This thesis is about hermeneutic bioethics and how it works in practice. Hermeneutic bioethics starts from the premise that our moral understandings and the ethical stances we take, the understandings of our practices as well as the way we adhere to values and norms are fundamentally interpretive. It assumes that we interpret ethical norms or principles differently due to our diverse cultural and social situatedness which lays the ground for our different moral understandings. Hermeneutic bioethics proposes to approach ethical questions in health care by fostering mutual moral inquiry and dialogue through which diverse moral interpretations are tested and moral learning is made possible.

Hermeneutic bioethics developed over the last decades. Much theoretical research has been done in hermeneutic bioethics, while at the same time it is successfully at work in bioethical practices as clinical ethics, long term care ethics, or empirical bioethics research. But not much is known about how hermeneutic bioethics is practiced. The aim of this thesis is therefore to investigate how hermeneutic bioethics is actually at work in the field. The central research question of this study is how the theoretical ethical ideas of hermeneutic bioethics work in clinical ethics and empirical ethics and what kind of practical and theoretical conclusions follow from this. This thesis has two parts: Part 1 focuses on reflections and case examples of hermeneutic clinical ethics consultation. Part 2 presents the findings of an empirical research project on wishes to die of cancer patients in palliative care. The first and the last chapter are the theoretical frame of this thesis. While the first chapter gives an introduction of hermeneutics as an approach to bioethics and delineates four characteristic aspects of this type of approach, the last chapter takes up these four aspects to answer the research question on the basis of the practical examples from part 1 and 2 of the study.

Chapter 1 explains the philosophical concepts underlying hermeneutic bioethics and places it within the broader development of ethics and bioethics. Hermeneutics maintains that all we know we know because we interpret it against the backdrop of our practically and socially gained fore-conceptions. This way of meaning-making is simply part of our epistemic human condition. Even though it is impossible to get the entire fore-structure into the view and thus arrive at a presuppositionless, objective understanding, we are able to become aware of the fact that we reason on the basis of our fore-understandings. For bioethics, this implies to acknowledge that we differ in the interpretation of our moral experiences, just as we differ in the fore-understandings through which we interpret what is morally at stake. Further, if our moral understandings (including our ethical principles and normative theories) are interpretive, we cannot assume that we are able to explain or justify them exhaustively through abstract, objective reasoning, or from an exclusive monological perspective. For hermeneutics the best way of moral reasoning, is therefore to come to ethical evaluations through the confrontations with others who think differently. In negotiating our understandings with the other through dialogue, we can establish what is right for us by reviewing and refining our moral understandings.
This chapter also lines out four main theoretical assumptions of hermeneutic bioethics: First, the importance of the exploration of subjective meaning. If there is no single moral truth, the first step in the ethical evaluation must be that we investigate how we and others interpret principles in the light of our particular experience and local epistemic traditions. Second, the importance of the ethical evaluation through a dialogical process: Hermeneutics assumes that it is inappropriate to deduce a solution from a seemingly objective canon of a priori established principles. If there is not one moral truth, the dialogue between different moral perspectives is of primacy concern. Third, the importance of moral learning: By gaining insights into alternative moral descriptions and ways of justification, we can modify and correct our own ethical evaluation and the moral claims we have towards ourselves and others. And fourth, the consequences for the role of the bioethicist and ethical theory: Instead of giving prescriptive, specialized advice versus moral learning) and the role of participants and the ethicist and about what it means to ‘facilitate’. The article ends with describing five important functions of ethical theory in the dialogical approach.

Chapter 3 analyses the features of hermeneutic clinical ethics and the consequences for the roles of the clinical ethicist more generally. It also discusses the synergies with and differences from two other clinical services that touch upon moral questions: pastoral care and psychosomatic counseling. It opens with a description of the aim and functions of clinical ethics consultation from a hermeneutic perspective. In line with Margret Walker, the main task of ethics consultation is seen in the function to keep reflective spaces open in the clinic and to foster a social process of mutual accountibility and negotiation. Referring to the writings of Richard Zaner and Georg Agich it is discussed that ethical problems are situated and co-constituted in complex ways through the various interactions and social context of those participating in a consultation, including the bioethicist. The chapter ends with a critique of the ‘expert-model’ of the clinical ethics.

Chapter 4 is a reflection on a clinical ethics consultation during an internship at the Cleveland Clinic Foundation, U.S. It describes the story of a complex ethics consultation with a COPD patient denying all options for further treatment. This text was published in a book with the subtitle “cases that haunt us” and describes aspects of the case that made us reflect in the time after the consultation. Several challenges to this consultation are described. Among the haunting aspects on which we elaborated is whether ethics consultants mislead a patient when they take over the patients’ religious vocabulary. What about the consultants’ own spiritual beliefs? Do they not necessarily influence the conversation? And what about the fine line between supporting a decision-making process and abandoning the patient by not providing guidance when referring to God as a decision maker? The article ends with four questions (as didactic tools) to foster further reflection and discussion.

Part 2 Hermeneutic empirical bioethics

The second part of this thesis contains four articles. It provides an example of how hermeneutic bioethics works in the field of empirical bioethical research. It presents findings of the research project “Terminally ill patients’ wish to die. The attitudes and concerns of patients with incurable cancer about the end of life and dying.” This interview-study with 30 palliative care patients, their families and health care givers aimed to investigate wish-to-die statements of palliative care patients in the last days of their lives. Based on the empirical results, we developed a model, that we called “contextual anatomy of the wish to die”. This model can provide help to health professionals to identify the various aspects a wish to die might have for the person who expresses it. We identified three dimensions as important for a better understanding of a wish to die: a) the intention of the wish to die, i.e. what the wish is aiming at, b) the motivations underlying this wish, i.e. why the wish is present, and c) the social interactions that surround this wish to die. The articles that are presented here, each tackle a different aspect of this model. The entire model is described in chapter 7 and more in detail in chapter 8.
Chapter 5 addresses the dynamic and complex character of wish to die statements and how misunderstandings about them can lead to tensions in palliative care teams. It investigates the fact that patients not only oscillate in time in what they wish, but frequently express various, seemingly opposing wishes towards life and death at the same time, which health professionals often regard as a sign of an ‘ambivalent’ attitude. On base of two in-depth case analyses, the experience of patients’ ‘ambivalent’ wishes to live or die near the end of life and the reactions of others are explored. The analysis shows that many patients (as most of us in everyday life) base their wishes on different moral values important for their identity, which they themselves in general do not perceive as contradictory. The article concludes that health professionals should not label patients for this seemingly ambivalent attitude.

Chapter 6 illustrates our findings with regard to the first aspect of the model: the intentions a wish to die can have. We found nine different intentions. The first significant differentiation between intentions regards the fact that some wishes to die are also wishes for hastening death, while in others the wish to hasten death is absent. The second important differentiation between intentions is that some wishes refer to an imaginary situation, while others are linked with concrete actions towards dying.

Chapter 7 reports the findings with regard to the second aspect of the model: the motivations underlying a wish to die. In the article these motivations of a patient’s wishes are distinguished in subjective reasons, meanings and functions a wish to die can have. Next to the self-reported reason that patients saw as underlying their wish to die, they also reported about the wider meanings this wish had for them. These meanings mostly contained moral reflections in narrative form and were based on larger frames of values that contributed to personal identity. Finally, we found that some wishes to die had a function in the patient’s life, either in relation to the inner, personal life or with regard to others.

Chapter 8 gives an overview of the entire phenomenological model of the ‘anatomy of the wish to die’ and a summary of all research findings together. It starts with a case narrative that illustrates the complexity of wish-to-die statements, and it points out the difficulties in talking about these wishes for others. In this chapter, the third aspect of the model, the effect of social interactions on the wish to die, is discussed more in detail. We found four ways in which the particular social relationships had an influence of what the patient was wishing: 1. wishing with respect to others, 2. constitutive preconceptions of others, 3. performative effects, and 4. master narratives.

Chapter 9 discusses the practice of hermeneutic bioethics, reflecting on the previous chapters. After a short summary of hermeneutic theory, the examples of practical hermeneutic work in clinical ethics and empirical bioethics are analyzed in the light of the four characteristics for hermeneutic bioethical theory outlined in the first chapter.

Regarding point 1) the importance of the exploration of subjective meaning, our studies on hermeneutic clinical ethics have demonstrated that the exploration of subjective moral meaning is indispensable for understanding what is morally at stake for those concerned. The investigation of moral narratives helps to link particular moral claims to personal values, self-understandings and moral commitments. It illuminates diverse epistemic knowledge, and helps to surmount prejudice through a deepened understanding of the other person’s perspective. Detailed knowledge of moral meanings is therefore imperative for an ethical evaluation in a dialogical sense. In empirical ethics research, our studies showed that hermeneutic investigation of subjective meaning enables the exploration of the complex moral reasoning behind moral phenomena such as wishes to die statements and therefore provides a deeper insight into how people do their moral work in linking moral self-understandings, values, social commitments and reasons for action.

Related to point 2) Ethical evaluation through a dialogical process, we learned from the studies on hermeneutic clinical ethics that a dialogical approach is epistemically more justifiable than a monological one, as it establishes truly inclusive, participative, democratic processes of ethical evaluation in establishing what is right through the dialogical testing of different moral claims. In hermeneutic empirical bioethics, the dialogical approach offers an alternative to more hierarchical research approaches and their consequences for the researcher-subject-relationship. Adopting a dialogical approach makes researchers not only aware of their own impact on the research process, but allows them to see their contribution as a creative and critical part in the process of meaning-making during research. In both bioethical settings, a dialogical approach furthers collaborative evaluation, richness and reflexivity of arguments and more responsible ethical justification procedures and knowledge.

As to point 3) the importance of moral learning, our studies have illustrated that moral learning is a crucial element of hermeneutic bioethical practice. Through dialogue with others, one can gain a deeper insight into a moral problem and revise and refine one’s views and arguments. While in a clinical setting this leads to a better understanding of each other, fosters communication and provides a basis for finding shared solutions, in empirical research this engenders a cyclical process of knowledge generation in which normative or theoretical ideas are revised through a critical-dialogical process of understanding the data. In discussing this point, it is also given an answer on the question how normative conclusions are drawn in a hermeneutics research project and how hermeneutics envisions the relation between the empirical and the normative.

Regarding point 4) consequences for the role of the bioethicist and ethical theory, our studies have demonstrated that hermeneutics in clinical practice requires ethicists to take an active and participatory role in the process of joint deliberation by sustaining dialogical evaluation and moral learning, while reflecting critically on the fore-understandings and preconceptions they themselves refer to in their performance. For empirical research, the ethics researcher needs specific hermeneutic-dialogical and
theoretical ethical skills. Hermeneutics acknowledges that the researcher has an influential role during the entire research process, as the researcher’s preconceptions, fore-understandings and performance are co-constructive in the interview. Ethical analysis requires methodological steps for strengthening transparency and self-reflexivity during the research process.

After this analysis, the chapter addresses three critical issues frequently raised against hermeneutic bioethics: 1) the alleged tendency towards relativism, 2) the suggestion that hermeneutic bioethics remains on a descriptive level of interpretation, and 3) the limits to the level of understanding and agreement that can be achieved through dialogue. It concludes in lining out points for future research in hermeneutic bioethics.

Curriculum vitae

Kathrin Ohnsorge was born on the 7th of April 1972 in Paderborn, Germany. She studied philosophy, history and art history at the Universities of Bonn, Rome, and Basel and graduated in philosophy in Basel in 2001. From then until 2005 she was research assistant at the Institute of Applied Ethics and Medical Ethics at the University of Basel, with a break of a one-year leave, when she was as a visiting researcher at the Fondazione Lanza in Padua in 2003. In the same year, she also graduated from the “European Master in Bioethics”, a postgraduate master program that run over two years in the Universities of Leuven, Nijmegen, Padua and Basel. From 2005, she worked for two years as a research assistant for the Federal Office of Public Health of Switzerland at the University of Basel, for an EU-funded European joint project on genomics. From 2006 to 2012 she worked at the Unit for Ethics in Biosciences, University of Basel, where she took part in the research project on wishes to die of cancer patients in palliative care, which became part of her PhD thesis. Since 2005 until today she teaches in two postgraduate bioethics programs at University of Padua. Currently she is employed as a bioethics researcher at the Hospiz im Park in Arlesheim, Switzerland, for continuing the research on wishes to die in palliative care, this time on non-oncological patients. Her main focus of research is on palliative care ethics, but she also publishes and teaches on different topics of the ethics of elderly care, long-term care and clinical ethics. She is married and the mother of two boys, 8 and 5 years old. She loves to practice and teach yoga and Sat Nam Rasayan.