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The Amsterdam Master’s in Medical Anthropology
Faculty of Social and Behavioural Sciences
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Universiteit van Amsterdam

Giving Birth to Death

The Experience of Dying in a Palliative Care Home in Switzerland

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**Preface**

**Personal Interest in the Topic**

I have been lucky in my socialisation to death to live with parents working both as nurses and considering that death was not something to be hidden from children. My first encounter with death is also my first childhood’s memory, my grandfather with a plaster on his broken leg, lying under a window in an Italian mortuary chapel. As a three years old child, I was disappointed and intrigued: why was he under a window? Why was his leg still broken if he was dead? I found the adults strange: they told me he was “happy in heaven” but instead of being happy for him, they were sad.

Another meaningful encounter with death happened about four years later in France, in the Algerian community where my father’s sister was dying from cancer. She was in coma and had been taken home from the hospital. We spent her last days with her. One morning my sister and I were woken up by people crying in the room next to ours. My aunt had passed away early in the morning and her room was full of family members and neighbours. My parents took us to her bed and told us that we could kiss her cheek and say good-bye to her if we liked to. They taught us to see death as part of life. This made it not less painful, but more meaningful, to see other beloved people leave us.

Some deaths seem to be less acceptable than others. While I spent a week as a trainee in a hospital, a woman was dying from a generalized cancer. The nurses were spending as little time as possible in her room and I was not allowed to go there, at the very end of the hall. They said that she was rotting on the spot and that the smell was terrible. Once a nurse took me with her, but she asked me to wait in front of the door. Then she came out to fetch something and let the door open. My eyes dived into the gaze of the woman, a burning gaze full of life. I was sixteen and I could not understand why this woman died in loneliness. Later on, my mother spent two years working in one of the first palliative care units in a hospital. She used to share with us her stories and she got upset when they closed it for economic reasons, as she found it a real progress in the care of people.

I noticed during my fieldwork how much our perception of death is subdued to our previous experiences with it, and how it evolves through new encounters with it. I found it important to explain a few elements that had contributed to my own perception. The reader can hardly escape from a confrontation with his own perception of death, that will filter his reading all along.
ACKNOWLEDGEMENTS

Many people shared with me the experience of this fieldwork.

I am thankful to the persons I met in the home and who shared bits of their experience with me, teaching me at the same time how to be more human. I am thankful to the staff who was friendly and helpful with me. In particular, I would like to thank Danièle and Paul Beck, for their warm welcome and their openness.

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CHAPTER 1

DEATH AND DYING IN EUROPE: THE WAY TO PALLIATIVE CARE

1.1. SHORT SURVEY OF THE CONTEXT

Changes in the perception of death and dying in Europe are tightly connected to macro changes in social, economical and scientific fields. Industrialisation, development of the third sector, increasing power of the media (Barrau 1993:60) spreading images of violent and or collective death have participated in the process of setting death apart from everyday life while keeping in touch only with the intellectual experience of death. The experiences of World Wars also contributed to a concept of death as something frightening (Lifton in Riley 1984: 393). The way of life of most families is making it difficult to care for dying people, that are given into the hands of specialists (Ariès 1975: 63).

The individual has become more and more anonymous and is at the same time claiming his individuality as a right. Material achievement is the purpose of many people, and the image of a perfect body is put forward. Time is regulating narrow and precise schedules and man has acquired a sense of power on his environment. There is little room for spirituality and social relations. Death is therefore the end of the individual, with a more or less vague idea that it can be controlled by technology (Palgi & Abramovitch 1984: 403).

Death is a central motive in Christianity. It is the time when sinless people will be rewarded. Christian rituals are also marking the separation between the dead and the living. With secularisation, the Church has lost power over the life and death of people. The individual has become the reference with a freedom of choice. He has also become more lonely, and death reminds it harshly. The meaning given to death has a tremendous influence on the meaning given to life, with or without a belief in God, as the example of existentialism shows. Even if the individual is the central figure, relationships with others can be a way of fulfilling the quest for eternity (Walter 1997: 169).
In the medical ideology, that has taken control over death from religion, there has also been a shift from community to individual. Medicine is more and more controlling the life of people. Barrau states that, at the end of the XXth century, about two thirds of all deaths in France happened in a medical setting (1993: 65). In Switzerland, the proportion was even higher: three quarters of the population. (Rapin 1989). Medicalization of death was partly due to demographic changes, dying people being mostly among elderly with various chronic conditions (Seale 2000: 918). The definition of dying is thus being challenged, especially combined to the development of effective technologies. In this context, the quest for eternity is an issue in the relationship between man and machine. The materialisation of suffering prevents the patient from any relief other than physical and from any attempt of transcendence.

The intellectualisation of death is a part of the basic learning of medical doctors, as a way of protecting themselves from emotions (Coombs & Powers 1976: 23). Together with the idea of death as a failure (Barrau 1993: 86), it has led to excessive attempts of keeping the body going with the help of machines. As a reaction, the idea of a right to die has come up. Euthanasia is a logical answer to these excesses (La Marne 1999: 10). It provokes biological death when social death occurs.

In contrast, palliative care postpones social death until biological death (Palgi & Abramovitch 1984: 404). Palliative care is the way of the middle. In its ideal perspective, death is an achievement, the moment in which life is reaching its full meaning (La Marne 1999: 109-110). By trying to offer to the individual the opportunity to live his death in harmony with others and with himself, palliative care also give the opportunity to the community of learning from the experience of death. This learning can evolve into a new perception of death within the population. Palliative care gives the opportunity to create new rites of passage at the end of life, involving not only the individual but also the community.

1.2. ESSENTIALS OF PALLIATIVE CARE

Palliative care originated from the Hospices movement, initiated at St-Christopher Hospice, London, by Cicely Saunders in 1967. As a nurse, a social worker, and later as a doctor, she had experiences with people dying from cancer and noticed that much more could have been done to relieve them at the end of their life (Van Eersel 1999: 60-
At that time, the efforts of medicine were focused on curing the patient. When this was not possible anymore, medicine was unable to fulfil the patient’s needs. For Saunders, the role of medicine was not only to cure, but also to improve the patient’s quality of life as much as possible. The aim was that “people should be helped not only to die peacefully, but to live until they die with their needs and their potential met as fully as possible” (Saunders 2000: 8).

This concept led to a new approach in the treatment of cancerous pain. It is based on a holistic idea of the individual, as the definition of the World Health Organization shows:

“Palliative care is the active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and of psychological, social and spiritual problems is paramount. The goal of palliative care is achievement of the best possible quality of life for patients and their families. Many aspects of palliative care are also applicable earlier in the course of the illness, in conjunction with anti-cancer treatment. Palliative care: affirms life and regards dying as a natural process, neither hastens nor postposes death, provides relief from pain and other distressing symptoms, integrates the psychological and spiritual aspects of patient care, offers a support system to help the family cope during the patient’s illness and in their own bereavement.”

(Omega 1990:11-12)

Others have explained how difficult it is to define precisely terminal care versus palliative care (Clark & Seymour 1999:83-6; Renard et al. 2001:155-9). In this study, I will not make a precise distinction between them, because I found that the border can be blurred in everyday reality. This difficulty is one more indicator of the changes taking place in the meaning of dying.

1.3. IN SEARCH OF THE MEANING OF PALLIATIVE CARE

The concept of palliative care has emerged as an answer to dilemmas related to death, that are consequences of socio-cultural characteristics of “Western” societies and the biomedical system. Medicalization of death, development of ever refined technology, individualism, together with changes in demographic patterns and in causes of death all play a role in this process.

As we have seen, another answer that has been given to these dilemmas is euthanasia. Significant discussions are held about the topic of palliative care and euthanasia. For Seale, “they offer very similar opportunities for control and self-direction near death” (2000: 925). Whereas Gordijn and Janssens explain that the health
care policy in The Netherlands is now encouraging the development of palliative care as a prevention of euthanasia:

“Expansion and improvement of palliative care is stimulated to rule out the possibility that future requests of euthanasia might perhaps be brought about through insufficient and inadequate palliative care.” (2000:36)

In opposition to a widespread opinion that palliative care is luxury, Barrau (1993:11) states, “all assessments tend to prove clearly that the cost of palliative care is less than the cost of curative care”. This opinion is shared by W.H.O.: “increased access to palliative care results in financial savings to health care systems.” (www.who.int 2001). The debate about financial aspects is necessary, as the purpose of health care systems is to serve the interests of a community by making the best out of limited resources. Yet economic studies are not answering to the question of usefulness.

Behind the political, economic, ethical or moral debate, another issue might have been left out. This is how meaningful the life of a person is for himself, as well as for the people surrounding or caring for him. The meaning both the patient and people related to him give to his life, his illness, his suffering, as well as to his loss of autonomy, dying and death should be taken into consideration.

Palliative care aims at improving the end of life of patients, so the experience of the patients is the ground to understand the need for palliative care. According to Clark and Seymour, “narratives of dying, as produced by dying people themselves, are surprisingly rare in the research literature” (1999:32). Most of the time, information is given by the carers themselves, who are highly enthusiastic about palliative care. The patients’ perspective is missing and could be important for three reasons.

First, only the patients can tell how much the care they receive fulfils their expectations and needs. As palliative care is expanding more and more, there is the fear that it might become “medicalized” and “routinized” (Clark & Seymour 1999: 105-124). This means that it would lose its first purpose, serving the patient, based on a holistic philosophy. The idea of providing a harmonious environment, so that some patients could experience a kind of achievement before dying, as well as the emphasis on relationships would be lost. So, it is important to know how much these elements specific of palliative care matter for the patient.

“After having purely and simply denied a whole essential part of human experience – agony -, the medical institution may now want to appropriate it. (...) This would be an
A second reason why the patient’s perspective can be of high interest is summarised by this quote from Clark & Seymour:

“We begin to see something of the importance of narratives of illness and dying, not just as stories about physical and mental suffering, but as tales which are told through the body itself.” (1999: 23)

This idea of embodiment is a logic part of a holistic approach of the individual. It can be assumed that by examining carefully these embodied stories, more could be understood of the meaning of illness and how it relates to human being.

A third reason for studying the experience of dying is given by the sociologist Walter:

“(A revival of death) is increasingly being shaped by neither the dogmas of religion nor the institutional routines of medicine, but by dying, dead or bereaved individuals themselves.” (1994: 2)

The meaning an individual gives to death is directly related to the meaning he gives to life. These meanings become part of a collective experience that is continuously evolving. Palliative care gives a new perspective on death, and also on life in contemporary society.

“Palliative care has to be seen as an aspect of culture through which the dilemmas of human mortality are being dealt with at a specific time. So it is important to keep in mind that palliative care arises in the context of religious pluralism; scepticism about medicine; health care consumerism; and reflexivity in the body and the self. In this sense palliative care has been engaged in the production of a new ethic of care for the dying which reflects late modern preoccupations.” (Clark & Seymour 1999: 179)
CHAPTER 2

METHODOLOGICAL ASPECTS

The description of methodology is important to make clear the interactions between the researcher and the studied context. At the same time, it gives information about the topic itself. These are the grounds for an extensive development of methodological aspects in this chapter.

“The point is to be aware of how one’s perspective affects fieldwork, to carefully document all procedures so that others can review methods for bias, and to be open in describing the limitations of the perspective presented.” (Patton 1990:482)

2.1. STUDY TYPE AND THE THREE LEVELS DESCRIPTION

This research was fully qualitative. It was intended to be descriptive, providing a short ethnography of the palliative care home and its patients. As I was not familiar with the topic, it gave me a general overview of the home: its philosophy, its reality, relationships between people, problems and challenges they have to face, besides the gathering of illness experiences at the end of life. However, these aspects are not fully developed, for the objective of the study was to deal with the following topics: how a person relates to his body at the end of life, the relevance of palliative care for the patient, as well as the influence of palliative care on the perception of death and dying.

The ethnographic description has therefore to be read at three different levels. The micro-level is a mere description of facts, events, attitudes related to the individual. The meso-level is where individuals interact, and emphasises how the level of the individual is the concrete representation of relationships and tensions in the community. Finally, the macro-level is trying to show how these tensions reveal a perception of death and dying in which the border between life and death is becoming less and less sharp. This last level will be more thoroughly discussed in the last two chapters.

“The purpose of observational data is to describe the setting that was observed, the activities that took place in that setting, the people who participated in those activities, and the meanings of what was observed from the perspective of those observed.” (Patton 1990:202)

Although the data were gathered among the patients, the study is more from the researcher’s perspective than from the patient’s perspective. It remains the interpretation
of what I have heard, what I have seen, and what I have felt. When I realised this, I got afraid to make distant objects out of the people I met during my fieldwork.

“But we are suggesting that anthropological analyses (of pain and passion and power), when they are experience-distant, are at risk of delegitimizing their subject matter’s human conditions.” (Kleinman & Kleinman 1998: 200)

Suffering is difficult to be analysed, because the people who suffer are experiencing it with their guts and their hearts, and analysing it is a way of locking it up in the brain. However, analysing can also be a way of trying to give a sense to suffering.

“But meaning mends. Study meaning, and we learn about mending. But study mending and we might learn about meaning.” (Moermann 1998: 318)

2.2. Choice of Conversation Partners

Rive-Neuve’s patients I met were women and men in the age of thirty to ninety. My conversation partners were about fifty to ninety years old. During my six weeks fieldwork, twenty-four patients spent at least one week in the home. Among them, only one did not agree to take part in the study, finding it useless. I chose not to include someone who was said to ignore his diagnosis, as the situation was complex and it might have been harmful to the family in my view. Three arrived in the last three days and stayed in their room, so I did not interact with them. One left on the second day of my stay. Four persons suffering from A.I.D.S. came each for one week to balance their treatment or as a transition from hospital to home. Although I had a good contact with them, I thought that their stay in the home was too short for the purpose of my study. Now I review my judgement, as I will explain in the limitations of the study.

Of the remaining fourteen people, I had small formal interviews besides everyday interaction and other conversations with eight of them. With the six other patients, I had less everyday interaction, and no conversation but casual talks. Among them, one had been in bad condition when I arrived and she died six days later, another one became unfit after three days and died after seven days. One person arrived one week before I left, had serious hearing problems and was extremely weak. Two other people, who died in the middle of my stay, had many visitors and were trying to do outings at home as often as possible. The rest of the time they were exhausted. Finally, a person came during one week and left, then came back after a fortnight and died two days later.
The choice of my conversation partners was thus based on convenience and willingness from the patients. Most of them were fathers or mothers, sometimes grandfathers or grandmothers, or even great-grandparents. They were somebody’s child, sibling, aunt or uncle, cousin or friend. They were coming from very different socio-cultural classes and had various interests. Besides life in the home community, what they were sharing was a common background as patients and the ordeals they had to face as such. One was suffering from both A.I.D.S. and cancer, whereas the others had cancer affecting various part of the body: lungs, lymph, face, breast, pancreas, prostate, guts with sometimes metastasis in the liver or the brain. Ten of them were coming from a hospital, one from an institution, one from home, and I did not get the information for the last two. When I left the home, one person out of the fourteen had gone back home, one had set a day for leaving, eight had died and four were still at Rive-Neuve.

I had planned to shortly interview family members. I did not do it for different reasons. Family members were often overloaded. When they came, it was to spend as much time as possible with their relative, and I wanted to respect their privacy. But first of all, relationships in the families were often far from being harmonious and I did not want to be the intermediary through which communication would happen. I thought that if I would meet their family, the patients would be less inclined to share some things with me. Another reason was that if discussing with me would have upset a patient, the staff told me that he could have found some comfort with them. The families were often upset leaving the home, and I was afraid to upset them more, as they had no one to comfort them.

So, I had very casual interaction with the families and visitors, with the following exception. One day, a woman came to do her “pilgrimage” (her word) to Rive-Neuve, as her husband had died there one year before. She was looking for contact and talking about her experience, so I introduced myself as a student researcher. She was very willing to share a bit of their story, and checking what I was writing down to be sure I did not forget important things. I will call her Mr. P.’s wife in the text.

How to name the patients in the study was a problem for me. In order to preserve anonymity, I chose to give them a random initial and call them Mr. or Mrs. For those who had asked me to call them with their first name, I did the same with a random first name. I have the impression that not using their true name is taking something away from them, and they had already had so many things taken away.
The staff appears at the background of the study. I discussed above all with the people living in the same house as me, and during everyday interaction. I did small semi-structured interviews with whoever was available when the load of work was not so big. I spent one day with the animator, and I made appointments to discuss with the minister and the art-therapist.

2.3. Data Collection

2.3.1. Taking notes

My main data collection technique was participant observation; thus I was interacting and having informal discussion with the different people in the home. As mentioned, I did short formal interviews with eight patients. I taped one of them and transcribed it fully, and then I was not able to tape anymore. I felt uncomfortable with it; it was too emotional for me. So, during the formal interviews, I was taking notes, also for interviews with staff members. For the rest, I was writing down from memory, if possible right after the discussion or the observation. During the staff meetings, I was taking notes of what was said, in the same way as staff members did.

Apart from the notebook for the staff meetings, I had five different notebooks. One notebook was for the conversations with patients, and for short sentences I caught from interaction with them. A second notebook was for interviews with staff members, in a third one I recorded observation topics, without developing them. Another notebook was dedicated to Thursday’s specific lectures and the last one was a kind of diary in which I was recording everything that had happened during the day, my feelings, and my difficulties. I was writing in this one mainly at the end of the day. Two or three times, I just jotted down some keywords and developed in the following day. Moreover, I also had a small notebook where I would write quickly some keywords or bits of sentences.

2.3.2. Schedules

After the first introductory week, my daily schedules were about the same as the caring staff, as I found difficult to do my own schedules. One schedule is from 8.15 a.m. to 4.45 p.m. and the other one from 3.30 to 9.30 p.m. At the beginning of each duty, there was a staff meeting, with both the carers from the ending duty and from the
starting one. On Tuesday afternoon, there was a multidisciplinary meeting with, in addition, a representative of each team working there: a cook, a house cleaner, the minister, a doctor, the animator, a member of the office, a manager. On Friday afternoon, it was the same, but for a medical meeting, where emphasis was put on medical problems.

When I had the morning schedule, I would go and have my breakfast at a quarter to eight, then I had lunch with the patients and the staff. With the evening schedule, I had dinner there. Towards the end of my stay, I also did one sitting up night, from half past eight p.m. to nine a.m. I was choosing the schedule by myself, although my name was inscribed on the weekly schedule. Every week I had two days free, that I was spending outside the home. I spent two weekends out of five in the home. On Thursday, I had four times lectures about palliative care, like every new person working in the home.

2.3.3. Introduction in the home

Before I arrived in the home, I had mailed a summary of my research proposal in French. It had been hung on the wall of different rooms and stayed there until I left. The director of the home was presenting me to every new person we were meeting together as a student in medical anthropology doing research in his home. On the day I arrived, there was a group of student nurses who had come from Italy to visit the home. I was invited to join them.

On the second day, I presented briefly my project during the staff meeting and then I was introduced to volunteer work by an experienced volunteer. It was mainly kitchen and intendancy work. Then we had a one-hour discussion about personal experiences related to death and dying with all the new trainees. On the third day, besides the two staff meetings, I hung around in the living room, discussed with three patients, helped to serve dinner, welcomed some visitors, and answered the phone.

The fourth day was a lecture’s day. As Rive-Neuve has also a pedagogic duty, it organises a series of four modules about nursing care and end of life, philosophy of the home, animation, volunteers, prevention of burning-out among the staff, ethics, conviviality, the families, the moment of death, spirituality and religion. These lectures were intended to every new person working in the home, and were also open to outsiders, mostly carers that were confronted to death in their work.
“Gatekeepers will generally, and understandably, be concerned as to the picture of the organization that the ethnographer will paint, and they will have practical interests in seeing themselves and their colleagues presented in a favourable light.” (Patton 1990:65)

I first thought that I was losing time by attending these lectures, as they presented the idealistic perspective linked to the home philosophy, and it was one day I could not spend with the patients. Then, I realised that it was an opportunity to meet people working in hospitals or other homes and that I could better apprehend the discrepancies between the ideal and the reality of the home. Lectures were also regularly organised for all the home staff. For instance, an undertaker gave a conference about his role and his interaction with the families.

2.3.4. Participation

At the end of the first week, I thought that I had lost my time and only gained insight from a theoretical point of view. I realised later that this first week had permitted me to be considered as trustful and willing to take part in the life of the home. From the second week on, my participant observation implied an increasing involvement in the care. In the last two weeks, I became able to participate without trying to stick to one of the home roles. Nevertheless, in the last week I was too tired for participation and I spent more time doing photocopies and discussing with staff members whose perspective was missing than involving myself in activities.

“The extent of participation is a continuum that varies from complete immersion in the setting as full participant to complete separation from the setting as spectator.” (Patton 1990:206)

Before going to the home, I had planned to give a hand to the volunteers, but they were mainly doing intendancy work. We quickly realised that I could not fulfil my plans and the volunteers’ duties at the same time. However, everybody was giving a hand when and where it was necessary, so it was easy for me to do the same. I was introduced into the care by spending two days with a student nurse. Then, I took part in the care from time to time, depending on the staff leader, on the load of work, and on my own willingness.

For instance, I assisted people in washing and dressing, going to the toilet, to the living room, to the garden, using the stair-lift, going to bed. I brought meal trays or tea to the rooms, did massages, helped to change diapers, went for the meals round, asking if the menu was suitable for each person. Twice a week, I was going to the winter
garden, where a volunteer was preparing flower arrangements for the home, and where patients could join. Once I went to the ecumenical sharing time and once to the Orthodox mass for the dead. One day, I drove a patient to the hospital for investigations and another day I drove someone else to the lakeside for a short walk.

I was not present in the very last moments of life of a person, in order to leave full space to the family.

“(Participant observation) also has great methodological merit, for, unlike survey research, it allows the investigator to check statements of attitude and value against actual behaviour. This is essential, as people often do not do what they say they should be doing, or even what they think they are doing.” (Murphy 1990: 174)

2.3.5. Contact with patients

I was presenting myself to the patients as a student researcher. Sometimes, I would remind them of my role as a researcher and ask if I could use what they were saying or if I could ask a question for my study. Valérie, one of the patients, suggested me to make use of the poems she had written during her previous stay. I had in general good contacts with patients and got attached to some of them very quickly. I was in the age of being their daughter or their granddaughter. Some asked me to call them by their first name. I viewed them as an outsider, trying to make sense out of what they were living, but I am not sure if they perceived me as such. I had the impression that I was just somebody that was there, and with whom they could interact.

2.4. Reflections

2.4.1. Roles

During the whole research, it was a constant struggle for me to find a balance between participation and observation. The main difficulty was about roles. I had a role as a student researcher, but as soon as I gave a hand in the care, I also had a partial role as a kind of carer, for carers’ role was much broader than in other medical settings. There was no hierarchy, everybody was giving hands to each other and was trying to go beyond the role of carer in order to be first a human being. The patients had very friendly contacts with the carers and were encouraged to talk with them about what they felt, and about the problems with their family. I was also a human being before being a student researcher. I found it important for the patients to be more aware of my role as
student researcher, but also for the staff and for myself. I had sometimes the impression that one or two members of the staff were considering me as an evaluator of their work. As far as I am concerned, “doing something” lessened my feelings of impotence towards suffering, until I understood the importance of presence and sharing. These are the reasons why I chose to do very short formal interviews with some patients, whereas I had planned to have unstructured conversations only.

“In any case, anticipation of the likely consequences of adopting different roles can rarely be more than speculative. Fortunately, shifts in role can often be made over the course of fieldwork. (...) Different roles within a setting can be exploited, then, in order to get access to different kinds of data, as well as to acquire some sense of the various kinds of bias characteristic of each.” (Hammersly et al. 1983:97)

2.4.2. Schedules

My name had been written down on the weekly schedules together with the names of the carers. I was embarrassed when I saw this and discussed with the staff. I was told that it was more convenient for the team, but that I could change it and do my schedules as I liked to. I did so and chose my free days and morning or evening duties. I also tried to have a different schedule, but I found it difficult. Without taking part in the staff meetings, I could not know in what condition people were. Moreover, I was unable to leave when I had planned to. For instance, I was discussing with a patient and then she asked me to bring her to bed. Schedules are very useful to give a limit to one’s involvement, where involvement could be endless. Therefore, I followed the carers team’s schedules, but sometimes I would come a little bit earlier or leave a little bit later. On the lectures’ day, I was usually spending some time with a patient after class.

2.4.3. Relationships with the staff

I was living in the house next to the home with some trainees, where I was sharing a room with a student nurse. I had various relationships with the staff, depending on affinity, but I was surprised to see how easily I was accepted. The permanent staff was pretty much used to incorporate in the team all kind of trainees and students, and for the majority, I was just one of them.

When staff members arrived in the morning, most of them used to greet each other in the familiar Swiss way, with three kisses on the cheeks. Some did it spontaneously with me on the first day; others began to do it as we got to know each other better. I noticed a change after two weeks, after people who had become meaningful to me had
passed away. Suddenly, I felt I was more integrated, and I also began to greet staff members with the three traditional kisses.

A problem for me was what to share during staff meetings. If I was not asked to, usually I did not intervene. I had good relationships with two patients that were considered as difficult by the staff. After my discussions with them, the staff expected me to say something, so I mentioned the topic of our discussion, and tried to be as vague as possible. I felt that what patients told me only belonged to them, and I only mentioned precise points if the patients had asked me to do so. This attitude did not fit with the idea that everything had to be shared for the benefit of the patient, but I never had open comments about it.

I noticed that the less I knew about the illness of patients, the easier it was for me to approach them, because then I had no prejudice in mind.

2.4.4. Emotions

To do this study was an emotional involvement before, during and after. Before going to the field, I thought of my own experiences with death, as well as of how I would experience the death of my beloved people or my own death. During the first week of fieldwork, it was painful to feel people’s suffering. Then I had to accept that coming back from my free days, I could never know what to expect: someone could have died, or could have taken a turn for the worse very quickly. Later, I got afraid to ask questions that could upset a person and I talked about it with staff members. Processing my data and writing the thesis was also painful, because the distance allowed me to have a comprehensive and detailed view and to understand some situations better.

“Moreover, each fieldwork experience and each interpretation of data is filtered through the mind and heart of the researcher. (…) Instead of suppressing personal views and feelings, the researcher should examine them carefully and try to use them in conversation, observation, and participation.”(Van der Geest 1998: 52)

Emotions prevented me from clarifying some points with the patients; in particular what I first called ambivalence, talking about hope and death at the same time. They made me unable to question the staff when they did not act in the way I had expected. I could not process or analyse the data immediately, not only because of the short time and tiredness, but also because of emotions. I only found the necessary distance to analyse with some distance in space and time.
“Reflection and introspection are important parts of field research. The impressions and feelings of the observer become part of the data. (...) The observer takes in information and forms impressions that go beyond what can be fully recorded in even the most detailed field notes.” (Patton 1990:205)

It is only by trying to analyse, to interpret my fieldwork experience that I understood the different levels of connections, as well as my own reactions.

“The task is to do one’s best to make sense out of things.” (Patton 1990:477)

2.4.5. Limitations

The families were not included in the study and this is an important limitation, as trying to solve family problems was one of the main tasks of the staff. Moreover, it cuts the individual from his context whilst I attempted to connect elements together.

I should have asked to the four persons who did a one week stay how they experienced being in a home where many people are dying, what kind of opinion they heard about the place, what their perception of the home was and many other interesting things. On the spot, I had many practical reasons not to include them in the study. They were a different category than my study population. I wanted to focus on people with a terminal illness and it was not the case for these patients. New medicines seem to have rendered A.I.D.S. “more chronic” in places where they have been made available to patients. The choice I had to make is an indicator of how difficult it is to define chronic illness, palliative and terminal care.

With the distance of the analysis, I asked myself what was lying under the reasons for my choice. Was it stigmatisation? But I had a very friendly contact with them, they were extremely open, and I had included a patient with both A.I.D.S. and cancer. So, my hypothesis is that I did not include them because they were all about thirty years old, and this is my age. They were close to me and I could identify to them easily. This is one of the limitations of such an open study, a bias of selection due to the personal characteristics of the researcher. Actually, this bias cannot be totally avoided in participant observation, because you usually share more with people with whom you have affinities.

Doing the research in the palliative care home was also limiting the study. In order to better understand what palliative care changes for the patient, one should follow patients as soon as the decision to go to Rive-Neuve was taken, when they were still at home or in hospital. However, this would only be possible with a much longer study.
CHAPTER 3

RIVE-NEUVE: A PALLIATIVE CARE HOME IN SWITZERLAND

3.1. STARTING POINT

Rive-Neuve opened in 1988, as a result of the united efforts of a nurse (Paul Beck) who had worked for a long time in a radiotherapy unit and a woman (Danièle Beck) who had accompanied family members in their last moments of life, and with the active support of an oncologist, Dr. L. Barrelet. It was the first palliative care home in Switzerland.

Nowadays, there are three more similar homes, one in La-Chaux-de-Fonds, one in Basel and one in Bern, whereas palliative care units are also more and more integrated into hospitals, or developed as mobile units. Rive-Neuve’s purposes are to provide specialised care for chronic illnesses, in particular at the end of life, and to educate carers in this subject.

The objectives of the home are the following:

“Effectiveness of pain relief and control of major symptoms, pacified image of oneself, authenticity in human relationships, satisfactory organisation of going back home, respect of death, favoured and encouraged mourning, diffusion of a practice of palliative and terminal care of quality.”3 (Beck et al. 1998:16)

The philosophy of the home is based on the theory of needs, developed by anthropologists like R. Linton1, existentialist psychologists like A. Maslow, and V. Henderson (Beck et al. 1998:11). The latter elaborated principles of nursing care, starting from fourteen fundamental needs: to breathe, to eat and drink, to eliminate, to move and keep a good position, to sleep and rest, to dress and undress, to be clean and protect one’s skin, to avoid dangers, to communicate, to act according to one’s beliefs and values, to be engaged in one’s fulfilment, to enjoy oneself, and to learn (Riopelle et al. 1984).

### 3.2. Health System

Whereas in England palliative care is a system in itself, separated from the National Health Care System, in Switzerland it is partially integrated in the health systems of the counties or planned to be integrated (Renard et al. 2001:99). Each county has its own system and policy of health care.

Health insurance is obligatory for every Swiss resident, who has to pay the fees by himself. For those who cannot afford to pay, the County State will provide financial help according to the person’s income.

Health insurance reimburses stays in public hospitals (www.rsv.vd.ch 2000). Besides care in hospitals, the County State can provide home care, but then it is only partially reimbursed and is not specialised for dying people (Renard et al. 2001:25-9). There are also homes for elderly people, called E.M.S., *Etablissement Médico-Social* (Medico-Social Institution). Most of them are private institutions and only partially reimbursed by health insurance. People who do not need intensive medical treatment, but still cannot stay at home can go to a C.T.R., *Centre de Traitemet et de Réadaptation* (Treatment and Rehabilitation Centre), that are fully reimbursed by the health insurance. Although Rive-Neuve is a private institution, it has been classified as a C.T.R. as far as health insurances and the County State are concerned (Beck 1992:10).

### 3.3. Some Figures

The home has fourteen beds. In about twelve years -by the end of 2000 -, it had received 1677 patients and the number of patients per year is increasing regularly: 87 in 1989 versus 166 in 2000. Until 1992, about two thirds of the patients died at Rive-Neuve and one third went back home each year. These proportions seem quite constant; in 2000, these figures were respectively sixty-nine percent and twenty-five percent (the six remaining percent were transferred to another place). The average duration of a stay is decreasing; it was twenty-four days in 2000. Most of the patients suffer from cancer, but also from A.I.D.S. and other diseases (Beck et al.: 1992, 1998 & 2000).

### 3.4. Location

Rive-Neuve, which means “New Shore”, is located in a little medieval town, Villeneuve, very close to the Castle of Chillon, on the side of Geneva Lake. This
French-speaking region is famous for its romantic landscapes, its mild climate - even palm trees are growing in the area - and its wine. The foundation faces lake and mountains from the hillside, below the motorway that connects both ends of the lake. To reach it, you have to climb up a little road, following two signboards. You will cross vine fields, then an area with family houses and rich estates. You will only differentiate Rive-Neuve from one of them by reading its name on a small signboard.

In medieval times, there used to be a hospice in Villeneuve. It was a place where the poor and the pilgrims, mostly tradesmen who were bringing textiles from Flanders to Italy, could eat and rest. However, Rive-Neuve is not a hospice, it is a foundation. In French-speaking Switzerland, hospice has a rather pejorative connotation. In the minds of the population, it represents a place where elderly are locked up. Moreover, “les Hospices” is the administrative designation of the County Hospital and its annexes.

Little by little, the term foundation was informally replaced by the term “maison” (home). “Maison” comes from Latin “mansio” from the verb “manere”, to stay. It has both meanings of private house and of institution for a specific kind of users, namely a house for a community. It is interesting to note that the English movement of hospices is represented by other “maisons” in French speaking areas: la Maison Sarrazin in Québec, la Maison Gardanne in France, described by Van Eersel (1999).

3.5. Arrangement

The house is built on three different levels. Because of the slope, both the lowest and the middle level are at ground floor. The fourteen patient’s beds are distributed in ten rooms. At the lowest level, there are two single rooms, with a washbasin each. At the middle level, the ground floor, there are four rooms, two singles with washbasin, one double without washbasin and one single with direct access to a bathroom equipped with different kinds of mechanical helps. At the upper level, you will find four rooms as well, two doubles with washbasin, one single with washbasin and one double without

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2 The English word “home” is also commonly used in French to designate an institution (for elderly, for children, for handicapped people). In the case of Rive-Neuve, it is properly the French word “maison” that is used.
washbasin. On that floor, sanitary equipment consists of one toilet, one bathroom, and one combination of both. On the middle floor, there are one toilet and one bathroom that opens into the equipped bathroom, and on the lowest floor, you will find one toilet and one bathroom with a Jacuzzi.

A small room converted into a chapel, a winter garden, with direct access to the outer garden, and different offices and storage rooms for the staff, as well as an access to the conference room complete the arrangement of that floor. The middle floor is where the main entrance is. The entrance hall is the first common space, a kind of crossroads. If you go straight on, you enter the dining room, which is also the living room. From there, you can access to the huge terrace facing the lake. If you pass the threshold on your right, just after a remembrance book and a white candle, you will be in the kitchen, between the outside and the common space. Stuck to the living room, the administrative office opens both into the living room and the entrance. If you follow the hall on your left, you will find yourself in a patient’s rooms area, with a short corridor leading to the nurses’ office. If you climb the stairs, you arrive directly in a small living room with a TV, from which you access to the rooms and bathrooms, as well to a hairdresser’s room.

3.6. The Staff

Around thirty wage earners and twenty lay volunteers were working at Rive-Neuve, most of them part-time. Nurses and caregivers were helping the patients perform everyday acts, giving medical and comfort care, counselling patients and families. One of them was a hairdresser as well. An animator, who had more a role of life binder, was present two days a week, providing the patients or their family with a support for performing small tasks of everyday life, like doing some purchases or going for a walk. The minister came twice a week to discuss with the patients, whatever their beliefs, and try to join them in their experience. An art-therapist spent a half day per week with patients, and let them express themselves through another means than verbal language. The two home cleaners were sometimes very good interlocutors for the patients. They were present, but not to look directly after the patients, although they gave a hand from time to time, to help wash and dress for instance. In the kitchen, two cooks, a help and an apprentice were working with alternate schedules. Two medical doctors were regularly visiting the patients, their time of presence corresponding to two and a half
days a week. In the office, there was one accountant, one person in charge of administrative formalities, and one apprentice. The director and his wife were coordinating the teams, keeping in touch with the medico-social structures, organising teaching and education, giving a hand when necessary. The director was having breakfast every weekday in the dining room, together with staff members and patients.

We will see later that, like for the house cleaners, the tasks of the staff were going beyond this formal description.
CHAPTER 4

THE SHIPWRECKED BODY AND ITS FATE

4.1. THE ELUSIVE BODY

The people I met had to undergo important transformation of and in their body. Some had lost a lot of weight, their hair, or an organ removed by surgical operation. Others had to get used to artificial parts, included bags to gather excretion material. Not only did they have to get acquainted to a new body, a new physical appearance, but they were also witnessing their own decay: becoming weaker and weaker, being less and less able to use their body as they were accustomed to. They were fighting to keep on using the functioning parts of it, that were slowly diminishing. One of the patients showed to me her drawing of a half smashed stranded boat, at the mercy of the raging sea, and she said: “Look, this is how we are at the end of life.”

One of the reactions towards this shipwrecked body was astonishment:

“It’s strange a human body, indeed.” (Mrs. G.)
“It’s bizarre how we function.” (name unrecorded)
“It’s strange how the body can be dissociate sometimes, as if it were in a few pieces.” (Mrs. C.)
“What surprised me most was to fall back from my legs when I wanted to get up.” (Valérie)

There was a kind of separation between the thinking part and the material part of the person, the material part being driven out of the control of the thinking part. This phenomenon could be a direct illustration of what Le Breton named “le corps insaisissable”, the elusive body (1997: 28).

“(The modern conception of the body) implies that man is cut from cosmos (it is not macrocosmos that explains flesh anymore, but an anatomy and a physiology that only exist in the body), cut from others (passage from a community-like society to an individualistic society where body is the border of the person) and finally, cut from himself (his body is considered as different from him.)” (Le Breton 1997: 29)

The patients were cut from their body, because it had to suffer from changes and losses that they had not decided themselves. Medicine had tried to heal their body through heavy interventions like chemotherapy and surgery:

“It was painful, to undergo this at the hospital.” (Mrs. G.)
Valérie described chemotherapy as a painful intervention that made her very nervous, impatient and tired. She added:

“You have the feeling that it crushes the bones, it shrunk me everything: brain, legs, stomach, guts...”

And later she said that it cost 3800.-Fr per week “and there were five weeks."

(Mrs. G.): “It is when chemotherapy begins that it is a little bit more difficult... I stand it pretty well, I haven’t lost my hair...but...It was kind of feeling bad somewhat constantly.”

About surgery: “They scraped until the bone.” (Mr. P.’s wife)

(Mr. T.): “Then they said: “You haven’t cleaned enough”, and here comes that they open for the third time. Oh, yes, I went through some things.”

Patients would sometimes talk about “this body” or “these legs”.

“You have to adjust yourself again to this body that does not belong to you anymore.”
“It’s difficult to accept this body.” (Mrs. L.)

Murphy called this dissociation from the body “a kind of etherealization of identity.” He explained it as a way of coping with the obligation of letting the other intrude in his intimacy:

“...as if this depersonalization would compensate for what otherwise would be an intolerable violation of my personal space.” (Murphy 1990: 100)

The following inventory illustrates the same phenomenon. The patient was showing to me different parts of her body. Her hair: “This is not mine.” Her glasses: “This is not mine.” Her hearing device: “This is not mine. The spleen, they took it away.”

Whereas Murphy was hinting to his carers, the intruders were in the case of this woman the heavy interventions she went through. It could also be the illness itself and its symptoms, as they were sometimes called with the demonstrative article: “this cancer”, “this water”, “this clot”, “these big ganglions”, a way of making them foreign to the body. On the contrary, a woman whose illness had been developing for some years seemed to have incorporated her illness as a normal part of her body:

“I live with my illness. It is like my tongue, my ears, my nose.”

Another recurrent topic related to the body was excretion. Urine excretion was one of the struggles of the end of life, whereas stools were often a constant preoccupation.

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1 Murphy was an American anthropologist who suffered from an increasing paralysis due to the growth of a tumor in his spinal cord. I will quote from his book, The Body Silent, especially in this section, for he was in the best position to share simultaneously the insider’s and the outsider’s view on his situation.
Both illness and medicines were creating some unbalance in the production of stools. When excretion products had to be gathered in a bag outside the body, this was usually unnoticeable from outside, but a source of preoccupation. A woman explained to me how difficult it was to get used to this artificial body part, how she had to tame it. It was a constant worry, as she could have no control on it. One more intruder.

The integration of the “modern conception of the body” was obvious in the description of illness. The people I talked to explained spontaneously their illness in a very precise way, using medical terms, explaining some of them and showing parts of their bodies.

For example, a man showed me his swollen belly, with little lumps scattered under the skin, and he told me:

“Do you see the lumps there? They came in one month; they are metastasis. Do you know what metastasis are? They are a kind of ramifications, it’s cancer that is spreading.”

Being able to explain what happened to oneself could be a kind of attempt of trying to keep some control on an illness that was too quick to be properly grasped. Not understanding where the illness came from, what made it get suddenly worse, could be a suffering, because it took away from the person the last pretence of control, intellectual control. The speed of evolution was often mentioned, and then it was the diagnosis that made people realise how serious the illness was. However, realise is not the exact term, for it was more a kind of intellectual knowledge, that would only be integrated bits by bits, as experiences and time would go.

Then there could be anxiety about what could happen to the thinking part. Losing control of “the head” was considered as the worst thing that could happen, as it was what allowed communicating to others, maintaining relationships.

“My thoughts and sense of being alive have been driven back into my brain, where I now reside.” (Murphy 1990: 102)

At the same time, there was a staggering between what people wanted to do and what they were able to. If it were not a specific part of the body that was failing in one’s duty, extreme tiredness and weakness were a constant limitation. So, the body was defined by its limitations to make use of time or space.

“I cannot read or write anymore. I am too tired.” (Valérie)
“To feel weak like this...” (Mrs. G.)
“I have to calculate the numbers of times I climb the stairs...” (Frédy)
A main expectation from the stay in the home was rest: “To have a rest”\textsuperscript{21}, “to regain strength”\textsuperscript{22}, “to untire”\textsuperscript{23} to use Alexandre’s neologism. To realise one’s own limitations was painful, to accept it difficult, and until the end people would try and make use of their body at maximum. As Murphy puts it: “I was badly damaged, yet just as alive as ever, and I had to make the best of it with my remaining capabilities.” (1990: 66)

There was something about falling down. People would sometimes fall down, mostly at night, trying to go to the bathroom. But the moment they fell was not really at random, it was in most cases linked with a kind of delusion, people making one brutal step in the realisation of their condition. Or maybe it was the contrary, falling was making them realise how weak they were. Here again, space was bringing awareness of bodily changes.

Another part of bodily changes was physical appearance. Emaciation created not only practical problems like adjusting clothes or being unable to warm up, but it was also “hard to see oneself”. A swollen face due to cortisone, swollen arms or legs under the pressure of oedema, scars were as many marks of changes that wrote the story of the illness. For an outsider like me, this could only be fully apprehended by contrast with a “before”, for example seeing some pictures. Identity through the body was therefore shaped by time and by the relationship to the other.

“Damage to the body, then, causes diminution of the self, which is further magnified by debasement by others.” (Murphy 1990: 93)

A woman had a lovely way of coping with the complete loss of her hair. She had three wigs and presented them to every interested person: “This one is for the day, this one for the night, and that one for special days.” One day, she asked the hairdresser of the home to have one of the wigs set, and then when she wore it she really looked as if she had a new and very smart hairstyle.

About this wig, an incident revealed how the body can become a mirror for the other. One could see in this case Frank’s “mirroring body”(1995: 43), and its search for predictability of appearance. Valérie, who was wearing the wig, made several times a loud comment about Mrs C. who had lost her hair, but was not wearing any wig. She said that she looked like a man. Finally, Mrs C. got angry and Valérie had to give her apologies. In those comments, Mrs C. was not the true target, however. To see in others what you are trying to hide from yourself can be painful.
The body was also a means of communication with others, as touching and kissing were very present, while intimacy somehow restricted. I have mentioned the common informal greeting in Switzerland by giving three kisses on the cheeks alternately. These three kisses are a way of recognising the other, and his belonging to the same group, as well as a way of telling how meaningful the person is. Kissing a patient was a way of showing more closeness to him. Through breaking the rules of social distance, you also consider the person and his body as one entity, as well as you weaken the concept of body as a border between individuals.

Touching the patients had the same effect. Touching was important, in particular through massages. Massages were usually proposed in the evening, sometimes also earlier as a help to relax. Any member of the staff did them. Massages were a mean of helping the person connecting better with his foreign body, as well as some space for communication between two individuals, with or without words.

Emphasis was put on relating to the other, and every act of care could be a mean of getting into touch with the patient.

A few hours before Mrs K. passed away, I had helped a student nurse to do a “caress toilet”, as she said. After we had greeted her and explained that we would give her some refreshment, she opened her eyes. Then, she closed them again and surrendered her body to the care. First we washed her gently with scented milk and body warm water, then we massaged her limbs with oil. This care was the opportunity of still relating to the person, talking to her even if she could not answer anymore. The body was not separated from the person like in Le Breton’s model; the body was the person.

“ The body is here the place and the time where the world becomes man immersed in the singularity of his personal history, in a social and cultural ground from which he draws the symbolism of his relationship to the others and to the world.” (Le Breton 1997: 39)

Care for the body had thus two roles. It was help for the individual to leave the refuge of the brain and to rebuild a complete image of the body despite the experiences it went through. At the same time, it was a way of binding the individuals together in a community. At the macro-level, and according to Le Breton’s model, one could say that these attempts were a way of connecting the individual with the cosmos.
4.2. The Dying of the Body

These attempts were getting more and more laborious with time. At the end of life, maintaining the ideals of autonomy and of smooth relationships was more difficult. I would like to develop three themes related to the dying body, namely excretion, respiration and confusion, before showing how the body is representing the person until after death.

To urinate seemed to be the last voluntary humane action. People did not eat anymore and drank almost nothing in the last moments. The problem with the excretion of urine is that one has to get up and go to the toilet, or to ask for the urinal or for the night commode, unless one has a urinary catheter with a collector bag or a diaper. Moreover, to go to the toilet, one had to get out of the room, so it was really a huge effort. A woman wanted to go to the toilet by herself, but was too weak for this, even to stay on the urinal.

Frédy refused the diaper, and tried to take it off. He could not ring his bell anymore; maybe he had even forgotten about the bell, he was said to be confused. Before this sudden worsening of his condition that confined him to his bed, he was very independent. For instance, he never used the stair-lift. He would climb the stairs, holding both handrails, struggling with his weak legs. I used to meet him during the meals, but also outside, on the terrace when he was reading his newspaper, or on the opposite side of the home, near the small herb gardens. One day, he sent me to fetch a leaf, as we were trying to identify the herbs. He told me that he could not do it by himself, and only then I noticed how tightly he was holding the barrier. And now, he was lying in bed but how could he accept to wear diapers? So, he tried to go to the toilet, but then did not find his way. The staff was afraid that he would fall. They lifted up the side rails on both sides of the bed, but he still managed to get up and was found in the hall. I imagined the huge efforts he was certainly doing for this.

What Frédy was struggling for was his autonomy. But he was in a situation in which his autonomy could only be preserved by the continual presence of a staff member or relative. Paradoxically, it was only through dependency on others that he could have kept a pretence of autonomy. It was a situation in which the interests of the community were clashing with those of the person. What complicated it even more was the uncertainty of the moment of death. The last “moments” could be hours, but they could also be days and nights. The constant presence of relatives created a different situation. Mr. E.’s family was very present for him, and helped him get up and go to the toilet until a few hours before he died.

If the struggle to urinate was made so visible at the end of life, it was because then, biological cycles alone were putting rhythm into a person’s time. And the rhythm became less and less regular, before ceasing completely. Biological cycles, like the
processes of ingesting food or drinks, digesting and excreting them are exchanges with
the outer world. They are energetic processes, combustion processes. Digestion is a
transformation of what is external to the body, and what living beings share from the
outer world. Filtration and reabsorbing of liquids is faster than digestion of solid food.
Respiration is the same kind of transformation and exchange process, but occurs at a
faster speed. Contacts with outside world were thus reducing progressively, first solid
disappeared, than liquid and finally air. The exchange with outside world became
looser, like the gaseous state. The sense of hearing was the last one to disappear, and
hearing is a transformation of air vibrations.

Respiration connects living beings together since they share the inhaled and expired
air. At the same time as the person was becoming less and less present to his
environment, his breath became irregular, was having regular breaks, was getting noisy.
When it got noisy, medicines were given, but the interesting thing is that this noisy
respiration seems not to be troublesome to the dying person (Nauck et al. 2000: 83).
Thus, the medicines were given more for the comfort of the surrounding people.
Respiration has also a peculiar place in coming to the world and in giving birth. So,
respiration is the closure of the life’s circle. At the end of their life, people are giving
birth to death.

Confusion is a strange word used to describe a state of an individual that an outsider
cannot understand. To be confused means more or less to talk nonsense. At the end of
life, reality seemed mixed up. The world of the dying might have another logic as the
one of the full living. The person mistook time, places, people. During the last
moments, agitation of upper or lower members could happen. Frédy, who had been
struggling to stand on his feet until four days before dying, kept on moving his legs
when he was in a comatose state, too weak to get up again. It was as if his body was still
trying to fulfil the person’s expectations.

One could say that confusion was an effect of the medicines, combined with lack of
hydration and failure of eliminating organs, or other medical reasons explained by
Nauck & al. (2000: 83). If we refer to Le Breton’s definition of the body as “the place
and the time indistinguishable from identity” (1997: 36), we could see confusion as a
moment in which the person is dissociated from these three fused components, as if they
were losing their meaning. This is distressing for the surrounding people, because time,
space and identity are our means of relating one to the other, of communicating, through
the intermediary of the body. A change in this system of reference is thus accompanied with a weakening of the connections with the outer world.

The body was the first indicator of the coming death. While washing Mrs. K., I was surprised by the differences of temperature in her limbs, one foot so cold and the other warm. Among the Indians from Alaska described by Trelease (1985: 75), the person was announcing his death to the community. In our case, the announcement was made by the body.

“The color and temperature of extremities is one of the most useful indicators that the end of life is approaching.”(Blues & Zerwekh 1984: 183)

After death, the body was treated with great respect, because it now represented the person. The body was the witness of the before and after. It was as if the whole person was transferred into materiality. I was told that the natural orifices were not filled up, even if it led sometimes to unpleasantness. Discharges were in general minor, as the dying people had not received any liquid perfusion, and there was no intake of liquid or solid in the last hours.

However, this respect for the body could be a source of tension for the staff. Mrs K. had died peacefully, but when the nurse entered her room, she had lost blood, and the nurse had to let the family wait until the body was made presentable again. The presence of this blood was making incongruous the efforts of representing the person through the body. It was a body full of red liquid that could leak, instead of Mrs K. and her peaceful smile.

The precautions taken in handling the body of a deceased person could be interpreted as a way of denying death by making it beautiful. However, I believe, like Hadders, that the importance of these rituals is more an indication that the border between life and death is not as well defined as we might think:

“So, for the family, the preparation of the body is going to play an important role in the continuity of its social relationship with the deceased.” (Hadders 2001)

The local undertaker who gave a conference also suggested that the body represented the person. He talked about the importance for the family to visit, touch, kiss, talk to the body, to maintain a relation of intimacy with the deceased person. Walter emphasises the importance of a personalised funeral in contemporary society:

“Increasingly, people want to do the funeral in a way that honours the deceased as a unique individual, not the undertaker’s way, or the crematorium’s way, or the religious way.” (1994: 33)
The body and the person’s belongings represented material presence. The same respect and friendship were shown to them. Going to the room to say good-bye, one would often knock at the door. I helped a carer carry the heavy cold blocks to be put on the body for its conservation. She told me that she did not like to see those heavy blocks on the person, as they were so heavy.

The deceased person was left in his bed and dressed with his own clothes; he could be holding some flowers in his hands. Flowers as a relational mean were used among the living, but also between the living and the dead. Out of the four people I could go and say good-bye after death, three had a beautiful and serene smile, expressing a sort of plenitude.

The undertaker would usually take the body away from the home within 24 hours, and bring it to a mortuary chapel where the family could gather again. If there was a roommate, it could be carried to the cold bed in the chapel instead of staying in “its” bed. Then, the name of the person was written at both entrances of the small chapel. A man was left longer than one day in his room, but this rose some concern about conservation. Materiality was the first prolongation of the person, but materiality is ephemeral. Arranging the room after the departure of the body was not easy, because every little detail was reminding that presence, and I wondered who would take off the wall the children’s drawings that were decorating it. Sharing the flowers that the patient had received to the common space was a way of coping with the disappearance of the presence.

The death of a person was announced during the following staff meeting, very briefly. Right after the death, a carer wrote in the remembrance book a sentence announcing it, with the name of the person and the precise time. For instance, “Mrs. Y. was born to Heaven on Monday, the 6th of June 2001, at 14h45” or “Mr. Z. passed on peacefully on Wednesday, 18th May 2001, at 2 o’clock a.m.” On the opposite page, the family and/or the friends could write their thoughts and feelings and a picture of the person was sometimes stuck. A caregiver who was turning over the pages of the book commented:

“It’s a pity when there is no picture; after some time we forget the faces.”

Next to the book, a white candle was lit, and was not blown out until the body had left the home.
CHAPTER 5

NARROWING OF TIME AND SPACE

5.1. TIME

I knew that time can seem shorter or longer depending on how we organise it, and what interest we put in our activities, if we are looking forward to or fear an event. I discovered that time could be thick, almost palpable. Time at Rive-Neuve was different from the time I was used to. There were different reasons for it, all of which were consequences of the intermingling of time, space and identity.

Time was the main problem for the patients. It was too short compared to the quick evolution of their illness. Illness had upset the life of people by plunging them into a different perspective of time, as Frank noted:

“The illness story is wrecked because its present is not what the past was supposed to lead up to, and the future is scarcely thinkable.” (1995: 55)

The fear of not having enough time left and the uncertainty about the amount of time available was a painful awareness. As Marshall describes the same awareness in his study about the end of life of old people, we could consider the illness as a catalyst of a usual process.

“At least in societies with our linear time perspective - as contrasted with societies in which time is viewed cyclically - increasing age lends new significance to the temporal ordering of lives because it increases awareness of impending death as the outer limit or boundary of our projects.” (1980: 98)

And further:

“It seems at first paradoxical that the aging person must be ready both to die and to live. However, this attitude follows from the certainty of death but the concomitant uncertainty of its timing.” (1980: 189)

Alexandre expressed it in a very clear way:

“'In three months at most, I will be dead.'”

“Time is the problem. I don’t know if I am here for two more weeks or three more months.”

Time was a limitation in itself, but it was not an independent concept. It was tied to space, like in Valérie’s poetry:

“To live intensely, time is running away
We cannot hold on to what is only a moment.”
While Mrs. L. was seated on the Big Blue, the stair-lift, on her way from her room to the dining-room, she told me: “I am learning how to be patient here. The Big Blue is teaching patience to me.” So, the time she spent to make use of space was making her aware of a limitation she had to get used to. We will see later how the use of space made visible a narrowing of time at the end of life.

Relationships with people are the coincidence of time, space and identity. We have already seen how “confusion” is upsetting this coincidence. And a major manifestation of confusion is called “time disorientation”\textsuperscript{32}. This expression in itself is showing how time and space cannot be completely dissociated, although they are in the present text. Actually, when all days look similar and without precise schedules, you do not need to be sick to forget what day today is. In the case of “time disorientation”, it meant asking for breakfast at two in the morning, or talking about “this morning” instead of “yesterday evening”. At the meso-level, it was revealing the tension between life of the individual and life of the community.

As schedules are an attempt to put together the time, the space and the identity of different individuals, they represent the bumping together of autonomy and dependence. In her study about the use of time and space in a psychiatric ward, Van Dongen (1997) described the interweaving of time, space and social life. She analysed how this interweaving made it difficult to attribute uncommon use of time or space to the patients’ illness or to social situations. This is certainly the case in every institution, as life in a community is limiting the individual’s freedom. In this study, I consider this tension as a part of the meso-level that is disclosing a macro-level in which “the individual self can die his or her own way, but only in company with others” (Walter 1994: 189).

There were no precise schedules except for the meals, which is one of the strategies to reduce the tension between the needs of the individual and the needs of the community. Therefore, the time for meals made this tension visible, through spatial interaction. The night staff set up the tables for breakfast in the dining room early in the morning. Patients would have their breakfast whenever they wanted, in their room or in the dining room. Part of the staff would have breakfast between a quarter to eight and a quarter past eight, right before the first meeting. One morning, Alain joined us while we were having breakfast. He had eaten half of his breakfast when everybody had to go to the meeting, leaving him alone at the table. He said with a surprised tone: “Ah, you’re leaving me? Well, see you later.”\textsuperscript{33} During lunch or dinner, we were having the meal all
together in the dining room, but it could happen that a carer had to leave to answer to the bell of a patient who was eating in his room, or to have a look at someone who was in bad condition. As Valérie commented: “When they are busy, suddenly they disappear, you may not see them anymore.”

Time was a source of inspiration for the patients: Valérie had written a poem during a previous stay and Mrs. C. told me:

“Time, here we have time, we take time, everybody is giving time.”

Time became a kind of money of exchange for relationships between people. Spending time with Mrs. C. was giving meaning to her identity. A presence, spatial proximity mixed with duration, allowed the encounter between two identities. Time and space together were thus a means of relating to the other, a means of communication.

“Time lets love pass, and love lets time pass.” For Mrs C., it was painful to see that her husband was living in a world in which time was precisely scheduled and organised, mastered to the point of making slaves out of the masters. Although he was quite often there and full of attention to her, she was complaining that he did not spend enough time with her. She wanted him to sit next to her, and just be there, without doing anything. Only sharing a bit of his time with her, only sharing some moments together, as life is a succession of shared moments. Time became something precious and appreciated, maybe the most precious thing.

I noticed a watch on the left wrist of Mrs. K. while I was helping to wash her. She was in a kind of coma and this detail of the watch pursued me, until a dying man asked for his watch. It was as if the person was slowly getting out of the time of the living, bits by bits. He then tried to keep a foot in time, for time belongs to the living. The importance of time was that of a last contact with space, with a world that the person was gently leaving. Time as a duration, as shared moments became very precious, and simultaneously, as schedules and watch time, it was only important to relate to others.

“The ability to fill time varies with degree and type of engagement with others.”
(Marshall 1980: 128)

It was a kind of realisation that time is a humane construction, therefore in absolute it does not exist. It can only exist as a succession of experiences, in relationship with others, with space or with identity.
This contrast between two times was also noticeable in the remembrance book, where the time of death was very precisely recorded. For the family and friends, it was very important to know exactly when their beloved passed away. Yet, dying was a progressive process, made visible by ceasing to eat, to drink, to talk, to urinate, and to breathe. These actions had all been connecting the person to time and space, allowing interactions with other people.

5.2. Space

The experience of dying was often a narrowing of space, making visible the narrowing of time. Space was where life of community and intimacy of the individual were constantly bumping together. It was also where the individual was making proofs of his autonomy. As a person became weaker, his movements were more and more difficult. In this case, the use of space indicated a dilatation of time. In order to continue taking part in the life of the community, one would use the elevator, the Big Blue, and maybe a rolling-chair with somebody to push it.

As Rive-Neuve used to be a family house, the spatial arrangement was not typical of Murphy’s description of a hospital: “It was a simplified setting, in which there were no steps or other obstacles to mobility....” (1990: 58). The obstacles were still there, but different devices could help to overcome them. Space was organised in a way that promoted interactions of the individual with others and with the environment.

A blue person-elevator, where you could sit or put a rolling-chair was in charge of the transport from one floor to the other, following the handrail. It was called “The Big Blue”, after Luc Besson’s famous film from the nineties1. The Big Blue was very slow, that’s why Mrs. L. considered it as her patience teacher. As a matter of fact, it was a patience teacher for everybody, since it occupied the whole staircase. If you wanted to climb the stairs, you had to wait for the transport to be completed, or to jump in front of it before it started. But then, you would not notice how the use of space was slowing down time, in order to enhance relationships. The Big Blue’s passengers had plenty of time to admire the small exhibition of pictures...

1 The film is about diving while holding one’s breath. The divers were trying to get as deep as possible down into the sea, holding their breath, until one of them did not show up anymore. It was a bet with life, and there also a question of time, though seconds and not weeks.
on the wall, that was regularly changed and represented a link with the outer world, or to discuss with the surrounding people. Some patients would call this stairway lift “the blue train”. One day when I was climbing the stairs to accompany Mrs. L., she invited me to share her space and her time: “You should have got on with me, come, there is still room.”37 When Valérie was seated on the chair, I used to stand facing her, the only position that let me be a passenger of the “Blue Train” as well, and we were pretending travelling together.

The Big Blue was not only encouraging encounters with the other, but also with oneself. The vertical displacements could be a gambling with the Big Blue, trying to use it as little as possible. Mrs L. would only use it to go up the stairs, and walked downstairs. Alexandre was often using it by himself, and he would lift up the heavy platform after use, in order to make it ready for the next user.

Horizontal movements, when supported with the helpful arm of a carer, a stick, a walking-frame or a rolling-chair, could also be a time for relationship.

At the end of life, the person’s time was narrowing, whereas the day’s time was expanding. This could explain my impression of a thick time. The person could only make use of space with an increasing amount of time, whereas his own time was inexorably decreasing.

Sharing common space was an indicator of good condition. When the condition got worse, this space was less and less often shared. Then, space shrunk to the room. And finally, it became the bed. There was thus a shift from common space to intimate space.

In Swiss society, a bed is the place where you sleep, where you make love, where you give birth and where you die. It is a place that links the individual with time and with the other, a witness of the daily cycle, as well as of the life cycle. Beds were hospital beds, where you could lift the head, the feet or the whole couch upwards or downwards. Sometimes the patient did it himself; sometimes a carer did it for him. The bed was not only lifted for the comfort of the patient, but also to let a carer have a good position while giving a massage or making the bed.

Special mattresses could be added, like a water-mattress, to avoid bedsores. Special pillows could also be used, to relieve from painful positions. Like hospital beds, there
were a handle and a bell hanging above them, so that the patient could reach them by stretching his arm. Unlike most hospital beds, there was not always an upper sheet, and a comforter with a covert in a mixture of blue lavender colours was giving an impression of cosiness. The bed was the first witness of the increasing weakness of its temporary possessor, eating in bed, washing in bed, urinating in the bottle. The sphincters’ weakness would let urine or liquid stool maculate the sheets. The bed was therefore a crossroads for all struggles, between intimacy and community life, between autonomy and dependence. All the people that died during these six weeks died in bed.

Intimate space was scarce at Rive-Neuve. Bathrooms and toilets were on the floor. A woman told me that she did not put anything over her nightdress when she was going to the toilet at night, nobody could see her. I was helping her to put her dressing gown on, and her breast was still uncovered, but she was not paying attention to it. She behaved as if she were at home, and I was the one embarrassed, thinking of the visitors we could meet in the hall and helping her to arrange the clothes.

Goffman’s model about public space, described by Murphy, demonstrates that implicit rules direct social interactions. A person should “put social space and distance around the self” in order to arouse respect from the others (1990: 119). According to this model, the patient mentioned was not putting the distance expected in a public space. Through her body, she made it clear that she considered the home as a private place. In the same manner, some patients asked expressly not to knock on their door.

To shift to the macro level, we need to recall Le Breton’s model of the body, and to listen to the explanation given by another woman: “I don’t care if somebody enters the room when I am naked, it’s just nature.” Here the body is the person, it does not represent a border between two individuals, and matter is explained by a macrocosm, nature. It is the reversed model of the modern body, as if the end of life was a way of pasting the different elements together.

There were six single rooms and four double rooms. Moving from one room to the other happened quite often, and usually it was a way of increasing the level of intimacy. Either it was at the person’s request, or, most of the time, when a person’s condition was getting worse. Then, people would move from a double room to a single room.
Mrs. G. shared her room with Valérie. During the day, they did not see each other very often, as Valérie spent her time in the living room downstairs, whereas Mrs. G. left her bed only to eat in the dining room and to go to the bathroom. She walked leaning on a carer’s shoulder and used the Big Blue to go down the stairs. After a few days, Mrs. G. moved on a wheelchair. Then, she did not go to the dining room anymore and had her meals at the table in the room, often with her family. Mrs. L., who reached the floor with the Big Blue, visited her once. Then, Mrs. G. did not get up anymore. She was transferred to a single room, where she died peacefully in her bed, in the presence of her daughter.

Besides moving from a double to a single room, another way of recovering some intimacy was to leave the home. Some people would spend an afternoon or an evening out with their visitors, whereas others would go home for a day or a weekend. These outings were also a way of testing one’s autonomy, in order to prepare a going back home. To do an outing at home is a strange thing. You go out to go back to the place where you are usually in.

Space was not only common or intimate, but also inside or outside. The garden was a kind of intermediary position, between intimacy and community, between autonomy and dependency. A high hedge surrounded it and set it apart from the neighbouring gardens. The main part of it was built on a slope, which explained the presence of the Big Blue’s brother. The Big Black, as it was called, was connecting the terrace of the home to the lowest part of the garden.

When someone was going down into the garden, he usually received a bell, to remain connected to the community. Another place where one could be at the same time inside and outside was the huge terrace facing the lake, whose access was from the living room. When the weather was warm, the terrace became a more public space where the meals were shared.

There was in the home some space that belonged to outsiders, as Rive-Neuve had also a pedagogic role. The conference room was located in the right side of the building, under the terrace, with a direct access from outside.

The living interacted by means of space. The vocabulary used to describe dying was often referring to a change in space: “partir” (to depart), “nous quitter” (to leave us), “s’en aller” (to go away). An interesting detail in the use of vocabulary was “mobiliser”, the medical term for helping a person to move. This term was used frequently, and indeed the staffs were trying to help the patient keep on moving, not only physically, but also on his life’s path. Dying would then be the ultimate movement, a movement to another space.
CHAPTER 6

THE PART OF THE OTHER

We have already seen how the body incarnates the time and place that makes an individual relate to his social environment. We will now examine the importance of these relationships for the individual. Like Walter, we have noticed how the dead body of a person is important to his others, as it permits to go on relating with the individual. Walter describes the post-modern death as a “do-it-yourself” death that has to be constructed together with others (1994: 189).

Both Marshall and Frank explain the importance of these others in terms of continuity for the individual. According to Marshall, the proximity of death enhances the necessity for a “symbolic construction of this sense of continuity” (1980:187). Frank states that the function of telling stories for ill people is not only to “work out their own changing identities, but also to guide others who will follow them” (1995:16). His perspective is that “the self is understood as coming to be human in relation to others, and the self can only continue to be human by living for the Other.” (1995:15).

The problem for the people I met at Rive-Neuve was that dependency resulting from their condition was a threat for their identity. Murphy describes this situation:

“Such dependency...is not so much a state of body as a state of mind, a condition that warps all one’s other social ties and further contaminates the identity of the dependent.” (1990: 199)

The tension between autonomy and dependency was thus the visible part of a coming and going between the individual and the others in a search for creating meaning. We will examine successively three categories of “others”: the family with the theme of reconciliation, the patients as companions, and the staff as witnesses.

6.1. FAMILY

In the palliative care perspective, the unit of care is the family and not a single patient. Actually, a tremendous part of suffering could arise from relationships with family members. For example, a man had discovered that his son was not his and the son of another person kept on asking money and arguing about inheritance. Discussions
during the daily staff meetings were more about relational problems than about medical treatments.

Illness and the perspective of death were adding even more trouble to these difficulties.

“This places unasked-for, acute demands on the family in terms of caring for the ill person or arranging for and coordinating care, rearranging priorities in personal lives, dealing with multiple emotions raised by the illness and expected death, and being involved in difficult decisions. Each member must also come to terms in his or her own way with the meaning of the illness and death, and the new beginning necessitated by the loss of the loved one.” (Blues & Zerwekh 1984: 247)

As we have noticed before, the notion of time was peculiar at Rive-Neuve. First, the staff tried to follow the rhythm of the person, and second closeness to death made time fade little by little, before disappearing. These were two reasons that could create a gap between an insider and an outsider. An outsider had many schedules to follow: go to work, appointments, school for children besides tasks for the household like grocery shopping, doing the washing, cooking. This gave to his time a very structured shape and something of a continual hurry. For an insider, time was made of experiences to be lived and of the struggle for autonomy.

“There is another face linked to time and increasing the gap. Realisation of what was happening needed time. It was difficult for the person and his beloved to be synchronised in their realisation of the illness’ progression. A man admitted being seriously ill and having a short life expectancy, whereas his wife did not want to hear how serious the illness was. Or the contrary: a patient was expecting to go home, whereas his family knew he would not be able to do so. These gaps were painful and the desire to protect the other was adding to the pain. People would rarely speak frankly with their family about their condition, and about death. More than once, the staff organised a meeting for the family members and the patient to make things clear about the diagnosis, evolution of the illness, or the eventuality of a going back home. The relief of having a clear dialogue with the beloved was every time mentioned by the patients.” (Murphy 1990: 57)

Murphy explains also how these gaps between the person and his visitors contribute highly to reinforce the sick role, the concept of the modern patient developed by Parson.
By encouraging the individual’s relationships to his others, the staff was thus trying to erase this role, so that the patient could play his own role.

The staff was trying to avoid being an intermediary between two people who did not communicate together and to favour clarity, counselling and reconciliation.

“Réconciliation”, the French word means “bringing back to harmony, to an agreement, people who were on bad terms”\(^1\). If we think again of the necessity of completing one’s own story both for the individual and the others, we can understand why this was one of the big challenges of the home. Whoever had a good feeling with a patient and his family could contribute to this process, an illustration of how Moermann’s mending can create meaning. This necessity only can justify what could be considered otherwise as an intrusion in the family, “a kind of secret society, a closed universe of information and dependencies, and also of loves, hates, suspicions, and jealousies” (Murphy 1990: 213).

At the very end of life, the number of visitors was often increasing. If family members wanted to be present, to extend the time and space shared, they could spend the night in the room, or even in a little apartment, in the contiguous house. Most of the time, there was someone from the family to be called when signs of death were becoming more obvious.

### 6.2. Patients

Patients were living together an intense period of their life. Unlike the staff or the visitors, they were on the spot permanently, with a few exceptions, like outings. Although their life’s story was unique, the patients were sharing life in the home, and they had been through similar losses and suffering. They could talk about their previous or actual experiences, they could understand each other better than any person present in the home. The other could be a companion sharing one’s life and giving a hand, but also sometimes a kind of mirror.

“Compagnon” (the French word for companion) comes from the Latin “the one that eats his bread (panis) with (cum)”. It means a person who shares - usually or occasionally - the life of another. Two more specific meanings are “the one that

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accompanies someone for a travel”, and “the one that underwent similar ordeals”\textsuperscript{1}. Indeed, the term “companion” suited the patients.

The interactions between patients were most visible during the meals. They were encouraging each other to eat, giving a hand to the other, like Frédy who was fetching Mr. T.’s stick every time he wanted to get up. Mr. T. himself enjoyed serving the wine for everyone. The conversations showed their shared experience, the process of creating meaning for the other and for oneself.

\begin{quote}
"- It’s hard to keep on sitting when you have no more padding.
- This is because you have lost weight.
- Personally, I have lost forty kilograms, I understand you."
\textsuperscript{38}
\end{quote}

About inheritance:

\begin{quote}
"- I put everything in order before I came here.
- Me too.
- We are still putting the papers in order, you see it’s different when you live together without being married."\textsuperscript{39}
\end{quote}

When a patient would suddenly not go to the dining room anymore, his companions worried about him. Let us recall Mrs. L., who visited Mrs. G. after enquiring about her condition. Valérie, who was sharing Mrs. G.’s space, knew already:

\begin{quote}
"My room mate is going down fast. I would not like her leaving before me, but she is not fine at all. She is always sleeping..."
\textsuperscript{40}
\end{quote}

The death of a member of the community was making the other members more aware of their own death, but there were few open reactions. Frédy explained that the dying of his roommate while they were sharing the same space enabled him to imagine how his own dying would be, as they were suffering from the same illness. Walter as well has pointed out this attitude:

\begin{quote}
" Patients learn from each other not only about dying, but also about the moment of death - a moment that many fear. (...) Those who had recently witnessed a death tended to rate this as comforting - to see someone die of the cancer that yourself are suffering from and will die of shortly, can remove the fear of the unknown.” (1994: 124)
\end{quote}

The mirror effect was not only about dying, but could be about behaviour. Mrs. C. and Mrs. M., living in the same room, were doing outings at home simultaneously. And the story of the wig has illustrated this phenomenon in relation to physical appearance.

People left tracks through their habits, through their relationships with other people. Mr. T. told me how sad he was to see the empty chair previously occupied by his helpful companion. Then he got up, and fetched his stick by himself.

6.3. Staff

Staff members were a special kind of companions for the patients, as they were not experiencing the same ordeals, and as they had a role of carer to play. Their dressing was the symbol for the double role of carers and outsiders: they were not wearing hospital dresses, but white or light coloured T-shirts together with everyday clothes.

Time was contributing to the fact that they were only partially sharing their bread with the patients. Staff members had their own schedules with their free days or nights, and their working time was at most four days a week. Moreover, a great proportion was temporary staff, as there were many student nurses or trainees.

This diversity was an opportunity for the patient to have a closer relationship with one or the other member of the staff, as there were as many ways of caring as carers. Communication between staff members had therefore to be good, in order to respect the patients’ time as far as possible, and to emphasise the role of witness versus the role of carer. Two patients described their impression of the home with the word “continuity”, and Valérie told me: “It is as if there were one head, with many hands.” Each member of the staff was doing more than his own tasks, participating in the life of the home. The office employee was helping to serve the meals. The cooks and the accountant helped carrying Charlotte’s body from her room to the chapel.

"Since few practitioners can hope to be so multi-faceted, the hospice movement has developed the concept of the multi-professional team. (...) each profession claims a particular competence, while accepting that preliminary work in each area can be done by most other members of the team.” (Walter 1995:91-2)

The tension between life of the individual and life of the community was reduced through different strategies. Here are some examples: no precise schedules except for the meals, transmission of the patients’ wishes and preferences to every member of the staff, no schedules for the visitors, very little private space for the staff, polyvalence instead of very rigid roles. These strategies were accompanied with different ways of giving support to the team (e.g. massage, supervision, sharing-times), since they could not use the structure of the institution as a shield.
The trainees that were coming from hospitals were first very surprised about the apparent lack of structure. They were used to a precise schedule with tasks to be performed and hardly any time to build relationships with the patients outside medical acts. Before realising that sharing time was "doing something", they wondered what they had to do. I had the same problem, until I realised that the patients did not want me to do anything, but to share time and space with them.

“...doing physical, achievable tasks gives nurses a sense of doing something, in contrast to the sense of inadequacy felt in listening to a hopeless story or just sitting with a dying patient.” (Walter 1995:96)

Staff members were witnesses of the patients’ experiences. Just as showing pictures of a previous time was a quest for giving meaning to their body, showing their experiences was a quest of giving meaning to their history.

“The moment of witness in the story crystallizes a mutuality of need, when each is for the other.” (Frank 1995: 25)

This witnessing of the other’s experience was not one-sided. Some patients were very eager to hear stories about what happened to members of the staff or to me during our free days; we were representing the outside world. They were teaching us how to make sense out of our experiences, and at the same time making sense out of theirs.

A few staff members had this specific role of representing exclusively the outside world: the volunteers, the animator, and the art-therapist for instance. Art-therapy consisted in artistic expression like drawing and painting, together with an analysis of the meaning of the work by its creator.

Three staff members had four legs: two cats and one dog were living on the spot. As in Switzerland many people have a cat or a dog at home, these animals contributed to making the place more home-like. But they did more: they were catalysts of relationships and unlike other staff members, they did not have to learn how to be. They were specialists in sharing time and space with people.
CHAPTER 7

THE MATTER OF RELATIONSHIPS

(food, medicines, flowers)

Relationships to the body, to time and space, to oneself, to the other, to the outside, were represented in matter through food, medicines and flowers. Van der Geest et al. explain how concreteness of medicines makes it possible to act on a problem:

“Their “thinginess” provides patients and healers with a means to deal with the problem at hand. (...) By applying “a thing”, we transform the state of dysphoria into something concrete, into some thing to which the patient and others can address their efforts.” (1996: 154)

Food and flowers, as relational agents, were simultaneously the means and a material representation of it.

7.1. Food

Rive-Neuve’s patients were first eating to regain strength. Food could make the body stronger, and was the symbol of strength. And strength meant hope. Being able to eat and drink meant being alive. Using one’s fundamental senses meant keeping a contact with the external world, communicating with it. The kitchen’s door would remain open all day long, so that nice smells would reach people’s nose and the rumour of pans, pots and plates ringing gently together reached their ears. While she was confined to bed, Mrs. G. asked me to let her room’s door open, so that she would enjoy these bits of life. The food’s taste was delicious; the dishes gave also pleasure to the eye, even when they were minced.

“You should not mince too much, so that you keep the eye’s pleasure. With small pieces in it, it looks better.”

There was a choice for three different homemade desserts and in addition the possibility of having something else, like ice cream, fruit, vanilla cream. Usually, there were no specific diets.

Food represented pleasure. I apprehended it fully when Alexandre admitted to me that it was difficult for him seeing all those nice dishes, smelling those nice odours, and not being able to taste them, as he had problems to chew.
Food was a means of relating to the other through the whole process of preparation, but also before and after it. First of all, the cook went to every new patient and asked his preferences and special wishes. Twice a day, a staff member would go to every patient and ask if he had special wishes for the next menu. This was a good opportunity for conversation. Then, meals were served directly in the dining room, one by one, the staff or volunteers distributing them at the tables. The cook knew everybody by name, and tried to fulfil the wishes, for example by serving a small portion.

In the dining room, four tables with six seats were set like a cross with space in-between. The table-clothes were in a warm apricot colour. On each table there was a set of pepper, salt and sugar, a candle and a small flower arrangement. The dining room occupied half of the living room. It held a coffee-machine, a cool glass cupboard with some desserts, cupboards with plates and dishes, as well as flower vases, and a fridge, in which Mrs. L. had put some of her own food.

Meals were providing the community for the rhythm of the day. It was the meeting between time and space. Everybody ate together: staff, visitors and patients. Outsiders coming for education or seminars were often taking part in the meals. Therefore, having a meal in the dining room was a means of relating to others and to the outside. When a patient was not going to the dining room, he received his meal on a tray in his room. At the very end of life, a staff or a family member could help a person to eat until it became impossible. There was no artificial feeding.

A meal could be a struggle for autonomy. Mrs C.’s hands seemed not to respond anymore while she was trying to cut her piece of meat. Finally, she managed to cut three big pieces and put them entirely in her mouth.

“As far as you can do it by yourself, you have to do it.”

I heard this kind of sentence several times, by different patients. After the meal, the staffs were clearing off tables, but on the day before he went back home, Mr T. brought his plate to the kitchen by himself, as a training he said.
7.2. Medicines

At table, a recurrent topic for discussion was medicines. Patients were showing interest or making jokes about them:

“You have to take all this?”
“After that, you’ve had your dinner.”
“All these colours, do they also colour what is coming out?”

Besides the jokes, medicines were tamed by giving them casual names, and consequently making them part of ordinary life, closer to oneself, inoffensive. Taking in his hand a number of coloured pills, Alain said: “These are my Smarties.” When Valérie was asking for “a little piece of paper”, she was referring to her thin tranquiliser tablet.

The staff brought oral medicines to the patient at precise times, but in general there was no systematic check if they were taken and when. The exceptions were if the consequences of forgetting could be for example pain, and at the very end of life. To be efficient, morphine has to be taken every four hour. In that case, the staff would wake up the patient for it, unless a prolonged delivery form could be used. In most other cases, if the patient was sleeping, the medicines were left on the table next to the bed.

Whereas the meals alone were structuring the day for both the individual and the community, medicines time was shaping it with a specific rhythm for each person. Thus medicines were a kind of link between the person’s time and the clock time.

After the admission of a new patient in the home, the amount of medicine he had to take before was usually reduced, a sign of this link’s weakening. Patients gave their opinion on some medicines, asked for others, or to have them earlier or later. This mostly happened for laxatives, sleeping pills or painkillers. Laxatives regulate the inside-outside cycle. Sleeping pills act on the oneself-others cycle and painkillers lessen the link between the body and space-time.

Pain was the crystallisation of the person’s story of suffering at one point in time and in one place through the body. When I asked Mr. F. what helped him cope with suffering, his answer was: “Painkillers. That’s all.”

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1 Smarties® are chocolate drops coated with coloured sugar.
Pain was strongly tied to the individual story. Mr. T: “Here they took the pains away from me; they allowed me to live a little again.”  

To stop pain meant to put one’s life in movement again, to go beyond the crystallisation of identity in pain.

Injections were relatively rare. Unless the person had to learn how to do it before going back home the staff gave them. According to Van der Geest et al. “every medication is to some extent self-medication, unless the health worker administers it (e.g. an injection)” (1996:165) and they define self-medication as a way of giving more responsibility over one’s own health. Consequently, the emphasis on oral medicines was a way of enhancing the patient’s sense of control on his illness, on his story of suffering.

Other medicines than pharmaceuticals were sometimes proposed, this depended very much on the staff that was present at the moment, as well as on the interest of the person for this kind of treatment. When the patient could not sleep anymore and it was too late to have a sleeping pill, he might have received orange flower tea. Solutions against constipation included ingestion of more fibres containing food, soaked plums or fig syrup. Food, fruit, herbs were thus used for problems related to biological cycles.

In a situation of crisis, or anxiety, a tranquilliser was easily proposed or asked for. In milder cases, Bach Flowers\(^1\) massages or a talk could be enough. Some medicines seemed to be a shield to protect from emotions, either the patient’s emotions or the carer’s emotions, or both. How much was the use of a chemical revealing a difficulty in relating to the other, a witness of the hidden vulnerability of human beings?

“The reason why the wounded healer can himself heal is that he understands the patient’s pain, suffering, and need, from his own experience of them. (...) The informal care of the hospice, which does not need specific medical knowledge to the extent that it is needed in cure-centred hospitals, may enable everyone to become a good healer once they understand their vulnerability as humans, and here the healer’s mask is very close to the person’s vulnerable human face.” (Chikako Maruyama 1999: 130)

This question relates to every situation that increased the carers’ feelings of impotence, anxiety and stress, and was particularly relevant to the very end of life. The institutional structure did not let the carers hide their vulnerability behind schedules and medical acts, but medicines could still have the role of medicalizing fear.

\(^1\) Dr. Edward Bach found out that vegetal vibrations of some plants can represent emotional states. He prepared drops with the quintessence of these plants. By acting on an emotional state, Bach flowers help the person to find healing resources in himself, which is sometimes called the placebo effect.
At the very end of life, while the link between the person’s time and the clock’s time was fading away, most medication was usually stopped.

“Every medicine that has no direct effect on symptoms has to be stopped...”¹ (Nauck et al. 2000: 82)

On the other hand, a pharmaceutical was typically used at that moment: Scopoderm®, with the aim of reducing secretions that hinder respiration. And a spray with the Rescue mixture of Bach Flowers was used to moisten the mouth.

An interesting thing about Scopoderm® is that it was developed for people who get sick while travelling. It looks like a round sticker that one has to place behind the ear before leaving, and to keep during the travel. I cannot help drawing a parallel with the patients travelling out of this world. Sticking this patch behind their ear would then be a kind of wishing them a peaceful journey.

7.3. FLOWERS

Flowers were present not only in the patients’ rooms brought by the visitors, but “aller aux fleurs” (to go to the flowers) was also a regular activity in which patients could take part. Flowers were a means as well as a support of communication. On Tuesday and Friday morning, a volunteer would come and prepare flower arrangements to decorate the home: four small pots for the tables, a big one for the chapel, another for the entrance, next to the candle and the remembrance book, one in front of the entrance door, tiny pots to be put on the meal trays that were brought to the rooms, and others for the office, or for the upper living-room. Everybody who wanted could join and help prepare the pots in the winter garden. You had to choose some flowers among the coloured bunches, cut their stalk and stitch it in the green synthetic holder. Sometimes the volunteer was working alone; sometimes one or two patients were present.

To go to the flowers was a mean of expressing fears or problems to an outsider, as well as doing something with no relation to the illness. “I came down to the flowers in order to forget a little bit all these problems” ², said Mr T., explaining worries about his family. Valérie was making an arrangement with red flowers and said: “I see red today.

²
-These red flowers, is it anger? -No, I am disappointed.” Flowers facilitated talking about emotions, relating to the environment, meeting other patients.

The relational role of flowers belonged also to the flowers brought by visitors. They were an opening door to encourage the family to feel at home, by getting a vase and preparing the bunch. They were saying to the patient that someone was thinking of him. They were giving information to other patients: Mrs L.’s neighbour asked me if Mrs L. had left the home, as she had not seen the flowers usually put in front of the door for the night. When Mr E. died, the flowers remaining in his room were distributed in the living-room and in the hall, and this movement from his intimate place to the common space was like keeping a little bit of his presence.

The most striking example of the relational role of flowers is the story of the purple orchid. Mrs G. offered a purple orchid to her roommate, Valérie, as it was her birthday. Valérie found the flower so beautiful that she drew it. Some time later, Mrs G. died. Coming back from my free days, I learnt about her death by seeing the drawing of the purple orchid carefully stuck in the remembrance book, opposite Mrs G.’s picture, and some words: “We will meet again in Paradise.”
CHAPTER 8

THE PATH TO DEATH

The individual’s body was a representation of time, space and identity, as well as a means to relate to them and to the others. Through this relationship, the whole attempt of the person was to make sense out of his life story, out of his suffering and to attain “self-fulfilment” (Rosenthal 1969:90). This process could only happen by sharing stories, as Frank (1995) puts it. Sharing stories needs witnesses, companions, and beloved ones. For the story of our lives, the structure of all our time, is made of a perpetually alternating movement between the inside and the outside, as Murphy reminds us (1990:227). The social nature of human being is emphasised likewise by Marshall:

“I find it useful to assume that people will seek to render their lives, including the end of their lives, meaningful; that this process is inherently social, that it is symbolic, involving the use of language, and that it concerns the social negotiation of identity - the sense of who we were, are, and will be.” (1980:164)

8.1. AWARENESS

The story of the people I met had started long before their arrival at Rive-Neuve. One element of it was making this search for meaning more urgent: awareness of their finitude.

“Before the illness, I was not thinking about death. Or I was thinking about it like everybody.”\(^{55}\) (Mr. F.)

“It allowed me to realise that life is short, that we don’t have eternal life.”\(^{56}\) (Mr. T.)

This awareness was a process that had often started with the diagnosis. The body, the other, dilatation of time and narrowing of space, losses were adding their part in the process. Actually, narrowing of space had happened before the admission at Rive-Neuve. Four patients told me how they missed driving their car. In a country like Switzerland, where most people have their own car, driving one’s car became the dream incarnating autonomy, driving one’s life. Then, the admission in itself was a narrowing of space: staying in a palliative care home, living in a community. However, what made it painful was the step in awareness that it implied:

“At first it was hard to think of coming here, because I had to realise that the condition of my illness was serious.”\(^{57}\) (Mrs. C.)
Mrs. G. explained that she got angry when a nurse in the hospital mentioned Rive-Neuve as a place for her, because in her mind it was a place for dying people. When she arrived in the home, she felt reassured, because she saw patients going back home, and this gave her hope that she might do the same.

Living at Rive-Neuve was making companions out of the patients, a symbol for a change in their identity. The main source of reflection was among the companions. Witnessing the decline of others, sitting at the table next to a companion’s empty seat were bringing awareness of one’s own mortality. “Yesterday she was here, she was speaking, and today she is dead.” When I asked Mr F., who was in the home for a second stay, what struck him first, he answered: “What even shocked me a lot, it’s the number of deaths. In one month, there were six, that’s a lot.”

A movement towards the inside followed the movement towards the outside. Patients were retiring from common space to intimate space. “It’s also good for me to be sometimes a little bit alone. I think we all need it a little bit.” (Mrs G.) “I prefer staying in my room. Well, the room, as I am sharing it with someone.” (Alexandre)

There was also awareness about beloved others: “By coming here, I realised how fond of me my wife is.” (Mr.T.) Or about values and important things in life: “There are many and there are a few. To be loved and to love: this is of greatest importance.” (Mr.F.)

8.2. Hope

To cope with suffering some patients seemed to rely more on their inner strength: being positive, knowing that nothing is impossible, struggling, thinking about one’s life, listening to music, reading. Mrs. G. mentioned talking to her family, her friends and Mr T. praying.

“Death makes manifest life and all its values; rather than being only a negation of life, it creates it and makes new life possible. Without death, the very concept of life would be meaningless. Total life, or pure being, and death, or pure nothingness, are one and the same.” (Murphy 1990:63)

“Life and death are bound together in people’s sense making.” (Marshall 1980:166)

I noticed this weaving through what I first called a constant ambivalence. My interlocutors were saying that they would die soon, and a moment later, they were talking as if they were immortal. As an outsider, I was taken aback every time I stepped
upon such attitude. I felt unable to ask for clarification, since I was caught by the vertigo of a huge gap between the person and me. So, I tried to reach the person where he was, to accept that he could show simultaneously the two faces of the coin. Then, I acknowledged that hope was present until the last second of life, whatever the level of acceptation of death. With the distance, I wonder to which point the gap was not made of the difference between the patient’s time and my own time.

Medical interventions were a thread in the weaving. They were at the same time revealing and contributing to the difficulty of deciding what was still to be done for the patient. You could never know how much a person was at the end of his life. And decisions had to be made in the present time. In the home, the patient was the one who decided, according to the information given to him. As the patients were usually coming from a curative setting, medical treatment meant hope, even if it was not intended to be curative.

Transfusion, chemotherapy, investigation had the meaning of hope, to the point that the meaning took over the means at the end of life. A couple of days before she died, Mrs. G. was talking about an appointment for investigations when there was none. A woman asked for a transfusion and died right after receiving it. Alexandre told me three days before dying: “I am going to have a transfusion. It seems that I am anaemic, then it will make me feel better.” I was very surprised to hear that, because he had expressed clearly his closeness to the end of life. When I learnt that no transfusion was scheduled for him, I understood how full of hope his statement was, and how much life was present until death.

When we think about it, a transfusion is a powerful symbol. Receiving the liquid of life from another body. Trying to share a liquid life until its ultimate drop. Blood, the intimate liquid “par excellence”.

During our second meeting, Alexandre had expressed clearly that he was going to die. The next time I talked to him, he was in an even worse condition, but he said that he considered Rive-Neuve as “un relais” (a relay) between hospital and home, a place where he could have a rest before going back home. Now he is dead, I think that maybe it is actually a relay, between life and death, and perhaps dying is going back home...

Hope lay in the progresses of others, or in one’s own progresses. “This morning I could move a toe again”, shouted Valérie in her excitement. A worsening implied a
search for another explanation than the evolution of illness. Valérie, whose hands were getting weak, said the knife was not sharp enough to cut her meat, and the scissors were not working very well, although she did not seem very convinced about her own explanations.

On my last day, I went to say good-bye to Mrs C., whose condition had worsened a lot since she was there. She was now moving almost exclusively in the wheelchair; she had problems cutting her meat and slept a lot. She was very sad about it and she had talked about her condition with the doctor and her family to make things clear. As I was kissing her, she told me: “Perhaps we will meet each other again when I’ll be walking along the lakeside.”

8.3. GIVING BIRTH TO DEATH

According to Murphy, dying is fearful because of the loneliness that it entails in our society (1990: 63). It is not the physical death that is to be feared. Just as for dependency, the threat for identity lies not in bodily changes, but in alienation from others. It makes us afraid of dying, because the interaction with others is a necessity for the fulfilment of our autobiography, namely making sense out of experience, out of shared time and space.

Meaning was created through a process, and understanding of oneself increased gradually until the moment in which time, space and identity of a person merge together. This process was what Alexandre called “l’activité de penser” (the activity of thinking). Nevertheless, it occurred with the help of mirrors, for time, space and identity are relative concepts. It needed interlocutors, for language is the symbolic construction of experience. And it needed the presence of beloved people, not only to give confidence, but also because love is the feeling of meaning itself (Hennezel 1997:18).

In Last Chapters, Marshall explains the process of building one’s autobiography as inherent to human beings, but becoming more urgent towards the end of life.

“My metaphorical understanding of aging and dying is that we come to a point in life where we realize that time before death is short. As meaningful and meaning-seeking creatures, with a sense of autobiography, we can now locate the self in the last chapters of life.” (1980:159)

For the individuals I met at Rive-Neuve, this awareness of finitude had suddenly jumped into their life through their materiality, their body.
“- I know that I’m going to die, I don’t have a lot of time left. A few months at most.
- And you said that you are not anxious about it?
- No, foutu pour foutu... What annoys me is time. Not to know how much time I still have left. And it’s too early to die. I am only 63 years old. I would have wanted to last a little bit longer.” 67 (Mr. F.)

Time was too short, and not knowing when one was going to die made preparation difficult. Materiality was both an enhancer of awareness and a brake for preparation. Preparing for one’s death meant putting all papers in order, as Switzerland is a country were administrative formalities have an important place. The testament was the first formality to fulfil, and when there were problems with the family, it could cost time and energy. But the testament was not only a formality, it was also a way of thinking of others.

“You have to prepare yourself, and to think about those who are going to stay. I made my will, I also asked my wife to make hers.”68 (Mr. T.)

Preparation was also about putting one’s things in order.

“I am putting small things in order, archives that I never had time to arrange. But after two hours of this type of work, I am exhausted.”69 (Alexandre)

Alexandre also said another time: “I am doing the assessment”70 (of his life).

Other persons were talking about important events in their life, or some achievements, reviewing their own story, trying to give coherence to it by making links with their values. Justice for Mr. T. and Valérie, sincerity for Mr. F.

Besides putting their things in order, what some patients still wanted to achieve were meaningful acts that reminded them of a part of their story, like a walk in the forest, seeing one’s home again, eating seafood.

As a matter of fact, preparation was in the succession of losses and awareness, and in the mixture of hope, revolt and acceptation inherent to them. Death was the last and most difficult loss, the loss of materiality: the body, the possessions and everything that makes a humane being able to communicate with others, to relate to this world.

Trying to make sense out of one’s experience was made difficult by the fact that, in most cases, religion was not considered as a means of coping with suffering. This tendency reveals that religion and spirituality are not as distinct as Walter seems to suggest when he states that religion binds individuals with an outer meaning, whereas spirituality binds each individual with an inner meaning (1994:28). Mrs. L., who found
support in religion, considered it as a way of living her spirituality that she described as something developing with the years.

“It’s a word, an exchange, a reading, a relationship with nature.” (Mrs. L.)

Whereas for Walter the focus on the individual leads to a loss of links with others, for de Hennezel and Leloup, as well as for Mrs. L., individuals bind together through their own experience, and this can be called spirituality.

“For our values are not rooted in dogmas and beliefs anymore. They are rooted in experience, and in particular in the experience of solidarity, of presence, of attention to the other, of discovering the reciprocal enrichment in each encounter. This is where the meaning of our existence and of our acts finds its source.” (1997:22)

These considerations can explain what first appeared to me a kind of ambivalence towards religion and spirituality. After saying that faith was not helping her, Mrs. G. added: “I don’t pray. Well, not very much.” Alexandre: “Now, if there is something, it’s rather the Orthodox Church. I am unbelieving.” I asked if he believed in a superior force, he answered: “Yes, but not necessarily a God. Spirituality is important. I don’t stand what is done in the name of religion. To massacre children in the name of God…” Valérie had the same feeling towards religion: “Since I am a child I say that as far as there will be a poor seated on the church’s stairs and a golden ciborium on the altar, I am not going to believe in God.” Nevertheless, Valérie was praying for a deceased patient, and asked for the minister when she was in a period of trouble.

The dominant religion in the area is Protestantism, so the minister was Protestant. There was an ecumenical “time for sharing” every Friday afternoon, sometimes a Catholic priest was dropping by, and an Orthodox priest came every month to perform a mourning ritual for the dead.

The ambivalence towards religion was part of a search for meaning and references, something that could reduce the fear of the unknown.

Charlotte’s sister remembered a souvenir from their childhood. “Are you afraid of dying?” she had asked her sister. And Charlotte had answered: “Yes, because I am not used to it”. It summarises what is waiting for us at the end of life: a new experience, where the unknown is the only expectation.

The first time I met Alexandre, he told me that he regretted not being able to read anymore, as he had just bought a book about philosophy and was afraid he would not have enough time to read it. I suggested that I could read it aloud, but he said that he preferred waiting until he would be able to read again. Two weeks later, right before dying, he expressed that he was ready for someone to read the book aloud. He said that
he wanted to hear other voices than the family’s voices. But he did not have the book with him.

In our successive discussions Alexandre, had told me about his origins, his illness, his despair, and his hope. He was in search of making sense out of his experience, out of his life. In the example of the book, I can see awareness besides losses, hope, and dying. Awareness about one’s own limitations, with death as the last limitation, and awareness that others, as members of humanity, contribute to give meaning to one’s life.

Giving birth to death is thus to accept death as a limit “appropriate at any time” (Marshall 1980:188) and “to free oneself of the restraints of culture, to stand somewhat aloof from our milieu, and to re-find a sense of what and where we are.” (Murphy 1990:231)
CHAPTER 9

LATENT PERSPECTIVE: LIFE IN DEATH, LIFE IN DEPTH

The home itself was representing hope. It was conceived as a place for community life, with which people interacted to make sense out of their experiences. It was classified as a centre for treatment and rehabilitation, whereas roughly two thirds of the patients would die on the spot. So, the findings above could be interpreted as a consequence of the specific structure of this home. In order to discuss this point, I would like to come back to my first objectives, the relevance of palliative care and how it relates to the perception of death. I will not deal with the third objective again, how a person relates to his body at the end of life, as this topic was extensively discussed in the first part of the findings.

A modern view of the patient, corresponding to the modern model of the body cut from the cosmos, the others and himself, would be Parsons’ sick role. In this model, medicine reduces the individual suffering to its general view (Frank 1995:11). This role did not apply to Rive-Neuve’s patients. Their individual story, their relationships were taken into account, the body was not cut from its context. Patients were transformed into companions. According to Nichter (1998:339), “by accepting and taking medications, patients acknowledge to themselves and those around them that they are truly ill.” As the amount of pharmaceuticals the patients had to take was reduced, and they were proposed together with other medicines or treatments like massages, medications were not totally fulfilling this function. Manifestations of affectivity like touching, kissing were common, whereas in the medical concept, the patients should be objectified as much as possible in order to treat their organs (Walter 1994: 37). Interactions with the visitors were favoured, so that gaps with them could not strengthen the “sick role”. These are signs that patients at Rive-Neuve were not representative of the “modern” way of treating ill people. Some use the labels of “postmodern illness” and “postmodern dying” (Frank 1995; Walter 1994). For Walter, hospices are a disguised way of empowerment of the patient by medicine, as well as a means of disguising death. The shift from modernism to postmodernism is a shift in the manner of controlling individuals by medicine.
“Hospice and palliative care link scientifically tested techniques of pain and symptom control with a commitment to the person dying in their own way. (...) The public sphere continues to manage the private, but more subtly.” (1994:40)

This kind of interpretation would lead to consider the experiences of the persons I met as consequences of their being in a setting like Rive-Neuve. It places the discussion at the meso level, the level of interactions between the members of a community. I would like to argue that Rive-Neuve can be see as an agent and a symbol of changes happening at the macro level, regarding the meaning given to death, life, and illness.

To see in Rive-Neuve only a kind of mutant, between the hospital as public place and the home as private place is at risk to cut the individual from the context of the community. The emergence of personalised rites for the funerals, the shift from “religion” to “spirituality” are all part of a same awareness about the meaning we give to life and to death. The dead are more and more seen as social beings, and the way of giving meaning to one’s life is correlated to how meaningful someone is for the others.

“... When death occurs, the deceased’s social identity seems to be tightly linked to the body and it is the centre of many acts and performed ritual. It is yet important to emphasize that the deceased’s social identity often keeps on existing even after disparition of his body.” (Hadders 2001)

Awareness is more obvious in a palliative care home, because palliative care is a consequence of the changes in mortality and morbidity rates mentioned in the introduction. As dying in hospital has become the norm, and as chronic illnesses and particularly cancer have become the first causes of mortality, attempts to give an answer to these changes came from medical settings or people. But medical people are also family members of a patient or patients themselves. In this case, private and public sectors cannot be separate entities.

“Culturally or societally oriented responses provide the framework within which individuals must do their own dying. It is important to emphasize that the cultural or societal responses are organized by humans for both personal and social reasons.” (Marshall 1980:190)

The only remaining perspective is that we have reached a point in our history where the period of dying is extended. This leads to a redefinition of death, life and illness. And maybe, we will realise that death is not beautiful, it is not ugly, it just is.

The diagnosis of a “terminal illness” has the effect of accelerating a process present in every human being, but above all at the end of life, awareness of finitude. If we understand that the process of making sense of one’s life occurs in interaction with others and the outer world, we can see better that if a place like Rive-Neuve enhances
hope, it is not to disguise or deny death, but to answer to the needs of human beings. We have to see Rive-Neuve as a place in which every element participates in this process, a place where people are taught how to live, because it is the only way of learning how to die.

“There is, then, no separate instinct for the oblivion of the self, for death. It is a part of a generalized life force that reaches out for total Being and finds Nothingness, for they are one and the same.” (Murphy 1990: 227)

“(…) for if all other meanings and values are arbitrary and culturally relative, then the only transcendent value is life itself. Life is at once both its means and its end (…) Life is less a state than a process (…) But the essence of the well-lived life is the defiance of negativity, inertia, and death.” (Murphy 1990:230)
CHAPTER 10
REINVENTING DEATH, CONCLUSION

Building one’s story until the end and sharing it with others is essential for human beings, because it is what builds their common history. Dead people are our story, our history. The current “discourse about the way of dying” (La Marne 1999:3) may be an awareness that the human being is not only a producer or a consumer of materiality, but also a producer and consumer of meaning.

“Without death, the problems of passing on meaning from generation to generation would be greatly reduced.” (Marshall 1980:42)

Stories can be shared verbally, but first of all by interacting with others, witnesses, companions, and beloved ones. As we have seen in chapter four, the body is where place, time and identity meet together, in order to let individuals interact one with each other. Life in a small community, like a palliative care home, is thus an ideal way of “passing on meaning”. Defining how we want to die is directly correlated with continuity of human experience, made of experiences of humans.

Walter’s chart (1997: 184) summarises roughly historical changes in the perception of death:

<table>
<thead>
<tr>
<th>Traditional death</th>
<th>Modern death</th>
<th>Humanized death</th>
</tr>
</thead>
<tbody>
<tr>
<td>Traveller</td>
<td>Soul</td>
<td>Body</td>
</tr>
<tr>
<td>Transport</td>
<td>Church</td>
<td>Hospital</td>
</tr>
<tr>
<td>Authority</td>
<td>Priest</td>
<td>Doctor</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Myself</td>
</tr>
</tbody>
</table>

This shift to the death of the individual might be a sign that our society is nowadays trying to connect elements of a whole together, while in the “modern” period, the trend was towards separation. We miss in this chart Walter's idea that the individual dies his own way, but in company of others.

The death of the individual might be a first step. Palliative care is ahead of this process, because dying from a chronic illness is giving the opportunity to prepare oneself. The patients I met became more and more aware of their finitude when they heard the diagnosis. From this point on, their path was made of losses, hope, and more awareness. The path was an attempt to gather all the pieces of their life’s jigsaw puzzle together, to give meaning to their experience, to their story. The next step would be to
enhance connections with the community, so that maybe, just as in the Middle Ages: “the dying’s room was then turning into a public place.”\(^7\) (Ariès 1975: 23)

To prepare oneself means to live more fully, to interact with others more deeply, and to understand that we build our own story from a point in time that is not our starting point as individuals, but our starting point as members of a family, of a community, of humanity. The awareness of death can thus make life more meaningful. A patient with a terminal illness experiences a sort of acceleration of this process, until his time and space collapse together at the moment of death.

By giving to a community the opportunity of having close relationships with dying people, palliative care is increasing the social survival of these people. The more people interact with a dying person in a meaningful way, the more his memory can live in the mind of these people. As our history, and our story build themselves upon our dead, this is a way of increasing continuity in humanity. This is the reason why every element in Rive-Neuve’s context was an attempt to enhance relationships with people, but also with the environment, animals, nature, food for instance. The more interactions with the world of the living, through the senses and relationships, the better society can integrate its past and go on constructing itself. History of society is made of the whole individual stories.

The expansion of this perception of death is happening very slowly, because it is mostly confined to medical settings. Change in perception needs confrontation with death. That is why medical staff is the first through which this change is happening. Every staff member I met at Rive-Neuve acknowledged that working with dying people was changing their perception of life and death. This change had consequences on the way they were living, and consequently, on the people with which they interacted. But the first condition for a real change is that they have to accept their “vulnerability” (Chikako Maruyama 1999:130). It means accepting impotence, recognising one’s fears and wounds, and try hard to go beyond one’s role in order to meet the other as a human being.

The need to believe in hope until the end is what binds human beings together. The dying were looking for a confirmation that they could still relate to others, that they still belonged to the community of the living, that they would not be excluded from it. This, I think, is what Mrs. C. meant when she told me that we might meet again for a walk along the lakeside.
The attachment between the dead and the living lay in materiality. For those left behind, the body and the belongings of a deceased person became the person. Preparation for death occurred through materiality as well, since it connects the individual and the world. Materiality was first represented by the body, the announcer of death, and the crossroads between identity, time and space. Materiality was in papers as well; papers about inheritance, funeral, and, in the case of Alexandre, in his own archives.

Boundaries of death and dying have become less precise and dying can be a kind of multi-steps process. Two patients were at Rive-Neuve for a second (and last) stay, a woman left for two weeks, came back and died there. What dying people needed was a space where to live, in which death was present (the white candle) but not dramatised, because it was the only way of learning and teaching how to be human. In this way, dying people were still part of life, and so were dead people.

If “death is viewed as the limit or the boundary of the individual’s participation in society” (Marshall 1980: 43), then a negotiation around this participation implies inevitably a shift in the limit, and hence a redefinition of death.

NOTES : ORIGINAL FRENCH VERSION

1 “toutes les études d’évaluation tendent clairement à prouver que les coûts des soins palliatifs sont inférieurs à ceux des soins curatifs”
2 “Après avoir purement et simplement nié tout un pan essentiel de l’expérience humaine - l’agonie -, l’institution médicale risque à présent de vouloir se l’approprier. (…) Il s’agirait là d’un glissement aliénant et réducteur, une grave dégénérescence mettant en cause le statut même de notre humanité.”
3 “Efficacité de l’antalgie et maîtrise des symptômes majeurs, image de soi apaisée, authenticité dans les relations humaines, organisation satisfaisante des retours à domicile, respect de la mort, travail de deuil favorisé et encouragé, diffusion d’une pratique des soins palliatifs et terminaux de qualité.”
4 “Regardez, c’est comme ça qu’on est à la fin de la vie.”
5 “C’est drôle le corps humain, quand même.”
6 “C’est bizarre comme on fonctionne.”
7 “C’est drôle comme le corps peut être dissocié parfois, comme en plusieurs morceaux.”
8 “Ce qui m’a le plus surpris, c’est de retomber de mes jambes en voulant me lever.”
9 “Cette conception implique que l’homme soit coupé du cosmos (ce n’est plus le macrocosme qui explique la chair, mais une anatomie et une physiologie qui n’existe que dans le corps), coupé des autres (passage d’une société de type communautaire à une société de type individualiste où le corps est la frontière de la personne) et enfin, coupé de lui-même (son corps est posé comme différent de lui).”
10 “ça m’était quand même douloureux, de subir ça à l’hôpital.”
“On a l’impression que ça vous broie les os, ça m’a tout ratatiné: le cerveau, les jambes, l’estomac, l’intestin...”

Elle dit ensuite que le coût de la chimio est de 3800.-Frs par semaine, “et il y avait cinq semaines.”

“Et puis bon c’est quand la chimio commence qu’c’est un peu plus difficile hein. J’la supporte assez bien, j’ai pas perdu mes ch’veux...mais...C’était un peu un mal-être constant.”

“Ils ont raclé jusque sur l’os.”

“Puis ils ont dit “vous avez pas assez nettoyé”, et voilà qu’ils ouvrent pour la troisième fois. Ah oui, j’en ai vu.”

“Je vis avec ma maladie. C’est comme ma langue, mes oreilles, mon nez.”

“Voyez ces bosses là? Elles sont venues en un mois, ce sont des métastases. Vous savez ce que c’est les métastases? Ce sont des sortes de ramifications, c’est le cancer qui se propage.”

“Je n’peux plus lire ou écrire. J’suis trop fatiguée.”

“Se sentir faible comme ça...”

“Je dois compter le nombre de fois que j’monte les escaliers.”

“reprendre des forces”

“se défatiguer”

“...le lieu et le temps indiscernable de l’identité.”

“Ainsi, pour la famille, la préparation du corps va jouer un rôle important dans la continuité de sa relation sociale avec le défunt.”

“Madame Y. est née au ciel lundi, le x juin, à 14h 45.

“Monsieur Z. s’est éteint paisiblement, ce mercredi x mai 2001, à 2 heures du matin.

“C’est dommage quand il n’y a pas de photo, après on oublie les visages.”

“Dans trois mois au plus, je serai mort.” “Le problème c’est le temps. Je ne sais pas si je suis là encore deux semaines ou trois mois.”

“Vivre intensément, le temps fuit en courant ;
On ne rattrape pas ce qui n’est qu’un moment.”

“J’apprends la patience, ici. Le Grand-Bleu m’apprend la patience.”

“désorientation dans le temps”

“Ah, vous m’abandonnez? Bon ben à plus tard.”

“Quand elles ont à faire, elles disparaissent tout-à-coup, on ne les voit plus.”

“Le temps, ici on a le temps, on prend le temps, chacun donne de son temps.”

“Le temps fait passer l’amour, et l’amour fait passer le temps.”

“Vous auriez du monter avec moi, venez, ’y a encore d’la place!”

“C’est dur de rester assis quand on n’a plus de rembourrage.
C’est parc’que vous avez perdu du poids.
-Moi j’ai perdu quarante kilos, j’vous comprends.
-Moi j’ai tout réglé avant de venir ici.
-Moi aussi.
-On est en train de régler les papiers, vous voyez c’est différent quand on n’est pas mariés.”

“Ma voisine baisse beaucoup. Je ne voudrais pas qu’elle parte avant moi, mais elle ne va vraiment pas bien. Elle dort tout le temps...”

“C’est comme s’il y avait une seule tête avec beaucoup de mains.”

“Il ne faut pas trop mixer, pour garder le plaisir de l’oeil. Avec des petits morceaux, c’est mieux que du mixé.”

“Tant qu’on peut faire soi-même, il faut le faire.”

“Vous devez prendre tout ça?”

“Après ça, vous avez soupiré.”
“Toutes ces couleurs, ça colore aussi ce qui sort?”
“Ce sont mes smarties.”
“un petit bout de papier”
“Les anti-douleurs. C’est tout.”
“On m’a coupé les douleurs, on m’a permis de revivre un peu...”
“Tout médicament qui n’a aucun effet direct sur les symptômes doit être arrêté...”
“Je suis descendu aux fleurs pour oublier un peu tous ces problèmes.”
“Je vois rouge aujourd’hui. - Ces fleurs rouges, c’est de la colère? - Non, je suis déçue.”
“On se reverra au Paradis.”
“Avant la maladie, je ne pensais pas à la mort. Ou j’y pensais comme tout le monde.”
“Ca m’a permis de me rendre compte que la vie est courte, qu’on n’a pas la vie éternelle.”
“Au début, c’était dur de penser à venir ici, parce que j’ai dû réaliser que l’état de ma maladie était grave.”
“Hier elle était là, elle parlait, et aujourd’hui elle est morte.”
“Ce qui m’a même beaucoup choqué, c’est le nombre de décès. En un mois, il y en a eu six, ça fait beaucoup.”
“Ca m’a fait aussi du bien d’être des fois un peu seule. J’crois qu’on a tous un peu besoin de ça.”
“J’aime mieux rester dans ma chambre. Enfin, LA chambre, puisque je la partage avec quelqu’un.”
“Je me suis rendu compte en venant ici à quel point ma femme tient à moi.”
“Il faut préparer son départ, en pensant à ceux qui vont rester. J’ai fait mon testament, j’ai aussi demandé à ma femme de faire le sien.”
“On règle des petites affaires, des archives que je n’ai jamais eu le temps de ranger. Aussi après deux heures de ce type de travail, je suis épuisé.”
“Je fais le bilan.”
“C’est une parole, un échange, une lecture, une relation avec la nature.”
“Car nos valeurs ne s’enracinent plus dans les dogmes et les croyances. Elles s’enracinent dans l’expérience, et notamment dans celle de la solidarité, de la présence, de l’attention à l’autre, dans la découverte de l’enrichissement réciproque de toute rencontre. C’est là que le sens de nos existences et de nos actes trouve sa source.”
“Je prie pas. Pas beaucoup quoi.”
“Mais maintenant, s’il y a quelque chose c’est plutôt orthodoxe. Je suis incrédule.”
“Oui, mais pas forcément un Dieu. Le spirituel, c’est important. Je ne supporte pas ce qu’on fait au nom de la religion. Massacrer des enfants au nom de Dieu...”
“Tant qu’il y aura un pauvre assis sur les marches de l’église et un ciboire en or sur l’autel, je ne croirai pas en Dieu.”
“Lorsque la mort survient, l’identité sociale du défunt parait étroitement liée au corps et elle est le centre de nombre d’actes et de rites accomplis. Mais il est important de souligner que l’identité sociale du défunt continue souvent d’exister même après la disparition de son corps.”
“La chambre du mourant se changeait alors en lieu public.”
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