

# Health professionals' subjectivation towards end of life and death in home care service

*Subjetivação dos profissionais de saúde no fim da vida e morte no serviço domiciliar*

*Subjetivación de los profesionales de la salud al final de la vida y muerte en el servicio a domicilio*

**Jéssica Siqueira Perboni<sup>1</sup>**

ORCID: 0000-0003-0097-1942

**Stefanie Griebeler Oliveira<sup>1</sup>**

ORCID: 0000-0002-8672-6907

**Franciele Roberta Cordeiro<sup>1</sup>**

ORCID: 0000-0001-6194-5057

<sup>1</sup>Universidade Federal de Pelotas, Pelotas, Rio Grande do Sul, Brazil.

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## Corresponding author:

Jéssica Siqueira Perboni

E-mail: [jehperboni@yahoo.com.br](mailto:jehperboni@yahoo.com.br)



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## ABSTRACT

**Objectives:** to analyze the modes of subjectification of health professionals towards end of life and death in a home care service. **Methods:** this is qualitative research carried out in a home care service at a teaching hospital in southern Brazil, with 12 health professionals. Participant observation and semi-structured interviews were used for data collection, from April to September 2018. Data were analyzed based on Foucault's concept of power and subjectivation. **Results:** professionals are sensitized by moral, spiritual and palliative care discourses, as well as experiences that constitute them subjects who modify their ways of life and professional practice based on the relation with death. **Final Considerations:** the discursive network of palliative care is internalized by professionals, who carry out their practices with behaviors aimed at promoting "a good death".

**Descriptors:** Home Care Services; Health Personnel; Death; Palliative Care; Qualitative Research.

## RESUMO

**Objetivos:** analisar os modos de subjetivação dos profissionais de saúde em relação ao fim da vida e à morte em um serviço de atenção domiciliar. **Métodos:** pesquisa qualitativa, realizada em um serviço de atenção domiciliar em um hospital universitário do sul do Brasil, com 12 profissionais de saúde. Para a coleta de dados, utilizou-se observação participante e entrevistas semiestruturadas, de abril a setembro de 2018. Os dados foram analisados a partir do conceito de poder e subjetivação de Foucault. **Resultados:** os profissionais são sensibilizados pelos discursos morais, espirituais e dos cuidados paliativos, bem como pelas experiências que os constituem sujeitos que modificam seus modos de vida e prática profissional a partir da relação com a morte. **Considerações Finais:** a rede discursiva dos cuidados paliativos é internalizada pelos profissionais, que realizam suas práticas com condutas voltadas à promoção de "uma boa morte".

**Descritores:** Serviços de Assistência Domiciliar; Pessoal de Saúde; Morte; Cuidados Paliativos; Pesquisa Qualitativa.

## RESUMEN

**Objetivos:** analizar los modos de subjetivación de los profesionales de la salud hacia el final de la vida y la muerte en un servicio de atención domiciliar. **Métodos:** investigación cualitativa realizada en un servicio de atención domiciliar en un hospital escuela en el sur de Brasil, con 12 profesionales de la salud. Para la recolección de datos se utilizó la observación participante y entrevistas semiestruturadas, de abril a septiembre de 2018. Los datos fueron analizados a partir del concepto de poder y subjetivación de Foucault. **Resultados:** los profesionales son sensibilizados por discursos morales, espirituales y de cuidados paliativos, así como por vivencias que los constituyen sujetos que modifican sus modos de vida y ejercicio profesional a partir de la relación con la muerte. **Consideraciones Finales:** la red discursiva de los cuidados paliativos es interiorizada por los profesionales, que realizan sus prácticas con conductas encaminadas a promover "una buena muerte".

**Descriptorios:** Servicios de Atención de Salud a Domicilio; Personal de Salud; Muerte; Cuidados Paliativos; Investigación Cualitativa.

## INTRODUCTION

Due to population aging and increased chronic diseases, the topic of death is gaining prominence, especially in the health field, which is financially impacted by these trends<sup>(1)</sup>. Both aging and chronic diseases are considered problems for health systems<sup>(2)</sup>; thus, strategies are developed to manage the end of life stage of people. One is the recommendation that death occurs at home, a modality that consists of a marker of a good death and an indicator of service quality<sup>(1)</sup>. Therefore, it is important to question the way in which the transition of patients undergoing palliative care from hospital to home occurs.

It is important to mention that palliative care is carried out from an interdisciplinary approach centered on patients with an incurable disease and their family, aiming to provide relief from suffering through symptom control, as well as quality of life promotion, valuing their beliefs and values<sup>(3)</sup>. However, palliative care is not exclusively intended for patients who are at the end of life stage, but it especially benefits those who are in this situation, given the intense suffering and severe symptoms that accompany this stage<sup>(4)</sup>.

Political strategies such as home care services and Primary Health Care deal with the end of life of people in their own home, a place that can be seen as having potential for care. These strategies have operated not only to optimize hospital beds and resources but also to use support services for the health system capable of providing a dignified death, with patients close to their family and with maximum comfort<sup>(5)</sup>. Thus, the home care service is considered a biopolitical strategy, according to which care and responsibilities are transferred to patients' families, who are cared for at home, a place that then becomes institutionalized as an extension of the hospital<sup>(6)</sup>.

In Brazil, the return of patients to their home is mentioned in the Home Care Manual, a document that contains guidelines for health professionals regarding care in the home space<sup>(7)</sup>. Moreover, the Palliative Care Manual also reinforces and directs palliative care at home based on guidelines that include priorities for this type of care<sup>(8)</sup>.

Scholars from the 1970s, such as Philippe Ariès and Elizabeth Kübler-Ross, were pioneers in the discussion about the theme of death in the health scenario. They reported inadequate conditions in which death occurred in the hospital, isolated and cold due to excess technology<sup>(9)</sup>, and were concerned with identifying dying people's needs<sup>(10)</sup>.

Faced with contemporary changes regarding the way of seeing and dealing with death, a movement of returning patients to home has been observed, supported by the discourse of humanization of health. According to this discourse, better patient care, with more comfort and adequate care is offered at home<sup>(11)</sup>. Accordingly, home begins to mirror the hospital's logic, incorporating the operation routines necessary to promote care strategies to deal with palliative patients<sup>(12)</sup>. These strategies respond to the logic of governing people's lives, i.e., it deals with biopower, described by Foucault as a power over life, considering the population's variables to also address economic and political issues<sup>(13)</sup>.

Thus, from the history of death in the West, there are different possibilities to signify and ritualize death, then it is worth asking:

faced with such a multiplicity of meanings and behaviors, how do health professionals deal with the death and dying process?

In this study, the term "constitution" is understood in two ways, both from the perspective of philosopher Michel Foucault: the first, from the point of view of objectification, through power relations and dividing practices; the second, from the point of view of subjectification, how the subject relates to discourses. Through objectification, the subject is characterized in relation to others: the insane and the sane, the sick and the healthy, etc<sup>(14)</sup>.

In view of these considerations, the following questions emerge about end of life and death in home care service: how do health professionals who work in home care service behave in relation to these events? How do they relate to the experience of caring for someone at the end of life? How do they make certain decisions and behave on behalf of others? What determines their choices when faced with death?

## OBJECTIVES

To analyze the modes of subjectification of health professionals towards end of life and death in a home care service.

## METHODS

### Ethical aspects

This study complied with Resolution 466 of December 12, 2012 of the Brazilian National Health Council, created by the Ministry of Health<sup>(15)</sup>. This research was approved by a Research Ethics Committee. Participants signed the Informed Consent Form, and anonymity was maintained. They were identified by the letter P (for Professional), followed by a sequential number (P1, P2, P3).

### Study design

This is qualitative methodological research based on Foucault's studies. The Consolidated Criteria for Reporting Qualitative Research (COREQ) was used to guide its construction<sup>(16)</sup>.

### Study setting

The setting was one of the home care service programs of a public university hospital in southern Brazil named Interdisciplinary Home Care Program. The program provides home care entirely by the Unified Health System (*Sistema Único de Saúde*) to oncology patients with a multidisciplinary team and the necessary supplies and equipment for care. A maximum of 20 patients receives home visits, and they are carried out up to twice a day, in morning and afternoon shifts. Patient referrals are filled out on the hospital's website, regardless of whether they are cared for in the region or not.

### Data source

Twelve health professionals were invited to participate in the research, including physicians, nurses, psychologists, nursing technicians and residents in psychology and nursing. No invited professional refused to participate in the study. It is important

to note that this does not cover all the professionals who attend the service.

The criterion for participating in the study was being a health professional who made regular visits to a patient. Health professionals were excluded from the study if they were on any type of leave, or who did not accept a voice recorder use. During data collection, some professionals went on vacation, but returned within the data collection period. Thus, they continued to be observed, and this exclusion criterion was not applied.

It is important to cite information from the researcher who went to the field for data collection, due to the techniques used. The researcher is a nurse and had a master's degree in science at the time of the study. She knew some of the professionals who participated in the study and visited the service before data collection, which allowed her to become familiar with the place and the participants, as well as expressing her interest in conducting the research.

Descriptive and reflective notes were written in a Word® file at the end of each observation. It is noteworthy that the researcher participated in workshops and subjects focused on qualitative research aimed at training for proper data collection.

### Data collection and organization

Data collection techniques included participant observation<sup>(17)</sup> and semi-structured interviews with key informants, selected according to their immersion in the field. A notebook was used to write down the information from participant observation. No type of recorder or audiovisual device was used. Keywords were annotated in front of participants, which was necessary to prevent the researcher from forgetting details. The observation was guided by a script created by the researcher. The main facts/ observations focused on the questions asked to participants, as shown in Chart 1.

**Chart 1** – Main questions/focus/observation/facts in data collection

Facts/observation focuses	Main questions
Relation of professionals with patients and their families as well as between team members (in visits and when the team goes to their homes).	Have you ever had any loss in your family, if so, how was it?
How orientations are carried out.	Tell me about your beliefs. Do you have a religion? Tell me about the first patient death you experienced? (If you don't remember the first one, tell me about a one that you do remember).
Relation with their emotions and how they behave and approach patients and families.	
How they relate to end-of-life experiences; questions about the end of life.	How do you approach end-of-life care for patients and families?
Observation of mention of moral, religious and spiritual discourses.	How do you feel about watching another person die? Tell me about some experience.
How team members' decisions regarding therapeutic decisions are conducted.	

The total period of fieldwork was six months, April to September 2018, with participant observation being carried out over five months, April to August 2018. The interviews were conducted from July to September, in order to complement information, with one physician, two nurses and one nursing technician, who conducted the procedures in relation to the end of life and death process. Among the topics addressed in the interviews, questions about professionals' beliefs stand out, commenting on losses in their families, experiences about the first death of a patient that they followed up, or the one that marked them most, the way in which they approach end of life with patients and relatives, and how they feel about following up a patient's dying process. Moreover, it is noteworthy that the interviews were carried out during professionals' work shifts, three of them at the home care service premises, in a reserved room, and one in a room available at the hospital. The interviews were carried out using a voice recorder, lasted about an hour and were transcribed by the researcher. Transcripts were not presented to participants or validated by them, due to the deadline for completing the research (December 2018). However, in July 2019, results were presented to them for questions and suggestions.

During the observation period, fieldwork occurred on Monday afternoons, and on Wednesdays and Thursday mornings, totaling 190 hours and 20 minutes over 53 days of observation. The mean number of hours worked in each shift was three hours and 58 minutes. The descriptive notes totaled 160 pages, formatted in single space, Arial font, size 12.

With the empirical material in hand, the notes and transcripts allowed initial reflection on the data. Then, data were to Digital Ethnography, a qualitative data analysis software, version 6.0 demo, allowing the researcher to code the data set and request the organization by thematic coding.

### Data analysis

In total, 33 thematic codes were developed. In this article, 12 were related to end of life and death from a home care service, which are presented hereinafter: ways of entering home; space occupation; death; palliative care; life span; religiosity; end-of-life care; other's death gestures; disease severity; other's death; relations (patients, health professionals and caregivers); and care practices. From this coding, the study corpus was constituted, allowing the beginning of the analysis through Foucault's theoretical notions of power and subjectivation.

The theoretical notion of power refers to the exercise of relations between relations, which can be loving or institutional. Power is not substantial, something one can have. In order to establish a power relation, it is necessary that both sides are in agreement and that these subjects are free. Additionally, in a power relation, there is always the possibility that one of the parties will present resistance<sup>(18)</sup>. Subjectivation is related to the way in which practices are experienced and start to guide certain people's relations with themselves, being able to develop some ways of subjectifying themselves in relation to specific events<sup>(19)</sup>. These issues generated the following analytical categories: "home space occupation"; "ways of conducting communication regarding worsening disease and death"; "procedures for "good death"; "health professionals' perception of death".

**Chart 2** - Categories, themes/codes and Foucault's concepts

Category	Themes/codes	Foucault's concepts
Home space occupation	Space occupation Ways to enter the home Other's death gestures Religiosity	Knowledge-power relation Subjectivation Speech
Ways of conducting communication in relation to worsening disease and death	Disease severity Life span Palliative care Relations (patients, health professionals and caregivers)	Knowledge-power relation Conduction of conduits Subjectivation Speech
Procedures for "good death"	Death Palliative care Other's death End-of-life care Care practices	knowledge-power relation Conduction of conduits Subjectivation Speech
Health professionals' perception of death	Death Palliative care Religiosity Other's death Care practices	Knowledge-power relation Subjectivation Speech

To visualize the analytical categories, a table was developed to demonstrate the taxonomy used between codes and also the relation with Foucault's notions used.

## RESULTS

The 12 health professionals who participated in the study were a physician, four nurses, four nursing technicians, a psychologist, a psychology resident and a nursing resident. Ten professionals were women, while only two were men.

Based on the issues of the subjectivation of health professionals for providing care towards end of life and death in home care service, the following analytical categories were elaborated:

### Home space occupation

Home care service professionals are available in a tactical way around patients' bed, occupying spaces in the home for the establishment of power relations necessary for care:

*Jun 7<sup>th</sup>: we entered the house and the patient, as usual, was lying in bed. (P3) started and checked the patient's vital signs while (P1) and (P2) talked to the caregiver. (P3) positioned him/herself in front of the patient, and I, along with the caregiver, around the bed.*

*Jun 7<sup>th</sup>: I feel like we are watching over the body. Everyone who arrives stays around, usually from the beds, looking at the patients and, sometimes, even talking as if they are not there [...].*

When death occurs at home, positions change, and silence favors the exercise of power relations:

*Jun 21<sup>th</sup>: [...] as we got out of the car, there was a family member coming to the house, crying. We entered the door [...]. (P1) asked*

*for permission and entered first; then (P2) and me. There was a tense atmosphere [...] we were walking through the rooms of the house and there were people crying in the corners, some sitting, others standing, and (P1) nodded as if to say "I'm sorry", pressing their lips. We moved to the room [...] the patient was lying in bed, lifeless, with his mouth open, the color of death, pale, his eyes half open. We stayed around the bed as if we were watching over the body, with sad faces, me not knowing what to do [...]. (P1) said, "imagine him there in the emergency room, alone [...] it is difficult to go through this, it must have been very difficult, but sometimes the patient is not even 'there' [in the body], and he was together with the family, with you all around him".*

### Ways of conducting communication regarding worsening disease and death

Professionals use communication techniques to establish power relation with patients and their families, paying attention to the use of words and conducting a dialogue according to patients' needs:

*Apr 12<sup>th</sup>: [...] on the way, (P1) told me that she and (P2) always try to bring patients to reality, never taking or setting expectations, but, yes, being frank as far as common sense allows. And they provide information as far as he/she wants to know. If they don't ask, it means they don't want to know.*

When they realize that the end of life is approaching, caregivers and patients start asking questions to health professionals, especially about death. Professionals then conduct conversations, placing themselves also as finite beings, using euphemisms:

*Jul 16<sup>th</sup>: (P10) asked what was going on in the patient's head [conversations about death arise] [...]. (P10) said, "Look, every day is a day... we are all going to die, but I don't have a date, nobody knows. But what I can say is that the situation is more severe [...] on Friday, when I left here, I didn't know how long you could take it... today you are better, more active".*

### Procedures for "a good death"

Health professionals who work with palliative care may end up fulfilling patients' wishes and desires, as well as helping them to adapt to current health conditions:

*Interview: there is no rule: everything will depend on what the patient wants to know, at the speed he/she wants to know, what are his/her plans, what are the goals. There are patients who, when they are diagnosed with a serious illness and are at the end of their lives, are terminally ill, they readjust their plans, they adjust their goals according to the functional limitation, with the lifetime they think they have. So, they make adjustments and then we talk, explain, try to adapt the limitations and control the symptoms so that they get the most out of it and do the things that are important to them. But there are patients that sometimes we have to be even a little tougher in explaining, because sometimes he/she is a patient who is serious and is doing projects for 15 years from now to enjoy, and is not enjoying the moment. [...] so sometimes we have to talk and explain to them that we need to adjust plans, remodel, that, in fact, we always compare that it is not because*

*he/she is sick that we are saying this [...] in fact, it would have to be a daily movement for everyone, to have at least one activity of pleasure every day, because we don't know when our last day will come [...]. (P10)*

After some time working in palliative care, professionals are constituted of speeches that a dignified death must be at home:

*Aug 13<sup>th</sup>: said she it was very sad, as she had been following this patient up for a long time. In addition, she said she was more upset by the way she died, at the hospital, with shortness of breath, and said it was not a dignified death. (P9)*

*Interview: the first patient, who was the first death at home, was a patient with breast cancer, who had a giant tumor [...] a circumference of half a meter on the side, so she embraced the tumor. This patient was a quadriplegic, living in a very poor house [...], low socioeconomic conditions, she remained in the living room... in the kitchen, then the whole family moved around her and she just moved her eyes, but always lucid and died smiling at home. When she died, she was so [...] during the death process, a lot of lucidity, and I arrived at the time of death and she was smiling, when she was dying [...] so that effected me a lot. [...] I feel sad, I get very attached to my patients, but I think: he/she might not be being cared for by a team; he/she could be poorly cared for, for instance, poorly cared for in a hospital bed. (P1)*

### Health professionals' perception of death

Professionals look for cultural and spiritual explanations in an attempt to give a new meaning to death based on their beliefs:

*Apr 26<sup>th</sup>: on the way, (P1) said, "See how nervous she is, anxious, and was not taking her pain medication. She does not accept the disease. She once told me that she doesn't know how to do anything without her mother, that she doesn't know how to make decisions alone". At that moment, (P1) said, "What will become of this woman when her mother dies?". Then (P2) said, "This disease is a way of preparing the daughter for the mother's death, for her to try to get used to the loss of her mother, it can only be this, because it is a way for her to overcome it faster, because, with this dependence, she would not be able to overcome it if it were sudden".*

*Jun 06<sup>th</sup>: when we got in the car, (P4) said to me, "Did you know that patient "X" died?". I said I already knew, because I had asked on Monday. I told (P4) that I felt sorry because she had died in the hospital and she was afraid to go to the hospital and die. Then (P4) answered me, "Yes, but now she is having a party in heaven".*

On the other hand, some professionals seem to be grateful to have experienced patients' death:

*Interview: [...] if I think about my death, I think it will be wonderful, do you understand? I think, "Oh, I'm going to be free, I will be free, but at the same time, I know that I have commitments here. [...] but I think I deal well with it; I think it's all very exciting, everything is beautiful. I think death is beautiful these beautiful goodbyes. I think the same way with birth: they are polarities, they are very similar, only death is still very alone, people do not care, right? So, I am very grateful to have learned, to be learning to experience it". (P4)*

*Interview: [experiencing death] I feel privileged, special [...] a special person, because [...] I think it is a privilege to be able to be in that place, because it is special [...] today I see that it is. When I came here, I had a perspective; now it is different. Death for me today is a moment that is very special for the person, and, if he/she leaves without suffering, it is what everyone longs for. So, in relation to being able to provide a peaceful death, a death without pain, a death without symptoms, I feel privileged, because I think that it brings me a little closer to what I believe, to what I follow in my life, because it is a way for you to be able to reconcile, so you can do good to the other, you know [...] that issue of you being able to help others. [...] so we always feel that what remains of people is a feeling of gratitude for what you managed to provide, not me, but the team and this palliative care philosophy. I feel good, but it doesn't mean that I don't feel sad, I cry a lot [...]. (P1)*

### DISCUSSION

Health professionals position themselves tactically around the bed to establish a power relation with patients, who, in turn, allow this relation, as they remain in bed, available to health professionals. It was possible to identify that home space arrangement is tactically inspired by hospital arrangement, as it facilitates physical access to patients. This positioning makes professionals look at patients from above, reinforcing the power relation between them.

In the hospital environment, health professionals need to follow routines and standards, as this reduces possible errors. Furthermore, standardizing care within hospital-based guidelines, checklists, and protocols allows for better quality control, as well as facilitating the learning process of practices<sup>(20)</sup>. Thus, in the hospital, professionals classify, organize and follow standards and routines in their practices, thus establishing control over patients.

Home, in turn, is a specific space of action demanding from professionals protagonism and creativity, so that they can adapt<sup>(21)</sup>. In the home setting, professionals need to organize and plan the work process from hospital discharge planning, especially on consecutive days, allowing them to prepare materials, equipment, hospital beds, and all the technology necessary for patient comfort<sup>(22)</sup>. As professionals working within the hospital, the power relations for conducting home care can be inspired by the hospital environment's "modus operandi".

According to Foucault, power is exercised from unequal and mobile relations, and their establishment allows control over people<sup>(13)</sup>. Foucault still understands that power relations can be established based on tactics and strategies<sup>(23)</sup>. Thus, the tactical distribution of bodies in the home environment makes the relation between professionals and patients productive: access to patients' body is facilitated due to professionals' spatially superior position, a position consented by patients, who are lying in bed. This distribution also allows for more agility, facilitating the conduct of care.

Death at home affects family members and health professionals, organized based on the subjectivation of religious and media discourses. An atmosphere of commotion with patients' stories takes over the team, which is also touched by the feelings of family members. So, like them, professionals walk around the house with sad faces and gestures. Therefore, the home space

seems to subjectify health professionals beyond the constitution of a subject of technical and scientific knowledge, as it becomes a professional-patient-family bond.

Some professionals who work in palliative care may perceive a natural home death as beautiful, due to the possibility that patients can be with their families, with social and spiritual support, in the comfort of their home. In addition to this, professionals perceive subjectivation as an important tool for patient care and experiencing death<sup>(24)</sup>. Furthermore, a study suggests that professionals should adopt a personalized view of a dying patient using techniques, such as adequate communication, to learn about values, preferences, concerns, and what matters to them at each stage of their disease<sup>(25)</sup>. These techniques make professionals subject to the "good death" discourse and humanization, leading them to experience patients' death more closely.

Power is established from the exercise of forces that can affect and modify something<sup>(26)</sup>. Therefore, health professionals affect and are affected by forces established in power relations between those involved in patient care.

Both the Home Care and the Palliative Care Manuals point out the need for professionals to pay attention to cultural aspects and recognize the values of patients' families in an intimate event such as death at home. The discourses are focused on the management of family members' anguish at the moment of death, recommending listening strategies and a spiritual approach to promote the relief of suffering<sup>(7-8)</sup>. Therefore, it is understood that, in the home space, when experiencing events focused on patients' lives, professionals become part of their story, and, consequently, end up immersed in the atmosphere of sadness due to imminent death.

In home care services as well as in the hospital, professionals seek to know patients, in order to manage care better, identify what they know and want to know about the progressing disease or talk about the subject. Due to the effects they can cause on patients, professionals pay attention to the use of words and give information only when patients ask and just what patients are prepared to hear. Care should be taken because words can greatly impact the mood of patients and their families.

Health professionals report having difficulty breaking bad news to patients, but stress that being available to listen to concerns, offering support and explanations, clarifying misunderstandings, assisting in decision making and helping them to deal with emotional aspects can be good strategies for introducing unpleasant information<sup>(27)</sup>.

The Palliative Care Manual highlights that patients have the right to know their health condition. Thus, professionals start to use communication strategies with prudence, observing patients' non-verbal language, as it is from it that they will be able to understand the effects of what was explained<sup>(8)</sup>. Thus, they use techniques such as effective communication, clarification of information, empathic attitudes, and qualified listening to establish the relation of knowledge and power with patients and, then, favor communication about their prognosis.

When patients abruptly question their own death, professionals seem to speak in a more subdued way, producing certain horizontality in the relation as a strategy to make patients think that everyone will die someday, although they do not know exactly

when. On the other hand, as patients are exposed, professionals seem to feel comfortable talking about death, fears, and anxieties and are open to talking and to therapeutic listening. In home care service, another way of conducting conversations with patients is established according to which professionals will discover the best way to talk to each one.

The Home Care Manual presents communication techniques that guide health professionals to manage patients and their families, using supportive strategies in difficult issues, such as talking about death and worsening of disease<sup>(7)</sup>. Thus, the strategy of seeing oneself as a finite subject, establishing a horizontal relation with patients, is successful in providing relief to patients through the established power relation.

Professionals try to fulfill patients' desires and wishes so that they feel fulfilled and comfortable with the circumstances of care. Moreover, they talk to patients about the importance of enjoying the present moment, because often patients undergoing palliative care still make plans for an uncertain future. Thus, especially when patients' clinical condition worsens, professionals draw their attention in an attempt to make the most of their remaining time. Patients are advised not to wait for a specific date to celebrate or to say what they want to their family members, as they do not know when their last day will be.

The content of the Palliative and the Home Care Manuals is in line with the discourse that defends the fulfillment of patients' wishes, with a view to promoting quality of life. Thus, professionals are advised to make room for patients to talk about their own finitude, with a qualified listening, in which they can talk about their priorities<sup>(7-8)</sup>.

Health professionals' actions in palliative care are aimed at satisfying patients' wishes. In the home environment, patients and caregivers point out that their health needs are met, and care routines are adapted to their reality and routine, in the comfort of their home, reducing concern and promoting satisfaction of those involved<sup>(28)</sup>. By using these techniques, patients feel more comfortable and valued, even in a condition in which there is no longer a possibility of cure. Speech and therapeutic listening seem to fill the gap when there is a lack of highly complex technologies.

From the discourses aimed at fulfilling patients' wishes and desires, one can think of the power relations established in home care service through the biopolitics supported by palliative care discourses to guide the population of patients with incurable chronic illness. Foucault<sup>(13)</sup> points out that biopolitics is one way of power over life, developed in the middle of the 18<sup>th</sup> century to refer to body-species, focused on the biological processes of functioning of living being, such as proliferation, birth, mortality, health status, life expectancy, and longevity.

This control occurs in some populations, including them in certain spaces and excluding them from others. One study<sup>(29)</sup> points out that the "naturalized" understanding of inclusion would be as if everyone occupied social spaces equally. If it were different, those who were left "out" would be called excluded. However, the author coined the term (in)exclusion to designate today's peculiarities, which do not encompass inclusion and exclusion as opposites, but as linked by interrelated.

From this perspective, can we call the homecoming movement an "(in)exclusion of people with incurable diseases"? For

the reflections here, yes, because, according to the study<sup>(11)</sup>, patients are excluded from the hospital, but included in their own institutionalized home, with several techniques that favor the establishment of power relations.

Also, discourses aimed at palliative care are also biopolitical strategies for controlling life and death. With strategies to control morbidity, mortality, and the right to health, people started to live longer; consequently, they can develop chronic diseases, many incurable. Thus, we start to think about how to manage this population, which escapes the control systems. Palliative care and home care service, therefore, are strategies to "make room" for these subjects, allowing control of their life and death.

With the return of death at home and the defense of the discourse that the possibility that patients being cared for in the comfort of their home, surrounded by family members, is preferable, health professionals come to believe that a death at home is a dignified death, a "good death", and that dying in the hospital, as a result, is not the best option, representing loneliness and anguish. In this regard, health professionals are subject to the discourse of home care service and help patients to die at home. However, when this does not happen, feelings such as sadness and anguish may arise, since patients' death did not occur according to the palliative care discourse.

In the palliative care field, death should not be delayed or rushed, but it must occur "naturally". The Home Care Manual also states that palliative patients have a preference for dying at home, better control of symptoms and to be with family members, maintaining habits and leisure activities<sup>(7)</sup>. Based on this, a "good death" starts to be configured as a "humanized" death, according to which actions are aimed at fulfilling patients' wishes until their last moments.

From what was seen in this study, health professionals are faced with death, seeking to access explanations of cultural, moral and spiritual nature. These explanations subject health professionals so that they can lead the other's death while triggering many concerns about the events that involve patients and families. Thus, they try to attribute some meaning to difficult situations related to the disease, death, and caregiver, who are often overloaded. This movement seems to help health professionals to go through situations about life and death that seem to have no explanation or justification.

According to Foucault, subjectivation is the relation with oneself that can happen based on relations of knowledge and power, although not depending on them. The subject is constituted from the establishment of relations with the other, whether they are of power, knowledge or resistance, and from the relation with the other, subjectivation occurs, the relation with oneself<sup>(26)</sup>.

When relating to different situations and patients' stories, team members change themselves as professional health subjects. Furthermore, they are moved by speeches of knowledge and experience on other's end of life, situations that act on their subjectivation. Subjectivation changes their care procedures for patients at the end of their lives and their interpersonal relations.

When providing care to patients undergoing palliative care for some time, professionals start to experience death more frequently. Often, they try to make sense of it, looking for strategies that give it a new meaning, so that they are constituted by discourses based

on "good death". They seem to feel gratified when they experience the other's death, controlling the conduct in an attempt to help patients to die with more comfort and less suffering.

Faced with death, home care health professionals try to be resilient when performing care. Amidst suffering, they try to turn painful experiences into learning and a willingness to help, and end up rethinking their own lives. Working in palliative care and recognizing their role in care makes professionals realize that their efforts were not in vain, even with patients' death, and they find satisfaction in the results of their care<sup>(30)</sup>.

In addition, medical and nursing students highlight that dealing with patients undergoing palliative care makes them rethink their own lives, as well as feeling satisfaction with the possibility of doing good to other people through more humanized care<sup>(31)</sup>. The humanization discourse, therefore, circulates as an axis in the field of palliative home care service. Health professionals should use techniques that involve empathy, compassion, and availability to listen to patients and their stories.

### Study limitations

This study does not seek exhaustion, nor generalization in relation to the theme, but presents a "photography" containing analyses with Foucault's notions of the studied context. Thus, the absence of feedback from the observations of the 12 participants and from the interview transcripts of four key informants is considered a limitation. This feedback could have generated other nuances regarding conduct and practices in the context of the study. Furthermore, as this research was carried out during an academic master's degree program, it is noteworthy that the time of two years is considered too short to carry out feedback during data collection. Also, it was noticed that taking some field notes with participants can also interfere with their behavior, especially in the initial phase of the research.

### Contributions to nursing and health

This study contributes to nursing and health because it allows health professionals to have a different perspective on patients undergoing palliative care, enabling carrying out other care practices that can be performed at home, prioritizing needs and making exceptions that can meet desires. Furthermore, regarding professionals' subjectivation in the context and also noting that most people currently die in community environments, participants' subjectivation can shed light on the approach to a series of challenges experienced in the death and dying process in the home environment, as well as enabling them to also rethink their own lives and ways of living it. Thinking about ways to deal with patients in the home environment allows professionals to be constituted in different ways, establishing other forms of power relations, but also proposing resistance to practices taught while training.

### FINAL CONSIDERATIONS

This research identified that health professionals are subjects from discourses that circulate in the fields of knowledge of palliative

and home care services and also by experiences that touch them. Furthermore, the discourse that people dying at home would be the best option for end of life, for the possibility of "a good death", is resumed. Caught up by this discourse, health professionals end up directing their conduct towards "a good death" and quality of life promotion, reducing suffering.

Experiencing death in the home environment makes professionals constitute themselves in different ways, tracing several

strategies in terms of dealing with death – sometimes in a more attenuated way, feeling grateful, and sometimes as a difficult situation to be faced. The home environment opens the possibility for end-of-life experience to be different from that experienced in the hospital, due to the fact that professionals are in contact with a unique story. However, the practices are often similar, especially when it is found that other strategies and ways of governing bodies are created even at the end of life.

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