# The volunteers at Hospice Veerhuis

A qualitative research on the diversity in volunteers as a result of the hospice's humanistic principles

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#### **Abstract**

The Veerhuis is a hospice that has been founded on humanistic principles. Whereas many hospices have a religious base, the foundation of a hospice on humanistic principles is a fairly unique phenomenon. The intended purpose of the humanistic base is to make everyone, both residents and volunteers, feel welcome in this hospice. However, the term humanism implies, from a philosophical point of view, a critical stance towards religious beliefs. Since Hospice Veerhuis does not make any value judgements regarding religion, it can be concluded that humanism merely serves as a method to create a neutral environment in which everyone can feel comfortable according to their own moral principles. The result is a highly diverse team of volunteers. The data demonstrate that the team of volunteers is made up of people with different motivations to become a hospice volunteer, varying ideas on death and dying, and religious and spiritual beliefs. Four volunteers serve as archetypes to demonstrate the high degree of diversity that exists within this hospice.

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#### **Introduction**

Although the only certain thing in life is that we will all cease to exist one day, death is still a taboo for a vast part of the population. Many people are still afraid of it and some even downright ignore it. Ample research has been done on death and dying, especially regarding rituals surrounding death and dying in many different cultures. Research has also been done on the experiences of terminally ill individuals in the face of their pending deaths. Little research, however, has been done on those individuals that choose to participate in situations where death is always around the corner. For this reason I have opted to do research among volunteers in Hospice Veerhuis in Amsterdam. I have specifically chosen this hospice since it is based on humanistic principles, in contrast to many Dutch hospices that have a religious foundation. The Veerhuis states that it is its aim to make everyone, both volunteers as well as residents, feel welcome without regarding one's personal background and religious and spiritual beliefs. It is supposed that the utilization of humanistic principles results in a diverse team of volunteers.

The research question of this thesis is:

*In which way do the humanistic principles of the hospice contribute to the diversity in volunteers?* 

The aims of this research are to (a) uncover which aspects of humanism are utilized in the Veerhuis; (b) what the objective of the utilization of these humanistic aspects is; and (c) what the practical result of all this is. In order to meet the goals of the research, this thesis is built up in the following manner. In the first chapter I will provide the reader with insight into the field of research, consisting of a short introduction into palliative and hospice care and an image of Hospice Veerhuis is provided. In the second chapter, the theoretical framework, I will discuss the theories on humanism and Bourdieu's concept of habitus. In chapter three I will analyse which aspects of humanism are utilized in the Veerhuis and to what end. In chapter four I provide an image of the diversity among volunteers by elaborating four case studies of volunteers. In the fifth chapter I will connect the research outcomes from Hospice Veerhuis to the theory from the theoretical framework. I will answer the following hypotheses:

- 1. Everyone can become a hospice volunteer
- 2. Religion and upbringing play an important role in the motivation to become a hospice volunteer.
- 3. Volunteers are likely to have (had) direct experiences with death and dying.

<sup>&</sup>lt;sup>1</sup> For further reading see for example: On Death and Dying (1969) and Death: The Final Stage of Growth (1974) by E. Kübler Ross; Palliatieve Behandeling en Communicatie (1999) by A. M. The; Death, Mourning, and Burial: A Cross-Cultural Reader (2004) by A.C.G.M. Robben (editor); Celebrations of Death: The Anthropology of Mortuary Ritual (1991) by Metcalf and Huntington; Death and Bereavement Across Cultures (1997) by Parks, Laungani and Young; Grief and Mourning in Cross Cultural Perspective (1976) by Rosenblatt, Walsh and Jackson; Mortality and Immortality: The Anthropology and Archaeology of Death (1981) by Humphreys and King (editors).

- 4. Volunteers are comfortable with death (their own, but also death of others).
- 5. Being a volunteer in Hospice Veerhuis has changed the attitude of volunteers when it comes to death and dying.

#### Chapter 1 - The field

In this chapter, I will give an account of my field of research. First, I will provide the reader with some information on hospices and palliative care. Secondly, I will zoom in on Hospice Veerhuis, the volunteers and their activities. Thirdly, I will discuss some ethical concerns and I will end with a short summary of the chapter.

A hospice is an institution where, in a homely atmosphere, palliative care is being provided to residents who are terminally ill, i.e. who have less than three months to live. According to the World Health Organisation, palliative care is

'an approach that improves the quality of life of patients and their families facing problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification of impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual' (Sepúlveda, 2002: 94).

#### The aim is of palliative care is

'no longer to cure a patient, but to optimize his quality of life, which may positively influence the course of the disease; death is considered a normal and natural process that will neither be accelerated nor decelerated; both physical and psychological discomforts are treated; the psychological and spiritual aspects will be integrated in the provision of care; there will be emotional support for the patient and his loved ones to live as actively as possible; there is also emotional support for the next of kin to learn to deal with the disease of the patient and their own feelings of grief; if necessary, a team of professional caregivers will support the patient and his next of kin, in order to satisfy their needs, also after the death of the patient' (translated from Dutch) (Stichting Voorlichting Palliatieve Zorg<sup>2</sup>).

The General Introduction in Palliative Guidelines add that the quality of life, management of symptoms, anticipating possible complaints and problems, autonomy of the patient and integral and multidimensional care for next of kin, are central themes within palliative care (Zylicz, 2010). In the definition of the WHO the focus is both on the treatment of symptoms, as well as the coping process of the patient and his family. Professional care givers and medical staff are challenged to adapt a method in which the 'patient as a human being' - one with fears, questions, feelings, family, a history, etc. – is the centre of attention and not as much the 'patient with the illness' (Sepúlveda, 2002). The palliative phase should not be confused with the terminal phase. In the terminal phase one has less than three months to live, whereas the palliative phase can last days, weeks, months and even years. Thus, someone who is terminal is always palliative, but someone who is palliative is not necessarily terminal. The palliative phase can set in gradually or suddenly and can be very unpredictable, with periods of stability and periods of deterioration. According to Stichting Voorlichting Palliatieve Zorg it is relatively clear when curative care has to be replaced for palliative care. Palliative treatment often contains elements are also used within curative treatment, such as chemotherapy and radiotherapy. These types of treatment, however, are not aimed at curing a patient, but are used to treat symptoms, like pain (Zylicz, 2010).

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<sup>&</sup>lt;sup>2</sup> Foundation for Information on Palliative Care

Hospices come in different shapes and sizes. There are high-care and low-care facilities with an average of three to five beds. High-care hospices provide care to residents with highly complex diseases which require hospital related care, for example pain treatment using invasive techniques such as epidural and spinal blocks. The staff, therefore, consists of medical professionals with different specializations, such as psychologists and physiotherapists. Moreover, high-care hospices provide 24-hour specialized and professional medical care. The staff is completed by volunteers, who work without receiving any monetary compensation. In low-care hospices, by contrast, residents have diseases that require little professional care. The majority of the staff are volunteers who perform as hosts and care givers. The volunteers are backed up by coordinators, general physicians and professional care givers.

# **Hospice Veerhuis**

Hospice Veerhuis is a low-care hospice that is founded on humanistic principles. This means that anyone with a disease that does not involve high-complex care is welcome to live in the hospice, without consideration of one's religious beliefs or personal background. The individuals who live in the Veerhuis are specifically referred to as 'residents'. The term 'patient' is considered inappropriate, since the aim of the hospice is to create a homely environment that resembles the living arrangements of the resident prior to moving to the Veerhuis, and not that of a hospital where the emphasis is on the provision of treatment of illnesses. The Veerhuis does not just aim to create this environment for its residents, but also for their loved ones.

The Veerhuis-staff falls under the responsibility of two coordinators, who are both professional nurses. The majority of the staff, however, consists of volunteers<sup>3</sup>. The coordinators arrange all the practical affairs of the hospice, such as the recruitment of volunteers and the intake of residents. A team of specialized nurses from PartiCura-Combizorg is responsible for the medical care of the residents. The general practitioner of the resident will continue to support and guide him<sup>4</sup>. Residents from outside the region can appeal to the general practitioner that is linked to the hospice.

If possible and desired, a resident's family and friends are allowed to be involved in the provision of care. They can stay in the hospice and take care of the meals for the resident and themselves. After the death of the resident, family and friends remain welcome in the Veerhuis. A few weeks after the loss of their loved one, one of the coordinators will contact the family to inquire if there is a need for aftercare.

Concretely, there are four different four-hour shifts: from 7 a.m. to 11 a.m., from 11 a.m. to 3 p.m., from 3 p.m. To 7 p.m. and from 7 p.m. to 11 p.m.. From 11 p.m. to 7 a.m. two professional nurses from

<sup>3</sup> In accordance with the website, I will address the volunteers in general with 'she' and 'her', as the majority of the volunteers is female.

<sup>&</sup>lt;sup>4</sup> I will refer to residents in the masculine form.

PartiCura look after the residents. Each volunteer shift has its own predefined set of chores. The early shift takes care of breakfast and groceries and helps the residents prepare for the day, the second shift provides lunch, the third shift makes dinner and the volunteers of the last shift help the residents prepare for the night. During these shifts, the volunteers are expected to provide the residents with food and beverages, look after their guests and make sure the resident is comfortable.

At the beginning of each shift the volunteers of the previous shift inform their colleagues what has happened during the day and what will need to be done during their shift. Volunteers also write a short summary of what happened that day with the residents in a file. The file is divided in four sections, one for each resident, and provides the volunteers with information about the residents: their names, type of disease, age, address, who to contact in case of an emergency, some background information on what kind of work they have done, what they like and dislike, how they want to be addressed and medical information. The file also contains a list of which resident should have what medicine at what time. Volunteers are responsible for supplying the medicines, which are set out by professional nurses. Volunteers are often confronted with situations in which they are not capable or allowed to undertake direct action. These are mostly situations which are the result of some sort of medical problem, like sudden pain or fever. In such cases volunteers are required to consult a trained professional. Volunteers are always backed up by the coordinators, who decide what the right course of action is in such events.

The wellbeing of the residents has the highest priority and household chores are always inferior to this. The entire shift revolves around the question: 'What can I do to make life as comfortable as possible for the residents?', which makes shifts highly dynamic and, at times, requires volunteers to step outside their comfort zone. At one moment you may be sitting in a residents room, talking with him and rubbing his feet, while the next moment you may find yourself cleaning excrements.

Asking the volunteers what they disliked about working at the Veerhuis, I expected that chores involving excrements would be least favourite among volunteers, but, to my surprise, many of them said that it is not something that really bothered them, that you will get used to it and that it is just a part of the job. Volunteer Karla:

*Karla:* 'I do not even know if there is something that I dislike. I think it is great that I do not feel that way in the Veerhuis. I am just servient here. It does not really matter if I am cleaning shit, doing groceries or have a nice conversation with someone. I do not really care'.

*Me*: 'That is something I hear very often. There are not a lot of things that people dislike. Some say: 'I do not like household chores'. But most say they do not like to iron at home, for example, but over here, it does not bother them'.

*Karla:* 'Indeed, I never iron at home. I do not even have an ironing board, but over here... It is also the setting. Sometimes you iron in someone's room or in the kitchen, while all kinds of things are happening all around you. But you know, for example, Sunday I have been cleaning up poop the entire shift and it was not the nice kind of poop, because that can vary a lot. And I did it with, well, 'pleasure' is a big word, but in a way it is true, because I was so happy that I did it and that someone can lie down comfortably. You just do it and you are not really contemplating if it is nice or not. You just do it because it has to be done'.

Off all the chores to be done in the Veerhuis, household chores are usually least favoured, but most

volunteers agree with Karlas statement that these tasks are part of the job and doing them in order to create a comfortable environment for the residents makes them less undesirable. Some volunteers say that being unable to understand someone or resolve a problem is very frustrating.

Diversity among residents and colleagues is an aspect that volunteers perceive as satisfying.

Wendy: 'It is the diversity in people that I think is so special. There was this man once and he was really well-mannered – he loved to wear suits. And at the same time, there was this lady, a typical woman from Amsterdam. And whenever he would say something, she would look at him and was like... [Wendy makes a sound of contempt]. And he would look at me as if he was asking: 'What did I do wrong?' And I told him: 'You did not do anything wrong, Just take the people the way they are'. And later on I told him that in this phase, people sometimes become a bit more uncivilized and that can be tough, but that is different with him, that he notices and other people do not notice'.

*Tineke*: 'It is so satisfying. And that is the nice thing, it gives me a great feeling. The contact with the residents, the huge variety in people. Just like a real society. Not just among residents, but also among colleagues. They are all so different and I think that is really interesting. And what I like about this hospice is that it is so small. There are only four residents and getting into contact with the coordinators is very easy'.

Contact with the residents and taking care of them is also an aspect that is satisfactory for many volunteers. Cindy's statement is exemplary:

Being in contact with the residents. When you really have the feeling that you are in contact with him or can do something for him. And this can be something very small, like holding someone's hand or rearranging a pillow or making something nice for them. That gives me the most satisfaction. But it can also be more profound. Getting into a conversation. But I have to admit that it does not happen a lot, because very often there is family. Well, you have probably noticed it yourself, that family is very welcome and that they often stay for a longer period of time'.

# History and organisation

The idea for the establishment of Hospice Veerhuis came from three individuals who volunteered at Markant, a foundation that provides informal care at home to terminally ill individuals. Through this volunteering job, two of the three founders noticed that some terminally ill individuals are in such a weak physical state that it is almost irresponsible to leave them all by themselves. They realized that there should be a place where terminally ill people can spend their last moments in a homely environment where care was provided by volunteers. The third of the three founders had been working as a secretary at the Dutch Hospice Movement<sup>5</sup> - a movement which committed itself to arranging informal care for terminally ill patients who were unable to stay at home. A workgroup was established. The members of the group discussed their wishes for the hospice. An important item was the scale of the hospice. Although they agreed that it should be a small-scale hospice, they realised that financing a larger hospice with professional nurses would be easier. Moreover, there was an ongoing debate in Dutch society about the question whether it was responsible to entrust volunteers with caring for terminally ill patients. Despite the reservations of many medical

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<sup>&</sup>lt;sup>5</sup> Nederlandse Hospice Beweging

specialists, the three founders of the workgroup agreed that it should be a small-scale hospice. The aim of the hospice was to provide a homely, cosy environment and, according to the three founders, a small-scale hospice seemed most suitable to pursue this goal (Jurgens, K., co-founder, personal communication).

On the 6<sup>th</sup> of February 1998, Foundation Hospice Amsterdam<sup>6</sup> was founded. This name was chosen in order to facilitate the possible expansion of the foundation with more hospices. At the present time, the board has six members. The minimum amount of board members is three. The members of the board decide which member performs which task – a chairman, a secretary and a chamberlain. One member can have more than one function. When the board has less than three members, it will remain in function. A member is appointed for three years, but after this period, he or she is immediately eligible. Membership can be ended by virtue of one of the following reasons: resignation by the member him- or herself, death, loss of the capacities of the board member, or in the cases stated in article 2:298 of the Civil Code. Any member of the board can be suspended or discharged at any time through a majority vote of at least two thirds of the board members.

The Hospice is financed through (1) gifts, inheritances and legacies, (2) interest, (3) contributions of thirds, (4) subsidies, (5) other income. The Ministry of Health, Welfare and Sport provides the Veerhuis with subsidies. These subsidies are based on the amount of residents – the more residents, the higher the amount of subsidies. Furthermore, the residents pay a contribution of 35€ per day. Depending on the degree of insurance, these expenses are partially or entirely covered by the residents' insurance. Medical expenses are compensated by the Exceptional Medical Expenses Act <sup>7</sup>. Capital is also yielded by a committee that actively raises funds. Funds raised by this committee have permitted the foundation to reconstruct the entire hospice. Benefactors usually prefer to donate money to specific projects. This means that they often do not structurally donate capital. In addition, Hospice Veerhuis is dependent upon volunteers. The only paid employees are the two coordinators. Other positions are filled by volunteers. Besides the volunteers that provide care for the residents, there are other volunteers such as gardeners, cooks and website and database administrators (Hospice Veerhuis, 1998).

Hospitals, general physicians and district nurses refer ill individuals and their families to Hospice Veerhuis. Others hear about this hospice through the internet or through word of mouth. The Veerhuis lets a possible resident decide when he wants to move to the hospice. This is, however, not always possible, due to waiting lists. Occasionally, an individual has already made arrangements to move in to the house before reaching the terminal phase. He then decides when it is time for him to move to the Veerhuis. Often, individuals need to come to grips with the fact that the Veerhuis will probably be their final home. When a terminally ill person is still well enough to live independently or with the help of informal care givers, this may lead to the postponing of moving to the Veerhuis. In other cases, residents are acutely moving into the hospice. This happens when their situation suddenly deteriorates. In some rare instances, the coordinators, in accordance with a possible resident, may decide not to admit him. This may happen when one's needs can not be met by the Veerhuis. In principle, residents are allowed to stay in the Veerhuis for a maximum of

<sup>6</sup> Stichting Hospice Amsterdam

<sup>&</sup>lt;sup>7</sup> Algemene Wet Bijzondere Ziektekosten (AWBZ).

three months. However, it may happen that a resident lives longer. In that case, coordinators will discuss with the residents how to proceed after these three months. When the resident is in a bad physical condition the coordinators can decide to let him stay. When the resident is doing well, they will help him make other living arrangements. This does not at all means that a resident will be thrown out when the three month limit is exceeded. Some residents have stayed in the Veerhuis as long as six months. In any case, the wellbeing of the resident is what is most important and coordinators will make arrangements that meet their needs (Kristensen, C., coordinator, personal communication in Ende, G.J. van 't, personal logbook).

# The neighbourhood and the house

The Veerhuis is located in Amsterdam in the neighbourhood that is called 'De Pijp'. De Pijp is a former working class neighbourhood built in the 19<sup>th</sup> century. It is a vibrant part of Amsterdam that houses a highly diverse population, consisting of students, artists, families, all from different nationalities. This diversity in nationalities – more than 150 - is reflected in the many exotic restaurants. Moreover, De Pijp is home to the famous Albert Cuyp market, the Sarphatipark and the Amstel River and many stores and coffee shops (Amsterdam.info, 2013). The Veerhuis is situated in the Vincent van Goghstraat. This is a quiet street where mostly families live. In the corner of this street, on the ground floor of a building with multiple storeys, is Hospice Veerhuis. This location was chosen because it is in a quiet neighbourhood, it has a big garden and is easily accessible (Zweers, I., coordinator, personal communication in Ende, G.J. van 't, personal logbook).

Entering the front door, one steps into a little hall. Behind the hall is a corridor. From the corridor one can enter several different space: the four resident rooms, the coordinator's office, a room where the volunteers evaluate their shifts and where books, basic medical supplies and resident files are stored, two laundry rooms where all the sheets and linens are stored, a guest room and the kitchen. The communal living room can be entered from the corridor as well as the kitchen. The kitchen is the heart of hospice. This is where volunteers do most of their chores, like preparing food or ironing laundry. Often, residents also sit in the kitchen. The Veerhuis has a large garden with a lot of flowers and plants. Three out of four resident rooms have direct access to the garden.

The Veerhuis is a big house with large windows that permit the sunlight to lighten up the house. The living room is painted in light, sober colours and furnished with chairs, a couch, rugs and a big table. The resident rooms consist of a bed, a television, a chair, a bathroom and some decorative items like paintings, lamps and rugs. In order to meet the goal of creating a homely atmosphere, residents are free to bring their personal belongings to decorate their rooms. They are also allowed to bring their pets (G.J. van 't, personal logbook).

# The hospice and I

Before I started volunteering in the Veerhuis, I did not really know what to expect. I was raised in a family where death was never a taboo or treated as something to be scared of. I remember that my mother from time to time inquired about my wishes regarding my own funeral, in case I would pass away at a young age. I also remember that she sometimes took me to funerals of deceased family members and she would let me choose if I wanted to see the dead person. Even as a little girl, the sight of a dead person did not scare me. Later on, I realized that what my parents did was very valuable – they showed me that everyone dies at one point and they taught me not to be afraid of death. And even though I felt comfortable with death, I wondered whether or not I would feel at ease in an environment where death is always present. Although I did not have the same expectations as many people have of hospices – a place with a grim atmosphere where everyone is always sad – I did not have a clue what I would encounter. After having read the website thoroughly and seeing a documentary about the Veerhuis<sup>8</sup>, I already knew that it was a house like any other house. The only difference was that it was a home for people who were really ill, but it seemed to me that it functioned as a normal household. This was confirmed by the coordinators during a selection interview in which they would decide if they thought I was suitable for the job. Still, I had my doubts – what kind of people would be working in this hospice? Would they accept me as one of their colleagues? How would I react to the death of a resident? What would be expected of me?

During my first shift, I was welcomed by a few volunteers. One of them showed me around the house and encouraged me to engage in the activities of the volunteers. Right away, I felt at ease, since nobody seemed to care that I was a lot younger. In the course of the weeks, I managed to familiarize myself with all the tasks and chores of the volunteers and I noticed that I really loved what I was doing. What really struck me was the air of serenity and purity in the house – not only the residents, but also the volunteers, could just be themselves. They did not have to hide themselves behind the masks that we put on in our everyday life. It was o.k. if someone just wanted to be sad or happy or angry. It seemed to me that all the frivolities of life, all the small things we worry about daily, vanished into thin air when we are confronted with something that is beyond our comprehension. I felt a deep sense of respect for my colleagues who, so selflessly, committed their time to the residents of this hospice. They did all their tasks with joy and would never complain.

In the course of the three months I spent in Hospice Veerhuis, I noticed several things. I was, as I had expected, comfortable with death, both practically and spiritually. I did not feel any discomfort being around people in the last phase of their life. However, at times I had the feeling that I was not the best care giver due to a lack of experience. The positive thing was that there was room for error and that nobody expected you to do everything perfectly. On a spiritual level, my thoughts and feelings regarding death were confirmed. I saw that death was, in my opinion, indeed a natural part of life. Moreover, the bond that loved ones share when death is imminent, can be of such profundity that it is almost impossible to put into words. What also really

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<sup>&</sup>lt;sup>8</sup> Het Veerhuis, Dir. Meyknecht, S., Humanistische Omroep, 2005.

struck me was that acceptance of death and coming to grips with the fact that we are all going to die, is of essence for how we experience the last phase of life. For many people death is still a taboo, causing them to avoid thinking about their own opinions, wishes and needs regarding death. I have seen people struggling with their pending deaths, bringing about such negative sentiments of fear, anger, sadness and the like. To me, it was painful to see that they were missing out on so much beautiful and precious time with family and friends. The time I have spent in the Veerhuis turned out to be a very valuable, instructive and rewarding time. I am truly thankful that I was allowed to conduct my research in this beautiful and pure environment (Ende, GJ. van 't, personal logbook).

#### **Ethical concerns**

As a volunteer in Hospice Veerhuis, I was expected to perform some minor nurturing tasks, like washing and clothing a resident and handing him his medication. Since I had no experience with caring for adults, I struggled with the question if it was ethically responsible for me to take care of a dying resident. I have discussed this with co-volunteers and they told me I was not obligated to do anything I was not comfortable with. In the beginning of the fieldwork, I watched how my colleagues would handle these kind of tasks, later on I did them under their supervision, until I felt secure enough to do them independently.

Another concern I had to deal with was the question of deceit. Although the goal of my presence in the hospice had been communicated in various ways – in the newsletter and by myself – I was worried about volunteers feeling betrayed. Despite the fact that they knew why I was there, it was important for my research that they would treat me like any other colleague, in which, I think, I succeeded. This resulted in volunteers telling me personal information that might be useful for my research at times that I did not specifically request permission to record this information, for example during shifts. I wondered if I was allowed to use these data, since, on the one hand, I did not ask for permission before, during or after these conversations, but, on the other hand, they knew of my role as a researcher. I have discussed this with my supervisor and we concluded that they were aware of what I was doing there and they, thus, had the opportunity to tell me I was not allowed to use certain information. Moreover, I was able to guarantee the volunteers that the interviews would be anonymous. I have, therefore, used fictional names since the use of their real names would not add any value to this research.

#### Conclusion

Hospices are facilities where palliative care is being provided to residents who have an expected lifespan of three months at the very most. As opposed to curative treatments, in palliative care the aim is not to cure someone, but to optimize one's quality of life. There are two types of hospices: high-care hospices, where

residents with highly complex diseases can spend the last days of their lives, and low-care hospices, for residents with low care diseases, like cancer.

Hospice Veerhuis in Amsterdam is a low-care facility funded on humanistic principles, which means that it is open to anyone without consideration of one's religion, social and economic background, age or gender. This also applies the volunteers, making it a highly diverse team. This, however, does not mean that anyone can become a volunteer. The expectation of fulfilling a therapeutic role, having unsolved emotional problems and having an already busy schedule may be reasons not to accept someone as a volunteer.

The day is divided into four four-hour shifts of volunteers from 7 a.m. until 11 p.m. Nights are covered by professional nurses. The volunteers have several duties: they take care of the residents and their visitors (providing them with food and drinks), assist the professional nurses, do minor household tasks and, most importantly, care for the residents (washing and clothing them and handing them their medicines). Volunteers indicate that there are not many activities in the Veerhuis they dislike. The contact with residents and other colleagues, and the diversity among volunteers is generally perceived as satisfying.

I have used several methods to gather data. Participant observation allowed me to gain access to the hospice and to the volunteers. I have gathered data on what the volunteers do and I was able to identify topics of relevance for the research. Furthermore, interviews I had with almost half of the group of volunteers yielded information, among others, on the motivations of volunteers, ideas on death and dying and experiences that contributed to the formation of these ideas.

One of the ethical concerns I have dealt with involved the question if it was ethically responsible that I, as an inexperienced volunteer, would care for terminally ill individuals. Another ethical question was if I was allowed to use all the data I had gathered, even if it was in situations in which I did not specifically request permission to write down the information. I have discussed these issues with several parties and created circumstances in which I felt comfortable doing research.

# Chapter 2 - Theoretical framework

#### Humanism

The Veerhuis has adopted the principles of humanism as a basis for the functioning of the hospice. According to the Encyclopaedia Britannica, humanism is a 'term freely applied to a variety of beliefs, methods, and philosophies that place central emphasis on the human realm' (Encylopaedia Britannica, n.d. – Humanism). Humanism has a longstanding history and can be traced back to the classical writings of Greek and Roman philosophers some 2500 years ago. Western humanism as we know it in this day and age, however, is a product of renaissance humanism that has its origins in the 13<sup>th</sup> and 14<sup>th</sup> century in northern Italy. It was during this period when there focus shifted from the bible to 'classical pagan virtues, and an effort to secularize morality' (Kurtz, 2007: 11). Contrary to the religious writings of the bible, philosophers promoted a cultivation of the earthly pleasures and happiness. The development of modern science and the Enlightenment provided a context in which humanism was able to flourish. Free thought, reasoning and education served as methods to free humanity from superstition and build a better world (Ibid.: 14). The term humanism was coined in the 19<sup>th</sup> century by German scholars, who used it to refer to the Renaissance emphasis on classical education, taught by professors and students of classical literature, called *umanisti*. The basis of this type of education was *humanitas* - 'the development of human virtue in all its forms, to its fullest extent' (Encylopaedia Britannica, n.d. – Humanism).

In the 20<sup>th</sup> century, two views of humanism were developed. In the first one, Christianity was a central feature. According to Maritain, this type of humanism has a theocentric focus, since God is at the core of this philosophy. Paradoxically, the human is both sinner and redeemed. The second type of humanism is the one in which the human is his own centre and is, thus, anthropocentric and atheistic (Maritain in Hanna, 2013: 55). Anthropocentric humanism has been influenced by two systems within philosophy: existentialism, in which the emphasis is on certain given facts of life, and phenomenology, which pays attention to the contents of consciousness. Humanism has drawn from existentialism its emphasis on human freedom. The phenomenological contribution to humanism can be found in the 'appreciation for conscious experience and human subjectivity' (Hansen, 2005: 5). In this thesis, I will focus on the second type of humanism, addressing it as anthropocentric humanism, since Hospice Veerhuis clearly states that it does not adhere to a certain religion and that the individual is free to express his beliefs and needs. I will elaborate on the humanistic principles of the hospice in the next chapter.

Closely related to the second type is Sartre's view on existential humanism. Sartre states that there are two definitions of the term humanism and explicitly mentions that he does not refer to the 'theory which upholds man as the end-in-itself and as the supreme value' (1996: 65). In this theory one ascribes value to man according to his achievements (Ibid: 66). Instead, he proposes that there is another form of humanism. In this form of humanism, man is outside of himself all the time and exists through the goals he sets for himself: 'It is in projecting himself beyond himself that he makes man to exist; and, on the other hand, it is by pursuing transcendent aims that he himself is able to exist' (Ibid.:67). For Sartre, it is not a question of

whether or not God exists. The issue is rather that it would not matter if he existed, because there is nothing that can save man from himself. There is no other universe than the human universe of subjectivity, which makes himself the heart and centre of his transcendence:

'This is humanism, because we remind man that there is no legislator but himself; that he himself, thus abandoned, must decide for himself; also because we show that it is not by turning back upon himself, but always by seeking, beyond himself, an aim which is one of liberation or of some particular realisation, that man can realize himself as truly human.' (Ibid.)

Kurtz asserts that there are three key humanist virtues, namely courage, cognition and caring. Humanist ethics, he states, therefore puts emphasis on human freedom:

'It encourages individual growth and development. It focuses on the need of humanists to control their own destinies; to take responsibility, individually and collectively, for their own plans and projects; to enter into the world not simply in order to understand or adore it, but with the intent to use it with prudence to satisfy our needs and desires. Humanistic ethics emphasizes independence, audacity, and resourcefulness.' (2007: 41).

In this sense, he claims, that humanist ethics do not differ much from religious ethics. Both support the idea of siblinghood of humankind – each individual has a responsibility to care for other human beings and each individual has equal dignity and value. However, the source for their morality are different ones. For religious individuals, this source is God. For humanists it is the human being that creates its standards of morality (Ibid.: 43). One can question what this really entails? According to Law, there are four features of a humanist moral outlook. The first feature is that humanists emphasize our moral autonomy. A humanist takes a certain moral stance, not because a deity or someone else instructs them to hold this position, but because they choose to maintain this moral view. Second, 'humanists reject moral justifications based on claims of divinely revealed truth' (Law, 2011: 89). Humanists may morally oppose to or accept something, but this is not based on religious prescriptions. Third, according to humanists, morality is related to human flourishing. Our choices should take into account the factors that promote a prosperous life of all human beings on the basis of scientific and other evidence. Fourth, humanists stress the role of reasoning in making moral judgements (Ibid.)

Baggini and Pym express that 'a central tenet of humanist thought is that this world and this life are the only ones we have, and that, in the absence of an after-life and a soul, death brings a natural end to our existence.' (2005: 1235) They define a humanist as a morally concerned, unreligious person, but acknowledge the fact that humanists come in various shapes and sizes:

'from atheists, who regard God as a human creation, to agnostics who might merely assert that although they can neither prove nor disprove God's existence, it is of no practical concern to them. But all humanists tend to share a scepticism toward, and a rejection of, traditional religion and religious ritual, and a positive commitment to living a morally responsible life.' (Ibid.)

They assert that morality can function independently from religious faith. In contrast to claims that without God there is no requirement for an individual to embrace any moral code, the moral life is desirable in itself

and that it is up to people to identify moral principles, instead of abiding by a set of God-given moral rules. Relating this to the field of palliative care, they, paradoxically, state that it may be difficult for a humanist to pinpoint his own needs in the face of death, since he may lack a set of prescriptive rules that dictates how he should approach death, how the body should be disposed and the rituals that should be performed.

#### **Bourdieu and habitus**

Pierre Bourdieu has written extensively on the mechanisms that govern human behaviour<sup>9</sup>. His theories deal, among others, with the question of what may be factors that unite individuals and which factors influence and stimulate human behaviour. Bourdieus theories are of interest for this thesis, since they may offer an explanation for the composition of the group of volunteers within Hospice Veerhuis. One of his key concepts is habitus. Bourdieu defines habitus as follows:

'The habitus is a mental filter that structures an individual's perceptions, experiences, and practices such that the world takes on a taken-for-granted, common sense appearance. (...) As an acquired system of generative schemes, the habitus makes possible the free production of all the thoughts, perceptions and actions inherent in the condition of its production' (Appelrouth & Edles, 2008: 686).

The habitus enables an individual to construct interpretive schemes and thoughts through which he is able to interpret and structure the world around him – his actions and those of others - to such an extent that it makes sense. The habitus does not only structure one's mind, but also influences one's body, 'by moulding one's 'natural propensity' for a wide range of movements including posture, gait and agility' (Ibid.: 687). For the formulation of his theory on habitus, Bourdieu has drawn from Husserl's phenomenological philosophy, which puts emphasis on the active construction of social life as a way to go through everyday life. Bourdieu, however, states that an individual does not construct his dispositions, but instead acquires them and it is, thus, an 'internalization of externality' (Ibid.). The externality that shapes the habitus is dependent upon the place you occupy within a certain social space and this space is structured by two types of capital: economic and cultural capital. Economic capital are the material resources, such as money and goods, one possesses. Cultural capital refers to non-material goods, such as education, knowledge and verbal skills, that one can use to his benefit to accumulate economic capital. The closer two individuals are when it comes to cultural and economic capital, the more likely it is that they will like each other. Bourdieu emphasizes, however, that this is not because of the similarities between the types and amounts of capital they possess, but rather because of the resemblance of their habitus. Also, the amount of capital one possesses influences his position of power in society. He who has a large amount of capital is able to assert his dominance over others who possess less capital. In addition to cultural and economic capital, Bourdieu uses the concept of social capital - social networks and acquaintances -, which is a means of securing one's position. The fourth type of capital

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<sup>&</sup>lt;sup>9</sup> See for example: Bourdieu, P. (1985), Social Space and the Genesis of Groups.

he defines is symbolic capital – prestige, charisma, honour – which serves as a source of legitimacy and authority (Ibid.: 692 - 3).

Bourdieu contends that it is possible to separate classes by analyzing the space of positions – 'i.e. sets of agents who occupy similar positions and who, being placed in similar conditions and subjected to similar conditionings, have every likelihood of having similar dispositions and interests and therefore of producing similar practices and adopting similar stances' (Bourdieu, 1985 in Appelrouth and Edles, 2008: 701). He adds that these are not actual classes but instead probable classes of which the agents are more likely to be able to mobilize in comparison to another set of agents. However, the mobilization of agents who are not proximate to each other in social space is not impossible:

'Though there is more chance of mobilizing the set of workers than the set composed of workers and bosses, it is possible, in an international crisis, for example, to provoke a grouping on the basis of links of national identity (partly because, by virtue of its specific history, each national social space has its specific structure – e.g. as regards hierarchical distances within the economic field' (Ibid.: 702).

Relating the theory of habitus and social classes to the present research, one could question how volunteers are bound together: is it because of their similar habitus, i.e. do the volunteers have similar amounts of capital by virtue of their education, upbringing, job, etc.? Or is this grouping based on other factors? Vice versa, one could hypothesize that volunteering in the hospice is a way of adding to one's habitus. These questions will be answered in the chapter Research Outcomes.

Actions of agents take place within a field. Bourdieu defines fields as 'autonomous arenas within which actors and institutions mobilize their capital in an effort to capture the stakes – the redistribution of capital – that are specific to it. Examples of fields include art, literature, science, religion, the family, and education' (Appelrouth and Edles, 2008: 694). Continuous battles between the dominant powers and subordinate forces define, shape and alter the field. Subordinate forces may in time become more powerful due to the efforts of its agents. For instance, within the field of arts, subordinate forms of art, such as graffiti, are increasingly being recognized as a proper branch within. Likewise, within health care these struggles are also present. Dominant powers, such as the World Health Organisation, have made efforts to convert the palliative care into a full-fledged part of health care. Palliative care knows a long tradition of subordination, since the emphasis has always been on the curative treatment of patients. The growing number of hospices and palliative units within hospitals and other care facilities, is evidence of its growing acceptation within the field of health care. Hospice Veerhuis is just one of many palliative care facilities that has emerged within this context of growing recognition for palliative care as an important part of health care.

# Chapter 3 - Humanism in the hospice

During my fieldwork in the Veerhuis, it became clear to me that everyone in the Veerhuis was aware of its humanistic principles. Many volunteers stated that the specifically chose this hospice because it did not adhere to any specific religion. All the individuals (volunteers and coordinators) with whom I talked about this issue were capable of telling me what they thought the humanistic principles meant. For them, it meant that everyone, staff as well as residents, was welcome without consideration of one's religion or personal background. The emphasis on personal freedom is, indeed, one of the features of humanism, as I have intended to demonstrate in the theoretical framework of this thesis. It is, however, too simplistic to assume that this hospice is in fact humanistic merely on the basis of statements made by volunteers and coordinators. The aim of this chapter is to verify these claims. I will argue that the humanistic principles can be found not only in the statements of the staff but throughout the entire hospice. I will do this by examining the image that the hospice presents of itself and by exploring the way in which volunteers are selected, while, at the same time, identifying discrepancies between the theory on humanism and the manner in which the hospice deals with its principles.

# **Image**

As is the case for the majority of organisations, the rules and regulations of the hospice are registered in its statutes. Typically, statutes contain information on objectives, prohibitions, rights and duties of all the parties involved with a certain organisation. Moreover, it usually includes statements on the intended purpose of the organisation and the image it wishes to send out to the target group. The statutes of the Veerhuis are very telling. While it contains an abundance of information on issues such as the board of directors and financial aspects, it provides only a single article on the purpose of the hospice and only one subsection on the way in which this goal will be pursued.

#### 'Objective

#### Article 2

1. The goal of this organisation is:

a. to promote the integration of the process of dying and death in daily life. The organisation orients itself towards and endorses the objectives of the Dutch Hospice Movement;

b. to promote that people, who are in the last phase of their life and who – because of a lack of informal caregivers – do not have the opportunity to be cared for in their own home, receive the possibility to die in an environment that resembles the homely environment as much as possible,

and furthermore everything, in its broadest sense, that relates to this goal or can be beneficial to it.

2. The organisation tries to meet this objective by:

a. creating care facilities in so called 'Bijna Thuis Huizen' 10, in which the individual life style will be respected

 $<sup>^{10}</sup>$  'Almost home homes'. By lack of a proper translation in English I have chosen to use the Dutch term.

as much as possible;

- b. by acquiring ownership and/or rent one or more houses and/or medical and care supporting equipment, as well as the maintenance and exploitation of these items;
- c. by cooperating with local volunteer organisations that provide care for terminally ill people;
- d. by recruiting, training and supporting volunteers, with consideration of the guidelines provide by the Dutch Hospice Movement;
- e. by all other legal means that can lead to the proposed objective.' [translated from Dutch]

Other than expressing that this hospice is for those who are in the last months of their lives, it does not offer any information on admission requirements, neither for residents nor for the volunteers. According to one of the coordinators, the absence of a clear description of admission requirements for residents and volunteers is intentional: 'Everyone is welcome, without taking into account one's religion, economic background, etc. This hospice is for the lady, but also for the tramp, from Muslim to Christian, it does not matter.' This attitude of tolerance towards one's personal (non-)religious beliefs is reflected in the neutral appearance of the Veerhuis and the rituals that are being performed. There is a clear absence of decoration that is symbolic for a certain religion or spiritual belief. Residents are, however, free to decorate their rooms with such symbols.

The most salient ritual is the one that is being performed when a resident has passed away. Volunteers, if necessary, accompanied by a professional nurse, make sure that the deceased and his room look presentable. Candles are lit and, in the absence of family members, volunteers will sometimes sit with the resident. When the resident is being picked up to go home or to the funeral parlour, a handmade plaid is put on top of him and the volunteers that are present will walk behind the deceased with a candle. The room of the resident will not be prepared for a new resident for a short period of time. His belongings stay in the room, a candle will be lit and the family of the deceased are free to spend time there. This ritual is, however, open to interpretation. Some volunteers state that the fact that the room is being kept in its 'original state' for a little while – the state of the room at the time the resident passed away – is a way of showing respect to the resident and his loved ones. One of the volunteers who was raised in a protestant home but was no longer practicing any religion, says the following about this ritual:

*Me*: 'You believe in the present and say that for you there is no afterlife. But when someone passes away and this person is picked up by the people from the funeral parlour, we carry candles. It seems like a ritual. And if you do not believe in an afterlife, would this not be superfluous?'

Marja: 'I do have something to say about that. In this hospice, it goes as far as... Candles and stuff like that creates a certain atmosphere. Leaving candles for a deceased person, that is what I did when my husband passed away. Well no, I did not, because he did not like candles, but something like music. What I always find very special is that they leave the room intact. Of course, this has to be done for the family. But saying the spirit has to leave the room, I do not believe that. But I think it is beautiful. I have heard someone say that the felt that the resident was still there. But I think it is wonderful if it happens and I always tell the family that we leave the room intact. And that the soul has to leave the room and I think that is beautiful.'

Others say that they can still feel the presence of the resident in the room. Although these kinds of statements may be indicative of religion or spiritual belief, I have never heard a volunteer put a label on this ritual. Another custom in the Veerhuis is the creation of photo albums which contain pictures of the deceased residents and (the text that was on) their funeral card.

#### **Selection procedures**

The establishment of a neutral atmosphere in the Veerhuis is, thus, created in order to make every resident feel at home. 'And this also applies to our volunteers. I think that the profile sketch on our website reflects that', says one of the coordinators. The Veerhuis-website contains a profile for aspiring volunteers. The profile provides a framework of the characteristics of the 'ideal volunteer' and does not describe a concrete person. 'A volunteer', it is stated on the website, 'is someone with her own past, present and future, with her own strengths and weaknesses'. Two features that are considered to be desirable in a volunteer, according to the founders of the Veerhuis, are *sensitivity* and *respect*:

'A volunteer in Hospice Veerhuis is someone who cares for people. She (m/f) has a lot of sensitivity and likes the differences between people. She realizes that everyone is unique, respects the dignity of the individual and is aware of the fact that he has his own life history. She does not define the individual by his disease. She leaves space for the other and is able to refrain from acting. She knows that she does not have to have an answer to everything. She can cope with the fact that she does not know much and has her own shortcomings. She deals flexibly with time and thinking and does not have a casual attitude. Those who establish a relationship with a dying individual and his loved ones, cannot fail in maintaining this relationship.' [translated from Dutch]

In addition to the desirable characteristics of a volunteer, the profile also contains a section on what is unfavourable:

'A volunteer in terminal care knows how to handle her own losses. She has dealt with the loss of loved ones to such an extent that she will not let her own sorrow and problems interfere with those of the terminally ill individual and his family and friends. When a volunteer who is already working for the hospice, loses a loved one, she will inform the coordinator. She will receive extra attention. If necessary, she can decide to quit volunteering temporarily.' [My translation]

In concrete terms, there are some reasons not to accept someone as a volunteer. According to a coordinator, some people are rejected when they seem to have a schedule that is too busy to fit in volunteering in the Veerhuis. The main reason not to accept an aspiring volunteer is when the coordinators sense that someone is 'on a mission'. Thus, the expectation of fulfilling a therapeutic role - i.e. the desire to safeguard the spiritual welfare of the resident – is a reason not to accept an aspiring volunteer. The coordinators have different strategies to uncover the motives of aspiring volunteers:

'First of all, we do an interview and if we think someone is suitable, she enters a trial period in which she accompanies two experienced volunteers during two shifts, sometimes three shifts, if we are not sure yet. After that we evaluate with the new volunteer how we both felt about the way she works. Furthermore, we have focus groups in which a few volunteers periodically come together to discuss their experiences in the Veerhuis. During the first meetings the group is led by a supervisor and after these first few meetings, the volunteers are able to run the meetings themselves. We also stimulate the volunteers to come to hospice meetings. Also, if we notice that someone tries to avoid us, for example, by only working at night or in the weekends, we encourage her to work another shift, so that we can see what she is doing. Moreover, the volunteers actively participate in filtering out the volunteers who are unsuitable for the Veerhuis. Of course, the Veerhuis is a small hospice and if they think someone is not fit to work here, they will tell us.'

Hence, one of the methods to intercept potential volunteers that have motives that do not fit the Veerhuis, is

through job interviews. The individual is asked to why she wants to become a volunteer and what she expects of the work. Furthermore, they ask her what she thinks the tasks of a volunteer are. When she<sup>11</sup> seems fit for the job, they provide her with the opportunity to work two shifts with experienced volunteers. Soon after those shifts, one of the coordinators schedules an evaluation on how the new volunteer (as well as the coordinator) has experienced volunteering in the hospice and it is decided if the volunteer will be accepted to work in the Veerhuis. If this is the case, a contract is signed in which the rights and duties of a volunteer are expounded. The use of a contract may seem to be in contradiction with the notion of volunteering, since one is offering her services to the hospice without receiving any monetary compensation. However, the Veerhuis (and many other voluntary organisations) employs the motto that the work is voluntary but not without obligations. This means that despite the fact that a volunteer is doing the work for free, she cannot come and go as she pleases, because this would result in an unreliable and unstable workforce.

In practice, despite the fact that the majority of the volunteers is female – 37 out of 43 active volunteers are female and only six of them were male at the time I was conducting my research – the group of volunteers is a diverse one. Although most of them are between ages 50 and 65, the youngest is in his late twenties and the oldest in his late seventies. The team consists of those who have a background in health care and those who have jobs that are not (directly) related to health care (such as volunteers who work in legal affairs, the financial business or confection). There are volunteers that have affinity with Zen Buddhism, Tibetan Buddhism, Roman Catholicism, Protestantism. Others do not believe in a deity and some feel no connection to a religion, but do feel they are connected to a higher power, usually referred to as an 'energy' or a 'god'. In the next chapter I will discuss the variety in volunteers in the Veerhuis as a result of this partial adaptation of the humanistic principles.

#### **Conclusion**

The data show that Hospice Veerhuis makes active use of strategies to create a neutral environment in which both residents as well as volunteers feel comfortable. Humanism lies, according to the coordinators, at the root of these strategies. The feature that has been taken from humanism in order to achieve these goals is the freedom of every individual. Firstly, the Veerhuis makes active efforts to portray itself as a hospice that is open to everyone. This is visible in (a) the lack of a description in the statutes of what is required of Veerhuis volunteers; (b) the image that is put forward by the Veerhuis on the website; (c) the absence of any religious symbols in the house; (d) the impartial character of performed rituals. Secondly, volunteers are not selected on the basis of their religious and spiritual beliefs, economic or professional background, age, gender, and so forth. In theory, everyone can apply to become a volunteer in the Veerhuis. However, some individuals are turned down when it becomes clear that one is on a mission to save the residents' souls.

<sup>11</sup> In accordance with the website, I will address the volunteers in general with 'she' and 'her', as the majority of the volunteers is female.

In a similar vein, the Veerhuis does not in any way make statements against religion and/or spirituality, thus emphasizing the impartiality regarding religiosity and the values held by volunteers and residents. The practical outcome of this neutral environment is a highly diverse team of volunteers.

#### Chapter 4 – Case studies

As discussed in the introduction, the aim of this research is to investigate whether the humanistic principles of the Veerhuis result in a diverse team of volunteers. It is, however, impossible to describe the stories of all the volunteers, so I have chosen four volunteers whose stories represent those of a larger group within the hospice. Four volunteer archetypes have emerged from the data: (1) The volunteer that has experience in caring for a terminally ill individual; (2) the volunteer who has an interest in death and dying; (3) the volunteer who wants to do something useful; (4) the volunteer that has other motives, such as adding value to a resume, than those mentioned above. Themes through which I intend to show diversity are (a) motivation to start volunteering, (b) experiences with and ideas on death and dying, (c) lessons they have learnt by working in the Veerhuis regarding death and their interactions with individuals in the palliative phase. However, in order to give the reader some insight into the daily life of the Veerhuis and its volunteers and residents, I will start the chapter with the description of some meaningful scenes.

That death is very unpredictable, was demonstrated by the sudden death of an elderly resident. One of the volunteers helped the resident to use the toilet. The fact that he was still able to go to the toilet himself was telling for his presumed physical state – most residents that only have days or hours left are unable to do so and usually wear a diaper or have a catheter. On their way to the toilet, the volunteer noticed that the resident was slipping out of consciousness and quickly got her colleague to help her. Noticing that he was dying, they put the man on the toilet, as this was the nearest seat. One of the volunteers started singing mantra's and they told him that it was o.k. for him to go. Later on they told me that he looked like an emperor on his throne, looking completely satisfied. The younger one of the two women thanked him that she was allowed to be part of this intimate process. She remembers that it was a very beautiful event and that she was grateful that she was there at that moment. The reactions from other volunteers regarding this event where multiple. Some reactions where neutral, stating that they had heard what had happened and thought it was comforting that this man did not have to suffer a lot as his death was relatively sudden. Others said they thought it was a beautiful way of dying and spoke positively about the way the two volunteers handled the situation. One of the volunteers (a woman who did not consider herself to be religious nor atheist) commented that the colleagues had handled the situation very well, but she did not know what to think of the singing of the mantra's:

'I am a very down-to-earth person and sometimes here those very spiritual people make me feel like 'pfffff'. And it is not that I am non spiritual. (...) But it [spirituality] should be practiced in a pure and clear way. And some people just give me the creeps. I have heard about a volunteer who is a sweet person, that is not the point. She was singing mantra's when someone passed away and she told met that it was so beautiful and she was so happy all day. (...) That drives me insane!'

At the other end of the spectrum was a lady that was suffering from cancer. She was already in the Veerhuis when I started volunteering and I was told that when she came in she was very sick. They did not expect her to live very long. However, as the weeks progressed, she flourished under the positive attention of all the volunteers and her family and friends. This woman relied on a feeding tube which caused a lot of

problems since it was often clogged. After changing the tube several times, the doctors in the hospital decided that she was not going to get a new one because of her life expectancy. This was cause for great dismay among the volunteers. They discussed how it was possible that doctors would just 'pull the plug' on this woman who, within the limits of her disease and life expectancy, had a fairly high quality of life. To everyone's surprise, the woman started eating small amounts of food and she continued to do extremely well. Paradoxically, the positive progress in her physical state also caused her worries. She was concerned that she would live too long and that they would 'throw her out' of the hospice. Moreover, she worried that maybe she was misdiagnosed and that her diagnose was actually someone else's. These worries caused her to sometimes be disheartened. Although these kinds of concerns where considered to be normal and therefore accepted by the volunteers, they sometimes told her kindly but firmly that she should cheer up. They assured her that they would not just send her away as soon as she had passed the three month limit. At the end of my three months of research, they where already discussing alternative options for her, since her situation was still stable. One of the volunteers told me that, against all odds, she moved out of the Veerhuis some time after I had left.

The volunteers do not only have to cope with the needs and mood swings of the residents, but also with those of their next of kin. I remember the son of a Portuguese man who was very concerned for his elderly father. Because of his weak physical state, his father did not eat very much. Every now and then he asked for coffee and cookies and sometimes he had soup. His son would urge the volunteers to make sure his father consumed enough calories, thinking that he would live longer if he would just eat. Various volunteers explained to him that this was not simply the case – that it was not the same as feeding a healthy person who did not feel like eating. He would probably not be able to process the food and start vomiting, weakening him even more. Furthermore, both father and son were very religious. Many times the son would ask me to go to with him to his church. It was really difficult for me to tell him that his requests made me uncomfortable. During one of my shifts he asked me and my colleague again if we wanted to join him. She, very bluntly, responded: 'No thank you, I am catholic and I am sticking with that religion'. This gave me the courage to tell him that his requests made me feel ill-at-ease. My colleague later on told me that it is sometimes necessary to tell people that they make you feel uncomfortable and that there was no harm in doing so.

At the beginning of the fieldwork I felt obliged to feel comfortable with all the residents. I thought it was not an option to feel hesitant to help someone, since they where in this tragic situation where there lives where nearly ending, and often too soon. During the months I noticed that this was a wrong assumption - that it was o.k. to sometimes feel uncomfortable with someone. One of the residents was a woman who suffered from a brain tumor which caused aphasia and paralysis of half of her body. Having always been a very independent and strong woman, her disabilities caused a lot frustrations. She was unable to speak properly and could often not express her needs and feelings. Furthermore, she was dependent upon others to do everything for her. These frustrations resulted in the woman sometimes lashing out to a volunteer or her children. Although most volunteers said that they did not take the anger of the woman personally and that they felt sorry for her, I noticed that some volunteers where hesitant to help her, fearing that they would not

be able to understand the woman. Later on, the woman hired a professional nurse who would take care of her during the day. This took away some of the fears of the volunteers.

Every shift begins with an evaluation of the volunteers with the previous shift. In the case of the early shift (7 a.m. until 11 a.m.) volunteers evaluate with the professionals nurses who have spent the night in the Veerhuis. All important issues are discussed in this evaluation: the physical in mental condition of the residents, any changes in their conditions, chores that where done or still have to be done, activities of the residents – everything that seems of importance. Often, the volunteers of the new shift will greet the residents and check if they are still comfortable. According to the volunteers and the coordinators the hospice functions as any other 'normal' household. Meals are prepared, chores are done, visitors are welcomed and in almost every shift there is time for fun and casual conversation. One shift may be busier than the next one, depending on the number of residents and their needs. Some residents like to leave their door open and to have a talk with the other residents or volunteers. Others like to be alone with the door closed. Volunteers check on the residents every once in a while, ensuring that they have everything they need. Every resident has a beeper to make sure they are able to contact the volunteers whenever they need something. Some residents never ask for anything, others use the beeper so often that it would sometimes impede the volunteers from caring for other residents. Very often, new residents have to become accustomed to using the beeper – they do not want to be a burden on the volunteers and feel uncomfortable asking the volunteers to do things for them. But of course, the volunteers are always happy to help a resident. At the end of the shift the volunteers make notes in the resident files to inform the other volunteers about the important events in their shifts. Afterwards they will evaluate again with the volunteers of the next shift or, in the case of the last shift (from 7 p.m. until 11 p.m.) with the professional nurses (Ende, G.J. van 't, personal logbook).

#### Laura

I met Laura (38 years of age) for the first time when I visited the Veerhuis to talk with the coordinators about my research and my expectations of working in this hospice. I rang the doorbell and Laura opened the door, welcoming me with a big smile. I was a little surprised when I saw her – brightly coloured clothes, seemingly cheerful and, most of all, very young. I expected her to be in her late twenties or early thirties and she instantly made my doubt my assumptions on the characteristics of the average volunteer. Expecting most volunteers to be female, in their fifties or sixties, and having ample experience with death, it was hard for me to imagine that Laura would have anything in common with the other volunteers. I decided I definitely wanted to work with Laura and, even better, interview her to find out more about her. So when the time came to put my name on the schedule, I made sure one of my shifts would be with her. During my first shift with Laura, I was kind of impressed by the way she performed her job – caring for others seemed to come natural to her and, despite the fact that she was much younger than the average volunteer, to me, it felt like she was surrounded by serenity. At the same time, even though many volunteers had already told me that age should not have to be an impediment for becoming a hospice volunteer, Laura was for me the confirmation that this

was really true.

When I emailed the volunteers to invite them for an interview, Laura replied enthusiastically that she was happy to cooperate. During the interview she told me that she was a mother of two daughters, had studied political science and was working in a collective of radio producers. Laura was interested in Buddhism, but that was not her religion, it was more of an interest. The work in the Veerhuis, which she had been doing for two years, had stimulated her to start studying to become a grievance counsellor. Asking Laura what motivated her to become a hospice volunteer, I noticed that she, despite her relatively young age, like many other volunteers, had experience with death:

'Well, to put it very bluntly, because three summers in a row, a few very young people died and I was increasingly touched by death and dying. And I thought, I want to do more with that in my own life, I want to integrate it into my life. I think dead is just so... You know, it is only when you are confronted with it that you start to think: 'Oh, we are all going to die'.'

Wondering how she got to the realization that we are all going to die someday, I asked her if she was kept away from death during her childhood. She answered:

'Well, yes and no. In our family we did talk about dying. My father was a preacher, so he also had to do funerals and I did know what it was about. But in my family, there were some very dramatic deaths. One of them was my aunt, who was a drug addict and when she lived with us, she committed suicide. And that was just so emotionally charged, because her death was surrounded by all kinds of family dramas. They told me that she had taken her own life, but not how. It turned out that she had hung herself on the swing in our backyard, but my parents did not want to tell us, because they were afraid that we would not want to play there anymore, and, in hindsight, I get that, but as a child, you just sense things. I have seen her when she was dead, but for a long time I have thought she jumped in front of a train and burst into a thousand pieces. And as a child, your imagination runs wild. So it is not that I have been kept away from it, but it was not out in the open, because it was just too painful. And also, as a child, I was very afraid of death. That was something totally rational for me. I struggled a lot with the concept of time and I applied this to death: 'Death is forever. Sixty seconds and again sixty seconds and again and again.' And that would just make me go completely mad. And I could not shake that feeling. It was only when my daughters were born that I was able to let these feelings go. Giving life, that is such a different dimension, you cannot imagine that. That is when the fear was totally gone. But before that it had already gotten less, but I kept struggling with the idea of death. I had not been confronted with it very often, but then five years ago a friend of ours passed away. I went with him to the AMC<sup>12</sup> and they told us that he only had about six weeks to live. That was such as bizarre conversation and such a weird situation! I was totally shocked. The doctor was not able to tell him this, as if she was asking him if he wanted sugar and milk in his coffee, that is how he heard he only had six weeks left. The message did not hit us, but the way in which she brought us the news and her intonation made it even harder to understand what she was saying. My husband thought it was horrible, because it was his best friend, and I had come along to be a neutral third party who was there to hear what was being said. But afterwards we were standing outside the AMC and I thought: 'Now what? What should be done?' They had not told us anything. It was kind of a weird vacuum in which we were put. I did not know what to say and our friend was not able to cope with it. (...) And that is when I thought: 'I do want to know what to say. I want to be more capable to handle these situations. What does one do in such a situation? I thought: 'One day I will do something with this'. And when he got really sick, I wondered where you would go if you are this sick, which facilities are there? I did not know anything about hospices. That was something religious...'.

When I asked her if she had been able to completely shed this fear or if this feeling was still lingering, she told me that, a few years ago, she had a near-death-experience<sup>13</sup>:

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<sup>&</sup>lt;sup>12</sup> Amsterdam Medical Center.

<sup>&</sup>lt;sup>13</sup> According to Greyson: 'Some individuals report having unusual experiences that they interpret as spiritual or

'We were in an accident at Oerol<sup>14</sup>. We were with some friends in a boat and that is where another friend of us died. And I almost drowned. When I was lying in the water, I thought: 'Hey, maybe this is it. Maybe this will not end well and then this will be it'. I was not afraid, it was more of a... It is as if everything expands. I do not really know. Everything becomes really pure, but it did not have anything to do with being scared. (...) I thought: 'This is nothing to be afraid of, it really is not'. It is not something we can understand. It has nothing to do with ratio. And that is when I realized that this was not something I had to think of in such as manner'.

After having this close encounter with death, Laura wanted to know more about it and started reading *The Tibetan book of living and dying* by Sogyal Rinpoche, a book based on Tibetan Buddhism, that deals with themes as reincarnation, caring for the dying and spirituality. This book offered her the means to think about death and dying. Laura states that she thinks that death is a natural cycle. Just as when the leafs of a tree fall to the ground and get eaten by worms, she believes that human life does not end when one passes away. She is, however, not sure what will become of our souls after death, but this does not really matter to her:

'You know what I think: who are we? People can be so arrogant, assuming that they can comprehend everything. And I just think we cannot understand these things. I do believe, when you read about all these near-death experiences, that something happens. And I do not really care if this is just a reaction in the brains. (...) I think that the not knowing makes people crave a need to fill in the blanks, to control it, think about what it will be like. But for me, it does not really matter. I just think there will be something else after death. Just like the fact that we do not understand nature, I believe that there is more. We do not understand the universe, what it is like and who we are'.

The fact that Laura was able to overcome her anxiety of death has played a role in becoming a hospice volunteer. She thinks that her near-death experience and, thus, her comfort with death, makes it easier for her to work in the hospice and influences the way she interacts with the residents. Although she realizes that her positive encounter with death and her conviction that dying is not a horrible experience are not necessarily universal truths, she feels that it is an advantage, since it offers her a legitimate basis for talking to frightened residents. She compares this to her experience with knowing what it is like to be in pain and being completely dependent upon others:

'Likewise, after the accident at Oerol, I got a hernia and was in the hospital for two weeks and was in tremendous pain. So when the people here are lying in bed, for example, I know what it is like to be put on a potty. I went through that and it is nice that I have this experience. Of course, everybody is different, so I do not know what it is like for a certain person, but I know what it is like to be in pain and be totally dependent, when morphine does not work... It helps that I can imagine what it is like for a resident. Knowing that some things hurt but have to happen, makes a difference for me'.

At the same time, working at the Veerhuis has taught Laura lessons on dealing with ill loved ones. She illustrated this by telling me about the illness of her brother-in-law and her reaction in comparison to that

religious when they come close to death. These profound experiences, called near-death experiences (NDEs), often include a sense of separation from the physical body, cosmic unity, divine revelation, ineffability, a sense that the experience transcends personal ego, and encounters with religious figures and a mystical or divine presence. Raymond Moody, the psychiatrist who coined the term near-death experience in 1975, defined them as "profound spiritual events that happen, uninvited, to some individuals at the point of death" (2006: 394).

<sup>&</sup>lt;sup>14</sup> A festival at the Dutch island of Terschelling.

of the rest of the family:

'Everyone was in total panic. I really felt like I had gained an experience in working at the Veerhuis. I thought: 'He will not just drop to the ground. There is still a whole trajectory prior to that and this trajectory can be very enriching'. It is not that I was happy that he was going to die, of course not. But the mere negativity that came from the situation – everyone being so dramatic. Of course, it is horrible that he is sick, but there are so many beautiful things that you can gain from it. And everyone dies...'

Laura also felt that she would be more capable to accept the death of a deceased loved one. Through her work as a hospice volunteer, she knows that it is like when people feel miserable and I know how to talk to a doctor about it. 'So, in short', I recapitulated, 'working here offers you the tools to go through the grieving process. You do not push it away, because you say that you would be very sad if someone close to you would pass away, but you can just face it and deal with it'.

#### **Tineke**

Tineke (57 years of age) is the volunteer with whom I worked mostly. At the beginning of my first shift with her, I was a bit intimidated by her assertiveness, since Tineke came across as a person who was capable of saying it like it is. During this shift we talked about the spouse of a resident, who was very much struggling with the pending death of her husband. Tineke expressed that she did not like the way the woman behaved herself when being in the hospice. I remember being surprised that she would be so honest to tell me this, because I held the naïve presumption that in a situation where this woman was in, one was not allowed to judge her behavior and certainly not say anything seemingly negative about her. However, later that evening, I was sitting with Tineke and the woman in the living room and Tineke showed sincere interest in her and talked with her about her husband. This is what I admired about Tineke - even though she seemed really assertive and honest, she was capable of putting her own sentiments aside and just be there for someone in need of care. Later on, Tineke told me that she had lost her husband to cancer and that she had taken care of him while he was ill. All these factors amounted to the way in which Tineke performed her duties as a volunteer: although she had been in a similar situation as some of the residents and their families, she always performed her duties as a volunteer in an assertive, but nurturing manner, without burdening them with her own experiences. Hoping that she was willing to cooperate, I invited her for an interview, to which she agreed.

Tineke is an unemployed mother of one daughter. She was trained to be a nurse, but did not do much with this. Furthermore, she has studied to work with the mentally handicapped, but finally did a study to become executive secretary and has spent most of her life working in this area, until her contract was not prolonged. She does not mind being unemployed, although she enjoyed her job and still had the energy to do it. Tineke was raised in a catholic home and she thinks this will always be a part of her, but she does not practice this religion, nor any other, anymore. At the time of my fieldwork, Tineke had been working in the

Veerhuis for about 1,5 year. At a certain point in her career, she started working one day per week and this made her feel useless. After having read an article about a hospice, she decided that she would like to start working at one. She found the Veerhuis through an online search and it seemed appealing to her right away – not only because it was located in the street where she had lived as a child, but also because the Veerhuis does not require any religious affinity and is not opposed to euthanasia. She states that the choice to start volunteering in a hospice was a very conscious one. She thought that she would be suitable for this kind of a job, because she was not repulsed by the banalities of life. 'Moreover', she states, 'it makes life purposeful: you can make yourself useful and it is a job in which you are appreciated'. Furthermore, death had always interested Tineke:

'I have always been fascinated by death. I always wanted to come very close to death, just to figure it out. (...) I do not know where this fascination comes from. I just know that I have never been afraid of it. Afraid in the sense that some people are scared of dead people. I do remember the first time I saw a dead person, my uncle. I was about 15 or 16 years old. When he had passed away, my sister caressed his cheek. I was standing next to his coffin and I did not think that was scary or anything. But she said: 'Tineke, you can do that too, it is nothing to be afraid of'. And then I realized that it was nothing special. So that kind of helped me.'

Besides her interest in death, Tineke was one of the volunteers who had ample experience with death. Her husband, two brothers and a brother-in-law had passed away. Despite the emotional value of these deaths, impeding her to analyze them rationally, Tineke believes that, in essence, death is a natural part of life and is not connected to spiritual or religious beliefs:

'I think death is the end. I am pretty down-to-earth, as a matter of fact. I do not think there is anything else. Of course, I was raised with the idea of the paradise and when my husband died, I always thought he would be having drinks with my dad. I like that idea and, in a certain way, it comforts me. But it is nothing more than some sort of fantasy. I do not really believe in it. (...) I do believe that people live on, but in the sense that my husband lives on in me and in his children. (...) I made an agreement with my husband that he would let me know if there was anything else – that he would knock on a door or something like that. But I never noticed anything or I am just not open to it. Hahaha!'.

Although death never scared Tineke, the idea of dying had been frightening for her. Working in the Veerhuis has taken away this fear:

'You know what seems like a horrible death to me? Suffocating. But of course, that never happens. You hear a lot people say that they do not want to suffocate. But that is not a realistic fear, because there is no reason that that would happen. That is what I have learnt from working in the hospice: you do not have to suffocate; you do not have to be in pain. You do not have to suffer, that is not necessary at all'.

Another lesson Tineke had learnt from working in the Veerhuis is that 'being there' for someone is not equivalent to 'saying the right things' or to talking in the first place: 'People do not always necessarily need words. Sometimes they just want you to hold their hand or let them cry. You do not always have to say something'. Despite these lessons, volunteering at the Veerhuis is mostly a way of practicing what she already had learnt from her encounters with death:

'I have dealt with my own experiences and I came out of it properly and now I can see them as a kind of

enrichment. I do not wish those things for anyone, but now that I had to face them I have learnt a lot from them and they made me stronger and wiser. (...) The positive thing I have learnt is that I know how to take care of someone without becoming therapeutic, because I am really not therapeutic'.

Me: 'I think it is a big accomplishment that you do not allow yourself to be in a spiral of negativity'.

'Yes, and now that this happened and when you deal with your grief... I feel that I am stronger on the inside from all the hardship I went through. You kind of start to think: 'Bring it on, world! I have been trough so much, bring it on. Try and put me down!' And it is not like I am always strong, but, yes, it also has something to do with a wisdom of life'.

(...)

Me: 'So, what I get from the things you have told me is that the Veerhuis enables you to practice what you already knew. Making use of the experiences...'

"...that I already had".

Me: 'So your experience can translate itself into how you treat people in the Veerhuis'.

'Yes!'.

#### **Jeanette**

I have not worked a lot of shifts together with Jeanette (54 years of age), but the first time I worked with her, she left a big impression. It appeared to me that Jeanette had a presence of self-confidence about her – as if she knew precisely what she was doing and capable of expressing her thoughts clearly for everyone to understand. Moreover, she seemed to be able to be sincerely there for the residents, but, at the same time, keep a professional attitude. That night we talked about Jeanette's ideas on death and dying and I noticed that her ideas were different to those of other volunteers. Jeanette had a deep curiosity for death and the afterlife she felt that she was here to fulfil a mission and that her soul had lived more lives.

Jeanette arranges funerals, teaches in this sector and advises companies. She did not go to school for this, but considers life to be her education. Jeanette was brought up in a protestant home, but does not practice this religion, or any other, although she has occupied herself with Buddhism. She is, however, happy that she was raised this way, because it allows her to move freely in different types of environment. Jeanette has been working at the Veerhuis for eight years:

'At first, I came here to gain some experience, because it looked good on my resume. I came to live in Amsterdam and I had to let go of my job. And when I came here I had a lot less work. So I was looking for structure and I wanted to find that here. But it was also: 'This looks good on my resume in order to find another job'. But I am still working here, so it is definitely a good place for me.'

Me: 'What made you stay?'

'Because this is a four-hour meditation, being mindful, being present. A constant meditation. I think that here... You constantly have to balance. I apply this in my job, when I am working with the next of kin of a deceased person. Constantly checking: what is needed in this situation? To me, that is a very important principle. It is never a given fact. For example, person A is grumpy, person B is happy, so I can walk in happy. But what does that mean and what will I encounter? And that is not excessive, but it has kind of become a second nature.'

Jeanette's perception of death and dying is a fairly unique one in comparison to that of other volunteers. Not only does it interest her, which is the case for many volunteers, but she is also curious to find out what will come after death and the notion of dying does not frighten her at all. Jeanette states that she thinks that we are in this world to fulfil a mission and feels that her soul has lived more lives, but she is unable to put in words why she thinks this. It is, according to her, an 'inner knowing'. Asking her why she is not scared of death, she responded:

'I do not know. I never got that from my mother, but even when I was a child I would say: 'If I could cure a 100 people by dying, then I would die for that'. I do not know why, but that is just me. But what I have felt for a long time, the spiritual side in me, and that is my struggle here on earth: what in am I doing here? At times I find it tiresome and tough and I feel like I do not want to be here. It is not that I want to die, because that would not be a solution for me and that is not even the issue. It is not that I am done with life. And if I would get cancer tomorrow, I would not be happy. I do not know if I would continue treatment as long as some people do, but... It has taken a long time before I was really incarnated. For a long time I have seen myself walking next to me and I have felt a second Jeanette who stood inside my head with just her legs. And at a certain moment, when I was about thirty years old, I descended, and I noticed that, finally I was here and I could not do anything else than just be here. Apparently I have to leave 'that' place, like many other people. But it seems like there is a continuous struggle that I know where I come from and that I really want to be there. And I know I should be on earth to develop myself, but sometimes it is so goddamn tough, something like that. And I do not know what the basis all of this is, but it is my conviction. (...) I think that the things I am doing really matter. So I find that of big importance that I follow my mission, why I am on earth, that is important to me. But when I think of having to do this all over again, having to learn to walk, etc., I think: 'Good lord, how tiresome'. It is the usefulness from every individual. As long as you are happy with your choices.'

The way Jeanette thinks about her own death reflects the way she feels about the death of others and, for me, explains the way she cared for the residents – combining her professionalism with sincere attention for the resident. At the same time, she admits that the death of a loved one would hurt her, but not because of death in itself, but of the way it affects her life and that of other people she cares for:

'It never bothers me when a resident passes away. There are also volunteers who say: 'I am so glad that they let me know before my shift to tell me that a resident has died, because I was really shocked'. I always think: 'This was your path. This was the path you had to take and it is good the way it is.'

Me: 'Is it right if I say that maybe the fact that there are people who are left behind, bothers you more?'

'Sure, but in my work, I only deal with the family of the deceased, so it is easy for me to not let it bother me. Also because I know that I can not change the situation. The only thing I can do is make sure they have a nice funeral. But after all of that: you have to deal with your own grief. I can give a bit of my love, but that is so.. (...) I can not really help with that.'

She does not, however, deny that her religious upbringing may be of influence on the way she perceives the notion of the afterlife:

'I am convinced that there is a life after death and I do not care what it is like. It is of a grandeur that we as humans can not comprehend. After this we will go on. It is some sort of inner knowing or a conviction, ever since I can remember. Maybe that was fueled by Christianity, but it has always been there. It used to be in the form of a human being, like a Santa Claus who gives and controls. But it is not like that anymore. I can not explain it in human words. It just know it is like that.'

Jeanette thinks that her ideas on dying are of influence on the way she deals with the residents of the

Veerhuis. Because death is such a normal aspect of life, she feels she is capable of addressing it in a realistic way without turning to pity:

'I think it is my gift that I can talk about it very casually. I do not care if people are very spiritual or not. I think it is important to keep death integrated in life. And that results in the fact that sometimes I have small, but interesting conversations with people. Mostly in passing. I am not going to sit down and say: 'Well, what is dying like for you?' In my opinion, you should let yourself be guided by what the other wants to say about it. So I am always happy when two out of fifty volunteers have a deeper relationship with a resident. (...) And you should be careful not to overdo the care giving. (...) But I think I have learnt to refine that in the Veerhuis, because I am also capable of overdoing it'.

#### Jaap

Jaap (67 years of age) was the first volunteer with whom I worked in Hospice Veerhuis. Right from the start I felt comfortable with this man who had been working at the hospice for about eight years. The things that struck me most about Jaap were his kindness, positive attitude and ability and desire to provide a warm and welcoming environment for everyone in the hospice - not just for the residents, but also for their visitors and his colleagues. The first day at the Veerhuis, I was a bit nervous – not knowing what to expect, worrying about whether the volunteers would accept my presence and if they would be willing to participate in my research –, but after talking with Jaap for a few minutes my nerves started to calm down. He showed me around the house, informed me of the volunteers' tasks and encouraged me to start doing some of the chores myself. It was clear that Jaap enjoyed creating a homely atmosphere for the residents and their guests. Putting an abundance of cookies on a tray next to the coffee he made for a resident and a family member, he said: 'I always like to do a little bit extra'. At the end of the shift, satisfied that I enjoyed volunteering at the hospice, I gathered up my courage and asked Jaap if he was willing to let me interview him for my research. Modestly he responded that he was prepared to do so, but that he doubted if he would be a suitable candidate, since he did not always know how to put his thoughts and feelings into words. But a few weeks later we made an appointment and I visited him at his house in Amsterdam some two months later.

Jaap told me that after a successful career in the confection industry, he was now enjoying his retirement, filling his time with volunteering. Besides being a volunteer in the Veerhuis, he was also a part of a team that committed itself to raising funds for the hospice and worked for other volunteering organisations. Jaap told me that he was raised in a catholic home, but is also interested in Zen Buddhism. Although he does not like the label, he stated that he is a religious man, but specified that he does not commit himself to a certain religion. He tries to look as much as possible to someone's heart and eyes. According to Jaap, meditating is a way of constantly coming in contact with yourself.

Jaap started volunteering because he wanted to do something that mattered. In a Zen-magazine he read an article about a volunteer from the Veerhuis:

about life and death. A young guy, whom I did not know, worked as a volunteer in Hospice Veerhuis and he thought that it was really worth his while. I called the editorial staff for his phone number and I got in contact with this really nice 29-year-old man who was working in the ICT-business en had a girlfriend. I thought: 'If he can do this with all his activities, and still have time for the Veerhuis, well...'. And then he said: 'The only thing I can tell you is that you should not be grossed out by poop and pee'. And I said I did not know if that would be the case. So I went there, still keeping my options open, because it was an entirely different world, of course. It was proposed that I would just try it two times to see if I would like it. And that is how I got into it'.

Jaap has accepted death as a part of life. Life and death are important aspects of Buddhism and Jaap expressed that he has a curiosity for death, but does not know what will await him in the afterlife. For him, it is important to live, because one can never know when life will end. His idea of dying, however, entails ambiguity:

'When we are talking in terms of 'frightening'... you do not always know a whole lot of ways to die. And the people who pass away peacefully, that is a soothing idea. But on the other hand, you come to know many other ways and that does not make you more comfortable.'

Jaap, like other volunteers, has had his share of confrontations with death. In a short period of time, many of his friends have passed away. Besides the influence of Buddhism, this has also contributed to the way he thinks about death. The death of friends that where younger than him, made him realize that this could also happen to him: 'So when something bothers me, I tell myself: 'Get over it, you have a good life and enjoy it as much as you can'.'

Jaap said that 'just being there', was for him the most important aspect of volunteering in the Veerhuis:

"Being there' is for me the most important thing. And whether you will get a conversation out of it, that would be an extra, but it is very clear that you should not assume that you will have a talk with someone and that that is what you do all the time. There are certain shifts – early in the morning and late in the evening – in which it is more likely to happen, because during the day there are friends and family. I have had the most beautiful conversations when I was very clumsy with their medicines. I did that on purpose, but we would have had to check the book. And it is dark or there is only a little bit of light and that is when the conversations start. But I think you should not assume it. Those are rare moments. Some colleagues are very capable of starting a conversation and will enter a room with the intention of having a chat. But I choose not to have an active role. I will let the resident start the conversation and you can feel it when it happens."

I responded that it seemed to me that the way Jaap thought about death – an attitude that was characterized by an openness to all possibilities and influenced by spirituality and religion – was reflected in his way of performing his job in the Veerhuis – maintaining a patient and awaiting posture and letting the resident decide the nature of the interaction. Jaap agreed:

'Yes, they are all so very different. Look, why is it, that the moment you start your shift in the Veerhuis, your heart knows no limits, because whatever this terminally ill person asks you, however rude it may be, it is just built in: imagine that it was you lying in that bed. I would probably give you hell. And that does not happen very often, but I can imagine. But I have never experienced any boundaries. And I also had some beautiful experiences. That someone wanted me to come back and this guy would stick out his hand and apologize. Not that I wanted him to. (...) But that is the thing that fascinates me about this place: your heart knows no boundaries when it comes to the residents and their family, but especially the residents. But that feeling is gone as soon as you are getting on your bike and get into traffic.'

Me: 'But I think that is a good thing. You go there with a certain attitude, one that is not constant, because most of the time you get irritated by people or simply do not put up with their behaviour. And in the Veerhuis you can let go of that and really understand that someone is angry or frustrated.'

'Yes, and it is the beautiful side of you as a person if you are able to do that. And you would like to not let go of that side. You can see that in babies and children as well. But as soon as they get spoilt, it will go the wrong way. But we call that the Buddha nature or the divine nature, retaining that attitude as much as possible. And there are those people who are actually able to do that. And that fascinates me, also among colleagues.'

Working at the Veerhuis has not made the loss of friends and family in his personal life easier: 'It is expected of you, but it keeps hurting, it does not ease the pain. (...) In Buddhism they say you have to embrace the pain. And that is what I try to do, to not push it away. In other words: that is not even possible. You learn that life is so evanescent.' For me, it became clear that Jaaps' thoughts about death where mostly a product of his own life:

'Well yes, because, you know, in the Veerhuis you do not really get a chance because you are there for 'only' two times per week. And that is enough, if you manage. But in the next shift, you are required to focus on the new resident. Of course, there are some people you do miss (...) but those are exceptions. I think it is a good thing to miss people, because otherwise these friendships would have been very shallow. (...) But that hardly ever happens to me in the Veerhuis, because there is a new resident with his family.'

Me: 'But do you think that the Veerhuis has some sort of impact on your life?'

'Well, the idea that.. God, I am doing something useful. I that is what you notice: you start this job with the intent to give, but in reality, all you do is receive. It does not feel like you are giving.'

#### Conclusion

As I have mentioned at the beginning of this chapter, the data shows that there are roughly four types of volunteers: (1) The volunteer that has experience in caring for a terminally ill individual; (2) the volunteer who has an interest in death and dying; (3) the volunteer who wants to do something useful; (4) the volunteer that has other motives, such as adding value to a resume, than those mentioned above.

Tineke is an example of the first type of volunteer. Volunteers in this category have direct experience with caring for someone who had limited time left. Being responsible for the care that is provided to such an individual may be an influential factor in becoming a hospice volunteer.

Laura is someone who fits in the second category. Interest in death and dying can be caused or influenced by several factors. There are those volunteers that mention that religious and/or spiritual beliefs are at the root of their interest, since this is a salient feature of many religions. The position that death has within the family structure also seems to be influential. Some volunteers mention that they have been kept away from death during their childhood and later in their life made efforts to integrate it into their daily life. This often happened under the influence of the death of a loved one. Other volunteers grew up in a family where death was treated as a natural part of life and this has fostered their interest. A few volunteers have mentioned that an interest in death has always been present in their lives and are unable to pinpoint why they

have this curiosity, just as some people have an interest in cars, cultures, music, and the like. There are, thus, several sources for an interest in death, such as religion, upbringing or 'just' being interested in death.

Jaap is the embodiment of the third category. In this category are the volunteers that express that they wanted to do something useful. Although many of them say they specifically elected a hospice and not any other volunteer job, it is often difficult to pin down the reason why they chose this type of facility. A much heard response was: 'I read an article about a hospice and it just seemed attractive.'

The fourth category is represented by Jeanette. Despite the fact that working at the Veerhuis gives her a sense of fulfilment, she has stated that initially she started volunteering to give her resume a boost. Other motivations that fall into this category are that it entails aspects of their (former) paid jobs that they enjoyed, such as working in a team, or that it counterbalances the undesirable features of a paid job. Those who have worked as professional nurses mention that in the Veerhuis they can perform their jobs the way they would have liked it to be in their paid job.

Of course, these categories are not mutually exclusive – the research has revealed that every volunteer has had an intimate encounter with death, mostly through the loss of a friend or family member. Moreover, a fair part of the volunteers mention at a certain moment that the feeling of being useful is a stimulus for becoming a volunteer and/or for continuing to volunteer. However, the categories have been constructed on the basis of what the volunteers themselves mention as the main motivator to become a Veerhuis volunteer.

The ideas of the volunteers on death and dying are diverse. A large part of the volunteers believes that death is the end. For them, the life that we are living at this present time is the only life we have. As is the case with Tineke, some, however, argue that we will live on, but that it is in the minds of the people that are left behind when we have passed away. The majority of the volunteers states that they believe that this is not the only life we live and that there is some type of an afterlife. This may be in the form that is promoted by many religions or in the sense that, as Laura states, we are part of the natural cycle of life and death. Another possibility is that we live on as spirits. In practical terms, volunteers are usually not afraid of death, but the process of dying can be frightening. Issues like whether it is painful and what it is like to die can cause feelings of anxiety. None of the volunteers, including those who consider themselves to be religious, are opposed to euthanasia. The fact that the Veerhuis allows this, is often taken into consideration to opt for this specific hospice. Despite the fact that nobody opposes to euthanasia, some people declare that they have some difficulties with this way of ending a life, in the sense that they wonder if it is the right thing to do.

When it comes to the lessons that volunteers have learnt in the Veerhuis, the volunteers can be divided in two groups. The first group mentions that the Veerhuis is a place in which they practice what they already knew about caring for a terminally ill person. The second group consists of volunteers that express they have learnt from working at the Veerhuis. Most, like Jaap, state that they have learnt to just 'be there', which means that it is not always necessary to say the right thing or say anything at all. Moreover, as Tineke mentions, part of the volunteers have learnt that the process of dying does not have to be a horrible experience and the last phase of one's life can positively influence relationships.

### Chapter 5 – Research outcomes

In this chapter I will discuss the outcomes of my research linking them to the theories that have been discussed in the theoretical framework. Furthermore, I will answer the hypotheses on the basis of the results of the research.

### Where humanism meets the hospice

In humanism the emphasis is on human freedom. Individuals are free to create there own principles of morality. According to Sartre (1996), man exists through the goals he sets for himself. Anthropocentric humanism takes a critical stance towards religion. This does not necessarily mean that humanists think god (or any kind of deity) does not exist, but that his existence does not really matter, since the only one who can save man is man itself. Kurtz (2007) exerts that humanist ethics do not differ from religious ethics in the sense that both emphasize the responsibility of individuals to care for others.

Hospice Veerhuis has been founded on humanistic principles, but one could question to what extent. According to coordinators and volunteers, human freedom is an important feature for the functioning of the Veerhuis. This is visible in several ways. First, the neutral appearance – i.e. the absence of religious symbols – of the house permits both volunteers as well as residents, to live by their own (non-) religious and spiritual rules. Secondly, volunteers are not recruited on the basis of their beliefs. Thirdly, residents are free to practice their faith if they wish to do so. In short, everybody is welcome in the Veerhuis. Clearly, the Veerhuis does not have a critical attitude towards religion and spirituality. The result of the humanistic principles in the Veerhuis is, thus, tolerance.

So if the aim of the Veerhuis is to welcome every individual without consideration of their religion and spirituality, then why apply the humanistic principles? In other words, what is the purpose of putting the label of humanism on the Veerhuis? In this hospice, the humanistic principles serve as a standard in critical situations. In situations where differences in beliefs may become problematic, humanism serves as a central reference point. This is, for example, why individuals that are on a mission to convert residents are not allowed to volunteer in the hospice. Here, humanism comes in to play: forcing religious beliefs on other individuals is an impediment to one's freedom and the right to set one's own principles of morality. In practice, critical situations hardly ever occur.

#### **Bourdieu and the volunteers**

Bourdieu (1985) offers a framework to interpret and explain social relations. According to him, individuals are often bound together by virtue of their similar habitus, which is made up by different types of capital.

One could question where the Veerhuis and its volunteers fit in to this theory and what are the forces that reign their unification – i.e., how it is possible that these volunteers are able to work together in this environment. First of all, the volunteers are not related to one another because of their similar habitus, since volunteers are not selected on grounds of economic background, education, taste, religious beliefs, and so forth. Moreover, volunteers are selected by coordinators, and, thus, do not in the first place commit to a group of people, but to a set of activities. However, as Bourdieu states, in certain circumstances, for instance during a national crisis, individuals are bound together by other factors than a shared habitus. This may also be the case within the hospice. Volunteers find common grounds through their motivation to volunteer in this care facility and this motivation is likely to be stimulated by experiences with and/or interest in practices relating to death. The hospice, vice versa, plays an active role in adding to the habitus – mostly to their cultural capital - of the volunteers, by means of contributing to their knowledge and experience. This is exemplified by the cases of volunteers Jeanette and Laura. Jeanette explicitly mentions that in the first case, she started volunteering in order to boost her resume. Laura, on the other hand, has indicated that the Veerhuis has stimulated her to start a study to become a grievance counsellor.

## **Hypotheses**

Hypothesis 1

Everyone can become a volunteer in Hospice Veerhuis.

In theory, this is true. Everyone who aspires to become a volunteer in Hospice Veerhuis, can apply for a job. Nobody will be rejected on the basis of personal background, age, gender, beliefs, etc. This is supported by the lack of a description in the statutes and the neutrality of the volunteer profile on the website of the Veerhuis. In practice, this hypothesis should be rejected. There are some factors that will negatively influence one's possibility of becoming a volunteer, such as having too busy a schedule to fit in any volunteering activities. The most important reason is when someone is trying to fulfil a therapeutic role. It is not accepted that a volunteer will force her beliefs on other volunteers or residents, let alone, that she tries to ensure the spiritual welfare of the residents. Coordinators have strategies to filter out individuals with these intentions, such as submitting them to an interview, a trial period and evaluations. Other volunteers are also likely to report back to the coordinators if they think that someone is volunteering for the wrong reasons. Throughout the three months I have spent in the Veerhuis, many volunteers have emphasized that the expectations of having profound conversations – for example, about the meaning of life and death – and to be of positive influence on the acceptance of one's pending death, are highly unrealistic and undesirable. Volunteers state that most of the time they perform as a host, and, of

course, if a resident wants to talk to a volunteer about these issues, then this is possible, but she should always maintain a reserved attitude in that regard.

### Hypothesis 2

Religion and upbringing play an important role in the motivation to become a hospice volunteer.

The second hypothesis can be rejected. Not a single volunteer that I have interviewed gave upbringing and religion as an explicit reason to become a hospice volunteer. In the case of upbringing, it cannot be denied, however, that this may have played an implicit role. When I asked them to tell me more about their ideas on death and how they think they were formed, a fair part of the volunteers made statements about experiences with death in their childhood or adolescence. These experiences range from the loss of family members to parents' attitudes towards death. Part of the volunteers expressed that they grew up in an environment where death was a taboo, which, in some cases led to a fear and/or ignoring of death. Later in life, these volunteers went through an experience altered their view on death. Laura's case is an example of this. Although death was not a taboo in her family, her parents tried to cover up some aspects of it that they considered to possibly be shocking for a child. Her fear of death was also stimulated by the conception of time and one's incapability of comprehending death. At the other end of the spectrum are those volunteers that grew up in a family in which there was an openness towards death, resulting in the integration of death into daily life.

When it comes to religion, none of the volunteers has made statements regarding the impact of their religiosity on their motivation to become a hospice volunteer. Despite the fact that a vast part of the volunteers have a clear image concerning their religious and spiritual beliefs, none of them has mentioned their religiosity as a motivation to become a volunteer. Nevertheless, religion and spirituality are of influence in some way or another on their ideas on death, for example on the way they view death, the manner in which they cope with the passing away of others, their judgement on issues like euthanasia, etc. The four volunteers that have been the subjects of the case studies acknowledge that religion - either the one that they have an interest in at the present time or the one that was central in their upbringing – may in some way have affected their perception of death.

#### Hypothesis 3

Volunteers are likely to have (had) direct experiences with death and dying.

This hypothesis is true for all the volunteers I have interviewed and can, thus, be accepted. The case studies demonstrate the different types of experiences volunteers may have had with death and dying. Part of the volunteers has cared for a dying loved one, as is the case of Tineke, whose husband and other family members have passed away. Especially in the case of her husband, Tineke was actively involved in the provision of care. Laura's case is fairly unique. Besides the fact that people have passed away to whom she was very close, Laura herself has had a near-death experience, which made her realize that death and dying are not to be feared. Jeanette is an example of someone who has been in contact with death because of her work in the funeral business.

#### Hypothesis 4

Volunteers are comfortable with death (their own, but also death of others).

This was another expectation I had when entering the field. It did not seem likely to me that someone who was fearful of death, would volunteer in an environment where death is always near. I should emphasize that being comfortable with death does not mean that one is insensitive to it, but rather that one can handle it to such an extent that he is still able to function within the limits of the situation. In general, this hypothesis has proven to be true. Volunteers state that they are comfortable with death in a practical sense as well as on a mental and spiritual level. With practical I refer to all the activities that involve caring for a terminally ill or a deceased individual. The mental and spiritual level refers to if one has, in any way, accepted death and is at ease with the passing away of others. The volunteers have a fairly clear image of their views on death and the afterlife. Those who have unclear ideas about death indicate that this does not bother them, since no one can really know what is waiting for them on the other side. They express that they usually are capable of dealing with the death of a resident. Those who have experienced the death of a loved one, where, despite their grief, able to deal with this and could talk about this without becoming very emotional. However, there are some aspects to death that may provoke feelings of anxiety or insecurity. Some volunteers state that the manner of dying is something which, at times, troubles them. Questions about how it would be to die, if it is painful or pleasurable, etc., are of importance.

#### Hypothesis 5

Being a volunteer in Hospice Veerhuis has changed the attitude of volunteers regarding death and dying.

This hypothesis is true to a large extent. Asking the volunteers whether or not they felt that volunteering at the Veerhuis had taught them something or changed their views on death and dying, many responded that this was indeed the case. The two prevailing responses were that (1) they had learnt that death was nothing to be afraid of and (2) that it made them more capable of dealing with a terminally ill individual. In the fourth hypothesis I have already mentioned that many volunteers are comfortable with death and dying. It is true that for a large part of the volunteers, this was already the case before joining the Veerhuis. There were, however, volunteers who indicated that the manner of dying may be troubling them. As is the case with Tineke, some volunteers mention that they have noticed that dying does not have to be a painful or frightening process. The possibilities of, for example, pain relief medication, euthanasia or palliative sedation, caused a change in the attitude of some volunteers. Also, volunteers indicate that they have witnessed that the last phase of life can be a very meaningful period. They mention that the life of the residents is often very pure – i.e. the relationship with friends and family becomes more intimate and the masks that one usually puts on in daily life are dropped. There is room for both negative as well as positive emotions. One can be happy, but also sad or angry, without being judged for it.

There are also those volunteers who stated that they are more able to deal with a dying individual. Surprisingly, only a small part of the volunteers refers to practical skills, such as washing, clothing, feeding, etc. The majority expressed that, at the beginning of their career as a volunteer, they often felt the need to talk to the residents or say the right things. Volunteering at the Veerhuis has taught them that many times it is enough to just be there or hold someone's hand.

There are also volunteers who stated that their attitude towards death and dying has not changed. This is often due to the experience they had gained by caring for a terminally ill loved one. For them, volunteering at the Veerhuis is rather a way of practicing what they already knew from personal experiences. Moreover, although none of the volunteers has mentioned that their spiritual and religious views on death have changed – i.e. how they think about afterlife -, some claim that this job has enabled them to integrate death in life and that it has, thus, become a more realistic part of life.

### **Conclusion**

In this thesis I have researched in which way the humanistic principles of Hospice Veerhuis contribute to the diversity in volunteers. In order to answer this question I have explored the following issues: (a) uncover which aspects of humanism are utilized in the Veerhuis; (b) what the objective of the utilization of these humanistic aspects is; and (c) what the practical result of all this is.

Many anthropocentric humanists have taken a critical stance towards religion. The existence of a god is often not rejected, but his influence on human life has been thoroughly criticized. Sartre (1996) is of the opinion that it is not the question whether or not he exists. It is rather that they assert that humans are responsible for their own set of principles by which they have to abide. This seems to be in contrast with the way in which the Veerhuis views humanism. The acquisition of humanism as a basis for this hospice, may, from a philosophical point of view, imply a critical attitude towards religion. Departing from an anthropocentric form of humanism in which the dignity and freedom of every human being is safeguarded, this means that, indeed, the volunteers and the residents are free to create their own personal principles of morality. It is, however, not the hospice's aim to take a critical stance towards, deny or question the existence or value of any kind of deity. It is rather a method to create a neutral environment in which both religious and non-religious individuals are able to feel comfortable and flourish. Thus, the use of humanistic principles in the Veerhuis guarantee tolerance and diversity.

This view is supported by two general factors. First of all, the neutral image that the Veerhuis manifests of itself. Besides the lack of statements made regarding any religion or spiritual belief in the statutes, the absence of religious symbols and the neutrality of the rituals performed in the Veerhuis, not a single individual, neither coordinator nor volunteer, has made value judgements concerning (non-)religiosity. Thus, the hospice as a collective has never questioned the possible existence of a deity, let alone, if it is humanity itself or a certain religion that provides moral guidelines, since this is of no concern. The Veerhuis respects the personal views of its residents and volunteers. It is, however, not condoned that volunteers force their own beliefs upon residents or their colleagues, which is why the coordinators try to intercept aspiring volunteers that are 'on a mission'. In conflict situations like these, where individuals impose their beliefs on others, humanism serves as a standard. Secondly, this view is supported by statements made by volunteers as to why they have chosen this particular hospice. A much heard answer to the question why they preferred this hospice is that it just felt right and that the diversity among colleagues was appealing. Another inviting feature of the Veerhuis is that there are no impediments regarding religion and spirituality.

Furthermore, Bourdieu's theory on habitus and social groups (1985) is used to explain how it is possible that these volunteers are able to cooperate in this context. I have identified for types of volunteers: (1) The volunteer that has experience in caring for a terminally ill individual; (2) the volunteer who has an interest in death and dying; (3) the volunteer who wants to do something useful; (4) the volunteer that has other motives, such as adding value to a resume, than those mentioned above. It can be concluded that the group of volunteers is diverse because they are not united by their similar habitus, since volunteers are not

selected on the basis of education, religion and social and economic background. Selection on the basis of habitus would have produced a more homogenous group of volunteers. Homogenous in the sense that one would be able to distill a 'typical' volunteer with certain recurring traits when it comes to social and economic background. This, however, is not possible for this group. Bourdieu states that sometimes individuals that seemingly have nothing in common, are bound together. This is the case for the volunteers in the Veerhuis. They are connected by their common motivation to volunteer in this hospice. It is possible to construct archetypes on the basis of the motivation to do this kind of volunteer job and the experiences they have had with death and dying. Vice versa, volunteering in the hospice has added to the habitus of (some of) the volunteers, for example by adding to a resume or stimulating someone to make a career change or start studying.

In conclusion, the Veerhuis' adaptation of the principle of human freedom is what makes it humanistic. By creating a neutral environment in which no value judgements regarding religion are made, it creates a context in which everyone is free to create and live one's own principles of morality. Had the Veerhuis completely adopted the anthropocentric humanistic point of view, it would have not been able to yield such a high variety in volunteers and residents, because a critical attitude towards religion may be a reason not to feel comfortable in this environment, similar to the fact that hospices that have a clear religious signature attract volunteers and resident with the same religious affinity.

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## Appendix A – Methodology

## **Participant observation**

Participant observation is one of the main method used for gathering information in this research. This methods allows the anthropologist to investigate the social life and life experience within a certain group. The anthropologist participates within the group to see and experience how daily activities are being performed. The aim of this method is to understand how the group acts and how they view the world. By participating, the anthropologist will be able to interpret the meaning and consequences of certain behaviours within a specific context (Oeye, Bjelland en Skorpen, 2007: 2299).

Participant observation has provided me with insights in to the daily activities of the volunteers and the other actors within the hospice. It has also enabled me to formulate research questions. Through participant observation I have gathered data on a number of things: (1) the daily chores and routines of the volunteers and the residents; (2) the daily interactions between volunteers, volunteers and residents and their family, volunteers and coordinators and volunteers and professional nurses; (3) discrepancies between what the volunteers say they do and what they actually do; (4) the skills and characteristics a volunteer has to possess to do this work.

Participant observation was not only useful for the formulation of questions and the gathering of information. It was, first of all, the only way to get access to the hospice, as they did not allow any researcher into the house if they would not get any direct benefits in return. Volunteering was a way to show that I was committed, not just to my research, but also to the hospice. Secondly, the aim was to be accepted as a volunteer and have other volunteers open up to me and be willing to engage in intimate conversations and not just see me as an intruder who was 'spying' on them. I realised I had been successful in this when the coordinator and other volunteers told me that they thought it was a pity that I had to leave them already because they felt I had really become part of the group of volunteers.

## **Semi-structured interviews**

During fieldwork I have done semi-structured interviews with 22 volunteers. I have formulated part of the questions before entering the Veerhuis, but the majority were formed during fieldwork. The aim was to gather information about the motivations of the volunteers to become a volunteer in a hospice, their ideas on death and dying and the experiences that contributed to the formation of these ideas. The interview was based on the constructivist perspective, as formulated by Hilleran and DiLuzio (2004: 3). They state that an interview is the product of the interaction between interviewer and interviewee and that, thus, emotions and

the social background of the interviewer play a role, because it can have an influence on the research. I have chosen a semi-structured interview, because of the possibility to let the interviewee speak freely about topics that may not occur in a structured interview but are relevant to the research. On the other hand, the formulation of a few questions provided me with the certainty that themes that were important for this research, were discussed, and gave me the opportunity to steer the interview in a certain direction. This method has yielded data on the volunteers' ideas on death and dying, motivation to do this kind of volunteering and the personal backgrounds of the volunteers.

## Life histories

Part of the interview was to gather information on the life histories of the volunteers. Through these life histories I have assembled information on how the volunteers were raised (this included for example questions regarding religion and the way in which parents handled death-related situations), their private lives (work, family relations, education) and their encounters and experiences with death. The data collected through life histories permit me to discover possible changes concerning ideas on and attitudes towards death.

# Appendix B - Interview

#### Personal background

- Name
- Age
- Gender
- Work
- Beliefs
- Education

#### Motivation

- How long have you been working at the Veerhuis?
- Why did you choose this kind of job?
- Which chores give you the most satisfaction and which ones do you dislike?

### Dying/last phase of life

- How do you think about death and dying?
- What would, for you, be the ideal last phase of life?
- How did you form these ideas on death and dying?
- Would you spend the last period of your life in a hospice? Why?
- How do you experience the death of a resident?
- Did your views on death and dying and the final stage of life change since you started working in the hospice? If so, what changed? And why?
- Do you think that your views on death and dying influence the way you perform your job at the Veerhuis? Why?

#### The emotional value of dying

- Would you do anything different when taking care of a dying person outside the hospice a friend or family member? Why?
- Has it become easier to let go of people? Why? And does this also count for your loved ones?

- Do you think that the Veerhuis has enabled you to cope with grieve? Why?
- Did volunteering at the Veerhuis change or influence your attitude to life? Why?
- Did the Veerhuis have any impact on your standards and values? How?