Surviving machines.
On how nurses cope with suffering, death, and medical ideology in an Intensive Care Ward

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In the intensive care unit

drips to give you fluid or blood

catheter to let you pass urine

chest drains

breathing tube

tube in your wrist to measure your blood pressure
to ECG monitor
Dedicated to

Gabriel Olarte Ariza, to his memory and to his life.
To Cecilia Sierra Mejia and to Sergio Adolfo Rodriguez Vitta
For their endless support.
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Abstract

Nurses working in Intensive Care Units are confronted with life threatening situations, death, and suffering every day as part of their work. Despite the possible routinization of death and the presence of technology as a key element of an ICU, it is argued that nurses achieve to maintain human care and human contact with their patients, and seek to guard for the patients’ own good and interests. However nurses’ permanent confrontation to suffering together with nurses’ perception of modern medicine’s lack of limits has an impact on nurses’ lives as well on the current practices at the Intensive Care Ward.

This study explores how nurses cope with suffering, death, and medical ideology in an Intensive Care Ward whilst they success in keeping human contact with and human care of their patients.

Introduction

Medical technology is gaining more and more space and legitimacy amongst Western health care systems. Medicine is committed to saving lives and this attitude towards life leaves little space to think about death, or about how people face death.

It seems a clear trend that (post) modern societies seek to deny the inevitability of death. The combination of high-tech medical equipment to diagnose and treat patients and provide high quality care is thought to be justified by the attempt at prolonging a person’s life. But often people forget that all those efforts are just about prolonging lives. No matter how hard we try to turn away death, sooner or later, people will die.

However, health professionals, especially those working in intensive care wards (ICW), are confronted with life threatening situations every day. Despite the possible routinization of death

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1 I use the term ward because in the hospital in which this study was developed, Intensive Care consists in a ward with in 6 units. This will be explored in more depth in chapter 1.
and the presence of technology as an omnipresent and omnipotent feature of an intensive care ward, nurses struggle to care of patients as much and as good as possible in the personal (comfort), medical (pain release), and technological aspects (following monitors, checking ventilators, filling patient’s data in the computers and so on). These duties often overlap each other so it becomes difficult, in practice, to distinguish the type of work that nurses are doing. Therefore, it can be said that nurses attempt to provide human care to their patients while they are also involved with the management and understanding of the equipment and procedures that take place in an ICW (Groen 1995).

In the decade of 1950s, in the United States intensive care units were introduced. Since that time up to now technologies have been changing nurses’ and ICW’s roles as the capabilities of both have also changed (Groen 1995). In today’s ICWs, monitors follow the patients’ vital signs, and, furthermore, keep patients alive.

Alongside these advances in medical practice, an aspect that can be seen as a fundamental characteristic of the ICWs is the role of nurses. Ever since the introduction of intensive care units, nurses have been in charge of the close monitoring of one or two patients. From the nurses’ perspective what has changed is that nowadays they are helped with technological means for monitoring the patients; before “they were the alarm” (Groen 1995: 18).

As this study was be done in an ICW in a hospital in the Netherlands it is useful to regard the place that nursing has in Dutch society. Van der Veen (n.d) states that this profession is highly recognized among society but not in the same way by others health professionals who undervalue nurses’ knowledge. However, this same author remarks, that since the sixties “the idea that nurses have their own responsibility in the process of healing (...) certainly gained ground” (19). This growing recognition of nurses’ responsibilities have helped the communication between them and physicians and other health professionals as well; this also reduced the emphasis on hierarchical organization of hospitals. As a result, such equalization of roles, teamwork and horizontal communication is believed to be present in Dutch hospitals.

Following Groen (1995), in the Netherlands it is possible to distinguish three different types of intensive care wards. Firstly, the general intensive care, this ward is especially for adults. The unit consists of nurses trained for intensive care. Physicians “are mostly consultants of medicine, surgery or anesthesiology, and in a few places there are consultants of intensive care, the
In addition, there are also co-assistants, who are doctors that have just finished the theoretical training at the medical school, and physician assistants who are doctors doing their specialization and fellows who are specialists “working towards a qualification as intensivists” (Groen 1995:5). This study was done in an ICW of this type.

The second types of intensive care wards are the Pediatrics ones. These types of wards were pioneered by pediatric hospitals. According to Groen (1995), there exists 8 Pediatrics Intensive Care Units (PICUs) in the Netherlands and are only present in teaching hospitals. The staff of this unit is: nurses trained in pediatrics and in pediatrics intensive care, pediatricians, doctors in training for pediatrics, and pediatricians or fellows training for intensive care pediatrics.

The third types of intensive care wards that can be found in the Netherlands are the Neonatal Intensive Care Units (NICUs). These units are focused mainly on newborn babies who are born prematurely or suffer from birth and congenital diseases. There are 12 units of this type in the Netherlands: “one in each teaching hospital and three in general hospitals” (Groen 1995:5). The staff of these units consists of neonatology and pediatrics nurses. The consultants who are neonatologists, the physician assistants who are doctors in training for pediatrics, and the fellows who are pediatricians training for neonatology.

The general organization of the ward consists of a head nurse and one or more nursing team leaders. The objective of these two groups is to give support and supervise the nursing staff as well as the patients. “On Dutch ICUs the medical and the nursing staff are the two main groups responsible for the patient care. Following the instructions of the doctors, most of the work on and around the patient is carried out by nurses” (Groen 1995: 8). Nurses’ work includes, as mentioned above, handling the bedside equipment that is required for the treatment and the care of the patient: ventilators, cardiac pace-makers, vital signs monitors, intravenous drips, catheters, and a computer which puts together the complete information of the patient, just to mention a few. Besides this type of tasks, nurses are also responsible for feeding, bathing, dispensing medication, and comforting the patient.

The capability of nurses to maintain good quality care that implies human contact, whilst they are also dealing with high-tech material is the subject of this thesis. I aimed to understand how nurses cope with suffering, death, and medical ideology in an Intensive Care Ward.

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2 In this case, the term intensive care units (ICUs) refers to intensive care wards (ICWs)
The main reason that moved me to do research regarding nurses’ perceptions of life and death, to give voice to their concerns, thoughts, and perceptions, as well as to study their daily behavior at work, is the result of a personal need to understand how life goes on, happens and ends in an intensive care ward. What role does being a human being play in a high-tech environment as intensive care wards are? This questioning started after my father died in such a place, near two years ago. Even though that happened in a different country, the way in which nurses took care of my father and of us, as family members, raised questions about how things happened in an ICW, why nurses are so dedicated to persons they hardly get to know, what is their role in the ward as being responsible of the care of the patient, and in permanent contact with them. Furthermore, does the fact of dealing with ending lives very often, as part of their work, change nurses’ perception of life and death? As a result, do practices at the ward also change along? There were questions that played in my mind for months.

In this regard, I find intensive care nurses a very interesting group for three important reasons. Firstly, they have had a different training from medical doctors and that may represent differences in the way the information, the condition and the needs of the patient are interpreted. Secondly, they interact more with patients and with families, than doctors do; “they are acutely aware of the family during this time. More often than not is the nurse to whom the family has been putting their urgent questions” (Lock 2002:111). In this sense, they represent the connection between families and the patient in the ICW. But also, “nurses’ activities are not confined to administering medications and monitoring the bedside technology. Nurses also engage in types of patients care (e.g. verbalization and (...) stimulation) that transcend [the] technical” (Anspach 1993: 60). Activities that produce a deep social interaction between patient and caregiver. Thirdly, nurses mediate the patients’ liminal state, as patients are in between life and death. Nurses are in between the patient (and the family) and the physicians who “have the knowledge for reaching life death decisions, but they may lack potentially valuable sources of information that can only be acquired through interaction [with the nursing staff]” (Anspach 1993:83).

Nurses, technology and death have been largely studied as separate areas. This is, nurses and technology, technology and death, and nurses in palliative care. The aim of this thesis is to find the relationship that exists between the three of them. How they shape and are shaped by each other, in the specific context of an Intensive Care Ward in the Netherlands.
The theoretical perspectives used in this research derive from Bourdieu's recognition of social actor's potential ability to negotiate meaning and consciously make choices and act upon the world and upon others. Therefore, nurses are themselves capable to construct and negotiate meanings and definitions of the main topics explored in this study. The theoretical perspectives will be presented through the text, so the reader will be able to easily comprehend the usefulness of them in relation with the development of the research.

There is not much information about this specific topic, therefore this is an exploratory qualitative case study developed by anthropological strategies. This approach focuses mainly on the individual's direct experience, in order to be able to understand the way subjective worlds interact with the objective world. In other words, this approach seeks to understand the social actor in his/her daily life (Miles & Huber 1994). For the case of this study, the qualitative research attempts to achieve insight into how nurses' perceptions of life, death, and dying are molded by the practices and mould the dynamics of an ICW by exploring their own conceptions of life and death, of nursing as a profession and of their role in the ward. The data collection to make this possible was gathered mainly by four techniques.

a. **Formal interviews** with the participants (A total of three interviews per participant) in which I asked open-ended questions in semi-structured interviews for about 45 minutes each, and were done individually. In these interviews I explored topics that nurses gave priority to, and I also explored in more depth topics that I found relevant to answer the research question. I focused on nurses' motivations for becoming an intensive care nurse, their duties, how they defined medical technology, how they perceived the relation of medical technology and human care in their daily work, how they place themselves in the ICW -their role-, and what are their notions of life, death and dying. All these interviews were recorded with the participants' permission.

b. **Ethnographical observation** on nurses' daily activities, the way in which they do their work, and the way in which they engage with patients, in order to understand the dynamics in the intensive care ward. As well as to observe nurses' relationship with patients, families, and doctors in the moment and the place that they occur. According to Hardon et al. (2001: 207), ethnographic observation is a technique that involves watching, recording and systematically selecting behavior and characteristics of persons,

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3 The description of the sample will follow this chapter.
their actions, relationships amongst each other and their environment, and the social phenomena of which the sample is part.

c. The participants and their patients: I accompanied two different nurses when they were with their patients. This type of observations stands in the same line that the one exposed before. The methodological reason behind this technique is that it helped me to have a closer insight of nurses' interactions with patients. These observations were done with the prior consent of the patients, except for one case in which the patient was unconscious.

d. Mapping: I developed a map of the ward, over the one that was given to me, in order to have a clear idea of how the setting is, physically and symbolically and how these two aspects relate to each other. This means that I did maps of the unit in order to be able to comprehend how the actions in, the relationships between, and the hierarchy of the individuals that form part of the setting define the space (See annex 1).

It is noteworthy that the methodology used in this study was a very flexible one. Given the participants' kind of work the activities, especially the interviewing, depended on participants' possibilities, and willingness to dedicate about 45 minutes to some activity not related with their patients. With this methodology I was able to respond to daily requests as new patients coming to the intensive care. It also helped me to not disregard practices that with the flow of time may become familiar and run the risk that I undervalued them. Each day has its own rush, therefore the need to use a methodology adaptable to the dynamics of the place, which also keeps the interest alive. Furthermore, this type of methodology also helped me to not feel frustrated if some interview had to be moved to another day, because of great activity in the ward, or very long days in which nurses were not so busy, and things looked the same hour after hour.

Before going any further it is important to remark that the present text is based on nurses' perceptions given by their answers as well on my own interpretation of the events, conversations, and dynamics that I observed. This text is the voice of nurses through my words and my interpretation.

4 In three cases I just did observation, no further interactions with patients were done since I am not qualified to do so.
The setting: who, where & how

For ethical reasons, and to protect the anonymity of the participants and the confidentiality of their information, the names of the people who collaborate in the study as well as the names of the people who are mentioned in any interview were changed. The gender, the situations and the dialogues are presented as they are and as they happened.

1.1 The participants

The population of this study is Intensive Care Nurses that, at the moment of the fieldwork, were working in the chosen ward and were willing to contribute to and participate in this study. To select the population I first contacted a professor of medical ethics (who is also a physician) at an important hospital in The Netherlands, some months before the fieldwork started. After two meetings with him, he put me in contact with Joost, an ex-intensive care head nurse who is now working as head nurse in the emergency room in this same hospital. Joost put me in touch with Matthijs, the head nurse of one of the units of the intensive care ward. I explained the intension, objectives, and methodology of the study to each of them as we met, and in the same way they agreed to participate in the research. After a week of conversations with them I started my fieldwork: a Wednesday at 10:00 when I went for the second time to that intensive care ward.

That first day of fieldwork, Matthijs said to me

"We have a committee of ethics here in the ward, I was thinking that they fit well with your topic".
In that meeting with Matthijs, we discussed again the methodology because he wanted to have it very clear, he answered some questions I had about the ward's dynamics, such as the nurses', doctors' and visitors' schedules. I also asked him if he wanted to participate in the study and he accepted. After we finished with our first conversation, which was in his office as it always happened, he went to look if one of the persons he had in mind as a participant was around. Five minutes later he arrived at his office with Annelies, a member of the ethical commission. After I explained to her the research objectives and the methodology she agreed in having a first interview two days later.

That same day, Matthijs and I went to the other units to look for the other possible participants and he gave me four more names and their schedules to contact them. He also gave me a map of the ward and he explained where his office was, so I wouldn't get lost. This sampling technique can be called convenience sampling since it consists in selecting the sample upon the sources available at the time of data collection (Hardon et al. 2001).

To complete the total population of participants was a difficult enterprise given their schedules and that one person preferred to not participate because she did not feel good talking in English. Even though I know that her comments would be very valuable for this study I thank Alex for her sincerity and her appreciation of the study. Alex' argument was that the essence of her thoughts will be gone if she translate them into English.

The sample was of 5 participants, 4 intensive care nurses who are members of the ethical commission and one head nurse. I was also hoping to work with Joost, the ex-intensive care head nurse, but unfortunately our schedules were impossible to arrange. All of the five participants had signed an informed consent form in which they allow me to use the information gathered during my fieldwork (see annex 2).

A common characteristic to this group is that all of them are deeply concerned about the human treatment and contact that nurses must have with their patients and their families. That is the reason why four of them are members of the ethical commission that will be explored in the coming pages.
Matthijs

He is a young nurse who has been an intensive care nurse for ten years. He is now the head nurse of one of the units at the ward. He likes his actual job but he also loved to be in permanent contact with patients.

He was very interested in this study since the beginning; even though he is a very busy man, he always had time for set up an interview and he never cancelled one. His answers were short and concrete; however, in the cases in which he thought that I might not understand he elaborated them, as was the case when he explained the procedure when a new patient is coming to the ward. As the other participants, Matthijs liked to talk about his opinions, about his role, his team, his profession and how all of them are related to and influence the dynamics of the ward. His objectives as a head nurse are to be able to create a good sense of teamwork that will result in a good treatment of the patients since he expects from his team to be fully engaged with the patients.

His reason to help people to live in such a dedicated and careful way is because:

"Everybody is willing to live, people are addicted to life, people do want to live, so why I shouldn’t support them?"

Matthijs was always asking me how the project was and if I succeed in finding the participants. As Alex also told him that she was not going to participate, he helped me to find another participant. He put me in contact with a young male nurse and we set up an interview for two days after, but the morning I went to interview him he was not there because his wife delivered at 4:00 that morning. Some days after that we met again and he apologized but I congratulated him for his new daughter.

As a final remark I would like to say that Matthijs was of central importance in the development of this project.
Annelies:

I met Annelies the second day I was at the ward. After I explained the research objectives and the methodology she agreed in having three interviews. She also allowed me to observe her during her work and I accompanied her twice when she was with one of her patients. Annelies did not hesitate to collaborate with me but she told me that she was going to leave in five weeks, fortunately the fieldwork fitted in her schedule.

She is a young woman who has been an intensive care nurse for almost five years. The longest conversations I had were with Annelies; she explained every answer in a way that I could understand the totality of her thoughts. She took the time to look carefully for the examples that could help to illustrate her opinions, worries, expectations and tasks.

She is a brave woman who is not afraid of suffering or death but she cannot stand that a patient is not well treated by the staff involved in his/her treatment. She is fully aware that the work at an intensive care ward is very stressful. For her, the best way to avoid the risk of becoming cold with the patients and only be busy with technology management is by talking amongst nurses and doctors about everyone’s preoccupations and difficulties. She has been involved with ethical concerns as the importance of communication between nurses, doctors, and patients almost since she became an intensive care nurse.

One reason for being so engaged with the human contact with the patients is because of her beliefs

“My religion is a reason to be interested in every human being; I think that everybody is counting. I’ve never had problems in taking care of a junky. I believe in God and I believe that he loves everybody that he wants to love everybody in the world. I know everybody is worthwhile, and that’s why I always want to stay in contact”.

Annelies, together with Mina, was always concerned with my feelings and experiences at the ICW since I am not used to be with people under life threatening situations. In the three interviews she asked me how I was doing. She always said that she was available if I wanted to talk about my feelings and myself. In the second interview I talked about them, although briefly.
Jaap

Japp is a very experienced intensive care nurse, who successfully combines the most technical knowledge and management of medical technology and the relevance of the person lying in bed. He is part of the PDMS’s (patients’ data management system) committee, since the use of medical technology is one of the features that he likes the most of his work. In this regard he comments

“I’m into how computers are working and what we can do with computers for the patients, to make plans for nursing so we can organize. I want to help and I want to learn and to develop that kind of things”.

He carefully explained to me the function and the use of every machine that is connected to the bed and to the patients, he also informed me about the latest advances in medical technology developed for nursing intensive care patients, as well as patients in other wards with communication problems.

However, he is also a member of the ethical commission. He is worried about ethical issues concerning decision-making process of continuing or withdrawing treatment to terminally ill patients, as well as the communication amongst professionals involved in the treatment of a person:

“The person, the patient in bed is the most important, but I like to do the technological side. But the main point is the patient, the patient does not have to suffer, does not have to feel pain and all the things like that”.

With Jaap I had the funniest conversations of the fieldwork; we laughed every two questions because of his temperament. He finds joy in everything and that helps him to manage the tension at work; also having fun with his colleagues helps:

“Here are some persons with whom you can have a lot of fun like in any other working place... it’s possible, if the nurses are fitting we can have a lot of fun”.
Mina

The day I met Mina she was changing shift with her colleague who was about to leave. Nevertheless she took five minutes to listen to me and after I explained what the study was about she agreed in participating in it. We scheduled an interview but she warned me that it was only a tentative appointment, given that she couldn’t have control over what may happen that day with the patients. She said that maybe she would be very busy with a patient but that I must go because maybe she was available. I explained that I was going to be there doing observations so if we couldn’t do the interview that day it was not a problem for me, that we could move it if necessary. The arranged date she managed to do the interview, but the third time we had to cancel it because a new patient arrived and she was in charge of her, therefore she was extremely busy. The next time I saw her she said

“That is how things are here in the intensive care, some days are very busy and some others are very quiet, today it has been very quiet”.

Mina is a very enthusiastic and funny woman who laughs easily and who uses her body and the volume of her voice to illustrate the examples that she is referring to. She is a very strong person for whom the biggest preoccupations are related to the importance of communications with patients and with family members. For her, it is very important to take patients’ wishes and worries into account in the treatment’s decision-making and in the daily performance of nurses

“I think that communication is half of the work if you want to go for a patient; it also makes the work easier for you. If you don’t tell people get scared, and then you will make everything more difficult for them and for you as well”.

In this same regard, but now referring to the communication with the relatives, she add

“It’s important to try to tell them (the relatives) everything and also be very honest to them if they (the patients) are really sick or not, or if they are still in danger or out of danger, that’s really important I think, that they know what’s going on”.

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As I mentioned in Annelies’ presentation, Mina was also very concerned with my feelings and thoughts while doing this study. In the last we met we spend the last 20 minutes of a long interview in talking about myself, how I found being so much time in the ward, how I related all the information that she and the other participants gave with my father’s death and his stay in an intensive care unit in a complete different country. She was also very interested in knowing what was I expecting of the research in relation to my personal growth and how it helped me in achieving personal objectives. This was a very interesting, useful, confronting and comforting conversation, which led me to a long process of introspection when I transcribed that interview, that last during the writing of this text.

**Juliette**

To get to meet Juliette was a difficult enterprise since we e-mailed each other for about two or three weeks and we didn’t succeed to get to meet and have an interview; finally she e-mailed me her mobile number to call her. After 3 times in which we called each other back we could talk and arranged a meeting. It was at “de ysbreker”, a café near Wibastraat because she had the day off. After she found me (because I was lost) we sat in the terrace of the café and started to chat. She was the first to ask. She was curious about my motivations for doing this research. I explained myself and my motivations and that made her more interested in the study. We talked for more than an hour in what could be called the official interview; but after the recorder was off, we talk for about 20 more minutes of themes related to this study, her personal interests, her present studies and my expectations of the fieldwork and of the research. Because of the atmosphere, this interview was very relax and informal. I enjoyed it so much.

She is a very young woman; I guess is the youngest I met. She’s now studying something completely different than any health related profession because she wants to combine her work with a parallel activity, it is a way to find balance in life and keep doing her work in the best possible way. She is very honest and has no problem in accepting that her work is a difficult one:

“One day I thought ‘well it is not so bad to say that I find things really difficult, or that they, that they make me sad or angry. I better say that than being cynical because it’s no fair to me and it’s not fair to my colleagues and it’s not fair to the patients as well’. I think that it is even better to react in a way like that because then you get a discussion or
at least you say what you feel (...) I don’t want my life only to exist only among suffering and people dying I also want nice things for myself”.

Juliette is deeply engaged with patients’ voice in the decision making process regarding treatment, as well as with the importance of communication amongst professionals involved with a patient’s healing process. She has been an intensive care nurse since 1997 and her concerns regarding patients’ well being and the need of communication have been growing since then; this is the reason why she is a member of the ethical commission. Even though she cannot participate as much as she would like because of her present studies, she is one of the pioneers in doing an ethical commission that stands for the patients’ interests over the medical interests.

She enjoys her work because she is taking care of people but also because they have a lot of fun in the ward, and because she has really good colleagues with whom she can talk about the things that are worrying her.

“This is a hard work but we can also have a lot of fun, there is people with whom you can laugh so hard and that makes the work much more easier for all of us (...) that’s why you can keep coming to work. When I find something really difficult with a patient I talk to my colleagues about it, we have a good group here”.

With Juliette I could only managed to have two interviews because time constraints by the time that we got to met.

1.2 The Ward

This study was conducted in a large hospital of one of the most important cities in the Netherlands. It is one of the most recognized academic hospitals in the country. Given the size of the hospital, the intensive care ward is composed of a complex of six different units, and it occupies a large part of the third floor of one of the hospital’s buildings (see annex 1). Four of these units are fully equipped for patients and the only difference between them is the size. The other two units are used as doctor’s offices and places for future beds. At the present time, the ward has capacity to admit 34 patients, but it is planned to grow in order to be able to hold up to 50 patients. This will be possible by using the two units that are currently not being used for these
matters. In average, the ward holds 29 patients and it is common to see empty beds. The beds are
distributed as follows: Unit 1 has capability for eight people, Unit 2 has also capability for admit
eight patients, Unit 3 is the largest, and it can hold up to 10 patients and Unit 6 has capability for
eight people as well.

The beds are distributed in rooms, which most of the cases, are double rooms. The reason for
being in a single room is as Annelies explained:

“It is only for isolated patients. Sometimes you have a very sick person over there but a
very sick person can also be in the room with 2 beds. But if you have family running in
and out, then it’s better to have the person in an isolated room. Some times we take care
of that, when we see that it’s necessary, when we feel that it’s necessary”.

All the rooms are equipped in the same way, because as Matthijs said

“Each bed can be for each patient”.

Matthijs also explained what the bedside equipment consists of:

“On each bed we have a basic equipment; this is ventilator, monitor, and several cables to
the monitor so you can see the blood pressure, the heart frequency and the other vital
functions as the oxygen in the blood. We have near each bed a PDMS: patient data
management system, so we have digital report. We have a pendulum that has the pumps
to give medicine. That’s basic equipment; if a patient comes with a special problem then
we also take what is required”.

There are 8 single rooms in the ward, they have glassed windows, which also have curtains, and
the room has a door. In double rooms, the curtains mark the physical boundaries; these are open
almost the whole day. As Juliette explained, nurses close them to maintain the patient’s privacy

“When I’m washing the patient, or when I have to do something in which I have to lower
the blankets I shut the curtains (...) but also sometimes when the person is crying or
when the family wants to have an intimate moment. When there are two persons lying
next to each other sometimes you keep it close all the time between them because
sometimes things are complicated so you don’t want the person here to see what is happening there. Also when you come to a situation, a really acute situation with one patient, of course you close the curtain so the other patient or the people walking around can’t see what is happening”.

1.2.1 The intensive care ward in three dimensions

Even though patients’ and visitors are not the central elements of this study, they are necessary for the ward to exist; they depend on the ward’s possibilities, rules, and schedules but at the same time these actors influence the dynamics of the ward. Therefore I will dedicate the following sections to explore their dynamics and roles.

Coming to this point, it is noteworthy that the following descriptions are based on my observations and on nurses’ points of view. No contact was established either with visitors or with patients given that those actors are beyond the limits of this study.

The Ward is a very silent place where the voices most heard are the nurses’ ones who speak much louder than doctors do; the latter’s voice is imperceptible. The smell of the ward, a mix of alcohol and medicines, is very strong and is noticeable the moment the automatic door of the intensive care opens. Such a characteristic added to the cold colors as white, light green and light yellow, which are the colors of the ward, together with the sepulchral silence that embraces the ward when nurses are busy with their patients, when there are no visit times and in the middle of the afternoon, mixed with the permanent beeping of the monitors and the wheels of chairs, beds, and cars to transport medicines, blankets or food, give to the ward the sense as if the world had stopped. Life goes on in a waiting line of expectations, acts and facts which are understood, perceived and lived differently by the actors that inhabit there. This makes the ward a three-dimensional place where the first dimension of it is a dimension of work and duty. It is the nurses’, doctors’ and the cleaning team’s working place where life threatening situations, suffering and death are common and ordinary events for some of them. The second dimension is a dimension of anxiety and passivity. It is the dimension where visitors play the central role. They wait to see the results of their growing expectations and hopes of a longer life for the person they are accompanying. The third one is a dimension of liminality. It is the patients’ dimension; they
are struggling to win the battle between life and death, to go through the situation that brought them here.

The meaning that the different social actors give to the ward depends on their role and on their dimension. Nevertheless, for the visitors and for the patients, the ward is marked by extraordinarity since, in most of the cases, people is not used to visit an intensive care ward either as a visitor or as a patient.

a. The visitors

Visitors are allowed to come to the ICW every day between 11:30 and 12:00 in the morning and from 18:30 until 20:00 in the night. Before they get in the ICW they have to register at a counter, which is next to the main door. There they give their names and the name of the person they are going to visit. A person, who changes daily and is always a woman, writes the names down in a notebook. After the registration, visitors are told to wait in the waiting room since only two people are allowed to go to the room. Then they can come in. After crossing the opaque glassed door, visitors find two screens. On the left side is a touch-screen that has a map of the ward with the units colored differentially; when one touches any of the units, the names of the patients in it appear with the number of their bedroom. On the right side the screen has a list with all the patients of the ward and their location. Nevertheless, the woman in the front desk always informs the visitors about the location of the patients.

In cases when a patient is very ill, a family member or a close friend is allowed to stay all they long, including the night. Nevertheless, sometimes they are asked to leave the room when nurses are going to do some procedures. As Annelies said:

"It is possible that a person stays, we have also sleeping places with a bedside bathroom so the facilities are very good right now. People can stay if somebody is really in a critical condition but not always in the room. If we are doing some technical things most of the times we ask them to wait in the hall way because we are maybe influenced by the looking, by the eyes of the family".
Even though only two people are allowed to be at the patient's room, visitors manage to come in groups, but never more than three people are with the patient.

Visitors are most of the times relatives. When they are with the patient they touch him or her and speak to them even if the person is sleeping or unconscious. If that is the case, visitors tend to lower their voice. This can be interpreted as a reflex to not interrupt or disturb the person lying in bed. If the person is awake, it is common that relatives bring audio material for the person to listen to, or they are talking to them and to the nurses in a sort of conversation amongst all the people in the room. In one occasion, a family brought to a patient something to listen to in a minidisk. A nurse got a pillow and a head’s holder so the patient could have the head in a comfortable position to listen to the record; when it finished all of them were laughing including the nurse.

Visitors' faces and talking depend on the patient's state. If the person they are visiting is critically ill they don’t speak much amongst each other, only when doctors, nurses, or any of them brings news. If the patient is stable and not in a high-risk situation they speak amongst each other, or read the magazines and newspapers that are in the waiting room. It is common to see people smiling and chatting when the patient is awake and with a good prognosis. Most of the visitors wash their hands before going to see the patient.

a.1. The waiting rooms

Visitors spend most of their time in the waiting rooms. Each unit has a waiting room and they are very comfortable places. Waiting rooms look and feel like living rooms, even though they are most of the times empty. These are the only places in the ward with different colors than white and light yellow. Their furniture only change in colors, all of them have a very comfortable couch and two chairs of the same color as the couch plus three, or four wooden chairs and two wooden tables; what changes is the color of the couch and of the chairs. Unit 1’s waiting room has orange and wooden furniture. Unit 2’s waiting room has red and wooden furniture. Unit 6’s waiting room has green and wooden furniture, and Unit 3’s waiting room has black and wooden furniture. The later waiting room is the biggest one and, together with Unit 6’s waiting room, has a window that looks to the central garden of the ward. This garden has a fountain in the middle and huge flowerpots with big green plants with no flowers. The garden has also 8 wooden benches. The
window gives a different feeling to the rooms because when looking through it the feeling of being in a hospital is gone. It also fulfills these two waiting rooms with natural light. Every waiting room has a black telephone, a big clock hanging above the door, and a sheet on the wall informing the visiting hours.

Waiting rooms stand as the bridge between the other two dimensions of the ward: the staff and the patients. The person that has been in the room with a patient serves as the informant of the patient’s state. It is a mix between doctors’ and nurses’ opinions with their own perceptions and ideas of the patients’ state. These places make possible the communication between the dichotomies of these two dimensions: sick and healthy, at risk and safe, illness and health.

Waiting rooms are also the lobby for having news from the nurses or from the doctors. This represents as well a communication of the dimensions and their dichotomies. Nurses and doctors hold the power of knowledge, they inform, comment and sometimes comfort. Two languages are spoken in this conversations: lay and expert, because of this it is common to see sometimes doctors using pencils and paper to try to express and explain better what are they talking about.

b. The patients

In Matthijs’ words

"The main criteria (for being an intensive care patient) is if you need ventilation or any health problem that puts your life at risk".

This range includes people that have had a heart operation, and they stay for one or two days in the ward, patients with neurological damage that has been operated or who are waiting for an operation, terminally ill patients, and any other life threatening situation that requires specialized treatment that the ordinary wards are not able to give. The intensive care ward holds the medical technology, knowledge and professional background to act upon patients under such conditions and needs.

Because of this criterion, most of the people that are in the ICW, are sleeping, unconscious, or cannot speak because they are intubated. This makes the communication with patients a bit
complicated. However, nurses succeed in communicating with patients most of the times; this will be explored in the coming chapters.

If patients are awake, most of them like to speak with nurses about their condition but also about things that are not related with their health. In some cases, patients can laugh with nurses, but it depends on the mood of both to make and to receive the joke. In this regard Jaap says:

“Sometimes it’s difficult to understand [the joke] because the communication with patients with the tube in can be difficult, but I try if my mood is good and the patient’s mood also is good (...) you can try and you will see the reaction (...) it’s not always so serious”.

Concerning this, Mina also said once

“This man that we visited today, he had a terrible night last night, that’s why he was so quiet today, because you can laugh really hard with him (...) he is so nice”.

However, no matter the laughs, nurses recognize the patients’ stay at the ward as a very difficult time in peoples’ life, for both family and patient. Mina once said:

“It is not nice to lie here because the things we do are not pleasant for the patient, most of the things, it’s a terrible time for the people, what they remember anyway, people have delusions if they lie here a long time. If you talk with them afterwards they had the worst time in life in the IC, what they remember of it (...) and sometimes it’s even harder for the families because the patient may be asleep and they don’t know what’s happening to them”.

Therefore they struggle to keep them as comfortable as possible. In Matthijs’ words:

“We try that they feel comfortable in this uncomfortable situation”.

It is common to see nurses encouraging patients during a respiratory therapy, exercising the muscles, or when they are unconscious, trying to bring them back to consciousness, as I saw once Annelies, doing with a patient that had been reanimated few minutes ago.
Since part of the fieldwork was done during the European Football Championships, two rooms, and the nurses' rooms had orange flags and signs that read 'HUP HOLLAND'. This to make reference that patients who stay for a long time in the intensive care have cards, pictures and some kind of decoration in their rooms. This material is either sent by relatives or friends, or brought by visitors. In one room, the patient had a TV to watch the football games. When analyzing these possibilities of transforming the room in a warmer place, it is easy to understand what nurses mean when they say they try to make the patients as comfortable as possible. But also it can be interpreted as a way to push patients to keep on fighting because 'life goes on'.

c. The staff

The staff working in the ICW that is involved with the healing process of the patients is composed as mentioned in the introductory chapter. For methodological reasons I find better to present them in two different groups (doctors and nurses) as they are very different one from the other. Nevertheless, the two groups are part of the staff group. Again, the following descriptions are based on my observations and on nurses' points of view. No contact was established with doctors as this study is focused on nurses' behavior and perceptions.

c.1 The Doctors

Doctors' rounds to do patient's check up are in the morning at 10:00, in the afternoon at 16:15, and in the evening at 23:30. During this visits, the doctors talk to the patient, if the patient is awake, and to the family, if someone is there. Most of the times, the nurse in charge of the patient is in the room while the doctor is visiting the patient. In this situation the doctor is the person who talks the most; s/he explains to the patient and to the visitors, if any, the patients' current situation and s/he explains to the nurse what to do with the treatment.

Nonetheless doctors are available to solve patients' and relatives' queries, they spend a lot of time regarding the computers and the monitors, talking to each other and filling in their patients' information. Sometimes they look more to the monitor than to the patient. In the brief time spent
with the patient, some doctors remain distant and they don’t talk much. For this reason some nurses see this situation in a need of change. Juliette said

“If I’m doing a case for a couple of days and I see that the doctor hasn’t spoke with the patient I go and ask him ‘what is going on, and what are your plans, and why, and have you talked to the family?’”

Nevertheless, it is noteworthy that many doctors are concerned with the contact with the patients and their families, as shows a case mentioned before, a doctor used pencil and paper to help the relatives to understand the patient’s situation. Moreover, during individual visits it is common to see doctors explaining to the visitors the figures on the monitors. To illustrate this better Mina said:

“The new generations of doctors are very preoccupied about the contact with patients and they are doing very well”.

Also Juliette referred to this:

“The contact is difficult in the morning because they really have to go quickly but, usually when one doctor is taking care of a patient; usually, I think, they are warm and polite and nice, of course there are always exceptions, but generally speaking I find the contact really good”

But what Juliette mentioned about the morning rounds represents an element that some nurses perceived as in need of change. Rounds with students start before 8:00 until somewhere near 9:00 or maybe a bit latter. A group of about 14 students go patient-by-patient discussing the cases. In this visits doctors stay a very short time with the patients and nurses are not there. In Juliette’s words:

“They just say about three sentences about the patient and then they leave”.

5 These schedule depends on the number of patients
These visits do not take longer than 10 minutes. But what nurses find disturbing about these rounds is that the person lying in bed is almost forgotten. Doctors are concerned more about the figures of the monitor and of the results of the exams. Because of this Mina said

"I find really important that also the doctors talk to the patients, because this is an academic hospital and what you see in the mornings are groups of 10 or 15 white coats walking by you and talking about you and sometimes is just one person like 'hi, how are you' (to illustrate the student's attitude Mina lowered her voice), making contact but not really, they are a lot of doctors by the patient and they're sometimes standing there and they are by the bed ignoring the patient, seeing how is it going, and there is maybe one who says hi, and the patients must be like 'oh my god they are talking about me but...what's happening'. I think that's very important, that you always see the person in the bed, the human being".

During this rounds, doctors stand next to the bed in a circle. Near the head of the patient is the main doctor, the doctor who is involved with the patient. S/he presents the case and asks some questions that the other doctors answer. No one is interrupted during this conversation, but some of them are not really paying attention. In one occasion I was with Annelies who was dealing with a very acute patient who had just arrive to the ward; while she was preparing the patient to be translated to the scanner and a doctor was trying to introduce a catheter into the patient's leg, a round was taking place in the bed next to us. Probably because of the action and the acuteness of the case, two doctors were looking at the other patient instead of looking to the one that was being presented to them. Ten minutes latter, all of them left.

All doctors were white coats; they walk fast and speak very softly. Outside the rooms, the communications with nurses is almost inexistent. Next to the nurses' room (see annex 1) called Bewakingpost - Verpleegkunde, is a room with two to four computers, depending on the size of the unit, called Arsen Kamer which, as the name says, is used by doctors. This room is empty most of the times as doctors are not in the ward the whole day. After visiting their patients, doctors go the Arsen Kamer and fill all the patients information in their respective files. In this room, doctors also check the results of the X-ray done to the patients in need of one. It is very rare to see a nurse inside the Arsen Kamer and when that happens often doctors are not there. The same dynamic presents the Bewakingpost - Verpleegkunde, which is nurses' ground. The few cases in which doctors cross the door is mainly either because they are going to check on the
blackboard the location and the general state of the patient or because it is empty and they need to leave or to pick up a file. Most of the times when doctors want to talk with nurses they stand by the door or talk through the central part that has no glass. Only once I saw a group of female doctors sitting in the empty Bewakingpost -Verpleegkunde. of unit 1, but they were discussing a case of a patient that had just arrived. As soon the finished their conversation they left.

Doctors and nurses do not spend much time together. Twice happened when I arrived to the ward at 8:00 most of the doctors that were in the ward at that time, if not all of them, were in room called Koffie Kamer Personeel. As the name suggests, doctors were having a coffee break, but given their number, some of them had to stand on their feet; although two doors away was the empty waiting room of unit. Moreover, next to the waiting room, in the Multifunctionele Ruimte was a single nurse looking through the window on a rainy day. However, all the participants agreed in saying that nurses and doctors have a good relationship. Participants said that they feel free to talk about their worries, to ask them questions, to discuss about a treatment and that most of the times their opinions are taken into account. This is mainly the function of the ethical commission, but I will discuss that latter.

c.2. The Nurses

In this ward, intensive care nurses are divided in four teams and each team has a head nurse. The team that Matthijs leads holds 44 nurses, including six students. 35 people of the team are working fulltime in the unit.

Nurses of the whole ward have the same schedule for changing shifts: The day shift is from 7:30 to 16:00, the evening shift is from 15:00 to 23:30 and the night shift is from 23:00 until 7:45 the next day. However, it is very rare that nurse leave at the end of their shifts, because many times they stay longer talking about the patient with the nurse who is starting the shift. Many days I arrived at 8:30 and there were still nurses from the night shift talking with other nurses and also with doctors.

Fulltime nurses change the time of the shifts every week, while part-time nurses can change their shifts during the week. Head nurses’ schedule is totally different. They have a single shift, which is from 7:00 until 17:00 four days a week. They are not in the ward neither during the night nor in
the weekends. When head nurses are not in their units, an experienced nurse, who is chosen by each head nurse, is in charge of each team.

Intensive care nurses wear green uniforms, that helps to distinguish them form the nurses of other wards who wear white uniforms. The shoes are a free option: red, orange, yellow, black, brown, white are common colors to see in nurses’ footwear. The only rule: they must be comfortable.

It is not so common to see nurses sitting for long periods in the Bewakingpost -Verpleegkunde, and it is even more rare to see them sitting alone. When this happens is either because the unit is very quiet or because they are filling forms with patients’ information or checking their agendas. If there is more than one nurse they are usually chatting.

The Bewakingpost -Verpleegkunde is nurses’ central place. Each unit has one and the nurses of that unit use them. Nurses congregate in their unit’s room when the work gives a break, when they answer the phone, or when they need to look for some other nurse; that is the first place to go. Here also nurses take their meals; therefore it is usual to see juice bottles, bread, and some sweets in the central table.

The Bewakingpost -Verpleegkunde are situated in the strategically corners of each units form were it possible to see all the beds (see annex 1). They have no door and they have an interrupted glassed window that goes from corner to corner. Inside the Bewakingpost -Verpleegkunde is a wooden table, a couch, chairs, two or three computers (depending on the size of the unit), a printer, a telephone, medical books, and the nurses’ mail boxes. There is also a computer that shows the information of each monitor that is being used that moment in the unit. Here also is a TV, which is on almost the whole day but it is very rare to see someone watching it. On one of the walls are two boards, one has general information for nurses; the other has specific information of the patients as the number of the bed, name, diagnosis, and the nurse in charge of that patient.

What is a common trend is either to see nurses walking up and down in their units or in the ward, or to see them with their patients. It is also usual to see nurses, mostly in pairs, having a chat in a room, which in some occasions is occupied by a patient. Given that in this situation nurses’ voice are very soft, it was not possible for me to understand if they were talking about the patient or
about something else. However, it is common that in this kind of conversations, nurses talk as if the patient is not there.

Although nurses laughs and loud voices are common in the hallways, when they are dealing with patients they are very silent unless that they are talking to the person lying in bed. For most of the nurses is very important to talk to their patients, as Mina explained:

“I try to talk always, I explain what I am going to do (...) I try to explain why they are here, what’s happening to them and why we do what we do”.

But nurses are not always talking to the patients because many of them are not able to speak because they are intubated, sleeping or unconscious, or because patients are not in the mood. Because of this, units can be very silent places where the permanent beeping of the monitors and the beds is the only sound.

Nonetheless, the ward can be, as well, a very busy place in the mornings because doctors are doing their rounds and at the same time nurses are changing shifts. When nurses are in these situations they refer mostly to the monitor’s and to the computer’s information. Therefore, sometimes in these conversations between nurses, the patient is ignored. During such moments, the information flows; nurses talk, ask, and answer to each other. Although the ones that are leaving are visibly tired, especially in the mornings, the exchange of information is done with calm and time; nurses do not rush to leave. Nevertheless, the shifts’ changes in the afternoon is slightly different given that doctors are not in the group rounds; although nurses’ practices are the basically the same. Nurses are walking and talking around and they speak loud.

Visit hours can also be very busy moments at the ward. Most of nurses talk with their patients’ visitors. As Juliette explained:

“I don’t give the medical information but I try to get to talk to them afterwards, after the doctor has talked to them, and see if I can help them to get all this information”.

When nurses talk to the relatives, it is common to see them making use of the monitor to try to explain better what the situation is. If nurses are in the room while the patient has visitors and they can be either not talking with the group, checking the monitor as well as they check the
patient or talking with the visitors and the patients whilst they do theses same activities. Nonetheless, nurses are not always with the patients while the visitors are there. They are in the room if they need to check the patient, if they are administrating a medicine, if they are exercising the patient, or if they are needed to talk with the relatives.

Having outlined this, it is needful to say that nurses daily choose the patients they want to care of. In Annelies words:

“You can choose them every morning and if somebody wants to continue one patient that’s always possible. So we take account of each other’s patients”.

All of the five participants said that they like to change cases but also some of them also like to maintain continuity with their patients. Juliette explained it as

“Today I choose this patient and tomorrow I’ll choose that patient, so I can keep myself broad, and also sometimes you are doing something really intensive and sometimes you feel like doing something more routine like a heart operation patients which is more like a routine”.

But Annelies added

“I always follow a patient to know what the patient wants (...) to stay in contact”

1.2.2 Dealing with new patients

Coming to this point, it is useful to explore how a nurses deal with new patients and how the units are chosen for sending new patients.

In Matthijs words

“There is a coordinator doctor, he has a special beeper and if there is a patient somewhere who needs intensive care, the doctor is called to that beeper. Then the doctor calls the coordinator beeper of the nurses. In daytime one of the head nurses has the beeper, during
the evenings, nights, and weekends one of the other nurses, who has a lot of experience, wears the beeper. So, at first the doctor is called with the question: we have that patient with that problem do you want to have him? Then the doctor calls the nurse and asks if there are beds free for that patient, and if there are beds he asks immediately where and then the patient comes in (...) the beeper is hold by a head nurse during one week and then it changes to another head nurse, it rotates”.

When the head nurse and the unit are informed that a new patient is coming in, they also are informed of what kind of patient they may expect. Before the patient arrives, a nurse is asked to deal with the patient and s/he will arrange all the basic equipment mentioned before, medicines to stabilize the patient, and the special equipment and required medicines needed for the specific condition that brings the patient in. Therefore when the patient arrives, the nurse in charge will not leave the patient. If s/he needs extra help s/he will count on the help of all the staff if needed. Most of the times there is at least one more nurse who is going in and out looking for new medicines, equipment or whatever else that is required by the doctor for the patient. In these situations, nurses and doctors share some practices, as is the insertion of catheters and lines for medication, but doctors are in the ones who intubate the patient or who practice the tracheotomy when necessary.

Nurses stay with the patient until s/he is totally stabilized but doctors, as Anneleis explained,

“"If the technical things that they have to do are finished and the patient is not too unstable they leave to do other things”.

Nevertheless, doctors remain fully available if they are needed.

Despite the acute situation, chaos is not part of the dynamics neither in the room nor in the ward. All nurses know what to do, where to find the required elements, how to deal with the situations, who to ask if something is needed. Every start is controlled with caution, calm, patience and care.

After exposing the setting, I may now explain what the ethical commission is about, since it is a space built by nurses to have a say in patient’s treatment on the one hand, and to express themselves about their difficulties with some cases in the other.
1.2.3 The ethical commission

The ethical commission started nearly one and a half years ago, as the result of intensive care nurses' concerns and questions about the limits that should be drawn to modern medicine for the patient's good, both in the ward as well as when they are back home. Such questioning started as Juliette said, because of

"The fact that everything is possible, or everything seems to be possible, especially with patients who are a bit older, they get something and it can be treated, and then they get another complication and you treat the complication and this goes for months and months because it's really slowly and every time there's something else (...) I stand up right next to the bed looking at the patient seeing in his eyes that he wants to stop, usually those people are awake, knowing that this is not going well and knowing that this person is going to die because in this work I got a good feeling for that, and still you have to go on because the doctors say 'oh no, no we can operate this, or no we can do this', they only look at the fragments of the person, they say 'oh, it is pneumonia so we give antibiotics, or it is this so let's do that' so, they forget that's everything is in a body and the person is just going to die and that's a really nasty way to die. So we ask 'we can do almost everything, what do we choose to do and when do we choose to stop, when is it reasonable to stop or to continue' (...) this is something that comes back every now and again and not always that bad but the ethical dilemma is there, you always encounter situations like that of course, so then we decided to start with this workgroup, ethical workgroup to, just to talk about things like that, and see how we can avoid situations like that";

Because as Jaap states

"To prolong the patient's life is not always good for the patient".
In this regard Mina also said:

"The reason of the committee is because in the work you see a lot of things. You can call them ethical problems. This is a hospital where they go quite far with therapy, they can do a lot, that's why sometimes you can ask yourself questions like 'is that good for the patient, what kind of life should she have afterwards, must that really be done'. Because everybody is going to die someday, and where is the limit? You know, how further do we go with that?"

But this ethical commission is not only about patients' interest; it has a parallel raison d'etre, which is the nurses' well being. As mentioned before, nurses are aware that their job is a difficult one. The fact that they face suffering and death also affect them in their heart of hearts. Therefore the ethical commission is also a space opened by nurses to establish a dialogue between nurses and doctors, and nurses amongst themselves about situations that they find difficult to cope with. Annelies explained this other function of the commission as:

"A lot of colleagues were very cynical because they didn't talk about their feelings about the patients and some people are very hard with patients, and it is because in most of the times they are not talking enough about what was happening with the patients, they are not able to deal with the situation (...) I started to question about this, about how to deal with ethical questions because I think that is the most important thing on the IC and we weren't talking about it. But, I think almost two years ago, things happened in the IC and people got post-traumatic stress disorder, two colleagues. Then everybody knew that there was something wrong in the IC that we had to do it differently, that we must try to talk. Because we see a lot of suffering. The ethics committee is also about communication about what's happening with the patients and, how to bring together the differences in a view or how to treat a patient, and how you can create a possibility to exchange and to decide together"
affected the nursing staff. When asking Jaap about the reasons of forming such a commission he referred to the case.

Jaap: “the ethics was formed after a case where a patient was treated to death you can say, nobody wanted to stop, nobody wanted to see the patient in bed, they (the doctors) only looked at the literature, and they only looked at the figures and they said ‘there must be a possibility that this woman—it was a woman, can survive’, but at the other side, for the IC side, there was a patient in bed going worse and worse and worse, and she had a lot of pain, and she was bleeding. At the end and nobody from the doctors wanted to see that she was a terminal patient, and she was suffering a lot (...) and from that case the group, the ethics group was formed. I was one of the initiative takers (...) one of the persons who came with the group to start, to participate”

Some of the other formers members of the group are the other three participants of the study, but Bianca, a head nurse of the ward, who is involved and concerned with ethical dilemmas in intensive care, played a central role at the time of getting the people together to form the ethical commission.

The ethical commission has two different types of meetings in which patients’ and nurses’ opinions are discussed. One is called patient meeting, which happens every morning at 11. Annelies explained it:

“We always decide in the morning if there is a special patient to talk about, if there are unclear subjects and we discuss them”

The other type of meetings are bigger. In those, all the staff involved with a patient, plus a doctor specialized in medical ethics come together to discuss critical cases as the ones mentioned before by the participants. That kind of meetings had happened four or five times. None of the participants could specify how many meetings have occurred. However, all of them evaluate the commission with positive results that had improved the communication between nurses and doctors regarding the patient’s own good.
Juliette explained when and how the bigger meeting takes place:

“Every day we discuss one patient in full depth and everybody is there, all the nurses, all the doctors to discuss this sort of dilemmas or practical things. If we can not work things out there, then still everybody disagrees, still everybody has great trouble with the treatment done to a patient we do a moral discussion. We have done that, for about 4 times. Everybody that has anything to do with the patient is there: physiotherapists, the psychiatrist, all the nurses, all the doctors, and there is a person who has studied ethics, he is the foreman of the discussion. Everybody can say what he thinks about the situation and what he knows about the situation. We have a discussion about what everybody thinks about it and also what the patient him or herself thinks about it, and the family, and what the circumstances are, and what the prognosis is. A few times something really good has come out of that, at the end everybody is ‘oh yes is better to continue this treatment although we have great trouble with it because now we know a lot more about the patient and the circumstances, or about her possibilities’. But one time when the discussion stopped we were even more against each other so it’s not always working but at least it’s a very good possibility”
Who cares?

After situating the reader in the context in which this study took place, it is now important to explore the nursing world. From this perspective, which deals directly with nursing as a profession, will come out elements that will help to understand why nurses’ perspectives of life, death and dying, together with the practices they encounter in nursing intensive care patients, play a role in the dynamics of the ICW.

There are mainly two approaches that have explored the nursing world: The first is the gender perspective, since caregivers have been traditionally women. The second approach can be called the motivation perspective, given that nowadays nursing is not exclusively a female domain. Nevertheless most nurses are still women.

2.1 Nursing as a gendered profession

Women have been in charge of the care of the dying, the dead, and the corpse throughout history in their roles as wives, daughters, and sisters. Much of the healing work was and is carried out in the home setting as a domestic routine and task. By the nineteenth century, medicine was established as the authority in health issues. Such a monopoly of life brought with it the medicalization of illness and death became pathologised (cf. Abbott & Wallace 1990; Field et al. 1997). Under such circumstances, the gendered role of decisions on care taking of the dying moved from women to men, as medicine was an exclusively male domain. This change was
followed by the displacement of childbirth, childcare and dying from the home setting to the hospital.

Hospitals were to become as the monuments of knowledge, science, and rational thought; therefore the untrained women were not accepted in such places. Nevertheless, physicians did not take care of the ill; they diagnosed and treated the body. In this context, the nursing profession was established as a response to the high degree of control in hospitals and because physicians required people who look after their patients. Such a work was initially a philanthropic (or underpaid) task exclusively for women (c.f Abbott & Wallace 1990; Adams 1993; Walter 1993; Field et al. 1997). Following Adams (1993), the exclusion of untrained women in the arena of patient care legitimized the activity of these in the care of the dead bodies. Thus, the space for women to be givers of care remained, albeit as a somewhat contaminating task of taking care of the dead body; while the living body was the physician’s domain and the soul was the responsibility of the male priest or other spiritual advisors (the care of the dying will be discussed later in this text).

Gender studies suggest that to care of the body, in modern society, is mainly a female task (usually undervalued in the care of the dying, whether in the family setting or in the hospital) (c.f. Abbott & Wallace 1990; Adams 1993; Field et al. 1997). This study, by contrast, suggests that these theories may need to be revaluated, given that these approaches tend to portray nurses as low-standard professionals dependant and subordinated to medicine. The results of the fieldwork demonstrate changes in relationships between the professions. This contradiction with well-known theories happens in two ways. Firstly, there are no marked differences between genders neither in number nor in division of tasks in the ICW. Most importantly, studies among intensive care nurses showed that the division of labor in this type of unit does not correspond to a gendered division of tasks but to theories of teamwork that based the importance of working as a group in order to improve the unit’s efficiency. “Nurses on the ward operate as a team that is responsible for the patient” (Groen 1995:8). In this context, “The team provides a mechanism whereby tasks assignments can be made and work performance can be controlled” (Bloom & Alexander 1982:85). Nurses’ work is both individual and collective. To give total care to a patient nurses must work as a group when needed. The reason of this is because nurses are not only aware and responsible of their own patients but they must always be alert of all the patients in the unit. If a patient needs help, if a monitor alarms, or if a patient calls, any member of the staff is in condition and in duty to help and assist at any given time. This means that inside the ICW there is
no gendered division of tasks. All nurses have the same responsibilities, possibilities, respect and status in the ward, regardless of their gender. Moreover, head nurses are both female and male. As Annelies mentioned earlier, nurses are free to choose their patients each day and that depends on their preferences rather than on a fixed or regulated pattern of a gendered division of labor.

Secondly, nurses in this case study perceive a changing trend in their relations with doctors. The participants agreed in saying that nurses’ opinions about treatment were, most of the times, taken into account thanks to the space opened by the ethical commission that they composed. Moreover, all of them expressed their freedom to talk with doctors about their concerns regarding a patient’s treatment:

Matthijs: “I feel free to talk in the same level (...) and yes, my opinions are taken into account by doctors”.

Annelies: “I always find difficult if I can’t cooperate together with doctors, if we are not in contact, if we have a different idea about the patient, but that doesn’t happen a lot lately. It was happening a lot here, but with the big meetings and the patients meeting we talk more about it, so things are changing (...) you do it together because the doctors are there and the doctor is explaining and I am explaining so it’s not too difficult”

Jaap: “the ethical committee is if there is some kind of struggle between nurses and doctors, the problem was that there was too little communication between us. We do that way and the doctors do it that way so the ways are crossing sometimes, so there was frustration. The nurses and the doctors thought ‘what is the matter here, we are doing our best’ and now we can talk about it”

Mina: “as a nurse, you take care of a patient quite long time, you see things happen and going on and on, and some times, you have to question if its ok, ‘shouldn’t we talk about it? Or must we really do this, or isn’t not another possibility, or do we really help this woman?’ (...) we can ask to talk about it, we say to the doctor who is in that day, or we talk about it with our doctor who is really on this unit, he is the one that most of the times you are going to ask about the patient. We can explain what we see, and he can tell us why they do things the way they do and some times it clears up for us, and sometimes you say ‘ok, that I didn’t know’, so ja, we can ask (...) here we have a good situation”.
Juliette: “it really depends on the group of doctors. With the doctors that have worked here for years and years I don’t find any tension because everybody knows what we are talking about (...) first I go to him or her (the doctor) to ask for information because I’ve found that sometimes I disagree with the doctor because I don’t have the full picture and then I try talk about it because of the suffering I see or if the patient is saying ‘I don’t want this anymore’, I want to start a dialogue and the meetings are a great possibility because everybody can say what he or she knows and what he or she thinks”

Nurses not only have a positive perception of their position in the ward but also sometimes they see themselves as on the same level as doctors. In this context Mina said:

“Sometimes there are some new doctors here and they do something, and we (the nurses) go and ask him ‘why did you do it like this? Or we are used to it like this’ you have a lot of doctors that come here and they have never seen a breathing machine or something like that, so we are, most of the times, the ones who knows more of it, we work together, sometimes like a team”

Nevertheless, as shown before, the ethical commission was formed to work on the struggles between nurses and doctors, some participants agreed in wanting the communication between the different professions to be improved:

Juliette: “I think I would like to change the relationships between certain groups here in this hospital, and that’s what we are also trying to do with this ethical commission, by getting everyone together concerning one patient, but still it isn’t always satisfying”.

Jaap: “I would like to have a better communication with all the personnel that works here, communication between the nurses, the communication with the doctors so that we are more in an equal ground and especially communication with, not with the IC doctors but with the doctors outside

Nurses face suffering, dying and death as part of their work. They spend more time with the patients and because of this they see the limits of medical technology and efforts to prolong a life sometimes harmful for the patients. It is in this context where nurses ask for a better
communication between doctors and nurses. Nurses want to have more voice when discussing a
patient’s treatment, as they perceive themselves as understanding and knowing, sometimes better
than doctors do what the patients need.

Juliette: “there are many people here that have certain bonds within, like for example the
surgeons. They have connections here and they have responsibilities for their patients, but
they also have responsibilities with other surgeons. The surgeons are the people that
never know when to stop or how to stop so they want to go on, and on, and operate. They
never stop, and here we really want to discuss ‘is this useful? What is the patient getting
out of this?’ sometimes we find that we shouldn’t do anything any more, and they have
something else to do. That brings a conflict, but it’s also difficult for the surgeon who
works here because he sees what we mean and he probably agrees with us but he cannot
tell that to his colleagues. I would like that people would not only care for they own
backyard but just be there for the patient and do what’s good for the patient and not for
their colleagues or their bosses. I think that you are here to do your job well and not
because your colleagues think something”

Jaap: “doctors like the surgeons, they are on top, they are sending the patient here and
they are thinking that they can do everything what they want because of what they see in
literature. They think ‘in 5% he is going to make’ it and they are trying to do the patient
in that 5%, they want to make results, so they make their operations”.

In such context, in which all the situations mentioned before occur, one can ask the reasons this
group of people have in deciding to follow a specialization in which they struggle with doctors,
which life is at permanent risk, and which demands a lot of extra work compared to the basic
nursing. Therefore it is important now to move to the other mentioned perspective, which I called
the motivation perspective, to understand more the intensive care nursing world.

2.2 The motivation perspective: why to care?

The usefulness of the motivation perspective is that it stresses that the reasons for becoming a
nurse depend on social and personal values. Even though the number of female nurses is higher
that of males, and that is visible in my sample, the growing appearance of men in the nursing
world led to changes into the same. To follow the changes in the population within the nursing world it is theoretically useful to draw on Bourdieu’s (1986, 1988) discourse of ‘distinction’ and the notion of ‘habitus’, as well as to take into account culture and personality studies (c.f. Mead 1971; Nanda and Warms 2002). Such perspectives highlight how the individual’s interests are shaped by specific cultural contexts; these individuals, in turn, are able to affect their social environment, what is also called agency. The reason of such a possibility is that individual’s acts are neither fixed nor predisposed by society. Individuals can improvise their behavior within the cultural dispositions, and as a result of these, they can change their social context. By such actions upon the social environment, individuals gain power and social recognition.

The way in which this social theory relates with intensive care nursing is visible in this intensive care ward. The fact that nurses have opened a space to establish a dialogue with doctors, have gave them the power to mould practices at the ward. Nurses are acting upon their social environment and by this choice, they gained the possibility to discuss with doctors about the patients’ treatment; a ground traditionally limited to doctors. This can be fully understood by the words of Mina, Juliette, and Jaap:

Mina: “I think as a nurse you see that a lot, that’s why it’s very important to be in the committee, because you are also in a good position, you see everybody, all the disciplines going to the bed, you are really central person between the patient and the doctors”

Juliette: “I’m one of the initiative takers, I really want to make a difference here, and I really want things to change”

Jaap “ being part of the committee gives me some influence in how things must go in the future. I can say what I want (...) I hope that some people will listen and maybe we can make some progress”.

But this is a result of already being an intensive care nurse. What moved them to become one, is now a central question to understand why they are willing to change the dynamics and the boundaries of the ICW.
The interaction with medical technology, the willingness to know more about the functioning of the body from the medical perspective, the wish to help and to take care of those who have their lives at risk, as well as for self fulfillment, stand as main reasons given by the participants for becoming intensive care nurses.

Matthijs: “at first I was a normal nurse, but I wanted to grow, and I wanted to know more about what’s wrong with patients, I wanted to develop myself more, so that’s why I do the intensive care, I have more of an overview of what’s happening to patients”

Juliette: “the reason I became an intensive care nurse was because I had enough of being a regular nurse. I wanted to learn more. Also to have more responsibility and to have more knowledge were really appealing to me. I wanted to develop myself more in another direction and I chose especially for this because of the extra responsibility and because of the broadness of the education, if you do another specialization it’s usually really narrow but this is quite broad and I wanted to develop myself in that broad direction”

Annelies: “because I like to do all my best for one or two patients, because I’ve studied how a sick body is working and how people are (...) if you want to care of a human being, and if you have the knowledge you want to do everything. That’s one of the main reasons that I first wanted to be intensive care nurse. To fight, really fight for somebody’s life”

Mina: “if you work for a long time in a hospital, or, I worked before at a rehabilitation center, people with motor problems and then I worked here (in this hospital) in a shift at the surgical unit, then you will ask to yourself ‘well there so much more to know’, because the care is going so much further, because before the patient comes into the unit he has gone through a lot and he’s usually coming from the IC, so I was really curious ‘what’s happening there, what they do there?’ so that’s why I wanted the education. Also to know a little bit more about the medical side because you learn here a lot more about medication and more acute things that people are going through”

Jaap: “Before I became a nurse I worked with apes, monkeys you know, in a research institute, and I took care there of apes, chimpanzees, in their childhood.”
Then I thought ‘I must go and do this work with humans’. Also because to take care of animals is a low standard profession and to take care of people is high standard. I did my studies of intensive care in 1990 to 1992. I also did studied dialysis and I work in that for 4 years in another hospital, in Leiden and then I came here because I like this work more than that, because that was only the kidneys and one kind of machines. Here you have variety, it’s more”.

Even though all nurses are able to treat all the types of cases that arrive at the ward, some nurses prefer some cases rather than others, and as mentioned before, they are able to choose which patient to care of. By looking closer, it is possible to see that this choice is deeply related with the reasons they gave for becoming intensive care nurses.

Jaap: “I enjoy the most if there’s lots of work and the patient is really going better after she or he came, when they need everything and we can give ventilation, monitoring. That’s the kind of patients I prefer. On the other hand, patients who are lying here very long, so they’re very standard, that they look the same every day, that’s not the kind of patients that I like (...) I like the acute patients. They’re coming here and there’s a lot to do, and there’s a lot to take care of them, and you have to see if the patient is going down or if he’s going up”

Mina: “I try to do a little bit like the same so we can give the patient a little bit of continuity, but it is also a bit of what you feel to do. When the people stay long in the IC, sometimes you know the patient very good and you say, ‘now I want somebody else, just not now that patient, just a little bit of distance’ but then it’s just good to see how its going with the patient. It takes a long time but you see him a little bit slowly going better and then it can be really nice. But I think it can also be nice to get somebody in the IC and you have to be really busy, really taking care of that patient, saving her life. I like both”

Annelies: “I like to work very hard so if there is a new patient coming in and he is terribly, terribly sick, then I really like to care in that situation and to see all the technical thing going wrong, and what to do about it, and to anticipate to things, and to divide all
the tasks, and to organize. I really like that moment so that’s, but that’s most the technical stuff. I like those acute situations, but I still like to just take care of a patient and to wash his hair and to have contact. I like the action of the IC, I think and that you always have to combine everything together. I like it, to think about what is going wrong with the patient, about how the body is working and to act on things that happen, and to take care of somebody”.

Matthijs⁷: “I don’t have a special category. I like to switch, sometimes somebody with brain damage, sometimes cardiac operation, different situations”.

Juliette: “I don’t have a favorite thing, that’s what I really like about this intensive care: that here are all sort of cases, so I can keep myself broad”.

In this context, when nurses decide what patient to care of, they are moved basically by the reasons that moved them to become intensive care nurses in the first place. It is part of the self-fulfillment at work. However, to have a complete notion of nurses’ understanding of their job I wondered about the tasks they prefer to perform. The alertness, the effort, to deal with technology needed to keep a person alive, together with tasks such as to talk to the patients, to wash them, to look after their personal appearance, are combined and enjoyed by nurses, as Mina explained:

“I think it is the whole thing together, when I worked the day and I’ve done a little bit of everything, when I talk to the patient, when have the time to do that, or when I make the time to do that if the patient is awake, when I speak to the family and the person lying good in bed and everything’s right and the monitors say what they have to say, I’m going home like ‘ja! I worked good today’. But it is also nice to be really busy with a patient, to have a very complicated patient”

Therefore it is important to explore on how nurses take care of their patients, how they combine their tasks, what is nurses’ understanding of care, and why they care of their patients in the way they do.

⁷ At the present time he is not dealing with patients given his administrative position. He is making reference when he was in full contact with the patients.
“For whom are we here?” Working at the ICW.

As showed above, nurses’ work is permeated with the almost permanent use of technology. It is impossible to imagine an intensive care ward without all its high-tech equipment; “it is seen as the monument to science and technology, a living testament to the vast resources that our society has committed to saving life (…)” (Anspach 1993:1).

Patients and practitioners agree that modern medicine increasingly provides effective tools to diagnose and treat people. But the medical profession’s increasing reliance on high technology can also be viewed as entailing a certain alienation: a dehumanization of the patient, of his/her care givers, and an erosion of the humanitarian professional values that have traditionally sustained medical care (c.f. Bronzino et al. 1990; Zussman 1992; Hudson 1993). The reason for this is because of the capabilities to sustain life under circumstances in which before death would have been inevitable. Such a possibility forces us to reconsider the nature of life and death, and to confront seriously the ethical dilemmas that surround questions about the quality of life and the definition of death (Bronzino et al. 1990).

Ethical approaches attempt to evaluate the potential adverse effects that frame such an aggressive use of technology in patients’ care in one hand, and what kind of moral values are at stake when decision-making moments arrive.

Following Quint (1967) “The question of deciding when a person is dead has become more complicated since the advent of many new life-preserving measures. Life-prolonging equipment gives the physicians greater control over postponing the patient’s death but also leads to complex and difficult decisions” (13). The acquired ability to sustain lives in current medicine developed an obsession with death, presenting all cases of death as a medical failure (Bronzino et al. 1990).
Shared notions of quality of life need to be taken into account in order to understand decision-making processes and life-prolonging actions. From such an understanding, one is enabled to comprehend major social values (Quint 1967; Bronzino et al. 1990; Anspach 1993; Groen 1995; Kayser-Jones 1995; Brock 1996; Lock 1996, 2002)

As the participants of this study agreed in saying, physicians, in the studied ward, employ all possible technological means to maintain people alive. “Here they go quite far”, “doctors don’t know when to stop” “sometimes is better to stop” were common comments made by the participants to refer to what is done in the hospital. In this context, nurses claim that when they differ from doctors, about a person’s treatment it is because nurses’ starting point is the patient’s quality of life, and such a prolongation of life will not represent any benefit to the patient. Nurses are concerned about the process and the results since sometimes, they feel, both are worse than death. Therefore, these considerations have to be framed by and nourished with nurses’ perceptions and understandings of their roles, tasks, duties, and social reasons of nursing as well as how technology represents—or not—a reduction on human care.

3.1 “It’s just a tool” Technology and medical care

As a result of their duties, nurses have been deeply concerned about the fact that the control and use of technology may distract them from the human contact with patients. As mentioned by Annelies at the beginning of this text, one great function and reason of the ethical commission is the possibility that nurses talk about their worries, preoccupations and difficulties regarding a patient’s treatment or situation, since this was leading to a loss of human contact from nurses to patients. However, nurses recognize that such an option requires extra energy form the nurse. Annelies stated:

“I chose to do that, but sometimes costs a lot of extra energy, because I really want to stay in contact, and because it gives me more pleasure in my work”

Nevertheless, nurses are quite aware of the fact that the permanent contact with technology drives them to, sometimes, forget about the patient. However, all of them explained that technology is seen as a tool to take care of, and to help the patients. Moreover, it makes the work highly
interesting, as nurses are more responsible for the patient; but it cannot distract them from the person lying in bed:

Juliette: “It’s very easy to only look at the technical side of it because it’s a lot of technology going on, and because often the things that you have to do are really technical. At first when I was doing the studies of course I had to learn all these new things, so I really thought ‘oh no I’m only looking to the technology’ because I was so focused on doing everything well. Now those things are routine for me and I’ve found the patient again more important. The basic things are even more important to me like taking good care of somebody’s body, talking to a person even if I’m not sure that he can hear me. You cannot say that one is more important than the other because if I forget about the technology the patient will die, but for myself is not that important anymore, I think that the person lying there is more important. I want to give to the person a comfortable feeling”

Jaap: “The person, the patient in bed is very important, but I like to do the technological side. But the main point is the patient”

Matthijs: “The main issue is care for the people, all the equipment are helping but the main issue is care for the patient, and to take care of him, that he’s comfortable in his bed, to look after his hair, his nails, that he’s clean, that he looks well and that he feels comfortable in this uncomfortable situation”.

Annelies: “I think, but that’s really my personal view, so that’s necessary to see it like that because it can be the other way around. My first care is really the patient and the technology is only a help. If there is a person that really has the chance to become better, and maybe the person is young and there are all reasons to fight for somebody, I use all the things that we have to help somebody. If you know that the person wants it, and you know it’s possible to be cured and you fight for it. But technology is not the most important thing for me. The most important thing is the human being”.

In this sense, it is visible that nurses’ understanding of care implies the contact with their patients, while technology represents a tool to assess the patients or to help him/her either to recover or to perform some vital functions, as for instance, to breathe. Because of such of understanding of
medical technology, its use and the place that human contact has for these care givers, sometimes they differ from doctors in a patient’s prognosis. In other words, nurses not only perceive technology in a different way, but also they draw on another source of information from which they take their own conclusions: the permanent contact and the follow up of the patients, together with their experience. These elements give nurses a special way to sense technology and to assess their patients. It is because of having this extra information that nurses see themselves with the possibility to speak on behalf of the patient’s. It is this other source of information that moves nurses to, sometimes, say and think that the patient has had enough of a treatment, or on the other hand, to say that the patient still has a chance to recover:

Matthijs: “sometimes I can see it just on the patient himself, even if I don’t look at all the equipment, I can see it on the patient, on how he looks, his skin condition, his eye look (...) I can see if he’s going to die”.

Juliette: “you see it in the face, in the eyes, that the person is going to die. It’s also your knowledge of course, I had a lot of experience; you can compare it to other people that had the same sort of things and also had died. But sometimes you just walk into the room and you see it in the person’s face and it’s always true, even though you don’t know anything about the person yet, and of course many people die in an intensive care, they are the most sick people (...) it’s some sort of instinct that you develop but I cannot really put it into words, but you just can see it in somebody’s face, in the eyes”

Maria Fernanda: “and what about the monitor, and the exams?”

Juliette: “sometimes it’s just a gut feeling, everything (...) all the numbers are right, and this is going a little bit better but still you have the feeling that things are not going well because too much is going wrong and usually is: ‘and this is wrong, and this is wrong, and this is wrong’ and every time things are going worse and worse, and even though the numbers are ok for now it’s just too much for one body”

Annelies: “that’s a combination of facts. I also think it’s a way of thinking because you learn to think in trends, if you see that the blood pressure drops and then this is going wrong and it has to do with this and this and this, you have a kind of trend in your mind. With some patients you see very, very clearly that the trend is going down. But
sometimes there's a patient that you see that the trend is going down but you think 'mmm I think he will make it' so the trends also fool you (...) It is a combination of thoughts and feelings. Sometimes it is easy for me, it is strange. It happened last week, I had a patient, she fell on her head, she had a very bad scan of her head and everybody was saying 'she is not going to make it, it is too bad', and I was standing by this patient and I was thinking totally different, I thought 'oh well she is going to make it' I felt it, I felt she was inside and then I came to her and I started to talk to her and she was so shivering over her body, so she was reacting on what I was saying and everybody was like 'oh, that's not possible'. But the next day somebody by mistake stopped the sleeping medication, so she woke up the next morning. That was not good for her so she had to go to sleep again, but she was reacting and we spoke to her and that (...) ja, it is something that you just know. It also happens the other way around, that you know that the patient is not going to make it; you know that there are no more possibilities. You're taking care of a patient and you think 'well every fact is ok but I feel it is going wrong' then you transfer the patient to the other ward and you think 'this patient is coming back' and maybe it's not today, not tomorrow but the day after they are bringing him again (...) sometimes you know it”

Jaap: “some patients with a good monitoring, that they are doing well but because of their illness and because of their past, and because of what happens and doesn't happen you can say 'this patient is not going to make it'. That's possible but that's tricky, sometimes, maybe 2 or 3 patients of a hundred you are wrong, then the patient makes it. But often you hear later, when the patient is on the ward or at home that he dies. We saved him but he died. Then is when you ask what the quality of life was after we have dismissed him from the IC, but I can't decide of course. That's difficult to say because we are not doctors, we have to rely, for the most part, on what the doctors are saying us to do, but on the other side is our experience to see cases and to see how it develops with the patients. From your experience you can say that's going that way, and if there is only down, well there is a point where you have to say 'well no more'”.

However, nurses are aware that sometimes they may be wrong because, as they said, “we are not doctors”, this means that sometimes they lack the full information about the patient’s diagnosis and prognosis. Therefore, they discuss such questions in the ethical commission. Nurses are very
careful in exposing their opinions until they are completely sure of what they are thinking about the patient.

Mina: "I find it difficult because sometimes you can quite fast be hard like: 'ah! That's gonna be nothing, don't waste your energy', then you have to try to be careful with that because sometimes you may be too quick to say it. I think that's also something to talk about in the ethical committee, we can think hard about it and see all the aspects. But yes, I think we are most of the times quicker with that than doctors, I'm thinking, ja, he's not going to make it, and ja, you say that quite fast and that's why it's very scaring to speak about it because you know sometimes you aren't right, some people do make it, that's why I will never say 'ok, I will cut the chain, I will say stop'. But sometimes you know".

Annelies: "yes, most of the times you know it, but it also is sometimes fooling you so it is important not to take it always, too serious, but many times I'm right".

As mentioned earlier, the possibility of having extra information to assess the patient, not only relying on what the monitor or the exams say is because nurses have a process with patients. A process in which the interaction between nurses and patients is required.

Nevertheless, the fact that nurses have to deal with technology in most of their tasks, has produced, what some see as a dehumanization of care amongst some other nurses of this same hospital. Nurses complain that some of their colleagues are more engaged with technology than they are with patients. Such an attitude towards their role and profession had filled these nurses with, what some participants called, cynicism. From the nurses' point of view, the lack of contact with the patients, as well as the lack of communication with other nurses, and doctors as well, about their difficulties or worries about some cases, have transformed some nurses into cynical people that joke about the patients in order to cope. Although Juliette and Jaap said that sometimes they joke about the patients as a way of coping, the difference with the other group of nurses is that the latter are not either able to see the human being lying in bed on the one hand, or to accept that there are cases that affect them. In this regard Annelies and Juliette stated:

Juliette: "I think that in a way everybody is cynical, is also a way of coping, I think there's a difference, there's way of being cynical and that's in coping with difficult situations or being cynical because it is a blot, and all the human warmth towards a
patient is gone. Some colleagues have lost the sense of the patient, they are very cynical, they just focus in the technical things and the patient is totally blurred”.

Annelies: “they were very cynical, some colleagues are still very cynical because they don’t talk about their feelings, about the patients and they are very hard for patients. I really don’t like that, and I was questioning ‘how could that be, how can people act like they do?’ and in the most of the times it’s just because they are not talking enough about what was happening with the patients, they are not able to deal with the situation; that is so bad for yourself if you are getting cynical, because you feel guilty afterwards sometimes, or don’t feel anything anymore and that means that you have too much to handle, and ja, one way or another that will break you up sometimes (...) that’s why I want to stay personal in my work, to keep the contact with the patient always”

Nurses highlight human contact, as one of the most important features of care, to not disregard the human being lying in bed, no matter what is his/her condition is a golden rule for these caregivers. Therefore, to comprehend how and why they feel they can speak on behalf of patients’ it is necessary to explore nurses’ perceptions of their role and their understanding of care as well as of the importance to maintain the contact with patients.

3.2 “Honesty is the best way for the patient” Nurses’ perceptions of their role

Nurses perceive their role as going much further than just following doctors’ prescriptions. Nurses express that as a search for the patient’s own good: that they can assess the patient differently than doctors do because they have the opportunity to follow the person and to, sometimes, know his/her interests. However, to have insight of the patients’ expectations of the treatment, to make him/her as comfortable as possible, as well as to keep him/her informed of the situation, nurses must communicate with patients. Communication plays a central role in such an enterprise and because of this, some nurses do not limit themselves to only talk to patients who are awake, even if the communication is not always easy or possible.

Mina: “I try to talk to them, to explain to them why they are here. Also to explain them what I am doing. I think honesty is the best way for the patient, to tell them what’s happening, because the patient isn’t a crazy in the bed, they know most of the time I
think. (...) I also touch them (...) and if they are unconscious or sleeping I always try to talk, sometimes I forget, but I try to talk, I say: ‘hello I’m gonna leave your arm, or I’m gonna do I don’t know what’ it sounds really stupid some times and you can think ‘hey he’s sleeping he doesn’t hear you’ but you never know if they hear you, I’m sure they do (...)

Annelies: “I’ve learnt how to communicate also with a patient who is not able to talk or is confused. I experienced that I got better in it. To communicate more and that is what I personally always want to fight for, to stay in contact with the patient. If the patient is unconscious I try to talk but not always. If somebody is sleeping 6 hours on his belly, and 6 hours on his back, and 6 hours on his belly then its difficult to communicate. But if I know, if I feel that there is a sign of communication then I react on it. Sometimes it is the blood pressure or because of the respirator. If I see that somebody is stressed, then I touch the patient, I’m not always talking, it’s more than that, but I am communicating. I do it more with a patient that is unconscious”

Juliette: “I want to see always the patient, that’s why talk to them a lot, even if I’m not sure that the person can hear me”

Nonetheless, behind such a willingness to stay in contact, to inform the patients of their state, to make them feel comfortable, lays a deeper understanding of nurses’ role in the ICW. Nurses perceive themselves as central to and needed by patients in their healing process. When asked about their reasons of caring in such a way for their patients, they answered:

Matthijs: “many of our patients are totally dependant on our care, so we have to think about everything, does he eat, does he drink, does he defecate, how are his dynamic parameters, how is his blood pressure, heart frequency, does he breathe enough, we have to have all those things in order (...) Many of our patients are sleeping, but if they are awake we try to make them have a ‘good time’”.
Mina: "you are the closest, most of the times, to the patients, the one that sees the patient, because you take 8 hours for the patient, so I think you have a position also, ja, it is to be a little bit the advocate of the patient, to say what you see, if somebody has pain you gonna ask the doctor 'can I give more medication?' and if somebody says to you that you have to do this and this and you say 'I don't think the patient would like that'. You have a few reasons to say that, you stand up for the patient. I think that's the most beautiful part of it. Most of the times the patients can't talk here and are totally dependant on you, on what you do (...) I think that's something that's really important for a nurse: what can you do for a patient, also be a little bit like ja, you standing between the patient and the doctors".

Annelies: "I also always follow a patient to know what the patient wants, so if a patient comes to the IC sometimes I'm following the patient for 6 weeks to stay in contact (...) if you get to know a person, you know what is changing in his head and you know when somebody is going wrong. I always choose to have contact with the patient because I know everybody is worthwhile, and that's why I always want to stay in contact. When I feel that I don't see the person anymore something always happens that brings me back in contact with the patient again, so you can really help"

Moreover, this professional understanding of centralness in a patient's treatment is enhanced by nurses' self-portrait as irreplaceable by technology. From the participant's point of view, technology cannot replace nurses' role even when it is fully required in their job. When asked about such a possibility, given today's developments in medical technology, all of the 5 participants deny it, without second thoughts:

Matthijs: "No. Never, I don't think that's possible. I think technology will take over some of the acts of a nurse but it cannot replace it. You always have to care of a patient, I don't think a robot is able to wash a patient, or to shave, or to look after, there's no human contact in it"
Mina: “I don’t think so, I think that you can look at the monitor and it’s going very good with the patient and then you look at the patient and you think “oh my god he doesn’t look good” that’s for the clinical side of a patient. But the mental thing is also very important, to talk with the families and the patients. That’s something a monitor can’t take over, the family needs to talk with somebody, and for that you will always need a nurse.”

Annelies: “no never. For a big part it can be, but if there is no soul, if there is not really involvement you cannot take care of a person. You can cure but you cannot care. Also for the patients, if they know that they are special for someone then they are motivated, and if they are motivated they get better, and you if can help them to be motivated, the person has a lot of more opportunities to get better. I’m totally convinced of that”.

Jaap: “no, because computers, monitors, ventilators are dumb as the people that have made them. We are always necessary to validate the information from the ventilation and the monitoring, that they are right. I don’t thing that we can be replace by technology. It takes great part of our job, we are more controlling then than doing, that’s a trend, that’s true, but we cannot be replaced. Also for the human contact”

Intensive care nurses have gained the role of taking care of people who are in life threatening situations, and moreover, they consider themselves as capable to know what is better for the patient as well as knowing what the patient wants. Nonetheless, there is still something lacking to fully comprehend why nurses formed such a group as the ethical commission, which stands for the patients interests, where nurses have a voice to express their points of view, and also that help themselves to cope with difficult cases that they encounter as part of their work. I argue that this missing part is based in nurses’ own perceptions and notions of quality of life, and quality of death. Therefore I will now explore the dimension that these concepts have in nurses’ understanding of their work and of themselves. However, before exploring this, it is needful to comprehend why intensive care nurses exists at all. To understand the social reason that supports the existence of caregivers and caretakers of such a group of people as intensive care patients.
Caring for the dying

To be able to understand the role of nurses in the care of the dying, it is important to have a look at the role that death plays in modern societies, and the place that nurses have in relation with it.

4.1 Societies and death

In the modern world it seems as though death has little or no place in society. Individuals do not think about death until they face their own death or the death of someone close to them. The dying have been segregated from social life limiting their interaction to close family members and health care professionals. However, the treatment and the understanding of death and dying is a “social phenomena deeply embedded within society as a whole” (Clark & Seymour 1999).

Theorists in search for a sociology of death, agree in saying that death has been re-conceptualized as society has changed. Different perspectives show a shift from a personal, family, and natural aspect in which God’s will was given as answer to death, to a public, pathologised and medical event in which the last word is hold by medicine (Aries 1981; Kearl 1989; Illich 1995; Small 1997; Seale 1998).

One reason given to explain the turning away from death, which characterizes modern and post-modern societies, is that modernity rejects any type of after-life. The body is the central axis of an individual for whom death represents the end. In late modernity, the body became the representation of the self and death represents the end for any living entity (Foucault 1980, 1984; Small 1997; Clark & Seymour 1999). In today’s Western societies the dying are mainly represented by the aging population and by the chronic ill. They are seen as contaminating and
dangerous for the social order, as is the case of diseases like HIV/AIDS. Therefore the dying are set aside: confined to health care (Clark & Seymour 1999).

Nevertheless this understanding of dying, and death cannot be reduced to the body. “It is impossible to interpret death [as] a merely physical event. The horror inspired by the corps does not spring from the simple observation of the changes that occur in the body” (Hertz 1960:76). Death is seen as a risk to the social bond. It represents the fragility of human beings. But moreover, it represents the breaking of the order; cultural life supposes the immortalization of the society. The loss of a member may suppose a loss in the social body (Hertz 1960; Kearl 1989; Seale 1998). In this context, ritual practices are set in motion, in order to maintain the society as a whole and to bear witness to the fact that life has just ended for one person and not for the entire group. Grief and mourning help the survivors to continue their roles in daily life and society could continue to be perpetuated.

Nonetheless, ritual practices are socially constructed. Foucault (1980, 1984) portrays a body devoid of self-agency and grief. Mourning practices are imposed by society and individuals accept them without any further questioning. Such an approach leaves no space for the differentiation that exists amongst people’s understanding of and relation with the dying. Phenomenological (Foucault 1980, 1984) and constructivist (Durkheim 1915) perspectives present death and the rituals after it, as the way to separate the sacred from the profane, the polluted from the unpolluted. Rituals are seen as the means to rebuild the lost social order.

These over deterministic approaches, constricts individual actions and present them as fixed. Such characteristics of the presented perspectives are very problematic. If this was the case, if death could be reduced to a biological phenomenon and individuals were pre-determined in how to react when death arrives, then there would be no place and need for nurses’ role as support givers for the families of the dying patients and for the patients themselves.

In these cases, again Bourdieu (1986, 1997) shows the contrast. As mentioned before, individuals are provided with the capacity to act upon and affect their social contexts. People react differently in any given situation of death. Their reactions are marked but not determined by different positions that social actors occupy in the social structure. This explains why nurses may have a central role for families and patients as support givers.
Drawing on Kearl’s (1989) argument, in modern societies, where the death of common individuals do not represent a major des-stabilization for the larger society, ritual is constructed to give elements to the affected survivors (the family network and closest friends) to be able to continue life. Because what can cause a social imbalance would be a long grief that maintain individuals away from their social roles (work for instance). Then policies on grief and mourning are established to regulate these practices.

In this context, nurses’ role in palliative care is to help the dying and the family to bridge the gap between the social and biological death. This process of recognition and acceptance of death allows a construction of the two types of deaths as one; or as it is in most cases, to help the family and the dying to get both types of death as close as possible. Thus, by grief, mourning and bereavement, societies are shortening the length of time that separates the social death form the biological death. In this context, the social raison d’être of ritual practices is to bridge as fast and as radically as possible those two types of deaths, which are what represent the instability of the social order (Kearl 1989, Walter 1996; Seale 1998).

The relation that these theories have with practice is that in fact nurses serve as a catalyst between medical prognosis and self-expectations of patients and families. Nurses portray themselves as the ones that take care of both the family and the dying patient when death is anticipated as a coming and irreversible fact. This other type of care supposes to let families and patients talk (if they can) about their worries, but also it supposes to help them to accept the inevitability of death as well to accept death when it comes.

4.2 Nurses and the dying patient

The care of the dying patient is known as palliative care. This word come from the Latin verb palliare which means “to cloak or shield” and it is from this notion that modern palliative care takes its cue” (Clark & Seymour 1999:79). To draw on this definition, it can be said that palliative care is seen as a way to integrate the very ill patients with their social environment when a time of profound disintegration is taking place. Such disintegration is a product of the life-threatening situation that patients are going through. Nurses in this area are helping the patient and his/her family to understand the liminal phase in which they find themselves. Palliative care is meant to build together with the patient the meaning of dying process. Palliative
care is meant to provide both physical and emotional well being for the dying as well as for their families (Clark & Seymour 1999).

Thereby, nurses working with dying patients are of high importance, since they play a key role in what can be the patient’s last stage in life. Nurse’s focus on relieving patients’ suffering as much as possible, and are concerned with his/her social interactions. Therefore nurses allow visitors to go to the patients’ bed and spend sometime with them; but furthermore, nurses create the space for such interaction to happen. Here, it is possible to better understand what Juliette said, earlier in this text, about closing the curtains when a family wants to have an intimate moment with the patient.

But the nurses’ role does not constrain patients and families in talking amongst themselves about death, in saying good-bye to each other. Nurses are also faced with the fact that patients and families approach them to talk about these matters.

As the participants stated, they are able to listen and to talk with them about their doubts, fears, feelings and ideas of death, the moment of death and, sometimes, after-life. These nurses are aware that they may not be able to answer the patient’s or the family’s questions but they give support to people in the need of care. As Mina commented:

“It’s of course very hard to comfort somebody, because the only thing that you can assure is that somebody doesn’t have a lot of pain, and you make sure of that kind of things. But also if you see that he needs to see his family for a little while, I think you have to give him the time, if you can talk to him or listen to him, you have to do that but I don’t know if you can really take away fear, you can try by listening or by talking to them”.

This attempt to help people find a little peace is also extensible to the families, as I already mention. In this regards, nurses explained:

Annelies: “the relationship with the family is mostly about the patient, condition of the patient, but I also prepare them, when I feel it’s going wrong then I try to prepare them that we are going in that direction”.

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Juliette: “I don’t give the medical information, of course, but I talk to them when the doctor says ‘well your wife is very sick and we think she’s going to die’ or whatever, then I’m always there, so I can talk to the family afterwards and I try to help them, I see if they want to talk about something”

Mina: “After the doctor had informed them what the situation is, afterwards, when they had that conversation and if they are still asking me things I will say how bad it is because I think you better can be honest about that (...) ja, most of the times it will take a time before a family really understands how bad the situation is. I talk to them because the family is sad and they have a hard time with it, some times harder than the patient himself because he’s out of knowledge so it’s important to try to tell them everything and also be very honest to them. I think, that they know what’s going on”.

When the situation comes, and either patients or families ask the nurses to have a talk, nurses listen and elaborate in the patients’ or families’ thoughts but they only give their personal point of view if it is directly asked.

Juliette: “I think my point of view is not of great importance, but if somebody ask me, in a direct question ‘what do you think?’ then I answer. I think is more important that somebody can express what does he or she think like ‘I’m afraid to die, or I want to go to heaven, or I still want to do this and this, or I still want to see this and this’. I think that’s more important because is that person dying and not me, unless someone wants to have a conversation about that, but then they have to ask me. So I don’t talk about death that much but about how people feel and how scared they are and some people are really happy, because their lives are so full of pain and misery, so that it is some sort of rest I think. I always try to talk about the feelings around it and sometimes also about some practical things like ‘what do we do with this and that’ and also some legal things”

Matthijs: “sometimes the patient is scared and we talk about it, we talk about what they want. Each person is different so we let him or her to talk, and then we can see what we can do. I respect each opinion, myself I don’t believe in a god, if the life stops it stops but I respect the opinions of other people, and if they believe in God, then it’s their opinion and I accept it”.

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Mina: “I think you try to move yourself a little bit to the situation of the person, to know a little bit what he is thinking, if that’s possible, if they can talk, if you can really feel what they feel”

Annelies: “when somebody is able to talk then I try to have the opportunity to talk about it if somebody wants to and because you know it’s a big possibility. It might be better to talk more with patients about that because it has a lot to do also with acceptance. I think that if you accept how you are that’s also good for the friends and family and for the patient. But you can also take then the fighting spirit away, so it’s difficult if you talk about it or not. It’s always something that happens when you are taking care of the patient, with one patient you do that with the other you don’t (…) but I don’t talk about my personal things. If they ask I do and if I know I can help them I do, and also I believe in God and I believe in the life after death, and that’s very strong, so if somebody asks me for it then I won’t miss the opportunity to say something about it, if I know it could help somebody”

As result of this commitment and attachment to patients, nurses are increasingly concerned by their involvement with the dying since most of them of them go through processes of grief and bereavement when they loose a patient. So much so that this group of nurses have also had some lecture on posttraumatic stress disorder, in order to talk about situations that deeply shocked them. For these extreme cases of affliction nurses refer to cases in which medical mistakes or medicine’s lack of limits produced the patient’s death in a way nurses consider traumatic for themselves:

Annelies: “there was one case that hurt me and that was because of a medical mistake that the patient died. This patient was depending on all kind of things and one of those things was the tube for the respirator. This patient was sleeping on his belly and on his back to have a better oxygenation in the body. I was putting a pillow on his head and while I was doing that the tube went out of his mouth. That was because the tube wasn’t deep enough, and that already existed for a few days; but just when I put the pillow under his head it removed. Because of the medication he used the throat was a complete mess, so the doctor couldn’t get a new tube inside, and when that was happening we had to start the reanimation because of the low oxygen in the blood. He got the tube finally in but the patient died. That was very difficult because you know; the tube was already a few days
not deep enough in the throat and because of something I did it came out. It wasn’t really
my mistake, but that’s difficult, that somebody dies because of a mistake”

For Juliette, the experience of dealing with a patient who was the trigger for starting the ethical
commission, had a great influence on her:

Juliette: “that case affected me greatly I didn’t dare to go to sleep that night because
every time I shut my eyes I saw this woman in front of me and I just spend the night in
the couch, I hardly slept in three days, and up to like 6 or 9 months later I still couldn’t
take care of a patients who were similar to her because if they started to bleed, like only if
the nose was bleeding, I stood next to the bed and started to cry, I couldn’t take care of
these people, it really, really had shocked my a lot, it was like a trauma what happened”

Because of these extreme situations some nurses prefer to keep distance between themselves and
the patients in order to protect themselves

Juliette: “sometimes I find a person whom I’m getting a bond to, whom I taking care for a
couple of days, and whom I see not going well, and I try to talk to the doctor and if I
don’t, if I can’t get through with them (the doctors) then I go back and I go to take care of
another patient, because of the thing I encountered, I want to protect my self, I’ve done
that now for two times and I think ‘oh, maybe that’s not good or whatever’ but I don’t
want to be in the same situation again. But I really try to find out what somebody wants
and to be there.

Mina: “I try, to keep a distance because, I think it’s a little bit of a protection of yourself
to do this work, you get a little bit harder for it. I think when I was a student I was not
hard as now, I’m already now used to see things, that often people die, it sounds really
hard but I think it’s a little bit of a protection of yourself also to do this work because
then you would get really emotional about every difficult situation”

On the other hand, given that all participants agreed in saying that some types of deaths, mainly
the ones that are of people of their same age or the situations exposed above, affected them I
argue that this can also be seen as a way of turning back form the possibility of their own death
Jaap: “to talk with patients about their process of dying, what is going to happen is difficult, sometimes the nurses are not going to do it, they stay on a distance, me too, not always, it depends on your relationship with the patient. There was a case, a young person, a young woman, she got intubated and then everything went wrong and wrong and she became ill and ill and she died in the long term. It affected me because she was someone of my age and the family and the emotions that took place that affected me I thought ‘that could happen to me!’”

Matthijs: “For me is difficult if there is a parent of a young child, a father or a mother of one or more children, someone of my own age, that is for me difficult, and if I see the patient more often and if I’ll have a bond then its difficult”.

But nurses’ role in the process of dying does not stop when the patient dies. After death comes, nurses also have to deal with a dead body as part of their tasks. Even though after years of dealing with dead bodies, it is now a routine for them, nurses take good care of the body because “is the last thing that you can do for some one” and because of the family. At this point, is important to remark that some nurses talk to the patients after they are dead and this is related with the belief in after life, as is the case of Juliette or Annelies.

Juliette: “I think that the spirit is still around, I don’t have a real conversation but just a few remarks like ‘oh I’m glad for you that the suffering is over’”

Annelies: “I believe in God and I believe that he loves everybody, that he wants to love everybody in the world, and I believe that they will go to him”

However, even if nurses do not believe in after life, the care of the dead body is a routinary process that has to be done with total respect to the person who died. But the care goes beyond the body as it includes the family of the person who died.

Mina: “we take out the tubes, the infusions, the lines, that the patient has and then we clean the patient a little bit and brush his hair, try to make him look nice in the bed if the family wants to see him we let them see him good”
Juliette: “I always try to take really, really good care of the person like, also for the family, and also because that’s the last thing you can do for some body”

Annelies: When the patient dies I have to take care of the family and to take care of the patient, to wash the patient, to take all the technical stuff out of the patient. I also take care of the personal appearance of the patient, for example to take care of the jaw, to put the teeth, and to wash the patient properly. You make sure that patient has dignity lying in the bed. But now your main task is to take care of the relatives”

Jaap: “We put the monitor out, we put the ventilator out, we take out all the lines, if you are taking care after death and a colleague is with you, you may talk to him, sometimes it is necessary. We also condolate the family”

After going through nurses’ opinions of death and dying, it is visible a detachment when they refer to the care of the dead body. Life has ended for the person lying in bed and the care of his/her body is a technical procedure that they have to follow. The care and the concern is displaced from the patient to his/her family. The reason of taking good care of the body, to treat it with respect has the as background reason: the family that is going to see the patient. In this point, the social function of nurses taking care of the dying that has been exposed earlier in this text, gains strength and sense. Nurses make sure that the body looks good for the family to say goodbye; to make sure that the patient has died.

For relatives and friends is easier to bridge the social and the biological death when the have no doubts about the death of their loved one; also because maybe death is easier to accept when the person looks close to the memory that relatives and friends have of him/her. But also, these processes of mourning and the expression of grief can bridge faster the gap between the two deaths if people are able to say good-bye and close the circle.
4.3 Nurses’ own perception of life and death

This exploration frames and gives full sense to this study. Why? Because by inquiring in nurses understanding of how a patient should be cared for, in what can be the last stage of a person’s life, brings up to surface their understandings of how life should be lived and how death should be experienced.

After having outlined the remarks about differentiation of death between the ones that affect them the most, form others that are acceptable by nurses, together with how and why nurses take care of both the body and the family after a patient has died, led me to, ultimately, introduce nurses’ own perception of quality of life and quality of death, and how these two notions shape and are shaped by nurses’ daily work.

I argue that nurses’ own perceptions of life and death are dynamic notions that are shaped by and at the same time shape nurses work at the ward. But furthermore, nurses’ understanding of how life should be lived and how death should be experienced is what has been molding the practices at the ward. The clearest example is the ethical commission. To comprehend the relationship between what nurses have been giving as reasons for the ethical commission as well as for treating the patients in the way they do, and nurses’ own ideas of life, death, and dying, I found useful to ask the participants questions that helped me to have a closer look to what they expect for their own life and death. The first question was about nurses’ ideas of a good death, how they would prefer to die. What is interesting in their answers is that as first reactions, and with no second thoughts, all participants said “not here”, referring to the ICW. Arguments as “no human death is possible in this place”, pushed me to inquire deeper. After taking a time to think about their answer, they add:

Juliette: I prefer to die in my sleep, without being sick, I don’t want to be in an intensive care. I rather commit suicide before that really! But you cannot say that because I think when you are getting sick or when is just a small thing, like when I need a heart operation, of course I’ll do that and then I have to be in the intensive care for one or two days. But that’s the difficult thing, there’s people who are in the intensive care for months and months and they are so terribly sick, and they don’t know that in advance, and when the time is there they don’t have anything to choose any more, they are in this whole machinery of the decision making, which is completely out of their hands”
Jaap: “not here, not with all this tubing, and all these lines, and that kind of stuff, I would like to die at home with my family, that’s what I like. Sometimes here there is no human dead. It is not possible (...) I think at home, with your family, that’s for me a human way of dying, and if there’s pain that there is pain medication, and if there’s a short of breathing there is oxygen, or there will be medication like morphine so you don’t become short of breathing, ja, at home with the family and especially not here. Because patients for whom the decision is made to stop all treatment they die within few minutes, and sometimes a few hours and if they stay, they prolong life for more than 24 hours then they have to go to other ward. It’s difficult for the family, is not so difficult to us to send the to another ward. That’s not part of dying in a human way I think, because they lie here, days, weeks, sometimes more than a month, and then when they stop the treatment and they do not die soon enough they will go to the ward for the continuing process. That’s not good for the family, new people and everything is different, so you can’t call it human dying I think”.

Annelies: “not in this way, not in this ward, no. It is different when I had a trauma, when there is an accident, that’s different than when I had a chronic disease, if a have a chronic disease and I know what the end would be like, then I would think for myself an ending point, and that ending point won’t be in an intensive care ward, also for my relatives. I know I’m going to die anyway so I don’t mind if it is a year earlier or more because, well that is going to happen anyway. But if there is an accident I would like to fight but not at any costs, so I’ve talked about those things with my husband. If I’m in a deep coma and my body is totally ruined and I cannot move my legs and my body, and also I cannot think, or I have minor reaction to things that are happening around me then it’s ok for me to die”.

Mina: “I would like to die in my sleep. In this work you see a lot of things. If I have an accident, and I have something neurological I want them to stop. I don’t want to be a plant or something like that. I think I’ll find it terrible, to lie in bed like some crazy woman who isn’t herself anymore, for me then would be like ‘please take plug off the thing, it’s ok’, that’s very hard”.

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Matthijs: “I would like to get very old, and to be in a good shape ‘till the old age, and then die in my sleep. That’s what I want”.

Drawings on these answers two elements deserve special attention. Firstly, the shared fear, among some nurses of loosing their cognitive capabilities. The possibility of having a neurological damage that them unable to choose what to do, since they cannot speak for them. But furthermore, that in some conditions it may represent death. Secondly the fact that if they have a chronic disease they would rather stay at home.

First I will explore the possibility of loosing the cognitive capabilities as a way of dying, as is the case of brain death, from nurses’ understanding of such a condition. Brain death has a double meaning as it has a double possibility. One is that after a brain damage, no functions are left, the other one is that after a brain damage, the lower part of the brain still has function, so the heart and the lungs can work by themselves (cf. The Cleveland Clinic Foundation 2000). If a patient tests no brain functions left, all treatment will stop. The reason for this is that in a case like that, life is prolonged by the use of the ventilator and drugs. As soon as the patient is disconnected form these devices s/he will die, since his/her heart and lungs will no function by themselves. Death for these people happens, most of the times, in a matter of hours. Under this situation there can be no doubts about the patient’s death. However, it is part of the procedure that morphine is given to this patients because, as Juliette and Mina stated “We are making sure that the patient wont feel uncomfortable if they feel anything” and “we don’t want anyone to suffer”.

On the other hand, if the brain has some functions left, if the heart is beating and the lungs functioning, nurses understand it differently. For some, death can be declared only until the heart and the lungs stop to function by themselves. If it is the case, the person with brain death will be transferred to an ordinary ward to wait until the moment of death comes. For others, to be brain-dead is to be dead already as it is not possible to live in such a condition: the brain is central to be alive, to be a person. In this context the lack of cognitive functions is what determines life. However, to all of them, there is a terrible situation to be in and the best thing for the person is to die. It might be helpful to use the participant’s words:

Jaap: “people can’t live like that, because they can’t live the life they did before, that’s the most important thing. They know nothing about their lives, about themselves, about what’s in their neighbor, in their environment. That’s no life”.
Juliette: “well, usually they said that there is no quality of life, so if the person cannot breathe himself they will take the ventilator away so the person will die. So what we do with a person like that is that we take away the ventilator and somebody will die, we give morphine of course so somebody wont feel anything, we don’t want anyone to suffer even if we are sure that he person doesn’t suffers but we still give them morphine. But if someone can breathe then you know this person is never going to recover, never going to get better, and he has no quality of life. So if the person is still breathing himself but has no other functions, then he will not stay here in the IC but he will go to an ordinary ward, and usually those people will die as well in the course of pneumonia. The policy is that you make those people as comfortable as possible so give them morphine as well and then they start to breathe slow and they get a pneumonia or hypoxia, so they die”

Mina: “When somebody really is brain–dead they don’t breathe, people don’t have the move to breathe, so then they stop the machine and they give morphine to him. We are making sure that the patient wont feel uncomfortable if they feel anything, you don’t know. But if they still breathe that is a terrible way to live, you are like a crazy woman and you don’t know nothing about yourself. Nobody wants to lay in a bed and be like a plant”.

Annelies: “I have no problem to say stop if the person is brain-dead because the person isn’t there anymore then there is no personality anymore, there’s only a function in the body it is even less than a baby. I think it is inhuman to keep a person if somebody is brain-dead. But if you stop treatment and the heart is still beating, then they are not death until the heart stops”

Matthijs: “if you are brain dead you are dead, because it doesn’t matter if your heart stops or your brain is dead, you are dead. You need your brain to have a function, life goes with brains, how are you supposed to live without brains? it is no possible to transplant brains, not now, then you are dead”

Having outlined this, the second element that deserves special attention regarding nurses’ ideas of their own death, must be taken into account, given that in the situations mention before, nurses rely completely on the doctors’ diagnosis.
When nurses mentioned their own fears of becoming intensive care patients, the possibility of lying for long periods in the intensive care as a result of a chronic disease was a recurrent example. Nurses will choose to die at home or somewhere else, not in the intensive care ward. Moreover, Jaap said “no human death is possible there” and Annelies added, “I know what the end would be like”. In this case, the worry is the prolongation of life by medical and technological means. Therefore, the participants expect from their colleagues that if they, the participants, were to become intensive care patients, the staff in charge of them would make the effort to know what they want, and to say stop when doctors are going too far. In Juliette, Mina, and Jaap words:

Juliette: “I want them to do their best to find out how I’m feeling, maybe I cannot say that really clearly at that time, but I want them to do their best and also to talk to the people that I love who know what I want and what I don’t want, and I want my opinion to be respected, basically, if I say it’s enough, then it’s enough”

Mina: “I hope that they tell me everything they do and why. I think I’ll be a terrible patient I’m sure. I find really important also that the doctors talk to me. I don’t want that I would sit there like ‘hello, its about me, you talk to me please’. I want them to tell me everything also the doctors, what are they planning to do and why and what is the situation. If I’m not awake I hope that my colleagues stand up for me. As a nurse is very important what you can do for the patient, you are standing between the patient and the doctors. I don’t want to live like a vegetable also. If I have something in my head, I don’t know because neuro patients they are really bad here. Sometimes I think that I have to write something down, ‘if I have this or this, or this do this, please stop’”

Jaap: “I hope that my colleagues will say not to go for the very newest developments and everything, unless they say ‘it is a real chance, he will make it’, that’s what I expect form them. Not going to the end, not everything what’s possible to do ‘this and this, and this, if that does not works then this and this, and this’ and then nothing more (…) I hope that my colleagues will stand for me if they know what I want. That they talk with the doctors ‘this is not what he wants’, stronger than we do, that’s part of our position here, we see the patient 24 hours day. I told you, the doctors go one way and the nurses other, and
there is not enough communication (...) I don’t want to come in that situation, but there is some progress, the committee of ethics is one of them”.

In this final sentence, together with the general feeling and worry of asking either to the patient or to someone close to him/her, showed that nurses are thinking about the possibility of their own death, but further than that, it shows that nurses find very important to talk about how they would like to be treated if they become intensive care patients. In this regard, and showed above, Annelies already told to her husband what to do if she cannot speak for herself, Juliette did the same with her boyfriend and Jaap has done that with his wife and amongst his colleagues

Juliette: “I’ve talked with my boyfriend about what I want and what I don’t want if I come to a life threatening situation”.

Jaap: “I’ve talked with my wife about it. I don’t have anything written down, maybe I have to do it because before you know you are here and they don’t want to stop. We also talk about it with my colleagues we say ‘if I’m in this situation don do this or this’, so they know”.

Nonetheless the fact that they are in permanent contact with death, nurses’ own possibility of death has no a pattern. Annelies claimed that she is not afraid of dying, as did Jaap, but he also added that he does not think about it. On the other hand, Juliette expressed her fear of dying. However, all of them are aware that life has no fixed ending date, therefore they live their lives without making long term plans, and rather, they try to enjoy it day by day.

Juliette: “I like to make plans for the future, but I also, and especially since I work in an intensive care, have learnt that every moment is important because it can be over any minute, I’m really trying to make the most every day and of course I started to study because, also because I also want to do it now and that’s how want to live, I always want to be a good person for the other people but I also want to be a good person for me”.

Mina: “you have to do the things that you want to do, and not do anything that you are not behind because I don’t know who says. You should try to live a happy life, but also you have take responsibilities”
Jaap: “on this moment are the European football champions and I like everyday of it I’m looking forwards Saturday that Holland plays again, I don’t know if you noticed the orange color. Ja, I don’t look far in my life I don’t. I like to enjoy every day”

When nurses give their answers of how life should be lived and of how they would prefer to die themselves, moreover they used cases to exemplify situations in which they would never want to be, the relationship between nurses’ perception of life and death, and their work comes to surface. Nurses recognize that such perceptions have been changed by their work at the ward. But what is remarkable in the dialogue between nurses’ ideas drawn up in advance and later ideas product of being intensive care nurses is not only the permanent reminder that death can come any time, but also the fact that people should not suffer when they are dying. Nurses find what they understand as unnecessary suffering much more difficult to handle than an already dead body, or the fact itself of dying.

Annelies: “always when somebody dies you have the feeling of sadness. but I’m also kind of happy when somebody dies in peace. If somebody dies I accept it, really because they have a better life than me then, and they are living in a total different world. But what really affects me is when you see somebody unnecessarily suffering affects me more”

Jaap: “I’m involved with life and death so I think more about life than if I was not working in a hospital. Life ends, it’s the contrary to the society, they think ‘we can live life longer, we have more technology, medicine is developing, it is improving, that there is much more to do, more things are possible’ and that’s true but on the other hand that’s not true because the patients have to beat their hearts themselves and there is a time when it stops. It is a time when we die, and we can prolong the patient’s life because without the ventilator, without the monitoring they had been already dead, but it’s just prolonging and sometimes they prolong it too long”.

Juliette: “I’ve been working in hospital for a long time, and I’ve been working here (in the intensive care) for 5 years. I know a lot more, I know what is possible but I also know what can happen, I know what the complications are, so I have started thinking much more in my own life like ‘if this happens to me I want this and this’ or when I’m terminally ill I wont go to a hospital I better go somewhere else and die myself. Before I
started working in a hospital I thought that dying was something really sad, and bad, and I don’t think it is true any more, in some cases yes, but in a lot of cases it can be a relieve. Often I’m happy for the people that they died, because they finally rest. For instance the cases which are taking too long, when the person is really, with a complication after complication, or takes a long time and you see a person dying but really, really slow, that takes days or months or weeks, and in the mean time they are trying to do everything to keep this person better, but still you know that this person is going to die, and you see it is too much suffering for the family or for the patient itself. I find that really difficult to deal with."

Trough nurses voices it can be understood that their work has shaped their perceptions of life and death. They see life as a process in which death represents its end. Therefore death should be experienced as a natural event that may happen at home when the dying person is surrounded by his/her loved ones, in the person’s sleep and with the minimum medical aids that assure a death as comfortable and natural as possible. In this imaginary of the perfect death, dying is devoid of suffering; the medical help to prolong life under all conditions is seen as inhuman. Therefore nurses are concerned about the patients’ human death that implies no suffer and a limit to medical intervention. Hence the need for the ethical commission.
5.

Conclusions

Humans' struggles to survive or to help people to live are sometimes understood as efforts that go hand in hand, one with the other, during a person’s healing process. The reason for such a belief can be placed in the almost complete denial of death in western societies. However, there are moments in which care givers and patients disagree: where the individual prefers to stop the treatment whereas the medical staff prefers to continue. Furthermore, there are moments in which the medical staff, involved in a person’s treatment, disagrees amongst themselves about what is better for the patient’s own good.

Nurses’ different training from doctors, the fact that they spend more time with patients than doctors do, and their role as mediators of the patients’ liminal state between life and death, provide nurses with different elements to assess a person, moreover, lead these Nurses to feel they can speak on behalf their patient interests. This, differ from what doctors understand and believe that needs to be done. Such disagreement, most of the times, moves around continuing or withdrawing treatment.

By the way nurses referred to death and dying, they understand death as the ending part of a process called life. Life has a course and some deaths are more difficult to handle than others, especially those that remind people that death is not only for the sick or for the elder. Young patients as well as patients who are in the ward because of an accident (of any kind) receive all human, medical and technical aid to save their life. For the old, chronically ill, as well as for the terminally ill patients, things happen in a different way: the staff has second thoughts, and sometimes they have different opinions about what else should be done to those patients. In this regard, from nurses’ perspective, life should not be prolonged or sustained if there are no enough and clear reasons to support that the patient would have a better life afterwards. This is, however, not always the case with doctors. For nurses, doctors fight at all costs to keep people alive, they
continue treatments even when great doubts about the options of recuperation are the only answers.

Such tensions between professions are rooted in their intrinsic professional values: doctors represent medicine and medical technology used until the last consequences to cure a person, while nurses represent the contact and the care of that same patient. In other words, the first cure, the latter care, and this difference represents two different languages and two different ways to approach and to understand health, life, and death.

In this context, nurses’ questioning about quality of life is not limited to what else can be done, but are about asking if all the efforts done, or to be done, are not too much for a single body. They pose to themselves and to the doctors’ questions along the lines as: is the suffering that the person is facing is worthwhile to prolong that life? Are all medical efforts done to prolong it, harmful for the person? Is not it better stop the treatment and let the person rest in peace, since prolonging such a life is to prolong unnecessary suffering, when no much options are left? Thus, when nurses claim their understanding of the patients’ needs, they are also claiming that they understand the human being as not liable to be divided into the pieces of his/her body. The person is a whole, is a single entity for which the complication of an organ or of a function represent the total alteration of the system.

Nurses do not perceive death as a failure in cases that life is prolonged and there are not much expectations for the patient. Moreover, in such cases life represents unnecessary suffering that has no justification: all efforts should be drove to avoid it, the dying person should experienced death as natural and comfortable as it can be in an intensive care ward. Death is something that living beings have to face sooner or latter and nurses cannot help such a reality. Nevertheless by organizing the ethical commission they are trying to help the way of dying. Nurses have opened a space to have dialogue with doctors to be able to solve the questions posed above. They are convinced of the need to draw a limit to the intervention between life and death when life is worse than death for the dying person.

Such a perception and understanding of death and dying is a result of nurses’ permanent contact with patients. They deal with patients’ bodies as well as with patients’ life: their pain, their worries, and their fears. Therefore, nurses see unnecessary suffering as a process that these patients should not go through. However, the fact that nurses are faced to the consequences of
never ending treatments in which patients voice are unheard, or nurses opinions about a patients
whishes or interests are disregard. This gives other dimension to suffering since it affects nurses’
personal life as well. Cases of trauma or dehumanization in the contact with the patients are just a
few examples. Then, if nurses are to keep human contact and human care of patients, as well as
their role of support givers in difficult situations for patients and for their families; there must be
a way to assimilate such situations. If nurses are to be the catalyst between medical prognosis and
the expectations of the patients and their families, they also have to go through a process of
understanding and coping.

Suffering, death, and dying are double-sided questions: one side is about bearing unnecessary
suffering where the patient plays the central role; what is at stake is the patient’s own good. The
other side is about coping with the confrontation to suffering and death in which nurses are
central. Thereby the ethical commission is a two-functional space: Nurses speak on behalf of
patients and on behalf of themselves. They seek a better way for patients to die by solving the
tensions between professions. Also they seek a way to cope and to bear the suffering of some
ending life.

Then I finally can ask and answer, how nurses cope with suffering, death, and medical ideology
in an Intensive Care Ward? As mentioned before, nurses are able to act upon their social
environment, which in this case is the intensive care ward. Nurses’ perceptions of how life should
be lived and how death should be experienced have triggered some changes in the practices at this
intensive care ward. They have created a space to solve the tensions amongst nurses and doctors
regarding the limits of treatment. Now they have an opinion in a ground that was restricted to
them. Nurses’ understandings of a patients’ needs are now combined with doctors’
understandings of the same. This indeed is leading to important changes in what has been thought
of the relationships between nurses and doctors throughout nursing history. However, the ethical
commission serves as well as a mechanism to cope. Nurses are able to pose questions and
express their worries and ideas about situations that they find difficult. They have enabled
themselves to freely accept the hardness of their work at the ward without diminishing their
commitment with patients and with life. Hence, the two dimensions of the ethical commission
have to be understood and comprehend as one, given that each is a consequence of the other and
the struggle to solve both is what is leading to changes in the practice at the ward.
Thus, after having outlined this, I will take the risk to say that it is not the permanent use of medical technology, neither its omnipresence at work for intensive care nurses what drive some of them to lose the warmth towards the patients. What can be drawn from this study is that nurses’ inability to stop a person suffering is what leads to such an attitude. Hence the importance of the ethical commission: by nurses’ talking about their own struggles with difficult situations and about patients’ needs (from the nurses’ perspectives), nurses will be able to face patients in such situations, given that they will stand on behalf of the patients’ interests and voice and they will be able to assure them that his/her opinions will be taken into account. In other words, it is not the permanent contact with technology what leads to a dehumanization in medical care but the lack of limits to its use, along with the nurses difficulties to handle suffering caused by such a lack of limits.

In this context, to ignore the person lying in bed can be understood as to ignore suffering and its consequences; it is again a turning away from death. Then one can ask, where do the results of the ethical commission will lead? By opening the space to solve these double-sided questions, nurses are securing a better treatment for the person in bed, as well as they are enhancing intensive care nurses’ well-being in their working place, which extends to their personal life. The ethical commission is the tool that helps nurses to cope with these situations, as well as provide them the power to change practices at the intensive care ward, which resulted from nurses’ own perceptions of life death, and dying.
Acknowledgments

To talk about life, death, suffering, medical technology and intensive care wards in one single text was a challenge to me. I needed to find answers to personal queries; I needed to understand life and death in an intensive care ward. At first, it was a bunch of dislocated ideas that moved around this main question; but after endless hours of talking about it gained form and structure. Therefore Stuart Blume and Sergio Rodriguez-Vitta deserve my heartfelt thanks for giving me the time, the words, and the opportunity to have it right. I would also like to thank Diana Gibson for her early interest and valuable comments that help this study to be what it is, and also for taking the risk of reading its final version.

Nevertheless, this project would not be possible without the help of Doctor Dick Willems who recognized the potential of it and opened me the hospital’s doors. I owe particular debts to Wouter de Graaf, to all of the 5 participants of the study who, ultimately brought it to reality, and to all the staff, patients, and visitors who I may disturb during my fieldwork. Further more, I would like to especially thank Joost and Juliette for giving me their opinions and comments about the final version of this text.

In addition I would like to thank Camilo Varela for his comments and corrections. To my Mother and my Sister for supporting this crazy idea and for following it day by day. To my Father for giving me the strength to continue during hard times, and for giving sense to all this.

To all, hartelijk bedankt. A bit of calm has been reestablished and I am a bit closer to the equilibrium.
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Annex 1

This is the official map of the ward. This was given to me by Matthijs.
My version of the ward.

This map represents the symbolic boundaries of the ward.
Green: Nurses’ space
Violet: Doctor’s space
Blue: Patients’ space
Red: Visitors’ space
Black: the physical boundaries of the ward
INFORMED CONSENT

Name of the study: how nurses cope with suffering, death, and medical ideology in an Intensive Care Ward

Researcher: Maria Fernanda Olarte Sierra.

I, ________________________________ certify that I voluntary accept to participate in the study How nurses reconcile the practices of an ICU with their perceptions of life, death and dying, study that will be part of the Master’s thesis of the researcher Maria Fernanda Olarte Sierra. I agree to collaborate with her and be part of the study, answer her questions, and allow her to observe my daily work at the Intensive Care Unite of the Hospital in which I work.

The researcher has informed me about the type of the study, the intension of the same, what is known about the topic and the study’s benefits. As well, she has clarified the type of collaboration I will give. She has stated that I am able to ask all the questions about the topic and the study that I find necessary.

I know that I am free to stop collaborating with the study at the moment that I decide to. If I choose to stop collaborating I am not forced to give my reasons of such a decision. I also know that all the information I will gave, during my participation in the study, will be destroyed and will not be included in the text that will follow this study.

I will have total guarantee of the confidentiality and anonymity of the information I will give and of myself. The researcher made clear that the only person who will have access to the research material (the interviews and field notes) will be herself.

This study will not have any cost for me as a participant.

Place: ________________________________
Date: ________________________________
Signature: ________________________________
Annex 3

As this study is meant to give voice to nurses. I include, under Juliette’s and Joost’s permission, the comments they gave to the final draft of this text. All five participants and Joost received the mentioned copy. Unfortunately, by the moment in which I had to submit the thesis, only theses too comments arrived. However, all the participants will receive a copy of this version.

I would like to thank them for their valuable opinions.

Juliette: “Dear Maria, I finally got to read your thesis, I enjoyed reading it! I'm sorry that it took me a while before I replied to you. I don’t know if any remarks are still useful, since you have to turn it in tomorrow. I do want to say that, reading what you wrote, you appear to be a very good observer. You have seen and named things very accurately. For me it’s very nice to read what somebody who doesn't work there but is interested in us as professionals, looks at us. Concerning the elements you used from the interviews we had, I have no comments, everything you need for your thesis is in there in the way I said it to you. Sometimes it is a bit difficult to understand, because you have used the exact speaking language. It was a pleasure talking to you and thank you for keeping me involved. Greetings (...)

Joost: “This is a message of Joost! Funny that you gave me the name of my oldest son! Indeed unfortunately our schedules were a problem but that had no negative effect on your impressive piece of work. I think that a few items are useable as a basis for new research and some of your describing "conclusions" deserve to present at conferences. So... a lot of things have to be done! Kind regards (...)”