CHARLES UNIVERSITY IN PRAGUE

FACULTY OF HUMANITIES

Anna Caterina Vaccari

The body in the palliative care context: an ethnographic study.

Bachelor's thesis

Prague 2019

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Supervisor: Mgr.
Alžběta Wolfová Prague
2019

Statement:

I hereby declare that the following text is my indipendent work and that all the sources and literature that I have used have been duly cited. I agree for this thesis to be stored in the Library of Social Sciences T.G. Masaryk in Jinonice in Prague and in the electronic database of the Charles University repository and to be used for study purposes in accordance to copyright. This thesis was not used in order to receive any other degree from another institution in the Czech Republic nor abroad.

In Prague, 27.06.2019

Anna Caterina
Vaccari

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Abstract

My diploma thesis concentrates on the interactions between the patients of a palliative care ward and the staff, moreover, it examines the function and meaning of the body within this relation. To be able to study these thematics, I conducted an ethnographic research for the period of four months in a palliative care ward as a volunteer. The main focus is on three different spheres of interaction between patients and staff; hygiene practices, nutrition, and medication. A critical-interpretive approach towards the body is employed whilst highlighting the links between body, society and power relations. It is argued that through palliative care a definite kind of body is constructed, through discourses about cleanliness and uncleanliness.

Keywords; palliative care, body, dying, hygiene practices, „bounded body", „unbounded body"

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1. INTRODUCTION

Death, thy servant, is at my door.

He has crossed the unknown
sea and brought thy call to my
home.
The night is dark and my heart
is fearful -- yet I will take up the
lamp,
open my gates and bow to him my
welcome. It is thy messenger who
stands at my door.
I will worship him with folded hands, and with tears.
I will worship him placing at his feet the treasure of
my heart. He will go back with his errand done,
leaving a dark shadow on my morning;
and in my desolate home only my
forlorn self will remain as my last
offering to thee.

Tagore, Gitanjali, LXXXVI

To explore the context of the palliative care and the role of the body in it, I have conducted an ethnographic research in a palliative ward. To do that, I applied to work in a Czech hospital affiliated to a particular church order where I have worked as a volunteer for a period of four months between December 2018 and March 2019, during which I conducted my fieldwork.

Entering the field as a researcher-volunteer enabled me to become acquainted with the daily routine of one particular ward, to be an active part of its staff and to have access to the interactions with patients that are peculiar to it. The analysis is based on the description and interpretation of the staff patients interactions and the meanings behind certain practices connected to the body in the palliative care context.

The relevance of the thematic is supported by the growth of the ageing population in Czech Republic that will be in the future even more in need of palliation than today (Lutz, 2001).
Furthermore, in Czech Republic, more than two thirds of citizens die in a hospital or in a hospice.[1] This thematic is also relevant from a philosophical and anthropological

perspective since Nancy Scheper-Hughes and Margaret Lock (1987) underline how the topic of the body and how we approach it influences not only healthcare but also the very basis of the discipline ofanthropology.

Palliative care is usually defined as an approach to terminal patients that aims to provide an adequate pain management therapy as well as psychological guidance for the patients and their families, according to Stephen Lutz (2001.). It can be provided to the patient directly at home or in a specialized institution such as a hospice or in the frame of a hospital. In Czech Republic there are 27 different structures that provide this service.[2]

My theoretical framework consists of several theories, which inspired me in my research.
I, following Scheper-Hughes and Lock (1987), take into consideration different kinds of 'body'.
The 'social body' is analysed in connection with the conceptualization of individual-social body of Mary Douglas (1970), it is underlined how the body of the patient can be read as a symbol, and that it can reveal how a given society thinks about itself; furthermore, it can embody certain preoccupations or attitudes towards disparate topics. The thematic of the 'body politic' will also be developed, and it will be linked to theories of Michel Foucault (1977) about 'medical gaze' and medicalization.

Julia Lawton (2005), in her ethnographic study of a hospice, argued for the distinction between 'bounded' and 'unbounded' bodies, and indicated the unbounded body as an embodied symbol of danger and derangement in our Western society. Connecting to these concepts, I will also show how bounded and unbounded bodies are present in the palliative ward.

The structure of the dissertation is the following; a theoretical part in which I illustrate the main frameworks in which my research is grounded, followed by a methodological one in which research questions and research strategies are outlined. In the empirical part I describe the daily routine of the ward and present the description of patients and personnel.

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[1] Uzis.cz. (2019). Zemřelí 2010 ÚZIS ČR. [online] Available at: https://www.uzis.cz/publikace/zemreli-2010

In the interaction between patients and personnel the body is always at the centre of their communication (being washed, clothed, fed, medicated and handled). My goal is also to describe the meanings that it conveys.

In the empirical part, I furthermore analyse how this interaction happens mainly in three spheres; nutrition, medication and hygiene practic

In the sphere of hygiene practices I explore, following Lawton (2005), how the notion of cleanliness/uncleanliness contributes to the creation of two different kinds of bodies, the 'bounded' and the 'unbounded' one.

In the chapter dedicated to the making of the dying and dead body, I analyse how is the medical gaze and authority involved in the process of dying.

My focus on the body and on the practices connected to it stems also from my position respectively to the ward. In fact, being a volunteer, my task was mainly to assist the personnel in its tending to the bodily needs of the patients. Other tasks and spheres, such as those of the doctors and chaplains were, because of my position, not accessible to me.

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2 Umenidoprovazet.cz. (2019). *Kde najdete hospice? | Umění doprovázet – nadační fond pro hospice*. [online] Available at: http://www.umenidoprovazet.cz/cs/Kde-najdete-hospice-31.htm

2. THEORETICAL FRAMEWORK

2.1 Introduction

In the following chapter, I would like to outline a brief history of the phenomenon of the palliative care and of the hospice In order to put it in its historical context. Then, I will examine the present situation in the Czech Republic, regarding palliative care.

Furthermore, I will introduce different conceptual tools which framed my interpretation. One of the main theoretical frameworks that I will employ is the structural symbolist approach of Douglas (1970) to the body and its significance, and her insights into the concepts of pollution. I will also introduce an empirical study by Lawton (2005) which focuses on the 'bounded' and 'unbounded' body in the sphere of terminal care. Another important interpretive frame that I will employ is that of Foucault (1977), which shows how the body of the patient is made in its interaction with the doctor, and underlines the power aspect of this relationship.

2.2 History of the hospice and palliative care

Hospices were originally dedicated to the care of the ill and dying travellers, and it is believed that Crusaders in the XI century first opened and managed hospices, where they cared for the terminally ill and also offered respite for the travellers (Lutz, 2001). After the middle ages, this kind of institutions began to be less available because of the decline of the religious orders that promoted them in the first place (Ibid.). The etymology of the word „hospice" is also revealing of the origin of these structures, meaning originally "rest house for travellers"[3]

The development of the modern hospice movement is connected to the figure of Dame Cicely Saunders. In fact, she developed some of the core ideas that still today form the principal tenets of the hospice movement, especially her concept of „total pain", which encompasses physical, spiritual and psychological suffering (Ibid.). Dame Cicely Saunders, an English nurse and social worker, opened the first modern hospice in London in 1967, and what distinguished it from other structures was its holistic approach towards the patients and their needs. Her approach comprised not only symptom and pain control but provided also spiritual and psychological guidance and help for the family of the patients and the patients themselves (Ibid.).

At this point, when St. Christopher's was opened, hospice movement was still volunteer-led, but in the „70s, a political discussion about dying and the peculiar needs of those who are terminally ill was developed mainly in the USA, which later led to the transformation of the hospice movement into a medical speciality and recognition of its great relevance (Ibid.).

Indeed, the etymology of the term „palliative" reveals some core information about it; coming from the Latin *Palliare,* meaning „to cloak", palliative care principally aims to achieve symptom control, to conceal and „cloak" the illness (Lutz, 2011: 307, Rome et al., 2011).

The term „palliative" was used for the first time by doctor Balfour Mound in 1974, and it referred to an approach aimed towards pain relief (Lutz, 2011). But the use of palliation does not automatically exclude the concurrent administration of curative therapies aimed towards defeating the illness; contrary to what the scope of hospice care is (Ibid.). The first palliative care program was offered in the USA at the end of the 1980s.

To summarize, the hospice is an institution with a long history, which is tied from its origin to a Christian religious order, and which has always had the aim to provide for those in need, especially terminal patients. Palliative care is, on the other hand, an approach to the dying patient which was born in the context of the hospice, and that is, however, not confined to it.

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[3] Etymonline.com. (2019).*hospice | Origin and meaning of hospice by Online Etymology Dictionary*. [online] Available at: https://www.etymonline.com/word/hospice

2.2.1 Present situation in the Czech Republic

Death and dying, and the way we approach them: these are themes that are becoming more and more strikingly political themes for the society at large; since death and dying are becoming a commodity. Developed countries in particular need to face these phenomena since their ageing population is constantly growing; in fact, only in the USA, as many as 78 millions citizens are in the phase of their life in which they are most susceptible to illnesses such as cancer and heart complications; its consequences, in turn, often require a lifelong program of treatments and medical care (Lutz, 2001). Both palliative care and hospice movement offer answers to these issues, hence their importance and relevance.

The situation in the Czech Republic is similar to that of the United States in regards to its increasingly ageing elderly population (Dufek and Minařík, 2009), which will most likely cause an increase in the relevance of palliative care.

In particular, in the Czech Republic in 2010, 59% of people died in a hospital facility, 20% died at home and 9% passed away in a hospice.[4] These data reveal that knowledge of the palliative care principles are crucial for the medical staff, since more and more patients are nowadays being admitted and subsequently passing away in the hospital, especially as a consequence of long illnesses and its repercussions (Ibid.).

There are many different options for terminal patients in Czech Republic which include their own homes, hospices, LDN[5] and senior nursing homes.

In conclusion, according to its general definition, hospice movement and palliative care offer respite to terminally ill patients and their families. It seems that, since the ageing population in developed countries is on the rise, palliation will be requested more and more in the future by patients. Therefore, its knowledge and understanding are important not only in the medical sphere but also broadly in the academical world.

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4. Uzis.cz. (2019). Zemřelí 2010 ÚZIS ČR. [online] Available at: https://www.uzis.cz/publikace/zemreli-2010

2.3 Concept and theories about dying, the body and cleanliness/uncleanliness

In the following chapter I will try to sketch some theoretical and analytical frameworks which were helpful for me to further understand the field which I was studying. The main frame that I will employ is the symbolical one, which I take from Douglas (1970), and I will use it to analyse different concepts such as the body and its propriety/impropriety. I will also make reference to empirical studies by Julia Lawton, which were particularly inspiring for me.

For clarity's sake I would like to differentiate the concept of illness from that of disease; the former is usually connected to a more universal meaning, and it identifies the objective reality of a “pathological entity” (Helman,1981:548), whereas the latter is defined as the more concrete and subjective perception that the diseased individual has of his own situation (Ibid.). In the frame of both hospice movement and palliative care it is mainly the disease that is tackled; there is an effort to cater to each patient in an individual and “ad hoc” fashion, namely by paying attention to their own recount of the disease.

Paul Áries (1974) argues that between 1930 and 1950 there has been a shift concerning death in Western society and the place where it occurs. Back in the days people would normally die at home, surrounded by their family, and to die in the hospital was an option for those without relatives and for the poor (Ibid). Nowadays, partly because of a process of medicalization of death, the hospital is becoming more and more the designated place where death takes place, especially when considering chronic diseases which make medical attention indispensable at all times. By medicalization I intend the extension of the medical gaze on human conditions, which entails that some processes pertaining to the life cycle such as birth and death came to be considered as medical issues (Maturo, 2012).

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[5] In Czech: Léčebna dlouhodobě nemocných, meaning „Hospital for long-term illness".

Michel Foucault (1977) also wrote extensively about corporeality, and about the body insofar as it is the primary subject of power, namely in the context of the clinic, where the patient and its body turn into subjects of the „medical gaze" by which they are understood and analysed; for him the body is produced by the power relationship between doctor and patient.

In the palliative ward, I will try to argue, a definite form of power is exerted on the body, which employs different forms and techniques that become apparent in its handling and in the way in which autonomy is negotiated and regulated. The focauldian concept of power does not bring with itself a necessarily negative connotation. Indeed, as Lupton (1997) argues, power is for Foucault as creative a force as it is constraining. Foucault (1977) in fact, argues for a definition of diffused power; this means that we encounter it especially in the micro-practices tied to everyday life and that it is not an attribute of a group or of some individuals, but it is rather an aspect of the relationship among them. I will try to individuate these micro-practices of power in the palliative ward and to define its aims and consequences, since, for Amanda Henderson (1997), these practices influence also the relationship between patient and staff. Moreover, I will show how the primary theatre of interaction between patients and staff is the body of the patient.

By „medical gaze" I understand, following Michel Foucault (1975), a specific way in which the body is understood, and that is based on knowledge produced by visual analysis conducted by doctors. This is connected to a historical shift which saw the doctors no longer basing their diagnosis on the patients' recount, but instead on tangible and visual elements such as X rays (Ibid.). Through the medical gaze the body of the patient and the patient too are examined, judged, known and manipulated. To be able to formulate a diagnosis, the bodies of the patients are also compared amongst them and, when they are judged to be deviant from the norm, an adequate regime is put in place to restore them to „normality" (Lupton, 2000). In the context of the palliative ward, as I could observe, the medical gaze is employed in the moment in which doctors, guided by visual cues mainly, determine if the patient is close to death; this in turns contributes to further isolation in the context of the ward, since these patients are usually moved to side rooms where they consequently pass away. Foucault's theoretical frame enabled me to research how is the body of the patient, in the context of the palliative ward, subject to certain medical practices, and how it is known and constructed.

Although some writers such as Julia Lawton (2005) affirm that the body seems to be a theme quite absent from the academic field of social sciences, others such as Featherstone, Hepworth and Turner (2001) state that the body has been studied extensively in anthropology since the 19th century (ibid).

Mary Douglas (1970) puts the body at the centre of her inquiry. She argues that Man has responded to the existence of chaos and derangement through regulation and classification and that the body has been and is the main tool through which this systematic operation is performed and embodied. Douglas extensively studied how certain beliefs about what is socially constructed as propriety and impropriety are symbolized in the body, and how it can be read as a metaphor of the society at large: this means that through the analysis of how the body is handled, changed and preserved we can understand how a given society thinks about itself (Ibid.). Analytically, I will work with Douglas‟s symbolic take on the body to show how some practices performed in the palliative care ward can be read through this analogy between body and society. Mary Douglas argued also that maintenance of cleanliness has to be connected with the upholding and protection of boundaries; therefore the effort that is put into maintaining the body clean could be linked to an effort in preserving the propriety of the society (Ibid.).

The analysis of Douglas (Ibid.) can be connected with the critical-interpretive perspective of Scheper-Hughes and Lock (1987), and their take of the “social body” (Ibid.:6), in which they assert that the body can be understood as a symbol, in the case of Douglas (1970), showing the relation between itself and the society.

Scheper-Hughes and Lock (1987) also take into consideration the “body politic” (Ibid.:6), in which the body is seen as a product of social and political forces that mould it.

Following Lawton (2005), I will argue that bodies can be „bounded‟ or „unbounded‟, according to the interplay of the degree of autonomy that they represent and also of the degree of defilement which they bring.

The „unbounded‟ body is characterized by the inability to maintain its boundaries, by some sort of leakage and lack of control over one‟s own orifices, whereas a „bounded‟ body is characterized by being contained and by an absence of leakage of fluids or odours.

To understand why certain bodies are placed in the hospice while others are not, Lawton (Ibid.) argues that attention should be paid primarily to the body of the patient and to the disease that operates on it. It is „unbounded bodies‟ that are confined in the palliative or hospice setting, since their qualities of unboundedness situate them outside the norm of the „bounded body‟. In her ethnography of a hospice, Lawton (Ibid.) analyses different case studies to support her claims.

In her case study "Annie", Lawton (Ibid.) follows the admission to the hospice of a patient, and she underlines that her increasingly serious incontinence was the ultimate cause of her admission to the hospice where she would eventually die.

In the hospice,Annie became double incontinent, meaning she had no control over either urine or faeces. Another problem was also presented by the smell which her urine gave off; this uncontrollable feature of her condition not only impeded her from returning home once her situation was stable again, it also further isolated her in the hospice, since other patients were shaken by the deterioration of Annie's body and were refusing to share the room with her. After becoming unconscious due to heavy sedation, she was moved to a side room, where she died alone. Lawton stresses that Annie's case is not isolated, but rather emblematic and representative of the majority of patients in the hospice. What causes unboundedness is not just incapacity to retain urine and faeces, but also vomit, weeping limbs[6] and fungating tumours[7].

Therefore, hospices and similar institutions configure as places where „unbounded‟ bodies are placed, since, given their polluting quality, they are pushed aside from society and family.

This is the reason why some type of bodies are more represented among the general population of the palliative ward: what repels the family or the caregiver of the patient is not the process of death in itself, but rather the „unboundedness‟ of the body.

Lawton (Ibid.) also underlines that the hospice cannot be seen only as a place in which the unbounded bodies are "sequestrated", since in some instances it functions more as a mediator. Once having reconstituted the bodily boundaries –for example by inserting a catheter–, the patients can be discharged.

Douglas‟s analysis, on which Lawton partially construes her own theories, is representative of the embodiment in the West, but it should be underlined that this attitude is not universal.

In fact, bodies are not "universally conceived as physically bounded identities" (Ibid., p.137).

For Crawford, (1997), the emergence of the „bounded body‟ in the West is tied historically to the increasing importance of individuality and the beginnings of the Protestant Reformation, and in this he mirrors the intuition of Douglas, who claims that attitudes towards the body are a reflection of the way in which a given society thinks about itself. Therefore, the self control and self mastery so typical of the Protestant doctrine were reflected onto the body, and the self contained body became the ideal body. Bodily waste is consequentially seen as polluting in our Western culture, however, in other cultures, in which there is lesser emphasis on individualism, bodily excreta are not seen in such ways since they are seen as carrying the identity of the person, more than being seen as refusal.

Taylor (in Lawton, 2005: 140) studied Rwandans and their attitude towards the body and its emissions. In his writings he describes a rite in which a newborn is for the first time presented to the extended family and members of its village. A small quantity of its excrements are mixed with the food of the children of its community, and they consume it together. Taylor (Ibid.) interprets this as a symbolic action which shows how the children, by ingesting the faeces of the newborn, accept him and make him part of their community. Excrements are therefore not seen in a negative way in this case, they in fact represent the baby and carry its essence.

The theoretical framework of Douglas and Lawton enabled me to understand how is the body of the patient constructed in relation to ideas about cleanliness and uncleanliness, and what are the consequences of it.

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[3] Weeping limbs are a consequence of swelled limbs that break the skin due to tension and let out lymph.

[4] A fungating tumour is a rotting tumour located on the skin.

3. METHODOLOGY

3.1 Research strategy and chosen methods of data collection

3.1.1 Research questions and their development

Before entering the field, my aim was to explore how the body, and in particular the dead one, is handled and what kind of meanings are attached to these rituals. After I began my fieldwork I realized that the scope of my research would have been necessarily influenced by the spaces that I was able to enter. I realized that my position as a volunteer did not allow me to explore the thematic of death to such depth. Therefore, after some time I began to envision different recurrent themes in my field notes on which I wished to expand. As a volunteer, my task was to assist the nurses and the medics in their daily routine, and the most prominent and recurrent tasks were those in which we were interacting with the patients and their bodies such as in the distribution of meals, hygiene practices and changing of diapers, bed linen and medication. Therefore, this led me to reformulate my initial research questions into the following main questions:

- **How is the body handled in the context of palliative care through personnel-patients interaction and what are the meanings attached to these actions?**

By answering theses questions I will be able to analyse the relationship between patient and staff, and to focus on the importance of the body in this relationship. I will show the centrality of the body in this context.

Particularly, I noted that the handling of the body of the patient takes place in different spheres such as the daily care for nutrition, hygiene practices and medication, that it constitutes the primary link between patient and staff, and that it is at the core of their relationship. Moreover, I discovered that the body can also be studied in relation to autonomy and how it is negotiated, and in regards to death and its enactment. This in turn led me to specify my somehow broad general research questions:

- **How does this happen in the sphere of hygiene practices, nutrition and medication?**
- **How is autonomy negotiated between patient and personnel?**
- **How is death enacted in the context of the palliative care ward?**

Therefore, by focusing on the different practices connected to the body I will be able to explore what meanings are attached to these actions, especially in the aforementioned spheres.

3.1.2 Ethnography

To answer my research questions I chose the qualitative strategy because it is best suited to my aim, which is trying to sketch the significance of certain interactions, to convey the opinions and points of view of the actors, and to generally depict the reality of a palliative care ward. In particular, I decided to use the qualitative method of ethnography, which permitted me to analyse and study in depth the specific features of the field. The most significant way of data construction whilst doing ethnography is the method of participant observation since it enables the researcher to immerse him/herself in the field by also participating; the aim of this is to try to understand the point of view of the actors.

3.1.3 Reflection about the position of participant observant

The main advantage of participant observation strategy lies in the fact that it enables the researcher to be in the field and observe closely the actors and the interactions. Mere observation and recording of what happens are not enough, the researcher must try to also interpret its data and to come as close as possible to a "thick description" (Geertz, 1973). Participant observation technique also generates some issues that came up during my fieldwork; soon I perceived how I was quickly internalizing the rules that govern the ward, and since I was carrying out almost all the duties of a hospital attendant, I felt I began to act and think like one. Observing this was interesting for two reasons. On the one hand, I experienced how the set of rules of the setting was very quickly changing my perception of my colleagues and patients, and on the other, I began to feel as being part of the staff so much that I became accustomed to what was alien to me before. Because of this, I had to work on the distance between me and the phenomena I was observing, and had to avoid merging with my role of an ordinary worker. This particular tool enables to not only gather data but also to be able to put them into a context which is crucial for them to assume meaning (Geertz, 1973).

To be able to conduct my research, I decided to contact by e-mail five different structures that were active in different ways in the palliation sector. I received only one answer in which I was asked to personally come for a meeting with the main nurse in the ward. Consequently, I was able to work in the ward as a volunteer and take part in almost every activity. My volunteering activity in the field spanned from December 2018 to March 2019, and I spent in the ward approximately 80 hours. I worked along the side of nurses mainly during morning shifts, as these are usually the busiest, and, by doing so, I was able to get as close as possible to the patients during meal time and hygiene. My tasks were similar, if not identical, to any other staff member; the only procedures I was not allowed to carry out were those for which medical training is needed, such as administration of shots and wound dressing.

I have taken into consideration to use the tool of semi-structured or structured interviews to gather more data, but upon further reflection, I abandoned this option. Trying to convey a sense of what it is the experience of palliative care means to strive to present this reality under different angles and perspectives, notably that of patients and that of the staff. Since most of the patients in the ward were at all times bed bound and in a semi-comatose state, it was difficult for me to initiate a conversation about a possible interview, and given the delicate psychophysical condition of the patients, I thought it was best to abandon this option. Another reason that discouraged me from seeking interviews with the staff, was that my research is already more inclined towards the description from the point of view of the staff, and by adding another source which would speak from the same position I would have underplayed the variety of interpretations that can be given. Instead, I strove for a more balanced perspective.

In addition informal interviews and participant observation I also gathered informations about the palliative care ward through their website, which I analysed so as to understand how the process of admission is structured.

3.2 Sampling strategy

Since I conducted my research using the strategy of ethnography, my main sample was the field itself, namely the palliative ward in its totality, including patients and staff.

With all of my informants –namely, patients and staff–, I conducted informal interviews. This kind of interviews are characterized by the fact that they take place between the informants and the researcher in the sphere of an already established relationship and they occur spontaneously. Unstructured interviews, on the other hand, presuppose that informants are aware that the aim of the researcher is to find informations that are instrumental to their aims. Since informed consent must be given by the informants in case they participate to an unstructured interview, I decided to only use informal ones. In fact, as the vast majority of the patients of the palliative care ward are unconscious or in a physical state of suffering, I found it inappropriate from an ethical point of view to disturb them with such questions and explanations concerning my role as both volunteer and researcher.

My main informant were my colleagues, mainly nurses and hospital attendants. In terms of gender and age, informants were homogeneous, mostly they were female and between 45 and 60 years.

3.3 Data analysis and research quality evaluation

My field work began in the moment in which I, for the first time, stepped into the field. Qualitative research and ethnography are typical in the way that data collection ad analysis begins at the start of the empirical phase of research.

Right away I started to note my observations and reflect on them. After having accumulated many notes and impressions, it became clearer on what topics I wanted to focus more than others.

The concept of reflexivity became very important once I became an active part of the staff; it enabled me to continuously reflect and think about my position towards the field and the actors and reminded me all the time the fundamental subjectivity with which I was observing phenomena around me. This reflection allowed me to be aware that my subjectivity could influence my data.

On the other side, my presence in itself and the notion that the staff had about my position as a researcher could have influenced their behaviour as well as their responses and attitudes towards me. This phenomenon, in the field of qualitative research, is known as reactivity.

Since the rhythm of work in the palliative care ward is usually sustained and the members of the staff are generally busy at all times, I had to choose the right moments during my shift –for example that of lunch breaks or occasional cigarette breaks– in which to engage in a meaningful conversation when I could socialize.

Regarding patients, I also had to assess very carefully whether I could converse with them in any given moment, since most of them are either unconscious or in a state of pain and discomfort, therefore my aim was to result as little intrusive as I could.

The description of the routine of the ward is clearly leaning towards the perspective of the nurses and the hospital attendants. In fact, by having operated as a volunteer, I experienced the routine mainly from this point of view, since this position allowed me to enter some spheres but denied or made access difficult to others. So, since my day was divided into different tasks that had to be carried out one after another, I had little time to spend in the patients' room trying to understand how they perceived their routine. At the same time, during my stay the vast majority of the patients of the ward was non communicative at all times, which made further difficult to present the perspective of the patient.

During my shift, I would take some time in between different chores to sit down in the 'sesterna' [8]and to quickly write down some important things that I observed and had caught my attention, along with snippets of conversations which were significant. Once at home, I would expand them and complete them with a more detailed account of my shift. Later, I would record them on my computer and add particulars or my personal reflections. In March, after I completed my last shift and exited the field, I focused on reading and reflecting on my field notes to extract the main and recurrent themes on which I subsequently built my final research questions, and started the process of writing itself. When my data reached saturation I ended my fieldwork. Therefore, was disconnected from the field during my process of writing and did not enter again to collect information.

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[8] `Sesterna` is the room in which the staff of the palliative ward spends time during brck

3.4 Ethics

My ethical approach assured informed consent, which I obtained from the institution. I had to sign a contract in which I assured I would maintain confidentiality about any sensitive information. I also ensured anonymity. In my research I strived not to cause any harm to actors, given the sensitive nature of the data. For the same reason I refrained from including in my work sensitive informations. Reciprocity has also been ensured, since, during the time of my research, I was an active member of the staff, and I regularly worked alongside the staff.

Problems of ethical nature arose quickly at the start of my fieldwork. The first issue was tied to the fact that most of the patients on the ward were, at the time of my research, non communicative. I was therefore concerned about how I would obtain informed consent from them. My gatekeeper, the primary of the ward, assured me that I could inform of my position in the ward as a researcher to the patients.

My major concern was the fact that I do completely lack any kind of medical training; and thus, I felt intimidated from the beginning by the idea of entering into the role of researcher, not knowing what I could offer back to those I was studying.

The field notes from my very first day in which I was interviewed are telling of the strong impact that I had:

> *While I wait to be introduced to the director of the ward, a stretcher exits from the door of the ward and passes by me, the two men who are taking it with them downstairs politely say hello and wait for the elevator. There is the body of a dead person, covered with something that looks like bed linen. This situation seems a little strange to me. I can distinguish the shape of his or her head and neck. I would expect dead bodies to be taken wherever they must be taken in a less mundane way.*[9]

This close encounter with a dead body, which is totally unfamiliar to me, signalled that my position towards the field was of total alienness.

Another issue was for me the way in which I was thrown into the reality of the tasks of the ward, without any prior explanations of what I should expect.

My initial shock is clear in my field notes from my very first shift:

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[9] Field notes from 18.12.2018

The first task that is given to me is to help a nurse wash a patient. Together, we take her from her room to the bathroom for a shower. She is lying on the stretcher, naked. The middle aged woman has had a stroke, and is now unable to move, speak or communicate whatsoever. Before starting to shower her, the nurse notes that the patient has not defecated in a while, therefore, to my surprise and shock, the nurse makes her do it in a mechanical way, and for some minutes it is difficult for me not to gag. The nurse simply inserts her fingers in the anus of the patient and moves them, the patient squeals and seems to be uncomfortable. I am not used to see someone's body "invaded" in such a manner. The smell is very strong."[10].

In this particular example, two things combine to elicit in me a strong response; nudity and bodily boundaries being „violated".

The first thing I noticed that breached my sense of normality and signalled to me that I was in a different setting was the ubiquitous nudity of most of the patients.

This particular episode was challenging for me because I did not undergo any kind of training before entering the field, instead I was simply thrown into the daily life and practice of the ward, and was taught by practical examples without any prior explanation or warning, in the same way as any other volunteer experiences.

I had to overcome my initial feelings of uneasiness at the frequent sight of naked bodies to be able to continue with my research. This was particularly challenging since I had to forgo all the basic rules about nakedness which were natural for me.

I had to come to terms with the fact that I would be dealing frequently with issues such as death and illness.

Another issue that I had to deal with was my position among the staff, since I quickly found out that not everyone was positively attuned with my presence. As a matter of fact, from time to time I perceived that some of my colleagues would not acknowledge my presence by not greeting me. In time I came to interpret this seeming unfriendliness as a consequence of long night shifts spent awake, not so as a personal stance towards me. Nevertheless, my uneasiness caused by this apparent dislike towards me influenced me during my field work, since, in order to compensate for their attitude, I was frequently stressed and concerned about the quality of my work. During my shifts, I was often asked as in why I decided to volunteer, and my explanation was generally met with interest.

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[10] Field notes from 08.01.2019

4. EMPIRICAL PART

4.1 Structure of the empirical part

Firstly, after having described the palliative care in the context of the Czech Republic,I will describe a typical day at the ward in the style of „thick description‟ on the basis of field notes created during several months of fieldwork. Then, I will present the structure of the ward and its daily rhythm and routine in more detail and lastly, I will examine its actors; that is, staff and patients.

Then I will move onto the topic of the handling of the body, taking firstly into consideration the sphere of hygiene practices, then that of nutrition, and lastly that of medication. I will show how is the interaction between staff and patients based on the specific ways of handling the body. Moreover, I will focus on issues such as autonomy, and how it connects with the aforementioned issues.

Finally , death and its enactment will be analysed.

Therefore, I will not only be able to generally describe the reality of a ward of palliative care and its day to day routine, but I will also dwell on the significance of the body in this realm. I will especially underline its importance in the palliative care practices and multiple meanings that are attached to it.

4.2 Palliative care in the Czech Republic

The following empirical part is a tentative sketch of the reality of a palliative care ward in Czech Republic and its main actors.

In Czech Republic, there are different institutions that are especially_aimed towards terminal patients are several: LDN, hospices and some wards of hospitals which offer palliative care. The vast majority of Czech citizens die in the hospital; and they represent 59%, then, 20% die at home, whereas 9% die in some kind of structure, be it hospice or LDN. The rest dies either while being transported to the hospital or directly on the streets.[11]

The main difference between LDN and hospice is that the first institution mainly caters to those who are convalescent from an illness, and therefore not terminal patients. Since most of the patients in these structures are also seniors, it follows that many of them pass away during their stay.

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[11] Uzis.cz. (2019). Zemřelí 2010 ÚZIS ČR. [online] Available at: https://www.uzis.cz/publikace/zemreli-2010

Hospices on the other hand cater to terminal patients mostly[12]

The fact that more than half of those who pass do so in the context of the hospital or a similar institution, makes it clear that palliative and end of life knowledge should be kept relevant to provide a good service to the patient. Moreover, it is estimated that as many as 70“000 patients yearly only in Czech Republic require palliative care (Sláma, O. et al., 2016), and that there is a general need to boost knowledge about it and to better the service which is offered also through education.

The palliative care centre in which I conducted my research is a part of a larger hospital, and is not therefore an independent institution, but it is a ward of a hospital. Moreover, it is peculiar since there are amongst its staff also members of a nunnery; in fact the hospital itself has been founded and still today is managed by a congregation.

4.3 A typical day at the ward

I usually wake up at 5:30am to be at the hospital at around 6:50am, just in time to quickly change clothes and begin my shift at 7am sharp. When I enter the ward, there is silence all around. Patients are still sleeping. I can hear some of them snore or breath heavily. This sleepiness makes me think I would rather be in bed at this time of the morning, especially since I am more of a “night owl”, and waking up at 5.30 to make it in time for the morning shift is an ordeal for me.

I gloomily tell myself: “Still twelve hours to go inside here” as the typical mixture of sweet, unidentified smell and disinfectant greets me. The day shift begins at 7am and finishes at either 13pm or at 19pm. The staff from the night shift and those who just arrived for the morning sit together in the nurse's room, mostly silently and looking tired, sipping some tea or a coffee. I quickly change clothes and put on my brightly orange t-shirt, which signals that I am a volunteer. I hope that there are no nurses and hospital attendants with whom I don't get along.

Slowly and patiently the main nurse from the night shift informs us about the night that just passed, every single one of the patients is mentioned; someone had pain and kept calling the nurses, someone else kept waking up and calling on their long dead mother…The personnel calls this morning meeting 'the pass over'.

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[12] Holčáková-Masto, R. (2013). V hospici je postaráno o celého člověka. Katolický *Týdeník*. [on line] Available at: http://www.katyd.cz/clanky/v-hospici-je-postarano-o-celeho-cloveka.html

Mrs. V., a patient that has been with us for some months, is dying. A nurse asks: “Is it even right in this case to keep washing her all the time? She has not long to go, and maybe we are disturbing her…” The doctor underlines without a doubt that our duty is to keep her clean no matter the circumstances and says: “I would rather have her dying while you wash her than being dirty““.[13] This rough topic shakes me from my tiredness, and reminds me that this is indeed a place where life is at stake, even on quiet and sleepy mornings like this one.

When the pass over is finished, the personnel sits together in the living room, having some tea and gathering energy for the upcoming shift. The conversation is sparse, but amiable: “Girls! Have you heard about Mr. J.?” exclaims Sister F., “He is soon getting married, here, in the ward!” this brings us to speculate if we will have to dress him up for the occasion: “Then we will need four people at least to get him ready!” a nurse says jokingly.

At 7:45am, we divide in two groups each composed by a hospital attendant and a nurse, ready to tackle the first duty which is hygiene.

Whilst I gather all the other things that we need such as clean sheets and pyjamas, I start to notice even more the sour smell of disinfectant that lingers almost everywhere in the ward, and its acre aroma wakes me up completely.

We divide in two couples and together we go wake up the patients: “Good morning everyone!” we almost yell, so that everyone can hear us. An old lady does not seem to be waking up, so my colleague goes over to her, and caressing her arm says: “Good morning sleepy head!”. After this, we quickly start to remove the bedsheets and pyjamas, spraying some detergent onto their bodies and scrubbing it off. The air in the room is stale; especially when there are more that two people the smell is particular; sweet and sweaty. Whilst me and my colleague wash the patients we do not talk much, after all it is still early. We accomplish our task quite mechanically, and the interaction between us and the patients is also minimal. During hygiene practice, we expose the whole body of the patient; first we remove the diaper and, after having tilted the patient on the side, we clean his/hers private parts. Then we proceed to take off the anděl[14] completely and to wash them. It seems to me that the nudity gives our task a gravity which impedes small talk. It is fine for me, since I realize I work better in silence: even after some time at the ward I am still learning all the different procedures involved in hygiene and feeding.

Since most of the patients are bed bound and often not able to change position autonomously, the staff has to position them every two hours to prevent bed sores. For this task, at least two people are required. There is an additional piece of cloth measuring roughly 50×100 cm that is placed underneath the patient and between them and the mattress, which is used to move the patient up, down, or on the side. This is achieved by firmly grabbing one side each and then simultaneously both pulling and slightly lifting the body of the patient. Depending on the size of the patient, sometimes as many as three members of the staff are required. To picture how labour intensive this is it needs to be considered that, to achieve maximum comfort, patients that are not able to move must be changed of position at least every two hours. The majority of patients on the ward require assistance with changing position. Moreover, the vast majority of patients wear a diaper and need to change it at least two times a day, and to perform this task, two people are optimal.

After having washed all the patients, it is time for breakfast. We distribute it and help those who are not able to eat by themselves or have some sort of difficulty. Usually some patients have a PEG tube[15], and in this case we pump the liquid food into their stomach trough an opening in it.

Today my colleague wants to teach me how to carry out this procedure. We enter in the room of Mr. P., he has been bed bound for a long time now, at least 7 years, and because of this his muscles have withered away completely; his body is extremely thin, and it looks fragile. Because of neural damage his muscles are not only wasted, they are always stiff and in an unnatural position. Two people are needed to keep his legs apart to wash him. Does not move nor communicate, He has had a tracheotomy[16], and from the hole on the centre of his neck there is always some mucus flowing, especially when he has bouts of violent cough. Therefore we put on our masks before entering, to protect ourselves from the spittle and mucus. “What a shame! Look how handsome he was!” my colleague says, looking at the pictures on the wall that depict him in his youth whilst giving mass. “Yes he was, poor thing...” I reply and ask if anyone ever comes to spend some time with him. Apparently no one ever comes. Then, I am shown how easy it is to pump liquid food into a stomach, using what looks like a very big syringe: my colleague fills up the syringe with a brownish liquid of a bottle and injects it into the tube that is in the patients stomach.

Lunch time is a long awaited moment for everyone. Everyone, excluding the doctor, has lunch together in the common room. The food is not so different from the food that patients get, with the exception that theirs is cut in small pieces to make it easy to swallow. I look at my food and think about my very first days at the ward, when I was almost not able to eat during lunchtime because of my encounter with situations that were unfamiliar to me, which did not stimulate my appetite, namely the ubiquitous nudity and corporal functions. Now, I have no problem, and I eat with gusto. After lunch, it is time to go back to work.

During the night shifts the ward changes completely, from being relatively busy and full of staff, the ward becomes silent and dark, except for the light in the sesterna, that is always kept on. Tonight we are only three: me, a hospital attendant and a nurse. When we begin our shift, at 7pm, there are no more tasks left to carry out, since dinner has already been distributed. Therefore we sit together in the sesterna, and occasionally we go around checking on the patients. Everything is silent and still, except for a new young patient, whose moans echo in the hallway from time to time; he has a brain tumour, and is quite confused and scared at times. At 2am we go and comfort him, offer some painkillers for the night. Me and my colleague say to Sister I. that we feel like going to say hello to the cats downstairs in the garden, and she smiles, knowing that we are instead going for a cigarette. We talk about our colleagues and how sometimes they seem oblivious to the pain of the patients, especially when they request to be turned in the bed frequently; "You know what I would say to them?" asks P., "I would suggest that they try and lie in their beds in an uncomfortable position for an hour or so, and see what they think of it!", I nod and smile, I understand her frustration.

At around 4am I am too tired, and since there is nothing to do, Sister I. insist that I sleep on the couch in the sesterna, so she makes me a bed with some spare sheets and pillows, and I sleep until morning. I am woken up at 7am, I quickly get ready and finally leave.

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[13] PEG (percutaneous endoscopic gastrostomy) is a procedure performed on patients that are dysphagic, which means they are not able to swallow. This issue is common in cases of heavy sedation and as a consequence of a stroke. It is usually inserted as a last resort to keep the patient alive in critical conditions, to hydrate and feed them.

[3] A tracheotomy is a surgical procedure in which a cut is performed on the front of the neck to the windpipe, to either insert a tracheal tube or to ease breathing, for example in presence of excessive mucus.

[4] Field notes from 18.01.2019

[5] In Czech "angel"; a knee long robe with long sleeves which fastens behind the back and is backless, leaving the front concealed and the back bare. The "anděl"enables the staff to quickly roll the patient on the side, and sincethe back is bare, simply look into the diaper to check if it is clean.

4.4 Description of the ward

The palliative ward is part of a larger hospital complex and it belongs to the same structure. It is run by a Christian congregation.

It is situated on the second floor of the building, and it is accessible by (after entering from the main entrance),walking through the corridors of the hospital, and then by taking the elevator to the second floor. The ward develops on a corridor, and on both sides of it there are patient's rooms. A large garden is also part of the hospital, and is accessible to both staff and patients of the palliative ward by using an elevator.

Although the building of the hospital itself is quite old, this ward in particular feels renovated; the walls are painted in bright yellow and the equipment all around is new and shiny. Moreover, the re are quite big windows not only on the corridor, but also in every room. They let enter bright light and make the atmosphere quite lively. As there is no sound coming from the outside, since windows are usually kept closed at all times, the ward is usually quiet. The only sounds that are heard are the muffled and monotone ones coming from televisions that patients have in their rooms and the occasional moaning and groaning of patients that are calling nurses or lamenting their pain. For this reason, most of the doors are always left open. There are in total 10 rooms for patients and most of them are suited for 2 and occasionally 3 people. Three rooms are suitable for one person only, and they are all located on the right side of the corridor. All the rooms have an en suite bathroom that includes a shower. Next to each bed there is a wooden bedside table and a foldable table which are used during meals. Personal belongings are scattered on both tables, usually there are only a few items; glasses, some favourite snacks brought by the relatives, a couple of pictures of nieces and nephews. The rest of these personal items are usually kept in a wardrobe in the room. Usually, patients do not bring many personal objects with them; most of the patients are usually so poorly in terms of health that their activities are limited to watching TV. Moreover, there is a television and another table and two chairs as well. The bed is always oriented so the patient can get a nice view of the city through the window, which is present in every room.

The patient's beds are specially designed to prevent bed sores, so they are automated and can be moved up and down to be more comfortable[17], also the mattresses are filled with air instead of fabric, for the same reason. All the sheets and pillowcases are white.

An interesting feature is that next to every patient's door there is a small plastic box that lights up for different reasons. If it lights up with red, that means that the patient inside has requested for someone to come for various reasons, if a doctor is present then it lights up with blue (when the doctor enters, she pushes a button) and when a hospital attendant is inside, then it lights up with green.

When someone has died and the body is still in the room, then the light is both green and blue to signal this.

On the right side of the main corridor there is the small room for the personnel that the staff calls 'sesterna'[18] equipped with two armchairs and a sofa. A kitchen with a fridge completes it. This is where time is spent during moments of pause and inactivity or during morning meetings. It has a quite nice atmosphere; there is always some tea ready, snacks are available to everyone, moreover, almost every day, someone brings a home made cake or snacks from home to share with everyone. In the sesterna is also a small library from which the staff can borrow books, most of them are about palliation.

Since most of the patients are not able to perform routine body hygiene by themselves, there is a bathroom specially equipped for bed bound patients right next to the sesterna. It is a large room, this is to enable us to wheel the patient in on a special waterproof stretcher, and to manoeuvre with it easily. It is located next to the nurses room.

Next to the entrance there is also what the personnel call „day room‟, which is meant to be used as a living room by patients and their families. It is equipped with a large table and chairs, a sofa, a microwave and a bookshelf. Given that most of the patients have very impaired to no mobility, the room is almost never used for this purpose, instead the personnel uses it to lunch together.

Next to the day room there is the doctors office, where patients are examined and where the interaction between families and doctors happen; this includes admissions of new patients and evaluation and assessment of present patients

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[3] These special beds are called „hospital cots‟ and their features include lockable wheels, elevation at the head and feet, side rails to prevent the patient from falling out.

[4] In Czech “Nurse‟s room”.

4.4.1 The staff

The personnel of the ward is formed largely by women from their late forties to sixties, and they make up at least the 90% of the staff. There are in total twenty people between nurses, doctors, nuns and volunteers and chaplains that work at the ward. The nuns are members of the congregation that runs the hospital.

I was curious as in why in a milieu where considerable physical force is required, there are almost no male nurses. I got two different answers to my question from two different nurses considering this gender asymmetry; one opinion was that this is a consequence of the fact that females are generally more nurturing and care oriented in their view than males. The other informant stated that since being a hospital attendant or a nurse is not at all rewarding in terms of salary, this option is usually chosen by those who do not seek to ascend in their career and that usually these individuals happen to be women, wives and mothers that are more content with a part time job which leaves them enough time to invest in their families.

The different positions of the staff are signalled by the colour of their uniform; doctors wear white pants and a white cloak, nurses wear a green uniform composed by a shirt and pants, hospital attendants have a yellow one and volunteers wear a bright orange t-shirt and white pants. Nuns wear their robe. The doctors usually are the ones who are seen the least in the ward during our daily operations, they come only in the morning, and go around the ward checking on the patients and to keep under control medicines and how drugs are administered to patients, they in short have the overview of what is happening daily. They are also those who deal with families almost exclusively, and this happens in their private room. Nurses are individuals with formal medical training who are supposed to take care of performing certain actions on the patients such as injecting them or administering drugs, but under the direction of doctors. The hospital attendants do not have a formal education equivalent to that of nurses and are more concerned with tasks such as feeding the patients and keeping them clean and in a comfortable position. Lastly, volunteers also operate in the ward, and they are allowed to come whenever they want. They can perform many of the tasks that hospital attendants or nurses carry out, obviously under supervision. During the day shift there is present the doctor, at least two nurses and two hospital attendants, whereas during the night shift there is only one nurse and one hospital attendant. A chaplain is also an important member of the staff, and he/she is present every other day to visit patients and offer them spiritual counselling and support if needed or requested. The presence of the chaplain is telling of the interdisciplinarity that is particular to palliative care service, which aims to bring respite not only to the body but also to cater to spiritual and psychological needs.

4.4.2 The patients

They can be referred to the structure by their general practitioner, and then the doctor of the ward must admit the patient. Usually patients that are admitted to the palliative ward are those with poor symptom control, and the aim of the admission is to put in regime an adequate pain and symptom therapy. Once entered in the ward and once an adequate pain therapy is administered, the patient may visit his home for some days, if their health allows it. It is also possible that the patient will go back home once that is stabilized.

The majority of the patients that are admitted are terminally ill, and palliation is offered to those suffering from consequences of illnesses such as cancer, cardiovascular and cerebral complications. If the patient is not by his senses, the person who is legally responsible for him/her decides.

The patients in the ward are predominantly females in their mid sixties to seventies, the other most numerous group is that of males of the same age. Sporadically, I have met younger patients in their forties, and the youngest patient that I know of was a young woman aged 28.

The absolute majority of patients are bed bound. During my work there I have never seen anyone venture outside of their rooms, so the spaces that are destined for recreation such as the common room are always only used by the staff, never by the patients.

In terms of autonomy at least two thirds of patients have to be helped to some degree during mealtimes, and all of them have either a catheter or a diaper that is periodically changed by the personnel.

I would like to introduce one particular patient, and through describing his distinctive attitude, which is exceptional in comparison to others, I will also be able to illustrate the norm by opposition.

Mr. H. is an exceptional patient under many aspects, and he was so from the first day he arrived at the ward:

> *There is a new patient in room 10, and he seems to be quite a problematic one, since I hear a lot of complains about him from the staff,during the pass over in the morning. I*

understand later, when I have a face to face encounter with him why he is so particular. Even the doctor, who is usually very measured in what she says, states that he is way too demanding, and that to satisfy some of his needs he should call his family and have them do it 'instead of harassing us'. Too bad he has only a daughter and she lives far away. She also warns the personnel and invite us to maintain a line between us and him, so he does not boss us around us. When we later during the day go to washhis mouth and dentures upon his request, this seemingly simple operation becomes difficult, he is telling us what to do to the most minute detail, he is even telling us the exact quantity of toothpaste that we need to put on the dentures to wash them properly. On the wall I see a picture, a sort of illustration drawn by someone, possibly his family. It depicts a denture and the exact three spots where he wants us to apply the toothpaste, in the centre a little bit, and then on the sides a bit more.

The whole scene is borderline comic: he tells us to bring the dentures to him, so he can oversee how we apply the glue on the dentures and if we do it something wrong he stiffens up, frowns and says with great effort[19] *with his low and raspy voice: „Noo...not...like...that!" I carry out his instructions, while my colleague oversees the scene with an amused expression on her face. I intercept her gaze and we snicker.*[20]

Later on, I gathered from various colleagues that Mr. H. was an army officer, and everyone interpreted his bossiness as a direct effect of his profession. Most of the patients, upon entering the ward, seem to be somehow deprived of their previous self; their clothes are removed and a standard clothing is given to them to wear, they are generally referred to by their surname and their previous identity is somehow unidentifiable in the new setting of the hospital. On the other hand, Mr. H was able to remind everyone around him most of the time where he came from and what expectations he had from us.

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3 Muscular dystrophy causes also important breathing problems that in turn cause difficulties with speaking in the last stages of the illness.

4 Field notes from 20.02.2019

In a few days he has become the 'star' of the ward, everyone talks about him, not in a very flattering way:

The doctor says he is so unpleasant that sometimes you would want to give him a slap.. He is getting worse, and because of this he also tries to control everything around him more than usual.[21]

It is worthy to notice that such a resolute man has contracted a disease which, perhaps more than many other ones, is merciless in reminding the sick person of their limits a little bit more everyday. Unfortunately, Mr. H. suffers from muscular dystrophy, which is characterized by a slow and steady deterioration of muscles and their functionality. He must wear a special mask which helps him to breathe at least 5 hours per day, since his lungs started collapsing he now speaks in a very low tone of voice, with long pauses between each small sentence. Because of this we must sometimes lean closer to him and listen to him slowly and softly telling us what we did wrong. He has also progressively lost strength in his arms and legs, and is now unable to move. This does not discourage him from protesting when something does not please him.

Since I started to interpret the bossiness of Mr. H. as a positive quality, our relationship started to improve. The only thing I had to do was to listen to his desires and directives and to execute them. I did not deem him a 'difficult one' any more, and just interpreted his ways as peculiar to his personality.

4.5 Making of the body in context

The relationship between staff and patients is based on a daily interaction that happens namely in three spheres: hygiene practices, nutrition and medication. This relationship is mediated most of all by the body of the patient, which is also a site in which certain meanings are inscribed.

Through this relationship, a certain kind of body is „made", not only the „unbounded" one in which boundedness must be reinstated, but also, by opposition, the healthy and „bounded" one is construed.

My aim is not only to describe how is the body of the patient handled in the palliative ward, but also to explore the consequences and meanings behind these actions.

The first and foremost interaction which has the body at its centre is daily hygiene practice; I will illustrate attitudes towards dirt and elaborate on the making of the „unbounded body".

In the sphere of medication and nutrition I will mostly dwell on issues of autonomy. My position as a volunteer impeded me to be present in the moments in which thematics like medication are discussed. These spheres were almost exclusively domain of the doctors, who decided who should have what kind of medicines and for what reason. Therefore, the subchapter "Hygiene Practices" contains more material: this is the reflection of my experience on the field.

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3 Field notes from 15.02.201

4.5.1 Hygiene practices

In the following subchapter I will analyse some excerpts from my field notes to underline the centrality of hygiene practices in the ward and their significance.
Moreover I will focus on the different attitudes of the staff towards dirt and hygiene and their meaning and impact in the making of the body in the context of the ward.

> *I noticed that before starting with the hygiene, the nurses and the hospital attendants consult a small blackboard kept in the „sesterna" on which there is the name of all the patients followed by two informations; when they were washed lastly and their last bowel movement. Before anything else, in a glimpse we know who we have to bathe and who shall have their suppository inserted. Right after the pass over in the morning the staff divides into two groups; we grab a little basket which contains everything we need; lotion,diapers, scrubs and we start washing the patientsbefore breakfast. We enter into rooms that are still dimly lit and we wake up the patients quickly. There is no time to spare; there are 17 patients as of today, and we have to wash them all before 9:30am, when breakfast is served.*[22]

The fact that nurses do not go around, asking each patient if they feel a bowel movement, but instead consult the blackboard and then walking in the room saying: "It seems like today we have to poo!" reveals what source of information is given priority. This detail reminds of the focauldian „medical gaze", and on the primacy of the doctor and visual cues to assess the state of the patient. Power relationships are also clearly distinguishable in this example: authority is not placed in the subjective recount of the patient, but rather in some, usually visual, cues that are deciphered by the doctors.

Hygiene is a key moment of the daily routine, since it is the occasion in which the patient comes in most direct contact with the staff, in fact, all patients that are not autonomous are washed in bed everyday with a damp sponge, and, every three days, they receive a full shower. The fact that hygiene is carried out before breakfast clearly reveals the hierarchy of tasks in this ward.

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[4] Field notes from 17.01.2019

We wash the patients carefully; first we remove the anděl, leaving the patient completely naked, and we scrub their whole body with a damp sponge and soap. We tilt the patient on one side, and we take turns in washing their backs. Then we also remove the diaper and we scrupulously wash the private parts. It is still, even after many times, difficult for me to bring myself to wash the genitals of both men and women, because we need to pull down the foreskin and to scrub between the labia.

I try to do it without looking at the body of the patient.

After lunch is served at 12, after cleaning up the food trays and having our short break, we go around the ward and position the patients so no bed sores develop, and, most importantly, wecheck the diapers attentively, changing those which are wet. After lunch, from 13 onwards, there is not much to do other than going around checking on patients from time to time, but I am instructed that diaper checking is paramount. So it happens that when we have nothing to do and we are sitting in the „sesterna“ chatting or relaxing and a doctor comes around, we just get up, so it does not seem like we are idle, and go around the ward, checking diapers.[23]

It is evident that most effort is spent in helping the patient deal with some sort of leakage in their bodies: urine, faeces, saliva, mucus etc., which they are not able to manage any more, having lost control over their bodily functions and boundaries.

In a way it seems to me that chaos and the threat of uncleanness are „at war“ with us, and that most of our time is spent in an infinite battle to try and dam it. I would go on to say that I agree with Lawton (2005) in her suggestion that the ward can be seen as a putative new boundary that reconstitutes the unbounded body of the patient and that, the meticulous hygiene performed on the bodies of the patients aims to make good of their deficiency of control over themselves, moreover it reconstitutes and reinforces the importance of the bounded body and what it means to be autonomous.

Mr. K. is a new patient that has arrived just yesterday evening. We go to check on him to see how he is doing. My colleague makes me put on a mask before we enter. Mr. K. has a ostomy bag[24] *and the room is filled with the smell of excreta. I am not sure why I was told to put on the mask, since it does not help at all with the smell.*[25]

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5 Field notes from 27.02.2019

6 An ostomy bag is a medical device that consists of a plastic bag which collects waste from the colon bybeing directly connected to the opening in the colon. It lets gases to pass through it.

7 Field notes from 01.03.2019

> *Every time we enter the room of Mr. P. we put on our masks, even though there is nothing to protect ourselves from. Sometimes, when he coughs, he also projects a bit of mucus, but it falls onto his dribble. Still, we are protecting ourselves.*[26]

Douglas (1970, p.121) wonders why bodily waste matters are a "symbol of danger and power" Since excreta and other matter exit the body from orifices, and orifices are by nature dangerous since vulnerable, what exits these orifices possesses a "marginal" quality. They are also dangerous because they transgress a discrete boundary of the body (Ibid.)

This explanation would also explain why I have often observed that hygiene precautions are taken even if there is no real risk of contagion, as it emerges from the aforementioned field notes.

Many patients have a catheter inserted, and this helps in the work load; we do not have to check their diaper so frequently for the catheterized patients.

Usually, the insertion of the catheter is concomitant with the loss of mental awareness of the patient more than it is connected with the loss of control over their bladder. Indeed I have noticed that patients that are incontinent or semi incontinent like Mr. H., but aware and mentally sound, refuse the insertion of the catheter:

> *While I am with Mr. H in his room and watching the news with him on the TV, he tells me abruptly that he needs to pee: at first I am unsure as of why he has told me, then I remember that he hasgot no catheter, only a diaper. Still, I need some moments to realize that he wants me to help him by taking the „bažant"*[27]*, so that he does not have to wet his diaper. I am embarrassed, but trying to look unphazed, I quickly pull his diaper down and put his penis in the opening of the urinal and wait for him to finish.*[28]

Since Mr. H suffers from advanced muscular dystrophy, he is not able to hold his penis by himself since his hands are too weak, but still prefers asking for help when possible instead of wetting his diaper. Thus, control over ones own excreta seems to be an indicator of ones residual autonomy, and there is an evident need to preserve this last bit of autonomy as long as possible in the case of some patients.

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[8] Field notes from 27.02.2019

[9] In Czech „pheasant"; a plastic urinal that takes its name because of its shape which resembles that of the bird. It can also be used to monitor the amount of fluids that are produced by the patient. After being used, they are quickly rinsed with soap and water and left at the bedside for future use.

[10] Field notes from 01.03.2019

The majority of the patients of the palliative ward are incontinent or double incontinent. Lawton (2005) argues that a definite kind of bodies are admitted to inpatient hospitals and palliative wards, and these are 'unbounded bodies'; bodies that cannot manage any more their orifices, being unable to retain various fluids and smells. By doing this, a definite image of a 'bounded' body is produced, along with a precise idea of what it means to be in control and autonomous: the 'bounded body' is constructed in opposition to the 'unbounded body'.

Before starting my fieldwork I entertained the idea that, being death a taboo in our society, hospices and palliative care wards were spaces in which the phenomenon of death and dying was hidden and tucked away, but Lawton (Ibid.) in her analysis argues that in fact this explanation is incorrect: she argues in fact that it is not death and dying *per se* that are concealed from society. Rather, it is a definite kind of decaying body that is marginalized and destined to the palliative ward or hospice, and she identifies this kind of body with the unbounded type, suggesting that it is, in our Western context, thought to be dirty and polluting (Lawton, 2005).

Lawton, working on the concepts of dirt by Mary Douglas, identifies the body of the incontinent patient as a symbol of disorder that contradicts the rules of society and must be, therefore, concealed from the society.

There are dispensers of disinfectant everywhere: near the sink in the staffs bathroom, on the table of the „sesterna" and also at the entrance of every patient's room. I am told that we should always rub some in our hands before we enter the patient's room.[29]

I am reminded of the importance of disinfection at all times, and it has some effects on how I perceive patients as well:

This afternoon while washing the hair of an older lady, I suddenly realised I was wearing gloves whilst doing this...and I thought this to be weird and maybe even offensive to the patient. In fact, the lady was not dirty or smelly, so why did I feel the need to put on gloves while accomplishing a task that hairdressers do not use gloves for?[30]

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[11] Field notes from 08.01.2019

[12] Field notes from 01.03.2019

Soon I noticed how this emphasis on cleanliness affected my behaviour: being always reminded to sanitize my hands after having come in contact with a patient, my attitudes towards them and their bodies began to change.
It seems to me that by employing a tool such as the gloves to carry out a procedure which does not result in pollution such as washing (already almost completely clean) hair, I was putting in practice some hedging off from the patients and their bodies.

I would argue that the attitude towards hygiene is quite dependent on the gender of the caretaker, too. Female staff, which makes up roughly the 90% of the total, is very particular and fussy when it comes to washing the patients, taking care of minute details to ensure that hygiene is carried out meticulously. P. instead, the only male nurse I have ever worked with, represents in this regard a notable exception. In fact, his whole approach to the patients proved quite unique.

The first thing I notice is his carefree attitude towards patients; instead of calling them by their surname in the expected polite way he simply addresses everyone by their name. Not only that, many times he even uses pet forms, never in a condescending manner, but rather as a form of confidence. Once, whilst we were washing a patient he abruptly said: "Hygiene is given too much importance in this ward, you know. Twenty years ago, in wards like this, patients were only washed during weekends, and this was because families were only allowed on these days. Today it is just too much".
Most of, if not all female nurses never actively expressed disgust for bodily fluids, smells or emissions that can be quite unpleasant. Instead I have for the first time heard the exclamation of disgust "Fuj" by the male nurse P.

Therefore, a distinct kind of body is made through practice and interaction between patient and staff; through fastidious and detailed care about bodily orifices, bodily waste and propriety the unbounded body is made bounded again, albeit for a short time. In this making good of a deficiency concerning control over one's own orifices, the bounded body is made by contraposition, and defined by opposition.

4.5.2 Nutrition

Feeding is a central part of the life in the ward. Food is distributed at breakfast, lunch and at supper. The majority of patients need to be assisted: this ranges to only cutting the food into smaller pieces and leaving them to eat by themselves, to instead aid in all the movements and feed the patient spoon by spoon. In some cases where the patient is unconscious or unable to swallow food, a PEG is put in place and patients are fed through it. In this case, issues of autonomy do come up frequently:

Me and my colleague F. are going around the ward, checking on patients to see if anyone needs anything and we stop at the bedside of Mr. D. He is just skin and bones, and not responsive any more, due to an accident. My colleague turns towards me and: „You see, doctor G. made a very good decision when she installed the PEG, without it he would have been long gone!". I nod silently. I think to myself that he has been long gone nonetheless.[31]

In cases where patients cannot give consent to certain procedures as for example insertions of catheters, or, as in this case, PEG, the family is consulted.

Mr. H. has gained a certain reputation in the ward during his relatively short stay. He is fussy about every little thing. Today at lunch time, since I noticed that the other nurses did not seem impatient to bring him his tray, I decided to go instead. My willingness to „sacrifice" myself was welcomed with hilarity: 'Really? You want to go? Good luck!', all followed by laughter. There was bread and cheese spread and fruit purée. Mr. H had his ideas clear about how he wanted me to feed him, since he is not even able to lift his hand to hold a spoon or fork. He painstakingly instructed me how to cut the bread and how much spread to put on it. Then he explained that he wanted to be fed two pieces of bread followed by one spoonful of purée, and that all had to be followed by a sip of water. The plate had to be placed on the bedside table, exactly between the water bottle and the napkin dispenser.[32]

The episode described represents an exception in the realm of nutrition and how it is carried out. Normally, the staff employs certain words and expressions such as "Papej!" or "nabumbej se!"[33] which are normally used whilst speaking to children, whilst feeding the patients. This is telling of the atmosphere in which these tasks are carried out. This infantilization is also evident in the fact that, some staff usually praises and caresses on the head those patients that finish their meals with exclamations such as: "Yes! You ate it all, good job!".

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[3] Field notes from 17.01.2019

[4] Field notes from 22.03.2019

[5] In Czech 'eat!' and 'drink!'

Since this attitude is the norm, it is easy to understand why Mr. H. is seen as 'particular': he does not remain passive during meals, instead, he tells the staff how he wants to be fed in detail. His attitude, in my opinion, overturns the roles between staff and patients, making the staff passively carry out his instructions, instead of the patient passively receiving food. The staff also refrains from using 'baby talk' with Mr. H. or from caressing him.

4.5.3 Medication

Mrs. B. has some problems with coordination also due to the fact that she is heavily sedated.

During lunchtime she needs to put on her dentures since she is still able to chew the food herself. But she has problems when it comes to inserting the teeth in the mouth, and for this she need the help of the nurse. Me and Sister N. go to her room to assist her. Mrs. B. tries to put the teeth in her mouth but it is difficult; she takes the dentures from a glass and lifts it up to her mouth, then she tries to insert them, but it is not working, she cannot find the right way to put them in. Me and sister N. silently look at her struggling. Sister N. tries to put them in for her, and after some trying she harshly tells the patient that she has no time for this and leaves the patient with her teeth in her hand. Mrs. B . stares at the dentures helplessly.[34]

Medication is regularly administered by nurses on the indication of doctors. I apprehend from the discussions during pass overs that most of the patients are heavily sedated by a mixture of heavy opioids and antidepressants. The administration of these drugs is discussed with the patients, and they are administered with their consent. If the patient is not able to give consent due to health issues, then the family is consulted. In this particular case, once it was clear that Mrs. B. was slowed down in her motion and confused because of a high dosage of medication, her dose was lowered.

During pass over, Doctor F. is complaining again about Mr. H.: „Oh, I don"t know how to deal with him any more...he is restless but does not want medication, he is afraid of dying but does not want to live, he is scared but does not want any medication...it's helpless to try and reason with him".[35]

It seems to me that the norm which is expected from the staff is the „well behaved patient", one that does not toss and turn in bed, one that is in a peaceful disposition and collaborative. This is achieved by the administration of antidepressants and antipsychotics mainly. Those who refuse as Mr. H., are seen, in my opinion, as rather particular and not collaborative.

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[3] Field notes from 25.01.2019

[4] Fieldnotes from 22.03.2019

4.6 Handling of the dead and dying body.

During my stay at the hospital I only once witnessed how death happens in the ward and what are the ways in which it is handled:

> *This afternoon, the patient on room X has passed away, and the body is still in the room. The morning staff has been waiting for the funerary service to come and pick the body up for the whole afternoon. Me and two other nurses go to have a look at him. I am told he had an easy death and that he did not suffer, although he died alone, the family was not present. We enter the room, the lights have been dimmed, and only a small one is left, the window is open since, as one hospital attendant says, the body starts to decay quickly after death. On the side table, a candle has been lit and a little flower in a vase has been added. He is laying on his back with his hands on the lap, holding a little bunch of flowers. He is wearing a black suit and a cravat, his skin is quite pale, and the hands even more so. I do not get close, I would not know what to do anyway. Me and my colleagues stand there awkwardly in silence. After a minute or so of silence, we exit. We all go about our daily chores, commenting on the lateness of the funerary service...*[36]

A symbolic preoccupation with cleanliness can be seen in the fact that, although the body only stayed in the room for few hours after the patient passed, still, the nurses kept the window open. Decaying corpses in fact do not give off any smell until one to three days since death, and still it was deemed necessary to keep the window open for ventilation at all times, even if there was no one inside.[37] Again, the body that is made by these actions and interactions with it recount of a body „out of place" and of dangerous miasmata that can potentially come out of it.

> *Once the body has been taken away by the funerary service, everything must be thoroughly cleaned and prepared for the next patient. This means that every surface in the room must be cleansed and disinfected; me and my colleague grab the spray disinfectant and start to spray every surface of the room. Special instruments need to be employed to totally cleanse the room, especially the bed and bedsheets. For this purpose we utilize a special lamp that radiates certain frequencies which*

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[5] Field notes from 22.03.2019

[6] I asked my colleagues as in why was the window open, and they answered that it was because of smells.

destroy the germs. The lamp is turned on and directed towards the bed on which we stake all of the pillows and bedsheets that were used by the deceased. Seeing how the lamp radiates its red- yellowish rays on the bed, it seems to me that death is being pushed away and made harmless in a tangible way.[38]

Before it was all around the room, it soaked objects and the air itself, and by virtue of the lamp it is gone somehow. The dead body seems to impregnate objects of a polluting quality that needs to be expelled.

On room X, there are two older gentlemen, both seem to be not so bad since they both eat by themselves and need less help with hygiene, also they like each other and the personnel often times comments on this positively. On the birthday of one of them we go and sing some songs and leave some little gifts. Unfortunately, after a while one of them gets worse so the gentlemen who is better is moved to a different room. After a while he is dismissed home and I hear that this is largely due to the fact that with a lot of willpower he got himself better, trough gymnastics. The men left on room X now is clearly sad because he lost his sort of companion and often refuses to eat. I notice that when two people share a room, and one of them gets worse, usually one of them is moved, I guess not to contaminate in a way the possibility of recovery of the other. So death in this case seems to be concealed.[39]

Usually the staff takes care that those who are near death, or judged to be so, are not in the same room as those whose condition is better. In some cases this goes as far as removing one of the patients well before his or her death, at the minimum sign of deterioration.

Death then, is not a sudden event in the routine of the palliative ward, but rather is a process that begins in the moment in which the doctor or the nurses notice certain signs that indicate the proximity of death that they „read“ on the patient's body. These signs include cold extremities, periods of longer somnolence and mouth breathing (Rome et al., 2011). This reliance on visual clues by the doctors to form a diagnosis is reminding of the notion of 'medical gaze' by Lupton (1997).

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[7] Field notes from 22.03.2019

[8] Field notes from 18.01.2019

Once it is judged that the patient will not survive for long, they are moved to a side room, which is at once a measure that ensures privacy to the dying and their family and also spares other patients from witnessing directly the death of their room mate. The power asymmetry between patient and doctor is evident in this case; what is paramount is the medical evaluation more than the subjective recount of the patient.

What is death and what it means to be dead and, by extension, to be alive? During my fieldwork I began to question myself about these issues, since I was presented with patients that, because of their peculiar physical state, escaped definitions and labels, they were not here nor there;

> *The patient on room X was a priest, and has been bed bound for a long time now. He has had a tracheotomy since he was not able to breath any more. Does not move nor communicate, and is being fed through the feeding tube directly into his stomach. He does not keep eye contact so there is no way to tell if he is so to say „here“. One of the cases that I find the most sad since no one ever comes to visit him.*[40]

The fact that no one comes to visit the patient, in my opinion, signifies that he has already been cut off from his close relationships, and this indicates that he is more close to the realm of death that to that of life.

In certain cases it seems that death does not happen abruptly, instead it slowly insinuates itself into life, indeed for Lawton (2005), social death happens when relationships and the previous status of the patient are compromised. Strathern (1992, p.15) holds that „individuality“ is „both a fact of and “after” kinship“, meaning that our identity is made in the relationship that we have with others, with our kin. Outside of this relationship, we, in a way, cease to exist.

Without interacting with those around us, such as family and friends, we may lose touch with ourselves, since we do not occupy any more the space that we used to in the lives of others.

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3 Field notes from 08.03.2019

5. CONCLUSION

Since in the developed countries life expectancy is on the rise and we are assisting to the phenomenon of a steadily growing ageing population, it is sensible to say that more and more people will be in need of palliation and hospice care in the future. Because of this, it seems important to analyse the space of palliative care institutions. Moreover, anthropologically relevant themes such as death and the body are connected to the palliative care.

In the broader context of the institutions that deal with death and dying, I carried out an ethnographic study of a palliative care ward for four months in which I employed mostly the technique of participant observation in the role of a volunteer-researcher.

In my research I tried to depict the environment of a palliative care ward, its daily rhythm and its actors. Moreover, I focused on the significance of the interactions between patients and nurses. I also focused on the body and on the significance of the practices connected to it.

During my field work I began to understand the centrality of the body in said relations in different occasions, and I tried to convey its relevance. My focus on these topics, namely the body and the ways in which patients and nurses interact, is due to my position as a volunteer; in fact, being a member of the staff, I could easily access all the spheres that pertain to hospital attendants and nurses, and I especially took part in activities in which the personnel tends to the bodily needs of the patients. Other spheres, such as those of the doctors or the chaplains were not accessible to me. This caused my point of view and my field notes to be more inclined towards other topics.

I focused mainly on three different spheres of interaction: hygiene practices, nutrition and medication.

Following the theories of Douglas (1970), I analysed how the body can be read as a symbol of society and its preoccupations and ideals. In line with this argument, Crawford (1994) argued that after the diffusion of the Protestant Reformation in the West, attitudes towards the body began to change. Since the protestants highly prized the idea of self mastery over ones life, this attitude also was reflected on the body and, by extension, on its fluids. The fact that this approach towards the body and its fluids is particular to a time and space is corroborated by the evidence given by Taylor (in Lawton, 2005: 140), that indicate that, especially in societies that do not put an accent on individuality as much as the Western ones, bodily fluids are often not seen as 'polluting' but carrying the identity of the person instead.

Lawton (2005), argues that a very specific kind of body is usually present in the hospice or in the palliative ward, and it is the „unbounded body". These bodies are characterized by a leakage of fluids or smells that the patients cannot contain, and because of this, they are in turn destined to specialized structures. Hospices and palliative care wards then intervene on the „unbounded" body, and by reiterating hygiene practices they aim to reconstitute the „bounded" body, one that is in control of its orifices and of what comes out of them. Therefore, these structures are defined as aiming to provide palliative care to terminal patients, when upon closer analysis they take care of those bodies which are, in our Western society, deemed as „polluting" because of their „unbounded" quality.

Hygiene is one of the most important aspects of the palliative care ward; it is scrupulously monitored and enforced on the body of the patient. I connect the repetitive and fastidious hygienic care that is provided in the palliative care ward with the concept of „bounded" and „unbounded body" by Lawton (Ibid.).

Therefore, the way in which the body is handled in the context of hygiene practices suggests that there is a symbolic preoccupation with cleanness and dirt, and that in this process two kinds of bodies are defined: one is the „unbounded" one, characterized by leakage and loss of control over borders, and the other is the „bounded" body, which is characterized by self-mastery.

In the sphere of medication, by employing antidepressants, anti psychotics and opioids, not only physical and psychological pain are targeted, but also an image of a „model" patient are construed, and certain symptoms connected to the end of life such as delirium are eliminated. Those patients who refuse this kind of therapy are often labelled and referred to as „difficult"and non collaborative.

Certain visual and sensory cues guide the nurses to individuate patients that are close to death, and this entails a change in status of the patient; they are from the moment of the diagnosis relegated to a side room by themselves until they pass away. Therefore, connecting to the focauldian concept of medical gaze, I show how there is a distinctive primacy of the personnel and their interpretations of cues rather than the subjective recount of the patient.

The dead body is seen and treated as a pollutant, and meticulous hygiene practices are put in place around corpses in the ward. To conclude, in the palliative care ward the body is mainly handled in three spheres; hygiene practices, nutrition and medication.

Especially in the sphere of hygiene practices, it seems that the body is seen as the locus of autonomy and self containment, which are paramount in our Western society. Therefore, bodies that are not able any more to exert control over their fluids are seen as deviant from the norm and are destined to the palliative care ward, which can be seen as a structure which provides the reconstruction of the boundaries.

The hygiene practices aimed at the reinstatement of bodily boundaries define also the norm of the „bounded" body by contrast with the dysfunctional „unbounded" one.

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