

## ESTUDO TEÓRICO

**In defense of society: the invention of palliative care and the production of subjectivities\***

**En defensa de la sociedad: la invención de los cuidados paliativos y la producción de subjetividades**

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### ABSTRACT

This article is a theoretical reflection that is part of a study named *Em Defesa da Sociedade: a invenção dos Cuidados Paliativos* (In Defense of Society: the invention of Palliative Care). In order to articulate this discussion, we used the 2007 edition of the Palliative Care Manual published by the World Health Organization (WHO), as we understand it is part of a body of work capable of producing subjectivities and ruling conduct. In this sense, we intend to understand how the discourses on palliative care are associated and promote the invention of a **new** subject that would work as a bio-political strategy in order to defend society. Based on the textual analysis of the discourse presented in the manual, with the help of the Cultural Studies framework and inspired by the works of Michel Foucault, we present one of the possible meanings derived from the readings of the WHO Guide. Thus, we observe the (re)organization and (re)invention of a subject that invests in the subjectivity of individuals and constitutes an actual framework that regulates and rules the population.

**Descriptors:** Palliative care; Health Policy; Government; Nursing

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## RESUMEN

Reflexión teórica que forma parte de un estudio denominado *En Defensa de la Sociedad: la invención de los Cuidados Paliativos*. Para articular la discusión, utilizamos el manual de Cuidados Paliativos, publicado en 2007 por la Organización Mundial de la Salud (OMS), entendiéndolo como parte de un artefacto capaz de producir subjetividades y gobernar conductas. En tal sentido, pretendemos conocer el modo en el que los discursos sobre Cuidados Paliativos se articulan y generan la invención de una **nueva** disciplina que funciona como estrategia biopolítica para la defensa social. A partir del análisis textual del discurso instituido por el manual, con ayuda del referencial teórico de Estudios Culturales y bajo inspiración de escritos de Michel Foucault, articulamos una posible lectura de la guía. Así, observamos la (re)organización y la (re)invención de una disciplina que invierten en la subjetividad de los individuos, constituyendo aparatos de verdad que regulan y gobiernan la población.

**Descriptores:** Cuidados paliativos; Política de Salud; Gobierno; Enfermería

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## THE BIRTH OF BIOPOLITICS

What do we need to defend ourselves from? Put another way, what are we afraid of? *Fear is the name we give to our uncertainty: our ignorance of the threat and what must be done*<sup>(1)</sup>. We believe that simply asking what our fear is would not justify this study; it is perhaps more necessary to ask: what threatens us as a species, threatens our very existence? Death, in addition to engendering fear, is the ultimate threat to life. We do not defend ourselves from the fear of death, but from the threat of dying. We could also ask: where does the concept of invention come from? Generally, the need for an invention comes from the identification of an unmet need or a discomfort. Based on this discomfort or recognized need, or on the need for an alternative, we are able to find our purpose and mobilize, making the invention feasible. Therefore, in order to understand the way an invention is presented to society it is necessary to point out that, previously, smaller inventions were necessary. Thus, at a certain moment, these smaller inventions merge and form another object, apparently of greater worth or value, to which it is necessary to attribute a name and a **pseudo-owner**. In order to propagate this invention, it must acquire value and status and be socially accepted, opening precedents for subjectivities and imposing new rules on the game of social operation<sup>(2)</sup>.

Whenever we read literature considered to be scientific, we immediately want to know: who has the right to say these words? Who invented or authored this concept? The principles of authorship work as the control and registration of produced truths and grant powers to those who make certain discourses<sup>(3)</sup>. In this context, we could ask, who invented palliative care? However, our intention is not to answer this question, but to look at palliative care as a body of knowledge that arises as an alternative proposal to think about the care provided to patients outside of the possibility of cure. Therefore, our objective is to learn how the discourses regarding palliative care – transmitted by the Palliative Care Guide, published in 2007 by the World Health Organization (WHO) – were articulated and invent a **new** discipline, producing a different rationality, building instruments of truth that subjectify and govern caregivers, patients, families, health professionals and administrators. Thus, studying the discursive formation of palliative care, outlined in the WHO guide, allows us to observe the way this knowledge circulates and how it assumes an identity, capturing subjects and configuring what we could call a modern invention.

## THE THEORY AND THE INSTITUTION OF KNOWLEDGE

By investigating the metaphors involving cancer, we come across the conceptions of this disease as a cruel, secret, untreatable and merciless invader, which acts slowly and treacherously. Even if cancer does not always cause degeneration of the body, cause pain or lead to death, this manner of characterizing the disease is widespread. Thus, the thought process that equates cancer to death is still broadly prevalent<sup>(4)</sup>.

If we understand death not only as a biological process, but also as a historical-cultural process, we come to realize that the way we think of this process is related to the forms subjectified by certain discourses. Although the biology of birth, youth, disease, maturity, aging and death are common to all living beings, death is only a problem for human beings. This is because we are aware that it exists and that it threatens our existence. In the past, both births and deaths were characterized as public and social facts rather than private, but through the civilizing process the problems changed and so did the manner in which subjects managed them<sup>(5)</sup>.

The technical and scientific knowledge prior to the XX century characterized medicine as predominantly palliative, aimed at the relief of suffering and at treatments that would improve quality of life<sup>(6)</sup>. The technological developments that began to take place more intensely as of the middle of the last century transformed subjects into healthcare consumers, leading to the development of specialties and medical care that not only aimed at relieving suffering, but at curing illness. Therefore, given the use of technology and medical interventionism within hospital institutions, medicine became fascinated with the possibility of extending and controlling life, thus delaying death<sup>(6)</sup>. The discussions regarding death in the hospital environment became stronger, more vocal and more frequent at the end of the 90's, in the XX century, when discourses regarding a new care modality, which appeared as a reaction to technical medicine, began to circulate, composing the knowledge that would aim at placing death under another discourse regime: palliative care. At that moment, a change began to take place in the formation of the propositions regarding death and dying, as well as in the way they would be accepted as **truth**, constituting the body of knowledge regarding palliative care as simply another way of looking at and managing death. This care philosophy is described as having its origins in the United Kingdom in the 60's, with the establishment of the St. Christopher Hospice in London by the physician, nurse and social worker Cicely Saunders<sup>(6)</sup>. The foundation of this hospice is generally associated with the birth of palliative care.

Aimed at organizing a body of knowledge focused on providing more humanized care in the period preceding death, Saunders created the hospice philosophy, a therapeutic proposal that would forgo the current technical and biomedical care which would be associated with this model<sup>(7)</sup>. This rupture between *modern death* and *post-modern death* did not have as its objective to release subjects from a silent and hidden death, but to place death within a new order of discourse, submitted to other devices of power and knowledge, modifying care practices and (re)producing subjects<sup>(8)</sup>.

## THE STUDY HERMENEUTICS

The methodological trajectory determines the path to be taken. Why do we choose to take certain roads instead of others? Certainly, the choice of study method is not made at random; it is an informed choice we make because we believe that in following a certain path, we will be able to develop the proposed reflections. Method, in this study, is understood as something more flexible, as a form of interrogation, as one of many possible forms of thought and analysis.

In order to meet this objective, we performed a textual analysis related to the field of cultural studies, especially the post-structuralist perspective of Foucaultian inspiration. The use of Foucaultian inspiration involves admitting that it is only possible to use this author when the objective is not to formulate concepts or identify pre-existing and hidden truths awaiting discovery, but when the objective is to examine documents to determine the concatenation of events in certain spaces, associated with certain stories<sup>(9)</sup>. Textual analyses contribute to the comprehension of phenomena and laws that govern the production of discourses at a particular time, showing the different meanings associated with the production of subjects. This type of analysis treats the different spaces of the contemporaneous world as producers of pedagogies; in other words, we are constituted by television, newspapers, books, photos, guides, etc<sup>(10)</sup>. Therefore, we have created a hypothesis of reading the World Health Organization's guide on palliative care, which is part of the series Cancer Control: Knowledge into Action: WHO Guide for Effective Programmes<sup>(11)</sup>. This guide, published in 2007, can be found in English on the WHO website on the Internet. In order to execute the analysis, it was necessary to translate the guide into Portuguese. This translation was performed by a bachelor of languages and validated by a health professional with knowledge of the language. As the researchers and authors of this study, we take over the responsibility for the translations made.

In this context, we proposed to use the instruments provided by the referential to travel through the guide's propositions, performing an interested reading of the texts; in other words, (...) *it involves learning what may be useful and what may be disposed of or rejected*<sup>(12)</sup>. Therefore, we have used some of the tools and theorizations of Michel Foucault, who made this way of thought and analysis viable.

## PRODUCING SUBJECTIVITIES

If it were possible to analyze Western society using the different technologies of power developed throughout Foucault's work, we could mention three different forms of governmentalities: sovereignty (which would be a governmentality of justice), disciplinarity (which would be an administrative governmentality) and governmentality (which would be a governmental governmentality)<sup>(13)</sup>. We cannot understand these three types of governmentalities as one substituting for the other, but as a triangle whose points are formed by sovereignty, discipline and governmental management, which makes population appear as a datum, an object of intervention<sup>(13)</sup>.

In a society of governmentality the environment is shaped in relation to the events, there is the regulation of the elements and they are become normalized; in other words, normalities are observed so that the norm is later produced. The focus is on the collective, starting with the collective and moving to the individual, and the population becomes a datum dependent on a series of variables, a collective subject. It is necessary to understand that *security is a way of making the old armatures of law and discipline function in addition to the specific mechanisms of security*<sup>(13)</sup>. Thus, governmentality, in the society of security, organizes the different technologies of power in its machinery for the preservation of life, constituting subjects.

The biopolitics of WHO's palliative care guide may be seen as a discourse that attempts to determine and define a field of knowledge. In order to do so, it defines regulations, produces subjectivities, determines certain fields of actions and behaviors, (re)invents this knowledge and defines positions of subjects to patients, families, health professionals and others, governing their lives and aimed at protecting the life of the population. In this context, the guide establishes how the teams that are going to provide care to patients in palliative care must be formed, as well as the actions of each member, suggesting that these work groups must be multidisciplinary and that each discipline will have a specific field of action, performing a certain role with well-defined actions. It highlights the importance of the teams to be integrated within the community and to be composed of community leaders, health agents, family members, caregivers, spiritual counselors, volunteers and health professionals, including physicians, nurses, psychologists, social workers and pharmacists. Therefore, each

member of the team would occupy a specific position so that, when united, they would form the necessary network for the existence of palliative care. In order to define the different positions of the subjects, the WHO determines the actions of the members of this team and dictates what must be done to occupy such positions. In order to understand the way these propositions are subjectified, constituting what we are, it is necessary to observe, for instance, the way the guide projects physicians and nurses, determining their behaviors and constituting them.

According to the guide, physicians play a crucial role, since they need to have adequate knowledge regarding general medicine, pain control and symptoms in order to manage the diseases of the patients, which at times would place them face to face with dilemmas regarding treatment. Moreover, these professionals could take over the coordination of the palliative care teams, playing an important educational role<sup>(11)</sup>. This proposition may be observed in the following excerpt:

*Physicians play a crucial role in interdisciplinary palliative care. They must be competent in general medicine, competent in control of pain and other symptoms (...). They may also be responsible for leading the interdisciplinary teams. They clearly play an important educational role<sup>(11)</sup>.*

According to the guide, nurses would be the professionals who spend most of the time in contact with the patients and their families, being more aware of the context in which they live and assisting in alleviating suffering when the disease reaches advanced stages. Also according to the guide, it would be substantially important for these professionals to provide physical and emotional support, to act in the management of symptoms and in the education of the patients and their families. In addition, it would be the responsibility of the nurses, when participating in primary care, to supervise and train community leaders, caregivers, family members and volunteers. The WHO suggests that nurses may manage teams whenever the number of physicians is insufficient, and in this case they would require special training<sup>(13)</sup>. It is possible to observe these propositions in the section below:

*The nurse is the team member who will typically have the greatest contact with the patient. This prolonged contact gives the nurse a unique opportunity to know the patient and the caregivers (...), and to assist the patient to cope with the effects of advancing disease. The nurse's expertise in providing physical and emotional care to the patient, symptom management, patient and family education, and in organizing the patient's environment to minimize loss of control, is critical to palliative care. Nurses are able to work closely with patients and families to make appropriate referrals to other disciplines and health-care services. In some settings, where the number of doctors is small, nurses may lead the multidisciplinary team and be responsible for the provision of all aspects of palliative care. In such settings, nurses need specialist training that is appropriate to the cultural and economic circumstances in which they work<sup>(11)</sup>.*

It is understood that these characteristics attributed to the physician and the nurse are associated with questions of gender, professional practice and to the meanings culturally and historically built and attributed to the different professionals. The physician – a professional most of the time represented by the male gender – emerges as a powerful being with superiority in relation to the professionals considered to be typically female, such as nurses, although changes have been occurring in these scenarios. He would be the professional with the *power* to cure, prescribing treatments and making decisions regarding the paths taken in the life and death of the patient, disqualifying and turning care practices into health, apparently subordinated to his command, configuring a gender-class asymmetry<sup>(14)</sup>. The nurses, who organize their practices based on sacred orders, would perform activities culturally considered to be *naturally* female – such as cleaning, care and nutrition, among others – because this professional was born in association with the figure of the woman-mother, detainer of typically female knowledge regarding health and care practices who becomes a professional and establishes work relations in a male-physician universe<sup>(14-15)</sup>. Therefore, it is the nurse's duty to assume a range of responsibilities designed to meet the basic human needs, including covering possible deficiencies of other services and professionals involved in

the healthcare process, answering to all types of situations regarding the patient<sup>(16)</sup>. Thus, in the excerpt extracted from the guide, there are functions in the nurse's activities that seem to be the responsibility of other professionals. There would be a differentiation between the physician's private activities and all others, which could be performed by the nurse when not performed by specialist professionals. In this context, in a politics directed towards healthcare and focused on the patient's comfort, the nurses become essential, working as the link that would connect and articulate other professionals and practices. However, it is interesting to observe that, even being a discipline that focuses on palliative care instead of the curative treatment of disease, these professionals are still in positions of inequality when compared to physicians, disqualifying their professional practice

It is possible to highlight that, in general terms, in the curriculum of the faculties of medicine, we have not found disciplines that prepare these professionals for administrative positions, whereas in nursing schools these disciplines are part of the professional education, considering that the nurse is prepared to lead a group of professionals who will be under her supervision. It is possible to observe how these professions carry historical and culturally produced ideals, which have been maintained even in present times, establishing that the nurse must be subordinate to the physician, as if it were possible to hierarchize professions that act in completely different realms of actions. This fact may be related to the manner in which nursing emerged as a profession, within the hospital environment to assure the continuous surveillance and exam of the patients, since physicians would not be able to do this. Therefore, we can observe how culture produces positions of subjects and reproduces ways of being either a physician or a nurse, a man or a woman, which are based on a discursive network, produced and articulated historically and culturally.

Based on this proposition that designates the nurse as a subject, it is possible to look at this professional using the logic of the pastoral power proposed by Foucault. The pastorate was introduced to the Western world by the Christian church as an individualizing power, which would be practiced by the pastor towards his flock. Thus, nursing is designed in this technology of power to perform its activities in the conduction of the flock (patients). The nurse or pastor would be responsible for gathering, guiding, leading and watching the flock, assuring their salvation and their lives. It would also be the responsibility of the nurse or pastor to offer individual attention to each member of the flock and to protect permanently the lives of each and every one of the them, helping them achieve their destiny<sup>(17)</sup>. It is productive to compare the nurse and her activities in the provision of health care, especially the care activities proposed by the WHO's guide, with pastoral power, because we realize this technology of power goes beyond the routine of typical nursing work. The pastor must be able to handle not only her sheep, but also their actions and everything that happens to them, meeting the needs of all of them individually without neglecting the group. What else but pastoral power could be likened to the daily routine of nursing care, especially regarding nursing expertise in palliative care? Therefore, the guide recommends the nurse to be the pastor, to watch over her flock and to govern the environment in which they live. In this scenario, it is necessary to perceive the pastorate as a way of governing human beings; that is, a way for the nurse to govern patients and families, constituting also their positions as subjects, teaching what they are supposed to be like and to do within this discipline of palliative care. According to Foucault, we could think of the pastorate in relation to the flock or, in this case, the nurse in relation to her patients, in the following way: *the theme of keeping watch is important. It brings out two aspects of the pastor's devotedness. (...) He pays attention to them all and scans each one of them. He's got to know his flock as a whole, and in detail. Not only must he know where good pastures are, the seasons' laws and the order of things; he must also know each one's particular needs*<sup>(17)</sup>.

Based on one or the other subject's position, we start to constitute and design other positions that would be involved in the discursive regime of palliative care proposed by the WHO. It is important to remember that subjects are constituted based on discursive arrangements, which promote an identification process, leading them to be interpellated, subjectified and constituted as subjects of a certain type. Therefore, the palliative care discourse, which is supported by integrated and multidisciplinary work, is also reaffirmed by the palliative care guide so that, when considering this field of knowledge, it is possible to remember the

importance of healers, social workers, psychologists, pharmacists, volunteers (subject positions also defined by the guide) and not only physicians and nurses. In order to govern the population, other types of knowledge need to emerge and ally with the already existing knowledge to make a *good* government viable. It seems that in the healthcare arena the professions of physician and nurse became insufficient, making the emergence of other professions necessary, including other discourse regimes that could devote themselves to the government of patients and families. Therefore, the exercise of the population government may take place in a rhizomatic way, in detail, subjectifying and constituting subjects and (re)inventing the regime of truth in palliative care.

## THE GUIDE'S GOVERNMENT

This study had the objective to learn how discourses regarding palliative care, transmitted by the WHO's guide, are articulated and (re)invent a **new** discipline, producing other rationalities, building apparatuses of truth that subjectify and govern us. In this context, the palliative care guide would work as an expertise system aimed at educating, governing and subjectifying the characters involved in this discursive regime. The biopolitics must be able to handle each and every phenomenon that passes through life, without letting anything escape, since they must manage social functioning. Therefore, programs and politics are designed and executed so as to promote the regulation of the population.

Our practices must receive the legitimacy of the science statute in order to have credibility, prestige and validity<sup>(18)</sup>, since *the 'truth' is centered on the form of scientific discourse and the institutions which produce it (...)*<sup>(19)</sup>. In this context, the palliative care discourse, being appropriated and systematized by the WHO, goes through the filter of science and acquires legitimacy to regulate certain practices in health care, minimizing the anxiety of the subjects and their families in facing the end of life, since they aim to assure a certain way of dying. The discourse instituted by the guide may be perceived as a regime of truth that (re)organizes and (re)invents a discipline that invests in the subjectivity of the subjects, constituting certain subject positions.

Therefore, our analyses aimed to look at the way the mechanisms of power imprinted on a culture act in constituting subjects and subjectivities, teaching, controlling and governing us, shaping our bodies and actions, defining fields of knowledge through a discourse that produces truth effects.

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