Chapter 1

Introduction
Yesterday I stumbled upon a letter from Bob. It had been hidden in a book I must have been reading last summer. I remembered the letter itself and the feelings it evoked in me. But over the passing months its special content was lost. I poured myself a coffee and sat down. Hesitating, glimpsing outside, thinking about our encounter the year before, I opened it again. A part of it read:

After I wrote to you I had to go and see our local doctor, a GP. It’s never clear who you will see of the five or six doctors who work in the practice. Because, until recently I had only been to the practice infrequently, a whole new set of people are in place. Yesterday I saw someone I didn’t know, an Australian (westerner from the east), 35 years, about a minor administrative matter and when that was done he gave me a rather strong look and asked if there was anything else I wanted – a delay from me, trying to work him out – then, Yes, I want a conversation.

And we had one – for thirty minutes. I ran my situation past him, told him my medical history which he didn’t know; he was rather sympathetic talking about how a kind of calculated indifference is cultivated around ‘collateral damage’. He was very good, he even used a few swearwords – and that’s something really special for a doctor and a sure indication he has stepped out from behind the mask of the professional. I shall cultivate him and one day ask him if he’d like to come for a meal some time, show him my art studio.

This ‘stuff’ helps me a lot. When I find myself in a different place my response is always to walk around, looking, looking, looking, getting the feel of it, getting to know it. I always do it because everywhere is interesting, has its own identity, its own differences. Cancer is like a new place for me, I learn. And, most of the pre-conceptions were completely wrong, as they usually are. Perhaps when it’s all over it will feel like, well – if not quite a holiday, then a kind of journey.

I held the letter in my hand and was slightly startled that I had not kept it in my ‘thesis box’. The box contains literary texts, poems, pictures and other things that I consider including in my book. I hadn’t been aware of it at the time. Bob’s letter embodied some of the themes and theoretical underpinnings of my thesis. Looking back, I now understand that Bob strongly highlights the ‘humanity’ he encountered when visiting a General Practitioner (GP) in Great Britain, which is where he lives. According to him, the ‘stuff’ that supports him includes a conversation with someone who takes off his professional mask and responds like another human being. It is also about becoming aware of your own preconceptions. That seems to happen along the way – with and without the support from his GP – as Bob is getting familiar with an unknown ‘place’ called cancer. As if he is seeking to find a new direction, trying new routines in order to continue the journey of his illness and his life.
Focus and scope

This thesis aims to understand how people experience and relate to modern health care practices. It explores the possibilities for humanizing those practices from the perspectives of people who have a stake in medicine and care. It is particularly interested in the experiences of people with a chronic illness who interact with care practitioners in in-patient settings. The aim of the study is to understand how patients and practitioners experience, safeguard and develop their own and others’ humanity within a context of modern demands.

In the last century, technology used to diagnose and treat illness and disease has advanced at an incredible pace. Modern health care flourishes on scientific knowledge and evidence-based medicine. However, at the same time these features of modernity are cause for concern. Present demands of health care settings involve situations that challenge us as people. Health care practitioners and patients experience discomfort during their encounters with the systems they move in. Practitioners report diminishing morale and professional fulfilment. They express a need for group affiliation, teamwork, and improved coordination (McHugh et al., 2011; Prins et al., 2010; Mechanic, 2010; Shanafelt et al., 2009; Linzer, 2009; Scott, 2003). Their work has speeded up, they consult many patients every hour. The time spent with a patient is reduced and this erodes the practitioner-patient relationship (Charon, 2001). On a more philosophical and existential level, patients experience a gap between their lifeworld and the medical setting they encounter (Ahizen, 2011). They expect health care practitioners to meet fundamental needs such as respect, recognition and acknowledgement (Teunissen et al., 2011; Karlsson, 2005). And the separation of fact and values in medicine is coming under ever increasing criticism (Taylor, 1993).

Many efforts are made in an attempt to improve treatment and care through efficiency and quality programmes. Examples include disease management, lean management, patient-centred care, shared decision making and self management. Existential and human dimensions are increasingly included in these standards, guidelines and programmes. They are, however, difficult to plan and are therefore not always found in daily practice. So what can be done when relying on new programmes and standards does not appear to be sufficient?

The tension between advanced techniques, between progress in general and personal experiences, can also be traced to other parts of society. This tension is a feature of our modern culture that values instrumental solutions to cope with an ambiguous and complex ‘interlocking world’ (Nussbaum, 1997). In this context, ‘interlocking’ refers to the inseparateness of patients, practitioners and the health care systems they move within. They are not just part of one practice that is disconnected from other social settings. Practices tend to be interrelated and people are ‘bound to other human beings by ties of recognition and concern’ (Nussbaum, 2006). The needs and aims of these groups are met and achieved differently in different circumstances (ibid).

Humanization

It might seem as though present health care practices allow little room for human and existential dimensions. ‘It might’ is used on purpose, because there may be situations where people, both practitioners and patients, seek and find ways to secure humanity in practices of medicine and care. We are interested in these processes of humanization.

This study aims to find openings for humanization while simultaneously preventing the creation of yet another ‘grand narrative’. It does not aim to replace one system with another. According to Zigmunr Bauman, in our modern society we cannot simply rely on instrumental principles and a ‘grand narrative’ of what a human practice is. He puts this well: ‘The demise of the power-assisted universals and absolutes has made the responsibilities of the actor more profound, and, indeed, more consequential than ever before’ (Bauman, 1995, p.6). When we speak of openings for humanization we mean situations within practices that take the perspectives and values of people who are part of the practice into consideration.

This 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 each other. Local contexts are dynamic, complex networks of interrelations, of the identities of the people involved, their dependencies and (normative) expectations of each other. Institutions, programmes or projects can be seen as moral ecologies; as a snapshot of vigorous processes between people in which they (implicitly) co-produce values, roles and relationships (Schwandt, 1995). The study questions how patients and practitioners experience their roles, relationships and values within moral ecologies. Answers may lead to a perspective on humanization from an open stance.

In order to find answers, the study explores the ontological dimensions of existence in health care practices itself: the practical activities and relationships that participants in the study experience and what they mean to them. The meanings of what they experience are not simply revealed, but can be known through social processes of interpretation (Gadamer, 1975). Such a perspective regards being human as dynamic and social, open and unfinalized. The patient or practitioner is always a ‘person-in-context’ (Larkin et al., 2006, p.106), someone who moves within situations that are often ambiguous and difficult to grasp. Throughout their lives, people respond and change because of how they experience events and situations. In a way they seem to be free, but at the same time they may feel restricted because of what they have encountered. They cannot move ‘outside’ their inner world to engage with the people and events outside because they are always part of a world. Their ‘relatedness-to-the-world’ cannot be ‘stopped’. This study explores the meaning and possibilities of this dynamic view on humanization in health care practices.

Research question

The thesis aims to understand how patients and practitioners experience health care practices. It investigates practices in which participants seek to find openings for humanity in medicine and care. The thesis wishes to contribute to the development of those practices by supporting humanity in medicine and care. 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?
Settings

The study focuses on local, complex and ambiguous health care settings. We focus in particular on chronic care practices, where patients often suffer from more than one chronic disease (more than 50% of the Dutch population over 55 has multi-morbidity, see Schram et al., 2008). People with a chronic disease generally experience several phases of healing and living with their disease. From the acute phase, where the first or recurrent symptoms occur to a phase of adjustment (physical, social, mental) and later on, acceptance (or not). Currently, depending on the severity and stage of the disease, people with a chronic disease enter either an integrated and multidisciplinary programme or they consult different practitioners themselves. These programmes are either group or individually tailored and in most cases designed to optimize the physical, social and psychological performance of participants (Tsiachristas et al., 2011, Busse et al., 2010; Lankhorst et al., 2008).

Despite efforts to foster a well-functioning integrated chronic care system, challenges remain. For example, financial challenges as a result of health insurance segmentation and the lack of incentives for insurers to substitute outpatient care with inpatient care (Tsiachristas et al., 2011). The solution is sought in a programmatic approach in which multidisciplinary teams of caregivers are reimbursed by an ‘all-inclusive’ payment for people with chronic conditions (ibid, p. 125). With this approach, chronic care will be provided in an integrated way by groups of providers. Each group becomes responsible for contracting providers and negotiating with insurers about output parameters. In order to enhance the design of chronic care, emphasis is put on better standards for care, well-defined performance indicators, written liabilities and clear responsibilities between health insurers, care groups and individual providers and better information technology to improve coordination between providers (ibid, p. 129). We do encourage the development and evaluation of integrated care programmes but we wonder how the patients and practitioners participating in these programmes experience possible tensions between standardization and humanization.

Philosophical and theoretical and underpinnings

‘Civiliser les théories, ce serait donc d’abord les complexifier et les ouvrir davantage.’

(Civilizing theories would be a process that would start by allowing complexity into them and opening them up more.)

(Morin, 2008, p. 1856)

This study is built upon theoretical notions derived from: (a) hermeneutic philosophy; (b) the value of personal accounts of particular experiences; and (c) practices of narration. This section describes these three theoretical underpinnings.

Hermeneutic philosophy

This study is based on the philosophy of knowledge known as interpretive or hermeneutic (Gadamer, 1975). Ontologically, it considers realities to be social constructions. According to Hans-Georg Gadamer, people interpret their situations not only consciously, but also preconsciously (Widdershoven, 2001). This occurs through a process of 'becoming at home in a situation by responding to it' (Gadamer, 1975, p.254). This is clearly expressed by Bob when, at the beginning of this Chapter, he wrote: “When I find myself in a different place my response is always to walk around, looking, looking, getting the feel of it, getting to know it.” From a hermeneutical stance, subject and object affect one another (Gadamer, 1975) and cannot be separated.

In his letter, Bob informs us that walking around in his new situation (having cancer) helps him get to know it. His knowledge and understanding of his situation is affected by other people and by how his body feels and responds to medical treatment. Understanding and gaining knowledge are not isolated events, but ‘part of a process of becoming involved in the phenomenon’ (ibid, p. 255). From this, knowledge can be seen as dialogical; the knower engages with the world around him, taking into account what society and its expressions mean. Knowledge is neither objective nor relative, but relational. To Gadamer (1975), philosophical hermeneutics is significant for our understanding of the world and for all the forms in which this understanding manifests itself, from interpersonal communication and personal experience to societal traditions, such as religion and law, art and philosophy.

Research from a hermeneutical philosophical stance does not focus on objective knowledge that is ‘out there’, but on dialogical knowledge that is value-laden and at the core of our being. The researcher’s main goal is the hermeneutic task of understanding the complexities of practices by relating to those practices. Understanding and interpretation happen through dialogue in which meaning is generated and transformed (Freeman, 2011). Hermeneutics is a ‘poetics of inquiry’ (Schwandt, 2004) rather than a methodology for research. This means that the way to access knowledge is not prescribed by a set of rules, but is the outcome of a way of being in and relating to the research setting. This ‘poetics of inquiry’ is the core of Chapter 9.

Multiple personal accounts

The study focuses on the meaning of personal experiences within the context of lifeworld and health care system. It describes and analyses ‘the particular’ (Nussbaum, 1994) in local health care practices through the lenses of multiple, personal and interrelated perspectives. It aims to learn from personal experiences and meanings endowed to these experiences in dynamic interactions with others. This study intends to find ways to nurture contact with people and to cherish dialogue and diversity of meanings.
Small sample personalized accounts of experiences provide us with as much learning potential as large scale findings (Abma & Stake, forthcoming). Brief accounts teach us about the way in which people move within the web of ordinary and complex events of their daily lives and how they respond to events (Schank, 2000, p. xi). Personal accounts are rich and include knowledge and understanding from an insider’s perspective. These accounts inform us about people’s preconceptions of and the richness of a specific practice. In addition to providing us with information, personal accounts are also performative: they evoke a response. When, for example, represented in the form of narratives they may elicit emotional identification and understanding (Denzin, 1989, p. 124, quoted by Humphreys, 2005, Schank, 2000). Next, they report on the processes that occur within practices, instead of solely focusing on outcomes.

Narrating is the process through which people articulate, understand and evaluate their personal and particular experiences. Given our focus on the personal experience of people, we aim to represent ‘the personal’ in this thesis accordingly. For that reason, some of the following chapters present narrative vignettes, in addition to the more traditional ways of representing findings. The vignettes enlighten personal experiences of individuals with health care.

**Practices of narration**

According to philosophical hermeneutics, people are ‘expressive agents’ (Taylor, 2011). This means that people are active interpreters of their world. Experiences and events do not have an inherent meaning, but people describe events in a meaningful way (Abma, 1999; Widdershoven & Smits, 1996). The patients and practitioners who participated in the studies for this thesis, were influenced by other people and their views on health and illness (Mold & Wolfe, 2006). This includes the perception of symptoms, changing personal behaviours that affect the course of the rehabilitative process and the return to daily activities (Hirani & Newman, 2005).

Narratives help ‘encapture’ the personal and particular (Nussbaum, 1994). Our view of narratives builds upon the relational and dialogical stance of hermeneutic philosophy. It regards people, relations and their evaluations of situations as being strongly entangled (Walker, 2007). Narratives provide an entry to understanding these concepts and their interrelatedness in an integral way. Instead of distinguishing personal aspects, interpersonal relations and moral judgements, narratives consider these dimensions as part of stories as ‘interpretative wholes’ (Schiff, 2006). The dimensions are not isolated, fragmented or easily assigned to categories. They tend to cover a complex set of intertwined experiences that affect one another. The researcher puts this set together into a ‘cogent understanding of meaning’ (ibid, p.25).

Health care practices can be considered as practices of narration. 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 practice of narration is inherently a moral practice because it informs us about normative expectations, dependencies between people and their (negotiated) responsibilities. According to Margaret Urban Walker, whose book Moral Understandings has inspired us profoundly, ‘morality itself consists in practices, not in theories’ (Walker, 2007, p.15). Morality is not about generalizing, predicting or explaining what is happening between human beings. We should rather attempt[s] to find out what people are doing in bringing moral evaluation to bear (...) on what they and others do and care about, and whether some ways of doing what they are doing are better than others’ (ibid, p.16).

**Research approach & methodology**

This section addresses the specific qualitative research approaches that this thesis follows. A research approach is informed by assumptions on how we view the nature of reality, what are the ways to acquire knowledge and the consequences for activities such as data collection and analysis. The latter are considered to be part of research methodology.

**Research approach**

We explored the research question by studying several health care practices with two aims:

1. to enhance our understanding of how patients and practitioners experience modern health care practices (Part A);
2. to learn of health care practices that aim to support the humanization of treatment and care (Part B).

Part A closely studies the experiences of people with cystic fibrosis and cardiovascular diseases: two chronic diseases with a different prevalence rate. Whereas cystic fibrosis is mostly diagnosed soon after birth, cardiovascular diseases generally occur after the age of 30. In addition, a study that aims to conduct a data synthesis of patient experiences in general is included. Part B presents studies of three different practices. In these practices, humanity is being valued and translated into pragmatic forms of health care. Firstly, we studied a project that aimed to enhance treatment, care and rehabilitation for people with Chronic Obstructive Pulmonary Disease (COPD) through a multidisciplinary programme (in- and outpatient). Secondly, we evaluated an initiative for integrated health care and social support for multi-problem families (outpatient). Thirdly, we evaluated our own role and responsibilities as researchers in the context of a multidisciplinary programme for palliative care (in- and outpatient).
Generally the studies in Parts A and B follow a qualitative research approach. A distinction can be made within qualitative research between descriptive and transformative approaches (Abma & Widdershoven, 2011). In Part A, a descriptive qualitative approach matches our research aim to understand individual experiences. The studies included in Part B follow a responsive evaluation approach to foster practices that aim for humanization. Responsive evaluation not only aims to understand and describe, but also actively develops practices. This means the researcher not only gathers perspectives, but also facilitates a dialogue on a variety of perspectives in order to work towards a mutual understanding between participants. The two research approaches and their methodologies are described below, before criteria to assess the quality of the studies and ethical considerations are presented.

**Part A: Descriptive qualitative research approach**

We followed a descriptive qualitative approach in Part A in order to understand people’s experiences of health care practices. A qualitative approach broadens the scope of evidence-based medicine by providing an enhanced understanding of how people make sense of their situation (Britten, 1995). As previously described, the study works from an interpretative stance (Gadamer, 1975). Qualitative studies that are conducted from an interpretative stance map out the complexity of meanings endowed to situations (Morehouse, 2012; Freeman, 2011). These studies acknowledge the complexity and ambiguity of contexts and regard people as actors who interactively give meaning to situations and events. This qualitative approach therefore focuses on meanings (rather than information) of participants regarding the subject at hand (Morehouse, 2012). The Method section below describes the sampling procedures, and the collection and analysis of data.

**Part B: Responsive evaluation approach**

The studies in Part B follow a responsive evaluation approach, which includes qualitative methods. Responsive evaluation research implies an approach that respects the differences in how people experience programmes and projects, including the researchers’ perspective. Responsive evaluation focuses on the perspectives of stakeholders, and aims to bring them into dialogue with each other (Stake, 1975; Guba & Lincoln, 1989; Abma, 1999, 2005, 2006; Abma & Widdershoven, 2008). Conducting responsive evaluation is a dialogical process between researcher, client, participants and others who have a stake in the research project. The evaluator elicits the multiple meanings, expectations and perspectives of these groups (Stake, 2004). Subsequently, people’s perspectives are exchanged and refined through a process where the researcher aims to generate a ‘shared construction’ of the perspectives of participants. The presence of conflicting perspectives or meanings is not negative, but may foster the learning process and quality of the dialogue.

Table 2 summarizes the philosophical underpinnings of the former section.
and the key concepts in our research approaches:

Table 2: Philosophical and methodological underpinnings (inspired by Morehouse, 2012).

<table>
<thead>
<tr>
<th>Question</th>
<th>Qualitative and responsive approach (from an interpretive stance)</th>
</tr>
</thead>
<tbody>
<tr>
<td>What do we believe about the nature of reality?</td>
<td>People interpret their world. Reality is socially constructed. Relational. There is more than one ‘truth’. Practices are complex and ambiguous.</td>
</tr>
<tr>
<td>What are ways to acquire knowledge?</td>
<td>Knowledge is contextual, relationally constructed. Tacit. Lived experience and narratives inform us about tacit knowledge.</td>
</tr>
<tr>
<td>What is the relationship between subject and object? What roles do values play?</td>
<td>Subject and object are strongly related. Non-dualist. Research is value-laden. There is no split between facts and values. Especially in responsive evaluation research work, from a subject and object perspective.</td>
</tr>
<tr>
<td>What is the aim of our research?</td>
<td>Qualitative research: in-depth understanding. Integral, holistic understanding. Responsive evaluation: transformation of practices in the light of humanization and social justice.</td>
</tr>
<tr>
<td>What methodologies for data collection and analysis contribute to these aims?</td>
<td>Preference for interpretative and interactive methods.</td>
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</table>

Methods

Each of the studies in Parts A and B follow a specific methodology, but generally the studies consisted of individual in-depth interviews and group sessions, occasionally enriched by the co-construction of narrative vignettes. The studies that were designed as a responsive evaluation (Part B) follow an iterative design that consists of a cyclical hermeneutical process (Abma, 2006) with stakeholders as partners who have a say in the study. Whilst the qualitative studies focused on understanding perspectives of one group (patients), the responsive studies aimed to work towards a mutual understanding of several groups (patients, practitioners) on the subject at hand.

This section briefly describes the sampling, inclusion of participants, the overall methods for data collection and analysis and subsequently highlights the main characteristics of each study. Precise descriptions of the methods are provided in the individual chapters.

Creating conditions and infrastructure

Each study starts by identifying the people who participate in the execution of the research itself, as a researcher, as a member of an advisory or steering committee, as a research partner or stakeholder. The degree of stakeholder participation differs according to the study design.

In three studies, patients were part of either the advisory team of a project (Chapter 2) or the research team of a project, as non-academic co-researcher (Chapter 3 or project leader (Chapter 4). Patient research partners are becoming increasingly active in research teams. Partners in this ‘inclusive research’ introduce their experiential knowledge in a process of collaboration with academic researchers (Abma et al., 2009; Nierse & Abma, 2011; Schipper, 2012).

In the cardiovascular study (Chapter 3), three research partners with a cardiovascular disease participated in the research process. Together we collected and analysed data and wrote the research report. We reflected on methodological steps and collaboratively presented the results of the study at several conferences. We invited them to cooperate in these research activities for several reasons. Firstly, we expected that their experiential knowledge would enhance the validity of our research project. Their experience with their illness could complement the researcher’s perspective (Hewlett et al., 2006; Schipper, 2010). Secondly, we regarded it appropriate to include them from a normative point of view: patients are participants whose lives will be affected by the outcomes of the research in one way or another. Given their role as end-users, we felt responsible for including them as research partners.

In the cystic fibrosis study (Chapter 2), one research partner joined the advisory team. Given the risk of cross infection, she cooperated from more of a distance than the partners in the cardiovascular study. This prevented her from cooperating with us in the major data collection activities. She did, however, contribute towards writing the research proposal, discussing the design and methodological decisions, testing the topic list for interviews, the interpretation of data. Once the project ended, she decided to share her experiences with her own lung transplant. Her narrative is included the intermezzo. The last study that included a research partner was initiated and managed by the same partner. It concerns a study on how patients appraise the quality of care and research (Chapter 4).

The study on cardiovascular practices (Chapters 3 and 5) was guided by a steering committee that met several times during the research process. Members of the steering committee were representatives of the Cardiovascular Group and the Cardiovascular Foundation. The study on cystic fibrosis was guided by an advisory committee consisting of the research partner and a representative of the Cystic Fibrosis Foundation (Chapter 2). The study on palliative care was closely monitored by members of the Consultation team and the funding client organization (Chapter 8). In order to critically reflect upon the course and outcome of the study on multiproblem families, there was an advisory committee that consisted of the funding commission and two advisors from stakeholders (Chapter 7). In all studies, the executing researcher worked within the research context under the guidance of her primary supervisors (Abma & Widdershoven). The supervisors functioned as critical peers, guides, coaches and teachers.

Sampling

The practices and participants were selected by purposeful, maximum variation sampling. This involves sampling as wide a range of perspectives as possible to capture the broadest set of information (Kuper, 2008). This supports learning about different perspectives on and the complexity of current health care practices.

Sampling of participants of the studies in Part A started with initial, explorative conversations with key persons in the settings and document
Chapter 1  Introduction

These activities informed us about factors that should be considered when defining the selection criteria for sampling. The criteria were developed with the advisory and steering committees. In one of the studies in Part A, the criteria changed because of problems with recruiting respondents. This involved the cystic fibrosis study in Chapter 2, where we eventually changed the criteria because new information came to light about the admission duration of patients.

The studies in Part B followed a responsive research design. The first important step of a responsive evaluation concerns the identification of stakeholders whose interests are at stake. Attention was deliberately paid to the identification of ‘victims’ or ‘silenced voices’ (Lincoln, 1993).

Data collection

Data were collected through semi-structured in-depth interviews. The interviews had the character of a natural conversation and lasted about 1.5 to 2 hours. Interview guides setting out topics were developed for all studies. The interview guides were developed by reading the relevant literature and discussing a draft interview guide with the research team, and sometimes the advisory team. Subsequently, the guide was tested during the initial interviews and changed if necessary. The interviews were conducted in a variety of places. The respondents chose where the interview would be held. Most interviews were conducted by one researcher. In some studies a research partner joined in the interview process. The researcher guided the interview and the research partner asked additional questions for clarification.

For triangulation purposes, after an interview round, data collection in several studies continued by organizing homogeneous and/or heterogeneous focus group meetings. Focus groups are semi-structured dialogues or discussions with groups of 4-12 people. Participants are encouraged to interact and explore issues together in order to deepen or enrich perspectives (Tong et al., 2011). Homogeneous groups consist of people with shared perspectives or similar backgrounds. Heterogeneous groups consist of a transdisciplinary group of people. The purpose of the group sessions depended on the project at hand. It varied from deepening, prioritizing or validating findings. In homogeneous groups, perspectives were deepened and enriched; heterogeneous groups supported the discussion on differences and similarities in perspectives. Focus group participants received a preparatory text with either questions or preliminary results. A protocol was developed for every focus group. Most focus group sessions lasted approximately 2.5 to 3 hours. Focus groups were moderated by one or two researchers with help from a research assistant.

All interviews and focus group sessions were digitally audio-recorded (after consent) and transcribed verbatim (line by line). Interview respondents and focus group participants received a report on the interpretations of the interview or outcomes of the focus group either by email or regular mail. They were asked whether they confirmed the report or had any additional remarks to make (member check). Sampling of new participants stopped when data saturation was reached (repeatedly no new themes were mentioned by new respondents).

Data analysis

While collecting the data, the researcher analysed transcripts and field notes and member checked her interpretations. The researcher invited respondents to react to interpretations of interviews and focus group sessions. Data collection and analysis are therefore intertwined in a hermeneutic cyclic process (Guba and Lincoln, 1989, p.178). This stimulates the collection of a variety of perspectives and links them along the way.

Data analysis varied according to the aim of the research project. Most studies involved a content analysis (Krippendorf, 2004) of interviews, focus groups and documents (e.g. case descriptions) combined with a more integral analysis of the narratives people shared (Riessman, 2008; Walker, 2007). A content analysis can be conducted deductively or inductively. We opted for an inductive content analysis starting with a close line-by-line reading of the transcript, and developing from there, a conceptual or coding scheme.

As mentioned, some chapters present the outcomes of an interpretative narrative analysis (Riessman, 2008). In addition to a content analysis, the researcher focused on the plot structure and linguistic devices (metaphors, silences, repetitions) that communicate meaning.

End report

Each study concluded with an end report. The report is sometimes deliberately written for dialogue (Abma, 1998). This meant that our research outcomes are presented as a ‘working document’: a contextual and thick description (Geertz, 1973) that was discussed during one or more focus groups or expert sessions. It provides readers with detailed information that enables them to determine whether (parts of) the study can be applied to their situation (this is part of the quality procedure, see next section). Other studies end with a report that summarized, represented and discussed our main findings and the applicability of them for daily health care practices.

Quality procedures

It is generally accepted that qualitative research requires specific procedures to enhance validity and reliability. Checklists and procedures may stimulate the researchers’ awareness of the route that is travelled, from what position and why. Yet we should be critical of the un-thoughtful application of these procedures. Rosaline Barbour (2001) convincingly argues that technical fixes ‘will achieve little unless they are embedded in a broader understanding of the rationale and assumptions behind qualitative research.’ (p. 1115). In line with this critical stance, we use quality procedures as a vehicle to question the quality of our work. One of the chapters in this thesis presents the researchers’ moral stance (Chapter 9).

Criteria to judge the quality of research traditionally include internal and external validity and reliability. The Table summarizes the meaning of quality criteria for qualitative study contexts.
Table 3: Criteria and procedures to enhance the quality of qualitative research

<table>
<thead>
<tr>
<th>Criterion</th>
<th>Meaning of criterion in qualitative research contexts</th>
<th>Definition</th>
<th>Procedures to meet criterion</th>
</tr>
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<tbody>
<tr>
<td>Reliability</td>
<td>The degree to which results are independent of the perspectives of the researcher, time and instruments.</td>
<td>Researcher reflexivity. Logbook or diary. Code checking. Multiple coding. Triangulation.</td>
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</tbody>
</table>

Credibility

Internal validity informs us about the ‘truth value’ of a given inquiry (Guba & Lincoln, 1989). It asks how we can be certain about the truth of the findings and their correspondence to the world ‘out there’. In qualitative research, one can speak of ‘credibility’ as the degree of correspondence between the researchers’ interpretation and the participants’ perspectives (Guba & Lincoln, 1989, p.237). One procedure to enhance credibility is to consider the perspectives of various participants. This also involves including the perspectives of marginalized groups, of people whose ability to share knowledge and experience differs from the majority of stakeholders. A fair inclusion of perspectives supports the credibility of a study and stresses the responsibility of the researcher to create conditions for open exchange between participants (Abma, 2006; Abma & Widdershoven, 2008).

Other procedures include member checks (Meadows & Morse, 2001). This means participants are invited to react and reflect on the researcher’s interpretations. Testing one’s interpretations among respondents is a vital quality procedure. This means not merely checking the transcript of an interview or focus group, but the researcher’s interpretation of what is being articulated, meant and – in case of responsive evaluation – brought into dialogue. The hermeneutical dialectical process naturally includes checking interpretations and inviting participants to respond to interpretations of others. Respondent validation acknowledges the respondent’s authority, and is particularly suitable in transformative research to create co-ownership (Barbour, 2001).

Triangulation encourages the inclusion of different perspectives to gain a more informed, and holistic understanding of the phenomena studied. Data triangulation means the researcher benefits from several data sources at the same time, such as the experiences and perspectives of a variety of participants. Methodological triangulation involves the use of several data collection methods, such as interviews, document analysis, keeping a reflexive journal, conducting a literature review, and organizing focus groups. Member checks and several triangulation methods aid researchers to determine whether data saturation has been reached or not. Data saturation occurs when no new perspectives emerge during fresh data collection activities. According to the literature, this happens after an average of about 12 in-depth interviews (Guest et al., 2006). Our studies confirm this.

Reliability

Another criterion to assess the quality of qualitative studies is reliability. This informs us about the degree to which results are independent of the propositions of the researcher, time and instruments. This closely relates to the ability to replicate the research project. The section on the philosophical underpinnings of this thesis describes the connectedness of subject and object, of researcher and the research setting. The reliability of a qualitative study can be reduced by providing the reader with information on the prejudices and identifications that may have biased the processes of selection, data collection and analysis.

A reflexive journal is a way of keeping track of the research process and the researcher’s role in it (Abma, 2005). Peer debriefing involves sharing one’s interpretations with peers and exploring what researcher prejudices are at play. Reflecting on the influence of over- and under identification and the dynamics of a research setting is important. The researcher and his/her peers may explore the question as to whether over- and under identification can be prevented and if yes, how. Research reports could, for instance, include reflexive sections where the researcher and his/her peers reflect on these aspects. The reader of the report evaluates whether the research can be conducted in the same manner, or whether the results have been biased. Finally, multiple coding and co-checking, where multiple researchers compare and discuss their interpretations, is a way of reducing bias.

Transferability

External validity relates to generalizability and deals with the question whether our findings are transferable to other contexts (Guba & Lincoln, 1989, p.234). From an interpretive paradigm, generalization involves the ‘empirical process for checking the degree of similarity between sending and receiving contexts’ (Guba & Lincoln, 1989, p.241). The reader of the research report determines the transferability of the findings to his or her context. In line with Stake, we prefer to speak of ‘petite generalizations’ that aim for small understandings of a local situation (Abma & Stake, 2001).

In order to do this, the reader needs detailed information. This supports him in judging whether conditions match or not. One of the procedures to meet this criterion is ‘thick description’ (Geertz, 1973) which challenges the reader to check interpretations by offering a detailed description that reads...
like a vicarious experience of how the researchers arrived at their interpretations and results.

A further way to enhance a study's transferability is referential adequacy (Abma, 1996), which refers to the collection of data that indirectly relate to the research setting, such as brochures and photographs. These data inform us about the context of the research setting and are used to write the thick description.

Ethical considerations

All studies aim for informed consent, anonymity and respect for privacy/confidentiality. After consulting the Dutch CCMO (Centrale Commissie Mensgebonden Onderzoek), it appeared that the studies did not need to be submitted to an accredited Medical Research Ethics Committee (aMRIC) for approval. In all studies, we worked with informed consent forms, and participant names were not used in any of the research reports. Pseudonyms were used instead.

This thesis highly values: openness, reflection, genuine inclusion, shared ownership and translation of our findings towards daily practice. Openness refers to an attitude of genuine listening to participants, hearing what they are trying to articulate and actively responding to and working with their perspectives. Reflection meant we took the time and space to contemplate, to sit back and rethink our interpretations and findings in order to explore whether we had been influenced by power structures, funding relations or personal identifications. Reflection is not solely a procedure to enhance the study's quality, but is appreciated as a moral responsibility that relates to the sincerity of our efforts. Actively collaborating with research partners and respondents (from inviting them to react to our interpretations to commenting on draft of reports) increased their sense of ownership. Shared ownership encourages participant involvement and the translation of research results into daily health care practices.

Reading guide

This thesis consists of two parts.

Part A presents four Chapters on experiences of people with a chronic illness with health care practices. Chapter 2 describes the perspectives of people with cystic fibrosis (CF). It provides an insight into the experiences of people with cystic fibrosis with their hospital admission. Two chapters in Part A present the experiences of people with cardiovascular diseases. Firstly Chapter 3 on what cardiovascular patients have to say about psychosocial support. Chapter 4 presents a woman with cardiovascular disease, whose narrative informs us about the importance of ‘understanding’ one’s illness. Part A ends with a presentation of how patients appraise quality of care and health research. The intermezzo presents a personal account: the narrative of a woman with cystic fibrosis on how she decided ‘to be or not to be placed on the waiting list’ for a lung transplant.

Part B presents three studies that give an insight into how patients and practitioners (including researchers) search for openings for humanization. The three chapters contain several case examples, some of which in the form of narrative vignettes. Chapter 6 concerns a responsive evaluation of a multidisciplinary approach for people with COPD. Chapter 7 analyses the course of a process manager when she experiences challenges working in a highly ambiguous context of an integrated health and social service network. The last chapter in Part B is written from the viewpoint of a responsive researcher and critically reflects on the relational practice of responsive evaluators. This thesis ends with a General Discussion that integrates the findings of the chapters in the context of the research question.

References


Chapter 1  s  Introduction


Evaluation (7)(2):253-263.