment for metastatic breast cancer was interviewed in a well-known Brazilian television program⁽¹⁹⁾ and presented to the community the daily life of patients who experience diseases without possibility of cure. This patient also reached thousands of followers on social networks and has participated in scientific events focused on PC in the country, reporting the needs of patients in different contexts of health care provision.

Thus, through the present discussion about the proposal of a specific public policy for PC in the country, strategies should be sought for PC patients and their families to actively participate in the formulation of national health policies. Considering the popular opinion ensures that health actions be offered in an assertive manner to the needs presented by the community. The role of nursing in strengthening this participation stands out, as nursing professionals are inserted in different spaces of care production, in the management of health policies and services, and in local and municipal health councils⁽²⁰⁾.

With this reflection, it is proposed that the organization of services related to the provision of PC in the country consider the participation of representatives of patients and family members in the collegiate instances 'Health Conferences and Health Council', so that they be able to present to the competent bodies, in an organized

way, more specific claims with respect to their needs.

CONCLUSION

This study presented reflections on the participation and social control in the political context of PC, with important implications for the implementation of this principle in the organization of services related to PC in SUS.

The publications found in databases of journals and health policies of different countries showed that few countries actually contemplate participation and social control in their health policies for PC. Thus, few studies address the impact of this participation of countries on the quality of PC services.

It is relevant to deepen the discussion about the importance of participation and social control aimed at patients under PC and their families, in the context of the formulation and management of public policies, for this care in Brazil and the role of nursing in strengthening this right.

It is emphasized that further studies addressing the theme are needed, aiming at improving the discussions and sharing the experiences about popular participation and the impacts provided by it within the context of PC.

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Mailing address:

Jacqueline Resende Boaventura

Street Marcelo Vitoria, 261. House 14.

ZIP CODE: 79622-042– Três Lagoas/MS - Brazil

E-mail: jacque_boaventura@yahoo.com.br