Summary

In the last century, medical technology advanced at an incredible pace. Health care flourishes on these improvements. However, at the same time, this and other features of modernity, such as financial and organizational strains, are cause for concern. The present demands of health care settings involve situations that challenge us as people. This thesis aims to understand how people experience and relate to modern health care practices. It explores possible openings for the humanization of those practices. The thesis is particularly interested in the experiences of people with a chronic illness who regularly interact with care practitioners. The study focuses on local, complex and ambiguous health care settings.

The aim of the study is to understand how patients and practitioners experience, safeguard and develop their own and others' humanity within the context of modern demands. 'Openings for humanization' are situations where the perspectives and values of people who are part of the practice are taken into consideration. The study considers humanization in health care settings to be a dynamic process that is a function of patients, practitioners and other people relating to the world and to each other.

The central research question is: *How do participants experience modern health care practices and what openings do they perceive to support humanity within those practices?* The thesis is built upon theoretical notions derived from hermeneutic philosophy, the value of personal accounts of particular experiences and practices of narration. This means the thesis does not focus on objective knowledge that is 'out there', but on dialogical knowledge that is value laden. It focuses on the meaning of personal experiences within the context of people's lifeworld and health care practices. It describes and analyses particular experiences and narratives of people. The thesis presents several personal accounts. These accounts are rich and include knowledge and understanding from an insider's perspective. Health care practices are considered to be narrative practices. Within these practices, human beings need each other in order to understand and express who they are and what they think should be done.

The thesis consists of two parts. Part A focuses on understanding individual experiences. Part B evaluates practices that aim for humanization. The studies in part A follow a descriptive qualitative approach. The studies in Part B are designed as responsive evaluations, which not only aim to understand and describe practices, but also to actively develop them.

Part A: experiencing health care practices

Part A begins with the perspectives of people with cystic fibrosis. The study in this Chapter (2) focuses on how people with cystic fibrosis experience their hospital admission. The study aims to investigate the perspectives of patients with CF of their hospital admission in order to improve their admission. The hospitalization of people with cystic fibrosis raises several challenges for the patient's quality of life, before, during and after admission. The study evaluates how CF patients perceive their room and stay, treatment and care and the impact on their social life (school or work). The admission of people with CF is complicated because of segregated treatment and care. Nineteen people with CF admitted for more than 5 days in one of the seven Dutch CF centers participated in this descriptive qualitative study. The chapter presents the results in accordance with five contexts and themes: Before admission & Arrival (1); Treatment & Care (2); Room & Stay (3); Discharge (4); Social & Societal context (5). The people with CF in this study are generally satisfied with hospital facilities and dietary options. However, a number of challenges concerning the patients' quality of life arise, such as the continuation of school activities and work during admission and after discharge. Patients express normative expectations of healthcare professionals, e.g. they want to be 'seen' and treated as human beings and not solely as 'cases'. The findings are relevant for the further development of patient-reported outcomes, particularly on patients' evaluation of their treatment burden.

Somewhat similar experiences are to be found in a completely different patient group: people with cardiovascular disease. These people also express clear expectations of their relationships with practitioners, such as the need not to be related to as a 'case' but as a 'human being'. Chapter 3 elaborates on this idea by presenting the perspectives of people with cardiovascular disease on psychosocial support. Even though practitioners make an effort to develop the right competences to enhance their understanding and sensitivity to patients' perspectives, patients still experience a rift between both worlds. The chapter examines a descriptive qualitative study conducted by a team of two scientific researchers and three cardiovascular patients as patient research partners. Twenty-four patients aged 37-79 participated in in-depth interviews and two focus groups. The interviews concentrated on articulating the perspectives of patients concerning psychosocial support.

The chapter discusses three findings in depth. Firstly, patients ascribe importance to the continuous provision of psychosocial support on a daily basis instead of primarily during framed interventions. Secondly, patients prefer to have a say in treatment and care. And finally, patients would like to see psychosocial support as more solution-oriented and empowering. The discussion section of this chapter argues that practitioners should learn how to establish a balance between engaging with patients from a deliberative stance on the one hand, whilst acting from a more paternalistic role on the other. The chapter discusses several implications for nursing. Nurses may, for example, further explore what it means to address a patient's humanity and lifeworld. In addition, they could explore the boundaries with other disciplines, such as psychology or (spiritual) counseling in more depth.

Chapter 4 analyses the process of understanding of a person with a chronic illness experience. It illustrates this process through the narrative of a woman with cardiovascular disease. The chapter analyses the importance she ascribes to understanding and obtaining knowledge about her disease. At the same time it demonstrates the need of patients to be understood by other people, including health care professionals. This chapter investigates the process of understanding from a philosophical hermeneutical perspective. It attempts to unravel the phases of understanding that the patient experiences. The chapter describes that understanding is not a clear-cut activity to be 'accomplished'. Instead, understanding tends to be a three-phase process. Moving through this process helps the patient incorporate a serious illness into everyday life and identity. The first phase

of understanding occurs when the patient relates to the 'strangeness' that has entered her life. An illness is 'that which is strange', a disorienting experience that draws people out of their familiar world. The chapter explains that the existential tension that is brought to bear may perhaps be necessary and can be a productive way to enhance understanding. The second phase of understanding is entered into when this patient looks for information about her illness, either in conversation with experts or written information to be found on the internet and from other sources. The third phase of understanding is dialogical: the patient's authority is acknowledged – by her cardiologist.

In the last chapter of Part A, the thesis briefly leaves the personal experiences and accounts, although it does focus on patient preferences, but from a more abstract standpoint. Chapter 5 presents a systematic synthesis of issues that matter from a patient perspective in quality of care and health research. The chapter describes how information was systematically gathered from Western countries with similar economic, societal and health care situations. Empirical scientific studies with a method section (primary sources) have been included in the synthesis, as have other highly relevant scientific studies or articles, either with or without a method section (secondary sources). Because of the limited number of primary and secondary sources available, a tertiary source group has been included: non scientific publications, reports and patient information databases. These tertiary sources, originated by patient groups, are assumed to reflect genuine patients issues rather than issues attributed to them by e.g. social scientists. This further defines the special nature of this study: the integration between primary, secondary and tertiary sources. The inventory of issues that were defined by patients covers a considerable array of domains. In total, 35 issue clusters, further referred to as criteria, were found, ranging from fundamental values such as quality of life, quality of care and personal development to information, dignity, self care, cost effectiveness and family involvement. Issues from a patient perspective reveal patient values and complement professional issues. This chapter demonstrates that quite a few issues are not reflected in the scientific literature in spite of their clear and obvious appearance from tertiary sources. This may indicate a gap between the scientific research community and patient networks.

An *intermezzo* presents the story of a young woman who suffers from cystic fibrosis. In 2007, she was to be put on the list for a bi-lateral lung transplant, which in the end proved successful. Her story is accompanied by a clinician's perspective from her medical doctor and transplant physician. We learn from her story that 'to be or not to be listed' for a lung transplant, was a process of shared decision making between herself and her clinician.

Part B: health care practices that aim to support humanization

The second part of the thesis presents three studies that help understand how patients and practitioners (including researchers) look for openings for humanization. The three chapters include several case examples, some of which in the form of narrative vignettes. Chapter 6 reports on a responsive evaluation of an innovative practice for people with Chronic Obstructive Pulmonary Disease (COPD). Over the past few years patients with COPD have been expected to play a key role in their recovery. Self-management and shared decision making have reached hype status. The chapter explores what, considering these recent trends, it means for the division of responsibilities between doctors and patients. What kind of role should health care providers play? The study consisted of in-depth interviews with people with COPD, physiotherapists and a pulmonologist. The chapter describes that shifting responsibilities requires a supportive attitude from healthcare providers and dialogical communication between patients and professionals. The chapter argues that more is needed in order to motivate people with COPD to take responsibility and become co-owners in a process of recovery. The case example illustrates that people with COPD need support from fellow patients to learn to accept their disabilities. Awareness that COPD is more than just a lack of air, that mind and body interact, is a first step towards investigating other potential problems and towards enhancing one's quality of life.

Chapter 7 also describes a responsive evaluation study. It reports on a study of an integrated health care and social service. It describes how integrating services is a complex challenge because of the ambiguous responsibilities of the participants involved. The chapter shows how professionals in a recently initiated integrated service for clients with multiple problems embark upon a moral learning process. In integrated services, professionals from different organizations and disciplines work from their own tradition and values. Building integrated services is far from easy, as any attempt to do so may lead to conflict across several disciplines, sectors and organizations. It is widely recognized that setting up integrated services requires a specific kind of management that focuses on collaboration and the coordination of a network. This article problematizes this instrumental view and provides an alternative way of looking at integrating services. The chapter offers an alternative for regarding responsibilities of service-members as instrumental, as if they can be 'assigned' by an authority. Instead, professionals may learn to ask and repeatedly reflect upon questions such as: who should do what, with whom and why? Similar questions are important in the next chapter, but this time from the researcher's perspective. Chapter 8 argues that responsive evaluators ought to develop their moral competence to learn how to maneuver within the socio-political fields they embark upon. Responsive evaluation contributes to the design and implementation of policy by working with stakeholders and coordinating the evaluation process as a responsible practice. The responsive evaluator has specific responsibilities, for example to include stakeholders and vulnerable groups and to foster ongoing dialogue. Responsive evaluators are confronted with stakeholders who express expectations and voice demands. It is difficult to respond to all these demands in their everyday work. The chapter shows that novice evaluators experience challenges concerning overidentification and underidentification with stakeholders, which may influence the quality of evaluations. Guidelines and quality criteria on how to act are helpful, but need interpretation and application to the unique situation at hand. Therefore, responsive

evaluators ought to become 'sensitive for the particular' in order to enhance the quality of their evaluations. The chapter explores how evaluators can enhance their understanding of the moral responsibilities in daily practices of responsive evaluation research. It introduces a framework for reflecting upon the moral dimensions of an evaluation practice. Responsive researchers can explore responsibilities by articulating three narratives: of identity, of relation, and of value. Reflecting on these narratives can be beneficial to determine what 'ought to be done'.

Finally, Chapter 9 integrates the studies, and presents and discusses the main findings. Looking at all the studies, we conclude that the health care practices of the studies are the outcome of alternating stable and dynamic phases of interaction among patients and practitioners. Experiencing stages of change and stability is necessary for the allotting of responsibilities within practices. On a daily basis, patients and practitioners sort out what should be done, by whom and when. They continuously assign responsibilities on a micro level in the context of their relationships. This division of responsibilities does not entail a formal process, but can be seen as a moral enterprise. This view on health care practices honors its interpersonal, moral and social features. The chapter describes that sharing responsibilities in treatment and care is a dynamic process among patients and practitioners where they explore who the patient is, what he/she values and what responsibilities derive from that. From this view, sharing decisions is a mutual learning process. The outcome of this process of allotting responsibilities cannot be predetermined. It is a function of the people involved, their preferences and how these are included, their skills, particular lifeworlds and personal histories. According to the participants in this thesis, a prerequisite for this moral learning process, is a 'good' relationship. A good relationship includes a personal approach, and to be responded to in a human way. Genuine listening, attentiveness, being responsive and sensitive to the interpersonal dimensions of the relationship are important features of a good relationship. The patients in our study set really appreciate attention for their particular situation and preferences. This goes beyond paying attention to the physical dimensions. According to patients, practitioners should also include psychosocial dimensions. They prefer an integral perspective on body and mind. Other themes should also be included, such as time, space, spirituality and vitality, all of which look upon the patient as a person with a story that is historically, temporally and spatially situated. Attentiveness and being responsive to these features of the patient as a person is a prerequisite for attuning responsibilities and, in the end, for a human approach. Consequently, moral and narrative competences of practitioners become increasingly important. This does not so much imply a behavioral change, but the development of sensitivity for other people's perspectives. These moral and relational features provide openings for the humanization of health care practices. The last chapter also explores how scientific research can lead to opportunities for the humanization of health care practices. This is possible through interpretive and responsive research approaches. Interpretive and responsive research assumes that events do not have an inherent meaning, but people actively interpret the situations they find themselves in. These research approaches acknowledge people's lifeworld and seek to generate knowledge that is based upon particular accounts of

people. Interpretive research therefore provides us with a way to access preferences and perspectives of people within the context of their lifeworld. They improve our understanding of how people experience the complexity of health care settings and what moral expectations they have. Responsive research aims to actually develop a health care practice by facilitating a learning process. It is regarded as a (trans-) formative approach. Responsive researchers feel responsible for including people whose positions may be challenged, for example vulnerable or marginalized people. This makes it a human approach. Lastly, the chapter discusses some implications of the studies. It would be interesting to explore how the moral and relational view on health care practices in this thesis relate to the organizational and economic dimensions of health care practices. Further research could focus on that. The thesis recommends research on how philosophical views on the relationship between mind and body, illness and wellbeing of a rich variety of stakeholders relate to each other and can be integrated. Furthermore, we could ask whether and if yes, we should aim to develop scientific evidence for a human approach. This should not be done through quantitative approaches because, as this thesis has illustrated, the cause and effect of a human approach are difficult to determine. This thesis suggests that there should be more attention for single case studies (n=1) that can complement quantitative studies. We conclude that a human approach is of the utmost importance at a time when we are confronted with serious financial and organizational challenges. This thesis demonstrates that there are indeed openings for this.