

## Medicalization of death and palliative care

*A medicalização da morte e os cuidados paliativos*

*La medicalización de la muerte y los cuidados paliativos*

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### ABSTRACT

**Objective:** to reflect on the historical process of the medicalization of death, and on how palliative care can modify this scenario. **Content:** the starting point was the discussion of how the process of medicalization of society and death has occurred over the centuries, then to examine the palliative care proposal, and discuss how this approach can promote the de-medicalization of dying. **Conclusion:** the medicalization of death, a process that has become established over the centuries, gained strength through the hospital-centered model of health care. On the other hand, the palliative care proposal offers the possibility of a paradigm shift towards coexisting with life-threatening diseases and the process of dying, because its aim is to improve individuals' quality of life according to their own priorities by favoring their autonomy. Palliative care can thus promote the de-medicalization of death.

**Descriptors:** Medicalization; palliative care; death; nursing.

### RESUMO

**Objetivo:** refletir sobre o processo histórico da medicalização da morte e como os cuidados paliativos podem modificar esse cenário. **Conteúdo:** o ponto de partida é a discussão de como ocorreu, ao longo dos séculos, o processo de medicalização da sociedade e da morte. É analisada a proposta dos cuidados paliativos, destacando como essa abordagem pode promover a desmedicalização do processo de morte. **Conclusão:** a medicalização da morte é um processo que se consolidou ao longo dos séculos, ganhando força através do modelo hospitalocêntrico de atenção à saúde. Por outro lado, a proposta dos cuidados paliativos se apresenta como uma possibilidade de mudança de paradigma na convivência com uma doença ameaçadora da vida e frente ao processo de morte, uma vez que seu propósito é melhorar a qualidade de vida do indivíduo de acordo com as suas prioridades, valorizando a sua autonomia. O cuidado paliativo pode ser promotor da desmedicalização da morte.

**Descritores:** Medicalização; cuidados paliativos; morte; enfermagem.

### RESUMEN

**Objetivo:** reflexionar sobre el proceso histórico de la medicalización de la muerte y cómo los cuidados paliativos pueden modificar ese escenario. **Contenido:** el punto de partida es la discusión de cómo ocurrió, a lo largo de los siglos, el proceso de medicalización de la sociedad y de la muerte. Se analiza la propuesta de los cuidados paliativos, poniendo en relieve cómo ese enfoque puede promover la desmedicalización del proceso de muerte. **Conclusión:** la medicalización de la muerte es un proceso que se ha consolidado a lo largo de los siglos, ganando fuerza a través del modelo hospitalocéntrico de atención a la salud. Por otro lado, la propuesta de los cuidados paliativos se presenta como una posibilidad de cambio de paradigma en la convivencia con una enfermedad amenazadora de la vida y ante el proceso de muerte, una vez que su objetivo es mejorar la calidad de vida del individuo de acuerdo con sus prioridades, valorando su autonomía. El cuidado paliativo puede ser promotor de la desmedicalización de la muerte.

**Descriptor:** Medicalización; cuidados paliativos; muerte; enfermería.

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## INTRODUCTION

The term medicalization emerged in the late 1960s in the field of health sociology to refer to the appropriation of human lifestyles by medicine<sup>1</sup>. It is a process in which the individual and society are handled in all their dimensions by this discipline<sup>2</sup>. Medicalization of society has been reported to have occurred more subtly since the eighteenth century when the capitalist economy developed, and intensified since the twentieth century, especially since the creation of hospitals that contributed to the development of the medicalized culture<sup>3</sup>.

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The hospital-centered model of health care brought to the hospital setting events such as birth and death, hitherto experienced at home. The migration from where death occurs contributed to alter the perception of society and the attitude of individuals towards it<sup>4</sup>, understood as a vital event capable of giving rise to thought and emotion in the dying individual and in their social environment<sup>5</sup>. The removal of the dying from their family members contributed to the development of a demotivation culture to participate in this process and created a strangeness that can be understood from the absence of previous experiences with situations related to finitude, which may cause greater suffering and loneliness to the individual than the experience<sup>4,5</sup>.

On the other hand, the assistance model proposed by the modern hospice movement, discussions and care proposals have emerged aimed at alleviating the suffering of patients with incurable diseases in search for a “good death”. From this perspective, the focus was no longer on the disease, but on the individual who experiences it; death was no longer seen as a defeat<sup>6</sup>. In this context, the purpose of this article was to reflect about the historical process of medicalization of death and how palliative care can change this scenario.

## MEDICALIZATION OF SOCIETY AND DEATH

Death in older societies was a public event, shared by the community, so that people died quite simply, surrounded by family, friends and neighbors, including children<sup>7</sup>. In primitive societies, it was considered to be the result of supernatural intervention, and during the Middle Ages it continued to be seen as the result of divine intervention, thus remaining in the times of the Protestant Reformation and the Catholic Counter-Reformation when the afterlife came to be understood as eternal<sup>8</sup>.

From the Middle Ages to the sixteenth century, individuals were under the aegis of the Church and the Monarchy. The power relations were intended to ensure the maintenance of a system in which these institutions could decide on life and death<sup>9</sup>. In the fifteenth and sixteenth centuries, the doctor answered for two duties: assisting in the healing process and alleviating human suffering by recognizing the impending signs of death<sup>8</sup>.

From the French Revolution and the Illuminist Movement, with the development of the Modern State, the bodies of the individuals became the object of work of various disciplines. Among them is medicine, which intervenes in the human body, in a context of a society in the process of industrialization, where human life was essential in guaranteeing the production and consumption of the produced goods<sup>9</sup>.

The eighteenth century marks the process of medicalization of society in the context of the Industrial Revolution and the development of the capitalist economy. In this scenario, medicine has established several control measures over the individual and the community, contributing to the maintenance of the necessary workforce for the developing economic model. It was necessary to analyze each stage of human life, endemic diseases, mortality, and birth rates, among others<sup>1</sup>.

At that time, the State invested in strategies of social hygiene, disease prevention and cure of convalescents. Being healthy was related to the ability to work, produce and consume<sup>10</sup>. The physician played a fundamental role in health, providing technical assistance to the population and assuming the role of an expert, capable of analyzing and interfering with the behavior of the individuals<sup>11</sup>.

The development of hospitals as therapeutic tools for healing and health recovery in the late eighteenth century significantly influenced the consolidation of the power of medicine and the understanding of the death process. Until then, the hospital was a charity providing assistance to the poor. The cares were performed by religious people, and the purpose was not healing but physical and spiritual assistance to the dying man to whom the last sacrament was to be given<sup>2</sup>.

The hospital setting was able to promote the doctor to the status of a holder of knowledge and powers over human life and death. Medicine has assumed the role of controlling the body, interfering in the ways of life of the subjects and the community, regulating and prescribing the forms of behavior and creating rules that should guide life, including themes such as sexuality, fertility, childbirth, birth, aging and death, which has made society dependent on this knowledge<sup>2</sup>.

Medicalization, as a process by which a natural situation, inherent to the human condition, is understood and treated as medical, has been strengthened from the twentieth century<sup>12</sup>. This process comprises three stages: description of the problem from a medical language; understanding of the problem, from a medical framework, and using a medical approach to solve the problem<sup>13</sup>. This is a controlling phenomenon of society that acts by creating standards of normality and pathological classification<sup>8</sup> where the meanings and significations of the vital processes are read from the medical discourse and practice<sup>3</sup>.

During the twentieth century, especially after World War II, there was an intensification of the medicalization process with the increasing technological development in the health area. These include life-prolonging features such as steel lungs, dialysis devices, defibrillators, and other harsh life-sustaining technologies. The creation of specific services such as intensive care units and the use of an artificial ventilator caused profound changes in the dying process, turning it into an exercise in silence in an attempt to conceal it<sup>14</sup>.

Death is prevented through the control of the body and diseases, resulting in the prolongation of the biological life. This movement is a feature of societies living under the sign of medicine as a discipline that prioritizes knowledge and control of the human body<sup>15</sup>. By acquiring the status of science, medicine legitimates itself socially and the physician is guaranteed the right to intervene in the processes of human life, centralizing the power to determine the boundaries between life and death<sup>16</sup>. Thus, a culture developed among the health professionals that death is an enemy to be defeated and such understanding spread throughout society. Death is no longer a natural phenomenon and is controlled through techniques and procedures for extending biological life that not infrequently cause increased suffering and may expose the subject to dysthanasia<sup>14</sup>.

### PALLIATIVE CARE AND DE-MEDICALIZATION OF DEATH

In the opposite direction from this medicalizing trend of death, from the 1960s, in Europe there was a growth of social movements in defense of the rights of the patients with claims related to the right to a dignified death, forming the so-called *Modern Hospice Movement*. In England, the cradle of this movement, Cicely Saunders stands out, who founded the first modern *hospice* in 1967, the *St. Christopher Hospice*, institution that continues to treat patients with life-threatening diseases<sup>17</sup>.

This movement reached the United States of America in the 1970s and was also successful in its spreading. Civil organizations were founded in this decade claiming the right to a dignified death and broadening the discussion on the care of patients with incurable diseases. In the following decades, this discussion was widespread in several countries, including Brazil, which in 1996 inaugurated the first palliative care service in Rio de Janeiro at the National Cancer Institute (*Instituto Nacional de Câncer, INCA*).<sup>17</sup>

It should be noted here that the first definition for palliative cares proposed by the World Health Organization (WHO) dates from 1990 and was reviewed in 2002. According to this latest publication,

“Palliative care is an approach that promotes the quality of life of patients and their families facing life-threatening diseases through the prevention and alleviation of suffering. It requires early identification, impeccable assessment and treatment of pain and other physical, psychosocial and spiritual problems”<sup>18:84</sup>.

Thus, we can understand that the proposal of palliative care presents itself as a possibility for a paradigm shift in living with a life threatening disease or condition and facing the death process. In this model, the effort is to improve the quality of life according to the individual's own priorities, valuing the autonomy of the citizen subject who is encouraged to decide whether or not to accept treatments and interventions, including the way they want to live and die. The purpose is to minimize human suffering as much as possible.

In 2018, the *International Association for Hospice & Palliative Care* published a consensus-based definition of palliative care herein transcribed: 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. Its purpose is to improve the quality of life of patients, family members and caregivers<sup>19</sup>.

It is, therefore, an approach that contemplates the totality of the human being in its biological, psychic, social and spiritual dimensions. To this end, it is presented as a care modality promoted by a multidisciplinary team capable of acting, preferably, in an interdisciplinary manner from the diagnosis of a life-limiting disease still in conjunction with controlling disease management when possible.

Seeking to detail the structuring basis of palliative care, the WHO described the principles that underlie this approach, namely: promotes relief from unpleasant symptoms; affirms life and regards death as a natural process, without the intention of accelerating or postponing it; integrates psychosocial and spiritual aspects in patient and family/caregiver care; acts in a multidisciplinary manner; aiming to improve the quality of life and positively influence the course of the disease; provides a support system where the patient can live as actively as possible until the moment of death (considering the limitations imposed by the disease); assists relatives during patient's illness and after death with bereavement follow-up<sup>18</sup>.

All these principles seem to point to palliative care as a proposal that surpasses the biologist and technocratic model of health care and, therefore, has the potential to promote the de-medicalization of death. De-medicalization does not mean excluding the medical professional who is an integral part of the health team, but eliminating clinical-medical reasoning as the only possible understanding of the health-disease process and the phenomenon of death<sup>20</sup>.

De-medicalization is linked to the appreciation of feelings and identity, as well as to the empowerment of each individual in the health context with encouragement of their autonomy<sup>21</sup>. It contrasts the reductionist view of medicalization that dissociates the subject from his social, economic, and cultural context<sup>22</sup>. Thus, de-medicalizing the death process concerns the provision of adequate care from the point of view of the subject who experiences a life-limiting disease and, therefore, needs care, understanding that they are biographical beings inserted in a socio-cultural context and that they must have secured their rights as a citizen, especially the right to dignity. In addition to the physical demands of the diseased body, many others of a psychic, social and spiritual nature need to be welcomed by the staff and worked with the patient and their family so that, effectively, the suffering is mitigated and the best quality of life possible gets promoted.

For this to become a reality, the health professionals in the various disciplines involved in care need to understand the process of illness and death beyond the biological scope, overcoming the biomedical model of health care and adopting an antitechnocratic attitude<sup>23</sup>. Only in this way they will be able to approach the individuals who experience their finitude and to assist them in this process according to their needs, contributing to the reduction of their suffering.

## CONCLUSION

The medicalization of society and the situations inherent in human life, including those that for centuries have been considered natural, has centered several decisions on the medical science, especially those pertaining to the process of death. Thus, the subject's loss of autonomy was verified, distancing them from what they might consider as a good death.

The hospital-centered model of health care caused death to migrate from the community to the hospitals, distancing those who experience their terminality from their family and social apparatus. Not infrequently, people die alone or in intensive care, under disproportionate measures to prolong life and human suffering.

For the palliative care professionals, death should not be hidden, but shared socially. Contrary to what has been designated as the expropriation of one's own death, one of the purposes of palliative care is to provide a support system that enables the individual to live the best way possible until the moment of his death, ensuring the dignity of living and dying. In this sense, this approach respects and stimulates human autonomy, articulating the bioethical principles with the individual demands. For this to be possible, the health team should develop skills and competencies to implement the principles of palliative care and promote the de-medicalization of the death process.

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