Organizing feeling

A relational constructionist inquiry of hospice work

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Content

> ‘I don’t feel that it is necessary to know exactly what I am. The main interest in life and work is to become someone else that you were not in the beginning.’ This was Foucault’s reaction to the question of whether he was a philosopher, historian, structuralist of Marxist (quoted in Martin, 1988: 9).

> (..) for me it still stands that, if the work would not move me anymore, than I would quit immediately. And we ask that of everybody who’s involved. Make sure you are moved, and make sure it doesn’t bring you down. And search somewhere in between. (Theresa, hospice coordinator).[i]

Foreword

A foreword is usually written as last. It should provide some reflection on the writing process. And of course the foreword is a place to express gratitude to the people that helped the author in his work.

This thesis was not written over night. And now that it is finished there comes an end, not only to the writing work, but even more so to a long process of re-thinking taken for granted conception such as the organisation and emotion. At the same time a new process begins: sharing. Over the last few months I have noticed the many interests in the topics of this thesis. I hope this text will serve many in an attempt to make sense of the organizing practices they participate in. Also I hope this texts provides some new ideas to give feeling a more prominent place in (working) life.

I would like to thank Heike, my girlfriend, for her uplifting spirit and her many attempts to motivate me at times that I did not know how to go on.

Many, many thanks to all the participants that where willing to share their personal stories with me. Not only would this thesis not have been possible without your contribution, your stories also convinced me that this inquiry could actually be relevant and meaningful to people beyond a small academic community. And special thanks to Ernst Kleisterlee for bringing me in contact with participants, and for your insightful reflections.

I would also like to express special gratitude to my supervisor. Dian, you have not only helped me in this thesis with valuable feedback. You are actually responsible for my interests in doing research at all. Through your teachings over the years I have developed an interest for philosophy of science and social theory. Without your teachings I would have never gotten to the idea for doing a relational constructionist research on feeling.

Michel, I would like to thank you for your feedback on my draft versions of this thesis. You have an uplifting personality and getting feedback from you has been a pleasant experience.

Last but not least I would like to thank Paul and Riet. You have given me great mental and financial support. My studies would not have been possible without you.

Dirk Schmidt

04-19-2011, Utrecht.

Chapter 1. Introduction & research orientation

During my studies in public administration and organization science I have become more and more familiar with postmodern, feminist and post-strucuralist critiques on mainstream organization studies (O-S) literatures. Learning from these critiques it struck me that I am dissatisfied with most research in the field of organization studies. I identify three shortcomings of which mostly at least one is (often implicit) present in mainstream organization studies (O-S) literatures.

1. Boundary issues: most O-S literatures keep an implicit separation between rational/goal oriented employee and emotional private person and family member.

   > 'There is a dichotomy that is central (..) to many organizational theories and practices, particularly those based on an ostensibly humanitarian philosophy of management. This is the public/private dichotomy that contrasts the public domain of the marketplace, the political arena, and the legal system with the "closed and exclusive sphere of intimacy, sexuality, and affection characterizing the modern nuclear family."' (Martin 1999: 343)

   Frankly, scholars of O-S consider "what happens at home" to be irrelevant to the workplace. As soon as the organizational doorstep is passed the human transforms in an "employee" who's performance depends on: wage, career perspective, motivations etc. Whether that "employee" just had a fight with her fiancée, or has a sick mother to care for does not seem to matter.
2. Rationality (and cognition): related to the first issue of dissatisfaction, I note that rationality and cognition are praised while emotionality and feeling are marginalized and frowned upon. In many writings the management is portrayed as rational organizational hero while employees are noting more than short-sighted, emotional, lower-beings that *just not feel the sense of urgency for rational decision making*.[1] Emotions, are often seen as nothing more that an obstruction in the way of organizational success:

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[1] See for an example of such writing Kotter 1996, for a intelligent discussion see Brunsson 2006

> ‘For cognitive theories of organizational learning, emotion tends to be of little interest except to the extent that it is regarded as an aberrant constraint on the smooth functioning of otherwise rational information processing activities.’ (Simpson & Marshall 2010: 352)

I see this as a shortcoming because human life is full of emotional experience. Excluding emotion from (analysis of) the workplace would not only mean the exclusion of an important part of human life, it also diminishes the possibility for emotion-associated behaviours such as care and compassion (Meyerson 2000; Frost et al. 2000).

3. Individualism: In many O-S literatures organizations are portrayed as nothing more than an accumulation of individuals. The existence of both the organization and the individual seems to be independent of one another. Examples of this are emotional intelligence (EI) and positive emotions; topics that recently enjoyed a growing attention and popularity (Fineman 2004; 2006). While at first sight these studies might seem a delight given the above, on second thought, they are not. Concepts such as E.I. or positive emotions theorize employees as bounded individuals that already have certain capabilities or certain emotions, prior to, or independent of any social life that these individuals are embedded in. The fact that concepts such as emotion or intelligence are themselves products of specific (local and historical) cultures is totally ignored in such studies (ibid).

In reaction to these dissatisfactions, this thesis tries to provide an alternative. The starting point forms my interest in emotions in organization. Hospice work is chosen as a site for the exploration of this interest. Although the start of this introduction suggests that emotions might be important in any organizational setting, they might be especially important in health care. Hospices are organizations that provide end of life care to persons that have less than three month to live. This is a practice for which any sensible person can imagine that emotions take a central place. In line with the tradition of relational constructionism (see chapter 2) this inquiry starts out with a very broad research question. Also in line with this tradition is the focus on text, or better, the focus on the textuality of all relating (Stenner & Eccleston

1994), including emotional relations. Therefore narrative analysis is chosen as a method for analysis.

To following question will direct me in the research process:

How is feeling organized in narratives of hospice work?

Although it is a broadly formulated question, its specific elements give some direction in the research.

The question asks about the *how* of organizing. This means that taken for granted notions such as person, organization and emotion themselves become object of inquiry. Instead of assuming their existence, the present research looks at how they are constructed. In other words, how they come into being.

The way through which this is inquired is narrative analysis. The term narrative implies that this research focuses on texts. Accordingly the present research will use open-ended interviews to collect stories and narrative analysis to analyse these stories.

In this question, the word *feeling* has replaced the word *emotion*. The word feeling is chosen to emphasise a break with individualistic notions of persons and emotions. Feeling is a relational constructionist concept that assumes that identity and emotions are constructed in ongoing interaction.

Following from the question of *how*, this inquiry speaks of hospice work instead of hospice organization. Hospice work is understood as a practice. This research is thus not concerned with a particular hospice organization, or a particular group of persons that participate in hospice work.

Further relevance

The question posed above might be relevant for other interests beyond my ego concerns that I started this introduction with. In a rather direct way this inquiry might be interesting for hospice workers.

There is a process of medicalisation of palliative and hospice care (Clark 2002). It used to be the case that people that could not be cured went to a hospice. That meant that there was no, or very limited medical treatment. As techniques and medicine have developed, there are more possibilities to provide treatment against pain and life-prolonging treatments. The risk, however, is that other, non-medical aspects of good care disappear. Care than becomes mechanistic activity that lacks human connection. This is well presented by a quote form a research participant that Bruce & Boston present:

> "You know they've been to all the chemo and all of the people poking and prodding, they're trying to survive and 'how long do I have to live' and 'what treatment will I pursue next', they've been through all that. Sometimes what they really want is not another pill or breakthrough med but someone to actually sit there while they're puking, you know, not trying to fix something or not giving up on making them feel comfortable, or not being afraid to have a difficult conversation." (Bruce & Boston 2008: 54)

The inquiry about feeling could be an interesting turn away from the medicalised practices and it might also help hospice workers and other care givers to centre human relations and feeling as a quality of those relation in their organizing practices.

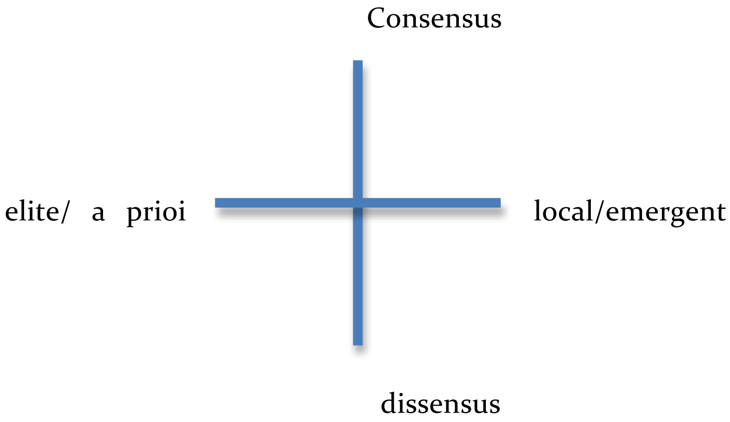
In a broader sense this inquiry might be relevant for other professional than caregivers. Over the past few years in the Netherlands there has been some debate about professional pain and professional pride. The argument is that professionals feel pain because off a reduction of their discretionary space and autonomy, the introduction of strict protocols, a growing demand for accountability, red tape and so on (Jansen et al. 2010). The professionals desire to retrieve pride in their profession. Some ways to achieve this are believed to be small-scale organizing, more discretionary space, refocus on the values that professional practices encompass and a focus on human relations (ibid). Professionals that seek pride in their work might benefit from the present research because it puts relational practices in the centre of organizing with feeling as an important quality. This, I believe, in line with the goals of the professional pride movement (http://beroepseer.nl/).

Chapter 2. Social science perspective, (developing a thought style)

My research topic and methods imply that I have certain assumptions about reality, what knowledge we can have of reality, and how we can produce that knowledge. I Therefore I will start by explaining my social science perspective. This is very important because it does not only influences the choice of methods, it shapes the very way in which this thesis is written, which questions are posed and how I try to answer them. In this chapter I will position my social science perspective in a broader context. I will argue that the various ideas about ontology, epistemology and method that inform this research together form a thought style. This particular thought style will be explained with a discussion on the concept of organization. The chapter ends with a discussion on the relation between language and the non-linguistic world. That discussion forms the prelude for chapter 3 and 4.

In most research articles, assumptions about ontology and epistemology are not discussed – and realist/modernist scholars are least likely to do so. Those scholars treat the world as existing independently of their engagement with the world. The knowledge that such scholars presented in their research papers is legitimized on the basis of research methods that are regarded as valid by “the scientific community”. I use brackets here, because there is no unified scientific community (Woolgar 1996: 19). Other scholars do find it necessary to tell their ontological and epistemological assumptions. These are mostly the scholars that recognize the world as socially constructed. I put myself within the latter group of scholars and will explain my assumptions about reality here.

To position my own research I use the grid developed by Alvesson & Deetz (2000: 24). The grid has two dimensions that together create four categories. Researches can be primarily interested in either “consensus” or “dissensus” over (social)-reality. Consensus research works within dominant conceptions of reality, persons and social categories. Dissensus research problematizes these dominant conceptions. Reality, person and social categories are not taken for granted and become themselves object of study. For example, the American census gathers information about persons, including one’s ethnicity. A researcher could use this information to test hypotheses about crime behaviour of groups such as whites, black and Hispanics (consensus). A dissensus type of research could look at the use and creation of the categories of race and ethnicity. Now the categories that are taken for granted in social life and in consensus style research become themselves object of study. It is not the differences in crime behaviour of various ethnic groups that is problematized, but the construction of the ethnic categories themselves. Questions might be: how do bureaucracies administer race and ethnicity, what are the inconsistencies of the categories and who is legitimate to assign ethnicity to a person?[2]. Back to the grid. The other dimension in the grid is about the origin of concepts and problems that the researcher studies. Are these local and emergent or elite and a priori? An anthropologist could for example go to a community with a predefined research question and conceptual framework (elite/priori)[3], or e.g, ask the community what outsiders should know about them (local/emergent)[4]. Within this schema, the present research could be placed in the local/emergent-dissensus category of the grid.



taken from Alvesson & Deetz (2000

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[2] example based on Yanow (2003).

[3] e.g Harris (1975).

[4] e.g Cruikshank (1990).

The local emergent position relates to my ideas about ontology, epistemology and method. I use for instance open-ended interviews to ensure that the research participants have a lot of freedom to talk about the subjects in their own words and tell what they think is important. Together my ideas about method, epistemology and ontology form a thought style, a term I borrow from (Chia 1996). I deliberately chose the words *thought style* here and not the word *paradigm* to describe my ideas. Kuhn developed the idea of paradigm to understand the history of science (Benton & Craib 2001: 58-61). Later, the term was used by Burrel & Morgan (1979) to describe differences in approaches in social science. I chose not to use the word paradigm here because the categories created by Alvesson & Deetz' grid are not coherent wholes like a paradigm implies. The grid groups together ideas that are conflicting and in debate with each other. Second, there are no hard or fixed boundaries between the categories of the grid. And third, researchers use ideas and concepts within a single publication that could be placed within different categories (Deetz 2000: 136-7).

The thought style that I try to put to work in this text could be called postmodern (Chia 1996) or relational constructionist (*Hosking, Dachler & Gergen, K.J.1995;* Gergen, 1999; Hosking 2011). Here I will use both terms interchangeably. This thought style can be contrasted with the modernist thought style that has been dominant in organization science and is represented by the elite/a priori-consensus category of the grid.

Gergen & Thatchenkery (2006) identify four key themes that typify traditional, modernist organizational science.

(1) Individual rationality is important in the modernist thought style. This idea has important roots in the Enlightment. The idea of individual rationality was an important break with royal and religious totalitarianism. The idea is that '*within each individual lies a bounded and sacred principality, a domain governed by the individual's own capacities for careful observation and rational deliberation*' (ibid. 35). Although the notion to think for yourself might have helped westerners to emancipate from religious and royal rule, it also gave rise to a rather atomistic view of people. This shapes ideas on how organizations work, how employees are motivated and how

managers take decisions. The modernist thought style constructs organizations and people as separate entities[5], employees as knowable subjects to be manipulated for productivity[6], and managers as rational decision makers and leaders of change[7]. In contrast, the postmodern thought style enables to see rationality as constructed by language. Language is not something individual (there is no private language), but constructed within a community. '*To do rational*' is to participate in a form of cultural life' (ibid. 39). In contrast to modernism that centers the individual, postmodernism as thought style centers the relation of the individual with others. Neither the individual, nor the community is defining, rather both define each other.

(2) The second theme is empirical evaluation. It is grounded in the idea that there is a '*world out there*' waiting to be studied. It centers methods of data collection and analysis as the means to do research. The postmodern thought style proposes social construction as the alternative. It enables to see alternative realities as co-existing. Which reality is credited as being real depends on the perspective of a community and power relations (ibid. 36-7). The modernist belief is that scientific theory can represent (mirror) the world in value neutral manner. For social sciences, such a claim seems rather problematic. The social sciences have never been successful in developing general predictive theory like natural sciences have (Flyvbjerg 2001). That is because the phenomena studied in social science are themselves theory laden. Theories are described in language. Language is by no means value neutral and does not have direct correspondence with an object outside of language.

> 'It might very well be the case that there are "objects" in the world to be studied. Yet even these physical objects cannot be examined outside of language. The discursive forms used by scientists construct the knowledge and information we have about the world.' (McNamee 1994: 70; underline in original)

Therefore many postmodern thinkers shift their attention to the scientific community and language to reveal what power relations inform supposedly neutral scientific descriptions. They try to uncover what is excluded and marginalised in

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[5] e.g Bolaman & Deal (2003)

[6] e.g Latham (2007)

[7] e.g Kotter (1996)

scientific writing, how a particular object is constructed and how that might be done otherwise.

(3) The third theme that Gergen & Thatchenkery identify in the modernist thought style, is the '*belief in the capacity of language to represent the real*' (2006: 38). It is the belief that language represents objects in a neutral, factual way; objects that exist separately from the language in which they are described. The postmodern alternative is the view language as social action. Words are tools in the construction of reality. Language gains meaning from its use in contexts (language games[8]). Thus language is not a mirror of the world, but meaning is attributed to words by their use in a specific context. Foucault argued for instance that homosexuality as a sexual identity resulted from the new language repertoire that was brought into being by the emergence of medical and psychological science. In the first volume of 'The history of Sexuality' he writes:

> 'As defined by ancient civil or canonical codes, sodomy was a category of forbidden acts; their perpetrator was nothing more than the juridical subject of them. The nineteenth-century homosexual became a personage, a past, a case history, and a childhood, in addition to being a type of life, a life form, and a morphology, with an indiscrete anatomy and possibly a mysterious psychology. (..) Homosexuality appeared as one of the forms of sexuality when it was transposed from the practice of sodomy onto a kind of interior androgyny, a hermaphrodism of the soul. The sodomy had been a temporary aberration; the homosexual was now a species.' (Foucault 1978: 43)

From this example we see that it is not so much that language reflects the existence of a life form (homosexuality), rather, language constructs homosexuality as an identity, which was non-existing before the rise of medical and psychological sciences.

(4) The fourth and last theme, is connected to the previous three. That is the believe in '*systematic progress*'. The idea that knowledge will accumulate towards objective truth. It is the idea that by testing and refining theories, all "gaps in knowledge" can be filled. Eventually that would lead to a total understanding of all phenomena in the world. The alternative is a progress towards acceptance of '*pluralism of understanding*' (Gergen & Thatchenkery, 2006). Now again I can illustrate this point

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[8] Wittgenstein (2001) Philosophical Investigations.

with an example of Foucault. Pierre Riviere was a French peasant in the 19th Century that murdered some of his family members. The trial of Pierre illustrates a dispute between psychiatry and the legal profession in determining if he was mad or bad.

> ‘It is not an argument that can be established according to some external or absolute standard outside of each of the conflicting discourses and against which both can be measured. Rather one constitutes him as a responsible agent who should be punished for his crimes, while the other constitutes him, from the same material, as an insane man in need of whatever treatment might be available.’ (Benton and Craib, 2001: 166)

Now that the postmodern thought style is contrasted with the more dominant modernist thought style, I will expand this style of thinking with a discussion on organization. In my discussion, I will present an alternative to the modernist concept of organization as an object-like stable entity. I will argue that how we understand organization shapes what organization is. In other words, organization is not independent of our thinking about it. Following that, narrative is introduced as a method to study feeling in organizing. The proposal ends with a first exploration of the topic of emotion as feeling.

The concept of organization, (thinking in entity or process?)

Seen from in the postmodern thought style, reality is a flux. It is the ongoing movement of atoms that form the universe, the constant flow of experience of sound, light, touch etc. Organizing than is the ordering of this constant flow of experiences; putting up boundaries to separate one experience from the other, and so reducing (but not removing) complexity.

> ‘Organizing involves ordering and reducing complexity such that as we embody and perform ordering modes, so, too, we delete. This is what agency is about. It is what ordering is about: ignoring; simplifying; fixing what is complex for a moment in a stable form; reifying.’ (Law, 1994: 132)

From this point of view, organization is a process and not an object (Weick, 1969; Hosking & Morley, 1991). Weick argues that scholars should shift the emphasis in their writing from nouns to verbs (Bakken & Hernes, 2006). In the English language, sentences are built around the use of nouns and English a sentence typically contains more nouns than verbs. The argument of Weick and Hosking & Morley is that a focus on nouns will also direct the attention of researches to entity rather than process. Czarniawska (2008: 15-6) notes that language in social science seems to move more and more to an orientation on entity. The word institution for example, originates from the verb “to institute”. However “institutionalization” is widely used as a verb. A signal that we have forgotten that the institute primarily developed as verb (process) and only later to become a noun with the addition of “tion”. Czarniawska (ibid) asks if we may soon be speaking of organizationalization. What should be clear is that an orientation on entity is aided by nouns, while an orientation on process is aided by verbs. Here I will contrast both orientations with each other starting with a quote.

> ‘(..) a focus on ‘becoming’ is one where ‘organizational phenomena are not treated as entities, as accomplished events, but as enactments—unfolding processes involving actors making choices inter- actively, in inescapably local conditions, by drawing on broader rules and resources.’ (Tsoukas and Chia, 2002: 577)

Hosking & Morley (1990) have analysed these two different conceptualizations of organization[9]. Thinking about organizations and persons as entities enables you to conceptualize organizations as

a. Having members and clear boundaries between the organization and its environment.
b. Having a (singular) identity, recognized by its members and others.
c. Having a purpose (goals and/or values that are shared by the organization’s members).
d. Having a formal structure that specifies e.g. responsibilities and lines of communication.
e. Organization and environment independently exist as entities that are linked by relationships of exchange.

A relational constructionist thought style conceptualizes organizations as process. Language changes from organization to organizing, to construct organization as an ongoing process. This enables me to not talk about “the organization”, but about hospice work (as activity or process). This leaves open possibilities for persons that formally are not members of a particular hospice (not employed by the hospice) to be included in an analysis of hospice work. The entitative concept of members and boundaries can be problematic – perhaps especially so – when looking at a hospice.

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[9] There are many different ways to conceptualize organization (Morgan 2006) but most perspectives implicitly or explicitly build on an entitative or process ontology of organization.

Many persons are involved in organizing hospice work, often people that are not employed by the hospice such as volunteers, family doctors that visit their patients who stay at the hospice, nurses that are not employed by the hospice, a chaplain etc. If the condition of a guest allows it, the guest might employ activities outside the physical location of the hospice. If we accept that a guest going outside the physical hospice is part of hospice work, and doctors and nurses that are not employed by the hospice come inside the physical hospice to participate in hospice work, than it is impossible to maintain the concept of organization as having well defined boundaries between inside and outside; as having members and "outsiders". When we centre process, on the other hand, we direct attention to the relational processes in which "the organization" is constructed. Organizing involves potentially many relations and thus potentially many conceptions of its identity. This makes it hard to see a hospice as having a single identity that is recognized by all its members.

A relational constructionist thought style also leads to critically rethink the idea of organizations as shared goals and values. Rather, various participants in hospice work have various goals and values that they negotiate with each other. Anne-mei The (2007; yes "The" is her surname!) shows so beautifully how conflicting ideas about morphine use, palliative sedation and euthanasia are negotiated between different nurses and doctors in the context of palliative care. The negotiation that happens around the difficult decisions about suffering and death is not what is described in the formal structure of the hospice. A focus on formal structure produces than a rather poor view of organizing hospice work.

From a modernist perspective it makes sense to think of organizations as relatively unified entities that could be studied and known. The language of organization (as entity) covers up the routines we have to perform (organizing as process/activity) to create what we recognize as the organization. It hides the multiplicity of practices and constructions. Speaking of organization in nouns rather than verbs is logic because messiness, chaos, unpredictability and emotionality are contrary to what it means to be organized: ordered, stable, predictable and rational (Clegg et al. 2005). But organizing is not only about ordering, there is also disordering involved. Because improvisation, myth, and accidents are part of organizing as well (e.g. Gabriel 2000), we could look at organizing as the process where order and disorder meet. Organizing is than balancing between the two. Too much order and the organization will come to a stand still; it will implode. Too much chaos and the organization will fall apart; it will explode (Clegg et al. 2005).

Organizing as relational construction

From the above it should be clear that the modernist thought style enables us to view organizations and persons in organizations as separate stable entities (Hosking & Morley 1991). This can be contrasted by the postmodern thought style that enables us to see organizations and persons as relational process and therefore not stable entities, but in the process of becoming (Chia 2003; Clegg et al. 2005). Organizations are not separated from persons, but both person and organization are socially constructed (in ongoing processes). Hosking (2004: 6-9) explains in more detail the process of social construction. She identifies four qualities of relational construction:

1. Act-supplement: Interaction is not an individual activity, but a relational one. A handshake can only become a handshake when two hands meet. Acts have to be supplemented with context to become reality.

2. Multiple co ordinations: Acts such as a handshake, rely on many simultaneous interactions or co ordinations. For two meeting hands to be a handshake, they need greeting conventions.

3. Local-social-historical: We construct in ways that are locally warrant as real and good. Acts that are not considered real and good by the local community are not supplemented, or they are supplemented by being discredited as unreal, unusable or immoral. We need particular knowledge (social constructions) for other constructions to become supplemented. Hosking gives the example of a mission statement that only makes sense if we have an understanding of organization, management and hierarchy.

4. Relational realities: Realities only exist in interaction. For a person to be a manager (s)he needs employees to interact with. Realities are multiple and relational rather than subjective or objective. The same person that is a manager in one relation can become a mother or friend in other relations. Also what counts as a manager, might differ per (organizational) culture. And, being a manager only makes sense if we can supplement it with a discourse of formal organization, hierarchy etc.

Further explanation of the thought style, (some help from discourse theory)

Hosking (2011) notes two common misunderstandings about relational (or social) constructionism. First, the notion that constructions are ongoing does not mean that they do not have longevity (ibdi: 26); that is constructions are temporal but can persist for very long times. The second misunderstanding is the idea that beneath the social construction is an unconstructed reality (e.g. Searle 1995). A particular social construction is than viewed as *just* a social construction, which is in a way blind for the physical reality. In such cases, social construction is viewed as a false consciousness, or ideology if we use Karl Marx' terms. As Hosking (2011: 59) notes: there is nothing *just* about social construction. I should emphasise that from the perspective of relational constructionism, all reality is socially/relationally constructed).

Another misconception about the thought style is that relational constructionists deny the existence of physical reality; a denial of objects, as if the computer on which I write this text is an imagination, or hallucination (Potter & Hepburn 2008). Such is not the case. The difference with the modernist thought style is that for relational constructionists the physical world has no meaning in itself. The problem is not that the physical world does not exist, rather, its "existence" depends on relational constructed meanings. I will explain this idea below.

With the help of Hosking (2004) I have tried to explain that reality is relational constructed (and therefore local, historical) rather than objective or subjective (like: this is how the world really is; or we can't really know how the world is, but this is how it probably is). Hosking (ibid.) was pretty detailed in her explanation of relational reality with her handshake example. But for the reader that is new to relational constructionism, I would like to expand Hosking's explanation with an example from discourse theory.[10]

Discourse theory draws on different traditions, but one central tradition to discourse theory is Marxism. One of Marx' contribution to social sciences was the notion of ideology. With ideology Marx mend false consciousness. According to Marx, the proletariat participated in its own suppression due to the ideology of capitalism

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[10] I owe this example to David Howarth who used it in his excellent teachings on discourse theory during the Essex Summer School 2010. Good explanations of discourse theory can be found in David's book: Howarth, D. (2000) "*Discourse*", Open University Press; or: Torfing (1999) *'New Theories of Discourse: Laclau, Mouffe, and Zizek'*. Blackwell.

that blinded their eyes for the “real” condition of the world. And the real condition of the world is the deep structure of class struggle that results from the separation of labour and capital, according to Marx. He believed that science would open the eyes of the proletariat and make them aware of this unequal distribution of power.

In contemporary discourse theory the notion of ideology has changed. Ideology is no longer seen as false consciousness. Rather *all* consciousness is seen as ideological (this is an other way of saying that reality is relational) (Torfing 1999).

What is mend by this: all consciousness is ideological? I will explain this with the example of a forest. And in the process of explaining I will draw on another tradition that is important for discourse theory: structuralism as developed by the linguist Saussure.

The question now is, in what sense is the word forest ideological? Forest clearly refers to a bunch of trees “out there”; trees that everyone can see, feel, build a house with, make a campfire with. A forest is real; it exists “out there”. On first appearance, you might think like this. But on second thought it is not that simple. Saussure (1983) teaches us that words (signifiers) have no natural relation to objects (signified). The meaning of a word can only be understood in their relation to other words (ibid: 118). Forrest can be understood in relation to other words such as trees, leaves, dear, elves etc. That the word forest refers to a bunch of trees is arbitrary, as it could (and has been replaced by) other words.

In this explanation so far I have changed the understanding of the signifier (forest) that directly relates to the signified (a bunch of trees) towards a relational understanding (trees, leaves, dear, elves). Now the second step is to understand the ideological quality of meaning.

As I stick to the example of forest, a forest never refers to *just* bunch of trees. A forest is always *something in the way of* an airport that the government wants to build, or a jewel of mother earth that we have to protect against economic interests. Thus a specific ideology provides a specific meaning (consciousness) to the word forest. And when an actor uses the word forest, we can understand its meaning not by looking out the window, but by looking at the words it is brought in relation with: economic growth, job creation, regional development; or: biological diversity, animal habitat, lungs of the earth etc.[11]

These relations of words, that we could maybe visualize as a network of words, are what we could call discourse. Discourse replaces the word ideology. Just as with ideology, discourse is a concept to understand consciousness, but is does not have the connotation of false consciousness such as ideology has in the way it was used by Karl Marx.

What at the beginning of this section appeared to be real, existing and obvious (a bunch of trees) now on second thought is ideological (in the way of an airport expansion *or*, mother earth that we have to protect). To finish the discussion about the claim that all belief is ideological (relational), I would like to explain the meaning of ideology in contemporary discourse theory. Marx referred to ideology as a well-defined "body" of ideas such as capitalism (free markets, rational calculating individuals), communism (class, exploitation, vanguard party), fascism (discipline, individuals act as one, strong leadership) etc. The meaning of ideology in discourse theory is not a well defined bodies of ideas, but more emergent and contextual. Ideologies themselves are constructed in-situ and small (as opposed to "large" ideologies as *communism*). To explain this I use a third important contribution to discourse theory, that of the late Wittgenstein (1953). As Wittgenstein walked through the streets of Cambridge he heard some builders scream the words: "block, pillar, slab, beam". While screaming these words would make little sense in (most) peoples bedrooms, on a building site the

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[11] One argument against this idea could be that in early forms of "writing" signs were abstract, figurative representations of the signified. And that therefore in the past there was a direct relation between sign and signified. Such an arguments depends on the idea that we can find the 'truest for' of a phenomenon if we trace later forms back to their origins. This 'logic of origins' is a fallacy because the truest form of mathematics would be counting with the use of sticks and stones, a prehistoric practice that we could hardly call mathematics (Chia 1996: 82-6). From this it follows that early "writing" with its supposed direct relation between sign and signifiers is not the true form of language. Instead the true form of language is the arbitrary relation between sign and signified. The meaning of words depends on their relations with other words, not on (non-linguistical) objects.

result in the construction of a house. Wittgenstein referred to this phenomenon as language games. A language game is than the use of words (block, pillar..), actions (handing over) and objects (blocks, pillars..) in a particular context (a building site, a bedroom). A language game only makes sense in the context in which it is "played" and the meaning which is created in the game can be limited (small) to the context (building site) opposed to Marx' notion of ideology (capitalism, communism, liberalism) that is rather "large" and well defined. Thus when I refer to discourse, the meaning is similar to Wittgenstein's language games *and*, I should add, does not only refer to language necessarily, but also to (other/non linguistic) actions and objects, because they are meaningful and can be "read" as language (Stenner and Eccleston 1994), and *together* make a language game. This also solves the last misunderstanding about relational constructionist: the (non) existence of a physical reality. Instead of language referring to a physical (non-linguistic) world, the physical world (trees) and language are used together in relational constructions (forest).

This extra explanation is an attempt to prevent some common reactions by readers that are not familiar (yet) with the language of relational constructionism. I hope that those readers now understand that for relational constructionist the computers they write their papers on really exist. But for relational constructionist this existence is not some brute reality beyond or below the social constructions. Rather objects (together with language and other actions) are used by actors in the construction of their worlds. The next section is a further discussion on language that will explain how interviews, as logistical representations, are understood from the viewpoint of relational constructionism.

Stories about organizing, (when language is not a mirror, then what is it?)

In the field of organization studies, various quantitative and qualitative methods have been used to study emotion (Fineman 1993; 2000; Askanashy, Härtel & Zerbe 2000). My aim is to study feeling with narrative analysis. Exactly narrative analysis is both for the research participant as well as for me as researcher a way to construct the emotionally rich and contextualized stories that I think are appropriate for the goals of this research. The research question of the present research asks for "thick description", and also for participants it might be more useful to respond in stories rather than survey answers. Because it is in stories that people communicate feeling Sandelands & Boudens (2000). And to gather the narratives for analysis I will conduct open interviews with hospice workers[12]. But how can we understand stories *about* the world if I just have claimed there is no reality "out there"; language does not represent (as a mirror) a non-linguistic reality (Hosking 2011: 49). But than the question arises: what is the relationship, if any, between practices of hospice work (linguistic and non-linguistic forms) and talk *about* these practises? In other words, do stories refer to a world beyond or outside the story itself? I try to answer this question here.

I will use language of action nets to explain the relation between the process of organizing (the object of study) and the texts that are generated in the conversations that I use as a means to study that process.

Czarniawska (2008) uses the concept of action nets to describe organizations as processes. An action net is formed by collective action. In the case of hospice work, an action net could be nurses giving medicine to patients, volunteers helping the nurses, hospice coordinators making the work schedule for volunteers etc. But each of these actors is also involved in many other nets of action. Nurses have interaction with people that arrange their salary (health care organization), the hospice coordinator makes appointments with cleaners, and volunteers call their work to check their schedule to plan the hospice work in their free time. When the collective action is repeated enough so that it can be perceived as an action pattern, the action may be questioned by outsiders, researchers for example. They may question why is this done and why in this way. If the natives that participate in the action net are able to justify their collective action to the outsiders, the action net will become taken for granted. In the case of hospice work the narrative could be that: I work at a hospice, an organization that gives end-of-life care.

What we call "the organization" or "the hospice" in every day language has no clear boundaries, no values or purpose as assumed in the entitative conceptualization that is described in the last paragraph. There is just a net of actions. But if asked, we tell narratives about those actions as "the organization" or "the hospice". The point I want to make is that the narrative itself is the construction of "the organization" in language. There is process (actions) that we could describe as action nets. But the

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[12] Other names for similar approaches to interviewing are: the in-depth interview and unstructured interview (Boeije 2010: 62-3).

action net does not have a clear boundary, nor does it have a unified purpose or values or other characteristics that are attributed to organizations such as hospices. If we see action nets as organizations, it is in the linguistic representations of those action nets that entitative (*or organizationa*l) characteristics as boundaries, values etc. are attributed to otherwise loosely coupled nets of action (ibid).

The foregoing enables me to argue that the narrative of the organization is all there is. There exists no organization outside the narrative (the linguistic construction) itself; just loosely coupled actions. The narrative is what constructs the organization. Therefore Weick writes that organizations only "exist" in retrospective (1993: 635). If we accept this line of reasoning and treat organizations as linguistic constructs, it makes sense to look at language and hence to do a narrative analysis.

And because constructions of organization are ongoing, I speak of organizing instead of "the organization". The construction of "the organization" happens in multiple inter-actions with multiple actors. Therefore we can call construction relational, or social. And because each construction is – depending on the participants – potentially open to be different from foregoing constructions, it is therefore that I argue that reality is not objective or subjective, but relational (*Hosking, Dachler & Gergen, K.J.1995;* Gergen, 1999; Hosking 2011). It is in a relation that "the organization" is constructed. And thus depending on the relationship, constructions can be different. None of the narratives of a hospice work corresponds to an existing organization "out there", but they refer to loosely coupled nets of actions, where none of the nets can be said to have a clear boundary, or any other characteristic that we commonly attribute to organizations in everyday talk. It is because some narratives of action nets have become so dominant that we take them for granted. And we have started acting on that taken for granted idea of the existence of the organization. By doing so, we reinforced (re-constructed) the organization as an existing entity "out there" (Czarniawska 2008).

In this discussion I have used one notion that I have not explained as yet: loosely coupled. I will explain this concept before I will go on to discuss how I will treat the accounts of organizing/action nets.

The concept of loose couplings originates in cybernetics. Two systems (for instance production lines or building structures) can be decoupled. In that case, what happens in one system has no effect on what happens in the other system. In the opposite situation, systems are tightly coupled. In that case there is no clear division between the systems. And what happens in one system directly effects what happens in the other system. At present, engineers claim that loosely coupled systems hold best. Buildings in areas with frequent earthquakes for example, are build with loosely coupled structures that hold the building together, but at the same time give room for some shaking and collapse of parts of the building, without a total collapse. In organizational theory a loosely coupled system acts as a metaphor for the relation between for example management and the primary organizational processes. They are connected, but good management does not always lead to success of the primary process. At the same time the primary process may work perfect in spite of bad management (Czarniawska 2008: 40-1).

Back to the relation of organizing and text. Narratives and stories of organizing construct "the organization", as one of many possible constructions. In the present research I propose to collect narratives through conversations (interviews). The difference between observations and conversations is that an observation is the story of the researcher, while a conversation is the story of the participant (and researcher). Neither the participant, nor the researcher has privileged excess to reality (Czariawska 1998). And neither the researcher's nor the participant's story can be fully ascribed to the individual that produces the story. Each narrative, whether that of the researcher or participant is produced in relation to other participants and earlier narratives.

To finish this chapter, I can conclude that "the organization" as entity is a linguistic construction. Language and the object of that language are not separated, but language constructs its object, in present research that is hospice work and hospices as sites where hospice work is performed.

Chapter 3. Theoretical orientations

Before moving on to the empirical material, let us first look at some theoretical orientations that directed me in the conversations and analysis during the research process. According to Domagalski (1999), studies on emotion in the field of O-S can be grouped in three currents. First there are studies that are concerned with the emotionality/rationality dichotomy. Second there are studies that look for the theoretical grounding of the concept emotion. And third, there are studies that deal with power relations that control emotion in organizations. In discussing these three themes I will put the relational constructionist thought style to work and develop a new concept for emotion. This chapter than ends with and overview of some studies that form an inspiration for the present research.

In the field of organization studies emotions are a rather neglected topic for research. One of the early exceptions is Arlie Hochschild's (1983) study of emotional labour. Hochschild uses the Marxist language to argue that organizations exploit their employees' emotions for profit. This exploitation – Hochschild calls it emotional labour – can potentially be harmful to the employee's psyche. Examples are stewardesses and other service jobs that require employees (often women) to display certain emotional states (e.g. to smile).

In 1993 and 2000 (2nd ed.) Stephen Fineman brought attention to the topic of emotions with his edited volumes '*Emotion in Organizations'*. In the first edition Fineman characterized organizations as emotional arenas. Although almost absent in scientific analysis, emotions are important in the working life of employees he argues. In the second edition the textures of emotion in organizing are explored; the appropriation and the use of emotion in the workspace. The book theorizes emotions as both an organizing force within organizations and as outcome of organizational practices[13].

Also Askanashy, Härtel and Zerbe (2000) offer a thorough overview of the topics

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[13] See Fineman (2003) for a more complete overview of topics on emotions in organizations.

in the field of emotions in organizational science in their edited volume '*Emotions in the workplace*'. A wide area of topics is addressed such as emotional labour, decision-making, change, gender, and bullying. Contrary to the mechanistic picture of organizations that arises in most studies, the conclusion from this literature is that emotions do matter in organizations. Organizations do something to our emotions, and emotions also effect organizations. The potential relevance of emotions is not restricted to certain sectors. Research on emotion has been done in both public and private organizations and has concerned itself both with high – and low skilled labour (Fineman 1993; 2000; Askanashy, Härtel and Zerbe 2000).

Rational/un-emotional – irrational emotional

In western culture, emotionality is often constructed as being in a binary opposition to rationality. And for long, rationality has, and still is, privileged above emotionality. Here I mean rationality in the sense of Weber's Bureaucracy "*impersonal and functional*" (1978: 959). The custom to separate emotionality and rationality and to privilege the latter can be traced back to Plato.

Two arguments can be put forward to reverse or make undone the privileged position of rationality. First there are arguments to privilege emotion above rationality. A number of studies show how emotions inform decision making; how they help rationality rather than interfere with it. (Mumby & Putnam 1992; Damasio 1994, 2000; de Sousa 1987). Neuro scientist Damasio showed that without emotion, we are unable to take decisions. One of his study subjects had a brain damage in the part that is associated with processing emotions. The subject of his study had not lost his cognitive abilities, but could as a result of the brain damage, not answer a simple assignment as picking one of two possible dates for the next appointment with Damasio. This would mean that decision-making ultimately is not only a rational/cognitive process, but rather an emotional process (1994). Damasio goes as far as stating an alternative to Descartes' famous declaration of existence and changed it to: "I feel, therefore I am." The second argument is that we have to move beyond the construction of emotionality and rationality as binary opposition. Rather than accepting rationality and emotionality as a binary opposition, we should look *why* people prefer to present decision-making (especially in the context of organisations) as rational, rather than passionate and emotional.

> 'What we term rationality in organizations is a remarkable facility to present – to ourselves and others – emotionalized processes in forms that meet "acceptable", "rational" images of objectives and purpose. We want to believe, and want others to believe, that we think and act rationally, so we construe the intentions and consequences of our actions as rational. We do this in social contexts that limit and shape our endeavours, and through social discourses that define norms and feeling and emotional display.' (Fineman 2000: 12)

Here Fineman argues that the supposed rationality of organizations and persons in those organizations is not the nature of their decisions and actions, rather it is the nature of their talk about those decisions and actions. Rather than being rational, or emotional, organizations and persons become rational through social construction that draws on discourses of rationality, objectives and purpose. A good empirical example of this is provided by Brunsson (2006). After studying an organizational change program in two Swedish and Norwegian public sector organizations, Brunsson argues that managers *sell* rationality rather than *act* rationally (e.g. not walking the talk). Rationality than becomes rationality for others. Managers themselves often act in 'irrational or a-rational' ways (ibid: 69). Through managerial talk and decision-making the hope for rationality is reproduced although past experiences with change programs proof otherwise. Interestingly, the discrepancies between talk and action are not a problem in Brunsson's view. "Rational" plans for change provide a common language and sense of clarity for the organizational members. Change programs would therefore be most useful if they were not implemented (ibid). Brunsson and Fineman make a similar argument as Weick (1969) and Hosking & Morley (1991) did before. They argue that there is not something "out there" that is a rational entity that we call organization. Rather in our narratives we construct the idea of a rational entity. Rationality should here be understood as that which counts as rational by the particular standards of the community in which one participates.

These two arguments show that it is possible to question the construction of rationality and emotionality as a binary opposition. As Damasio shows, there is no reason to privilege rationality over emotionality. In the next section the construction of the binary opposition between rationality and emotionality is further explored, in order to develop a concept of emotion that is in line with a postmodern thought style.

Emotions as universal, biological concept or local historical performances

The second current in O-S on emotions is about the theoretical grounding of the concept emotion (Domagalski 1999). Scholars of biology and psychology that employ a modernist thought style have studied emotions as universal biological or neurological patterns that make up a bounded and separate individual. Their conception of emotion is similar to the entitative concept of organization as discussed by Hosking and Morley (1991). In attempts to identify and define emotions, it seems that these scholars have not come to an agreement. Many different definitions of emotion exist and scholars have not come to an agreement on the number of emotions. There are different problems with the argument that emotions are universal biological or neurological patterns. Facial expressions of emotions are well recognized across cultures, but this goes only for a limited number of emotions: fear, sadness, disgust and enjoyment (Ekman 1984, 1998). Other emotions such as guilt, humour and embarrassment are not recognized easily across cultures (Plutchick 1980). This makes a weak case for emotions as universal patterns, and is consistent with the view that emotions might have an important cultural quality. The strongest scientific evidence (by modernist standards) comes from a controlled laboratory experiment (Schachter & Singer 1962). Research participants were given epinephrine. One group was given information about possible effects of this drug, one group was given the wrong information and another group was given no information at all. Then several experiments were done to change the emotional state of the research participants. The effects of attempt were collected through observations and self reports. The researchers summarize their findings as: 'Given a state of sympathetic activation, for which no immediately appropriate explanation is available, human subjects can be readily manipulated into states of euphoria, anger, and amusement' (ibid: 396). In a later publication the researchers argue that physiologically there is little distinction between feelings of fear, excitement or feeling overwhelmed. Furthermore, physiological changes in the body do not necessarily make the person feel the way his chemicals should (?) tell him (Schachter & Singer 1984 in Laseke & Kusenbach 2008). Thus our emotions do at least not entirely depend on chemical and physical reactions in the body, but they also depend on the social cultural environment. The construction of emotion as biological or neurological pattern is thus also difficult to maintain. We can observe biochemical processes, but we don't know how they relate to the experience we describe as a specific emotion.

> '(..) sight, smell and touch will produce bodily changes and neural-chemical excitations, some of which are "know" to the actor. But they become felt emotions of disgust, pleasure, excitement or apprehension according to (a) prior learning about the type sensation as being disgusting, pleasurable and so

> forth, and (b) the social/ cultural protocols of what emotional body display is appropriate (such as professional, non-insulting, face-saving) in particular circumstances. In this manner embodiment, emotion and social-cultural processes intertwine.' (Fineman 2000: 9)

From the perspective of a relational constructionist thought style, emotions are not seen as universal patterns, but emotional display is seen as a local historical performance. What counts as an emotion and what variety of emotions exist is seen as local historical construction rather than an universal truth (Gergen 1999: 108).

How we can understand emotion as a local historical construct is shown by feminist studies. Feminist scholars showed that the language of emotions is not neutral but socially and politically loaded. The following cluster of binaries are commonly used in western culture (Shimanoff 1993):

Rational	Emotional
Culture	Nature
Strong	Weak
Effective	Ineffective
Responsible	Irresponsible

These binaries have two characteristics. The first term is often associated with men and the second term with women. Secondly, the first term is also often privileged above the second term. In western culture it is better to be rational than emotional, better to be strong than weak, better to be responsible than irresponsible etc. According to Lutz (1990) these binaries also reflect power differences. What Lutz means with this, is that the terms that we privilege are the terms that we attribute to powerful groups. The following is an example of that. In a study of self-managing work teams Ollilainen (2000) described the gendered construction of emotions. Here analysis shows that the team members consider some emotions as masculine while other emotions are considered feminine. Further the emotions that are regarded as masculine are often regarded as valid ways of feeling, while the emotions that are regarded as feminine are regarded as invalid ways of feeling.

Another example is the study of Tiedens (2000) that showed that emotions can communicate status. Social status influences emotions and emotions influence perception of social status. People reported different emotions after interactions with higher status colleagues than after interactions with lower status colleagues. But people also attributed higher status to people that display certain emotions and lower status to people that display other emotions. In the same set of studies, it was also found that positive outcomes of group assignments where attributed to people with higher status and negative outcomes where attributed to people with lower status. Both Ollilainen (2000) and Tiedens (2000) present emotion as a local historical performance. They have moved beyond the idea of emotions as a biological construct and show the power relations that are (re)constructed in emotions. These studies are in line with the relational constructionist thought style because they describe how emotions are supplemented by multiple co ordinations within a local historical context (for instance ideas about masculinity in Ollilainen's study or ideas about power in Tiedens' study).

Feeling, (a new concept for emotion)

How can we theoretically understand emotion? In the last section I argued against a purely biological concept of emotion. In this section I start with such a definition and consider the limitations. After that I will develop a new concept for emotion. This new concept radically differs from modernist ways of thinking about emotions. To emphasise that difference, for the new concept I use the label *feeling* instead of *emotion*.

Consider the following definition of emotional intelligence:

> 'The subset of social intelligence that involves the *ability* to monitor one's own and others' feelings and emotions, to discriminate among them and to use this information to guide one's thinking and actions.' (Salovey & Mayer 1990:189; emphasis in original)

Clearly this definition sees emotions as a biological phenomena. Implicitly persons are conceptualized as bounded individuals that prior to any social interaction already have (a certain capability of) emotions, which act in a stimulus-response fashion, and are part of (universal) human instincts.

Such definitions however run into at least three problems: First, the relational quality of human identity is ignored (e.g. Fineman 2000).

> 'That is, there is no essential self that exists before and independently of its social interactions. Even the most solitary moments of contemplation or reflection are still thoroughly social because such introspection takes the form

> of an inner conversation that relies on the embodied experience of past social actions.' (Simpson & Marchall 2010: 354)

Second, biological or neurological definitions hide the cultural quality of emotions. Instead of universal biological experiences, emotions are better viewed as local, historical specific performances. In western culture, emotions are for example shaped by gender differences (e.g. Ollilaine 2000; Tiedens 2000).

Third, the implicit dichotomy between emotionality and rationality marginalizes human life in organisations. Possibilities for human relations and compassion in organizations is limited by a strive for rationality (Fineman & Gabriel 1996; Fletcher, 1999; Meyerson 2000).

An alternative understanding of emotion is provided by Gergen. He proposed to view emotions as a culturally provided scenario of action. Each action sets the stage for what will follow. What follows in turn gives intelligibility to that which has preceded (Gergen 1999: 136-8).

There is however a shortcoming to such a definition as it gives the impression that emotions can be controlled or modified at will (Simpson & Marchall 2010: 353). It ignores the experience of people that feel overwhelmed by emotions: 'While emotions have social implications and may be civilized, modified and controlled as a result of learning, they remain potentially unmanaged and unmanageable' (Antonacopoulou & Gabriel 2001: 442).

Although Gergen (1999) contributes to a relational understanding of emotion, the embodiment of emotions is neglected. A more satisfactory definition of emotion is given by George Herbert Mead as explained by Simpson & Marchall (2010):

> 'He [Mead] proposed that emotion expresses the relationship between the intended meaning of a gesture and the perceived meaning of the response it engenders. Put simply, emotions arise when a difference is recognized between what was intended by an inquiring gesture and what was interpreted from it. As such, emotion is not only felt as an embodied experience but also it acts as a communicative gesture in the ongoing flow of experience.' (ibid: 357)

> 'Mead proposed that these interactions may be understood as conversations of communicative gestures and the responses that they engender. Neither gestures nor responses are necessarily limited to linguistic exchanges; they may

> also incorporate more broadly based symbolic gestures such as facial expression, tone of voice, and we will argue, emotion.' (ibid: 355)

Note that emotions are no longer individual experiences, but part of communication and interaction. However I am not completely satisfied. The dissatisfaction is not in the description of emotions, but it is the word itself that is dissatisfying. To emphasise a shift away from definitions that see emotion as purely biological or as purely cultural, I propose an alternative to the word emotion. That alternative to the word emotion is provided by Sandelands & Boudens' (2000). They use the word feeling instead of emotion. To make their argument they contrast job satisfaction theory, which is highly modernist, with narratives of work life that illustrate the relational quality of feeling. According to the authors, people talk mostly about their relations to other people when they talk about work. Feeling is central to these relations, or as the Sandelands & Boudens put it: 'Feeling is how social life appears in consciousness' (ibid: 47).

Sandelands & Boundens' use of the word *feeling* can be contrasted by the word emotion. Inspired by Weick's idea of nouns and verbs (Bakken & Hernes 2006), I replace the word emotion (which is a noun) by feeling (which can refer to both a noun and a verb). In the word *emotion* implies modernist constructions of persons as bounded entities with individual cognition and individual emotions (Hosking & Morley 1991). In contrast, the word *feeling* implies persons, cognition and feeling as relationally constructed in ongoing processes of interaction. At the same time feeling can also refer to embodied experiences such that are marked with labels such as happiness, anger, anxiety etc.

Organizing feeling

Now I have argued that we can conceptualize emotion as socially constructed, I will explore how this is part of organizing. I end with an exploration of where the relational constructionist thought style might bring me: a description of emotion as ongoing relational process in organizing.

An interesting publication that centres emotions in organizing is an article on compassion by Frost (1999). Frost calls to our attention the pain and hurt that people carry to their work. Within organizational contexts there is much pain and heeling that remains largely unnoticed by researchers (ibid).

Frost uses the following observation to introduce the concept of compassion. During his stay in a cancer ward, Frost noticed another man that was recovering from surgery. This other man was in bad shape and one morning he failed to reach the washing room in time. From his bed, Frost observed the reaction of a nurse to this devastating and humiliating event.

> 'She brought in experts and did other things that I am sure were technically and professionally correct, but it was the quality of care, the way she spend time with him, the compassion she brought to his humiliated, depressed, defeated human being that really caught my interest. (..)By the end of the shift, near the end of the day, he was looking cheerful, communicating with us, and moving with some degree of confidence and comfort. (..) He smiled and said that he was feeling a lot better than he had in the morning and that at the beginning of the day, after his "accident" in the hallway, he felt his life slipping away. He felt useless, helpless, and held out little hope of coping.' (Frost, 1999: 127)

In Frost's analysis of this event he claims it was the compassionate way that the nurse treated the man on the cancer ward that made him feel better. And it was not (only) the technical, medical interventions that relieved the suffering of the man but '*subtle*' and mostly '*invisible*' work of the nurse (ibid: 128).

> 'There appears to be recognition of the human being in the situation – the man struggling for his dignity, and for his life in the standardized gown in an institutionalized ward. There was a commitment by one person, the nurse, to the dignity of the other, the patient, as part of whatever theories and practices that informed the nurse's actions.' (Frost, 1999: 128)

This attention *for* and response *to* suffering centres human relations within organizational contexts and breaks with the public/private divide that is so dominant in the field or organization studies; a divide that I named in the introduction as one of the shortcomings of many studies in the field of organizational science. Frost et al. (2000) analysed narratives of compassion told by faculty colleagues. They concluded that faculty staff that received compassionate acts of colleagues felt valued as a person and connected to their work. Also Frost at al. (ibid) concluded that organizations both enable and limit possibilities for compassionate actions by their members. Compassion is thus not naturally occurring, but enabled or limited by organizing practices as they give space – or not – for compassionate action.

One organization that theoretically should provide much "room" for emotions and compassion is the Body Shop. Martin et al. (2000) studied emotional labour at the Body Shop. Their hypothesis was that employees of this corporation do not experience emotional labour because the aim of the organization is to treat human (and animals) with respect. The founding mother of the organization is an explicit feminist (and environmental activist). Therefore the expectation of the researchers was that there would be enough space in the organization for compassion and expression of emotions. The authors did not expect that employees of the Body Shop would report experiences of emotional labour.

The conclusion of the study is that even at the Body Shop there is conformity pressure for feeling and emotional display, although quite liberal. Everyone is engaged in emotional management sometimes. Organizational culture puts pressure to act a certain way; at the same time we manage our emotions for the smoothening of interaction and personal gain.

I think that this study shows that organizing means restricting emotional display to some extend, even at organizations such as the Body Shop that strive to give space to emotions and compassionate behaviour. Thus no matter how a culture is, it always shapes emotional behaviour and strives for conformity. But that does not mean it does not matter how organizations deal with emotions.

In an ethnographic study of medical social workers in two hospitals Meyerson (2000) shows how experiences are shaped by the cultural and institutional conditions of the organizations. Her study focused on the experience of burnout. In one of the two hospitals room for emotional display was rather limited. Burnout was viewed as an individual problem and a sign of professional weakness. Burn out was someone's own fault, and someone's own responsibility to deal with, therefore making it difficult for people to express and share feelings. In the other hospital, a burnout was seen as a normal consequence of the stressful work. This did not prevent the social workers from getting burned out, but it did enable them to share their emotions because feeling burned out was seen as a legitimate feeling that results from the stressful work. Meyerson (ibid) concludes that three mechanisms suppress emotional display: 1) professional ethic of emotional control and rationality suppress the expression and sharing of feelings, 2) emphasis on individuals, 3) social science legitimises language of detachment and control (objectivity and rationality).

To end this chapter on theoretical orientations I'll provide a short summary. The aim of the chapter was to provide an overview of theories about emotions that guide me in the present research. First I have discussed the binary opposition of rationality and emotionality. I have argued that rationality is often privileged above emotionality. This hierarchy, however, could be reversed. Also I argued that rationality is not a quality of behaviour itself, rather it is a way of accounting for behaviour. Further I have argued that emotions have an important cultural quality. This makes a weak case for conceptions of emotions as universal biological constructs. Taking the argument one step further I have proposed a new definition of emotion as feeling. Feeling is a concept that is in line with the postmodern thought style and it directs attention to how emotion emerges in relational processes. Lastly I have discussed some examples of studies from the field of OS that describe how in organizing the construction of feeling unfolds. These studies form an important starting point in the analysis, as I will describe in the next chapter.

Chapter 4. Data collection & analysis

This chapter describes the methods for collecting and analysing the research data. As will become clear, the relational constructionist thought style invites us to use the methods of interviewing and narrative analysis in a very particular way. After a general discussion on narrative analysis, the chapter ends with a description of how the analysis was conducted for the present research.

Story telling, (the interview as conversation)

The narratives for the present research are collected through conversations that some might call interviews. Hosking & McNamee (2006: 148-50) stress the relational nature of interviewing. Both researcher and participant bring something to the relation in which the narrative is co-constructed. Thus for relational constructionists an interview event is not considered as a flow of information form research object (participant) to subject (researcher). Instead researchers should:

> '(..) shift the focus from mining individual minds to the coconstruction of (temporarily) shared discourses (..) Rather than the researcher studying what participants know about a particular topic or what kind of experiences they have had, they instead engage in dialogue with participants and thus actively contribute to the knowledge production.' (Koro-Ljungberg 2008: 431)

In order to allow the interviewees to tell the stories that they find important, the researcher must "*get out of the way*" of the interviewee. This can be done by conducting a relatively open or unstructured interview. By asking only one or a few general questions *a conversation of equals* is stimulated. In comparison to a survey with predetermined questions and answer possibilities, the open-ended interview gives more power to the respondent. The open-ended interview is thus a move away from the quantitative, number driven research methods that produce unequal power relations:

> 'The methods of modern science then serve to simplify and reframe reality in standard categories, applied from a distance . . . Those who manipulate these units are empowered and the subject of analysis disempowered: counting promotes the counter and demotes the counted. Top-down, centre-outwards patterns are then self-reinforcing through rewards, status and power.' (Chambers 1997: 54)

A similar argument is made by Hosking & McNamee (2006: 86-90) as they speak of subject-object relations. When the researcher conducts research through survey questionnaires ore structured interviews, the research participant is made into an object. Research participants become literally the objects of the researcher (the subject). It is the researcher that creates knowledge *about* an object. It is the researcher who determines what answers the subject *can* give through predetermined answer categories. It is the researcher that so produces knowledge *about* the subject. That knowledge is legitimated superior to the subject's self-knowledge on the basis of the "reliability and validity" of the researcher methods. And in that sense the relation between researcher and participant is unequal.

But in the case of open–ended interviews the respondent can chose how to answer a question; in what kind of words and which classifications are used. The less an interview is structured; the more room there is for the interviewee to determine the direction of the interview; to more room to choose what the researcher should know about the participant, the more central the self-knowledge of the participant becomes (Boeije 2010: 62).

Considering the specific understanding relational constructionist understanding of interview events, 'the label of *interview* might not be most appropriate to describe the social exchange and interaction that takes place when knowing subjects engage in a dialogue with each other about a particular topic' (Koro-Ljungberg 2008: 432). As with my explicit choice to speak of feeling, I choose to speak of conversation and participant/partner rather than interviews, interviewees and subjects. It is to emphasize my attempt for more equal relations in research interview setting.

This does not mean that there is a totally equal balance of power between researcher and participant. As inquirer I bring my own narrative to the conversation (Hosking & McNamee 2006: 148-50), and these narratives are dominant in that they are the reason the conversation is taking place at all (Kvale, 2006). And therefore I tried to be explicit about my interests towards the participants so they know what it is they participate in. I started the conversations by telling the participants about my study and my interest in emotions in organization. Part of this story was my opinion about the lack of emotions in mainstream O-S literatures and my expectations of the emotional nature of hospice work. My story ended with an invitation to the participant to tell me stories that they thought would be of my interest.

The conversations I had with the research participants have the character of an open-ended interview. Another name for the open-ended interview is unstructured interview (Punchch 1998). This means that some questions and topics were prepared before the conversation, but not in great detail. For me as researcher it is not necessary to strictly keep to the questions and topic during the conversation. The questions are not very specific and there is no fixed order assumed. The questions are not meant to elicit a specific answer. Rather the questions and topics serve the conversation partner to be able to talk about hospice work in her or his own words. The "data" that relatively unstructured interviews generate often have storied qualities. This makes open interviews the perfect tool for collecting the narratives that I can analyse (Coffey & Atkinson 1996; Riesmann 2001).

The method of sampling is snowball- or convenience sampling. It is a useful method to select participants in a study of sensitive topics (Boeije 2010: 40). In this case it was important that the participants were both willing and able to talk about their feelings in relation to their work in the hospice. Therefore I did not want to approach them through the management of the hospices they participated in. Because that might pressure them to agree with an interview that they do not feel comfortable with.

To come in contact with initial conversation partners, I placed a call in the digital newsletter of hospice De Liefde. The front man of Hospice De Liefde was very interested in my research. Hospice De Liefde was at the time not yet a full functioning hospice. It only existed virtually on the Internet and in the activities of trainers and hospice workers that prepared future hospice practices. The network of the website was the ideal starting place for recruiting participants. Through the first three participants I came in contact with other participants. At the end of the interview I asked my conversation partners if they knew other people doing hospice work that might be interested in talking with me.

In total I had conversations with ten persons that worked or had recently worked in different hospices. The eleventh participant was a trainer. She had no experience in palliative care. Her background was in education and management and she did the training of the would-be volunteers for Hospice De Liefde.

Three of my participants were working or had been working as hospice coordinators. Four participants were working as nurse in a hospice, or worked in hospices through a homecare organization. And three participants were working as volunteer in a hospice. Non of them had medical training, except for trainings offered by hospices they participated in. The experience in hospice work of the participants ranged from one to eleven years. As described in chapter 5 there are more roles involved in hospice work, but coordinators, volunteers and nurses are present in the hospice the most. Doctors, spiritual counselors etc. only visit the hospice on special request and mostly for short periods in comparison to the coordinators, volunteers and nurses.

Four of the conversations were held inside three different hospices. The other conversations were held in offices of health care organizations or at the participant's homes. In all cases conversations took place in a closed room that provided us with the privacy to talk freely. The conversations lasted between 40 minutes and an hour and a half. The audiotapes were transcribed (see below) and emailed to the respondents before analysis.

At the beginning of each conversation the participant was promised anonymity and requested permission to audiotape the conversation. The names used in this thesis are thus not the real names of the participants in order to ensure anonymity. Further I promised the participants a copy of the conversation transcript with the possibility to remove parts from the transcript if they were to feel unhappy about anything they told me. None of the participants used this possibility delete parts of the conversation transcripts. Further I promised them a digital copy of my thesis and a summary in Dutch. Both of these documents will also be published on the website of Hospice De Liefde.[14] Next I told the participants about my study and my interest in emotions and hospice work. After this introduction I started the audiotape and began the conversation with a broad question. Usually I asked my partners to tell what work they did and how or why they had started to work in a hospice. Most conversations followed quite naturally from there and I had to ask few questions. Most of my questions were requests to elaborate further on something the participant had already been talking about earlier on in the conversation. I made sure that in each conversation we talked about emotions and how the participant coped with them. Sometimes the participants moved the conversation towards this subject by

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[14] www.hospicedeliefde.nl > hospice > publicaties

themselves, other times I had to ask them more explicit to talk about the subject of emotion. Besides asking questions I stimulated participants to talk by nodding and numbing.

Narrative analysis

To analyze the "data" I treat the interview text as narrative or story. There are a large variety of definitions of narrative. Therefore I will start this paragraph with an overview of some existing definitions of narrative. These definitions do not always fit a postmodern thought style. At the end of this paragraph I will try to explain what I understand as narrative and how I have analyzed the conversations.

Aristotle said that a narrative has a beginning, middle and an end. Since then, many definitions of narrative have followed Aristotle's idea and incorporated sequence as key characteristic (Riessman 1993: 17). One such standard definitions of narrative is the following:

> 'A story…tells a sequence of events that are significant for the narrator [the respondent/social actor] and his or het audience. A narrative as a story has a plot, a beginning, a middle and an end. It has internal logic that makes sense tot the narrator. A narrator relates events in a temporal, causal sequence. Every narrative describes a sequence of events that happened. Hence narratives are temporal productions.' (Denzin 1989: 37 in Coffey & Atkinson 1997: 55)

A narrative can be seen as a way to organize experience and memory (Sødenberg 2003: 8). Narratives were part of human life before the development of writing and print. They can be seen as the device for sharing knowledge and experience in illiterate societies and can therefore be seen as pre-modern. In the evolution to modernity, the development of print enabled three new forms of text: tables, lists and recipes (Goody 1977, 1986 in Czarniawska 1998: 8). Tables and lists contain disjoined and abstract information that has no connections. Therefore we need a mnemonic device (print) to memorize it. Recipes, contrary to tables and lists assume a chronological connection, but a cause or intention is absent (Czarniawska 1998). Lists and tables are typical for modern knowledge, but pre modern knowledge that is reflected in metaphor and narrative is still very much part of human life. Both in modern and pre modern society we learn through narrative (Goody & Waltt 1968 in Czarniawska 1998: 9). In face-to-face interaction stories are exchanged, what is remembered reflects what is of social relevance, the rest is forgotten. For modern society, forgetting often constitutes of storing information away in an archive (ibid).

According to a certain sort of narrative theory, events become a narrative through a plot. One way (the common way) of introducing a plot is using chronology (and then). This brings the parts and otherwise separated events into a whole. A narrative requires three elements: an original state, an action or event, and an end state or consequence (Sødenberg 2003: 8). If we would look at organizing, we would see a chaos of meaningless actions and objects. It is in our narratives of organizing, that we reduce the many actions and objects to a few. With the use of plot, chronology and characters, it is that we organize the chaos to a coherent whole. In narrative, seemingly separate events are tied together by causal explanations. Action is explained by intention. This is how narrative is involved in the social construction of the organization (Czarniawska 2008).

In many publications, the words story and narrative are used interchangeably. Here I use both words in a fairly casual way. However, there is a subtitle difference in meaning of both words. In a narrow definition, narratives can be understood as having chronology, a protagonist and plot (Czarniawska 1998; 2008). Also, narratives – in the narrow meaning of the word – are believed to have a specific set of structural characteristics (see Robichaud 2003; Sødenberg 2003; Riessman 2008). Most important is that the narrative form is conclusive or in the words of Ricoeur (1983): 'To narrate and follow a story is already to "reflect" upon events with the aim of encompassing them in successive totalities' (p. 279). With this Ricoeur wants to tell that a narrative already attaches meaning (a particular moral or understanding) to the events it portrays.[15] Boje notes that many stories that people tell do not meet the narrow definition of narrative. Many stories lack 'narrative closure' and coherence (2001: 293). Boje calls these stories antenarrative. The prefix – ante – refers to a story before closure; still open to interpretation so to speak. To make it not to complicated I will

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[15] In similar vein, discourse theorists note that discourses promote a singular understanding of the world by naturalizing (Glynos & Howarth 2007: 141). In the language of narrative theory we could say that a narrative promotes a singular interpretation of the text. This is not to say that a narrative has only one interpretation that is already embedded in the text itself. Of course that singular interpretation can be deconstructed by brining out inconstancies and false dualisms etc. Through deconstruction the possibility for multiple (different) understandings can be opened up (Boje 2001).

not use the word antenarrative, but the word story to refer to texts that do not meet the narrow definition of narrative. The word narrative than refers to texts that are more conclusive and more “closed”. The *fairly casual use* of both words is because whether a piece of text would fall within the definition of narrative or within the definition of story is not of central concern in the present research.

For the present research an analytical tool is needed that fits all texts (both narrative and story) and is in line with the postmodern thought style. For beginning researchers Riessman (2008) advises to do a thematic analysis. This type of analysis is similar to grounded theory approaches, however codes refer to larger units of text (for instance whole paragraph instead of just a few lines or single words). Thus in a thematic analysis (opposed to grounded theory) interviews are not fractured to small pieces and re-combined into thematic categories, but analyzed separate and as a whole (ibid: 57).

The notion of thematic analysis does say very little about what the analyst codes for. How does the researcher come to choose a particular code for a section of text? To explain how I have coded the narratives in the present research I will draw upon the work of Monin & Monin (2003). I will also describe some key moments that influenced my coding and analysis.

Monin & Monin (ibid.) do not speak of coding and analysis but about reading. They distinguish two “ways” of reading; horizontal reading and vertical reading. It is a style of analysis that fits the present research because it has no requirements to the characteristics of a text in the way that structural analysis has. In a horizontal way of reading we connect words to words and sentence-to-sentence as the argument is build with a plot. The underlying assumption of this way of reading a narrative, is that structure provides meaning to the text. The meaning, so to speak, is in the text itself. By contrast, a text can also be read in a vertical way. When a text is read vertically, the reader is of equal importance as the writer. The text gets its meaning in the context of reading. Meaning is constructed as a reader interacts with the text.

> ‘(..) meaning is not considered a property within the interiority of individual actors that can simply be transmitted to others via narrative. Narratives instead generate meaning by virtue of their place within the realm of human interaction.’ (Sparkes & Smith 2008: 299)

Not only the text at hand provides meaning, but also, meaning is constructed in interaction with prior readings of other texts. In a vertical way of reading, the reader is sensitive to that what is left out of the text, ignored, dismissed or marginalized.[16]

> 'The threads of meaning that the deconstructive reader follows weave patterns of meaning that criss-cross the horizontal line of meaning, whirling in many directions around it, but all in some kind of vertical angle to it.' (Monin & Monin 2003: 64)

It is in a vertical reading of a text that we can see which discourses are woven together in the construction of the narrative.[17] The vertical reading looks at which act-supplements are brought together and how? Monin and Monin (2003) name their chapter '*Re-navigating management theory*'. I take this to be in line with what I have been trying to emphasize earlier on, that we do not have to view language as a representation of reality. Rather language (among non-linguistic actions and objects) can be seen as constitutive of reality. Language can be viewed as a resource that helps us to coordinate interaction (i.e., to navigate in Monin & Monin's words) in the constructions of reality. If we treat language as such, than narrative analysis becomes a search for the discourses that are resourced in reading a text. A narrative is no longer seen as a story who's content is a falsifiable representation of reality. But instead the narrative is a particular construction that draws upon particular discourse that legitimate and make intelligible the content of the narrative. The truth or falsehood of the story is no longer central in the analysis. What is instead central to the analysis are the ideas and interests that the story is resourced with that matter.

> 'When talking about their lives, people lie sometimes, forget a lot, exaggerate, become confused, and get things wrong. Yet they are revealing truths. These truths don't reveal the past "as it actually was," aspiring to standard objectivity. They give us instead the truths of our experiences…. Unlike the Truth of the scientific ideal, the truths of personal narratives as neither open to proof nor self-evident. We come to understand them only through interpretation, paying careful attention to the contexts that shape their creation and to the views that inform them. Sometimes the truths we see in personal narratives jar us from

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[16] As I understand it, vertical reading is similar to what others have called deconstruction. Martin (1999: 340) writes for example; 'deconstruction can be defined as an analytic strategy that exposes, in a systematic way, multiple ways a text can be interpreted.' In order to deconstruct a text, Boje (2001) describes seven 'deconstructive moves' that can be deployed. Martin for example uses a feminist perspective to interpret the speech of a CEO. In analyzing the speech she looks for dichotomies, silences (what is not being said) and disruptions.

[17] See e.g Iedema et al (2004) or Barrett et al (1995).

> our complacent security as interpreters "outside" the story and make us aware that our own place in the world pays a part in our interpretation and shapes meaning we derive from them.' (The Personal Narrative Group 1989a: 261 in Riessman 1993: 22)

To this quote I like to add my own example. During my second year of study, my colleagues and I did research at the inspectorate of a Dutch ministry. The inspectorate was working with competency management as a method for human resource management. Two stories appeared during the interviews. One in which the management was ordering a deck of cards. Each card had written on it a certain competency. The cards were grouped to form a profile of required competencies for different functions. The second story was about a reorganization process at the inspectorate a couple of years before our interviews. All employees were labelled as animals and in the end certain "animals" where fired.

If any of these two narratives really happened the way they were told is unimportant. The "truth" they reveal is that competency management is seen as a management game/toy, not as something which is thought about very well. Second the story of the animal's signals that labelling (which competencies do you master) is very dangerous and could lead to the loss of your job. In other words competency management is something to stay away from, or to use in a strategic way to one's own interest (keep your job).

Doing the analysis, (issues of transcription, translation and reading)

This section describes how the text were transcribed and analysed in the present research.

It goes for any text that multiple interpretations are possible. This makes the qualitative researcher vulnerable for claims by critics of over interpretations or misinterpretation (Barnister at al. 1997). Presenting the transcripts in the research report is a way to try to be as transparent as possible about how I as researcher came to particular interpretations and conclusions. This is so because the presentations of the empirical materials enable readers to judge the researcher's interpretation. The transcripts provide 'immediacy and transparency' (Nikander 2008: 423).

Turning the audiotape conversations into written transcripts is not just a technical issue. Many aspects of a conversation get lost during audio taping and during transcription of the tape. Facial expressions, tone of voice etc. often disappear during transcription (Riessman 1993). Turning audio into text involves many choices. One can for instance chose to include or exclude the voice of the researcher depending on one's thought style (Riessman 2008). Because postmodern researchers view interviews as co constructions, I have chosen to include my own voice (the researcher) in the transcripts. The level of detail is guided by other narrative analyses (ibid: 30-1). It includes a number of things such indication of pauses (see below) but is less detailed than transcripts used for conversation analysis and micro-sociology/ethnomethodology (e.g. Potter & Hepburn 2008). The level of detail that is common in the later types of study is not required for narrative analysis which does not concern itself with the conversation as an object of study, but with the arguments and lines of reasoning that are build in the narrative. Further, in ethnomethodology the analysis references only to events inside the narrative/interaction. Narrative analysis references to other texts "outside" the narrative. Bringing these "outside" texts into relation to the narrative is central to narrative analysis as it is employed in the present research. And as argued, such an analysis can do with a little less detailed transcripts.

Morse & Field (1996: 107-8) explain how the audiotape could be transcribed. Identifying information such as names is indicate by an inserted line and a classification between square brackets : ___ [mother]. Pauses are indicated with dashes and prolonged pauses by ellipses: (p). Expressions such as laughter are placed between square brackets: [laughing]. Researcher comments are paced between square brackets too, but in a bold fond: [**she was talking about…**] When part of the text in a quote is left out, this is indicated by ellipses and dots (..).

Riessman (1993) warns us that many aspects of the actual interview are lost during transcription (facial expressions, tone of voice, soft sounds). I have tried to include sounds as much as possible. Tone of voice is not included, but emphasis (louder speaking) is included by use of *italics*.

Another issue concerning transcription is translation. The conversations were held in Dutch, while this thesis is written in English. The general excepted norm is to present the original data alongside the translation (Nikander 2008: 424). In the present research I present the original data in endnotes. The reason for this is that some extracts are quite long. If the translations were put alongside the English translation or in footnotes at the bottom of the page, I feel that the readability and outlook of the text would be jeopardised. Readers that want to check the original data can easily take the endnotes out and keep them next to the main text. In case of a digital version, the document could be opened twice with the second document scrolled down to the endnote section.

A second issue regarding to transcription and translation is the translation itself (ibid). I have tried to translate the texts as literally as possible. Sentences are not edited for readability but remain in their original character. To help the reader, I have sometimes included comments between square brackets. Sounds other than full words are not translated due to the difficulty of such an enterprise.

In the present research the analysis of the conversations is a combination of vertical and horizontal reading (Monin & Monin 2003). The conversation transcripts were coded in three ways: for stories and narratives, for horizontal reading, and for vertical reading. Each transcript was printed out with an extra wide margin on the left side of the page. On the right side was a double margin. In the left margin I marked the beginning and end of a particular story that was told. If a participant told a story about a particular event in the hospice that illustrated a particular point or argument in the conversation, than that would be marked in the left margin. I gave the story a name that I found suitable. In one of the two right margins I indicated the topics of the text, very similar to open coding in a grounded theory approach (Boeije 2010). Together with the left margin this formed the “horizontal” reading of the text. This horizontal reading helped me to notice that many of the conversations read as a story of personal, emotional or psychical/spiritual development. In that sense the whole conversation is considered as one story. While at the same time many small stories where identified within each conversation (marked in the left margin). The story of Paul in chapter 7 is a clear example of how the whole conversation could be read as one story. It was only after the analysis that I realized how much everything he told me was about his personal development in relating to death and dying persons. Although the order of telling does not follow the neat chronology of his lived experience, the conversation reads as a story of development from IT worker to spiritual counsellor. Learning to relate to death and dying persons forms the central theme in this narrative.

Coding example from conversation with Susan (p. 7-8) (In Dutch).

Een levendig verhaal.	Dirk: dus een dacht begint met de overdracht en eindigt ook in de overdracht? Susan: Ja, ja want je moet dan de overdracht aan je volgende collega weer over geven van wat er allemaal gedaan moet worden, en wat er voor bijzonderheden zijn geweest die dag. En dan sluit je het af. Dirk: En wat zijn nou ervaringen in je werk waar, ja die je goed doen voelen, of waar je energie van krijgt. Waar je van denkt hier doe ik het voor? Susan: Ja ... het is niet zo'n, ja dat klinkt misschien gek, het is geen dooie boel hier. Het, de alledaagse dingen zijn gewoon heel belangrijk. Mensen hebben niet meer zo lang, maar weten ook niet hoe lang nog. Dat is ook *he*! Je weet het niet. Dus het werkt ook niet zo van: nou ik ga dood, maar ik weet niet wanneer en dan hou ik er maar mee op. Nee, want de daginvulling blijft toch wel doorgaan en mensen willen toch nog wel heel graag wat dingen doen. Dus dat je dat kunt bekijken voor mensen. We hebben hier een jongen gehad en die had, een man, die wilde graag nog naar het orgelmuseum in Utrecht. Nou dat heeft een collega voor hem geregeld. En dat zijn gewoon hele leuke dingen. Dan komt hij helemaal stralend, dat is helemaal goed. Ja - als je en beetje hebt zitten kletsen met iemand, ook over dagelijkse dingen, of over familie of over, maar ook het serieuze werk natuurlijk ook. Als mensen aangeven, want dat is het, tenminste, dat doe ik, wat mensen aangeven, van als ze	Levendigheid tegenover de dood. Geniet van “levende” gast. Dood op de achtergrond?	Mensen weten niet hoe lang ze nog leven dus ondernemen nog dingen. Man wilde naar t orgel museum. Geregeld door hospice werker.

	opmerkingen maken van:"maar ik heb niet meer zo lang." Of als, het voelt moeilijk aan, of ik heb veel pijn, dan ga je daar op in, van, om te kijken om van hoe is het dan met die pijn. Dat zijn toch wel die praktische dingen, maar ook meer van, hoe kunt u daarin ontspannen ook nog of, he er is ook een bubbelbad. We hebben een gast die daar bijna elke dag in gaat. Dat ontspant hem ook heel goed. Hij is ook meer met een psychiatrische achtergrond, dus dat is ook wel natuurlijk weer wat moeilijker ff, maakt het dan moeilijker. Hij is hier al vanaf november, dus hij is hier al hel lang. Hij stabiliseert. Wat doe je ook dan? Ja dan moet je toch ook wat meer kijken weer naar een dag indeling. Ja wat ie wel kan en wat ie niet kan en wat ie wil. Dat is natuurlijk ook. Dus daar krijg je een goed gevoel voor als je dingen geleerd hebt.	Geestelijke klachten, lichamelijke oplossingen	Bubbelbad voor ontspanning Hospice rondersteunt in dagindeling.

The second margin on the right was used for coding and notes that fit a “vertical” way of reading. In this margin I did for example pay attention to language use and metaphor. Also I indicated what surprised me, what was in contrast to earlier arguments and what was not talked about. In one of the transcripts it struck me that the participant was telling a story about a euthanasia. She was asked by the person that had euthanasia to be present at the event. During his residency in the hospice, she (the nurse) and the guest had developed a bond. What particularly struck me about this story is that she talked about medical practices. Her conversation was about how she assisted the doctor in spite of not have a medical role in the event of the euthanasia. What to me appeared as what was left out of this story were her personal feelings she experienced while being present at the euthanasia of a person she had grown attached to. It helped me to theorise that attention on medical discourse and practices might help hospice workers to detach from otherwise overwhelming feelings. Later I connected this idea to the *presence approach* versus *intervention approach* (see chapter 7).

In the postmodern thought style, reading – or analysing – a text is not just a matter of decoding the meaning that is embedded in a text. As argued above reading is a relational practice in which the reader relates the present text with earlier texts (Monin & Monin 2003). In the words of Hosking (2004) this is called act-supplement. The act (narration) is supplemented by other acts (narrations). Meaning than arises from the interaction of the texts. In the words of Hosking (ibid) we could say multiple co ordinations. The interview transcripts are "coordinated" with many other texts at once. The question than arises which texts did I "bring in relation" with the conversation transcripts? Besides the literatures on emotion, the transcripts are also coordinated with literatures on quality of care and literatures on philosophy of science. Besides the texts that are explicitly discussed in chapter 6, 7 and 8, I think especially two texts where very much on my mind during reading of the conversation transcripts. Those of Meyerson (2000) and Frost et al. (2000) (see chapter 3). Meyerson (2000) describes the difference in dealing with burn out between social workers at two hospitals. Her cultural analysis showed that the difference in *talk* for the way social workers gave meaning to burn out and their ability to recover from burn out. What I brought to the analysis from Meyerson's study was attention for the way my participants talked about feeling. Was it talked about at all (?), Was it seen as a distraction from work (?), Was it regarded as unprofessional (?), and so on.

The second text that inspired my analysis was that of Frost et al. (2000). Their study of compassion directed my attention to the process of organizing and how the ability to share emotions is limited or enabled. It helped me to identify the organizing practices that are discussed in chapter 7. Again referring to Hosking's (2004) writings on relational construction, the texts by Meyerson (2000) and Frost et al. (2000), but also the texts on ethics of care by Tronto (1993), Leget (2010), and Van Heist (2005) can be seen as local-social-historical constructions of reality (in this case quality of care). Other writings can offer different understandings that could be equally valid. And because in the present analysis the conversation transcripts only become meaningful in relation to other texts, we could speak of relational reality (Hosking 2004).

In the language of discourse theory (Howarth, 2000), we could say that the studies by Meyerson (2000) and Frost et al. (2000) function as discursive structures[18]. They structure the meaning of the conversation transcripts.

Another key text was a conversation with the program leader of the transmural network Midden Holland[19]. In our conversation, he made me aware of the importance of ideas about dying and how those ideas inform practices of hospice work. As program leader labour and care he also organizes trainings about palliative care for professional caregivers. One thing that is done in those trainings is making caregivers aware of different ideas around a good death and making them think what they themselves would consider a good death (and good care for the dying).

One story he told me was about when he talked with a nurse during one of those trainings. He asked a nurse about who should be allowed to wash her private parts in case she could not do it herself any longer (due to chronic illness). The response of the nurse was: '*Only my partner should wash me*.' And immediately after that she realized how she reacted to the patients she took care off. That she always said to patients and their partners that she would wash the patient because it is faster that way. The nurse voluntarily promised on spot to not do that again.[20]

This conversation helped me to connect the conversations to the debate about quality of care and the position that Carlo Leget (2010) and Van Heist (2005) take in this debate. Especially the conversation made me aware of the importance of relating to the Self (the caregivers perception of a good death and care for the dying).

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[18] 'By discursive I mean that all objects are objects of discourse, in that their condition of meaning depends upon a socially constructed system of rules and significant differences' (Laclau & Mouffe 1985: 170).

[19] www.transmuraalnetwerk.nl this organization is also responsible for www.stichtingstem.info and www.doodgewoonbespreekbaar.nl that are both discussed in chapter 5; transmural care can best be thought of as health care outside of the hospital. It is the care for patients that need medical care, but cannot stay in a hospital, for instance because of chronic illness.

[20] Personal notes.

A third key text was a Skype[21] conversation with the founder of Hospice De Liefde and nurse Joan, who is a volunteer for De Liefde and participant in the present research. I had read the conversation transcripts and gathered some first themes and ideas. The Skype conversation was meant to discuss these ideas and ask my informants how I could make sense of the stories. One of my questions was how I could understand differences between stories that centre medical practices on the one hand and stories that centre emotional connections on the other hand. The idea that I took from this conversation is that being confronted with the emotions of another person is only overwhelming because they confront a person with his/her own emotions and fears for death. Again this related very much to Leget's (2010) text.

Until now this thesis has been presented in a fairly modernist fashion. It started with an introduction and research question – or in this case more a general interest – which was followed by a discussion of my social science perspective, followed by a description of the theoretical concepts and a discussion of the methodology. This modernist/mainstream presentation might raise certain expectations by the reader. You might for instance expect that the following chapters will be about: presentation of the research data/findings, followed by a discussion, followed by a conclusion. Unfortunately (?) such expectations will not be met because as outlined in chapter 2 my social science perspective – or better thought style – requires something different. First of all, relational constructionism emphasises the importance of reflexivity of the researcher (Hardy et al. 2001). A requirement that comes with reflexivity is that the position of the researcher becomes visible in the text. This has resulted in three things. Firs, I have tried to be as explicit as possible about the meta theoretical pre-suppositions that inform this research (labelled as the relation constructionist thought style). Second, I frequently write in the first person. Third, this text is a reflection of the thinking process that led to this thesis. The text reflects the process of "discovery", and that process does not follow the modernist format of: presentation of the data/findings, discussion, and conclusion. Rather, I learned a bit about hospice work through the conversations (chapter 5), after which I started to make a connection between some of the stories and the debate on quality of health care (chapter 6), after

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[21] Skype is a program that enables video conferencing over the Internet. It is free for download.

which I started to make a connection of some of the stories to the *presence approach* (chapter 7). In the remainder of this text this chronology of "discovery" is followed rather than the modernist format.

Besides the requirement to become visible as researcher in the text, it is also in the nature of the analysis that the modernist format cannot be followed. When we put the relational constructionist thought style to work, we cannot assume texts to speak for themselves. The meaning of a text is not in the words themselves, but emerges as a text is brought into relation with other texts (who's meaning in turn depend on other texts)[22]. This bringing-into-relation of texts hardly fits the format of presentation of findings, discussion, and conclusion. It is more like a dance, where one step and turn lead to another and so on. As an example of such a type of research I would like to refer to David Boje's (1995) piece "*Stories of the storytelling organization: A postmodern analysis of Disney as "Tamara- land""*". He lets different stories of the Walt Disney Company "dance" with each other, not to arrive at a conclusion, but to open up room for multiple understandings of Disney as a storytelling organization.

The aim of the present research is to bring the conversation transcripts into relation with other texts that open up a relational constructionists understanding of feeling in hospice work. This will not result in a finalizing conclusion, but in one (of many possible) articulations that might be of help for hospice workers to make sense of their practices and how feeling is embedded in those practices.

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[22] See also chapter 2, especially the paragraph: "*Further explanation of the thought style*".

Chapter 5. Hospice work

When I started with this inquiry I was not familiar with hospice work. Chances are you do not now what hospice work is. Therefore I have collected some general definitions, website info, reports, conversation extracts, and photo's to give some impressions of hospice work and its relevant themes. The aim here is not to give a definite answer to the question "what is hospice work?" but to give some context to the following chapters. [for readability I have put references to websites in footnotes as much as possible].

Although there is little analysis in this chapter, the text presented here could be seen as "data" and thus the selection of what is presented needs some explanation. This chapter is largely based upon the inquiry by Pluut (2008). Het inquiry was concerned with themes that should be taken in consideration by starting hospices. It can therefore be assumed that the most relevant themes are taken into account.

As for the discussion of all participants of hospice work, I chose to include family because from a relational constructionist perspective persons do not exist as separate entities but as people engaged in relations. Therefore dying does not only involve the guest (patient) but also the family and friends.

The pictures in this chapter are chosen with the idea that I want to present the insight of hospice building, the places that hospice work takes place, rather than the outside of the buildings.


[23]

Palliative care.

In medical literature hospice work is often called end of life care or palliative care.

The WHO gives the following definition of palliative care:

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

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten or postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patients illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness;
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.'[24]

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[23] www.chanshomehealthcare.com

[24] http://www.who.int/cancer/palliative/definition/en/

This definition does not necessarily provide an accurate definition of actual practices of what I have been calling hospice work, nor of different discourses on hospice work. As you will see in the following chapters, there can be many different ideas about discourses of (palliative) care or hospice work. For now we stick to this definition as one of many possible constructions of what hospice work could be.

Note also that the definition of palliative care is part of a sub menu of the WHO webpage on cancer. Today in the western world palliative care is mostly associated with people suffering from a chronic form of cancer. This was very different in the nineteen eighties when many hospice guests suffered from the consequences of HIV/AIDS.[25]

Palliative care can be provided as homecare, in hospitals and elderly homes sometimes in a separate ward and in hospices.[26]

Hospices

In the Netherlands it is customary to talk about a hospice (de hospice in Dutch) when we refer to a physical building in which hospice work takes place. In the international context the word hospice can refer to any of the forms of palliative care that are mentioned in the section above, as well as a virtual place on the internet that provide a sort of meeting point for volunteers and people in need of care[27]. The Zen Hospice Project for example refers to physical locations for provision of hospice care as 'the guest house'.[28]

In the 1980's palliative care gained attention in the Netherlands. And during the 1990's the first hospices were established. Later on palliative wards at elderly homes

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[25] Conversation with Caroline (volunteer); Joan (nurse).

[26] www.palliatievezorg.nl

[27] e.g. www.buddhisthospice.org.uk

[28] www.zenhospice.org > hospice care > overview.

and hospitals were added. Dame Cicely Saunders and Elisabeth Kübler-Ross are often spoken of as sources of inspiration for Dutch hospices[29].

Saunders lived in the United Kingdom and under her guidance the world's first purpose-built hospice opened it's doors in 1967. In the hospice special attention was given to pain control. The aim of the hospice was to give holistic care to meet physical, social, psychological and spiritual needs of the dying[30].

Elisabeth Kübler-Ross made career as psychiatrist in the United States. She pioneered in near-death studies and received 20 honorary degrees for her work. In het research she identified five stages of grief: denial, anger, bargaining, depression, and acceptance. She was a big supporter of the hospice movement.[31]

Hospices provide palliative care for people that have three months or less to live. Palliative care aims to improve the quality of life of patients that face a life-threatening illness. Patients come to a hospice because their home situation does not provide a good place to die, for instance if a patient has not (enough) relatives or friends that are able to provide care. But also because some patients need complex medical treatment that is difficult to provide in a home situation. Especially for such guests the presents of 24 hour medical support makes hospices an attractive option.

We can distinct two sorts of hospices: the high care hospice and the low care hospice. Low care hospices are also called home-away-from-home[32]. The main difference between high- and low care hospices is that in a high care hospice the medical personnel is employed by the hospice organization. In a low care hospice, the medical personnel is employed by the homecare organization, just as it would be if the patient would stay at home. Contrary to the high care hospice, the low care hospice is volunteer driven. Both low care and high care hospices depend on a large number of

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[29] 'Spirituele zorg: verbindende schakel in palliatieve zorg' 2010: 4

[30] www.en.wikipedia.org/wiki/Cicely_Saunders

[31] http://en.wikipedia.org/wiki/Elisabeth_K%C3%BCbler-Ross

[32] In Dutch: Bijna-thuis-huis.

volunteers, but in a low care hospice, the volunteers have a more central position[33]. This is because in a low care hospice, medical personnel are not present for 24 hours a day. Usually a nurse will come in the morning to provide care to the patients. After handing out medicine and washing she will leave around noon. After that it's up to the volunteers to respond to patients needs until the night nurse comes. The volunteers thus have to survey the condition of the patient and decide at what moment a doctor should be called for. Although formal tasks of volunteers in a low care hospice are not necessarily different from a high care hospice, volunteers in a low care hospice are much more involved in the care process.

The name home-away-from-home comes from the idea that low care hospices attempt to provide a homey environment that is almost as a normal home. Many hospices are also situated in ordinary houses in ordinary neighbourhoods. Hospice workers will mostly not speak of patients, but of guests or residents. Hence I use the word guest here to refer to the patients that come to the hospice for care in the last phase of their lives. To prevent confusion I will use the terms *family and friends* to refer to the people that come to visit the guests that reside in the hospice.

The word *guest* is used instead of *patient* to signal that the hospice does not try to cure their guests. People that come to the hospice do not have to be "fixed", the aim is to relief people from suffering, and help them to die in a dignified and peaceful way. Medical treatment is mostly limited to pain relief, and no improvement in the physical condition of the guest is expected. Besides fighting pain, hospice workers give support. They listen to a person's live story or support the family and friends with their bereavement.

Usually the legal organizational form of a hospice is a foundation. In case of a low care hospice, the only paid employees will be one to three coordinators. Further the low care hospice depends on volunteers. The nurses, as said, come from a homecare organization. In some cases the hospice arranged a fixed pool of nurses with a homecare organization.

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[33] Conversation with Joan (nurse); Van der Lee et al. (2008).

Compared to hospitals, hospices provide more rest. Things happen at a slower pace, there are less people around, and personal has more time to get to know the guests (Sandgren et al. 2006: 79).

> It is a house, yes where people come that have been trough a lot, treatment has been stopped, sometimes they have been back home for a while, other times it goes very quickly. [They] enter the hospital, the doctor tell he can't help any more. He's in a bad shape, than they enter a hospice and than there's a time that people have arrived and they find rest because it's much more quiet [than a hospital]. In all hospices, the atmosphere is much more quiet, there's no further treatment. Everything is focussed on a homey atmosphere, on service. All volunteers are focussed support and care, with a cup of tee, with attention and conversation. SO the atmosphere is very different. People that come from their home experience it as, sometimes a relief but there's always also the mourning because of the farewell from home, that's more pronounced in those cases. (Joan, nurse: 3)[ii]

> (..) that is a totally different approach than in a hospital, in there [**the hospital**] people have to become independent as soon as possible, but in here [**the hospice**] it is very important, if something costs a lot of energy we say: you don't have to do it yourself, we support you. So that people have a choice, today we do it and not tomorrow, maybe just showering two times a week, just what they can manage and what they prefer. (Marie, nurse: 7)[iii]

Vision

Some hospice websites explicitly state a vision that inspires the practices of hospice work. These visions can be informed by a certain religion, but that is not always the case. The role of the religion can vary per hospice. Guests are not expected to share the hospice's signature religion. For volunteers and employees it is sometimes expected that they share the signature religion[34].

> The Zen hospice:
>
> 'We welcome all spiritual traditions for both patients and volunteers. We wish to encourage a multicultural community. Not everyone can be at the bedside, but there are many ways individuals can help create a caring environment and actively assist us with fulfilling our mission'.[35]

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[34] Conversation with Caroline (volunteer at a hospice that has a Christian signature); Van der Lee et al. (2008)

[35] www.zenhospice.org

> Bijna Thuis Huis Zoetermeer:
>
> Everybody is welcomed, regardless of religious background, age, income or background. In our home-away-from-home we work on the premise that life is worth it also in the last phase of life, amongst others, because of deepening in the contact with family and friends or personal growth.[36] [iv]

Hospice buildings

[37]

The above picture is taken from the website of one of the hospices I visited during the research for this thesis. This case is a high care hospice. The building is two stories high with rooms on both sides of the opening in the middle. On the ground floor at the left side there are three guestrooms. On the right side there is an office for the hospice coordinator, a kitchen, a washing room and a laundry room. At the first floor there are guest rooms located on both sides. At the back you can see a part that is used as living room with high windows that look out on the garden.

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[36] www.bijnathuishuiszoetermeerhospice.nl > informatie

[37] www.hospicefdw.nl


[38]

Above a small room in a low care hospice that I visited.


[39]

A large room with big windows in a high care hospice. This room is part of a building that was specially designed by an architect as a hospice building.

Hospices attach great importance to the physical space of the building. At their websites there are often references to atmosphere of the building. The websites speak of: small, intimate, homey or quietness and privacy (Pluut 2008: 14).

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[38] www.bijnathuishuiszoetermeerhospice.nl

[39] www.hospicefdw.nl

A typical hospice has three to five beds, but hospices with more beds exist. There is only one bed per room, so each guest has their own room. Guests can personalize their room with pictures or artwork, in some cases even with their own favourite chair or other small furniture.

Further the hospice building has a room for the coordinator, a bathroom if the guestrooms do not have their own, and a central living room where guest, friends and family, and hospice workers can gather. The kitchen is sometimes part of the living room, or it is separated. Hospices might also have a separate room for hospice workers for lunch breaks or meetings, if the building allows it. Some hospices also have a separate room where guests can welcome friends and family. A spare bedroom can also be found in some hospices. It is used for friends and family that stay over, or for the night nurse.

People involved in hospice work

Not all hospices are organized around a physical location. Some hospices function as community outreach group (home care), others are virtual and are organized around a website. The hospice workers that participate in the present research all participated in hospice work organized around a hospice building. The next sections discuss the roles that are usually involved in this form of hospice work.

Guests

Guests come to a hospice to die. However, most hospices do not mention the event of dying on their website. Most websites state whether euthanasia and palliative sedation are allowed or not. Special rituals that accompany the event of dying are mostly not mentioned (Pluut 2008). What is mentioned is that the wishes of the guest are central in hospice work. Also websites offer some short perspective on dying.

> Dying is a inextricable and meaningful part of our life.
>
> In the light of our farewell, every moment is irreplaceable
>
> Every leaf that falls touches our heart directly [40] [v]

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[40] www.hospicedeliefde.nl

The website of agora, offers links and suggestions for books about chronic illness and dying. The website states:

> 'Will I experience a lot of pain?
>
> What is awaiting me?
>
> Can I cope with the grief?
>
> Will it all become too much?
>
> When you hear you have a fatale illness, there are all sorts of questions coming up. What can you expect, will there be agony? Such questions that might also be on the mind of your loved ones, can make you anxious and paralyzed[41] [vi].

Another website is www.stichtingstem.info. This website has on it's front page

> 'Living is also dying. Think about it, talk about it. We will all eventually die, so much is sure. Some people do not have much time left, or experience this close by. For others death is still far away. But almost anybody has difficulties talking about it. Because were should you talk about? How do you do that? And why should you talk about dying?[vii]

Stichting STEM translates as foundation Voice. Stem is an abbreviation of dying (Sterven) in your own (Eigen) way (Manier). The goal of the foundation is to end the taboo about dying and take dying out of a medical discourse into social discourse and make it part of life[42].

The foundation provides training to professional caregivers, does research and promotes awareness and conversation of the mortality of human life and wishes in regard to dying. One way conversation about dying is stimulated is through a website.

The address of the website roughly translates as: death as casual talk (in Dutch: doodgewoon bespreekbaar). The website offers a blog and columns by people who are chronically ill of a life threatening disease, or people participate in hospice work. Also

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[41] www.agora.nl > patiënten en naasten > problemen op het gebied van de geest.

[42] www.stichtingstem.info

the site offers a test that helps people to map their wishes and ideas about the process of dying[43].

Family and friends

The last phase of someone's life can be a very intense time. Hospice guests know the moment of death is near. Family and friends might want to spend as much time with their loved one as possible. In some hospices friends and family are therefore offered the opportunity to stay the night in a spare bedroom or in an extra bed in the guest's room[44]. But not all hospices have the space to offer this opportunity.

Hospice work does not always end when the guest has passed away. Grief support is part of the services provided by some of the hospices[45]. Programs for grief support can differ from one-time feedback conversations and one-on-one support to group-support over the course of eight weeks.

An example of a grief support program for people that are at the beginning of their grief process:

Session 1: Telling one's story of loss & reaching out for support

Session 2: The common grief responses and how to manage them

Session 3: The importance of self-care and cultivating inner resources[46]

Some hospices offer memorial services. Family and friends of the deceased can come to the memorial services, volunteers and nurse often attend as well. The Dutch hospice Issoria organizes a memorial a few times a year. At the memorial music is

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[43] www.doodgewoonbespreekbaar.nl

[44] E.g. www.hospicefdw.nl

[45] www.zenhospice.org > grief support > overview; www.issoria.nl > rouwondersteuning.

[46] www.zenhospice.org > grief support > overview > grief 101.

played, there is poetry and a story about each person that pasted away in the hospice in the period between memorials[47].

Hospice coordinators

The coordinator is responsible for recruiting, selecting and supporting volunteers. She will make the work schedule, do the intake with new guests and have meetings with stakeholders such as doctors and homecare organizations and hospitals. Coordinators are also responsible for training and support of the volunteers. Training and peer meetings will be done by the coordinators themselves, or sometimes by professional coaches. Some coordinators host the volunteer evening, others will invite speakers. Some coordinators will hold feedback sessions once a year with all volunteers, others will only have feedback sessions with people that are not performing at optimum or with people that they see not often because they have mostly evening/night shifts.

Nurses

In a high care hospice the nurses are employed by the hospice. In this case, the nurses have a central role in the organization and the hospice coordinator is their manager. In low care hospices, nurses are external to the hospice. They are employed by homecare organizations and only come at the hospice in case one of their patients resides there. In many cases the hospice has a fixed pool of nurses from a particular home care organization. In such a case, the nurses come in the hospice regularly and they are familiar with the hospice coordinator and the volunteers. There are two main reasons to work with a fixed pool of nurses. First there is better coordination between the hospice organization and the homecare organization. Second, not all nurses that work at a home care organization like to do palliative care. By working with a fixed pool, nurses that like to do palliative care can be selected.

Volunteers

Volunteers are very important for hospices, and particular for low care hospices. The volunteers do the daily activities; they run the household so to speak. Volunteers

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[47] www.issoria.nl > na het overlijden.

do not provide medical care – that is done by nurses – but they give assistance to the nurses and give support and care to the guests when the nurse is not around. The tasks of a volunteer can be as diverse as assisting a nurse with washing a guest, making a round with a guest through the park, welcome family and friends of a guest or clean the rooms.

Medical training is not necessary to become a volunteer in most hospices. (Pluut 2008).

> 'Medical experience is not necessary, because volunteers work with a team of skilled professionals, who provide the specific medical and clinical services of Hospice care. The volunteer contribution to the Hospice care giving community is not medical but rather psychosocial, providing compassionate companionship, therapeutic touch, and a listening heart'.[48]

Medical practices are strictly done by nurses and doctors. However, volunteers can help patients with taking their pills for example, as long as the pills are handed out by a nurse[49].

Being a volunteer at a hospice means there are quite some expectations:

> 'Of volunteers we expect that they stick to their agreements. A volunteer is available 2 times a week for one part of the day (a part is 4 hours). Flexibility is important, to be able to react to new demands for care. Once a month a volunteers evening is organized. Volunteers are expected to attend'[viii] (www.hospicemiddenholland.nl translated to English).

> This program brings together people with a meditation or spiritual practice and individuals facing the final months or weeks of life. It encourages a mutually beneficial relationship between people who are cultivating a "listening mind" and heart, and people who need to be heard and seen.[50]

Volunteers work in shifts. Usually they work one or two four-hour shifts in a week. A day at a hospice could look like the following: the first shift will start in the morning at seven. The next shifts will be from eleven till three pm, than from three till

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[48] www.zenhospice.org

[49] Conversation with Joan (nurse); Kate (ex hospice coordinator); Van der Lee et al. (2008: 26).

[50] (www.zenhospice.org > volunteer programs > volunteer caregiver program)

seven and from seven till eleven in the evening. Mostly, two volunteers will assist two nurses in the morning. After that, two volunteers work together the rest of the day. In high care hospices nurses are present 24 hours a day.

A hospice of 4 beds will need around 45 volunteers at least to be able to fill their schedule. Some hospice however have much larger number of volunteers, for instance to fill up holiday shortages (Van der Lee et al. 2008).

Here some examples of selection criteria for recruiting volunteers:

> 'In an intake, volunteers are checked on characteristics as servitude, openness, eagerness to learn, curiosity and modesty. Also it is very important that future volunteers have coped with their own losses and past' (Van der Lee et al. 2008: 21)

> Living life eve-minded and being able to cope with the grief, the pain and the suffering of others
>
> Being able to behave humble en leave room for others
>
> Being able to listen to the other and not putting your own values and norms upfront
>
> Discreetly chose your position in the dying process of the other
>
> Keep your responsibilities
>
> Being available for at least two day parts a week [ix]
> (www.hospicemiddennederland.nl > vrijwilligers > vrijwilligers)

Adequate training of volunteers is important for all hospices (Pluut 2008). People that want to start working as volunteer get a training first. This training has two aspects. One part of the training deals with basic medical care skills that are relevant to hospice work, for example how to help a person in an out of the bed or how to use the po. Another part of the training is about how to relate to people that are dying. This part deals both with the contact with the guest, as well as the volunteer's own reasons for wanting to do hospice work and experience with death. After the training, a new volunteer will first work a couple of shifts together with an experienced volunteer before becoming a member of the pool of volunteers.

Besides training organized by a hospice, there are various possibilities for training in palliative care. The palliative care network and the foundation for volunteers palliative terminal care (in Dutch: Vrijwilligers Palliatieve Terminale Zorg) organize trainings[51]. In some hospices volunteers can participate in an external training once a year. These trainings are regarded as a reword for the voluntary work[52].

Finaly, besides training for volunteers, some hospices offer trainings and workshops for others that are interested, such as professional caregivers, people with chronic illness or people caring for others[53].


[54]

The living room of the zen hospice.

Others

Most hospices have made arrangements with family doctors in the region. Guests can bring their own doctor if they want. But guest that come from a greater distance or do not have a good relationship with their own doctor will be assisted by one of the hospice doctors.

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[51] www.vptz.nl and www.networkpalliatievezorg.nl

[52] Conversation with Barbara (ex hospice coordinator).

[53] For example www.zenhospice.org > education > workshops; www.kuria.nl > educatie.

[54] www.zenhospice.org > hospice care > see the rooms.

Besides assistance from a doctor many guests feel the need for psychological and/or spiritual assistance. Guests can bring their own spiritual counsellor or priest. But usually hospices have also a special arrangement with spiritual counsellors, priests and psychologist that is located near the hospice.

Agora published a report about spiritual care. They claim that spirituality in palliative care does not get enough attention while it is of existential importance for patients. One of the reasons for the absence of spirituality in palliative care is seen in separation of domains. Thus spiritual questions are seen as the domain of spiritual counsellors and not that of doctors, nurses or volunteers. Another surprising reason is that there is no evidence for spiritual care. That gives the impression that practices in palliative care have to be evidence based. [55]

In this chapter I have only touched the surface of some of the themes that might be relevant in hospice work. The aim of this chapter was to give the reader that is not familiar with hospice work some ideas what hospice work might be. Although much more could be said, I hope this first impression helps you in understanding the following chapters.

This chapter offered a first glance of some of the practices of hospice work. In the next chapter the meaning of such practices is discussed. The discussion about quality of care is used to discuss what good care might be from a ethical perspective. Central to the ethical perspective are relating to the Self and relating to Other. It will be argued that relating to Self and Other an opening into a relational constructionist understanding of feeling in hospice work.

Other issues:

Palliative sedation:

Palliative sedation is the lowering of the consciousness of a patient in the last phase of his life. The goal is to relief the suffering patient by bringing the patient to

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[55] 'Domeindenken hindert integratie spirituele zorg in het multidisciplinaire zorgproces'; 'Het ontbreekt aan evidence voor spirituele zorg' ('Spirituele zorg: verbindende schakel in palliatieve zorg.'2010: 3).

sleep/coma. Sedation is used if normal treatments are not fast enough or not effective. The treatment can continue till the patient dies. Patients or their families can ask for sedation, but it is the doctor that decides if palliative sedation is used. It is thus a medical decision (The 2007: 25, text box). One of the nurses that I interviewed told me that sedation does not have to be a final decision. In accordance with the patient it can be decided to start sedation for a couple hours a day. In such a case the patient will wake up again and can decide if further sedation is preferred.

Euthanasia:

Since the first of April 2002, the Review for termination of life on request and assisted suicide act came into force in the Netherlands. Since then Euthanasia and assisted suicide are still part of criminal law, but it is no longer forbidden if the doctor keeps a record of his actions. After the euthanasia, the doctor reports to the municipal coroner. The coroner will gather all necessary documents and send them to a regional commission that will review if the euthanasia meets the requirements of due care.

Requirements of due care mean that the doctor:

- Is convinced fully that the request for euthanasia is well considered and out of free will.
- Is convinced of hopeless and unbearable suffering of the patient.
    a. The patient is informed about his future perspective.
    b. Together with the patient has become convinced that the patient has no alternative to reduce suffering.
    c. At least one doctor has done a second opinion.
    d. Acted carefully.

The Netherlands has five regional commissions. The commissions are formed by a lawyer, a doctor and an ethicist that review of the requirements for euthanasia are met (The 2005: 61, text box).

Chapter 6. Quality of care, an ethical perspective, (connecting conversations and other texts)

To make sense of the stories that the participants told me, I will position them within a debate on quality of care. The stories will be interpreted from an ethical perspective on care. The relational constructionist thought style implies a focus on ethics. The reason for this is the relational constructionist position on ontology. In chapter 1, relational constructionism is explained as ontology of becoming that centres process instead of entity. For relational constructionists the question is not what reality really is, but *how* is reality constructed? When inquiries are driven by how-questions, ethics become of vital concern. As McNamee puts it:

> 'If particular ways of talking <u>construct</u> our worlds, then the discursive forms that emerge and gain viability within particular communities construct the *ethical* standards by which we live. A "way of talking" can only be given space if others engage in and add to it. Thus, the relational aspect of meaning is featured.' (McNamee 1994, 71, underline in original; italics my own)

For relational constructionists, ethics is not limited to "big" questions of life and death. Ethics should be understood as the ethics of the mundane, everyday (ordinary) practices. An example of this is given in chapter 4 where researcher – participant relations in a modernist style of research are described as subject – object relations. The modernist thought style constructs research relations as a subject (the researcher) that gains *power over*, and knowledge *about* the object (research participants). In such subject-object relations the researcher is privileged to say something about the object. The researcher occupies the expert position and determines the terms and conditions of the research. In contrast the relational constructionist thought style directs attention the ethical dilemma's that "normal" science practices produce. Why should the researcher be privileged to say something about his/her research objects? Why shouldn't it be the research objects to decide how and on what the research is done? Why shouldn't we tread them as the experts? It is *their* lives we inquire. This is how the relational constructionist thought style implies a focus on ethics and therefore the ethical perspective is used to look at hospice work.

The debate

Opinions vary on what the words quality and care ought to mean. An economical perspective dominates the debate. Health care is framed as a marked place. Consumer choice and innovation are seen as driving forces for improvement in quality. Competition, privatization and benchmarking are the preferred instruments. Besides these market (like) instruments, the government does a great deal to improve quality. There are rules, regulations and inspection agencies. The effect is that health care is organized more and more according to economic principles of efficiency and clinical principles of safety. At the same time, health care loses its relational character. Care becomes a bundle of desirable functions, organized according to the principles of Fordism. In this transformation towards an economic perspective of care, health care as an institution collapses. As economic efficiency takes over, health care's own efficiency is lost and the *why* of health care is forgotten. Giving and receiving care become an economic transaction arranged in a contract (Heist & Vosman 2010).

But there is also opposition against this economic perspective and its subject object constructions towards the quality of care. One of the opposing perspectives is the ethical perspective, which has some powerful and fundamental critique against economic ideas of health care and the production of the cared-for as an object in subject – object relations. At first consumer choice and innovation might seem attractive. But if we stop and take the time to think what quality of care actually means, we might look at it differently. Quality of care has two elements: care and quality. Thus before discussing quality, first we have to know what is meant by care. How can we understand care from an ethical perspective?

Care

Joan Tronto (1993: 127): identified four elements of care: 1) caring about, noticing the need for care; 2) assuming responsibility for care; 3) care giving, the actual work that needs to be done; 4) care receiving, the responses of the person that is cared for[56].

I will make three observations about these elements of care. First, to care about means that a person is empathetic with the person in need of care. Tronto's first element centres the stories, the morals and motivations of the caregiver. Caregivers can give reasons why they choose to care for someone; in every day language, we call those reasons motivation. The caregiver is not just a means to perform a bundle of desirable functions or services (Heist & Vosman 2010). Instead in Tronto's view, the caregiver is a human being in a relation with another human being. That means that the motivations and morals that drive – or inspire – the caregiver have a place in the care process. Because of that, we can conclude that besides rules, regulations and professional codes also personal motivations and believes are at work in the care process.

Secondly, I note that assuming responsibility (the second element) directs attention to articulations of the medical discourses. Besides being motivated to care for a person, what it is that is cared for has to be part of someone's sense of responsibility. It has to fall within the realm of tasks that are articulated within a particular (medical) discourse. If the social and emotional issues that patients in hospices have to deal with are not part of the medical discourse that nurses draw on, than discursive powers will not make nurses feel responsible for the social and emotional side of the process of dying. As a result nurses and doctors will neglect the social and emotional well being of a hospice guest. They will consider those issues as private matters, or in the best case, they will call a social worker or spiritual counsellor to assist the guest. How the perspective of dying is formulated, will make what counts as hospice work. Are conversations with guest just superficial conversations, or is the purpose also to help the guest to accept that life has come to an end, or to rebuild the

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[56] Some authors interpret Tronto's (1993) concept on an institutional level and as a chronological description (Van Heist 2005). I however think the concept is also useful to look at care on the level of practices. Thus the interactions between caregiver and care receiver.

relationship with a son or daughter that has become distanced? All of these issues can be seen as part of hospice work or as private matters. And that will in turn influence how hospice workers deal with these issues in relation to the guests.

And thirdly, I note that in Tronto's definition care is an interactive – or relational – process that not only involves the actions of the caregiver, but also the care receiver. The receiver of care is an active participant in the care process (even if the hospice guest is not "active" in the literal sense). Care is not only given, it is also received. Seen this way, care is constructed by giver and receiver together. In other words, care is not a one-way process, but an interactive process that can never fully be planned or pre-determined in advance. This means that both the process and end result are to some degree uncertain. Just as the hand shake example by Hosking (2004) in chapter 2 of this text, for care to become (good or bad) care, acts depend on act-supplements that involve multiple co ordinations simultaneously. Patients past experiences and culturally provided understandings of care will influence how care will become to be good, rude or compassionate.

Now I want to enrich the observations about Tronto's concept with some of the stories the hospice workers told me. The goal is to bring the ideas of Tronto to live.

Reasons for doing hospice work

First I noticed that in the concept of Tronto, motivation and morals play a role in care. The process of care is thus not only influenced by the rules and regulations, but also by ideas that motivate caregivers to do the work they do. Why would anybody want to work in a place where people come to die? Especially if those people are very often sick, anxious, and their bodies deteriorate.

During my conversations with participants I heard different reasons why a person started doing hospice work. And considering my limited number of interviews, I am sure there are many more reasons for people to want to work with patients that are in the end phase of their lives. But I think it is useful to look at two of those reasons that are referred to quite often and that give important context for the rest of my analysis. The two following extracts illustrate, on the one side, people that are motivated to do hospice work because they lost a loved one, and on the other side caregivers that want to have an intimate connection with people in the end phase of their lives.

> Caroline as she tells why she wanted to work in a hospice:
>
> Dirk: Yes, why uh, did you want to do hospice work? Or maybe we should start earlier, why did you want to do that…
>
> Caroline: End of life support…
>
> Dirk: Yes wanted to do end of life support, or that minor?
>
> Caroline: Yes, uhmmmmmm – I have training in law. I studied law. I work for a while at (name of organization). Uhm, - through the course my life took, I ended up in another job that did not give me enough satisfaction, a administrative position in ___[name of a city], at a research group, that is kind off funny [laughs] therefore that I liked this research. Eh, but it does not give me satisfaction. I have the idea that there's more to life, uhm, it captures me; death. There's also a personal story behind it. My sister passed away when she was 23, she took her own life. I wasn't able to be there, in the last phase of her life. Therefore that part of life is always something griping, something that attracts me, well something that interests me to say it positively. So that's where my fascination with death comes from, I think. My curiosity also, what happens, where are you going, what does it looks like, that last phase of someone's life. (Caroline, volunteer: 1-2)[x]

> Theresa (hospice coordinator) about why she wants to do hospice work:
>
> Dirk: Because what, what does it to you, that you do this work here?
>
> Theresa: Uhm, it gives me an immense satisfaction to - yes to, actually form, pre, to make the preconditions, to be allowed to make that they have it as good as possible in that last period, that I play a part in that. And the closeness in such an intimate process I think is not so self-evident, that's also what I like. We just had a conversation, yesterday a man came in the hospice, his wife, she just wanted to speak over, it happened in the office, more or less naturally. And she had to cry so much, but at the same time she was so powerful… Well I think that is wonderful, that I am allowed to be close to that. And when she left the office, my colleague and I said: beautiful isn't it? (Theresa, hospice coordinator: 12)[xi]

Both motivations bring feeling in the centre of hospice work. The loss of a loved one and the emotions of that experience motivate many people to work in a hospice. They have experienced a traumatic death of someone close, the experience of someone that could not find rest and comfort in the face of death, or a troubled relationship that could not be brought to an peaceful end. They want to do it right this time, give these people the better, more comfortable, more dignified process of dying. The emotional experience of the past can also be the trigger for emotions to come out when working in the hospice and getting confronted with similar situations. Hospice coordinators are wary during recruitment of new volunteers. They explicitly look if candidate volunteers have come at peace with their past experiences of losing a loved one. Someone who is still mourning the loss of a loved one is not considered to be able to relate to the guest. Their own loss is considered to be too much on the forefront.

The second extract presented above, shows a coordinator that gets fulfilment from being nearby another person's emotions; a position that usually falls within the realm of privacy within the western culture.

One other motivation that might be an obvious one, but is not named here, is religious duty. Because many hospices have a signature religion, we can assume that religious duty is part of the motivation of some hospice workers. In the next chapter I will go into the matter of religious duty ant it's relevance for feeling.

Perspectives on dying

My second observation about Tronto's (1993) concept of care was that caregivers have to assume responsibility. I argued that articulations of medical discourses are relevant for this point because they guide caregivers in what to feel responsible for. Especially it is relevant what kind of perspective such a discourse constructs about death or the process of dying. The perspective that the caregiver draws upon will direct the attention and feeling of responsibility of the hospice worker. In chapter 5 I already gave a brief description of hospice work. The WHO definition of palliative care that is presented in that chapter is a definition that includes medical, social and emotional or spiritual elements of care. Here I will quote two stories that present three perspectives on dying. In the next extract Anne talks about what nurses write in the notebook as she shifts to conversation to the topic of family relations.

> Thus that - notice the things but don't write them in the notebook because the notebook can be read by the patient and the family. They can read everything that is in there. We don't have secrets. But you have to realise what you write down. Not that you really have secrets. But sometimes you have doubts, yes that is difficult sometimes, yes, those family troubles. Because what you experience is that there are, a lot of worries, in regard to the family of the client. Because there are often a lot of problems, children that did not see their parents for years. Well what you see then, contact is re-established, sometimes

> for only one time, and than it is settled, but that are thing that can prevent people from dying. (Anne, nurse: 3)[xii]

This quote is not particularly extraordinary for the story of Anne. The conversation is full of stories about family troubles that either come to light or come to climax in the face of an approaching death. Anne takes an active role in managing these relational processes. Although she sees these matters as private, the conversation illustrates at many points that Anne takes up an active role in resolving family troubles. She tries to manage her activities and interactions with patients in such a way that relational problems of the guests can be resolved. So for Anne, social relations are very much part of the process of dying.

Next, Kate (ex hospice coordinator) talks about the tasks of the volunteers in the hospice. Her story combines two different perspectives on dying. In the text excerpt she talks about the notebook that hospice workers use to inform each other about changes in the conditions of guests.

> Well it is all very practical [**that what is written in the notebook**]. There are things written in it how to lift someone, uh, those kind of things. It is a mixture, at the one side you have to be *there* and in that sense you have to be available for the resident. It can be that he likes to be read to or make conversation. And sometimes it is very practical, that you enter a person's room and the bed is wet. And than you have to clean the bed, such things can also happen. It is almost both psychological social support as well as physical. And there are also things like, someone can be very nauseous and you start working at 7 [a.m.] and you have to support someone's uh, support with vomiting. Well that's not so nice. So you are very much confronted with bodily processes that aren't always very beautiful - Sometimes *raw* and *painful* en sometimes people are so stuck in their own process and they are very angry or denying that their end is near. (Kate, ex-hospice coordinator: 11)[xiii]

Here Kate constructs the process of dying as both a physical and an emotional process. A clear example is given of the physical discomfort that many terminal cancer patients have to go through. But in addition it is also acknowledged that dying is also an emotional process. Not only the emotions that the physical process can trigger are part of dying. Dying itself is constructed as an emotional process in which patients have to come at peace with their approaching death; a mourning process that involves existential questions.

The two stories combined provide three different possibilities to articulate hospice work: as medical physical work, as social work and as emotional or psychological work. In the light of Tronto's (1993) second element of care, these three possible articulations of hospice work will help to understand what it is that a hospice worker will assume responsibility for. Is that the physical elements of hospice work – handing out medicine, washing and feeding the patient – or is that also giving support in difficult family relations, or emotional support for a patient that is scared because of the approaching death?

Relational construction of care

Third I noticed that the concept of care by Tronto is relational. With this I mean that care is not a one-way process, e.g. something that is done *to* a person, but something that emerges in interaction between the persons. Because of the interactional quality, care is not totally predictable and cannot be totally standardized. Competence than is not just achieving a good end result. The process itself matters, and that process is formed in interaction. This point is illustrated by the following narrative:

> Recently we had a woman of 90 years old that had to go on and on in life, and she always worked hard and for years she had build on an administrative career, until she was 65 she worked and after that she did a lot of voluntary work. So she was always busy for other people, also for her family, for her nieces and nephews. And at a certain moment she couldn't go on and she depended on others for care. Well, that was *so* difficult for her. That was like: "yes but all this that you are going through to take care of me," and uh, well, she could not handle that. And you should actually try to give people the feeling that they still do a lot themselves, that they are in control, and at the same time that you are their arms and feet. And that is wonderful to see, if that works and she is like (whispering): "it's fine if you do it." Well that makes such an impression. (Anne, nurse: 8)[xiv]

This narrative shows how the receiver of care only becomes a "patient" when she is able and willing to receive care from others. It is in interaction that the "right" mode of care is determined. In this case a mode in which the receiver of care has the feeling she is 'in control'.

After this discussion on care, the next section deals with the topic of quality. How does an ethical perspective on care construct quality?

Quality

Based on Tronto's (1993) concept of care, Carlo Leget (2010) examines what quality means. According to Leget quality of care has to do with four things: a) to understand your profession; b) to relate with the patient; c) to relate with the self; d) to be in good relationship with the team. Before discussing each of the elements, you should notice that relating to the patient and relating to the self are the focus of the present research since they embody what I mean with organizing feeling.

a) With understanding your profession, Leget (ibid) does not only mean the technical competence of care that leads to a satisfactory end result: (a needle that is successfully pierced into a vein, or a clean washed patient). Quality, for Leget, is in the practice itself, in the *how* of care. Does the nurse wash the patient without any interaction as if she works in a factory, does the nurse comfort the patient before piercing the needle in the vein to make a drip? Care is not factory work, nurses work with persons that feel sick, persons that might be nervous or frightened. Therefore to put a needle in a vein is an interaction where the process itself is an indication of quality, not only the end result. The *how* of the process is not determined in advance, it has a certain freedom that is filled in by the caregiver and receiver during the unfolding of the process. Besides process and end result, care has another layer of quality when it comes to competence. The process of care is an articulation, expression or performance in the theatrical sense; it expresses meaning. Leget gives the following example to show what he means by this. During one of his observations in a hospital, Leget noticed how a young doctor washed his hands between patient visits. He visited four different patients within a time frame of five minutes. The tap that the doctor used to clean his hands was located in the same room as the four patients. The doctor in this example perfectly acted in accordance with the protocol to wash hands between patient visits. But in terms of quality of care the expression of this practice is: you are to dirty to touch.

b) Quality of care also means that the caregiver can relate to the care receiver (ibid). Caregiver and care receiver engage in a relation so to speak. On the surface this relation is a relation between client and professional. A relation between a service provider and a consumer; nurse and patient. The consumer is free to choose between different providers. The consumer is emancipated and has a voice through a patient's council. But underneath that surface the relation is asymmetrical. The caregiver has knowledge, health and freedom of choice and room for manoeuvre. The care receiver lacks knowledge, is unsure, sick and not free. Given this asymmetrical relation, care has quality if the caregiver can relate to the position of the care receiver; if he or she can feel what the needs of the patient are. But underneath this, there is a deeper layer. Beneath the relation of the roles of caregiver and role of care receiver, there is also a relation between two persons, a relation of one human being caring for another human being. Care is a very intimate practice in which people enter a space that is considered private. The practice of care forces one to show something of him or herself to the other.

c) Then third, quality of care is about relating to the self (ibid). The practice of care demands a lot from the caregiver. The caregiver is confronted with suffering and pain of patients. Caregivers do not always have solutions for the pain and suffering they are confronted with. This can cause panic, fear or a sense of helplessness on the part of the caregiver. And the emotions that the caregiver can feel during the work are subsidiary to the emotions of the care receiver. The care giver is thus expected to be empathic with the patient, to feel the hurt, pain or needs of the patient, but at the same time he or she is expected to provide support, to calm, to come up with solutions. This means that the caregiver is expected not to be overwhelmed by emotion. The caregiver needs to engage in a relation with the guest, yet remain professional in the sense that the caregiver can cope with the confrontation with pain and suffering. It means that the Self with its emotions is subordinate and in service of the Other.

d) Fourth there is the relation with the team in which care is provided. In care institutions, and especially in hospices, important decisions are made. Some of the decisions deal with life and death. It goes without saying that in such situations the relations within the team of caretakers are of utmost importance. On a practical or technical level there are many things that have to be coordinated: how to give medicine, can a guest still wash herself, how do we have to help that old man to get in and out of bed etc. But in a hospice, many of the decisions that are technical or practical, are also ethical at the same time. The decision that it is irresponsible for a hospice guest to come out of bed to walk the room, is also a decision about the quality of life and in that sense it is an ethical decision[57].

The team is also important in the ability of the hospice worker to relate to the guest and to the self. Does the team for instance stimulate members to develop emotionally? Does the team provide an environment to share feelings, an environment that is supportative whenever the work is too much? In all of these issues we see the influence of the team on hospice workers' ability to cope with emotions.

Now that the Leget's view on quality of care is discussed I want to connect the theory with the empirical material. The conversation transcripts are brought into relation with the text by Leget (ibid) to provide meaning to them.

Relating to the guest

The relation between hospice worker and guest is asymmetrical. Therefore the hospice worker needs to be empathic – or relate to – the guest. It is not just a service exchange, although it is also that if care has quality there is a deeper, more personal relation. The relation between hospice worker and guest goes beyond the roles of caregiver and patient; it is also an intimate relationship between two human beings. Because of this intimate quality, the person behind the professional mask becomes visible. The next text illustrates how a hospice coordinator connects to the guests in a hospice.

> And through having a conversation with the dying and also say out loud: "well you will pass away soon," and often you notice that people appreciate this very much, because they did not have to uh, to hide, hmm, like oh look at the weather the sun is shining, nice isn't it? Uh, that you can leave out. You instantly have contact with your heart. Or soul contact, or how you want to call it (..). (Kate, ex-hospice coordinator: 6)[xv]

What this illustrates is for Kate, being a good hospice worker is not having just nice small talk with guests. It is about making a connection and addressing what is

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[57] Wright, Brajtman & Bitaz (2009) also emphasise that in care, and especially palliative care, ethical dilemma's are not restricted to "big dramatically events". Just the day-to-day practices of caring for a dying person are ethical in nature.

relevant for the other. It is the acknowledgement of the other's identity as a dying person.

Following this, I want to quote a story at length, to illustrate what the last story hinted at, but did not yet make explicit.

> Dirk: Would you like to tell me a something more about that, because you say: that the whole process of dying, that you are much more involved [compared to her former work at an elderly home], can you maybe describe that process and how you are involved in that. What your?
>
> Janet: It is more people come to us. There are a lot of volunteers and people see a lot of different faces. Ennuh, we get all the information. Thus what has happened or if people have important thing to tell, that is passed on in a notebook. Thus you know a lot about people thus you don't have to ask everything, so people do not have to tell the same story over and over again to each volunteer. And actually, if I look at myself, what I do is, with, in the hospice you are more menial. It is at the background. People call you when they need you, you do not enter a room like that because it is their private space. Everybody can come in, but it is their space. Thus if people call me I go to them and I always try very, to be wait-and-see, like what do they want from me? And than, in *that* you follow. Sometimes people want, for example they want to eat something, or to drink something, or they are not comfortable and than you can feel: there's something more. If that is so, than you can be a bit like, well like. Make some conversation en than look, do people need other things? Do they need attention or… well you have to be constantly open for what there is. (..) and if people become more sick they start talking less, and. Than it often is, well - conversations are about pain. Or that they [the guests] are not comfortable. And than you can do a 100,000 things and they are still not comfortable. And that's when a light bulb goes on, they are afraid. You can always assume that people are afraid. You know, it is al very uncertain, you do not know what will happen. Than you can take those signals and start talking about it. (..) often it are those little moments that you, you can be with someone and that you, that you have attention for it. That you notice that people are sad, than you can, than you can say, like: I see you laying like this and I have the feeling that you are sad, is that right? And sometimes people want to talk about it, and sometimes not. So it is not like people talk a lot, actually not. It is just being close to someone, and that are sometimes short moments in which not a lot is being said, but things are being said that matter. (Janet, volunteer: 2-3)[xvi]

What this illustrates is that to relate to the guest, the hospice worker has to pick up the small cues. Easily those small cues can be overlooked; a hospice worker could react to the first question, make up the bed and leave the patient alone. From a market perspective, care has quality because the wish of the guest is fulfilled. But as illustrated above, many times a decisive and simple reaction to a question is not at all what is asked for. To connect to the patient means here that the hospice worker makes room to express those emotions. An emotional conversation is not avoided but encouraged in a subtle way. What becomes clear is that the professional repertoire of the hospice worker is not what is central to the interaction. Janet uses the word “follow” to indicate that relating to a patient is not so much about reacting to what a patient asks for. Instead to follow means to listen and then to further listen, to not draw any conclusions, but to stay open.

The next extract illustrates that the relation to a patient, can be a personal connection that goes beyond the ideal of a “professional” relationship in terms of a consumer and service provider.

> (..) Especially in the last phase, when it is very tough and you dare to talk about it, that you are able to say: well can you still take it, is it still bearable? And I said once to someone: the most precious thing you posses you have to let go of now. And that was so, for that man on that moment, eh - what he struggled with. And at that moment we had a certain click, a relation of trust and ehh, through which you can really mean something to someone in that last part. And you can never with all guest that are here, eh, have the same relation of trust. That’s why it is so good we work in a team of different kind of people, because this one has connection with that one and that with that one. (Marie, nurse: 2-3)[xvii]

What Marie argues for here is that the relation between caregiver and care receiver is personal in character, and therefore not the same with everyone. With some guests there is a “click” but not with others. What the extract further illustrates is that that personal connection is established by an acknowledgement of the feelings of the care receiver. Instead of providing comfort and uplifting remarks, it is the acknowledgement of the seriousness of the situation that enables a “click”.

Relating to the Self

Leget (2010) argued that for care to have quality, caregivers do not only have to relate to the guests, but also to themselves. Hospice workers are confronted with the pain and suffering of the guests. Problems for which there is not always a solution. Because there is no hope for improvement, this confrontation with suffering of the guest cannot be overcome, or fixed, by an intervention of the caregiver (as in “normal” cure). The caregiver has lost the normal repertoire of intervention when confronted with suffering. Thus especially in a hospice, caregivers need alternative repertoires to be able to cope with the pain and suffering. Leget (ibid) argues that these confrontations are also a confrontation with the caregiver's own fear for pain, and the fear to loose their life. Confrontation with the Other is thus also a confrontation with the Self. At the same time the hospice worker's experience of emotions is subsidiary to the emotions of the guest. The hospice worker needs to be open to emotions to be able to be empathic, but this should be in service of the Other. The empathy with the other cannot lead to empathy with the self, or self pity. Or in other words, care has quality when caregivers are open to the emotions of the guests, but just as important, do not get overwhelmed by the emotions they are confronted with. To be able to do that, the caregiver needs to relate to the Self and discover how close the emotions of the other can come, before it is to much to handle. The following two texts illustrate this.

> People, volunteers can become very angry, for example - my experience is that anger is the result of feeling powerless because someone uh, is in severe pain that has no remedy to it. Some say: "suffering from pain is no longer necessary", well bigger nonsense doesn't exist. I mean it is possible to do allot about pain, or at least reduce it till it is bearable. But that is not always successful. *And* then there can be such unbearable pain that breaks through everything, and guests but also volunteers panic, and then there is fear, I always believe that it is fear for the confrontation with your own pain that makes that you cannot handle with it, deal with it. Completely powerless, you can't do anything, the other is constantly screaming for your help, and there's really nothing you can do, well that results in some powerful emotions. That can be anger, it can be grief. Well than it is very important that there is a safety net. It is very nice if you can send your colleague when you can no longer handle it, that you can call the coordinator, that you can call a nurse that will stand by you, and that you can count on a very close network to bear it with each other, that you are not standing alone. (Barbara, ex-coordinator: 20-1)[xviii]

Marie works as a nurse in a high care hospice. She tells about an experience that moved her:

> Marie: But you see people coming in and as time passes their condition gets worse, they get worse fast, you see it becomes a heavier burden and than death comes as a friend. And than it is good to see that someone does not has to suffer any longer and can let go. And how sad it might be for the bystanders, for the person in question it is a relief that life ends, yes -
>
> Dirk: yes -
>
> Marie: Yes and I know that in the beginning, we had a few very young people, and that was the most difficult thing in this work, that some people could have been your own child, but I have developed the last years, I am able [now] to make contact with them. (..) And uhm, because then, it hurts me very intensely when people could have been your own son or daughter and than it comes very close, that's way more touching. Yes. I once stood at the deathbed of a twenty-

> one years old lat, (..). And you know what I liked very much, it had of course a lot of impact on both the volunteers and us, the team had a gathering, because the mother of that boy died as well, to make the story complete, but also how do you stand in this en how can you cope with this? I think that is very good. (Marie, nurse: 4-5)[xix]

The stories of Barbara and Marie illustrate the theoretical argument made by Leget: to relate to someone else's suffering means also a confrontation with the Self. We see it most clearly in this story as Marie says: '(..) it hurts me very intensely when people could have been your own son or daughter and than it comes very close, that's way more touching'. Here Marie relates the suffering of the Other (a twenty-one years old lat) to the Self (the imagination what it would mean if it was her son or daughter). Another interesting point is that Barbara relates the confrontation with the Self to the impossibility to relieve the suffering of the guest. In other words the impossibility to intervene. This point will be treated in depth in the next chapter, for now we will just leave it with the hypotheses that the emergence of feeling might be understood as outcome of practices (intervention or non-intervention). [58]

To illustrate this point of relation of Self and Other some more I present an example from existing literature that is in line with the relational constructionist

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[58] The need for relating to the Self is also acknowledged in other studies:

'Participants urged what one termed "navel gazing" as essential to ensure that caregivers are able to respond as much as possible without overshadowing the patient and families' needs with one's own. The centrality of self-awareness was seen as key to connecting more deeply in relationships across the team and with families. Although caregivers urged open acceptance of self-care practices that may include personal therapy, supported time away from work, rituals, and designated time for debriefing, participants were quick to acknowledge that more work needs to be done on individual and organizational levels. Self-care practices for hospice palliative care professionals were seen as essential and needed to be fore grounded if professionals are going to remain healthy and able to continue this work.' (Bruce & Boston 2008: 53)

In a quantitative study (Lobb et al. 2010) found higher levels of burn out among oncology nurses than among palliative care nurses. Both oncology and palliative nurses are confronted with similar situations; therefore the authors expect the difference in levels of burn out to stem from organizing practices. The practice of debriefing, which is more common among hospice workers than palliative nurses, is suspected to facilitate the expression of grief. The expression of grief would than account for the lower level of burn out. This study also suggests that both oncology and palliative nurses had a need for debriefing that facilitates sharing of 'subjective' experiences and grief education.

thought style. The extract is a quote from Steve Fineman's (ed.) book "Emotions in Organizations". The chapter bears the title "If emotions were honoured: a cultural analysis". Meyerson starts the chapter with a personal story of a professional development workshop she attended. At the workshop she gets into an argument with her mostly male colleagues about working mothers. Key parts of the text are underlined:

> 'What I had to say was not popular and some of my fellow participants seemed eager to shift the conversation. I did not oblige. I was offended by my colleagues' comments. The conflict escalated until the dinner break. I felt angry and misunderstood, and I contemplated not returning for the evening session. I suspected that many people were angry at me and resented the time we spent talking about the pulls on working moms. The more I thought about it, the angrier I became at my colleagues for not "getting it". (..) For no clear reason, I decided to stick it out through dinner. As I waited in line, a man who had taken a rather vocal stand among the opposition approached me, put his hand on my shoulder, and said 'Thank you. It must have been awful for you because I'm sure this hits you very close to home. I really appreciate your struggles and I wish I could completely understand.' (..) Through the dinner break, I engaged with this man in a different way. We both shared how we felt and what we thought, and we listened to each other. I felt validated in this conversation and gained the courage to return to the session. That conversation transformed me; it shifted my intent and gave me the capacity to re-engage. But more important, it helped me encounter my feelings of guilt and inadequacy that lurked just beneath my surface anger. That evening, I revealed some of my own struggles and feelings of guilt as a working, travelling mother. My colleagues listened and I sensed they began to empathize. Some told their own stories, revealing their sense of inadequacy as they tried and failed to live up to their ideals of being active fathers and good providers. As the conversation deepened, we began to bridge some unexpected divides. That evening, we all learned.' (Meyerson 2000: 167-8)

This narrative presents two arguments. First, the Self as an emotional being is constructed in interaction with Other. The clearest example is when Meyerson writes: '*Through the dinner break, I engaged with this man in a different way. We both shared how we felt and what we thought, and we listened to each other. I felt validated in this conversation and gained the courage to return to the session.*' Both feeling and identities are changed in interaction. This provides a powerful argument against the entitative thinking (as discussed by Hosking & Morlye 1991) that sees people as having an identity and emotions. In this example identities change in interaction form a 'angry' and oppositional Self and Other to a 'validated' Self and 'empathising' Other. The example is thus in line with the relational constructionist view that Self and Other emerge in process and are not independently and stable existing entities.

Secondly, the extract is an example of how relating to Self, and relating to Other occur at the same time; they are connected. When Meyerson writes: 'it helped me encounter my feelings of guilt and inadequacy that lurked just beneath my surface anger. That evening, I revealed some of my own struggles and feelings of guilt as a working, travelling mother.' It shows that the relation of anger with the Other is at the same time a relation of struggle with the Self. So in the *oppositional relation* with Other (her mostly male colleagues) it is that she is at the same time in a *struggling relation* with the Self (as a travelling and working mother). In my reading of Meyerson's narrative the anger is not so much about the Other (mostly male colleagues), but about the Self (feelings of guilt and inadequacy) that is recognised in relation to the Other. As Leget (2010) notes that relating to the Other also asks for a relation with the Self. The Other acts as a mirror to recognise emotions in the Self.

In this chapter I used the discussion about quality of health care as a context to present the stories of hospice workers. Health care can be seen as a market place where consumers "buy" care. In such a vision, care has quality when offered services fulfil the wishes of a client. I also argued that in such a vision, consumer choice and innovation are central in achieving quality of care. And although al those elements are laudable, they neglect what care ought to be. With the help op Tronto (1993) and Leget (2010), both care and quality were given meaning from an ethical stance. In the stories that illustrate the concepts of Tronto and Leget, care is not about a caregiver that provides something *to* a patient, as if a service provider relates to a consumer. Instead care emerges out of interactions between caregiver and receiver. And it is this process itself that is important. For Leget, as for some of the participants that told me their stories, care has quality when the hospice worker can relate to the guest. This could also be described as a compassionate relationship. And in that relationship the hospice worker relates to a person that often is in pain, anxious and dying. This confronts the hospice worker with his or her own pain and fear for death. To not be overwhelmed by emotions triggered by this confrontation, the hospice worker should not only relate to the guest, but also to herself. It is this relation to the Self that enables a connection between caregiver and care receiver. Care and quality of care are only possible if the caregiver relates to the own Self. If she is able to relate to her own fears for pain and death and formulate her own questions about the meaning of sickness, life and death. In other words, in an ethical perspective of health care, both caregiver and care receiver are presented as emotional human beings.

The next chapter is an inquiry about what makes it possible for hospice workers to relate to themselves and the guests. The question that will be answered is how hospice workers cope with emotions.

Chapter 7. Organizing practices & discursive recourses in hospice work

This chapter discusses some organizing practices that hospice workers use to cope with – or manage – feeling in order to engage in compassionate relations with the guests. Employing a relational constructionist thought style, the inquiry focuses on organizing practices that can enable or obstruct hospice workers to share and digest emotional experiences. Second, three narratives are presented to show how organizing practices are resourced with discourse (see chapter 2 especially page 17-21) so that these practices reach their enabling potential. In relational constructionist language, this chapter inquires how discourses function as act-supplements for organizing practises in ways that enable or limit feeling.

Organizing practices…

In the last chapter the work of Leget (2010) was used to describe quality of care from an ethical perspective. I argued that two elements are central to the question of the present research. Those two elements are: relating to the guest and relating to the Self. For Leget (ibid) care has quality when the caregiver is able to have an emphatic relation with the patient (in language of relational constructionism we could speak of a relation that gives room for feeling). However, this emphatic relation is a confrontation with the suffering of the other. In such a confrontation, emotions can be overwhelming for hospice workers. Therefore Leget (ibid) argued that the caregiver should also relate to the Self to learn to cope with the emotions and digest old traumas. That way, the caregiver will be able to bear the confrontation with hurt and pain of others without being overwhelmed by this him/her- self.

Boeije (1997) did empirical research on how caregivers relate to their patients and deal with the emotions that these relations trigger. She does not use the concept of relating to Self and relating to Other, but her study is useful in further understanding of what enables feeling in the relating of caregivers and patients. In her study of nursing homes, Boeije (ibid) identified a number of different organizing practices[59] that nurses help to deal with the problems they encounter in their work. One group of practices increase their emotional involvement with the patients, while another group of practices result in detachment or emotional distance. In other words, one set of practices opens up the possibility for feeling, while another set of practices limits the possibility for feeling.

Three practices that withhold emotion or prevent emotional relation with patients are:

a. Standardization: fixed rules and routines combined with allocation of tasks results in a standard treatment for all. This reduces personal contact with patients and limits the possibilities to express feelings or engage in personal relations.

b. Normalization: nurses try to ignore the impact of physical or mental limitations and illnesses. In talk, they emphasize instead the possibilities that a person still has and construct the lives of patients as “normal” as possible.

c. Avoidance: nurses avoid intensive contact with the patients by spending minimal time with the patients, spend time instead on trivial things such as preparing activities later that day. Also nurses avoid talking about topics that demand empathy or that are emotionally laden.

Boeije (ibid) also recognised practices that bring nurses in a closer, more personal or emotional connection with patients. I would call this practices that open up the possibility for feeling.

d. Consultation: consulting each other on tasks, feelings and experiences. This makes that nurses feel less submerged by the overload of work. Also it helps

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[59] Boeije (1997) uses the term strategies. But because she describes what nurses *do* in the setting of a health care *organization* it is legitimized to us the relational constructionist term *organizing practices* instead.

them to acknowledge, accept and cope with emotions they experience in their work.

e. Acceptance: this practice is the opposite of normalization. The nurses accept that patients have limitations and they do not try to reduce the seriousness impact of these limitations. However through small changes they try to make the lives of patients as pleasurable as possible. Also is deviant behaviour of patients accepted to some degree.

f. Dosage: nurses find a balance between distance and involvement by rationalizing emotional events and drawing a division between work and private life. If a patient passes away, they rationalize this by arguing that it was better to die than to live in the terrible condition the patient was in. Also they try to avoid thinking about their work once they are at home.

In the conversations with hospice workers a number of practices were mentioned:

<u>A canteen</u> or “private” space for hospice workers: in a private space, hospice workers feel secure enough to share their (emotional) experiences with each other.

> Yes than you come from someone and there happened something upstairs in a room en then (inhales deeply) you enter the kitchen (exhales loudly). Well, what I’ve just experienced. Go and sit down - or if you are with each other. There are always moments you can. And the nurses too of course. Yes, that happens mostly directly, if the opportunity comes by. If there are guests sitting in the kitchen you cannot do that, or with family or so. (Janet, volunteer: 8-9)[xx]

<u>A hospice coordinator that gives support</u>: hospice workers and especially volunteers describe it as comforting when the coordinator asks them how they are doing.

> ‘But the coordinator, what I have experienced is that the coordinator is very important because there are certain critical in the care process for the guest, especially when it concerns cases of euthanasia, or when there is a case of fast decline of the condition, let me put it like that, of the guest and when we can speak of a crisis situation and that coordinator has taken the effort to [**ask**] how I, how I was doing. (..) And that is very valuable when the coordinator asks: “How are you doing?” And that there is the space to talk about it and that, that it can be difficult for yourself, are allowed the feel it is difficult, that you

> can talk about that and - Thus that is a very important role. (Paul, volunteer: 7-8)[xxi]

<u>Debriefing</u>: every shift starts and ends with a debriefing. Besides the “technical” matters that are debriefed, like in what condition the guests are in, the debriefing also offers opportunity for personal reflection.

> Here Caroline was talking about guests and how they prepare for the approaching end.
>
> Dirk: And how do you deal with that yourself. Because you come in contact with all those things?
>
> Caroline: Uh, ‘s funny, I can with most people, if I close the door behind me [**when I leave**], I go on my bicycle, I have to cycle for half an hour, forward. And than on the way to here I can prepare myself for the things I will encounter here, or I hope to encounter here. Because it also happens that you arrive here and the curtains are closed and that (inaudible 19:56 minutes) that has passed away. And back home I go again half an hour, literally away from here. And than there are of course people that stick in your head and that, touches me, and that I think about. And there are also people that (inaudible 20:19 minutes) but I don’t really feel that. That’s more psychological, like. *And* there are of course things that you see, deterioration of the body. And that is a total different aspect than how people cope with it psychologically. Uh - that costs more effort. *If* you see people with open wounds, or a emaciated body, that is much more difficult. You loose that, but it takes more time, like.
>
> Dirk: And in the work itself with your colleagues, do you talk about that?
>
> Caroline: Yes - that also depends how you like each other. Uhm – almost (p) yes – no - at the end of almost every shift it is asked: are there things you feel like sharing, did the work go well, did something special happen? Thus at that moment you can start a conversation with them [the colleagues]. (Caroline, volunteer: 7-8)[xxii]

<u>Volunteer evenings</u>: volunteers gather for special evenings at the hospice a couple of times a year. These evenings are used for medical training, but also for reflection and discussion. One of the coordinators told me that she talked about a book from Carlo Leget in her most recent volunteer evening. She did this with the explicit aim of helping volunteers to cope with their emotions and to provide perspective and meaning in their work.

Theresa as she tells about the board that was present at the volunteer evening to inform the volunteers about the plans for the future, which involves an expansion of the hospice.

> Uh, after that I talked about the book, “Room To Die” by Carlo Leget. We have bought it for in the library here. And I had taken a few things out, that I thought of they will be recognized in practise, I have put them with the volunteers, uhm, yes I put them up for discussion and we have exchanged some ideas. When I took an argument or a part of the book, asked them, well do you recognise this and so some old guest came to mind. Because then [memories of] that man or that women pop up. And that is very nice because I think that this way although those people have passed away, they keep their place in this house. They still play their role. (Theresa, hospice coordinator: 5-6)[xxiii]

<u>Peer group meetings</u>: some hospices have peer groups. The subjects that are talked about are determined by the group members. Coping with emotions is of interests for some of these groups.

> Anne about peer group meetings.
>
> They should make that obligatory because there are a lot of people that think: oh I don’t like al that role-playing en I don’t like al that stuff, let me just do my things. But you see very often the emotions that come to the fore and that is… I sometimes uneasy but it is a good thing that they come out, that they are not suppressed. Yes. (Anne, nurse: 11)[xxiv]

<u>Training</u>: hospices provide trainings for their volunteers. Before a volunteer can start in a hospice, there is an obligatory training. Part of the training deals with emotions. Candidate volunteers talk about their past experiences with death. This way they learn to relate to themselves.

> Dirk: and uh, maybe you can tell me a bit more about, you’ve had a training when you started working here?
>
> Caroline: Yes?
>
> Dirk: And how did that go?
>
> Caroline: I have to dig. It is, it was two days I think, on a Friday evening and Saturday the whole day. And than it goes from different directions. First practical, just how the shifts are, what time, what is expected from you as a volunteer. Very practical. A whole piece of medical information. What do

> people suffer from, the most people that come here. How does that go, how has that changed over time. When they had just begun, it were mostly patients suffering from AIDS that came here. We don't have those any more, mostly cancer. Thus that a bit. And a piece of social work. How do you cope with it, what does it with you, where are your boundaries? Uhm - and also the pastoral minister that played an important role in it, with explaining things. And lifting techniques, we also had that. And that was Friday evening. And Saturday the whole day. And an evaluation afterwards. So that was the training we got. After that, I think four times I've walked along. So you are linked with a volunteer who is linked with a nurse, to learn what you do as a volunteer. (Caroline, volunteer: 14-15)[xxv]

Paul had recently done a second training for a new hospice. I asked him to tell me some differences he had experienced in the two trainings.

> Uhm, a big difference is that the training of ___[name new hospice] directs much more attention to death and suffering. And it is asked of you to think about that. And how your own stance in it. In the first training here in the hospice in ___[name city] that I have done than of course it is also talked about, about the first experience with death and what experience you have with the death of loved once and family. But it remains relatively, I am the one to claim that now, superficial. The first training back then was also thrilling. But now in the training of hospice (name hospice) there is much more attention for your own death and your own suffering, how that influences. There's much more being asked to go there and pay attention [to your own death and suffering]. (Paul, volunteer: 10-11)[xxvi]

Humour: humour provides relief of emotional tensions. It also put things in a different perspective that helps to accept them.

> And what surprises me is that there is quite some humour among hospice workers, and actually you need it. That it is really nice to really laugh sometimes. Because, it is heavy stuff you are dealing with. And it relieves as well, that humour that you have with each other, the jokes you make about it. That is normal in every work situation, which also happens here, that there is a crude joke. But that is good. Yes, that, that relieves the tension for a while. (Caroline, volunteer: 9)[xxvii]

Time out: some hospices provide the option of a time out for their volunteers. Especially when volunteers have to do with sickness or death within their private situation the hospice work can become too much. A time out can help them to focus on their private situation, or act as a time for emotional healing before getting back to work as hospice volunteer.

> There are of course a lot of older people [volunteering at the hospice], or they have a parent that becomes ill, or a grand child is born and therefore they can't have enough attention and enough shifts to remain connected to the work [at the hospice]. Than we came to the construction in the organization to have three months time out and the possibility to return without "but". That became, that was used allot, like yes there is something now for a short period what needs my attention and I like it, uh, it works better than expected. People also returned like wow, actually I like it not having anything to do with this for a while. I have a fresh gaze, I have taken a distance. (Barbara, ex hospice coordinator: 21)[xxviii]

<u>Support and understanding at the home front</u> can also be important for hospice workers to cope with emotions they experience in their work.

> (..) it is of course like, if you finish your shift and there was a crisis situation, so heavy stuff happened, yes than it happened, than you come home for example, that you have from 3 till 7 [**pm**], than you come home, than you have dinner, than it is very important is such a situation that you get the space, to not be there [laughs] in the home situation. That it takes some time to let it go. Yes that is a very important part. How the home front reacts to what you have experienced. (Paul, volunteer: 12)[xxix]

<u>Personal rituals</u>: some of the participants told me how their trip towards their work or towards home was a way to clear their mind or prepare themselves for the work in the hospice. One respondent told how the three in front of the hospice helped as an object to focus the mind and get in the right mode before entering the hospice. Here a story by Paul as he tells how he enters the Guest's room.

> He, so you walk down the stairs, you knock on the door, the way you enter the room, how, your standing in it like. It is a sort of consciousness of, in fact a sort of practice in living here and now, that's what it really is, [laughs] in Buddhist terms. Maybe. But that is really what it is. Going, yes every time I had my shift, I had a sort of habit for myself, that when I opened the gate at the ditch near the hospice, than there is a beautiful beech, there I always stand still. You came from home and were still distracted by everything, which you have to let go. So I used the going trough the gate and looking at the tree as a moment to (p) yes to let go of that and concentrate myself on my shift. (Paul, volunteer: 5-6)[xxx]

Different organizing practices have been discussed above. Boeije (1997) makes a difference between practices that enable a more personal and emotional relation between caregiver and care receiver, and practices that limit such relations. According to Boeije (ibid), the practices that enable a personal and emotional relation are those practices that enable the nurses to cope with their emotions. This is in line with the argument of Carlo Leget, who claims that to be in relation to the Other, you also have to be in relation to the Self. Besides practices that help nurses to cope with emotional experiences, Boeije (1997) identified strategies that help nurses to avoid relations in which there is space for emotion (what I have been calling feeling). Avoidance practices limit the emotional depth of the relationship between caregiver and care receiver and thereby prevent nurses to be confronted with the emotions they would experience in such a relationship.

In addition to the organizing practices observed by Boeije (ibid), I described practices that I identified in the present research. These practices enable hospice workers to cope with emotional experiences in hospice work. In addition to these practices, I think we need to move one step further and look at discourse that makes these organizing practices intelligible (in the words of Hosking (2004) this is called act-supplement). But first I will present two stories that show that organizing practices described above are by themselves no guarantee for compassionate relations.

> Theresa I ask if there is time during the shift for reflection for volunteers:
>
> They debrief each other. And depending on the four persons that sits there it has a lot of this, or little. Because of course I hear everything in the distance [from the office in the hallway]. Than I think nha, is this really important, that uh, I believe there's missing something. *And* at other times there is more reflection. (Theresa, hospice coordinator: 10)[xxxi]
>
> Marie as she talks about the peer group meetings, she tells me that in her experience, her team members are rather closed as it comes to sharing emotions. In her own words:
>
> Uhm, and I notice that there is, there is not much openness within our team of nurses, that people find it difficult to make themselves vulnerable. (Marie, nurse: 5)[xxxii]

The explanation for this lack of 'openness' she finds in the regional culture that she thinks is rather focused on keeping emotions for oneself. But she adds to that an explanation that is very interesting in terms of medical discourse. For her explanation she describes a difference between her training in psychology and the medical training of the other hospice workers in her team:

> Yes psychiatry is largely nursing with your hands behind your back and here you have to go at it and that is a big difference.[xxxiii]

Here Marie makes a distinction between a focus on action or intervention (go at it) and a focus on mental reflection (nursing with your hands behind your back). A difference that is also emphasized by Kate as she describes:

> It are often people that work in health care, but at the moment that you work as volunteer, you have to hold your hands behind your back. You are really a volunteer; you are not allowed to perform any medical procedures. So you are not a caregiver, in that sense, not the way you are used to. So your professional mask, that you could put on when you came somewhere in the role of nurse, you have to leave that of now. Thus it makes you more vulnerable. And in that sense, feelings and emotions of others can affect you extra deeply. That is also what people like, because of that you can make soul contact, what I just said (..). (Kate, ex hospice coordinator: 15)[xxxiv]

Together these examples bring to our attention the importance of discourse. As I already noted about Tronto's (1993) concept of care, medical discourse makes a difference. It forms the resource that helps the caregivers to determine what has to be done and in which way. From the stories that are quoted above I take the idea that organizing practises that enable feeling have to be resourced by discourses that make them intelligible in a way that feeling becomes valid. Hosking (2004: 6-9) wrote about this as she explains the process of social construction, which involves 'act-supplements'. The acts, the practices as described above, have to be supplemented. In other words, the practices only enable feeling when supplemented by specific discursive recourses. In the following section I present some discursive resources and show how they supplement organizing practises.

… & discursive resources

Van Heist (2005) concludes that, historically (in the western world), care was motivated by the Christian notion of self-sacrifice. She refers here to care provided by nuns. They provided care out of religious duty, not out of compassion with another human being[60]. In this notion of self-sacrifice the ignorance of the personal identity of the caregiver is also embedded. The nun is in the first place a bearer of religious values instead of a unique individual. The self of the caregiver is dominated by the duty to provide care, to be in service of others. The Self is thus marginalized.

Van Heist notices that in the present, the idea of self-sacrifice has largely disappeared. Caregivers have become health care professionals. Taking care has become their job for which they receive an income. The identity of the caregiver in the role of professional is not necessarily the same as their identity during leisure time. During work, the professional role is fulfilled; free time is for fun, hobbies, passions, and thus the expression of identity. As Sandgren et al. describe:

> 'The nurses mentally distance themselves from emotional threats engendered by their work. Putting on the white working coat transforms the nurse into a different person. Because there are so many expectations to be met, this causes insecurity, and nurses therefore use their profession as a shield. "It's only a job, just like any other job." Taking off the white coat after the work shift is like cutting off emotions and lifting the problems away. Through this action, nurses become themselves again, perhaps with different values and a different philosophy of life.' (2006: 85)

In terms of compassion and care relations this means that engagement with the receivers of care is a professional one, not necessarily a personal one. The conventional idea of appropriate engagement is: engagement with professional distance[61]. There is engagement, but it should not go as far as to touch the "real" and private feelings of the caregiver. The caregiver is but a professional that acts rational and in accordance to the protocols of safety and the rules of efficiency. Personal and emotional engagement of the professional are believed to lead to emotional exhaustion or burn out. Van Heist[62] thinks this is problematic. According to her an attitude of professional

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[60] My reading of Van Heist's work is not that nuns did not have compassion, rather that the main motivation is religious duty. In individual cases nun could very well have compassionate relations with the people they cared for.

[61] In Dutch: betrokkenheid met behoud van professionele distantie. English speaking caregivers sometimes speak of "Healthy detachment" (Bruce & Boston 2008: 52).

[62] Leget and Baart have similar critiques (see Pijnenburg, Leget, Berden, (eds.), 2010).

distance does not reach the full meaning of care: to relate to another person in need. Van Heist finds an alternative in the *presence approach* as described by Andries Baart.[63]

The *presence approach* is based upon observations of the pastoral work in the deprived and disadvantaged neighbourhoods of large cities. The pastoral workers go into these neighbourhoods to get in relation with people that are in need of compassion. They visit people for whom all attempts of professional support and care have failed, people that have come to stand alone in life, people that no one is caring for any longer, like junkies for example, people that have become completely lonely. The pastoral workers try to engage with those persons. They try to be a sort of friend, a sort of friend that accepts the suffering of the other. They are willing and able to be close to that suffering, without the intention to change something about it. Especially the latter is important. The people that the pastoral workers relate to are people that have been living in difficult situations for a long time. Suffering has become part of the identity of those persons. To suffer is often the only thing that is still akin to the person. A relation that is focussed on changing the Other, on relieving the suffering would be a negation of the identity of the Other. Exactly a relation based on the acceptance of the suffering is a real acknowledgement of the other person.

In the presence approach, suffering is accepted; it does not have to be denied, or to be changed. The pastoral workers that take this approach try to accept suffering to the fullest, and try to engage with it. In the core, the presence approach is about the idea that persons that do not matter to anyone any more, do matter to the pastoral workers. The pastoral workers accept the Other as he/she is, without wanting to change their identity of which suffering has become a part. The suffering is still the suffering of someone else, but is felt *with* the Other. The pastoral worker is moved by the suffering of the Other. And that is what makes the relationship possible.

And precisely because the relationship is not based on an attempt to relief suffering, it makes change possible in some situations. Even if there is no change, that

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[63] Here I use Van Heist's work, Andries Baart published his ideas originally in: Baart, A. (2001) "*Een theorie van de presentie*", Lemma, Utrecht.

is not a problem, the Other is good enough as he or she is. The Other does not have to reach any potential other than he is willing and able to. If the other is full of pain and suffering, so be it, the other still matters to the pastoral worker. The theory of being present is not about *doing* something for the Other, it is about *being with* the Other, as a companion. In a relational constructionist way of saying, the presence approach is an attempt to construct relations in a way that is not goal-oriented.

The presence approach paints a discourse of non-intervention; doing nothing. Although action and intervention do have their own value, they can distract from being in relations ship with the other. In being present, feeling cannot be ignored. Confrontation with the Other cannot be escaped and masked by an attempt to do something; an attempt to relief suffering.

Is the presence approach a characteristic of some sublime caregivers? Van Heist (2005) places the presence approach within a discursive context. So although the pastoral workers that inspired Baart's writing might be fantastic caregivers, the presence approach should not be understood as action coming from within bounded individuals with specific capabilities embedded within them. Rather we should see that within a specific discursive context the presence approach becomes a legitimate script for action. Van Heist's (2005) description of context is identity at work (see also above). At present identity is separated from care giving, she argues. At work is where we do the thing we have to do, but closeness, emotional connections, affective relations are moved to the private sphere. How to (re)install the personal connection as part of work? With the use of Taylor (1989) Van Heist (2005) argues that we have to acknowledge that the work is part of our identity, it is part of who we are, but only a part, it is not all we are. Thus being involved (emotionally) in working life is not bad or dangerous.

This involvement however is different from the old discourse of self-sacrifice, it is involvement with a distinction between Self and Other. Both Self and Other are allowed to exist as emotional beings. The caregiver engages with the care receiver and "feels with".

Connected to Taylor's idea is the study of Karlsson, Ehnfors & Ternestedt (2008). In a narrative analysis of hospice nurses' stories identify the need of nurses to shield themselves of from death and sickness in their private live: '(..) be someone else when not working' (ibid 229). They did that by not thinking about work during leisure time or to focus on hobbies and sports. It is also in line with organizing practices described earlier in this chapter. The personal rituals and the possibility to take a time out can also be understood as a way to shield of death in private life. The time out can function to not be surrounded by death and sickness all the time.

To illustrate the argument made by Van Heist I present three narratives. The narratives illustrate how discourse informs the hospice worker's way of coping with emotions.

The first narrative is from Susan that tells me about palliative sedation and that it is a heavy event for the family of the guest (that is sedated). I asked if she thought it was a heavy event for herself as well and if it was something she talked about with colleagues. Susan acknowledged that it was a heavy event and that she finds support with her colleague because the nurses work mostly in a team of two. I follow her answer with the question if there are special moments or places where she talks about such matters.

> Dirk: And is there a place or a moment that you talk about these matters?
>
> Susan: Yes that is mostly during debriefings, or during coffee break, quickly with a cup of tee to the office to be able to talk about is, yes. I think it is very important to close it for myself and to discuss it before you get into the car or the bicycle on the way home, that you were able to. And than you can still think about it from time to time, but that is not a problem, because if you can fully cut yourself off, there has to remain some feeling he. That isn't like, hey we just do that and I don't care. No that's not possible. I always feel like, and I also say this to my husband, when I start talking like that I have to look for something else because that is just not right. It wouldn't be good for myself; I've got to have some feeling. And emotions are there sometimes as well. But that also depends on the situation, what you do at that moment. We've had a few weeks ago also a euthanasia. Yes and that is also very different from sedation. And that man, he had the same age as I have (..). He was a while, he was with us for eight weeks and uh, and he asked me if I wanted to be there. So that is different and the intern, also had good contact with him and she was like I want to be with him, be there. So than we were there with, we were both there. And the hospice doctor did, did it, the injection, because further there is nothing, well you look what he does, if the inlet of the drip is open, if - You know, those small things, they have to be looked at. (Susan, nurse: 9-11)[xxxv]

What this tells is that her orientation at the moment of euthanasia is directed to medical practices. She goes on:

> (..) because it happened very quietly, very beautiful, talking, uh, the way he was, he fell asleep at once, falls asleep first and than he dies. And I did not feel so many emotions at the time. But a few days later, there happened some things at home, and then at once everything came out. Eventually it will come, like. Then you think like how is that possible just like that, then you think it comes up, you have to digest it. It doesn't have to be at the moment itself, for example the intern did have it at the moment itself [**having to cry**]. Yes it is all right, that sort of things [**having to cry**]. But I didn't have to; I had it at a later time. You also think like: you have to be strong. You have to do things. All kind of things have to be done. You have to be there for the family. That is of course also the case. When you walk around here, completely in tears, yes, than people are going to comfort you, instead of the other way around. You can of course show some emotion, that is all right, but you have to remain professional as well. You have to, you can get tears in your eyes and show that you are touched. Of course. But completely loosing it, yes than you are of no use. (Susan, nurse: 9-11) [xxxvi]

Here we see the importance of orientation towards the medical practices. It helps her to take a distance from overwhelming emotions. The emotions come back to her at a later moment. The emergence of feeling is prevented when she draws on a intervention approach and centres medical issues: 'well you look at what he does, if the inlet of the drip is open, if… You know, those small things, they have to be looked at.' The quotations were not selected to argue that Susan's relation to the guest was without compassion. It is just an illustration of how emotional connections are being enabled and in this case how a caregiver can distance herself from the confrontation with the emotions that can be present in an event of euthanasia.

By *doing something*, suffering is kept at a distance. But as we can understand from the presence approach, the other is not always helped with this. Sometimes just being there is what the other needs most. And to be able to be there – to relate to the other (Leget 2010) – it is very important to know your own suffering and fears; otherwise it is impossible to relate to the feeling of the other because that would be overwhelming. My reading of Susan's narrative is supported by several studies:

The study by Whitmer et al. (2007) shows for instance how the introduction of a grieving cart literally gives space to grief in a cure environment. The cart that is introduced on an Intensive Care Unit contains drinks and pastries to enable the family of a patient to stay at the bedside for a longer time. Before the introduction, grief literally had no place in the care process and for nurses it was difficult to connect to the patients' families. With the card this changed and nurses felt they ware better able to give emotions, such as grief, a place in the process of care.

Another study is the one by Bruce & Boston (2008) they inquire the effect of increasing medicalisation of hospice work. From their study we can conclude that there is less possibility for nurses to connect to patients in ways that leave room for feeling when medical work takes up increasing attention form hospice workers and guests.

Also I like to refer back to the study by Sandgren et al. (2006) that shows how professional practices and professional identity (the white coat) can shield of from relations that enable feeling.

In contrast to the story by Susan, I would like to present two stories that construct a different discourse. I will argue that this different discourse can make intelligible the organizing practices that have been mentioned so that compassionate relations between caregiver and care receiver can exist (i.e. non- subject object relations).

Paul is a competent speaker. As a volunteer he has been working at a hospice for 5 years and just finished his studies to become a spiritual counsellor. The conversation we had is full of examples of organizing practices that help him to cope with the emotions he feels when engaging in emphatic relations with hospice guests. But besides these examples I think his narrative offers another message. His narrative reads as a learning path in which Paul has developed in an emotional and spiritual way. He tells me that he used to work in information technology. At a certain moment he got fired. At that moment he already wanted to do different work that involved people rather than machines and technique.

> Yes what can I do? And after a year I thought well (p) I am going to do what I have always planned to do, but what was very scary for me, really. And that was working in a hospice. (..) And well I was fascinated by death in a way, in that way that I was very scared of it. And maybe even now at times. But I was such afraid that I avoided everything that had to do with death. (..) And I just had the experience of the death of my father-in-law. And that had me, had me, in a sense it comforted me, because I experienced that I could let it imbue me. I didn't distance myself, I could relate to it. (Paul, volunteer: 1) [xxxvii]

Later on in the conversation the narrative continuous as Paul describes the start of his work in the hospice.

> And I still remember that in the beginning I was very tense, insecure. But(p) I was for the first time with a guest and that was very surprising, it all disappeared. Just doing it, being there, it felt immediately right. Ehm (p) Actually that feeling has always stayed, it is good that I am here, I, learn a lot, just, in fact it really is about that you get to know yourself. And…you find yourself in a situation where it does not matter any more what you know, and -- and how interesting you are. No you just have, just try to be yourself. And that is a beautiful learning process. And yes, it is good to know that you are developing, that you are not, are not. Yes everything goes with trial and error. Of course you will encounter difficult situations. (Paul, volunteer: 2) [xxxviii]

Several things strike me when reading this narrative. The first extract ends with 'I didn't distance myself, I could relate to it.' Paul talks about care for dying people, here his father in law, as being able to relate to death. Second, Paul talks about 'a beautiful learning process' (second extract) in relation to the ability to relate to dying persons. This makes relating a skill that has to be acquired. And the acquiring of the skill will go with 'trial and error' (second extract). Paul speaks of an appreciation of the difficulties and insecurities of learning to relate to hospice guests. We can imagine that such a discourse opens up the possibility for feeling.

What this narrative illustrates is that relating to the Other as well as relating to the Self are central for Pauls involvement in hospice work. It has been difficult for him to cope with the pain and despair he encountered as hospice worker. But clearly in his story is an acknowledgement that his own relation to death and his own fears for death are the obstacles that he has to overcome. Also central to the story is the acknowledgement that it is difficult to relate to someone else that is dying.

Following Paul, the story of Theresa is of relevance. In addition to Paul's narrative of development, Theresa constructs a similar discourse that puts development and learning at the centre. Theresa is hospice coordinator at a hospice she worked for from the very start of the organization. The next extract comes from the end of a section of the conversation that started with my question about the start-up of the hospice. Theresa tells about the first group of volunteers that were trained and the opening of the hospice. In the beginning, volunteers were obliged to call the coordinator (Theresa or her colleague) first before contacting a doctor. The doctors in the region were afraid that the new hospice would cost them a lot more work then the situation of home care. To be able to control the instances in which the help of a doctor was called in, volunteers had to call the coordinator first.

> Well, slowly but surely it turned out to work and we thought, yes it is nonsense to be in between [**the volunteers and the doctors**] all the time. They can do it well. They work in pairs mostly so there is someone they can ask: what do you think of it, shall we [**call a doctor**]. *And* than they call. Thus we have to let go of that. Uh, in the end personally I think that all people here, we have three guests at a time, they have to let go, they have to let go of their lives, and *everybody* around them, us as well, whether we are paid or not, we have to let go too. And I think it's right that way. Because it can't be that in such a small place there are three persons that have to let go of everything and the rest seems to be in control, I don't think that's right. If you are in the same mode, than you talk about the same thing. But I have to learn to let go of something else than you have. *And* that man that was sitting at the table, he has to let go of something else. And that's were the opportunities are to grow, and we see that happing with the volunteers very often, that is really nice [to see]. (Theresa, hospice coordinator: 3-4)[xxxix]

Theresa develops a discourse in which hospice workers are not differentiated from the guests in the sense of relating to the self. She sketches a picture of personal, emotional or spiritual growth that is central to all persons involved in the hospice, whether it are the guests, the family, the nurses or the volunteers. Theresa goes on:

> And everybody thinks at the start, well this will not happen to me [**to lose control**], and everybody will encounter something and say:" I didn't expect this to happen, but actually it is an unresolved issue", and that is touched in this situation, or it is brought into motion and a step forward can be made. Yes personally I enjoy when that happens. (..)Betty [colleague] and I, we are, to clean the channel in case of repetition. And that's were those moments are of [inner] silence sometimes, and sometimes insight. It is very important. And sometimes also, yes leave it, you blame someone else, you for example think someone is demanding, take the time to look at yourself and see what it is [within yourself] that the other makes you feel this way. (Theresa, hospice coordinator: 7)[xl]

Theresa here illustrates that engaging in relationships with people that suffer is a difficult thing to do. It is something in which the caregiver is confronted with pain and fears within oneself. It is also something that cannot be controlled. One will find the point at which this confrontation becomes to much. But that is not a failure; it is a learning experience that helps to develop one's own emotional end spiritual path.

The narratives of Theresa and Paul connect to a study by Karlsson, Ehnfors & Ternestedt (2008). They analysed hospice nurses' feelings towards death and dying.

After two rounds of interviews with an interval of eleven years they concluded that death had become less threatening, and more an accepted part of life for the nurses. While in the first[64] interviews death triggered existential questions and an awareness of mortality, in the second round of interviews, working with sick and dying people was characterized as a source of personal and professional growth. From this we can infer that a discourse that constructs the confrontation with sickness and death as a source of learning helps hospice workers to relate to guests in a way that leaves room for feeling.

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[64] At the time of the first interviews, the nurses had two ears working experience in a hospice.

Chapter 8. Speaking to the organization studies literatures, (brining in the language of compassion)

So far I have not connected the empirical material to any concepts or theories form the field of O-S. In chapter 5 and 6 I have attempted to construct a context of hospice work and a discourse on quality of care. Necessarily the context I constructed is my interpretation (act – supplement) of the conversations with hospice workers. The quotations from the conversations are meant to illustrate the connections between the conversations and theories by Tronto (1993) and Leget (2010). What is constructed is a discourse on (health) care that was labelled *an ethical perspective* and is in line with the relational construtionist thought style.

I felt it was necessary to construct the context that chapter 5 and 6 provide to understand anything that the participants told me about how feeling get a place in hospice work and what hospice workers experience as limiting or enabling for sharing emotions.

Following chapter 5 and 6, chapter 7 discusses some organizing practices that hospice workers experience as enabling or limiting for dealing with emotions in their work. Following examples of such organizing practices, the discussion went on to argue that such organizing practices only “work” if they are made intelligible by discourse. The presence approach was introduced to show what it would mean if a organizing practice actually “works”. The presence approach provides a frame that helps us to see what it might mean to ‘*engage with the other*’ (Leget 2010). Than the narrative of Susan presented an example in which a hospice worker was not able to supplement an emotional event – the euthanasia of a guest she got familiar with – with the result that her emotions were kept at a distance by focussing on *doing things*, in this case checking if the infuse inlet was open. Chapter 7 ended with two narratives that presented a discourse which makes intelligible organizing practices that enable hospice workers to cope with emotional experiences.

Now in this chapter the narratives and theories are connected with O-S literatures. In chapter 3 different theories and concepts from O-S were discussed. From those different concepts compassion seems most relevant. As I will argue in this chapter, the concept of compassion connects to all the diverse interests that informed the present research, and the many arguments that were made.

Second, I will argue that compassion is a useful concept but can be elaborated/refined/expanded on bases of the empirical materials as presented in chapter 7.

Compassion, (the review)

In chapter two, compassion was briefly introduced; here I will review some of the O-S literatures on compassion more extensively.

The Latin roots of the English word compassion are “com” and “passio”. Passio means to suffer and the prefix “com” means together. The meaning of compassion is than *to suffer together.* Besides it’s role in various religions, compassion has been the subject of some recent O-S literatures. The meaning that scholars have given to compassion in the context of organization is discussed. After that I will discuss how the meaning of compassion can be changed based on the presence approach and the empirical material of the present research.

In the definition by Clark (1997), compassion consists of three elements: noticing, feeling and responding.

1. To be compassionate with someone we first have to notice the pain and despair of that other person. To notice the pain of someone else requires openness towards other’s emotions and often involves reading subtle cues (Frost 2003). People notice the suffering of others more easily when that other person is similar to themselves, or when they have experienced a similar pain (Clark 1997). To notice pain in another person means that you have to be able to imagine for yourself what it must be like. This brings us also to the second element of compassion: feeling.

2. The meaning of compassion is *to suffer with* (von Dietze & Orb 2000; Solomon 1998). To feel compassion towards another person we have to put ourselves in that other person’s position. Nussbaum calls this *‘imaginative reconstruction of the experience of the sufferer* (2001: 327).’ It seems logic therefore that Clark (1997) claims

that we notice pain and suffering in other persons more easily if they are alike, or if we've experienced the pain ourselves. It is easier to identify with someone that is similar to ourselves or to imagine his pain when we've experienced such pain ourselves.

3. Noticing en feeling are reflected in a response to the suffering and pain. This response can be as diverse as holding someone's hand to giving money. The response is meant to elevate the suffering or make the pain more bearable (Kanov et al. 2004).

> Rinpoche explains, '[**compassion**] is not simply a sense of sympathy or caring for the person suffering, not simply a warmth of heart toward the person before you, or a sharp recognition of their needs and pain, it is also a sustained and practical determination to do whatever is possible and necessary to help alleviate their suffering.' (1992: 187)
>
> 'Compassionate responding may or may not be instrumental in fixing or correcting the immediate cause of one's suffering. For example, holding someone's hand as she talks about the painful process of caring for her terminally ill father can be just as compassionate as giving money to someone who incurs unexpected medical expenses.' (Kanov et al., 2004: 11)

Organizational compassion.

Kanov et al. (2004) see compassion as a relational concept, not as an individual characteristic. Individuals in their view are not compassionate or un-compassionate, rather compassion can emerge in a situation that allows people to notice, feel, and respond to the suffering of others. This concept of compassion fits with the relational constructionist thought style that is discussed in chapter 2. It opposed entitative thinking that would construct individuals as either being compassionate or uncompassionate. Kanov et al. (ibid) speak of organizational compassion when noticing, feeling and responding happens in a coordinated way within an organizational setting.

> '(..) organizational compassion involves a set of social processes in which noticing, feeling, and responding to pain are shared among a set of organizational members.' (Kanov et al. 2004: 15)

This means that for example for the sub-process of noticing:

> 'Collective noticing is not simply a matter of multiple people within a social system independently recognizing another person's pain. Rather, it refers to a collective acknowledgement of pain within a social system such that individuals within the system have a shared appreciation that pain is present.' (Kanov et al. 2004: 15)

Organizational compassion can emerge when organizations allow for coordination of noticing, feeling and responding, when compassion is legitimized and promoted within the organization. According to Kanov et al. (ibid) compassion is legitimized and encouraged through organizational values and routines. Great importance is ascribed to leaders that set positive examples of compassion and organizational practices that stimulate members to talk about personal or non-work issues (see also Dutton et al. 2006; Lilius et al. forthcoming a; Lilius et al. forthcoming b).

Lilius et al. (forthcoming a) studied a unit within a health care system that was identified by its management as particular compassionate. The focus of the research was on organizing practices and what they achieved. The authors identified a set of seven practices that achieved two relational conditions that in turn enabled compassion between the members of the organization[65]. High quality connections are claimed to help members to notice changes in one another's condition and contribute to identification with the group. This makes it more likely that the suffering of one of the organizational members is noticed, and makes it more likely that people are willing to devote time and energy to each other in the face of suffering (ibid: 19). Second, a dynamic boundary-permeability norm is believed to legitimate people to share personal and non-work-related issues amongst each other (ibid 20).

In another publication Lilius et al. (forthcoming b) claim that compassion can be institutionalized in an organization through formal roles and programmes such as an ombuds person or peer group meetings.

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[65] The practices that Lilius et al. (forthcoming a) identified are: Acknowledging, Addressing problems directly, Bounded playing, Celebrating, Collective decision-making, Help-offering, Orienting.

Why compassion is a useful concept.

Until now it has been left implicit why compassion would be a useful concept. In my analysis of feeling, I have used hospice work as a site for inquiry. And hospice work was placed in a context of quality of care (chapter 6). It was argued that care has quality when caregivers relate to Self and Other. The concept of compassion is very much in line with that idea:

> 'In understanding that ethical nursing practice happens through engagement, we are compelled to believe that compassion is the truest response to suffering. This is suggested as the most essential ingredient in working with people, both individuals and whole families, at the end of life. (..) A commitment to relational ethics as an underlying framework for palliative care nursing does not deny the usefulness of normative theory in approaching moral dilemmas but rather situates openness to others as the beginning of our ethics and locates relationship as the primary focus of our moral attention.' (Wright et al. 2009: 225)

This quote connects the concept of compassion to both hospice work as well as to relational constructionism. It is argued that compassion is 'the most essential ingredient' for ' end of life care' and relating is made the 'primary focus'. Of moral attention for hospice workers that provide care. In my reading this quote also connects to the work of Baart (2001). The words 'openness to others as the beginning of our ethics' seem be in line with the presence approach in which it is important to accept the Other as he or she is; not wanting to change the Other. This is, I believe, to be similar to 'openness to others'. The connection between compassion and the presence approach is further discussed in the section below.

A new reading of the concept

The concept of compassion in its current use connects to the relational constructionist thought style because it presents a relational view of emotions. The concept does not specify particular emotions and it presents emotion as emergent in relations, just as the present research does with the concept feeling (see chapter 6 & 7). However, based on the discussion of how feeling emerges in relating (chapter 7) the concept of compassion could be redefined. In the light of what is discussed in chapter 6 and 7 there are two shortcomings in the current use of the concept of compassion. First compassion seems to re-construct an intervention approach opposed to a presence approach. Second, in the studies discussed above (Kanov et al. 2004; Dutton et al 2006; Lilius et al. forthcoming a/b) compassion seems to spontaneously arise in the face of suffering when organizing practices allow for it. I think such an idea misses the importance of what Hosking (2004) calls *multiple co ordinations* that are at play when an act is supplemented. Thus the act of suffering is only supplemented by compassionate responses if multiple co ordinations make such responses intelligible. Here I will discuss both shortcomings in greater depth.

Why do I read the current compassion articles as a re-construction of an intervention approach? The examples of compassion that are presented always speak of taking over work tasks, raising money for people that have lost their belongings in a tragic event etc. Dutton et al. (2006) for example speak of 'resource allocation' in regret to compassionate acts. Connecting this to the stories by Susan and Paul *and* the presence approach that were discussed in chapter 7, compassion seems to be very much about intervention.

Very similar to the foregoing, but even deeper, the current use of compassion can be criticized to be blind for presence. The goal of palliative care is to relieve suffering. But suffering is part of the human condition. It is said to be in a dialectical relation to joy, and as such cannot be eradicated (Wright et al. 2009: 220). This creates a paradox:

> How can we commit ourselves to genuinely respond to the suffering [**third element of compassion**] of our clients while remaining respectful of the grief and sorrow that quite naturally constitute a significant portion of our clients' journeys through death and dying? (..) While it may sound simple to suggest that compassion serve [**sic**] as the underlying moral foundation to guide our response to suffering, true compassion actually requires great courage. It involves being open and available to suffer with, instead of recoiling from the suffering experience.(ibid)

From the quotation above I want to discuss two things.

First very implicitly the authors argue that a presence approach can overcome the paradox when they write 'remaining respectful of the grief and sorrow (..) It involves being open and available to suffer with'. The moral responsibility shifts from relieving suffering to feeling with the Other. This argument is similar as what Baart (2001) and Van Heist (2005) write about the presence approach. Presence is about *being with* the Other that suffers. It was put in opposition to *intervention* which is about *doing things* in an attempt to alleviate suffering. *Intervention* is here understood as shielding behind medical practices in order to remain distanced form the suffering Other; an attempt to stay distanced from the confrontation with emotion.

In connection to the narratives presented in chapter 7, I argue that *responding* as third aspect of compassion should not be understood as *intervention*, but as *presence*.

Secondly, the quote mentions 'true compassion actually requires great courage', something that resonates with the narratives of Paul and Maria (see chapter 7, p. 104-7). When we accept presence as third aspect of compassion, it opens up attention for an aspect that seems to be lost in the recent publications about compassion. Courage and competence seem to have disappeared after Frost (1999) brought attention to the concept of compassion in the O-S literatures. Compassion seems to be a spontaneous result of "compassion capability" (Lilius et al. forthcoming a). Such a view however hides the discursive context (multiple co ordinations) in which compassion takes emerges. To stay in relation to suffering without being able to alleviate it asks both courage as we saw in Pauls narrative, and competence or skill that has to be learned as became clear in Maria's narrative.

In this chapter compassion was introduced as a meaningful concept that can connect the narratives of feeling (chapter 6 & 7) to the O-S literatures. But bringing the narratives in contact with the concept also made visible a lack in the contemporary use of compassion. Therefore it was argued to change the understanding of compassion from intervention to presence. Relating to Other in a way that allows for feeling to emerge than becomes the essence of compassion. This new meaning of compassion also brought back some "old" concerns of compassion: courage and competence. Connecting these concerns to the narratives of chapter 7 deepened the insight of how compassion is enabled.

Implications for practitioners.

The postmodern or relational constructionist thought style holds that no ready-made solutions or guidelines are available for practitioners. No standard method that assumes control and expresses an economic input-output/means-goal rationality can help when we want more feeling or compassion in our organizing practices. To enable feeling and stimulate compassion, spontaneity and ambiguity need to be central in organizing.

That no ready-made solution is available does not mean that no lessons can be learned from this the present inquiry. First of all, I would encourage every reader to draw his or her own lessons from the empirical material present in this text. My analysis of the material is but one (local, historical) reading and you might have your own reading that might be more valuable to you.

Following my reading, lessons that can be drawn from the present research are:

1) Organizing should allow for insecurity and learning processes. Emotional overload should no longer be considered a professional failure, but a source of learning. To be able to relate to the Other, hospice workers should be supported to relate to the Self. Chapter 7 contains a whole range of organizing practices that enable feeling in organizing. These practices could be "implemented" or adopted in other organizations, or by other caretakers. One should note that any of the practices should not be considered as a ready-made solution. To become meaningful, practices are supplemented by multiple co ordinations. Therefore careful attention should be paid to language practices that render a practice legitimate and meaningful or illegitimate and meaningless. To relate to the Self, practitioners could also turn to various (psychoanalytical) therapies and meditative practices such as mindfulness.

2) Another consideration that has to be taken into account is the degree to which medical treatment is part of hospice work. Although I do NOT argue that hospice guests should be refused medical treatment, it is important to acknowledge that medical interventions limit feeling in organizing and prevent guests to prepare for a "good" death.

3) Language is a very important form with which we create reality. *What* language we use will effect *how* hospice work is constructed. During the writing process of this thesis I presented the research to a group of hospice workers. One of them told me that she missed the language to talk about what she thought was most important in her work and what I have called *feeling*. I hope this thesis (at least partially) answers to the need for a new language. But a lesson we could take from this is that in organizing attention should be paid to language use: “Who’s language do we use?”, and “How do those words make us feel?”. One way to achieve attention for language use could be storytelling. Practices as debriefing and voluntary evenings enable storytelling to some extend, but practicalities take up much of the time. New ways could be developed to share stories, either through telling or writing to make storytelling an integral practice of organizing.

Bibliography

Alvesson, M. Deetz, S. (2000). *Doing critical Management research*. London: Sage Publications.

Ashkanasy, N.M., Härtel, C.E.J., Zerbe, W.J., (eds.). (2000). *Emotions in the workplace: research, theory, practice.* West Port, USA: Quorum Books.

Bakken, T. & Hernes, T. (2006). Organizing is Both a Verb and a Noun: Weick Meets Whitehead. *Organization Studies,* 27.

Baart, A. (2001). *Een theorie van de presentie.* Utrecht: Lemma.

Banister, P., Burman, E., Parker, I., Taylor, M., Tindall, C. (1994). *Interviewing*. In Banister et al. *Qualitative Methods in Psychology: A Research Guide*. Buckingham: OUP.

Barrett, F.J., Thomas, F.G., Hocervar, S.P. (1995). The central role of discourse in large-scale change: a social construction perspective. *Journal of applied behavioural science*, 31 (3): 253 – 388.

Benton, T. & Craib, I. (2001). *Philosophy of social science: the philosophical foundations of social thought*. New York: Palgrave.

Boje, D. M. (2001). *Narrative Methods for Organizational & Communication Research*. London: Sage Publications Ltd.

Boeije, H. 2010. *Analysis in qualitative research.* London: Sage Publications Ltd.

Boeije, H.R., Nievaard, A.C. & Casparie, A.F. (1997). Coping strategies of enrolled nurses in nursing homes: shifting between organizational imperatives and residents' needs. *International Journal of Nursing Studies*, 34(5): 358-366.

Bolman, L.G., Deal, T.E. (2003). Reframing Organizations: artistry, Choice and leadership. San Francisco: Jossey-Bass.

Bruce, A. Boston, P. (2008). The changing landscape of palliative care emotional challenges for hospice palliative care professionals. *Journal of Hospice and Palliative Nursing*, 10(1), 49 55.

Brunsson, N. (2006). *Mechanisms of Hope: Maintaining the Dream of the Rational Organization*. Copenhagen: Copenhagen Business School Press.

Burrell, G., & Morgan, G. (1979). *Sociological Paradigms and Organizational Analysis: Elements of the Sociology of Corporate Life*. London: Heinemann.

Cameron, K.S. (2008). Paradox in Positive Organizational Change. *Journal of Applied Behavioral Science*, 44(1), 7-24.

Chia, R. (2003). Organization Theory as a Postmodern Science. In Tsoukas, H., & Knudsen, C. (Eds.), *The Oxford Handbook of Organization Theory* 113-140. Oxford: Oxford University Press.

Chia, R., King I.W. (1998). The organizational structuring of novelty. *Organization*, 5(4), 461-478.

Chia, R. (1996). *Organizational analysis as deconstructive practice*. Berlin: De Gruyter.

Clark, C. (1997). *Misery and company: Sympathy in everyday life.* Chicago: The University of Chicago Press.

Clark D. (2002). Between hope and acceptance: the medicalisation of dying. *British Medical Journal, 324, 905–907.*

Clegg, S.R., Kornberger, M., Rhodes, C. (2005). Learning/Becoming/Organizing. *Organization,* 12(2), 147-167.

Coffey, A., & Atkinson, P. (1996) Chapter 2: Narratives and stories. In *Making sense of qualitative data*. London: Sage Publications.

Cruikshank, J. (1990). *Life Lived Like a Story*. Vancouver: University of British Columbia Press.

Czarniawska, B. (2008). *A Theory of Organizing*. Cheltenham: Edward Elgar Publishing Limited.

Czarniawska, B. (2001). Narrative, interviews, and organizations. In Jaber F. Gubrium and James A. Holstein (Eds.), *Handbook of Interview Research: Context & Method*. Thousant Oaks: Sage Publications.

Czarniawska, B. (1998). *A narrative approach to organization studies*. Thousant Oaks: Sage Publications.

Deetz, S. 2000. Describing differences in approaches to organization science. In Peter J. Frost, A. Y. Lewin, R.L. Daft (Eds.), *Talking about Organization Sciences* (pp. 123-152). Thousand Oaks: Sage Publications.

Domagalski, T.A. (1999). Emotion in Organizations: main currents. *Human Relations,* 52(6), 833-852.

Dutton, J.E. Worline, M.C. Frost, P.J., Lilius, J.M. (2006). Explaining compassion organizing. *Administrative Science Quarterly*, 51(1), 59–96.

Fineman, S. (2006). On being positive: Concerns and counterpoints. *Academy of Management Review*, 31(2) 270-291.

Fineman, S. (2004). Getting the measure of emotion – and the cautionary tale of emotional intelligence. *Human Relations*, 57(6), 719-740.

Fineman, S. (Ed.), (2003). *Understanding emotion at work.* London: Sage Publications.

Fineman, S. (Ed.), (2000). *Emotion in Organizations* (second edn.). London: Sage Publications.

Fineman, S., Gabriel, Y. (1996). *Experiencing organizations*. Thousand Oaks: Sage Publications.

Fineman, S. (Ed.), (1993). *Emotion in Organizations* (first edn.). Sage Publications: London.

Flyvbjerg, B. (2001). *Making social science matter: why social inquiry fails and how it can succeed again*. Camebridge: Camebridge University Press.

Frost, P. J. (2003). *Toxic emotions at work: How compassionate managers handle pain and conflict.* Boston: Harvard Business School Press.

Frost, P.J., Dutton, J.E. & Worline, M.C. (2000) Narratives of compassion in organizations. In Fineman, S. (Ed.), *Emotion in organizations* (25-45). London: Sage Publications.

Frost, P. J. (1999). Why compassion counts!. *Journal of Management Inquiry*, 8(2) 127-33.

Gabriel, Y. A. (2000). *Storytelling in organizations: Facts, fictions, and fantasies*. London: Oxford University Press.

Gergen, K.J. (1999). An invitation to social construction. London: Sage Publications.

Gergen, K.J., Thatchenkery, T. (2006). Organizational Science and the Promises of Postmodernism. In Hosking, D.M. and McNamee, S. (eds.), *The Social Construction of Organization* (pp. 34-51). Ljubljan: a Liber & Copenhagen Business School Press.

Glynos, J., Howarth, D. (2007). *Logics of Critical Explanation in Social and Political Theory*. Oxon: Routledge.

Hardy, C., Phillips, N., Clegg, S.R. (2001). Reflexivity in organization and management theory: a study of the production of the 'research subject'. *Human Relations*, 54(5) 531-60.

Harris, M. (1975). *Cows, Pigs, Wars and Witches*. New York: Vintage Books.

Heist, A. van. (2005). *Menslievende Zorg: een ethische kijk op professionaliteit*. Kampen: Klement.

Hosking, D.M. (2011). Telling tales of relations: Appreciating relational constructionism. *Organization Studies*, 32(47), 47-6.

Hosking, D.M., McNamee, S. (Ed.s). (2006). *The Social Construction of Organization.* Lubjana: Liber & Copenhagen Business School Press.

Hosking, D.M. (2004). Change works: A critical construction. Ch. 12 in Boonstra, J., ed. Dynamics of Organizational Change and Learning. Chichester: Wiley.

Hosking, D.M, Dachler, H.P., Gergen, K.J. (*1995). Management and Organization: relational alternatives to individualism.* Avebury: Aldershot.

Hosking, D.M., Morley, I.E. (1991). *A social psychology of organizing : people, processes and contexts*. New York: Harvester Wheatsheaf.

Howarth, D. (2000). *Discourse*. Open University Press.

Iedema, R., Degeling, P., Braithwaite, J. & White, L. (2004). It's an Interesting Conversation I'm Hearing': The Doctor as Manager. *Organization Studies,* 25(1), 15-33.

Jansen, T., Brink, G., Klase, J. (2010). *Professional Pride - A Powerful Force*. Amserdam: Uitgeverij Boom.

Laclau, E., Mouffe, C. (1985). *Hegemony & Socialist Strategy*, London: Verso.

Kanov, J., Maitlis, S., Worline, M.C., Dutton J.E., Frost, P.J., Lilius, J.M. (2004). Compassion in organizational life. *American Behavioural Scientist, 47(6), 808-827.*

Källström Karlsson I.J., Ehnfors, M., Ternestedt, B. (2008) Five nurses' experiences of hospice care in a long-term perspective. *Journal of hospice and palliative nursing,* 10(4), 224-32,

Kotter, J.P. (1996). *Leading Change.* Boston: Harvard Business School Pres.

Kvale, S. (2006). Dominance through interviews and dialogues. Qualitative *Inquiry,* 12(3), 480-500.

Laseke, D.R., Kusenbach, M. (2008). The social construction of emotion (511-30). In Holstein, J.A., Gubrium, J.F. (Eds.), *Handbook of Constructionist Research*. New York/ London: The Guilford Press.

Latham,G.P. (2007.) *Work motivation: history, theory, research and practice.* London: Sage Publications.

Law, J. (1994). *Organizing modernity*. Oxford: Blackwell Publisher.

Leget, C. (2010). Kwaliteit in de zorg: een zorgetisch perspectief. In Pijnenburg, M., Leget, C., Berden, B. (Eds.), *Menslievende zorg, management en kwaliteit*. Nijmegen: Uitgerij Damon Budel.

Lilius, J.M., Worline, M.C., Maitlis, S., Kanov, J., Dutton J.E., Frost, P.J. (2008). The contours and consequences of compassion at work. *Journal of Organizational Behavior*, 29(2), 193–218.

Lilius, J.M., Worline, M.C., Dutton J.E., Kanov, J., Maitlis, S., Frost, P.J. (forthcoming a). Understandng compassion capability. *Human Relations.* accessible on: http://www.compassionlab.org/publications.htm

Lilius, J.M., Kanov, J., Dutton J.E., Worline, M.C., Maitlis, S. (forthcoming b). Compassion revealed: what we know about compassion at work and (where we need to know more). In K. Cameron & G. Spreitzer, (Eds.), *The Handbook of Possitive Organizational Scholarship*. Oxford: Oxford University Press.

Lobb, E.A. Oldham, L. Vojkovic, S. Kristjanson, L.J. Smith, J. Brown, J.M. Dwyer, R.J.W. Couns, M. (2010). Frontline grief: the workplace support needs of community palliative care nurses after the death of a patient. *Journal of Hospice and Palliative Nursing,* 12(4), 225-33.

Marin, R. (1988). Truth, power, self: an interview with Michel Foucault, Oktober 25, 1982. In *Technologies of the Self: A Seminar with Michel Foucault*', Amherst: University of Massachusetts Press.

Martin, J., Knopoff, K. & Beckman, C. (2000) Bounded emotionality at the body shop. In Fineman, S. (Ed.), *Emotion in Organizations* (second edn.) (115-139). London: Sage Publications.

Mastenbroek, W. (2000). Organizational behavior as emotion management. In Ashkanasy, N.M., Härtel, C.E.J., Zerbe, W.J. (Eds.), *Emotions in the workplace: research, theory, practice*. West Port: Quorum Books.

Maxwell, J.A. (2005). *Qualitative research design: an interpretative approach* (second edn). Thousand Oaks, California: Sage Publications Inc.

McNamee, S. (1994). Research as Relationally Situated Activity: Ethical Implications. *Journal of Feminist Family Therapy*, 6 (3), 69-83.

Meyerson, D.E. 2000, "If emotions were honoured: a cultural analysis (167-183). In Fineman, S. (Ed.), *Emotion in Organizations* (second edn.) (115-139). London: Sage Publications.

Monin, N. and Monin, J. (2003). Re-navigating management theory: steering by the star of Mary Follet. In B. Czarniawska and P. Gagliardi (eds.), *Narratives We Organize By*. Amsterdam: Jhon Benjamins Pubilshing Company.

Morgan, G. (2006). *Images of organization*. Thousant Oaks: Sage Publications, Inc.

Morse, P.A., Field, J.M. (1996). Principles of data analysis. In Morse, P.A., Field, J.M. (Eds.), *Nursing Research: The Application of Qualitative Approaches*. Cheltenham: Stanley Thorns Ltd.

Mumby, D.K. & Putnam, L.L. (1992) The politics of emotion: a feminist reading of bounded emotionality. *Academy of Management Review*, 17(3), 465-86.

Nikander, P. (2008). Constructionism and discourse analysis. In Holstein, J.A., Gubrium, J.F. (Eds.), *Handbook of Constructionist Research*", New York/ London: The Guilford Press.

Nussbaum, M. C. (2001). *Upheavals of thought: The intelligence of emotions.* Cambridge: Cambridge University Press.

Ollilainen, M. (2000). Gendering emotions, gendering teams: construction of emotions in self-managing teamwork. In, N.M. Ashkanasy, C.E.J. Härtel & W.J. Zerbe, (Eds.), *Emotions in the workplace: research, theory, and practice* (82-96). Westport CT: Quorum Books.

Potter, J., Hepburn, A. (2008). Discursive constructionism. In Holstein, J.A., Gubrium, J.F. (Eds.), *Handbook of Constructionist Research*. New York/ London: The Guilford Press.

Punch, K.F. (1998). *Introduction to social research: quantitative and qualitative approaches*. London: Sage.

Ricoeur, P. (1983). The narrative function. In Thompson, J.B. (trans), *Hermeneutics and the human sciences: Essays on language, action and interpretation* (274-299). Cambridge, UK: Cambridge University Press.

Riessman, C.K. (2008). *Narrative methods for the human sciences*. Thousand Oaks: Sage publications.

Riessman, C. K. (2001). Analysis of personal narratives. In Jaber F. Gubrium and James A. Holstein (eds.), *Handbook of Interview Research: Context & Method*. Thousant Oaks: Sage Publications.

Riessman, C. K. (1993). *Narrative Analysis*. London: Sage Publications.

Rinpoche, S. (1992). *The Tibetan book of living and dying.* London: Rider Books.

Robichaud, D. (2003). Narrative institutions we organize by: the case of a municipal administration. In Barbara Czarniawska and Pasquale Gagliardi (Eds.), *Narratives We Organize By*. Amsterdam: Jhon Benjamins Pubilshing Company.

Salovey, P., Mayer, J.D. (1990). Emotional intelligence. *Imagination, Cognition and Personality*, 9(3), 185-211.

Sanderlands, L.E. & Boudens, C.J. (2000) Feeling at Work. In Fineman, S. (Ed.), (2000). *Emotion in Organizations* (second edn.). London: Sage Publications.

Sandgren, A., Thulesius, H., Fridlund B., Petersson, K. (2006). Striving for emotional survival in palliative cancer nursing. *Qualitative Health Research* , 16(1), 79-96.

Saussure, F. (1983), *Course in General Linguistics*, Chicago: Open Court

Schachter, S., Singer, J.E. (1962). Cognitive, social, and psychological determinants of emotional state. *Psychological Review*, 69(5), 379-99.

Scott, P.A. (2000). Emotion, moral perception, and nursing practice. *Nursing Philosophy*, 1, 123–33.

Searle, J.R. (1995) *The construction of social reality*. London: Penguin Books.

Simpson, B., Marshall, N. (2010). The mutuality of emotions and learning in organizations. In *Journal of Management Inquiry* , 19(4), 351- 65.

Sødenberg, A.M. (2003). Sensegiving and sensemaking in an integration process: a narrative approach to the study of an international acquisition. In Barbara Czarniawska and Pasquale Gagliardi (Eds.), *Narratives We Organize By*. Amsterdam: Jhon Benjamins Pubilshing Company.

Solomon, R. C. (1998). The moral psychology of business: Care and compassion in the corporation. *Business Ethics Quarterly, 8*, 515-33.

Sparkes, C., Smith, B. (2008). Narrative constructionist inquiry. In Holstein, J.A., Gubrium, J.F. (Eds.), *Handbook of Constructionist Research*. New York/ London: The Guilford Press.

Stenner, P. and Eccleston, C. (1994). On the Textuality of Being: towards an invigorated social constructionism. *Theory and Psychology*, 4(1), 85-103.

The, A. (2007). *Naast de stervende patient: beslissen over palliatieve edatie, eathanasie en morfine*. Houten: Bohn Stafleu van Loghum.

Tiedens, L.Z. (2000). Powerful emotions: the vicious cycle of social status position and emotions. In N.M. Ashkanasy, C.E.J. Härtel & W.J. Zerbe, (Eds.), *Emotions in the workplace: research, theory, and practice* (71-81). Westport CT: Quorum Books.

Weick, K.E. (1993). The collapse of sensemaking in organizations: The Mann Gulch disaster. *Administrative Science Quarterly*, 38(4),628-52.

Weick, K.E. (1969). *The social psychology of organizing*. Massachusetts: Addison-Wesley, Reading.

Whitmer, M. Hurst, S. Stadler, K. Ide R. (2007). Caring in the curing Environment: the implementation of a grieving cart in the ICU. *Journal of Hospice and Palliative Nursing,* 9(6), 329-33.

Wittgenstein, L. (2001). *Philosophical Investigations* (third edn.). Oxford: Blackwel.

Woodilla, J., Forray, J.M. (2008). Justice and the political in organizational life: a narrative inquiry. *Journal of Management Inquiry,* 17(1), 4-19.

Woolgar, S. (1996). Psychology, qualitative methods and ideas of science. In Richardson, J.T.E. (Ed.), *Handbook for qualitative research methods for psychology and the social sciences* (11-25). Leicester: BPS publications.

Wright, D.J. (2001). hospice nursing: THE SPECIALTY. *Cancer Nursing* 24(1), 20-27.

Wright, D. Brajtman, S. Bitzas, V. (2009). Human relationships at the end of life: an ethical ontology for Practice. *Journal of Hospice and Palliative Nursing,* 11(4), 219-227.

Von Dietze, E., Orb, A. (2000). Compassionate care: A moral dimension of nursing. *Nursing Inquiry*, 7(3), 166-174.

Yanow, D. (2003). *Constructing "Race" and "Ethnicity" in America: Category-Making in Public Policy and Administration*. New York: M.E. Sharpe, Inc.

Web sources and rapports:

All web sources visited between 4th and 6th of March 2011.

http://www.agora.nl
www.buddhisthospice.org.uk
www.chanshomehealthcare.com

www.hospicedeliefde.nl

www.hospicefdw.nl

www.issoria.nl

www.kuria.nl

http://www.who.int/cancer/palliative/definition/en/

www.stichtingstem.info

www.transmuraalnetwerk.nl

www.vptz.nl

www.en.wikipedia.org

- Agora (2010) “Spirituele zorg: verbindende schakel in palliatieve zorg”. Bunnink, The Netherlands. Rapport can be found on www.agora.nl
- Pluut, H. (2008) “*Stervensbegeleiding door hospices Een webonderzoek voor Hospice ‘de liefde’*, the rapport can be found at: www.hospicedeliefde.nl > hospice > publicaties.
- Van der Lee, M., Martens, Y., Stevens, H.J., Wouda, T., (2008) “The last phase of life: a moment to learn?” [research by second year students at Utrecht School of Governance] the rapport can be found at: www.hospicedeliefde.nl > hospice > publicaties

Apendix

Interview

Moi.

Vertrouwelijk.

Interview vragen.

kun je me wat over jezelf vertellen? Wat je nu doet, wat je hebt gedaan?

Wat is de organisatie van het Hospice voor jouw?

Wat is jouw plek daarin? Ben je daar tevreden over? Zo nee, heb je dat kenbaar gemaakt?

Wat deed je daar? Hoe ervaarde je dat? (goede/slechte ervaringen?).

Vrijwilligers beleid, ken je dat? Wat weet je er van? Wat zou je anders doen?

Waarom ben je in het hospice gaan werken?

Wat is jouw motivatie om in het hospice te werken? Wat brengt het je? Wat maakt dat je er energie van krijgt?

Wie werken er allemaal in een hospice, wat zijn de rollen?

Hoe verhoud je je tot de beroepskrachten/vrijwilligers?

Hoe ervaar je het om te werken met stervenden?

Masker valt af. (docu Kruispunt).

Zingeving, waar haal je de kracht vandaan iemand te ondersteunen, hoe doe je dat? (tijdschrift thuisverpleegkunde).

Hoe laadt je je op als er iemand is overleden? Voel je je daarin ondersteund?

Colega's?

Zijn er plekken of momenten in het hospice waar ruimte is om op het werk te reflecteren (samen met collega's), ruimte om emotie te delen? Is daar behoefte aan? Wat maakt dat die ruimte er (niet) is?

Hoe reflecteer je op je handelen?

Kom je stress/burn out tegen in je werk, bij jezelf, bij collega's? Hoe wordt daar mee om gegaan?

Hoe ga je er zelf mee om? Voel je je gesteund, waarom (wel/niet)?

Wat gebeurt er als iemand is overleden? (is daar een ritueel voor, praat je daar over?)

De Liefde, hoe ben je daarbij gekomen/waarom? Wat zeggen de begrippen aandacht liefde en compassie jou?

Nabespreken:

Als ik onderzoek wil doen onder hospice medewerkers. Wat zou ik hen dan moeten vragen? Wat is interessant om te onderzoeken?

Andere respondenten?

End notes

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[i] (..) voor mijzelf blijft het staan, als ik niet meer geraakt wordt, dan hou ik er onmiddellijk mee op. En dat vragen we van iedereen eigenlijk die er bij betrokken is. Laat je raken, en zorg dat je er niet op om valt. En daar moet je ergens tussen zoeken.

[ii] Joan: het is een huis, ja waar iemand binnen komt als iemand al heel veel heeft mee gemaakt, behandeling is opgegeven, soms eerst nog een tijd thuis, soms gaat het heel snel. Komt in het ziekenhuis, de dokter zegt ik kan niks doen. Hij is er slecht aan toe, dan rollen ze zo'n hospice binnen en dan is er meestal eerst een tijd waarin mensen aankomen en vaak heel erg ontspannen omdat het er veel rustiger is. In elk hospice is de sfeer veel rustiger, er worden geen behandelingen gegeven. Alles is gericht toch op, op huiselijkheid, op dienstbaarheid. Alle vrijwilligers zijn erg gericht op he ze kunnen helpen met verzorging, en met thee, en met aandacht en met gesprek. Dus de sfeer is vaak wel heel anders. Mensen die van thuis komen ervaren het als, soms ook als een opluchting maar daar is ook altijd de rouw om het afscheid van thuis, is daar wat duidelijker aanwezig.

[iii] Anna: (..)dat is een totaal andere insteek als in het ziekenhuis, daar moeten mensen zo snel mogelijk weer zelfredzaam worden, maar hier is het gewoon juist belangrijk, als iet heel veel energie kost zeggen wij: u hoeft het niet allemaal zelf te doen, wij kunnen u daarin ondersteunen, dat mensen de keus hebben, vandaar wel en morgen niet, misschien maar twee keer per week onder de douche, net wat voor hun haalbaar is en wenselijk.

[iv] Iedereen is welkom, ongeacht levensbeschouwing, leeftijd, inkomen of achtergrond. Het BijnaThuisHuis werkt vanuit de basisgedachte dat het leven ook in de laatste fase zinvol kan zijn, onder andere door mogelijke verdieping van het contact met familie en vrienden of een verdere persoonlijke groei.

[v] Sterven is een onlosmakelijk en zinvol deel van ons leven

In het licht van ons afscheid is ieder moment onvervangbaar

Ieder blad dat valt raakt ons rechtstreeks in het hart

[vi] 'Zal ik veel pijn lijden?'
'Wat staat met te wachten?'
'Kan ik het verdriet aan?'
'Wordt het mij niet te zwaar?'

Wanneer u hoort dat uw ziekte niet meer genezen kan worden spelen er allerlei vragen door uw hoofd. Wat kunt u verwachten, wordt het een lijdensweg? Dergelijke vragen, die ook bij u als naaste kunnen spelen, kunnen u angstig maken en een verlammende werking op u hebben.

[vii] Leven is ook doodgaan. Denk erover, praat erover. Dood gaan we allemaal. Zoveel is zeker. Sommige mensen weten dat ze niet lang meer te leven hebben of maken het van dichtbij mee. Voor anderen is dit nog heel ver weg. Maar bijna iedereen vindt het moeilijk om erover te praten. Want waar moet je het over hebben? Hoe doe je dat? En waarom zou je praten over doodgaan?

[viii] Van vrijwilligers wordt verwacht dat zij zich aan de gemaakte afspraken houden. Een vrijwilliger is 2x per week een dagdeel beschikbaar (een dagdeel is 4 uur). Flexibiliteit is daarbij van belang, om snel en adequaat op een nieuwe hulpvraag in te kunnen springen. Eén keer per maand wordt er een vrijwilligersavond georganiseerd. Van de vrijwilligers wordt verwacht dat zij hierbij aanwezig zijn.

[ix]

- evenwichtig in het leven staan en kunnen omgaan met verdriet, de pijn en het lijden van anderen
- in staat zijn tot een bescheiden opstelling en ruimte laten voor anderen
- kunnen luisteren naar anderen en eigen normen en waarden niet voorop stellen
- tactvol een eigen positie kiezen in het stervensproces van anderen
- zich houden aan eigen verantwoordelijkheden en bevoegdheden
- minimaal twee dagdelen per week beschikbaar kunnen zijn

[x] Dirk: Ja, Waarom uh, wilde je dit hospice-werk gaan doen? Of misschien moeten we nog wel eerder beginnen, waarom je die

Caroline: Stervensbegeleiding…

Dirk: Ja stervensbegeleiding wilde gaan doen, of die minor?

Caroline Ja, uhmmmmmm…, ik ben opgeleid als jusrist. Ik heb rechten gestudeerd. Ik heb een tijdje gewerkt in (naam organisatie). Uhm, … door de loop van het leven ben ik op een gegeven moment in een andere baan terecht gekomen die mij niet voldoende voldoening gaf, een administratieve baan, in (plaatsnaam), bij een wetenschappelijke onderzoeksgroep, dat is wel grappig (lacht) daarom dat ik ook dit onderzoek wel weer leuk vond. Eh, maar het geeft me niet de voldoening. Ik heb het idee er zit meer in het leven, uhm, het boeit mij, de dood. Er zit ook een persoonlijk verhaal achter. Mijn zusje is op haar 23e overleden, is zelf uit het leven gestapt. Ik heb niet de laatste fase van haar leven mee kunnen maken. Dus dat blijft iets wat spannend is, wat me aantrekt naja wat mij boeit om het positief te zeggen. Dus daar zit mijn fascinatie voor de dood in, denk ik. Mijn nieuwsgierigheid ook, wat gebeurt er, waar ga je naar toe, hoe ziet zo'n laatste levensfase er uit.

[xi] Dirk: Want wat, wat doet dat met jou, dat je dit werk hier doet?

Theresa: Uhm, het geeft mij een enorme voldoening om……. ja om, eigenlijk vorm, voor, voorwaarden te maken, te mogen creëren dat zij het zo goed mogelijk hebben die laatste periode, dat ik daar een rol in speel. En de nabijheid in zo een intiem proces vind ik ook niet vanzelfsprekend, dat vind ik ook fijn. We hadden net een gesprek met, er is gisteren een meneer opgenomen, zijn vrouw, wilde net even iets bespreken, dat

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ontstond in het kantoor min of meer toevallig. En ze moest van de ene kant zo verschrikkelijk huilen, maar ze is ook zo verschrikkelijk krachtig... Nou, dat vind ik geweldig dat ik daar bij in de buurt mag zijn. En toen was ze het kantoor uit en ik.. toen zeiden [naam collega] en ik tegen elkaar: mooi he?

[xii] ‘Want vaak merk je wel dat er ook heel veel, zorg is, naar de familie van de cliënt. Omdat daar nog heel veel problemen spelen, kinderen die jaren hun ouders niet gezien hebben. Nou uiteindelijk zie je heel vaak dat er toch wel weer enigszins contact is, soms is er eenmalig contact en dan is het ook afgesloten, maar dat soort dingen die er toch spelen en die mensen toch beperken om te kunnen gaan sterven.

[xiii] ‘Het is wel vrij praktisch allemaal. Er staan ook dingen in van hoe je iemand moet tillen, of iemand nog uit bed komt, uh, dat soort zaken en uh. Het is een mix tussen, aan de ene kant want moet je er zijn en in die zin uhm, je beschikbaar stellen voor die bewoner. Het kan zijn dat die het bijvoorbeeld fijn vindt als je iets voorleest of een gesprek aangaat. En soms is het heel praktisch dat je bij iemand op de kamer komt en iemand z'n bed is nat. En dan moet je even het bed verschonen, dus dat kan ook allemaal gebeuren. Het is bijna, psychosociaal ondersteunen als gewoon fysiek. En er komen ook dingen bij van iemand kan heel erg misselijk zijn en kom je 's ochtend om 7 uur binnen en je moet iemand z'n uh, ondersteunen met overgeven. Nou dat is niet zo lekker. Dus je wordt ook wel geconfronteerd met lichamelijke processen en het is niet altijd mooi... Soms is het heel RAUW en heel PIJNLIJK en soms zitten mensen zelf vast in hun eigen proces en zijn ze heel erg boos of heel erg aan het ontkennen dat ze komen te overlijden.’

xiv Recent hebben we een mevrouw gehad van 90 jaar die altijd alleen gewoond en geleefd heeft en altijd maar door heeft moeten gaan, en hard gewerkt en jaren lang toch een administratieve carrière opgebouwd, tot haar 65e gewerkt en daarna heeft ze heel veel vrijwilligerswerk gedaan. Dus ze was altijd voor anderen bezig, ook voor haar familie, voor haar nichtjes en neefjes. En toen kon ze op een gegeven moment niet meer en toen was ze afhankelijk van hulp van een ander. Nou dat koste haar ONTZETTEND veel moeite. Dat was van: ja maar dat jullie dat voor mij doen, en uh, nou, dat, daar kon ze eigenlijk niet mee over weg. En dan moet je eigenlijk proberen om de mensen toch het gevoel te geven dat ze zelf nog een heleboel doen, dat ze zelf de regie houden en toch dat jij die handjes voor hen bent. En dat is prachtig als je ziet dat dat lukt en dat ze zo iets heeft: (fluisterend) “doe jij het maar.” Nou dat is indrukwekkend.

[xv] En door het gesprek aan te gaan met die stervende en ook te benoemen: “nou u komt binnenkort te overlijden,” en vaak merkte je dat mensen dat al heel fijn vonden, want ze hoefde niet uh, te verstoppen, he, van oh kijk eens de zon schijn he, fijn he? Uh, dat laat je achterwegen. Je hebt gelijk hartscontact met zo'n persoon. Of zielscontact of hoe je het wilt noemen

[xvi] Dus als mensen bellen dan ga je er naar toen en ik probeer altijd heel, zelf altijd heel afwachtend, zo van wat willen ze van me? En dan, daar volg je in. Soms komen mensen die willen, bijvoorbeeld willen ze even iets eten, of wat drinken, of ze liggen even niet lekker en dan kun je wel voelen: er is wat meer. Dus als dat zo is, dan kan je daar wel een beetje van: nou goh. Beetje een praatje maken en dan kijken, hebben mensen behoefte aan andere dingen? Willen ze misschien aandacht of... ja dat is eigenlijk voortduren heel open zijn voor wat er is. (..)En als mensen ook zieker worden gaan ze

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ook steeds minder praten, vaak. Dan zijn het ook wel vaak, uh…,gesprekken die gaan over dat ze pijn hebben. Of dat ze niet lekker liggen. En dan kun je 100.000 dingen doen en dan liggen ze nog niet lekker. En dan gaat er bij mij een lampje branden, ze zijn gewoon bang. Je kan er altijd ook gewoon van uit gaan dat mensen ook bang zijn. Weet je wel, het is gewoon allemaal heel onzeker, je weet niet wat er gaat gebeuren. Dan kun je gewoon van die signalen pakken en dan kun je daar over praten. (..)het zijn vaak van die hele kleine momenten dat je, dat je daar even bij iemand kunt zijn en dat je daar even en daar eventjes oog voor hebt. Dat je merkt dat mensen verdrietig zijn, dan kun je daar, dan kan je dat zeggen, van: goh ik zie dat u daar zo ligt, ik heb het gevoel dat u verdrietig bent, klopt dat? En soms willen mensen daar over vertellen. Soms ook niet. Dus het is niet dat mensen heel veel praten, eigenlijk niet. ja het is gewoon heel dicht bij iemand zijn, en dat is soms hele korte momenten waarin ook niet VEEL wordt gezegd, maar waarin essentiële dingen worden gezegd.

[xvii] (..) juist in de laatste fase dat ze toch heel zwaar zitten en dat je daar gewoon over durft te praten, dat je kunt zeggen van: goh kunt u het nog verdragen, en is het nog te doen? En ik heb eens ooit tegen iemand gezegd: het dierbaarste dat je hebt moet je nu loslaten . En dat was zo, voor die man op dat moment, uh,… waar die mee worstelde. En van dat moment komt er toch een bepaalde click, een vertrouwensrelatie en uhm, waardoor je dus eigenlijk ook iets werkelijks kunt betekenen voor iemand in dat laatste stukje. En je kunt nooit met alle gasten die hier zijn, uh, dezelfde vertrouwensrelatie hebben. Daarom is het ook heel goed dat we in een team werken met veel verschillende mensen want die heeft met die een click en die met die.

[xviii] Mensen, vrijwilligers kunnen ook heel erg boos worden, bijvoorbeeld.. (lacht) ze mijn ervaring is dat boosheid vooral voortkomt omdat ze zich onmachtig voelen omdat iemand uh, pijn heeft die niet te bestrijden is. Er wordt altijd gezegd: pijnlijden hoeft niet meer, nou grotere onzin bestaat er niet. Ik bedoel er wordt ongelofelijk veel gedaan aan pijnbestrijding en er kan ongelofelijk veel pijn betreden worden of in ieder geval op een niveau worden terug gebracht worden dat dragelijk is. Maar het lukt niet altijd. *En* dan kan er echt zo ongelofelijk veel pijn zijn dat overal doorheen breekt, dat gasten maar ook vrijwilligers daar behoorlijk van in paniek kunnen raken, dan komt er angst, ik geloof zelf altijd dat er angst is voor de confrontatie met je eigen pijn waardoor je het niet kunt behappen, niet kunt bolwerken. Hartstikke machteloos, je kan niks, de ander schreeuwt echt constant om je hulp en je hebt echt niet smeer in handen, nou daar ontstaan de heftigste emoties omheen. Dat kan kwaadheid zijn, dat kan verdriet zijn. Nou dan is het heel belangrijk als dat vangnet er is. Dan is het fijn als je jouw collega er naar toe kunt sturen als jij het niet meer op kan vangen, dat je een coördinator kan bellen, dat je de wijkverpleegkundige kan bellen dat die je bij staat, en dat je eigenlijk een heel close net vormt om het met elkaar te kunnen dragen, dat je daar niet alleen staat.

[xix] Maar je ziet hier mensen binnenkomen en van lieverlee wordt het slechter, gaan ze hard achteruit, zie je dat ze het ook zwaarder krijgen en dan komt de dood gewoon als vriend. En dan is het ook goed om te zien dat iemand gewoon niet langer meer hoeft te lijden en het los kan laten. En hoe verdrietig het ook voor de omstanders is, het is voor de persoon in kwestie gewoon wel heel bevrijdend dat het leven eindigt, ja <ja> ja en ik weet wel dat ik in de begin fase, toen hebben we ook wel een aantal hele jonge mensen gehad, dat vond ik ook wel het moeilijkste aan het werk, van zeg maar mensen die je eigen kind zouden kunnen zijn, en maar daar ben ik wel de afgelopen jaren wel in

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gegroeid, het lukt wel om daar contact mee te leggen. (..) En uhm, want toen, dan raakt het dus mij intens aan als het dus mensen die je eigen zoon of dochter kunnen zijn dan komt het heel dicht aan je eigen huid, dan grijpt het gewoon veel meer aan. Ja. Ik heb ooit aan een sterfbed gestaan van een eenentwintig jarige jonge knul (..). En ik weet wel wat ik daarin heel prettig vond, het had natuurlijk heel veel impact op zowel de vrijwilligers als op ons, het team en dat we een hele bijeenkomst, want uiteindelijk is die moeder ook overleden, van die jongen, om het verhaald compleet te maken maar ook van hoe sta je daar nou in en hoe kun je daar mee verder. Dat vind ik wel heel goed.

[xx] Ja dan kom je van iemand en dan heb je iets mee gemaakt boven op een kamer en dan (inhaleert diep) kom je de keuken in (blaast lucht uit). Nou, wat ik nou toch. Ga even zitten of, of als je met elkaar toevallig bent. Er zijn altijd wel momenten dat je eventjes je hart kunt luchten. En de verpleegkundigen ook. Ja, dat gebeurt meestal vrij direct, als de gelegenheid zich voor doet. Als er natuurlijk gasten in de keuken zitten dan ga je dat niet doen, of familie of zo.

[xxi] Maar die coördinator, wat ik heb ervaren is dat die ook heel belangrijk is omdat er bepaalde spannende momenten zijn in de zorg voor die gast en dat met name gaat het dan om gevallen waarneer er sprake is van euthanasie, of als er spraken is van een heel plotselinge sterke achteruitgang is in het lichamelijke welzijn, zeg maar even, van de gast waar dus echt sprake is van crisis situaties en die coördinator heeft dan toch wel, in mijn geval, toch wel heel erg positief een rol gespeeld, omdat een coördinator dan op een gegeven moment als er iets gebeurd is de moeite heeft genomen hoe het met mij is, hoe het met mij ging. (..)En dan is het bijzonder waardevol als een coördinator op een gegeven moment vraagt: "hoe gaat het met je?" En dat daar dan ruimte is om daar over te praten en dat daar dan, dat je het ook zelf moeilijk kan hebben, mag hebben, daar over kan praten en... Dus dat is een hele belangrijke rol.

[xxii] (..) aan het eind van bijna iedere dienst wordt er gevraagd: zijn er dingen die je nog even kwijt moet, heb je lekker gewerkt, waren er bijzonderheden? Dus op dat moment kun je gewoon een gesprek hebben met hun beginnen.

[xxiii] Uh, en daarna heb ik het boek van Carlo Leget uh, ruimte om te sterven, met hun besproken. Dat hebben we aangeschaft hier voor in de bibliotheek. En ik had er een aantal dingen uitgehaald, waarvan ik dacht die zijn heel erg herkenbaar hier in de praktijk, die heb ik met de vrijwilligers, uhm, ja op de tafel gelegd en hebben we uitgewisseld. Als ik dan een stelling of eens tukje daaruit haalde, uit dat boek, bij hun gevraagd van nou, waar ligt hier de herkenning en zo kwamen we ook op een aantal bewoners terug uit. Want dan popt bij iedereen die meneer of die mevrouw weer op. En dat is juist heel erg leuk want daarmee denk ik ook al leven die mensen niet meer, ze blijven toch een bepaalde plek houden hier in huis. Ze spelen toch nog een rol er in.

[xxiv] Dat moeten ze ook echt verplicht stellen want er zijn een heleboel mensen die: oh ik heb geen zin in al die rollenspellen en ik heb geen zin in dat soort gedoe allemaal, laat mij maar gewoon de dingen doen. Maar je ziet dat daar heel vaak wel gewoon emoties vrij komen en dat... is soms niet makkelijk maar het is wel goed dat ze naar buiten komen, dat ze niet verdrongen worden. Ja.

[xxv] > En uh.. misschien zou je nog wat meer kunnen vertellen over, je hebt een training gehad toen je hier ging werken. > Ja, > hoe dat ging. > Een beetje graven. Het is, het was twee dagen volgens mij, op vrijdag avond en op zaterdag de hele dag. En dan gaat

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het vanuit verschillende invalshoeken. Eerst het praktische, gewoon hoe zien de diensten er uit, welke tijden, welke dingen worden van je verwacht als vrijwilliger. Dus gewoon het praktische. Een heel stuk medische informatie. Wat hebben, de meeste mensen, die hier komen. Hoe gaat dat, hoe is dat in de loop van de tijd veranderd. Toen ze net opgericht waren, waren het vooral Aids patiënten die hier kwamen. Die hebben we nu bijna niet meer, bijna allemaal kanker. Dus dat een stukje. En een stuk maatschappelijk werk. Hoe ga je er mee om, wat doet het met je, waar liggen je grenzen? Uhm, .., en ook de pastor die daar een belangrijke rol in had, met dingen vertellen. En nog tiltechnieken, dat hadden we toen ook. End dat was vrijdag avond. En zaterdag de hele dag. En nog een evaluatie daarna. Dus dat was de training die we kregen. Daarna , ik denk of vier keer meelopen met iemand. Dus dan wordt je gekoppeld aan een vrijwilliger. Een vrijwilliger die weer gekoppeld is aan een verpleegkundige, om te leren wat je doet als vrijwilliger.

[xxvi] Uhm een heel groot verschil is dat er in de training van hospice (naam hospice) veel meer aandacht is voor de dood en het lijden. En dat er dus gevraagd wordt om daar mee bezig te zijn en over na te denken. En hoe je er zelf in staat. In die eerste training die ik voor het hospice hier in (plaatsnaam) heb gedaan dan wordt er natuurlijk ook wel over gesproken, over de eerste ervaring met de dood en wat voor ervaring je hebt gehad met het overlijden van naasten, familieleden. Maar het blijft allemaal relatief, dat zeg ik nu he, oppervlakkig. Die eerste training destijds vond ik dat ook wel spannend. Maar nu in de training van hospice (naam hospice) is er toch veel meer aandacht voor hoe je je eigen dood en je eigen lijden, hoe dat allemaal mee speelt. Er wordt veel meer gevraagd om daar dan naar toe te gaan en daar aandacht aan te besteden.

[xxvii] En wat me opvalt is dat er eigenlijk vrij veel humor is onder de medewerkers, en dat je dat eigenlijk ook wel nodig hebt. Dat het ook heerlijk is om af en toe ook ff ontzettend te lachen. Omdat het natuurlijk, heftig is waar je mee bezig bent. En dat ontlaad ook voor een heel groot deel, die humor die je met elkaar hebt en die grappen die je er over maakt. Dat doe je natuurlijk in iedere werksituatie, dat gebeurt ook hier, dat er een behoorlijk grove grap de wereld in gaat. Maar dat is lekker. Ja dat, dat haalt de spanning er weer eventjes af en daarna dan kan je weer eventjes verder.

[xxviii] Het zijn natuurlijk veel oudere mensen, of ze krijgen ineens te maken met een ouder die ziek is, of er wordt een kleinkind geboren waardoor ze met de aandacht niet voldoende er kunnen zijn of eigenlijk ook niet meer voldoende diensten te kunnen draaien om de verbinding met het werk te houden. Toen zijn we eigenlijk gekomen tot een constructie in de organisatie om gewoon drie maanden een time out te vragen en daarna zonder enig ja maar terug te kunnen komen. Dat werd eigenlijk, dat wordt wel vaak aangegrepen, van ja er is tijdelijk even iets waar ik mijn aandacht voor nodig heb en dat vind ik wel heel prettig, uh, et werkte ook onbedoeld heel goed. Mensen kwamen ook terug zo van jeetje, eigenlijk is het wel lekker om hier een aantal maanden niks mee te maken hebben gehad. Ik heb nu een frisse kijk er op, ik heb even afstand genomen.

[xxix] (..) het is natuurlijk wel zo, als je zo'n dienst afsluit en er is een crisis situatie geweest, dus heel heftige dingen die gebeurd zijn, ja dan is het wel gebeurd, dan kom je bijvoorbeeld hier thuis, dan heb je van 3 tot 7, dan kom je hier thuis, dan ga je eten, ja, dan is het heel belangrijk dat je thuis situatie zo is dat je dan de ruimte krijgt om dan er nog even niet te zijn [lacht] in de thuis situatie. Dat het nog even tijd kost om

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het los te laten. Ja, dat is wel een heel belangrijk stuk. Van hoe je, hoe er thuis gereageerd wordt op wat je hebt meegemaakt.

[xxx] He, dus je loopt naar beneden, je klopt aan, de manier waarop je de kamer binnen komt, hoe, er in staat als het ware. Het is een soort bewustwording van, in feite een soort oefening in het hier en nu leven, daar komt het in feite op neer,(lachend) in Boeddhistische termen. Misschien. Maar dat is het wel eigenlijk. Gaande, ja iedere keer als ik dienst had, had ik ook een soort gewoonte voor mezelf, dat als ik het hek bij het slootje naar het hospice open deed, dan staat daar een hele mooie grote beuk, daar stond ik altijd even bij stil. Je kwam dan van huis af en was met van alles en nog wat bezig, dat moet je eigenlijk allemaal los laten. Dus ik gebruikte dat door het hek komen en dat kijken naar die boom eigenlijk als een moment om,.., ja dat allemaal los te laten en mij te concentreren op die dienst.

[xxxi] Ze dragen sowieso de dienst aan elkaar over. En afhankelijk van het viertal wat daar zit heeft het ook veel van dit, of weinig van dit. Sommige hoor ik eigenlijk alleen maar praktische dingen overdragen. Want ik hoor dat natuurlijk vanuit de verte. Dan denk ik nha, is dat nou zo belangrijk, dat uh, geloof ik dat er hier iets mist. EN de andere keer is er wel meer reflectie.

[xxxii] Uhm, en ik merk daarin dat, er niet zo heel veel openheid binnen ons verpleegkundig team is, dat mensen het moeilijk vinden om zich kwetsbaar op te stellen. Liever het probleem mee naar huis te nemen en er weer mee terug komen dan zich open en bloot in het team… te bespreken.

[xxxiii] Ja ik denk het wel. Ja psychiatrie is vooral verplegen met de handen op je rug en hier moet je vooral de handen uit de mouwen en dat is wel een heel groot verschil.

[xxxiv] het zijn vaak wel mensen die werken in de gezondheidszorg, maar op het moment dat jij als vrijwilliger werkt, moet je je handen op je rug doen. Je bent echt vrijwilliger, je mag geen medische handelingen doen. Dus je bent geen zorgverlener, in die zin, zoals je het gewend was om te doen. Dus jouw professionele masker, wat je mooi kon opzetten als jij als verpleegkundige ergens binnenkomt eh, moet je ook weg laten. Dus het maakt je eigenlijk extra kwetsbaar. En in die zin ook kunnen gevoelens, en emoties van anderen extra bij je binnen komen. Dat is ook wel wat mensen fijn vinden, want daardoor kan je ook dat hartscontact maken, wat ik net zei, (..).

[xxxv] Dirk: En is er dan ook een plek of een moment waar je daar over praat?

Susan: Ja dat is meestal wel met die overdrachten, of tijdens koffie drinken, ff met een kopje thee naar het kantoor toe om toch even met elkaar daar over te kunne praten, ja. Ik vind dat heel belangrijk om het voor jezelf af te sluiten om het te bespreken voor je weer in de auto of op de fiets stapt naar huis, dat je het ff hebt kunnen. En dan kun je er af en toe nog we even aan denken, maar dat is ook niet zo erg, want als je je helemaal af kunt sluiten dan, dan je moet er ook wel een beetje gevoel bij houden he. Dat het niet, niet zo van hup dat doen we gewoon en het zal wel en uh, voor de rest niks. Nee dat gaat niet. Ik heb altijd wel zoiets van dat zeg ik tegen mijn man altijd zo van als ik zo er over ga praten dan moet ik wat anders gaan doen want dan is dat gewoon niet goed. Voor mezelf zou dat niet goed zijn, ik moet wel gewoon het gevoel er bij houden. En emoties zijn er af en toe ook. Maar uh, ja en dat is ook van de situatie afhankelijk en of je, ja wat je op dat moment doet. We hebben een paar weken geleden ook euthanasie, is er geweest. Ja dat is ook weer heel wat anders dan sedatie. En die

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man, die had, die was ook net zo oud als ik en die, met die (vertrouwelijk). Die is een tijdje, die is 8 weken bij ons geweest en uh, en hij vroeg ook of ik daar bij wilde zijn. Dus dat is ook weer anders dan en de stagiaire die had ook heel goed contact met hem en die had ook zoiets van ik wil bij hem, daar wil ik ook wel graag bij zijn. Dus toen zijn we daar met, toen zijn we daar beide bij geweest. En toen heeft de hospice arts heeft het, heeft het gedaan, het spuiten zeg maar, want dat heb je verder niet, nou je kijkt wel met hem mee of het kraantje van het infuus goed staat, of ... Weetje dat soort kleine dingen, het moet wel goed gebeuren.

[xxxvi] (..)Want dit ging heel rustig, eigenlijk ook gewoon heel mooi, pratend, uh, zoals hij was, viel hij zo in een keer toch in slaap, valt hij eerst in slaap en dan overlijdt hij. En daar heb ik eigenlijk niet zo heel veel emoties zelf bij gehad. Maar een paar dagen later gebeurde er thuis van alles, en toen in een keer kwam het naar boven. Zo uiteindelijk komt het dan toch wel, zo van zeg maar. Dan denk je van he hoe kan dat in een keer, dan denk je van ja dat komt dan toch weer even, dat moet je dan even weer kwijt. Het hoeft niet op het moment zelf, bijvoorbeeld bij die stagiaire was dat wel. Die had dat meteen op het moment zelf. Ja dat is ook goed. Ja dat is ook goed, dat soort dingen. Maar ik had dat dan weer niet, ik had het dan weer later. Je hebt ook wel zo van: je moet ook wel wat sterk zijn. Je moet dingen regelen. Er moet van alles en nog wat. Je moet er voor de familie zijn. Dat is natuurlijk ook zo. Als je helemaal in tranen hier rond loopt, ja, dan gaan mensen jouw troosten in plaats van dat het andersom is. Je mag best wel af en toe wat tonen he, dat is natuurlijk zo, maar je moet, ja, je moet professioneel blijven ook he. Je moet, je kunt ff tranen in je ogen krijgen en ook laten zien dat het jouw wat doet. Natuurlijk. Maar als je helemaal onderuit gaat, ja dan hebben de mensen niks aan je.

[xxxvii] Ja wat moet ik nog? En na een jaar dacht ik van nou, ... ik ga doen wat ik eigenlijk altijd al van plan was te doen, maar daar vreselijk tegenop had gezien, eigenlijk. En dat was, het werk in een hospice. (..)En ja ik was ook wel gefascineerd door de dood, in die zin dat ik er vreselijk bang voor was. En nu ook misschien nog wel af en toe. Maar zo bang dat ik gewoon alles wat over de dood ging een beetje van me af hield. (..) En ik had net de ervaring achter de rug van de dood van mijn schoonvader. En dat ja dat had mij wel...in zeker zin gerust gesteld, omdat ik ervaarde dat ik...dat ik tot mij door kon laten dringen. Ik hield het niet af, ik was er gewoon bij en ik kon er bij zijn.

[xxxviii] En ik weet nog wel dat in het begin was ik vreselijk gespannen, onzeker. Maar... ik was voor de eerste keer bij iemand en het was heel opvallend, het viel gelijk weg. Gewoon het Doen, het Er Zijn, dat voelde gelijk goed. (..) Ehm, ... Eigenlijk, dat gevoel is steeds gebleven, het is goed dat ik hier ben, ik, leer er enorm veel van, gewoon, het komt er in feite toch op aan dat je, ja als het ware jezelf leert kennen. En... in een situatie komt waar het er niet meer op aan komt van wat je allemaal weet, en... en hoe interessant je bent. Nee je kunt gewoon, eigenlijk moet je proberen jezelf te zijn. En dat is een prachtig leerproces. En ja, het is het is mooi om te merken dat je groeit, dat je, dat je niet. Ja het gaat natuurlijk met vallen en opstaan. Je krijgt natuurlijk bepaalde moeilijke situaties.

[xxxix] Nou langzaam maar zeker bleek dat gewoon allemaal goed te lopen en dachten we, ja dat is onzin dat wij er iedere keer tussen zitten. Dat kunnen ze goed. Ze werken hier meestal met zijn 2en en dan is er nog iemand waarmee ze kunnen zeggen: wat vind jij er van, zullen we? EN dan bellen ze. Dus wij zijn dat meer los gaan laten. Uh, uiteindelijk denk ik persoonlijk dat alle mensen hier, we hebben drie bewoners

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tegelijk, die gaan ook loslaten, die gaan het leven los laten, en IEDEREEN er omheen, ook wij, of we nou wel of niet betaald worden, die moeten dingen leren loslaten. En dat hoort denk ik ook zo. Want op zo'n klein aantal vierkante meters kan het niet zijn dat je er drie hebt die alles moeten loslaten en de rest zogenaamd overal controle over heeft, dat lijkt me niet kloppen. Als je in dezelfde energie zit, dan gaat het over hetzelfde. Maar ik moet iets anders in het leven loslaten dan jij. EN die meneer die aan tafel zat, die moet weer iets anders loslaten. Daar liggen ook hele mooie mogelijkheden voor groei, en dat zien we bij de vrijwilligers ook weer heel vaak gebeuren, dat is ERRUG leuk.

[xl] En iedereen denkt van te voren altijd, nou dat gaat mij niet overkomen, en iedereen loopt een keer tegen iets aan dat ie zegt: “nou had ik eigenlijk niet verwacht, maar eigenlijk was dat toch een oud punt”, en dat wordt hier toch aangeraakt, of in beweging gebracht waardoor er eigenlijk ook een stap gezet kan worden. Ja persoonlijk vind ik dat heel erg mooi. (..)Betty en ik, zijn wij voor, om dat als kanaal ook zeg maar schoon te vegen bij herhaling. En daar liggen die momenten van ja, soms verstilling en soms van inzicht krijgen op iets. Het is wel belangrijk. En soms ook van, ja daar moet je mee ophouden, je legt het bij een ander neer, je vind een ander bijvoorbeeld veel eisend, ga nou eens naar jezelf en kijk eens naar je zelf en waar het mee te maken heeft.