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Chapter 9

General discussion:
Openings for humanization

In 1967, in his New York studio, the American artist and philosopher Robert Motherwell just happens to lean a small painting against a large canvas. The large canvas is resting against the wall and is still work in progress. It has been painted ochre yellow and Motherwell is intending to paint something figurative on it.

The beautiful proportions of the small painting against the large one suddenly strike Motherwell. He stops and ponders. He allows the newly found to arrive. He likes the proportions between the small and the large rectangles. On impulse he takes a piece of charcoal and draws a line around the smaller canvas, leaving one side open. Almost by chance, he creates an image of an opening or door.

This painting is the start of Motherwell's *Open* series, but he does not arrive at this title immediately. Only after a few other *Open* works, the title occurs to him. Whilst his previous work is about dualism and struggle, his *Open* works evoke quite different ideas in him. To Motherwell, the *Open* works are about wholeness, freedom and fluidity. He particularly likes the simplicity of the word in its sense of 'effortless'. It is as if the *Open* emerges on its own from a triadic relationship between himself, the canvas and the charcoal. Motherwell believes in dialogue, in the entwinement of subject and object. He once wrote: 'That is *why* and only *how* a picture can be *creative*, and why its conclusions cannot be predetermined. When you have a predetermined conclusion, you have "academic art", by definition' (1963, italics by Motherwell). As far as I know, he and Hans-Georg Gadamer never met. How wonderful that would have been.

The word Open feels like an invitation. As Bob said at the start of the introductory chapter: walk around, get a sense of it, get a taste of what's new. And that is precisely how we looked at the studies in the previous chapters: What's different? What is unfamiliar and how does it improve our understanding of the humanization of health care?

This concluding chapter invites the reader to enter the Openings for Humanization that have been presented throughout this book. It looks to answer the main question of this thesis: *how do patients and practitioners experience modern health care practices and what openings do they perceive to support humanity within those practices?*

The chapter reflects on aspects of the Open that have been addressed in the studies of the thesis, connecting them and combining them in order to get an insight into the possibilities of humanization in current healthcare practice.

Dynamic health care practices: play and game

The studies presented in this thesis include multidisciplinary practices and more traditional, mono-disciplinary oriented practices. These settings do not conflict, they co-exist: sometimes discretely, next to each other, and at other times interconnected. Multidisciplinary practices all aim to enhance a human approach by including patients' preferences in care and by integrating disciplines and services in a new practice. Examples include the COPD approach (Chapter 6), the multiproblem case approach (Chapter 7), and the palliative care program (Chapter 8). The stages of development vary,

but the developments share a dynamic in which participants from different backgrounds look for new ways of working. In the absence of procedures and routines, participants find themselves in an uncertain situation where rules for interacting with colleagues and new responsibilities have to be (re-) negotiated. Take, for example, the development of the multi-problem case approach (Chapter 7). The design, aims, purpose and structure of this approach have been thought through carefully beforehand. Practitioners are invited to join and cooperate with colleagues. They soon learn that developing an approach is not a matter of implementing a design in an instrumental manner. Each participant has specific moral expectations of how the approach should be developed, of what is 'right' and 'necessary' to do, how one should behave and how the desired outcome should be accomplished. The main purpose is to develop an 'outreaching approach' for clients with multiple problems. According to one of the process managers, this requires the willingness to move beyond formal responsibilities in order to 'reach out' to the client. He expects his colleagues feel morally responsible for their clients in the same way as he does. This used to be his line of work as a social worker in the past. Now, however, the process manager is confronted with new colleagues who do not share his view and who do not share the responsibility he feels. There is a lack of shared meaning. He implicitly responds by his attempt to change interactional rules, which is a prerequisite for being able to create new meanings of the outreaching approach.

Another example of a lack of shared meaning can be found in the study on palliative care (Chapter 8). This study shows a clash of expectations between the patient's husband and the nurses on how palliative care should be provided. The nurses, the oncologist and the patient's husband lack a shared understanding of the meaning of 'good' palliative care and what it entails in day-to-day situations. Whereas the nurses believe 'good' care includes taking care of patients with love and attention, this is not the view of the patient's husband. He apparently expects something different. This case example addresses the conflicting expectations of the nurses and the husband. Their expectations become the subject of a discussion on the meaning of 'good' palliative care. Voicing mutual expectations helped the nurses and other practitioners to develop new meanings of palliative care.

In both examples, developing a new approach or program is a dynamic undertaking. At the begin of a dynamic phase, participants suddenly find themselves in a situation where old rules and routines are no longer self-evident. This destabilizes the practice they are used to. They are confronted with uncertainty and ambiguity. This is caused either by an absence of shared meaning or by an overabundance of meaning. Both situations constrain people's understanding of what should be done in a given situation. Participants gradually establish (new) relations, ways of interaction and routines. This is called a dynamic phase of 'play'. They, for example, look for someone to be responsible. After a while, new relational patterns are established and responsibilities clarified. During this relatively stable phase, the 'game' phase, routines, codified ways of interaction and functional responsibilities are established. A new equilibrium is found. In the 'game' stage, participants have reached shared understandings on the subject matter, what should be done and how, and who is responsible for what and why. Participants focus on the subject matter of the situation they find themselves

in. However, this phase is temporary, as new needs, preferences or values may again open up a new dynamic, starting a new 'play' phase. Health care practices need these alternating stages of stability (game) and change (play) in order to grow (Abma, 2000; Voogt, 1990).

Health care practices are therefore the outcome of interchanging stable and dynamic phases of interaction among people. The alternating stages of change and stability, play and game, are necessary in the ongoing process of organizing (Abma, 2000) and of establishing what people believe 'should be done' in certain situations.

Responding to unmet moral expectations

The studies in this thesis illustrate that people's expectations are not always met. Some patients feel as though practitioners are unable to provide suitable treatment or care in technical terms. Others miss a certain quality in the relationship with practitioners. Both practitioners and patients sometimes feel that their preferences are not enough taken into account. Failures of expectations can be found in a variety of health care practices. Patients and practitioners express and anticipate moral expectations. How do they respond to unmet expectations?

Patients react either by increased or decreased ownership and sense of responsibility for their situation. Some patients respond with an increased sense of responsibility and ownership. A case in point is the patient in Chapter 4. When she is confronted with her illness, she eventually takes charge, feels responsible for her situation and decides to find information in order to improve her knowledge about her disease. Other patients feel lost and overwhelmed by their new situation and don't know how to act when a practitioner doesn't meet their expectations (Chapter 3). They frequently seek contact with fellow patients in order to share experiences, which gives them strength. Some of the cardiovascular and CF patients in this study experience resentment and anger towards practitioners and hold them accountable. They believe practitioners are responsible for their needs not being met (Chapters 2 & 3). These patients react by evading healthcare and seeking other ways of coping with their life. Other studies show that patients may file a formal complaint with a Patient Advisory Committee or a complaint officer of a hospital or patient organization (Friele et al., 2006). These complaints tell us about patient expectations and preferences. They address an 'expectation gap' between patients and practitioners (Bismark, 2012). In the case of a formal complaint, the response of individual practitioners to patients with unmet expectations may influence the patient's feeling 'that justice has been done' (Friele et al., 2006). Patients express a need to have the practitioner acknowledge that they have failed to meet the patient's expectations by, for example, admitting a mistake has been made. However, insurance companies in the Netherlands make it difficult for medical professionals to do this. Practitioners are allowed to explain why expectations clashed, but they must refrain from admitting accountability (Legemaate, 2006).

There may also be expectation gaps among practitioners. The practitioners in this thesis seem to respond to unmet expectations either by enhanc-

ing 'control' or by relying on formal procedures to diminish uncertainty and ambiguity. A clear example can be found in the multi-problem case approach. Managers and policymakers experience challenges in 'implementing' strategic agreements at operational levels. Their response aims at increasing control and improving coordination mechanisms. This is a problem, particularly because of the wide variety of disciplines and mutual dependencies involved. Whilst the process manager appreciates long-term relationships and an engaged approach, some people prefer to follow and sometimes even 'hide' behind formal procedures. A clash between expectations then occurs. The process manager feels handicapped by micro-political conflicts and this results in ambiguous commitments among participants in the integrated service. In the end, he feels compromised because it is difficult to stay with his own perspective of what morally responsible practice should be. Responding to moral expectations can be difficult, as it is closely linked to people's integrity. This also can be seen in the practitioners in the COPD practice. At the start, they experience challenges that involve cooperation with other disciplines, both from inpatient and outpatient Settings. The lung specialist says that his colleagues do not always support his ideas on what and how COPD care should be provided (Chapter 6). Other studies report similar situations where participants resist and hold each other accountable for situations that fail or when relations stagnate (Harker et al., 2004). People in these situations tend to focus on protocols or formal procedures.

Assigning responsibilities in the sense of formal accountability is a well-known technique for problem solving, and a majority of the practitioners and patients seem to expect this will improve their particular situation. Practitioners expect it will solve problems with uncooperative colleagues, and patients expect it will improve their agency, decrease their dependency on practitioners and give them hope for other ways to recover. Does this response improve the quality of health care? Does it contribute to the humanization of practices? This thesis demonstrates that how participants handle differences in moral expectations, is situational. Assigning responsibilities by holding people formally accountable, might be effective in a game setting – the rather stable organizational stage –, because people have reached a shared understanding of who is responsible for what. Yet, it might be less effective a stage of play, when there is no shared understanding of the meaning of 'good' care, and the division of responsibilities that is needed.

Practices of responsibility

The studies in this thesis show that in the context of their relationship, patients and practitioners continuously allot responsibilities towards each other. This does not so much entail functional, legal or formal responsibilities, but rather ethical and moral responsibilities.

These latter kinds of responsibilities imply that patients and practitioners take part in a dynamic practice of responsibility (Walker, 2007, p.16). They participate in a practice of 'mutually allotting, assuming or deflecting responsibilities' (ibid, p.67). They continuously attune, interpret and anticipate responsibilities, either consciously or implicitly. Patients and practitioners have specific interpersonal understandings that show how they make

each other accountable, how they define who they are and what they care about. These moral expectations are not fixed and context free, but fluid, intertwined with place, time, the stage of their practice (play or game) and the quality of their relationship. In the context of their relationship, patient and practitioner follow a collaborative-interpretive process through which they align their moral expectations. This view of practices of responsibilities stresses the interpersonal, moral and social features of health care practices.

Identifying and understanding moral expectations requires listening to personal accounts of patients and practitioners in the context of their social setting. Their accounts incorporate expectations and responsibilities as felt at specific times and places. In this process, practitioners take on the role of listener in order to determine what a patient holds dear, cares or doesn't care about, and what one feels should be done. The lung physiotherapists in the COPD practice clearly pay attention to this when a patient is invited to share his life story during the initial intake and in the process of recovery, in the context of the patient's rehabilitation (Chapter 6). Another example is the patient with cystic fibrosis telling that her doctors support her in 'helping me handle a disease we could not defeat' (intermezzo). She speaks of 'we': this assumes that responsibility is shared between herself and her doctors. She also stresses that although she expects the patient should make the final decision about treatment (in her case a lung transplant), a patient needs the doctors' expertise.

This example shows that allotting responsibilities also occurs in decisions on treatment and care. The intermezzo and other studies in this thesis illustrate that taking decisions together goes beyond making a judgment on the basis of information as 'decisional responsibility' (Edwards & Elwyn, 2006, p.317). Sharing responsibilities and deciding together on subsequent steps in treatment and care is not an instrumental 'act'. Instead, Chapter 4 demonstrates that this is an interpretive process. Practitioners and patients interpret the meaning of 'facts' about the disease in the context of the life of the patient and the traditions the practitioners come from. It can be seen as a process that consists of a web of roles, values and responsibilities of practitioners and patients together (Chapters 4, 6, 7, 8 of this thesis). Patients and practitioners explore who the patient is, what he/she values and what responsibilities for treatment and care derive from that.

While responsibilities in a functional approach are presented as facts, responsibilities from an interpretive perspective are explored and 'learned' together. This can be seen as a relational approach to working with responsibilities in line with other interpretative studies (Czarniawska, 2008; Van Dongen et al., 1996). It involves finding out 'who should do what, for whom, why and when' (Walker, 2007) as a joint interpretive undertaking.

The outcome and process of this joint undertaking cannot be predetermined. In line with hermeneutic philosophy, it is dependent on the specific situation of the people involved, their particular lifeworld, their personal history, and the competences they embody. People's relationships, values and competences determine how they attune, are attentive to, articulate and anticipate each other's expectations. To illustrate this we may again turn to the issue of sharing responsibilities for decisions in treatment and care. Elwyn et al. (2012) present a model for sharing decisional responsibility in three steps: a) introducing choice; b) describing options, often by integrat-

ing the use of patient decision support; and c) helping patients explore preferences and make decisions. The literature shows that shared decision making is important in the case of 'preference sensitive decisions' (Coulter 2006, p.341). The studies in this thesis demonstrate that patients sometimes expect practitioners to take a more paternalistic role without considering, too much, the patient's preferences (Chapter 3). This modifies Elwyn's model and advocates a personal approach in which the practitioner should explore if and how a patient views his/her decisional responsibility. From this it follows that sharing decisional responsibility is a relational activity where both parties attempt to find a shared understanding of what 'good care' is. It might be possible that 'good care' means that a patient gets less decisional responsibility.

A prerequisite for exploring and sharing decisional responsibility is a 'good' relationship. Elwyn's study shows that sharing decisional responsibility 'depends on building a good relationship in the clinical encounter so that information is shared and patients are supported to deliberate and express their preferences and views during the decision making process' (Elwyn et al. 2012). Our studies corroborate this. According to our patients, including patient preferences alone is not enough. They find a 'good' relationship of the utmost importance. Other research addresses the importance patients ascribe to relational aspects such as how they are treated by practitioners. They show, for example, that negative experiences with how practitioners treat them can cause distress, despair and a 'feeling of [being] dehumanized' (Shay et al., 2012; Lindemann et al., 2009; Thorne et al., 2008, p.35; Todres, 2007; Step et al., 2009). But what exactly is a 'good' relationship that enables patients and practitioners to develop practices of responsibilities? Is it even possible to develop a 'good' relationship? Or should we focus on creating the conditions for it to evolve?

'Good' relationships

According to the patients in our studies, a 'good' relationship entails to be approached in a personal way and to be responded to in a human way. This approach requires genuine listening, attentiveness, being responsive and sensitive to the interpersonal dimensions of the relationship.

Attentiveness involves recognizing a preference or a need (Tronto, 1993, p. 107). It is an important prerequisite for care. This is addressed by patients when they expect their practitioner to be attentive to their wellbeing, which includes listening with genuine attention (Chapter 3). The majority of patients in this study feel not being treated well, when their physician does not explicitly consider their preferences, values and particular situation. These patients perceive their physician as distant instead of responsive. Tronto calls responsiveness a 'moral moment that arises out of caring' (ibid, p.134). These two features of a good care relationship – attentiveness and responsiveness – are mentioned by several participants in the studies as important. For example, the process manager in the multi-problem case approach who looks for ways to be responsive to his fellow practitioners with different views on their moral responsibilities. Or the cardiovascular patient in Chapter 3 who reports that his physician suggests lifestyle

changes: stopping smoking and drinking (Chapter 3). Since this patient neither drinks nor smokes he gets the impression that his doctor is not attentive to his particular situation. Other examples can be found in Chapter 2. People with cystic fibrosis are bothered by practitioners who – despite their legitimate reason for doing so – do not shake their patients' hand. They feel it is inappropriate to be approached in this way. Another example concerns the patient who expresses her wish for an anesthesiologist to insert an intravenous line. The nurse takes no notice of her request. She might however have responded by addressing the patient's concern, ask 'why?' and maybe even share the patient's concern. This reflexive moment could have enabled a more human approach. This does not refer to instrumental empathy, but to empathy as a moral commitment which further deepens the nurse's understanding (Pedersen, 2008).

Some patients in our studies report relatively positive experiences with the care relationships with practitioners. They feel their practitioners actively seek to establish relationships with their patients as a person, instead of as a 'case' (Chapters 4, 6 and the intermezzo). These practitioners manifest openness, listen and actively invite patients to share concerns and ask questions. Patients experience these notions of humanity in situations where there is friendliness (Chapter 2) or when they are genuinely listened to (Chapters 3, 4, 5). Sometimes, practitioners reveal certain aspects of their own personality. Bob addresses this in the introductory chapter. Other studies have shown that revealing something personal makes patients feel acknowledged as people (Radwin, 2000; Izumi et al., 2006). When a practitioner discloses personal detail, the relationship with the patient becomes more humane. Chapter 3, for example, shows that knowing something about a nurse helps patients feel connected (Rchaidia, 2009).

Being attentive to the patient's preferences requires taking more than just the physical dimension into consideration. Patients in the study regard their illness and bodies as complex and closely connected to their social and physical surroundings and their lifeworld. In line with Slatman (2009), these patients not only experience their bodies as 'a thing' that can be replaced by any other thing, 'but also as something that is very intimate and personal'. This can be seen in the way the patients experience their bodies in Chapters 4, 6 and the intermezzo. They feel that their mind and body are connected. Their physical problems relate to their emotional and mental state and, more generally to their quality of life. They express a need for treatment and care that also takes account of their psychosocial wellbeing (Chapters 2-6, intermezzo). Cardiovascular patients, for example, experience emotional challenges when they leave the hospital or a rehabilitation centre. They wish physicians would address this emotional dimension more openly (Chapter 3). Patients with cystic fibrosis are in favor of enhanced understanding of the psychosocial impact of care in isolation (Chapter 2). Chapter 6 provides examples of treatment and care from a non-dualistic mind-body stance. The patients in that study receive care from a multidisciplinary approach, and experience that their practitioners work from a more integral perspective on body and mind. They report that their care practitioners do not solely aim for physical recovery, but also focus on psychosocial wellbeing. They renew physical resilience and mental strength through shared learning.

These positive experiences are in contrast with the experience with the biomedical model, which, according to most participants in the study, still dominates health care practice. Other sources confirm the dominant focus on physical functioning (Ekman, 2011; Silva et al., 2010; Lapum et al., 2010; Karlsson et al., 2005; Teunissen et al., 2011).

In a biomedical model, events that happen to the body do not automatically happen in and to the mind; the physical and mental worlds are distinct (Mehta, 2011) and the body is – wrongly – positioned opposed to the subject (Slatman, 2009, p.113). The outcomes of our studies encourage practitioners to explore the preferences the patients express and be open towards alternative views on mind-body interaction. Other studies confirm the need to move beyond a biomedical model (Taylor, 2011, p.445; Merleau-Ponty,1968). They argue in favor of moving towards a biopsychosocial model that views bodies as expressive and social agencies (Taylor, 2011) and to understand the body in a more complex way (Slatman, 2009, p.113). An opening for humanization may be found in a psychosomatic and expressive view of the human body.

Clearly the patient's main concern is to recover physically, but patients would like to get more attention for other dimensions of their wellbeing. This phenomenological-existential perspective deals with themes such as time, space, spirituality, movement and vitality (Dahlberg et al., 2009). It regards people with a disease as interwoven with the world around them, their lives and their relationships (Dahlberg et al., 2009; Todres et al., 2007). Take, for example, the experiences of cardiovascular patients who are confronted with the proximity of death. When confronted with their disease they feel that the view they had of their future has gone. They may ask themselves what it means to have limited possibilities. What does it mean to know that life will end soon? This refers to the 'temporality' of their lifeworld, to the 'continuities and discontinuities of time as it is humanly experienced' (Todres et al., 2007, p.56). Another lifeworld dimension is 'spatiality', which is of great importance for patients with CF, who spend a substantial amount of time in hospital settings. People with CF are nursed in isolation when admitted to hospital (Chapter 2). As we have shown, this has a considerable effect on their experience of space and on their lifeworld.

Other studies confirm the need to include a patient's lifeworld in medical care (Todres et al., 2007; Charon, 2004; Galvin, 2005; Johanson et al., 2003; Frank 1995). Patients focus on questions such as: who am I with this disease in this situation? How do I relate to people that I meet in health care settings? What do I believe to be important for my wellbeing and how do I communicate my needs to others? From this stance, a person with an illness is seen as someone with a story that is historically, temporally and spatially situated. Being attentive and responsive to these features of the patient as a person with a lifeworld, is a prerequisite for attuning responsibilities.

Moral and narrative competences

Good intentions are not enough (Ward & Gahagan, 2010). Tronto expresses this well when she writes: 'Intending to provide care, even accepting responsibility for it, but then failing to provide good care, means that in the end the need for care is not met' (Tronto, 1993, p.133). To find out 'how to act'

does not simply imply a behavioral change. As we have seen above, a social practice should not be regarded as an accomplishment of purposive, knowledgeable actors (Giddens & Pierson, 1998). In order to mutually learn 'what should be done', people need to (learn to) be continuously morally sensitive to each other's values, preferences, knowledge and skills. Good care requires a shared understanding of the patient's lifeworld, preferences, expectations, felt responsibilities and being truly responsive towards them. Universal principles can be of help, but they are not sufficient. The patient's lifeworld may be accessed by eliciting and listening to narratives. Narratives are wholes that not only include experiences with illness, wellbeing, body and mind, but also a particular relationship history of the one doing the telling. And this, in turn, informs us about moral expectations and felt responsibilities. This requires practitioners to develop their narrative competence (Charon, 2004).

Understanding the meaning of the patients' experiences in the context of their lifeworld is an interpretative process that requires a dialogue. This includes the competence of interpretation and being responsive. A prerequisite for being competent is an open attitude.

The studies in this thesis shed light on moral competences that contribute to a personal and human approach. The development of moral competences is increasingly embedded in daily health care practices in the form of moral case deliberation or clinical ethics support (Porz et al., 2011; Widdershoven et al., 2009). These training models and deliberation methods aim to support practitioners in their search for shared understanding on relational and moral dilemmas and responsibilities. This helps fostering quality of care and a human approach (Abma et al., 2009).

The importance of interpretive and responsive research approaches

May scientific research provide openings for humanization? Only a small number of patients are able to benefit from knowledge developed by scientists (Woolf, 2008). To improve this, connections need to be made between scientific knowledge and daily health care practices. This can be fostered by using research approaches that work from an interpretive stance. A first approach is descriptive research: supporting practitioners and patients in enhancing the understanding of each other's experiences and preferences. This is the interpretive hermeneutic approach. A second approach is transformative: translating knowledge into programs, plans, policies and ethics. This is a 'formative' approach such as responsive evaluation (Dahlberg, 2009; Mertens, 2009; Charon, 2001; Widdershoven et al., 2009). We will now describe each approach in more detail.

Approaches that enhance our understanding of people's experiences, preferences and expectations in a contextual way, can be categorized as 'interpretive approaches'. An interpretive approach is grounded in the hermeneutic tradition. It comprises qualitative, quantitative and mixed methods. An interpretive approach views people as active meaning makers of experiences, embedded in local contexts. An interpretive approach acknowledges people's lifeworld. An interpretive approach does not aim to reduce realities, but to understand their complexity (Morehouse, 2012). It focuses on meanings that people create by relating to each other, rather than on information and behavioral dimensions (Bruner, 1990).

Formative research approaches regard research as a vehicle for learning and for developing practices. Responsive research regards the research process itself as a transformative practice. Instead of testing or describing the effectiveness of a health care program or intervention against a set of criteria from a single perspective, responsive research is understood as a democratic process that supports the implementation of change. The researcher in responsive research fosters a process that aims to enhance mutual understanding between the people involved. Responsive researchers have extended their role to being change agents (Mertens, 2012). They see research as a value commitment to a particular ideal such as democracy or social justice (Greene, 1997, 2010; Mertens, 2009; House & Howe, 1999) and, in the context of this thesis: humanization. Responsive research pays particular attention to the inclusion of several groups of participants, such as 'agents', 'beneficiaries' and 'victims' of research projects. Agents are those who have an interest in the research. Beneficiaries are expected to benefit from the process or outcome of the research, such as research commissioners or patient groups. Victims are those whose position might be damaged or negatively affected by the research (Guba & Lincoln, 1989), for example, people with vulnerabilities or less power. Responsive researchers feel responsible for determining and working with asymmetric relations between the participants involved (Baur et al., 2010). They are under no illusion that everyone should or can become an equal partner in the process, but they aim to include a variety of perspectives that are present in the research context. Because it is impossible to respond to and include all stakeholder perspectives or demands, responsive researchers need to systematically reflect on the steps they undertake. Particularly, they feel the presence of possible underidentification or overidentification (Chapter 9). When responsive researchers critically reflect on their position and choices, they nurture a human approach.

Table I: How interpretive and responsive research fosters humanization

Openings for humanization of interpretive and responsive approaches
Aims to improve our understanding of complexities of practices from a hermeneutical phenomenological stance. Inclusion of lifeworld of participants in the study. Works towards mutual understanding of similarities and differences of perspectives on the subject at hand. Regards knowledge as dialogical, relationally constructed. *Phenomenological-existential openings*
Research is a value commitment to an ideal. Normative stance of the researcher. Moral reflection on the research process and possible overidentification and underidentification. Openness, dialogue, inclusion. Supports reflexive practices by enhancing moral sensibility in health care practices *Moral openings*
Democratic, participative and developmental. Partnerships with the people whose interest is at stake. Acknowledgement of each person's authority. Co-constructing meaning. Research as a social practice. *Participative openings*

Methodological reflection

In the introduction, three criteria were mentioned with which the quality of our studies can be assessed: credibility, reliability and transferability.

Credibility

Credibility is the degree of correspondence between the researchers' interpretation and the participants' perspectives. The credibility of this study has been enhanced by following the procedures set out in the introduction. Member checks were conducted in all studies. This meant all interpretations of interviews or focus groups were shared with respondents. They received the interpretations by mail or email and were asked: does our interpretation match your experiences? Did we leave out important information? In some studies we worked in collaboration with the participants of the study. For example, Chapter 6 was written by ourselves together with one of the participants in our study, the physician. We used multiple data collection methods: interviews, focus groups, observations and occasionally journals written by respondents. This contributed to more balanced interpretations. The interpretations of interviews, for example, were checked during a focus group and if necessary, deepened in line with new insights. The final reports of the studies were written as thick descriptions. We kept a field journal in all the studies. This encouraged our self-awareness of theoretical assumptions and perspectives in relation to the study design, relationships with participants, and the development of the study. We debriefed with peers at least every three weeks. During these debriefings we critically reflected upon issues surrounding method and content. Some of the research reports included reflexive sections where the researchers, and research partners, reflect on this (for example the research reports of the studies included in Chapters 4,5,7,8,9). Moreover, the studies took at least 10 months. This prolonged engagement made it possible to better determine the significance of experiences of participants. The researcher in responsive evaluation is specifically responsible for who or who not to include in the research process. We reflected in particular on overidentification and underidentification and on how they influenced the inclusion of participants. Overidentification and underidentification might diminish the quality of our interpretation. Chapter 8 describes our learning process in detail and includes a grid that other researchers may benefit from.

Reliability

Reliability means that if the study were repeated, in the same context, with the same methods and with the same participants, similar results would be obtained. Reliability informs us about the degree to which results are independent of the propositions of the researcher, time and instruments. The study's reliability has been enhanced in several ways. Firstly, by providing the reader with detailed information on the research design and processes of selection and recruitment of participants, data collection and analysis and implementation strategies of our findings. This should provide the reader with sufficient information to repeat the research process. Next, during the content analyses of the data, multiple researchers coded the transcripts, which enhances inter-rater reliability. During the studies for Chapters 2-5, at least two researchers coded transcripts, compared the coding and discussed differences in interpretation. In the study in Chapter 3, inter-rater reliability was improved as a result of an analysis process among five research (partners).

Transferability

Transferability is the 'empirical process for checking the degree of similarity between sending and receiving contexts' (Guba & Lincoln 1989, p.241). As discussed in the introduction, we prefer the term 'petite generalizations', focusing on small understandings of a local situation that may mean something for others (Abma & Stake, 2001). By providing the reader with detailed descriptions, we aim to foster the transferability of the study. For example, Chapter 8 reports in detail about the practice of the responsive evaluator. Chapter 7 gives a detailed description of how a case was handled by a process manager and other participants in the practice. By doing so, we created conditions for the reader to have a vicarious experience. Vivid descriptions and narrative vignettes in the chapters provide the 'opportunity for vicarious experience' (Stake, 1995, p.86). This means the reader may experience what it is like to be in the practice through the researchers' texts.

Limitations and strengths

Because of the qualitative nature of the studies and the number of research activities involved, we worked with relatively small samples compared with quantitative research, and we were not always able to include all the people with a stake in our research. However, this enabled us to explore in depth the perspectives of those patients and practitioners who did take part. We strongly recommend further research into perspectives of practitioners and their relations with patients because practitioners are underrepresented in the studies in this thesis. The selection of studies and the relatively small samples may have led to selection bias. In order to overcome this to some extent, we collaborated in an international data synthesis to be able to reflect on the individual perspectives of patients of our studies, with collective perspectives in mind (Chapter 5).

A qualitative study that focuses on experiences of people from a hermeneutic dialogical perspective, could have been written in a more 'dialogical', contextual and narrative way. Despite the several narrative vignettes, texts could have taken up even more space than the current texts for multiple voices and self-reflexive sections (Abma, 1998). Only Chapter 8 explicitly includes our voice in self-reflexive texts. We chose to represent our findings in different ways because firstly we hope to invite readers from several disciplines to read and respond to our work. Secondly, we aim to publish in journals that are widely read in the field in order to – ultimately – establish connections between researchers and disciplines who work from different (ontological) stances.

The inclusion of several health care contexts provided us with different views on how people experience health care and what they expect from it. The 'maximum variation' criterion for selecting participants within indi-

vidual studies made it possible to access the richness and complexities of practices. The study included participants with several chronic diseases, some with high (cardiovascular), others with low incidence rates (cystic fibrosis). Another strength is the richness of our data. The data consist of transcripts of in-depth interviews and focus groups, field notes, inventories and observations. We enhanced the quality of our study by combining several data collection methods (triangulation). The societal impact and relevance of our study is high as we have worked from, with and in practices. Our insights have been shared with the people who participated in the studies and with several organizations and scientific audiences. Through member check procedures, participants cooperated when we were looking for ways to represent their experiences as well as possible. Our main goal was to enhance the recognizability of our representations by participants. We did not aim to validate historical facts about situations or events, but focused on the experiences and stories about them, on their narrative truth for individual participants (Schultz, 2011; McAdams, 2006; Spence, 1982). We regard our studies as a co-creation between the researchers, respondents and other participants. We are convinced that the, often enthusiastic and active, participation of people with a chronic disease and practitioners, has intensified the credibility and dialogic validity of our data. The relationships that we have established were not just functional or instrumental for the specific study at hand. We expect these relations to continue in the future and open up opportunities for new practice improvements. With this, we hope to have contributed to a *community of participants* who share our ideals and cooperate by sharing their authority on areas that are different from ours. In this context, we mention in particular the participation of research partners in the studies into people with cardiovascular diseases and CF, and the data synthesis.

We have illustrated the relevance of specific ethical concerns such as openness, reflection, genuine inclusion, shared ownership and translation to practice. Personal reflection is a necessary ingredient in our research approach. Chapter 8 demonstrates how identities, relationships and values influenced the research practice and the researcher and participants as people. It demonstrated that the author was not fully aware of processes of underidentification and overidentification. Reflection on the moral dimension of the study could have prevented this. We therefore believe it to be of the utmost importance to safeguard the quality of responsive research through moral reflection. There is a grid in Chapter 8 that may serve as a useful guide.

Implications for practice, policy and research

This thesis is published in a time when the health care system is burdened by severe financial and organizational difficulties. Health care is financially strained and practitioners see many patients in a short period of time. Reforms like efficiency procedures and quality of care programs aim to provide solutions. There is an increase in policies and practices that 'empower' users of health care services by examining their experiences closely and including them in care and medicine (Abma et al., 2009a; Abma et al.,

2009b; Todres, 2009). Including patient experiences in the development of health care services is accepted widely. For example the Dutch Consumer Quality Indexes (Delnoij et al., 2010, p.3; Rademakers et al., 2011), participation of patients in the development of Patient Reported Outcomes (Nicklin et al., 2010), involving patients in planning and development of health care (Crawford et al., 2002) and lean management. The latter aims to stimulate efficiency- and customer oriented thinking by process improvement within hospital settings. This thesis, however, shows that processes of interaction in daily health care settings are chaotic, unpredictable and part of a complex flow of events. According to the studies in this thesis, health care practices are social enterprises which cannot be reduced to one frame of meaning, one interpretation of responsibilities. Instead, the thesis learns that most of the time values and moral understandings conflict. Learning how to relate to conflicting values may be more fruitful than trying to control differences by, for example, predefined concepts and standards. We recommend further research on the application of these ideas to upcoming health care concepts like lean, shared decision making and self-management. Further conceptualization of these developments from a relational and moral stance is recommended. A relational and moral view presupposes that these new health care concepts are implemented as a joint learning process of patients and practitioners.

This thesis shows the significance of subtle relational features that inform practitioners and patients about moral appeals, expectations and questions on treatment and care. Learning to listen and becoming sensitive to the patient's perspective is the starting point of a human approach. Listening is a social and moral activity. Learning to listen is not only and not primarily a matter of promoting a motivational approach that 'stimulates' practitioners to learn individual listening skills; i.e. a behavioral method. Instead, learning to listen starts by reflecting on the practice of listening. In practice, listening is based on a felt responsibility and curiosity to understand what the other one is trying to articulate, where the other person comes from and what concerns he has. This contributes to a human approach. Therefore, health care practices should create space for the development of moral and narrative competences of practitioners and patients. Narrative sensitivity enables practitioners to 'enter the patient's circle' (Charon, 2011), to access the patient's lifeworld. Patients, in turn, may learn to systematically reflect on personal understandings of their disease in the context of their lifeworld and on how this influences their view on responsibility. Reflection on their illness story might provide them with experiential knowledge. The inclusion of experiential knowledge within the practitioner-patient relationship, may contribute to the allotting of decisional responsibilities.

A further implication for practice concerns the need to transcend disciplinary boundaries and to connect medicine, nursing, technology, humanities, health care policy and economics. We recommend additional policy and organizational management research that explores the relationship between financial, organizational structures and moral processes of humanization in health care. This thesis showed that a human approach is dependent on the way in which people continuously assign responsibilities to one another and respond to each other's needs. We plea for the conduction of single case studies. Case studies, as single, freestanding studies, can

be complementary to quantitative studies 'if clear algorisms and cause-effect relations are lacking or when it concerns strategic and value-laden moral issues' (Abma & Noordegraaf, 2003; Abma & Stake, forthcoming). They can also function as a vehicle for dialogue in responsive, transformative research approaches that foster humane practices.

Todres (2007) wonders whether humanization is a luxury. Should we pay attention to moral dimensions in health care practices given the costs? With Todres and others (Taylor, 2011; Todres, 2007; Charon, 2011; Dahlberg, 2009; Woolf, 2008) we believe that the opposite, not paying attention to a human approach, will have severe consequences. The more high-tech, cost-conscious and fast-paced health care becomes, the more we are confronted with boundaries. These boundaries challenge day-to-day interactions between practitioners and patients. The inclusion of a human approach in daily practices, research and policy is essential to preserve a healthy balance. This thesis shows that there are openings for that.

Epilogue

March 27, 2012

Hello Merel,

Thanks for your message. It sounds as though life with you is not unlike life here. So many things to do, so many things that cannot be done until just before or on the day itself. Jane keeps saying ''Have you tried those trousers on yet? What if they don't fit?'' Well, I will, I will. My trousers are not the most important thing in the world, I think. There are flowers to find, wild flowers, a church to be cleaned – a party of seriously dedicated ladies will do it tomorrow, I will join them. Tom has mowed the grass around the church and the village green between us and the porch. It all comes together. I just planted a tree for F and A, a coast redwood which, if allowed can live for 2500 years and grow to perhaps 100 metres – more when in California but that will do for us.

Everyone I speak to, asks about the wedding and has a smile – it's a great thing, people being married, it fills everyone with an optimism and goodwill. I'm sure it's the same around you in Gouda. I hope the joy on your wedding this Friday washes over everything, that the sun shines, the birds sing, the ...

Yes, I'm feeling good, making steady progress towards being fit again – (Was I ever so fit?). It's a complicated equation – healthy, unhealthy, no more smoking, side effects, growing older. Never a clear position, but – for the moment – not bad.

I failed to get to the Ackling show, but I will. We have to be in London twice in April. I imagine in this sun that he is working flat out – amazing energy, losing strength – There are other shows coming up in the summer – Berlin and Geneva – the man is unstoppable and it is a wonderful thing to see. And a lesson.

I think you will be pleased to complete this academic work – stick to your title but allow the other as a subtitle in smaller typeface. Then it will be 'Dr Merel' – wonderful. But – what next – really?

Work in the artstudio is beginning to flow again – also collecting some pieces of writing together and wondering who I know who can read it and give me a real literary criticism. How crazy can I be? – ''Can't make any money as a painter – I know, I'll be a poet''.

Every good wish for the wedding on Friday and for your life together beyond that. So sorry not to be there.

Love,
Bob

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