

It is a Matter of Life and Death:
about the worlds of hospice
volunteers

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Kvalitatiivisen tutkielman tarkoituksena on löytää kuolevien hoitokodissa tapahtuvan vapaaehtoistyön sisin olemus; selvittää sosiologisesti, mistä siinä on kyse. Aihetta lähestytään tarkastelemalla vapaaehtoisten maailmoja; millaisia merkityksiä he antavat tietyille elämään ja kuolemaan liittyville asioille. Vaikka vapaaehtoistyötä kuolevienkin parissa on tehty kautta aikojen, tässä yhteydessä sitä kuitenkin tarkastellaan yhtenä modernin ilmiönä. Työssä selvitetään myös sitä, miten vapaaehtoistyö vaikuttaa minän rakentumiseen. Koska vapaaehtoistyötä kuolevien hoitokodissa ei ole aikaisemmin tutkittu sosiologisesti, tutkielmassa pyritään antamaan kokonaiskuva siitä, mitä siellä tapahtuu: mitä hoitokodissa tehdään? Millainen on vuorovaikutus eri osapuolten välillä? jne.

Pääasiallinen empiirinen aineisto koostuu viidentoista naispuolisen vapaaehtoistyöntekijän teemahaastattelusta. Potilaiden näkökulmaa aiheeseen valottaa kolmen potilaan ryhmähaastatteluaineisto, ja henkilökunnalta on muutama kyselyvastaus. Tutkielmassa on käytetty fenomenologis-heuristista tutkimusotetta, jossa myös kirjoittajan oma ääni ja kokemus saattohoidon vapaaehtoistyöstä tulee esiin.

Vapaaehtoistyöhön hakeutumiseen liittyy usein jokin sisäinen tarve ja elämän käännekohta; läheisen kuolema, työttömyys, lasten lentäminen pesästä jne. Vapaaehtoistyö lahjanvaihtona tarkasteltuna Marcel Maussin mukaan osoittaa, että se ei ole ilmainen lahja vaan osa vastavuoroista lahjanvaihtosysteemiä, jossa on kolme osapuolta: potilaat, vapaaehtoiset ja hoitokoti. Vapaaehtoistyön myötä kuolemasta on monille tullut aiempaa tutumpi ja kesympi. Kuolema saa eri merkityksiä riippuen siitä, kenen kuolema on kysymyksessä, missä kuolema tapahtuu ja miten se tapahtuu. Potilaan kuolemaan on helpompi suhtautua kuin läheisensä kuolemaan. Hoitokoti mielletään paikaksi, jossa on lupa kuolla, eikä kuolema ole erehdys. Hyvässä kuolemassa ihmisen sisäiset asiat ovat tärkeitä: ihminen on hyväksynyt kuolemansa ja järjestänyt suhteensa kuntoon muiden ihmisten ja Jumalan kanssa. Syövän aiheuttaman riisumisen katsotaan olevan sen pahin puoli, mutta samalla se nähdään autenttisuuden tuojana.

Vapaaehtoiset usein kokevat, että he saavat työstä enemmän kuin mitä pystyvät antamaan. Työhön liittyy oleellisesti siitä saatu hyvän olon tunne. Vapaaehtoistyötä kuolevien parissa voidaankin pitää yhtenä modernin hedonismin muotona.

Asiasanat: death. hospice. identity. modern hedonist. volunteer.volunteer work.

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The purpose of this qualitative study is to capture the essence of volunteer work at a hospice. The subject matter is approached by examining the worlds of hospice volunteers; what kind of meanings they give certain matters concerning life and death. Despite its old status, in this context volunteer work with the dying is being examined as one phenomenon of modern world. The study pays attention to the ways volunteer work affects the construction of self. Because of the novelty of the subject matter in sociological research, the study aims at giving an overall picture of what it is that is going on at a hospice.

The main body of the empirical data consists of interviews of fifteen female hospice volunteers. The patients' perspective is illuminated by a group interview of three dying patients, and there are a few questionnaires filled by staff members. The study employs features of phenomenology and heuristics as a methodological background. The self of the researcher is present in the study.

There is often some inner need and rather significant turning point involved in the volunteers' motives for volunteer work. Applying Marcel Mauss's ideas on exchanging gifts revealed that volunteer work with the dying is not a free gift from the volunteers but a part of a system of reciprocity that involves three parties: the patients, the volunteers, and the hospice. By working at the hospice, death becomes tamer and more familiar for the volunteers. Death receives different meanings depending on whose death it is, where it happens, and how it happens. The death of a patient is easier to relate with than that of a close one. The hospice is viewed as a place where one has a permission to die instead of death being a mistake. A good death is one where the inner world of the dying is considered most important: the dying person has accepted his death and has a good relationship with other people and God. Most volunteers think that the worst thing about cancer is that it strips one off, but simultaneously the disease is viewed as one factor to cause authenticity.

The volunteers often feel that they get more from their volunteer work than they are able to give. An essential characteristic of the work is that it brings about a good feeling. Volunteer work with the dying can be regarded as one form of modern hedonism.

Keywords: death. hospice. identity. modern hedonist.
volunteer. volunteer work.

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1. INTRODUCTION

In February 1995 I took part in a course held by the local Cancer Association to become a volunteer for terminally ill cancer patients. At the time being I was planning on doing my final study on a very different kind of topic, but volunteer work took my interest completely. As early as during the course I was filled with dozens of questions. My mind kept wandering as I looked at the other candidates for volunteers and wondered why they were there and what they were searching for. As I got into the "field" I found several intriguing aspects that I wished to take out to be examined. A certain lecture for people involved in dying patients aroused my interest in hospices and the philosophy behind them, and I contacted the oldest Finnish hospice without the cooperation of which my work would not have been done in its present form. I already knew about volunteer work with the dying, and I use my own experiences in this study. With the help of fifteen female volunteers I familiarized myself with the world of hospice. I also had a discussion with some patients and received little written material from members of the staff.

At the time being hospices are gaining popularity, and there is a present trend of adopting some hospice principles at ordinary hospitals, in their terminal wards. Volunteer work, in its turn, has increased significantly in many fields of life in the recent years. Therefore, it should be interesting and useful to take a look at matters of life and death viewed by volunteers. I am not aware of any other sociological study with a similar approach, and thus the choice of topic should be justified. In order to illuminate the ways in which death is being produced Peräkylä (1990) has studied the interaction between dying patients and professionals in health care. I concentrate on people who voluntarily expose themselves to the proximity of death to work with the dying.

Because the world of hospice is rather unknown for most people, I have tried to give an overall picture of what it is that is going on at a hospice. I tried to reach the

essence of volunteer work with the dying by using a phenomenological approach. For example, I clarified the volunteers' motives and attitudes toward work and volunteer work. And more importantly, I took under scrutiny the meanings that the volunteers gave death and matters concerning it. Moreover, I tried to illuminate the effect of volunteer work to the construction of self, and how volunteer work fits modern life.

2. MAPPING THE BACKGROUND

2.1 About hospices and terminal care

In the Middle Ages the monks built safety homes for travellers in the Alps and those homes were called hospices. The word is based on Latin term *hospitium* which stands for hospitality, a guest hut and a shelter. The principle of hospice care is based on the law of hospitality of Greek and Roman traditions; that is sharing friendship, bread and wine. Hospice is not a building but a philosophical view according to which no one has to die frightened and in pain. The situation with a dying patient is met openly and realistically. The Finnish version, terminal care, carries the ideas of hospice care, namely that the dying patient is seen off as far as possible. The care is not technical but involves emotion. The dying patient is tenderly seen off to die alone but not deserted. (Suurla 1986, 154-157.)

There has been a recent tendency to avoid the Finnish term equivalent to terminal care due to its cold and clinical sound. The most acceptable term, directly translated, would be **seeing off -care**. But because it is not a conventional term in English I shall use the concept **terminal care** to avoid confusion.

Terminal care means treatment and care which is given in that stage of an illness in which the prognosis of the patient can no longer be made better with the current knowledge of medicine. The decision of going on to terminal care from active care is made by a doctor with the patient and relatives if possible. Passing on to terminal care does not mean the end of care but enhancing the quality of life and removing the pain. (Hietanen 1986, 81-83.) The training of terminal care in Finland is directed mainly to volunteers who wish to work by helping people, often on the basis of their own experiences (Fried 1988, 34-35).

Finnish terminal care has originated from British hospice movement that has been influenced by Christianity, and it was initiated by Cicely Saunders in 1967. In Finland National Board of Health prepared instructions in the early stage of terminal care, and they emphasize personal compassion and respect for human dignity. Whether the patient is taken care of at home or at hospital, the care-takers should be people that consider it a calling to make the lives of dying people as good and consoling as possible. (Fried 1988, 32-34.) It has been said that terminal care is a modern attempt to face death partly by returning to the old community-like living, partly by developing new forms of institutional care. (Pentikäinen 1990, 228.)

2.2 Volunteers at hospices

Along with hospices a new support group, volunteers, have found their place in seeing off the dying patient and in supporting the relatives. The experiences of the volunteers have been positive and supportive. (Sailo 1992, 11-12.) The objective of the volunteers is to help a suffering human being and to get some content in one's own life. The Finnish volunteer work at hospices stems from the 1980's when training was started in Turku by Cancer Association and the city of Turku, and in Helsinki by a group project of pastoral care center at hospital of the Lutheran Church. (Sailo 1992, 78.)

The volunteers need to be chosen well and to be given proper training to succeed in their task. It is imperative to clarify their expectations because false ones bring disappointment for the volunteer and the patient, and that should be avoided. In helping others it is important to pay attention to one's own ability to endure in which counselling is useful. Various people are suitable for volunteer work: young ones, people in working age, retired people. Their common factor is willingness to help and spend time in favor of other people. According to Sailo

(1992) the volunteers are responsible, well balanced and they have insight into other people's feeling and a good sense of humour. They are no super humans but they have daring and knowledge on how to meet with dying people and their relatives. Many sensitive and creative people seek themselves to taking care of the dying. (Sailo 1992, 75, 79.) In many respects this portrait is analogous to that of the volunteers interviewed for my study: They appeared to be responsible and sensitive people who were often involved in some creative form of art.

In our constantly changing world one tradition, cultural model has remained, namely that we still die in the hands of women. At both homes and hospitals women carry the main responsibility of the immediate care of the dying and the dead. (Utriainen 1994,12.) In addition to mostly female staffs the volunteers are, with only few exceptions, female. One plausible reason for that is offered by Walter (1991, 298) who claims that women, compared to men, seem to be more capable of accepting the failure of rationality that terminal disease represents, and of working with feelings in case of technology failing to cure a deadly illness. That could be one explanation for the assumption that it is somewhat easier for women to deal with death compared to men. Perhaps because of that, the extreme ends of life, birth and death, have remained the natural domains of women despite all the social changes that have taken place in the course of time.

2.3 Becoming acquainted with a hospice

Pirkanmaan Hoitokoti is the first hospice of the Nordic countries for dying patients in Finland. It was started in a new building close to Tampere University Hospital in January 1988. Its activity is supported by a foundation founded by Cancer Association of Pirkanmaa. There are 24 beds of which ten are in single rooms, five in double rooms, and four in a room for four. Most rooms have kitchenettes and an extra bed for relatives who wish to

stay the night. In addition, there are ten guest rooms. A winter garden with a fountain, summer pavillion, sauna and a room with a fireplace offer the patients pleasant moments. (brochure on Pirkanmaa Hoitokoti.)

Most of the patients are cancer patients of all ages. The main idea of the hospice is: "When there is nothing to be done, there is still plenty to do". The treatment emphasizes the value and dignity of life. The patients are encouraged to live a life as normal as possible. They have the right to be heard, to enjoy company, to get treatment, and to get support in getting prepared to die. The hospice provides the patient a friend, a volunteer worker, if it is wished so. The support is expanded to the patients' relatives in order to help them return to their own lives. Every patient has his or her own nurse who has intimate knowledge of the patient and relatives. The whole staff has a broad training and experience, and for them, the death of every patient is an unique experience. (brochure on Pirkanmaan Hoitokoti.)

In June 1996 I drove to Tampere in order to get acquainted with this hospice with the help of the social worker. Never before had I even visited a hospice, and I knew very little of the activity of one. Therefore it was imperative for me to familiarize myself with that environment, and that was a very useful starting point for my study.

I detest the atmosphere of ordinary hospitals and homes for the aged which give me the creeps. So naturally I was somewhat sceptical on my arrival to the hospice which turned out to be unnecessary. To my surprise, I did not arrive at a sinister place with a deathly stench but to a pleasant, home-like place as promised. The hospice is known of its hospitality, and coffee is offered for visitors on arrival. The coffee shop, which is run by volunteers, is in the lounge which seems to be the area where the volunteers are at home. The volunteer workers stand out from the staff by wearing blue coats that have paper name tags attached with safety pins.

Death is not emphasized but neither it is hidden at the hospice. There is a little table in the hallway where a candle is lit whenever a patient has died, and sometimes there is a picture of the deceased as well. It is very common even today that people are taken out of sight to die (to single rooms or even storage rooms or bathrooms) at an ordinary hospital so that fellow patients or visitors would not get upset. At a hospice death is not an accident or a failure of medicine but patients are allowed to die in peace even in rooms with other patients. There is no hurry in transferring the body, and relatives and friends may take their time in saying goodbye to the beloved. That may be continued in the chapel room. In addition to Christian symbols there are seats and a table for the mourners beside the bench in the chapel room. The nurses dress and tie the corpse with the help of relatives or volunteers if they wish to assist them.

I had expected that the volunteer work at the hospice would be mostly being with patients, interaction. But being a patient's friend is only one task among others. This particular hospice has the following groups of volunteers: groups of lounge hostesses, hobby crafts, recreation committee, day center, outing, sauna, practical work, patients' friends, and special duties. Practical work includes for example baking and gardening, but except for being patients' friend all the other groups involve practical work as well. The diversity of groups and tasks influenced my interview questions to which I made additions and specifications. Moreover, it affected my criteria on the choice of volunteers to be interviewed.

2.3 What do the interviews tell us about?

I interviewed 15 volunteers, and afterwards I was bothered about truth and reality concerning my study. Surely I would have liked to find out about the real, genuine feelings and experiences of the volunteers, but that is an infeasible idea. Eventually, I started to agree with Silverman (1993, 96) who believes that interviews do not necessarily illuminate the interviewee's "authentic" experiences but perhaps they simply produce predictable forms of how they think it is appropriate to talk about certain things. For example, in his opinion the authenticity delivered by the media may be produced by culture:

The media aim to deliver us immediate 'personal' experience. Yet what they (we) want is simple repetition of familiar tales. Perhaps this is part of the post-modern condition. Maybe we feel people are at their most authentic when they are, in effect, reproducing a cultural script. (Silverman 1993, 96.)

Silverman calls his point of view realistic. Realism presumes that social constructions are real in a sense that they are reflected in social relations that an individual may not detect. It means that the data of interviews expresses cultural realities that are not distorted or accurate but simply "real". (Silverman 1985, 157.)

According to Alasuutari (1994, 128) it is characteristic for data of interviews that to begin with, the interviewees try to form a general picture of the study; what things are relevant and what the aim of the questions is. In other words, all knowledge is context bound and it is received through our own interpretations. Hammersley and Atkinson (1983, 110-112) claim that not even an informal interviewing method, despite its apparent freedom, can avoid the researcher's influence on how the interviewees

mould their talk in the interview situation. Trying to adjust your speech accordingly was characteristic in my interviews as well: Many volunteers were careful and tentative in their answers. A few volunteers were thinking out loud what I might be after with each question or asked about my motives point-blank during or after the interview.

When examining the "truth" of the data of interviews the externalists believe that interviews can be treated as reports on external reality. For the internalists interviews are context bound narratives that contribute information mainly on the practices of communication and narration. I find sensible Silverman's view in which interviews tell us about both external reality and context bound communication which both could be examined simultaneously without contradiction. (Silverman 1985, 170; Silverman 1993, 106-108.) In my work I do not try to go to the interviewees' minds through the interviews, but I examine what and how they talk about different themes; what kind of meanings they are given. I am chiefly interested in what the interviews contribute on the external reality, the lives of the volunteers, the culture we live in.

2.4 About the theoretical tools used

In this study I employed features of phenomenology and its derivative, namely heuristics. Phenomenology is a philosophical orientation introduced by Edmund Husserl. The phenomenologist is in search for of a pure or reduced object, the essence of a special thing or of a process:

The aim is to determine what an experience means for the persons who are able to provide a comprehensive description of it. From the individual descriptions general or universal meanings are derived, in other words the essences or structures of the experience. (Moustakas 1994, 13.)

The interviewed volunteers provided comprehensive descriptions of the phenomenon of being a volunteer at a hospice. With the help of the interviews I was hopefully able to catch something to illuminate the essence of the phenomenon. Husserl's most basic assumption was that we can only know what we see and experience. According to the phenomenologist there is no objective reality for people but only the knowledge of an experience and its meaning. The view has two implications that have often created confusion. The first implication is that it is important to know how people experience and interpret the world. The other implication is methodological; the assumption that we cannot completely know what the other person experiences unless we experience it ourselves. (Heritage 1984, 38-43; Husserl 1964, 46; Patton 1980, 68-71.)

I do not intend to follow all phenomenological implications slavishly. For example, Husserl insisted on a purely descriptive orientation in approaching experience and understanding human experience holistically, but I try use an analytical approach in addition to a descriptive one (Heritage 1984, 40; Patton 1980, 37). My main employment of the phenomenological perspective is that I am interested in the essence of being a volunteer at a hospice. I hope that my own experience of being a volunteer in the same field helps me understand what the hospice volunteers experience.

To the phenomenological approach I add an heuristic touch; not its every implication. The word heuristic comes from the Greek equivalent meaning to discover or find. Heuristic

inquiry does not focus on casual experiences but intense human experiences. It is derived from phenomenology, and it brings fore the researcher's personal experience and insights. (Patton 1980, 71). The self of the researcher is present in the study in its every stage. In trying to answer or illuminate a question that has been a personal challenge or puzzlement, the researcher gains deeper understanding of the phenomenon along with growing self-awareness and self-understanding. Although the heuristic process is autobiographic of nature, there is also a social significance with virtually every question. (Moustakas 1994, 17.)

Death, and being voluntarily surrounded by it, is hardly a casual topic and therefore suitable for having heuristic influence. The orientation allows the presence of the self of the researcher in the study, and I intend to use my own experience of volunteer work with the dying. By doing so I hope to gain a better self-understanding concerning the subject matter which also carries social significance.

3. THE PRESENT STUDY

3.1 The purpose of this study

Volunteer work with the dying is a rather uncharted phenomenon in a sociological sense. Therefore, it requires research that is pioneering by nature. I have tried to capture the essence of volunteer work by approaching the phenomenon from many different angles.

Firstly, my aim was to give the reader an overall picture of the mundane world of the hospice by answering for example the following questions: Why do the volunteers work at the hospice, and what do they do there? What kind of meanings do they give to their work and how do they experience it? What is the interaction between the different parties like? How do the volunteers react to some issues that are closely related to the world of hospice, such as cancer and euthanasia? Secondly, I was interested in some more sacred elements involved in the volunteer work; matters of death and afterlife, and the meanings that the volunteers give them. Thirdly, one purpose of the study was to view volunteer work as one way of creating and sustaining an identity in a modern world.

3.2 The volunteers as subjects

The hospice has about forty volunteers in paper but only about twenty of them are actively involved. In June 1996 the hospice had sent all the volunteers a questionnaire on whether they wanted to continue, quit, or possibly rest for a while. Furthermore, they were asked to list all the groups they wish to participate in. On grounds of the questionnaire I received a list on people who wanted to be a patient's friend. I wanted to interview those people

because I am interested in the theme of death. All the volunteers do not necessarily need to face questions on death at all if they participate in partical chores such as baking or gardening. In addition, I wanted to interview some of those who wanted to rest for a while to find out what it was that made them tired.

I approached the chosen twenty volunteers with a letter of explanation before I called them and set a date for the interview which I planned to tape. It was a pleasant surprise that they were positive about it, and some of them even called me as soon as they got the letter. In the summer time I reached thirteen people who all agreed to be interviewed in July. Later in the fall I made two more interviews. Originally, I had planned to interview twenty volunteers, but after fifteen of them I got a feeling that it was more than plenty although all the interviews contributed some intriguing material.

All the volunteers interviewed were women. The youngest volunteer was twenty-nine, and the oldest over seventy, but for the most part they were middle-aged. They were a very heterogenous group in terms of education and occupation. All the volunteers were positive and cooperative about the interview. I found them friendly, open, and some them were very talkative. Our conversation often continued after the official interview. Some of the volunteers were somewhat frustrated with some of the questions which they found demanding, and sometimes they contemplated the answers for some time. They were generally interested in my work and supportive about it. One of them even gave me suggestions and ideas for my work, and sent me suitable newspaper articles. Due to the delicate topics the interviews were held behind closed doors in the winter garden at the hospice. One interview was at the volunteer's home, and one at the volunteer's working place in her own time. The

interviews took approximately one hour each with a few exceptions to both directions.

Because the volunteers interviewed were all women, you must keep in mind while reading the findings that they are gender specific. The world of the volunteers, the essence of volunteer work is being captured from the accounts and experiences of female volunteers. It would be interesting to include some men in the study, and to make comparisons between genders. But it is somewhat impossible because there are hardly any male volunteers working at hospices: At Pirkanmaa hospice there were at the time being only two male volunteers. I got hold of the other one but we did not manage to arrange a convenient time for a meeting.

3.3 The data

The fifteen interviews of the hospice volunteers consist the main data of this study. The outcome of the transcription was 123 tightly typed pages with the average of about eight pages per interview. Another part of the data consists of my observations and my own experience of being a volunteer with the dying.

I had planned to interview some patients of the hospice, but bureaucracy hit my plans. Therefore, my intentions boiled down to talking with three patients, one woman and two men. I was allowed to have an informal conversation with a little group, but for some reason no private conversation with only one patient, without a permission from some ethical board. I seized the opportunity because I had no time for a long process that getting a permission would have taken. I understand that the hospice wishes to protect the patients from disturbances that people interested in them might cause, but in doing so the right

to decide for themselves is denied from the patients which is against hospice principles. An awkward situation was created when a friendly patient, aware of my study, volunteered to be interviewed, and I had to tell him that I was not allowed to interview him privately.

The conversation with the three patients was very warm and friendly, but not very informative although it provided some interesting points of view. My questionnaire for the staff about the volunteers was not very successful either; only three nurses returned it. However, even a small number of answers can be a result in itself, and all pieces of information were analyzed.

3.4 Analyzing the data

I transcribed the fifteen interviews as accurately as possible which was a tremendous task. It could have been possible for my purpose to transcribe the interviews partly or even to take notes, but I chose the harder way to be on the safe side.

Naturally, the interviews were held in Finnish. Because I wanted to realize my study coherently in one language, I chose to translate the extracts used. With a *laudatur* degree in English philology I ought to have a sufficient amount of knowledge of linguistic and cultural matters that are needed to make adequately good translations for this purpose. Naturally, texts always lose something of their authenticity in translations, but I hope that I have been able to convey most of the atmosphere of the interview extracts.

The risk of misrepresenting the meaning in the original text and in the translation was partly minimized by

nonstandard punctuation because Finnish and English have different punctuation rules. I used a comma to indicate a short pause, a dash to show an interruption in thought, and other punctuation marks according to intonation. (Yow 1994, 229-230.) In addition, I used the following transcription marks (Heritage 1984; Silverman 1993):

H: The interviewer (haastattelija)
 V: The interviewee (vastaaja)
 [The point at which a current speaker's talk is
 overlapped by another's talk
 = No gap between the lines
 --- Underscoring indicates some form of stress
 WORD Especially loud sounds
 () The transcriber's inability to hear what is said
 (word) Possible hearings
 (()) Contain author's descriptions rather than
 transcription

In my letter to the volunteers I promised that all information is confidential and the interviews are processed in a way in which no one is identified. As Yow (1994, 93) noted, guaranteeing anonymity for the interviewee is highly problematic. In this case it is especially challenging because the particular group of volunteers is small and they all know each other. Therefore, I chose to present the interview extracts without any first names, real or assumed, ages, or professions. In addition, I tried to choose extracts that reveal no identity and to eliminate names, places and other factors from which one can directly draw conclusions on the narrator. In the final text, I used square brackets [] to indicate an elimination in the chosen text extracts. Short extracts, less than four lines, are being placed in the main text.

In analyzing the data my main tools were paper and pencils. The analysis was made crosswise and lengthwise. The extracts of different themes under scrutiny were gathered from every interviewee under the same headline. And I made observations of the interviewees as individuals and their interviews as a whole.

4. MATTERS OF LIFE

4.1 Why do people voluntarily face death?

To begin with, why should we ask why? My dying patient's friends were amazed at why a young person volunteers in terminal care. I found that kind of astonishment totally unnecessary because in my view volunteering in terminal care was as mundane a hobby as, for example, painting porcelain. When you participate in the latter one nobody usually inquires your motives for doing that. However, after some consideration the question is actually worth asking and it deserves scrutiny. Why? Because in so many ways death in our society is something unwanted, unpleasant and hidden. And still, some people seek its vicinity and even seem to like it. Are you getting curious by this apparent perversion? I think I am after all.

The volunteer workers and their motives for the work seem to have one common factor: There has been some rather significant turning point in life involved. Prior to becoming a volunteer worker one third of them had lost a spouse, a parent or a close friend at the very same hospice. In some cases it had involved spending plenty of time at the hospice which therefore became a familiar place. Despite the grief or even despair they felt that the hospice was a good place to die at. I think that it was not only the gratitude they felt towards the hospice that made them volunteer. I believe that the hospice being the concrete site of death has become a somewhat holy place in the eyes of the survivors. Therefore it deserves to be cherished, and it keeps the memory of the deceased alive. By working at the hospice these people feel close to the beloved one and it lessens the pain of letting go. Furthermore, there is probably some guilt or sense of incompleteness involved: By being there for other dying

people you can somehow continue the process of compensating and taking care.

One volunteer worker had her own cancer experience which led her to work at the hospice. The cancer had changed her in a valuable way by creating a some kind of center from which she can work and express herself. That part of her can exist only at the hospice, and that part helps her help others. Moreover, she needs the work for her own well-being.

One major reason for seeking volunteer work was unemployment, retirement, or children leaving home. The people with those reasons found it frustrating with nothing to do and needed something to be occupied with and some place to go to. They are middle aged or older and feel that they have to do something and do not know how to be idle.

Lacking work may cause loneliness but it seems to be a problem even to working people who sought volunteer work to ease it. Most people answered that their social contacts had increased considerably and they had made new friends, mainly among the other volunteers. Few volunteers stated that it can also get lonely if you are not active in some groups or committees, and have only a patient friend whom you visit and then leave the hospice. The patient is bound to die sooner or later, and the feeling of loneliness may grow deeper. A volunteer who wanted to make new friends among patients got disappointed, but eventually she got new friends among other volunteers:

The reality was different from what I had expected because, obviously I hadn't thought it through, I mean this is a house where people don't stay for very long and in that time you don't get to know the patients well.

The false expectations may be even stronger in another setting than that of a hospice: When I took part in a course for volunteers of a Cancer Association and observed the participants, I got the impression that many of them were there to escape loneliness. Apart from some gatherings the volunteer work do not bring company and lasting relationships, and that is the reality that probably many people were to meet with.

Some volunteers said that they just had some kind of inner need; they needed something in their lives and they came to the hospice to find it. The reality may not have been what they expected but they have got some content in life. The general opinion was that they have got more than they have been able to give. A few women had a fateful belief that it was God's guidance or calling that brought them there, and that it was exactly what they needed to grow as human beings.

Two volunteers told that they wanted to learn how to be around dying people; the other mainly out of curiosity, the other because she needed that in her work:

...I wanted to learn to live as a whole, to live and to experience life as a whole in a secure manner so that I had the courage to be close to a human being in every moments, when sick or healthy, in the nearness of death as well as other days. Because it's usually something that we people are scared of, we kind of step back, and at any case I am distressed with a person who is approaching death. I mean what to do and what to say. I wanted to learn that security that I have the strength to be with a person in a secure manner to the last moments. That's what I wanted to learn. And that's what I've really learned here.

This extract illustrates how alienated modern people are in terms of death and dying. To be with dying people seems to be a skill that has to be learned instead of being a natural part of life and human interaction. We all are dying people, but only when the time of death is assumingly close, we run into trouble.

Whatever the reason for becoming a volunteer was, the common factor is that person's own needs seem to come first in priority. No one claimed that the foremost reason was the desire to help dying people. And that is only human; I do not think that purely altruistic deeds are very longlasting due to lack of motivation if you do not get anything in return. I find that an altruistic deed to occur more than once requires that the actor receives at least a good feeling about it. And in that case, can we talk about an altruistic deed any longer?

A specialized nurse of the hospice had some insight on the motivations of some volunteers, and she wrote about it on my free-form questionnaire:

---I find it very important that the volunteers realize the importance of their work and that they commit themselves to it sincerely. That is the case with some, but I feel that some of them have not internalized the essential nature of their work. They rather come and spend some time together, to attend schooling or other pleasant occasions.---I wish that all the volunteers were those people who want to put their minds and souls to it and know why they volunteer at the hospice.

My own motivation for volunteer work among dying people is somewhat similar to the stories I heard at the hospice. Some years ago I was going through some kind of crisis in my life. I started to look back in life and wondered what I had accomplished. And that was nothing much. I had good grades from school, plenty of study weeks from the

university, but all the things, accomplishments I could think of were only for myself. I thought how terrible it would be if died then because I had done nothing good to anybody else. I often wondered how much food I ate, how much garbage and waste water I created, and I felt that I somehow had to earn my excuse for living. But all that was not yet enough motivation for me to do anything about it. There was a time when I desperately wanted something to happen in my life, and I made a deal with God. I promised to become a good person and help people if I got what I wanted in return. And when my wishes came true I was vexed at my promises at a weak moment, and I tried to forget them without success. I am overly conscientious and I was afraid that I got struck by a lightning or something like that. Then there was an article in the newspaper on the need of volunteers in terminal care of cancer patients, and I got a feeling that it was what I had to do. I was not thrilled about the idea at all, and I tried to postpone calling the contact person. But eventually I went to be interviewed, participated in a preparatory course, and later on got my first dying friend whom I visited almost a year.

4.2 Volunteers and protestant attitudes toward work

One theme in the interview was work. I tried to chart their attitudes toward work, their working history etc. in order to illuminate the volunteer work they do and its motives.

The volunteers interviewed represented a broad field of work. Their education varied from no professional training to academic education. Some of them were in professionals in nursing or other kind of care-taking, but some people of different careers preferred care-taking which they could realize at the hospice, as the woman with background in industry:

Well now afterwards when I come to think of it, what, where I've been all my working years in textile industry I mean, I feel that I've been in a wrong field. I always did my work scrupulously, I could never be away and stuff like that but. Now when I think of it it wasn't what I had wanted to do 'cause I had wishes of going, well in the very beginning there was that I wanted to become a nurse but it didn't work out then. Now when I think of it that would have been the right choice because this work feels mine, I had specifically wanted to work with people.

The question of what work is received very different kinds of answers. "For me it ((the definition of work)) is kind of in a state of ferment because it's not what it used to be", concluded a young woman who had finished her university studies and was in a turning point in her life. Generally, the work they did or were doing, paid labour or domestic work, was regarded as work. The common feature being that proper work was not necessarily pleasant although it was an essential part of life. There was no consistency in whether voluntary work at the hospice was work or not; some people said that it was work and some people not, which arose from the differences in the definitions of work. Voluntary work is work in the sense that you must commit yourself to that: "It's also work because you are committed to it. And it's no impulsive activity but it has an objective. It's work." Especially if the volunteer worker had a patient friend of her own, she considered it work. That being the case you must feel responsibility toward the patient whom you cannot let down.

Voluntary work at the hospice was not regarded as work it being meaningful and rewarding to its workers. There was an amazing conformity in the opinion that the voluntary work gives you more than you can give back. However, some volunteers criticized volunteer work of losing its nature, the sense of freedom:

---but it shouldn't follow timetables so strictly that you should come here then and then but it should remain specifically volunteer work. You should be able to come here whenever you wish. And if you really wanna come here it should work out just like that, not that you don't go after all because it's always Wednesday or something when you usually go. Like volunteer work shouldn't be turned into, like real work. Although I understand the staff's point of view that they want to know that there's always somebody here at any times. I understand that but it shouldn't be so strict so that it takes the idea of it away. You can't expect a volunteer to come here every week. Of course it depends on the job. If you are a patient's friend a week may be a long time. But in these practical jobs it should be rather free. You get a better feeling for yourself when you can go whenever you want to.

On the whole, the volunteers' attitudes toward work were very positive. As workers, they seemed to be very diligent and scrupulous, most of them, in my view, almost excessively so. If they regarded their work as hard, it seemed to stem from their painstaking attitude toward it. Some of them had experienced health problems caused by overzealous working. For these people problems had arisen when met with unemployment and volunteer work has been their saviour:

For example, if I hadn't had, if I hadn't thought of this I don't know what I would have done, how I would I have got through because ever since I was a little girl I was used to hard work being from the countryside. We were always taught that first comes labour and only then pleasure and when you are taken it all away at once, it's really hard. But when I came here I realized that hey, things aren't that bad.

A human being needs work, absolutely and it's really important. I became unemployed in early [] from my real job, and I realized how important it is for you to belong to something, go somewhere. I'm lucky to be able to do volunteer work two or three days a week. Of course it's not

my own line of work but it's nice to belong to some group, I find it really important.

In [] I became in a way unemployed because then the project ended that had occupied me for five years. And when I left it unemployed I got a feeling that that, my kids being big and all that I don't know how to be idle because I worked all my life. ((And then she met a friend who worked at the hospice and she joined in))

What is common to all of these people is that they had a need to work, as a volunteer if there was nothing else, and they had no specific urge to work with dying people at a hospice. They just happened to find their way to the hospice that needed volunteers. The general attitude toward work is well expressed by a Christian woman in her sixties when asked of her relation to work:

Well it's very Lutheran and traditional, that work is extremely important and, that through that you create yourself and the picture of yourself. And nowadays I've become even more demanding towards myself. In recent years I've noticed that I get a bad conscious of being overly idle. Luckily that's not the case with my children and people of that age, that they don't think badly of themselves if they are being lazy. But, me and my siblings, it's probably that we've been raised so that work belongs to everyday life.

What is traditional about being a volunteer worker is that there is an apparent Protestant working ethic and Paulinism in the background. Except for one, every volunteer interviewed belonged to a generation that was generally raised to avoid idleness and appreciate hard work. The old attitude toward work included the implication that the value of the human being is defined in terms of his relation to work. People sought acceptance through work, and when lacking work, voluntary work offered the solution in retaining appreciation in the eyes of your own and

others. That kind of general attitude is so deep rooted in Finnish tradition that it does not involve only the aged. I was raised in a similar manner which, however, was not very successful in terms of duration. But when I started doing volunteer work I still suffered from guilt of being lazy and sense of worthlessness. Only recently I have learned to take it easy without feelings of inferiority. In that sense my motives for volunteer work have changed.

Work, and especially volunteer work, seems to contain religious features. Lutheran view of life favourable to God is to perform mundane duties as they are shown to an individual. Therefore they become an individual's calling, the highest content in moral life. (Weber 1980, 57-58.) The volunteer did not always regard their paid labour as their calling which was often the case with the volunteer work at the hospice. In retrospect, many volunteers thought that there had been some superior guidance in their finding the way to the hospice. They had a sense that they needed that work and it helped them grow as human beings. "I just felt that that's where I wanna be. Maybe it was a, I don't know, an old-fashioned word calling, that you are guided somewhere", was one view of celestial interference in life.

According to Jallinoja (1991, 77) a hedonist works hard because he enjoys it, and a traditional person works hard because it is his duty. In my view these two types are combined in most volunteers; they enjoy their volunteer work which acts as a source of self-fulfillment, and they work because they feel that they have to work.

4.3 Work at the hospice

As mentioned before, volunteer work at the hospice includes much more than talking and being with patients. In advance,

many of the volunteers were not aware of what kind of work that was being done by volunteers. Some of them had not even visited a hospice before they volunteered and had no specific expectations. Others assumed that being a volunteer consisted of sitting by the bed of the dying patient and talking, and all kind of practical work often came as a surprise, or the amount of it:

---, we just had a questionnaire on the jobs you'd like to do and I realized that I had spent a lot of time doing those things which I didn't want to do that much in the first place. Being with patients is more like for me, being by their side and helping them where I can.

Most of the volunteers preferred spending time with patients instead of doing household affairs which they got to do enough in their own homes:

I really like being with patients, by their sides. It's really weird because I could have never imagined that when I was young girl, that I would do this kind of work. Or that I would have even gone near to a hospital. That was really awful ((laughter)). Nowadays I enjoy being with patients, to the kitchen I go only if I really have to.

One reason for household work being so unpleasant seems to be that its subjects want to help patients and they do not see clearly that work's connection with patients. For some, gardening, baking or indirect chores of that kind can be boring and unrewarding because it is not obvious at that moment how a tidy garden with flowers or freshly baked buns can bring joy to patients. One volunteer herself made the same analysis of the reasons why practical work feels hard:

Sometimes it's that you don't have any contact with the patients, that there isn't (), that it's something so indirect. Although I know that

it's important to do those things. But I get thanks afterwards. But sometimes it's hard at those moments when you don't see the connection.

The volunteers who protested against practical work participated in it regularly despite their preferences. They seem to feel responsible for the things to be done for which the hospice does not have other working resources. The reason for that seems to be that the volunteers appear to regard the hospice as a home. There are obligations at home to keep it running. They are not always pleasant but they have to be done. The volunteers have this "obligations at home"- attitude toward the hospice, and that is the price they are willing to pay so that they are allowed to belong to that group, to consider it their home. Like a lonely, retired woman put it: "I've told people that the hospice is my family now". The volunteers with "obligations at home"- attitude (which is the majority) seemed to be emotionally involved with the hospice and they had a strong feeling of belonging to that community. Therefore, even unpleasant tasks are met with responsibility: "Every task is necessary to do and it's only a matter of the right attitude. When you take it that way that it has to be done so it will be done".

In the beginning a few volunteers specifically wanted to do all kinds of practical work so that they would be softly familiarized with the hospice and in that way get courage to meet with dying patients and death. Or some remained doing practical work or at least preferred it to working with patients. It seems to me that the further off the volunteers do their work from the patients the less comfortable they are with death, of others and their own.

Many of the volunteers were able to carry out their own specific skills at the hospice. Women with foreign language

skills have entertained foreign visitors and done translations. An art-lover has arranged several art exhibitions. A woman interested in poetry and literature has read poetry in many celebrations and is responsible for the library. A woman with a marketing background excels at sales in aid of the hospice. It is important that the volunteer worker would find her own place, the most suitable form of working which would profit all the parties in the hospice community. That is also the view of the nurses who returned the questionnaire on volunteer work. One of them suggested that the volunteers should participate more in the work done in the ward. She thought that they could do tasks that do not require training: making beds, answering bells, assisting in eating. Indeed, that kind of practical work is useful and it is closely related to the patients which makes it rewarding. Maybe the hospice, for the most part, should utilize the various skills of the volunteers in tasks that carry immediate involvement with patients, and leave such tasks as baking and gardening to paid professionals.

When you are a volunteer of some regional cancer association your work is done either at patient's home or hospital depending on the patient's condition. I remember well my first visit to my patient friend who at that time was at a hospital. I did not know what to expect and what to discuss with a total stranger. I was extremely nervous and had prepared almost a lecture in my head on death and dying. To my surprise I did not have to perform in any way, mainly just listen. And even if you are a patient's friend and do mainly talking, it is not necessarily that you lean on your cheek and philosophize about death. On the contrary, conversing can be very mundane and about practical matters, especially if the patient cannot cope with death. In that case it is not your place to bring out death and other matters that may cause anxiety.

When my late patient friend was still at home I occasionally did some household work that the housekeeper had not time for but it was very little. I remember once being mildly annoyed when taking the rugs out but then I thought that why not if that makes her happy at the moment. It is probably easier to do household work at some patient's home when you get your reward instantly from the patient. For example, it can mean the world to a dying person when she/he is able to organize her/his belongings so that the outer circumstances are ready when death comes. So it gives you satisfaction that you can help someone and see the content face of a person who can be made happy so easily.

The attitude that the hospice volunteers have toward household work done at the hospice reflect the ways in which the hospice is being viewed. Many volunteers seem to consider the hospice their home, at least their second home. At the hospice they have searched and found subjective matters, as described by Ziehe (1986, 345; 1989, 155): closeness, mental intimacy, authentic experiences, and opportunities to express yourself. The volunteers may feel close to the patients, especially if they have promised to take care of one specific patient. Close relationship can be found among the volunteers themselves, and that is where the only long-lasting friendships can be created. Death is an ultimately authentic experience which the volunteers can witness at the hospice. Various courses and guidance of work provide the stage where one can express oneself and share one's feelings. All this can be found at the hospice, and participating in the practical work is one way in which the volunteers show their gratitude.

5. MATTERS OF DEATH

Many matters that involve death, directly or indirectly, seem to be taken out in the open in recent years. Death is openly discussed in the media, and various forms of spirituality are even trendy: Visiting a psychic may be considered as normal as going to a hairdresser. The thought of reincarnation has ceased to be a strange concept; you may talk about your previous lives without being stigmatized. People have started talking about matters that they have so far kept to themselves, for example near death experiences. The material concerning angels is enormous; you may talk about angel boom. When you view volunteer work with the dying against this background, it seems to fit the atmosphere of our times. Let us go into the twilight zone, matters concerning death and afterlife, in the following two sections.

5.1 Death of an individual, and death in a society

Death is a phenomenon that cannot be reproduced, accurately prognosed, or changed, and therefore it causes fear. Only human beings possess the knowledge of themselves as unique individuals, and only humans are aware of their mortality which distinguishes man from animals. Without conscious self animal lives in timelessness, but man's self depends on time and thus man knows death. Death can be viewed as phenomenon creating the basic paradox of human existence, the burden of being human. (Pirskanen 1987, 100-101; Heikkilä and Jokivuori 1994, 11-12.) Elias (1982, 5-6) points out that death does not create problems for humans but the knowledge of it. Death is problematic only for those alive.

Death is something unknown because we do not know what it is like to be dead or what, if anything, there is after death. It is not an enigma because it can be solved, but a secret. (Heikkilä and Jokivuori 1994, 8.) According to Elias (1982, 62-63) there is nothing secretive about death because it does not open any doors. Death is the end of an individual, and only memories of the deceased remain. There is nothing horrifying about death; man just goes to sleep and his world disappear. Another sociologist, Bauman (1992, 2), seems to have a similar view of death:

It is impossible to define death, as death stands for the final void, for that non-existence which, absurdly, gives existence to all being. Death is the absolute other of being, an unimaginable other, hovering beyond the reach of communication. Whenever being speaks of that other, it finds itself speaking, through a negative metaphor, of itself.

I find it rather bold to claim that there is nothing after death, no matter how prominent a scientist you are. As Bauman (1992, 15) himself puts it, death is the ultimate humiliation of reason. One explanation is that scientist, who work with reason, cannot accept a phenomenon which they are not able to explain. And to avoid being humiliated themselves, they deny the phenomenon having content altogether. Therefore, I find it reasonable to state that death is a secret which is not known to the living.

Death can be experienced in many different ways: Death can mean deprivation or annihilation. It can also mean peace or getting connected with family, nature, or God. People's conceptions of death are often similar to the Bible's tales on heaven and hell, although they may be expressed differently. Fears of total disappearance and wishes of eternal life are essential in the conceptions. (Makkonen 1987, 170.)

Death can be spiritual, social, mental, and biological. Spiritual death means the relationship with God fading away. Social death indicates human relationships dying out. Mental death stands for the loss of will, feeling, and understanding. Biological death can be regarded as a process which means the loss of all vital functions. Death has occurred when the organism as a unity dies out, which essentially depends on brains. The borderline of death is thus the death of the brain. (Hirvonen 1986, 39-45.) It is desirable that all these deaths occur somewhat simultaneously, but unfortunately it is not the way it happens in most cases.

Frequently, social death can be the worst death, especially when it occurs long before biological death. I remember a dying person who used to start reminiscing by saying "**When I was still alive**, I used to...". That kind of phrase gives the listener the creeps, and it may be interpreted that social death has occurred. Even though we know that serious diseases, such as cancer, are not contagious, people carrying them are often stigmatized and shut off from the society. Volunteer work with the dying can be considered one way of breaking the convention of causing terminally ill people social deaths. However, not even the patients with volunteer helpers are taken back to the society **from** isolation, but a volunteer is assigned **to** them.

I asked the volunteers what death is like, what happens in death. Most people emphasized that death is not the end of existence but life continues in a different form or level of existence. Only the body dies as the soul keeps on living, or at least existing. Only one volunteer regarded death as the total and final end of existence without any hesitation. A striking feature in the descriptions of death was that a somewhat romanticized view of death prevailed. Many volunteers who had witnessed death used the word

beautiful when describing death as an event. At best, death was seen as a beautiful sunset.

But what does death mean in a broader sense? What kind of meanings does it receive in our society? It is commonly claimed that death is a taboo. However, there is an apparent inconsistency if death is viewed as a taboo: When you take even a superficial look around you, you find almost every week articles on death in newspapers. Talk shows have dealt with death, and there are even TV-series concerning it, not to mention the amount of literature. Tony Walter (1991, 293) offered six possible explanations to the discourse of death being a taboo:

- 1) that there was a taboo, but it is now disintegrating;
- 2) that death is hidden rather than forbidden;
- 3) that the taboo is limited largely to the (influential) occupational groups of the media and of medicine;
- 4) that the loss of a coherent language for discussing death leads to conversational unease;
- 5) that all societies must both accept and deny death, so that pundits are able to pick whatever examples fit their thesis;
- 6) that it is the modern individual, not modern society, that denies death.

All of the statements could easily be both supported and protested against. Therefore, I am tempted to believe that all of these explanations could be valid at some place, at some time. Disparate frames a la Peräkylä (1990) belong to the group number four which suggests that experience of death has become fragmented, postmodern of nature (Walter 1991, 303). The fragmented nature of death seems to be a plausible explanation. But what comes to framing, I feel that different uses of language are not enough to create the various meanings of death, but many concrete factors are involved as well, as will be shown in 5.6.

5.2 Some ways in which death has been written about

5.2.1 Preindustrial death

Since the Middle Ages both western and eastern culture of death have prevailed in Finland. By their ideological history, both are connected with their mission church, Rome and Byzantium. The most essential border between them goes back to the old religious borderline to the west of which was inhabited by the Catholics in the Middle Ages and the Lutherans after the Reformation. In the eastern side there were the Orthodox or the Old Believer Ritualists who separated from them in the seventeenth century. The western cult of death was more concentrated on the Church than the eastern. In the east the occurrence of death gathered all the people in the area whereas in the west funerals were family affairs that strengthened the feeling of solidarity in the family. Both in the east and the west people used to sit up by the corpse. (Pentikäinen 1994, 10-11, 77-80.) It would be interesting to know whether these alleged geographical differences still exist in Finland or not, and if they do, to what extent.

In agrarian society death was perceived as an unpleasant but familiar guest that was part of nature's circle of life. Death was visible publicity of everyday life, and it often took place in mundane surroundings. It was a shared experience that supported social sense of togetherness. Names of the deceased were used only for about a year after which they belonged to the family's nameless community of the dead. (Heikkilä and Jokivuori 1994, 149-154.)

Aries lists five different stages in the development of attitudes toward death. He calls the earliest stage, the oldest death there is, the tame death starting from the early Middle Ages. That kind of household sort of death did

not come as a surprise, even when it was accidental or the result of too great an emotion to bare. One essential characteristic of this death was familiar simplicity, the other being its public aspect. Until the end of the nineteenth century it was most desirable that the dying person was the center of a group of people. (Aries 1974, 1-25; Aries 1981, 6,18.)

Aries's categories have been commonly criticized because of their simplified assumptions, but in my opinion they illuminate the different attitudes throughout the history when thought as some kind of ideal types. Writers who employ a historical perspective often view death as something better or more normal in the old days than what it is today. I suspect that at all times death has received various meanings in a similar way that it receives in our times, which will be discussed in 5.6.

5.2.2 Death in modern society

According to Pentikäinen (1990) the Second World War meant a period of transition in the culture of death in Finland. The war made death a familiar everyday occurrence. The traditional culture of death began to rupture in the aftermath of industrialization becoming increased because of the war reparations. The old culture had to give way to development that emphasized effectiveness and division of labour. Death became institutionalized and moved away to appear only on paper as death certificate and death notice. Many roles that once belonged to family and village community then fell in the hands of specialized institutions and officials. The death denying generation came into existence.

Aries (1974, 1981) writes about the invisible or forbidden death of modern age. According to him, the modern attitude toward death was born around the beginning of the twentieth century in the United States from where it spread first to the Netherlands and other parts of industrialized Europe (Aries 1974, 86,94). Death has turned to something shameful and forbidden that disturbs our happiness. Except for the death of prominent people, society has made death disappear. The death of an individual no longer affects the continuity of society. Death has ceased to be regarded as a natural phenomenon but it has turned into a failure, especially in the medical world. (Aries 1981, 560,586.) However, Aries recognizes the contemporary rapidness of changes in attitudes and notices how death is once again becoming something that we can talk about (Aries 1974, 103). In other words, he approaches the view on death which claims that death used to be a taboo but it is now disintegrating (Walter 1991, 293).

5.2.3 The dying can be lonely and isolated

According to Norbert Elias (1982, 4,11,17) one of the most frequent problems of modern times is that people are unable to give the dying the help and affection they need. The early, silent isolation of the dying is typical in modern, industrialized societies, and it is one of their weaknesses. People participating in the deaths of others has radically lessened. Elias claims that this development stems from people's inability to identify themselves with other people's destinies, and because the death of the other reminds you of your own.

Elias continues with an argument that along with the process of civilization death, as a event and an image, is pushed away further and further from the social stage. The

dying are removed from sight; they are isolated. The silence continues in the ways dead bodies and graves are taken care of. They have become the tasks of professionals instead of family and friends. Seeing dying and dead bodies does not belong to life any longer. Elias writes about the rejection of death which is enhanced by the individual's relative security of life and the risen span of life. When people tend to live longer, thinking about death can be postponed further on. (Elias 1982, 10,113,29.) All this sounds very familiar concerning life outside hospices. However, recently the media have told us, for example, accounts of people who have wanted to participate in the funeral arrangements of their beloved ones. What remains unclear is that we do not know whether it is a sign of people starting to take death and dying from the hands of professionals, or merely one way of saving some money.

Elias asserts that covering death and dying, especially from children, is connected with the anxiety that people feel around the dying. People do not know what to talk to the dying, and the amount of words used may be very small. That can be understood as a bitter sign of desertation while the dying are still living. Social tradition offeres less and less typical expressions and standardized forms of behaviour for younger generations who have to use their own imagination in finding the right words for their feelings in the company of the dying. The responsibility of right words and inappropriate behaviour remains on the shoulders of the individual, which increases the individual's own pressure in those situations. Natural talking to the dying and conversation is more difficult than before. (Elias 1982, 23-24,27-28.) At hospitals nurses often avoid visiting dying people, or the visits remain short. They are not necessarily conscious of their behaviour that is connected with the problemacy of their own death and the experience of helplessness. (Lindqvist 1986, 153.)

People suffering from loss of words in the presence of the dying seems to be very common in our society. People need to take courses to learn to talk to the dying, as it is the case with hospice and other volunteers who work with them. What is it with dying people that makes people not that close to death shiver? I have never felt that the dying should be spoken to in any other way than to other people, or that they ought to be treated with more respect because we all are mortal. Despite my own feelings, I could imagine that there could be at least two possible explanations to the commonly experienced anxiety: Firstly, as Lindqvist already stated, the problemacy of dying may bother people. Because you do not know about death or you have not accepted its unavailability, it scares you, and the dying represent death which you do not wish to think about. Secondly, you may consider that the dying are already partly in other form of existence, or non-existence. According to your way of thinking, the dying might be regarded as somewhat holy or sacred, and you do not know how to behave or talk in the presence of holiness. Or you may think that the dying are on their way to non-existence, and you do not want that it rubs off to yourself and you start disappearing as well. The insecure person could have a narcissistic personality with unclear boundaries of the self, as described by Lasch (1978), and therefore vulnerability could be the main experience with the dying.

Unfortunately, many of Elias' views on death and dying seem very credible when you take a look, even a cursory one, at the issues in our modern society. Hospices are one attempt to make a difference concerning death and the treatment of dying people. In a way, a hospice isolates its patients to a certain place, it is somehow its own oasis. But inside a hospice death is not either hidden nor it is an enemy. Staff and volunteers maybe need to take courses in how to be with the dying but they do participate in the deaths of

others. The patients are not left to die alone but they are surrounded by a secure environment that allows and prepares you to die in peace.

5.3 What is a good death like?

The question above is very relative. For example, in Siberia among the Chukchee voluntary death, suicide, was very common. It could be caused by a disease, accident, shame, grief, or generally unhappy life. Every kind of violent death was considered better than death caused by illness or old age. They regarded that kind of death as the result of the work of evil spirits. Instead, according to Finnish popular belief people who committed suicide caused dismay, and their destiny was to receive a quiet, dissolute, or disgraceful funeral. (Pentikäinen 1990, 96-98, 126-127.) People's attitudes towards death, and a good death, seem to be to a great extent culturally bound.

According to the principles of terminal care a good death is one which is preceded by sufficient basic care and other care in which human dignity is respected. The principle of terminal care is that the patient's life and sufferings are not prolonged by useless tubes and other technical devices of medicine. The objectives are symptomlessness and analgesia. (Hietanen 1986, 81.) When weighting the quality of life of the dying, the environment must also be taken into consideration. The dying patients should be able to spend the rest of their lives in a place which is the best possible for them and their family. (Fried 1988, 29.)

There was a special project of STAKES (center of research and development of social field and health care) in 1991-1995 which was titled as Good Death. The objective was to

develop the possibilities of the humane death as a part of the public social and health care services. Paradoxically, finances were behind the project: The director of Terho-hospice contacted the director general of STAKES in 1991. His worry was the future of the hospice as the municipalities of Helsinki were reducing their purchases of services in the years of economic recession. The concern for economics brought about paying attention to the quality of the care of the dying. It came into consideration how to promote public discourse on death and how to develop public services of dying people and support their families. The topic received plenty of attention in 1993-1994 when there was a writing contest of death primarily for the workers in social field and health care. (Simonen 1995, 12-13.)

According to Aries (1981, 587) the good death of today is what used to be accursed in earlier days, that is, death that gives no warning. For example, not waking up, dying in sleep, seems to be a good way to die. But where? In the Good Death- project it was discovered that patients, their families, and the medical staff shunned the idea of dying at home. However, there was detectable atmosphere of changing attitudes in the answers. People are eventually giving up the thought of dying in institutions. (Sinnemäki and Simonen 1995, 18.)

I asked the interviewed volunteers the same question of the nature of good death. Only four of them emphasized the importance of external conditions of death in a way Aries described it:

A good one would be when you are allowed to die in a good shape. That it would happen in an easy manner.

Well I think that a good death is when you just like sleep away. Or one that happens really fast.

A car accident for example where you go immediately, or if you think about cancer and it should spread that the last phase would go as quickly as possible. So quickly and without pain, the worst case being that you have to suffer for years and you can't live a normal life. That the cancer just spreads and spreads and you just try to be at home and do chores as if nothing is wrong. That's what I feel the hardest way to go. If you have cancer life shouldn't last for long, that condition. The prolongation is the worst part.

The common factor of the volunteers who emphasized the external conditions of death is that they did not believe in any kind of greater force or afterlife. The majority of volunteers had some kind of belief in God, and they emphasized the internal factors that are involved in a good death:

The director of the hospice once said that here you can settle up with your life. I feel a good death comes when you have done what you are supposed to have done as a human being. --- And a bad death is when everything is mere battle. And the person is - how would I put it - somehow hardened and very bitter or something like that.

I think a good death is absolutely, is one when you have a good relationship with God and with people of course. That you could go in peace. That's what I think a good death is.

There could be many kinds of good deaths. A person who has thought of his own death has settled his affairs as they say it, has settles his relations with God and people. For him a good death could be so called sudden death, that's not bad then but good. And then a good death could be for a patient of long-term illness after pains and suffering, the liberating transferring to the unknown. You can settle your affairs here at the hospice and why not elsewhere too, relationships and other affairs, everything settled. In that case going away is not that difficult. And oftentimes it can be wonderful.

In sum, a good death for the majority was one that you were prepared for. It requires that you had thought of death and accepted it as the inevitable part of your life. You must have settled your relations with God and people, and preferably you do not have a sense of incompleteness. A good life precedes a good death. Your dying is a good death when you are allowed to die as it is at a hospice.

5.4 Deadly cancer makes you authentic

Every year over 20 000 new cases of cancer are detected in Finland. The yearly amount of cases is bound to grow by thousands because the population is growing older and older people are susceptible to falling ill with cancer. The most common forms of cancer are cancer of the breast among women and cancer of the lungs among men. Cancer illnesses are not incurable, and a great part of cancer patients live symptomless after the detection and treatment of cancer, and eventually die of reasons other than cancer. However, the common cancers of the stomach and the lungs are ill-omened which has affected the notion of cancer as a dangerous disease. (Pukkala and Vertio 1994, 3,11,47,57.)

Cancer. Even in a foreign language the word tastes bad in my mouth, not to mention what it does in Finnish. I also asked the volunteers what kind of feelings the word arouses in them. Without exception the word had a negative cling to it:

Even though I know from fact that there are many other chronic diseases that could be even worse than cancer and oftentimes cancer can be removed completely by operation, and yet it sounds bad if cancer has been operated off of someone.

For the most part, the word aroused feelings of fear and bitterness. Even though knowledge of cancer has increased and medical science has developed the sinister image of cancer lies deep in people's minds. One volunteer first offered her view of cancer as "The greater part of cancer can be overcome" imitating the campaign slogan of Cancer Associations of 1996 "Cancer can be overcome". But after a few minutes she came to a conclusion of "---it's an awful disease after all when you really think of it".

Although the word cancer does not bring pleasant associations many of the volunteers are not exceptionally afraid of it. Nobody wants to get it but attitudes toward it are fatalistic "You get it if it's meant that you get it" or realistic "You have to die of something, don't you". As Linden (1995) noted, the image of cancer seems no longer mystical compared to earlier days when there was little or no knowledge of cancer. Its causes were magical of nature, and its methods of treatment were highly undeveloped. Cancer has become a "normal" disease.

Linden (1995) claims that cancer is no longer equalled with death it being often curable. The situation seem to be somewhat different among people involved with a hospice where people have come to die, mainly of cancer. Cancer is most often equalled with death:

It's just that although they say that cancer is often curable my experience is that almost everybody that has had it their cancer has renewed itself. Sometimes I'm sort of bitter of the whole cancer and of course I'm afraid of it for myself because there has been so much cancer in my family.

Likewise, my own experience is that cancer is more lethal than anything else. I find it hard to believe slogans like "Cancer can be overcome" because I know only very few

people who have survived cancer. I realize that it is caused to a great extent by the surrounding you are exposed to. Cancer can get a very different meaning at a hospice or when you otherwise deal with terminal care patients than, for example, at a hospital specialized in treating cancer where curing can occur frequently. Despite my sinister sentiments, the fact is that in the 1990's every other cancer patient, fifty per cent, overcome the disease. Radical change has occurred in the prognosis of cancer when you compare the present situation with the 1950's when only every fourth patient could be saved, and in the 1970's, every third patient. (Lantto-Tolvanen 1996, 7.)

When I asked what it is that is worst about cancer very little external, concrete matters such as pain were mentioned. Maybe it is that at least at this particular hospice the deadly diseases are well analgized so that pains do not appear as main problems. Loneliness or even isolation did not come across as matters that touches you most about cancer although that could be easily the case in other institutions. Instead, the phenomenon of cancer stripping off a human being was considered the most difficult feature of all. It was amazing how so many people used exactly the verb **strip** when describing the condition of cancer patients. I suppose that the uniformity stems from some mutual lecture or gathering where those matters have been discussed.

What does stripping off a human being mean? The volunteers could not describe it any further: "---It's hard to say more, it's ((cancer)) just so totally stripping". I understand it so that, first of all, with a deadly disease your body is deteriorating to an extent where you are not in total control of it any longer. Even simple matters such as going to the toilet stop being simple, and you may need constant assistance. That if anything can be concretely

stripping, even humiliating. Furthermore, your bodily integrity is disturbed by operations and all the daily procedures that the particular type of cancer demands.

In addition to physical stripping there seem to occur also social role stripping. It is hard to tell whether it is the result of physical stripping or an independent process, and I do not intend to get into that in this study. What is important and apparent is that an extremely ill, dying person deserts many of the everyday roles she/he has possessed and used. According to Goffman (1982, 76-77) there seem to be two models through which we formulate our conceptions of behaviour: There are real, sincere performances which we tend to see as honest performances that are the products of the individual's unselfconscious response to the facts in his situation. In addition, there are false performances that are regarded as something painstakingly constructed, containing one false item on another.

It appears to me that the dying are considered to perform in a sincere way, whatever it may include, and it seems to be highly valued. In fact, this "genuine and honest" atmosphere seems to be something that the volunteers have been looking for in their lives and found at a hospice. In other words, psychoculture is alive and kicking. People search for realness that the surrounding world tries to smother. The hospice seems to be regarded as a oasis of sincerity and the patients, stripped by cancer, as their most sincere. The demand for authenticity is extended to yourself as well:

I've been trying to be more the person I am. At this age I've noticed that I've started to demand it from other people too because it's the masks of life that you usually meet with. Of course I have my own masks as well. But here the people are so

genuine compared to people elsewhere. But on the other hand you can't demand authenticity from anybody else than yourself. Maybe I've changed in a way that I try to be more the person I am everywhere.

Gustaf Molander and Tuire Parviainen (1996) interviewed 25 people who worked at wards of dying people in the Nordic countries. One of their descriptions was that there does not exist a world of emotions that is more genuine than a ward of the dying. The volunteers of the Finnish hospice seem to agree.

What does it mean to be genuine? When the volunteers talked about it they referred to certain ways of communication and behaviour. We may wonder what it is that makes the dying abandon certain roles or codes of behaviour. Maybe they are so wrapped up with their own bad condition that they do not have the strength to behave as they used to, or maybe they feel that they have nothing to lose any longer. Do they not fear that other people may desert them although they desperately need the help of other people? Apparently not. The reason for that could be that there seem to be unwritten rules, a certain frame of discourse, that protects the dying from potential desertation. Goffman's (1974, 8) frame illuminates what it is that is going on in a current situation. The structure of this particular frame is that the dying are allowed and even expected to be honest which in practice mean that they can say whatever they please. And the others do not have the right to be hurt. For example, if a patient says "I hate your perfume. Go away!" you are supposed to laugh about it and admire the honesty in this particular frame.

However, the straightforward style of communication is not a two-way street. I could not imagine that I would greet a dying person by saying "My godness, you look like a corpse

already!" even though it would be my thoughts exactly. On the contrary, there is an unwritten agreement that other people, those who are not in immediate danger of dying, are supposed to be subtle and discreet, not to hurt the patient's feelings. After all, she/he could die at any moment. In the extract above the volunteer wished to be more genuine but she cannot be that way, or realize it in words, among the dying. Many researchers (f.e. Peräkylä 1986) have noted that the communication between dying patients and hospital staff can be very inhibited and filled with tensions. It has been very common that the patient's condition was kept secret from himself, and even direct questions on the condition were answered with lies. There is a long history of protectiveness that is realized in gentle and careful communication even in these days.

I do not know whether it follows the alleged genuineness, the lack of certain social roles or not, but it can be easy to get a contact, to make friends with a dying person. Maybe it is easy to start trusting a person whom you consider genuine, and the basis for friendship on your half is ready. One reason for becoming friends in a short time could be that, in a Freudian sense, the approaching death is the ultimate foe in the lives of people, and therefore people get united. Whether the dying actually are genuine or not, my view is that they can easily exploit their condition and manipulate other people who may see it clearly but they are not in a position to fight it.

In sum, cancer as a word is considered ominous although cancer has lost its mystical nature. The volunteers are not particularly afraid of it although nobody wants to get it. In the minds of volunteers who are involved with a hospice cancer equals with death more than with anything else. The worst about cancer is that it strips off a human being in various ways. But nothing bad without something good:

Cancer patients are regarded as genuine and honest people which is appreciated by others who, in turn, are not expected to share the straightforward ways of communication. I have to remind that the implications cancer has are not necessarily its own, they do not depend on the specific features of cancer. Any other deadly disease that proceeds in a similar way could have parallel implications.

5.5 Death may and may not be furthered

In the interviews I asked the volunteers about the opinions on euthanasia. Afterwards I realized that I should have been more specific because it was active euthanasia that I was interested in. However, the volunteers understood euthanasia as the active one, and my carelessness caused no harm. Euthanasia being a controversial issue, it seemed that it was no simple matter among the volunteers either. There were only two women who were strictly against it. They thought that it was not a human being's position to decide when life ends. People may not interfere with the timing in life because it is God's privilege. Most people were for euthanasia or they did not know what to think about it. Two volunteers who approved euthanasia unconditionally did not believe in any kind of afterlife. However, euthanasia was accepted by volunteers with Christian perception of life, and in doing so they put individual choice above the Bible. But many of those who would stand for euthanasia would not like to assist anyone in executing it.

Individualism, the emphasis on the choice of the individual, is strongly present in the discourse on euthanasia. Despite an approving attitude toward euthanasia it seems that most people are not keen on helping anyone die. Maybe they are not certain whether it is right or not

after all, and they want to escape responsibility - namely responsibility to some greater force and celestial laws even though euthanasia would be approved by civil law. Moreover, without any celestial references potential guilt may cause hesitation in the issue. An Australian model of euthanasia evades the problemacy of responsibility by giving it to the patient who wishes to die. Phillip Nitschke has developed equipment called Deliverance that makes the patient give an unambiguous answer on a computer screen. For example "If you press "YES", you will cause a lethal injection to be given within 30 seconds, and will die. Do you wish to proceed?" The patient has to press either YES or NO. ("Armokuolemailta" by Ajankohtainen kakkonen Nov. 12th 1996)

Many volunteers did not know whether to be for or against euthanasia. It was seen as a multidimensional issue with no simple answers. One reason for hesitation in opinions seemed to be that man was seen as a social and spiritual creature whose relationship with people and God should be fine before death. Among the volunteers, one of the main problems concerning euthanasia was that conditions and timing of death should not be violated by the action of man:

It ((euthanasia)) is a very broad and difficult matter. It's very difficult for us people to know what the right moment to die is. How an earth could we know it if someone is given that much strength that he's able to solve some unfinished matter for example. No matter how small a thing it would be for example done by gestures or something, and if that remains undone because the patient's death is somehow hurried in that case man has taken in his own hands something that he has no permission to do. So in principle I'm against it although I feel that sometimes there are no limits to people's sufferings which should be relieved. But then there is this matter of artificially extending man's days and supporting vital signs by machines. In my opinion there is no sense in doing that.

One major concern among religious people is that they are anxious about the dying person's relation to God, or the lack of it. Their fear is that the person who dies without faith in God cannot go to heaven. It is common among priests to console the mourners that we cannot know what happens in the last moments of life; maybe the faithless people get a last change to accept salvation. Views like this hinder the justification of euthanasia, and the view comes forward in the writings of Tada (1993, 130):

God works in your life to the last moment. It may seem that nothing happens in the life of your dying beloved or seriously injured person, but God is not unable to complete his work in the lives of people although it may seem that nothing is happening on the surface. God's work is spiritual and it does not depend on the functioning of the brain, nerves, or muscles. Only eternity reveals the work of God. (my translation of the Finnish translation)

Causing death to another human being has been regarded as wrong mainly because of four different reasons: It has been considered that 1) human life is absolutely valuable, 2) every person wants to live, 3) a human being may not use humanity as an instrument, or 4) every person has an indisputable right to live. (Häyry 1987, 133.) Mattila-Pyykkönen (1996, 121) appeals to the second argument. According to her, the pain of the suffering person is partly formed by the fact that the pain reminds him of death and threatens him. He would like to live, and the pain causes fear of his wish not coming true. In that position a human being wishes to live, not to die. I find Mattila-Pyykkönen's reasoning overly theoretical and unrealistic to meet with a real situation. Even though a person would wish to live it has no relevance in a situation when there are severe pains that cannot be relieved and there is no hope of recovering. It is often claimed that nowadays painkillers are so effective that

pains can be removed and therefore the whole discourse of euthanasia should be ended because there will not be any need for it. I find it hard to believe that all kinds of pain could ever be treated, and after all, pain is too subjective a matter to be decided on behalf of other people.

The problemacy of euthanasia is increased by the fact that man is still seen as consisting of body and soul as it has been the case since ancient times. As early writer as Plato emphasized the duality of the human being, and concluded with the voice of Socrates that soul was divine, immortal, rational, undecomposable, and unchanging of nature, and body received opposite values to soul. (Platon, 35-36.) In Western philosophy there has been a long and strong tradition of a view according to which death does not mean total annihilation of the human being. It is based on a idea of a human being consisting of two different part, namely body and soul. (Harva 1985, 13.) The volunteers seem to acknowledge the duality of man which makes the decisions on death of people more difficult than of animals:

---I don't know, I don't really know how to react to that ((euthanasia)).

H: It is a difficult matter.

V: Yeah right, like there is no, like you should tailor the decisions to the last details.---Well I've done by myself, I've had dogs for forty years and I've made every - I don't have any at this moment - I've had to make every decision on putting down because it's always that mother decides. In that sense I've been playing God in heaven in this case. To do the decision on putting the dog down, I feel it's done purely because of human reasons that I haven't wanted the dog to suffer. This is how it goes, I didn't want the dog to suffer. But it is in a certain way different when it's about a human being. Well life is life. You can kill mosquitoes and flies and you don't get a bad conscious.

Problematic as euthanasia is, it is approved by 77 per cent of the Finnish population (gallup made by Ajankohtainen kakkonen in 1996). In the recent years there has been a debate on the legalization of (active) euthanasia in Finland. At this very moment the acceptance of passive euthanasia - understood as the right to refuse care-taking - does not require changes in legislation because the right to decide on treatment belongs to the autonomy of patients. (Mattila-Pyykkönen 1996, 109.) The idea of legalizing active euthanasia is being promoted by for example Exitus-association. Voices of opposition can be heard especially from the rows of Christians. Mattila-Pyykkönen (1996, 109) feared that the moral and legal security of the dying would be distorted by a specific legislation on euthanasia. Lindqvist (lecture on Kuoleman salaisuus - Secret of Death - Oct. 11th 1996) suspected that a law on euthanasia would be impossible to prescribe because it would be excessively general and broad. Moreover, he feared that the people lacking legal capacity would become victims, and the vicious circle of loneliness would grow deeper.

Euthanasia stems from the Greek word **euthanatos** which is formed by two parts: The meanings for the first part **eu** are "good", "easy", and "well", the second part **thanatos** stands for "death". (Häyry 1987, 142.) Euthanasia is a very controversial issue. It can receive various perceptions from both ends of the continuum and anything between it. The hospice principle is that the sufferings of human beings are not unnecessarily prolonged. Some medical treatments are unpleasant and painful, and they are avoided if they extend living only with few days. The quality of life during the last days is more important than the quantity of the remaining days. Naturally the patients are offered good basic treatment and nutrition. However, if the patient chooses to refuse medicines or food and drink, his

decision is to be respected. All in all, passive euthanasia is accepted at hospices if it is defined as Lindqvist (1986, 148); giving up such procedures that prolong a suffering person's life.

5.6 Death receives various meanings

Death seems to be a fragmented phenomenon. The meanings it receives are by no means constant and invariable. The individual's outlook on death seem to be **diachronic** and **synchronic** of nature. A **dischronic** outlook is that death can be perceived as a process, often a process of a lifetime. Death may appear as the ultimate foe when a person is young and vital. During the late years death can be regarded as a friend that eventually takes you home. A process with an ending, direction like that would probably be most favourable. Instead, it can happen that in younger years death does not receive any particular meanings because it does not seem relevant at that moment. And later on, when mortality reminds you of its existence as illnesses, death may suddenly become the worst nightmare. Many volunteers stated that due to their working at the hospice death had become tamer and more familiar. Being with the dying had removed or lessened fears of death. In other words, work as a volunteer at a hospice had affected the process of dealing with death in a positive way.

A **synchronic** outlook on death refers to death receiving various meanings at the same time. One attempt to define death synchronically is Peräkylä's (1990) ethnomethodological study on hospital care of dying patients. He studied face-to-face interaction situations of patients and hospital staff. On grounds of interaction he defined four different frames: practical frame, medical frame, layman frame, and psychological frame. In the four

frames death received different meanings. Frame analysis rejects the idea of whole subjects that are unchanged in different situations. Frames define the qualities, rights, and responsibilities that the participants in an interaction assume themselves and the others to possess. Frame analysis claims that in different situations and frames people adopt various patterns of thought and action. (Peräkylä 1990, 22-23.)

In my study the synchronic aspect of death emerged in an observation of death receiving different meanings depending on **whose** death it is. Many volunteers told me heartbreaking stories of the deaths of their beloved ones. Due to the high average age of the volunteers, many of them had experienced the death of their parents, siblings, or spouse. Especially the death of a parent often raised turbulent emotions by appearing as a major shock or crisis of life. However, the death of a patient usually meant something milder. Almost all the volunteers said that they experienced relief as the main emotion although there was also sadness involved.

H: Yeah, well have you experienced a death of a patient? You have had several own patients, what did it make you feel?

V: Of course it always, feels. But usually it feels like an enormous relief when the person gets to go away. Like you don't think that I wish he could suffer here for some more time. You clearly miss some people with whom you've had a good relationship. Although it's been short.

There are a few exceptions of attitude concerning the death of a stranger: It seems to be upsetting for most people when children and young adults, especially if they have young children of their own, die. There is a tangible feeling of unfairness; children and young adults are not supposed to die. When older people are concerned, there

seems to be a very practical and rational attitude involved when dealing with dying patients. When there is no hope of recovering, death seems to be the best alternative. And the crucial point is that when a patient dies, there is no death of you or your beloved ones involved:

I have to say that no matter how close you try to be with them ((the patients)) there is a certain distance that it's far easier to go through after all. Like although it's tough, but it's ((death)) not yours. We people are like that, that this is mine and so on. Like you can deal with it with no trouble.---

For me the mere thought of someone of my family dying is overly appalling to deal with. But the loss of my long-term patient friend did not upset me although at the time I was pregnant and overly sensitive about everything. I remember barging in to the hospital room and found a strange woman occupying my friend's bed. Only then I found out about her death because her relatives had failed to inform me. After talking to her own nurse and finding out about the details I felt almost cheerful and happy for my late friend. Then I came to think of myself. What about me? I hated the hospital ward and its smell but I used to visit it every week. I felt empty because I realized that from that moment on there was one weekly ritual less in my life. The most ridiculous and shallow thought of all at that moment of death news was that I was disappointed because I was wearing a new outfit and she did not get to see it.

It is not only whose death it is that is involved, but the meanings death receives depend on **the site of death** as well. At a hospice you have the permission to die which is not usually the case at an ordinary hospital where death is often regarded as a failure, an accident:

---I was there ((at a hospital)) having a surgery and once in the night-time I happened to go to the toilet and one person was being prepared to die, she was in a really bad shape. It felt really bad and I had to think why it felt so bad. I work here all the time with people like that. Of course it was partly because I was myself somehow in a similar position, that could affect that. But then I got a feeling that in this house ((hospice)) you have a permission to die. There wasn't any permission, it didn't feel right to die at the hospital. After that experience I came to realize that hey, here a human being has the right to die and you should have the same right there. After all there's nothing terrible about dying if you happen to die. I don't know whether she died or lives at this very moment. It's considered a completely natural thing that a person dies.

In other words, a patient has a licence to die at a hospice. In addition to **who** it is who is dying and **where** the death takes place, it is naturally relevant to the different meanings of death **how** you die which has already been discussed in 5.3 when asking what a good death is like.

6. AFTER DEATH

What happens after you die? Does life continue in a different form, in a different place? Or is there going to be total annihilation, non-existence? Or does anybody even really care? At any rate, there are more questions than answers available concerning the happenings as the thread of life breaks off. Even the predominant religions are reticent about the matter; they do not offer specific answers, only vague insinuations.

In our culture views on afterlife are surrounded by silence. Stories on afterlife are not popular and they do not have any unanimous public. According to Utriainen (1994, 7) they may have lost their interest partly because we have plenty of other stories: novels, movies, cartoons, vacations, journeys, places, times of year, foreign cultures, and natural environments, which all are more or less imaginary or real, and we can live another life among them. However, most people have a some kind of picture in mind concerning afterlife. Most of the volunteers offered laconic views which implies that afterlife as a thought had not bothered them to a great extend, not to mention that it would have inspired them to create any specific doctrines of their own. In spite of that, their answers helped me map some perceptions of afterlife.

6.1 Is there any life after death?

Man's belief in life continuing after death in one form or another is an universal belief that involves all cultures and religions. The desire to be immortal and the capability to create an image of your own eternity is characteristic of the species of man. (Nissilä 1992, 171.) According to Nissilä (1992) the wish of your own immortality eventually

becomes an essential and important part of your personality. That wish was part of the basic being of the dying patients that Nissilä interviewed. Even the deepest anxiety did not banish the wish but, on the contrary, fears and anxieties emphasized the wish to be immortal.

Among the volunteers human life was commonly considered irrational if there was not going to anything that follows life: "Sometimes I think that a human being's time just cannot be so short that everything would end in the hour of death". Only one volunteer woman was convinced that there was nothing after death, and she left no room for questioning. Maybe because of that she found death a most dreadful thing. Another woman offered contradictory views: She first defined death as going from one time to another, life continuing in a different form. Later on she stated that she does not believe in afterlife if she is completely honest. However, the great majority of volunteers believed in some kind of afterlife. An older woman who had had a near death experience was convinced that life does not end in death:

V: Well then, I was in a state of paralysation and, I heard loud and clear when I was asked whether I was ready to go or not. Earlier I had already said that I was going to die, and then I had risen a bit in the bed and looked up and said that I'm coming I'm coming. Then I had fallen down and looked dead so that the woman whom I had become friends with started crying in the next bed. It was a very short moment. It was difficult to come back because I had thought that I would go. Like I could easily go because nothing holds me back. My daughter comes along fine. But then I remembered my husband, and I felt so ultimately sorry for him. So I came back, I had even bounced when I came to when all the nurses were around my bed with all kinds of tubes. And so I came back and I said to my husband that because of you I got to come back. And after that experience I haven't been afraid of even surgeries because I know that I can survive them.

H: So it was a pleasant experience?

V: Yes. Enormous light, and a wonderful feeling. I remember hearing beautiful music but I can't say that I had seen any figures, angels or something. But it was a very pleasant feeling and the light. I have read about these things and about tunnels and such. There was no tunnel there. There was that enormous light but then there was this really weird, I've said that I could try to draw it sometime. I was wondering what it was, and it was as if it was seen from down there, a black ball or something. It was a feeling like ((talk mixed with laughter)) I went with speed.

There are controversial opinions on near death experiences. Some find them real and regard them as evidence of life continuing, as for example Moody (1995) who bases his arguments on 150 cases of the experience. Some, especially doctors, commonly consider the experiences the result of the brain producing consoling images and feelings in the moment of ultimate distress. The truth may not ever be found as the experience seems almost impossible to be studied with the help of current scientific knowledge.

What remains is your own view, intuition on whether there is any afterlife or not, and that cannot be proved either right or wrong. Personally, I believe that life continues in some form after your body dies. I also believe that my late patient friend came to tell me about her death in my dream: The night after she had died - I was not aware of her death - I woke up to a sense of someone whispering in front of my face. I was startled because I was alone my husband being on a working commission out of country at that moment. I pulled the covers over my head and continued sleeping. I had a dream where my friend was surrounded by many other women who seemed cheerful and they were all talking at the same time. My friend looked excited and happier than ever, and she tried to tell my something but I could not hear a thing because of the many voices. Then she tried to say it by gesturing, pantomiming. I tried to guess

and guess, and she nodded her head at every wrong answer. I woke up and thought that something special must have happened; the dream felt meaningful. The next Sunday morning I wondered whether I should go to see her at the hospital or not. But the weather was bad and I thought that nothing that exciting can happen at the hospital that cannot wait until Monday. Only then when I received the death news the dream got a some meaning.

What happens to the human being in death? It was a common belief among the volunteers that in death only the body dies as the soul remains untouched: "Well, I do think that when a person dies, it's the body that throws in the towel and the soul then, it soars around here somewhere". As a matter of fact, this kind of thinking, although it is very common, is against what protestant theologians have been teaching, namely that both body and soul are destroyed in death. Man was regarded as a unity, and therefore death could no longer be defined as the separation of body and soul. During the last day God was supposed to revive the human being with body and soul. (Harva 1985, 13.) Although we live in a protestant environment, all of its teachings do not seem to reach the majority of people. After all, it is a more consoling thought that in death soul would survive instead of total annihilation, despite the Christian promises of being revived during the last day.

6.2 Unfashionable hell

Most ancient peoples imagined that there was a underground dark world that was not evil but merely sinister or dull. The image of heaven above the clouds developed only later in classical period. The birth of the image has been explained in two ways. Firstly, it became ever harder to combine mythological images of the abode of the dead and

geographical views on what an underground world might look like. Secondly, the sun, the moon, and the planets were regarded as gods especially among the people in the Middle-East. The thought of two-part abode of the dead with different places for the good and the bad became eventually prevalent. The thought of compensation and fair judgement after death was, without doubt, most pleasant among the living, and therefore it is included in most religions. (Fellman 1985, 30-32.)

According to Fellman (1985, 49) the views on eternal questions have commonly been secularized in Western cultures. People have often stopped believing in eternal damnation or eternal happiness. Heaven and hell are regarded as stages of mind that can prevail even here and now. The volunteers offered somewhat similar views in terms of hell: Current life on earth with wars, violence, depression, unemployment, and severe illnesses was often considered so sinister that it seemed that worse places than this world could not be even imagined. The majority of volunteers believed in afterlife, and afterlife received positive definitions, equalling with heaven:

I think it ((life after death)) is something where everybody has it well. I can't say that it is something specific because everybody don't like the same things. But it is something good for everybody.

I believe that we go to a different level and well, that's why I believe that we should not cry too much for our close ones who are going to the different level because I believe that we make it slower for them that way. Like I believe that there everybody, I don't believe that we all become children, that's not what I think. I think that we get to be healthy and we all can feel wonderful joy there in heaven. ((talk about video on heaven)). I also think of heaven as a place where we all can be beautiful the way you want to be. I believe that it's good to be with God.

Life after death was commonly considered pleasant and enjoyable. In heaven you enjoy yourself like a child in a candy store; surrounded by wonderful things, without any worry or responsibility. There is an apparent belief in compensation: Life can be tough, therefore afterlife has to be pleasant. There seemed to be no fears of ending up in the flames of hell which has suffered from loss of respect in the minds of modern people. We all have been thought that man cannot save himself by doing good deeds but a good person is expected to do them. Thus, there is no imperative to perform good deeds, and hell has lost most of its meaning. Therefore the volunteers, who live strongly in this moment, do not try to secure their place in heaven by working among dying people. However, there is a sense of holyness involved which will be discussed in 8.2.

6.4 Reincarnation is not a completely strange concept

It would not have occurred to me to ask the volunteers about reincarnation if I had not attended a lecturing day on dying patients held by Marita Moring. She claimed that some people who have it easy dealing with death believe in reincarnation. Therefore I decided to inquire the volunteers about their outlook on the possibility of man being born again, having many lives in a sequence. I found out that three of of fifteen, one fifth of the volunteers in question believed in reincarnation. The picture of man as developing is closely related to the belief in reincarnation. In addition, in the next extract there is a wish of a dead family member reincarnating:

V: Yes, I do believe in it ((reincarnation)), maybe I somehow believe in it. I've read about it a lot and, I've read that kind of books and, but you can't get any answers. I've been thinking about it - my son got his first child now on the

ninth day - and it occurred to me that it wasn't that long time ago when my [] died so that she can't come back yet. I've read about these things that it takes time before you () she might come down here again in the family. Maybe as her son's child or then as some grandchild, like only then she could come back. If it's not good enough to be with God, if you have to come back. By the way, have you read about these things?

H: Well yes, for example the one on Shanti Devi.

V: Yeah right. If you are good enough, namely to stay there you may stay but if, if you have to return to this time, then then. Like then you have to be there longer, or you have to be for some time on that level. And only then you may return here and it's only three years since my [] died so she surely can't come back here.

H: In order to be born again is it that man isn't good enough or it's not good enough for man to be there with God?

V: If man isn't good enough to be with God, if you aren't developed enough.

H: So you come back here to learn more?

V: I think it is just like that but then, I'm not absolutely sure it goes like that, but I'm willing to believe so because many of my beloved ones are gone.

The thought of reincarnation serves as a consoling factor for the woman who has lost family members. What strikes me as contradicting in the extract is that sometimes, by using certain choices of words, human life was considered more valuable than alledged life with God, and sometimes vice versa. Perhaps the longing of the speaker caused the apparent inconsistency; at the same time, on one hand she missed the dead relatives and wished that they could come back, and on the other hand she realized that it was good to be with God as well.

Western people often have a hard time dealing with doctrines of reincarnation. Many reasons make us appalled by the thought of reincarnation: for example the doctrinal foundation or the mere habit of thinking in a certain way. In addition, the thought of starting everything all over

again is unpleasant for most Western people. (Elmgren-Heinonen 1985, 274.) However, it seems that the attitudes of Western people are changing. Nowadays you can discuss for example reincarnation with a straight face even in public, in talk-shows etc. What does it tell about us and our time? Is there some sort of major syncretism of main religions going on? One volunteer who believed in reincarnation regarded herself as a Christian although her outlook on life appeared to be somewhat Hindu. Syncretism may be one potential explanation in our world that is getting ever smaller in terms of knowledge and awareness of other cultures. Even more so I find the visible rise in the popularity of spiritual matters and spiritual science responsible for the phenomenon. They are in, and people are more open to them than before. Reincarnation is one of those things that has strictly belonged to the twilight zone in Western societies but has started emerging in bright daylight.

7. INTERACTION AT HOSPICE

In this section I intend to treat the subject of interaction at the hospice in a general manner. The theme has already emerged in several previous sections as many things are intertwined. In addition to giving an outline I take forward some specific issues.

7.1 Volunteers

As mentioned earlier, most volunteers reported that their social life had become more active due to their work at the hospice. The degree of social involvement depends on the nature of your volunteer work. For example, if you have your own patient friend who happens to stay at his/her own home for the time being, your social contacts with other parties of the hospice may remain nonexistent. However, most volunteers are involved in many social activities. Neither the dying nor the staff are to be thanked for the increase in social contacts of the volunteers: The friendships with the patients often remain short, and there is be a gap between the volunteers and the staff that might prevent close relationships. Thus, the volunteers socialize with themselves, and some of them have become the best of friends. The friendships are not restricted to the setting of the hospice, but they are taken into other areas of life as well.

Despite even close friendships the volunteers are not always a big, happy family. Many of them referred to some disagreements in a vague manner, but simultaneously understated them. By doing so, they reinforced their family-like attitude toward the other volunteers: Normal problems of the "family" are recognized, but nobody wants to say a bad word about a family member. The primary

experience seemed to be the pleasure and privilege of belonging to the group of volunteers.

Guidance of work, arranged by the hospice, was often considered one of the most enjoyable things at the hospice. The volunteers are under promise of secrecy concerning the patients, but in those meetings the volunteers are allowed to talk about matters that bother them. At times when the hospice could not arrange those meetings, some volunteers kept on gathering together without any outside instructor. Some volunteers confided in their best volunteer friend, as one volunteer put it: "We are each other's physicians of the soul". In a sense, the volunteers form a secret society which promotes solidarity among them.

7.2 Volunteers and patients

Although life at a hospice is much more than just waiting for death, it is a place where terminally people come to die. They may stay there only for a few days or even several months. The relationship between volunteers and patients often remains short. However, many volunteers stated that despite the time spent together the relationship can be very meaningful and rewarding. A common view was that the volunteers had learned a lot about life from the patients. Helping someone in a difficult situation of life gives you an opportunity to live a second life. Thus your perspective on life becomes broader and that was what the volunteers were grateful for.

A patient may play such an important role in a volunteer's life that the latter can be envious of all the other people who visit the patient; some volunteers want the patients completely to themselves. It is somehow understandable if you view the volunteer work as a means to feel important

and needed. A jealous volunteer may imagine that the more people are involved with one patient the less important you are. I was once asked whether I minded if my patient was to receive another volunteer. I did not find it necessary to ask my permission, and I was only pleased that the volunteer work would not rest on my shoulders only.

What does the relationship offer the patients? For one thing, the volunteers seem to be simultaneously close enough and distant enough. A patient who thought the world of his wife told me that a volunteer gives her whole heart to the job, and he can talk to a volunteer about things that he cannot talk to his wife. Many volunteers had noticed that it often seemed to be easier for patients to talk to volunteers about certain things than to their relatives:

---And maybe it's so that it's easier for them ((patients)) to talk to volunteers about things that they don't want to talk about to their relatives. Like there are overly painful matter to be discussed with relatives.

The patients may use the volunteers as some sort of garbage pins which I find just fine because volunteers most often do not react as emotionally as relatives would. Patients need to deal with unpleasant things, and it helps when you can talk to someone you trust. And there is no need to be protective about volunteers:

---And my patient said to me that it's good to be with me because he didn't have to keep me company. He probably felt that when friends and relatives came over he had act perky and be talkative.

The patients I talked with found it important that the volunteers do their work for free. For them it was a sign of sincerity; their motives were considered pure and

therefore it was easy for them to trust the volunteers and to have a positive attitude starting from the very beginning.

At Pirkanmaa hospice there is one day a week when patients who are not at that moment at the ward come to the hospice to spend a day with the assistance of the volunteers. During this "day center" the patients go to sauna, have lunch, chat and sing together, and there is a doctor available for check-ups. Every patient has her/his "own" volunteer there during the day, and in addition, there are extra volunteers without patients of their own to take care of the recreation. I got to participate in one of these days, and I was surprised at my observation: There was a very cheerful atmosphere, and it was fun being there. The interaction between the patients and the volunteers seemed very uncomplicated, warm, and joyful. Diseases, pains, death, or any other unpleasant matter did not emerge in the conversations. The topics were retrospective of nature; the patients were reminiscing good old times and shared many happy and funny events of their life with the rest of the party.

Against all expectations, the going was not very typical of elderly, terminally ill people in its cheerfulness. Similar attitude toward life seem to be found at Australian hospice Sacred Heart where the patients party every Friday night by dancing, singing, and drinking (TV-series *Death: The Trip of a Lifetime*, part II). The dying having a good time have apparently internalized the limited nature of life, and they try to live now because it might be too late tomorrow. The appreciation for every moment of life is one thing that many volunteers have learned from the dying, which will be further discussed in 9.3.

7.3 Volunteers and patients' relatives

The family of the dying may spend time without any restrictions at the hospice. Some people practically live there, and therefore staff members and volunteers become familiar to them. Relatives may occasionally pour out their troubles and frustration on the professional and volunteer workers of the hospice, but most volunteers reported having good relationships with them:

---many of these relatives have become really good friends which gives you a feeling that you've been able to deal with that side too although it may be hard. Like we are really good friends and, we go to our children's weddings and, someone might call that now I've got my first grandchild or something. Many of them keep in touch. Or you see someone walking somewhere after a year and you don't necessarily quite remember, you have only a feeling of having seen the person somewhere. Like only recently a young woman came across and took my hand and asked if I remembered because she hasn't forgotten how I was there by her mother's side. Those are that sort of, really great moments.

Those relationships may last for a long time; during the illness of the patient and after the patient is gone. It seems to me that the volunteers may act as links to the memory of the deceased, and meeting the specific volunteer during the period of mourning may be helpful:

There was this one contact with a relative when a female patient's son was often present when I visited his mother. This mother and son has English language as their hobby and we often spoke in English the three of us. And when this mother died, I was at the funeral, this son suggested that could we meet the two of us. So we met several times at some department store's cafeteria and we spoke some English and some Finnish. But then it just faded away naturally after some time.

The relationship with the patient's relatives may not always be uncomplicated but filled with suspicion for the relatives' part. It is not uncommon, and perhaps it is only human, that the relatives question the motives of the volunteer, especially if the patient happens to be wealthy. They perhaps fear that the dying might change the will because of warm feelings or gratitude toward the volunteer, or that the outsider might try to manipulate the dying to do so. As a volunteer reminisced:

---but then again I noticed that a relative did not quite accept me although he could not visit himself that often. So would it be jealousy or something that you wonder if there are some ulterior motives behind my visits. But it's not that often that it happens but, sometimes - although no words had been uttered - I have sensed that maybe it's better if I stay in the background so that there won't be any, of course everybody don't understand it quite.

7.4 Volunteers and staff members

When I first started interviewing the volunteers I had no questions concerning the relationship with the staff. It had not occurred to me to examine their interaction because I had assumed that there was no problemacy at all in it. I thought that the staff was merely grateful for having volunteers to ease their workload. At a very early stage I realized that the situation was not that simple, and I started asking about it from the rest of the volunteers.

Months later I spotted an interesting article which claimed that volunteer helpers in care-taking have caused friction at many places. Vappu Taipale, the president of STAKES, urged the parties to solve the problems at a local level, and believed that a meaningful division of work is possible although the situation can be diverse and multi-

dimensional. She also reminded that volunteer work has a long history in Finnish welfare although the depression promoted it, and it is an essential part of the society. (Korpijärvi 1996, 5.)

There seemed to be a clear division of territory between the volunteers and the staff at the hospice. The actual ward was the staff's territory, and the lounge with the coffee shop belonged to the volunteers. As one volunteer put it, there is an invisible gate between the areas. Some volunteers said that they were getting along just fine, or diplomatic answers were offered:

H: What's your relation to the staff like?
 V: It's just fine yeah. I have to say that if there's been something you have to remember that as you treat others you will be treated yourself. You should be friendly yourself and, I realize that we trouble them by asking where this and that is although we've been here for years, and some of their time go wasted. I've been thinking about it and realized that you have to remember that you get treated as you treat others.

But if we are to assumed that there is tension between the volunteers and the staff, what does it involve? My first thought was that the staff might feel threatened by the volunteers and be afraid of losing their jobs. Some volunteers offered similar kind of explanations:

---There are some people who understand the nature of volunteer work but then there are others who don't. No matter how you'd explain that we, for example I'm from the field of [] and I could by no means eat their bread, because I don't have any training in health care whatsoever. And I do this work for free.---

---The depression has been going on and the staff has been thinking that we somehow step on their toes or we take their wages or something like

that. There's been a fairly huge gap between the staff and the volunteers. We don't want anything from them, we don't want to do this work to harm them, there's nothing like it. We all have a lot to learn.---

When you take a closer look at the issue you find that the problem does not lie at the alledged fear of staff members losing a job. If that would be the case you could assume that the volunteers with a training in health care would have the most unpleasant experiences in their relation to the staff. However, it seems that the persons who could act as professional threats actually get along with the staff better than the others:

---I guess I'm in a better position in relation to the staff than some other people who don't have training in health care. My relationship with the staff is less complicated.---

---The way the staff respond to the volunteers was awfully good. Like it wasn't like oh no they're here again and they're on our way. I really felt doing something meaningful.---

It is probably that people with similar training understand each other well. They, so to speak, speak the same language which lessens false expectations and problems in communication. Moreover, mutual respect which is essential in cooperation is easily built among people with similar training, and the parties are professionally at the same level in hierarchy.

If the volunteers with training in health care get along fine with the staff, what is it that cause friction between the majority of volunteers and the staff? I imagine it is a tangled skein with various factors. One possible explanation could be that the staff would like to spend

more time with the patients, to get a good contact with them but their time is limited and their work consists mainly of technical, mechanical procedures which are not that rewarding. I can imagine that a patient is more grateful to a volunteer with whom you can spend time talking than to a nurse who comes to give you an injection. Maybe some nurses are envious of the close contacts that the volunteers are able to make with the patients. As a volunteer put it:

---Many times you can have a closer relationship with a patient than a nurse has because they don't have time no matter how much heart you would have to be with a patient. And then it can cause jealousy or something like that.---

Naturally jealousy is not some common characteristic of the staff although it can occur. As a staff member, who sounded mature in every respect, wrote: "I do not view them ((volunteers)) as rivals but co-workers whose presence is a valuable aid to the patients and their close ones as well as to us employees".

Hospitals are often considered as rigid in their hierarchical systems as, for example, the army. If that is the case, volunteers may represent chaos in a well-defined system. After all, the position of volunteers is somewhat vague; there are no exact and detailed rules on what they can and cannot do at a hospice. Volunteers with a training in health care must be more aware of the "hidden curriculum" of the field than the rest of the volunteers, and they know how to act and behave accordingly. But the majority of volunteers cannot use the existing code of behaviour, and they do not have one of their own that would be harmonious with the existing one.

7.5 Patients and their relatives

"This kind of place is absolutely wonderful because here you can be a relative around the clock without being responsible for the treatment", a volunteer described the situation at the hospice. Tuija Saarinen (1994, 22) wrote about the relief she experienced when leaving her husband at the hospice:

When I closed the hospice door behind me that August night and went home with Niina and Valtteri, I felt how an enormous burden had fallen off my shoulders. That burden wasn't Rauno but the tremendous doubt of not being able to help Rauno, despite my love, in that painful, insecure, and frightening situation of life. I didn't feel like I was deserting Rauno but I knew that I had found a haven where we could live and love each other to the day of his death. I had to share the responsibility of Rauno's illness with the hospice so that our love would not die but that it would be our strength in the face of death.

Not only the worries of the family members are eased but those of the patient as well:

The fears stemming from the insecurity had worn out Rauno's strength. The knowledge and the security of the staff brought back Rauno's confidence which revived his strength to live. The hospice offered us both a place where we could live together the days that were meant for us. We both knew in our hearts that despite the longing the other one had it as well as possible. (Saarinen 1994, 33.)

At the hospice the family with small children could live as normally as possible. The children were able to be children and play like they used to. The family spent ten months at the hospice which holds good memories: "Despite Rauno's serious illness the hospice became a place where we can always return to reminisce". As Saarinen (1994, 46) concluded:

At the hospice our family found a haven where it was good for Rauno to die. At home or at hospital our love might have died. Our love continued existing at the hospice. At our home life continues and memories fade out. At the hospice I kissed Rauno on his forehead for the last time. I meet with that memory every time I return to the hospice.

The hospice principle is that not only the patient but the family as well is taken into account and supported in a life situation that is bound to involve every member of the family. Therefore it is no wonder that the hospice system seems to be ideal for most families, and voices of complaint are seldom heard.

8. FEATURES OF VOLUNTEER WORK WITH THE DYING

8.1 Practicing death

An essential feature of the volunteer work among the dying is that the volunteer is able to be simultaneously close enough to death to see its face, and far enough to be safe from it. If you view death as a somewhat problematic matter for most people, volunteer work can act as an ideal aid in dealing with it. No matter how close a relationship you could have with the dying, you remain an outsider in the death of the patient. Therefore, a volunteer is not blurred with mixed emotions as family members usually are, but is able to examine and learn from death and dying in a real situation.

Many volunteers who had witnessed the death of their patient friend considered themselves blessed and fortunate. Death as a phenomenon, as birth as well, seems to mean for most people something most unique and sacred, at least when it happens to somebody else than yourself. Fears of death are not present when the other person dies, and after witnessing the death of the other your own fears often diminish or vanish. Even the mere sight of a dead person may have the same effect:

---I had visited her a day before and noticed that she was kind of drowsy but I hadn't imagined that the end would come at that stage yet. When I came here the next morning and saw her dead, she was so, she somehow looked so happy and she had a beautiful smile on her face. After that my view on death changed completely because she had an easy death although until then she had cancer and terrible pains as you have when death approaches. But then when I saw her happy smile my view just changed.

Those volunteers who had not been present when their patient had died, wished that they had been. Likewise, I would have liked that my patient friend had died at my presence. That is somewhat peculiar because I have never even seen a dead person, nor witnessed someone die. Why would I have wished to experience a completely new situation? Maybe there is a hidden fear of death which I would like to overcome by witnessing it. In addition to overcoming fears of death, it may be that death causes that kind of excitement that modern people pursue.

I remember an occasion when I went to visit my patient friend at her home. I had called before I left to make sure that she was at home, and I knew that she was a light sleeper. Therefore, I was puzzled when I rang the door bell several times and nobody came to answer. I started panicking and had a hard time trying to think straight; should I call an ambulance or the janitor or both? My heart was bounding and I imagined what kind of sight it was that would meet me at the apartment. I decided to rang the bell once more before I took any action. Then the door was answered, and I felt somewhat disappointed which I am ashamed to admit. What is wrong with me? Is it only me or does it apply to other people as well?

I heard bells ringing when I read about "making aesthetic" which is one of Ziehe's (1989, 158-159) searching movements. There is not necessarily anything aesthetic about death or its potential in a conventional sense, but it may offer the ultimately intense, exciting experience. Death is literally out of this world. Our modern world is full of wonders but eventually they may suffer from inflation. Modern man seems to have seen it all, and more excitement and novelties are graved for. I suspect that even virtual realities cannot compete with death which is simple but mysterious and, most importantly, it is not

anything make-believe but for real. That could be one reason for why people seek themselves to the vicinity of death, or why they stay there, and act as some sort of Peeping Toms.

8.2 The sense of holyness

An apparent analogy between the hospice and the church emerged in many stories of the volunteers. The hospice was commonly considered a place where one could calm down and experience a sense of holyness:

---This house is such an amazing place in a way that when I was still working every day, was busy all the time, and when I drove here and almost ran through the door and I wondered how to be able to keep up the pace when I had to rush everywhere. When you opened the door amazing peace and quietness - not that kind of quietness that a house of death would have as they may say - but you are met with such a tranquillity when you pass the threshold and then you are overwhelmed by a feeling of how wonderful it is to be here.

The hospice as a site is given sacred meanings which seems to be the result of death occurring there. As shown in 7.5 the hospice may become the place of pilgrimage for the relatives of the deceased. Not only death and its site receive sacred meanings, but the dying have their share in holyness as well which seems to rub off to the people close to them. Although I visited my patient friend at a hospice I always got a feeling as if I had been to church; namely the feeling of having done some good deed and getting closer to spiritual matters. During my visits I often read the Bible out loud when asked, but reading some women's magazine had the same effect. In working with the dying you become a participant in the holyness the dying are considered to possess.

It seems to me that nowadays religiousness has partly turned into spirituality, and death represents it for many people. As a volunteer stated: "---the cemetery is more like my church and that's where I feel more comfortable than at a real church." Although nobody really knows what happens in death or after death, it involves a dead body which, with its tangible nature, is easier to grasp than some abstract, religious doctrines. Therefore it appears to me that modern religiousness, spirituality, is often defined through corporality which is strongly present in every other area of our culture as well.

8.3 Present and return present

In the interaction between patients and volunteers presents are exchanged as in any other social relationship. However, the content and the system of exchanging gifts are unique and deserve scrutiny. Marcel Mauss has studied the form and reason for exchange in archaic societies, but he noted that it is possible to extend his findings to our modern societies and lives where the same atmosphere of the gift, with its obligations and liberties, is still present (Mauss 1990, 65). Levi-Strauss (1969, 52-68) developed Mauss's idea on the gift and showed that the principle of reciprocity still flourishes in our modern societies, especially at Christmas time.

According to Mauss each gift is a part of a system of reciprocity that involves the honor of the giver and the recipient. The system engages a rule that every gift has to be returned. The whole idea of a free gift is based on a misunderstanding, and there should not be any free gifts because it puts the act of giving outside any mutual ties. A free gift does not enhance solidarity, and therefore it is a contradiction. (Douglas 1990, vii-viii.)

If you do not look beneath the surface, volunteer work may appear as charity, a free gift, which it is not. At the hospice there are three parties involved in the system of the gift, namely in volunteer work: the hospice, the patients, and the volunteers. The hospice receives free labour from the volunteer workers and gives them the right to belong to a certain group. The reciprocity system between the volunteers and the patients is more complicated. The volunteers give the patients some of their time which is used according to patients' wish. The patients are not expected to return the services in any direct way to the volunteers because they are dying people who never get back on their feet and who are not able to perform any services. However, what the patients give the volunteers is like a by-product of the interaction; the volunteers are able to learn from the life and death of the patient which the volunteers consider most valuable.

Lindqvist (1986, 116) rightfully points out that in order to be able to give one needs to get something for himself; a person requires as much strength as he has to give away. But according to him, only training, team cooperation, guidance of work, and personal therapy are important sources of strength; they are all outside sources that do not involve the relationship with the ones that need help. I protest against Lindqvist's view of patients as strength-taking, bottomless recipients that easily wear out those who take care of them and offer nothing in return.

Patients do have something to offer their helpers, but because the patients' gift is like a by-product of nature, the patients do not necessarily realize that they are actually giving the volunteers something in return. It may bother them if they do not acknowledge their exceptional free-rider position in the system. For one, my patient friend felt anxiety because she thought that she could not

pay me back in any way. Therefore, she was most pleased to hear about the subject of my pro gradu thesis, and that I could use my experience of the volunteer work with her in my work. Mauss (1990, 65) wrote that even today the unreturned gift makes the recipient inferior, especially if he has accepted the gift with no intention of returning it. It might be the case in any other form of interaction, but not in the interaction with the dying, death representing the escape from the reciprocity.

As mentioned earlier, most of the volunteers felt that they get more from their work than they are able to give. But what is it that they get or expect to get? You might think that these elderly women are concerned about their own approaching old age, and by helping the old and the dying they somehow try to make sure that they would be treated the same way if they ever needed help. However, that is not the case. In fact, one volunteer was even appalled by the mere thought of having to accept help from anybody, especially strangers:

Your own sickness is a complicated matter when you live alone, and I'm so selfish - not only independent - that I rather do not accept help from strangers. Even though I myself now help out one 88-year-old person, even though it took a while before she agreed to it. I'm not afraid of illnesses but I'm afraid of needing outside help if I get to be so sick that I need help. --- I would leave it to the last moment that I would ask anyone for help.

The attitude of the volunteer probably stems from her own personal history and the fact that she had had to manage on her own in many difficult life situations. The volunteer felt responsibility for an old woman but did not expect reciprocity; the intersubjective relationship is asymmetrical, as Levinas (1996, 80) put it. According to him, the identity of human self is defined on the basis of

responsibility. One is responsible for the other without expecting reciprocity. While the human subject is totally in a subordinate position, the responsibility makes the person irreplaceable; nobody can take the person's place. (Levinas 1996, 80-82.)

The volunteers do not expect to get their reward in the near future if they happen to need help from other people. Nor do they perform good deeds in order to be paid back after death; the volunteers do not pursue their place in heaven. There is no need to do that because, as mentioned earlier, afterlife is viewed as heaven-like if anything. In the system of the gift in this particular case, there seems to be a strong **here and now** mentality. This is where we come to hedonism: Volunteer work makes its workers **feel good** which acts as the reward, the return gift.

However, pleasant feelings are not the only ones that are involved in the work with the dying. Many volunteers told that after their visits they are often melancholy and need to watch some silly TV-programs, do crossword puzzles or something totally different to get their thoughts away from the sad life stories. The grim fate of the patient friend makes you sad, but the fact that you have tried to do something for him makes you feel good about yourself which usually exceeds possible bad feelings. After all, you cannot change the circumstances, you are not able to cure anyone, but doing volunteer work you can do what can be done. Thus, rationality makes the good feeling the topmost feeling.

The good feeling does not last for long, therefore it must be repeated regularly. It may become an addiction. I could say that volunteer work is like jogging; you do not necessarily like to go for a jog, but you remember from the previous time how good it made you feel, and that is why

you start putting your running shoes on. As one volunteer put it:

Volunteer work gives a lot of meaning to my day, I probably get a lot more out of it than I'm able to give, at least that's how it feels. When I've been away for a week I really miss it although I may leave the house in a doubtful state of mind thinking that nothing comes out of my being there that day or something like that. But when I've been here for half a day or so, I get such a peaceful feeling and, well a very good feeling to myself.

What comes to feeling good, I have noticed a terrible contradiction. Namely, your feeling good provides that the patient feels bad. In fact, **the worse the patient feels, the better it makes you feel.** It may sound strange at first, and therefore it deserves an explanation: It is characteristic of cancer that it makes the patient feel sometimes almost fine and sometimes very bad. If you happen to visit the patient on a good day, you may not necessarily feel yourself so needed. On the other hand, on a bad day the patient may welcome you with open arms and you may get a feeling that your visit really makes a difference. You are able to console the patient and lift up the spirits, and you notice that you leave the patient in a better shape than what he was when you first came. The patient feeling bad is a prerequisite for making him feel better which causes your own good feeling.

9. THE MAKING OF THE VOLUNTEER IDENTITY

The volunteer work with the dying is not that simple that you do your job, go home and that is it. So much more is involved when the identity of the volunteer is concerned. A helper makes simultaneously a two-way trip both to the reality of the patient and one's own reality (Lindqvist 1992, 160). In this section I try to illuminate the trip to one's own reality by examining identity matters of the volunteers.

9.1 Identity as reflexive project and a situational formation

Identity was one of the grand promises of the modern era. It was hoped that the domination of collective suppression would come to an end and that identity would be based on one's own person and responsibility. As a result remaining true to oneself became one of the major demands on the modern individual. In modernity identity becomes more mobile, multiple, self-reflexive, and subject to change. It is personal and yet social. Identities are still relatively circumscribed and limited although the boundaries of possible identities are continually expanding. As the pace, extension, and complexity of modern societies accelerate, identity becomes more and more unstable and fragile. The problem of identity consists of how we constitute, perceive, interpret, and present our self to ourselves and others. (Hoffman-Axthelm 1992.) The hospice acts as a setting where the volunteers search for authenticity and meet with demands of remaining true to oneself. In general, volunteer work can be regarded as one way of doing identity work.

Giddens (1991, 32, 52) claims that the reflexivity of modernity extends to the core of the self and the self becomes a **reflexive project**. Self-identity is something that has to be routinely created and sustained in the reflexive activities of the individual. The problemacy of identity is present in the writings of Lasch (1978) as well. According to him the modern man experiences inner emptiness, loneliness, and inauthenticity. There is an inner void, a frightening experience of being nobody with a collapsed identity; there is nobody inside you. (Lasch 1978, 21-25.) Where is my own self? How can I find it? Yankelovich (1981, 242) proposes that you do not "find yourself", the essence of self, by looking inward because there is no "real" me to be found. In the search for self you must set your direction outward. Yankelovich (1981, 239) offers the seekers of self-fulfillment the Christian guideline that one must first lose oneself to find one's self. That is not a bad piece of advice because it seems that is exactly how many volunteers have found themselves, in helping other people.

I see no contradiction in the possibility of viewing identity simultaneously as a reflexive project and on a smaller level as having various situational properties as frame analysis does. Namely, it rejects the idea of permanent subjects. A frame does not only define a situation which is interpreted, but it also defines how the subject interprets himself and how the others do it. The identities vary with the frames which does not equal with people being superficial or unreal. It is just that social life is so constructed that people are required different qualities in different situations. (Peräkylä 1990, 22-23.) All in all, I assume that you have to create your own self which is a life-long, reflexive project. I try to illuminate how the interaction with the dying and other parties at the hospice affect the creation of self among

the volunteers. In addition, I take a brief look on micro level formation of identity realized in situational frames.

9.1.1 Volunteers and their unprofessional identity

If we view identity as a multiple, mobile construction, an unprofessional identity is something that comes naturally from the volunteers, and it is a quality that seems to be required of them in their work. The volunteers usually do not have any professional training in care-taking and thus no restraining role expectations of themselves which can be considered an asset. There can be a certain double role for the workers in professions involving other people: A professional self which has roles different from those of for example patients. The human self is closer to patients and feels empathy toward them. Between the two roles there is tension that is either creative or destructive. (Lindqvist, spoken communication.)

The professional role is usually viewed as imperative in order to protect oneself from excessive strain, as Lindqvist does. My view is that the more you try to protect yourself, the more you get hurt. I see there an analogy with love; if you try to protect yourself from it, you are bound to get hurt or you just do not get anything from it. It seems to me that most volunteers put their whole personality to the job without worries of role expectations, and therefore they can get a great satisfaction from the work.

If you take Peräkylä's (1990) four different frames into consideration, layman frame is the main domain of the volunteers. Feelings and experiences are essential in that frame, and the identity of the staff (in this case the volunteers) is a subject that feels and experiences and is

involved with the death of the fellowman. (Peräkylä 1990, 18, 23.) However, I do not claim that the volunteers keep themselves to layman frame at all times. Let us look at a imaginary fragment of conversation between a patient and a volunteer:

Patient: The nausea is always there, and I feel real bad just before my shot.

Volunteer: I'm sure you do. I bet I can't even imagine what it's like to feel sick in your stomach all the time.

Patient: I bet you can't. Today I feel exceptionally sick. Maybe you should stay a bit longer because it could be that this is the last time we ever see each other.

Volunteer: Yeah, you never know. I might get hit by a bus on my way home.

In the first reply the volunteer feels for the patient and acts empathically according to layman frame. Then the patient implies that he might die shortly and tries to take an advantage of it. In order to stop the patient wallowing in self-pity the volunteer shifts away from layman frame to that Peräkylä (1990, 18,23) calls psychological frame in which feelings and emotional reactions aroused by death are analysed and directed. Thus, professional staff is able to use layman frame, and it should be easy because they are ordinary people with professional training in health-care. In addition, the volunteers are able to use, or imitate, psychological frame, but its basis is different because they do not have professional training and thus no knowledge on roles and their expectations. Instead, the volunteers use common sense and common social skills in their quasi-professional role.

The strain of professional conduct hang over a volunteer with an education in health-care. She felt that she was being overly sentimental when she once took a piece of apple pie to her patient so that the patient could taste

the apples of his last autumn. With my background, I did not feel guilty of always taking samples of my baking to my patient. On the contrary, I felt guilty if I did not have anything to take with me. Volunteers, including me, usually employ their unprofessional layman frame in the interaction with the dying. They take forward their own personality which is often considered most negative in professional care-taking relationships. It has been commonly thought that using your own personality is selfishness and deprivation of space from the patient. (Lindqvist 1992, 76.)

9.1.2 The way you see yourself

As shown in previous section, volunteers are met with situations that require them of different kind of characteristics that, in turn, affect the way you see yourself. The interaction with the dying you may result in causing more permanent characteristics that are independent of some specific situations. Those characteristics may have not emerged in other life situation, or some old traits of character are activated and become stronger. You may find that you possess for example more empathy and patience that you had imagined, and you like what you see in yourself. Naturally it is possible that the volunteer work with the dying would bring about negative experience; you notice that you are not the least suited for that kind of work. I just have not heard of any such cases.

It seems that for some people, volunteer work has received addictive features. In the data of interviews there were some accounts on how the volunteers felt that they absolutely **needed** the work. One volunteer told that she started feeling almost sick if she did not get to be at the hospice regularly. According to Giddens (1991) addiction is

involved with self-identity, addiction being one tribulation of the self that can be regarded as a result of detraditionalism. The threat of personal meaningfulness is ordinarily controlled by routinised activities that sustain ontological security (Giddens 1991, 201). Volunteer work at the hospice may mean security and meaning in life, and without the work there could be feelings of being lost. When I lost my patient friend I felt I had been deprived of something important in addition to the person who had died.

9.1.3 The competitive self

How other people see you is a crucial feature in the way how you see yourself. In fact, it can be claimed that a self cannot be described without reference to those surrounding it (Taylor 1989, 35). We always define our identities by having a dialogue with the identities that the significant other people see us to possess (Taylor 1995, 62). Reflexivity is apparent in the story of how one volunteer happened to start her work as a volunteer: A respected member of society asked her to join in which the woman did. "And because other people thought that I could make it I went to the course to see how it would feel."

The way how other people see you seems to be very important for some volunteers. For example, it is not unusual to constantly tell stories that are most favourable to you, stories that make you look good, as if your existence depended on it. Some volunteers at the hospice had noticed the same thing, and the competition of the superiority was criticized as a negative phenomenon:

Well now, let me mention one negative thing that can be found anywhere - because we are human - especially at places where there are plenty of women working together. It can turn very suddenly

into a competition of who it is that's best. I put it this way. The hierarchy doesn't bother me at all because I have this attitude that my livelihood did not depend on it and I didn't go there to score some points. But it soon turned into a competition, that some people wanted to be more than some others. And then it bugged me that in the gatherings of the volunteers it was always emphasized whether we were appreciated or not. And I found it silly. At least I didn't go there to have my appreciation to be measured. If there's something to be looked up in me I will certainly be appreciated. But is there's not, I won't be appreciated. So I felt that all that was completely unnecessary.

The volunteer who did not seek appreciation had a Christian view of life, a belief in God. Another believer did not take the credit of her good deeds to herself, as material for positive self image. "--- when you come to think of it, you're nothing but an instrument because everything good comes from upstairs. And we are only channels." Because of the outlook of these people, it is not important for them how the other people see them, and therefore they find no need to be competitive about their work and to pursue a higher place in hierarchy. Even though you regarded yourself merely as a channel through which God works, volunteer work may do wonders to your self image. If you get positive feedback from the patient, it is bound to influence the way you see yourself. Despite the truth-value of the feedback, the patient is the most prestigious person to evaluate how you have succeeded in your work.

Portraiting yourself in a positive light and competing with others are linked with the need of getting recognition and admiration. Lasch (1978, 10) writes about the personality of our time, the narcissists who depend on others to validate their self-esteem and cannot live without an admiring audience. The culture of narcissism, which is claimed to gain a foothold in all Western cultures, is

closely related to Taylor's (1995) culture of authenticity which is characterized by the need of getting recognition. The conception of self-identity stemming from the ideal of authenticity has molded and enforced the importance of getting recognition. Our identity requires recognition from other people, the importance of which is nowadays commonly accepted in one form or another. (Taylor 1995, 73, 75, 77.) I view volunteer work with the dying as one form of getting recognition necessary to self-identity.

The competitive nature of the self is by no means exclusively characteristic to people involved in volunteer work. The reflexive nature of the self causes the competition, the need of being better than the next person:

There are various ways in which we can realize that self. Since it is a social self, it is a self that is realized in its relationship to others. It must be recognized by others to have the very values which we want to have belong to it. It realizes itself in some sense through its superiority to other, as it recognizes its inferiorities in comparison with others. (Mead 1934, 204)

The sense of superiority does not necessarily mean that the person wants to lower others to get himself in a higher position. But there remains a constant demand to realize one's self in some kind of superiority over other people. (Mead 1934, 205.) In this case, it is an undeniable fact that some volunteers try to realize themselves in comparison to other volunteers. I see wisdom in an opinion that a helper cannot solve his own life problems by becoming a helper for other people, and that one needs to accept oneself and to be enough for oneself without performing and seeking for external recognition for one's goodness (Lindqvist 1992, 198).

9.2 Volunteers as modern hedonists

In our times people are claimed to suffer from personal meaningless, the feeling that life has nothing valuable to offer. Or that people are losing their ability to feel. (Giddens 1991, 9; Lasch 1978, 11.) Many of the volunteers had sought for something worthwhile in some turning point of life and found their star at the hospice. And the lives and deaths at the hospice are bound to evoke any person's world of emotion if you are concerned about your ability to feel.

According to Campbell (1987, 69) the key to the growth of modern hedonism lies in the shift of main concern from sensations to emotion because the latter can offer powerful and prolonged stimulation. In the hedonistic self-fulfillment individuality becomes secured when the motivation for action lies at one's internal world which is expressed by talking about the primary meaning of feelings and emotions. When a person has turned to himself and started listening to himself he is on his way to hedonistic self-fulfillment. But he needs to do something more to be assured of his authenticity, namely to pay attention to situations that arouse feelings. Hedonists tend to seek themselves to stormy situations that cause strong, intense emotions. (Jallinoja 1991, 74-75.)

Because "negative" emotions often bring about stronger feelings than others, they provide a greater potential for pleasure. The emphasis is not on the emotions that can supply most pleasure but the right circumstances that are required before any emotion can be used for hedonistic purposes. Before any emotion can become enjoyable it must become subject to emotional control, adjustable in its intensity, and separated from its association. Modern hedonism provides all individuals the possibility of being

their own despots, exercising total control over the experienced stimuli, and thus the pleasure they receive. It is gained through a degree of control over the meaning of objects and events. (Campbell 1987, 70, 76.)

What does all this have in common with volunteers working at a hospice? After all, volunteering at some institution sounds a rather traditional form of action. According to Jallinoja (1991, 77) the boundaries between modern and traditional have started becoming obscure, and, in principle, anything may become the target of self-fulfillment because you can get an emotional experience from practically anything as long as you feel that you can react to some stimuli. Therefore, you can fulfill yourself in some community and by taking care of other people or common well-being.

This kind of volunteer work is mostly done with your heart. Feelings, emotions are strongly present in every aspect of the work: They are involved in the interaction with the patients. Discussing your experiences and feelings are the main material in the guidance of work of the volunteers. There is a strong demand for honesty and authenticity. The whole world of hospice is saturated with emotions, good and bad. The hospice creates circumstances in which negative experiences and emotions are not necessarily repellent and fatiguing. On the contrary, the death of the other may make you feel most alive. Although emotions are essential in the work with the dying, most volunteers who continue with their work are able to practice emotional control; to decide the nature and strength of feelings. In the hospice environment the volunteers work in a position that create and require **ambivalence of emotions**; to be a human self and to throw oneself to the job emotionally unprotected in an unprofessional manner, and to practice emotional control.

Below surface, volunteer work with the dying may be one form of hedonistic self-fulfillment but not just like any other one. Yankelovich (1981, 7-8, 225) claimed that at least in America people reassessing what is sacred and what is instrumental in life, and they have a yearning to elevate the "sacred/expressive" aspects of their lives and, at the same time, to downgrade the impersonal or manipulative aspects, instrumental forces. Behind the search for self-fulfillment search there is the moral intuition that the very meaning of life can be found in its sacred/expressive aspects, and therefore they deserve to be respected.

This analysis on American life could hold true in Finnish life as well, and volunteering with the dying might be one attempt to heighten the sacred/expressive elements in life. In my view this kind of volunteer work offers both sacred and instrumental elements. The elements are combined so that often the instrumental aspects are disguised in the sacred ones. And I would go even further by claiming that even the sacred elements have instrumental value, and they are used to foster the search for self-fulfillment. With all this I do not mean that there is something wrong with self-fulfillment or it being realized in the volunteer work of terminal care. On the contrary, because the search for self-fulfillment is characteristic of our time it is only positive that can be realized in activities that benefit also other people; those who are in need of help from other people. It is like killing two birds with one stone, even though the saying might not be most appropriate in this context.

9.3 The meaning of volunteer work to your self and life

In addition to death becoming tamer than before, most volunteers saw that the work at the hospice had changed them in some ways:

I feel that this job has somehow given me so much. I think that I wouldn't be exactly the same person if hadn't found my way over here. Like I think it's a really significant thing in my life that I've found this place. And this is not merely fun here because of all the troubles in the personal relationships and all. But they are part of every job. And those crises always take you forward.

The nature of man was often viewed as changing and evolving. The hospice with its people was regarded as a stage where one can learn valuable things to develop oneself as a human being and to improve the quality of life. The personal changes the volunteers reported were always something positive. Some volunteers said that only at the hospice they had learned to take other people into consideration; their unselfishness had increased. Some volunteers had noticed that they had become more patient and learned how to listen which is also my sentiments. Similar kind of views were found in Molander and Parviainen's (1996, 38) study on people working with the dying. The work was considered enriching, and its workers reported that it had helped them grow as human beings and taught to see shades of grey instead of only black and white.

"Man has to live in the shade of death, and the one who clings to life and enjoys its fullness has to be afraid of the threat of life coming to an end. The one who is face-to-face with death turns to the promise of life." (my translation) (Malinowski 1960, 49.) That is exactly what seems to have happened in the lives of the volunteers. The

limited nature of life is realized at the hospice, and thus life itself is more highly appreciated. The emphasis has shifted to the present day which is worth living to the fullest; it has almost become imperative. Seeing someone die and maybe suffer helps you put your own troubles in proportion when you compare your life with those of patients. Many volunteers told that they have ceased complaining about little things, and they gratefully see their own lives happier than before.

10. DISCUSSION

This study was an attempt to capture the essence of the phenomenon of women working as volunteers with the dying at a hospice. Women taking care of the dying is not some new phenomenon but apparently an ancient one, but hospice volunteers and volunteer work with the dying is a subject that has not been studied widely. Therefore, I hope that I have been able to illuminate the issue and to make fair interpretations concerning it.

I found out that the heterogenous group of volunteers had various reasons for volunteering, but a common factor was that there had been some rather significant turning point in life involved. They were all searching for something to fulfill their lives with; to have a meaningful life. And their expectations were even exceeded: A common feeling was that they get more than they are able to give. At the hospice the volunteers had found a small, warm community which was often considered an authentic oasis in a pretentious world. The hospice was given even meanings of holyness. The volunteers work at the hospice because they feel that they need to be working and because they like the rewarding work at the hospice. The work with the dying had often made the volunteers appreciate life in a greater extend. The volunteer work is not a free gift to the hospice and the patients, but a system of exchanging gifts exists between the volunteers, the patients, and the hospice.

Attitudes toward death had often changed along with the work at the hospice. Most volunteers had ceased to dread death and dying. However, death received different meanings depending on whose death it is that is involved, where the death takes place, and how it happens. A good death for most volunteers was one in which the dying person was

prepared for it and accepted it; the internal conditions were considered most important. The majority of the volunteers believed in some kind of afterlife which was commonly regarded as something heaven-like.

In this study volunteer work was regarded as one way of working with your identity; constituting, perceiving, and presenting your self to yourself and other people. The reflexive nature of identity came forward especially in the competitiveness that had sometimes occurred among the volunteers. The volunteers are required of even contradictory properties of identity; to act as a fellow human beings who do not try to protect themselves emotionally, and to practice emotional control, to separate emotions from their association. Volunteer work with the dying may be considered one form of hedonistic self-fulfillment in which sacred elements of life are elevated. All in all, my interpretation is that volunteer work with the dying at a hospice is a phenomenon in which traditional and modern features are intertwined.

What should we be thinking of this all? What is the social relevance of the phenomenon? It appears to me that the hospice creates a social world of its own which is like a peculiar oasis in the very different kind of world outside. I have tried to describe and analyze a phenomenon which is restricted to a certain place and it seems to remain that way. The volunteers come from the outside world, but they come to the hospice to find and fulfill something, or to escape something. It seems that there is an invisible one-way street sign that points at the hospice. Therefore, I suspect that interacting with the dying and helping them will not become a general, frequent phenomenon, one factor of strength in a society. Furthermore, I doubt that death would eventually receive the meanings outside the hospice that it does inside it. But then again, I could be very

wrong, and the hospices and their volunteers would become the pioneers in a brave, new world in which death and dying are taken out into the open and the dying people back to the society as its full members.

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APPENDIX 1. Teemahaastattelukysymykset/ Interview questions:

YLEISTÄ/ BACKGROUND INFORMATION

- ikä/ age
- sukupuoli/ sex
- koulutus/ education
- perhesuhteet/ family relations

TYÖ JA AJANKÄYTTÖ/ WORK AND LEISURE:

- Mikä on mielestäsi työtä? (Onko vapaaehtoistyö työtä?)/ What do you regard as work? (Is volunteering work?)
- Millainen on suhteesi työhön?/ What is your relation to work like?
- Mitä teet työkseksi?/ What do you do for a living?
- Koetko työsi raskaaksi?/ Do you consider your work hard?
- Millaisia töitä olet tehnyt?/ What kinds of work have you done?
- Mikä on tärkeintä työssä?/ What is the most important thing about work?
- Mikä on huonointa työssä?/ What is the worst thing about work?
- Millaisia harrastuksia sinulla on?/ What kind of hobbies do you have?
- Paljonko niihin menee aikaa päivässä/viikossa?/ How much time do they take per day/week?

VAPAAEHTOISTYÖ/ VOLUNTEER WORK

- Mikä sai sinut lähtemään vapaaehtoistöhön?/ What made you volunteer?
- Ovatko motiivisi muuttuneet työn myötä?/ Have your motives changed along with the work?
- Kauanko olet tehnyt tätä työtä?/ How long have you been doing this work?
- Millaisia odotuksia sinulla oli, kun aloitit vapaaehtoistyön?/ What kind of expectations did you have when you first started with the work?
- Miten todellisuus on vastannut odotuksiisi?/ How has reality met with your expectations?
- Mitä työhön kuuluu?/ Mitä tehtäviä sinä teet?/ What does the work include?/ What is it that you do?
- Mikä on mieluisin tai helpoin työ? Miksi? Which chores are the nicest or easiest ones? Why?
- Mikä on helpointa/ mukavinta työssä? What are the easiest/ nicest things about the work?
- Mikä on raskain työ? Miksi? What is the hardest job? Why?
- Mikä on vaikeinta työssä?/ What are the hardest things

about the work?

-Valmistaudutko jotenkin erityisesti työhön? Jos kyllä, miten?/ Do you prepare yourself for the work in some way? If yes, how?

-Mitä ajattelet työn jälkeen?/ Miten työ sinuun vaikuttaa?/ What do you think after the work?/ How does the work affect you?

-Millainen on suhteesi saatettavan omaisiin?/ What is your relationship with the relatives of the patient like?

-Mitä saat vapaaehtoistyöstäsi?/ Mikä on työsi merkitys sinulle?/ What do you get from the volunteer work?/ What does the work mean to you?

-Mitä menetät työn vuoksi?/ What do you lose because of the work?

-Mitä arvelet työsi merkitsevän saatettavallesi?/ Minkälaista palautetta olet saanut?/ What do you think your work means to your patient?/ What kind of feedback have you received?

-Oletko saanut koulutusta tehtäviisi? Onko se ollut riittävää?/ Have you received training that you need in your work? Has it been adequate?

-Saatko tarpeeksi tukea hoitokodilta työhösi?/ Has the hospice given you enough support concerning your work?

-Koetko vapaaehtoistyön yksinäiseksi työkse vai ovatko sosiaaliset kontaktisi kenties lisääntyneet toiminnan myötä?/ Is your work lonely work or have your social contacts increased along with the work?

-Oletko tyytyväinen siihen, miten hoitokodissa vapaaehtoistyö on toteutettu? Jos et, mitä parannuksia toivoisit?/ Are you satisfied with the ways in which volunteer work is being organized at the hospice? If not, what kind of improvements would you suggest?

-Mitä teet, jos työ alkaa väsyttää/ahdistaa sinua?/ What do you do if the work makes you tired/causes anxiety?

-Onko sinulla mahdollisuus työnohjaukseen?/ Do you have an opportunity to participate in guidance of work?

-(Jos lepäät tällä hetkellä, miksi?) (If you are not active right now at the hospice, why?)

SYÖPÄ/ CANCER

-Onko sinulla tai läheisilläsi ollut syöpäkokemuksia?/ Have you or your close ones had cancer experiences?

-Millainen on suhteesi syöpään?/ Millaisia tunteita sana sinussa herättää?/ What is your relation to cancer like?/ What kind of feelings does the word cancer arouse in you?

-Miten suhtaudut sairauksiin yleensä?/ How do you react to illnesses in general?

-Mikä sinua eniten koskettaa syövässä?/ What touches you the most about cancer?

KUOLEMA/ DEATH

-Oletko kokenut läheisen ihmisen kuoleman? Miten?/ Have you experienced the death of a close one? How?

-Oletko kokenut saatettavasi poismenon? Miten?/ Have you experienced the death of a patient friend? How?

-Millainen on suhteesi kuolemaan?/ What is your relation to death like?

-Jos olisit kuolemansairas, miten haluaisit itseesi suhtauduttavan?/ If you were terminally ill, how would you like people to treat you?

-Jos saisit päättää, miten ja missä haluaisit itse kuolla?/ If it were up to you, how and where would you like to die?

-Onko vapaaehtoistyö muuttanut suhtautumistasi kuolemaan? Miten?/ Has volunteer work changed your attitude toward death? How?

-Millainen mielestäsi on kuolema? Mitä kuolemassa tapahtuu?/ What is death like in your opinion? What happens in death?

-Miten määrittelisit hyvän kuoleman? Entä huonon kuoleman?/ How would you define a good death? What about a bad death?

-Onko sinun mielestäsi elämää kuoleman jälkeen? Jos on, millaista?/ Do you think that there is life after death? If so, what kind?

-Mitä mieltä olet eutanasiasta?/ How do you feel about euthanasia?

MAAILMANKATSOMUKSESTA/ ABOUT THE OUTLOOK ON THE WORLD

-Millainen on ihminen, ihmiskäsityksesi?/ What is a human being like, your vision on man?

-Mikä on sinulle elämässä tärkeää?/ What is it that is important for you in life?

-Millainen on maailmankatsomuksesi?/ What is your outlook on life like?

-Millainen on hyvä elämä?/ What is good life like?

-Uskotko jälleensyntymiseen?/ Do you believe in reincarnation?

IDENTITEETISTÄ/ ABOUT IDENTITY

-Millaisena ihmisenä pidät itseäsi?/ How do you view yourself?

-Onko vapaaehtoistyö mielestäsi muuttanut sinua? Jos on, miten?/ Do you think that volunteer work has changed you? If so, how?

APPENDIX 2. Kysely henkilökunnalle/ Questionnaire for the staff:

TAUSTASTA/ ABOUT BACKGROUND

- Nimi/ Name:
- Syntymävuosi/ Year of birth:
- Koulutus/ammatti/ Education/profession:
- Valmistumisvuosi/ Year of graduation:
- Kauanko olet ollut töissä Pirkanmaan Hoitokodissa?/ For how long have you worked at Pirkanmaa Hospice?
- Aiemmistä työsuhteista: missä, kuinka kauan?/ About your earlier employers: where, for how long?

MIELIPITEENI VAPAAEHTOISTYÖSTÄ JA SEN TEKIJÖISTÄ/ MY OPINION ON VOLUNTEER WORK AND VOLUNTEERS

Kerro mielipiteesi omin sanoin. Ajatuksesi apuna voit käyttää seuraavia kysymyksiä: Miten koet vapaaehtoistyön ja vapaaehtoistyöntekijät työyhteisössäsi? Miksi? Mitä hyvää/huonoa näet siinä työssä ja sen tekijöiden toiminnassa? Miksi? Mitä muutoksia tai parannuksia ehdottaisit nykyiseen tilanteeseen?/ Write about your opinion in your own words. You can use the following questions to help your thinking: How do you view volunteer work and volunteer workers in your working community? Why? What good/bad features do the work and the workers have? Why? What kind of changes or improvements would you suggest to the present situation?