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Human Dignity

A Study in Medical Ethics



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Abstract

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Human dignity is an enunciated ethical principle in many societies, and it has elicited a great deal of interest, not least because it is central in health care. However, it has also been the subject of criticism. Some have argued that it is sufficient to rely on a principle of autonomy, and that dignity is a redundant principle or concept in health care. Other discussions have focused on the precise meaning of dignity, and how a principle of dignity should be interpreted and applied. This dissertation discusses questions on the principle of dignity and the meaning of the concept. In addition to a theoretical analysis of these questions, a qualitative research study has been carried out, based on interviews with physicians in palliative and neonatal care, and hospital chaplains, looking at dignity at the beginning and end of life. This dissertation can be categorised as empirical ethics because of its methodological approach. Based on a narrative analysis of the interviews, the results from the study shed light on the theoretical discussion on dignity. Through the history of ideas, dignity has often been linked to human abilities such as autonomy and rationality. However, autonomy is only one of the aspects which emerged from the qualitative research in this dissertation. Other aspects introduced into the discussion on dignity include human vulnerability, interdependence and the responsibility to face vulnerability in others. Some theoretical perspectives on dignity are criticised in the light of the empirical results. Furthermore, the dissertation includes a theological perspective where a Christological view – connected to Bakhtin's ethics of responsibility – forms a critique to both the Kantian deontological perspective and dignity acquired by virtue. The dissertation also considers how the results can be applied to medical practice.

Keywords: Human dignity, Medical Ethics, Empirical Ethics, Narrative Analysis, Christian Ethics, Vulnerability, Autonomy, Responsibility, Mikhail Bakhtin, Palliative Care, Neonatal Care

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Introduction

In the last two decades the discussion on human dignity has been intense and has included many areas of concern. Researchers from academic fields such as philosophy, theology, medicine and law have contributed, and topics dealt with have ranged from the conceptualisation of human dignity, to the relationship between human dignity and human rights¹ and how to interpret a principle of human dignity in medical treatment. The field of research last mentioned is the focus of attention in this dissertation.

In many countries human dignity is an enunciated ethical principle which should guide medical treatment. For example, in *the Swedish Health and Medical Services Act*, it is prescribed that medical treatment should be given with respect for all humans' equal value and dignity.² Human dignity is also one of the ethical principles that should be considered in priority settings within Swedish health care and medical services.³ On an international level, references to dignity are also common; they are, for example, included in the ethical codes of nurses and physicians.⁴ The significance of regulation in medical treatment is seen also

¹ For discussions on the relationship between human dignity and human rights, see for example Waldron, Jeremy: *Dignity, Rank, and Rights*. Dan-Cohen, Meir (ed.). The Berkeley Tanner Lectures. Oxford University Press, New York, 2012. Kateb, George: *Human dignity*. Belknap Press of Harvard University Press, Cambridge MA, 2011. Habermas, Jürgen: "The Concept of Human Dignity and the Realistic Utopia of Human Rights", in Corradetti, Claudio (ed.): *Philosophical Dimensions of Human Rights: Some Contemporary Views*. Springer, Dordrecht, 2012.

² Socialdepartementet: *Hälso- och sjukvårdslag*. 1982, SFS 1982:763, § 2.

³ Socialdepartementet: *Prioriteringar inom hälso- och sjukvården*. 1996/97, Proposition 1996/97:60. In the government bill it is suggested that priorities within health care should be based on three ethical principles, of which the principle of human dignity is one.

⁴ The International Council of Nurses states in its code of ethics that "Inherent in nursing is a respect for human rights, including cultural rights, the right to life and choice, to dignity and to be treated with respect". International Council of Nurses: *The ICN Code of Ethics for Nurses*. 2012, p. 1. [Http://www.icn.ch/images/stories/documents/about/icncode_english.pdf](http://www.icn.ch/images/stories/documents/about/icncode_english.pdf). (Downloaded 13 July 2016). Furthermore, in the

in, for example, *The Universal Declaration on Bioethics and Human Rights* (2005).⁵ Human dignity also stands as a foundational value in the United Nations' *Universal Declaration of Human Rights* (1948), where in article one it is stated: "All human beings are born free and equal in dignity and rights."⁶

Even though the idea of human dignity has a central role in many guiding documents for medical practice, the discussion continues about the meaning of the concept and the interpretation and application of the principle of human dignity. Regarding these matters there are a plethora of understandings, and criticism has also been voiced against the very notion of human dignity. Some have claimed that dignity only means respect for autonomy and as such is a 'useless concept' in medical treatment.⁷ Some of these concerns relating to medical ethics and dignity will be explored in this thesis.

Aim and research questions

Within medical ethics, the idea of human dignity is often discussed in connection with questions concerning the beginning of life and the end of life. The method used has often been to conduct a critical analysis on the subject of human dignity, and the results of such a study have then been applied to specific medical-ethical concerns. However, in this dissertation another perspective is presented, namely an examination and discussion on human dignity which is empirically informed. This means that the starting-point for the discussion on dignity is contextualised through medical practice, more specifically neonatal and palliative care. Hence, the present research project also includes empirical research. The research study examines different perspectives from the medical practice that would be of importance to include in a comprehensive ethical analysis on human dignity.

code of medical ethics, the World Medical Association refers to the principle of dignity: "A physician shall be dedicated to providing competent medical service in full professional and moral independence, with compassion and respect for human dignity". World Medical Association: *WMA International Code of Medical Ethics*. Adopted 1949 and amended 1968, 1983, 2006. [Http://www.sls.se/Page-Files/229/intocode.pdf](http://www.sls.se/Page-Files/229/intocode.pdf). (Downloaded 13 July 2016).

⁵ UNESCO: *Universal Declaration on Bioethics and Human Rights*. 2005.

⁶ United Nations: *The Universal Declaration of Human Rights*. 1948, article 1.

⁷ Macklin, Ruth: "Dignity Is a Useless Concept", in *BMJ* Vol. 327, No. 7429, 2003.

The overall aim of the study is as follows: To formulate an empirically informed and context-sensitive constructive proposal on human dignity and show how a qualitative research study can concretise and challenge conceptions of human dignity. Furthermore, the study will also consider the implications such a constructive proposal would have on medical-ethical concerns.

Two main questions are guiding this study, and the first one is as follows: What is meant by the concept and the principle of human dignity? In the study, a critical examination will be conducted on some theological and philosophical theories on the meaning of the concept of human dignity, as well as on a principle of human dignity. These theories provide different answers to the question posed. In addition to a purely theoretical analysis I will also analyse what a plausible understanding of the meaning and principle of dignity could be, given a critical ethical analysis complemented by an empirical analysis.

The second question is related to the first one: How can the results from the qualitative research study concretise and challenge certain conceptions of human dignity? This question is important to research since the results of the empirical study provides contextualised perspectives from medical practice. When these results are discussed in relation to conceptions on human dignity, one can analyse whether certain perspectives – in the theoretical approaches – have been neglected or made invisible. Moreover, the contextualised results can thus provide important views to take into consideration in a constructive proposal on dignity.

A short history of medical ethics and methodological approaches

A central aspect of this dissertation is that I have chosen to combine empirical research with an ethical analysis, a method which has gained increasing interest in the last 20 years. I will point to certain aspects of the American and European history of medical ethics and bioethics, especially in the 20th century, to give a brief context to the history of medical ethics and the methods which have been dominating, and to put my deliberation on empirical ethics into context.⁸

⁸ If one regards medical ethics from a global perspective, alternative ways of understanding the history of medical ethics can be seen, and, in addition other ethical values

The history of medical ethics is intertwined with the history of bioethics. Bioethics has for example been described as a newer version of medical ethics.⁹ Even though the terms ‘medical ethics’ and ‘bioethics’ can be understood as relating to similar topics and sometimes are used interchangeably, I will distinguish, between the two in the dissertation. I consider medical ethics to include a critical and ethical analysis of issues in health care. These can include medical-ethical questions regarding specific technical-medical issues, such as organ transplantation or abortion. The issues can also regard the relation between health-care professionals and patients, as well as questions relating to social ethics.¹⁰ I regard the term bioethics as a broader term including perspectives on the relation between humankind and nature and, as pointed out by Chadwick et al., “[...] discussions in bioethics still tend to focus primarily on issues in medicine, the life sciences, and new technologies [...]”.¹¹ Hence, there is no sharp dividing line between medical ethics and bioethics.

In the 20th century there was remarkable progress regarding scientific invention. After the Second World War and up to the 60s there were advances such as the discovery of the DNA code, organ and heart transplants and the usage of ventilators, and such advances in medicine raised new and urgent ethical concerns.¹² Carole Levine has remarked that modern bioethics was born in a time that was turbulent in many different ways, not only regarding scientific inventions. She describes the social movements in the late 60s as creating a radical change in society. One of these concerned the view on authorities, which were gen-

can come to the forefront apart from the dominating value of autonomy in the American context. I have chosen to focus on American and European history since this has influenced the context within which this study is situated.

⁹ Jonsen, Albert R.: *A Short History of Medical Ethics*. Oxford University Press, New York, 2000, p. vi.

¹⁰ Bexell, Göran and Grenholm, Carl-Henric: *Teologisk etik: en introduktion*. Verbum, Stockholm, 1997, p. 317.

¹¹ Chadwick, Ruth, Have, Henk ten and Meslin, Eric M.: “Health Care Ethics in an Era of Globalisation”, in Chadwick, Ruth, Have, Henk ten and Meslin, Eric M. (eds.): *The Sage Handbook of Health Care Ethics: Core and Emerging Issues*. Sage, London, 2011, p. 2.

Additional terms are ‘clinical ethics’, ‘nurse ethics’ and ‘health care ethics’. Clinical ethics and nurse ethics focus on specific areas of interest in relation to their respective practices. Health care ethics has sometimes been suggested as a broader term including these perspectives.

¹² Jonsen, Albert R.: *A Short History of Medical Ethics*, pp. 99-100.

erally questioned and challenged, as was the authority of the physician.¹³ Albert Jonsen, in his description of the history of medical ethics, points to another important change. He claims that the most dramatic novelty during this period is that medical ethics moves from its long tradition of ‘benign paternalism’ to focussing on respect for the autonomy of the patient.¹⁴ Medical ethics had been understood as a matter for internal medical discussion, and concerned, for example, ethical codes for professionals. However, during the latter half of the 20th century medical-ethical questions also gained public awareness regarding questions on patients’ rights but also legal abortion and contraceptives, to mention but a few.

Since the 60s and 70s, medical ethics and bioethics have been multidisciplinary research areas where philosophers, theologians, scientists and medical expertise have been discussing new and urgent ethical matters.¹⁵ Maurizio Mauri points out that in the 70s and 80s many bioethical institutes were founded, for example one in Barcelona in 1975 (Instituto Borja de Bioética) and one in Rome in 1985 (at the Università Cattolica del Sacro Cuore of Rome). In Europe many of these institutes were established by Roman Catholics and were influenced, according to Mauri, by the now well-known Kennedy Institute of Ethics at Georgetown University, founded in 1971.¹⁶ It was at the Kennedy institute that the term ‘bioethics’ was used to describe a multidisciplinary field where science and ethics were combined and complex dilemmas of medicine were discussed from the point of view of moral philosophy.¹⁷ Philosophy and

¹³ Levine, Carol: “Analyzing Pandora’s Box: The History of Bioethics”, in Eckenwiler, Lisa A. and Cohn, Felicia G. (eds.): *The Ethics of Bioethics: Mapping the Moral Landscape*. The Johns Hopkins University Press, Baltimore, 2007, pp. 6-7.

¹⁴ Jonsen, Albert R.: *A Short History of Medical Ethics*, pp. 116-117.

¹⁵ Op. cit., p. 115.

¹⁶ Mori, Maurizio: “The Discourses of Bioethics in Western Europe”, in Baker, Robert B. and Laurence, McCullough B. (eds.): *The Cambridge World History of Medical Ethics*. Cambridge University Press, Cambridge, 2008, p. 491.

¹⁷ Reich, Warren Thomas: “The Word “Bioethics”: Its Birth and the Legacies of Those Who Shaped It”, in *Kennedy Institute of Ethics Journal* Vol. 4, No. 4, 1994.

Reich, Warren Thomas: “The Word “Bioethics”: The Struggle Over Its Earliest Meaning”, in *Kennedy Institute of Ethics Journal* Vol. 5, No. 1, 1995.

As Reich describes in his articles, tracing the history of the definition of the word ‘bioethics’ is a complex matter. In 1970, the American cancer specialist Van Rensselaer Potter was the first to define the term bioethics. Potter saw a need for a new discipline which combined concern for humankind with concern for nature, resulting in a broader understanding than what came to be the dominant focus, namely the focus on medical issues. Have, Henk ten: “Potter’s Notion of Bioethics”, in *Kennedy Institute of Ethics Journal* Vol. 22, No. 1, 2012. Lately Potter’s ideas have been gaining new

theology gained an important role in the discussions and some important theologians who contributed greatly to the medical-ethical and bioethical discussion were Paul Ramsey,¹⁸ Joseph Fletcher,¹⁹ Richard McCormick²⁰ and Karen Lebacqz.²¹ They dealt with complex ethical issues and they approached these questions not only from a philosophical or theological perspective, but they engaged in the topics also in a practical sense, for example with questions concerning decision-making. Albert R. Jones describes that many theologians crossed from a denominational scholarly context to bioethics and their scholarly background influenced their contribution to bioethics.²² Regarding methodological approaches Albert R. Jonsen points out that ethicists standing in the Catholic tradition draw on at least two methods when considering ethical issues within medical practice, namely natural law and casuistry. To these ethicists, natural law could be understood as providing a framework where moral concerns could be discussed and understood by any rational person. Casuistry, with its roots in the Jesuit tradition, provided a case-based model in discussions on medical-ethical concerns.²³ However, as Darrel Amundsen has pointed out, the Second Vatican Council (1962-1965) contributed to some Catholic moral theologians approaching bioethical issues from other angles than natural law. Moreover, the Second Vatican Council also contributed to a new view on ecumenicalism. In bioethics this led to Catholic moral theologians

interest. See for example Chadwick, Ruth, Have, Henk ten and Meslin, Eric M.: "Health Care Ethics in an Era of Globalisation", p. 8.

¹⁸ Ramsey, Paul: *The Patient as Person: Explorations in Medical Ethics*. The Lyman Beecher Lectures at Yale University. Yale University Press, New Haven, 1970. Ramsey discussed for example questions on informed consent and organ transplantation.

¹⁹ Fletcher, Joseph: *Morals and Medicine: The Moral Problems of the Patient's Right to Know the Truth, Contraception, Artificial Insemination, Sterilization, Euthanasia*. Princeton University Press, New Jersey, 1954. Fletcher discussed for example questions on personhood, abortion and euthanasia.

²⁰ McCormick, Richard A.: *How Brave a New World?: Dilemmas in Bioethics*. SCM, London, 1981. McCormick discussed for example questions on surrogate motherhood and patients' rights.

²¹ Karen Lebacqz has discussed areas such as genetics and she was one of the members in the commission developing *the Belmont Report*. For one of her more recent contributions see Peters, Ted, Lebacqz, Karen and Bennett, Gaymon: *Sacred Cells? Why Christians Should Support Stem Cell Research*. Roman & Littlefield Publishers, Lanham, 2008.

²² Jonsen, Albert R.: "A History of Religion and Bioethics", in Guinn, David E. (ed.): *Handbook of Bioethics and Religion*. Oxford University Press, New York, 2006, p. 23.

²³ Op. cit., p. 25.

coming into dialogue with theologians from other denominations as well.²⁴

Ethics as an academic discipline is divided into different fields, often characterised as descriptive ethics, normative ethics, meta-ethics and applied ethics.²⁵ Within applied ethics, normative ethical theories are related to a specific area of concern and understood as such medical ethics is one form of applied ethics. Even though medical-ethical questions were discussed from many different perspectives such as virtue ethics or the ethics of responsibility, one can claim that medical ethics and bioethics are areas of research where a principle-based approach has dominated. In 1979, the *Belmont Report* was published, which defined principles that should guide ethical considerations regarding research on human subjects. These principles were respect for persons, beneficence and justice.²⁶ The report was a response to the Tuskegee Syphilis Study (1932-1972), a study by the U.S. Public Health Service with the aim to study the progression of syphilis. The participants were African-American men in Alabama. Most of them had syphilis, and they participated but under false premises namely that the project was providing treatment. The participants were left untreated for syphilis, even after penicillin had been shown to be effective as a cure (1947). The research on humans had been conducted without concern for human life and well-being, and the research study led to fatal consequences for the participants.

As Daniel F. Davies describes it, principlism has become dominant as a theory of ethical justification in relations between patient and physician and nowadays does not only refer to research on human subjects, as in the *Belmont Report*.²⁷ The idea was later elaborated by philosopher Tom Beauchamp and theologian James Childress in their influential work *Principles of Biomedical Ethics* which was first published in

²⁴ Amundsen, Darrel W.: "The Discourses of Roman Catholic Medical Ethics", in Baker, Robert B. and Laurence, McCullough B.: *The Cambridge World History of Medical Ethics*. Cambridge University Press, Cambridge, 2008, p. 237.

²⁵ Bexell, Göran and Grenholm, Carl-Henric: *Teologisk etik: en introduktion*, pp. 22-23.

²⁶ National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research: *The Belmont Report: Ethical Principles and Guidelines for the Protection of Human Subjects of Research*. 1978.

²⁷ Davis, Daniel F.: "Human Dignity and Respect for Persons: A Historical Perspective on Public Bioethics", in Pellegrino, Edmund D., Schulman, Adam and Merrill, Thomas W. (eds.): *Human Dignity and Bioethics*. University of Notre Dame Press, Notre Dame, 2009, p. 25.

1979.²⁸ In this they argue in favour of four principles. The first one is autonomy, which highlights respect for a person's right to make her own decisions and the right to decide about her own treatment, for example, the right to refrain from treatment. Non-maleficence refers to the duty not to hurt others and also to minimize suffering. Beneficence refers to taking care of the patients' needs such as relieving pain. The last principle is justice, which refers to equality: all patients have an equal right to treatment. The four principles, according to the authors, "[...] are drawn from the territory of common morality [...]"²⁹ By common morality they mean a universal morality which is not dependent on for instance religion or culture. In other words a morality which is shared by all persons in all places. The underlying idea is that these principles could be neutral in the sense of covering different ethical perspectives and as such could promote agreement. In her discussion on theological bioethics, Lisa Sowle Cahill points to the postmodernist understanding that all principles are grounded and articulated in a specific context.³⁰ Such a perspective, with which I agree, problematises a de-contextualisation of ethical principles. It is therefore problematic to claim that certain principles are neutral, when in fact they are clearly situated in a specific context.

In the 80s and 90s some ethicists were concerned by what they understood as a gap between ethical analysis and medical practice. This is noticeable for example in the work by the above-mentioned Albert Jonsen and Stephen Toulmin in the book: *The Abuse of Casuistry: a History of Moral Reasoning*.³¹ The authors distance themselves from principlism and instead refer to Aristotle and point to the importance of *phronesis*, the understanding that ethics concerns practical knowledge and concrete situations and therefore differs from *episteme*, which refers to eternal truths and universal principles. The authors claimed that a critical and comparative analysis of cases is more appropriate with reference to reaching an agreement and resolution in bioethical concerns than discussing different ethical principles. The method suggested relies on analogy: through the experience of previous cases one could

²⁸ Beauchamp, Tom L. and Childress, James F.: *Principles of Biomedical Ethics*. Seventh edition. Oxford University Press, New York, 2013.

²⁹ Op. cit., p. 410. Italics original.

³⁰ Cahill, Lisa Sowle: *Theological Bioethics: Participation, Justice, and Change*. Moral Traditions Series. Georgetown University Press, Washington D.C., 2005, p. 19.

³¹ Jonsen, Albert R. and Toulmin, Stephen: *The Abuse of Casuistry: A History of Moral Reasoning*. University of California Press, Berkeley, 1989.

draw an analogy to new, similar cases. One thereby develops a maxim which can give guidance on how to act when dealing with an ethical problem which still takes the specific case with its specific circumstances into account.

The combination of empirical research and ethical analysis – Empirical ethics

Medical ethics and bioethics was, as seen, multidisciplinary and theology and philosophy were influential. According to Borry et al., the influence from philosophy underlined the importance of logical reasoning and rational justification in research on bioethical issues, and the focus was on normative ethics rather than on descriptive ethics.³² It is with regard to this history that one can understand the turn to empirical ethics. In 1992, Barry Hoffmaster wrote the article “Can Ethnography Save the Life of Medical Ethics?”³³ He considered that a more fruitful approach was to use empirical methods and include these results in ethical analysis. That way one would reach greater sensitivity to the specific areas concerned.³⁴ The article was the starting point for a discussion on what has been labelled ‘empirical ethics’. This discussion concerns relevant methods for ethical analysis, since studies including empirical research have been understood as challenging certain prevalent methods within the academic field.³⁵ As Charles Foster has noted, empirical ethics is now recognised within the discipline of ethics.³⁶ However, during the last three decades, different understandings have emerged – among those defining their work as empirical ethics – regarding the reasonable interaction between empirical material and ethical analysis.³⁷

³² Borry, Pascal, Schotsmans, Paul and Dierickx, Kris: “The Birth of the Empirical Turn in Bioethics”, in *Bioethics* Vol. 19, No. 1, 2005, pp. 60-61.

³³ Hoffmaster, Barry: “Can Ethnography Save the Life of Medical Ethics?”, in *Social Science & Medicine* Vol. 35, No. 12, 1992.

³⁴ *Ibid.*

³⁵ Molewijk, Bert and Frith, Lucy: “Empirical Ethics: Who Is the Don Quixote?”, in *Bioethics* Vol. 23, No. 4, 2009, p. ii.

³⁶ Foster, Charles: *Human Dignity in Bioethics and Biolaw*. Hart Publishing, Oxford, 2011, p. 68.

³⁷ Molewijk, Bert et al.: “Empirical Data and Moral Theory. A Plea for Integrated Empirical Ethics”, in *Medicine, Health Care and Philosophy* Vol. 7, No. 1, 2004, p. 57. In their article, Molewijk et al. make a classification of five different approaches: ‘the prescriptive applied ethicists’, ‘the theorists’, ‘the critical applied ethicists’, ‘the

This dissertation can be labelled as empirical ethics in accordance with the definition by Borry et al., where it is stated that researchers who define their work as empirical ethics mainly agree on a few aspects, namely that to study people's moral beliefs can be meaningful for ethical analysis, that through using empirical methods one can gain insights of importance in ethical analysis and that empirical and normative approaches do not need to stand in opposition to each other.³⁸ The last aspect is probably the most discussed one, since it has concerned the risk of lack of critical analysis in relation to the empirical material. As Carlo Leget and Pascal Borry observes: "The inductive approach runs the risk of lacking a critical attitude and assigning a sacred meaning to the facts without testing them against normative principles and theories."³⁹ In this dissertation, the results from the empirical research study has indicated areas of concern for ethical analysis and the empirical results have been discussed in relation to normative ethical theories. Moreover, I regard the empirical results and ethical analysis to stand in a dialogic, critical relation to each other. I agree with Carlo Leget and Pascal Borry in claiming that ethical analysis and empirical research are equally important for the project. Furthermore, both co-determine the process.⁴⁰

In questions concerning the beginning of life and end of life, the discussion on human dignity is often vivid, and was therefore regarded as an area of interest and relevance to this study. I agree with Albert Musschenga on his analysis regarding the contributions from empirical studies in ethical analysis. In particular, the empirical material has given certain views on problems which are relevant in the specific context. It has also contributed with angles on complexities and moral concerns

particularists' and 'integrated empirical ethics'. Especially the group 'the particularists' is questioned, since in this line of research one pays close attention to the empirical material and study morality within a social practice. However, the interaction between normative theories and empirical material is scarce.

³⁸ Pascal, Borry, Schotsmans, Paul and Dierickx, Kris: "Empirical Ethics: A Challenge to Bioethics", in *Medicine, Health Care and Philosophy* Vol. 7, No. 1, 2004, p. 1.

³⁹ Leget, Carlo and Pascal, Borry: "Empirical Ethics: The Case of Dignity in End-of-Life Decisions", in *Ethical Perspectives: Journal of the European Ethics Network* Vol. 17, No. 2, 2010, pp. 241–242.

⁴⁰ Ibid.

which are of relevance and importance in the specific context.⁴¹ In this study this pertains to areas in neonatal care and palliative care within Swedish medical care. This context influences the views and perspectives which are discussed in the study and other contexts could, of course, have pointed to different angles and aspects.

Previous research

As mentioned, during the last 30 years empirical ethics has contributed to the areas of medical ethics and bioethics. This is also the case regarding the subject of human dignity and medical ethics. David Hollenbach has discussed that which he calls an “[...] inductive approach that begins in human experience”.⁴² Hollenbach remarks that an inductive approach to dignity does not only indicate “[...] that we should show respect towards one another but what it will mean to show such respect”.⁴³ Paulo Carozza points to a similar understanding, stating that experience of human dignity is a way to both comprehend and establish the meaning as well as the implication of dignity.⁴⁴ Even though all inductive approaches to human dignity do not necessarily include empirical research, the following presentation will concern this area and the contributions made therein.

In his research, Edmund Pellegrino has a thorough discussion on how one can understand human dignity in a complementary way: as an

⁴¹ Musschenga, Albert W.: “Empirical Ethics, Context-Sensitivity, and Contextualism”, in *Journal of Medicine and Philosophy* Vol. 30, No. 5, 2005. Musschenga points to four areas: “Description and analysis of the actual conduct of a group with respect to a morally relevant issue. Identification of moral issues that escaped the attention of ethicists but are relevant in a specific context. Description and analysis of the cultural and institutional aspects of a context or practice – procedures, processes, nature of the relations between subjects, their beliefs, attitudes, and so on – relevant for evaluating the practicality of ethical guidelines and principles. Description and analysis of the actual moral opinions and reasoning patterns of those involved in a practice.” Op. cit., p. 469.

⁴² Hollenbach, David: “Human Dignity: Experience and History, Practical Reason, and Faith”, in McCrudden, Christopher (ed.): *Understanding Human Dignity*. Proceedings of the British Academy 192. The British Academy by Oxford University Press, Oxford, 2014, p. 129.

⁴³ Ibid.

⁴⁴ Carozza, Paulo G: “Human Rights, Human Dignity, and Human Experience”, in McCrudden, Christopher (ed.): *Understanding Human Dignity*. Proceedings of the British Academy 192. The British Academy by Oxford University Press, Oxford, 2014, p. 626.

‘abstract idea’ as well as including what he describes as ‘the lived experience’ of human dignity. He defines the latter in the following way:

By a “lived experience” I mean the way human dignity is perceived by human beings as they respond to the valuations of their worth and worthiness by others or by themselves.⁴⁵

While the abstract idea of human dignity is necessary as a critical tool, the experience of dignity is needed to understand its complete meaning. Hence the two perspectives should stand in a dialogical relationship. As an example of the importance of this he points to the horrific experiences from World War II. These concrete experiences give perspectives on dignity which a solely conceptual analysis would not succeed in doing. Pellegrino also points to the lived experience of human dignity from the perspective of clinical encounters, and he points to the fact that dignity in these cases always involves ‘intersubjectivity’, meaning that the patient’s sense of dignity is interrelated to how others act towards the patient; whether the dignity of the other will be recognised or not.⁴⁶

From the perspective of lived experience, Rebecca Dresser is one of those who, from the perspective of the patient, has discussed experiences of how one’s dignity as a patient can be respected or not in the clinical encounter. She describes her research as examining the question from a ‘bottom-up’ perspective, meaning that she draws on a combination of scholarly work and her own experiences as a cancer patient. She identifies four areas where the patient’s dignity can be compromised or honoured: privacy, communication, personal knowledge and dependence. Examples of when dignity is compromised are when patients become an object of study (privacy diminished), or the loss of recognition (dependence), where Dresser discusses how staff sometimes shun patients since a seriously ill patient can remind the staff about their own human frailty. The conclusion of Dresser’s argument is that within health care, autonomy has been regarded as important for empowering the patient and enabling the patient to avoid being devalued, and for that reason it has been promoted as a central ethical principle. Nevertheless, patients still feel devalued when receiving medical treatment and

⁴⁵ Pellegrino, Edmund D.: “The Lived Experience of Human Dignity”, in Pellegrino, Edmund D., Schulman, Adam and Merrill, Thomas W. (eds.): *Human Dignity and Bioethics*. University of Notre Dame Press, Notre Dame, 2009, p. 516. Italics original.

⁴⁶ Op. cit., p. 522.

Dresser concludes that “[...] failure to emphasise protection of dignity has hindered efforts to improve the medical experience for patients”.⁴⁷

Dresser analyses the lived experience of dignity from the perspective of the patient but others have researched dignity in health care from a different perspective, described by Roberto Andorno, as ‘a standard for patient care’.⁴⁸ Andorno refers to this area of research as subjective, focussing on the consequences that an idea of dignity can have in medical treatment in relation to the care of the patient. Many of these studies are within palliative care and nurse ethics and the focus in much of this research is on how the treatment of the patients affects ‘the patients’ sense of dignity’.

One of the most noted research studies within research focussing on ‘dignity as standard for patient care’ has been conducted by Harvey Chochinov. In 2002 Chochinov et al. published their results from a study on how dying patients in palliative care perceived their sense of dignity. The 219 participants were asked to rate their sense of dignity; 16 found loss of dignity to be a great problem. For these patients, feelings of being degraded, ashamed or embarrassed were identified. Another result of the study was that patients who were in palliative care in a hospital instead of at home, were more likely to have their sense of dignity impaired. Chochinov’s interpretation of this result was that autonomy and independence could be better maintained with care in the home compared to institutionalized care.⁴⁹ The interpretation and outcome of the study was the insight that dignity should be a central aim in treatment of the patients, and such a treatment was later developed in the so-called A, B, C and D of dignity-conserving care. In this later work, the dignity of the patient is discussed in terms of self-perception, the importance of showing respect for the patient as well as seeing the patient as ‘the person they are’. This understanding of dignity becomes central for deliberations on what Chochinov considers to be good care, care which upholds the patient’s sense of dignity. Just like the ‘A, B, C’ mnemonic for critical care (airway, breathing, and circulation), the

⁴⁷ Dresser, Rebecca: “Human Dignity and the Seriously Ill Patient”, in Pellegrino, Edmund D., Schulman, Adam and Merrill, Thomas W. (eds.): *Human Dignity and Bioethics*. University of Notre Dame Press, Notre Dame, 2009, p. 511.

⁴⁸ Andorno, Roberto: “The Dual Role of Human Dignity in Bioethics”, in *Medicine, Health Care and Philosophy* Vol. 16, No. 4, 2013, p. 971.

⁴⁹ Chochinov, Harvey Max et al.: “Dignity in the Terminally Ill: A Cross-Sectional, Cohort Study”, in *The Lancet* Vol. 360, No. 9350, 2002, p. 2027.

components of this theory are the fundamental elements of dignity-conserving care. The first component is attitude: emphasising the importance of healthcare providers examining their attitudes. Secondly, Chochinov points to the importance of certain behaviour towards the patient, such as respect and kindness, compassion, and awareness and recognition of the patient's situation. Lastly, the importance of an honest and open dialogue which can enhance the care of the patient is discussed.⁵⁰ Other studies have drawn on Chochinov's model in their research. Instead of focussing on dignity-preserving care, Linda Mah has focussed on what patients in palliative care experience as dignity distress.⁵¹ Sylvia Enes and Patricia Duarte have done a phenomenological study, interviewing patients as well as clinicians and relatives on the meaning of dignity. In the discussion the focus is on how to preserve dignity in the care of the patients.⁵²

An example of how dignity within nursing practice has been discussed is a Danish study, conducted by Tina Seidelin Rasmussen and Charlotte Delmar. A qualitative research study consisting of interviews with surgical patients in Denmark was carried out where the patients described their perceived dignity in medical care. The results of the study were described under one central theme, namely "to be an important person". The patients underlined the importance of being perceived as an equal, for example being included in decision-making regarding one's treatment in discussions with nurses. The study also found there were problems perceived by the patients regarding dependence on nursing staff due to physical inability; how the nurses handled the situations correlated with the patients' sense of dignity being intact or compromised.⁵³

In many of the studies which deal with dignity in medical care, often in palliative care and nursing care, the focus and the aim with the research is practical. The aim is to understand how dignity in the clinical encounter can be perceived and how dignity can be understood or felt

⁵⁰ Chochinov, Harvey Max: "Dignity and the Essence of Medicine: The A, B, C, and D of Dignity Conserving Care", in *BMJ: British Medical Journal* Vol. 335, No. 7612, 2007, pp. 184-187.

⁵¹ Mah, Linda et al.: "Assessment of Patient Dignity in Geriatric Palliative Care", in *Journal of the American Geriatrics Society* Vol. 60, No. 11, 2012.

⁵² Enes, Sylvia and Duarte, Patricia: "An Exploration of Dignity in Palliative Care", in *Palliative Medicine* Vol. 17, No. 3, 2003.

⁵³ Rasmussen, Tina Seidelin and Delmar, Charlotte: "Dignity as an Empirical Life-world Construction – In the Field of Surgery in Denmark", in *International Journal of Qualitative Studies on Health and Well-Being* Vol. 9, 2014.

by the patient as maintained or lost and the results can lead to improved care. One can conclude by saying that the centre of attention is on a psychological dimension of dignity, how it feels and how dignity is perceived. Since the focus is on the psychological dimension, dignity can be described both as something which is lost and on the other hand something which cannot be lost. This is of course different than a philosophical discussion where such a logical inconsistency is problematic. However, I want to mention two studies where the researchers have developed their conceptual analysis in relation to empirical material, in form of interview studies with patients and clinicians. In their analysis they have included these different meanings of dignity. This is the case in the work by Nora Jacobson. She distinguishes between human dignity and social dignity:

Social dignity is grounded in human dignity, and is one consequence of its recognition. Social dignity enacts the abstract notion of universal value in behaviour, perception, and expectation. In contrast to human dignity, however, social dignity is contingent, comparative and contextual.⁵⁴

Nora Jacobson makes a distinction between human dignity and social dignity and juxtaposes ‘human dignity’ – for that which is indestructible – and ‘social dignity’ – for the experiences or feelings of patients when they describe how they have ‘lost their dignity’. Human dignity is the basis for social dignity. Moreover, it is also related to human rights. In later works, Jacobson develops a taxonomy of dignity.⁵⁵ In this study she conducts 64 semi-structured interviews with both patients and staff. Her analysis of these interviews furthers the understanding of the concepts of ‘human dignity’ and ‘social dignity’. Jacobson uses a grounded theory analysis where “[...] the product is a theory of a phenomenon grounded in the lived experience of research participants, rather than an analysis that enlists existing theory to explicate that experience”.⁵⁶ Some of the results of the study deal with dignity violations such as contempt, dependence and objectification and dignity promotions in

⁵⁴ Jacobson, Nora: “Dignity and Health: A Review”, in *Social Science & Medicine* Vol. 64, No. 2, 2007, p. 294. See also her extended work in Jacobson, Nora: *Dignity and Health*. Vanderbilt University Press, Nashville, 2012.

⁵⁵ Jacobson, Nora: “A Taxonomy of Dignity: A Grounded Theory Study”, in *BMC International Health and Human Rights* Vol 9, No. 1, 2009, p. 3.

⁵⁶ Op. cit., p. 2.

health-care settings such as presence, empowerment and independence.⁵⁷

Between 2001 and 2004, the European Union financed a project called “Dignity and Older Europeans”. The aim with the study was to identify persons’ conceptions on dignity and older people, and the project had participants from seven European countries. In this project, Lennart Nordenfelt did a conceptual analysis based on the results from the empirical material and identified the concept of dignity in the following categorisation: dignity as merit, dignity as moral stature, dignity of personal identity and the universal human dignity.⁵⁸ I will further elaborate on these distinctions in the next chapter. However, in the project much research was made, apart from the conceptual work, on the subject on dignity and older persons drawing on the empirical results. As a result of this research rather extensive literature is at hand on the topic. Interesting research to mention is for example the study conducted by Win Tadd and Michael Calnan. In their results they point to aspects such as the importance of language and dignity in relation to care for older persons.⁵⁹

Much research carried out within the area described as empirical ethics has had as its purpose to discuss the question of dignity guided by a mainly practical aim, namely how to improve the care of the patient. This was the case in the works of, for example Chochinov and Mah. Moreover, much of this research does not have as its main aim to further a philosophical or theological discussion on dignity. The philosopher Eva Kittay’s work is therefore of interest to regard. Eva Kittay has often drawn on her understanding of her daughter Seshas’s experiences of disability in her ethical analysis. This is also true for her work on dignity. The perspective guiding Kittay’s research is “[...] the possibility of dignity and equality in the face of disability, frailty and dependency”.⁶⁰ In her research, she conveys how experiences of disability challenge philosophical perspectives and she claims that certain arguments for the justification of dignity can be excluding. In Kittay’s own

⁵⁷ Op. cit., p. 8.

⁵⁸ Nordenfelt, Lennart: “The Concept of Dignity”, in *Dignity in Care for Older People*. Wiley-Blackwell, Chichester, 2009, p. 30.

⁵⁹ Tadd, Win and Calnan, Michael: “Caring for Older People: Why Dignity Matters – the European Experience”, in Nordenfelt, Lennart (ed.): *Dignity in Care for Older People*. Wiley-Blackwell, Oxford, 2009.

⁶⁰ Kittay, Eva Feder: “Equality, Dignity and Disability”, in Lyons, Mary Ann and Waldron, Fionnuala (eds.): *Perspectives on Equality: The Second Seamus Heaney Lectures*. The Liffey Press, Dublin, 2005, p. 93.

constructive proposal she argues that dignity is “[...] bound to our capacity to care for one another and in our being cared for by another who is herself worthy of care”.⁶¹ Therefore, for Kittay, as for many philosophers, human dignity is located in the moral sphere. Caring, she claims, is a characteristically human trait and as such it is as valid a basis for human dignity as, for example, moral autonomy is.⁶²

Apart from research from the inductive approach on dignity it can also be interesting to regard some more general contributions to the discussion on dignity and medical ethics and bioethics.

A characterisation of how dignity is discussed within contemporary bioethical discussion has been made by Robert Ashcroft and he has identified four approaches. Firstly he refers to those who regard dignity – talk to be incoherent and secondly those who have reduced dignity to autonomy. In the third group dignity is related to capabilities. Ashcroft writes that these researchers: “[...] considers dignity to be a concept in a family of concepts about capabilities, functionings, and social interactions”.⁶³ Lastly he refers to the group who regards dignity as a metaphysical property possessed by all humans. In this sense dignity is seen as the justification of human rights. The last group Ashcroft claims, is most common in European bioethics and in theological analysis on dignity.⁶⁴

Ashcroft points to that within the European discussion the reference to dignity is much more accepted and widespread than in the American discussion. As an interesting contrast one can notice that while Beauchamp and Childress dismissed dignity as an ethical principle to regard in bioethics the authors to the Biomed project regarded dignity as a central value in a European context.⁶⁵ Furthermore, in the project, dignity was one of four principles which were said to reflect the European tradition and these principles were considered to stand as a European counterpart to the four Georgetown principles.⁶⁶ This project was led by

⁶¹ Op. cit., p. 112.

⁶² Op. cit., p. 113.

⁶³ Ashcroft, Richard E.: “Making Sense of Dignity”, in *Journal of Medical Ethics* Vol. 31, No. 11, p. 679.

⁶⁴ Ibid.

⁶⁵ Beauchamp, Tom L. and Childress James F.: *Principles of Biomedical Ethics*, p. 65.

⁶⁶ Dahl Rendtorff, Jacob: “Basic Ethical Principles in European Bioethics and Biolaw: Autonomy, Dignity, Integrity and Vulnerability – Towards a Foundation of Bioethics and Biolaw”, in *Medicine, Health Care, and Philosophy* Vol. 5, No. 3, 2002.

Peter Kemp and Jacob Dahl Rendtorff.⁶⁷ The four ethical principles of autonomy, dignity, integrity and vulnerability are in the project described as representing a normative framework to take into consideration on bioethical concerns. The project was presented to the European Commission in a policy proposal called the Barcelona Declaration, which is described as “[...] a philosophical and political agreement between experts in bioethics and biolaw from many different countries.”⁶⁸ In the project the discussion on dignity draws on both an understanding of dignity as intrinsic, a value which can never be lost or degraded, as well as an understanding of dignity as constructed in human relationships.⁶⁹

Research which can be characterised as that which Ashcroft describes as the group who regards dignity as a metaphysical property are some of the contributions in the extensive anthology *Human Dignity and Bioethics*.⁷⁰ This volume was commissioned by the President’s Council on Bioethics and the purpose of the essays was to enable a deeper understanding of the meaning of human dignity and its application on bioethical concerns, since different understandings of the idea had played a significant role in the council’s work.⁷¹ One of the conservative voices within the American debate who is represented in the volume is the above-mentioned Leon Kass. In the chapter “Defending Human Dignity” Kass points to the understanding that in the American

⁶⁷ Dahl Rendtorff, Jacob and Kemp, Peter: *Basic Ethical Principles in European Bioethics and Biolaw. Vol 1. Autonomy, Dignity, Integrity and Vulnerability*. Report to the European Commission of the BIOMED-II Project Basic Ethical Principles in Bioethics and Biolaw 1995-1998. Centre for Ethics and Law, Copenhagen, 2000.

⁶⁸ Op. cit., p. 235.

⁶⁹ Op. cit. pp. 31-38.

⁷⁰ Pellegrino, Edmund D., Schulman, Adam and Merrill, Thomas W. (eds.): *Human Dignity and Bioethics: Essays Commissioned by the President’s Council on Bioethics*. Notre Dame Press, Notre Dame, 2009. During recent years some comprehensive anthologies apart from this one have been produced. These do not only regard the question on medical ethics and dignity but have a broader approach to the question on dignity but certain articles treat the named area of concern. See for example: McCrudden, Christopher (ed.): *Understanding Human Dignity*. Proceedings of the British Academy 192. The British Academy by Oxford University Press, Oxford, 2014. Düwell, Marcus et al.: *The Cambridge Handbook of Human Dignity: Interdisciplinary Perspectives*. Cambridge University Press, Cambridge, 2014.

⁷¹ Kass, Leon R.: *Life, Liberty, and the Defense of Dignity: The Challenge for Bioethics*. Encounter Books, San Francisco, 2002, p. 298.

debate the language of dignity has not been prominent.⁷² By this he means that the concept of dignity carries too many religious connotations for secularists and libertarians, and too many connotations of aristocracy for egalitarians.⁷³ Kass' discussion on dignity evolves around his interpretation of human nature, and which actions and treatments standing in correlation with human nature, an interpretation where he draws on the Christian tradition. To prohibit certain treatments, often treatments which are made possible due to new technology, is a way of ensuring that the human being is not degraded. The question of procreation can stand as one example of this, where Kass states: "The dignity of human procreation, threatened by cloning-to produce-children and other projected forms of 'manufacture'."⁷⁴ His way of reasoning in the article is similar to that found in his other works on dignity and bioethics, for example *Life, Liberty, and the Defense of Dignity: The Challenge for Bioethics*, where he elaborates his understanding of subjects such as organ donation and cloning.⁷⁵

Within the theological discussion on human dignity and medical ethics there is also an extensive discussion regarding the concept of 'person', a distinction between a human being in the biological sense and a human being as a person. The discussion revolves around the consideration of when a human being becomes a person and on what grounds. The debate on personhood has been extensive in some areas of bioethics, especially on topics such as abortion and euthanasia, since the idea is that when it is established who can be considered to be a person, then this understanding can be applied to medical-ethical concerns and can be the solving argument in complex dilemmas. Christopher Kaczor does in his book *The Edge of Life: Human Dignity and Contemporary Bioethics* undertake a comprehensive discussion and argues in favour of an 'ontological conception of personhood' beginning at conception.⁷⁶ This stands in opposition to the idea as formulated by Peter Singer who

⁷² Kass, Leon R.: "Defending Human Dignity", in Pellegrino, Edmund D., Schulman, Adam and Merrill, Thomas W. (eds.): *Human Dignity and Bioethics*. University of Notre Dame Press, Notre Dame, 2009.

⁷³ In the latter form, aristocracy, Kass points to one of the important strands in the understanding of human dignity namely as dignitas, dignity as a status or honour attributed to certain persons due to, for example, high rank.

⁷⁴ Kass, Leon R.: "Defending Human Dignity", p. 298.

⁷⁵ Kass, Leon. R.: *Life, Liberty, and the Defense of Dignity: The Challenge for Bioethics*.

⁷⁶ Kaczor, Christopher: *The Edge of Life: Human Dignity and Contemporary Bioethics*. Philosophy and Medicine 85. Springer, Dordrecht, 2005.

argues in favour of an understanding that means awareness of one's existence. A complementary perspective on the discussion on personhood is presented by the American bioethicist Tristram Engelhardt. In his article *Sanctity of Life and the Concept of a Person* he argues for a 'social concept of person'. He makes a distinction between human beings and persons but regards all human beings from birth as persons in a social sense.⁷⁷

One of the strands in the discussion on human dignity and bioethics identified by Ashcroft is, as mentioned, on the connection between dignity and autonomy. The book *Human Dignity in Bioethics and Biolaw*⁷⁸ by Deryck Beyleveld and Roger Brownsword has gained much attention and appreciation in the discussion. The theory of Alan Gewirth on agency and human rights plays a significant role in their analysis. They regard dignity in two senses; dignity as empowerment and dignity as restraint. In their discussion on dignity as empowerment the authors discuss the strong connection between dignity and autonomy. They point to the importance of dignity as a basis for the freedom of agents to pursue their own autonomous goals. The latter aspect, dignity as constraint, concerns the prohibition of certain acts due to a person's dignity.

A comprehensive overview regarding research on dignity and bioethics is provided in Charles Foster's book *Human Dignity in Bioethics and Law*. This accomplishment is an important contribution. Foster also argues, against critics, on human dignity being a redundant principle in bioethics. Instead he argues that it is, in his own description, the only principle to regard in bioethics. Foster also claims that the definition of dignity is human flourishing.⁷⁹

One interesting anthology to regard is *Human Dignity in Bioethics-From Worldviews to the Public Square* edited by Stephen Dilley and Nathan Palpant.⁸⁰ As in most of the anthologies on human dignity the articles covers three areas; the sources, meaning and the justification of dignity, human dignity and law and applications of dignity in specific

⁷⁷ Engelhardt Jr, Tristram: "The Sanctity of Life and the Concept of a Person", in *Life and Death: A Reader in Moral Problems*. Pojman, Louis P. (ed.). The Jones and Bartlett Series in Philosophy. Jones and Bartlett, Boston, 1993.

⁷⁸ Beyleveld, Deryck and Brownsword, Roger: *Human Dignity in Bioethics and Biolaw*. Oxford University Press, Oxford, 2001.

⁷⁹ Foster, Charles: *Human Dignity in Bioethics and Law*.

⁸⁰ Dilley, Stephen and Palpant, Nathan J. (eds.): *Human Dignity in Bioethics: From Worldviews to the Public Square*. Routledge, New York, 2013.

areas and in this anthology the focus is on bioethical concerns. The applications often concern rather traditional areas such as abortion and euthanasia. However, there are also contributions which regard which challenges to our understanding of dignity which will be facing humanity in the near future in light of technological development.

Another anthology to be mentioned is *Perspectives on Human Dignity – A Conversation*.⁸¹ In this anthology similar subjects are encountered as in the previously mentioned anthology. However, there are here a number of contributions on the subject of human dignity in the end of life. One of the contributors, Jack Coulehan, discusses what it can mean to die with dignity and if this always has to be interpreted in accordance with existing understandings on what a good death means, for example as peaceful death.

I have presented certain research on dignity and medical ethics, and on bioethics, research which has given important contributions to the discussion. As said earlier, research which takes an inductive approach to the study of dignity has in many cases the aim of improving care for patients. However, my own research is more in line with the work of Eva Kittay, where the empirical material goes into dialogue with ethical analysis and normative theory.

Some researchers, as seen, are developing context-sensitive contributions to dignity, like this dissertation does. However, it is far less common to also include the aim that the empirical research should contribute to ethical analysis. The aim is more often only that a context-sensitive proposal should improve the treatment of the patients. The contribution of this dissertation is therefore at least twofold: the results from the empirical study shed light on the theoretical discussion on dignity and some theoretical perspectives on dignity are criticised in the light of the empirical results. Another significant contribution in this dissertation is the theological interpretation of a principle of human dignity. This theological contribution is based on the results from the empirical research.

⁸¹ Malpas, Jeff and Lickiss, Norelle (eds.): *Perspectives on Human Dignity: A Conversation*. Springer, Dordrecht, 2007.

Neonatal care

In the dissertation the focus in the interview study is on concerns regarding dignity at the beginning of life and the end of life, and the medical areas which are concerned are neonatal care and palliative care. Since the interview material is contextualised within these areas I want to provide certain information about these two areas.

The technological development during the 50s dramatically changed methods for medical treatment of premature infants. The incubator is a good example of how technological intervention improved medical treatment for neonates and led to a reduction of child mortality. The technical improvements solved many medical problems but also created others. Survival rates increased, but for some of those children with severe illnesses, Swaney et al. claim that, the quality of life was diminished.⁸²

The neonatal period is regarded as being the first 28 days after the child is born and today around 10-15 per cent of all newborns are treated in neonatal care in conjunction with birth and some of these children face severe risks regarding medical and psychological problems.⁸³ They especially affect children who are born prematurely, i.e. where the term of pregnancy is below 37 weeks. A child born before 32 weeks of pregnancy is defined as very preterm, while those children who are born before 28 weeks of pregnancy are considered extremely preterm. It is in particular the two latter groups in which most illnesses and mortality occur, especially among the extremely preterm.⁸⁴ For a family it can be combined with extreme stress to give birth to a child with severe illnesses. Studies have shown that depressive symptoms are more frequent for mothers giving birth to very premature children than among those who have given birth to children that are fully developed and healthy. A child might need prolonged hospital care and the diagnosis for the child can be very uncertain, causing stress for the family. This

⁸² Swaney, Julie, English, Nancy and Carter Brian S.: "Ethics, Values, and Palliative Care in Neonatal Intensive Care", in Merenstein, Gerald B. and Gardner, Sandra L. (eds.): *Handbook of Neonatal Intensive Care*. Sixth Edition. Mosby Elsevier, St. Louis, 2006, p. 970.

⁸³ Stjernqvist, Karin and Hellström-Westas, Lena: "Uppföljning efter neonatalvård", in Lagercrantz, Hugo, Hellström-Westas, Lena and Norman, Mikael (eds.): *Neonatalogi*. Second edition extended version. Studentlitteratur, Lund, 2015, p. 503.

⁸⁴ Håkansson, Stellan and Norman, Mikael: "Registerdata och vitalstatistik", in Lagercrantz, Hugo, Hellström-Westas, Lena and Norman, Mikael (eds.): *Neonatalogi*. Second edition extended version. Studentlitteratur, Lund, 2015, p. 528.

concerns not only the parents but also for example siblings who may react strongly to the situation.⁸⁵

Neonatal care in Sweden has high rates of survival for the extremely preterm. Around 300 extremely premature children a year are born alive in Sweden, and Sweden is among those countries in which the chance for survival for these children is the highest in the world.⁸⁶ However, there is also an ongoing discussion regarding whether one should give full intensive care when the child is at the limit of viability (around week 22). It is important to clarify that all children born alive, regardless of their age, should receive medical treatment as long as this can be regarded as standing in agreement with science and proven experience; otherwise, one could claim that some children are discriminated against due to their age, which is prohibited.⁸⁷ However, the question today concerns not only increasing the number of survivals but also improving the results regarding these children's development. Important research has been done in the EXPRESS study regarding areas such as cognitive development as well as studying which problems may occur for extremely preterm children of older ages.⁸⁸ For example, the NIDCAP method (Newborn Individualized Development Care and Assessment Program) has proven to give positive results on the child's cognitive progress.⁸⁹

Palliative care

One of the pioneer institutions which became important for the shaping of palliative care of today is St. Christopher's Hospice in England, founded in 1967 by Dr. Cicely Saunders. As has been described before, the scientific advancement was rapid during the latter part of the twentieth century, which had profound implications for medical care, also in

⁸⁵ Stjernqvist, Karin and Hellström-Westas, Lena: "Uppföljning efter neonatalvård", p. 508.

⁸⁶ Socialstyrelsen: *Vård av extremt för tidigt födda barn: en vägledning för vård av barn födda före 28 fullgångna graviditetsveckor*. Socialstyrelsen, 2014, p. 8.

⁸⁷ Op. cit., p. 48.

⁸⁸ Fellman, Vineta et al.: "One-Year Survival of Extremely Preterm Infants after Active Perinatal Care in Sweden", in *JAMA* Vol 301, No. 21, 2009.

⁸⁹ SBU: *Individanpassad vård av underburna barn - NIDCAP*. Statens beredning för medicinsk utvärdering, Stockholm, 2006, SBU Alert-rapport nr. 2006-03.

relation to death and dying. As treatment for end-stage patients advanced and improved, more patients came to be at hospitals and also died there instead of in their homes. During this period the medical advancements also meant that life for patients with a terminal diagnosis could be prolonged. On the other hand, these patients could not have adequate pain and symptom control since the progression of this had not kept the same pace.⁹⁰ The philosophy of palliative care which was developed at St. Christopher's has had a great impact on the conception of good palliative care as it is considered today.

One of the most common definitions of palliative care is formulated by the World Health Organization as follows:

Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.⁹¹

The patients who are in palliative care have incurable, deadly diseases and the care is focussed not solely on the patient but also includes the patient's family. One should also take into consideration that palliative care can be required for persons of all ages, from very young children to the elderly. Palliative care in its earliest stage is palliative care for patients with incurable diseases but where one has life-prolonging treatment. The later stage concerns palliative care in the end of life where the treatment is not focussed on prolonging life.

The purpose of palliative care is never to hasten death but neither to prevent death and dying is considered as a normal process. An important part of the treatment is of course to relieve pain. For this purpose it is permitted to even, in certain cases, use methods such as sedation which can be offered to patients experiencing severe suffering. This

⁹⁰ Capasso, Jamie, Kim, Robert Byron and Perret, Danielle.: "Hospice for the Terminally Ill and End-of-Life Care", in Vadivelu, Nalini, Kaye, Alan David and Berger, Jack M. (eds.): *Essentials of Palliative Care*. Springer, New York, 2013, p. 50.

⁹¹ World Health Organization: *National Cancer Control Programmes: Policies and Managerial Guidelines*. Second edition. World Health Organization, Geneva, 2002, p. 84.

means that the patient can be intermittently or continuously sedated (although evaluated every 24 hours) until death.⁹² Here an important distinction is needed. It should be noted that sedation in these cases is used as palliative treatment, as a way of relieving pain. Sedation is not a form of euthanasia but the intention of sedation is to relieve pain. However, the moral complexities of sedation have been discussed.⁹³

In palliative care it is important to attend to the patient's physical needs but also to psychological and spiritual ones. According to the Swedish national program for palliative care there are four main values which form the basis of palliative care, namely: presence, holism, knowledge and empathy. With presence one points to the importance of regarding the human being as social and the importance of social contact and the presence of others in the process of dying. Holism concerns the view of the person as having physical, social, psychological and existential needs. Knowledge is seen as important in order to constantly provide good care, and empathy is central since the patient is in a vulnerable situation and the staff's handling of the person is of the utmost importance.⁹⁴

In Sweden, one can distinguish between general palliative care (which is palliative care which can be given to patients by staff with general competence in palliative care) and specialized palliative care (which is palliative care given to patients with complex symptoms or with specific needs). Within specialized palliative care the teams have specialized training and competence.⁹⁵ In Sweden, palliative care has been a prioritised area of care. This was established in 1995 with the report *Vårdens svåra val*.⁹⁶ In 2001 a separate report on palliative care concluded with suggestions regarding the development of palliative

⁹² Läkemedelsverket: *Smärtlindring i livets slutskede: ny rekommendation*. Läkemedelsverket, Uppsala, 2010, pp. 22-23.

⁹³ Have, Henk ten and Welie, Jos V.M.: "Palliative Sedation Versus Euthanasia: An Ethical Assessment", in *Journal of Pain and Symptom Management* Vol 47, No. 1, 2014.

⁹⁴ Regionala cancercentrum i samverkan: *Nationellt vårdprogram för palliativ vård 2012-2014*. Regionala cancercentrum i samverkan, Stockholm, 2012, p. 13.

⁹⁵ Op. cit., p. 42.

⁹⁶ Socialdepartementet: *Vårdens svåra val: Slutbetänkande av prioriteringsutredningen*. Statens offentliga utredningar, 1995, SOU 1995:5. The main title is in translation: *Difficult Decisions in Health Care*. My translation.

care and how it could be offered equally in the whole country. However, how to reach this aim is still a question of great concern.⁹⁷

Qualitative research interview

In the interview study I have interviewed hospital chaplains, physicians in neonatal care and physicians in palliative care. Regarding the interviewees in palliative care they all have specialized training and competence within this area and they all worked at specialized palliative care units. I have interviewed hospital chaplains since this is a dissertation in which theological perspectives are of importance and I regarded these theologians, who both have theological expertise and experience of the area of concern, to be an important group to include. In the interviews the particular focus has been on dignity at the beginning of life and the end of life.

In much of the theoretical discussion on human dignity and medical ethics, the focus has often come to concern decision-making. This understanding came to influence the choice of interviewees. Within the health care service different professions have their specific competence and much of the work is team-based. However, in the forming of the research project, I choose to interview physicians, since their particular area of responsibility and competence was regarded to be of importance for this study. Attention is drawn to practical reason in the interviews, in order to understand how they reflect on the questions concerning what to do and how to act, and what values they understand to be of importance in forming a particular decision.

I have chosen the narrative method of conducting interviews because I agree with the understanding that by using the narrative form, we explain our actions and thoughts to others as well as to ourselves and create meaning of our world and our experiences.⁹⁸ The storied form does not offer arguments in a philosophical sense; instead, the interviewees

⁹⁷ Socialdepartementet: *Döden angår oss alla – Värdig vård vid livets slut*. 2001, SOU 2001:6.

⁹⁸ Ewick, Patricia and Silbey, Susan: "Narrating Social Structure: Stories of Resistance to Legal Authority", in *American Journal of Sociology* Vol. 108, No. 6, 2003, p. 1340.

in using the storied form⁹⁹ get involved in a meaning-making activity, constructed in such a way that it becomes a description of how the narrator understands the world, its complexities and moral concerns.¹⁰⁰

One important way in which narrative analysis has been used within medical ethics is as a tool of emancipation. Arthur W. Frank, has in his research studied narratives about illness experience and embodiment. The narratives give new perspectives on the situation of the patient, who has often been looked upon as a passive victim of disease, and he discusses important ethical concerns illuminated by this perspective.¹⁰¹ Rita Charon and Martha Montello, like Arthur W. Frank, also focus their analysis on patient narratives. The ethical concerns are related to the ethics of ordinary life, the patient's decisions and the patient's concerns.¹⁰² However, in this dissertation I have chosen to interview professionals, a choice which only renders an indirect perspective from patients and family. Since one of my research interests in this study is the medical decisions being made, I have chosen to focus, due to limited time and space, on interviews with the selected groups and not on patients or patients' families. I regard my research as a complement to research conducted from these other important perspectives.

I have interviewed a total amount of 18 persons, six within each group. The criteria that were firstly considered in choosing participants were age and gender. Regarding the criterion of gender, an equal number of women and men were interviewed. Regarding the criterion of age, I found it to be practically impossible to reach this criteria and my analysis is that this criteria was of less importance than first believed. It is also important to note that this research study does not claim that its data is generalizable in a statistical sense. As regards the number of interviewees, I chose 18 as an estimate based on the perspective of reaching saturation. Steinar Kvale comments that after a certain point (in his

⁹⁹ I use the term 'story' or 'storied form' relating to separate interviews, while I preserve the term 'narrative' for the narrative analysis of general patterns which will be described later.

¹⁰⁰ Ewick, Patricia and Silbey, Susan: "Narrating Social Structure: Stories of Resistance to Legal Authority", p. 1341.

¹⁰¹ Frank, Arthur W.: *The Wounded Storyteller: Body, Illness, and Ethics*. Second edition. The University of Chicago Press, Chicago, 2013.

¹⁰² Charon, Rita and Montello, Martha M. (eds.): *Stories Matter: The Role of Narrative in Medical Ethics*. Reflective Bioethics. Routledge, New York, 2002.

description around 15+/-10) more interviewees render less knowledge.¹⁰³

It is crucial in a research project which deals with interviews that the research is in line with ethical guidelines concerning matters such as anonymity, confidentiality and discretion. This research project follows the ethical guidelines of humanistic research¹⁰⁴ and during the autumn of 2010 it was examined and approved by the Regional Ethical Review Board in Uppsala.¹⁰⁵

Two test interviews were carried out in spring 2011 in order to analyse how the questions were perceived and understood. This was important because a preliminary judgment could then be made on whether the questions would work as a means for reflection. Another important matter was to analyse if the interview guide should be supplemented with new themes. The result of the test study was that certain rearrangements were made in the interview guide, but overall a positive evaluation of the outline of the study.

The interviews were carried out between spring 2011 and spring 2013 at hospitals in mid-sized cities in the middle and southern parts of Sweden, in total nine different cities and twelve different hospitals. The interviewees were contacted by letter, which included information about the research project as well as information about the interview in order to give a comprehensive understanding of the research project. It was stressed that participation in the interview was voluntary and that the interviewees had the possibility to refrain from the interview without explanation. Information was also given concerning the interview being recorded and transcribed, how the interview material would be preserved and used, and explaining that all the material would be coded so that no information of a personal character or other which might identify the participants, could be gathered from the transcribed material. After approximately ten days I followed up the letter with an e-mail and the interviewees who decided to participate in the study could freely choose the location for the interview. All of the interviews, including both hospital chaplains and physicians, took place in offices and reception rooms at the different hospitals. The interviews lasted between 45 minutes to an hour. At the interview the participants were

¹⁰³ Kvale, Steinar and Brinkmann, Svend: *Den kvalitativa forskningsintervjun*. Translated by Torhell, Sven-Erik. Second edition. Studentlitteratur, Lund, 2009, p. 130.

¹⁰⁴ Vetenskapsrådet: *Forskningsetiska principer inom humanistisk-samhällsvetenskaplig forskning*. Vetenskapsrådet, Stockholm, 2002.

¹⁰⁵ Date for approval 8 Dec 2010. Registration number 2010/408.

given the following information: they could end the interview whenever they wanted without explaining why, the interview would be coded, and they could be sent a transcribed copy of the interview which they were asked to read through and then return with any changes they wanted made. A letter of consent was signed before the interview started.

When conducting the interviews the overall theme was dignity, but the questions regarded both this specific theme and ethical situations more in general. The questions concerned three areas: The interviewees' reflections on, and experiences of, situations and choices that they considered had an ethical dimension, ethical situations and experiences of meetings with patients and relatives of patients, and situations and experiences of dignity regarding the beginning of life and the end of life.

The interview schedule was of a semi-structured character. The open-ended questions were followed by certain questions which could be of a more specific character, intended to gain a more detailed understanding. One area which I had first considered to discuss was the discussion with colleagues about ethical experiences. However, this area did not elicit much attention or interest from the interviewees.

One important aspect to consider in an interview situation, as well as in analysis, is 'co-construction'. Phillida Salmon and Catherine Riessman point to this when they claim that storytelling is a social activity and that stories are told in a specific context and influenced by factors such as the interaction between interviewee and researcher.¹⁰⁶ Riessman formulates it thus: "Stories don't fall from the sky (or emerge from the innermost "self"); they are composed and received in contexts – interactional, historical, institutional, and discursive – to name a few."¹⁰⁷ An interview situation is always an encounter in which even subtle influences or non-verbal aspects can play a part in the co-construction, and where the audience (the interviewer) always has an influence regarding what the interviewee perceives can or cannot be said, and how that which they wish to tell can be described and expressed.¹⁰⁸

¹⁰⁶ Salmon, Phillida and Riessman, Catherine Kohler: "Looking Back on Narrative Research: An Exchange", in Andrews, Molly, Squire, Corinne and Tamboukou, Maria (eds.): *Doing Narrative Research*. Second edition. Sage, London, 2013, p. 199.

¹⁰⁷ Riessman, Catherine Kohler: *Narrative Methods for the Human Sciences*. Sage, London, 2008, p. 105.

¹⁰⁸ Salmon, Phillida and Riessman, Catherine Kohler: "Looking Back on Narrative Research: An Exchange", p. 199.

Many aspects can affect the presentation of what is said and in this interview project I can assume that the presentation, for instance, has been influenced by the purpose of the study, one presents information in a different way to a layman than to a colleague and that one wants to present oneself as a morally responsible person.

Methods of analysis

I have chosen to use a simple form of transcription which means that I have transcribed verbatim, I have registered longer pauses (more than one second), laughter, and simultaneous talk. I regarded this level of transcription to be satisfactory for my analysis, which mainly focuses on content rather than form, such as in analysis of structure of speech.¹⁰⁹ The transcribed material has been given a code so that no personal information or other information which can be used to identify the participants can be recognised.

The interviews were performed in Swedish and transcribed into Swedish but the excerpts that are included in the dissertation have been translated into English. When making translations it can be difficult to find the exact word which has the same meaning and connotation in the two different languages, and a translation always involves interpretation. To enhance quality, professional translators have been consulted in the translation of the material.

Narrative analysis

Already in classic philosophy, Aristotle provided a theoretical discussion about literature in his work *Poetics*.¹¹⁰ In modern times the last four decades have been described as ‘the narrative turn’, meaning that narrative became the focus of study. Narrative research is carried out in several different research areas such as linguistics, philosophy, sociology and theology.¹¹¹ In the latter, not least the biblical narratives’ correlation to a Christian life story have been studied. One of the ethicists to be mentioned here is Stanley Hauerwas and his narrative theology,

¹⁰⁹ Riessman, Catherine Kohler: *Narrative Methods for the Human Sciences*, p. 54.

¹¹⁰ Aristotle: *Poetics*. Translated by Kenny, Anthony. Oxford University Press, Oxford, 2013.

¹¹¹ Johansson, Anna: *Narrativ teori och metod: med livsberättelsen i fokus*. Studentlitteratur, Lund, 2005, p. 17.

in which the story of God's people is the narrative pattern for even contemporary congregations.

Narrative analysis can be considered as a diverse set of methods and theories. However, the common features are explained by Riessman: "Narrative analysis refers to a family of methods for interpreting texts that have in common a storied form. As in all families there is conflict and disagreement among those holding different perspectives."¹¹² Among researchers working with narrative analysis there is no agreement about the definition of the concept of narrative. Nevertheless, how the individual researcher defines this is crucial for the result of the analysis. Salmon and Riessman point to the understanding that a narrative cannot only be random ideas but needs to be held together in such a way that there is a "[...] consequential linking of events or ideas."¹¹³ This draws attention to that events in a narrative has a form of temporal ordering. Salmon and Riessman also point to that the order or events are related to another, there is an overarching idea and this is often referred to as a plot.¹¹⁴ I understand the narrator to form the events into a meaningful order and understand storytelling as a meaning-making activity. I agree with Patterson in pointing out that the events that are chosen by the narrator intervenes with an evaluative aspect. Hence, the story is told in such a way that it creates meaning.¹¹⁵ The narrative therefore does not just say something about a specific theme but also something about narrators, the context of the narrator, and the context of the interview situation. I also regard that the narrative can be about the narrator and/or others.¹¹⁶ A central aspect of my definition of a narrative is what I here have referred to as the evaluative aspect or what sometimes is called the point of the narrative. The point can be regarded as being a part of an evaluation; the events are told in a specific way and lead up

¹¹² Riessman, Catherine Kohler: *Narrative Methods for the Human Sciences*, p. 11.

¹¹³ Salmon, Phillida and Riessman, Catherine Kohler: "Looking Back on Narrative Research: An Exchange", p. 197.

¹¹⁴ Polkinghorne, Donald: "Narrative configuration in qualitative analysis", in *International Journal of Qualitative Studies in Education* Vol 8, No. 1, p. 5.

¹¹⁵ Patterson, Wendy: "Narratives of Events: Labovian Narrative Analysis and Its Limitations", in Andrews, Molly, Squire, Corinne and Tamboukou, Maria (eds.): *Doing Narrative Research*. Second edition. Sage, London, 2013, p. 33. Patterson also claims that there cannot be a distinct difference between an objective true story and an evaluative part of the story; they cannot be separated in the human being's meaning-making activity

¹¹⁶ Ewick, Patricia and Silbey, Susan: "Narrating Social Structure: Stories of Resistance to Legal Authority", p. 1341.

to something which the narrator wants to be emphasise.¹¹⁷ However, one also has to regard that there can be different evaluative aspects.

Viveka Adelswärd draws attention to the notion that a story can indicate normative aspects concerning how one ought to behave, which can be expressed in the point of the story. She observes that when a person experiences that the question has a certain moral undertone and feels a need to justify or explain, or almost defend a certain action or behaviour then the narrator can use the storied form and construct the story in such a way that it shows that the individual is a moral agent and someone who takes moral responsibility.¹¹⁸ Adelswärd writes: “The reason we strive to account for and explain our actions is because we want to be seen as people capable of acting freely, thinking clearly, and acting with moral responsibility.”¹¹⁹ I agree with Adelswärd on this matter and what was implicit in Adelswärd’s study is explicit in this study.

Adelswärd also discusses what she describes as the narrator point, which is an analysis of how the narrator describes him/herself, a way of expressing social identity, and relates to self-representation. In the further analysis I will not discuss this perspective, but will mention that the interviewees position themselves, and through their positioning mark a narrator point. Expressions in the interviews such as “I experienced this as being very bad” and “I thought that was horrible” mark the narrator point and give voice to a specific self-presentation. In this way, one marks oneself as a moral being who is accountable for one’s moral actions.¹²⁰

One point of clarification should be made between the individual interviews, in which the interviewees describe events which have a storied form, and how this relates to the term ‘narrative’. I use the term ‘narrative’ to describe a general pattern which is interpreted among the interviews. This means that in the analysis I have searched for similar patterns among the interviews, patterns which have certain parts and

¹¹⁷ Ibid.

¹¹⁸ Adelswärd, Viveka: “Berättelser från älgpasset – om metoder för att analysera jaktberättelsers struktur, poäng och sensmoral”, in Hydén, Lars-Christer and Hydén, Margareta (eds.): *Att studera berättelser: samhällsvetenskapliga och medicinska perspektiv*. Liber, Stockholm, 1997. Adelswärd makes a tripartite categorisation of the point which she refers to as: ‘berättelsepoäng’ (the point of the story), ‘berättarpöäng’ (the narrator point) and ‘underliggande poäng’ (underlying point). My translation.

¹¹⁹ Op. cit., p. 227. Swedish original: “Därför strävar vi efter att redogöra för och förklara våra handlingar för att bli betraktade som kapabla att handla fritt, tänka klart och uppträda med moraliskt ansvar.” My translation.

¹²⁰ Op. cit., pp. 212- 213.

evaluative aspects. When referring to narrative I therefore do not make reference to an individual interview but to an interpreted overall pattern. This points to concerns recognised by Riessman in claiming that a researcher is part of the creation of the narrative since one needs to interpret and make decisions regarding the boundaries of the narrative.¹²¹

As a first step in the analysis of the interview material I carried out a close reading of the interviews, identifying a number of recurrent themes, which I then ordered into preliminary groups in the separate interviews. I then analysed all the interviews and identified common thematic elements which developed across stories.¹²² In the next analytic step I analysed an order of events and evaluative aspects. Squire explains that when the thematic overview is done, the researcher develops and tests theories which give an explanation of the narratives. This is interpretive work where one moves between the interviews and generalizations about them.¹²³ The narratives that I have interpreted, in different ways, have a bearing on the question of dignity but I have also analysed and interpreted narratives on decisions which I regard as raising concerns on human dignity.

I earlier described that the interview does not offer arguments in a philosophical sense, and this is important to underline in relation to the narrative analysis. I fully agree with Ulla Schmidt in her analysis:

The more general point here is that empirical research with the purpose of being constructively relevant, should not be carried out as though its object is coextensive with ethical theory. It should not treat data-material as though it simply displays ethical theory, similar to scholarly, academically developed theory and it must avoid viewing informants and treating the material deriving from them as though they were ethical “mini-theorists”.¹²⁴

As I will discuss further in the next chapter, the concept of dignity can have various meanings; for example it can refer both to autonomy and human flourishing. It can also be noted that the Swedish adjectives ‘världigt’ and ‘övärdigt’ can be translated with two different sets of English

¹²¹ Op. cit., p. 41.

¹²² Riessman, Catherine: *Narrative Methods for the Human Sciences*, p. 74.

¹²³ Squire, Corinne: “Experience-Centered and Culturally-Oriented Approaches to Narrative”, in Andrews, Molly, Squire, Corinne and Tamboukou, Maria (eds.). *Doing Narrative Research*. Second edition. Sage, London, 2013, p. 57.

¹²⁴ Schmidt, Ulla: “Christian Ethics and Empirical Research”, in *Studia Theologica - Nordic Journal of Theology* Vol. 63, No. 1, 2009, p. 86.

adjectives, namely ‘dignified’ and ‘undignified’ as well as ‘worthy’ and ‘unworthy’.¹²⁵ They relate to nouns which refer to different meanings of dignity. The Swedish adjectives can include both these connotations. It can then of course be the case that when someone uses a term such as ‘dignity’ they refer to different understandings depending on the context. This of course raises a methodological concern, namely: When the interviewees refer to a term such as ‘dignity’, how can one know what they mean by this term? The appearance of a word does not in itself reveal the full meaning. However, in the analysis the meaning of the term is interpreted from the context within which it is set and in the presentation of the narrative analysis this interpretation will be discussed and explored.

The possibilities and restrictions on interpretation is a problem which has been considered within the hermeneutic tradition. Hans-Georg Gadamer claims that as human beings we have fore-conceptions which limit our understanding but on the other hand also make an interpretation possible; they enable a possibility for interpretation.¹²⁶ In this study this in particular relates to the understanding of dignity. One can regard a material with a clear conception of what dignity means, for example one can focus on equality and autonomy. This can lead to one only focussing on material which is in line with one’s preconceptions, and disregarding material which does not fit one’s understanding. The results of the findings risk only fitting with what was already known while other aspects and angles risk being disregarded. I have tackled the problem in the following way. Firstly, in the interviews the questions are open-ended, as mentioned, which gave the interviewees the possibility to talk about events which they understood as being in relation, or contrary, to a patient’s dignity, and this provided certain perspectives. Secondly, I have also discussed the interview material with other researchers in order to broaden the perspectives on the analysis of the interpretation of the transcribed material.

¹²⁵ ‘Dignified’ can relate to dignified manner and ‘undignified’ to being silly for example. ‘Worthy’ can have a connotation to equal, and ‘unworthy’ can mean having little or no value.

¹²⁶ Gadamer, Hans-Georg: *Truth and Method*. Second edition. Translation revised by Weinsheimer, Joel and Donald, Marshall G. Continuum International Publishing Group, London, 2004, p. 271.

Ethical analysis and material

In the next chapter an analysis will be made of historical and contemporary understandings of the concept and the principle of human dignity which are of relevance in the research study. However, here I want to mention some of the philosophical and theological perspectives which will be discussed in more detail. Theoretical contributions are discussed with the guiding aim of furthering the analysis of the concept of human dignity and the principle of human dignity as well as furthering the interpretation and analysis of the empirical material, always guided by the study's overall aim and the research questions. As with all philosophical analysis, it is important to strive for conceptual clarity and theoretical consistency. In the analysis I have regarded it as important to be transparent with my interpretations of the arguments and to do justice to the argumentation of the theorists.¹²⁷ It is also important that the arguments provided are possible to analyse inter-subjectively.

Two philosophers will be discussed in more detail. The first philosopher to be mentioned is Immanuel Kant. Within the discussion on human dignity the importance of the Kantian perspective has historically been, and still is, influential in contemporary discussion. In particular, I discuss Kant's conception of dignity and its relation to autonomy. In my analysis I have mainly focussed on the question of how to understand Kant's philosophy on the meaning and the justification of human dignity and I have mainly researched this question in his work *Critique of Practical Reason*¹²⁸ and *Groundwork for the Metaphysics of Morals*.¹²⁹

The second theoretical perspective is the Russian philosopher Mikhail Bakhtin. In the analysis of the empirical material I have searched for theories which could give explanations and further the analysis. In chapter three, where I discuss dignity and responsibility, I have chosen to further the analysis in discussion with Bakhtin since I regarded his analysis of responsibility, which he calls answerability, as providing a

¹²⁷ Grenholm, Carl-Henric: *Att förstå religion: Metoder för teologisk forskning*. Studentlitteratur, Lund, 2006, p. 213.

¹²⁸ Kant, Immanuel: *Critique of Practical Reason*. Translated and edited by Gregor, Mary. Revised edition. Cambridge Texts in the History of Philosophy. Cambridge University Press, Cambridge, 2015.

¹²⁹ Kant, Immanuel: *Groundwork of the Metaphysics of Morals*. Translated and edited by Gregor, Mary and Timmermann, Jens. Revised edition. Cambridge Texts in the History of Philosophy. Cambridge University Press, Cambridge, 2012.

comprehensive understanding which deepens the analysis of the empirical material. In my analysis of Bakhtin I have mainly focussed on how responsibility in the Bakhtinian sense can be understood. The material by Bakhtin which I have used is his earlier work, namely *Toward a Philosophy of the Act*¹³⁰ as well as essays in *Art and Answerability: Early Philosophical Essays by M. M. Bakhtin*.¹³¹ Bakhtin does not discuss the question of human dignity but, as will be shown in my research, the discussion of my empirical material, analysed through the Bakhtinian understanding of answerability, forms a critique of Kantian ethics, and is central to my own constructive proposal.

In the late 20th century, there has been much discussion on the question of what a theological contribution to medical ethics can be. Lisa Sowle Cahill is one of those who has discussed this matter and also formed a critique, claiming that many theologians have abandoned their theological analysis and become moral philosophers instead. However, she also claims that a new interest is awakening regarding what the identity of theological medical ethics can be.¹³² In my dissertation I have made use of both philosophical and theological material, the latter in particular within the Christian context. I understand theology as one of many constructive sources to be used when reflecting on morality, and that theology can contribute to the analysis of questions within medical ethics.¹³³ In the dissertation this means that Christian beliefs, symbols and narratives are used as interpretive tools when analysing experiences from medical practice. Within the discussion on human dignity the theological contribution has mainly revolved round the question of *Imago Dei*, but in my research I will show how a Christological contribution can enrich the understanding of the principle of human dignity. Even though I, in this dissertation, draw on Christological perspectives and claim that this perspective can be a tool for articulating

¹³⁰ Bakhtin, Mikhail: *Toward a Philosophy of the Act*. Holquist, Michael and Liapunov, Vadim (eds.). Translated by Liapunov, Vadim. University of Texas Press Slavic Series 10. University of Texas Press, Austin, 1993.

¹³¹ Bakhtin, Mikhail: *Art and Answerability: Early Philosophical Essays by M. M. Bakhtin*. Holquist, Michael and Liapunov, Vadim (eds.). Translated by Liapunov, Vadim and supplement translation by Brostrom, Kenneth. University of Texas Press Slavic Series 9. University of Texas Press, Austin, 1990.

¹³² Cahill, Lisa Sowle: "Religion and Theology", in Sugarman, Jeremy and Sulmasy, Daniel P. (eds.): *Methods in Medical Ethics*. Second edition. Georgetown University Press, Washington, 2010, pp. 75-76.

¹³³ Sundman, Per: *Human Rights, Justification, and Christian Ethics*. Uppsala Studies in Social Ethics 18. Almqvist & Wiksell, Stockholm, 1996, p. 13.

a principle of human dignity, I do not regard this to be an exclusive claim. This means that I regard other traditions, such as the Jewish and the Muslim traditions, to contribute with similar important insights.

Disposition

In chapter one, ‘Theoretical Perspectives on Human Dignity’, I analyse the meaning of the concept of dignity and in particular draw attention to attributed, intrinsic and inflorescent dignity. An important difference between these perspectives concerns whether dignity is attributed to a person, if it belongs to a human being due to her moral worth or if it is regarded as intrinsic. I also study the principle of human dignity and point to, among others, the Kantian proposition of always treating humanity in a person as an end and never merely as a means. In chapter one I also present theological perspectives, such as *Imago Dei* and personalism, as well as philosophical perspectives, such as dignity due to moral worth or humanity in every person characterised by rationality and autonomy. From a more general study of the meaning and justification of human dignity I proceed to the particular area of criticism regarding the meaning and function of dignity that has been raised within medical ethics.

In chapters two, three and four I present the narrative analysis and discuss the results in relation to philosophical and theological theories.

In chapter two, ‘Autonomy and Human Vulnerability’, I discuss the relation between dignity and autonomy but also further the discussion on this matter from the perspective of human vulnerability – a perspective which plays a significant role throughout the book. In this chapter I take the starting point in a Kantian perspective on dignity where the human being is regarded as rational and autonomous, and where autonomy is understood in a particular way. I then proceed to the narrative analysis where, in the empirical material, I have interpreted not only a connection between dignity and autonomy but also the significance of human vulnerability. A person is autonomous and at the same time vulnerable, and I claim that this has implications for the understanding of dignity.

In chapter three, ‘Presence and Responsibility’, the relation between dignity, presence and responsibility is analysed. To respect a person’s

dignity is here discussed in terms of being present and sharing vulnerability. I analyse this from, among others, a Christological perspective and understand the idea of Christ sharing human vulnerability as a theological tool for understanding the meaning of a principle of dignity. In this chapter, the subject of responsibility comes to the forefront. I develop my analysis of responsibility in close dialogue with the Russian philosopher Mikhail Bakhtin's discussion on answerability.

In chapter four, 'An Analysis of Dignity – Complexities in Medical Care', narratives which focus on decision-making within neonatal care are presented. I have regarded the results from the narrative analysis to raise questions and concerns regarding the subject of dignity. In the discussion I analyse the results from the narrative analysis in relation to the categorisation on the meaning of dignity as attributed dignity, intrinsic dignity and inflorescent dignity. The different meanings raise different results regarding who should be recognised and respected.

In chapter five, 'Human Dignity, Vulnerability and Responsibility', I expand the analysis of the results, and relate these to medical practice. In the discussion a theological perspective where a Christological view – connected to Bakhtin's ethics of responsibility – forms a critique to both the Kantian deontological perspective and dignity acquired by virtue.

1. Theoretical Perspectives on Human Dignity

Professor of law and philosophy Jeremy Waldron has pointed out that major values, such as dignity and freedom, have always invoked different interpretations and usages.¹³⁴ Hence, a specific value can be used in different ways in ethical discussion, and, given the interpretation of that value, different conclusions will be reached. This is noticeable in how dignity is referred to in the medical-ethical debate, for example in the discussion regarding euthanasia. Some argue that a human being should be allowed to die with dignity, meaning that at a certain stage – when people feel they are no longer able to live a dignified life – they should be able to end their own life. A contrary view holds that it is precisely human dignity, in the understanding of the sanctity of life, which requires this practice to be prohibited. The meaning of human dignity is closely related to an understanding of what it means to be a human being and the different views on this matter are mirrored in the different positions described above. M.D Meeks has formulated it in the following way: “To be able to say what dignity is would be to describe the fundamental meaning of being human.”¹³⁵

In this chapter, my aim is to analyse theoretical perspectives on human dignity. The notion on dignity has a long history within both theological and philosophical thought and some of the perspectives which will be discussed still have a great influence in contemporary debate. Certain viewpoints that are discussed will also be of importance in the analysis later on in the dissertation.

¹³⁴ McCrudden, Christopher: “In Pursuit of Human Dignity: An Introduction to Current Debates”, in McCrudden, Christopher (ed.): *Understanding Human Dignity*. Proceedings of the British Academy 192. The British Academy by Oxford University Press, Oxford, 2014, p. 13. Speech given by Jeremy Waldron and referred to by McCrudden.

¹³⁵ Meeks, Douglas M.: “Introduction”, in Moltmann, Jürgen: *On Human Dignity: Political Theology and Ethics*. Translated and with an introduction by Meeks, Douglas M. Fortress Press, Minneapolis, 2007, p. ix.

In this chapter I will also analyse the concept of human dignity. In the contemporary discussion the ambiguity of the concept is debated and there is no consensus among researchers regarding its meaning. Following Daniel Sulmasy's characterisations of dignity, I will distinguish between attributed dignity, intrinsic dignity and inflorescent dignity. I will also analyse different understandings of the principle of human dignity.

Lastly I will present certain criticisms which have been raised against the notion of dignity, but this analysis will be limited to issues pertaining to the medical-ethical debate.

The concept of human dignity

The concept of dignity has a rich history with ancient roots. Etymologically, the Latin root of the term 'dignitas' referred to honour and nobility, a special elevation, and as such it was a term which marked distinction. In ancient Rome, dignitas referred not to all, but to a select few persons with a special rank or status, such as senators. The person became worthy of dignity due to, for example, the special position that person had. Dignity was in this way connected to a high social status.¹³⁶ This understanding of the concept of dignitas is noticeable even today. For example, in contemporary Swedish, the term 'dignitär', or in contemporary English, the term 'dignitary', point to someone who has elevated status, for example a king or a bishop. Lennart Nordenfelt analyses this understanding in his discussion of what he calls 'dignity of merit' where merits can be formal (for example a king) or informal (for example a sportsman) but both grant dignity to the holder of the merit.¹³⁷ Human dignity understood as dignitas, as described here, has connections to what Daniel Sulmasy calls attributed dignity. He characterises attributed dignity as:

¹³⁶ Nordenfelt, Lennart: "The Concept of Dignity", p. 31.

¹³⁷ Dignity of merit is defined as: "A person who has a rank or holds an office that entails a set of rights has a special dignity." Ibid.

[...] worth or value that human beings confer upon others by acts of attribution. The act of conferring this worth or value may be accomplished individually or communally, but it always involves a choice. Attributed dignity is, in a sense, created.¹³⁸

This means that in the eyes of others or society the person is made worthy of dignity. Dignity can in this sense be described as created, conferred and social. For example, if a person loses that which caused that person to be attributed dignity, then the person's dignity can be lost.¹³⁹

The terms 'honour' and 'worth' are sometimes used as synonyms for the term 'dignity', and the choice of synonym can reflect a particular view of the meaning of the concept. Meir Dan-Cohen claims that, in the last few decades, the meaning of dignity has often been linked to worth rather than to honour. When dignity is used as equivalent to honour, this can point to the understanding of dignity as connected to social position, which earlier was described as attributed dignity. However, Dan-Cohen claims that when dignity is used as a synonym for worth, this use is more in line with a Kantian meaning of dignity; in other words, an universalisation of dignity and an equalisation of dignity.¹⁴⁰

¹³⁸ Sulmasy, Daniel P.: "Dignity and Bioethics: History, Theory, and Selected Applications", in Pellegrino, Edmund D., Schulman, Adam and Merrill, Thomas W. (eds.): *Human Dignity and Bioethics*. University of Notre Dame Press, Notre Dame, 2009, p. 473. Sulmasy makes a tripartite classification of the concept of dignity: attributed dignity, intrinsic dignity and inflorescent dignity. He has discussed other versions of this classification elsewhere, but in this dissertation I will follow the classification described above. For other versions, see for example Sulmasy, Daniel P.: "Dignity and the Human as a Natural Kind", in Taylor, Carol R. and Dell'Oro Roberto (eds.): *Health and Human Flourishing: Religion, Medicine and Moral Anthropology*. Georgetown University Press, Washington D.C., 2007.

¹³⁹ In contemporary debate on dignity, this particular understanding of human dignity has not been prominent, but in recent years a new approach can be exemplified with Jeremy Waldron who has developed an understanding of human dignity in which he draws on the understanding of dignity as attributed, but instead of dignity being related to a few people in society with high status, he introduces a claim on equality, an 'equalization of rank'. The respect that was formerly accorded to the high status of nobility is now accorded to every human being; every person has the status of a dignitarian, and as such every human being deserves respect. Waldron, Jeremy: *Dignity, Rank, and Rights*, p. 33.

¹⁴⁰ Dan-Cohen, Meir: "Introduction: Dignity and Its (Dis) Content", in Waldron, Jeremy: *Dignity, Rank, and Rights*. Dan-Cohen, Meir (ed.). The Berkeley Tanner Lectures. Oxford University Press, New York, 2012, pp. 3-4.

I have discussed attributed dignity and will now proceed to the meaning of intrinsic dignity. Sulmasy states the following definition:

By intrinsic dignity, I mean that worth or value that people have simply because they are human, not by virtue of any social standing, ability to evoke admiration, or any particular set of talents, skills, or powers. Intrinsic dignity is the value that human beings have simply by virtue of the fact that they are human beings.¹⁴¹

Let me describe what I understand to be some general aspects of the meaning of intrinsic dignity. Firstly intrinsic dignity belongs to all human beings, independent of, for instance, gender or social status. This differs from an understanding of attributed dignity where dignity was attributed to a few, due to talent or position. Secondly, intrinsic dignity belongs to human beings regardless of other's or one's own recognition of one's dignity. According to Sulmasy, intrinsic dignity is not attributed by someone else and this means that intrinsic dignity is not dependent on the recognition of others.¹⁴² Thirdly, intrinsic dignity cannot be degraded or lost, and a person has intrinsic dignity during her whole life. A person can for example be treated inhumanly, in a way which does not stand in correlation to her dignity, but the person's intrinsic dignity is still not lost or degraded. In the understanding of attributed dignity, on the other hand, dignity can be lost, if a person loses his or her position, or loses that which once attributed dignity to the person. Fourthly, intrinsic dignity is an equal value. There is no difference in level of dignity, it cannot be graded. All human beings have dignity to the same degree and in this sense it is equal.¹⁴³ Dignity in the form of attributed dignity is only attributed to some, due for example to talent, and is therefore not equal to all.¹⁴⁴

It can also be illuminating to look closer at how some have defined what dignity as intrinsic dignity is not. The philosopher Ingemar Hedenius claims that there is a difference between having dignity (in the

¹⁴¹ Sulmasy, Daniel: "Dignity and Bioethics: History, Theory, and Selected Applications", p. 473.

¹⁴² Ibid.

¹⁴³ Grenholm, Carl-Henric: "Människovärdets okränkbarhet - var går gränsen?", in Stenström, Hanna (ed.): *Religionens offentlighet: om religionens plats i samhället*. Arto, Skellefteå, 2013, p. 165.

¹⁴⁴ This, of course, does not relate to certain contemporary understandings such as the position mentioned by Waldron.

sense of intrinsic dignity) and a recognition of how valuable human beings are considered to be. Hedenius asserts that some people are considered more valuable than others, for example according to how important they are in society compared to other people. However, this is different from having intrinsic dignity, according to Hedenius.¹⁴⁵ People also have different moral values and can be considered to live virtuous lives in different degrees. In this sense, Hedenius claims, we often make a distinction between the value of a person who carries out criminal acts and a person who has high moral standards.¹⁴⁶ Hedenius also points to all persons not being equally valuable to us, because of the different kinds of relationship that we have with specific persons. For example a child is more valuable to its own parents compared to a child who is not their own. However, such circumstances are irrelevant in relation to a person's intrinsic dignity, according to Hedenius.¹⁴⁷

Attributed dignity, which was earlier discussed, was the definition used to describe dignity which was conferred by others to a person, for instance based on that person's high rank. Hence, dignity was a term that marked distinction of the particular individual, here distinction in social status. In this sense dignity was, connected to those elevated in society, elevated through their rank. However, it is also important to remember that even in the understanding of intrinsic dignity there can be a connection between dignity and a special elevation, but then in a transformed sense. Among some philosophers and theologians, a specific capacity is understood to be characteristic of the members of the human species (most often identified as rationality) and this specific human characteristic is what gives the members of the species dignity. Thus dignity, when discussed as intrinsic dignity, is sometimes understood as being equal among all members of the human race, but in relation to other species it can be a sign of distinction as well as elevation.

Within the ethical discourse, virtue ethics has gained much interest in recent years. Dignity is a concept that is sometimes used in the sense of a virtue, connected to a person's character. A person who carries himself or herself with dignity is often understood as having a behav-

¹⁴⁵ Hedenius, Ingemar: *Om människovärde: essayer*. Bonniers, Stockholm, 1982, p. 12.

¹⁴⁶ Op. cit., p. 15.

¹⁴⁷ Op. cit., pp. 17-18.

our characterised by “[...] having a sort of presence, self-control, uprightness of bearing.”¹⁴⁸ The last characterization of the concept of dignity, inflorescent dignity, describes the connection to virtue. Sulmasy describes this connection in the following way:

[...] inflorescent dignity is used to refer to individuals who are flourishing as human beings – living lives that are consistent with and expressive of the intrinsic dignity of the human. Thus, dignity is sometimes used to refer to a state of virtue [...].¹⁴⁹

I regard inflorescent dignity in a slightly different sense than Sulmasy does. I agree with Sulmasy that dignity in this form is connected to a person’s moral character; dignity is connected to human beings’ behaviour and virtue. However, in my view inflorescent dignity is not always an expression of intrinsic dignity. Rather, I would claim that inflorescent dignity can be seen as dignity which can be acquired by moral effort. In later discussions, I will develop this view.¹⁵⁰

Some scholars in contemporary debate have set aside the term ‘human dignity’ as a term solely used for the claim of equal human rights. Other terms are used in order to grasp alternative meanings of dignity. In this study human dignity and dignity will be used interchangeable and in certain discussions I will use the distinctions by Sulmasy for distinguishing between the meanings of dignity.

¹⁴⁸ Waldron, Jeremy: *Dignity, Rank, and Rights*, p. 22.

¹⁴⁹ Sulmasy, Daniel: “Dignity and Bioethics: History, Theory, and Selected Applications”, p. 473.

¹⁵⁰ Sulmasy’s characterisation of inflorescent dignity can be compared to Andorno’s and Nordenfelt’s views. Roberto Andorno makes a distinction between inherent dignity and moral dignity. Andorno points to inherent dignity being the same for all; it belongs to every human and cannot be lost or graded. Moral dignity is connected to human beings’ behaviour and their ability to behave with dignity. Moral dignity can indeed be lost or one can lack moral dignity. Andorno, Roberto: “Human Dignity and Human Rights as a Common Ground for a Global Bioethics”, in *Journal of Medicine & Philosophy* Vol. 34, No. 3, 2009, pp. 231-232. In Nordenfelt’s description this characterisation of dignity, connected to a person’s moral character, is referred to as “dignity of moral stature”. Nordenfelt says that “this kind of dignity is tied to the idea of a dignified character and of dignity as a virtue”. Nordenfelt, Lennart: *Dignity in Care for Older People*, p. 40.

The principle of human dignity

I have pointed to different interpretations of the meaning of the concept of dignity, but an equally important analysis concerns the understanding of the principle of human dignity. McCrudden points to the relational ethical claim that a person's dignity involves. This means that certain acts and treatments of oneself or others can either be inconsistent or consistent with a human being's dignity.¹⁵¹ This points to the understanding of a principle of human dignity. David H. Calhoun states that researchers focussing on the practical implications of dignity mainly discuss the principle of human dignity directed towards how human beings should act. However, he states that the discussion regarding human dignity to a great extent revolves round what human beings are. He also claims that "[...] we should keep in mind that dignity is less a guide for action than it is a mode of understanding, revealing, and relating to human persons".¹⁵² In my analysis, the focus on a principle of human dignity is particularly important and I do not agree on why it is necessary to make such a sharp distinction between the meaning of dignity and the principle of dignity as Calhoun makes. In my understanding, it is important to develop and explore both the meaning of dignity and the principle of dignity.

One of the most well-known formulations of a principle of human dignity originates from Immanuel Kant. In the second formulation of the categorical imperative, the formulation of humanity, it is stated: "So act that you use humanity, in your own person as well as in the person of any other, always at the same time as an end, never merely as a means."¹⁵³ This principle describes the implications that follow by a person having dignity. In this formulation of the categorical imperative, the idea that we ought to have respect for ourselves and other persons is underlined. The important point to be made is that humanity within a person cannot be treated merely as a means; persons cannot solely, for example, be instrumentalised to another's needs but humanity within a person ought to be treated as an end in itself. Human beings are not things that are replaceable, but human beings are persons and thus

¹⁵¹ McCrudden, Christopher: "Human Dignity and Judicial Interpretation of Human Rights", in *The European Journal of International Law* Vol. 19, No. 4, 2008, p. 680.

¹⁵² Calhoun, David H.: "Human Exceptionalism and the *Imago Dei*: The Tradition of Human Dignity", in Dilley, Stephen and Palpant, Nathan J. (eds.): *Human Dignity in Bioethics: From Worldviews to the Public Square*. Routledge, New York, 2013, p. 36.

¹⁵³ Kant, Immanuel: *Groundwork of the Metaphysics of Morals*, p. 41 (Ak. 4:429).

should be respected. It is important to remember that the formulation of humanity is one formulation of the categorical imperative where the categorical underlines that it should apply always, without exception.

There have been discussions, among philosophers regarding the interpretation of the meaning of 'treated as an end'. To my understanding, one can at least adhere to the interpretation of an end in a negative sense, namely in the understanding that certain actions towards another should be prevented. To be treated as an end puts limitations on what can be regarded as a morally justified act towards a human being.

Roberto Andorno has stated that within medical ethics the second formulation of the categorical imperative has been interpreted and applied in several ways. For example, the prohibition of the instrumentalisation of the person is underlined with regard to informed consent: No person should be used only as a means to research, regardless of what results could be achieved. The meaning of being an end in oneself has also been interpreted and applied in medical practice, underlining the respect for every patient as a person, regardless of the patient's illness or diagnosis.¹⁵⁴

Within medical practice, the principle of human dignity is interpreted in at least two major ways: namely as respect for persons' autonomy and respect for the equal dignity of every person. As an egalitarian ideal the principle of dignity marks that no differentiation should be made between patients due to factors such as gender, age or race. Every patient deserves equal respect and treatment. If one considers the documents and restrictions for Swedish medical care, it is the understanding of dignity as respect for equal dignity which is at the centre of attention. This egalitarian ideal is underlined in *the Swedish Health and Medical Services Act*.¹⁵⁵ Within medical practice the interpretation of a principle of dignity is also commonly interpreted as respect for the patient's autonomy. In a minimum sense, the respect for a patient's dignity is included in the practice of informed consent.

In contemporary theological thought, the Swiss theologian Johannes Fischer has made an interesting contribution to an understanding of a principle of human dignity. In his understanding, the focus is on human dignity as a social status which should be respected and recognised, and

¹⁵⁴ Andorno, Roberto: "Human Dignity and Human Rights as a Common Ground for a Global Bioethics", p. 231.

¹⁵⁵ Socialdepartementet: *Hälsa- och sjukvårdslag*. 1982, SFS 1982:763, § 2.

he describes the principle thus: “[...] having human dignity means being a creature which is to be recognised and respected as a human being in the sense of a member of the human community, and which is to be treated accordingly.”¹⁵⁶ Respect, in Fishers’ description, is connected to the rights a human being has due to the social status as a member of the community. However, recognition is also of importance in his understanding since one should be recognised as a human being – not in a biological sense, but in a social sense. It is possible to have the empirical status of being a human being, in a biological sense, but not have normative status; the normative status as a human being is due in the act of recognition of someone as a member of a social community. Fischer admits that there is a possibility that those who possess human dignity therefore can be a smaller group than those who are human beings in a biological sense.¹⁵⁷ However, Fisher claims that the criteria for who should count as a human being in a social sense are not arbitrary; on the contrary, the criteria are already established due to our cultural and religious understanding of the human being.¹⁵⁸ Thus Fischer believes that a shared social understanding, which has developed over history, can provide a basis for the ideal regarding who should be recognised and respected.

The respect for a human being’s dignity in our culture, has often been conceptualised in the understanding of respect for equal human rights. Many would claim that human dignity is the justification for the claim of equal human rights. However, in contemporary discussion this is much discussed and also criticised. Yechiel Michael Barilan claims that the idea of human dignity stands as the theoretical foundation of human rights. However, rights, he claims, differ in specification and enforceability in relation to human dignity.¹⁵⁹ This has implications for not least the protection as well as the promotion of central human values such as welfare and freedom. However, even though the respect for dignity in

¹⁵⁶ Fischer, Johannes: “Human Dignity and Human Rights: On the Normativity of the Social World”, in Namli, Elena, Sundman, Per and Wigorts Yngvesson, Susanne (eds.): *Etiska undersökningar: Om samhällsmoral, etisk teori och teologi*. Uppsala Studies in Social Ethics 40. Acta Universitatis Upsaliensis, Uppsala, 2010, p. 30.

¹⁵⁷ Op. cit., pp. 31-32.

¹⁵⁸ Op. cit., p. 34.

¹⁵⁹ Barilan, Michael Yechiel: *Human Dignity, Human Rights, and Responsibility*. The MIT Press, Cambridge MA, 2012, p. 149.

many cases finds its expression in respect for rights, the principle of dignity cannot exclusively be captured in the use of such language.¹⁶⁰

Even though rights discourse has a long tradition, the contemporary understanding of human rights adheres to the documents of the United Nations. In these documents one can also notice the close connection between the concept of human dignity and human rights as have been mentioned earlier. Roberto Andorno claims that the concept of dignity is never defined in the international human rights declarations. However, in these declarations he identifies the meaning of dignity as dignity inherent to all members of the human family, human beings as free and equal in dignity and rights, and lastly that rights derive from the inherent dignity of the human person.¹⁶¹

One very important discussion has concerned the interpretation of human rights and that the discourse on human rights has been characterised by a Western political, liberal discourse and interpretation. Theorists such as Abdullahi Ahmed An-Na'im and Seyla Benhabib have claimed, albeit in very different ways, that human rights need to be understood and interpreted in context in order not to be understood as a new form of Western colonialism. An-Na'im points to the importance of human rights as being in harmony with cultural norms in order for human rights to gain respect and not be understood as cultural imperialism.¹⁶² To a great extent, An-Na'im also focusses on the possibility for cross-cultural dialogue and claims that it is possible to agree on certain human rights, even though we provide different reasons for these based on differing cultural contexts.¹⁶³ Benhabib has dismissed a Rawlsian proposal and liberal understanding of a minimal version on human rights and instead she makes an argument in favour of discourse ethics.¹⁶⁴ On a similar note, Elena Namli has discussed this problem in relation to the right to freedom of speech, where she claims that the Western world

¹⁶⁰ McCrudden, Christopher: "In Pursuit of Human Dignity: An Introduction to Current Debates", p. 46.

¹⁶¹ Andorno, Roberto: "Human Dignity and Human Rights as a Common Ground for a Global Bioethics", p. 229.

¹⁶² An-Na'im, Abdullahi Ahmed: *Muslims and Global Justice*. Pennsylvania Studies in Human Rights. University of Pennsylvania Press, Philadelphia, 2011, p. 69.

¹⁶³ Op. cit., pp. 105-106.

¹⁶⁴ Benhabib, Seyla: *Dignity in Adversity: Human Rights in Troubled Times*. Polity Press, Cambridge, 2011.

tends to disregard that certain rights are prioritised because they are important in the Western culture.¹⁶⁵

Theological perspectives on human dignity within the Western tradition

One of the most influential Christian theological understandings of human dignity is to be found in the idea of *Imago Dei*, the idea that man is made in God's image and, thus, ultimately God is the one who assures each individual of her dignity, which is given to all.¹⁶⁶ The idea of man as made in God's image derives from the story of creation:

Then God said, "Let us make man in our image, in our likeness, and let them rule over the fish of the sea and the birds of the air, over the livestock, over all the earth, and over all the creatures that move along the ground." So God created man in his own image, in the image of God he created him; male and female he created them.¹⁶⁷

The idea of *Imago Dei* is prominent in different Christian traditions, and it will be discussed alongside with other important theological perspectives. Criticism towards the idea of *Imago Dei* will also be analysed. Even within each Christian tradition, there are a plethora of understandings regarding the interpretation of dignity, and in this dissertation I will mention but a few of these. In the Catholic tradition, the ideas of Thomas Aquinas are naturally influential and I will describe his idea on dignity as well as a modern personalist view in the works of the Catholic philosopher Jacques Maritain. From the Protestant tradition, I find the Lutheran theologian Gilbert Meilaender's discussion on dignity interesting to discern since he has discussed the question on dignity extensively as well as questions on bioethics. Lastly, certain criticism of the idea of *Imago Dei* is of interest to discern and I will analyse the criticism

¹⁶⁵ Namli, Elena: *Human Rights as Ethics, Politics, and Law*. Uppsala Studies in Social Ethics 43. Acta Universitatis Upsaliensis, Uppsala, 2014.

¹⁶⁶ Hailer, Martin and Ritschl, Dietrich: "The General Notion of Human Dignity and the Specific Arguments in Medical Ethics", in Bayertz, Kurt (ed.): *Sanctity of Life and Human Dignity*. Philosophy and Medicine 52. Kluwer Academic Publishers, Dordrecht, 1996, pp. 96-97.

¹⁶⁷ *The Holy Bible* (New International Version). 2001, Genesis 1:26-27.

by the Protestant thinker Nicholas Wolterstorff. In addition I will analyse his idea of bestowed worth.¹⁶⁸

The tradition from Thomas Aquinas

The theology of Thomas Aquinas is influenced by Aristotelian philosophy. Aristotle claims that it is form which defines matter, and he exemplifies this correlation with a stone block that does not become a statue until it has the form of a statue. Thomas Aquinas makes use of the idea of form and matter and for him the soul (form) determines the specific nature (matter). There are three powers of the soul, and these can be understood as the organizing principles of matter.¹⁶⁹

The first of these powers is the vegetative soul, found in plants, which activates the power of life. The second one is the sensitive power, possessed by human beings and other animals, which gives them the ability of sensation and imagination, among other things. The third power is the intellective soul, which is exclusive to human beings and defines human nature. Aquinas writes:

Now we may consider four things in man: his *reason*, which makes him like to the angels; his *sensitive powers*, whereby he is like the animals; his *natural forces*, which liken him to the plants; and *the body* itself, wherein he is like to inanimate things.¹⁷⁰

It is worth noting that Aquinas creates a hierarchy where man, through the intellective soul, stands above plants and animals. A human being is what Aquinas calls a whole, namely one substance consisting of both

¹⁶⁸ In the dissertation, only Christian perspectives on dignity are regarded. However interesting perspectives are of course provided in other religious traditions as well. For Jewish interpretations on dignity, see for example: Barilan, Yechiel Michael: *Human Dignity, Human Rights, and Responsibility*, pp. 41-45. Here Barilan discusses the Jewish interpretation of Imago Dei and he points to the important interpretation of the body, and here particularly the face, as understood as the image of God, the idea which is visible in the work of Levinas. In Jewish thought, Barilan marks, the violation of the body is a violation of the dignity of God. For a discussion on how dignity has been discussed within a muslim context, see: Fazlhashemi, Mohammad: "Människans värdighet i muslimsk context", in Stenström, Hanna (ed.): *Religionens offentlighet: Om religionens plats i samhället*. Artos, Skellefteå, 2013.

¹⁶⁹ Eberl, Jason T.: "The Beginning of Personhood: A Thomistic Biological Analysis", in *Bioethics* Vol. 14, No. 2, 2000, pp. 137-138.

¹⁷⁰ Aquinas, St. Thomas: *Summa Theologica of St. Thomas Aquinas*. Translated by Fathers of the English Dominican Province. Complete English Edition in Five Volumes. Sheed & Ward, London, 1981, Vol. 1, Q. 96 Art. 2. Italics original.

body and soul. Etienne Gilson points out that it is vital to understand that “[...] body and soul are not two substances but the two inseparable elements of one and the same substance”.¹⁷¹ The intellectual soul, as seen, is vital in understanding Aquinas’ view on human nature and it is important to recognise that one cannot identify pure intellect with man. Gilson writes:

Everything therefore goes to show that man is a being composed of a corporeal matter organized by a form, and of an intellectual substance which informs and organizes this matter. So much we must admit if we would merely remain faithful to the data of the problem: it is the intellect itself, an incorporeal substance, that is the form of the human body.¹⁷²

The intellectual soul is important in Aquinas’ definition of a person. For Aquinas, a person is not only a biological organism, an individual, but the intellectual soul is what defines a person.¹⁷³ Not matter in itself – the body – or form in itself – the intellectual soul – but the unity of these is what constitutes a person. This understanding of Aquinas’ anthropology is vital in order to understand how he justifies human dignity; it relates to a human being’s personhood. As Servais Pinckaers points out, Aquinas never discussed the subject of dignity. However, where Aquinas has used the term dignity, it is in relation to his discussion on personhood and it is mainly through his understanding of the person that Aquinas’ understanding of human dignity can be traced.¹⁷⁴ It is the intellect that characterises a person and gives her a special worth. As Pinckaers writes: “[...] person is defined by its dignity, which results from its rational nature”.¹⁷⁵

In *Summa Theologica*, Aquinas states the following: “Since man is said to be to the image of God by reason of his intellectual nature, he is

¹⁷¹ Gilson Etienne: *The Spirit of Mediaeval Philosophy: (Gifford Lectures 1931-1932)*. University of Notre Dame Press, Notre Dame, 1991, p. 176.

¹⁷² Op. cit., pp. 185-186.

¹⁷³ Eberl, Jason T.: “The Beginning of Personhood: A Thomistic Biological Analysis”, p. 140.

¹⁷⁴ Pinckaers, Servais: *The Pinckaers Reader: Renewing Thomistic Moral Theology*. Berkman, John and Titus, Steven (eds.). Translated by Thomas, Mary et al. Catholic University of America Press, Washington D.C, 2005, p. 146.

¹⁷⁵ Op. cit., p. 147.

the most perfectly like God according to that in which he can best imitate God in his intellectual nature.”¹⁷⁶ Göran Collste points to the relationship between human intellect and God’s intellect. Collste claims that it is clear in Aquinas’ argumentation that the human intellect is dependent on God’s superior intellect, since the human intellect is both produced by and participating in God’s own intellect.¹⁷⁷ Aquinas discusses the question that the image of God can be understood in different ways. Man, according to Aquinas, is created in the image of God, and this means that she has an intellectual nature. And, as Collste points out, this is equal for all human beings.¹⁷⁸ However, Aquinas explicitly mentions different meanings of being in the image of God. One such meaning is that one can lose the image of God due to sin but also become the image of God through the conformity of grace.¹⁷⁹

Dignity for Aquinas is closely connected to the rational capacity of the human nature, as has been discussed above. However, James Hanvey remarks that even though reason and rational capacity are vital for the understanding of dignity, for Aquinas “[...] reason is always ordered to the true and the good, which is ultimately God’s self, it is not an independent self-grounding faculty”.¹⁸⁰ In this way Hanvey wants to point out that this tradition differs from a Kantian perspective where rationality, according to Hanvey, is elevated.¹⁸¹

Personalism

In his discussion on human dignity within the Aristotelian-Thomistic tradition, Michael A. Smith writes that there are two central themes in Catholic social teaching. The first one is the dignity of the human person and the second one is the common good.¹⁸² In the following I will

¹⁷⁶ Aquinas, St. Thomas: *Summa Theologica of St. Thomas Aquinas*. Vol.1. Q. 93 Art. 4.

¹⁷⁷ Collste, Göran: *Is Human Life Special?: Religious and Philosophical Perspectives on the Principle of Human Dignity*. Peter Lang, Bern, 2002, p. 49.

¹⁷⁸ Op. cit., p. 51.

¹⁷⁹ Aquinas, St. Thomas: *Summa Theologica of St. Thomas Aquinas*. Vol.1. Q. 93 Art. 4.

¹⁸⁰ Hanvey, James: “Dignity, Person, and Imago Trinitatis”, in McCrudden, Christopher: *Understanding Human Dignity*. Proceedings of the British Academy 192. The British Academy by Oxford University Press, Oxford, 2014, p. 221.

¹⁸¹ Ibid.

¹⁸² Smith, Michael A.: *Human Dignity and the Common Good in the Aristotelian-Thomistic Tradition*. Mellen University Press, Lewiston, 1995, p. 1.

focus on the Christian personalist perspective as it is understood by the Catholic philosopher Jacques Maritain, who stands in an Aristotelian-Thomistic tradition. In Maritain's discussion on dignity, both his understanding of the person and of the common good are vital for his conception of dignity. It is also important, as Paul Valadier describes, to remember the context in which Maritain lives and works, that of totalitarian regimes. In Maritain's work on dignity he is searching for a way of meeting these challenges of his time, according to Valadier.¹⁸³

It is clear in Maritain's work that dignity has a strong metaphysical basis. He makes a distinction between the human being as an individual and as a person. He says:

There is not in me one reality, called my individual, and another reality, called my person. One and the same reality is, in a certain sense an individual, and, in another sense, a person. Our whole being is an individual by reason of that in us which derives from matter, and a person by reason of that in us which derives from spirit.¹⁸⁴

The quote clearly shows the Aristotelian-Thomistic influence concerning matter and spirit. Matter and, individuality relate to that which is potential or ability and are bound to the physical world.¹⁸⁵ However, the human being cannot be reduced to only matter because of her spirit; she is therefore distinguished from things. She should be regarded as 'a whole' where matter has been informed by form and looked upon as both carnal and spiritual.¹⁸⁶ Maritain stresses the importance of the person's spirit and this has its foundation in the idea that the human being is created in the image of God, God who is spirit. He says:

Finally, we turn to religious thought for the last word and find that the deepest layer of the human person's dignity consists in its property of resembling God – not in a general way after the manner of all creatures, but in a *proper* way. It is the *image of God*. For God is spirit and the human person proceeds from Him in having as principle of life a spiritual soul capable of knowing, loving and of being uplifted by grace to

¹⁸³ Valadier, Paul: "Jacques Maritain's Personalist Conception of Human Dignity", in Düwell, Marcus et al.: *The Cambridge Handbook of Human Dignity: Interdisciplinary Perspectives*. Cambridge University Press, Cambridge, 2014, p. 260.

¹⁸⁴ Maritain, Jacques: *The Person and the Common Good*. Translated by Fitzgerald, John J. University of Notre Dame Press, Notre Dame, 1966, p. 43.

¹⁸⁵ Op. cit., p. 38.

¹⁸⁶ Op. cit., p. 41.

participation in the very life of God so that, in the end, it might know and love Him as He knows and loves Himself.¹⁸⁷

There are two important points to consider in Maritain's view: first that the person is regarded as participating in a relationship with God. Secondly it is important to underline the teleological perspective. Maritain points out that dignity is closely related to God as the absolute end. With the description of the human being as an individual, the understanding that a human being is a material being is underlined, but Maritain stresses that the person is 'a whole' and not divided. It is as a person that she has dignity, and dignity is rooted in human nature. Dignity therefore does not depend on recognition from a society or from other people, but is metaphysically grounded.

Maritain's understanding of the person is closely related to his understanding of the common good. This is a reciprocal relationship where the common good is needed for a person's development, and vice versa. Maritain describes this in the following way:

There is a correlation between this notion of the *person* as social unit and the notion of the *common good* as the end of the social whole. They imply one another. The common good is common because it is received in persons, each one of whom is as a mirror of the whole. [...] The end of society, therefore, is neither the individual good nor the collection of the individual goods of each of the persons who constitute it. [...] The end of society is the good of the community, of the social body.¹⁸⁸

Maritain's personalism therefore differs from individualism which fails to correspond to the person as in relations, and fails to recognise her as a social being. Furthermore, Maritain underlined the importance of a democracy which was resistant against individualism. As Deborah Wallace describes it, Maritain understood democracy as rooted in Christian principles and he thought that a theory of human rights had its source in natural law. For Maritain, the importance of regarding human rights was necessary for forming the common good. That all citizens are guaranteed equal human rights is a claim which is grounded in his metaphysical understanding of the person, and hence grounded in the understanding of every person's human dignity.¹⁸⁹

¹⁸⁷ Op. cit., p. 42. Italics original.

¹⁸⁸ Op. cit., pp. 49-50. Italics original.

¹⁸⁹ Wallace, Deborah: "Jacques Maritain and Alasdair MacIntyre: The Person, the Common Good and Human Rights", in Sweetman, Brendan (ed.): *The Failure of*

The status of in-between – A vertical perspective on dignity

I shall turn to the idea of human dignity from the perspective of the Lutheran professor of Theology, Gilbert Meilaender.¹⁹⁰ Meilaender's theory on dignity is, according to himself, a way of unifying two perspectives from the concept's history; namely, on the one hand Aristotelian conceptualisation with an emphasis on flourishing and, on the other hand, a Christian conceptualisation of the person. These two strands resulted in a division between human dignity and personal dignity. The latter, according to Meilaender, refers to equal dignity for all human beings. However, I will analyse his understanding on human dignity.

Meilaender's discussion on human dignity can be understood by making a distinction between a horizontal and a vertical perspective on dignity. The idea of human dignity has often been connected to a specific understanding of what is characteristically human, that which distinguishes the human species. Hence, this certain characteristic is what gives humans a specific human dignity and also gives a human being, as part of the human species, a certain position in the hierarchy between species. In this hierarchy the human species has been regarded as higher than other creatures. When regarded in such a way, the idea of human dignity can be understood from a vertical perspective. It is vertical in the sense that the idea of human dignity and how it refers to individuals becomes a discussion regarding the human species in relation to other species.

Following from a vertical understanding of human dignity one finds the foundation for a horizontal understanding of human dignity. This horizontal understanding is what is seen to guide moral actions between

Modernism: The Cartesian Legacy and Contemporary Pluralism. American Maritain Association Publications. Catholic University of America Press, Mishawaka, 1999, pp. 128-129.

¹⁹⁰ I have previously mentioned the anthology *Human Dignity and Bioethics: Essays Commissioned by the President's Council on Bioethics*. The aim of the anthology was to clarify the meaning of the concept of dignity. However, the result of the discussion was not a homogenous understanding of the meaning of the concept, but rather a heterogeneous one. The interpretations took their starting point in Kantian, Stoic, Aristotelian and Christian views and thus resulted in different understandings. Meilaender's discussion was influenced by the heterogeneity visible in the anthology, to which he was one of the contributors. Meilaender, Gilbert: "Human Dignity: Exploring and Explicating the Council's Vision", in Pellegrino, Edmund D., Schulman, Adam and Merrill, Thomas W. (eds.): *Human Dignity and Bioethics*. University of Notre Dame Press, Notre Dame, 2009.

humans. For example, a common understanding is that all human beings have human dignity to an equal degree; hence all should be equally respected. However, it is also noticeable that some understand the idea of human dignity exclusively from a horizontal perspective. In other words, they claim that it is an important principle guiding moral actions between human beings, but without reference to a vertical perspective on human dignity.

Meilaender's conception of human dignity points to a vertical perspective in two ways, namely regarding the human species and the human individual. Meilaender claims that the human species has certain characteristics which distinguish it from other species. It is "lower than the gods, higher than the beasts".¹⁹¹ In Meilaender's understanding of what characterises human nature is this place in the hierarchy where the human species is "neither beast nor God" but has the status of "in-between". Human nature is tied to the beast through the body but at the same time is directed towards God through the soul.¹⁹² Meilaender says: "[...] human dignity is the dignity of a particular sort of creature, who is neither the 'highest' nor the 'lowest' sort of creature we can imagine."¹⁹³ It is significant that Meilaender expresses that human nature is characterised by being directed towards God; God is telos. Meilaender points to there being a purpose embedded in all organic life and the human being's purpose is to strive towards God.¹⁹⁴ This specific telos characterises what it means to live a flourishing human life. This teleological understanding of human dignity is also a critique against the dominating aspect of autonomy; it is a telos which makes humans understand what a flourishing human life is, the human being cannot autonomously choose her life as she wishes.¹⁹⁵ Meilaender also specifically points out that the Christian and the Jewish traditions give us insight into what human dignity involves.¹⁹⁶

Meilaender's understanding of the flourishing of human nature which is characterised by its particular telos has similarities to an Aristotelian understanding of human nature. According to Aristotle's teleological philosophy, which has been encountered earlier, the human is

¹⁹¹ Meilaender, Gilbert: *Neither Beast nor God: The Dignity of the Human Person*. Encounter, New York, 2009, p. 4.

¹⁹² Op. cit., p. 24.

¹⁹³ Op. cit., p. 4.

¹⁹⁴ Op. cit., p. 17.

¹⁹⁵ Op. cit., p. 29.

¹⁹⁶ Op. cit., p. 5.

more than plants and animals due to her rational faculty and he also points to contemplation as the specific telos for human beings. Even Meilaender makes a distinction between human beings and other creatures and in the same way draws attention to the importance of the connection between human nature and our particular telos. But, while Aristotle connects rational nature with the striving of our telos, which is contemplation, Meilaender identifies human nature as being in-between but striving towards God.

Even though Meilaender's conception of human dignity is connected to what is characteristic for humanity as a species, individually this could manifest itself to a higher or a lower degree. Hence, human dignity understood vertically also refers to human individuals; some more than others display that which is characteristically human, namely when someone lives in accordance with what is characteristic for human nature.¹⁹⁷ Meilaender describes this in the following way: "[...] they offer an image of the flourishing of our full humanity. In so flourishing they display what I will call human dignity."¹⁹⁸ They are 'distinguished individuals'. In this sense, Meilaender's discussion focusses on human dignity as a moral value, and his understanding can be categorised as inflorescent dignity.

Criticism on the idea of Imago Dei

Another theological perspective on human dignity is proposed by the protestant theologian Nicolas Wolterstorff. He questions the idea of Imago Dei as the justification of human dignity. Wolterstorff discusses what the connection is between being made in the image of God and having dominion, and he claims that the Bible reference "Let us make man in our image, in our likeness, and let them rule [...]"¹⁹⁹ should be understood to mean that God does one thing in order to do another. If one reads the text with this in mind one can interpret it in the following way: If human beings are to have dominion then they have to be, what Wolterstorff calls, lofty creatures. He concludes:

What the text thus interpreted entitles us to say is that the image of God consists of resembling God with respect (at least) to whatever be the

¹⁹⁷ Op. cit., p. 3.

¹⁹⁸ Op. cit., p. 4.

¹⁹⁹ *The Holy Bible* (New International Version), Genesis 1:26.

capacities necessary for receiving and exercising the blessing or mandate of dominion.²⁰⁰

Wolterstorff is critical of this understanding since it leads to exclusion of those who lack certain capacities, who do not have the capability to exercise dominion and thus resemble God.²⁰¹ It is worth noticing that it is the actual mandate that defines what it means to be made in the image of God. To have dominion (the mandate) is the lens through which Wolterstorff's understanding of *Imago Dei* is regarded.

Another understanding of *Imago Dei* is as grounded in human nature. The idea is that human nature is created in the image of God. If one is a human being and thus has a human nature, one has worth, regardless of whether one is sick, healthy etc. Wolterstorff opposes the idea that people who are very sick, for example in a coma or with Alzheimer's, have worth, or to be more specific, should be looked upon as having worth just because they have a human nature. Instead he argues that their injuries and illnesses demean their worth and he compares their situation with a car. Imagine someone owning a car that is of a specific model and all of a sudden the engine stops working and the owner wants to repair the car but that is not possible. Then the value of the car will of course diminish because it does not function as it should. Wolterstorff concludes that the same can be said about human beings. They will not be looked upon as having worth if they do not function properly. Just the fact that they have a human nature will not safeguard this.²⁰² Instead something else is needed, according to Wolterstorff: "What we need, for a theistic grounding of natural human rights, is some worth-imparting relation of human beings to God that does not in any way involve a reference to human capacities."²⁰³ Wolterstorff's solution is bestowed worth. Here, he is moving away from an understanding that it is a specific human characteristics that gives human beings worth. Instead it is the relation to God that bestows worth. Wolterstorff explains the meaning of bestowed worth as a painting painted by Rembrandt. The painting's worth lies in that it is Rembrandt himself who has painted it. It is not that it is such a beautiful painting in itself. There are many copies that also are exquisite, but they do not have the same

²⁰⁰ Wolterstorff, Nicholas: *Justice: Rights and Wrongs*. Princeton University Press, Princeton, 2008, p. 346.

²⁰¹ Op. cit., p. 349.

²⁰² Op. cit., pp. 350-351.

²⁰³ Op. cit., p. 352.

worth; the painting's worth comes from being painted by Rembrandt. Wolterstorff concludes his discussion about bestowed worth by looking at whether love can give bestowed worth; his conclusion is that it cannot, in the form of affection or benevolence, but it can in the form of attachment. This latter form of love as attachment is explained with a reference to a queen. The ones she loves and is attached to will receive worth not because they are great people in themselves but because of the relationship they have to the queen.²⁰⁴ Wolterstorff concludes with these words:

[...] if God loves a human being with the love of attachment, that love bestows great worth on that human being; other creatures, if they knew about that love, would be envious. And I conclude that if God loves, in the mode of attachment, each and every human being equally and permanently, then natural human rights inhere in the worth bestowed on human beings by that love. Natural human rights are what respect for that worth requires.²⁰⁵

Summary

In the theological theories on dignity metaphysical claims are made which are important for the different interpretations of dignity. Dignity as due the human being in the image of God and as person as well as dignity characterised by a nature which is 'in-between'. The idea of bestowed worth has also been discussed.

Philosophical perspectives on human dignity within the Western tradition

A few theological perspectives on human dignity has been presented and I shall now turn to analyse three philosophical positions, namely that of the Stoics, of Pico della Mirandola, and the Kantian view of dignity. These three positions are chosen to discuss in more detail since they contribute with important perspectives which still are of relevance in the contemporary debate on dignity.

²⁰⁴ Op. cit., pp. 358-359.

²⁰⁵ Op. cit., p. 360.

The tradition from the Stoics

In Stoic philosophy a sharp distinction is made between human beings and animals. Humans' rational capacity, i.e. human nature, separates and elevates man over the animals. Cicero points to this in *De officiis* and claims that animals are impelled by instinct to sensual pleasures. Human beings, on the other hand, have a rational nature, which elevates them over animals.²⁰⁶ Even Seneca points to the understanding that human nature is characterised by reason. In one of his letters, Seneca writes:

For man is a reasoning animal. Therefore, man's highest good is attained, if he has fulfilled the good for which nature designed him at birth. And what is it which this reason demands of him? The easiest thing in the world, – to live in accordance with his own nature. But this is turned into a hard task by the general madness of mankind; we push one another into vice.²⁰⁷

Reason is closely connected to moral virtue; reason demands that one lives in accordance with one's human nature. One of the central ideas in Stoic philosophy was that a human being should free herself from the impulses that can distract her, such as thoughts about the future, economic wealth and social status. Hence, the ideal for a Stoic was apathy, which meant that a human could, through contemplation, find a way of accepting life, and live virtuously. As described above, all human beings have a nature characterised by reason and it is reason that enables the human to transcend her vices.²⁰⁸ Oliver Sensen draws attention to the following:

[...] human beings are special in nature in virtue of possessing a certain capacity, namely reason. Being elevated, or having dignity, in this way was said to yield a duty to behave in a way that is worthy of this dignity.²⁰⁹

²⁰⁶ Cicero: *On Obligations (De officiis)*. Translated by Walsh, P.G. Oxford University Press, Oxford, 2008, pp. 36-37 (1.105. -107).

²⁰⁷ Seneca: *Epistles 1-65*. Translated by Gummere, Richard M. Loeb Classical Library. Harvard University Press, Cambridge MA, 1917, pp. 277-278 (epistle XLI).

²⁰⁸ Lindberg, Bo: *Seneca: Människosläktets lärare*. Svenska humanistiska förbundets skriftserie 124. Atlantis, Stockholm, 2010, pp. 31-32.

²⁰⁹ Sensen, Oliver: "Human Dignity in Historical Perspective: The Contemporary and Traditional Paradigms", in *European Journal of Political Theory* Vol. 10, No.1, 2011, pp. 77-78.

At the end of the quote, Sensen points to the importance of virtue, to live a life worthy of this dignity. The focus is directed towards human behaviour. For Cicero, certain types of behaviour seem not to be in accordance with the dignity of man. He claims for example that

[...] if we are willing to reflect on the high worth and dignity of our nature, we shall realise how degrading it is to wallow in decadence and to live a soft and effeminate life, and how honourable is a life of thrift, self-control, austerity and sobriety.²¹⁰

Dignity in the Stoic sense is strongly connected to the way a human being lives one's life. It is to live virtuously, to live in a dignified way. In this way one can describe the Stoic sense of dignity as relating to a moral value which is developed. Adam Schulman uses the term 'possibility' to describe the Stoic understanding of dignity: "Yet while dignity as the Stoics conceived it is a universal possibility for all human beings everywhere, it nonetheless sets a rigorous and exacting standard that few of us, in practice, manage to attain."²¹¹ It should be made clear that even though dignity could in theory refer to everyone, because everyone has a rational nature, dignity only seems to apply to a few for whom it is actually possible to live life according to the high reaching Stoic ideal. Rational nature is equal for everyone; it is independent of whether the person is a slave or master, rich or poor.²¹² It is only the slave's body that is subordinated to his master; his soul is free and because of his capacity for reason and therefore virtue the slave could very well live in accordance with his dignity, in a dignified way.²¹³ In letter 47 to Lucilius, Seneca discusses the topic of slaves and he urges Lucilius to consider the fact that the slave, just like his master, has the same origin:

Kindly remember that he whom you call your slave sprang from the same stock, is smiled upon by the same skies, and on equal terms with yourself breathes, lives and dies. It is just as possible for you to see in him a free-born man as for him to see in you a slave.²¹⁴

²¹⁰ Cicero: *On obligations (De officiis)*, p. 37 (1.106).

²¹¹ Schulman, Adam: "Bioethics and the Question of Human Dignity", in Pellegrino, Edmund D., Schulman, Adam and Merrill, Thomas W. (eds.): *Human Dignity and Bioethics*. University of Notre Dame Press, Notre Dame, 2009, p. 8.

²¹² Lindberg, Bo: *Seneca: Människosläktets lärare*, p. 74.

²¹³ Op. cit., p. 77.

²¹⁴ Seneca: *Epistles 1-65*, p. 307, epistle XLVII.

He might be a slave but he can still have the mind of a free person and live in accordance with his reason and thus live a life of dignity; what matters is the person's character.

The human being as autonomous

Another philosopher whose ideas on human dignity are historically interesting but also an important source in contemporary debate, is the Renaissance philosopher Pico della Mirandola. Mirandola is important for the reasons pointed out by Michael Rosen: "In his oration Pico gives an account of human nature that was to be in many ways seminal for the self-understanding of human beings in the modern world."²¹⁵ In Mirandola's work on dignity, the difference between human beings in relation to other beings becomes clear, and a specific position for the human being in the order of creation is established.

In his oration on dignity, Mirandola writes that God created the world with all sorts of living beings. He also wanted someone to admire the beauty of his creation and that someone should be man. However, according to Mirandola the problem occurred that God had created all beings in accordance with a form but lacked a form for the creation of man.²¹⁶ When Pico della Mirandola refers to the idea of a form for all things he is referring to the Platonist view on ideas. According to Plato the idea exists before the thing being created and everything that exists on earth is an imperfect version of its idea. Therefore, it is interesting that Mirandola abandons this thought regarding the creation of human beings. This is also the key to the understanding of Mirandola's view on dignity. In Mirandola's oration it is clear that the particular form gives a being its features and characteristics, its nature. If these characteristics are altered, then its nature is also altered and it becomes something different. A being's specific nature also determines its life; it has to live in accordance with its nature. According to Mirandola, a human being differs in that she has been given everything that was characteristic for all the other beings, and in particular she is free to create her own nature. That is described with these famous words:

²¹⁵ Rosen, Michael: *Dignity: Its History and Meaning*. Harvard University Press, Cambridge, 2012, p. 14.

²¹⁶ Pico della Mirandola, Giovanni: *On the Dignity of Man*. Translated by Wallis, Charles Glenn. Hackett, Indianapolis, 1998, p. 4.

Neither heavenly nor earthly, neither mortal nor immortal have We made thee. Thou, like a judge appointed for being honorable, art the molder and maker of thyself; thou mayest sculpt thyself into whatever shape thou dost prefer. Thou canst grow downward into the lower natures which are brutes. Thou canst again grow upward from thy soul's reason into the higher natures which are divine.²¹⁷

Mirandola claims that the human being can form her own nature and that this is the foundation for her dignity. Human beings should strive to become like the cherubs, forget about earthly matters, and become one with God through contemplation.²¹⁸ Hence, the foundation for a human being's dignity is having been created as a being who has the freedom to create her own form, irrespective of what form she then chooses – the angel's or the animal's.

The human being as self-legislative and rational

Even though the Stoics and Pico della Mirandola have given important contributions to the understanding of the meaning of human dignity, it is the German philosopher Immanuel Kant who has been the most influential in Western philosophical thought. In discussing the work of Kant I also find it important to underline that for Kant it is central to discuss human dignity as a principle. This is different from, the work of Mirandola, which describes on what grounds a human being can be regarded as having dignity, but Mirandola does not discuss the claims this dignity creates. For Kant, on the other hand, it is vital to discuss human dignity even as a principle, as seen previously.

Kant's normative moral philosophy can be characterised as an examination of the moral law and how the moral law can be the basic principle of morality. This examination is strictly approached a priori. Kant often refers to the discussion on the will and he establishes that the only thing that is good without qualification is the good will. Kant hereby points out that morality is about good will which should be interpreted as acting from duty. To act from duty is to act in accordance with the moral law. The categorical imperative is the foundational principle of morality to which a rational person's will should adhere. In determining the imperative as categorical, Kant underlines that it is an unconditional command; it is, so to speak, binding for the will.

²¹⁷ Op. cit., p. 5.

²¹⁸ Op. cit., p. 7.

Kant distinguishes three formulations of the categorical imperative. The first is the formula of universal law “[...] act only according to that maxim through which you can at the same time will that it become a universal law”.²¹⁹ To point to universality – that a maxim should be formed as a universal law – is crucial, since for Kant it would be irrational to regard a moral act as morally justified if it did not apply to all rational beings, in all places. An individual can therefore not form maxims which are only in the individual’s own interest; maxims should be applicable to everyone, regardless of context.

I have previously discussed the second formulation of the categorical imperative, the formula of humanity, which pinpoints the respect for persons, the understanding that every person is an end and not merely a means to someone else’s end. This respect for the other is grounded in Kant’s understanding of humanity in every person, and this humanity ought to be respected. For Kant, humanity is understood as self-legislation and rationality, a topic which I will return to in later chapters. One could claim that self-legislation and rationality for Kant are dignity-conferring characteristics. It can also be illuminating to regard Kant’s view on dignity as he explains his view through a discussion about the difference between price and dignity. In his understanding, that which has a price is such that something else can be put in its place, something else can be equivalent to that thing. A human being on the other hand, because of her rational nature, does not have a price, but dignity, and this means that a person’s dignity cannot be affected by exterior factors, i.e. it cannot be removed and nothing can be put in the person’s place or be equivalent with the person. The person is above all price.²²⁰ Michael Rosen points out that Kant’s theory on dignity is egalitarian. All human beings have dignity; this is common for all since all are “[...] subjects to its demands, whatever place in society we may happen to occupy [...]”.²²¹

It is important to notice the difference between the categorical imperative in the first formulation in comparison to the third formulation, the formula of autonomy. This formulation regards the idea of the will of every rational being as a will that legislates universal law.²²² Here

²¹⁹ Kant, Immanuel: *Groundwork of the Metaphysics of Morals*, p. 34 (Ak. 4:421).

²²⁰ Op. cit., p. 46 (Ak. 4:435).

²²¹ Rosen, Michael: *Dignity: Its History and Meaning*, p. 24.

²²² Kant, Immanuel: *Groundwork of the Metaphysics of Morals*, pp. 44-45 (Ak. 4:432-4:433).

Kant points out that the rational person is a lawgiver, and as such autonomous, and not only a follower of the moral law. This formulation is also strongly linked to Kant's important thought on 'a kingdom of ends'. With this idea he points to an ideal state, where all rational beings live in accordance with the categorical imperative. Kant writes:

The concept of every rational being that must consider itself as universally legislating through all the maxims of its will, so as to judge itself and its actions from this point of view, leads to a very fruitful concept attached to it, namely that *of a kingdom of ends*.²²³

After this brief overview it is worth noticing that important criticism has also been made of Kant's philosophy and this has concerned, for example, the interpretation of the term 'humanity' and to whom humanity relates. Some understand Kant as claiming that humanity in each person relates to a specific capacity in the specific individual. Hence, if lacking this capacity, the individual also lacks dignity. Others would argue that humanity should not be understood as an individual capacity but as something significant for the human species. Individuals can possess this capacity to different degrees or even not possess it but nevertheless the person belonging to the species has humanity, thus dignity, regardless of the individual's capacity.²²⁴

In the Kantian description, humanity is characterised by rationality. Some philosophers, such as Martha Nussbaum, has rejected such an understanding where a certain inherent characteristic is the foundation for the justification of dignity, since this can lead to the exclusion of certain individuals. This is something Nussbaum cannot agree with, which is in line with her claim that a theory on justice should include all citizens as fully equal citizens. To pinpoint a certain characteristic such as rationality leads not to inclusion but to exclusion of certain human beings, for example those with a disability.²²⁵ Nussbaum wants to include individuals with severe cognitive disabilities in her account of dignity. However, focussing on the dynamic side and the development of capabilities creates other problems of exclusion which become apparent in

²²³ Op. cit., p. 45 (Ak. 4:433). Italics original.

²²⁴ Grenholm, Carl-Henric: "Människovärdets okränkbarhet – var går gränsen?", pp. 170-172.

²²⁵ Nussbaum, Martha Craven: "Human Dignity and Political Entitlements", in Pellegrino, Edmund D., Schulman, Adam and Merrill, Thomas W. (eds.): *Human Dignity and Bioethics*. University of Notre Dame Press, Notre Dame, 2009, pp. 362-363.

an analysis of her understanding of dignified life. She claims that her theory could include persons with different disabilities but on the other hand it would exclude others. This is apparent in her view on humans with severe medical conditions. Nussbaum says: "At one end, we would not accord equal human dignity to a person in a persistent vegetative state, or an anencephalic child, since it would appear that there is no striving there, no reaching out for functioning."²²⁶

Eva Kittay has also formulated concerns regarding the justification of dignity based on certain capacities. She points to the problem that such a justification can to some extent include those persons who have the potential to acquire a certain capacity, as well as those who have once had the capacity but who have lost it. However she questions if such a justification can include those who have never had these capacities or never will acquire them.²²⁷

Important criticism has also been raised from a phenomenological perspective. Here the Kantian proposition that the rational and universal can be equated with what is required in a moral sense is challenged and sometimes even rejected. In Kantian philosophy that which is one's duty is exclusively connected to that which is rational; what is morally required is also rationally required. Maybe the most well-known critique is formulated in the work of Emmanuel Levinas. Levinas formulates a view on ethics which stands in stark contrast to a Kantian view. Levinas voices the idea that in what he refers to as Western philosophy, ontology has been prior to ethics and ontology has reduced, what he defines as 'the Other' to the same. Peter Kemp points to Levinas' resistance towards Western philosophy as a philosophy of logic and control. The general and the universal is preferred and universalism even that which marks ethical justification. Hence Western philosophy therefore risks controlling the Others' face.²²⁸

Levinas develops the philosophy of the face. In the face-to-face encounter the Other urges me not to violate her and a responsibility for the Other is evoked. It is this encounter, where the Other shows her

²²⁶ Op. cit., p. 363.

²²⁷ Kittay, Eva: "Disability, Equal Dignity and Care", in Ammicht-Quinn, Regina, Junker-Kerry, Maureen and Tamez, Elsa (eds.): *The Discourse of Human Dignity*. SCM Press, London, 2003, p. 107.

²²⁸ Kemp, Peter: *Lévinas : En introduction*. Translated by Hedenblad, Rikard. Daidalos, Göteborg, 1992, pp. 65-66.

vulnerability, which is the centre of ethics for Levinas.²²⁹ Responsibility is important also in the work of Mikhail Bakhtin. He presents an interesting discussion on that which constitutes the normative and forms a critique against Kant's view where normativity is connected to the universal. I will return to this discussion and especially Bakhtin's understanding of responsibility (which he calls answerability) at a later stage in the dissertation.

Before continuing with the criticism on dignity from within the medical-ethical perspective it is worth noticing that a prominent idea in many theories on dignity, which have been discussed, is that dignity is connected to the idea of the human being as having a specific nature. Carl-Henric Grenholm explains this idea when he says:

In classic humanism, human nature – that which is truly human – is perceived as essential for what is valuable. There are characteristics shared by all human beings and specific for mankind as a species. These mark the being of man, the essence of man.²³⁰

However, the idea of human essence has been criticized by, among others, Judith Butler. According to her, there are no authentic characteristics or inner essence specific to a human being. Butler also questions the distinction between biological sex and constructed gender, which had been an important distinction in feminist theory. What we believe to be characteristics are, according to Butler, different performative acts. She says:

Such acts, gestures, enactments, generally construed, are *performative* in the sense that the essence or identity that they otherwise purport to express are *fabrications* manufactured and sustained through corporeal signs and other discursive means. That the gendered body is performative suggests that it has no ontological status apart from the various acts which constitute its reality.²³¹

²²⁹ Levinas, Emmanuel: *Totality and Infinity: An Essay on Exteriority*. Translated by Lingis, Alphonso. Duquesne University Press, Pittsburgh, 1969.

²³⁰ Grenholm, Carl-Henric: *Bortom humanismen: en studie i kristen etik*. Verbum, Stockholm, 2003, p. 49. Swedish original text: "I klassisk humanism uppfattas människans natur, det sant mänskliga, som avgörande för vad som är värdefullt. Det finns egenskaper som är gemensamma för alla människor och specifika för människan som art. Dessa anger vad som är människans väsen, hennes essens." My translation.

²³¹ Butler, Judith: *Gender Trouble: Feminism and the Subversion of Identity*. Routledge Classics. Routledge, New York, 2006 (1990, 1999), p. 185.

Summary

In the Stoic understanding one can discern an understanding of dignity which in one sense could be described as intrinsic since every person, due to her rational nature, has the ability to live a life in accordance to the high reaching Stoic ideals. However, dignity is as such only understood as a potential in every human being. It is in living a virtuous life that dignity is so to speak actualised. Dignity is then connected to a human being's moral value, and to developing virtue. This can be compared to the focus on intrinsic dignity which is prominent in Kantian philosophy, where dignity is due a human being, regardless of the person's moral value. An important difference between Kant and the other two positions being presented is Kant's focus on the principle of dignity. Hence, the discussion on dignity does not only concern a subject's dignity but also how dignity is respected in the treatment of others.

Criticism on the idea of human dignity within medical ethics

In the current debate on dignity there are critical voices being raised, and in the following I will consider the criticism which explicitly concerns medical ethics. In my opinion, there is a stark contrast in the debate whether human dignity as a philosophical concept is of any importance or not. The central question in this debate can be stated thus: What would be the loss in medical ethics if the concept of human dignity was abolished or replaced by other concepts?

In 1987, Helga Kuhse wrote the influential book *The Sanctity-of-Life Doctrine in Medicine: A Critique*.²³² Here she claims that there is a significant distinction between the principles of 'sanctity of life' and 'quality of life'. The former specifies, according to Kuhse, life as important to save in itself regardless of the consequences such as the suffering that can be caused when saving the life of a seriously ill person. Here it is important to note that Kuhse particularly criticises the principle of human dignity interpreted as the sanctity of life.

In Kuhse's philosophical contribution it is clear that her view on human life is radically different from what most advocates of the principle

²³² Kuhse, Helga: *The Sanctity-of-Life Doctrine in Medicine: A Critique*. Clarendon, Oxford, 1987.

of sanctity of life would defend. Life need not be protected for its own sake; instead, Kuhse points to the importance of the principle of quality of life as a guiding principle in medical-ethical concerns.²³³ This means that the individual's understanding of his quality of life is decisive for the actions being carried out, which can include euthanasia. This idea is also represented by Peter Singer who claims that the principle of sanctity of life leads to inhumane consequences for an individual. It is noticeable in the discussion that Singer and Kuhse interpret autonomy as meaning that the person is free to choose that which is in accordance with one's preferences.²³⁴ That a person should be able to decide about one's own life is extended to autonomously being able to decide regarding one's own death. In the argumentation, the ethical problem is not about taking a life, but about going against a person's preferences. This leads to the conclusion that creatures who are not autonomous and who cannot express their preferences are not persons according to the definition of Kuhse and Singer. If a person's life is guaranteed to lead to suffering, then their life should not be sustained, as that would be inhumane.

In current debate, both the principle and the concept of dignity are challenged, mainly from a utilitarian perspective, as has been shown above. However, other types of criticism are also voiced, such as concerns regarding the assumed religious character of dignity and the many various meanings of the concept. The former have been discussed by Steven Pinker, among others. Pinker has voiced his criticism in his discussion of the publication on dignity by the U.S. President's Council on Bioethics.²³⁵ Included in this publication are articles where researchers discuss the subject, mainly from a Judeo-Christian theological perspective. These articles were then subject to criticism by Stephen Pinker who clearly opposed the view that ethical challenges should be dealt with by using arguments from a certain religious position.²³⁶ Pinker

²³³ Carlberg, Axel: *The Moral Rubicon: A Study of the Principles of Sanctity of Life and Quality of Life in Bioethics*. Lund Studies in Ethics and Theology. Lund University Press, Lund, 1998. The Swedish ethicist Axel Carlberg questions the contradiction between sanctity of life and quality of life which is made by Kuhse and instead he argues that the two are compatible.

²³⁴ Singer, Peter: *Rethinking Life & Death: The Collapse of Our Traditional Ethics*. St. Martin's Griffin, New York, 1995.

²³⁵ Pellegrino, Edmund D., Schulman, Adam and Merrill, Thomas W. (eds.): *Human Dignity and Bioethics*.

²³⁶ Pinker, Steven: "The Stupidity of Dignity – Conservative Bioethics' Latest, Most Dangerous Ploy", in *The New Republic* Vol. 238, No. 9, 2008, p. 29.

seems to think that, especially if interpreted in a conservative way, the idea of dignity stands in opposition to other ideals which he understands have guided American bioethics, such as the recognition of liberty.²³⁷ Pinker also considers arguments that are based on the idea of human dignity to often be opposed to technical advancement and, hence, the development of human welfare, at least according to some critics. He says:

This collection of essays is the culmination of a long effort by the Council to place dignity at the center of bioethics. The general feeling is that, even if a new technology would improve life and health and decrease suffering and waste, it might have to be rejected, or even outlawed, if it affronted human dignity.²³⁸

Another critical perspective on dignity has been voiced by Ruth Macklin, albeit from a different perspective than Pinker. In 2003, Macklin wrote an editorial in the *British Medical Journal* called “Dignity is a Useless Concept”.²³⁹ In the last decade, this has been one of the most debated articles regarding the criticism of human dignity within medical ethics and bioethics. Within medical ethics, Macklin discerns two areas where dignity is referred to as a central ethical principle. The first one is *the Convention for the Protection of Human Rights and Dignity of the Human Being with Regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine*.²⁴⁰ Macklin concludes that in this convention, dignity seems to mean ‘respect for persons’, which she understands as an established principle in medical ethics involving voluntary and informed consent, protection of confidentiality and avoidance of discriminating and abusive practices.²⁴¹ As has been shown, there are different understandings in Western tradition of the concept of a person. However, Macklin does not regard these traditions, but her understanding of the concept adheres to the above

²³⁷ Op. cit., p. 30.

²³⁸ Op. cit., p. 28.

²³⁹ Macklin, Ruth: “Dignity Is a Useless Concept.”

²⁴⁰ Council of Europe: *Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine*. 1997.

²⁴¹ Macklin, Ruth: “Dignity Is a Useless Concept”, p. 1419. For a similar criticism see: Schroeder, Doris: “Dignity: Two Riddles and Four Concepts”, in *Cambridge Quarterly of Healthcare Ethics* Vol. 17, No. 2, 2008. Schroeder, Doris: “Dignity: One, Two, Three, Four, Five, Still Counting”, in *Cambridge Quarterly of Healthcare Ethics* Vol. 19, No. 01, 2010.

mentioned description and thus she claims a liberal, individualistic view on the person. The second area which Macklin discusses is end of life situations and the right to die with dignity, but she claims that dignity in this discussion seems to mean respect for autonomy. The conclusion of her argument is that we can eliminate the concept of human dignity in medical ethics since it means nothing more than respect for persons or their autonomy. The concept of dignity is, she claims, too vague to give guidance in medical-ethical concerns; it is not clear when dignity is violated. Therefore, the principle of autonomy is a better alternative in complex moral concerns according to Macklin.

Macklin's now well-cited article stirred up many reactions since she questioned a basic ethical principle within medical treatment and medical ethics, and the reactions to the article were extensive and the criticism raised pointed in different directions.²⁴² Some researchers claimed that Macklin disregarded the understanding of human dignity with its long and rich history in philosophical thought as well as in legal tradition. Hence, human dignity could not be reduced in the way Macklin suggested.²⁴³

Conclusion

In this chapter different theoretical positions within the discussion on human dignity have been analysed. Regarding the meaning of human dignity I discussed the distinctions made by Daniel Sulmasy between intrinsic dignity, attributed dignity and inflorescent dignity. In the latter description I have shown that the importance of moral worth is underlined. This differs from an understanding of intrinsic dignity where dignity belongs to the person as such and is not attributed by others or due to the person's moral worth. The idea of intrinsic dignity is also connected to an egalitarian ideal.

Different understandings of the principle of human dignity have also been discussed. The Kantian proposition includes the view that humanity in every person should be treated as an end and never merely as a

²⁴² See for example reactions to Macklin's article in Kirchhoffer, David G: *Human Dignity in Contemporary Ethics*. Teneo Press, Amherst, 2013, p. 101. And Davis, Daniel: "Human Dignity and Respect for Persons: A Historical Perspective on Public Bioethics".

²⁴³ Sulmasy, Daniel: "Dignity and Bioethics: History, Theory, and Selected Applications", p. 469.

means. The interpretation of what this includes is much debated but one can at least adhere to the interpretation of an end in a negative sense, namely in the understanding that certain actions towards the other should be prevented. To be treated as an end places limitations on what can be regarded as a morally justified act towards another human being. The Kantian proposition is also often interpreted as respect for autonomy, an interpretation which I will return to in the following chapter. Within medical ethics this interpretation of the principle is important. I have also discussed an understanding where the principle of dignity is understood as recognition and respect as a member of the human community as well as discussed respect for dignity in the form of respect for human rights.

Philosophical and theological sources of the understanding of human dignity have also been analysed and attention has been drawn to the idea of *Imago Dei* and personalism. These are important in the theological discussion on dignity not least in regard to the question on justification of dignity. In my own research the theological discussion will not revolve round these particular theological understandings, but instead I will discuss how a principle of human dignity can be interpreted through a discussion relating to Christology.

In the philosophical debate the theories of the Stoics, Pico della Mirandola and Kant have been discussed. Here the distinction and even tension between attributed, inflorescent and intrinsic dignity is once again articulated and these distinctions will be further discussed in the dissertation.

In this chapter I have also pointed to some criticism being raised within the context of medical ethics and I have discussed three different perspectives. From a utilitarian perspective the criticism was raised that a principle of human dignity can lead to inhumane treatment of an individual. Criticism has also regarded the religious understanding of human dignity, especially as formed in a Judeo-Christian tradition, as it could be seen as standing in stark contrast to important values in a liberal society. Criticism has also been voiced that dignity is a concept with an unclear meaning or a meaning which can be reduced to respect for autonomy. As such it was claimed that it can be eliminated.

2. Autonomy and Human Vulnerability

The principle of autonomy has gained status as one of the most important principles within health care in the American as well as in the European contexts, and in Sweden this is certainly the case. As seen earlier, when considering the history of medical ethics, there was a shift from paternalism to the idea that individual patient's rights were important and that the patient should have more authority to decide regarding his or her own health care. Onora O'Neill describes this as "[...] no themes have become more central in large parts of bioethics, and especially in medical ethics, than the importance of respecting individual rights and individual autonomy."²⁴⁴ For example in the Belmont Report, respect for persons is one of the ethical principles which was established, and this principle had two convictions. In the report it is stated:

Respect for persons incorporates at least two ethical convictions: first, that individuals should be treated as autonomous agents, and second, that persons with diminished autonomy are entitled to protection.²⁴⁵

The principles in the report relate to research on human subjects but as Daniel Davis points out, especially the principle of autonomy has been developed and become one of the most important principles within health care, and now applies also in the clinical sphere, not only relating to research subjects.²⁴⁶

²⁴⁴ O'Neill, Onora: *Autonomy and Trust in Bioethics*. Gifford Lectures. Cambridge University Press, Cambridge, 2002, p. 2.

²⁴⁵ National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research: *The Belmont Report: Ethical Principles and Guidelines for the Protection of Human Subjects of Research*. 1978, p. 4.

²⁴⁶ Davis, Daniel: "Human Dignity and Respect for Persons: A Historical Perspective on Public Bioethics", pp. 25-26. Davis also acknowledges a development which has taken place where the principle of respect for persons is understood by some as equivalent to the principle of respect for autonomy.

In medical-ethical discussions the principle of autonomy is sometimes discussed independently from the principle of dignity, for example in the work of Tom Beauchamp and James Childress. It has also been noted earlier that some regard the concept of dignity as only meaning respect for autonomy.²⁴⁷

In this chapter I will not solely discuss the principle of autonomy but the relation between dignity and autonomy. At the beginning of this chapter I will discuss how one can understand this relation and will analyse the Kantian proposal on this subject. The philosophy of Kant has had, and still has, a great impact on Western understanding of human dignity. I agree with the feminist ethicist Margaret Farley when she points out that even though the shortcomings of Kant have been and still are discussed, from a feministic perspective among others, his theory is still in many respects relevant to the contemporary debate on identifying the meaning of human dignity and the obligation of respect that this creates.²⁴⁸

Following this, I will present the narrative analysis. In the discussion I will show what I have interpreted as two distinct aspects in the analysis of the empirical material, namely a close connection between dignity and autonomy and the central aspect of vulnerability, a subject which I will return to in future chapters.

In line with the aim of the dissertation, I will discuss how the results of the narrative analysis can contribute concretisations and challenges to certain understandings of human dignity. I will especially discuss the difference a recognition of human vulnerability can make to an understanding of human dignity and its relation to autonomy.

A theoretical perspective on dignity and autonomy

Autonomy means self-law and comes from the Greek word *auto* which means self and *nomos* which means law, and as we will see in this chapter there are many different understandings of how autonomy can be interpreted and how it can be connected to an understanding of human dignity. In Kant's discussion on the relation between dignity and autonomy, the focus is literally on the law, albeit it the moral law.

²⁴⁷ Macklin, Ruth: "Dignity Is a Useless Concept".

²⁴⁸ Farley, Margaret A.: "A Feminist Version of Respect for Persons", in *Journal of Feminist Studies in Religion* Vol. 9, No. 1-2, 1993, p. 186.

When analysing Kant's moral philosophy it is noticeable that his epistemology has implications for his understanding of the possibility for morality, and therefore I will consider certain distinctions which are of importance.

In his epistemology Kant distinguishes between the realm of noumenon (das Ding an sich/the thing-in-itself) and the realm of phenomenon (as the thing appears to an observer). It was a revolutionary idea to claim that one could never attain knowledge of the thing-in-itself but that our knowledge is dependent on the preconditions of our mind, and that certain categories such as space and time form our knowledge. Based on this understanding, the objects adjust or conform to the mind. According to Kant's distinction one cannot have any knowledge concerning whether the will is free or not when it is regarded as a thing-in-itself; this goes beyond the grasp of human knowledge. However, for Kant it is important to postulate the idea of the free will and the understanding that even though we can only know the appearance of determinism, we are noumenally free. This idea is central in relation to enabling a possibility for morality. Kant claims that there are good reasons for considering the possibility of a free will even though a free will cannot be proved as such, and he argues that in a practical sense, concerning morality, we must assume that the will is free. In *Groundwork of the Metaphysics of Morals* Kant states:

Now I say: every being that cannot act otherwise than *under the idea of freedom* is actually free, in a practical respect, precisely because of that; i.e. all laws that are inseparably bound up with freedom hold for it just as if its will had also been declared free in itself, and in a way that is valid in theoretical philosophy.²⁴⁹

To act under the idea of freedom is central in order for moral practice to be meaningful since if everything is bound by causality, an act has no value in a moral sense, one cannot be held morally responsible. However, it is important to emphasise that freedom is understood by Kant in a particular way, where freedom stands in close relation to the moral law.²⁵⁰ Otfried Höffe describes this by saying that a person cannot be conscious of freedom as such, but it is only through the moral law

²⁴⁹ Kant, Immanuel: *Groundwork of the Metaphysics of Morals*, p. 57 (Ak. 4:448). Italics original.

²⁵⁰ Op. cit., pp. 56-57 (Ak. 4:447).

that this can be established. He says: “[...] one cannot become conscious of freedom in an immediate manner, but solely through the moral law or morality itself.”²⁵¹ The connection between freedom and law is elaborated in the second *Critique* where Kant discusses which law can determine the will. If one supposes that a will is free then the quest is to find the law which can determine the will. The form of the law, not the content, is understood by Kant as binding for the will.²⁵² Thus the importance of universality of legislation is underlined, since when a maxim is universalized, i.e. transformed from a maxim to a law, it determines the will, i.e. is binding for the will of every rational being.²⁵³ As Höffe points out, it is only the criterion of universality which determines the morality of the maxim.²⁵⁴ Hence, since a will can be determined by the universal form of the law, through reason, the will must be thought of as independent of the law of causality. The human being is not a slave to her inclinations; reason makes it possible for a rational being to transcend these and in the conflict between duty and inclination a person can, through reason, be conscious of the moral law and also the freedom, in a moral sense, that one has to follow it.²⁵⁵

According to Kant, the moral law is holy and so is the person who forms it. Kant claims in his second *Critique*:

The moral law is *holy* (inviolable). A human being is indeed unholy enough but the *humanity* in his person must be holy to him. In the whole of creation, everything one wants and over which one has any power can also be used *merely as a means*; a human being alone, and with him every rational creature, is an *end in itself*: by virtue of the autonomy of his freedom he is the subject of the moral law, which is holy.²⁵⁶

²⁵¹ Höffe, Otfried: “The Form of the Maxim as the Determining Ground of the Will (The Critique of Practical Reason: §§4-6, 27-30)”, in Ameriks, Karl and Höffe, Otfried (eds.): *Kant’s Moral and Legal Philosophy*. Cambridge University Press, Cambridge, 2009, p. 176.

²⁵² Kant, Immanuel: *Critique of Practical Reason*, p. 26 (*KpV* 5:29).

²⁵³ I will further this discussion in relation to the analysis on the philosophy of Mikhail Bakhtin since he is very critical of the criterion of universality in relation to normativity.

²⁵⁴ Höffe, Otfried: “The Form of the Maxim as the Determining Ground of Will (The Critique of Practical Reason: §§4-6, 27-30)”, p. 161.

²⁵⁵ Kant, Immanuel: *Critique of Practical Reason*, p. 27 (*KpV* 5:30).

²⁵⁶ Op. cit., p. 72 (*KpV* 5:87). Italics original.

Hence, it is only the moral law that is holy or inviolable, according to Kant. Michel Rosen points out that dignity “[...] is a quality of a class of valuable things that, as it turns out, only has a single member: ‘morality, and humanity itself insofar as it is capable of morality’”.²⁵⁷ Hence, it is humanity in every person that is inviolable and not the individual, biological human being. Humanity is identified as something which is unconditionally valuable, and must be treated accordingly. One is reminded of the claims from *Groundwork of the Metaphysics of Morals* where Kant claims that, that which can be considered as an end in itself, humanity, is not only having a relative worth but rather dignity.

The term ‘humanity’ is also used in the second formulation of the categorical imperative: “So act that you use humanity, in your own person as well as in the person of any other, always at the same time as an end, never merely as a means”.²⁵⁸ Respect for dignity is due not to the human being as a biological being but due to one’s humanity. As Dietmar von der Pfordten clarifies, the term ‘humanity’ can be understood in Kantian writing as a characteristic which stands in contrast to the characteristic of animality of humans.²⁵⁹ This is an important distinction since humanity represents the characteristics of the human being as a rational being who is free to form her own moral law; this is distinguishing. It is humanity in ourselves and in others which should be treated as an end in itself, and Kant claims that a person who is not subordinated to any other law than the law that one has legislated, has dignity; it is autonomy, understood as the capacity for legislation, which is the basis for this.²⁶⁰ Kant says:

For nothing has any worth other than that which the law determines for it. But precisely because of this, the legislation that determines all worth must itself have a dignity, i.e. unconditional, incomparable worth, for which the word *respect* alone makes a befitting expression of the estimation a rational being is to give of it. *Autonomy* is thus the ground of the dignity of a human and of every rational nature.²⁶¹

²⁵⁷ Rosen, Michael: *Dignity: Its History and Meaning*, p. 22.

²⁵⁸ Kant, Immanuel: *Groundwork of the Metaphysics of Morals*, p. 41 (Ak. 4:429).

²⁵⁹ Pfordten, Dietmar von der: “On the Dignity of Man in Kant”, in *Philosophy* Vol 84, No. 3, 2009, p. 378.

²⁶⁰ Kant, Immanuel: *Groundwork of the Metaphysics of Morals*, p. 46 (Ak. 4:434).

²⁶¹ Op. cit., pp. 47-48 (Ak. 4:436). Italics original.

So for Kant autonomy should be understood through the lens of his understanding of self-legislation. However, there are different understandings regarding how to interpret the Kantian view.

Onora O'Neill, in her interpretation, points to the importance of the term 'legislation', the importance of persons living by principles. The principles are, according to her, the centre of importance and not that they are legislated by the autonomous and rational self. She says:

Kant's concern is not a *self* that actually legislates for all, but principles that are fit to be laws for all. The stress he places on the term *self-legislation* is on the notion of legislation: the advocates of individual autonomy by contrast stress the notion *self* and have little to say about any conception of (moral) legislation.²⁶²

Here O'Neill points to a Kantian perspective concerning legislation which does not only regard oneself, but legislation which also regards others. Autonomy is therefore not an individualistic concern.

As seen, Kant describes autonomy as the basis for a human being's dignity and he describes this as an unconditional or incomparable worth. I have earlier pointed out the distinction between attributed and intrinsic dignity, where the latter describes dignity as something which one has in oneself in contrast to being attributed dignity from someone else. This distinction is applicable to Kant's philosophy where humanity characterised by rationality and autonomy forms the basis for intrinsic human dignity, the basis for the respect that others ought to show a person. Kant uses the word 'respect' in his description regarding what the dignity of every person requires. This means that a human being, since one has dignity, should be treated in accordance with this status. The second formulation of the categorical imperative makes rather explicit what the respect for humanity in every person involves, namely that since every person has dignity intrinsically, they in themselves are worthy of respect and are not dependent on whether others regard them as important or not; the person's dignity is situated intrinsically, and is not something that is attributed. The other has value in oneself, and cannot be used by anyone to fulfil that person's own aims and purposes.

Many would agree with Kant's understanding of dignity as intrinsic and that a human being is worthy of respect, but would disagree with Kant on his interpretation of humanity as characterised by rationality

²⁶² O'Neill, Onora: *Autonomy and Trust in Bioethics*, pp. 85-86. Italics original.

and autonomy. Regardless of whether one agrees with the basis on which Kant regards a person's human dignity, the importance of the meaning of the respect for the human being's dignity has been influential. Margaret Farley has, I think, concluded well what this respect for the person means:

The moral response appropriate to and required by this radical personal dignity or worth, is respect. To respect persons as ends in themselves is to *relate* to them as valuable in themselves, not just valuable for me; to *treat* them as absolutely valuable, not just conditionally and contingently valuable. [...] no one is to be wholly subordinated to another's agenda.²⁶³

In Kant's discussion, freedom, as seen, is always related to the person's rational nature and hence to her ability to be self-legislative, meaning that she can form her own maxims in accordance with the categorical imperative. It is when acting in accordance with the moral law that she acts out of free will. She is therefore not free in the sense of 'doing whatever she wants' but in a moral sense. The autonomous moral choice that a person makes in a certain situation does not only relate to that specific person; instead, by relating it to the categorical imperative it is central that the choice becomes a universal law. In this way, the moral subject's moral choices do not only relate to the individual in question. However, in contemporary discussion on autonomy, for example in the medical-ethical debate, autonomy has to some extent come to be equated with the fulfilment of a person's wishes. However, such an interpretation is remote from a Kantian understanding. Fiona Randall points to this aspect saying:

It is worth stressing that Kant's view on dignity are the reverse of many claims made in healthcare. For example, to provide a treatment solely on the grounds that the patient (or relative) desires it but which the best evidence suggests will not work is far from respecting the patient's dignity; it is treating the patient as a child to be humoured. Moreover, the doctor who provides such a treatment is not acting as an autonomous or

²⁶³ Farley, Margaret A.: "A Feminist Version of Respect for Persons", p. 187. Italics original.

dignified professional but has become merely an agent of the desires of someone else.²⁶⁴

What becomes specifically clear in Kant's discussion on dignity and autonomy, and which is underlined in the discussion above, is that for Kant dignity does not only concern the subject's dignity, that one has an unconditional value, but instead he focusses on the principle of dignity. What does it mean to respect someone as autonomous? Does it only concern to regard another person's wishes or does it adhere to another interpretation? In the narrative analysis, which is to follow, a different understanding of dignity and autonomy will be analysed in which autonomy is not specifically connected to the moral sphere and self-legislation. It is also visible that a principle of dignity, as respect for autonomy, is interpreted in a specific sense.

Dignity and lack of respect for patients' ability to engage in autonomous choice and decision-making

Some ethicists would argue that autonomy has become the dominant ethical principle in medical care in America as well as in many European countries. Regardless of whether this claim is correct, at least one can conclude that it is a central ethical principle which is commonly accepted within the health-care systems of many Western countries, including the Swedish health-care system. In *the Swedish Health and Medical Services Act*, for example, it is stated that good health care is based on respect for a patient's autonomy.²⁶⁵ However, autonomy can be understood in various ways and a distinction is sometimes made between moral autonomy and personal autonomy. Jeremy Waldron, in his discussion on the matter, has characterised the general understanding of personal autonomy as being in charge of one's own life and making one's own choices regarding life. This is contrasted to moral autonomy which is particularly associated with a Kantian understanding, as was discussed earlier, where autonomy is placed within the moral sphere

²⁶⁴ Randall, Fiona: "Autonomy, Dignity, Respect, and the Patient-Centered Approach", in Randall, Fiona and Downie, Robert Silcock (eds.): *The Philosophy of Palliative Care: Critique and Reconstruction*. Oxford University Press, Oxford, 2006, p. 54.

²⁶⁵ Socialdepartementet: *Hälsa- och sjukvårdslag*. 1982, SFS 1982:763, § 2.

and concerns not only individualistic matters but, as Waldron formulated it in the following characterisation of moral autonomy: “[...] a universalized concern for the ends of all rational persons.”²⁶⁶

If one follows the distinction between moral autonomy and personal autonomy it will be clear that in the narrative analysis a different view than the Kantian will be visible. In the interpretation, there is instead a closer connection between dignity and personal autonomy.

A contemporary understanding of personal autonomy is described in the following: “[...] to be autonomous is to be able to make choices and act in line with one’s reflectively endorsed beliefs, values, goals, wants, and self-identity.”²⁶⁷ Tom Beauchamp and James Childress in their understanding on autonomy have also suggested that one important aspect of forming an autonomous choice is that one is not prevented from doing so. It is therefore important to abolish hindrances.²⁶⁸ These perspectives on autonomy bear a certain resemblance to the perspectives on autonomy which will be discussed in the narrative analysis. In this first narrative, which I will discuss here in greater detail, concerns the limitations which staff can place on patients, and I have interpreted the narrative point to mean that disrespect for the patients’ dignity pertains to patients receiving incorrect or incomplete information regarding their medical condition and possibilities for treatment, hence obstructing the patients’ autonomous decision-making.²⁶⁹

In the following narrative the patients are undergoing treatment for severe illnesses and are continuously discussing their situation with their physicians. The discussions concern the patients’ prognosis and what the future prospects are. Apart from the discussion concerning the patients’ medical condition they also discuss options for treatment. To

²⁶⁶ Waldron, Jeremy: “Moral Autonomy and Personal Autonomy”, in Christman, John and Anderson, Joel (eds.) *Autonomy and the Challenges to Liberalism - New Essays*. Cambridge University Press, Cambridge, 2005, p. 307.

²⁶⁷ Mackenzie, Catriona: “The Importance of Relational Autonomy and Capabilities for an Ethics of Vulnerability”, in Mackenzie, Catriona, Rogers, Wendy, and Dodds, Susan (eds.): *Vulnerability: New Essays in Ethics and Feminist Philosophy*. Oxford University Press, New York, 2014, p. 43.

²⁶⁸ They conclude that personal autonomy at least “[...] encompasses self-rule that is free from both controlling interference by others and limitations that prevent meaningful choice, such as inadequate understanding. The autonomous individual acts freely in accordance with a self-chosen plan [...]” Beauchamp, Tom L. and Childress, James F.: *Principles of Biomedical Ethics*, p. 101.

²⁶⁹ As described in the introduction, I conducted a narrative analysis of the interviews which resulted in several general patterns which I refer to as narratives. The narratives referred to therefore do not relate only to a single interview.

obtain accurate information about the development of one's health, information about treatment as well as options for treatment is of vital importance for a patient since it is essential for making a well-founded decision and choice about one's own situation and future. The patient is dependent on the medical staff for receiving this information. However, I find there to be a connection between a lack of respect for patients' dignity and lack of respect for patients' autonomy. The following situation from an interview with a physician in palliative care will stand as an example.

Nils: A patient suffering from a cancer disease. Quite a young patient with a family, is in treatment, is rather stable, rather well, they make an evaluative x-ray; this is done rather regularly and that x-ray really shows quite a severe deterioration. (S: Yes) The tumour has grown despite the treatment, but the symptoms haven't become apparent yet, so the patient is feeling rather stable, quite OK. Goes to see the physician who will inform the patient about this and the physician then chooses, based on the patient feeling quite well, to give the wrong information. Says: "Oh, but it, it looked quite all right on the x-ray. The x-ray looked good."

Sofia: Aha, so he tells an outright lie?

Nils: Kind of outright lies about it and the patient is really happy and the family is also really happy, you know, and then they leave (S: Yes) and then this happens: when the patient then, quite soon after that, displays symptoms of this [the tumour], when the last straw is finally placed on the camel's back. It's a process, then you have a really hard time to understand, right? (S: Yes, of course) "But the x-ray was OK" he said. "Why is it like this then?" The guy who talked to me about this he then asked me: "Wasn't the x-ray OK?" And then I was asked about this, and of course I told him how things really were: (S: Yes) "No, then one saw [at the x-ray] that there was a rather severe deterioration." I think that was really undignified.

Nils continues:

Nils: You deprive them of the possibility of running their own lives, and in this case they made some decisions about what they wanted to do with their lives but then it all went to pieces because it didn't match with reality. (S: No.) They would've reached very different decisions about their social situation and (S: That's right) where they were going to live, and what they would do, and lots of other things if they had been given correct information.

What is highlighted is that the patients are hindered in making autonomous decisions by the medical staff who do not provide the correct or adequate information which is needed. Kristin Zeiler points to that a patient needs information that make it possible for the patient to be able to reflect on a certain course of action and if one is not provided this information then the patients' opportunity for autonomous choice can be hampered.²⁷⁰

Beauchamp and Childress point to the importance of two conditions in their understanding on autonomy, namely liberty which they understand as meaning "independence from controlling influences", and agency meaning "capacity for intentional action".²⁷¹ They also describe three conditions for autonomous actions. For autonomous action to be present the person should act intentionally, with understanding and without controlling influences that determine their action.²⁷² In this narrative the patients can be described as agents according to the definition above: they are persons who have a capacity to make choices, and have the capacity for intentional action.²⁷³ However, one very important aspect of this which Onora O'Neill discusses, is that when a person is seriously ill, he or she might not even have the energy or strength to accomplish cognitive tasks such as making decisions and choices about his or her own medical care and treatment. Rather, these constraints can temporally restrict their capacity for autonomous decision-making.²⁷⁴ However, in this narrative I have not interpreted this as an extenuating circumstance even though the patients were seriously ill. In my interpretation, the underlying normative thought is that the physicians should provide adequate and correct information in order to enable the patients' autonomous choices and decisions. In other words, it is not the patients' capacity for making choices or decisions which is problematic

²⁷⁰ Zeiler, Kristin: *Chosen Children? An Empirical Study and a Philosophical Analysis of Moral Aspects of Pre-Implantation Genetic Diagnosis and Germ-Line Gene Therapy*. Linköping Studies in Arts and Science No. 340, Linköpings universitet, Department of Health and Society, Linköping, 2005, p. 196.

²⁷¹ Beauchamp, Tom L. and Childress, James F.: *Principles of Biomedical Ethics*, p. 102.

²⁷² Op. cit., p. 104.

²⁷³ The term 'intentionality' is defined as "Intentional actions require plans in the form of representation of the series of events proposed for the execution of an action. For an act to be intentional, as opposed to accidental, it must correspond to the actor's conception of the act in question, although a planned outcome might not materialize as projected." Ibid.

²⁷⁴ O'Neill, Onora: *Autonomy and Trust in Bioethics*, p. 38.

here but instead it is the lack of information or receiving incorrect information which prevents the patients from making an autonomous decision and choice.

As I pointed out above, one of the conditions for autonomous action which Beauchamp and Childress point to is understanding. They say: “Deficiencies in the communication process also can hamper understanding”.²⁷⁵ It is of course always a matter of discussion regarding how much information is needed for the patient in order to make an autonomous choice and decision and what constitutes adequate information. However, the important aspect of this narrative is the concern regarding how the patients are deprived of the opportunity to exercise autonomy. External factors, in this case consisting of not enough or incorrect information (even a lie), create a hindrance to making an autonomous choice and decision. In my interpretation, the patients are treated almost like children who need to be protected as well as treated as people who are incapable of handling the difficult information and in that process they are diminished.

Douglas, a physician in palliative care, described the situation concerning the patients’ possibility in forming decisions and choices with the following words:

Douglas: Then I perhaps think that these people, their freedom of choice and the decisions they are going to be making, they don’t have enough facts, information, to make it possible for them to exercise their autonomy and I think that is really undignified for any society. It turns into something else: on the one hand, self-determination, autonomy, is important. But then, on the other hand, we don’t provide the individual with those tools so that she or he can exercise their autonomy. (S: No, that’s right) That is something that I consider to be undignified.

I have in this narrative interpreted that disrespect of someone’s dignity pertains to the patients receiving inadequate or incorrect information since this is a hindrance to autonomous choice or decision. The patients’ autonomy are restricted and the patients are not treated as autonomous persons capable of handling information about their own lives. However, even though autonomy is discussed in this narrative analysis, I have also interpreted an equally important feature, namely vulnerability.

²⁷⁵ Beauchamp, Tom L. and Childress, James F.: *Principles of Biomedical Ethics*, p. 104.

Seriously ill patients have, as a group, sometimes been described as vulnerable. However, in this narrative analysis it is not vulnerability in the sense of vulnerable groups or populations which I will refer to, even though the patients are seriously ill and this is one of many characterisations of them as patients. Later on in the chapter I will develop my view on vulnerability in more depth, but here I point to two interpretations of vulnerability as I understand them in relation to the specific experience being presented.

First I regard vulnerability as referring to the fragility facing all human life, an inherent condition of human life. This means that we all as humans, in our embodiment, are vulnerable since we are susceptible to illness and death. This is part of our common, human condition. The patients, as seriously ill, are facing the fragility of life, an inherent condition of human life. However, since the patients are seriously ill, they will unavoidably be in relationships where I understand their dependence on others to be apparent. I understand dependence as a form of vulnerability and it is especially this issue which I will discuss further in the following. In my analysis, the patients are dependent on others in a particular way. To discern what this dependence can mean is important to analyse in order to understand what the respect for the patients' dignity can mean.

Susan Dodds points to the relation between vulnerability and dependency. She describes dependency as a specific form of vulnerability, and I agree with her. She writes:

Dependence is one form of vulnerability. Dependence is vulnerability that requires the support of a specific person (or people) – that is, care. To be dependent is to be in circumstances in which one must rely on the care of other individuals to access, provide or secure (one or more of) one's needs, and promote and support the development of one's autonomy and agency.²⁷⁶

It is the patients' inherent vulnerability – the fragility facing all human life, which appears here in the form of serious illness – that has required the patients to seek and need care. It is this inherent vulnerability that forms the basis for patients' dependence. In this narrative analysis it has

²⁷⁶ Dodds, Susan: "Dependence, Care, and Vulnerability", in Mackenzie, Catriona, Rogers, Wendy and Dodds, Susan (eds.): *Vulnerability: New Essays in Ethics and Feminist Philosophy*. Oxford University Press, New York, 2014, pp. 182-183.

been shown that due to the patients' severe illness they become dependent on the medical staff in the physical sense of receiving care for their physical needs, but what is specifically important to highlight in relation to the narrative analysis is that receiving care also includes obtaining accurate information about the development of one's health and treatment. The patients must rely on the professionals to provide accurate information in this regard. In this way the hospital staff hold the key to the information that patients are dependent on for exercising that autonomy. Dodds states that it is not possible to overcome all dependency but that it is important to discern the sort of vulnerability which exists in order to understand what an adequate response to the particular vulnerability should be.²⁷⁷ Hence, in relation to the current discussion, in my opinion, it is not possible to remove the vulnerability in the form of the patients' dependency on the medical care, including information. As a patient, one is dependent on medical expertise which one cannot provide oneself; this is why one has sought help and in this situation dependence cannot be avoided. In my opinion, this dependence which is unavoidable, means that the risk of being harmed also increases. In the situation currently discussed, the medical staff do not respond to the vulnerable situation of the patients. The patients are dependent on the staff for information about their health so that they can make decisions. However, the responses from the medical staff fail to enable the patients' autonomy, since the staff do not provide correct or adequate information. Furthermore, this treatment of the patient is connected to not respecting the patients' dignity.

In the narrative analysis the view on autonomy has been discussed in terms of self-determination. However, the view on vulnerability in the form of dependence can be understood to challenge such a view. The question which comes in the forefront is how independent the patients are in regard to making choices and decisions concerning their lives.

In discussions on autonomy, the relation between autonomy and independence is sometimes discussed. Onora O'Neill points out that within medical ethics, autonomy has often been understood as a feature

²⁷⁷ Op. cit., p. 187.

of individual persons and that it concerns at least capacity for independent decisions and action.²⁷⁸ In pointing to the importance of dependency as a form of vulnerability and in pointing out that this form of vulnerability cannot be abolished it is also difficult in my opinion to regard autonomy as closely related to independence. Dodds points out that autonomy is often understood as the ability of an individual, who is self-determining but also independent, to make choices. She underlines that relational approaches to autonomy also recognise the importance of an individual to make decisions and choices regarding one's own life. However, she also points out that such an act is not independent of relations; on the contrary, in exercising one's autonomy, the relations to others – for example how they promote or obstruct autonomous decisions – are recognised and are of interest to explore. Autonomy therefore becomes more related to interdependence than independence. In conclusion she claims that our social relations are of importance in forming autonomous choices and decisions.²⁷⁹

In the narrative, the patients' vulnerability and dependency also create an unequal relationship where one party (staff) has more power over the situation than the other party (patients). It is an unequal relationship between the hospital staff and the patients, and the former have information which is of importance for the patients in order to be able to make autonomous decisions about their own lives. This also highlights the patients' dependence as well as highlights questions regarding the moral claim and response which can be regarded as placed on the health-care personal.

If one draw attention to the circumstances in the narrative it is noticeable that the patients' autonomy can be described as relational since the patients, who depend on the staff for treatment and information, are dependent on others to enable the conditions for autonomous choices and decisions. In the narrative, it has been seen that staff do not always act in accordance with such an understanding, and this has been interpreted as meaning that patients' dignity, in such circumstances, are not being respected.

²⁷⁸ However, in O'Neill's understanding autonomy is relational, since it is autonomy from something and also it is selective, since individuals are independent in some regards but not in others. She also describes autonomy as graduated, since individuals have greater or lesser degrees of independence.

²⁷⁹ Dodds, Susan: "Dependence, Care, and Vulnerability", p. 197.

To consider and respond to patients' choices and wishes in the end of life

In the following narrative the subject of autonomy and dignity is again encountered but from a different perspective. In the previous narrative the subject was approached from a negative perspective where the patient's autonomous decision-making was obstructed. This was due to them receiving incorrect or incomplete information regarding their medical condition and possibilities for treatment. The following narrative considers patients at the end of life, which means that they are beyond curative care and that death is inevitable.²⁸⁰ The patients are much restrained in their capacity and the aspect of vulnerability is present. The patients' inherent vulnerability – in the form of exposure to severe illness – makes them require care and treatment by the medical staff. However, dependency, which became very clear in the previous narrative, is not explicit in this narrative but present.

I earlier related to the understanding of autonomy as “[...] to be autonomous is to be able to make choices and act in line with one's reflectively endorsed beliefs, values, goals, wants, and self-identity.”²⁸¹ This understanding of autonomy comes in the centre of attention in this narrative.

The patients in end of life care are much restrained and the care of the patient is focussed on alleviating pain but also on securing and improving quality of life for the patient. To improve quality of life for the patient is also one of the aims with palliative care in this stage and is one aspect which is in focus in the narrative. In the narrative the staff's understanding regarding what quality of life is and what good care of the patient in the end of life means is explicit. This can adhere to how they are trained to give good palliative care. Examples of this is pain relief for the patient but also that the patient should be offered the

²⁸⁰ I make a distinction between palliative care (palliativ vård) and palliative care at the end of life (palliativ vård i livets slutskede). The first definition, 'palliative care', refers to medical care where the aim is to alleviate pain and improve the quality of life for patients with progressive, incurable diseases. There is, at one stage, a transition from palliative care to palliative care at the end of life when the aim changes from having concerned prolonging life to mainly alleviating pain. However, also in palliative care at the end of life, the patient's quality of life should be enhanced. These definitions are in accordance with the terms suggested by the National Swedish Board of Health and Welfare.

²⁸¹ Mackenzie, Catriona: “The Importance of Relational Autonomy and Capabilities for an Ethics of Vulnerability”, p. 43.

chance to do certain activities, that the patient is not left alone and that staff is informed regarding the patient's condition in order to provide adequate treatment.

However, in this narrative the staff's understanding of what good care of a certain patient is, what they regard could improve the patient's quality of life, and the patient's own autonomous wishes and claims regarding how he or she wants to live his or her life in the end to a certain extent stand in contrast.

One can remember that the patient is severely ill so it can be difficult for the patient to accomplish cognitive tasks due to physical restraint.²⁸² One important aspect in this narrative is also pinpointed by one of the hospital chaplains in drawing attention to the understanding that one's severe illness also can have an effect on one's autonomous choice being taken seriously:

Immanuel: [...] and sometimes it seems like at the same time as one's autonomy is degraded, the possibility to take care of oneself is degrading, then it is like ... it is more difficult to be regarded as autonomous, to have the right to express one's autonomous choices and decisions and that others really respect this. It sometimes seems like the one who slur or have other physical difficulties, has more difficulty with being taken seriously.

I will exemplify the situation between staff and patients with an excerpt from one of the physicians working in palliative care.

Sofia: But if you were to tell me about a specific situation that you think has been dignified for a patient, what situation would that be then?

L: I have a patient, a professor, lying upstairs and who is very ill. He really doesn't want to do anything, and we've tried to encourage or entice him with different things that he could do, but no, he just wants to lie there and be left alone, and take a shower every two days (S: Yes). He wants to lie there and await death. And that's his choice and his quality of life and he's really delighted with this, you know. But we may think:

"But seriously, don't you deserve a little more fun?"

"No, but leave me alone, this is how I like it and I think I've never had it as good as I have now."

²⁸² O'Neill, Onora: *Autonomy and Trust in Bioethics*, p. 38.

He's lying there preparing and thinking about the good old days and has a shower every second day, and that's just what he wants. I mean, we the staff, can become impatient: "That would be nice and that would be good." Yes, but for whom? Perhaps for us and for you sister so and so, and for me doctor so and so, but for this specific patient, it might be quite the opposite.

S: In other words, really profound sensitivity?

L: Yes, for the choices and thoughts and so on, of the individual patient. We can't presume to have the ability to live the life of that patient and how his or her life has been and so on, but we'll just have to read and listen and be considerate and try to individualize treatment [...] As long as one still has a will of one's own, then that is human dignity and there is nothing else that is respect for human dignity than to let the individual person think and have opinions about his or her own life.

In this narrative, to be respected for one's own choices and decisions in the end of one's life is important and underlined. To be able to do that can also be an expression of one's self-identity. However, in the excerpt an important feature in this narrative is expressed, namely that the staff has an understanding regarding what good care and the quality of life for the patient is, but in this narrative the staffs' ideas of good care contradict the patients' wishes; the patients have other ideas regarding what the care of them in the end of life should involve, for example they give voice to a wish be left alone.

In the relation between staff and patient there is a dialogue; the patients have made up their mind but the staff do not want to act on the patients' decisions immediately. Why this is the case can be difficult to discern but one reason can be that staff want to be sure that the patient feels that he or she is pleased with the decision and that this is an expression of concern of the patient. Another reason can adhere to what was pinpointed by the hospital chaplain that the patient has more difficulties being taken seriously in one's autonomous decision-making when severely physically impaired. In the dialogue between patient and staff there is always a risk of staff being intrusive, regarding what they understand to be the best choice. For the patient who is seriously ill and in a situation where they have to rely on staff for medical treatment and care such a situation can be difficult. Hence, it is important to consider the aspect which Mackenzie points to, namely that certain social rela-

tions can have a negative influence on the exercise of someone's autonomous decision, and in other words they form a constraint.²⁸³ In this narrative the sensitivity for the patient's decision is also underlined. This can also mean that the ideas and interests of staff concerning what they consider to be meaningful for the patient have to be put aside. This is exemplified by Ida:

Ida: If we succeed in doing what the patient wants. (S: Yes). Perhaps it's not exactly what we think is right (S: No). Sometimes it's so easy for us to think that 'this is a good death' (S: Yes, exactly) and that's really kind of dangerous, but if the patient got his or her way. (S: Yes) And sometimes we feel that 'well, I didn't really do what I am used to, but the patient got his or her way...' It might be a patient that says: "No, I don't want you to come in and wake me up in the night; I don't want you to check to see how I'm doing." Because normally, at least if you're at a hospital or in hospice, that you check up on them from time to time. "I want to be left alone." Then some say: "If you feel more poorly then perhaps you...", I'm not sure if they say "die alone", but if they then quietly pass away just like they wanted to, without calling for the family or such things. That is like how they want things to be even though it's perhaps not according to our plan. I think that if we are a bit more alert and listen to the patient without thinking that we always know what's best for them, then I think that we can also see that it's good, without us having to... well normally we might think that this is not the best way of doing things (S: No, all right), that she died alone (S: I see), but if that is something we have really worked for, to let her decide. (S: Yes).

It is clear that the staff's understanding of what would be good for the patients can differ from the patients' autonomous choice, but the staff's will has to be set aside in order for the patients to be allowed to make their own autonomous decisions, and in the narrative this is connected to dignity, the respect of a patient's dignity is to respect his or her autonomous decision and choice. One important remark on this subject is that it has been suggested that even though the patient is seriously ill, vulnerable and dependent, the patient does not surrender his autonomy; one might still have the ability to, for example, give informed consent.

²⁸³ Mackenzie, Catriona: "The Importance of Relational Autonomy and Capabilities for an Ethics of Vulnerability", p. 43.

Thus, to respect the patient's autonomous choice and wishes should always remain prioritised.²⁸⁴ This is an idea which I interpret in line with the narrative point in the current narrative.

Summary of the empirical research findings

In conclusion, the narrative analysis has shown that the interviewees experiences that there is a connection between autonomy and dignity. In the narrative analysis this connection has been interpreted to mean that respect for patients' dignity can mean respect for patients' autonomy. However, what autonomy means can vary and range between making autonomous decisions about one's life to listen and regard the choices and wishes of the patient. It is also important to consider that disrespect of patients' dignity can be interpreted as not enabling an autonomous decision for patients, particularly in the situations where medical staff are a hindrance in not providing patients with relevant and accurate information regarding their medical condition. I have also in the narrative analysis drawn attention to the important aspect of vulnerability and dependency. The patient is autonomous but also vulnerable, which I regard as important to discuss further in relation to the issue of human dignity.

Vulnerability

The Latin word *vulnus*, from which the word vulnerability is derived, means 'wound' and emphasises that suffering, is "inherent in human embodiment" as Mackenzie et al. describe.²⁸⁵ Human vulnerability can be understood in several ways: in the exposure to physical illness, death and dependence on others, but also exposure to socio-political circumstances such as lack of economic means to health care and availability

²⁸⁴ Biller-Andorno, Nikola and Ganguli-Mitra, Agomoni: "Vulnerability in Healthcare and Research Ethics", in Chadwick, Ruth, Have, Henk ten, Meslin, Eric M. (eds.): *The Sage Handbook of Health Care Ethics*. Sage Publications, Thousand Oaks, 2011, p. 242.

²⁸⁵ Mackenzie, Catriona, Rogers, Wendy and Dodds, Susan: "Introduction: What Is Vulnerability, and Why Does It Matter for Moral Theory?", in Mackenzie, Catriona, Rogers, Wendy and Dodds Susan (eds.): *Vulnerability: New Essays in Ethics and Feminist Philosophy*. Oxford University Press, New York, 2014, p. 4.

of medicine, just to mention a few. Vulnerability has also sometimes been associated with negative characteristics such as helplessness and victimhood, and sometimes has even been interpreted as standing in opposition to autonomy.²⁸⁶

Within the fields of bioethics and medical ethics there is an ongoing discussion on the subject. Vulnerability, is for example, described as a core ethical principle of bioethics as discussed in *Basic Ethical Principles in European Bioethics and Biolaw*. The authors conclude that vulnerability is part of our human condition. Since we cannot fully control conditions such as illness and death, we are limited by the conditions facing us as humans.²⁸⁷ I agree with the authors' understanding of vulnerability as part of our human condition but the description of vulnerability regarded as a principle raises concerns since it is unclear how one ought to act in regard to such a principle. In this dissertation vulnerability is regarded to be an important feature in an understanding of a principle of dignity, a condition to take into consideration in respecting the patients' dignity.

In the report, vulnerability is not only described as a universal condition for all human beings. Vulnerability is also described in a narrower sense, which is extensively discussed within the field of bioethics, namely as identification of vulnerable groups, sometimes referred to as vulnerable populations. Identifying certain groups or populations as vulnerable has been regarded as important within research ethics. The assumption is that certain vulnerable groups, such as children, can have difficulties safeguarding their own interests and can therefore be mistreated as participants in research. It is therefore of importance to characterise who can be considered vulnerable, in order to protect these participants in research. However, Levine et al. claim that if vulnerability is understood to refer to human beings in a broad sense it loses its applicability. They state: "[...] so many categories of people are now considered vulnerable that virtually all potential human subjects are included."²⁸⁸ Recognition of human beings in general as vulnerable or

²⁸⁶ Mackenzie, Catriona: "The Importance of Relational Autonomy and Capabilities for an Ethics of Vulnerability", p. 33.

²⁸⁷ Dahl Rendtorff, Jacob and Kemp, Peter: *Basic Ethical Principles in European Bioethics and Biolaw. Vol 1. Autonomy, Dignity, Integrity and Vulnerability*, p. 49.

²⁸⁸ Levine, Carol et al.: "The Limitations of 'Vulnerability' as a Protection for Human Research Participants", in *The American Journal of Bioethics* Vol. 4, No. 3, 2004, p. 46.

identification of too many groups as vulnerable can, they claim, obstruct the identification of who should provide a certain protection when considering research ethics. A too broad, or too narrow, description could be regarded as failing to achieve such an identification.²⁸⁹ However, it has also been discussed whether, in categorising certain individuals or groups as vulnerable, one is taking a risk of stereotyping specific groups or individuals.²⁹⁰

In this dissertation, the concept of vulnerability is not understood as it has been discussed in research ethics, i.e. as regarding vulnerable groups. Instead it is discussed in two forms: as inherent vulnerability and dependence, the latter is regarded as one form of vulnerability. I have previously discussed dependence but will here elaborate the understanding of inherent vulnerability.

Many theorists point to vulnerability as ontological, as part of our human embodiment, a condition of all human life, and this is a description of vulnerability which I find plausible. Mackenzie et al. write:

Human life is conditioned by vulnerability. By virtue of our embodiment, human beings have bodily and material needs; are exposed to physical illness, injury, disability, and death; and depend on the care of others for extended periods during our lives. As social and affective beings we are emotionally and psychologically vulnerable to others in myriad ways: to loss and grief; to neglect, abuse, and lack of care; to rejection, ostracism, and humiliation.²⁹¹

When vulnerability is understood in this sense it refers to the fragility facing all human life, since the conditions of human life are frail; all humans face vulnerability to suffering, sickness and death. In this sense a human being cannot eliminate his or her vulnerability, it is part of human life. In a broad sense this view on human vulnerability stands in agreement with Fineman's definition of vulnerability as: "[...] universal and constant, inherent in the human condition."²⁹² I also agree with her that a description of the human as vulnerable correlates with human experience.

²⁸⁹ Op. cit., p. 47.

²⁹⁰ Luna, Florencia: "Elucidating the Concept of Vulnerability: Layers Not Labels", in *International Journal of Feminist Approaches to Bioethics* Vol. 2, No. 1, 2009.

²⁹¹ Mackenzie, Catriona, Rogers, Wendy, and Dodds, Susan: "What Is Vulnerability, and Why Does It Matter for Moral Theory?", p. 1.

²⁹² Fineman, Martha Albertson: "The Vulnerable Subject: Anchoring Equality in the Human Condition", in *Yale Journal of Law and Feminism* Vol. 20, No. 1, 2008, p. 1.

Mackenzie et al. point to embodiment in relation to vulnerability and this is discussed by Judith Butler in a very fruitful way. Butler discusses what she calls ‘corporeal vulnerability’ and in doing so underlines vulnerability as an ontological condition of human life. In exploring the connection between vulnerability and corporality Butler uses the concept of ‘socially constituted bodies’. With this concept she wants to clarify that a human being is always attached and connected to others instead of separated and independent; the relations to others are part of the human condition through our corporality. Butler claims that there is always an uncertainty connected to bodily life since a person is always dependent on the actions of others towards him or her. Others can hurt or ignore but also show care to a person, but in this way a person’s life is vulnerable to the actions of others. This is also what makes human life precarious, to use Butler’s term, the condition that all are vulnerable to the actions of others. That life is precarious is not something that one can safeguard oneself from; human life is vulnerable. This is an inescapable condition of human life.²⁹³

One dimension of vulnerability which was highlighted in the narrative analysis was the close connection between vulnerability and dependency. Since humans are vulnerable to the actions of others, they are also dependent on others. For example, people must respect, care about, and not use violence towards others. Butler writes: “Loss and vulnerability seem to follow from our being socially constituted bodies, attached to others [...]”²⁹⁴ Here Butler describe the relation between corporality and dependence as it relates to all humans, and as concerning the vulnerability inherent in the human condition. However, in the narrative analysis, in the relation between staff and patients, the concern for dependence and its relation to vulnerability needs to be clarified further since I believe there are nuances in the understanding of dependence.

I agree with Butler that through our corporality, we as humans are social and interdependent throughout our lives but, as Fineman has pointed out, dependency can also be “[...] episodic and shift in degree on an individual level [...]”²⁹⁵ Humans can for example become more

²⁹³ Butler, Judith: *Precarious Life: The Powers of Mourning and Violence*. Verso, London, 2004, p. 31.

²⁹⁴ Op. cit., p. 20.

²⁹⁵ Fineman, Martha Albertsson: “The Vulnerable Subject: Anchoring Equality in the Human Condition”, p. 11.

dependent on others, for longer or shorter periods of time, as a consequence of for instance disease, as was described in the narrative analysis. As discussed before, there is a strong connection between vulnerability and dependency, where dependency is a form of vulnerability, even though they should not be regarded as identical. It is important to stress that while humans are always vulnerable, and in our corporality we as humans are social and interdependent, we are not always dependent in the sense that has been shown in the narrative analysis, where focus was on the dependence on others for care.

Dignity and autonomy within the frame of vulnerability

I have labelled the discussion on the relation between dignity and autonomy ‘within the frame of vulnerability’. I have chosen this description since I regard vulnerability as an important feature in the narrative analysis and a plausible description of human experience. However, a discussion on dignity and autonomy within the frame of vulnerability also raises questions. As seen in Kant and also in the interpretation of the empirical material, respect for a person’s dignity can be understood as respect for her autonomy – even though autonomy is understood in differently by the two. However, the question which I will elaborate further is this: What difference can a recognition of human vulnerability make to an understanding of a principle of human dignity and its relation to autonomy?

In this chapter I have discussed the Kantian position on human dignity. In Kant’s discussion it is notable that in his specific view on the human being, the distinguishing features of humanity are rationality and autonomy. These are the dignity-conferring characteristics of humanity; these are what distinguish a person from a thing, and this humanity deserves respect. As seen, Kant’s discussion on dignity is placed within the moral sphere, where autonomy should be interpreted as self-legislation. I earlier pointed to the characterisation by Waldron where he points to moral autonomy as a universalized concern for all, by all. This is an important feature in the Kantian position, where the decisions being made not only relate to one’s own interests and preferences; this is not another individualistic project. However, one can still raise concerns regarding the Kantian view on the self. Kant discusses the human

self as free and rational, as a creature who, independent of context or relations, forms autonomous decisions. As Farley said in her criticism of Kant:

Here, seemingly, is a freedom that needs no social context, no affective ties, no history of desire. Here is a rational freedom that opposes duty to inclination and remains deaf to claims from anything but its own logic. The charges are formalism, indifference to human vulnerability, the delusion of a self-generating self.²⁹⁶

Within the kingdom of ends there is, as I understand Kant, no recognition of human vulnerability. Rather, he points to the importance of the respect by all for all, but regarded only as rational and autonomous selves, not vulnerable selves. The perspective of human vulnerability in my analysis raises a challenge and criticism regarding Kant's view of the self which, in my opinion, make invisible the self as vulnerable and only regard it as autonomous and rational. In making vulnerability invisible I believe that one excludes a central aspect of the human condition and the human experience.

The results from the narrative analysis also draw attention to a view where the human being, implicitly in the narratives, is understood as being rational, having a capacity for autonomous choice and having autonomous goals. These features have a clear resemblance to the theoretical approaches where the human being, for example, in a Kantian understanding of humanity, is characterised by rationality and the person as free and autonomous. However, there are also important differences to consider. It is important to notice that autonomy, as in the understanding of self-legislation, is not understood as individualistic choices but has to be, in accordance with the categorical imperative, transcended to universal law, which is applicable to all. This is the core of self-legislation – an individual can create a maxim but the universality of the maxim is essential if it is to become normative; it should be applicable to any person at any time. To make an autonomous choice does not mean that one can choose freely as best suits oneself.

In the narrative analysis, my interpretation is that autonomy is understood not as self-legislation but as self-determination in the sense of having a possibility of making individual choices and decisions. The individual ought to be free to make her own choices about her own life.

²⁹⁶ Farley, Margaret: "A Feminist Version of Respect for Persons", p. 188.

The individual should be given different opportunities and information in order to form a choice and decide how she wants to act; to give the other opportunities and information but respect her choice can be understood as an interpretation of a principle of dignity.

As has been described in the narrative analysis, the feature of human vulnerability is an important one and I have described my understanding of vulnerability as meaning both an inherent condition of human life since all face the fragility of life, and also relating to vulnerability as dependence. Dependence becomes obvious in the relation between patient and medical staff where the patients' inherent vulnerability forms the ground for their dependence on others, for example regarding medical care and information. A central conclusion from the analysis was that the person who is autonomous is at the same time vulnerable and in certain situations even dependent on others. However, human vulnerability should not be interpreted as victimisation of the patient. It is important to clarify that being vulnerable does not mean that one is incapable of autonomous decision-making; vulnerability should not be used as a justification for paternalistic practices. Rendtorff writes that in modern society, vulnerability has not been a condition of human life that is acknowledged; rather, he says that vulnerability has been considered as something which should be reduced or even eliminated, "in order to create perfect human beings".²⁹⁷ Charlotte Delmar points to a similar problem in her description regarding the view that vulnerability as dependence can be seen as a violation of the patient's dignity, since it can stand in such a stark contrast to that which has been understood as respect for the patient's dignity, namely respect for autonomy.²⁹⁸ The importance of respect for autonomy is also pinpointed in order for the patient not become a victim of exploitation.

However, this raises questions regarding whether if human vulnerability can be eliminated. I do not regard that it can. Instead it could be regarded as important to include the human experience of vulnerability in considerations regarding an understanding of a principle of human dignity.

²⁹⁷ Dahl Rendtorff, Jacob: "Basic Ethical Principles in European Bioethics and Biolaw: Autonomy, Dignity, Integrity and Vulnerability – Towards a foundation of Bioethics and Biolaw", p. 237.

²⁹⁸ Delmar, Charlotte: "The Interplay Between Autonomy and Dignity: Summarizing Patients' Voices", in *Medicine, Health Care and Philosophy* Vol. 16, No. 4, 2013, p. 976.

In the presentation of the narrative analysis I have pointed to vulnerability in the form of dependence, where the patients are dependent on the medical staff for knowledge and medical care. Dependence does not need to be regarded as a problem as such, one could instead regard dependence as an adequate description of the patients' situation within health care and medical treatment. The patient's vulnerability can evoke different responses to how the staff decides to act towards the patients. These responses are central to analyse. The relation – where the patients are dependent on the care of others – points to an important responsibility of the staff to promote and respect patients' dignity. As was shown in the narrative analysis the patients' dignity was not respected when they were obstructed in their autonomous decision-making due to lack of information or sometimes even incorrect information. One could regard this as situations where the medical staff fail to see the patient as both autonomous and vulnerable.

A principle of dignity which both acknowledge the patient as autonomous and vulnerable could mean that to respect a person's human dignity is to respect the person's autonomy, but the human condition of vulnerability is an important condition for how to understand what this respect for autonomy means. To pinpoint human vulnerability is important in order for others, in this context the medical staff, to be aware that another person is vulnerable and that this vulnerability sometimes means that he or she is dependent on others, as seen for example in relation to receiving correct information. One has to be aware that this dependency can create hindrances to the autonomous decision-making, and here I agree with Mackenzie in her understanding that to respond to human vulnerability can mean that one has to promote autonomy.²⁹⁹ The exercise of autonomy does not occur in a vacuum, but in a context. This, on the other hand, creates a moral responsibility on the other to respect the person's dignity in the sense that one also enables the person's autonomous choice and decisions and that one is aware of the specific and sometimes asymmetric relation which our human vulnerability can create.

²⁹⁹ Mackenzie, Catriona: "The Importance of Relational Autonomy and Capabilities for an Ethics of Vulnerability", p. 34.

Conclusion

As I have shown, respecting patients' dignity can mean respect for patients' autonomy, and this interpretation of dignity is important in regard to empowering the patient. I have discussed the philosophy of Kant who in his discussion on human dignity understands the self as rational and autonomous (in the sense of self-legislative). However, in the narrative analysis I interpreted an important understanding namely that the one who is autonomous is at the same time vulnerable, a central aspect which is absent in Kant's philosophy but an important feature in the narrative analysis. I have claimed that vulnerability can be understood as an ontological feature - it is part of our human condition - and I have declined a discussion on vulnerability as only relating to specific groups such as seriously ill patients. Instead, I understand vulnerability as relating to our humanity. As humans we all face death and illness, and as humans we can be dependent on others; our vulnerability is part of our humanity and is not a feature which can be removed. In the specific situation of the seriously ill patient, human vulnerability in the understanding of dependence becomes highlighted, a situation where the dependence on others for care and treatment is apparent, and also in some perspectives problematic. However, in my discussion I have pointed out that a denial of human vulnerability is a denial of human experience, and that vulnerability is an important perspective to consider concerning the understanding of respect for patients' dignity. This means that autonomy is not exercised in a vacuum but in context. This on the other hand creates a moral responsibility on the other to respect the persons' dignity in the sense that one enables the persons' autonomous choice and decision-making and is aware of the asymmetric relation which our human vulnerability can create.

3. Presence and Responsibility

In the previous chapter the connection between dignity and autonomy was discussed and it was shown that autonomy can be understood and interpreted in various ways. The discussion also concerned one of the important features which was interpreted in the narrative analysis, namely vulnerability. This topic will be further discussed in this chapter. In the present chapter attention will be drawn to an understanding of a principle of dignity which does not necessarily stand in opposition to the interpretation of respect for dignity as respect for autonomy, but gives a complementary perspective. I will discuss an interpretation of respecting someone's dignity from the understanding of being present and sharing a vulnerable situation. I will also discuss lack of recognition and respect for a person's dignity due to abandonment. In addition, I will analyse how a Christological perspective can enrich the analysis of the principle of human dignity, as it is interpreted in this chapter.

A central focus will be directed to the subject of responsibility as it has been interpreted to be a central theme in the narrative analysis. Mikhail Bakhtin's philosophy on answerability (responsibility) will be prominent in the analysis on this subject. In addition, a comparison will be carried out on the concern regarding what could be understood to be a Bakhtinian and a Kantian contribution to the discussion on dignity.

In the light of the results from this chapter, I will claim that a principle of human dignity cannot be reduced to simply mean respect for a person's autonomy. Instead I will show and discuss how a principle of human dignity can be understood as sharing vulnerability.

Presence and sharing vulnerability

The narrative analysis concerns patients, both children and adults, who are in palliative care at the end of life. The situations within neonatal care and palliative care units might seem to differ from each other and maybe even seem to be incompatible. In neonatal care the situations only concern the specific situation for a small child while at a palliative care unit the patients are of all ages, from the very young to the very old. However, in both cases palliative care at the end of life can be a very short period of time and the patient can rapidly proceed to a stage of dying, but the palliative care can also continue over a longer period of time. However, I have analysed a common pattern and interpreted it as one narrative.

The patients in this narrative have incurable, deadly diseases. The patients' conditions are described as, for example: 'patient with incurable brain tumour' and 'so ill that he had no treatment'. The patients are beyond curative care; these conditions are so severe that every possibility to cure the patients has been exhausted, and further analysis and hope of recovery is not realistic. These patients are neither in care aiming at prolonging life. Instead the situation can be characterised as palliative care at the end of life in accordance with the following definition:

The end of life means that death is inevitable in the near future and the primary focus of care changes from life-prolonging to being palliative.³⁰⁰

Hence, it is in accordance with good palliative care to attend to the patient's needs even though this does not refer to recovery. It is also in line with the Hippocratic oath; when the patient cannot be treated, the medical staff should consider other duties, namely to relieve pain and to comfort.

Due to the patients' severe physical conditions, they are in situations of vulnerability. As I have discussed previously I also regard dependence to be one form of vulnerability. This is an applicable description

³⁰⁰ Regionala cancercentrum i samverkan: *Nationellt vårdprogram för palliativ vård 2012-2014*, p. 20. Original Swedish text: "Livets slutskede innebär att döden är oundviklig inom en överskådlig framtid och det huvudsakliga målet med vården ändras från att vara livsförlängande till att vara lindrande." My translation.

It has earlier been described that I make a distinction between palliative care (palliativ vård) and palliative care at the end of life (palliativ vård i livets slutskede).

to when the patients, to a great extent, are dependent on others for medical care and pain relief. They need medical attention and at the same time they become dependent on others. Onora O'Neill has described the relationship between a seriously ill patient and medical staff thus: "A person who is ill or injured is highly vulnerable to others, and highly dependent on their action and competence."³⁰¹ However, I have not interpreted the patient's physical pain and the correlative medical care to be the particular focus in this narrative.

The situation is also burdensome at what could be described as an existential level, and points to vulnerability which is inherent; all humans are vulnerable, for example to death and illness. In the later stages of life, the fragility facing all human life becomes visible in the patients' life. Even though medical progress can cure and help overcome certain illnesses, medical progress and treatment cannot overcome the vulnerability which belongs to all human life and which is visible in these situations. The fact remains that finitude, death and illness cannot be overcome.³⁰² The patients' illness will necessarily lead to death and separation and this is emotionally difficult for everyone involved: patients, family and staff. This is described by one of the physicians in an encounter with a patient and her family:

Nils: [...] a fourteen-year-old girl with a brain tumour together with her parents, and gradually getting worse you know. And the parents were at home taking care of her ... there is of course pain in that whole situation and you see their frustration and their grief and their despair, and also the despair of this teenage girl too.

In these situations which are characterised by powerlessness and finitude there is also an important focus on presence of others, rather than what those surrounding the patients ought to say or do. This can be exemplified with an excerpt from one of the physicians in neonatal care:

Sofia: If you were to describe a situation that you thought was dignified to a patient, what kind of a situation would that be then?

³⁰¹ O'Neill, Onora: *Autonomy and Trust in Bioethics*, p. 38.

³⁰² Dahl Rendtorff, Jacob and Kemp, Peter: *Basic Ethical Principles in European Bioethics and Biolaw. Vol. 1. Autonomy, Dignity, Integrity and Vulnerability*, p. 49.

Rakel: [...] you try to do what is the best thing possible for the child itself, but also ensure that the child gets a chance to sense that the mother and the father are around. We take the child out of the incubator and place it with the mother and father and to have close bodily contact. That they, that the child perhaps after all senses that: “They are by my side even if I’m not feeling so well or so.” (S: Yes, that’s right) “They are with me, they go together with me the whole way...” that was dignified.

Sara Ahmed points to an important understanding when she claims that even though the pain belongs to an individual and only to the individual, in this case the patients, pain can be experienced solitarily but never privately. The people around the person in pain will be drawn into living with the person’s pain as it is such a great part of that person’s life. Ahmed says about her mother who suffered pain: “Through being with her, through being so attached to her, I felt the unfeeling.”³⁰³ This draws attention to a relational aspect. The patient has someone around him or her who, even though the pain is not possible for the others to feel, ‘feels the unfeeling’. In this lies an understanding that even though the patients carry the pain themselves and maybe have no words with which to express their pain, the presence of others can be understood as an attempt to mitigate someone else’s difficult situation.

Another aspect is that at the same time as the situation for everyone involved is burdensome, and the situation for the patient is demanding, the focus of dignity is important. Ninna, one of the hospital chaplains, describes the situation with the following words:

Ninna: To sit down and remain in this room of despair, that is dignity. In other words, to dare to remain in powerlessness. That is, to somehow recognize the limitation and powerlessness of us humans, and to dare to remain in that sometimes.

Here attention is also drawn to the situation as characterised by powerlessness, there is nothing more to do and this is in one sense unbearable, and as said a situation of despair. However, one must sometimes remain in that and share that with the patient. To be present with the patient is in this narrative interpreted in a specific sense namely that when one is present in a situation of despair and powerlessness one also remains and shares the vulnerable situation with the patient. The patient and the one

³⁰³ Ahmed, Sara: “The Contingency of Pain”, in *Parallax* Vol. 8, No.1, 2002, p. 23.

being present with the patient shares the inherent vulnerability, a vulnerability which sets limitations to all human life and which in this situation becomes very clear. In facing this common vulnerability one can only remain and share this situation.

I have interpreted the narrative point to mean that it shows respect for the patient's dignity if others are present with the patient, in the sense of sharing and remaining in the vulnerable situation. The context of this narrative analysis is that I have analysed the interviewees' ways of describing dignity and situations described as dignified. In the narrative analysis I have interpreted the situations to concern a principle of dignity. It is in respect for the patients' dignity that one stay and is present with the patients. The focus, is not on the staff or others as virtuous persons, attention is not drawn to them and their behaviour. Instead I regard focus to be on the other, the patients, and that certain acts towards the other is to respect the other's dignity. To be present with the other is in focus and this in the understanding of someone remaining and sharing the vulnerable situation, and I have analysed this as the narrative point.³⁰⁴ This correlates with what can be described as a relational claim, namely that certain acts and treatments are either inconsistent or consistent with a human being's dignity.

In the narrative analysis I also want to draw attention to what I have identified as a responsibility of the persons around the patient. A responsibility which means being present with the patient in the meaning of remaining and sharing the vulnerable situation. Here, it is important to note that this responsibility is particularly held by staff and not by

³⁰⁴ In the dissertation, *Nursing Care for Patients on the Edge of Life*, Reidun Hov discusses what is considered to be good care of a dying patient (not specifically dignified care). There, one negative aspect identified is that the patients felt alone and that the staff rarely spoke to the patients about their situation. In the dissertation, attention is drawn to the fact that the patients are in need of other people and to the importance of not being abandoned in an end of life situation. In the narrative discussed, however, I have not understood presence just as good care but also as relating to the dignity of the patient. Hov, Reidun: *Nursing Care for Patients on the Edge of Life: Nurses' Experiences Related to Withholding or Withdrawing Curative Treatment, in the Contexts of ICU and Nursing Home*. Karlstad University Studies, 2007:33. Faculty of Social and Life Sciences, Nursing Science, Karlstads universitet, Karlstad, 2007. Presence is also pinpointed as one of four important values in palliative care, as shown, for example, in Regionala cancercentrum i samverkan: *Nationellt vårdprogram för palliativ vård 2012-2014*. Here, presence is connected to the importance of staff being present in order to be receptive to the patient's needs, for example, pain relief.

family members. An excerpt from one of the physicians can stand as one example of when such a responsibility is encountered:

Nils: It might also be that you, quite literally, don't have the strength, this resistance one might have to go there [to the patient in end of life], to encounter the sorrow and the despair. It's both a feeling and we also face a choice, quite simply. The basic thought is that you can't let someone down just because you yourself think it's tough. You can't let someone else down because you can't do anything, I mean you can't, you just have to realise that I will remain here. We walk with the patient, the whole way. I normally use this type of terminology. (S: I see) We follow the patient all the way... Even if you just go to their home and sit there for a short while and look and confirm them, as those kinds of situations also occur. To be close, to not abandon, to confirm [...] In those situations I can think that: what I do or what we do (S: Yes), is that we maintain human dignity.

The excerpt above exemplifies what this responsibility involves. The situation for everyone involved is burdensome not only for the patients and the patients' families, but even for staff. The staff's reaction can be a feeling of resistance as in this case: they might not want to face such a difficult situation, their instant reaction might be that they just want to leave the place and the patient and not be involved. However, I have interpreted it as an understanding of this being a responsibility which they take on themselves, almost in the form of a moral claim.

A reflection that springs to mind is why the staff should see it as their responsibility to stay with the patient. This could be understandable regarding the family, but one can consider why staff draw attention to such a responsibility. It could be considered rational and understandable if for example physicians made clear that there was nothing more to be done, that the patients were beyond cure, and that the physicians could be of more use to other patients elsewhere. It could be regarded a rational prioritisation which could save both time and money. However, the interviewees do not consider these kinds of arguments even though of course prioritising is an integrated part of modern health care. Instead, they point to the importance of presence and I interpret this as pointing to an ethical ideal, an ideal which sometimes can be met and sometimes cannot be met.³⁰⁵

³⁰⁵ Elena Namli, in her analysis of Dostoevsky, explains that Dostoevsky understands rationalism to give an alibi when facing meaningless suffering. Namli shows how Dostoevsky in *The Brothers Karamazov* portrays the rationalist physician who, in

However, I want to raise one concern regarding the analysis. In my material I exclusively interview physicians and hospital chaplains; the narrative analysis rests upon interview material with these groups and the patients are not included in this material. Could it not be that what has been interpreted here as a relation between presence and dignity could, from the perspective of the patient, be interpreted as an intrusion? Alisa Carse stresses that when caregivers attempt to be emphatic towards others there is always a risk of them being intrusive. There is always a risk that one can overstate one's understanding of how the patient in the situation feels and what they need. In the worst form this can be understood as a violation of the patient's privacy.³⁰⁶ This is of course an important remark. However, research, for example work by Jacobson, including interviews with patients regarding dignity, shows how presence also appears as an important understanding of dignity promotion in health-care settings.³⁰⁷

A principle of dignity in my interpretation can be interpreted differently. I have previously shown that respect for the patient's dignity was connected to respect for the autonomy of the other. In this narrative analysis I have interpreted that respect for the patient's dignity cannot be reduced to respect for the patient's autonomy but, that a principle of human dignity can be interpreted as meaning being present with the other, to share and remain in a vulnerable situation.

meeting the desperate and despairing parents of a dying child, remains calm and in a reasonable way explains that there is nothing more to be done, thus distancing himself from the parents' despair. Dostoevsky, she argues, does not agree with the alibi found in rationalism. Instead he underlines that we have a duty to stay and face the suffering. Namli, Elena: *Human Rights as Ethics, Politics, and Law*, p.72.

Naturally, here one can see that from a utilitarian perspective, for example, the situation described could be considered highly immoral. One could for example argue that the physicians ought to be efficient and help as many patients as they could. One could argue that if the physicians stay with their patients, then other patients could suffer from that choice and one could regard this as a waste of hospital resources.

³⁰⁶ Carse, Alisa L.: "Vulnerability, Agency, and Human Flourishing", in Taylor, Carol R. and Dell'Oro, Roberto (eds.): *Health and Human Flourishing: Religion, Medicine, and Moral Anthropology*. Georgetown University Press, Washington D.C., 2006, pp. 42-43.

³⁰⁷ Jacobson, Nora: "A Taxonomy of Dignity: A Grounded Theory Study", p. 6.

Abandonment

In the analysis of my interview material I have also interpreted a parallel and contrasting strand to the narrative above. The narrative point in the previous narrative concerns what it is to respect someone's dignity – the presence of others in the meaning of that someone is sharing the vulnerable situation. The narrative point in this contrasting strand has been interpreted differently, and concerns an interpretation of when someone's dignity is not recognised and respected. The situation concerns a patient who is in a dying phase and who is left to die alone. I have chosen to exemplify this narrative with an excerpt from an interviewee working in neonatal care, even though I have also seen similar narrative patterns within palliative care. However, since this analysis regard a child, the focus on dependence is underlined in a specific sense.

Agneta: It was a, one of these extremely prematurely-born children that I took care of a few years ago. It was very, very premature and very, very transparent [...]. I took the child anyway and went in to see the mother and said that he is not dead yet, but it will not work, his lungs are too undeveloped so we cannot help this child survive. And then I left him there. [...] Well, but when I came back, the child was no longer there together with the mother. (S: No) They [the staff] had placed him in a bed (S: OK) and pulled him out to the room where they were running tests, and that is where the child was and the heart was still beating and I think that was really horrible. I thought that was one of the worst things I had ever experienced... and I don't think a child should have to die in a bed in a small room where staff are running tests. I really don't. I thought it was awful... I can understand that the mother couldn't bear being with it, she was in shock, but that they [the staff] just placed the child there, sort of... I thought that was really horrible, I thought that was undignified.

Before proceeding, I wish to underline that the focus in the analysis is not on psychological concerns. Hence, I will not go into a discussion here regarding possible psychological causes for a certain behaviour or reactions, such as depression or shock; I only want to stress that whatever the cause of the situation, there remain questions regarding how others neglect of the child, that the child dies alone, can be connected to understandings of what can be regarded as undignified.

In this situation, vulnerability is striking and points to the uncertainty facing all human life. The child has been left alone, physically alone in the room, and the lack of people in the room becomes a reminder of the

lack of human contact as a whole. No one is present with the child, sharing the vulnerable situation and remaining there with the child.

Here I also find it important to point out that the word respect or disrespect to some extent does not fully capture the attitude towards the other. In Johannes Fishers' description of human dignity, which I have discussed earlier, he points to the importance of respect as well as recognition of the other in his discussion on dignity. What I find important in his analysis and applicable in the narrative analysis is that Fischer, through regarding recognition, points to the social status which we as humans have or do not have. He says: "[...] having human dignity means being a creature which is to be recognised and respected as a human being in the sense of a member of the human community, and which is to be treated accordingly."³⁰⁸ Recognition is a social act and in the narrative analysis I regard there to be a lack of recognition of the child in the sense that no one even seem to notice the existence of the child.

In the analysis it is also important to point to the existential dimension of abandonment. We as humans understand ourselves as social creatures and, hence, abandonment and loneliness are two of our existential fears. To die on one's own becomes one of the ultimate examples of isolation from others, in our time of most need. That the excerpt concerns a child, one of those who can be considered to be the most dependent on others, also underlines the severity of the situation.

In my understanding, this narrative comes to point to a social dimension of dignity. To respect dignity is not only to respect an individual, but also common humanity. In Kantian terms, dignity is understood as respect for humanity within ourselves and others, but it is important to bear in mind that Kant's humanity is characterised by rationality and autonomy. However, the term humanity can sometimes refer to brotherhood, a sense of community within the human family. It is the idea that there is a communion between persons in contrast to isolation. In one sense, one can consider this narrative as an example of when recognition and respect for common humanity fails, when interdependence and communion is disregarded.

³⁰⁸ Fischer, Johannes: "Human Dignity and Human Rights: On the Normativity of the Social World", p. 30.

Summary of the empirical research findings

Let me conclude with what I understand as the central results in the narrative analysis. Both narratives concern patients with no hope of recovery; the patients are beyond curative care and are thus in palliative care at the end of life, and in the second narrative the situation concerns a dying patient. I have interpreted vulnerability as an important feature; the situations in these narratives are marked by vulnerability in the sense in which I characterised it earlier, namely as regarding the fragility facing all human life, since the conditions of human life are frail and all humans face vulnerability to suffering, sickness and death. In this sense, a human being cannot eliminate his or her vulnerability; it is part of human life and as such I understand it here as: “[...] universal and constant, inherent in the human condition.”³⁰⁹ In the first narrative, I interpreted the narrative point to concern respect for the patient’s dignity in the meaning of that others are present in the sense of sharing and remaining in the vulnerable situation. The second narrative can almost be regarded as standing in sharp contrast to the first, namely that the other is neither recognised nor respected when abandoned by others in the vulnerable situation of dying. However, there still remain questions to be analysed, and in the following I will develop the analysis of how these results can be understood.

How can the presence of others be connected to dignity?

In Stoic philosophy the comprehension of dignity mainly comes in the form of dignity as a virtue. The Stoic ideal of apathy, to accept life and the difficulties of life with great calm, is illuminating. Since human nature was regarded as characterised by reason, the possibility to achieve this virtue, to live a dignified life, was possible. This idea can to some extent be visible even in a contemporary understanding of dignity. A person who carries oneself with dignity is sometimes understood as a person who carries oneself with a sort of self-control or uprightness of bearing.³¹⁰ In this understanding, dignity is closely connected to virtue,

³⁰⁹ Fineman, Martha Albertson: “The Vulnerable Subject: Anchoring Equality in the Human Condition”, p. 1.

³¹⁰ Waldron, Jeremy: *Dignity, Rank, and Rights*, p. 22.

a way of behaving, what has earlier been described as inflorescent dignity. Expressions such as ‘carrying one’s illness with dignity’ point to a characteristic meaning that a person faces illness and vulnerability in a way which is by some described as a behaviour which is worthy of one’s dignity, in the sense of self-control and in an upright manner.³¹¹ When dignity is interpreted in this way I understand it to be interpreted in a very different way than I have interpreted it in the narrative analysis. I have pointed out that respecting dignity is connected to sharing a vulnerable situation but in the understanding of dignity characterised as inflorescent there is no connection to human vulnerability or weakness; dignity is instead conjoined with transcending those human conditions.

As have been shown in the previous chapter dignity can be closely connected to autonomy. When dignity is connected to the autonomous self, the focus on self-determination and choice often becomes prominent and this correlates with adequate treatment of the patient, for example respect for the patient’s autonomy. Courtney S. Campbell, makes the observation that in certain discussions where dignity is closely connected to self-determination then it can seem that “[...] dignity is incompatible with a dying state in which pain, dependency or loss of control is present to some degree.”³¹² The results of the narrative analysis can then point to a certain tension. The respect for a person’s human dignity can be understood as respect for her autonomy, as seen in the previous chapter. However, in the narrative analysis the human being as vulnerable and dependent is instead in the foreground. Even though it has previously been discussed that vulnerability is inherent to all humans, situational vulnerability has also been discussed. With this perspective the specific situation for the patient is pinpointed. They are in a specific situation of vulnerability due to their illness. In these situations it is important to respect every person regardless of their illness or possibility of autonomy. In the interpretation of the principle of human dignity that I have discussed in this chapter, as sharing vulnerability, the respect for dignity is not formulated in the understanding of par-

³¹¹ Kottow, Michael H.: “Vulnerability: What Kind of Principle Is It?”, in *Medicine, Health Care and Philosophy* Vol 7, No. 3, 2005, p. 284.

³¹² Campbell, Courtney S.: “Suffering, Compassion, and Dignity in Dying”, in *Duquesne Law Review* Vol. 35, No. 1, 1996, p. 111. Campbell discusses dignity in dying in relation to the question of legislation of euthanasia. Even though I discuss the question within medical treatment I regard there to be important similarities in the discussions.

ticular characteristics or capabilities. Instead respect for dignity is recognised and respected even in vulnerability and the person who is vulnerable. Roberto Andorno expresses it in the following way: “[...] either one is able to recognise the inherent dignity of human beings in the most vulnerable individuals, or will never really understand what dignity means”.³¹³ However, to make such a claim can be associated with certain difficulties since this can be connected to victimisation, especially in relation to the situation of the patient.

From a feminist perspective the problem of victimisation has been a central issue and I find there to be similarities to the current discussion. The feminist theologian Elizabeth Johnson points to the problems with the suffering Christ who himself becomes weak and powerless and who gives voice to helplessness in the cry on the cross: “My God, my God, why have you forsaken me?”³¹⁴ In Christian theology there are a plethora of understandings regarding the view of Christ, and Dietrich Bonhoeffer points to one of these understandings in his description of Christ. For Bonhoeffer, Christ does not present excellence or power. Neither is it Christ as triumphant or transcendent which is in the centre of his theory. Instead the perspective is reversed in Bonhoeffer’s description. Christ personifies a suffering and merciful God. Bonhoeffer writes:

God consents to be pushed out of the world and onto the cross; God is weak and powerless in the world and in precisely this way, and only so, is at our side and helps us. Matt. 8:17 makes it quite clear that Christ helps us not by virtue of his omnipotence but rather by virtue of his weakness and suffering!³¹⁵

The cross then stands as a symbol for how God in the Christian tradition has been understood to share human vulnerability.

In Johnson’s feminist discussion, the vulnerable Christ can become a negative and inhibiting model for women’s claims for equality and full humanity. This understanding of Christ can enhance victimisation, and oneself as dependent and victimised. Instead she finds it important for those oppressed to “[...] awaken to their own dignity and worth and

³¹³ Andorno, Roberto: “The Dual Role of Human Dignity in Bioethics”, p. 971.

³¹⁴ *The Holy Bible* (New International Version), Matthew 27:46.

³¹⁵ Bonhoeffer, Dietrich: *Letters and Papers from Prison*. Translated by Best, Isabel et al. Dietrich Bonhoeffer Works: Reader’s Edition. Fortress Press, Minneapolis, 2015, p. 465.

begin to exercise their own power".³¹⁶ The situation is similar in the discussion regarding patients in medical treatment: the patient has often been victimised, there is always a risk that the patient becomes helpless, the one who is dependent and also weak while others become those who help, those who are capable. The focus of autonomy in medical treatment has been one of the tools that has been regarded as important for empowering the patient.

However, Johnson also points to what she refers to as a 'pathologic tendency' to deny vulnerability.³¹⁷ This in turn leads to a denial of human experience and can lead to values being interpreted in a banal and shallow way.³¹⁸ I agree with Johnson in this complex picture of victimisation and denial of experience and that one needs to be aware of and take these perspectives into account. However, with this in mind, in one of the narratives I have interpreted vulnerability as central for the understanding of how dignity in this situation of end of life can be understood. The narrative point was interpreted thus: respect for a patient's dignity is to be present with the other, sharing and remaining in the vulnerable situation. I want to underline that in my analysis of presence this does not mean that staff need to be constantly, physically, present with patients who are in palliative care at the end of life. Some patients would understand this as intrusive, as discussed above, and some patients ask the staff to be left alone. To stay and remain with the patient during such circumstances could rather be understood as disrespect of the patients' dignity, understood as disrespect for the patient's autonomous choice.

Edmund Pellegrino, in his discussion on dignity as a human experience, has shown how sensitive patients who are seriously ill and dying are to the way others behave towards them. He says:

The visitor's look of shock on entering the patient's room, the poorly disguised pity, the slight turning away of the eyes, the ever shorter visits, the struggle to say something meaningful, the mournful countenance, the recoil from bodily contact – those reactions all sustain the patient's convictions that she or he is no longer a respected, needed, or wanted member of their community or society.³¹⁹

³¹⁶ Johnson, Elizabeth A.: *She Who Is: The Mystery of God in Feminist Theological Discourse*. Crossroads, New York, 1992, p. 253.

³¹⁷ Ibid.

³¹⁸ Op. cit., p. 254.

³¹⁹ Pellegrino, Edmund: "The Lived Experience of Human Dignity", p. 527.

Others' treatment of a patient can, as Pellegrino describes, underline the understanding that one is respected, as well as work in a contrary way.

I have also used the terms 'sharing' and 'remaining' when explaining presence. As one of the interviewees said:

Ninna: To sit down and remain in this room of despair, that is dignity. In other words, to dare to remain in powerlessness. That is, to somehow recognize the limitation and powerlessness of us humans, and to dare to remain in that sometimes.

The roots of the term 'compassion' are the same as those for suffering. *Pati* in Latin in the original definition means 'suffering together with another' and 'participate in suffering'.³²⁰ It has been suggested that those who want to suffer with the patient must be willing "[...] to adopt a position of relative powerlessness" which here relates to those surrounding the patient.³²¹ In my opinion, this means that to be able to share the patient's vulnerable situation one also has to recognise one's own vulnerability. Compassion can, so to speak, never be given from 'above'. Paul Valadier points out that in such a situation human dignity does not concern human capacities but can be understood as an equal relationship. In this relationship it is manifested that the other is a human just as oneself and "[...] we honour the naked humanity of another [...]".³²²

From a Christian perspective one can underline the theological understanding that Christ suffers with the human being, Christ is the one present in the human being's suffering. The suffering and the vulnerability are not removed from the human being, but Christ endures the pain with the person and in one sense adopts "a position of relative powerlessness". As Johnson remarks: "In the midst of the isolation of suffering the presence of divine compassion as companion to the pain transforms suffering, not mitigating its evil but bringing an inexplicable consolation and comfort".³²³

³²⁰ Campbell, Courtney S.: "Suffering, Compassion, and Dignity in Dying", p. 121.

³²¹ Op. cit., p. 122.

³²² Valadier, Paul: "The Person Who Lacks Dignity", in Ammicht-Quinn, Regina, Junker-Kerry, Maureen and Tamez, Elsa (eds.): *The Discourse of Human Dignity*. SCM Press, London, 2003, pp. 54-55.

³²³ Johnson, Elizabeth A.: *She Who Is - The Mystery of God in Feminist Theological Discourse*, p. 267.

The suffering Christ can in a theological interpretation therefore become a pattern for how one can understand a theological interpretation of a principle of human dignity. The cross stands as an interpretive pattern for God's sharing in human pain and suffering.

Bakhtin on responsibility

In the narrative analysis, to respect someone's dignity is in my interpretation to be present with the person, understood as sharing and remaining in someone's vulnerable situation. However, in the analysis this act was also recognised as an act that one initially can resist; one might not want to face such a difficult situation, one might want to leave the place and the patient and not be involved. However, at the same time I have interpreted that to be present and to stay with the patient is felt to be a responsibility, something that one ought to do. I interpret this as a moral demand on oneself, it is one's own responsibility to be present, to share the patient's situation; this is to respect someone's dignity. I will develop the discussion on how this responsibility towards the other can be understood through a fairly extensive analysis of the Russian philosopher Mikhail Bakhtin's discussion of responsibility. In my opinion, the philosophy of Bakhtin on this issue is explicatory and can have bearing on what this responsibility can mean. Therefore, in the following I will analyse the philosophy of Bakhtin regarding responsibility and set his perspective on this matter within the greater picture of his philosophy.

The work of Bakhtin has been, and still is, very influential in a number of areas in the social sciences, perhaps mostly within literary studies. In his early works, mainly *Toward a Philosophy of the Act*³²⁴ and *Author and Hero in Aesthetic Activity*³²⁵, he discusses the question of responsibility, which he calls answerability, and which is of primary

³²⁴ Bakhtin, Mikhail: *Toward a Philosophy of the Act*. Katerina Clark and Michael Holquist point out the idea that during 1918-1924 Bakhtin worked on at least six pieces of work which all deal with the same subject. They claim that these texts, although not finished, should have been part of a large project which they refer to as *The Architectonics of Answerability*. Clark, Katerina and Holquist, Michael: *Mikhail Bakhtin*. Harvard University Press, Cambridge MA, 1984, pp. 53-54.

³²⁵ Bakhtin, Mikhail: *Art and Answerability: Early Philosophical Essays by M. M. Bakhtin*. In *Author and Hero in Aesthetic Activity* (one of the essays) Bakhtin discusses how the activity of authorship, the writing and work on a text, correlates to the forming of the self. To a great extent, the forming of the self in Bakhtin's work revolves around the relation between self and other.

interest in the following discussion. Bakhtin did not, as far as I am aware, discuss the question of dignity but my purpose in this section is to discuss responsibility, which makes Bakhtin relevant for this study.³²⁶

In *Toward a Philosophy of the Act* the question of answerability is discussed, and since answerability is closely connected to Bakhtin's discussion on normativity it is important to understand his idea of 'the ought', to use his own description. Bakhtin develops his theory with reference to and, in some aspects, in opposition to Kantian philosophy.³²⁷ He does agree with the Kantian proposition of finding a form for normativity and, not a particular normative content.³²⁸ Just like Kant, he wants to examine the categorical, that which binds the will. However, Bakhtin finds the Kantian proposal to be inadequate.

The question of the will is of central importance in Kant's discussion of the moral law. It is important that the will is bound by reason since it is only through reason that one can determine whether an act is right or not. If reason determines the will without exception, then the actions of such a being, which are recognised as objectively necessary, are also subjectively necessary, i.e., the will is a faculty of choosing only that which reason, independently of inclination, recognises as practically necessary, i.e., as good.³²⁹

For Kant, reason is necessary for steering the will, and in the categorical imperative, Kant finds the form for normativity. This becomes the form which determines the will. The form of the categorical imperative also stresses that the moral act should relate to an abstract subject.

³²⁶ In the following, I mainly relate to Bakhtin's own work and Elena Namli's reconstruction of Bakhtin's moral philosophy in: Namli, Elena: *Kamp med förnuftet: Rysk kritik av västerländsk rationalism*. Artos & Norma bokförlag, Skellefteå, 2009. Where Namli's focus is on the Russian criticism of Western rationality, my purpose is to analyse Bakhtin's idea of answerability as a contribution to my discussion on dignity. Bakhtin never explicitly discusses the question of dignity and my purpose is not to conduct an analysis of his work in this respect. The reason I want to draw attention to Bakhtin concerns his understanding of responsibility and his ideas on the self.

³²⁷ Clark, Katerina and Holquist, Michael: *Mikhail Bakhtin*. In this biography Clark and Holquist point out that Bakhtin during his period in Nevel and Vitebsk (1918-1924), the time when he wrote the two works referred to, was strongly influenced by a neo-Kantian discourse and phenomenology.

³²⁸ Bakhtin is not negative towards theory as such; one can agree with a theoretical proposition and it might even be a very useful proposition but this cannot in itself become normative for a person. This is the reason why Bakhtin rejects what he calls content ethics. Instead, Bakhtin discusses how 'the ought' is bound to the individual will. Bakhtin, Mikhail: *Toward a Philosophy of the Act*, pp. 22-23.

³²⁹ Kant, Immanuel: *Groundwork of the Metaphysics of Morals*, p. 29.

It is important that the maxim relate to any person, not a specific subject, at any time. Hence, the maxim which is formed by a subject in accordance with the categorical imperative should be universalised in order to become a moral law. As I have pointed out earlier, Kant discusses which law can determine the will. He believes that if a will is free then the quest is to find the law which can determine the will, and the form of the law, not the content, is understood by Kant as binding for the will.³³⁰ Thus the importance of universality of legislation is underlined, when a maxim is universalized, i.e. transformed from a maxim to becoming a law, it determines the will, i.e. is binding for the will. As Höffe points out, it is only the criterion of universality which determines the morality of the maxim.³³¹

Bakhtin claims that with the form of the categorical imperative, Kant ‘theorizes the ought’; this means that he criticizes Kant for theorising away the ought, abolish the ought. Bakhtin is directing strong criticism towards this. Bakhtin discusses ‘theoreticism’ and when he refers to this concept it is not only Kant he refers to, but rather he seems to reject a paradigm which has reduced normativity to a rational and abstract system; the will becomes subordinate to reason and the form of universalization.³³² Bakhtin considers it to be a great mistake that the act, in the Kantian proposition, i.e., to become normative, has to be made universal. Such an understanding will lead to the death of the individual will according to Bakhtin.³³³ Bakhtin seems to regard the theoretical ought to leave no room for the individual ought, hence making it impossible for the person to be responsible. He says:

In that world I am unnecessary; I am essentially and fundamentally non-existent in it. The theoretical world is obtained through an essential and fundamental abstraction from the fact of my unique being and from the moral sense of that fact – “as if I did not exist”.³³⁴

In Bakhtin’s philosophy, ‘the will’, ‘the act’ and ‘the ought’ are closely related. Bakhtin says: “The ought is a distinctive category of the ongo-

³³⁰ Kant, Immanuel: *Critique of Practical Reason*. p. 26 (*KpV* 5:29).

³³¹ Höffe, Otfried: “The Form of the Maxim as the Determining Ground of Will (The Critique of Practical Reason: §§4-6, 27-30)”, p. 161.

³³² Bakhtin, Mikhail: *Toward a Philosophy of the Act*, pp. 26-27.

³³³ Op. cit., p. 26.

³³⁴ Op. cit., p. 9.

ing performance of acts or deeds [*postuplenie*] or of the actually performed act [...].³³⁵ That which makes an act normative is not that it can be universalized; rather Bakhtin claims that it is an attitude of consciousness which is phenomenologically described.³³⁶

Bakhtin regards a moral act to have a certain tone, and this he refers to as the ‘emotional-volitional tone’. This tone can be understood as that which makes me as a subject become participating in Being. To Bakhtin, tone is closely related to how an act becomes normative for a person in a specific phenomenological position.³³⁷ Hence, tone is that which makes one identify the act as one’s own, my own act. This stands in stark contrast to an act where I am not participating, which is connected to Bakhtin’s criticism on theoreticism. Namli points to Bakhtin’s idea about the emotional volitional tone having implications for what one as a subject understands as normative. The tone steers a thought for a subject and it becomes normative, binding for the will, when the person is in a specific phenomenological position.³³⁸ Hence, normativity is connected to the person’s unique place in Being and can never be applicable in general.³³⁹ When a person admits her unique place and that no one else can take this place then the moral norm becomes binding for the will. Namli says: “The will is creative in the act, it >>claims<< (*utverzjdajet*) the norm and >>recognises<< (*priznajot*) it.”³⁴⁰

Bakhtin wants to draw attention to the fact that the moral act is not a matter of any person at any time. For Bakhtin, ethics cannot be understood as disconnected from the concrete subject; on the contrary, normativity depends on the subject. Bakhtin marks the connection saying:

[...] there *is* a moral *subiectum* with a determinate structure (not a psychological or physical structure, of course), and it is upon him that we have to rely: he will know what is marked by the moral ought and when, or to be exact: by the ought as such [...].³⁴¹

³³⁵ Op. cit., p. 6.

³³⁶ Ibid.

³³⁷ Op. cit., p. 37.

³³⁸ Namli, Elena: *Kamp med förnuftet: Rysk kritik av västerländsk rationalism*, p. 170.

³³⁹ Bakhtin, Mikhail: *Toward a Philosophy of the Act*, p. 31.

³⁴⁰ Namli, Elena: *Kamp med förnuftet: Rysk kritik av västerländsk rationalism*, p. 166. Original quote: ”Viljan är kreativ i handlingen, den >>hävdar<< (*utverzjdajet*) normen och >>erkänner<< (*priznajot*) den”. My translation.

Bakhtin’s theory of the will should not be understood for instance as a Nietzschean idea of the radical return to oneself where the will is understood as a force and energy, a possibility to create one’s own and new values in the absence of a God.

³⁴¹ Bakhtin, Mikhail: *Toward a Philosophy of the Act*, p. 6. Italics original.

As seen, in Bakhtin's philosophy 'the ought' is connected to an attitude of consciousness, and Bakhtin wants to disclose this phenomenologically. He identifies three phenomenological positions: I-for-myself, the Other-for-me and I-for-the-other.³⁴² It is the position of I-for-myself which is connected to normativity, the answerable position. Answerability is therefore not defined by Bakhtin with a specific content but it is defined by position. One can describe Bakhtin's view on answerability as being that a person becomes aware of her own place in Being and sees that no one else can act from this unique position. When referring to unique position it should also be mentioned that what Bakhtin intends is not that the person stands in a unique position understood as a unique situation which has no resemblance to any other situation; instead, it should be understood to mean that the person takes up a specific place in existence which no one else can take, from a phenomenological perspective. When the person in her consciousness realises and admits her unique place in Being, the answerable position, the ought is experienced:

I am actual and irreplaceable, and therefore *must* actualize my uniqueness. It is in relation to the whole actual unity that my unique ought arises from my unique place in Being. I, the one and only I, can at no moment be indifferent (stop participating) in my inescapably, compellingly once-occurrent life; I must have my ought. In relation to everything, whatever it might be and in whatever circumstance it might be given to me, I must act from my own unique place, even if I do so only inwardly.³⁴³

Bakhtin wants to emphasise the importance of the self as being situated in a concrete way; the person has a unique place in existence and it is from this unique place that one must act.³⁴⁴

This thought of one's unique place of I-for-myself is explained in theological terms when Bakhtin refers to Christ descending, the incarnation. That even God has to be incarnated, i.e. act from a specific place in Being, underlines the importance of acting from a unique place. Bakhtin points to that God actually descends from the abstract position of justice, and instead, God is incarnated and takes a unique place in Being. Through the incarnation, according to Bakhtin, God takes the

³⁴² Op. cit., p. 54.

³⁴³ Op. cit., pp. 41-42. Italics original.

³⁴⁴ Op. cit., p. 9.

position from which God can take the sin of the world on himself, the ultimate sacrifice, but from this position, and only this position, he can then bestow mercy upon others.³⁴⁵ This is a rather remarkable statement – that God himself has to be positioned be able to act. This underlines the vital importance of a person being situated in a unique position in Being which means that one cannot take a point of view from an abstract position. Moreover, Namli points to the idea that Bakhtin in this understanding of Christology finds a pure form for his phenomenological idea on normativity.³⁴⁶

One central concept which Bakhtin uses is the ‘answerable act’: “Every thought of mine, along with its content, is an act or deed that I perform – my own individually answerable act or deed [*postupok*].”³⁴⁷ The Russian word for deed, *postupok*, emphasises activity in the form of movement. This is important since through choosing this word Bakhtin draws attention to an ethical activity, ongoing just like in a movement, where it is not the result of the deed which is of interest but the ethical activity in itself. ‘The ethical deed in its making’ to use the expression of Clark and Holquist.³⁴⁸ It is also important to notice that an answerable act embraces human activity as a whole, including thoughts, utterances and emotions.

In Bakhtin’s description, the gravity and seriousness of the act is striking, it is ‘once-occurrent’, ‘never repeatable’ and, ‘concretely individual’.³⁴⁹ For Bakhtin, the act and ethics are intertwined. Ethics for Bakhtin is therefore not understood as a set of ethical principles but “[...] the pattern of the actual deeds I perform in the event that is my life”³⁵⁰. Answerability can therefore be understood as my own responsibility for my own existence. My life is unique in time and space, no one else can have my life. My existence can therefore only be my responsibility, no one else’s, and my existence is not passive but understood by Bakhtin as connected to activity, an event.

³⁴⁵ Bakhtin, Mikhail: *Art and Answerability: Early Philosophical Essays* by M. M. Bakhtin, p. 129.

³⁴⁶ Namli, Elena: *Kamp med förnuftet: Rysk kritik av västerländsk rationalism*, p. 213.

³⁴⁷ Bakhtin, Mikhail: *Toward a Philosophy of the Act*, p. 3.

³⁴⁸ Clark, Katerina and Holquist, Michael: *Mikhail Bakhtin*, p. 63.

³⁴⁹ Bakhtin, Mikhail: *Toward a Philosophy of the Act*, p. 39.

³⁵⁰ Clark, Katerina and Holquist, Michael: *Mikhail Bakhtin*, p. 64.

In discussing answerability it is interesting to notice that Bakhtin uses the concept of ‘non-alibi in Being’.³⁵¹ He wants to stress the importance of the person’s unique place in Being: one cannot be in any other place but in this unique position and it is the person’s responsibility to take this position and act from this position since no one else can accomplish this task. When using such a strong word as ‘alibi’, it emphasises the importance of the responsibility of the person. Randall Poole stresses that theoreticism, as it is understood in Bakhtin’s philosophy, gives an alibi in Being, since the unique responsibility is diminished when it is made universal. Instead of, as in Bakhtin’s own thought, being a question of the position of the I, Poole points to theoreticism displacing the responsibility to anyone and in doing so displacing it to no one.³⁵² There are thus many ways for a person to act and live as if she or he had an alibi in Being.

In the introduction to the Russian edition of *Toward a Philosophy of the Act*, in explaining his understanding of the meaning of ‘non-alibi in Being’, S.G Bocharov refers to the parable of the buried talent.³⁵³ I find this very illuminating regarding answerability. The well-known parable concerns a master who gives talents to each of his servants and their task is to administer the talents which they have received; two of them succeed and multiply the value of the talents they were given, but one of them, due to fear, does not accomplish the task and he fails in his responsibility. In the parable there is a feeling of gravity; this is a task which is given to the servants and they have this one chance. The servants have to decide how they are going to proceed with their task, how they ought to act and they need to make a choice.³⁵⁴ In my opinion this draws attention to the seriousness of a person’s answerability, one does not have an alibi-in-Being, one is responsible for how one respond to others and the social environment. I can fail or accomplish my task of answerable existence. I have a choice regarding how I am going to act.

³⁵¹ Bakhtin, Mikhail: *Toward a Philosophy of the Act*, p. 49.

³⁵² Poole, Randall A: “The Apophatic Bakhtin”, in Felch, Susan M. and Contino, Paul J. (eds.): *Bakhtin and Religion: A Feeling for Faith*. Rethinking Theory. Northwestern University Press, Evanstone, 2001, p. 164.

³⁵³ Matthew 25:14-30, Luke 19:12-27.

³⁵⁴ Bakhtin, Mikhail: *Toward a Philosophy of the Act*, pp. 28-29. Bakhtin says: “[...] for the answerable act is, after all, the actualization of a decision – inescapably, irremediably, and irrevocably. The answerably performed act is a final result or summation, an all-round definitive conclusion.”

Bakhtin underlines the importance of the act that can only be accomplished by oneself and not by anyone else. Ruth Coates comments on this understanding in the following way:

Faced with this fact I can either ignore it, or acknowledge it and structure everything around an awareness of my moral responsibility for my unique actions. In the latter case everything I do becomes a confirmation of my uniqueness in being and links me to it.³⁵⁵

Answerability can therefore only be understood as a person's own and this is interesting since it is important to make explicit that Bakhtin does never define what the content of answerability could be as, this is always related to a specific person. The person has a unique responsibility, a decision is needed to be made, and it is the task of the person to interpret what this means in a particular situation. However, Namli points to an important aspect regarding ethical relativism in Bakhtin's theory. She claims that since Bakhtin is not analysing the content of the normative, only the form, the question of relativism does not apply to his theory.³⁵⁶

The self and other

Since Bakhtin explicitly emphasises the importance of the person as being situated in a specific phenomenological position this, for Bakhtin, means that one person can see the self of the other which he or she cannot see himself or herself. Bakhtin explains this in a very concrete way describing that there are parts of a person's body which only the other can see. Bakhtin describes this using the concept of the 'excess of seeing'. The excess of seeing from the perspective of the I, is the lack of the other and the perspective is of course reversible. A person, in the

³⁵⁵ Coates, Ruth: *Christianity in Bakhtin: God and the Exiled Author*. Cambridge Studies in Russian Literature. Cambridge University Press, Cambridge, 1998, p. 28. Ruth Coates has analysed the work of Bakhtin through a theological perspective. In Coates' analysis, Bakhtin's world is described as 'an existential drama' where Bakhtin's worldview in her analysis is defined by a 'primal fault' and the moral importance of healing plays an important part. Hence, she draws attention to the theological motifs of the fall and incarnation. If the person fails to acknowledge her answerability, she can fail to understand her uniqueness in Being.

³⁵⁶ Namli, Elena: *Kamp med förnuftet. Rysk kritik av västerländsk rationalism*, p. 222.

position of ‘I-for-myself’ cannot see herself fully, she ‘lacks seeing’.³⁵⁷ Bakhtin’s discussion of the excess of seeing is informative regarding his view on alterity. The other is essential for the forming of one’s self. He writes: “[...] one can speak of a human being’s absolute need for the other, for the other’s seeing.” Bakhtin points to this in a concrete way in his example with the experience of the child. In Bakhtin’s view, the child in his position of “I-for-myself”, is dependent on others, for him to become aware of himself, the child’s selfhood is constituted in social relationships. He understands himself due to the acts and words towards him from others, and the picture of himself is given through these acts of others; others formulate how they see him and this is how he will understand himself.³⁵⁸ This will continue to form through the rest of a persons’ life. The self in Bakhtinian thought can therefore never be understood as an autonomous, independent self since one is always dependent on the dialogue with others in the forming of one’s self. The forming of one’s self is therefore always built in interdependence on others and never independently.³⁵⁹ Hence alterity for Bakhtin is important since it is only in the meeting with the other as the other that the self can be formed. The goal is therefore never to abolish the alterity between I and the other. It is only when one is in the place of ‘I-for-myself’ that one can form a dialogic relationship where the other can see one and one’s self can be formed. Holquist and Clark point out one interesting perspective when noting that the Russian word for friend, ‘*drug*’, has a relationship to the word for ‘other’, ‘*drugoj*’. The other is not someone who is dangerous for me or a stranger to me but a friend who I am strongly dependent on and who is strongly dependent on me.³⁶⁰

This relation between the I and the other is also interesting to examine through Bakhtin’s theological analysis: “What I must be for the

³⁵⁷ Bakhtin, Mikhail: *Art and Answerability: Early Philosophical Essays* by M. M. Bakhtin, p. 23.

³⁵⁸ Op. cit., pp. 49-50. Bakhtin is important in literature theory due to his ideas regarding dialogism. This is the idea that all language (speech act to use Bakhtin’s own term) and all thought are always a response to something which is previous (or future). Hicks, for example, views Bakhtin’s philosophy on answerability to be the philosophical foundation for his later ideas about dialogism. Hicks, Deborah: “Self and Other in Bakhtin’s Early Philosophical Essays: Prelude to a Theory of Prose Conscience”, in *Mind, Culture, and Activity* Vol. 7, No. 3, 2000.

³⁵⁹ Clark, Katerina and Holquist, Michael: *Mikhail Bakhtin*, p. 65.

³⁶⁰ Ibid.

other, God is for me”³⁶¹ Bakhtin draws attention to Christ who in the position of I-for-myself assumed the burden of sin, which means absolute sacrifice; at the same time, towards the other Christ only shows loving mercy.³⁶² Bakhtin seems to understand that it is impossible to love oneself; only the other can have mercy and love one from his or her unique position. Namli conducts an extensive analysis of Bakhtin’s understanding of Christology but I want to point to one particular aspect of her discussion which concerns self-sacrifice. Namli shows that in Bakhtin’s work, the moral claim which Bakhtin understands that Christ directs towards himself, which implies absolute self-sacrifice towards himself but love and mercy towards the other, stands as a “[...] clear contextual articulation of the phenomenology of ethics [...]”.³⁶³ Bakhtin’s Christology therefore becomes an important interpretative pattern, an articulation, for Bakhtin’s idea on responsibility.

I have earlier mentioned the Christological interpretation that I made concerning a principle of human dignity. I pointed to Christ’s act on the cross as standing as an interpretive pattern for God’s sharing in human pain and suffering, a theological interpretation of a principle of human dignity. One can also compare such a view with Bakhtin’s view on Christology. Namli shows that Bakhtin’s Christology points to Christ who renounces all power. It is not a powerful Christ which is characterised in his work, on the contrary. Namli points to Christ by Bakhtin being described as the one who “[...] put his fate in the hands of man, which among other things, is manifest in the fact that it is left to man to recognize or crucify his God”.³⁶⁴ Through such an understanding two aspects are identified namely what can be seen as a radical responsibility of one in relation to the other. It is in one’s own power, in facing the other’s vulnerability, to act or to reject the other. The second striking aspect is dependence where Bakhtin through his Christology points to the notion that even God is dependent on the other, just like any human is.

³⁶¹ Bakhtin, Mikhail: *Art and Answerability: Early Philosophical Essays* by M. M. Bakhtin, p. 56.

³⁶² Ibid.

³⁶³ Namli, Elena: *Human Rights as Ethics, Politics, and Law*, p. 163.

³⁶⁴ Ibid.

Dignity, vulnerability and answerability

In the narrative analysis I concluded that I interpreted a responsibility of others to respect the patient's human dignity but not in the understanding of, as seen earlier, respecting the patient's autonomy but respect for human dignity in the understanding of being present with the other, sharing and remaining in the other's vulnerable situation. In the analysis, the philosophy of Bakhtin has had a bearing on what this responsibility may mean.

An important question for Bakhtin, as for so many other philosophers, is the question concerning normativity. Why should I act in a certain way? For example in the narrative analysis, why is it the responsibility of a person to respect the other's dignity by staying with the patient, being present with him or her and sharing the vulnerable situation? On this question the Bakhtinian answer is very different to Kant's suggestion. For both of them it is important to examine the categorical but the reasons a moral act becomes categorical differ. In the Kantian proposition it is the form, that a maxim can be universalized which is the answer, here he finds the form for normativity. And as seen for Kant, it is of vital importance that the moral act can be related to any person at any time; normativity cannot in any circumstance be related to a specific subject. Bakhtin rejects this understanding, since for him it seems to be equated with the death of the individual will. Other philosophers have made similar criticisms, for example the philosopher Emmanuel Levinas, but for Levinas the face of the other becomes the centre for normativity while for Bakhtin it is the phenomenological position of the I, an attitude of consciousness in this particular position. As said earlier, Bakhtin draws attention to the fact that ethics is not a question of any person at any time, but concerns the subject's particular responsibility in a specific position and situation. Bakhtin pinpoints the importance of the unique person in his or her unique place in Being. When one takes the position of I-for-myself, the answerable position, something can become my ought, my responsibility, my task. This is also a realisation that only I can act from this position, no one else can take this place.

In my interpretation the staff around the patient stand in the position of I-for-myself, realising that only I can act from this position in this situation, meaning that they ought to stay with the patient. This becomes their specific task. One of the interviewees thinks to himself: "You just have to realise that I will remain here". It is important from a Bakhtinian perspective that I have to remain since no one else can act from this

position; this becomes the specific task for one specific person. What the respect for the other means is once own particular task, no one else's. It is interesting to see that the interviewees describe the responsibility in negative terms: one should not leave, one should not abandon. Bakhtin also describes in negative terms the moral responsibility – we do not have an alibi in Being, which means that we cannot abdicate from our moral position, no one else can take my place and take my responsibility, and I have no alibi in Being. The answerable act from one's unique position in Being is always one's personal and concrete task, it is one's unique responsibility which cannot be accomplished by anyone else. Every human being, the staff, in meeting the other's vulnerability, can ignore the responsibility or acknowledge it but one cannot surrender it to someone else.

Bakhtin's understanding of the unique responsibility is radical (maybe too radical). This radicalness of the responsibility underlines a seriousness which was described through the parable of the talents. The act is once-occurring and never repeatable. Bakhtin also underlines that a person has a choice, either I act or I do not, but the person has to make a choice regarding how to act, if one takes the position of I-for-myself or if one does not. This severity of the act is also something which I have interpreted in the narrative analysis. The staff are facing a choice, which was underlined in the narrative analysis; either they stay with this patient and in doing so respect the patient's dignity or they do not stay with the patient but leave. In my view the physicians could have referred to rational arguments, declared that they were needed somewhere else but instead, as I have interpreted it, it became their responsibility to stay, their responsibility to share the vulnerable situation. One does not abandon a person in a situation where one's inherent vulnerability is visible, in facing death and suffering. To abandon a person in a vulnerable situation stand in stark contrast to the former idea.

A very important aspect of Bakhtin's philosophy that is relevant for the analysis of the meaning of responsibility, is what Namli has described in the following words:

What he [Bakhtin] observes, and in this sense I fully agree, is that morality is about the realisation that I have the power to either change the situation of the other (and in doing so participate in the act of Being) or

not to change it. [...] It is when faced with the vulnerability of the other that the unique character of duty becomes apparent.³⁶⁵

To respect the other's dignity becomes a unique responsibility in meeting the patient in the vulnerable situation. The response to the other, the ought, takes here a specific form namely to be present with the other, remaining and sharing vulnerability.

Bakhtin, in his discussion, emphasises the self as dependent on others and as formed in relation to others, shown for example in Bakhtin's description of the child in relation to his family. This view stands in stark contrast to the idea of the autonomous and independent self. It is important in relation to this discussion to point out that Bakhtin stands in the tradition of personalism. In this way it is underlined that the human being is a being in relations.

For Kant, respect for humanity in every person is categorical. An important interpretation of what this means is the respect for the others rational and autonomous decisions and choices, these ought to be respected even though one do not agree with the specific individual's decisions or way of reasoning. This is an important interpretation of a principle of human dignity which was discussed earlier. However, in this chapter I have analysed different interpretations of a principle of dignity. I have pointed to the importance of including a perspective where a principle of dignity is broader in scope and also can include recognition and respect for a human being's vulnerability, a view which is absent in a Kantian proposition. Such a perspective does not exclude a perspective on respect for autonomy. However, it can challenge an understanding of a principle of dignity which emphasises a one-sided understanding of respect for dignity as reduced to the meaning of respect for one's autonomy.

³⁶⁵ Namli, Elena: *Kamp med förnuftet: Rysk kritik av västerländsk rationalism*, p. 337.

Original quote:

”Den han [Bakhtin] uppmärksammar, och där instämmer jag helt, är att moralen handlar om insikten om ens makt att antingen förändra den andres situation (och i och med det skapa varats skeende) eller att inte göra det. [...] Inför den andres utsatthet aktualiserar pliktens unika karaktär.” (My translation)

Conclusion

In this chapter I have discussed responsibility and developed the understanding of responsibility from the perspective of Bakhtin. In my opinion, the philosophy of Bakhtin elucidates what the responsibility for the other can mean, namely to be prepared to share vulnerability and to be present with the other. Here I have also identified a difference between Kant and Bakhtin. The Kantian autonomous, rational self is far from the Bakhtinian view on the self, which is interpreted through the lens of personalism; the individual is always related to the other and formed by the other and Bakhtin never refrains from the person as vulnerable.

I have also interpreted respect for human dignity from a theological perspective and interpreted the presence of others in a vulnerable situation from the Christological perspective, namely of the God who shares human vulnerability through Christ. This theological perspective therefore points to a different theological interpretation of what respect for human dignity can mean than many other theological interpretations which instead understand this from a creational theological perspective, especially as seen in the understanding of *Imago Dei*.

Within the discussion on human dignity in the last decade some philosophers have suggested that human dignity, as a guiding principle in medical treatment, only means respect for persons or their autonomy. Although I have pointed to the strong connection between dignity and autonomy, to reduce the meaning of respect for human dignity to mean respect for autonomy is, in my opinion, problematic since it would exclude perspectives such as those that have been encountered in the analysis in this chapter. In my interpretation of the narrative analysis in the present chapter I have instead pointed out that even though respect for a patients' dignity can mean respect for her autonomy, respect for human dignity cannot be reduced to respect for autonomy. In my interpretation respect for a persons' human dignity also means respect for her vulnerability and I have shown that respect for human dignity can be understood as being present and sharing the vulnerable situation.

4. An Analysis of Dignity – Complexities in Medical Care

Within neonatal care there are many difficult ethical concerns. There are concerns for example regarding at what age one should save a child, in week 24 or already in week 22? There are also concerns of a more social character, such as how much consideration, if any, should be given to the social situation of the family when deciding on the care for a seriously ill child? In this chapter two narratives will be presented which concern situations within neonatal care. However, in the discussion I will not conduct a normative ethical analysis on decision-making. This chapter is slightly different than previous empirical chapters in that an analysis of questions pertaining to the subject of dignity, that these decisions in neonatal care raises, will be discussed. I will analyse how within neonatal care, concerning decisions about the treatment of severely ill children, there can be different appeals which have to be taken into account when decisions are being made. These appeals often coincide but sometimes they do not, and in my opinion this raises ethical concerns and questions relating to the subject of dignity. These concerns will be analysed in this chapter.

The outline of the present chapter is as follows: first a presentation of the two narratives ‘For the sake of the child and in consideration of the family’ and ‘Best interest of the child – best interest of the family’. This will be followed by a discussion regarding how these results can raise concerns regarding dignity.

The choice to analyse these particular situations from neonatal care adheres to that this material most clearly, in my analysis of the interview material, raises concerns regarding dignity.³⁶⁶

³⁶⁶ My analysis of the interview material is that decision-making in palliative care mainly concerns issues regarding the patient’s autonomy, which was discussed in chapter two. It should be noted that this is of course only related to my material. I am convinced that the difficulties raised in this chapter might also relate to the care of

Withdrawing and withholding treatment within neonatal care

Before proceeding to the narrative analysis, which concerns withdrawing and withholding treatment for seriously ill children, a short description of the background regarding these procedures is in order.

Within neonatal care the technological advances have meant an increase in the number of children who survive, despite being born prematurely or having a severe illness. This is a rather new development. In the 50s and 60s, children born in gestational age 32 had some chance of survival, but children below this age would often die. Today, the situation is remarkably different and the threshold for viability is gestational age 24-25 in developed countries, but even children as young as gestational age 22 can be saved, although in these early weeks the risk of neuro-developmental abnormality is high.³⁶⁷ However, this new situation also creates a new ethical dilemma, which is that often a treatment can be given, but the ethical question which needs answering is whether it should be given or not. This is very much related to the question of withdrawing and withholding treatment.

To withdraw or withhold treatment for a seriously ill child is part of the neonatal care in Sweden and in Europe. This was shown for example in the EURONIC project, which had as its aim to study practitioners' own description of the practice around end of life decisions in neonatal care. The project showed that the vast majority of neonatologists had been involved in limiting treatment, for example due to incurable conditions. The study showed that 90 % of Swedish physicians had been involved in ending respiratory care, and almost 90 % had given painkillers to ease pain, but in such high doses that there was a risk of hastening death.³⁶⁸ Two professors, Orvar Finnström and Jan Persson, who were part of the EURONIC project, stated that ten years after the study, the practice in Sweden has hardly changed at all compared to when the

adults in palliative care but it is not something I have found in my analysis of the interviews.

³⁶⁷ Oh, William: "The Field of Neonatology", in Elzouki, Abdelaziz Y. et al. (eds.): *Textbook of Clinical Pediatrics*. Vol. 1. Second edition. Springer, Berlin, 2012, p. 86.

³⁶⁸ Cuttini, Marina et al.: "End-of-Life Decisions in Neonatal Intensive Care: Physicians' Self-Reported Practices in Seven European Countries", in *The Lancet*, Vol. 355, No. 9221, 2000, p. 2112. It was noticed that Sweden, together with the Netherlands and the UK, are among those countries that have the highest rates of withdrawal of respiratory care.

study was made.³⁶⁹ The results of the EURONIC project also stand in agreement with the guidelines of the National Swedish Board of Health and Welfare. There it is stated that life-sustaining treatment should not be given or upheld when it is not in agreement with science and proven experience: for example, if treatment does not yield results or if the patient experiences extreme suffering as a result of the treatment.³⁷⁰

An important aspect to take into consideration is the status of the child from a legal point of view. Before birth, the child is considered part of the mother's body; she has the right to make decisions about her body in which the child is included. After birth, the child is regarded as separated from the mother; the child is considered as a separate individual. All children who are born alive should therefore, as long as it is in agreement with science and proven experience, be given a chance to survive.³⁷¹ If the medical profession regards the child as benefitting from a certain treatment that they regard to be in the best interest of the child, this should be given. However, the authors Hellström-Westas et al. conclude that what is regarded as the best interest of the child is sometimes an ethical grey zone.³⁷² The newborn child is regarded as an individual with human rights, just like the adult patients. In treatment one takes into consideration the United Nations' Convention on the Rights of the Child and in particular the idea of acting in the best interest of the child.

In Swedish medical care, as noted earlier, the principle of autonomy is important to regard. Since the children who are in neonatal care are too small to have autonomy, the parents have surrogate autonomy. This means that the parents should consider the interests of the child and guarantee that someone speaks on behalf of him or her in regard to medical decisions.

³⁶⁹ Finnström, Orvar and Persson, Jan: "Avsluta behandling – svåra beslut i neonatalvården", in *Läkartidningen*. Vol. 16, No. 13, 2009, p. 909.

³⁷⁰ Socialstyrelsen: *Om livsuppehållande behandling*. Socialstyrelsen, 2011, SOSFS 2011:7. In the accompanying handbook, which also deals with the question of interpreting the guidelines in relation to newborns, it is clear that newborns should be treated in the same way as other patients; they should be treated in their own right, independent of criteria such as age or weight. Socialstyrelsen: *Om att ge eller inte ge livsuppehållande behandling: Handbok för vårdgivare, verksamhetschefer och personal*. Socialstyrelsen, 2011, p. 44.

³⁷¹ Hellström-Westas, Lena, Lagercrantz, Hugo and Norman, Mikael: "Etik", in *Neonatologi*. Studentlitteratur, Lund, 2015, p. 519.

³⁷² Op. cit., p. 520.

For the sake of the child and in consideration of the family

In this first narrative,³⁷³ a child is born with a serious illness and is in need of life-sustaining treatment. Due to this fact, upon birth the child is laid in a respirator and the situation becomes very dramatic and chaotic for the parents. Within a very short period of time they have to process the information about their child being seriously ill, the uncertainty of the diagnosis for the child, the uncertainty of the chances for the child to survive, and the prospects for the future. While the parents are described as being in a state of confusion and uncertainty, the medical team and the physician make various medical assessments in order to gather information and decide on a diagnosis for the child. In the interviews, the diagnoses include for example cerebral haemorrhage, an extremely premature child with immature lungs, a severe deformity which prevents the child living a life without a respirator, and an extreme disease with no possibility of treatment.

During this period, the interviewees present how in addition to being supportive of the parents, they also discuss the situation with them, they inform them about the child's critical condition and underline the gravity of the situation. Then, after a period of observation, processing tests and further discussions with the parents the physician comes to the conclusion that the right decision to make is to end the life-sustaining treatment for the child. In the interviews I regard the interviewees to present themselves as taking the decision with great seriousness and with great consideration and concern. They voice a feeling of responsibility; that this is literally a decision between life and death and it is not taken lightly.

One should also point out that even though the physician state clearly that he or she make the final decision, it is discussed with the parents who also have to agree with the decision in accordance with the principle of surrogate autonomy. Within the medical services, the principle of autonomy is prominent but, due to the child's inability to express an autonomous choice, the parents have surrogate autonomy. As earlier described the idea is that the parents are the best candidates to plead the child's cause and to understand and give voice to what is in the best

³⁷³ As described in the introduction, I have carried out a narrative analysis of the interviews, which resulted in several general patterns which I refer to as narratives. The narratives referred to therefore do not relate only to one interview.

interest of the child. In *the Swedish Health and Medical Services Act* the parents' right to participate in the care of the child is expressed and emphasised. This includes parents receiving information about the progress of the child as well as their opinion being sought regarding treatment. Moreover, if the physician decides to end the life-sustaining treatment on the basis of the patient not benefitting from the medical treatment, the parents need to be included in the decision-making process. However, the National Board of Health and Welfare in Sweden is clear on the fact that it is the physician's responsibility to make the definitive decision about the child's treatment. The underlying idea being that the parents should not be burdened by the final responsibility of choosing whether or not to treat their child.³⁷⁴

An important part of the narrative analysis is the underlying reasons as to why the physician makes the particular decision to end life-sustaining treatment and for whom. Why the physician draws this conclusion is related to what the physician and the parents understand as being in the best interest of the child. Some conditions are so severe that maintaining life-sustaining treatment is not considered to do any good to the patient. These can be conditions such as extreme suffering or, as described by Ragnar³⁷⁵: "And here was this idea that the child, it wouldn't make it without a ventilator and that's no life, it's so very clear here in this situation". I understand the reference to 'no life' as a normative statement. A life in a ventilator, which of course is a life in a biological sense, is not considered to be a life in a normative sense. A life in a respirator for the rest of the child's life could be understood as insufferable and as a life with no advantage for the child.

An important distinction between this narrative and the following one is for whose sake one makes the decision. The narrative point here is interpreted thus: a decision to end life-sustaining treatment is made on the basis of the child's condition and what is considered to be in the child's best interest, whereas the question regarding when one should end the treatment is made in consideration of the interests of the family.

³⁷⁴ Socialstyrelsen: *Om att ge eller inte ge livsuppehållande behandling: Handbok för vårdgivare, verksamhetschefer och personal*, p. 53. For an interesting comparison of legislation and guidelines on end of life treatment in European countries see McHaffie, H.E. et al.: "Withholding/Withdrawing Treatment from Neonates: Legislation and Official Guidelines across Europe", in *Journal of Medical Ethics* Vol. 25, No. 6, 1999.

³⁷⁵ All the interviewees who are referred to in this chapter are physicians within neonatal care.

Let me develop the analysis of the first part of the narrative point – that the decision is related to the child – by starting with an excerpt by Eva:

Eva: It felt that it was unequivocally the right decision, medically speaking (S: Yes, right), but it is, nevertheless, when one realises that it... that it is not beneficial for the patient to continue care at this level, well then there is only one thing to do and that is to remove the ventilator, but it means that you really manually remove the hose. (S: Yes, right). And it has, of course, affected me, but at the same time it was a... that, that at the same time one did something good for the patient, in a way. (S: Yes, right) Then this little child didn't have to suffer, which it really, really did. Then you come back to this thought, over and over again: for whom? That you really know that it was done for the sake of the child.

In this narrative I interpret the physician to base the decision on circumstances relating to the child. The child in my view is regarded as someone whose perspective cannot be neglected or dealt with in an arbitrary way; on the contrary, the child has the status of being the one from whose position the decision is being made. The child is of course strongly connected to her or his family but it is the perspective of the child, with its difficult condition and experience of suffering, which is mainly considered.

The decision to end life-sustaining treatment is therefore not based on considerations regarding to what is in the best interest of the family or of society. The physician could, for example, have regarded the situation from a societal point of view and claimed that to continue the care for the child would be too costly for society and therefore one should end the life-sustaining treatment. However, my conclusion from the narrative analysis is that life at any cost is not always regarded as being in the best interest of the child. Furthermore, it is considered right to end life-sustaining treatment in some situations. However, attention must be drawn to the consideration that whenever a decision like that is made, such a decision has the child as its subject.

When life-supportive treatment should be ended it is described as something which is 'planned' and 'controlled' and during this time it is described as important that the child does not suffer and that the parents have time to come to terms with the situation. During this period it is described that it is important to take time with the parents, listening to the parents' needs, and not rush the course of action.

Agneta: You don't think you want to expose the child to any more suffering either... and then you really have to plan for the time that is left and make it, well, as good as possible, despite everything, for everyone involved and not have the child suffer. It, it is kind of the only thing that you can do, and so that the parents can have some kind of reasonably beautiful memory when they leave.

The child is often described as taken out of the ventilator and will, instead of dying in the ventilator or surrounded by technical devices, die in the care of the parents. Ragnar:

Ragnar: It is at least a beautiful ending that way, and I think that is really important, that you have that aspect too, that it is not just a medical closing down of a ventilator, and the child dies and that's that, but that this is something that you really have to deal with delicately and with great respect.

Let me therefore conclude with what I understand to be the result of the narrative analysis. I have drawn attention to the following: when a decision concerning ending life-sustaining treatment is made, that decision has the child as its subject; and when to end the treatment is regarded as being done in the care of the family.

Best interest of the child – best interest of the family

The following narrative has many similarities to the previous narrative 'For the sake of the child and in the care of the family'. The situation is similar: here too it concerns decision-making within neonatal care. A child is born and it is clear that it suffers from a severe illness or deformity and it is also clear that the child will, if it survives, live with a difficult illness or deformity. The physician makes medical assessments and follows the child's development, discusses the situation with colleagues at the hospital and talks to the parents about the situation. The parents are in a situation of distress, but there is a distinct difference with the previous narrative, namely that in the discussion with the physician, the parents receive information about the child's situation but the parents also, directly or indirectly, make the physician aware and informed about the family's point of view. The family, for different rea-

sons, think that a life with a seriously ill child would be extremely difficult and they feel they do not want to, or they cannot, live with a seriously ill child. Therefore, the physician, for their sake, does not need to be proactive in the treatment. This means that the parents express the view that from their point of view everything does not need to be done for the survival of the child.

The physician decides to listen to the parents and take into consideration their situation and views when deciding on the treatment for the child. The physician find that he or she have to consider the severity of the child's illness, suffering, and life prospects, but also consider the parents' wishes about the treatment of their child and the situation for the family as a whole, and what it would mean for the family to live with this child. As described by Rakel:

Rakel: Then you have to listen carefully to what the parents think and say, and what they consider to be quality of life.

and

Rakel: The quality of life for the child itself, but also for the family.

In the previous narrative, decision-making was related to the child's own condition but in the present narrative the interviewees point to an understanding where the decision does not exclusively have to relate to the child's perspective. Rather, social aspects, especially regarding the family's situation, are taken into consideration when making a decision. The perspective of what lies in the individual child's interest and what lies in the family's interest is a distinction which I regard that the physicians considers, but it is a distinction that the physician does not strictly uphold. I understand the physician to be concerned with the best interest of the child in an extended sense, by which I mean that the best interest of the child is not understood from a strictly individualistic sense only regarding the situation for the child. The physicians also considers what it would mean for a child to live in a family that has said they do not want to or feel that they cannot, live with a seriously ill child. In this sense one could understand the best interest of the child to be interrelated with the best interest of the family, instead of being separate concerns. The child is regarded as a part of a family and what is in the best interest of the family can also be regarded as being in the best interest of the child, and the treatment of the child therefore relates

to the situation of the family. To take the situation of the whole family into consideration in decision-making, including the newborn child, is described by Simon:

Simon: I slowly realise that this child will not make it without oxygen and then I realise that she will not even survive that; rather, she must be put on a ventilator. I think that we [the physician and the mother] have had three, four or five talks that evening and then she comes back [the mother] exactly the same way and then I feel that, that it must be possible for one to say that it would be seen as serious abuse of her [the mother]... Based on the girl having an illness that is serious, well then there is no reason to push this, that's what I think to myself, so I go to inform her about what is happening to the girl and that her condition is slowly deteriorating. I decide not to put her on a ventilator [...] Here I took the mother's strong desire into consideration (S: Yes), but I didn't actively interfere and the child didn't suffer at all.

However, the situation can also be that the family's appeal is stronger than the child's appeal, which can result in a situation where the decision regarding the child would have been the opposite if the situation had been different and the family had decided on a different course of action, as described by Simon:

Here there was a diagnosis that worked as a guiding principle. A serious prognosis, but if this woman had said: "Please do whatever you can for my, for this child" - it might have been so very much longed-for, it might have been the only child - well then I think I might have acted differently. (S: Yes). I would definitely have acted differently. Then we would have put the child on a ventilator and we would have analysed it. Perhaps the child would have died, but during those six months the child would have lived and developed and acquired worth.

One can compare this situation with an adult patient where the patient's appeal cannot in the same way be negotiated in relation to the appeal of relatives. In comparison to the interviews in palliative care the situation is different. In that case the patient's situation is the foundation for the decision, regardless of social aspects or views of the patient. This of course relates to the fact that the patient can express an autonomous choice, but even in the care of adult patients in end-of-life care where the patient is seriously ill and cannot express their own autonomous view, the physician regards previous discussions with the patient as guiding and does not rely on relatives' views. This is of course not possible in neonatal care since the child cannot express an autonomous

choice. However, the physician would, in treatments of adults, with difficulty, make a decision regarding the patient's treatment on the basis that if the patient had relatives who regarded the situation differently, then one would have treated the patient differently.

In the excerpt above, the interviewee draws attention to an understanding where a value is developed. I understand this as a relational view of the child's value which means that as the relationship and the attachment grow stronger between the parents and the child, the value of the child also increases.

The physicians find themselves in a very complex situation, where they have to be concerned for the individual child and the family but they also reflect on the situation for the seriously ill children from the perspective of society, as described by Rakel:

Rakel: Yes, and it's so incredibly important too, and it's very clear when the children have survived and then come home, because we can do a lot here, but then, how are the children then and how does it affect the whole family? That is important. And then you have to consider whether society is really prepared for these kinds of children too? Not that you... It's OK that we do our best and the children survive but might be damaged. Then they leave the hospital and the parents are left quite alone with a severely injured child. I think and I have heard from certain parents that they really have to fight for their children. Unfortunately the same is true in society.

Sofia: You mean that they don't receive the help and the support that they really need?

Rakel: Yes. (S: OK. I see) And that is not only referring to medical help or such things. It's also a matter of getting help with everyday life and ensuring that these children are really also welcome in society.

In my interpretation, societal aspects are not considered by the interviewees as a morally acceptable basis for decision-making but the societal aspects still appears as a consideration, a perspective which the physician has to relate to even in a negative sense. In the interview material this is also underlined and considered as a dilemma, as described by Agneta:

Agneta: Can I decide what a good life is, for another human being so to speak? And what is that all about? Is it about the limitations of society to help these people have a good life? Should I stop the treatment and

let someone die for that reason? Because society doesn't stand by these people and provide the resources necessary to give them an acceptable quality of life? To me that is crazy. It is absolutely crazy.

Health care decision-making is not made in a contextual vacuum; the care of an individual is provided in the context of a particular family and in a particular society. Judith Butler, in her discussion, draws attention to the fact that a precarious life needs support if it is to be a liveable life. This includes support from other persons such as the family of the child but also relates to social and economic aspects. The physicians draw attention to what I have interpreted as a grave concern that families with seriously ill children do not receive sufficient help and support; society does not provide the support needed to make the child's and family's life liveable.³⁷⁶

Let me conclude with what I see as the result from the narrative analysis. The narrative point has been interpreted to mean that the decision regarding the treatment of the child does not exclusively have to be related to the child's perspective in an individualistic sense. Rather, social aspects, especially regarding the family's situation, are taken into consideration. The child is regarded as a moral subject but one whose moral appeal can be negotiated with appeals from the family. However, whereas the situation of the child's family seems to be acceptable as a foundation for decision-making, societal attitudes and factors are considered but rejected.

Summary of the empirical research findings

In the narrative analysis it has been shown that humans from birth are exposed to others and dependent on others, both those we know and those we do not know. In the first narrative attention was drawn to the understanding that when a decision concerning ending life-sustaining treatment is made, that decision has the child as its subject. In the second narrative attention was drawn to that the decision regarding the treatment of the child does not exclusively have to be related to the child's perspective in an individualistic sense. Rather, social aspects re-

³⁷⁶ Butler, Judith: *Krigets ramar: när är livet sörjbart?* Translated by Lindeqvist, Karin. Tankekraft, Stockholm, 2009, p. 29.

garding the family's situation are taken into consideration in the decision-making. However, societal attitudes and factors seem to be rejected as foundation for the decisions being made.

Dignity and neonatal care

The situations I have described in the narrative analysis are difficult and complex. They draw attention to what I have previously discussed, namely vulnerability. Human beings are susceptible to illness and death, but also vulnerable to others in the form of dependence. Judith Butler discusses the 'precariousness of life' and she claims that all human life is precarious, in the sense that life, from its very beginning, is in the hands of others.³⁷⁷ This is true for any newborn child but it is a subject that becomes striking in the narratives.

As described earlier, my aim is not to give a detailed analysis of decision-making in relation to these difficult situations and suggest which course of action that ought to be taken. Rather, at this stage, the results from the narrative analysis point to important areas for discussion in relation to the question on dignity, and in this analysis previous results will be regarded and some of the results will also be discussed further in this chapter.

In research on dignity focussing on questions in medical ethics or bioethics, there are often only a limited number of areas where complexities concerning dignity are discussed. These areas often involve abortion, palliative care and euthanasia, but also areas where new technological development has raised concerns on the question on dignity, such as reproductive technologies. However, the question of dignity and complexities in neonatal care are rarely paid attention to, either by those doing purely theoretical analysis or by those doing empirical ethics. In the analysis it will therefore be of importance to show and discuss how the question on dignity is brought to the fore in these situations in neonatal care. This analysis is done in accordance with the tripartite categorisation on attributed dignity, intrinsic dignity and inflorescent dignity which has been previously analysed. The different meanings of dignity lead to different understandings with regard to who ought to be recognised and respected.

³⁷⁷ Butler, Judith: *Precarious Life: The Powers of Mourning and Violence*, p. 20.

Intrinsic dignity, attributed dignity and equality

One of the definitions of dignity which has been previously discussed is intrinsic dignity. It is the idea that all human beings, regardless of attributes such as age or gender, have dignity. Furthermore, all human beings can be regarded as having equal dignity. As has been shown earlier, the idea in the *Universal Declaration of Human Rights* adheres to an intrinsic sense of dignity and also claim every human being's equal rights.³⁷⁸ This interpretation, with a focus on equality, is prominent in Swedish medical care.

Annie Janvier and her research group have conducted research on ethical dimensions in neonatal care. Janvier et al. claim that studying decision-making can say something indicative about the view of human beings and about the value of human beings.³⁷⁹ The question on equality is one aspect that they discuss. However, they do not analyse this question from the perspective of human dignity; nevertheless, their research is of great interest to regard since they deal with similar topics as those seen in the narrative analysis.

Janvier et al. have claimed that decisions regarding the treatment of newborns in clinical care in some cases are made differently than if the child were older. Practices as well as recommendations within neonatal care suggest that neonates are regarded differently from a moral point of view, according to the authors. They exemplify this by describing a situation in neonatal care where a child has a condition with an uncertain outcome. However, experience of children with a similar condition shows that some of these children have had a good outcome. This prognosis is a justified basis for withdrawal of treatment in neonatal care, while in the case of treatment of an older child in the same situation, uncertainty of outcome and the possibility of a good outcome would lead to continued treatment. How to proceed with the treatment of an older child would not be a case of deliberation.³⁸⁰ So treatments which are routinely given to older children are optional for neonates, and the

³⁷⁸ Andorno, Roberto: "Human Dignity and Human Rights as a Common Ground for a Global Bioethics", p. 229.

³⁷⁹ Janvier, Annie, Bauer, Karen Lynn and Lantos, John D.: "Are Newborns Morally Different from Older Children?", in *Theoretical Medicine and Bioethics* Vol. 28, No. 5, 2007, p. 420. Annie Janvier is a neonatologist and has led research on ethics and neonatal care on the particular subject of the view on the neonate.

³⁸⁰ Op. cit., p. 419.

authors claim that these practices suggest that the lives of newborns are valued differently than the lives of older children.³⁸¹

In my narrative analysis, attention was drawn to a situation where the child is treated, since medical assessment has determined that the child will benefit from treatment. At the same time, the practitioners point to the importance of listening to the parents' views and opinions about the treatment of their child. The practitioners are willing to continue treatment for the child if that is in agreement with the parents' decision, but on the other hand, the practitioners are also willing to alter that decision if the parents disagree with a particular treatment suggested. This can result in different outcomes for a child, depending on the parents' view of the situation.

In the narrative analysis, a specific situation concerned a child whose mother eagerly asked the physician not to be proactive in the medical treatment. However, had the parent been persistent and it had been a child much longed for then the medical treatment would instead have been more proactive.

Janvier et al. draw attention to similar procedures as have been presented in the narrative analysis. They point to what is sometimes referred to as 'precious children' and they describe how neonatologists are prepared to intervene more intensively if the circumstances of the parents are taken into consideration, for example if the mother is older and the chances of getting pregnant again are rather small. Janvier et al. interpret this situation in the following way: "Such a phenomenon suggests that the value of a baby's life is determined, in part, by the family context into which he or she is born."³⁸² Janvier et al. draw the conclusion from their research that the different practices which they have described indicate that the moral status of a neonate seems to be between the moral status of intrauterine life and the moral status of extra uterine life. This distinction is made due to the connection between human rights and extra uterine life, where birth is the dividing line.³⁸³ Janvier

³⁸¹ Op. cit., p. 420.

³⁸² Op. cit., p. 418.

³⁸³ Op. cit., pp. 419-420.

One can also compare this to the guidelines from the European Academy of Paediatrics (the ethics working group of the Confederation of European Specialists in Paediatrics) where it is claimed that a child who is born has a right to life and human rights, and the confederation has developed guidelines concerning ethical dilemmas in neonatology. Some of the recommendations say that: 1) Every human individual is unique and has the right to live its own life. 2) Decisions should not be influenced by personal or social views on the value of life or absence thereof held by the caregivers.

et al. understand the treatment of neonates to indicate that the neonate is recognised as more than a foetus, since it is not seen as part of the woman's body over which she is autonomous, but on the other hand, the neonates are not recognised as older children, in which case the child's human rights are respected on their own, regardless of the parents' views.

This discussion can also be understood through the norm-critical perspective of Judith Butler. An important aspect of Butler's discussion is that certain epistemological frames form the understanding of what qualifies as (human) life. As the word 'frame' suggests there is a certain normative spectrum within which a life can be interpreted. If it is in alignment with the norms of the frame, then a life is in correlation with the understanding of what constitutes that which Butler defines as a grieveable or a liveable life.³⁸⁴ These frames are certain norms, and like all norms they steer the understanding regarding which life should be recognised. These frames are also expressions of power since they form what is considered to be a life, although the frames can be criticized and renegotiated.³⁸⁵

From the perspective of dignity one can regard the situation in neonatal care in terms of the child's dignity being intrinsic or attributed. In the intrinsic sense, dignity is connected to equal dignity and equal rights. In an attributed sense, on the other hand, dignity is dependent on others' recognition of the child. Dignity in this sense is conferred to others through acts of attribution.³⁸⁶ It is a valuation of the other that forms the basis for that person's dignity. In the narrative analysis this can relate to the circumstance where the parents' wishes, or as have been described as 'appeal', are stronger than those of the child. The problem that can appear is therefore that a severely ill child, where the medical assessment determines that it is not in the child's interest to

3) Ending life intentionally is not permitted, but it is permitted to give medical treatment which reduces suffering, even if that will hasten death.

Sauer, Pieter et al., "Ethical Dilemmas in Neonatology: Recommendations of the Ethics Working Group of the CESP (Confederation of European Specialists in Paediatrics)", in *European Journal of Pediatrics* Vol. 160, No. 6, 2001, pp. 364–68.

³⁸⁴ Butler, Judith. *Krigets ramar: när är livet sörjbart?*, p. 13. When Butler discusses the frames of human life she does so from a norm critical perspective, especially in relation to war, but I find her way of discussing these frames as important in the analysis.

³⁸⁵ Op. cit., pp. 16-17.

³⁸⁶ Sulmasy, Daniel: "Dignity and Bioethics: History, Theory, and Selected Applications", p. 473.

continue treatment, can be overruled by the parents' wish to continue treatment. In that case one could regard the child not to be respected, since the decision is not taken regarding to that individual but only dependent on the parents.

Wai Chee Dimock has analysed some of the problems which dignity in an attributed sense can give. He says:

[...] dignity is not just self-executed and self-validating; instead, it is dependent on the validation rendered by others, the tribute that they pay in acknowledgment of our high standing. Dignity in this sense – as something that requires outside proof, outside backing that has to be supplied by other people – is obviously much more problematic, since it runs the dignified person from an autonomous individual into a relational dependent, a recipient of the respect that he might or might not get.³⁸⁷

Even though Wai Chee Dimock points to an important perspective, the abstract ideal, namely the intrinsic dignity of every human being, the situation in neonatal care is always that the child is a 'relational dependent'. Our vulnerability through dependence on others is an issue which has appeared several times in the dissertation. There are few other, if any, situations in health care where the relational can stand in such a stark contrast to the independent as in neonatal care. On the other hand, it has also been pointed to the moral response that one's vulnerability and dependence can be thought to create.

Certain decisions in the medical treatment of neonates do raise questions regarding neonatal care and dignity. I have pointed to instances of medical treatment of neonates where the recognition of a child's dignity in an intrinsic sense can be questioned. In other words, one can point to situations where the neonates do not seem to be included within certain normative frames that suggest who should be recognised as an individual with equal intrinsic dignity; or to use the words of Janvier et al., the moral status given to extra uterine life does not seem to be applicable to all neonates.

At the same time one can also discuss respect for intrinsic dignity in terms of respect for autonomy, which I have previously discussed. The child in neonatal care is one of many in health care who does not have

³⁸⁷ Dimock, Wai Chee: "High and Low", in Waldron, Jeremy: *Dignity, Rank, and Rights*. Dan-Cohen, Meir (ed.). The Berkeley Tanner Lectures. Oxford University Press, New York, 2012, pp. 123-124.

autonomy. If one would agree with a reductionist view on dignity, like Macklin has shown, the child would not be regarded to have dignity. Or as discussed by Carter Snead in stating:

[...] under Macklin's approach, human dignity can be diminished by restraints on autonomous choice wrought by disease, disability, or coercion [...] Lives characterised by radical dependence and vulnerability would, according to this view, be undignified. Similarly, people who lack the cognitive capacity for free choice – young children, the mentally disabled, and individuals suffering from dementia – do not possess human dignity in any measure. Conversely, those individuals who have the strength, intelligence, and means to exercise robust free choice possess human dignity in abundance.

The newborn child does not have autonomy but can still be regarded to have intrinsic dignity. However, the parents to the child should also, in respect for their dignity, be respected in their autonomous choice. However, one can also raise concerns regarding what respect for autonomy means in health care. In the earlier discussions on I pointed to Fiona Randall's description of modern health care, where she is very critical of how autonomy within health care has come to be approached, since autonomy has to some extent come to be equated with fulfilment of a person's wishes. What the patient desires becomes equated with respect for autonomy, and Fiona Randall's discussion concerns the danger of staff merely becoming an agent of someone else's desires.³⁸⁸

The question on intrinsic dignity and equality in these situations can also be regarded from a socio-ethical level. In the results of the narrative analysis I concluded that the physicians rejected the idea of basing their decisions on societal attitudes. However, I find it interesting to note and discuss the fact that concerns regarding societal interests appear in the narratives, even though they do so in a negative sense, i.e., as a rejection of what should influence their decision. The experiences of families who live with a seriously ill child and who do not receive the help and support needed from society are taken into consideration in the narrative analysis. As one of the interviewees said:

And then you have to consider whether society is really prepared for these kinds of children too? Not that you... It's OK that we do our best and the children survive but might be damaged. Then they leave the

³⁸⁸ Randall, Fiona: "Autonomy, Dignity, Respect, and the Patient-Centred Approach", p. 54.

hospital and the parents are left quite alone with a severely injured child. I think and I have heard from certain parents that they really have to fight for their children. Unfortunately the same is true in society.

In my interpretation, the signals from society – most certainly not in policy, but in practice – in some cases, have been that it does not provide the help and support needed and that the family will run the risk of being economically and socially exposed. In my opinion, these signals from society, concretised in a family's own situation and experience, point to a view that decisions about health care are situated in a certain context. How the particular physician decides to act – in accordance with, or in opposition to what they understand as the societal attitude – is, however, another matter. Nevertheless, it is not too farfetched to consider a situation where the physician, faced with a difficult decision, can consider questions like: Will this family get help if their child survives? Can this family, which seems to already be socio-economically distressed, also handle a seriously ill child? What is really the best interest of this child from a contextual point of view? However, I would certainly not imply that the physicians would act upon these considerations.

Lisa Sowle Cahill has pointed out that there is a strong connection between the societal context and the individual's health and welfare. Cahill underlines the fact that we cannot talk about a real choice for a caretaker if the caretaker is not absolutely certain that there are resources which can support the patient and the family, for example publicly financed assistance.³⁸⁹ Cahill, in her discussion, points to the situation for many caretakers who often have inadequate access to support from society.³⁹⁰

The Swedish EXPRESS study showed that on a group level it is more common that extremely preterm children have neuro-psychological defects such as autism or impaired vision. In older years, extremely preterm children have shown a higher risk for heart failure and diabetes, although this is on a group level and can vary individually.³⁹¹ The two neonatologists, Hugo Lagercrantz and Lena Jacobson, wrote an article and voiced a concern regarding the follow-up and societal support of

³⁸⁹ Cahill, Lisa Sowle: *Theological Bioethics: Participation, Justice, and Change*, p. 98.

³⁹⁰ Op. cit., p. 80.

³⁹¹ Fellman, Vineta et al.: "One-Year Survival of Extremely Preterm Infants after Active Perinatal Care in Sweden".

these children. The care they receive from the neonatal care services is world-leading, but afterwards the families are left on their own they claimed.³⁹² The authors claimed that society needs to increase support, for example regarding special needs education, but since resources are scarce and these children often lack a distinct diagnosis, they risk not getting access to support and rehabilitation.

Or as Eva Kittay states, when claiming that a society which is “committed to the equal dignity of its members must be committed to providing resources for disabled people to participate in all areas of human life.”³⁹³

Inflorescent dignity

Inflorescent dignity, the last of the tripartite characteristics of dignity, has been much discussed in current debate. In this sense, as described earlier, dignity is referred to persons’ moral character and those who flourish, those who express virtue.³⁹⁴ In the beginning of the dissertation I discussed Gilbert Meilaender’s theological discussion on dignity, and now an examination of the meaning of inflorescent dignity from his position will be carried out. This will stand as one example of how inflorescent dignity can be understood and how it can relate to certain perspectives from the narrative analysis. Meilaender distinguishes two interrelated senses of dignity, namely human dignity and personal dignity; the latter adheres to equality, but here I will only discuss his view on human dignity.

As a short recollection of Meilaender’s view on human dignity one can mention his view on human nature. Meilaender describes his view on human dignity with the following words: “[...] human dignity is the dignity of a particular sort of creature, who is neither the ‘highest’ nor the ‘lowest’ sort of creature we can imagine.”³⁹⁵ Humans have, according to Meilaender, a particular place in creation as ‘neither beast nor God’ but ‘in-between’. Human nature is directed to God, through the

³⁹² Jacobson, Lena and Lagercrantz, Hugo: ”Extremt för tidigt födda måste få hjälp senare i livet”. *Dagens Nyheter*, 3 Oct, 2011.

³⁹³ Kittay, Eva: “Equality, Dignity and Disability”, p. 99.

³⁹⁴ Sulmasy, Daniel: “Dignity and Bioethics: History, Theory, and Selected Applications”, p. 473.

³⁹⁵ Meilaender, Gilbert: *Neither Beast Nor God: The Dignity of the Human Person*, p. 4.

soul, and therefore higher than the beasts.³⁹⁶ It is the striving towards God that characterises a flourishing life and some individuals do this to a higher degree than others, according to Meilaender.³⁹⁷ He describes this as: “[...] they offer an image of the flourishing of our full humanity. In so flourishing they display what I will call human dignity.”³⁹⁸

According to Meilaender, some individuals also lack those characteristics which mark human dignity. They do not display human dignity, which means that they do not live a life in accordance with human nature as a creature ‘in-between’. Let us also remember that Meilaender does not highlight a certain characteristic as specific for humanity (for example rationality), but that Christian and Jewish traditions inform us about what it is to live a life in accordance with human nature. So who are these individuals who “lack the dignity that characterises genuinely human life”?³⁹⁹ They are, for example, those who are “profoundly retarded”, those who have “achieved little” or those who “suffer from dementia”.⁴⁰⁰ This statement from Meilaender is, in my opinion, complicated. Why cannot an individual who has a severe handicap live a life in accordance with our nature as ‘neither beast nor God’, with a telos of striving towards God? What are the underlying claims of what human nature involves? Is it human excellence that Meilaender actually means? Meilaender points to the idea that Christian and Jewish traditions inform about this human nature, but it is not clear what this means, since these traditions point to different ideas. However, it is clear that human beings with severe illnesses, such as newborns with the severe illnesses as described in the narrative analysis, are not to be considered as displaying human dignity in Meilaender’s sense. The seriously ill child could be identified as one of those who in the least way has developed what is characteristically human, or can be understood as someone who may never have gained human dignity.⁴⁰¹

I regard it to be problematic that when identifying human dignity as connected with dignified life in the sense that Meilaender does, some individuals, often those who are sick or disabled, will be excluded. In my opinion, this view on human dignity highlights certain impairments

³⁹⁶ Op. cit., p. 24.

³⁹⁷ Op. cit., p. 17.

³⁹⁸ Op. cit., p. 4.

³⁹⁹ Op. cit., p. 7.

⁴⁰⁰ Ibid.

⁴⁰¹ Op. cit., p. 87.

as not being in accordance with human dignity; it excludes certain human life and uplifts other. This creates an ideal of being human which is not based on human vulnerability but on human excellence, and in doing so creates and reaffirms a strong connection between human dignity and excellence and virtue.

Conclusion

The narrative analysis in this chapter concerned decision-making in neonatal care. In the narrative analysis attention was drawn to that decision regarding ending life-sustaining treatment could be made with from either the child or not exclusively from the child but social aspects were regarded. In the analysis I have discussed the results in relation to three sense of dignity namely; intrinsic, attributed and inflorescent. The different meanings of dignity lead to different understandings with regard to who ought to be recognised and respected.

5. Human Dignity, Vulnerability and Responsibility

It would be no understatement to suggest that the discussion on human dignity over the past two decades has turned out to be an engaging one. It has sometimes evoked different and contrary perspectives, and as I have discussed in this dissertation, the debate can at times even be described as polemic. However, in my view, this debate has been important. Perhaps it has even led to necessary scrutiny of the concept and principle of dignity, as well as its practical implications for health care. In this dissertation I have suggested that important insights into dignity can be obtained from a discussion which is empirically enriched. In this chapter, I will further explore the results of this discussion.

The overall aim of this thesis is to formulate an empirically-informed and context-sensitive constructive proposal on human dignity, and to show how qualitative research could concretise and challenge conceptions of the issue. In terms of fulfilling this aim, one of the research questions which has guided the study involves what is meant by the concept and principle of human dignity. Throughout the work, the principle of human dignity has gradually become a particular focus. However, in this chapter I will also discuss the meaning of dignity, even though the discussion is related to my results concerning the principle.

Throughout the dissertation I have also analysed theoretical questions on dignity in close dialogue with the results from the qualitative research. This has led to a critique of certain theoretical perspectives in the light of the results of the empirical material. This chapter will summarise and further this discussion.

I will also analyse the implications of a constructive proposal on human dignity for medical-ethical concerns, and this discussion will also be furthered in the chapter.

A Bakhtinian understanding of the self in relation to a Kantian perspective on humanity

In the analysis on dignity, the theoretical perspectives of Kant and Bakhtin have been discussed. There are interesting similarities between their perspectives, but also clear differences which will now be further discussed and compared.

The understanding of human dignity is closely related to a view on what it means to be a human being. As Douglas Meeks said: “To be able to say what dignity is would be to describe the fundamental meaning of being human”.⁴⁰² In the dissertation I have discussed the theoretical perspectives of Kant and Bakhtin. They both give important insights into the understanding of human beings as moral beings, and the human capacity for morality. However, essential differences can also be found between their perspectives.

Kant’s epistemology has implications for his understanding of the capacity for morality and the human being as a moral being. Human beings are free, in a moral sense, and can act under the law which they themselves have formulated. Autonomy is one of the characteristics of humanity, as is rationality.⁴⁰³ Rational beings can distance themselves from their inclinations and act instead as their reason dictates.⁴⁰⁴ This characterisation of humanity within the person is central to understanding Kant’s perspective of dignity; the word respect can be used in terms of humanity in ourselves and others.⁴⁰⁵ In this sense a person’s dignity is not attributed but intrinsic. In my view, Kant offers an interesting perspective on dignity by suggesting that humanity should be respected in every being. This is categorical and hence binding for the will. Bakhtin also discusses this categorical aspect, though his view differs from Kant’s. Bakhtin understands it instead through a discussion on answerability. The Bakhtinian view on the self and on responsibility can provide important keys in a discussion on dignity, even though Bakhtin himself does not discuss dignity as such.

The Kantian view on humanity, characterised by autonomy and rationality, is, in effect, an opposite perspective to the Bakhtinian view of the self. The Bakhtinian view does not offer any theoretical analysis on

⁴⁰² Meeks, Douglas M.: “Introduction”, p. ix.

⁴⁰³ Kant, Immanuel: *Groundwork of the Metaphysics of Morals*, p. 46 (Ak. 4:434).

⁴⁰⁴ Kant, Immanuel: *Critique of Practical Reason*, p. 27 (KpV 5:30).

⁴⁰⁵ Kant, Immanuel: *Groundwork of the Metaphysics of Morals*, pp. 47-48 (Ak. 4:436).

the autonomous self, if autonomous can be taken to mean the independent self. This concept is unfamiliar to him. A central aspect of Bakhtin's discussion suggests that the self is always related to the other and formed by the other. For Bakhtin, the self is understood as interdependent and not in any sense independent, and cannot be formed independently of others. There is no autonomous self which is independent of relations with others. Instead, the self is defined in terms of its response to others. Clark and Holqvist describe this as follows:

"My self is that which through such performance [the deeds I perform] answers other selves and the world from the unique place and time I occupy in existence."⁴⁰⁶

Bakhtin's view of the self is clearly related to, and dependent on his discussion of a person's unique place in being; this is how someone sees the world. This means that individuals, from their (own) position, can never see themselves but only the other. One is therefore dependent on the other since the other enables an individual to view him/herself. This is a radical understanding of the importance of interdependence, stressing that alterity is not threatening but absolutely necessary. It is only through alterity that I can view myself.⁴⁰⁷

I consider the Bakhtinian understanding of the self to form an interesting contrary perspective to a Kantian understanding of the view of humanity as characterised by autonomy. For Kant, we should never treat humanity in ourselves merely as a means but always as an end in itself. It is possible to agree with such a strong principle on dignity but nevertheless raise concerns about Kant's view that autonomy forms the basis for respect. I shall return to this discussion later in this chapter.

A Bakhtinian view, in my understanding, also challenges a very common view within medical ethics and health care where respect for dignity is sometimes interpreted exclusively as meaning respect for autonomy, in the sense of independence. The Bakhtinian view points to

⁴⁰⁶ Clark, Katerina and Holquist, Michael: *Mikhail Bakhtin*, p. 64.

⁴⁰⁷ Regarding the view on alterity, it is interesting to compare the difference between Bakhtin and Levinas. For Levinas, alterity is something to be extinguished, assimilated or domesticated, and this view creates an ethical problem for him. Thus, ethics for Levinas is to refrain from the urge to violate the other in any way. Instead, he suggests 'the other' be allowed simply to be 'the other'. Bakhtin does not share Levinas' problematisation of the relation between the self and the other, and instead sees the other as 'a friend', '*drugoj*'. For Bakhtin, as noted above, alterity is viewed as necessary for forming of the self.

the importance of recognising the self in terms of relations and interdependency, and suggests that human beings cannot manage without this perspective; alterity is central to forming the self. A discussion on the interpretation of autonomy and how it is related to interdependence is incorporated into the following discussion on the principle of human dignity.

Respect for dignity in terms of an understanding of respect for autonomy and the vulnerable other

The principles which should guide medical ethics are the subject of an ongoing discussion. The Biomed project suggested that, alongside dignity, the principles of autonomy, integrity and vulnerability should be taken into consideration in medical-ethical concerns.⁴⁰⁸ In this dissertation, vulnerability and autonomy have not been discussed as separate principles. Instead, I have discussed a principle of dignity which involves respecting a patient's autonomy, but – and this is a central claim in the thesis – in respecting the patient's autonomy, vulnerability in its different forms also has to be taken into consideration. Since the research is situated in a specific context, certain perspectives have inevitably become central, specifically the importance of human vulnerability.

Vulnerability was a central observation in the narrative analysis and it has been discussed in two different forms: inherent vulnerability and situational vulnerability. When vulnerability is understood as an inherent condition of all human life, it makes the fragility of human beings more visible. They are susceptible to conditions such as illness and death, for example, which are shared human experiences. It is impossible for people to safeguard themselves from circumstances and experiences in life which do them harm.⁴⁰⁹ As such, vulnerability is an aspect

⁴⁰⁸ Dahl Rendtorff, Jacob and Kemp, Peter: *Basic Ethical Principles in European Bioethics and Biolaw: Vol. 1, Autonomy, Dignity, Integrity and Vulnerability*. This can be compared to Beauchamp and Childress, who address the principle of autonomy but only discuss vulnerability in the context of vulnerable populations or vulnerable individuals, people who are, due to different circumstances, incapable of protecting their own interests. Beauchamp, Tom L. and Childress, James F.: *Principles of Biomedical Ethics*, pp. 90-91.

⁴⁰⁹ Mackenzie, Catriona, Rogers, Wendy and Dodds, Susan: "What Is Vulnerability, and Why Does It Matter for Moral Theory?", p. 4.

of the human condition, part of our humanity. The previous discussion has also noted that inherent vulnerability is linked to situational vulnerability. By this I mean that, although humans are inherently vulnerable, there are certain situations where their vulnerability is apparent in a specific sense. This dissertation has discussed situational vulnerability mainly in terms of the fact that it is invoked by dependence. I have found Susan Dodds' description of dependence useful as a form of vulnerability. Patients' inherent vulnerability means they require care, and this, in turn, makes them dependent. Dodds defines this as follows: "Dependence is vulnerability that requires the support of a specific person (or people) – that is, care".⁴¹⁰ In this study, this is explicitly related to healthcare situations where patients' dependency is imposed on them by their health situation. They are dependent on the care of others and on the improvement of their condition, which makes them dependent on others to meet their own basic needs.

The importance of autonomy in medical care is not disputed.⁴¹¹ Our society expects patients to be autonomous. Joel Anderson formulates this as follows: "[...] everyone is under pressure to become autonomous, in this sense of developing the skills to make complex choices, guided by a clear understanding of what one really cares about."⁴¹² In the analysis it was proposed that to respect a person's dignity is to respect her autonomy, but respecting someone's autonomy must also involve recognising the other as both vulnerable and autonomous. I have suggested that ignoring the fact that patients are vulnerable (both inherently and in terms of situation, but particularly in the latter form here) does not support the patient in making autonomous decisions. If, instead, we go beyond a dichotomy between vulnerability and autonomy, and recognise that a person is both vulnerable and autonomous, it will help develop important perspectives on what respect for dignity can involve, and what it can mean.

Autonomy has often been understood as closely connected to independence, where a person forms his or her own ideas, and makes decisions independently of others. However, in medical practice, as shown above, dependence is more significant than independence. Patients can

⁴¹⁰ Dodds, Susan: "Dependence, Care and Vulnerability", pp. 182-183.

⁴¹¹ O'Neill, Onora: *Autonomy and Trust in Bioethics*, p. 2.

⁴¹² Anderson, Joel: "Autonomy and Vulnerability Intertwined", in Mackenzie, Catriona, Rogers, Wendy and Dodds, Susan (eds.): *Vulnerability: New Essays in Ethics and Feminist Philosophy*. Oxford University Press, New York, 2014, p. 153.

clearly be independent in some respects and not others. I have indicated that patients are dependent on information from medical staff in order to make a decision, which they do not do independently of others. Decisions are made in interaction with others. For patients to be able to exercise their autonomy, medical care needs to be formulated to support this. Patients do not have access to information concerning their illness and the options for treatment, so their ability to make an autonomous decision is therefore closely bound to those who are providing care and treatment. Autonomy in this sense is a co-constructed process; although the final decision is taken by the patient, the process leading up to a decision is, in my view, a co-constructed process involving information from staff.⁴¹³

I have indicated that it is important to move beyond a dichotomy between vulnerability and autonomy in order to form a context-sensitive understanding of what respect for a patient's dignity can mean. A principle of dignity in this sense can be described as respect for the other in terms of both vulnerability and autonomy. This also has implications for treatment in health care. Patients' vulnerability, in the form of situational dependence, underlines the importance of staff promoting patients' autonomy, and their duty to do so. In my view, autonomy and vulnerability are interconnected, and if medical staff fail to recognise this, the outcome can be very problematic for the patient. Patients are both vulnerable (inherently and in terms of their specific situation), in addition to which staff can promote or undermine a patient's ability to make autonomous decisions. This demands that staff take each patient seriously, as staff are, to a certain extent, co-constructors of a person's ability to make autonomous decisions, and this demands they show respect for each patient and give an adequate response.

A principle of human dignity - sharing human vulnerability

As noted throughout the dissertation, respect for dignity has often been interpreted as respect for autonomy, and has in some cases been interpreted exclusively in this way.⁴¹⁴ However, the discussion in the dissertation has claimed that this type of reduction tends to diminish central

⁴¹³ Anderson, Joel: "Autonomy and Vulnerability Intertwined", p. 139.

⁴¹⁴ Macklin, Ruth: "Dignity is a Useless Concept".

understandings of what respect for dignity can mean, and can make these forms of understanding invisible. Instead, it has been proposed that to respect someone's dignity can mean sharing human vulnerability. This is a perspective which could be of great importance in medical care and will be elaborated further in this discussion.

In recent years, many important empirical studies have been conducted on how patients experience their dignity. The focus of this research has been the psychological dimension of dignity, and some studies indicate that patients experience and express feelings of diminished dignity as a specific result of their vulnerability. Vulnerability is to be understood as affecting a patient's sense of the self in such a way that they consider themselves to have suffered a loss of dignity. It can also involve situations where the way members of staff treat a particular patient results in their feeling this type of loss. In these studies, dignity tends to be described from a psychological perspective, where it is, in fact, more related to self-esteem. In this sense, it can be described as something which can be lost. On the other hand, dignity can be described as an ethical ideal, as something intrinsic which can never be lost.⁴¹⁵ I believe these discussions have contributed important insights into how vulnerability can affect people's understanding of themselves, in the sense that people can describe themselves as having lost their dignity. This involves a real sense of dignity being lost, stolen or taken away. However, my focus is not on a psychological dimension of dignity but on dignity as a moral principle. A more pertinent way of framing the question in terms of this dissertation has been described by Pellegrino in his discussion on dignity: "Has my vulnerability diminished the respect I deserve as a fellow human being?"⁴¹⁶ This is a central question in medical care where, as has been seen in this dissertation, human vulnerability intensifies during illness. Pellegrino highlights the fact that our vulnerability, such as when we know for certain that our illness will lead to death, or when we are dependent on others for care, can influence how others respect our dignity. As an ethical ideal, a person's intrinsic dignity can be understood as a value which cannot be removed, and which cannot be lost or degraded. However, this ideal is not always

⁴¹⁵ Pols, Jeannette: "Through the Looking Glass: Good Looks and Dignity in Care", in *Medicine, Health Care and Philosophy* Vol. 16, No. 4, 2013. Delmar, Charlotte: "The Interplay Between Autonomy and Dignity: Summarizing Patients' Voices".

⁴¹⁶ Pellegrino, Edmund D.: "The Lived Experience of Human Dignity", p. 522.

adhered to in reality, and the dignity of the individual is not always respected or recognised. This is the essence of Pellegrino's definition, namely that in social interaction individuals are exposed to how others choose to respect or not respect them. For patients in particular, this is always a matter of uncertainty. It has also been highlighted that vulnerability can be a specific cause of disrespect towards individuals.

In my discussion on the principle of human dignity, I have shown that an understanding of the principle involves being prepared to share vulnerability. One of the interviewees described it in the following words:

To sit down and remain in this room of despair, that is dignity. In other words, to dare to remain in powerlessness. That is, to somehow recognize the limitation and powerlessness of us humans, and to dare to remain in that sometimes.

This highlights the importance of sharing vulnerability, an act which underlines the fact that all humans are vulnerable. This is the opposite of an act where others observe a patient's vulnerability. This type of situation can have the opposite effect of objectifying a person as a patient, making them 'the vulnerable' compared to others who are not considered vulnerable. The focus is on participation, which also involves recognising one's own vulnerability; vulnerability can never be shared from above. I have described this in terms of adopting 'a position of relative powerlessness', which involves indicating to the patient that others do not shun the human experience of vulnerability and that, on the contrary, the patient is still worthy of respect. The patient's dignity is recognised and respected even in this situation. For Kant, respect for dignity involves never considering the humanity within a person and never treating vulnerability in others as a means but always as an end. In my understanding, in contrast, humanity is characterised to a great extent by its inherent vulnerability.

In this dissertation, an interpretation of respect for dignity involving sharing vulnerability was discussed primarily in relation to concerns regarding the end of life. Although these results refer to a specific context, I believe this principle of human dignity can also be applied to other areas of health care. The medical treatment of patients always involves a situation where our common vulnerability to sickness impedes us. However, in the case of many patients this situation might not be described as severe. In very severe cases of medical treatment, on the other

hand, situations can be described as life-changing for the patient or even a crisis situation. Examples involve when patients receive a diagnosis of a severe illness where the prognosis is uncertain, or when they are diagnosed of a disease for which there is no cure. It can also involve situations where a person receives information about an accident involving relatives who are in intensive care. These situations are characterised by inherent vulnerability where the victims are powerless in terms of facing severe illness and death. Respecting human dignity in these situations by sharing vulnerability can mean something different depending on the situation. This dissertation has taken the view that an appropriate response to patients at the end of life involves being present not only in a physical sense but in a participatory one, and it has been emphasised that the patient should not feel abandoned. What this can mean in a concrete sense in different healthcare situations might differ. However, the central aspect of this principle of dignity in terms of sharing vulnerability can generally be understood as not abandoning the patient in a vulnerable situation, and empathising with the patient in terms of feeling their powerlessness with them in the wake of illness and death.

A Christological perspective on a principle of dignity

In the dissertation, human dignity has been discussed as a principle involving an understanding of sharing vulnerability. This has also been analysed from a theological perspective.

In terms of how dignity can be interpreted in the teachings of Jesus, the human being as described in the parables is often a focus of attention. Jesus does not single out those with lofty human ideals but promotes a perspective where human vulnerability becomes the centre of attention. Collste indicates that Jesus' view on the people he met, often the poor and those identified as social outcasts, completely reverses the perspective on who is worthy of respect. Collste suggests that Jesus' preaching claims equal dignity for everyone, regardless of honour or rank. Collste also points to the fact that, in the society where Jesus lived,

individuals were valued in direct relation to their place in the social hierarchy.⁴¹⁷ In this sense, the preaching of Jesus can be interpreted as turning away from what is referred to above as an attributed meaning of dignity, reserved for those with a specific rank or position in society.

One parable in particular which points to human vulnerability has been interpreted by some as illuminating Jesus' view on dignity. This is the parable of the Good Samaritan, and Paul Valadier especially draws on the narrative of this parable in interpreting Jesus' view on human dignity. He sees a pattern where human dignity in the teachings: "[...] is not an attribute peculiar to persons and their singularity; it is a relationship, or rather it manifests itself in the gesture by which we relate to others to consider them human, just as humans as we are, even if their appearance suggests non-humanity, indeed inhumanity."⁴¹⁸ In my Christological perspective in the discussion on a principle of dignity, I have drawn on a theological interpretation of Christ suffering on the cross. Christian theology involves a plethora of ways of understanding the views of Christ. Dietrich Bonhoeffer points to one of these in his description of Christ.

God consents to be pushed out of the world and onto the cross; God is weak and powerless in the world and in precisely this way, and only so, is at our side and helps us. Matt. 8:17 makes it quite clear that Christ helps us not by virtue of his omnipotence but rather by virtue of his weakness and suffering!⁴¹⁹

This agrees with theological perspectives on the cross, which attribute similar motives to Christ. They can be interpreted as those which appear in his teaching, where he does not pursue a high ideal in terms of humanity. He has himself becoming suffering man. In the Christian tradition the cross stands as a symbol for how God has been understood to be participating in human vulnerability and suffering. From a Christian perspective, I have underlined the theological understanding that Christ suffers with human beings, and is present in human vulnerability and suffering. He is not removed from human beings, but endures pain

⁴¹⁷ Collste, Göran: *Is Human Life Special?: Religious Perspectives*. Studies in Applied Ethics 5, Centre for Applied Ethics Linköpings universitet, Linköping, 1999, pp. 16-17.

⁴¹⁸ Valadier, Paul: "The Person Who Lacks Dignity", p. 55.

⁴¹⁹ Bonhoeffer, Dietrich: *Letters and Papers From Prison*, p. 465.

alongside them, and in one sense adopts “a position of relative powerlessness”. In this theological interpretation, the suffering Christ becomes a model for human dignity in the same way as God shares human vulnerability. It becomes an interpretive pattern for an ethical ideal involving respect for human dignity. As Johnson remarks: “In the midst of isolation the presence of divine compassion as companion transforms suffering, not mitigating its evil but bringing in inexplicable consolation and comfort”.⁴²⁰ I have in the discussion pointed to the important perspective of Christ act on the cross as standing as an interpretive pattern for a theological interpretation of a principle of human dignity. The cross stands as a symbol for God sharing in human suffering and pain. Its strongest interpretation does this idea get in Bakhtin’s philosophy where Christ must take a specific position in Being in order to show love and mercy towards the other.

Responsibility

I have discussed the understanding of responsibility from the perspective of Bakhtin as I considered Bakhtin’s philosophy to elucidate the narrative analysis. Bakhtin’s view of the self is closely related to his idea of an individual’s unique position in the world. If a person takes a position of me-for-myself, an answerable position, a problem can become something I ought to do, my responsibility, my task. Every person has a unique position, and when we are responsible we also admit our uniqueness, our unique place in Being. It is from this place that I respond to others, and I am responsible for how I respond to or answer others.

Peter Atterton indicates that, in the phenomenological tradition “[...] the meaning of something is not given to us in the manner of abstract theoretical knowledge but arises out of our *concrete*, non-theoretical dealing with the world.”⁴²¹ This view is representative of the work of Bakhtin and his understanding of ethics. For him, the deed rather than

⁴²⁰ Johnson, Elizabeth A.: *She Who Is - The Mystery of God in Feminist Theological Discourse*, p. 267.

⁴²¹ Atterton, Peter: “Dignity and the Other: Dignity and the Phenomenological Tradition”, in Düwell, Marcus et al.: *The Cambridge Handbook of Human Dignity: Interdisciplinary Perspectives*. Cambridge University Press, Cambridge, 2014, p. 276. Italics original.

principles take precedence. There is no alibi to be had from this answerable place. I have to take responsibility, and no one else can perform the ethical deed for me. This illustrates differences between a Bakhtinian and Kantian view which are interesting in terms of a discussion on human dignity. The questions on dignity revolve around what makes one person respect another, and what makes someone morally linked to another.

From one perspective, ethics are closely connected to rational deliberation, the different forms of categorical imperative where people reach some sort of insight into the logical necessity of the ethical principle by means of rationality. Individuals should always seek insight into respecting humanity in themselves and others as an end and never simply as a means, as this is a principle to which all rational, self-legislative creatures can adhere. The ethical principle can be formulated by anyone for anyone, and this universal aspect of the principle is significant. Respect comes from moral law and the person who formulates it. From the other perspective, ethics become a question of responsibility and cannot be caught in abstract principles, but the moral demand is connected to a person's unique position. I am a responsible, ethical subject and have to act from my unique position in relation to others. A person's responsibility is invoked when they meet the vulnerability of the other, when they are involved in a specific action, not a universalised form. Bakhtin's understanding of responsibility is always directed to the other, or as Elena Namli suggests: "When facing the vulnerability of the other, one's own unique responsibility is recognized."⁴²² If dignity were to be seen from a Bakhtinian view, it could be interpreted as relating to a concrete action. The respect of the other can be defined through the understanding of responsibility, where I am responsible for how I choose to answer the other, and where the other's vulnerability invokes my response, not any prior knowledge of the other, such as their ability.

In Bakhtin's work, the form of the normative is the focus of attention. However, in my discussion I have interpreted the responsibility to enact a specific situation in terms of health care. My discussion on responsibility has, in particular, emphasised presence, or sharing a vulnerable situation. It involves the responsibility of the other to share the vulnerable situation. This is how I analysed their specific response, and how they respected the patient's dignity. To respect a person's dignity

⁴²² Namli, Elena: *Kamp med förnuftet*, p. 37.

is to take personal responsibility and share vulnerability, not to refrain from this. Ruth Coates describes answerability in a similar way to my informants: “What can be accomplished by me cannot ever be accomplished by anyone else”.⁴²³ This is also a realisation that only I can act from this position, and that no one else can take my place. Responsibility was also described in negative terms: one should not leave, one should not abandon. Here I find similarities to Bakhtin’s description of no-alibi-in Being, which means that we cannot abdicate from our moral position. No one else can take my place and shoulder my responsibility.

One criticism which might be levelled at my interpretation of a principle of dignity is that respecting human dignity in this form is impossible in terms of health care. In the form in which I have come to understand it, the principle of human dignity underlines the importance of responding to patients in their situation by not abandoning them in their specific suffering and by not refraining from empathy with the patient in a vulnerable situation. In terms of health care, it is recognised that this particular patient-centred perspective cannot always be met, sometimes as a result of the organisational structure of the healthcare system. It can be the result of restrictions in terms of staff schedules, sometimes scarce economic resources or the fact that time with patients is not unlimited. In fact, at times, periods spent with them can be rather short. However, a principle of human dignity can also function as a critical tool towards and within a healthcare system.

There has been a debate in the Swedish healthcare system in recent years about whether economic efficiency and quantitative results are rewarded and encouraged at the expense of medical and ethical values,⁴²⁴ as some claim. Financial incentives, for example, have been criticised in relation to a patient-centred view. Patients are categorised according to a diagnosis, and certain types of diagnosis bring more funding to the hospital. The discussion has therefore indicated that certain types of diagnosis are more profitable than others. In other words, a patient can be regarded in quantifiable terms, and has a price. Sometimes healthcare authorities have rewarded the number of patients treated rather than the quality of the treatment provided, and in some

⁴²³ Coates, Ruth: *Bakhtin in Christianity*, p. 28.

⁴²⁴ Halldin, Jan: ”Vilken ledarstil krävs i vården”, in *Läkartidningen* 2016:113. June 2016.

cases this has meant that healthcare providers have only treated patients with mild illnesses rather than the severely ill.⁴²⁵

There has also been criticism of the one-sided focus on economic growth and production over the needs of patients in health care. The criticism has focused on the fact that healthcare staff concentrate on administrative tasks instead of making use of their time to take care of patients. This has also resulted in feelings of inadequacy and frustration from healthcare staff when they are not able to provide what they regard as good health care. It could even be claimed that economic incentives – where quantifiable results are rewarded and encouraged and where administrative tasks take up more and more staff time – is not in accordance with a principle of human dignity, at least not at all levels. Economic efficiency is not always consistent with a principle of human dignity in terms of sharing human vulnerability.

However, in my view, a principle of human dignity can help formulate a critique of certain tendencies in health care which other dominant ethical principles, such as a principle of autonomy, cannot fully meet. The principle of human dignity, with its focus on respect for the individual, can provide a framework for criticising a view which concentrates far too much on quantifiable results and financial efficiency, rather than on the individual patient. A human being cannot simply be reduced to a price; we must not simply commodify patients. This is also why a central principle of autonomy in health care is not enough, and a principle of human dignity is required. A principle which focuses narrowly on free choice cannot incorporate the moral requirements of a patient such as the ones which have been described above.

The meaning of dignity

Many researchers have discussed the different understandings of the concept of human dignity and indicated that this concept can be used in various ways.⁴²⁶ It has been noted throughout this dissertation that theorists differ not only on how the concept of dignity ‘can’ be understood, but also on the question of how it ‘should’ be understood. The question

⁴²⁵ Riksrevisionen: ”Primärvårdens styrning – efter behov eller efterfrågan?”. Stockholm, Riksrevisionen, 2014. RIR 2014:22.

⁴²⁶ See for example research studies such as Schroeder, Doris: “Dignity: One, Two, Three, Four, Five, Still Counting”.

of how dignity can be understood involves a descriptive examination. Good examples of this type of analysis include empirical studies which have analysed how patients and different groups working in health care use the concept of dignity. A conceptual study is then developed from the empirical material.⁴²⁷ However, Daniel Sulmasy has pointed to the importance not only of conceptual clarity, but discussion on which understanding of dignity can be considered “foundational from a moral point of view”.⁴²⁸ This leads to a normative question. He recognises that an understanding of dignity has implications for who should be recognised and respected, and what this recognition and respect ought to mean.

This dissertation has gradually focused prominently on the interpretation of a principle of human dignity, and a dominant perspective to emerge from the analysis of the empirical material involves vulnerability. The following inquiry therefore revolves around the contribution an understanding of human vulnerability can make to a discussion on the meaning of dignity.

The perspective of human vulnerability clearly involves challenges when dignity denotes what can be described as ‘elevation’ and ‘eminence’. Leon R. Kass notes that dignity has always conveyed something elevated, something deserving of respect. He says:

On anyone’s account, the idea of “dignity” conveys a special standing of the beings that possess or display it. Both historically and linguistically, dignity has always conveyed something elevated, something deserving of respect.⁴²⁹

Dignity, according to Kass, involves the idea of elevation. The concepts of dignity, elevation and respect are closely related in his understanding. This elevated status is the reason someone has dignity, and is therefore the reason one is deserving of respect.

Dignity as connected to elevation and eminence can also be seen in what earlier has been described as a vertical perspective on dignity. This idea meant that because humans have characteristics such as rationality, humans are superior to other creatures which lack these characteristics.

⁴²⁷ See, for example, Nordenfelt, Lennart: “The Concept of Dignity”. Jacobson, Nora: *Dignity and Health*.

⁴²⁸ Sulmasy, Daniel: “Dignity and Bioethics: History, Theory, and Selected Applications”, p. 474.

⁴²⁹ Kass, Leon: “Defending Human Dignity”, p. 308. Italics original.

This view has been criticised, and criticism has focused largely on how dignity is justified.

The following discussion will introduce another perspective which links dignity to eminence and elevation in human beings, not only in relation to how dignity is justified, but particularly in terms of the meaning of dignity. Cases presented as examples of this view on dignity, indicate that dignity can be acquired by moral effort, such as living a virtuous life. In other words, dignity is understood through virtue.

Two perspectives focusing on meaning, which involve a concept of inflorescent dignity, can be found in the work of Gilbert Meileander and the Stoics. Sulmasy considers inflorescent dignity to “[...] refer to individuals who are flourishing as human beings [...] Thus, dignity is sometimes used to refer to a state of virtue [...]”.⁴³⁰ Theologians such as Gilbert Meileander have focused on the importance of living a virtuous life, something they consider to be in accordance with human nature as revealed in Christian and Jewish tradition. In Meilaender’s understanding, some people behave in a way which is characteristically human, while others do not as seen in the previous chapter.⁴³¹ The Stoic account, as Cicero describes it, considers dignity to be closely related to human virtue as earlier seen:

[...] if we are willing to reflect on the high worth and dignity of our nature, we shall realise how degrading it is to wallow in decadence and to live a soft and effeminate life, and how honourable is a life of thrift, self-control, austerity and sobriety.⁴³²

There were individual differences in this sense; human beings could live their lives in a dignified way to different degrees depending on how well they reached the Stoic ideal. In the Stoic account of dignity, an individual who is living a virtuous life also has dignity. Or, as Sulmasy notes: “For him [Cicero], to have dignity was to have a merited degree

⁴³⁰ Sulmasy, Daniel: “Dignity and Bioethics: History, Theory, and Selected Applications”, p. 474.

⁴³¹ Meilaender, Gilbert: *Neither Beast nor God: The Dignity of the Human Person*, p. 7.

⁴³² Cicero: *On obligations (De officiis)*, p. 37 (1.106).

of respect from others because of one's excellence as a human being.⁷⁴³³ The Stoic concept of dignity could perhaps be described as referring to both attributed and inflorescent dignity. Attributed dignity has been described above as a value or worth which is conferred on someone as a result of their skill, position or power, for example.⁴³⁴ Since dignity is created in an act of attribution, it follows that if a person who is attributed dignity loses the characteristics on which this dignity was based, then his/her dignity can be lost.

However, it might be useful to consider this view of dignity and virtue in terms of an example from a contemporary discussion. Charles Foster's book *Human Dignity in Bioethics and Law* has been much appreciated and discussed. Foster identifies dignity with virtue. He starts with what he considers a concrete situation from the ward illustrating the meaning of dignity. He says:

A woman is dying of cancer. She is fearful of dying, and is in intense pain. Nonetheless she shows great fortitude. She is far more concerned about the welfare of her carers than she is about her own needs. She greets pain, fear and death with a smile. Whatever dignity is, she has it and displays it.⁴³⁵

Foster claims that important insights into the meaning of dignity can be found in situations where human beings are virtuous. In the example, the person displays dignity when she is capable of transcending her illness and, at the end of her life, focusses not on herself and her illness but on those around her. In the example, the severely ill and dying woman can be described as inherently vulnerable to illness and death. However this vulnerability is transcended. Through her virtue, the woman elevates herself above what could be expected from a person in this situation. Instead she "greets pain, fear and death with a smile". In transcending human vulnerability, dignity is acquired as a result of moral effort. Even in Foster's description of the meaning of dignity, the three concepts of dignity, elevation and respect seem to be closely related. As I understand his concept, it is virtue which is deserving of

⁴³³ Sulmasy, Daniel: "Dignity and Bioethics: History, Theory, and Selected Applications", p. 471. Although Sulmasy defines the Stoic account as more related to an inflorescent sense of dignity and only sometimes to an attributed sense, in my understanding the Stoic sense of dignity can be regarded also as a form of attributed dignity.

⁴³⁴ Op. cit., p. 473.

⁴³⁵ Foster, Charles: *Human Dignity in Bioethics and Law*, p. 4.

respect. It is not when a person gives voice to the despair brought about by human vulnerability that dignity is manifest. Quite the opposite. Moreover, in some cases, such as in the description by Foster, human vulnerability is even identified as something a person needs to transcend.

An interesting contrast to Foster's description can be found in the material for this dissertation, in the interview with Nils, which is presented in the discussion on a principle of dignity above. Even this refers to a situation at the end of life:

Nils: [...] a fourteen-year-old girl with a brain tumour together with her parents, and gradually getting worse you know. And the parents were at home taking care of her ... there is of course pain in that whole situation and you see their frustration and their grief and their despair, and also the despair of this teenage girl too.

In the interviews with hospital chaplains, physicians in palliative care and neonatal care, I did not encounter descriptions like Foster's concrete example from the ward of a dying person who "[...] greets pain, fear and death with a smile". When the discussion on the meaning of dignity is framed from a perspective of human eminence, understood here as virtue, other aspects such as vulnerability tend to be made invisible. If the conceptualisation on dignity, in the interpretation of virtue, is the determining then such a conceptualisation has implications for who we regard as deserving respect. Even when people are not transcending illness or limited by their inherent vulnerability to illness and death, they still have dignity. Roberto Andorno described the situation thus: "Either one is able to recognize the inherent dignity of human beings in the most vulnerable individuals, or will never really understand what dignity means".⁴³⁶ In situations which I have described, where patients express despair in the face of illness and death, they still deserve unconditional respect from the other, which I also showed in the interpretation of the principle of dignity as sharing vulnerability. In my understanding a more plausible understanding of dignity is if it is to a closer degree connected to vulnerability. Instead of a description of dignity where the concepts of dignity, elevation and respect are closely related, I find that a meaning of dignity which is context-sensitive could be understood through the connection between dignity, vulnerability

⁴³⁶ Andorno, Roberto: "The Dual Role of Human Dignity in Bioethics", p. 971.

and respect. This would include a meaning of dignity where one's dignity is recognised and respected regardless of the ability to live a virtuous life. This is a meaning of human dignity which calls for recognition and respect even in human vulnerability.

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