Narratives of Death

Death is a part of the individual’s life and a determining event thereof. Every human being, just for the fact of being born, has a clear ending, which is an event that involves the physical death of the person. Louis-Vincent Thomas (1993) establishes the difference between biological death and social death. Biological death is defined by the evaluation of clinical signs, which are decisive in such biological processes. Social death occurs when a person ceases to belong to a social group and his memory disappears.

During the internship period of the third year at the University School of Nursing of the Universidad de Barcelona (EUE.UB), students work on the topic of death in a seminar held in three different level 3 hospitals. The statements presented in this issue belong to the academic years 2009-2012. The aim of the seminar is that participants express their feelings and experiences on deaths that occurred both in the hospital and the socio-familiar environment, permitting an analysis of how they construct their own losses.
How death is constructed in the social sphere

Death is a taboo topic in our society. Generally, people don’t speak or talk about it, even though it is a universal event. Although people have a clear perception that they are going to die, this doesn’t necessarily mean that is seen as something immediate. Rather it is seen as an event to occur in the distant future. The general idea is that it doesn’t to happen to us; it happens to others. Thus, when a serious illness threatens death, it is usually misunderstood and not accepted. Society tolerates even less an early death than a late one, which is more accepted and is considered as the end to the life cycle. Socially, an early death is more regretted than death at a mature age, even if it is not directly related to the feeling of loss and grief. Our society perceives death in a different way when it is predicted and announced because of a chronic or acute disease than a sudden and unexpected death because of a heart attack or an accident. In the past, the first kind of death was considered preferable because it allowed the dying person to settle his or her affairs and say goodbye to loved ones. Nowadays, the second type of death is often preferred, because we want it for ourselves, but not for our relatives. This is an unexpected way of dying: people die away from their relatives, anywhere, preventing relatives from caring for them. For the family, this turns into a traumatic and undesired death. These days, expected death takes place in a hospital, since houses, especially in the urban environment, aren’t prepared to receive the dying person.

Every society builds its cultural interpretation of death through beliefs, meanings and values. Knowledge about death is acquired during childhood and it is the social group and the historical moment that we live in that determine this knowledge. In general, people who participate in the seminar...
are aware of the fact that during their parents’ childhoods, death was socially organised and it wasn’t hidden. Nonetheless, they report that their parents act differently: “They hide it from me in order to protect me”. One of the participants points out that when she was a child, she wasn’t informed of her aunt’s death: “They hid her from me.” Another participant describes her mother-in-law’s death as a “medical negligence”, which makes her feel that she must “prove what they did wrong.” These experiences usually complicate the mourning process because they lengthen the process more than usual and, sometimes, professional help is required.

For students in the seminar, the beginning of their internship in level 3 hospitals is usually a very stressful situation, as they anticipate the experiences they may have. The first weeks are filled with nervousness, so any extreme situation is even more disturbing.

The perception of death in the hospital environment happens with their first internship for some students; for some it is in fact the first death they see. When they witness a patient’s death, they usually think that since it is a predictable event, they are not affected. However, in some cases they are deeply affected and some can even see the image of the dead person for days. What usually impacts them even more is entering the patient’s room to wash or check on the patient, only to find that the patient has just died or is dying at the moment. These unexpected situations make them feel “helpless” and “useless”.

When the students establish an emotional bond with the patients they feel a particular loss when they die and it becomes more difficult for them to “control” their feelings. When a young
fact that an incorrectly managed death leads to mourning processes that affect the individual and his or her environment.

Sometimes, a person is in the last stage of an illness asks questions such as “Am I going to die?” The question is clear and concise but the answer is usually “Don’t think about it. We all die one day or another; it’s okay.” These statements don’t answer the question and the patient realises that the truth is being avoided. It is better to figure out what the person really wants to know and what worries him or her, by beginning with a series of questions, such as “What do you know?” or “What would you like to know about the illness?” This will help to understand what the person really knows and to clarify or reinforce the information.

The first deaths at the hospital are usually recorded in memory forever. Factors, such as age, diagnosis, the way of dying, the relationship with the patient and relatives as well as the degree of grief of the person in the grieving process. This is the main theme that is questioned in all seminars along the different internship periods.

The answer that the students receive from some nurses is that they also feel moved and affected by the death of some patients, sometimes more than others. The memories nurses have from their internship and first deaths remind them of those of the students, but it’s no longer the same. After acquiring some years of experience in the profession, they benefit from a more developed capacity to arrange their emotions and have moving memories of the patients they treated, while preventing these deaths from disrupting their family and social lives. However, advice from other professionals is to build a barrier for their feelings in order not to suffer and bring the suffering home. Both answers bring up different strategies to deal with death, deriving from either the acceptance or denial of it. The dilemma lies in the person or someone who reminds them of someone they know dies, they usually feel affected and they “bring these deaths home”. The dilemma that they face is whether it is better to protect themselves and not bring anything home or participate with the relatives. The answer that the students receive from some nurses is that they also feel moved and affected by the death of some patients, sometimes more than others. The memories nurses have from their internship and first deaths remind them of those of the students, but it’s no longer the same. After acquiring some years of experience in the profession, they benefit from a more developed capacity to arrange their emotions and have moving memories of the patients they treated, while preventing these deaths from disrupting their family and social lives. However, advice from other professionals is to build a barrier for their feelings in order not to suffer and bring the suffering home. Both answers bring up different strategies to deal with death, deriving from either the acceptance or denial of it. The dilemma lies in the person or someone who reminds them of someone they know dies, they usually feel affected and they “bring these deaths home”. The dilemma that they face is whether it is better to protect themselves and not bring anything home or participate with the relatives.
involvement during the process affect the reaction of the intern. Even if they want to cry, the students tend to avoid crying in order to fulfil their role of offering help and support. Some of them explain how they cried with the family of the patient, although they question if it is “the right thing to do.” When they are asked about how they felt afterwards, they generally answer that they felt relieved and closer to the families.

**Death representation in family environment**

Learning acquired from childhood determines behaviour in the face of loss and death. The family and social group are transmitters of such learning. First deaths that most of the students remember within the family environment are their grandparents’ deaths. These usually take place when the students are children or during puberty. They generally express that they were very close to their grandparents, they had a very direct relationship with them and their loss is usually painful and they don’t understand it. Mourning might still be present and duration is undetermined.

Another behaviour that affects them is the fact that their parents didn’t warn them or let them see their grandparents, or any other close relative; neither were they allowed to attend the funeral. This lies on the idea of “protection” because they didn’t want their children to “suffer”. Such intervention creates a situation of helplessness for the children because they don’t have the opportunity to decide and, at the same time, they can’t even discuss it with their parents afterwards, since they refuse to talk about it. Participants who were ’protected’ in this way ranged in age between five and 18 at the time of the death. This protection system is also complemented by the idea of not discussing the issue of death within the family.

There are some testimonies that explain how the grandparents’ death is announced and discussed together with the parents, which allowed them to live it as an event integrated into everyday life and remember it as a positive experi-
and youth) are usually experienced as traumatic and they are very difficult to accept. These deaths aren’t socially accepted because they are considered to interrupt the life cycle of the individual and they become a loss and suffering that cause irreparable damage to the family.

The topic of death—how we experience it and respond to it—is related to the process of mourning that we have previously experienced and the way we manage our losses and personal mourning.

That is why, at the end of the seminar, we ask the participants to describe what the seminar has provided them. Students generally highlight that it helps them to express their feelings of fear and uncertainty facing death. Although what other participants say can affect them, this experience enriches them and they consider that “they have expressed beautiful and positive things with others”. At the same time, they realise that they share a common experience, since they are allowed to have a mourning and farewell process. For one of the students, her grandmother went to sleep and was dead the following morning, but even though he was a child, he wanted to see her and was able to kiss and touch her.

The deaths of siblings, nephews or nieces, friends at early ages (childhood and youth) are usually experienced as traumatic and they are very difficult to accept. These deaths aren’t socially accepted because they are considered to interrupt the life cycle of the individual and they become a loss and suffering that cause irreparable damage to the family.

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Students also value the possibility of getting to know that mourning can reach an end. This allows a better management of emotions, as well learning how feelings work through communication.
Students feel overwhelmed when a patient dies. As a consequence, they ask for an almost “magical” formula in order to solve the overflowing feelings and achieve the chance to help the patient and family in a complete and professional way. One initial idea is the fact that the lack of control of the situation means that they are not acting as true professionals. As they are still in a training period, some even question if they should continue with their studies or not. In the family environment, they consider that being able to say farewell to family members and other important people is necessary in order to help grievers maintain positive memories and avoid trauma.

In the same way that children are included in everyday family actions, the behaviour surrounding death should be similar, by dealing with the topic as something “natural”, informing the child and asking them about their wishes to say goodbye and healthily remember their beloved ones.

Guilty feelings are related with our early learning during childhood and they appear in moments of “difficult control”. We tend to hold on to guilt without accepting the loss of important people in our lives. The problem lies on the fact that we keep distancing death from our everyday lives and we lack the resources to accept it when we are obliged to face it.
Kübler-Ross, E. (1993 [1975])
*Sobre la muerte y los moribundos*
Barcelona: Grijalbo

Doctor in Psychiatry, Kübler-Ross, is a pioneer in helping and giving voice to dying people who express their feelings about death. In this book, more than 200 interviews to people in their terminal phase and their families are collected. These talks were looking for the patients to express everything that was happening to them: the pain, their fears, anxieties, needs, wishes... Although it has been a while since its publication, it is still of great interest to understand and look after patients in their terminal phase.

Canseco, M. (2012)
*La Espera: Construcción social de la muerte en el mundo de los cuidados paliativos*
Barcelona: Laertes

The book deals with the life experiences of patients of cancer in their terminal phase, also with their main carers (the close family members) and the professionals who offer palliative attention to both groups. The world of palliative care is a fact that both the ill and the family have to face and it shows them, as the illness advances, a reality that is difficult to face and, also, to accept. The topic of the death is a present reality in the consciousness of people, but only apparently because in practice is something that we don’t consider and we don’t include in our everyday life, because it belongs to the others. We are used to living not being aware of it, both socially and individually.

*Ayudar a morir*
Buenos Aires, Madrid: Katz Editores

Why are there so little people that have what can be considered as a good death? And, also, what is a good death? What kind of death do we want for ourselves and for our loved ones?

“I understand that for many a good death is that in which the dying person can control the process and die with calm and dignity, and everyone who surrounds the person feels privileged, in a way enriched by the situation.” However, these deaths are not very common. There are a lot more that are object of lack of respect, many that suffer. Dying is hard. But it is also hard to be a doctor: witness every day the agony and become aware again and again of the limits of science.
Through Plato, Nietzsche, Kierkegaard and Lévinas, and also literary references to Melville and Kafka, Derrida offers a profound and suggestive analysis about the inconceivable but certain death in first person. Again, everything that Derrida plays with in this text, from the history of Europe until the possibility of literature, allows us to appreciate the ambition of one of the most original and complex thinkers from the second half of the 20th Century.

Death has always been subject to profound philosophical reflections. Since the natural and resigned disposition in the Middle Ages to the individual desperation of the current Western world, our view towards death has been transformed, filled with beliefs and constructions that are not universal at all. Ariés, historian and sociologist, enlightens with this broad essay a topic that has been categorised as dark and impenetrable through the study of the psychological history of the human being. The revelations about the thinking and the action in front of death will surprise the reader, not only due to the discovery of different customs of generations and nations, but also because the reading will bring them closer to a healthy and cultivated reflection on death.

Since the 70s, Philippe Ariés has developed an exhaustive research on the topic of death. This book is an unavoidable classic in the bibliography regarding our relationship towards death and its role in the configuration of a cultural environment and the ways of exchange that can take place in such. It is presented like a collection of essays which were thought first as a series of conferences for the John Hopkins University. They cover different branches within the Humanities (History, Ethnology and Cultural Anthropology) and they present a fascinating history of the gradual change of death, from a familiar and “domesticated” view in the Middle Ages to a more modern, wicked conception from which people try to flee.
Death is a person, actually, a lot of people. It is a hard job, but someone has to do it, in the same way that something doesn’t disappear just because we stop talking about it. The little Parka runs the little world which is the death, which we will all reach, sooner or later. But we will not go there on our own; the Little Parka will hold our hand and the way will be calmer. Because the Little Parka lives for it, studies for it and prepares herself for this.

This book presents a beautiful and tender tale about a girl who tries to become familiar with the idea that she will not be seeing her grandfather anymore. The little girl asks her parents and her grandmother. Although they don’t talk about death, she understands that her grandpa Pepe will not come back and when she dies, she will be able to talk to him and give him the box filled with memories that she has prepared. It is a moving story about how a very young girl sees death.

INTERESTING LINKS

Sociedad Española de Cuidados Paliativos

Mar Cortina Blog

Mar Cortina Selva. Maestra. BA in Psychology. PhD in Education at the Universidad Autónoma de Madrid (May 2010). Thesis: “The didactics of the death through cinema and children’s literature”. She works as an educational psychologist in Secondary Education. She’s a specialist in Emotional Education, running workshops for teenagers on self-discovery and education based on values through the cinema. She was trained in Creative Accompaniment in 1992.

Acompañar en el duelo AVES Barcelona

Association helping people who have lost a dear one.

Maria Getino Canseco on the press

Blog with 101 films about death
Sweden, second half of the 14th Century. The Black Death devastates Europe. After ten years of useless fights in the Crusades, the Swedish knight Antonius Blovk and his loyal squire return to the Holy Land. Blovk is a tormented man full of doubts. On the way, he finds the Death, who demands him. That’s when he suggests playing chess, hoping to get from the Death the answers to the big questions in life: the Death and the existence of God.

This documentary follows Carlos Cristos in his last years and portrays not only the “human experience” of the death but also the “state of the scientific research, of the hope in human beings, their courage, their preoccupations, their success and failures and the reflections about life and its value.” Carlos Cristos was a family physician who was committed to public health. His humanitarian approach to medicine led him to undergo some dissemination actions like his health section in Radio Nacional which was on air for many years until the disease he was suffering, systematic multiple atrophy, made locution very hard.

Ann is 23 years old. She has two daughters and a husband who spends more time unemployed than working, a mother who hates the world and a father who has spent ten years in prison. She works as a cleaner in the night shift at the university where she could never attend during the day. She lives on a caravan in her mother’s garden, in the outskirts of Vancouver. This grey life changes completely after a medical examination. Since then, paradoxically, Ann discovers the pleasure of life, guided by an impulse to complete a list of “things to do before dying”.

It is a comedy about the story of an old lady and the stubbornness of a physician who can’t accept the limitation of therapy. An arrogant doctor, the Death itself and an endearing old lady are the protagonists of this film which was awarded with the Goya for the best animated short film and it was nominated to the Oscars.
Films starred by children:

Ball, A. (2001-2005)
*Six Feet Under*
United States
Television series
(63 episodes of 55 minutes; organised in 5 seasons)

Six Feet Under is a television series from the US about a dysfunctional family that runs a funeral home. It is usually recognised by the critics as one of the greatest series in the history of television, as well as its ending has been widely considered as one of the finest series finales of the decade.

*Cuarta Planta*
Spain, 100 min.

The film talks about a group of teenagers whose leader is Miguel Ángel. They spend their time in the hospital playing some sports and doing mischievous actions, although their playground is the 4th floor of the hospital, devoted to bone cancer. Among chariot races, photo booth sessions and live concerts, they fight against their illness with in a good mood.
Suitable for children from 10 to 14.

*My girl*
United States, 90 min.

Veda is a girl who is obsessed with the death: her mother died and her father runs a funeral home. Since she is in love with her English teacher, she enrolls in a summer course on poetry to impress him. Thomas J., her best friend, is allergic to bees. Veda’s father hires Shelly, a make-up artist, and falls in love with her, but the girl will try to ruin the relationship.
**ABOUT THE AUTHOR OF THE TEXTS**

**María Getino Canseco**

Professor at the Department for Fundamental and Medical-Surgical Nursing at the Universidad de Barcelona. Courses: Clinical Nursing II and “Interculturality and the Socio-Sanitary Environment.” PhD in Social Anthropology at Universidad Rovira i Virgili (Tarragona).

She has taught postgraduate and PhD courses in medical anthropology in universities such as Universidad de La Habana y Santa Clara (Cuba), Belo Horizonte y Florianópolis (Brasil), La Paz (Bolivia) in Medicine and Nursing Departments. She participates in the Doctorate Program at EUE, where she supervises doctoral theses on the topic of death and her line of research: chronicity and death in the hospital or primary health care environment.

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**ABOUT THE AUTHOR OF THE IMAGES**

**Vega Cillero**

is an artist born in Haro and adopted by Bilbao. Their quality is evidenced by his long expository way and for his years of dedication to the art. In a first step the symbolist painting dye by the shape and color, was based on the representation of women as a wonderful human being and blur into an ethereal atmosphere. Over the years the paint has been leading toward abstraction with geometry as the basis of his work. Through the compositions she creates, achieve to express the passion and desire in deterring the canvas and allowing a deep connection with their feelings, and the feeling of accomplishing something caught in a moment that will be forever captured by a color, form or a stain. ( ... ) They are romantic paintings that reflect the artist, her life and circumstances. The practice of art is restorative for her, because she found by the abstract technical, the ability to create and recreate tirelessly what is affecting her sensitivity giving life to new things, images, colors and landscapes.


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**AFIN NEWS**

**The Catalan Government recognises the trajectory of AFIN as a Research Group**

The Catalan Government (Generalitat de Catalunya) opened a call to recognise the research groups in Catalan universities which are defined by their excellence and strength of their research work. We are glad to announce that the Group AFIN has been recognised as such.

**IV Escuela Internacional de Posgrado de la Red INJU**

Between the 28th of April and the 2nd of May, in Colef (Colegio de la Frontera Norte) in Tijuana (México), it took place the IV Escuela de Posgrado de la Red INJU under the theme “Democracy, human rights and citizenship: childhood and youth in Latin America and the Caribbean”, which gathered more than 100 people among researchers and students. Beatriz San Ramón participated in the event by giving a seminar of four days on the research and implementation of public policies in relation to the childhood.

**AFIN en el 47th Annual Rudolf Dreikurs International Summer Institute**

Susan Frekko and Beatriz San Román have been selected to participate in the intensive course organised by the ICASSI (International Committee of Adlerian Summer Schools and Institutes), which will take place in the University of Kent (United Kingdom) in July and August. In the event, there will be workshops and sessions run by international experts in topics like familiar counseling, the intervention with children and teenagers with attention difficulties and impulsiveness, techniques for short therapies or how to work safely on the trauma.