




Hospice care as humanized end-of-life care

El cuidado hospice como un cuidado humanizado en el final de la vida

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ABSTRACT This study aims to analyze end-of-life care practices carried out at a hospice institution located in the province of Buenos Aires, Argentina. Based on a qualitative research methodology, ethnographic fieldwork was carried out between 2016 and 2020. Fieldwork included participant observation of the day-to-day work of diverse volunteer teams and nursing professionals, which was complemented with informal conversations and two surveys. Additionally, semi-structured interviews with key actors were conducted. The data collected reflect some of the values of hospice care that directly challenge the biomedical model, such as integrality, holism, and respect for the autonomy of the sick person. This article puts forth the hypothesis that care – as a constitutive practice of human interaction – produces and reproduces values that make up the structures of social life. Therefore, analyzing care practices in non-clinical contexts, based on proposals that seek to humanize the context of health care, provides tools to think critically about the values that structure our health system.

KEY WORDS Hospice Care; Palliative Care; Terminal Care; Argentina.

RESUMEN Este trabajo se propone analizar las prácticas de cuidado de personas enfermas en el final de la vida llevadas a cabo en el contexto de una institución hospice ubicada en la provincia de Buenos Aires, Argentina. A partir de una metodología cualitativa de investigación, entre 2016 y 2020 se realizó un trabajo de campo etnográfico, con observación participante en los diversos equipos de voluntarios y personal de enfermería en su labor diaria, complementada con charlas informales y dos encuestas. Adicionalmente, se realizaron entrevistas semiestructuradas con actores claves. Del material recabado, se muestran algunos de los valores sobre los que se sustenta el cuidado hospice y que discuten directamente con el modelo biomédico, tales como la integralidad, el holismo y el respeto por la autonomía de la persona enferma. Como hipótesis, se sostiene que el cuidado, como práctica constitutiva de la interacción humana, produce y reproduce valores que componen el entramado de la vida social. Por tanto, analizar prácticas de cuidado en contextos no clínicos, a partir de propuestas que buscan humanizar el contexto de la atención de la salud, brinda herramientas para pensar críticamente los valores que estructuran nuestro sistema sanitario.

PALABRAS CLAVES Cuidados Paliativos al Final de la Vida; Cuidados Paliativos; Cuidado Terminal; Argentina.

INTRODUCTION

The constitution of modernity in Western societies occurred within the framework of a secularization process that led scientific rationality, based on a positivist epistemology, to become the ultimate legitimizer of the social order.^(1,2) As a consequence of this development, biology became the understanding schema of clinical practice, and biomedicine emerged as a result of the technical efficacy granted by its incorporation into the canons of the scientific method, as a legitimate knowledge concerned with the organic function of human beings.^(3,4,5) Diseases that were considered moral deviations in earlier times, are constructed in modern medicine exclusively as biological deviations.^(6,7,8)

This identification of biomedicine with scientific rationality⁽³⁾ has led to an understanding of the person that split their biological dimension from their subjective experience,^(9,10) focusing on the former to the detriment of the latter. Clinical practice eliminates from the health-disease-care process the understanding of individuals of their situation, in order to prioritize the manifestations of an “objective” organism, interpreted from indices that systematize the information in a quantitative way.^(11,3,12) As a result of this sacrifice of the suffering subjectivity in terms of the objectification of the organic characteristics of the disease – and the diseased person – the cure and care begin to be understood as two differentiated parts of the therapeutic process.^(11,13) The cure would then be defined as the main goal of biomedicine, with care being overshadowed.

In the light of the proliferation of incurable diseases (such as cancer or tuberculosis), this shift towards a cure that is mainly understood in biological terms, caused that people without a therapeutic possibility were abandoned by the health care system.⁽¹⁴⁾ In the post-war context several ethical-political initiatives emerged, both from within or outside the formal health care, which denounced the way that biomedicine treated the dying people. Bioethics,⁽¹⁵⁾ the patient’s rights

movements – mainly focused on requests for euthanasia – and the modern hospice movement⁽¹⁶⁾ were among these initiatives. The focus of the criticism was mainly placed on the growing technification of medicine, which was understood as a loss of its humanistic dimension in favor of scientific knowledge (and categorized as a *dehumanizing* attitude), as well as on the expropriation of death that this technification caused, whereby people ceased to be the owners of their own dying process as a result of the establishment of a doctor-patient relationship described as paternalistic.⁽¹⁷⁾

In the specific case of the modern hospice movement, the main subject matter of this article, a central target of its criticisms of biomedicine was aimed at the way that this discipline understood the clinical practice, mainly in relation to its prioritization of cure over care. Since its modern beginnings in the United Kingdom in the 1960s, the hospice movement attempted to recover the essential value of care in the health system,⁽¹⁶⁾ focusing on the accompaniment of patients suffering from life-threatening diseases, emphasizing the control of symptoms and the understanding of pain as a constitutive dimension of the subjective experience of individuals (which is synthesized in the concept of *total pain* introduced by Cicely Saunders, a pioneer of the movement). Understanding the practices of the health system as *dehumanizing*, in that technical and biological matters prevail over the human and the subjective, this movement activated a demand for humanization of the health system by establishing an end-of-life accompaniment of the dying person, based on a humanist philosophy.

As a way of closing this introduction, I would like to present several historical and conceptual considerations that will enable the reader to understand more accurately the way in which this movement is integrated into the Argentine context. Sometime after its emergence, end-of-life-care, guided by the thoughts of Cicely Saunders, began to spread throughout the United Kingdom, eventually becoming a global movement. Nevertheless, this development was not univocal, as

differences arose based on how the countries around the world adapted this philosophy within their respective national contexts. Moreover, in parallel with its international expansion, the movement went through a professionalization process, with its incorporation into the health care system, which distinguished the philanthropic tradition that gave rise to it (mostly associated with the Christian values of charity and compassion) from the specific technical competencies through which end-of-life care is carried out. The incorporation of the hospice philosophy into the formal health system led to different discussions about the “secularization of the movement,”^(18,19) with the risk of losing its original values – associated with the less scientific components of care, such as spirituality – when faced with a greater technification and specialization of the competencies required in end-of-life care, associated with a specific expertise in the management of pain caused by incurable diseases.⁽²⁰⁾ One of the fundamental distinctions between palliative care – as a medical specialty or subspecialty – and the modern hospice movement stemmed from the abovementioned. Despite emerging from a nucleus of common ideas, which leads to understand both notions as synonyms or parts of the same and univocal development, the relationship between palliative care and the modern hospice movement is always a contingent association, not lacking in tensions and reformulations associated with the cultural context in which they occur.

In this regard, the Argentine case exhibits several interesting specific characteristics. In the first place, palliative care and the hospice movement have two different developmental trajectories in Argentina. While the former arose as a result of the initiative of anesthesiologist Roberto Wenk and the Prager-Bild Foundation in the 1980s,⁽¹⁾ two Catholic priests, Ángel Rossi and Juan Pablo Contepomi, had a leading role in the creation of the first hospices in Argentina. They were the ones who laid the foundations of the future Argentine Hospice Movement in the 1990s. In the case of Contepomi, his relationship with the hospice philosophy arose from the

contact established with the Irish Sisters of Charity, who had been directly involved in Cicely Saunders’ formation. This relationship had several consequences. One of them has to do with the place that hospices occupy in relation to the health system. Although, in the 1990s some authors highlight a tendency of the movement to incorporate to formal health care in the countries where it developed,^(21,22) in Argentina, the hospice institutions founded in the new millennium, remained outside this movement, operating independently (though in a complementary way), and financially supporting themselves through third party donations. This, along with the search to preserve the value of Christian charity, with which the movement was associated at the time of its inception, has caused hospice institutions to dedicate themselves to the care of the marginalized sectors of society – rather than to palliative care, as it was a national health care plan – and in the last stage of suffering of a life-threatening disease, while palliative care is usually established as an option based on the diagnosis. Moreover, there is also a component that is directly related to the fact that hospices operate outside the formal health system. As they do not have to comply with the international standards of care in which palliative care is framed, they can mainly operate with volunteer staff who are not necessarily professionally trained in health (which does not imply that in the hospices there are no paid nurses or doctors devoted to the technical-pharmacological matters of care).

These points being clarified, I will now analyze some of the fundamentals of hospice care as put forth by its representatives, as well as the care practices conducted in an institution belonging to the hospice movement located in the Province of Buenos Aires, Argentina. The focus will be placed on the way that these discourses and practices transmit several values that constitute the movement proposal for the humanization of health care (generally, partly opposed to the ideological scheme prevailing in the biomedical system).

ANALYSIS METHODOLOGY

The data used to prepare the following sections were obtained from an ethnographic fieldwork conducted in a hospice institution located in the province of Buenos Aires, Argentina, between 2016 and 2020. This study was carried out as part of the research required for the development of my doctoral dissertation, which was funded by a doctoral fellowship from the National Council for Scientific and Technical Research (CONICET), and in which I analyze the concepts of person and dignity in end-of-life care within the framework of the modern hospice movement in Argentina. Participant observation was conducted by constantly accompanying the different teams and nursing staff – the main caregivers in the institution – in their daily work, with the emphasis of the analysis placed on the meanings that these actors ascribe to the care that they provide in the hospice. For this purpose, the observation was supplemented with informal chats held in the everyday context of the institution, in addition to the semi-structured interviews conducted with key actors, such as managers and coordinators of the different sectors. All these instances were recorded through field notes, which were subsequently digitized and coded according to the thematic axes that were more closely connected, based on the logic of the actors in the field, to the idea of hospice care: the need for a comprehensive and holistic care (covering all dimensions of the human) that respects the person's autonomy.

In the first section of the analysis, the information surveyed is based on the reading of the documents prepared by the people who belong to the hospice movement⁽²³⁾ in Argentina, as well as by different researchers who have written about the specific practices implemented in the different institutions.⁽²⁴⁾ In the remaining sections of the analysis, the compiled information was obtained from two surveys aimed at the entire volunteer team, with whom I shared the field work, in the first case and volunteers and nurses in the

second case. The sample included the entire volunteer team and all the nursing staff who worked there. To become eligible for the sample, the surveyed people had to be mainly in charge of care in the institution, and, also, had to be acquainted, to a greater or a lesser extent, with the axes that shape the hospice care philosophy (which will be explained in the following sections).

From a demographic perspective, the analyzed hospice volunteer team is made up of 180 volunteers who are divided into 21 groups of approximately eight volunteers each, with an average age of 53 years and a distribution by gender of 75% of women and 25% of men. More than 80% have completed studies at the tertiary level and 25% have an occupation related to health (psychology, nursing, therapeutic accompaniment, diagnostic imaging, nutrition, surgical instrumentation, dentistry, medicine, podiatry and occupational therapy) or to activities specific to the field of end-of-life care (such as *counseling*, thanatology, accompaniment in mourning and music therapy and personal accompaniment). Although this knowledge can be applied in their day-to-day volunteer work, they are not necessarily expected to do so and they are not paid when this happens. Moreover, the hospice has a nursing team of approximately 12 people – all of whom are women and only one is a man – two doctors, an associate director, a volunteer coordinator and administrative staff. Although the surveys were mainly focused on the volunteers and the nursing staff, during the fieldwork, contact was maintained with all the members of the institution.

In the case of the first survey, 145 responses were received from the 180 people surveyed. It was conducted in mid-2018, and invited the hospice volunteers to reflect on the tools which for them were non-pharmacological care tools – without drug intervention – that they implemented when they cared for a guest (the name that was given to people who are cared for under hospice care standards within the institution). Each one of them prepared a written report that was subsequently compiled, coded and analyzed

using the Atlas.Ti software, taking as analytical axes the ideas of integrality, holism and autonomy related to end-of-life care. A document⁽²⁵⁾ was elaborated based on some conclusions obtained from the final product, whose main objective was to understand the relationship existing between the use of non-pharmacological care tools in individuals suffering from terminal illnesses at the end of life and the development of the person's perception of dignity, based on the concept of *existential/spiritual needs*, elaborated by the Spanish Society of Palliative Care (by its Spanish acronym, SECPAL).⁽²⁶⁾ The preliminary draft of the document was presented at the IX Latin American Congress of Palliative Care held in Santiago de Chile in April 2018 and its final version at the X Argentine Congress of Palliative Care held in Salta, Argentina in October and November 2019.

The second survey, conducted at the beginning of 2019, asked the volunteers and nurses to reflect on what they understood by caring, which was guided by the following topics: caring for oneself, caring for the other and care for the caregivers. The survey was responded by 14 of the 21 groups of volunteers and people from the nursing staff. Each team prepared their responses in writing, which were compiled, coded and analyzed using the Atlas. Ti software, including the same analytic axes as in the first case. So far, this material has given rise to a document for internal use only that systematizes the general considerations about how the individuals in the hospice understand their care practices. All these materials are analyzed along with ethnographic situations surveyed during the fieldwork.

The development of the surveys, the ethnographic fieldwork and the preparation and publication of this document was approved by the directors of the institution, in addition to the consent of all the participants. Although a specific ethical evaluation was not required, this research is framed within the "Guidelines for ethical behavior in the Social Sciences and Humanities" approved by the National Council for Scientific and Technical Research (CONICET).

Hospice care as compassionate and competent care

Broadly speaking, hospice care represents the practice on which the work of hospices, understood as institutions that provide end-of-life care, is built. In the case of the hospice analyzed here, its own website defines it as "a non-profit NGO that provides comprehensive care to the diseased person and their family, placing the emphasis on care understood as "the control of symptoms, and spiritual and emotional support". Both in everyday and institutional language, the people who are part of the movement often use the word hospice with a double meaning: on the one hand, to talk about the specific place where the hospice institution operates (it should be noted that not all hospices have this space) or, on the other hand, highlighting the fact that this is not the only meaning of the word or the most important one, to refer to a specific philosophy of care.⁽²⁷⁾ There is a way of understanding the work of the hospices that is constantly repeated by those who participate in the hospice moment: "*the hospice is where the sick person is*". This phrase synthesizes the need to understand the hospice, rather than as a physical space, as a way of caring that can (and must) be carried out anywhere (several other care modalities that are generally found in all the institutions belonging to this movement stem from this assertion, namely: care in one's own home, care in the sick person's home, and hospital care), as long as this care is based on the cornerstones of the hospice philosophy. In this respect, Isabel Pincemín, a palliative care physician, states that "it is not necessary to have a house to set up a hospice" as it is a "way of caring" that can be provided at home, at a hospital or at the home of the diseased person.⁽²⁷⁾ The latter brings to the fore the three modalities of care which have characterized the movement since its inception and which still now remain as the characteristic features of hospice institutions. The relationship between hospice care and hospice philosophy can be described as follows: it is a particular type of care that is rooted on the foundations of the

philosophy on which the hospice mission as a movement was built.

With the rise of the modern hospice movement in the mid-1960s, the category of care started to take a central role in understanding the health care aimed at the terminally ill. The dehumanization and abandonment suffered by the dying after the Second World War was addressed in terms of the impossibility of biomedicine of understanding the intrinsic limits of a therapeutic approach that, by focusing on the cure of the disease, stopped being concerned about/with the fundamental principle of the medical profession that is constitutive of the Hippocratic oath: to cure, sometimes, to relieve often and to comfort always.^(28,11) This comfort was translated into the need for an increasingly effective approach to control of symptoms – mainly of pain – and the reincorporation of patient care into health care, a practice that began to be viewed as the human pole of an increasingly technical and bureaucratic medicine. Humanizing the end of life would be directly connected with taking care of the sick person, although the person may be beyond any therapeutic possibility (understanding treatment as directly linked to the cure), by relieving the symptoms that cause discomfort and demonstrating, as Cicely Saunders synthesized in her famous phrase “a person’s life matters until the last moment of his or her life”.

However, this incorporation of care, as part of the human pole of medicine, does not replace the technical and specialized nature of the health professionals’ knowledge. On the contrary, the figure of hospice care attempts to synthesize in a common core both parts of clinical care at the end of life. Both in the abovementioned book as well as in different training talks given to the volunteers and nurses who are part of the hospices in Argentina, it is emphasized that hospice care is, above all, a compassionate and competent care. In this respect, Pincemín⁽²⁷⁾ argues that the science pole (referring to what the technological advances have achieved in terms of symptom control) and the compassion and care pole are always in constant tension. The mission of the hospices is, partly, to unite

these two poles to achieve the best science for providing the best care to people, and the best compassionate care, “no one has to die alone.” Moreover, Mazzini,⁽²⁴⁾ who has particularly conducted research on the practice of hospice care in the same institution where I had done fieldwork, defines it as a compassionate and competent care. Competence, he explains, “is manifested in the multiple ways of trying to accompany, relieve and surround with mercy the pain of the *guests* and their families,” while compassion is defined as the “attitude and [...] capacity to feel with the other and put oneself in the shoes of the other.” At the 2017 Annual Meeting of the Argentine Hospice Movement, the coordinator of the volunteer team at one of the participating hospices gave a talk about gratuity and gratitude in the volunteer service. There, she defined hospice care again as compassionate and competent, highlighting that “compassion implies a movement, feeling with the other. Compassion alone is indeed nice; however, it is a lame duck if we are not trained. On the other hand, being an amazing academic [in relation to competence] without having the heart at the service of others is useless.” Hospice care is understood, in these discourses, as a practice that synthesizes the two poles of health care: the competent pole that is technical, professional and implies expert knowledge, and the compassionate pole that is empathic, intrinsic to the capacity of humans to be feel with others.

HOSPICE CARE FROM THE INTERLOCUTORS’ PERSPECTIVE

Beyond these formal definitions of hospice care, there are various meanings associated with the implications of end-of-life care among the volunteers and nurses of the institution in which I worked. Care as a constitutive practice of human interaction produces and reproduces the values on which society is structured^(29,30); therefore, it has the power to confirm or challenge the associations of meaning that characterize the fabric of social

life.^(31,32) The importance of systematically analyzing the meanings associated with hospice care lies in understanding the values underpinning them, while understanding, in turn, how these values create a tension with several tenets of the ideological scheme of the biomedical model (or with the current practices conducted within the health system), in order to establish itself as a proposal for the humanization of health. At the same time, the analysis of non-formal care practices can lead to the development of health care proposals that take into account variables that have been relegated by the current medical system. As a way of presenting the data and, when the words of a volunteer or a nurse are taken literally, the extract will be enclosed in double quotes. If an original sentence needs adjusting to preserve the narrative coherence of the paragraph, it will be enclosed in square brackets.

Comprehensive and holistic care

Much of the understanding of care by the hospice volunteers and nurses is related to the idea, currently incorporated into general clinical care and, particularly in end-of-life care, that a person comprises multiple dimensions that must be approached comprehensively. Caring for or using non-pharmacological care tools, in the hospice staff's opinion is "to attend to all the person's dimensions that may be diseased," or "to address the emotional or social sphere of both the guest and their environment, as disease causes fear, anger, hopelessness, depression and feelings of guilt, among others. In their words, "we try to provide support in all these aspects." Therefore, the understanding of the disease process as a situation that not only affects the body of the person who suffers it – in a purely biological sense – but also their subjective experience, which is usually conceptualized through the psychological and social dimensions and is generally linked to the management of emotions – fear, anger, depression, hopelessness, depression and feelings of guilt – and to the promotion of the diseased person's emotional bonds with their families.

For others, the care provided in the hospice is mostly aimed at "the suffering souls" and not only at "the disease" or "the worn out bodies", thus "the concern is comprehensive, it involves body and soul" and caring implies "accompanying the other physically, psychologically and spiritually." When it comes to understanding hospice care as the comprehensive care of a sick person, it may be noted how, simultaneously, certain dimensions are restricted to the notion of being inherent of non-pharmacological care (such as the social, psychological and spiritual dimensions), while the physical dimension, without losing importance, continues to be understood as the jurisdiction of the nursing staff, which does not mean that the volunteers may continue to mention the existing connections between the physical and non-physical dimensions of human experience. Moreover, the spiritual dimension of care is explicitly expressed here. This dimension is connected to those issues that transcend the sphere of the sensitive, whether or not they are related to the religious sphere. The Catholic nature of most of the hospices is reflected, in turn, in the understanding of care as an action intrinsically linked to the spiritual sphere. Caring is for some of them "to help without pressure" so that the guests "explore their beliefs and accept in the best possible way what they have to endure". In turn, the relationship with the guest is understood as "a channel to allow God to 'work' through us." Although it is often highlighted that there are diverse religious and spiritual beliefs in the hospice and all are respected, it is also emphasized that caring is related to the relief of spiritual suffering through the institutionalized mechanisms of Catholicism – generally the different sacraments – seeking among other things that, if the guest is a Christian, they should be cared for in "reconciliation with God" and "having received the extreme unction of the sick". The scope of the Catholic nature of hospices in Argentina should be explained here. Some of the consequences of the "secularization" of the hospice movement have had an impact on these institutions. One of these effects is their appropriation, in the institutional discourse,

of the distinction established between spirituality, as an experience of the transcendental, and religion, as the institutional framework of that experience.⁽³³⁾ Although the hospices are recognized as institutions of Catholic tradition – which is reflected in the need to have a chaplain and a chapel, and the routine celebration of the Catholic sacraments – they accept and accompany the people of all creeds or beliefs, understanding the spiritual as a search to build the meaning of one's life in connection with oneself, the others and that which is beyond us.

The recognition of the social dimension of care is related, as mentioned above, to the inclusion of the *guest's* family members as part of the care unit. Based on the way the volunteers understand the work they carry out in the institution, this sphere is mainly linked to how the family members are being treated, as they are recognized as a fundamental part of the containment network of the sick person. Being aware of the physical, economic and emotional burden implied in caring for someone who is going through the last stage of a life-threatening disease, the volunteers generally mention the fact that caring is listening, supporting and being attentive to the needs *"of both the guests and their families."* Although caring for the family members is understood in general terms as *"containment"*, on certain occasions the volunteers refer to practical issues that have to do with hospitality, that is, making the other feel comfortable when they visit the sick person. In this sense, they highlight the fact that care has to do with *"offering something to eat or drink to the families"*, or *"pamper them a little,"* or *"listening to them when they are emotionally moved or need to talk."* The volunteer sometimes acts as a bridge between the family member and the sick person, especially in situations in which the distance makes it difficult to visit the sick person on weekdays and, due to this reason, the family member uses the telephone to communicate and find out about how the *guest* is doing. Caring is also to provide containment to the families *"giving them information about the health status of the guests and the different*

stages they are going through, their needs, among others." Finally, directly linked to the care modality known as *home hospice*, the idea of care at the end of life emerges as an attempt to encourage death to occur at home and not in the hospital. In this sense, the idea is that those who *"are reaching the end of their lives, may live that final time at home and with their families,* by providing *"containment and assistance"* so that the family members can organize themselves in relation to this new situation of care.

This comprehensive care of the sick person, on which the hospice care is structured, is expressed based on the caregivers' discourses, in specific practices. Including the family as part of the care unit, which refers to the social dimension of the people, leads, among other things, to the extension and flexibility of visiting hours. The admission of a sick person to the hospice includes a written report prepared by the volunteers, which gives a detailed account of the family situation (with the emphasis generally placed on potentially conflictive family ties). Sometimes, both the nurses or the volunteers assume an active role in maintaining and restoring the family ties that, due to the nature of the disease that often confines the person to bed, have deteriorated over time. From the perspective of the social analyses in clinical settings, all these practices would be aimed at avoiding the person's *social death*, that is, the loss of interpersonal ties due to the reduction of the interaction capacities in social life.^(20,34,35,36) From the institutional logic, this directly challenges the aggravation of this sick person's situation by the biomedical system because the isolation resulting from the typical dynamics of the health care system (such as the restriction of visiting hours or the treatment of the sick people based on their illness and not on the fact of being subjects inserted in a network of interpersonal relationships)⁽¹²⁾ would be added to the decrease in interpersonal capacities due to the physical deterioration caused by the disease.

Both the psychological and spiritual dimensions are also expressed in the care practices carried out in the hospice. The

celebration of various sacraments in the case of the *Catholic guests* or other religious traditions such as Judaism or Buddhism that promote the exercise of spirituality are daily actions that take place in the hospice (in which I had the opportunity to participate). The emotional management, in turn, plays a specific and important role in the meetings in which the care strategies are defined, and, at the same time, there are specific institutional instances, both for the *guests*, their family members and volunteers, in which an attempt is made to provide psychological support (they are coordinated by hospice volunteers with a training in psychology).

All this directly challenges the way in which clinical practice is understood from the institutional logic. It is considered *dehumanizing* to treat the other only in terms of one of their dimensions. The biomedical model is interpreted as a structure in which a person is only understood from its biological organic dimension, as a disease rather than as a person. Keeping a comprehensive and holistic approach to care, a fundamental feature of hospice care, seeks to question this approach, accounting for the multiple facets that exist in the human experience, and trying to develop care practices aimed at pursuing a person's comprehensive well-being (in which, obviously the physical factor is not neglected).

Care and autonomy

Another fundamental factor that comes up in the comments of both the volunteers and the nurses with regard to the implications of care has to do with specific practices aimed at managing the autonomy of *guests* and their families. Although on some occasions this is broadly mentioned, directly linking care to "*promoting autonomy*," the activities specifically directed to this issue are varied and linked to different components associated with the search in the other of the exercise of an autonomous will. In this subsection, I will reconstruct the way in which each of these components are presented and how they relate specifically to the manner in which the

volunteers and nurses understand hospice care.

Going back to the claims that gave rise to the beginning of the modern hospice movement in the mid-1960s, one of the ways in which autonomy in caring for the other is commonly conceptualized has to do with the respect of their will. When the volunteers and the nurses define hospice care, they explicitly mention that what should be prioritized is "*the will of the other, not ours*", thus, the sick person must be cared for "*prioritizing and respecting [their] will*." This respect for the will of the other is usually linked to issues related to the handling of information of the guest's personal history, or, in other words, to their private aspects. Although sometimes care can be understood as a personal and constant accompaniment of the other, the volunteers emphasize the fact that hospice care implies "*respecting their times, their silences, their desire to be left alone or be accompanied*," without trespassing their personal space and respecting their privacy, and fundamentally, always bearing in mind "*when to intervene or [when] not*." This reference to "*the times of the other*" is not fortuitous, and is usually understood as a basic element of care in terms of respect for the autonomy of the sick person. The volunteers explicitly mention how caring is directly related to "*demonstrating the unconditionality of time*," making the guest feel that "*there is no hurry at all*". This is manifested both in practical matters, such as feeding the guest by taking all the necessary time, as well as in the search to respect the time of the other "*to go through the necessary processes to feel well*." This last point shows how hospice care is associated with the elaboration of a "*process*" on the way toward the end of life.

Understanding autonomy as respect for the will of others to act according to their own value schemes (and not to external value schemes imposed on them) requires care to be permeated by an active search for "*getting to know the guests individually*", "*talking to them and interacting about those aspects that distinguish them from others*." The volunteers understand that part of the

management of the autonomy of the sick person is traversed by the recognition of their individuality, allowing them, among other matters, to express aspects of their personal history that they consider essential. Thus, the person is allowed to connect to issues related to their life prior to the deterioration caused by the disease, such as work (if there is an occupation with which they identify themselves), hobbies (some specific type of board game to entertain themselves) or personal wishes (on occasions some guests like to go out to the garden to sunbathe or enjoy the view, which is allowed and encouraged by the institution). Here, there is a direct connection between autonomy and identity that, as shown by Dworkin,⁽³⁷⁾ has to do with the relationship existing between the effective exercise of autonomy and the expression of the self as itself).

When the volunteers are asked about what they understand by caring, some of their most common answers are *“getting to know the guests’ interests”*, *“meeting their food preferences,”* or *“identifying the guests’ tastes and preferences to know the best way to accompany them.”* Hospice care is expressed here as personalized care, in the sense that it seeks to know the specific characteristics of the other’s personal history with the aim of adjusting the accompaniment parameters in terms of what they want and need (the latter refers to the connection existing between recognizing the individuality of the other and respecting their autonomous will). At the same time that these particular aspects of the person are recognized, the volunteers also mention that part of the care provided to the sick person has to do with encouraging them to express themselves: *“preparing the person’s bed with their names and not with a number,”* and *“letting them stick photos or drawings to the room walls”* – both things actually occur – and they make possible to give an identity to a subject that in the institutional discourse has been depersonalized by the biomedical system.

Another aspect where hospice care, as understood by the volunteers, is related to the management of the sick person’s

autonomy, refers to the active promotion of their self-determination. Autonomy can even be understood through the relationship that is established with the other: in a passive role, in the form of respect for the subjects’ will, and, in an active role, as the active search to promote attitudes of self-determination. The latter fact is usually expressed in attitudes such as *“encouraging the guests to bathe, to get up, go to the garden or the street, depending on their possibilities”* or *“promoting autonomy depending on what they can do”* (such as *eating or walking around,”* which shows that care is permeated by the other’s need to do by themselves all the things that they can still do. At the same time, by saying that the actions must be performed in accordance with the guests’ possibilities suggests a recognition of the loss of both cognitive and motor skills that a life-threatening disease generally causes. In turn, this loss of autonomy is usually interpreted as a risk to the integrity of the self, showing again the connections existing between one’s own integrity and the effective exercise of the autonomous will. The encouragement of self-determination in the sick person as a constitutive part of hospice care is expressed, in relation to this loss of capacities as a result of the suffering caused by the disease, in the attempt to get the host to regain certain control over the performance of their daily activities. As the volunteers and nurses sometimes express, this capacity to perform their daily tasks was thought to have been lost due to the state of abandonment to which the sick person is subjected at the end of life in hospitals, not to a “real” loss of motor or cognitive functions. The volunteers state that *“some guests who were admitted after several days of being bedridden in a hospital, are accompanied to the bathroom, to clean themselves with their help, go down to the garden or even, if possible, go for a walk”*, and they mention that *“they had received tracheostomized patients that started to be fed by mouth with great caution and patience.”* Hospice care is described in these interpretations as a care that takes into account the nature of the process involved in the sick person’s loss of autonomy, encouraging the

guest to perform all the activities that they still can carry out by themselves.

The search to implement a care that respects the other's autonomy, not only challenges the sick person's biologization, but also directly gives rise to tensions on the paternalistic values on which, from the hospice logic, the doctor-patient relationship is built in the biomedical system. An ethnographic case⁽³⁸⁾ accurately illustrates this point, which describes a person admitted to the institution with very limited life expectancy, for whom chemotherapy was no longer feasible due to the overall deterioration of his body. However, and against the clinical prognosis, this patient decided to undergo one last chemotherapy round just to live only twenty days more. The reason for his decision was not related to the hope of a cure: his granddaughter was about to be born and, before dying, he wanted to be able to say goodbye to her, which he happily could. More than a case of therapeutic obstinacy, this situation was experienced by the institution as a sign of respect for the autonomy of the sick, prioritizing his or her wishes even beyond the "madness" (as ironically defined by part of the care team) of undergoing another chemotherapy round in the actual patient's condition. This enabled us to realize how, in this helping relationship that characterizes hospice care, the sick person has the power to choose whether or not he or she wants to receive a specific treatment based on the wishes they create in connection with all the dimensions of their personal history, and not only taking

into account aspects related to their biological existence.

FINAL WORDS

The analysis presented here sought to understand the different elements associated with a care practice for people with terminal diseases at the end of their lives that takes place beyond the formal health care system. Taking as fundamental axis the idea that care, as a constitutive part of the interaction among human beings, produces and reproduces values that make up the fabric of social life, I have sought to address some points of the scheme of ideas which underpins hospice care. This is, in principle, a care that is described by those who provide it as a proposal for the humanization of care at the end of life, which is characterized by a comprehensive and holistic nature and respects the autonomy of the sick person. Based on an interpretation of the biomedical model, in which several of its actions are characterized as dehumanizing, the hospice movement seeks to provide a care that incorporates human dimensions that have been relegated by the traditional health system. Analyzing and understanding the multiple ways in which care is presented in non-clinical contexts enables to understand how care can be associated with values that create tensions or challenge the foundations of the rationalism that characterizes biomedicine.

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