GOING, GOING, GONE

An analysis of the dying process

BACHELOR THESIS
Hanna Büker

Züricher Hochschule der Künste | Department Design
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Mentors: Anna-Brigitte Schlittler | Basil Rogger

INDEX

"Lo único que llega con seguridad es la muerte".
Gabriel García Márquez

1.1 PREFACE

On 30th December 2016, my aunt died of cancer.

My sister and I flew to Barcelona on the 27th to spend time with her. At that time, it was not clear how much time she had left to live: it was quite clear, however, that she was dying. My mum had warned us about what to expect, but no matter how hard you try to prepare yourself, you are never prepared to see a loved one dying, and to understand what dying really means in physical terms. My aunt looked 30 years older, had lost half her body weight was not able to get up to use the bathroom or shower, and could not speak because the cancer had destroyed her vocal chords. She was however, 100% present in her mind, she could understand us perfectly and talk to us by whispering or writing.

When my sister and I arrived in the hospital we felt lost. What do you do in a situation like this? How can you help a dying person? My mum gave us some ideas about what might make my aunt feel better: "...there is oil in a tall bottle, use that to give her leg massages, as she has very dry skin from all the medicine. That really helps her."
We took the best care we could of my aunt in her final days. It was hard but we felt like we had a purpose, we were there to keep her company, soothe and pamper her in any way we could.

Once back home, I started reflecting upon what had happened over the last few days and what strategies we had applied to make the situation bearable. As I was searching for an idea for my practical Bachelor project I realized that I always had these thoughts in the back of my mind.

I think much can be learned from listening to people who have lost a loved one, or from people who professionally deal with dying and death. My wish is to collect these personal experiences, analyze them and reach a deeper understanding of the dying process to be able to extract the information necessary to create the basis for the practical part of my Bachelor project.

1.2 INTRODUCTION

1.2.2 DEFINITION

This dissertation investigates dying, not death. The focus is directed to the limited time before a person dies and what happens during this time. What strategies, tools or actions are used to deal with these situations?

The investigation is limited to the present, Western Europe and adults. The dissertation considers situations in which it is clear (or as clear as it can be) that the affected person is dying. The dissertation does not investigate situations in which a person suddenly dies, such as in an accident. The focus of the work is on people who suffer a terminal illness and who are mentally fit to the end, such as cancer patients.

For several reasons cancer will form the main field of observation. On the one hand, cancer patients are often sound of mind until they die, as they suffer from physical problems and not neurological ones, unless they have a brain tumor. These patients usually spend a lot of time in hospital, a further important part of my research. On the other hand, we all know of someone who has died of cancer or is suffering from this illness, as it seems to be the disease of our time. Cancer does not know age, gender or social status. "In 2013, more than one and a quarter million people died from cancer in the EU-28, just over one quarter (26.0%) of the total number of deaths."[1]

1.2.3 DYING TODAY

Death is universal, but how we respond to death, is defined by the society in which we live, by our beliefs, religion, age, status, fears and education.[2] There are many unanswered questions on this subject: what is important is to understand why we act in certain way and what the defining factors of our time are that influence our conduct towards the dying and death.

An aging society

"Aging and dying are inevitable." [3]

Increasingly today, we live in a time where one of the biggest demographic changes is our aging population.[4] Statistics show that, by 2050, over half of the population of Europe will be over 50. Life expectancy has increased dramatically in the last 20 years, which has to do with factors, such as improved diet, healthier lifestyle, quitting smoking, improved healthcare or advances in medicine. Life expectancy at birth worldwide is 67.2 years for the period from 2005 to 2010.[5] All in all, this means that there is a rapid increase in life expectancy, death will become even more present as our population ages.

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1 **Eurostat, Cancer statistics** / 2017. www.ec.europa.eu.

2 vgl. Sarga, Hofmeier, 2017, p.2

3 nach Chatterjee, Patnaik & Chariar, 2008, abstract

4 **Jeremy Myerson** / Dezeen, 2017. The stigma of growing old needs to be creatively challenged Status. www.dezeen.com

5 vgl. Wildevuur, van Dijk , Hammer-Jakobsen, Äyvari , Lund , 2013, p. 17

The death taboo

"Im Kreis seiner Lieben flüstert der Sterbende ein paar bedeutungsvolle letzte Worte, schliesst dann die Augen. Er verlässt die Welt voller Frieden im Gesicht, vielleicht sogar mit einem Lächeln, als spaziere er auf Zehenspitzen und Hand in Hand mit dem Tod davon.

So geht Sterben – in vielen Filmen zumindest. In der Wirklichkeit serviert der Tod schon mal ein Kontrastprogramm: wochen- und monatelanges Hadern. Zweifel und Verzweiflung. Fragen, Sorgen, Ängste. Morphium, das die Schmerzen vertreibt, aber nie die inneren Dämonen: Das Gefühl, der Welt noch etwas schuldig zu sein. Reue über das, was war und nicht war. Einsames Warten auf den Enkel oder die Tochter, die nicht kommen werden, weil man sich vor Jahren schon entzweit hat. Der Kampf um jeden Augenblick, weil man die Lieben nicht allein lassen will. Oder Schuldgefühle, die Familie so leiden zu lassen. Nach Happy End klingt das alles nicht.[6]

There are several reasons why death is considered to be a taboo subject in our society. Death, dying and grief are topics often discussed in the news and in public, but this portrayal of death does not correspond to our reality. This has to do with the fact that one cannot totally understand death until one is confronted by it.

These topics often become taboo in our private and personal environment.[7] When a friend loses someone, it does not feel right to ask questions and go into the details. We have superficial conversations on the matter and offer platitudes, such as; well the most important thing is he/she didn't suffer, I hope you and your family are holding up. But we never truly ask any "real" questions. It is a subject about which you are not supposed to ask too much, it seems impolite and morbid.

The fact that people are dying at a much older age has also added to the fact that death is not as present in our life as it used to be. Most of our grandparents' generation were confronted with death as a child, the probability of somebody dying at home being very high. Furthermore, children today are often not involved in the dying and grieving process, on the pretext that we try to protect them, that it could affect them and just be too much.[8]

6 nach Pfersdorf, 2016, p. 71

7 vgl. Kulbe, 2010, p.2

8 vgl. Kübler-Ross, 1969, p. 20

Esotericism & Spirituality

> *"We use the term spirit in many ways, to refer to the vitality of a high school team, to the content of beverages, as well as to the position that there are conscious beings that are immaterial. In this last sense, the term fundamentally means independence from matter: either that the creature is an immaterial being or that there is something about the being that acts in an immaterial way, that is, in a way that cannot be fully explained by bodied functions. Other meanings of spirit are extensions of this idea of immateriality, which we inherited from classical thought."* [9]

Another big change of our society are our beliefs. We are shifting from religion towards another kind of spirituality and esotericism. The category "Spiritual But Not Religious"[10] [11] has become a growing and popular trend in western culture. Furthermore, there is a huge boom in seminars and practices like Shamanism*, Yoga, Reiki* and Therapeutic Touch*.[12] This is happening at a time when facts are at the center of our lives and we have more scientific knowledge on the world and the human body than ever.

The fact is that, for many people, it is no longer a disparity to combine the rational and irrational, empirical knowledge and esoteric beliefs.[13]

This new kind of spirituality is in some ways replacing the comfort and answers that use to be found in traditional religious beliefs, which offered guidance and clear answers to life after death. [14] Death has always been a frightful subject, certain rituals and beliefs comforting many generations as people departed life.

*Shamanism is a religion practiced by indigenous peoples of far northern Europe and Siberia that is characterized by belief in an unseen world of gods, demons, and ancestral spirits responsive only to the shamans.

http://www.dictionary.com/browse/shamanism

*Reiki is a healing technique based on the principle that the therapist can channel energy into the patient by means of touch, to activate the natural healing processes of the patient's body and restore physical and emotional well-being.

https://en.oxforddictionaries.com/definition/reiki

* Therapeutic Touch is a form of therapy in which the therapist's hands pass over the patient, involving little or no physical contact.

https://en.oxforddictionaries.com/definition/therapeutic_touch

9 nach Bryant, 2003, chapter 12, Spirituality

10 **Peter Baksa** / Huffington Post, 2014. www.huffingtonpost.com

11 **David Alexander** / Patheos, 2012. Spiritual but not Religious. www.patheos.com

12 vgl. Utsch, 2017, p.35

13 vgl. Utsch, 2017, p.35

14 vgl. Pfersdorf, Silke, 2016, p. 73

Fig..1:
Hanna Büker, 2017

„Rejected by her family, often overlooked or ignored by the hospital personnel, she became a pitiful figure, a disheveled-looking young woman who sat desperately lonely on the edge of her bed, clutching the telephone to hear a sound. She found temporary refuge in delusions of beauty, flowers, and loving care which she could not obtain in real life“ [1]

Kübler-Ross

1 nach Kübler-Ross, 1969, p.60

1.3 THESIS QUESTION

What strategies, tools, actions or objects are used to deal in an imminent death situation, which may help the dying as well as the relatives in a spiritual, physical or material way?

1.4 HYPOTHESIS

The *dying process* is a very complex situation due to the fact that we are usually not familiar with this situation and as it is a subject we tend to avoid when dealing with it in a private or personal setting.

Every person develops their own strategy and tools to learn to deal with this situation.

Fig.2:
Philippe Halsman 1951
USA. New York City. Salvador Dalí. „In Voluptate Mors."

2.1 INTRODUCTION TO THE INTERVIEWS

Method

The most important part of the research and investigation for this thesis are the conversations and interviews held with people who have been confronted with dying and death. These people range from patients, relatives, doctors, nurses, physicians to assisted suicide escorts. The aim was to compile as many experiences as possible from people close to the subject who have lived through the "dying process" experience.

Interviews were held in person with a total of nine people, aged from 26 to 65. Five experts in the field, people whose profession it is to deal with death, three people who have lost a relative, and one person who has lived through a near-death experience and who was told she would die. Seven were women and two were men. I did not purposely talk to a majority of women: contact was made with people or institutions in my surroundings and interviews held with whoever was available and open to talk about dying and death. However, it is not a mere coincidence that I talked to more women than men since the health care industry is predominately dominated by women.

There was not a strict list of questions put to the interlocutors, rather it took the form of a talk. As there was no clear structure, not everyone was asked the same questions. The conversation developed and was molded according to the individual. Most conversations started with an open question similar to: "what is your relationship or experience with dying and how did you deal with this situation?" There were also other more concise questions, which differed slightly if addressed to experts or affected persons.[15]

All quotes have been left in the original language in which they were spoken so that the voices of these people can really be heard. Certain remarks were expressed too beautifully and spontaneously to be translated.

When referring to the dying, the terms patient or affected person are also used.

15 See Annex. Fragebogen p.35

2.2 INTERVIEW ANALYSES

As would be suspected, there are many answers to my initial question "What strategies, tools or actions are used to deal in a situation in which we know dying is inevitable?"

Before answering the main question, there needs some explanation about the most important findings made when speaking to these nine people as they form the base and foundation of the thesis.

1. DYING IS AN INDIVIDUAL MATTER

The one thing heard from every person talked to, is that dying is individual. Every person dies differently, as differently as they have lived. That it is not possible to generalize and find solutions which work for every individual, because that is precisely what we are: individuals, different in many ways, and different in the way we want to die and the way we end up dying. People want to be treated as individuals with individual needs and not as a standard.

> *"[...] und was ich einfach merke ist, dass das Sterben so individuell ist wie du auf die Welt kommst. [...] was ich wichtig finde ist, dass man wirklich bei den Leuten versucht zu spüren was der Mensch in dem Moment braucht." MW*[16]

EH explained that she suffered a terrible experience in the hospital because everything was globalized, the doctors and medical staff followed a protocol and did not attend to her individual needs, which frustrated her gravely and made her feel unattended and miscomprehended.

> *"[…] todo era muy globalizado y todo era protocolo, hay que seguirlo, y hay que hacerlo así, así, así, así, así...Cuando eso no es así. Cada persona somos un mundo y, y cada, y cada familia también somos un mundo. [...]" EH*[17]

The medical staff interviewed believes one of the most important things in this situation is to act according to each patient's individual needs, to understand these needs and respond accordingly.

> *"[...] und dass man wirklich versucht die Bedürfnisse wahrzunehmen und nicht einfach nur sagt, Medikamente so und irgendwie Blutentnahme morgens, sondern das man wirklich mit ihnen gemeinsam versucht herauszufinden was jetzt ihre Bedürfnisse sind, ihr Wunsch ist. Es ist ja zum Teil sehr unterschiedlich." CN*[18]

16 nach Interview MW, 16.02.17, 01:05

17 nach Interview EH, 01.02.17, 12:26

18 nach Interview CN, 15.02.17, 08:55

2. THERE IS A SIGNIFICANT DIFFERENCE IN THE CARE A PATIENT WILL RECEIVE DEPENDING ON WHETHER HE IS IN AN ACUTE OR PALLIATIVE CARE INSTITUTION

There are many strategies and tools applied, which are very individual depending on the needs and wishes of the dying but also on what the institution this person is confined to has to offer. The dying will receive very different care depending on the institution. The biggest difference that exists between acute care institutions and palliative care institutions and hospices, is that one institution tries to save the patient and applies active measures while the other focuses on diminishing the suffering.

> *"Also im Prinzip ist es die, ist so die Forderung nicht dem Leben mehr Tage zu geben, also es geht nicht um lebensverlängernde Massnahmen, sondern es geht um die Qualität dem Tag mehr Leben zu geben. Also, dass man wirklich die Zeit, die man hat auch einigermassen mit guter Lebensqualität verbringen kann." CN*[19]

Two of the nurses interviewed had worked in acute care hospitals in the past and explained that there was an enormous difference between how death is dealt with in these hospitals compared to where they work today. One of the biggest differences they felt was that in acute hospitals, death is an unwelcome intruder, people are not allowed or supposed to die. [20]

> *"[…]Ein Akutspital hat halt auch andere Ansätze, oder, sie wollen die Leute wieder lebend daraus bringen und diesen Ansatz haben wir schon gar nicht. Also in dem Sinn, bei uns darf man halt auch sterben" JP*[21]

The purposes of these two institutions are very different. It is important to understand in which context a person died; did it occur at home, in a palliative center, acute care hospital or hospice. This will define the dying person's experience as well as the relatives' experiences. Many patients are scared when confronted with the word palliative, because our understanding of this word in colloquial speech equals immediate death, whereas is in a medical setting it refers to a change of focus from active treatment to a symptomatic treatment.[22]

Furthermore, in a regular medical setting, in an acute care facility, dying people go against the purpose of the institution itself, and are therefore often confronted with negative reactions.[23] As AM explained, if a surgeon operates on a patient, he does not want his efforts to go to waste and it is therefore not ok for the patient to die.[24]

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19 nach Interview CN, 15.02.17, 04:59

20 nach Interview AM & JP

21 nach Interview JP, 07.02.17, 34:55

22 nach Interview CN & AM

23 nach Bryant, 2003, chapter 43, Dying as Deviance

24 vgl. Interview AM, 20.02.17, 02:13

3. THERE IS A LARGE DISCREPANCY BETWEEN MODERN MEDICINE AND THE DYING PROCESS

We are a high-performance society, which also affects our understanding and acceptance of death. Even in this aspect of life we expect to perform as highly as possible,[25] associated with our beliefs anchored in traditional medicine. Traditional medicine works against death and focuses on making us live longer, making us indestructible, which makes it difficult for us to accept that there is nothing left to do. [26]

> *"Es ist halt auch so, dass diese moderne Medizin, viele Machbarkeitsvisionen oder Illusionen weckt. [...] es gibt viele Patienten die bis zum Schluss einfach finden, man müsste doch noch irgendwas versuchen." CN[27]*

> *"Weil, für viele Patienten ist es auch ein riesen Stress immer die Medikamente zu schlucken und der Druck irgendwie leisten zu müssen, obwohl sie eigentlich sterben möchten. Das passt ja irgendwie überhaupt nicht zusammen." JP[28]*

4. THE ENVIRONMENT PLAYS A VERY IMPORTANT ROLE IN THE WELL-BEING OF THE PATIENT AND HIS/HER RELATIVES

Everybody interviewed explained that they thought the environment was important in one way or another, that some people are more sensitive to their environment than others. When asked about the environment, both medical staff and affected persons responded that it is not only about the physical room and what it looks and feels like but also about the people who work there. Medical staff, doctors and nurses have a major influence on the patient's environment.

EH explained that she felt very uncomfortable in the hospital because she felt it was a death hole, it was a very sad, dismal, grey place, the walls were not even white or colorful, there were no paintings on the walls, and there was no life. Everything revolved around death. A death foretold. The situation was also chaotic and the staff unfriendly: in short, the entire situation felt very dehumanizing.[29]

JB's answer when asked what she thinks about the clinic in which she works, was not positive when talking about the room itself:

> *"Nicht schön. Also ich meine es sind keine schönen Räumlichkeiten, [...] dort ist nichts Schönes in dem Spital. Ich glaube das einzige Positive ist das Personal. […] Ich glaube das ist das einzig Schöne dort, es lebt von den Kontakten, weil die Räumlichkeiten, das ist nichts Schönes." JP[30]*

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25 vgl. Sarga, Hofmeier, 2017, p. 2

26 vgl. Bryant, 2003, chapter 43, Dying as Deviance

27 nach Interview CN, 15.02.17, 07:42

28 nach Interview JP, 07.02.17, 05:45

29 vgl. Interview EH, 01.02.17, 06:59

30 nach Interview JP, 07.02.17, 15:02

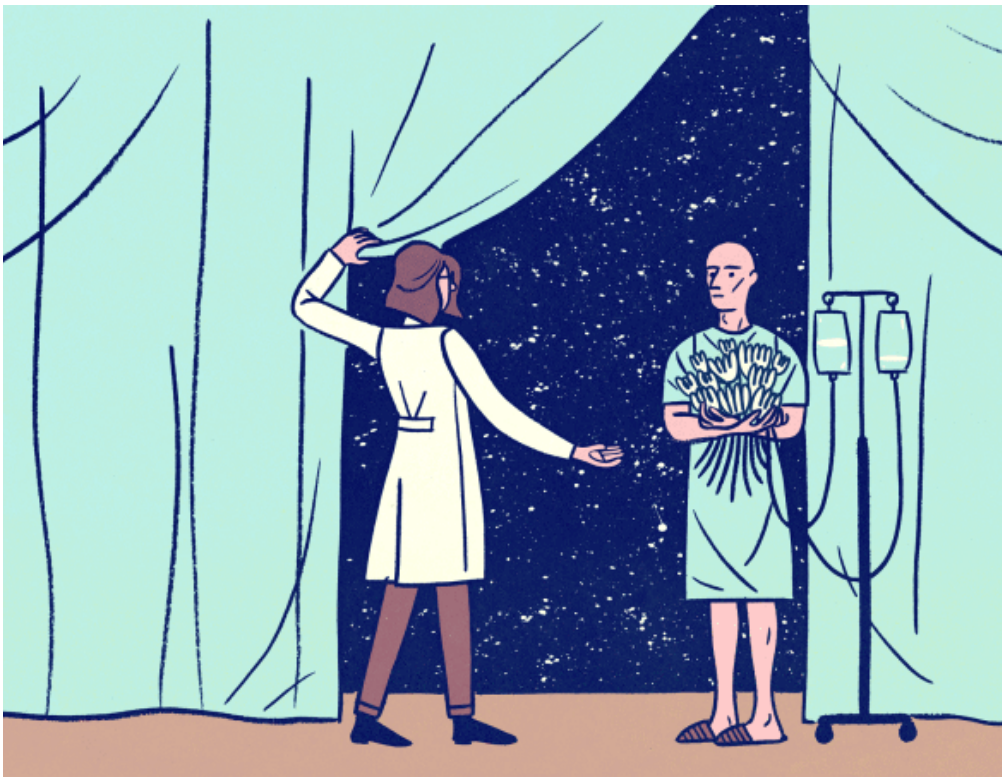

Fig.3 Atul Gawande, 2014

When asked what patients or their relatives brought with them to the hospital, my interviewees explained that the dying usually do not bring anything themselves, rather the relatives do. Generally patients do not bring or ask for many personal belongings, and relatives often bring drawings from children in the family, paintings, photographs and cds.

Some did of course decorate their rooms more than others, usually the more so, the longer their stay was.[31] Some patients are so far gone in their thoughts that material things no longer seem to matter, they are already somewhere else.

> *"Kommt drauf an, manche sind halt wirklich so krank und manche sind halt so weg von der Welt, in ihren Gedanken, das es nicht so wichtig ist." CN[32]*

Three relatives interviewed said their loved ones found comfort in music.[33]

> *"[…] er hat seine ganzen Salsa CD's mitgenommen und es laut, es hatte eine gute Musikanlage […] so ein Radio [...] Boxen hat ihm noch jemand mitgebracht, und dann konnte er es noch lauter machen. Und dann hat er Salsa gehört bis es alle hörten." MM[34]*

Furthermore, several studies have been published on the effects of nature or art, to help improve a patient's health. One article published in NZZ Folio reports on a study, which shows that the view an ill person sees, can improve or worsen their situation; a patient confined to a hospital bed will heal faster if they see something green outside their window rather than a brick wall. [35]

5. NOT MANY PEOPLE DIE AT HOME ANYMORE

The wish of most patients is to die at home. As doctor CN explained: 80% of patients would like to die in their homes and only 20% are able to do so in the end.[36] Usually this is due to the fact that the relatives feel overwhelmed by the situation.[37]

> *"[…]die Angehörigen haben Angst. Oftmals wenn es ältere Patienten sind, die Ehepartner oft auch...Entweder sind sie alleinstehend oder die Ehepartner sind halt auch älter, und man kann natürlich viel mit Ambulanten Diensten machen, Spitex, aber die Angehörigen sind doch über weite Strecken mit ihren Kranken daheim und dann passiert plötzlich etwas. Sie haben plötzlich Schmerzen oder es ist ihnen schlecht oder sie haben Luftnot und dann geraten die Angehörigen in Panik und deswegen ist es häufig doch so, dass die Patienten eben doch in dieser letzen Phase im Spital sind und halt auch im Spital sterben." CN[38]*

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31 nach Interview CN, 15.02.17, 13:00

32 nach Interview CN, 15.02.17 , 13:00

33 vgl. Interview AE, 16.02.2017 19:32

34 nach Interview MM, 26.01.17, 09:55

35 vgl. Schneider, 2017, p.14

36 vgl. Interview CN, 15.02.17, 04:59

37 vgl. Kulbe, 2010, p.3

38 nach Interview CN, 15.02.17, 06:54

6. THE RELATIVES ARE A VERY IMPORTANT PART OF THE DYING PROCESS

When a patient is diagnosed with a terminal illness, he or she is usually not the only person going through a difficult process and stepping into unknown territory.

> *"Weil du betreust eigentlich den Patienten, aber du betreust auch zu einem sehr grossen Teil die Angehörigen." JP*[39]

Most institutions who specialize in palliative care have a clear procedure when dealing with dying patients, and with their relatives. Relatives are part of the process and are also taken care of and treated as such.

> *"[…] die Palliativmedizin ist nicht nur für die Patienten zuständig, sondern eben, in der Definition der Welt Gesundheits Organisation 2002, wird ja auch ausdrücklich verlangt, dass es eben Patienten und Angehörige sind, Patienten und Bezugspersonen." CN*[40]

Several of these hospitals give out brochures about what to expect when somebody is dying; explaining the symptoms and how to deal with grief.[41] Another clinic offers their patients talks in which both patients and their relatives are invited to join a so-called round table where important things can be discussed with the medical team, such as their diagnosis, as this is often not as clear as one might think.[42]

One of the most important aspects when caring for the relatives is to keep them informed and let them know that their requests are also being taken into account, as JP explained in the following example:

> *"Also ich glaube die Gespräche sind extrem wichtig und auch Erklären, auch immer wieder. Ich habe das Gefühl, man nimmt ihnen so ein bisschen die Angst und auch, ehm, wie drauf zu reagieren. Wen sie sagen ich habe das Gefühl, der hat so Schmerzen, dann auch als Fachperson sagen können, ehm, keine Ahnung, ein Beispiel. Ich habe jetzt vor 5 Minuten Morphium gespritzt, es geht vielleicht noch 5 Minuten bis es wirkt. Wir schauen in einer viertel Stunde nochmals, wenn es nicht besser wird, gebe ich nochmals etwas. Mit ihnen im Austausch bleiben, dass sie wie das Gefühl haben sie werden auch betreut. So. Ich glaube das ist so das wichtigste." JP*[43]

39 nach Interview JP, 07.02.17, 06:51

40 nach Interview CN, 15.02.17, 02:45

41 vgl. Interviews JP & CN, AM

42 vgl. Interviews CN, 15.02.17 10:53

43 nach Interview JP, 07.02.17, 11:44

7. PEOPLE ARE OFTEN MORE AFRAID OF THE PROCESS OF DYING AND SUFFERING THAN OF DEATH ITSELF

The dying are often scared of the process of dying and the suffering it might bring. When it is explained that they will suffer as little as possible and that the staff will do everything in their power, people are usually able to let go of their fears and embrace death.[44]

"[...] Ich habe sie dann auch irgendwann gefragt, hast du noch Ängste, willst du noch etwas. Da hat sie gesagt; nein, ja, nein. Ich habe höchstens Angst vor den ganz grossen Schmerzen und die sind zum Glück nicht gekommen." MW[45]

44 vgl. interviw CN *15.02.17,* 17:01 / AM 20.02.17, 12:55/ MW 16.02.17,*19:08*

45 nach Interview MW, 16.02.17, 19:08

"La muerte es algo que no debemos temer porque, mientras somos, la muerte no es y cuando la muerte es, nosotros no somos".

Antonio Machado

2.3 THESIS ANSWER

WHAT STRATEGIES, TOOLS, ACTIONS OR OBJECTS ARE USED TO DEAL IN AN IMPENDING DEATH SITUATION, WHICH MIGHT HELP THE DYING AS WELL/OR AS THE RELATIVES?

The answers received to one of the main questions in my thesis are as different as people themselves. What comforts, or helps patients and their relatives during the dying process? EH, for one, explained that she asked her brother to bring a mirror to the hospital.

"Los espejos son mágicos" EH[46]

Which means, mirrors are magic. She looked at herself in the mirror every day and told herself she was ok. Then she asked some friends to bring some paintings to decorate her room, some big colorful paintings.

The medical staff interviewed used different strategies to put their patients at ease and give them a better quality of life. One of the main ones was massage. EH also said this was the one thing which helped her during her hospitalization, beside the visits from her relatives and the mirror. In this case it was her mother, brother or sister who gave her massage, not the medical staff, as this was not offered at the hospital she was in. [47]

Massage seems to help patients for several reasons. The human touch[48] factor for one and its healing and therapeutic benefits. MW, for example, explained how she used a massage and tactile therapy, which helps activate the self-healing forces. Not to help the dying person to heal, since this is no longer possible, but in order to help them find their own way, to help them in letting go. She also uses different natural oils consisting of a mix of minerals and herbal extracts. Each oil has a different composition, scent and color, and serves a different purpose. The pink oil is for love and the orange oil is for when somebody has suffered a shock. She told me she thought smell was very important because this sense becomes very sensitive towards the end.[49] JP also said that they applied different aromatherapies* to help patients, as well as homemade mixes to help to get rid of the strong smells the dying body releases.[50]

"[...]was gegen den Gestank hilft ist zum Beispiel Kaffeesatz, tun wir oft ins Zimmer, oder Rasierschaum, das ist wie Geruchsbinden, hat selber keinen starken Eigengeruch [...]. Und dann gibt es irgendwie noch die ganze Aromatherapie Palette [...] da gibt es hunderte von Düften und da steht immer, wirkt es anregend, beruhigend, schmerzlindernd [...]" JP[51]

"[…]wir versuchen da immer mehr, auch Symptom Behandlungen zu machen, wie Übelkeit mit Pfefferminzeöl zu behandeln. Oder auch gegen Angst, so Sachen." AM[52]

*Aromatherapy is the practice of using the natural oils extracted from flowers, bark, stems, leaves, roots or other parts of a plant to enhance psychological and physical well-being.

The inhaled aroma from these „essential" oils is widely believed to stimulate brain function. Essential oils can also be absorbed through the skin, where they travel through the bloodstream and can promote whole-body healing.

www.aromatherapy.com

46 nach Interview EH, 01.02.17, 34:40

47 vgl. Interview EH, 01.02.17, 11:34

48 vgl. Interview EH, 01.02.17, 11:37

49 vgl. nterview MW, 16.02.17, 14:37

50 vgl. Interview JP, 07.02.17, 18:32

51 nach Interview JP, 07.02.17, 18:32

52 nach Interview AM, 20.02.17, 06:53

Fig.4:
Peter Hujar, 1973
„Candy Darling on her Deathbed“,

Fig.5:
Juan Guzmán, 1950
México City. México. Frida Kahlo in body cast at the Hospital Inglés

Another concept used to help dying patients is what is known as *Basale Stimulation*. JP explains it is a kind of therapy in which you work with touch as well as fragrances: for example with the use of rose scent which relaxes and helps with sorrow.

> *"[...]Oder, Basale Stimulation ist das man die Beine beruhigend wäscht, oder anregend, da gibt es so verschiedene Waschungen, das können wir anbieten. Und dann [...] haben wir viele Therapeuten, Ergo und Physio. Und die machen teilweise auch so Sachen mit den Patienten. Mal ein warmer Wickel oder Irgendjemand mal so durch bewegen im Bett, weil sonst werden sie so steif," JP*[53]

Art has also been proven to help patients.[54] [55] [56]

> *"[…]wir bieten auch Maltherapie an für die, denen es noch besser geht und zum Teil wird das noch sehr gerne wahrgenommen, weil dann wirklich so auch die Möglichkeit besteht sich selber auszudrücken, über Kunst." CN*[57]

It helps patients who may not express their feelings through words, express themselves in a different way.

> *"Bei meiner Schwägerin war es so, dass man absolut nicht darüber reden konnte, gar nicht, die war sehr krank, die hatte auch Krebs. [...] Ich habe aber das Gefühl, die hat im letzten Jahr, noch angefangen zu Malen und hat unglaubliche Bilder gemalt. Ganz farbige Bilder. Und vorher ist sie immer eher so ein bisschen ein depressiver Typ gewesen und ich habe das Gefühl sie hat dort einfach alles in die Bilder gelegt was sie nicht Aussprechen konnte." MW*[58]

Some institutions adapt to their patients' needs with less conventional strategies, like letting them see their pets for example.

> *"[...]was wir manchmal auch machen, wenn es irgendwie nicht gerade eine Bulldoge ist. Wenn jemand zum Beispiel ein Haustier hat oder so, dass man es so in eine Tasche packt und dann ins Zimmer tut und dass dann wirklich nochmal ein Kontakt möglich ist. Solche Sachen [...] können sie sehr geniessen. Sind sehr wichtig." CN*[59]

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53 nach Interview JP, 07.02.17, 15:49

54 Jess Bidgood / NY Times, 2012. Hoping That Art Helps With Healing. www.nytimes.com

55 Hannah Fiske / Social Workers, 2003. Creativity at the End of Life. www.helpstartshere.org

56 Kübler-Ross, 1969, p.59

57 nach Interview CN, 15.02.17 19:56

58 nach nterview MW, 16.02.17, 16:16

59 nach Interview CN, 15.02.17, 14:07

3.1 CONCLUSION

As initially thought, the complexity of the situation and of dealing with the dying process has much to do with the little understanding we have about the subject until we experience it for the first time. It is an unfamiliar subject, which differs totally from the death we see in movies or read about in newspapers, because, by contrast, it is personal and unique. Furthermore people no longer die at home as used to be the case, which systematically makes the dying process, and our relationship with it, a different one. We are not familiar with this situation and thus often lost and scared when dealing with it.

> *"Es ist einfach eine komische Einstellung, es ist einfach schwierig. Eben, es ist ja eigentlich etwas wo man nicht so Erfahrung hat, oder, oder man nicht weiss wie, es ist immer noch so etwas heiliges. Irgendwie so etwas unantastbares und man darf keine Witze darüber machen, es ist so...etwas komisches, wo man nicht versteht. Und darum ist es, glaube ich, komisch." MM*[60]

Grief, disorientation, anger, loss, shock, numbness, relief; death and dying set of different feelings in every person. There is not a universal death, although we all die, every person lives their own death as they live their own life.

Individualism[61] is a growing mega-trend and it is no surprise that we seek individuality on matters relating to the end of our life. When it comes to death and dying we also want to be recognized as an individual rather than as a mass product.

So when it comes to the care a dying person receives we also expect it to be individualized. As discovered in the research, there are many different therapies, techniques or strategies when dealing with the dying and their relatives. There is no one ritual, process or strategy, but an abundance of approaches, which are defined by the people who perform them, the education they have received on the subject of dying and death, their beliefs, personal preferences and the institution for which they work.

Although everybody explained how individual dying and death are, I could always relate to some aspect of their story from my personal experience. This makes me conclude that there are commonalities in dying and death. There is a list of physical symptoms[62]: : confusion, restlessness, lack of appetite, fever, incontinence, as well as emotional and spiritual signs[63]: including restlessness, vision-like experiences, withdrawal, spiritual demands or new perceptions. There are printed guidelines for medical staff for dealing with the dying and brochures for relatives explaining what to expect. There are certain patterns and situations, which repeat themselves and allow medical staff to have a certain routine and be able to deal in this specific situation.[64] There is therefore a set of tools and ingredients that can be implemented, depending on the patient's needs.

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60 nach Interview MM, 26.01.17 17:30

61 Zukunfts Institut / Die Individualisierung der Welt. www.zukunftsinstitut.de

62 vgl. Handlungsempfelung Sterbephase, p. 9-10

63 vgl. Handlungsempfelung Sterbephase, p. 10

64 vgl. Interview AM, 20.02.17, 13:54

Hospitals are usually not particularly beautiful or cheerful places: white or grey walls, maybe even pale yellow if you are lucky. There is no decoration apart from the boring curtain which separates one bed from another and usually a chair in the corner. The rooms have an undertone of bleach and the floors are simply grey, the bedlinen a faded white. The only thing that stands out is the medical equipment, the stands for intravenous drips, the monitors and the dispensers for hand sanitizer. When you step into a hospital room you understand why people feel the need to bring flowers, photographs or drawings. Something that reminds them of life and not of sickness and death. It seems that there is a need to consider what could be done to give the dying a better quality of life by improving the environment in which they spend their last breath.

> *"Bellvitge para mí es un antro de muerte, es muy triste, es muy tétrico, es muy gris, las paredes no son blancas, no son de colores, no llevan cuadros ni llevan vida. Todo es una muerte. Es una muerte ya anunciada."*[65] *"[...]les dije que me trajeran unos cuadros, pero, unos cuadros que eran así de grandes. Eh, con muchos colores, y cada color, me daba pues una sensación de vida. Claro, yo lo hice colgar ahí enfrente, cuando yo abría los ojos, veía ese cuadro, veía la vida." EH*[66]

Finally, from different books and articles and from many interviewees it was confirmed that, to live a fulfilled life one must learn to understand and accept death.[67]It seems our understanding and relationship of death and dying has changed: it has become more distant and less personal, we have institutionalized death[68] and pushed it to the side. We must learn again to accept dying and death as a natural part of life, as part of the circle of life.

> *"[…] ich denke, wenn man immer wie mehr lernt den Tod zu verstehen, dann lernst du auch viel intensiver zu Leben. […] und so lang du es einfach ausgeklammerst, oder es einem Angst macht, dann ist man auch gar nicht so im Leben wie das eben eigentlich möglich ist. Wie wenn du jetzt das ganze probierst als Einheit zu sehen." MW*[69]

65 nach Interview EH, 01.02.17, 06:59

66 nach Interview EH, 01.02.17, 34:40

67 vgl. Pfersdorf, 2016, p.71-72

68 vgl. Kulbe, 2010, p.2-3

69 nach Interview MW, 16.02.17, 2:52

3.2 LAST WORDS

At the beginning, I was unsure whether it was a good idea to research dying and death. Would people want to talk about this subject? Did I want to spend so much time thinking about such a "difficult" subject? But there was no reason to be doubtful, as every person approached was open and willing to share their experience and opinion on the matter.

Were I to continue investigating dying and death, I would talk to more people. Every person I talked to gave me a new approach and answers to my question, which makes me believe there is still much to be learned. I would open my field of investigation and not only talk to people who are specialized in the field of dying and death, but also talk to people for whom this is not such a relevant subject. To see if they also dispose of a set of tools and strategies and, if so, what these are.

I am grateful to all the people who opened up to me and told me their stories and experiences, which has allowed me to gain a true insight and new view about this subject, which I take with me for the present and for whatever might come.

"Cada día estamos dando. Dando al exterior. Viviendo para el exterior. Todo es materia, materia, materia, materia. Cuando en verdad te vas, y lo dejas todo. Que tontería."

EH

ANNEX

4.1 LITERATURE AND SOURCES

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Fig.1:
Hanna Büker, 2017, Collage

Fig.2:
Philippe Halsman 1951
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Fig.3:
Atul Gawande, 2014
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Fig.4:
Peter Hujar, 1973
„Candy Darling on her Deathbed",
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Fig.5:
Juan Guzmán, 1950
México City. México. Frida Kahlo in body cast at the Hospital Inglés
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4.2 FRAGEBOGEN

FRAGEBOGEN FÜR ANGEHÖRIGE / PATIENTEN

Was ist dein Bezug zum Thema Sterben?
- Beruflich, Persönlich, Spirituell etc.

Wie nahmst du diese Situation wahr?
War der Patient in einem Spital / Hospiz / Zuhause?
Wie lange war der Patient im Spital / Hospiz bis er gestorben ist?
Wie war der geistliche Zustand des Patienten?
Wie gingst du mit der Situation um?
Was waren die Schwierigkeiten?
Was half dir?
Was hast du vermisst?
Im Nachhinein was denkst du hätte dir und deinen Angehörigen geholfen?
Würdest du etwas anders machen?
Entstanden mit der Zeit, sich wiederholende, Handlungen?
Welche Handlungen oder Hilfsmittel halfen dir in dieser Situation?

FRAGEBOGEN FÜR EXPERTEN

Was ist dein Bezug zum Thema Sterben?
- Beruflich, Persönlich, Spirituell etc.

Wie gehst du mit der Situation, wenn du weisst das ein Patient am sterben ist, um?
Was beobachtest du bei Leuten die am Sterben sind, was hilft Ihnen und/oder den Angehörigen?
Was denkst du könnte ihnen zusätzlich dienen?
Was ist für dich ein gutes Sterben?

4.3 PROFILE INTERVIEWEES

AE is 26, she accompanied her boyfriend at the time, through a long and difficult illness. This young man was diagnosed with hodgkins cancer 5 years ago, he was in and out of hospitals for a period of 2-3 years during which time he underwent a number of sessions of chemotherapy and other treatments. The treatments seemed to work at first, but after a certain time the metastasis always came back. After coming very close to death he regained part of his health, we was however, never the same person again, both physically and emotionally. He lived for two years after the last chemotherapy and died last year at home, in the shower, from meningitis, consequence of all the chemotherapy and other treatments.

CN is in her mid 50 and is the head doctor of a small hospital with 34 beds. This clinic is set in an old vila, surrounded by a vast garden with lake view. This clinic has 8 beds available for palliative care patients, these patients are not on a separate floor but mixed with the rest of the patients. This care is payed by the health insurance companies and in part by the canton but only for a limited time, approximately 3-4 weeks maximum, after that they have to be relocated to a hospice, to a home, or back home.

AM is the head nurse at the same clinic CN works for, described above. AM is in her mid 40 and also has a personal interest in the subject of death and grief. She leads a grief support group outside of work.

EH is a 56 year old woman living in Spain who was diagnosed with severe endometrial cancer, hospitalized several times, the longest over a period of one year, during which she went through an extensive amount of chemotherapies and surgeries. In 2013 she had a colostomy which means they had to amputate and insert a colostomay bag. This happened 5 years ago, today she lives a more or less normal life.

JK works as an end-of-life attendant for EXIT and in some occasions for Diginitas. Accompanied Suicide is meant for anyone suffering from an illness which will inevitably lead to death, or anyone with an unendurable disability, who wants voluntarily to put an end to their life and suffering. JK has accompanied many people who wish to die. The time it takes until a person decides they are ready to die depends on each individual, he has had cases which have taken from 8 days to 14 years.

JP is 28 and works as a nurse in a geriatric clinic with 88 beds. The city where this hospital is located, does not have a hospice. This means they often take in this function since there is no where else to send the patients. This hospital is specialized in palliative care. The patients stay in this facility is limited to 3-4 weeks, after that they must be relocated.

MM is a 25 year old student who lost his father in december 2015 due to leukaemia. His father was diagnosed with blood cancer in september 2015 and died 3 months later. He was hospitalized in the cantonal hospital in Aarau and spent longer periods of time in protective isolation, his son and other visitors were required to wear masks, gloves and gowns when entering his room.

MW is a 56 year old woman, practitioner for ortho-bionomy who runs her own practice for "Ortho-Bionomy & Movement". She has accompanied 4 people during the dying process. Two family members, her mother and her sister in law, one close friend and a client.

INTERVIEW TRANSCRIPTS