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Deliberative dialogue on euthanasia in girls, boys and adolescents. Prequel to the Cabildo Ciudadano (Citizen Council) carried out in Colombia

Diálogo deliberativo sobre eutanasia en niñas, niños y adolescentes. Precuela del Cabildo Ciudadano llevado a cabo en Colombia

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Abstract

Background:

To date, there is a lack of published information on the utilization of the Deliberative dialogue methodology and the right to a dignified death in minors under 18 years of age in Colombia and Latin America.

Objective:

To examine the issue of children and adolescents' entitlement to a dignified death, including the criteria for exclusion, and to formulate a comprehensive plan for pediatric palliative care. A public policy document will be created with the aim of supporting the implementation of Resolution 825/2018.

Methods:

Participatory Action Research utilizing a Deliberative dialogue methods that has been adapted based on feminist epistemological principles.

Results:

The outcome of the exercise was the production of a document containing Public Policy recommendations regarding euthanasia in minors and its submission to the Ministry of Health and Social Protection of Colombia a few days prior to the release of the Resolution regulating the right to a dignified death for this population. Additionally, the conclusions of this event enabled the creation of a guide for the implementation of (Cabildos Ciudadanos) Citizen Council, in which girls, boys, and adolescents are included, trans-disciplinarity is encouraged, and feminist epistemological foundations are explored.

Conflicts of interest:

The authors declare that they have no conflicts of interest related to the topic, the participating institutions, or any stage of the work.

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Conclusions:

The deliberative dialogue method may serve as a cost-efficient alternative to replace or complement participatory approaches utilized in the development of public health guidelines and policies.

Resumen

Antecedentes:

En Colombia y Latinoamérica no se cuenta con registros publicados de temas abordados desde los métodos del diálogo deliberativo frente a temas de salud sobre la población pediátrica.

Objetivo:

El diálogo deliberativo fue utilizado para deliberar sobre el derecho a la muerte digna en niñas, niños y adolescentes, sus criterios de exclusión, y el marco de acción de los cuidados paliativos pediátricos.

Métodos:

Investigación acción participativa recurriendo a la metodología Deliberative Poll.

Resultados:

Redacción de un documento de recomendaciones de Política Pública en torno a la eutanasia en población pediátrica y entrega del mismo al Ministerio de Salud y Protección Social de Colombia días previos a la expedición de la Resolución que reglamentó el derecho a morir con dignidad para esta población; así mismo, las conclusiones de este ejercicio posibilitaron la estructuración de una guía metodológica para la realización de Cabildos Ciudadanos en donde se integra a niñas, niños y adolescentes.

Conclusiones:

el diálogo deliberativo puede constituirse en una alternativa costo-eficiente para reemplazar o complementar metodologías de participación empleadas en la construcción de lineamientos y políticas públicas en salud

Remark

1) Why was this study conducted?

The present study was undertaken in order to complement the methodological exercises of the doctoral thesis in Public Health, entitled *“Public Policies, Implementation, and Emotions: Towards an Alternative Approach to Analysis. Case study: “Childhood Cancer Public Policy at the National Institute of Cancerology in Bogotá, Colombia”*⁽⁶⁾ was chosen as the focus of the research. The opportunity to conduct this study was seized upon in light of Resolution 825 of 2018, which pertains to cancer patients as a target population. The study was organized with the support of the doctorate program and the two research groups affiliated with the doctoral research.

2) What were the most relevant results of the study?

The primary outcome of the study was the compilation of a document containing Public Policy recommendations, which synthesized the perspectives and tensions expressed by all participating parties. This document served to inform decision makers within the (Ministry of Health and Social Protection) of the key considerations pertaining to key stakeholders. Additionally, through this study, a public discourse on the topic of euthanasia was initiated, which contributed to a greater understanding of the issue and facilitated a scenario for reflection utilizing both scientific and, experiential knowledge, and personal experiences. Furthermore, the conclusions drawn from this exercise enabled the development of a methodological guide for the implementation of (*Cabildos Ciudadanos*) Citizen Council, which includes the integration of children and adolescents, and emphasizes the importance of transdisciplinarity and the epistemological contributions of feminism.

3) What do these results contribute?

The utilization of diverse research methodologies to address health-related issues is deemed necessary. The implementation of the deliberative dialogue methodology, which incorporates feminist epistemology, for the formation of democratic spaces for discussion on controversial topics, represents a valuable contribution to the academic community and civil society organizations interested in the development of public policies in Colombia and throughout Latin America. The deliberative dialogue approach facilitated the establishment of the (*Cabildos Ciudadanos*) Citizen Council methodology, which emphasizes feminist contributions and empowers children and adolescents to actively participate in proposing, criticizing, and mediating on matters that pertain to their health and well-being.

Introduction

The purpose of a prequel is to delve into the past and reveal the events that led to a particular situation. In this case, with the goal of enhancing understanding of the generation of knowledge that underpins the “Cabildos Ciudadanos” Citizen Council methodology, the experience of the Deliberative dialogue on euthanasia in children and adolescents¹ conducted on March 5th, 2018 will be presented. Through this exercise, a summary of positions regarding the draft of Resolution 825 of 2018 was submitted to the Ministry of Health and Social Protection of Colombia, which regulates the right to die with dignity for children and adolescents¹. The key elements of this resolution are outlined in Table 1.

¹ The Deliberative Dialogue, also known as Deliberative Poll, is a mechanism for citizen participation that fosters the exchange of arguments on contentious issues, leading to the potential modification of positions and, if feasible, the attainment of consensus. This approach was applied to the topic of euthanasia in children and adolescents and the criteria for its exclusion, as well as the framework for pediatric palliative care. As a result of this exercise, a document containing public policy recommendations was generated and submitted to the Ministry of Health and Social Protection in Colombia, prior to the release of Resolution 825/2018, which governs the right to die with dignity for children and adolescents in the nation. The outcomes of this event also facilitated the creation of a guide for the implementation of (*Cabildos Ciudadanos*) Citizen Council, an innovative proposal that incorporates minors (under 18 years of age) into democratic deliberation processes, promotes trans-disciplinarity, and incorporates feminist epistemologies into the Deliberative Dialogue.

Table 1. A summary of the key provisions of Resolution 825 of 2018, “which regulates the right to a dignified death for children and adolescents”.

Aspect	Featured items
Conceptualization	Age of the minor as a determinant in the conception of death. The decision must be free, voluntary, informed and unequivocal. Newborns and neonates.
Exclusions	Girl or boy under 6 years old Person between 6-12 years of age presenting with: 1) altered state of consciousness, 2) intellectual disability, 3) psychiatric disorders that impair competence in understanding, reasoning and/or reflective judgment.
Key Stakeholders	Boy, girl or adolescent: central subject. Person with parental authority over the minor: legal representative of the child or adolescent. Treating physician: receives the patient's request or dissent for palliative care and accompanies the patient in the request for euthanasia. Physician carrying out the act of euthanasia: physician with training, and without conscientious objection to the application of the euthanasia act. Scientific-interdisciplinary committee for the right to die with dignity: composed of a pediatrician, a psychiatrist and a lawyer. Hospitals and clinics Health insurance companies (EAPB): institutions in charge of health administration National Health Superintendency: in charge of inspecting, monitoring and controlling the resources of the health system, in addition to enforcing compliance with the rules that regulate the Health System. Ministry of Health: responsible for formulating, adopting, directing, coordinating, executing and evaluating public policy on health, public health and social health promotion.
Procedure for the request by the child or adolescent	The child or adolescent submits the request to the treating doctor Restate the existence and availability of palliative care Reconfirm the possibility of the right to die with dignity, and to withdraw from euthanasia at any time. Assessment of the patient by the comprehensive care team: 1) Establish the terminal status of the underlying disease, 2) Assess the child's concurrence of decision-making skills, 3) Provide reasonable support and adjustments as appropriate, 4) Identify the concept of death according to age. Emphasize the proper concept of death (adolescents) Assess the manifestation of suffering. Define that it has been adequately cared for so far. Psychological/emotional assessment of the parental caregiver. Rule out the possibility of Tired Caregiver Syndrome. Record the information collected in the medical record. Question the child or adolescent again about their decision, and reconfirm that they wish to continue with the process. Submit a documented request by the child or adolescent (and if applicable also by the person exercising parental authority), for the analysis of their case to the Scientific-Interdisciplinary Committee of the clinic or hospital.
Analysis of the case by the Scientific-Interdisciplinary Committee	Confirm compliance with the requirements. Define whether or not there are irregularities in the process. As and when required, summon experts to a meeting to provide guidance on a particular case. Offer contrasting opinions both positive and negative regarding the completion of the procedure. Compile a documented record of the process. Provide a report on incidents reported to hospitals and clinics, informing the Ministry of Health, the Superintendence of Health, and the appropriate Health Administrator EAPB.

This document serves as a supplement to previous publications regarding the deliberation on euthanasia in children and adolescents in Colombia^{2,3,4} and aims to enhance understanding of the emergence of the Cabildo methodology. The Cabildo methodology is characterized by its emphasis on transdisciplinarity and the inclusion of historically marginalized groups, - such as children and adolescents⁵ in deliberative processes that pertain to their interests. Additionally, the Cabildo methodology is defined by its interest in exploring an epistemology of emotions⁶ in order to contribute to the advancement of social participation in health in Colombia and throughout Latin America.

This prequel is organized into two sections. The first section, which serves as an introduction, explains the methodology of “Deliberative dialogues” and highlights the contributions that feminism has made to understanding emotions as epistemological elements within the Cabildo methodology. The second section provides a detailed description of the exercise conducted, including the results obtained and the ensuing discussion.

It should be noted that the phase of the work presented in this document did not involve direct participation from children and adolescents, it was a one-day meeting held in response to the impending issuance of Resolution 825 of 2018 by the Ministry of Health and Social Protection of Colombia. Following this event, a methodological guide was developed and implemented for holding Cabildos ciudadanos (Citizen Councils), which did include the participation of children and adolescents² in health deliberation processes and citizen education exercises as a result of the outcomes of this exercise³.

The two objectives that guided the experience were: first, to bring the issue of euthanasia in children and adolescents to the forefront of attention for relevant social actors through a methodology that integrated feminist foundations into the deliberative dialogue, thus promoting public debate and future deliberation opportunities; second, to collect and synthesize the perspectives and tensions expressed by each participating actor, in order to provide the Ministry of Health and Social Protection of Colombia with valuable information to consider as part of the argumentative support for the resolution.

Deliberative dialogue

Inspired by the methodology known as Deliberative Poll⁷, the deliberative dialogue is grounded in the exchange of arguments for mutual understanding between parties, who may or may not initially share common perspectives on a controversial topic, and on the potential for modification of positions on said topic. Additionally, it is considered a mechanism for interaction and knowledge sharing with the aim of informing political decision-making, with active participation from both members of society and those responsible for political administration⁸.

The deliberative dialogue methodology serves as a means of constructing public policies through the exchange of arguments and knowledge between parties with varying perspectives on a controversial issue of collective interest. This approach enables the inclusion of multiple perspectives and experiences in the formation of policy decisions, promoting active engagement of society in the political process, and ultimately leading to the development of more effective policies. This is in line with the idea that the best policies are formed through continuous dialogue and engagement between experts and citizens in the public sphere, thereby enhancing the functioning of democracy⁹.

The deliberative dialogue process aims to cultivate four interrelated components: 1) the formation of coherent, stable, and consistent preferences and arguments; 2) the establishment of educational processes for the participating audiences; 3) the enhancement of mutual understanding among citizens; and 4) the reduction of narrow perspectives based solely on self-interest and the substitution of these with arguments that integrate the perspectives

of other individuals or groups⁷. Given that deliberative dialogues capitalize on specific circumstances to introduce new topics onto the public agenda, it is a process that aims to attract the attention of significant social actors, allowing for the generation of *windows of opportunity* and timely political action¹⁰.

The deliberative dialogue methodology faces the challenge of balancing the legitimacy of deliberation by incorporating both rational and objective arguments, as well as affective and subjective perspectives. This approach allows for the recognition of individual positions and reflection on circumstances that affect groups. While the deliberative dialogue is non-binding in nature, it transforms the traditional flow of information from experts and scholarly actors to inexperienced audiences and those considered passive into a multidirectional exchange between citizens, the State, trade union organizations, and various interest groups involved in the discussion topic⁹.

In summary, deliberative dialogues 1) involve the utilization of both verifiable and contrastable information, as well as knowledge derived from human experience, as crucial inputs for discussions. 2) These dialogues also provide opportunities to contextualize and give meaning to evidence-based knowledge in relation to tacit knowledge and real experiences shared by key social actors. 3) Additionally, they furnish decision-makers with useful, timely, and easily-applicable knowledge during the construction and implementation of public policies¹¹.

Contributions of feminist epistemologies

The feminist theory of knowledge informs the deliberative dialogue approach by incorporating three key epistemological contributions: 1) recognizing the value of knowledge derived from lived experiences, emotions, and bodily perspectives, 2) incorporating the perspectives of marginalized individuals and groups who have been historically oppressed, and 3) constructing knowledge that is situated within specific contexts of time, space, and social dynamics.

In terms of the first epistemological contribution, feminist theory posits that knowledge can be *derived from personal experiences, emotions, and physical bodies*. This perspective, encapsulated in the well-known feminist mantra “the personal is political,” is exemplified in the works of authors such as Bell Hooks¹² and Michelle Rosaldo¹³. This approach critiques the disconnection between theory and practice in the production of knowledge and challenges the institutionalized, totalizing ways in which knowledge is traditionally generated.

Categories such as *embodied thought* proposes an understanding of knowledge that is derived from the body and its interactions with others. This concept highlights the role of emotions and affections as epistemological factors that shape these relationships. Through reflective and politically conscious examination of the self, this embodied form of knowledge can lead to transformative and liberating outcomes, potentially even promoting healing¹⁴.

Continuing with the feminist perspective - represented by authors such as Patricia Hill Collins¹⁵ Sandra Harding¹⁶ and Dorothy Smith¹⁷, it is argued that knowledge is not only derived from the body and experience, but also that subordinate subjects possess a form of epistemic privilege, which enables them to understand dynamics from their unique perspective that would not be possible to comprehend from other vantage points. Common among subordinate subjects, - such as women, children and adolescents, ethnic groups, among others-, is the organization of social relations that have led to their exclusion¹⁷. From this privileged perspective they are able to comprehend the entirety and particularity of society.

In accordance with the feminist perspective, the concept of situated knowledge, as proposed by Donna Haraway, represents the third significant contribution. Haraway¹⁸ posits that all knowledge is partial, limited, and situated, and that the notion of objectivity as espoused by

modern science is a fiction. She advocates for recognizing the position from which one speaks in order to comprehend the impact on the knowledge-making process. Additionally, Haraway calls for the development of a successor science that emphasizes “irreducible difference and the radical multiplicity of local knowledge”¹⁸ and the acceptance of responsibility for one’s role in shaping narratives about the world and potential alternative realities.

From a feminist epistemological perspective, the concept of democracy is problematized by the notion of expanded citizenship, the understanding of the public sphere, and the deliberation process itself. Two key premises emerge from this perspective. The first premise is that there exists a citizenry that is interested in and committed to public affairs - the public concerned as proposed by John Dewey. The second premise is that the notion of citizenship must be expanded to include all potentially affected subjects.

In regards to the initial aspect, we are encouraged to contemplate the voices of individuals who have been historically oppressed or had difficulty being recognized as citizens. Merely incorporating these voices is not sufficient justification, rather, it is crucial to comprehend that incorporating diverse perspectives will serve to bridge the gap in our understanding of the world and its workings, both politically and epistemically.

From an academic perspective, it is essential to comprehend the multifaceted nature of the social world and to acknowledge the validity of the experiences of individuals who are impacted by the decisions made within the realm of public policy. This approach leads to a critique of traditional decision-makers, who are often privileged in terms of gender, ethnicity, class, sexuality, and age. Additionally, this critique extends to the inclusion of children and adolescents as valid interlocutors and citizens, and the consideration of their experiences and interests in decision-making processes.^{5,20}

Adults are often perceived as morally and politically superior to children and adolescents, similar to how women are often relegated to the private and domestic sphere. This leads us to the second aspect of the issue, the public sphere, which encompasses the political arena and deliberation. Feminist epistemologies advocate for reevaluating the barriers, both material and symbolic, that prevent marginalized groups from participating in public discourse and deliberation.

Feminist epistemologies have made significant strides in bringing attention to the political nature of the private sphere, highlighting the complex intersections and connections between these traditionally separate spheres. This presents a challenge when contemplating which issues should be brought to the public sphere, and how emotions and the physical bodies they impact can be understood and acknowledged, even at an individual level.

One of the criticisms that is often made of deliberative democracy is that not all individuals have the necessary knowledge or skills to participate or be interested in this type of deliberation²¹. To address this, it is commonly suggested to inform, educate, or politically literate individuals. However, the true challenge lies in re-evaluating the forms of political deliberation, acknowledging the epistemological value of lived experience and emotions, and considering how they can be included in democratic processes to ensure that the perspectives and experiences of marginalized groups are not further neglected.

Materials and Methods

Based on the aforementioned considerations, and with the objective of addressing the opportunity presented by Resolution 825 of 2018, entitled “Regulation of the Right to Die with Dignity for Children and Adolescents,”¹ an investigative study was designed and conducted within the framework of a doctoral project in Public Health at the Universidad Nacional de Colombia, entitled “*Public Policies, Implementation, and Emotions: Towards an Alternative Approach to Analysis - A Case Study of the Public Policy on Childhood Cancer at the National*

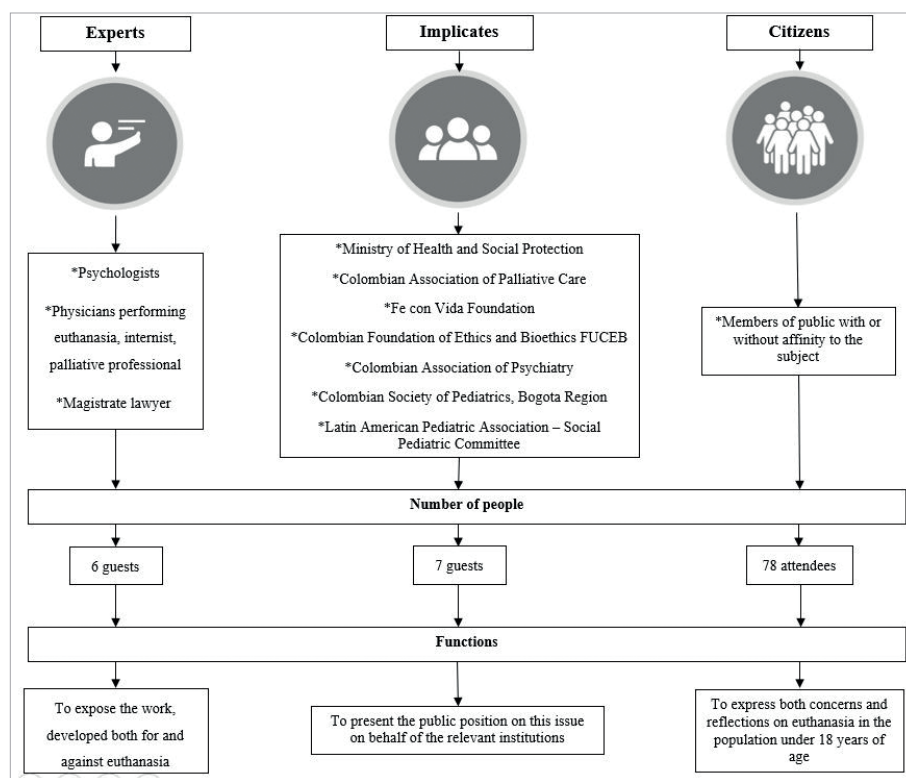


Figure 1. Composition of the work panels

*Institute of Cancerology in Bogotá, Colombia.*²⁶ The objectives of this study were to: 1) reduce the gap between citizens, academia, and politics, 2) deepen democracy by promoting deliberative participation in political processes, and 3) balance the distribution of power among the various stakeholders involved in legislative or political decision-making.

The guiding inquiries were: What points of agreement and disagreement exist among relevant stakeholders or those potentially impacted by the issue? And, what aspects of the problem, potential solutions, or crucial considerations for implementation were not being considered in the draft resolution?

Participant selection strategy

An intentional and snowball sampling approach was employed based on the identification of crucial social actors, recognizing that the Deliberative dialogue should center on the diverse scenarios of euthanasia application, the potential impact on specific groups, as well as the multiple perspectives and implementation alternatives.

The following were considered as inclusion criteria: 1) individuals responsible for policy decision-making; 2) administrators of health care institutions, non-governmental organizations, and other pertinent groups; 3) members of civil society organizations such as patient associations and trade associations; 4) academics, educators, and researchers from reputable national institutions. The sole exclusion criteria was individuals with cognitive impairments that prevented them from effectively representing the perspectives and experiences of the group they belonged to.

Convocation

One week prior to the resolution's official publication, direct contact was established with thirteen key actors in the capital district of Bogotá, by means of telephone and/or electronic communication, and the draft document of the resolution was attached. The draft was published on February 28th of the same year.

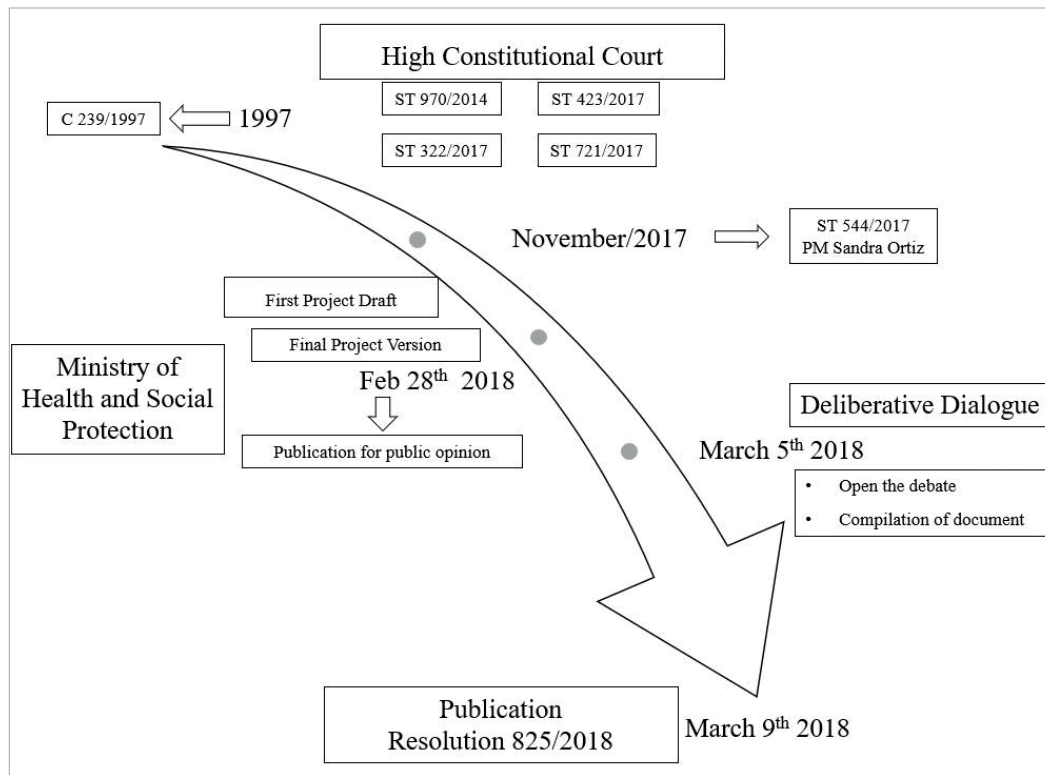


Figure 2. Depicts the timeline of the legal evolution of euthanasia in Colombia between the years 1998 and 2018. The following acronyms are used in the figure: C239-1997: Constitutional Judgment C-239/97 issued by the Constitutional Court in 1997 and presided over by rapporteur magistrate Carlos Gaviria Díaz, marking the beginning of the legal debate on mercy killing in Colombia. ST 970/2014: Guardianship Ruling T-970/14 issued by the Constitutional Court, presided over by rapporteur magistrate Luis Ernesto Vargas Silva, regarding the right to dignified death for individuals with terminal illness. ST 423/2017: Guardianship Judgment T-423/17 issued by the Constitutional Court, presided over by rapporteur magistrate Iván Humberto Escrucería, on the fundamental right to die with dignity. ST 322/2017: Guardianship Judgment T-322/17 issued by the Constitutional Court, presided over by rapporteur magistrate Aquiles Arrieta, on the right to a dignified life for the elderly beyond dignified death. ST 721/2017: Guardianship Judgment T-721/17 issued by the Constitutional Court, presided over by substantiating magistrate Antonio José Lizarazo, against the right to die with dignity for individuals in a vegetative state. ST 544/2017: Guardianship Judgment T-544/17 issued by the Constitutional Court, presided over by rapporteur magistrate Gloria Ortiz, on dignified death and the provision of adequate health services for minors. PM: Rapporteur Magistrate. Source: Own creation.

At the same time, the Interfaculty Doctorate in Public Health of the National University of Colombia extended a formal invitation to participate in the event through its official communication channels. Additionally, the initial thirteen participants, through snowball sampling, invited additional stakeholders with an interest in the subject matter to participate.

Case description

On March 5th 2018, a meeting entitled “Discussion on the Draft Resolution Regulating the Right to a Dignified Death for Children and Adolescents” was held at the Universidad Nacional de Colombia, Faculty of Medicine. The gathering was attended by 91 individuals, including 13 key stakeholders related to the topic of euthanasia and the majority being representatives from diverse groups, primarily consisting of caregivers and professionals in the fields of law, bioethics, and health sciences. Figure 1 depicts the composition and roles of each working panel during the event.

The deliberative dialogue was composed of six distinct stages. The facilitator, whose primary responsibility was to maintain the discussion’s focus on relevant issues and create a secure environment for all participants to express their opinions, gave a detailed overview of the current status of euthanasia in Colombia. The methodology was then explained, followed by guiding reflections that aimed to ensure the necessary conditions were met in order to gather valuable input for the decision-making process.

Additionally, the representative of the Ministry of Health and Social Protection presented the draft resolution that regulated the right to die with dignity for children and adolescents. This presentation included an explanation of the legal-technical context that led to the guardianship sentence T-544 of 2017², which ultimately gave rise to the ministerial resolution in question, Resolution 825 of 2018 (refer to Figure 2).

Subsequently, theoretical arguments for and against euthanasia were shared based on a philosophical framework and moral judgments by a doctoral candidate in Psychology from the National University of Colombia. The Panel of Experts, composed of 6 of the 13 guests and consisting of experts in the field including lawyers, psychologists, and doctors specializing in psychiatry, pediatrics, and palliative care, were each allotted 10 minutes to present relevant aspects from their respective areas of expertise. The fourth stage was dedicated to the interventions of the Citizen Panel, a diverse group of individuals summoned through a public invitation by the research team. Each member of the Citizen Panel was given 5 minutes to express their concerns and reflect on the information presented.

In response to the Citizen Panel, the seven remaining guests, collectively referred to as the Panel of Involved due to their explicit and declared inclination and interest in a specific position on the subject as depicted in Figure 1, were each given 5 minutes to clarify and/or complement arguments. During this period, questioning by a member of either the Panel of Experts or the Citizen Panel was permitted if it contributed to providing additional information or arguments not previously presented by other participants.

The deliberative dialogue concluded by presenting the key insights that emerged from the meeting, and inviting the Interfaculty Doctorate in Public Health to submit additional comments or arguments that were not expressed during the session due to time limitations, but which could be included in the final rapporteur report.

The conclusion of the event was followed by a sixth step carried out by the two principal researchers. This step involved the creation of a synthesis manuscript that augmented the report presented during the Deliberative dialogue, along with the addition of any supplementary documents received from the event participants. The entire proceedings were recorded by DISP³ and were monitored by a correspondent from Unimedios, the news agency of the National University of Colombia⁴.

Results

The primary outcome of this methodology is a document of public policy recommendations produced by the various participants, which summarizes the discussions held and identifies areas for improvement or consideration in future policy monitoring (Table 2). This result was significant for the design and implementation of the Cabildo Ciudadano (Citizen Council)^{2,3,21}, particularly in two aspects: the incorporation of the perspectives of children and adolescents and other marginalized forms of experiential knowledge into decision-making processes; and the reinforcement of a commitment to transdisciplinary approaches.

The recommendations document was promptly submitted to the Ministry of Health and Social Protection the day after the event took place, thereby effectively communicating the key considerations to decision-makers on the matter. Additionally, in response to the invitation extended at the conclusion of the event, to submit further supporting documents or to express

² In the Colombian state, the normative hierarchy complies with the postulates of Hans Kelsen's theory of law. The Constitution is the most relevant norm for resolving constitutional conflicts, followed by laws issued by the legislative power, decrees issued by the executive power, and finally resolutions generated by the government ministries. Thus, the Constitutional Court pronounces a writ of protection (T) in cases that require a thorough review because there is an infringement of fundamental rights, requiring clarity on a specific matter with the intention of setting jurisprudence for other future similar cases. In the particular case of euthanasia in minors, in the absence of a law issued by the national legislative power, the writ of protection of the Constitutional Court led to the Ministry of Health being ordered to issue a resolution [Resolution 825 of 2018] as an initial response to the constitutional void. Therefore, the ministerial resolution, even though it is hierarchically inferior for resolving conflicts around the topic, is the one that ultimately directs the legal order in the situation.

³ Check the following links to see the deliberative process carried out <https://www.youtube.com/watch?v=6jiE-bIQK04>; <https://www.youtube.com/watch?v=rgrQDqMRKnI>; <https://www.youtube.com/watch?v=tnzHTelqNDE>; <https://www.youtube.com/watch?v=cVWgQ1xt7SM>

⁴ In the following link is the journalistic note about the event <https://agenciadenoticias.unal.edu.co/detalle/eutanasia-en-menores-vulneraria-derecho-a-la-vida>

Table 2. Summary of public policy recommendations derived from the deliberative dialogue by participants

Participant/Role	Deliberations
Psychologist, PhD(c) in Psychology National University of Colombia	Moral arguments in support of euthanasia: The worth of human life is characterized by its capacities and potentials that lead to self-awareness and complete autonomy. The respect for the human life and well-being of another, as well as their desires and interests, is also a factor. Despite the potential for contradiction, autonomy takes precedence. Moral arguments against euthanasia: A demonstration of a lack of intention to cause harm must be shown and alternative solutions must be proposed. The valuation of life is not based solely on rational considerations, but also takes into account emotional, economic, and religious factors, making the decision-making process complex.
Internist, specialist in pain and palliative care. Representative of the Colombian Association of Palliative Care	The aim of palliative care is to enhance quality of life for patients suffering from terminal illnesses, and to alleviate both their own and their family's suffering. The concept of "euthanasia" must be differentiated from that of "dying with dignity", with palliative care being oriented towards the latter. If proper Palliative Care were available to those in need, including the patients' family and the home environment, there would be no need for euthanasia. An alternative solution is to promote the use of advance directives. Furthermore, it is crucial to differentiate palliative sedation from euthanasia. It is essential to increase training in palliative care and pain management, particularly in the field of pediatrics, as well as to develop support programs for caregivers.
Representative of the Social Promotion Office of the Ministry of Health and Social Protection	The incongruities between commitments made to the rights of individuals with disabilities, interdiction, and the availability of euthanasia pose a challenge. To address this challenge, ruling T-544 of 2017 demands a comprehensive evaluation of the childhood and adolescence law with regard to the rights of children and adolescents to a dignified death. In situations of disability, decisions should be made with appropriate support and carefully defined exceptions, ensuring the utmost respect for the individual's autonomy. In instances of subrogation, authority should only be transferred to someone who holds parental authority.
Physician with experience in the practice of medically assisted euthanasia	There is concern regarding administrative support structures. Although palliative care is of great importance, the right to make a personal choice must be maintained. The sanctity of human life should be paramount, encompassing the ability to self-identify, recognize others, and engage in meaningful communication. The rights of parents must also be acknowledged, and as such, the composition of scientific-interdisciplinary committees should include relevant parties such as children, adolescents and parents, as the current regulations only account for professionals in the fields of medicine, law, and psychology.
Physician, specialist in family medicine and in pain and palliative care. Representative of the Department of Palliative Care of the National Institute of Cancerology	The delegation of decision-making is a multifaceted issue and only two nations have made significant progress in this area. Identifying the capacity for self-determination in minors can be challenging, as there may be instances of parental estrangement and requests may be influenced by misunderstandings between euthanasia and the desire for a dignified or painless death. There is a need for a comprehensive policy that prioritizes the care and well-being of caregivers. From a peaceful perspective, promoting a culture of life care is preferable to a culture focused on death.
Caretaker mother of a child with cystic fibrosis. Representative of the Fe con Vida Foundation	Adopting a business-oriented approach to euthanasia, as is currently the case, would be a disservice to many children and adolescents, resulting in premature loss of life. Priority should be given to transforming the Colombian healthcare model, which frequently fails to provide adequate care and support to countless children and families, instead of offering euthanasia as a solution. Healthcare professionals should "exhaust all available options" before considering euthanasia. Therefore, it is imperative to provide sufficient and appropriate palliative care in a timely manner.
Representative of the Colombian Foundation of Ethics and Bioethics FUCEB	The proposal would require Doctors to forsake their ethical obligation to uphold life, which is not a matter of personal belief, but rather a biological fact of existence, i.e. life either exists or does not exist. This is a scientific subject that deserves extended discussion and contemplation, given its utmost importance. "Doctors are caregivers, let us engage in a discussion regarding palliative care" Terminating a life is not therapeutic, and the notion of a dignified and natural death, rather than euthanasia, should be the preferred concept.
Citizen	It is imperative to inquire about the availability of opiates within the country and to evaluate the healthcare system's approach to this matter. He considers there is limited information available for the advancement of palliative care.
Member of the Colombian Association of Palliative Care	Compared to other nations in the region, Colombia's provision of palliative care is not unfavorable. However, the management of pain should not solely be the responsibility of specialists, but rather all healthcare providers. There is a need for improved accessibility to morphine and related medications. Additionally, further training in palliative care, specifically targeting pediatricians, is essential to address specific needs in this field.

Continuation table 2.

Participant/Role	Deliberations
Coordinator of the specialization in Family Law El Rosario University and former Attorney General for the Defense of the Rights of Children, Adolescents and the Family	It is imperative to clearly define the terminology and protocols involved. Distinguishing euthanasia from dying with dignity and recognizing that death is not a right is crucial. The distinction between disability and incapacity must also be made. Subrogation must be assigned to individuals with parental authority, not simply custody. The physician's input, as well as evidence, must be taken into consideration when determining these matters. The situation of children without parents must be specifically addressed. The process of withdrawal must be carried out with a step-by-step approach and ongoing monitoring. It is recommended to establish a committee comprised of a lawyer specializing in childhood and adolescent law. A request for a postponement of the publication of the resolution, with an emphasis on urgency, should be made in order to fully consider and address the various issues and debates that have arisen from the Deliberative dialogue, and to clarify any vague concepts within the legal field.
A lawyer. Magistrate of the Constitutional Court of the Palace of Justice	She provides a justification for her partial dissent from the vote on three of the six orders of judgment T-544 of 2017, citing the following reasons: The judgment originates from a guardianship (hence the "T" prefix), but the matter merits a full court hearing (a type C sentence addressing constitutional issues). The application of subrogated consent ignores the essence of the autonomy upheld by Judgment C-239 of 1997. Despite the recommendation of Ruling C-239 to legislate, it has not been done yet, probably due to opposition from Congress. An order by two magistrates should not dismiss this fact, as it can be perceived as the judiciary overstepping into the domain of the executive and legislative branches. On ethical-legal grounds: The concept of "dignified life" cannot be external, as it may result in a hierarchy of valuation of the dignity of individual lives. Dignity is the same for all people and cannot be classified into degrees or traded as a value. The principle of equality in dignity of life would lead to the notion of a life without suffering or pain through palliative care, as well as the option of refusing treatment.
Child Psychiatrist, Representative of the Colombian Psychiatric Association, Child and Adolescent Psychiatry Committee	The Association lacks a unified stance. The project should clarify whether it refers to the medical subspecialty of Child Psychiatry, Clinical Psychology, or Psychiatry with two years of experience in working with minors. Both Child Psychiatry and Developmental Psychology, with expertise in working with minors, should be included in the scientific-disciplinary committees. The chronological criterion for determining decision-making capacity or awareness of death is inadequate. Providing palliative care is crucial, but it is also important to acknowledge cases where therapeutic zeal, driven by parents or other parties, is present. The criteria for excluding "intellectual disability" is also inadequate, as there are varying degrees and specific cases. The same applies to psychiatric illness, which can change and be treatable (e.g. depression with suicidal ideation). It should be noted that the person with parental authority is not always the caregiver.
Psychologist, PhD in Complex Thought. Expert in Child Psycho-development	The definition of capacity to make decisions or comprehend death among children and adolescents is contingent upon their development and cannot be solely determined by chronological factors. It is recommended that a child developmental psychologist be incorporated into the scientific-disciplinary Committees, instead of a clinical psychologist, in order to fulfill this criterion. It is emphasized that the inclusion of the Colombian Association of Psychology Faculties (ASCOFAPSI) in the deliberation is crucial in order to incorporate the latest advancements in evolutionary psychology theory.
Pediatrician. Representative of the Colombian Society of Pediatrics - Bogotá Region	It is crucial to address the systemic shortcomings of the healthcare system, such as the scarcity of pediatric beds, inadequate and untimely care, and prioritizing profits over the needs of children and adolescents, before considering euthanasia in this population. The unexpected contrast between the ability to respond quickly to extraordinary situations and the sluggishness in addressing ongoing daily issues regarding the quality of care and attention for children and adolescents is surprising.
Social Pediatrician. Representative of the Social Pediatrics Committee of the Latin American Association of Pediatrics (ALAPE)	The inadequate functioning of the healthcare system is causing medical professionals to resort to passive euthanasia in situations where limited resources force them to make difficult decisions between patients. It is imperative to address these routine challenges before considering the exceptional cases that prompt euthanasia.
M.D., Master in Bioethics. PhD in Public Health	Bioethics acknowledges significant moral tensions, including evaluations of quality of life, assessments of suffering, and concepts of euthanasia and orthothanasia. The right to choose palliative care or euthanasia must be acknowledged. Holding additional deliberative dialogues, particularly if they engage a wider range of citizens, parents, children with chronic or terminal illnesses, and/or disabilities, would be beneficial.

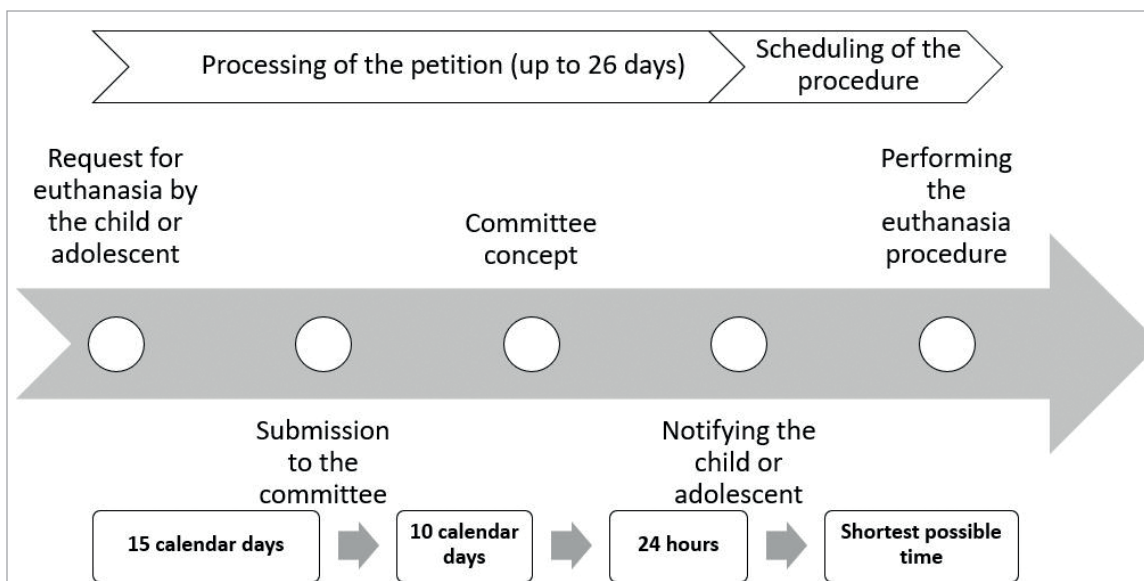


Figure 3. Times contemplated in Resolution 825 of 2018 for the request, analysis and performance of euthanasia in case of a positive concept.

positions not previously presented, several organizations and individuals, including the Colombian Association of Palliative Care, the Colombian Ethics and Bioethics Foundation, the Family Law Specialization from the Universidad del Rosario, and a pro-life citizen leader, submitted additional documents, which were attached to the formal letter sent to the Ministry⁵.

The objective of this study was to examine the alignment between the guiding questions of the investigation, the information present in Resolution 825 of 2018's draft document (which served as the foundation for the Deliberative dialogue), the policy recommendations that emerged from the Deliberative dialogue, and the final version of the resolution that was published post-meeting and is still in effect. The key findings are summarized in Table 1 and Figure 3.

Convergences

In accordance with the provisions of Law 1098 of 2006, which establishes the Code of Childhood and Adolescence²², all relevant parties acknowledge that a child refers to individuals between the ages of 0 and 12 years, while an adolescent is defined as individuals between 12 and 18 years. Additionally, the period between 0 and 6 years is referred to as early childhood.

There is a consensus that human life must be respected and valued, along with its transcendental aspects, such as the health and well-being of patients during the health-disease process. Furthermore, the public emphasizes that "the protection of life in general is a responsibility of the State and the protection of life in particular is a personal, autonomous matter"

In regards to the fundamental right to die with dignity, there is agreement that this encompasses more than just early death or euthanasia. Instead, it encompasses comprehensive care during the end-of-life process, including support from Pediatric Palliative Care. Pediatric Palliative Care is defined in Article 4 of Law 1733 of 2014²³ as appropriate care for patients with a terminal, chronic, degenerative, and irreversible disease, which requires medical, social, and spiritual support, as well as psychological and familial support during illness and bereavement. The aim of palliative care is to improve the patient and their family's quality of life to the greatest extent possible. Palliative medicine upholds life and views death as a natural part of the life cycle.

⁵ From the arguments presented in the four documents submitted by the four participants, only that of the leading pro-life citizen had not been heard during the dialogue session. As indicated in Table 2, the rest of the interventions had already been included in the "results of the deliberation".

The participants concurred that all children and adolescents should have access to a pediatric palliative care team that is sustainable, holistic, family-centered, of high quality, and adequately equipped with resources and services to ensure timely, comprehensive, and appropriate care.

The participating public and the Resolution exhibit agreement regarding the decision-making capacity of children and adolescents. This consensus is rooted in the understanding that children and adolescents' perception of death evolves from intuition to abstraction, and is influenced by factors related to their cognitive and emotional development, as well as the environment and life experiences they encounter, including previous experiences with death.

The Deliberative dialogue resulted in the proposal to consider the ability to recognize oneself and others and effective communication as criteria for making a decision. However, the final version of the Resolution omitted the terms "competence and capacity" and the paragraph from the draft document of the Resolution stating: "when euthanasia is requested for children and adolescents, it is a *sine qua non* condition that the capacity and competence for decision-making in the medical field can be evaluated."

The need to specify exclusions was a point of agreement with regards to individuals with disabilities. Both the final resolution and participating audiences emphasized the importance of referring to the concept of "parental authority" rather than "custody."

Regarding the application of the resolution regulating the right to die with dignity for children and adolescents in the Colombian General Social Security and Health System, the participants in the deliberative dialogue agreed with the list of key actors outlined in Resolution 825 of 2018⁶. They also emphasized the pressing need for further advancements on this issue for children and adolescents through legal precedents and regulations.

Divergencies

The disparities that have been noted are numerous. Members of medical associations and caregivers have expressed their concerns regarding the resolution, which include the following issues: the ambiguity in the definition of certain terms; the age limit for involving children or adolescents in the decision-making process; the responsibilities and duties of the pediatric palliative care team; and the significance of interdisciplinary expertise within the "Scientific and Interdisciplinary Committees for the Right to Die with Dignity," as recommended by the resolution.

Regarding the first issue, the outcome of the Deliberative dialogue highlights the necessity to clarify and accurately define terms and procedures⁷. It is imperative to clearly distinguish between concepts such as euthanasia and dignified death, and parental authority. It was determined that there is a lack of clarity between *euthanasia* and *dignified death*, as they are interchangeably referred to in the Resolution. For instance, the Resolution mentions guaranteeing the right to die with dignity through Euthanasia.

It is noteworthy that after comparing the draft resolution, which served as the basis for the Deliberative dialogue, with the final issued Resolution, the latter has shifted the title of "withdrawal" from the "procedures" section to the chapter of "final provisions," without clearly outlining the process, steps, or monitoring mechanism for its implementation by the relevant parties or institutions.

In regards to the understanding of death based on the developmental age of the children and adolescents, the Resolution depicts the 0 to 3 year range as a period in which death is

⁶ The Colombian Health System (SGSSS) is organized through the Health Benefit Plan Administration Entities (EAPB), formerly known as Health Provider Entities (EPS), which manage health funding and ensure access to the Health Benefit Plan. The Health Provider Institutions (IPS), consisting of both public and private facilities, provide health services to citizens, including health centers, clinics, and hospitals. Users can be categorized as follows: those in need of assistance due to economic difficulties or inability to pay receive state-funded services, those who can afford to pay for their health insurance through salaried or independent work are under the contributory regime, the impoverished and vulnerable population receive subsidized services paid for by contributory regime users, those connected to the teaching profession of basic education teachers, the Armed Forces and National Police, Ecopetrol, or public universities fall under special regimes, and users of complementary health plans make additional voluntary payments for extra services beyond the mandatory health plan coverage.

⁷ On this point, it is also noted that after comparing the draft resolution - on which the Deliberative Dialogue was held- and the final Resolution document issued, the latter transfers the title of "withdrawal" from the "procedures" section, placing it in the "final provisions" chapter, without clearly specifying the route or the steps for its actual development, execution and follow-up by the parties involved or the institutions involved.

Table 3. Glossary of terms

Scientific - Interdisciplinary Committees for the Right to Die with Dignity	Initially, the right to die with dignity was regulated by Resolution 1216 of 2015. Later, the scientific-interdisciplinary committees were included as a crucial component in Resolution 825 of 2018. These committees must comprise of a physician specializing in the patient's pathology, separate from the treating physician; a lawyer; a psychiatrist or clinical psychologist; and, if necessary, additional experts in related fields such as Medicine, Law, and Psychology ¹ .
Custody	Refers to having physical control, direct personal care and attention of a child or adolescent. This is a right of children and a responsibility of parents or legal guardians ³⁰ .
Ministry of Health and Social Protection	The public entity responsible for directing the operation of the health social security system in Colombia is tasked with formulating policies, plans, and programs, and fostering coordination among health actors to enhance the quality, timeliness, and accessibility of health services ²⁷ .
Paternal authority	The set of rights recognized by the law to parents over their minor children encompasses administration of assets and legal representation. Parental authority does not necessarily entail physical custody of the minor, and a parent who does not have custody may still exercise such authority unless restricted or suspended by a court order ³¹ .
National Superintendence of Health	The regulatory agency responsible for overseeing, examining, and regulating the implementation of the Colombian General System of Social Security in health, with the aim of safeguarding the rights of its beneficiaries ²⁸ .
Tutelage	A legal mechanism that provides any individual the opportunity to approach the judicial authorities for immediate protection of their basic rights in cases where these rights are violated or threatened by the actions or inactions of any public authority or individuals, as specified by the law ²⁹ .

neither real nor formal. Additionally, the period for logical thinking is extended by one year on both ends of the range stated in the draft (7-11 years), finally setting the milestone for this development at between 6 and 12 years of age. Although this range is acknowledged as the stage at which children and adolescents form cause-and-effect relationships, the decision-making section does not sufficiently delve into this matter.

From the perspective of the caregivers, the provisions regarding palliative care are questionable. The absence of mental health care and home care, suboptimal availability of medications, and a lack of information and professional training in pediatrics were noted. Thus, the caregivers emphasized the need to address the structural shortcomings of the Colombian health system, including inadequate training of health professionals, insufficient resources, and poor quality and timeliness of care.

Finally, while the deliberative dialogue recommended the inclusion of professionals with expertise in child psychiatry, developmental psychology, childhood and adolescence, as well as people involved, a facilitator, and a bioethics professional in the committee proposed by the resolution (as detailed in Table 3), the Final Resolution only includes the participation of a psychiatrist, pediatrician, and lawyer in decision-making, eliminating the inclusion of the psychologist and disregarding the rest of the suggested actors.

Discussion

With the aim of promoting democracy - which is defined as a political decision-making process that involves active participation of all individuals who could be affected by the consequences of these decisions - both the Deliberative dialogue and the Citizen Council initiated public discourse regarding the topic of euthanasia^{3,18}.

Returning to the first feminist epistemological contribution, *knowledge from experiences, affects and bodies*, it was central for the deliberative dialogue to include the embodied knowledge of the participants (health professionals, caregivers and citizens), by generating a space conducive to questioning by anyone interested in doing so, without restricting or limiting the contributions to exclusively academic or scientific knowledge. The interventions of the participants contributed to the understanding of the problem of euthanasia, mixing scientific knowledge and their praxis, as well as knowledge derived from personal trajectories and experiences. The Cabildo Ciudadano (Citizen Council) sought to deepen this aspect through longer intervention times and more appropriate scenarios for trans-rational deliberation. It is worth mentioning that the panel of “experiential trainers” of the Cabildo Ciudadano was made up of adults, children and adolescents².

Regarding the second contribution of feminism, which is centered around understanding the perspectives of historically marginalized individuals, the deliberative dialogue created spaces for reflection and engagement among these individuals. However, the absence of significant caregiver participation and the lack of representation of the population under 18 years of age were limitations that required the Cabildo Ciudadano (Citizen Council) to address. The Citizen Council actively sought the involvement of these populations through various methods to ensure their participation and representation.

The significant challenge facing Latin American democracies, particularly in the case of anocratic Colombia²⁴, is to question the traditional forms of political deliberation. Embracing the epistemological value of lived experiences and emotions, and recognizing alternative democratic exercises that incorporate situated knowledge and the perspectives of marginalized groups is a step towards true democracies. Despite the presence of formal democratic institutions and processes, the authoritarian elements of our democracies must be challenged through interdisciplinary and trans-rational approaches, beyond mere formal democratic practices.

Compared to other Latin American nations, Colombia has taken a pioneering step in initiating the discussion on euthanasia for minors by recognizing their right to a dignified death through a specific regulation issued in 2017 and regulated by the Ministry of Health and Social Protection through Resolution 825 of 2018. However, to date, no advancement has been made for children and adolescents in terms of legislation or jurisprudence. Despite the lack of progress, as of 2023, no legislation has been passed by the Congress of the Republic of Colombia to provide clarity on the issue, nor has there been any regulation that provides a viable means to effectively exercise the right to a dignified death for children and adolescents.

Given that the issue of euthanasia extends beyond its procedural aspect and requires a thorough examination of the methods for evaluating life or quality of life in terminal situations, it is imperative to engage in exercises similar to the one proposed.

The deliberative exercise conducted a week prior to the release of the resolution facilitated the collection of perspectives and tensions expressed by each participating party, so that the Ministry of Health and Social Protection could consider and incorporate them into the official document's supporting argument. The deliberative dialogue enabled the creation of a shared understanding of the problem, highlighting the most controversial issues and differing opinions regarding decision-making regarding the procedure, chronological age, its impact on human development, and particularly the tension surrounding the responsibility of protecting life.

Although the aim of the deliberative dialogue was not to have a statistically representative sample of the individuals interested and directly affected by the topic at hand, it was notable that there was a higher number and diversity of attendees compared to the limited participation in the public consultation held by the Ministry of Health and Social Protection regarding the draft resolution.

Despite the significance of the research findings, they were not embraced by the Ministry of Health and Social Protection, which demonstrated limited political will and interest in both the Deliberative dialogue and the Cabildo Ciudadano (Citizen Council). This rejection is believed to stem from a divide between academia and the public sector and the limited

recognition given to subaltern, experiential, and transrational knowledge¹⁹ as well as the public management model and elements of the political culture of the country, such as the tendency to discontinue support for strategies established by prior governments⁵.

Conclusions

Based on the findings of this research, it is suggested that the use of Deliberative dialogues should be considered as an essential aspect in the planning, formation, implementation, and evaluation of health policies in Latin America. This would involve promoting partnerships between academic, political, and civil society organizations, and promoting open public discussion on health-related topics, which due to their complexity and emerging nature, require a diverse range of approaches, methodologies, and perspectives.

Therefore, this research highlights the importance of enhancing social engagement in health and corresponding homonymous national policies^{2,25}. This would lead to greater fairness in the allocation of political power and the creation of opportunities for citizens and non-scientific knowledge to be heard and taken into account. Topics such as euthanasia, abortion, financing of healthcare systems, and mental health issues present ideal circumstances for promoting Deliberative dialogues, which allow for the recognition of common and differing viewpoints among the state, private sector, unions, experts, and the general public.

Finally, the study highlights three main limitations. Firstly, the sample size is limited in terms of representation of religious groups, advocates for the right to die with dignity, and groups of children and adolescents. Secondly, there was a low turnout of non-religious participants, and their contributions were limited due to time constraints. Lastly, participants were not given enough time to provide written documents that could further elaborate on their positions, resulting in a limited number of documents submitted, with one of them not being representative of the discussion.

Given the limitations mentioned, it is proposed to enhance the deliberative dialogue methodology in future replications. This can be achieved by incorporating an ethnographic approach with a broader scope in terms of time and scope, either in one session or several. Additionally, participants should be informed in advance of the requirement to submit a document summarizing their position, which should reflect the discussion in which they took part. Furthermore, it is suggested to consider using the Cabildo Ciudadano (Citizen Council) method, which is derived from the deliberative dialogue, when appropriate. The Citizen Council methodology has a comprehensive guide that includes transrational knowledge, experiential trainers, subordinates and caregivers, as well as specific provisions for individuals under 18 years of age to facilitate their participation in the deliberation. Other notable strategies include incorporating art-based critical research tools^{2,19,26}.

Given these considerations, it may be suggested that the Deliberative dialogue could serve as a cost-effective alternative or supplement to traditional methods used in the development of guidelines or ministerial resolutions, such as expert consensus, Delphi groups, and public consultations. Meanwhile, the Cabildo Ciudadano (Citizen Council) should be employed in instances where conditions permit it, particularly in terms of adequate allocation of resources in terms of time, personnel, and funds. Furthermore, the use of the Citizen Council should be prioritized in scenarios where the goal is not only to enhance social participation in health, but also to foster deliberative values among citizens through training processes³.

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