Exploring the Meaning of Medicine

A Reflection Upon Three Key Examples

Ástríður Stefánsdóttir

Dissertation towards the degree of Doctor of Philosophy

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UNIVERSITY OF ICELAND
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Exploring the Meaning of Medicine

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Abstract

This thesis explores the meaning of medicine and considers ethical challenges that arise when medicine's limits are tested as it enters new grounds. The methodology and argumentation used in the thesis can be described as a two-step process. In the first part, the author investigates three ethical examples representing current controversies on the limits of medicine. This is done in three peer reviewed articles. In the second part the focus of the discussion is on common themes visible in all of the three articles. By paying special attention to these themes important elements of the papers are teased out and the argumentation for them strengthened. Through this reflection it is possible to gain a deeper understanding of what medicine is and ought to be.

The three examples that are used to throw light upon medicine’s expansion are surrogacy, obesity, and fetal diagnosis. These examples were chosen mainly because they demonstrate this expansion and have all been in public debate in Iceland in the last decade. They have mainly been approached and discussed as medical issues. In three peer reviewed articles, these categorizations are questioned and the constructional forces in society are investigated to determine how they influence medicine's limits.

The second part of the thesis is an ethical reflection upon the discussion of the three key examples in the articles. When this discussion is investigated further, four common themes appear that reveal how medicine has the potential to be oppressive, especially toward already stigmatized and marginalized patients.

In the second part, the research question is, “When medicine enters new grounds, as described in the articles, it can deviate from its ends and inherent values. What characterizes this deviation and how can that knowledge be used to interpret the meaning of medicine?”

The four themes that are common to the key examples in the articles show how medicine can deviate from its ends and inherent values. The first theme shows how the medical description of the disease and the diagnosis gain a separate existence without a clear connection to the patient's experience. This diverging dichotomy undermines the patient's humanity as he is no longer at the center of the doctor’s attention. The second theme shows how overemphasis on biomedical science can cast a shadow on the patient as a human being. As a consequence, it enforces the tendencies described in the first theme and makes the patient more vulnerable.

The third theme regards the voices of people in marginalized positions. It shows how they are especially vulnerable towards trends in medicine that can undermine their humanity. The fourth theme is on social justice. It reveals the importance of viewing the patient relationally. If that is not done, medicine can lead to oppression and therefore social justice in health care is not respected.

Investigation of the themes above shows that they are interconnected. They reveal medicine as an endeavor with inherent uncertainty, unavoidable power imbalance, and finally, the dynamic core concept of “disease” that will never be accurately defined. These “ontological characteristics” of medicine make the harm described above prone to happen. It is, therefore, important to recognize these processes, described under the themes, in order to avoid them from causing harm to patients and groups of people.

It is necessary to ask how to address these processes that may lead medicine away from its ends and inherent values and ask how can we use that knowledge to interpret the meaning of medicine. Here, an interpretation of medicine as being three dimensional, i.e. based on science, with a clear vocation and inherent values, is proposed. Each dimension is described and the investigation of the themes is used to gain a more concise understanding of the meaning, ends, and inherent values of medicine. This approach, firstly, underlines the importance of a holistic view of medicine where its ends and inherent values are not marginalized. Secondly, the three dimensional model is introduced to argue for the importance of guarding a common core of medicine which can be referred to as a frame of reference in medicine's progress.

Ágrip

Þessi ritgerð rannsakar merkingu læknisfræðinnar og beinir sjónum að siðferðilegum álitaefnum sem vakna þegar læknisfræðin fer inn á ný svið og það reynir á mörk hennar. Aðferðafræðin og rökfærslan í ritgerðinni er sett fram í tveimur hlutum. Í fyrri hluta rannsakar höfundur þrjú siðferðileg dæmi sem varpa ljósi á núverandi umræðu um mörk læknisfræðinnar. Þessi umræða birtist í þremur ritrýndum greinum. Í síðari hluta ritgerðar er umfjöllunin um þessi þrjú dæmi í greinunum, skoðuð saman, hún yfirveguð og endurmetin. Með því að skoða sérstaklega hvað er sameiginlegt í umfjöllun um öll þrjú dæmin má setja fram fjögur þemu. Rannsókn á þeim dýpkar skilning á mikilvægum þáttum sem fjallað er um í greinunum og varpar betra ljósi á það hvað læknisfræði er og hvað hún ætti að vera.

Dæmin þrjú sem notuð eru til að varpa ljósi á útþenslu læknisfræðinnar eru: staðgöngumæðrun, offita og fósturgreiningar. Þessi dæmi voru valin þar sem þau hafa öll verið fyrirferðarmikil í opinberri umræðu á Íslandi síðastliðinn áratug. Þar voru þau skilgreind og ávörpuð sem læknisfræðileg álitamál. Í þremur ritrýndum greinum er þessi flokkun dregin í efa og jafnframt rannsakað á hvern hátt samfélagsleg öfl móta læknisfræðina og mörk hennar.

Í síðari hluta ritgerðar eru ofannefndar þrjár greinar yfirvegaðar saman til að greina hvað þær eiga sameiginlegt. Þessi athugun sýnir að í öllum þremur lykildæmunum sem greinarnar fjalla um má sjá fjögur sameiginleg þemu, sem afhjúpa hvernig læknisfræðin getur aukið á kúgun hópa sem þegar glíma við jaðarsetningu og stimplun. Rannsóknarspurningin í síðari hluta ritgerðar er: Þegar læknisfræðin fer inn á ný svið, eins og lýst er í greinunum, getur hún vikið frá tilgangi sínum og innri gildum. Hvað einkennir þessar breytingar og hvernig getur sú þekking verið hjálpleg til að túlka merkingu læknisfræðinnar? Þemun fjögur sem sjá má í öllum lykildæmunum sýna hvernig læknisfræðin getur fjarlægst tilgang sinn og innri gildi. Fyrsta þemað fjallar um það hvernig sjúkdómsgreiningin og læknisfræðileg lýsing á sjúkdómnum öðlast sjálfstæða tilvist án skýrra tengsla við upplifun sjúklingsins. Sú tvíhyggja og það bil sem myndast á milli þessara þátta grefur undan mennsku sjúklingsins þar sem athygli læknisins beinist ekki fyrst og fremst að sjúklingnum sjálfum heldur fremur að sjúkdómnum sem einangruðu fyrirbæri. Undir öðru þemanu er rakið hvernig ofuráhersla á vísindi getur varpað skugga á mennsku sjúklingsins. Það eykur þær tilhneigingar sem lýst er í

fyrsta þemanu og gerir sjúklinginn enn berskjaldaðri. Í þriðja þemanu er röddum jaðarsetts fólks lýst. Þar er bent á hvernig sjúklingar í jaðarsettri stöðu verða sérstaklega berskjaldaðir fyrir þeim straumum innan læknisfræði sem geta grafið undan mennsku þeirra. Fjórða þemað fjallar um félagslegt réttlæti. Þar er bent á mikilvægi þess að skoða sjúklinginn aðstæðubundið til að hindra kúgun og standa vörð um félagslegt réttlæti í allri læknisþjónustu.

Við rannsókn á þessum þemum má sjá að þau tengjast öll innbyrðis. Ennfremur afhjúpa þau að læknisfræðin fæst við hluti sem aldrei eru fyllilega fyrirsjáanlegir, hún inniber óhjákvæmilega valdamismunun og byggir á óljósri kjarnahugmynd, þ.e. sjúkdómi, sem aldrei verður skilgreind nákvæmlega. Þessi eðliseinkenni læknisfræðinnar gera þann mögulega skaða sem lýst er í umræðunni um þemun ávallt yfirvofandi. En einmitt þess vegna er þekking á þeim ferlum sem þar er lýst mikilvæg til að geta fyrirbyggt þann mögulega skaða sem læknisfræðin getur valdið sjúklingum og tilteknum hópum fólks ef ekki er brugðist við.

Þegar því hefur verið lýst hvernig læknisfræðin getur fjarlægst tilgang sinn og innri gildi er hægt að spyrja hvernig sú þekking geti gagnast til að túlka merkingu læknisfræðinnar. Hér kynnir höfundur þríhliða sýn á læknisfræðina þar sem henni er lýst þannig að hún grundvallist á vísindum, byggist á köllun og hafi sterk innri gildi. Sérhverju þessara sjónarhorna er lýst og umfjöllun um þemun er notuð til að fá dýpri skilning á merkingu, tilgangi og innri gildum læknisfræðinnar. Þessi þríhliða sýn dregur í fyrsta lagi fram mikilvægi þess að sjá læknisfræðina í víðara ljósi þar sem tilgangi hennar og innri gildum er ekki ýtt til hliðar. Í öðru lagi er þessi þríhliða sýn sett fram til að rökstyðja mikilvægi þess að standa vörð um sameiginlegan kjarna læknisfræðinnar sem vísa má til sem viðmiðs þegar lagt er mat á framþróun hennar.

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Preface

This thesis is an exercise in how to do applied medical ethics. It shows how concrete current problems can be ethically analyzed and evaluated. It is also a work on the philosophy of medicine as it employs philosophical ideas and ethical values to give deeper insight into the meaning, aim, and inherent values of medicine, and argues for the importance of doing so. Finally, this thesis expresses my love for medicine. More than 30 years ago, when I had just finished my education and was starting my medical career, I decided to leave clinical medicine. At the time, I felt very strongly that, in practicing medicine, I was doing something good but there was also something that troubled me. I just could not put my finger on it. I have now tried to express my love for the subject as well as formulating more precisely my criticism. Although I did not continue a career in clinical medicine but transitioned to philosophy and ethics, I never cut the "medical cord." I have always had some connection to medicine through working as a physician in the field from time to time; doing committee work in the health sector; working for the health authorities on health policy and law; teaching medical students, doctors, and other health care professionals; doing research related to medical issues; and through close contact with family and friends who were either medical doctors or patients in the health care system. I might be criticized for being judgemental towards medicine in this thesis. If I am, it is because I care deeply about the issue. I hope the text mediates not only criticism but also concern and even the inherent beauty that medicine truly possesses.

Finally, I want to emphasize that I did not write this thesis alone. The text reflects ideas and insights from an author who has already worked in the field for decades. Hence, there are many who have enlightened me and been a source of inspiration through the years. I want to express my sincere gratitude towards my supervisor, Dr. Vilhjálmur Árnason, who urged me to take on this task. I would never have done it if he had not encouraged me and introduced me to the idea. I am grateful for his patience throughout the years and for giving me the freedom and space to find my own voice in writing this project. I have always felt and known that my work matters to him and that is encouraging. I further want to thank the other members of the doctoral committee, Dr. Bjørn Hofmann and Dr. Stefán Hjörleifsson, for their assistance and willingness to spend their time and energy over the years to read my texts with the single aim of trying to make them better. Both of them have throughout this process been very supportive and Stefán together with Vilhjálmur encouraged me to begin the writing of this thesis. I have had the fortune over the years to work at the University of Iceland, in the School of Education. I want to thank my colleagues and administrators for always being supportive and giving me the flexibility to finish this project. It is hard to single out names as there are so many that have been supportive and encouraging. However, I want to mention Dr. Guðrún V. Stefánsdóttir and Dr. Kristín K. Björnsdóttir. They have remained by my side this entire time like "living encyclopedias," ready to help if I needed anything. Finally, I am so fortunate to have a family who is interested in my doings and a spouse that is inspiring and always says the right things at the right moment. This has been my most valuable support. Jón, a million thanks to you, especially.

1 Introduction

1.1 Aim

Long before the Covid-19 pandemic, I was beginning to have doubts about the development of modern medicine and feared the true meaning of medicine might become lost. I saw it stretching into spheres of life where its place could be questioned. There was doubt in my mind about whether the essence of medicine was still the patient's illness, and if the aim of the doctor was no longer to make the patient's life better? Was there no limit to what could be labeled medicine?

These questions matter because when medicine takes on new tasks, certain characteristics e.g. being fat or having Down syndrome are labeled as symptoms of disease. As a consequence, new groups of people are declared patients in need of medical attention. This categorical change and what follows when a person falls under the domain of medicine can have profound consequences for the person receiving this new attention as well as for the health care system in general. It affects the self-image of the newly identified patient as well as the professional understanding of the doctor and it changes the understanding we have of the limits and essence of the social contract between medicine and society. All professions have a role within society that is generally known and accepted. When I speak about a social contract between medicine and society, I am referring to the general purpose that medicine is expected to serve in the community. Accordingly, each profession is meeting a need or demand for its service where the underlying aim is to benefit us and make our lives better (Koehn, 1994).

Nevertheless, we rightly expect medicine to progress and serve us in new situations. Thus, medicine is always and should always be evolving and taking on new questions and problems. It is a profession that needs to be constantly ready to face new challenges. But how do we know whether these challenges are medical or not and does it matter how they are defined? These thoughts sparked the writing of the three articles in this thesis. In this text, I argue that, when we evaluate and justify changes in the spheres of medicine, we need some frame of reference. We need guidance that tells us whether new tasks can rightfully be understood as the progress of medicine or if they are examples of the knowledge and technology of medicine being used in a non-medical manner. If this distinction is ignored, people can experience undue harm and the medical profession can lose sight of its identity and purpose. This can lead to a poor practice of medicine and a bad health policy undermining our well-being. In other words, it requires us to reflect upon both the ends and inherent values of medicine in order to understand its meaning. This demands a teleological and normative understanding of medicine and is therefore an ethical challenge. To gain a better insight into what happens when medicine enters new grounds as described above and faces these ethical challenges, as well as to gain a deeper understanding of medicine, I propose this thesis. The discussion is in two parts. In the first part, I use three peer reviewed articles (papers I–III) to demonstrate specific examples of how these changes can present themselves in real life. I refer to the examples focused upon, i.e. surrogacy, obesity, and fetal diagnosis, as key examples. In the first paper the question is whether surrogacy should be conceptualized as a form of medical treatment or if it should be defined as a form of adoption. The second paper questions whether the medical treatment of obesity has benefitted fat people, and the third paper asks why the fetus with Down syndrome is seen as a sign of functional impairment that should be systematically screened for? By asking these questions, the issues discussed are introduced as not necessarily being medical at all. This categorical doubt places the key examples in the papers at the fringes of medicine and therefore makes them of interest to this thesis. All of the papers are reflecting upon debates where the role of medicine in society is the core issue.

In the second part, I reflect upon the examples discussed in papers I–III together and focus on four themes common to all of them. They are labeled as, “The difficult concept of disease and the power of the diagnosis,” “The scientific doctor and the danger of dehumanization,” “The marginalized patient and the oppressed voices,” and finally, “Using a relational lens to detect oppression.” In discussing the common themes, I want to draw attention to certain ethical challenges that the papers reveal regarding medicine's expansion. The research question I focus on in this second part is: “When medicine enters new grounds, as described in papers I–III, it can deviate from its ends and inherent values. What characterizes this deviation and how can that knowledge be used to interpret the meaning of medicine?”

To answer the question, “What characterizes this deviation?”, I discuss the themes and show how medical attention has the potential to cause harm in situations like in the examples described in the papers.

When answering the latter half of the research question, i.e. “how can that knowledge be used to interpret the meaning of medicine?”, I build on the insight gained from my examination of the four themes and attempt to spell out how we should interpret medicine's meaning. The aim of this interpretation is to be better capable of guarding the ends of medicine as well as its inherent values and consequently prevent the potential harm described under the discussion of the themes. I use this interpretation to argue for the importance of seeing medicine as based on science, with a clear vocation and inherent values. By describing medicine through these three dimensions, I endeavor to outline a common core that can serve as a frame of reference when evaluating medicine's expansion.

Finally, it can be said that the whole text is a search for a better understanding of what medicine is and ought to be, where the focus is on its meaning, ends, and inherent values. In this quest I start with a more general view on medicine, introduced in the chapter on the theoretical perspectives. By investigating the outlined themes, I am able to formulate a more precise description of medicine in the chapters on the three-dimensional view and in the conclusion of this thesis.

1.2 Influences; Other Texts and Authors

Although my formal background is in medicine and philosophy, my research and teaching in applied ethics is done within the fields of education and sociology. Most of my work in applied ethics has been done in cooperation with scholars in disability studies as well as in social education. In these fields, the attention to the voices of service users are of fundamental importance. This background has without doubt shaped my approach in this thesis.

My thoughts on the papers analyzing the key examples have been gradually developing over the years through my former publications on the same issues. I have previously published five peer reviewed articles and book chapters besides those contained in this thesis, reflecting upon the content of these examples (Stefansdottir, 2009, 2011a, 2011b, 2012, 2016). All of these papers analyze different ethical questions related to each of the key examples, discussing them both in Icelandic context and internationally. The texts reflect upon the ethical challenges related to them where they are categorized as medical problems. The process of writing these texts has shaped my thoughts on the issues.

The ideas I work from in this text are rooted in the works of other authors. Here, I want to draw attention to some of them that I have found the most influential in writing this thesis. Many of these authors who have criticized medicine are situated outside medicine, e.g. within the social sciences and humanities.

What has mostly inspired my thoughts on the inherent values of medicine, as well as its aim, is the book *The Goals of Medicine: The Forgotten Issues in Health Care Reform,* edited by Callahan and Hanson (1999). I have especially benefitted from the international report on the goals of medicine published in the beginning of this book as well as the article “The Goals and Ends of Medicine: How Are They to be Defined?" by Edmund Pellegrino. I discuss their approaches to medicine in the following chapter on theoretical perspective. I further want to mention two other books that have influenced my thoughts on the meaning of medicine or how medicine is to be approached and understood. These are *How Doctors Think; Clinical Judgement and Practice of Medicine* by Katheryn Montgomery and *The New Medicine and the Old Ethics* by Albert R. Jonsen. I also want to mention feminist writers like Susan Sherwin in *No Longer Patient: Feminist Ethics and Health Care,* and writers from the social sciences, especially from disability studies, e.g. *Disability studies: An interdisciplinary introduction* by Dan Goodley. All of these references are important to my discussion on the themes mentioned above, where these authors have influenced my ideas on the subject as well as on the chapter where the three-dimensional model on medicine is outlined.

I have further benefitted from current critical voices within medicine. Some of my criticism and ideas are derived from the discussion by the group behind the project, "Preventing Overdiagnosis: Winding back the harms of too much medicine" (See: https://www.preventingoverdiagnosis.net/). Through their publications, as well as by attending their conferences, I have gained better insight and understanding into some of the problems we face in modern medicine.

The methodology of the thesis has its roots within philosophy and humanities, but is influenced by social science scholars, mainly those working within qualitative studies (Esterberg, 2002). Further, I regard the ideas described by Jonsen and Toulmin (1988) in *The Abuse of Casuistry: A History of Moral Reasoning*, as helpful in shaping my approach in this discussion. In their book, they show how it is possible to gain knowledge from particular cases and extract general ideas. They describe this as a reflective model of thought that resembles approaches in medicine where the description of diseases is based on a collection of symptoms. This has influenced my approach where I use the key examples and extract from them common themes that are helpful in understanding the ethical concerns we need to pay attention to as medicine progresses. Finally, I have grounded some of my writings in the feminist ideas on relational autonomy (Mackenzie & Stoljar, 2000b). Other feminist approaches based on similar groundings are introduced in the articles, "Foundations, Frameworks, Lenses: The Role of Theories in Bioethics" (Sherwin, 1999) and later in "Whither Bioethics Now? The Promise of Relational Theory" (Sherwin & Stockdale, 2017). They show ways of discussing and analyzing bioethical problems that have been inspirational for my work.

1.3 Structure, Methodology and Outcome

As outlined above, the discussion in this thesis is in two parts. The first part is composed of three peer reviewed and published papers included in the thesis. The papers are each to be approached as separate arguments leading to specific conclusions. Nevertheless, they are connected as they all reflect upon debates on the role of medicine in society and they all share the common themes discussed and analyzed in the second part of thesis.

What further characterizes the key examples in papers I–III is the way they were chosen. First, when doing research in applied ethics it is important to use current and relevant examples from public debate as a starting point. All three examples have been in the medical ethics discussion in Iceland, in the last decade. I have been a participant in that discussion. Surrogacy and fetal diagnosis have repeatedly been debated in the Icelandic Parliament and obesity has been addressed in numerous public health policy statements, both from the Icelandic Parliament and from the Directorate of Health. These discussions have prompted difficult ethical questions. This gives the examples increased relevance. Secondly, the examples demonstrate the limits of medicine since they can be categorized as being both medical and not medical. In public discussion, they were usually defined and approached as health issues deserving medicine's attention. In the papers, it is highlighted how this categorization can be doubted and by doing that the examples as such are placed at the boarder of the medical sphere.

It is further characteristic of the key examples that they all reflect upon debates or certain views related to medicine‘s role in society when it enters new grounds. This is explicitly stated either in the title, or in the abstract and/or in the conclusion of each of the papers. This influences their structure and focus. Hence, it is not the aim of the papers to give a comprehensive account of each of these issues. Instead, they are ethical reflections upon certain debates with reference to what and how medicine is. These discussions further highlight the voices of the users of the health service and of marginalized populations as having central importance in casting light on possible ethical concerns within medicine. Finally, the examples in the articles show how the constructional forces of society can influence the progress of medicine. Consequently, these three examples have the potential to draw attention to important criticism medicine faces.

The second part of the thesis is a theoretical discussion and ethical reflection grounded in common themes visible in all the articles. In this diagram, the structure of the second part is shown:

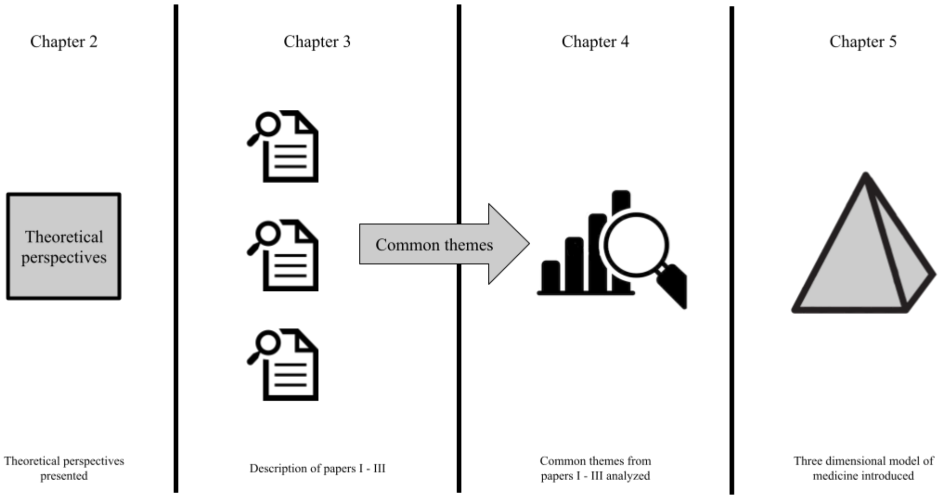

Fig. 1. Structural overview of part two of the thesis

The a forementioned international report on the goals of medicine (Allert et al., 1996; Callahan & Hanson, 1999) has provided a theoretical perspective for my work. This international report is valuable research on the goals of medicine and how social forces may influence them. I have also based this writing on ideas on the ends of medicine by Pellegrino (1999). Originally, the articles in this thesis were written to explore and discuss how society enters into such a dialogue with medicine as described in the report mentioned above. In viewing the different articles together, a new dimension was revealed in the interplay between medicine and society. As the papers reflect upon the critical voices of the users of medical service, they describe a process that may repeatedly cause harm to certain patients or groups of patients. I argue that this is especially prone to happen for those who are already in a marginalized position. By investigating these processes, a new light was thrown on the discussion, describing what can occur when medicine enters new grounds. The specific processes described in this thesis are not generalizations on what happens when medicine enters new ground; rather they are specific description outlining certain concerns for certain groups of patients within the health system.

Consequently, the outcome of the thesis is: Firstly, the key examples in the papers show how a dialogue between medicine and society can unfold as medicine expands and progresses into new grounds. This dialogue reveals tension between the inherent values and ends of medicine and constructional forces in society that can change medicine, e.g. the influence of the market, science and technology, medicalization and human enhancement to name a few. Secondly, four themes common to all of the papers are described. They show how medicine has the potential to harm certain patients or groups of people. The debates described, especially in the papers as well as in the discussion on the third and the fourth theme, show how those already stigmatized and marginalized in society are vulnerable towards oppression within the health services. This may happen when medicine is under the influence of constructional social forces and expands and enters new grounds. Thirdly, a description of medicine is formed where three dimensions are highlighted. These are the scientific foundation, the vocation based on the ends of medicine, and finally, medicine's inherent values. These dimensions are all necessary elements of medicine and need to be viewed as a whole. It is argued that this holistic view is helpful to prevent the possible harm described under the themes. Hence, this is an attempt to describe the core of medicine and provide a better understanding of what medicine is and ought to be.

1.4 The Added Value and the Limitations of This Work

The main value of this work lies in drawing attention to how harmful effects of medicine can present themselves. By investigating the themes from the articles and showing how they connect to certain ontological characteristics of medicine, it is possible to gain a better understanding of the potential harm medicine can cause especially towards marginalized groups within society. These four themes that are present in all three articles have, to my knowledge, not been introduced together as signs of ethical concern in medicine. It is further argued that to prevent this potential harm it is necessary to highlight the vocation and the values of medicine. This three-dimensional model is an attempt to spell out, not the heterogeneity of medicine, but its common core, that can serve as a frame of reference when evaluating medicine´s expansion.

This analysis can deepen our understanding of how medicine can increase the marginalization of already marginalized groups in society. It requires a special type of awareness to prevent that. The description of the possible harm medicine can cause, described in the papers and in the discussion of the themes is a step towards that realization. Highlighting medicine as a profession with a clear vocation and inherent values suggests ways of meeting this challenge. A deeper understanding of the meaning of medicine as well as its role in society is helpful in: (a) shaping health policy; (b) understanding what happens in the interaction between the doctor and the patient; (c) shaping our self-identity when we are either in the role of the patient in need of medical service or as a health service provider, medical scientist, or policy-maker.

I will now reflect briefly on the limitations of this thesis. First, it is inter-disciplinary. That is a double-edged sword. On the positive side, the theoretical reflection in both parts occurs by referring to at least three different fields: medicine, philosophy, and the social sciences. By considering three theoretical fields, it is possible to get a more nuanced picture of the ethical challenges at hand and a deeper understanding of their complexities. On the negative side, these three disciplines use different methodologies and ways to analyze and express knowledge. In medicine for example there is a strong emphasis on quantitative results and general knowledge, whereas in radical sociology, like in disability studies, qualitative results with emphasis on the voices of people in marginalized positions are important. To combine these approaches without giving any discount to the ethical analyses can be challenging. Both are important to gain the necessary understanding of the issues under discussion. Nevertheless, because of these differences there is sometimes a mutual suspicion between them, e.g. the medical sciences and disability studies. Consequently, it is challenging to write with reference to both fields.

Another important limitation of this thesis is its wide scope. A focus on fetal diagnosis and Down syndrome only or to focus on surrogacy would certainly have made a more thorough thesis where it would have been possible to analyze these issues in more detail and do them perhaps better justice. However, extensive description of each example is not the purpose of this thesis. It is primarily aimed at evaluating medicine and the examples discussed in the papers are used to throw light upon special weaknesses in medicine where it has the potential to harm certain groups of patients in a specific way. This reflection gives an opportunity to evaluate big and important ethical issues related to medicine and its role in society in general. I am here referring to issues like medicine’s ends, inherent values and meaning. The discussion presented in this thesis on these particular issues will hopefully be of importance, but they will certainly not be complete (see conclusion of the thesis on further research).

Finally, to be able to discuss the issues introduced above it is necessary to use terms like disease, illness and sickness as well as terms like oppression and stigmatization. These concepts are central in the thesis, both in referred texts and in my own interpretation. These terms are both complicated and value laden and there is a danger of inaccuracy when using them, especially if there are references to many authors who refer to these terms in a slightly different way. To meet this challenge, I have included explanations on how I use and interpret their meaning where I begin to apply them in the text. Chapter 4.1.1 is outlining the approach in this thesis on the disease concept, where the three perspectives: disease, illness and sickness are explained. Oppression is defined in chapter 4.3. and stigma is addressed in chapter 4.3.1. These concepts are not explored in depth in this text. This is a limitation since there is the possibility that these terms will not be done full justice through a brief explanation and their use will most certainly be open to criticism. Nevertheless, this difficulty must not be a reason for averting the discussion at all.

In the next chapter, I will describe in more detail the theoretical perspective that serves as a basis for the papers and the thesis itself. There, I will discuss and outline the main concepts and phrases I refer to when reflecting upon the ethics of medicine. I will nevertheless continue to explore the meaning of these main concepts throughout the thesis and their understanding will be revisited in its final form in the three-dimensional model of medicine as well as in the conclusion.

2 Theoretical Perspectives

Medicine is constantly evolving and entering new grounds. This is the case in new reproductive technology as well as in fetal diagnosis and in managing obese patients. We need clearly defined concepts in order to discuss and describe these changes as well as to be able to do an ethical evaluation on the expansion of medicine. It is necessary to have a common understanding of what is referred to when these concepts are used, as well as understanding medicine itself. In this chapter, I want to introduce a way to conduct this dialogue, as well as reflecting upon what we refer to when we discuss the ends and inherent values of medicine. I will begin this theoretical quest by outlining the discussion on the goals of medicine introduced in the international report published by the Hasting Center. Following that, I will focus closer upon the meaning, ends, and inherent values of medicine as we understand them at the beginning of this journey. In the last two chapters, these concepts will be addressed again in further detail.

2.1 The Progress of Medicine and the Social Dialogue

In 1999, Daniel Callahan and Mark J. Hanson edited a book called *Goals of Medicine: The Forgotten Issues in Health Care Reform*. The book was the result of a research project initiated in 1993 by the Hasting Center which was founded on the question, “What are, or should be, the goals of medicine and what is the implication of our thinking about goals for the delivery of health care, the research agenda, and the education of medical students and other health care personnel?” (Callahan and Hanson, 1999, ix). The book begins with a consensus document reached by an international group working on this project. The project report, “The Goals of Medicine: Setting New Priorities” was first published in the *Hastings Center Report* 1996 (Allert et al., 1996). This work has been referred to as one the most important discussions on the goals and aims of medicine in later years (Calman, 2007). I will use their approach as the initial ground for my own discussion on the subject.

In a search for answers to the question introduced above, the project report describes two positions regarding how to approach the goals of medicine. The former they label the inherentist position:

> The inherentist position holds that medicine's proper ends are constituted as a response intrinsic in medicine's practice to the universal human experience of illness. This response calls forth the need to heal, help, care and cure. Medicine begins with the doctor-patient relationship, which in turn generates for its viability and inherent values – such as the doctor-patient bond – to maintain and strengthen itself. Medicine should, moreover, hold on to those inherent values. They allow it to resist domination or manipulation, and give medicine its own direction, and doctors their own integrity, independent of societal values. (Callahan & Hanson, 1999, pp. 15–16)

The inherentist position stems from the idea that medicine has an intrinsic end, and this is an essential part of what medicine is that gives it direction and reference in order to resist societal pressure. Doctors have their own integrity independent of societal values.

The authors go on to describe the other way of defining medicine and its goals: what they call the social construction view. This view contrasts the inherentist position:

> The social construction view, in contrast, notes the great variation over time and in different cultures in the nature and goals of medicine. While it is true that the care of the sick constitutes a consistent historical and cultural thread, as does the centrality of the doctor-patient relationship, so varied is the interpretation of disease, illness, and sickness, and so complex the response to them that it is difficult to pin down a meaningful set of inherent values and convictions. Medicine is thus best thought of as an evolving fund of knowledge and a changing range of clinical practices that have no fixed essence. (Callahan & Hanson, 1999, p. 16)

The authors claim that the question is not just what the nature of medicine is according to one view or the other, but also how medicine should seek to define itself. The questions asked are thus also:

> Ought medicine seek to define, from within, its own history and traditions, its own values and direction? Or, should it let society do that from the outside? Or, again, should medicine find its direction by means of a continuing dialogue with society in which each seeks its legitimate sphere, duties, and rights? (Callahan & Hanson, 1999, p. 16)

When evaluating whether medicine ought to enter new grounds, the evaluation is referred to as an ongoing dialogue between medicine and society:

> [S]ome open and ongoing dialogue between medicine and society seems most appropriate, each seeking to express its understanding of disease, illness and death, as well as its perspective on the delivery of health care, what constraints and perspectives should be taken into account? From the medical side, the ethic and integrity of medical practice will be of obvious importance. ….How can medicine best remain true to its own traditions, and yet discern when a change in scientific knowledge, or social values, requires some fundamental change in its values? (Callahan & Hanson, 1999, p. 17)

The project report points to a middle ground, neither stating that medicine has inherent ends nor claiming it to primarily be a social construct. Rather, it advocates for a way where some truth is accepted in both perspectives, the inherentist position as well as the social construction view: "[M]edicine has essential ends, shaped by more or less universal ideals and kinds of historical practices, but its knowledge and skills also lend themselves to a significant degree of social construction" (Callahan & Hanson, 1999, p. 17). Thus, by viewing the relationship between medicine and society as a dialogue that expresses the two views, a fruitful tension is created. This is a tension that respects the inherent values of medicine but has the potential to shape the identity of doctors and the evolution of medicine so it can better serve society.

I agree with the authors that this tension between medicine and society can be a fruitful way of reflecting upon difficult ethical questions regarding the expansion and essence of medicine. It gives us a conceptual model of how to describe and talk about external influences as well as contemplating the inherent values and ends of medicine, and then outline how these interact and what should be their results.

There are multiple constructional forces of society that can change the scope of medicine. They are caused by scientific, economic, social, and political reasons. I will now name those that are most influential and briefly outlined in the international report under the heading "Sources of Stress." They are the following:

- S*cientific and technological developments* and how new techniques and knowledge have advanced medicine and increased public faith in it.

- The *balancing of the curative bias*. This refers to an ideological change where medicine tends to place more attention on the duty to cure the patient rather than caring for him. This can come at a cost to patients with chronic and lethal diseases where they do not receive the compassion they need.

- *Aging population* creates a changing demand on medicine and has the potential to change health care.
- *Cultural pressures*. There are two important cultural influences. Firstly, the commitment to scientific progress where there is a strong demand on medicine to become better at eliminating diseases. Secondly, the satisfaction of individual desires, demanding medicine to expand human choices and possibilities.
- *The market and public demand* are also influencing medicine, often provoked by cultural pressures and the belief that medicine is driven by scientific progress and can lead to unrealistic public demand.
- *Medicalization of life* is when medical knowledge and technologies are used to solve new problems that were not previously regarded as medical problems thus widening the scope of medical praxis.
- The will for *human enhancement* as a force shaping medicine and diverting its scope into new directions, where medicine and medical means are used to cure diseases but to also "improve human capacities to optimize as well as to normalize" (Callahan & Hanson, 1999, pp. 7–12).

How can we reflect upon the tension created between the inherent values and ends of medicine and the constructional forces of society? This tension is visible when we evaluate questions regarding the limits of medicine, i.e. when we need to evaluate whether these limits have been transgressed. For instance: When do we operate on a patient to lower his weight? When do we use Non-Invasive Prenatal Testing (NIPT) to diagnose deformities in fetuses? Should we develop complicated fertility treatments? In light of the discussion above, we can ask: What constructional forces in society might influence the way we think about these new treatments? Could we refer to some sort of ethical calculus and ask ourselves if these particular tasks are in harmony with the inherent values and ends of medicine? In contemplating this, we need to take into account the fact that, although medicine has universal ideals, it should accept that "its knowledge and skills also lend themselves to a significant degree of social construction" (Callahan & Hanson, 1999, p. 17).

This evaluation helps us gain a better understanding of medicine's expansion. As was discussed in Callahan's and Hanson's project report (1999), medicine is a constantly evolving profession in dynamic relation to society. In their report, they also claim that medicine has to have a strong ethos, represented in clear aims and inherent value reference (Callahan & Hanson, 1999). While it progresses and changes, it also has to possess the means to resist outside pressure, otherwise society can easily misuse it (Callahan & Hanson, 1999, p. 30). There are examples of ethical accidents or even disasters where the use of medical knowledge and technology is applied to ethically unacceptable aims. Such use of medical knowledge and technology would not be in line with what is labeled medical practice according to the report under discussion.

Here, a reference to defined ends and a set of inherent values is used to resist ethical wrongdoings like those described above. When doing this evaluation, some sort of a balance may have to be reached. Although the examples mentioned above are clearly outside the spheres of medicine, there are other examples that are not so clear. Some have not been of medical concern before but they might be now since it is necessary for medicine to develop and enter into new areas as societal demands change. An example would be transgender operations which were not viewed as acceptable medical practice but are now mainstream procedures. Other areas of medicine might have been accepted earlier but are at present in contrast with what is accepted within society, like the former practice of "curing" the homosexual person. There are always cases and forms of medical practice that create controversies. How do we know what is appropriate and acceptable practice on the one hand and what transgresses the limits of medicine on the other? To better approach that question, we need to know more about the meaning, aim, and inherent values of medicine.

2.2 More on the Inherent Values, Aim, Goals, and Ends of Medicine

So far, the meaning, aim, and inherent values of medicine have not been distinctively outlined. I will, however, underline the fact that gaining a thorough understanding of these concepts is an ongoing task throughout this entire thesis. Hence, their meaning is approached in a systematic way in the conclusion.

In his book chapter the "Goals of medicine", Schramme (2016) identifies two basic approaches to medicine's goals.

Firstly, there is the consensual approach, which assembles a list of goals we can all agree upon and which are identified in a deliberative process. This approach is used in the project report on the goals of medicine, as described above. The goals chosen were, "the Prevention of disease and injury and the promotion and maintenance of health," "the relief of pain and suffering caused by maladies," "the care and cure of those with a malady, and the care of those who cannot be cured," and finally, "the avoidance of a premature death and the pursuit of a peaceful death" (Callahan & Hanson, 1999, pp. 20–30). At first glance, these goals seem to capture well the aim of medical work. The goals are clear and descriptive, but it is the approach itself—how this conclusion is arrived at—that has been criticized. By simply resting on a consensus makes the goals open up to debate, they can always change if we agree on changing them. Hence, they are not stable enough to provide normative guidance (Schramme, 2016). Secondly, Schramme describes another approach to the goals of medicine; it is teleological (Schramme, 2016). This view describes medicine as a practice with an inherent telos. Pellegrino outlines this approach and criticizes the idea behind the goals introduced in the international report from the Hastings Center (Pellegrino, 1999).

This is an important criticism since viewing the goals of medicine as the outcome of a consensus makes these goals prone to changes. They give neither the doctor a clear identity nor the patient any real reason to trust the doctor. Pellegrino (1999) further claims that this approach gives us no idea of what goals are most important and how we are to understand and interpret their meanings. We need to know when we are curing the patient and when we are improving health. That is, in itself, a value judgement where we need to decide whether one condition is better than another. Pellegrino's (1999) answer to these concerns is that physicians must cultivate an inner compass that guides the way to answer these questions and this inner compass must be used in all their tasks as medical doctors. He talks about this as the end of medicine distinguishing the "ends" from the "goals" where the ends are interpreted in the same way as the Greek understanding of telos. He describes the ends in the following way:

> They grow out of the phenomenology of medicine, that is, out of that which is more fundamental than medicine itself – the universal human experience of illness. It is the universality of this experience, its existence beyond time, place, history, or culture – and the need of sick persons for care, cure, help, and healing – that gives medicine its essential character. These ends make medicine what it is. (Pellegrino, 1999, p. 60)

He further contends that, "It is this healing end of medicine in the context of patient vulnerability that determines not only the technical practice of clinical medicine but also the ethic of medicine" (Pellegrino, 1999, p. 63).

How does this connect with the goals of medicine? As stated earlier, the ends are like a compass point for the goals so, as Pellegrino puts it, "Whenever medicine is used for any purpose or goal – however defined – that distorts, frustrates, or impairs its capacity to achieve its proper ends, it loses its integrity as a craft and its moral status as a human activity" (1999, p. 64). Pellegrino concludes his article by stating that:

> Preserving the ends of medicine, and not just the goals society may construct for medicine, is an essential safeguard not simply for the integrity of medical ethics and practice, but for the safety and well-being of all the vulnerable members of our society. (Pellegrino, 1999, p. 67)

According to the project report's definition, Pellegrino would be an inherentist. He wants us to begin to define medicine from within, look into the vocation and roots of medicine when we try to understand the essence, and find that the meaning of medicine is in its ends. Pellegrino clearly wants to preserve the tradition that has defined medicine. We cannot make medicine be whatever we want. It has to be true to its ends, visible in its roots and vocation.

I tend to agree with Pellegrino. It is necessary that the goals are true to the ends of medicine if they are going to have meaning and value. The ends give teleological guidance; it is not sufficient to only base the goals on a consensus. It has to be something more fundamental, so Pellegrino points to the vocation to meet "the need of sick persons for care, cure, help, and healing" where the intention of the doctor to relief suffering gives direction for the goals (1999, p. 60). In this thesis, the reference to these concepts will be according to Pellegrino's interpretation.

At this stage, it is possible to say that the inherent values of medicine, guided by the ends of medicine, would at least include the will to promote good, like health, well-being, and life itself.

The medical profession is recognized by the acts that guard these ends and the inherent values. Pellegrino points to the doctor who cares and cures, relieves suffering, and promotes the good but not just for anybody but for those who suffer and are ill (1999). I want to draw attention to how illness and vulnerability play a role here. Medical doctors are not just interested in the general welfare of all human beings; their primary focus is on those human beings who are ill. Hence, it is necessary to have an insight into what it means to be vulnerable and as such, be sensitive towards our own humanity and the frailty that comes with it. This sensitivity and acknowledgement is discussed in relation to the parable of the good Samaritan in the paper on fetal diagnosis. To be aware of what it means to be a human being; to notice those who are vulnerable; to value the life, health, and well-being of the patient and to care, cure and promote the patient´s health is what it means to be a doctor.

We can reflect upon this by considering an example. How we answer questions like whether to operate on a particular patient depends, in part, on whether the operation is in harmony with what we view as medicine. Not all surgical procedures fall under medicine's domain. Removing a swollen appendix is medicine, but to surgically remove a person's kidney to sell it on an open market for profit would not be medicine. Hence, a certain procedure is not medical simply because it applies tools and techniques that are developed by medicine, and will not be defined as such by referring to general consensus. Consensus can easily change if those making the decisions decide to do so, thereby making this profitable procedure liable to becoming medicine. We could argue, in line with what Pellegrino states, that it is not medicine because it is not in accordance with the proper ends to promote health and relieve the suffering of those who are ill and vulnerable. Consequently, when trying to clarify what is medicine, we search for its ends and inherent values. That is what guards its meaning and helps to identify what is medical help and what is not.

We can take another example of how we use this frame of reference to ground our justification. How do we justify breast cancer screening as being medicine? Are people's desire for breast cancer screening a sufficient reason to do so, regardless of benefit? No, we need verification of true benefit based on scientific knowledge and evidence. The benefit is not measured by whether this pleases the politicians or the public. When I refer to true benefits, I refer to medicine's inherent values like lowered mortality and better health for those screened. If that is not the case, this could at best be labeled bad medicine or even not medicine at all, since it is not true to the proper ends and values of medicine described above. It is a complicated task to identify what is medicine and what is not medicine. Reference to the ends and the values are not the only thing this distinction relies on but it is nevertheless both important and helpful in making this distinction.

I have so far outlined how we can describe medicine's expansion as a dialogue between medicine and society. What characterizes this discussion is, firstly, the inherentist position where medicine is seen to have inherent values and ends that are a response to the universal human experience of illness. Secondly, the social construction view that describes medicine as a clinical practice with no essence but as being formed and reformed by societal forces. Both views are important. It must be accepted that medicine needs to adapt to societal changes, but for medicine to be able to progress it also needs to be able to resist misusing medical knowledge. I have favored Pellegrino's approach as described above. He outlines the ends of medicine as a teleological concept that can be referred to as an inner compass of medicine guiding us when choosing between good and bad goals. I also want to highlight what gives medicine its essential character and meaning according to Pellegrino: “the universal experience of illness” (Pellegrino, 1999, p. 60) and “the need of the sick person for care, cure, help and healing” (Pellegrino, 1999, p. 60). I have also outlined the importance of approaching medicine as a profession with a vocation to promote good by preserving life, health, and well-being, especially noticing those who are vulnerable. These are important cornerstones I will use and refer to in my analysis.

In this chapter, the initial understanding of key concepts and clarifying the meaning of medicine has been discussed. This initial understanding is the background shaping the discussion of the key examples in the papers. In the next chapter, the focus is on the papers describing how the tension between the constructional forces of society and the inherent values and ends of medicine unfold.

3 Describing the Key Examples (Paper I–III)

The papers in this thesis discuss three separate issues: surrogacy, obesity and fetal diagnosis and use them to reflect upon medicine's expansion. The first paper[1] (pub. 2017) is on surrogacy. While the article was written, a bill had been drafted in the Icelandic parliament on surrogacy and this topic was repeatedly in public discussion. Since it is the first paper of the thesis, it has a slightly different focus from the latter two. The focus is mainly on surrogacy as a current example on the edge of the medical scope in a field that is progressing rapidly (ART). It shows how different conceptual approaches in the surrogacy debate can have ethical relevance. It further reflects upon the "dialogue between medicine and society" where it highlights how specific forces in society influence the progress of medicine.

The second paper[2] is on obesity (pub. 2020). This is a subject I had taken part in debating publicly for several years. At this point in time, my ideas on the thesis itself were better formed. The paper is written primarily to highlight alternate views in the debate on the "obesity epidemic" to draw attention to its complexity. The objective medical description on obesity outlined in the first part of the paper is certainly important, but there are other views regarding obesity that have not received due attention in the mainstream media. These are views criticizing the mainstream medical approach. Those described in the article are labeled: "The critical view from the constructionist pole" and "The personal position". It is argued that in order to gain a better perspective on what it means to be fat, these aspects need to be recognized as well as the "scientific position", dominant in the medical discussion.

The third and most recent paper[3] in the thesis is on fetal diagnosis (pub online 2020, waiting for print). Since, I have been engaged in research within disability studies, I have participated in this discussion for decades. The debate has gained increased attention in recent years since the use of NIPT became mainstream. The core of the argument in paper III is more clearly in line with the main argument of the thesis than the other two papers. It reflects upon two highly polarized views on fetal diagnosis; i.e. the writings of disability study scholars and disability activists, on the one hand, and views appearing in mainstream medical journals on

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[1] Hereafter in thesis referred to as paper I

[2] Hereafter in thesis referred to as paper II

[3] Hereafter in thesis referred to as paper III

the other. These two views in this debate are then used to highlight specific ethical concerns regarding medicine's development.

3.1 Paper I: Is 'Surrogacy' an Infertility Treatment?

> Abstract: In this article it is argued that it is problematic to construe the debate around the process labelled 'surrogacy' as a form for infertility treatment. Firstly, this way of defining what happens opens up for a new form for medical desire where a growing number of people wishes to have children through 'surrogacy'. This medicalizes childlessness and creates pressure within health services to respond to the desires of an ever-growing group of patients. Secondly, this labels the woman who carries the child as a 'surrogate' and defines her as a core element in a 'treatment method'. This way of phrasing and defining what happens puts the woman carrying the child in an unacceptable moral position within the health system. Thirdly, by viewing the woman carrying the child as a 'substitute' for a mother or as a 'temporary custodian' ignores the unique relationship between the fetus and the pregnant woman. To keep the ethical issues in focus in the 'surrogacy' process it is necessary for health professionals to always accept the woman who goes through gestation and birth as the mother of the child. This unconditional acceptance shifts the core of the process away from the idea of 'treatment' and towards 'adoption' as the defining element in the process. Consequently, it will be easier to accept 'surrogacy' as a complicated and wide-ranging process as well as to secure the basic human rights of the pregnant woman and the welfare of the child being born. (Stefansdottir, 2017)

In this paper, I discuss whether surrogacy should be a part of medical services and ask whether childlessness should be regarded as a medical problem. If surrogacy is a form of medical treatment, it implies that it offers a form of cure that involves using a healthy person to carry a child to birth and give it to the prospective parents. In this conceptual frame, accepted when surrogacy is viewed as a form of medical treatment, the prospective parents are the patients, the surrogate mother is the means to a cure, and the baby is the cure to the disease of infertility. In the paper it is argued that this way of conceptualizing what is really happening during the surrogacy process can undermine medicine's role in society and a different way to conceptualize this process is proposed. By framing this as an adoption process, it would not undermine medicine and would better serve those in a vulnerable position during the process.

It is contended that the effects this form of "cure" could have on our medical services are twofold. Firstly, if surrogacy became a medical cure for the condition of not being able to have a child, it could put pressure on new groups in society to use the service. This could lead to the medicalization of the inability to have a child. Secondly, if surrogacy became a cure that medical services offered, there is always the danger of the surrogate mother to be viewed as “a device” that physicians use to cure infertility. A medical service that uses surrogacy and offers it to its patients as a solution to infertility has then entered new and ethically questionable grounds. It places physicians in a difficult position where they can lose sight of the meaning of their work, based on the relationship with the patient and a duty to cure diseases and promote health.

How does the dialogue between the constructional forces and the inherent values and ends of medicine unfold in this example? The paper reflects upon the tension between new scientific and technological innovations on the one hand and the inherent values and ends of medicine on the other. It asks to what extent we can and should use medical knowledge and technique without the presence of an actual disease. Here the reference is e.g. to the use of medical technology to assist two men in having a child. It further discusses whether medical knowledge and techniques are used as a consequence of social pressure and/or because a person is unable to accept life’s natural limits. It also reflects on how medicalization can develop when new possibilities raise new demands. This is further related to the concept that being unable to have a child is the cause of imperfection and shame. These feelings draw our attention to the suffering of those who long for a child. But does the suffering always raise a moral obligation for doctors to respond?

The discussion shows how the sources of stress identified in the Hasting Center’s project report (i.e. scientific and technological developments, the market and public demand, medicalization and ideas on human enhancement) act as a force shaping medicine and diverting its scope into new directions. By weighing these constructional forces against the inherent values and ends of medicine, a deeper understanding of the ethical dilemmas related to these new tasks is gained. In the conclusion, the ethical shortcomings visible after this analysis are primarily related to a lack of insight into the essence of the relation between the surrogate mother and the fetus during pregnancy, and their weak moral position in the process. It is further asserted that these ethical shortcomings can better be met by a different conceptual framework where this process is defined as a form of adoption rather than viewing this as a medical treatment. That would construct the roles of all participants and the discussion differently. Thus, the duties and responsibilities of those involved are less likely to compromise the meaning of medicine and the rights of the gestating mother as well as the baby being born.

3.2 Paper II: Three Positions on the Fat Body: Evaluating the Ethical Shortcomings of the Obesity Discourse

> Abstract: This article raises serious ethical concerns regarding the medical discourse on obesity. It offers a description of three alternate positions on the fat body: the scientific approach dominant within medicine, the critical view mainly raised by social scientists, and the voices of fat people themselves. By viewing and comparing the perspectives these positions reveal, it is possible to underline the complexity of the problem labelled as the 'obesity epidemic' and draw attention to serious ethical concerns in the mainstream medical discussion. Medicalization of fat people narrows the focus on the 'obesity epidemic' where it is framed as private and personal rather than social and political. It is also argued that the hegemonic discourse of medicine omits the social embeddedness of fat people and ignores their own voices and narratives. This undermines the well-being of fat people and hides their humanity as well. (Stefansdottir, 2020a)

This article considers three different conceptions of obesity. According to the first conception, obesity is primarily a medical problem, described either as leading to a disease or as a disease itself as well as being a public health hazard. The former focuses primarily on the obese individual and her physician. The latter is a public health approach concentrating on the obesity epidemic and highlighting the importance of environmental changes and political responsibility when discussing obesity. The public health approach points to the importance of taking care not to define the problem too narrowly since it leads us to respond to it by ineffective means. According to this approach, the main reasons for obesity lie in the fact that an increasing number of children and adults are living in an environment that makes it more and more difficult for them to lead healthy lives.

The second conception does not regard obesity in itself as the main problem focus; rather, it focuses on oppression and stigma and how this particular form of violence affects fat people[4]. This position focuses the debate on the social construct of obesity and the oppression of fat people. According to these critics of the medical debate, this oppression and stigmatization is rooted in the health system and in how the medical system medicalizes the lives of fat people.

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[4] In this thesis, I will use the labels: "fat people", "disabled people" and "mad people". These labels have been chosen by fat, disabled and mad people themselves when they describe their own experience of being a patient within the health care system. These labels are reflected in university disciplines like: Fat Studies, Disability Studies and Mad Studies.

The third position describes the subjective view on obesity: the personal feeling of being fat. It uses the insight of academic disciplines like fat studies and highlights the importance of giving the narratives of fat people themselves a central focus in the discussion on being fat.

The article repeatedly underlines the importance of context. It is argued that obesity needs to be seen not primarily as a disease of the individual but also as a social, and even as a political issue. This contextual focus shifts the responsibility for the problem and its solution in important ways. Instead of placing the responsibility for this condition almost entirely on the shoulders of the obese person and the medical services, politicians and others who have the power to shape society should share this responsibility.

This article reflects on the question of the extent to which it is fruitful to solve the problem of obesity—or in other words, the problem of being fat—by medical means. It asks whether it would be better to emphasize the view of obesity as an environmental problem instead of handling it as a personal disease. Such a stance prioritizes environmental changes in order to enhance the possibility of avoiding health problems associated with obesity. An integrated part of the problem of obesity is the disgrace and shame connected to the situation. Those who are obese have to live constantly with the feeling of not being as they should be.

By describing the arguments of the "critical view from the constructionist pole" and the "personal position" it is shown how the "objective view of science" can add to the social stigmatization and oppression of fat people. These different positions introduced in the article rely on different methodologies in the search for knowledge. Including these views in the obesity debate, and accepting them as valuable, does not mean that the mainstream scientific position dominant in the medical discourse needs to be refuted. Additional insight is gained through inspecting other positions on the state of being fat. Some of the problems related to obesity might be resolved through medical means but many are not solved in the discussion between the physician and the patient and not even by public health measures. The additional insights of critical sociology and fat studies might there prove to be beneficial, especially in demonstrating where the approach of medicine can cause harm.

The constructional forces of society outlined in this discussion are scientific and technological developments that promise quick solutions through new techniques. This ignores the problem's complexity. It places the problem within the person and projects the image that it is easily solved by scientific and technological means of medicine. This is a false promise and when it fails, the blame tends to be shifted onto the fat person herself. As obesity is a chronic condition, it is also influenced by "the curative bias" that is named under the constructional forces of society outlined earlier (Callahan & Hanson, 1999, pp. 8–9). The curative bias refers to the emphasis on cure rather than care. When the medical doctor fails to cure the obese patient, as happens in most cases, they lose interest in the patient. The article outlines how those who criticize medicine claim it has the wrong aims. They claim it is a place where doctors no longer see their role as making the patient's life better and healthier for those who stay fat and will be fat; rather, treatment progress has a tendency to be solely measured and aimed at the goal of "making the fat person thin." Obesity is also a classic example of how the market and public demand, and cultural pressures are all influencing medicine. These pressures can further be connected to the ideas of human enhancement or human perfection, where being thin is the culturally accepted aspect of being the perfect human being and being fat is not. The article also outlines how obesity can be seen as an example of medicalization, and asks whether this medicalization of the state of being fat has benefitted fat people or not.

This can be described as a tension between the constructional forces in society named above and the ends and inherent values of medicine. The article criticizes the scientific emphasis that is dominant in the medical approach. By inspecting the criticism of both critical sociology and the personal position, it is possible to see how this approach can undermine the humanity of the fat person. The personal position reminds us that the medical discussion on obesity has a tendency to forget that the fat person is a human being with feelings and a history. The patient's own story or narrative is of primary importance in clinical work. The most important aid of the medical doctor is her ear—the ability to listen—thus creating a thread between the doctor and the patient to keep a firm connection between the complaint of those ill and the diagnosis of the disease. Thereby, the doctor remembers that medicine rests on connections and sympathy between human beings. In the mainstream medical description of obesity, there is hardly any subjective story of what it feels like to be fat. That is where medicine fails; in its enthusiasm over new possibilities, it has a tendency to forget the humanity of fat people which appears in their own stories.

This article on obesity underlines the complications in medical tasks. The problem should be faced on many levels: not only through the biomedical means of science, but through political action, in the relationship between the doctor and the patient, and through the self-perception and self-worth of the fat person.

3.3 Paper III: ‘A World Without Down’s Syndrome’ – An Evaluation of Foetal Diagnosis in Light of the Ethos of Medicine

> Abstract: This article is an ethical evaluation of two familiar views in the debate on foetal diagnosis; one being the mainstream view in medical texts emphasizing early detection of foetuses with Down´s syndrome so they may be aborted, and the other coming from Down´s syndrome activists claiming that such screening is never acceptable. The core question asked is: What ethical weaknesses in modern medical practice does this discussion reveal? I argue that the marketization of noninvasive prenatal testing (NIPT) and the mainstream discussion in the health sector on its application shows two trends undermining the traditional ethos of medicine. Firstly, that doctors are, in their work, concentrating on diseases as isolated entities, whereas the patient and her life remains in the shadow. Secondly, the emphasis has been on the scientific foundation of medicine where the clinical evaluation of these scientific facts has not received due attention. (Stefansdottir, 2020b)

This article, examines the medical view on fetal diagnosis on the one hand and criticism of medicine put forth by disability activists on the other. It also reflects on the ideological basis of these two differing views with the purpose of trying to better understand the nature of the underlying disagreement between them. In disability studies, the aim of medicine and the doctor’s role are often described as first being to change people with disability and make them “normal”. It is further argued that the doctor’s attention is focused on the individual’s impairment instead of admitting that disability is rooted in society. By focusing on the impairment, the medical view seems to categorize people and consider some as worth less than others. The crux of this criticism lies in the view that the doctor does not see the inherent worth of the person with disability. In the article, it is argued that this criticism defines the ideology and purpose of medicine too narrowly. In order to explain why the interpretation of disability scholars is too narrow, the ethical foundation of medicine is outlined, based on its tradition and historical roots where the doctor’s prime attention is always on the patient. It is further argued that in line with the medical ethos and in clinical work, the doctor should be especially sensitive towards vulnerability and remember that every person is unique and of invaluable worth. This important element in the medical ethos seems to be lost in the description of medicine that disability scholars are criticizing. Nevertheless, even though the criticism from disability studies may be partly flawed, it is still important for doctors to take it seriously and use it to sharpen their ideas on their role and ideology.

The underlying questions in this polarized dialogue, paper III describes, are: To what degree are we confronted with a medical problem? To what degree are we confronted with any problem at all? Are we using medicine and medical means to eliminate a disease or to eliminate fetuses with certain characteristics? Is the use of NIPT an example of a lack of tolerance towards the lives of people with Down syndrome rather than an act of disease prevention? According to the mainstream medical view outlined, the main argument for performing the diagnosis and justifying an abortion as a consequence is the assumption that the unborn individual will either suffer or cause suffering for his family. That seems to call for a medical intervention. This approach has been criticized by both people with Down syndrome and their families, claiming that there is no special suffering related to their existence and therefore no need for a screening of this nature. These voices criticizing medicine are well known in this debate. There are certainly indications that this is the mainstream view among families of people with Down syndrome (Sangster et.al, 2022). Quality of life assessments are though difficult to perform and both the value of these assessments in this debate as well as their outcome has been criticized (Nizar, 2016). For the current discussion these questions are not the main focus of interest. What is of interest is the fact that this criticism exists and is a part of the disability rights debate (Lord, 2013). Therefore, it is important to try to understand it.

It could also be argued that what drives this search for the Down syndrome fetus is not only the aim to prevent suffering for the families but also the unspoken idea of imperfection where it becomes the doctor’s role to prevent that imperfection (Nizar, 2016). The use of medical technology to describe the fetus’s attributes and even predict its future gives the doctor new power and new demands are made of her.

To summarize and outline the dialogue in this key example, the social forces affecting our views regarding NIPT and the need for prenatal diagnosis are scientific and technological developments as well as the effects of the market and public demand on medicine. When we evaluate the relevance of prenatal diagnosis as a medical procedure, we have to regard the social constructional forces influencing that evaluation. In this case these forces are medicalization of life and human enhancement. When faced with a new demand, like the use of NIPT for medical purposes, we need to use the inherent values and ends of medicine as a reference guide. In the course of this evaluation, and by inspecting the opposing views described in the article, an ethical weakness in modern medical practice is located; namely, the tendency to focus on medicine in a scientific sense and forgetting the subjective experience and narratives of those involved. Here, the key example described in the article reduces the fetus to an abstract idea and an entity that has to be eliminated not because it "is" but because of "how it is". In other words, this is not simply an abortion because the woman does not want to have a child, but an abortion because the fetus has Down syndrome and this no longer is seen as a normal pregnancy.

This conceptual frame where the fetus with Down syndrome becomes a sign of an affected pregnancy that has to be terminated, undermines the worth of this particular fetus. In the article it is outlined how this attitude can be dehumanizing towards all people with Down syndrome. This claim is quite strong but it has nevertheless been debated and acknowledged by human rights lawyers interpreting the Convention on the Rights of Persons with Disability as well as by many disability scholars (Diaz, 2019; Lord, 2013; Bryant et al., 2022). This undermines the important core in medicine, that sees and regards all human beings of equal worth.

3.4 The Themes Common to the Key Examples

When we broaden our view and regard the examples in the articles together, we can see that, in all of them are the constructional forces of society changing medicine. Medicine is entering new grounds influenced by scientific and technological developments, medicalization, the market and public demand, cultural pressures, and ideas about human enhancement. The papers I–III describe how this tension between constructional forces and the inherent values and ends of medicine becomes visible in all of the key examples. A closer look at the way this tension is formed shows us the same four themes in all of the articles. The fact that these themes repeat themselves in the key examples gives reason to inspect them further. I will now outline the themes briefly.

Firstly, in all of the papers, the questions, "What is a disease" and "What is not a disease" arise. As a consequence of medicine's expansion, it is possible to locate tension in all of the key examples regarding the question, "Who is and should be medically diagnosed and who is not and should not be medically diagnosed?" In the discussion on surrogacy, it becomes a "disease" to be unable to have a child when one wants one. The same goes for being fat; it becomes the "disease" of obesity. Finally, the fetus with Down syndrome is a sign of an abnormal ("diseased") pregnancy that needs to be terminated. When stating this, I put the disease label in quotes to show that these conditions are at the boarders of medicine. They can be defined as health related issues, but they can also be seen and conceptualized as not being primarily a medical pathology as we will discuss further in the next chapter.These examples also show how getting the disease label through the diagnosis can change the lives of those labeled patients. In all of the key examples, it is necessary to evaluate whether the description and the label connected to the medical diagnosis are the best ways to discuss and solve the problems at hand.

Secondly, in all of the cases discussed in the articles, I reflect upon another dichotomy in medicine: the emphasis on biomedical science on the one hand and the emphasis on the patient as a human being and a vulnerable person on the other. In the discussion on surrogacy, this is demonstrated in the technological advances that seem to construct the surrogate mother as an incubator where the special connection formed between the fetus and the gestating mother are invisible as if they were irrelevant. This is a lack of insight into the lives and feelings of those who are the most vulnerable in the surrogacy process. In the discussion on obesity, these two threads are reflected in the discussion on the classic medical view which uses the language and research methods of biomedical science on the one hand and the subjective view of fat people on the other. Lastly, this dichotomy is clearly spelled out in the article on fetal diagnosis where the scientific view on the fetus with Down syndrome conflates its existence with a medical pathology. The main idea behind this theme is that becoming medical where there is an overemphasis on science can make us blind to the humanity of those who are vulnerable. There is a tendency to rely on science, scientific thought, and argumentation as the only truth and thus blur our thoughts on other aspects of life. It can lead to blindness to ethical insights based on values and ends that give life meaning and purpose. To counter this, it is necessary to recall the important ends and inherent values of medicine: to notice the humanity of others and respond to their suffering. That insight must not stay in the shadow when medicine enters new grounds. It thus has to be emphasized that medicine relies on these norms as well as the facts of science.

Thirdly, in each of the key examples, we have marginalized voices; the voices of those who are vulnerable in the medical system. I am here referring to, in the case of surrogacy, the vulnerability of women who are poor; in the case of obesity, fat people; and finally, in the case of fetal diagnosis, the voices of disabled people and people with Down syndrome. When medicine, under the influence of the constructional forces of society, enters new grounds, there is danger of medicine becoming oppressive towards those who are in a marginalized position in society.

Fourthly, reflecting upon the role of medicine in new situations where it is responding to new demands, we need to pay attention to the relational view. In all of the key examples, it is concluded that it is not sufficient to view the role of medicine as a private matter solved in a discussion between doctor and patient; the expansion of medicine has to be viewed and evaluated contextually as well. The potential oppression of medicine, especially towards marginalized groups, can only be detected if we broaden our view and acknowledge the importance of other people, our culture and context in general. Our environment and situation affect our self-understanding as well as the self-identity of physicians and policy-makers. When ethically evaluating these changes, the context has also to be given ethical relevance. This is because some problems that are now labeled as medical problems can only be sufficiently met through political action. If the ethical relevance of the context is omitted, the perspective is too limited where problems are not correctly located and solutions can be ineffective.

This is very evident in the case of obesity. We need to be able to view obesity not only as a personal problem, but also as a flaw in our environment that inhibits us from leading good lives. If the aim is to lower the incidence of obesity, given that it is a public health problem, this needs to be met through political action. Stigmatization and oppression of fat people should also be met on a relational basis. The screening of fetuses with Down syndrome is another example of a political agenda that controls our ideas. By forming policy decisions where it is the norm to prevent the birth of children with Down syndrome, the line is drawn regarding what should be viewed as normal and what is deviant. This line is the single most influential factor when parents choose to end a pregnancy. The private discussion between doctor and patient does not determine this line; it is a cultural and political decision. Additionally, to construct surrogacy as a private contract between the commissioning parents and the gestating mother is a narrow view on a very complicated and global process. This framing misses the potential vulnerability of poor women in countries where their position is weak, like in India, Thailand, and Ukraine, to name a few. It further misses the complicated changes necessary regarding ethical and legal duties and responsibilities that come with the role of motherhood and parenting.

These four themes can be noted in all of the papers. In the next chapter, I will analyze them further. By doing that, the argumentation in the articles is strengthened and the potential harm medicine can inflict upon marginalized groups is outlined in more detail.

4 The Themes; a Closer Look

I see the common themes from the articles as revealing certain characteristics in medicine's structure that are strained when medicine expands and this tension is formed. The processes described can lead to situations that may cause harm to patients and groups of people. By investigating them, it is possible to see how this potential harm can manifest itself where the meaning of medicine can be affected as it deviates from its ends and inherent values.

4.1 The First Theme: The Difficult Concept of Disease and the Power of Diagnosis

Disease is a fluid and dynamic concept, difficult to both define and demarcate (Hofmann, 2001, 2010, 2021). I will not elaborate in detail on this complex concept in this text; rather, I will focus on the diagnosis. It is approached as a tool to diagnose diseases and health related issues. In the papers, I show how the diagnostic label itself influences, for good or worse, people's understanding of themselves and others. In the article on surrogacy, it is revealed how the underlying diagnosis that initiates the surrogacy process is infertility or not having a child when a child is wanted. When discussing the lives of fat people, we need to evaluate the use of the diagnosis of obesity and how it shapes the lives of fat people. Finally, in the discussion on fetal diagnosis, the impact of the diagnosis of trisomy 21 in the fetus, and hence Down syndrome, is our focus point. The diagnosis draws the line where the distinction is made between what is medical and what is not medical. Consequently, the diagnosis bears with it power; it is a game-changer. Under this theme, I will discuss in more detail the influence of the diagnosis.

To set the background, I will describe three different perspectives on the concept of disease and outline the understanding of terms regarding it that will be my reference point when I discuss this concept. Following, I will turn to the power involved when setting the diagnosis. A diagnosis can be liberating; it can free the patient from stigma, but it can also bring with it oppression and stigma (Garand et al., 2009). The diagnosis has the power to shape both the patient's self-definition and the way society defines him. It can, in some cases, restrict the diagnosed individual from social goods and, in others, give him access to social goods and values. Finally, I will describe the tension between the illness as being the patient's subjective experience, on one hand and the the disease as being the professional perspective on the other, and the ethical danger involved when these two perspectives i.e. the professional and the personal drift too far apart. That will lead us to the second theme: the scientific doctor and the danger of dehumanization.

4.1.1 The Three Perspectives on the State of the Patient.

As mentioned earlier, I have no intention of searching for the correct definition of the concept of disease. Nevertheless, no matter how it is defined, it is fundamental to our understanding of medicine. The way we understand the concept of disease has implications for the health care service as well as any interaction between physicians and patients. I am not going to defend these statements. I am only declaring my own position within this dialogue.

There is a practical way to approach the fundamental concept of disease and the role of being a patient. I will use reference to Parson's sick role and ground my understanding on the perspectives described by Cockerham (2009/2016) in his book on *Medical Sociology:*

> In medical sociology, the term *disease* has been characterized as an adverse physical state, consisting of a physiological dysfunction within an individual; an *illness* as a subjective state, pertaining to an individual's psychological awareness of having a disease and usually causing that person to modify his or her behavior; and *sickness* as a social state, signifying an impaired social role for those who are ill. (Cockerham, 2009/2016, pp. 188–189)

Cockerham is outlining three different perspectives that are all important to medicine. The first one describes the term *disease* as a physical state, the second term being *illness* referring to the experience of the patient, and finally the third term, *sickness* referring to the social reaction (Cockerham, 2009/2016). This gives the disease concept three perspectives where it is viewed as being professional, personal and societal. There is an important insight in all of these perspectives. They sometimes are in harmony but certainly not always. We can have a person with a diagnosed disease that calls for treatment, like raised blood pressure. The person herself would not describe herself as ill nor would she be expected to act as a patient. We could also describe a person's illness, where there are no measurable disease parameters but nevertheless the person feels unable to take on the duties of daily life, e.g. because of severe anxiety, without any known or visible reason. This distinction also gives us an opportunity to separately describe the sick role. Talcott Parsons initially described this in his book *The Social System* (Parsons, 1951/1991). He revises his description in a lecture given in 1975 where he explains the sick role in the following way:

> [B]eing in a state of illness is not the sick person's own fault, and that he should be regarded as the victim of forces beyond his control. A second social-structural feature of the sick role is the claim of exemption from ordinary daily obligations and expectations, for example, staying at home in bed instead of going to school or office. The third is the expectation, if the case is sufficiently severe, of seeking help from some kind of institutionalized health service agency. (Parsons, 1975, p. 262)

In this description, Parson expresses what we all know and take for granted when we talk about sick people. In general terms, we do not expect them to fulfill all of their normal roles in life, e.g. they can be excused from going to work, we do not hold them accountable for their condition, etc. They should try to get well and they should seek professional help and obey or comply with the advice of those who know better. This is a background against which we measure the sick person. When someone has the flu but still shows up for work, he or she is "the Viking," going the extra mile to be a good worker. Or on the other hand, especially after Covid-19, we say, "You should stay in bed, get tested and try to get better." If you are not feeling well and do not seek help or you do not follow the doctor's advice, you are considered careless. We make these judgements because we have underlying expectations of those who are sick.

Consequently, sickness is related to how society defines the patient, as it outlines how the patient should be treated and how the patient should behave. What this tells us is that, by becoming sick, we enter a certain role. Being in a role means that there are duties and responsibilities as well as expectations. This is the interesting bit: a diagnosis can change a person's life in some fundamental way and if the patient has been diagnosed, he is in this new role.

4.1.2 The Power of Diagnosis

The medical doctor holds the power of diagnosis. The diagnosis is the turning point when illness also becomes a disease, when the narrative of the patient describing how he feels becomes a scientific symptom of a recognized classified disease. When this occurs, the person becomes a patient and enters the role of a sick person in society. This is a very important process with diagnosis at the center. Jutel (2009) describes diagnosis as follows:

> Diagnoses are the classification tools of medicine. … It organises illness: identifying treatment options, predicting outcomes, and providing an explanatory framework. Diagnosis also serves an administrative purpose as it enables access to ser-

> vices and status, from insurance reimbursement to restricted-access medication, sick leave and support group membership and so on. Being diagnosed gives permission to be ill. What was previously a complaint is now a disease. (Jutel, 2009, p. 278)

After the diagnosis, the patient's narrative, the complaint, and the description of the illness are organized and explained. The diagnosis is the doctor's tool; they put an order to the complaint so it becomes understandable, and along with it comes the sick role where the complaint is legitimized. The authority to put forward a diagnosis brings power. Changing the patient's description and experience into a formalized and structured disease redefines the patient's life where duties and responsibilities change as well as their status within society.

The diagnosis is not merely a classification of some ontological truth in the body. What becomes a diagnosis is usually related to the patient's symptoms but it is also relational and political. For a symptom or a complaint to gain the status of a diagnosed health related issue or disease can be a negotiating process where contesting voices and groups rally for different solutions (Jutel, 2009). An example of a disputed use of the disease diagnosis is the decision made by the American Medical Association (AMA) to define those with a BMI of 30 or higher as having the disease obesity (Stoner & Cornwall, 2014). This has been debated where many, not least fat people, reject this diagnosis as being unhelpful and stigmatizing. Whereas others, mainly medical doctors, claim this to be beneficial in the battle against obesity which now has reached epidemic proportions. The patients narrative and subjective experience describing the illness may gain the right to be diagnosed as health related issues and diseases but it can also lose the status coming with the professional description. Sadness and sexual problems are non-medical, but when the diagnosis has been made, they are referred to as depression and erectile dysfunction, and they become medical. In a similar sense, the state of being fat becomes obese and showing bad behavior in class becomes attention deficit hyperactivity disorder or ADHD.

The way that diagnosis is used is closely related to medicalization. This medical classification through diagnosis triggers medical action. It can be medication, behavioral treatment, and all sorts of programs that those labeled with the diagnosis are expected to follow. When that happens, the diagnosis becomes a step or an enabling factor of medicalization (Jutel, 2009). This would be the case when the "fat person" becomes the "obese patient." At that turning point, the person has a medical pathology and becomes sick and has obligations to obtain treatment and to use various means to change her body shape. It can also be the other way around where medicalization is the primary factor. An example would be new scientific and technological developments, like advances in fertility medicine, that drive on the medicalization and as such, they create the need for new diagnosis. This is discussed in the article on surrogacy where the technological ability to create babies medicalizes not only the creation and formation of a new life, but also the longing for a child. Single parents, as well as same-sex couples, are potential recipients of the diagnosis label of "involuntary childlessness," and through becoming the consumers of medical procedures, they gain the status of "patients" in the health system. That, in turn, needs to be responded to by medical means where the surrogate mother is conceptualized as a form of treatment method in medicine.

The classic way to structure the physician-patient relationship is by outlining the physician's role as someone who listens to the patient's story, conducts her examinations, draws conclusions, and sets the proper diagnosis. The diagnosis then explains and provides foundation for the proper treatment. There is no doubt that during this process the diagnosis is a powerful tool of medicine, both necessary and helpful. The medical doctor must be able to rely on a categorized knowledge and generalized scientific facts. Nevertheless, the diagnosis can be a double-edged sword. Although its use can be very helpful, it can also bring with it downsides for the patient. This is most likely to happen when there is a gap between illness and disease. Here, illness refers to the patient's description or feeling, whereas the diagnosis is the doctor's definition, making sense of the sometimes messy narrative and changing it into a categorized fact where it is generally accepted and placed within an explanatory framework. There are those who long for the diagnostic label but do not get it because there are no visible biological indications, and as such, no negotiated generalized scientific reference for the complaint. However, when the patient finally receives a diagnosis, he might experience relief and a feeling that life suddenly makes sense. An example would be patients with chronic fatigue syndrome. They experience unexplained fatigue and are unable to face simple tasks in life without a visible biological explanation. Without a diagnosis, their feeling seems unreal and they are not receiving the necessary understanding in society. Some are faced with the stigma of not behaving accordingly, labeled with some stigmatizing psychogenic explanation. To them, the diagnosis and gaining access to the sick role are a relief.

On the other hand, the diagnosis itself can limit a person's options and be traumatizing. Some people will deny their diagnostic label. We see this in the discussion on obesity where fat people claim that, instead of defining the state of being fat as a medical pathology, this diagnosis is instead a label causing discrimination (Patterson & Johnston, 2012). People with

Down syndrome have also denied their diagnostic label, like Pablo Pineda who, in a television interview, denies the categorization of Down syndrome as a medical pathology but refers to it as a characteristic (Pineda, 2015). Pineda, having Down syndrome himself, describes the need to escape the factual definition of the diagnostic label and the limitations that can come with it.

Jutel (2009) further names routine screening of people without any symptoms for cancer as an example of disputable diagnosis. Claiming that this is a way of using medicine as a means to examining everyone, going from the assumption that we are all potentially sick until proven healthy. Jutel refers to this and says: “The disease potential is a salient means of social control and is amplified by the ever-expanding technical access to new screening tools” (2009, p. 291). Through screening, people without any known illness receive positive screening results that sometimes lead to diagnosis of a disease. This early diagnosis can indeed prevent harm as some screening programs most certainly do. However, there are also screening procedures that are highly debated since the diagnosis itself of potentially precancerous conditions is based on biological changes that, if left untouched, do not always lead to illness and death. These false alarms, also called overdiagnosis, can be harmful in triggering unnecessary treatment as well as causing anxiety and even death to the diagnosed person (Adami et al., 2019; Moynihan et al., 2012).

These examples show the forceful impact of medical diagnoses. The ethical problems related to a diagnosis are especially likely to arise where there is a tension between illness and disease. This occurs when the connection between the personal experience of the patient (illness) and the professional perspective (disease) —based on the categorization and explanatory framework of the diagnosis, —are drifting apart. This deepens the dichotomy between the illness and the disease where the patient’s experience has little and sometimes no connection to the doctor’s professional perspective, as in the cases of Pablo Pineda and screening above. This gap is a potential ethical danger zone since the thread between the patient’s subjective experience (illness) and the doctor’s professional perspective (disease) is what forms the connection between the doctor and patient. This connection is very important since it is a part of the foundation of medicine as a profession, resting on the caring bonds between human beings. For the doctor to understand the illness, she must be able to listen to the patient and to sympathize with him. She must further realize and understand the connection between the patient’s particular case and the general knowledge of the medical explanatory framework. This leads us to the next theme where the discussion addresses the danger of viewing science as the core of medicine and forgetting the importance of seeing medicine also as a humanistic endevour.

4.2 The Second Theme: The Scientific Doctor and the Danger of Dehumanization

In the papers, I have already described how medicine can silence the patient's voice and narrative through the biomedical language of science. Pablo Pineda reflects upon this point when he, having Down syndrome himself, says, "I always say I am Pablo Pineda and that I have Down's Syndrome. There is a big difference between 'having' and 'being.' 'Being' can crush you down and 'having' shows it is only one feature" (Pineda, 2018). In this interview, he refuses to be defined only by a diagnostic label. I highlight a similar example in the article on fetal diagnosis where I discuss how the reference changes in medical texts where, instead of speaking about a fetus with trisomy 21 or Down syndrome, the authors refer to a pregnancy affected with (the disease of) Down syndrome and that can be dealt with by terminating this affected pregnancy.

A similarly structured example already described in the article on obesity is when "fat people" are reduced to the medical pathology or "disease obesity". In this example, the scientific position describes the obese person primarily through objective descriptions of numbers, hormones, and morbidity and mortality risks with no real insight into the personal feelings and lives of fat people. In the article on surrogacy, it is argued that because of how surrogacy is conceptualized, scientific medicine is prone to undermine the humanity of the women carrying the fetus. She is then under the danger of being described as a part of the toolbox of the scientific doctor in the surrogacy process.

The second theme will reflect further upon what has already been introduced in the papers; the potential danger of reducing people into organs and biochemical processes and even into medical pathologies like diseases. At the center of this discussion is the acknowledgement of medicine's two important threads: the scientific and the humanistic threads. This challenge medicine faces, being an enterprise based on science for the good of the patient, creates a delicate balance that can easily be disturbed. I will here describe two possible ways of leading medicine astray: One possibility is the danger of science diverting medicine away from its ends where it instead aims towards "perfection" where medicine does not accept us as the imperfect mortal beings that we are. Another possibility is that the aim of medicine becomes too narrowly defined, where medical knowledge reduces the patient to organs, cells, and biochemical processes. The focus is on the systematically and biomedically structured medical pathology like the disease where the patient as a person can be lost. The then narrow aim of medicine is only to mend organs, not to heal patients. To connect this to the earlier discussion regarding the first theme, these two fallacies are more prone to happen when the disease or the professional perspective drifts too far apart from the illness or the subjective experience. In other words, the doctor's diagnosis does not have proper contact, understanding, and sympathy with the particular patient and his experience, narrative and sufferings. Then, there is the ethical danger of the doctor placing herself primarily with the generalizations of science which form the explanatory framework grounding the definition of the disease. This could undermine the importance of the subjective view inherent in the patient's illness, i.e. the importance of the patients' narrative and complaint. This overemphasis on the generalizations of science can cause harm to the patient, occurring when the ends of medicine, being "the need of sick persons for care, cure, help, and healing" (Pellegrino, 1999, p.60) are no longer the primary focus.

To gain better insight into this line of thought, I begin the discussion on the second theme by outlining further Jonsen's historic description of medicine. This discussion was introduced in paper III, where the ethos of medicine and its emphasis on attention towards the patient was outlined. There, the two roots of medicine Jonsen introduces are discussed and it is highlighted how the development of the diagnosed diseases as a separate entity has deepened scientific influence. I will then turn to examples showing how overemphasis on science can pose dangers to the humanity of the patient.

4.2.1 Jonsen's Two Roots of Medicine

In his book, *The New Medicine and the Old Ethics,* Jonsen (1990) refers to an ancient foundation of medicine which is constituted of two distinct traditions: one is the influence of Hippocrates, the ancient Greek root of medicine, and the other is the medieval Christian tradition of medicine.

In the Christian tradition, the general understanding was that the physician was, first and foremost, the instrument of God and a servant of the sufferer. The guiding light of those who looked after the sick and suffering in the Middle Ages is traced to the parable of the Good Samaritan in Luke 10:30-37. The attitude so clearly manifested in this story remains an important undercurrent in the relationship between doctor and patient. The story explains how suffering is noted and responded to (Winch, 1987). Accordingly, the medical doctor is called upon to heal and minister to anyone in need; the parable contends that every doctor follows in the footsteps of the Samaritan and every patient is his neighbor in God's image. In other words, working to heal and alleviate suffering means serving God and being concerned about a human being. One *sees* the person and, through one's work, *reveals her humanity* regardless of identity; that is, cares for a human being without pronouncing a judgement (Gaita, 2002; Winch, 1987). This tradition is bringing with it a powerful duty where, "The Christian physician was obliged to remain in the plague-ridden city and to treat the poor without charge" (Jonsen, 1990, pp. 9–10). This strong duty is not only ancient history, or a dead letter. It is still very much alive as has been demonstrated in the current Covid-19 pandemic. As outlined in an editorial in Lancet, we see health care personnel all over the world tending to sick patients, and many of them are doing this without having the proper equipment to defend themselves (COVID-19: learning from experience, 2020). As a consequence, the lives of doctors and nurses, as well as other health care staff, have been lost in the ongoing battle against this disease.

The other tradition found when investigating the roots of medicine is what Jonsen refers to as the ancient Greek tradition of medicine. This is traced to ideas attributed to Hippocrates, the father of medicine. Three considerations in particular have caused him and his ideas to be considered the origin of modern medicine (Nuland, 1995). The first is the Hippocratic tradition and the idea that it was not a divine or supernatural power that was influencing diseases and their cure. In Hippocratic medicine, the physician was seen as a human and the disease was considered natural in origin. It was a part of the normal process of causes and consequences. Thus, the cure was also a natural process. Therefore, it was important for the physician to depend on his reason and perception to describe a disease. Through reason and perception, the disease could be understood, its processes analyzed, and a cure sought. With these ideas, Hippocrates laid the foundation of medicine as an empirical science (Nuland, 1995). Nevertheless, the physician always has to look at each individual case and evaluate it as such since each individual could respond in a unique manner. Thus, in the Hippocratic sense, medicine was not only an academic subject; it demanded insight which not everyone could grasp and was also a form of art.

This takes us to a second consideration that characterized Hippocratic medicine and strongly influenced the development of Western medicine. The Hippocratic physician saw the disease not as a part of a general theoretical framework. She defined the disease in relation to each particular patient. In that sense she was a clinical physician, drawn from the Greek word kline which may be translated as bed (Nuland, 1995) and refers to a physician who attends to the patient at his bedside. Thus, the clinical physician is first and foremost the person who takes care of the patient. She understands how the disease affects this particular person.

The third hallmark of Hippocratic medicine was the Hippocratic oath (Hippocrates, 2008) which laid the foundation of a professional class. As a professional, the physician respects her profession and promises to always be guided by the patient's welfare. Hippocrates emphasized that only by devoting your life to the profession was it possible to succeed and help the patient move towards better health (Hippocrates, 2008).

The medical profession is now characterized by the tension between the natural sciences which can be traced to its Greek analytical background i.e. the idea that the disease was a process of natural causes and consequences and the Christian tradition with its emphasis on caring and compassion.

Phrased in a different way, we can point to the medical student who has to understand the subject of medicine by learning the processes and the system which must be adopted: the symptoms, leading her to the correct diagnosis and treatment. But she must not stop here. She must understand that medicine is something more. To succeed in her profession, the physician must be aware that the patient is not simply a collection of natural processes, causes, and consequences, but also a person with feelings, desires, and will. She also has to learn that things do not always turn out as intended. There is uncertainty and risk. The task of the clinical physician is to bridge the gap between the natural sciences and the insight into the particular patient's life and experience. This has always influenced the professional career of the physician and carved its unique character.

With the advances of medicine, the influence of biomedical sciences as the founding element has increased. This tension between general knowledge based on the methods of science and the particular insight into this particular patient's life and needs is again reflected in the history of diagnosis:

> [M]odern diagnosis did not emerge until the mid-nineteenth century. Before that time, diagnoses were fluid, fluctuating, and focused on the individual patient. Central to modern diagnosis was a conception of specific diseases that existed independently of individual patients. Each disease had a narrative or clinical course – a history, a present, and a prognosis, as well as an underlying mechanism (or pathophysiology). (McGann et al., 2011, p. XV)

Here, it seems as though the diagnosed disease has almost gained a life of its own, where its connection to the individual patient is not the main thing but rather the systematic categorization to which it belongs. The common description of the disease becomes a world of its own and is almost independent of the patient. Instead of describing the patient's narrative and viewing that as the origin, the fundamental truth comes with the general explanatory framework of the diagnosis. There lies the knowledge against which everything is measured. The patient's narrative has to be explained and understood in light of the diagnosis. This separation between the diagnosed disease and the patient continues:

> Beginning in the nineteenth century, the practice of diagnosis moved away from the patient's subjective narrative toward clinical signs of diseases, detected through the physician's unaided senses – palpation, observation, and percussion – which in turn gave way to a reliance on diagnostic technology. (McGann et al., 2011, p. XV)

This new series of technological advances—at first, simple medical instruments like the stethoscope and later, more refined measures like x-rays, EEGs, and MRIs—have revolutionized medicine. They are the foundation of medicine's progress. However, it also increases the distance between the patient's experience and the doctor's objective world. The doctor is the expert in the objective world; she understands the scientific language used, places her trust in it, and begins to redefine medicine primarily as a scientific endeavor where the patient stays in the shadow. Here is where the danger of reducing medicine to science begins.

It is necessary to base medical decisions on scientific evidence. But reducing medicine to medical science is problematic. This reduction omits medicine as an art and as a humanistic endevour. It further creates inaccurate aims for medicine. Firstly, the aims have a tendency to be unrealistic. As a result, it is forgotten that human beings are inherently imperfect, mortal beings and medicine's true aims are in its ends, i.e., to support us in our weakness. If medicine becomes medical science, there is a tendency to deny the frailty and inescapable mortality of human beings and the importance of helping and caring, not only healing and curing. In the next chapter, I will explain and discuss further how the ideal of the "immortal and healthy person" is an illusion that seems to become scientific medicine's aim. It is then forgotten that we are all with some inherent faults, and as such we all have diseases and tendencies to get diseases simply because we are mortal beings.

Secondly, medicine's aims can be shortsighted where the scientific lens is most often narrow. Medical science tends to divide and compartmentalize the patient. If medicine is reduced to medical science, we can lose what is most important: the core of it all, the person herself. Then the aim is no longer the patient's needs and well-being, as defines its ends, but instead, the fate of the diagnosed disease. Both of these aims have lost their connection with the medicine's proper ends, and as such, can harm patients. I will now reflect upon both of these ethical concerns.

4.2.2 When Medicine is Not True to its Ends: Ignoring the Vulnerability and Mortality of Human Beings[5]

> "Georgiana" said he, "has it never occurred to you that the mark upon your cheek might be removed?"
>
> "No, indeed," said she, smiling; but, perceiving the seriousness of his manner, she blushed deeply. "To tell you the truth, it has been so often called a charm that I was simple enough to imagine that it might be so."
>
> "Ah, upon another face, perhaps it might," replied her husband, "but never on yours. No, dearest Georgiana, you came so nearly perfect from the hand of Nature that this slightest defect, which we hesitate whether to term a defect or a beauty, shocks me, as being the visible mark of earthly imperfection." (Hawthorne, 1843/1987, p. 119)

This quote is from a short story by Nathaniel Hawthorne called *The Birthmark*. The story is about the scientist, Aylmer, who marries the beautiful Georgiana. Although Georgiana is both beautiful and intelligent—in fact, almost perfect in every respect—she has one blemish: a birthmark on her cheek which, in her husband's opinion, casts a shadow upon her beauty. Aylmer develops an obsession with this birthmark and wants to do all in his power to rid his wife of this flaw; she can only become perfect if the mark is removed. Aylmer is a famous scientist and he expends all of his energy on finding a scientific way to remove the birthmark. Finally, he blends a drink for her to consume to help the mark disappear. All goes according to plan: Georgiana ingests the drink and the birthmark vanishes. At long last, Aylmer has a perfect wife, with nothing to mar her beauty. But then the drink proves fatal.

Hawthorne's story deals with human imperfection and our attitudes toward it. Aylmer sees the birthmark "as being the visible mark of earthly imperfection," and it is this earthly imperfection that is the cause of his animosity. It is this—the vulnerability, difficulties, disharmony, mortality, etc.—which Aylmer wants to eradicate at any cost. He is not prepared to face the fact that imperfection is an inescapable aspect of human existence and, in an important sense,

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[5] A part of this discussion has already been published in Icelandic in the article: Stefánsdóttir, Á. (2009). Fósturgreiningar: Tengslin við læknisfræðina, ófullkomleikann og lífshamingjuna. *Hugur, 21*, 30-51.

the key to the best qualities of human life. As Georgiana lay on her deathbed, the birthmark gone but her life ebbing away, her last words were:

> "My poor Aylmer" she repeated, with a more than human tenderness, "you have aimed loftily; you have done nobly. Do not repent that, with so high and pure a feeling, you have rejected the best that earth could offer. Aylmer, dearest Aylmer, I am dying!" (Hawthorne, 1843/1987, p. 130)

It can be argued that if medicine is primarily considered a scientific endeavor it has the wrong aim, and does not adequately acknowledge its ends. This can happen when the acceptance of our imperfection and humanity stays in the shadows. This sort of endeavor would assume the same tendencies as the young scientist in the short story above: he only focuses on the flaw and forgets his wife. Conflating medicine with science can shift the aim from helping a vulnerable patient to something else entirely. The aim is to eliminate the "flaw" at all costs. Sometimes this goes so far that, if the "birthmark cannot be removed", if it is an inherent part of the human being, as in cases of a fetus with Down syndrome, it is thought better to abort the foetus and thus prevent such an individual from being born. This could imply that the aim of medicine is to avoid all that can make us different, weak, and create difficulty in our lives, even to the extent that it is considered better to avoid their existence.

We can also see these tendencies where the aim shifts in the discussion around obesity. Propaganda phrases like, "War against obesity," are examples of ways when the debate is constructed in such a way that the person herself gets lost. Her vulnerability, and her feelings stay in the shadow and obesity is seen as an isolated "flaw" that is to be eradicated. Fat people themselves have described how they experience this "war against obesity" as a war against fat people (Pausé, 2014). As in the case of Aylmer, the aim to eradicate the "flaw" overshadows everything else, where no attention is paid to the possible consequences, and without ever trying to see the beauty in the imperfection.

Sandel (2009) discusses in his book, *The Case Against Perfection*, the problems that face us if we make perfection our aim. I sympathize with Sandel's view; I think it is fundamentally wrong to aim for some sort of perfection or to try to create only perfect people. Nevertheless, that is not the main point of my argument here; rather it is to show how medicine has a tendency to deviate from its ends. I want to draw attention to the importance of guarding the old aim of medicine understood as ends. I am in this respect referring to Pellegrino's description of the ends of medicine as "the need of sick persons for care, cure, help, and healing" (1999, p. 60). In other words, to remember that medicine's aim is primarily a humanistic endeavor dominated by the need to help and support a human being in need. All medical deeds gain their meaning through these ends.

Medicine under the dominance of science has not merely been criticized for being unable to accept us as we are with all our imperfections. It has also been depicted as aiming to make our lives shallow and meaningless since the only thing that matters is to reduce pain, increase well-being, and prolong life. This view is reflected in the book, *Discussions of Simone Weil*, by Rush Rhees (2000) which discusses the philosopher, Simone Weil, and her vision on suffering. Weil maintains that meaning may be found in suffering and the book presents a certain perception that medicine encourages the mirage that life must be free of suffering; a view which exposes the inability to accept our limitations and mortality:

> People think of human suffering as some sort of mistake, or something which the advance of medicine has not yet managed to deal with but given time we shall be able to put it right. With the progress of medicine and of genetics and other sciences, suffering can practically be stamped out. (Rhees, 2000, pp. 174–175)

The above quote appears to describe a similar attitude to human imperfection—in this case, suffering—and the same kind of vision of medicine where its progress is the progress of science, as presented in Hawthorne's story. Medicine is here depicted as sharing the same aim as science where medicine aims to remove all of our suffering, and suffering is described as mere mistakes in human existence. The quote above could be interpreted as science viewing the perfect life as one that is free of pain. If science-directed medicine could help us mold our lives in this fashion, should we do it? We should keep in mind that when Simone Weil is criticizing this view, she is not claiming that suffering itself is desirable or an aim in life; rather, she is pointing out that it is a grave mistake to assume that difficulties and sufferings will reduce the value of people's lives. Life simply has a deeper meaning than the sole search for well-being and the avoidance of suffering. It is also an oversimplification to describe the aim of medicine as eradicating suffering and seeing suffering as some sort of mere mistake. To understand the true aim of medicine, it is necessary to describe it by referring to the ends that give medicine its meaning, i.e., where medicine responds to "the need of sick persons for care, cure, help, and healing" (Pellegrino, 1999, p.60). Here, as in the example of Aylmer's wife, it is necessary to focus on the sick person, not their alleged flaw.

I will now continue to reflect upon this important difference and relate it to the discussion in paper III. When the fetus—or maybe more correctly, the pregnancy—is labeled with the diagnosis "Down Syndrome", the question is aroused whether the pregnancy should be terminated. By doing so, the future frequency of those with the functional impairment of "Down syndrome" is lowered in the population. Since Down syndrome is associated with a higher incidence of many diseases this intervention is seen as a way of disease prevention. When those families of people with Down syndrome who criticize the policy to abort the fetus with

Down syndrome, they deny this as being a solution to a problem. They do not accept this way of structuring the discussion. They question the premise that a problem exists and they do not view this as e.g. disease prevention since they are not viewing the label of Down syndrome as a medical pathology or as anything that needs to be prevented (Björnsson, 2001). Some describe the process to abort the fetus like removing a natural variation that occurs in life. Life is unexpected, varied, and rich, and above all, not always as we want it to be. The sociologist, Dóra S. Bjarnason—mother of a disabled young man—describes this as follows:

> Human diversity is at the core of society. A community where highly educated health care staff advise parents to have a fetus aborted on the grounds that it may be born with disability, is guided by prejudice and ignorance. In my view, this is as unthinkable as aborting a foetus because of its gender or skin colour. Disabled people are a necessary aspect of the social spectrum, in the same way as the chorus in Beethoven's ninth symphony or the strings in Mahler's music. (Bjarnason, 2001, p. 35)

According to this view, unexpected circumstances in life, such as the birth of a disabled child, do not signify a mistake or accident; as indicated by both parents above, such events help assign meaning to life.

If those who criticize the search for fetuses with trisomy 21 in the texts above are right, then physicians have a very limited insight into human existence. Doctors, according to their critics, appear to be strictly focused on lowering the frequency of diseases and eliminating pain. As a consequence, they show a lack of comprehension of life itself, where you do not comfort a person in pain by eliminating her. It should be noted that here they would be referring to fetuses or, in other words, future persons with Down syndrome, where excessive emphasis was put on preventing their birth instead of accepting them as they are with their qualities and faults.

This criticism of medicine, voiced by Down syndrome activists and their families described in the article on fetal diagnosis, refers to the "scientific doctor" or in other words the doctor who has reduced medicine to medical science and thereby forgotten the Christian root of medicine described earlier. The Christian root outlined above reminds us that the core of the physician's focus is always the patient and the role of the doctor is to help and heal. Such a doctor knows that the patient is vulnerable and mortal. If this knowledge is forgotten, medicine is no longer true to its ends.

I might now be criticized for painting the challenges of life in strong colors by using the example of NIPT to reflect upon the doctor, who understands medicine primarily as a scientific endeavor. I further refer to this particular example of fetal diagnosis and the search for the Down syndrome fetus as being steered by an incorrect aim where medicine is no longer true to its ends. Or as claiming the use of NIPT to be an example of a type of medicine aiming at eradicating human imperfection thus potentially harming "the best the earth can offer" (Hawthorne, 1843/1987, p. 130).

When science becomes too dominating, medicine has a tendency to deviate from its ends by following a new aim instead of focusing on "…the need of sick persons for care, cure, help, and healing" (Pellegrino, 1999, p. 60). I want to highlight that it is the need of the sick person that shapes the end, where the existence and infinite value of the imperfect, vulnerable, and mortal person is never doubted. Of course, this description of medicine, where the "scientific doctor" plays the leading role, is not to be taken as all encompassing. It does not describe all doctors but describes some doctors and what can possibly happen. It should be noted that I am primarily outlining ethical concerns, where medicine may cause a specific type of harm towards patients or groups of people and the purpose of the discussion is to show how this harm can occur.

In this discussion, the fetus with Down syndrome is referred to as being in some sense equivalent to "the patient", whereas the will of the prospective parents are not addressed at all. This can be seen as a weakness in my argumentation. There are many who would not accept the fetus as having any possibility of being referred to as a patient in any discussion. The fetus has a questionable position in this respect and certainly the position and the will of the parents does matter. The article on fetal diagnosis reflects upon both the status of the fetus and NIPT as a reproductive choice. In the current discussion, it is necessary to recall that and to highlight three things in defense of focusing on the fetus in this argumentation. Firstly, that the functional impairment or the "flaw" itself is located in the fetus, not in the parents. Secondly, although the fetus is not a person, it can be referred to as having the potential of becoming a person. Thirdly, the decisions we make regarding this potential or future person are influenced by and does influence the way we regard people with Down syndrome that are alive today (Diaz, 2019; Lord, 2013; Bryant et al., 2022).

Finally, although, I refer in this discussion to NIPT as an example showing how medicine can deviate from its ends, I am not making generalizations about fetal diagnosis. Fetal diagnosis is one of the important tools of modern medicine. As such, it can certainly prove beneficial. Nevertheless, its proper use is very ethically challenging for the medical doctor. The difficulty in handling the information coming from fetal diagnosis is always hard since it involves predicting the value of the future life of any person based only on their genetic traits. What matters in this discussion is also the difficulty of this particular diagnosis where the gap between illness, (the personal narrative of people with Down syndrome and their families) on one hand, and disease, (the doctor's idea of Down syndrome) on the other, can be wide. This gap is further heavily influenced by social, cultural, and even political forces. This influence on the decisions and choices, e.g., regarding NIPT, have also been discussed in the article on fetal diagnosis. When I claim the gap between illness and disease in this discussion to be wide I am referring to those who deny this as being pathological at all. In other words, those who do not accept Down syndrome as being a functional impairment that should be screened for and claim that such policies lack tolerance towards human diversity and difference (Lord, 2013). For them, there is not a matching illness, or increased suffering, hence there is no need for this screening policy. The human rights lawyer Janet E. Lord (2013) has pointed out that human rights law has evolved in its conceptualization of disability whereas it now views disability not as medical pathology but as a human rights matter impacting a highly marginalized population (Lord, 2013). This perspective is at the core of the Convention on the Rights of Persons with Disability (CRPD). Those interpreting this convention have claimed that using NIPT in antenatal screening is a form of discrimination against fetuses with Down Syndrome and as such a breech of this convention (Diaz, 2019). These views conflict with the mainstream medical view described above. Regardless of whether Down syndrome is an impairment that needs to be screened for or not, those offering NIPT to prospective parents must be aware of both views, i.e. the understanding of Down syndrome as an impairment that should be prevented from being born and Down syndrome as a sign of human diversity or characteristic of a highly marginalized population. For the medical doctor to remember these two views as worthy of respect, it is helpful to keep in mind some fundamental perspectives in life. I am here referring to what was discussed above that the medical doctor needs to remember that there is beauty in what might be seen as imperfection, and that we are all vulnerable, and that we are all mortal. By saying this, I am not trying to defend a view claiming that medical doctors should ignore the wishes of parents wanting to abort a fetus with Down syndrome. What I am on the other hand drawing attention to is that when doctors and policy makers structure policies around fetal diagnosis and when medical doctors speak to parents two things need to be clear: Firstly, as disability scholars, Down syndrome activists as well as human right lawyers have repeatadly pointed out, it is not possible to claim the Down syndrome fetus as being of less value than that of other fetus. Secondly, the decisions that follow when tests like NIPT are offered have a normative dimension from which the doctor cannot escape. In other words, medical decisions have an ethical dimension and it is necessary for medical doctors to be familiar with what that entails.

In summary, when the aim of medicine deviates from its ends where the main focus is eradication of pain and imperfection, the humanity of those who are sick and vulnerable can be threatened. As a result, the meaning of medicine can change since medicine is no longer true to its ends.

I will now turn to the second ethical concern that can occur if medicine is only described as a scientific endeavor. Here, I refer to the doctor who sees only organs and diseases but misses the person.

4.2.3 When Medicine is Not True to its Ends: Seeing Organs and Diseases but Missing the Person

In paper III, there is a reference to the story, *The Death of Ivan Ilyich*. There, Tolstoy draws up an excellent example of a physician who lacks the understanding of how a disease relates to a patient's life. He only speaks about organs but seems to be totally ignorant towards the patient as a person, his feelings and the fact that Ivan Ilyich is dying.

The doctor completely omits what is, in fact, the core of a clinical doctor's profession and what separates him from the scientist: the human connection where the doctor has to notice and care about the patient. The story is written more than a century ago, yet is illustrative of how a certain trend in modern medicine can manifest itself, reducing the patient to organs and letting their disease overshadow them. I will reflect further upon this trend in this chapter.

Advances in science and the focus on the diagnosis has laid the foundation for what has been labeled "the biomedical model" as dominant in medical research. New medical knowledge thus being analytical, biochemical, and reductionistic where the truth about diseases is primarily sought at the deepest biological levels (Allert et al., 1996; Kirkengen et al., 2016). This way of constructing medical knowledge has also been very successful, especially in fighting infectious diseases. It does, however, have its downsides. In the report published by Hasting Center, mentioned earlier, this is described in the following way: "At the clinical end, a purely biomedical model too often leads to a reductionistic approach to patients, encouraging clinicians to treat them not as whole persons but as collections of organ or molecular systems" (Callahan & Hanson, 1999, p. 35).

This reduction of the person to collections of organ or molecular systems can manifest itself in many ways in modern medicine. The evaluation of mammography screening is a current example of how compartmentalizing the patient can be misleading. In this case, instead of viewing the whole person, only certain organs are in focus and thereby the results of questionable value. Mammography screening to prevent breast cancer is an accepted form of cancer prevention in many countries and recommended in the European Union (Basu et al., 2018). The benefit of this screening is nevertheless debated (Adami et al., 2019; Autier et al., 2017; Njor et al., 2013). Most researchers agree that, by screening for breast cancer, it is possible to reduce mortality from breast cancer, which at first glance is a positive measure. What complicates this, however, is that the screening process does not lower total mortality. It has even been debated whether groups of women who participate in screening for breast cancer have a higher total mortality rate than those who do not participate in such screening. This might be interpreted as an action where the "lives and health of women" are reduced to the "life and health of breasts" since only by doing that there is a clear benefit in screening. In other words, by simply viewing the breasts and the only parameter being death from breast cancer, the benefit is clear. Here, it seems to be forgotten that the core of the issue is human lives, not simply breast cancer rates. If the whole person is kept in perspective, the results become more complicated and the harm and benefits much more difficult to evaluate. The number of deaths from breast cancer prevented must be weighed against possible harms and deaths resulting from overdiagnosis and anxiety related to screening. These deaths are related to adverse reactions from over-treatment, heart and vascular diseases, and anxiety and depression, all of which can result from screening. These additional deaths which the screening *per se* causes, can outweigh the possible benefits of screening. In light of this, breast cancer screening may well be questioned (Adami et al., 2019).

Another example where the patient might be reduced to a mere collection of organs is considered in the article on surrogacy. When surrogacy is conceptualized as medical treatment, there is always the danger of giving the prospective parents priority. They would then be in the role of the patients and the gestating mother is referred to not as an agent but as a "surrogate" and becomes "instrumental" and a part of the medical means to cure infertility. One of the ethical concerns regarding this conceptualization is therefore the danger of reducing the pregnant women to a fertility organ. Although, this is not likely in the more affluent parts of the world where the social status of the gestating mother and the prospective parents is similar, this is a concern in transnational surrogacy arrangements in poorer countries (Gunnarsson Payne et al., 2020).

The biochemical model is not only criticized for compartmentalization of the patient; it also shows lack of insight into what the patient truly wants and even is. In response, there is a movement that advocates for a different model to describe the connection between the doctor and the patient. This has been labeled "patient centered medicine" (Stewart et al., 2013). The aim is to change the doctor-patient relationship based on paternalism and authority and refer instead to a model that is founded on the ethical principle of patients' autonomy. This approach is, in many ways, promising in its attempt to advocate for a more holistic view of the patient and involving the patient in decision-making in health care service. Sacristán (2013) has described this model and responses to it:

> In fact, in the last few decades, health care has been characterized by a provider-centered model [2] with an emphasis on the evaluation and treatment of diseases rather than the evaluation and treatment of patients. Personalized medicine reaches its full significance as the opposite of “depersonalized medicine” or “illnessoriented care”, the aim of which is to treat the illness, not the patients with the illness. (Sacristán, 2013, p. 1 of 8)

Sacristán (2013, p.2 of 8) summarizes the highlights of it in a comparison in the following table:

Characteristics of the traditional medical model and patient-centered medicine

Traditional medical model	**Patient-centered medicine**
Provider-centered model	Patient-centered model
Founded on the principles of beneficence and authoritarianism	Founded on the principle of autonomy
Disease-oriented care	Patient-oriented care
Focuses on outcomes of importance for physicians and regulators	Focuses on outcomes of importance for patients
The patient’s perspective is usually ignored	The patient’s preferences, objectives and values are taken into account during decision making and delivery of health care
Compliance with the physician’s decisions	The patient and physician share decision making
Improve outcomes for the average patient	Improve outcomes for the individual patient
Population-oriented research	Patient-oriented research

In this approach described by Sacristán (2013), the attention is on the patient's preference but it is nevertheless founded on evidence-based medicine. This comparison emphasizes the fact that medical knowledge should not be solely based on the biomedical model and population-oriented research. Information and knowledge should also be gathered from the individual patient. This takes into account the fact that the knowledge that medicine needs is not only biological processes—where the human being is structured as a machine without the ghost—or in other words, are depleted of a soul. To base medical knowledge on a real human being and see character, thoughts, and will as an integrated part of it calls for additional ways of constructing medical knowledge. This needs to be done by giving alternative manners of research—like research based on qualitative methods—a role along with the former named classical scientific methods of biology.

This approach, being evidence-based but placing the patient and his preferences at the center, promises to lessen the gap between the patient and the disease or, in other words, is an attempt to put the lost person back into the lens of the scientific doctor.

It is promising when medical work does not leave the patient in the shadows. Nevertheless, I want to name three concerns regarding the view described by Sacristán (2013) where the emphasis is on patient autonomy as the founding principle in medical work.

First, it is important to be careful that this approach does not undermine the importance of beneficence in medicine. The medical profession must value both the patients' autonomy and their beneficence. In her work, the medical doctor must listen to the patient and respect his wishes, but she is also bound by the promise to do what is in the patient's best interest and not to harm him. It can be difficult to value both. On the one hand, the patient that is seeking the doctor's help is in a weak position where he always needs support and has to be able to trust the doctor to perform in his best interest. On the other hand, it is important for the doctor to know the patient's values and goals so she can meet his needs within that framework (Árnason & Hjörleifsson, 2016). The doctor has to support the patient and use her knowledge to benefit him while also respecting his wishes within the framework of medicine. In Sacristán's (2013) description of the patient-centered model, there is the danger of an overemphasis on patient autonomy. That could lead to a system where the main drives are preferences but welfare and needs stay in the shadow. Although this may not be the case in other models on patient-centered medicine, I do find it necessary to draw attention to this possibility and the need for it to be addressed as these models develop.

The second concern, is that we must also remember that if the emphasis on autonomy within the health system becomes too strong, there is an unrealistic belief in the patient's ability to express a clear opinion within the health system. As a consequence, the patient might gain more responsibility for the treatment than is justifiable and is then less likely to receive the support he needs. Why do I doubt the ability of the patient to express his opinions within the health system? The health care system is a system of power and the physician-patient relationship is not based on a mutual connection between equals. I am not saying here that it should be; I am simply stating this as an inescapable fact. The $ system is structured to meet the needs of those who often cannot take care of themselves and are dependent on receiving help (Árnason & Hjörleifsson, 2016). That per se moulds the way the medical system tends to work. To illustrate my point that autonomy is an elusive value within the health system, I want to recall the description of how women in maternity care make decisions, as discussed in the article on fetal diagnosis. The article provides examples of young, relatively healthy, and often, well-educated women in maternity care who are given a choice regarding fetal testing. It can be debated whether these women are ill at all. Although pregnant, they are healthy, and yet they are placed in a system where they take on the role of a patient, and simply to be in that role seems to make them less autonomous. Research has shown that, in these circumstances, even these healthy women were choosing what they thought their doctors and midwives expected of them (Kristjansdottir & Gottfredsdottir, 2014). Pregnant women are most certainly a vulnerable group, but not necessarily when compared to other patients. These women are usually not suffering from more debilitating illnesses, and they are well-informed and physically able to make decisions. Hence, the vision of a well-informed autonomous person in a discussion with health care personnel within the health care system on an equal basis is very challenging to achieve, even among the relatively healthy and most affluent people.

That leads us to the third concern: if health care is "founded on the principle of autonomy" as Sacristan (2013) describes it above, that might increase the gap within health care services between the patients who are strong and well-informed, on the one hand, and those who are marginalized and weak on the other. Sacristán (2013) mentions this worry in his description of patient-centered medicine:

> For the patients, decision aids have been developed that could help them in this process [23], but the patients would need to fundamentally change their attitudes and have a greater level of literacy to fully benefit from these aids. Patients must clearly describe their expectations and choices, and accept the uncertainty that

> surrounds each medical decision. The patients must also understand that their responsibility is to not just follow their doctors' orders but also take joint responsibility for the decisions and therapeutic strategies agreed with their doctors, and accept the results of these decisions. (Sacristán, 2013, p. 3 of 8)

A health care system where there is this strong emphasis on patient autonomy may marginalize those who cannot speak up for themselves, whereas patients who are strong and powerful would use up the restricted resources of money and health care personnel in the system in order to meet their personal preferences. This could undermine just distribution of health care, where there is not enough attention to helping those who are the most vulnerable and in need.

The biomedical model described above has a tendency to compartmentalize the patient and forget the most important thing in the work of the doctor which is the person; the patient himself, and his life, the person whose needs medicine should attend to according to the ends previously described. The patient-centered model briefly outlined above is an important and promising reaction to the criticism the biomedical model has received. The three concerns regarding the patient-centered model are not meant to undermine this approach, but rather to highlight challenges that need to be met when it is practiced. In health care services, it is always fundamental to keep the patient at the center. Nevertheless, it is also important to focus on the patient's needs as well as his preferences and not to overestimate the patient's power and underestimate the patient's need for help and support. Finally, it is also necessary to prevent processes that lead to a health system where those most vulnerable and in the most need of help are marginalized.

4.2.4 How Does Medicine Deviate From its Ends?

Under the second theme, we have discussed how the aim of medicine can change when medicine enters new grounds, as described in papers I–III. The focus has been on how undue emphasis on scientific aspects of medicine can influence the aim so medicine loses connection with its ends. I have described two ways in which this can happen. Firstly, when our imperfection and mortality are no longer acknowledged within medicine. Secondly, when the medical lens becomes too narrow and human beings are reduced to organs, biochemical molecules, and processes. Here, the patient as a person is no longer at the center and so medicine is not true to its ends.

When medicine is described solely from the perspective of peer-reviewed articles in contemporary medical journals—where the emphasis is on scientific facts—the Christian root Jonsen (1990) describes seems to be lost. As a consequence, we might think that patients within the field of medicine have already been reduced to biomedical processes. Of course, that is an oversimplification of what medicine stands for. Fields like family medicine that cultivate ideas like those presented by advocates of patient centered medicine prove otherwise. Nevertheless, there is this tendency within medical work to reduce the art of medicine to a simple scientific endeavor and, as a consequence, the patient as the central focus is forgotten. That is why we need a reminder telling us that, although scientific facts are fundamental elements of medicine, they are not adequate to describe everything which medicine stands for. I want to argue that all models describing medicine need to include awareness of the infinite value of the vulnerable and mortal patient. The trend of describing medicine as a biomedical science must be met by reminding us that it is also an endeavor based on a calling where the vocation is a response to a need (Koehn, 1994, pp. 54–69). It is based on what Pellegrino describes as "the universal human experience of illness.…the need of sick persons for care, cure, help, and healing" (Pellegrino, 1999, p. 60). When medicine is conflated with science these ends of medicine stay in the shadow and can even be lost. To remember the ends of medicine, it is necessary to resist influences undermining the humanity of the patient, described above under the discussion of the second theme.

Pellegrino further reminds us why we need to remember the ends of medicine and resist undue influences on medical practice:

> Preserving the ends of medicine, and not just the goals society may construct for medicine, is an essential safeguard not simply for the integrity of medical ethics and practice, but for the safety and well-being of all the vulnerable members of our society. (Pellegrino, 1999, p. 67)

This description is in harmony with the Christian root that Jonsen (1990) describes, and in that tradition, the doctor is not only keeping her focus on the patient but on the vulnerable patient. The weakest call coming from those most vulnerable is the most important call. That is why the medical doctor has to be especially sensitive to the marginalized voices. This leads us to the third theme: the marginalized patient and the oppressed voices.

4.3 The Third Theme: The Marginalized Patient and the Oppressed Voices

"One of the central insights of feminist work is that the greatest danger of oppression lies where bias is so pervasive as to be invisible" (Sherwin, 1992, p. 10). This quote captures the essence and the necessity of the third theme, where I will describe the marginalized voices. I examine the personal voices of patients who are marginalized and in a vulnerable position in health services. When they have the opportunity to speak they describe oppression within the health system. Oppression is a value laden concept, sometimes complicated to interpret. In its simplest form it can be said to "occur[s] when one group has more access to power and privilege than another group, and when that power and privilege is used to maintain the status quo (i.e., domination of one group over another)" (David et al., 2014 p. 3). In my discussion I rely on a definiton of oppression based on the works of Marilyn Frye which Sherwin draws upon. Sherwin (1992) describes the concept in the following way:

> Marilyn Frye (1983) has defined oppression as an interlocking series of restrictions and barriers that reduce the options available to people on the basis of their membership in a group. Oppression is often insidious, because the individual practices that make up the system of barriers may look innocent when examined on their own; their role as restraints may be easily obscured. As Frye notes, however, when the various oppressive practices are seen as an interwoven set of institutionalized norms, the pattern of restriction becomes clear. (p. 13)

In the current discussion, the focus is on people in a marginalized position in society and within the health system. They describe their encounter with the health system where they feel powerless and dominated. I focus on the voices of fat people, disabled people, and women in a marginalized position participating in surrogacy procedures. I will argue that insight into these groups' conditions from their own perspectives is an important part of the theoretical work in medicine. It is important to recognize them and their criticism to understand the key examples in this thesis. To notice these voices and respond to them is in accordance with the old Christian idea where the medical doctor has to note and respond to the vulnerable. It can also be seen as a feministic approach in medical theorizing since it relies on viewing the patient in relation to his surroundings as will be discussed further under the fourth theme.

These voices, and their lack of visibility (or audibility) in mainstream medicine, are addressed in all of the papers. In paper I, on surrogacy, the absence of accepting the gestating mother as a driver in the surrogacy process when it is regarded as medical treatment is noted and reflected upon. The conceptualization of her role as being a surrogate, or some sort of a temporary substitute and tool towards some other persons' end within the health care system, is troubling. It further highlights the shortcoming of any description of this process that does not give her voice a clear presence. Paper II, on obesity discusses fat people's criticism of medicine along with the need to give their voice a central role in the medical discussion on obesity. I further take up this discussion in paper III, on fetal diagnosis. There, the criticism of medicine comes from disability studies and Down syndrome activists. Their simple question is "Why?" Why are fetuses screened for Down syndrome? What is wrong with us? They themselves have Down syndrome and are leading good and worthy lives.

In this section, I reflect upon similar voices belonging to the same group of people as those described in the articles. The emphasis is on voices in a marginalized position. I start by outlining them and looking at how they are expressed. I will describe why it is so important to listen to them and how medicine can deviate from its ends and inherent values if we ignore them. It is noteworthy that the majority of them, at least in the three key examples, are women's voices. I will reflect briefly on that fact and connect the discussion to the feministic criticism of medicine which leads us to the description and meaning of oppression in this context. Finally, I will introduce the last theme reflected in the papers which focuses on how to avoid oppression. This fourth theme highlights the importance of social justice and the need to see medicine in a political light where we focus on the relational view.

4.3.1 The Voices

I will now address the question: How are these voices presented and why can medicine deviate from its ends and inherent values if we ignore them? First, the voices of fat people, disabled people, and gestating women will be described. These voices are chosen since they reflect those discussed in the key examples of the thesis. These voices are not necessarily reflecting the experience of the majority of those belonging to these groups and are using the healths services. They are to viewed primarily as marginalized voices highlighting potential harm that can occur in the encounter between the doctor and the patient. Although, these examples can not be generalized it is necessary to take these voices seriously. In the end of this section, I will spell out why it is important to listen to them as they express how medicine can deviate from its ends and inherent values.

The journal *Narrative Inquiry in Bioethics* published personal narratives from a symposium inspired by the American Medical Association's decision to label obesity as a disease (DuBois et al., 2014). These personal narratives are from fat people who describe their encounters with the health system. They were specifically asked to describe whether and how their weight affected their relationship with their doctor. The stories give us insight into the often difficult and sometimes stigmatic relationship between the doctor and the fat patient. The stories reflect how some physicians lack insight into what it really means to be a fat person as well as totally ignoring the complexity of it:

> In the middle of an annual pelvic exam, the gynecologist said to me, “You should apply to be on ‘The Biggest Loser.’” I was too stunned and embarrassed to mutter anything more than a comment that I didn’t think that, being quite introverted, I was a good candidate for a reality TV show. She argued with me about that. I felt blindsided, intensely vulnerable, and dumbstruck—completely unable to respond—and later, when the shock wore off, incandescent with impotent rage. (Brass, 2014, p. 89)

The text shows a lack of sensitivity towards the complexity of being an unique person with a history, hopes, and feelings. The doctor sees only an obese patient. There is no possibility that the patient has other diseases than “obesity” and as a consequence, the doctor hinders the patient from receiving accurate treatment for other illnesses:

> [S]he rolled her eyes, gave a very deep sigh and said to me, “Every fat woman wants to believe it’s because of her thyroid and it never, ever is.” I was so embarrassed for having even brought the subject up that in an effort to save face, I reacted to my shame by replying, “Yeah, I just assume my extreme lack of energy and excess weight is simply because I eat too much.” She said, “Right, so let’s not even bother running these tests.” It was at least ten years later that I finally had the thyroid panel run and found out it was very low functioning. (Bruk, 2014, p. 91)

Another woman describes the same experience where there seems to be some sort of an inherent impossibility for her to suffer from anything other than obesity:

> [S]ince I first hit my teens and was told I was obese, I have never had a doctor’s appointment where my weight was not under discussion. I can visit for a rash, or a stomach bug, or contraception, or just be registering with a new doctor, but every appointment will become about my weight … Sometimes my problem may be put down to a condition associated with weight, such as high blood sugar (which I do not have) or high blood pressure (which I do not have), but it is assumed I have because of how I look. Wheezing and heavy breathing due to the flu are considered to be due to my weight. If I contradict, I am considered a liar. When I talk about my diet no one believes me, because I am morbidly obese and everything I eat must be fast food. If I talk about enjoying long walks, I must be lying, because I’m morbidly obese and therefore can’t be exercising. If I talk about avoiding group exercise activity due to discrimination, I must be lying about its occurrence, because they have not experienced the same discrimination. Clearly I am just lazy. (Moore, 2014, p. 110)

Lack of insight into the lives of fat people and not seeing them as the persons they really are creates shame and stigma, especially in relation to health services:

> All during these years I struggled to control my weight. I went to Weight Watchers four times. I tried hypnosis. Between those programs I went on numerous diets. But I always gained the weight back, plus a little more. In total I have lost and gained almost 200 pounds though dieting. I was terrified of going to the doctor. I did not want to be shamed. I did not want to be lectured to. I did not want official confirmation of my absence of worth. (Anonymous One, 2014, p. 97)

This feeling is further described:

> From a fat person's perspective, the "war on obesity" is a war on fat people. It's a license to bully, shame, and ostracize fat people and deny us employment, medical care, and even ordinary family life because we don't look right. Fat people, proclaimed by medical authority to be the enemy and identifiable on sight as outsiders, are made into targets for all kinds of free-floating anger. (Hansen, 2014, p. 99)

Fat people also criticize the solutions they are offered from health care professionals. Most often these solutions consist of telling them they are not as they should be and they should do something about that:

> After several appointments like this, one of the OBs hesitantly said, "Well, you know, we're concerned . . . do you know you're obese?" What I wanted to say was, "Gosh, that's why most of the clothes in the catalogs don't fit! I had no idea! Thank you so much, Doctor!". (Hansen, 2014, p. 100)

The health system is criticized for both a lack of understanding of what is labeled as the problem of obesity as well as not being able to come up with any real solution. It is further criticized for systematically excluding fat people and marginalizing them:

> Before I even talk to my doctor, I am set apart from the other visitors by my size. Chairs in waiting rooms and treatment rooms may be too flimsy for me, or have arms that prevent me using them. Sometimes I attempt to sit on an examination table and it groans, or I will be asked not to sit on it at all. More than once I have had to stand during my appointment, or ask for another chair, or sit on the floor whilst waiting to see someone. Every visit to a doctor begins with the anxiety that this will happen, and the embarrassment of dealing with it if and when it does. This is the starting point for my interactions with doctors—the physical reminder

> that I am apart and different and that it is not their job to take care of me but my job to change and accommodate them. In this way the physical limitations of a doctor's office are emblematic of the relations between patient and doctor. (Moore, 2014, p. 110).

There is much debate around the AMA's decision to declare obesity a disease (Stoner & Cornwall, 2014). The voices of fat people themselves are diverse on the issue. Some are relieved and hope for more real support to meet the challenges of life when being fat (Brass, 2014). Others express certain fears for further stigmatization:

> The AMA's decision to further medicalise my body and refer to it as diseased—a body that I love, a body that is carrying me around with no health problems, is just another reason for me to fear the medical establishment that wants to hurt me and have me thank them for it. (Moore, 2014, p. 112)

As discussed in paper II, the health care system and medical doctors are criticized by fat people for ignoring them as individuals, as persons with history, feelings, and narratives. They are instead reduced to something which is "scientifically obese" and should change or made to disappear in some exotic way. We see scientific phrases where the prevalence of obesity is to be lowered or obesity even eradicated. Fat people are rebutting this: "But no matter how many times we get told that we are wrong just for existing, we go on existing, in public even. How dare we?" (Hansen, 2014, p. 99).

This discussion and these narratives of fat people have similarities to how people with disabilities have described their encounters with the health system (Bishop & Sunderland, 2013). They complain about being first and foremost seen as being a diagnosis or some label instead of being the unique person they are:

> What I failed to realize was that because physicians tend to see disabled persons only in a patient role, rather than recognizing the multiple facets of a human being, which includes the professional aspect, it is challenging for them to alter their perspective. (Minicozzi, 2013, p. 211)

Another person describes this in the following way:

> All I can say is that it felt like the doctor only saw me as a medical diagnosis. Assumptions were made about my intellect based on my size, even despite having been given a bit of background on me as a person. (Birmingham, 2013, p. 187)

They are labeled through the diagnosis which also emphasizes their inadequacy:

> Until those with disabilities are able to stand up and speak freely, labels will continue to take precedence over our true identities. Not being good enough is inadvertently projected. The expected standards are represented in our everyday lives; in magazines, in television, in the media; it is unavoidable. When we see these things from an early age, we grow up with reinforced beliefs of inadequacies. (Michael, 2013, p. 207)

Being inferior to others because you have a diagnosis of disability that labels you increases the feeling of exclusion. It emphasizes how disabled people are not as they should be and, even as in the case of fetal diagnosis like NIPT, that they should not exist. Their existence should be hindered and prevented. Claims like these are increasing their marginalization within society (Hofmann, 2017).

Although disabled people are being described as patients, where their disability diagnosis seems to be what primarily defines them, research has shown that they are also marginalized within the health service. When they really need the attention of medical doctors and assistance from the health system, they often meet systematic hindrances as well as prejudice because of their disability, and in some cases their doctors even consider them unable to have any other diseases than the disability itself (Drainoni et al., 2006; World Health Organization, 2011).

These stories reflect examples of when the diagnosis itself or their label can hinder people. Hence, these are examples of when these groups are stigmatized and marginalized within the health sector. When I refer to stigma in this context it is understood as a negative marker where the way the person is (e.g. by being fat) automatically influences the way other people behave towards her. Cockerham (2016) characterizes those who are stigmatized as follows: "People with such attributes are those who are different from the majority of other people, but different in a negative way and are subjected to discrimination because of it" (p. 211). In the stories above, both fat people and disabled people are describing how they meet attitudes where they are not listened to, where their narratives on what is wrong or how they feel are dismissed because of their diagnosis and/or their appearances. Although these stories cannot be generalized as referring to all interactions within the health system, they are not merely isolated stories but a verified reality through multiple studies on the lives of both fat people and disabled people (Drainoni et al., 2006; Tomiyama et al., 2018; World Health Organization, 2011). Another example of stigmatized groups where people have risen against the diagnosis itself, felt it stigmatizing and tried to reclaim their own identity, is those with a psychiatric diagnoses or deemed "mad" as they themselves say. Here I am referring to "Mad studies", where scholars, who many have acquired a psychiatric diagnosis, criticize what they call "biomedical psychiatry" often being "so distant from our lived realities" (LeFrançois, 2016, p. v). They describe a need to rebut the way medicine has defined them and their lives, because it has not been altogether helpful. They attempt to do so through mad studies, finding that, "This allows those of us deemed mad to formulate and advance our own understandings, theories, research, actions, practices and knowledges, each of which carries an inherently enhanced credibility because of direct experience" (LeFrançois, 2016, p. v).

These voices represented by the academic fields of Disability studies, Mad studies, and Fat studies all demonstrate the need of people with medical diagnoses to describe their personal experience and rise up against oppression within medicine, where stigma and the power of the diagnosis have marginalized them even further within society. This underlines the importance of medicine being described and understood not only as a biomedical science but also as a practice with a humanitarian grounding that can sympathize with patients as well as groups of patients and systematically tries to understand their feelings and experiences in life. These personal stories described in the text above and the field of academic research reflecting on them is not from mainstream medical research, but mostly from critical social sciences. Nevertheless, they are a helpful addition to the necessary insights that doctors need in order to be true to their vocation.

I have so far not discussed these encounters with the health care system as an issue of gender. The stories above from fat people and disabled people, as well as stories of mad people, could be stories from both men and women. Nevertheless, it is interesting that most of the stories come from women (Bishop & Sunderland, 2013; DuBois et al., 2014; Russo & Sweeney, 2016). It was also fat women in the US who first voiced their criticism towards medical doctors (Rothblum & Solovay, 2009). When the voices of disabled people within the health system are described, they are most often the voices of women, perhaps because what is often under discussion is reproduction, contraception, and childbirth, all of which seem to be women's private concerns (Björnsdóttir et al., 2017). In all three articles discussed in this thesis, women's experiences are at the core. This raises the question of whether women are, in general, more prone to be objectified within the health care system than men. If that is the case, it raises special concern that needs to be addressed.

Feminist bioethicists examine the women's positions within the health system. They have argued that women constitute an oppressed group within the health system (Sherwin, 1992). The articles in this thesis support that claim. In the next section, I will reflect further upon these views and connect to the voices of women who have given birth to babies at surrogate clinics in India.

4.3.2 Women's Voices

Feminist studies have shown that women, in general, are in a more vulnerable position within society than men. We further know that women have historically received worse health care than men only because they are women, as have other oppressed groups in society (McMurray et al., 1991). Many of the normal experiences of women, like menstruation, gestation and childbirth, as well as menopause, have been addressed as illnesses, thus medicalizing women's sexuality (Sherwin, 1992). Through medicalization, it is possible for the medical profession to gain increased control over women's lives. These facts make it necessary to be gender-specific and regard their position within the health system separately from men.

Viewing surrogacy practices gives us the opportunity to reflect upon gender issues within health care. Although there are several studies that give voices to gestational women participating in the surrogacy process, more research still needs to be done in order to gain sufficient insights into the experience of women acting as surrogates (Yee et al., 2020). These experiences are varied since the issues under discussion in places like India, Canada, and the U.S are not the same. What primarily influences the motives and experiences of women is not least the background and the circumstances in which they live (Gunnarsson Payne et al., 2020). In the current discussion, it is important to pay special attention to the voices of vulnerable and marginalized women and view their position in relation to new technology within medicine. Several qualitative research studies have occurred regarding women giving birth to children in surrogacy clinics. Some of these practices reveal the oppression of women, medicalization of the female body, and global inequalities. To follow up on these cases, I will here use as a reference an ethnographic study on commercial surrogacy in India by Amrite Pande (2010). She describes it as follows:

> I conducted fieldwork in Anand between 2006 and 2008. My research has included in-depth open format interviews with forty-two surrogates, their husbands and in-laws, eight intending parents, two doctors, and two surrogacy brokers. Typically, the interviews took a narrative form, with the woman responding to my request to "tell me about your life and how you got into surrogacy." (Pande, 2010, p. 974)

In this research, Pande throws light on the situation of the Indian women taking part in the surrogacy process as gestating mothers, as well as interviewing other stakeholders. This research highlights the complexity of this issue and the importance of viewing the process through a wide lens where nothing can be interpreted adequately without taking into account at least class, gender, and culture (Sherwin, 1999). The poverty of the women, as well as their duty towards their family, are shaping their choices:

> Naseem, a thirty-year-old surrogate and mother of a three-year-old boy, heard about surrogacy from the nurses when she went to have her second child aborted: "When Jayati [a nurse at the clinic and an informal broker] heard that I am getting the cutting [abortion] done because I can't afford to feed another child, she told me about surrogacy. She told me there is nothing immoral about it, so I agreed. (Pande, 2010, p. 976)

Difficult circumstances and poverty heavily influence these women's decisions in the matter:

> Who would choose to do this? This is not work, this is majboori [a compulsion]. It's just something we have to do to survive. When we heard of surrogacy, we didn't have any clothes to wear after the rains—just one pair that used to get wet—and the roof of our house had collapsed. What were we to do? (Pande, 2010, p. 988)

Instead of describing the act of surrogacy as an informed choice, they constructed the meaning of it as a gift they had a chance to give their family:

> I will use the money to educate my children and repair my house. I know I won't have anything left for later but I don't want to do it (surrogacy) again. Matron Madam is right. God has been generous this time. He has given me the biggest gift – the opportunity to help my family. I don't want to be greedy and try for the second time. (Pande, 2011, p. 621)

Another woman expresses the same attitude:

> I am doing this basically for my children's education and my daughter's marriage. I am not greedy for the money. This surrogacy is like God has blessed me and given me the opportunity to do something for them. (Pande, 2011, p. 622)

These stories show how vulnerable women in marginalized positions, i.e., because of poverty, can be. Here, one of the women "working as a surrogate" in India lists her daily schedule at the clinic:

> Get up at 8 a.m. and have some vitamins with our breakfast. Sleep. Get up in time for Doctor Madam's visit. Sleep. Get up for lunch. Mostly we get served a fixed

> lunch, along with whatever medicines we have left. The doctor wants me to eat too much here. I enjoyed it in the beginning, but now sometimes I feel like I would burst! Madam has told us that all mothers who want a healthy baby should take this diet. I know it's required for the baby, so I can't create a fuss. (Pande, 2010, p. 982)

The clinic even controls the most basic bodily functions, like how much you eat, and then imposes disciplinary measures:

> I am being extra careful now because Doctor Madam has said if everything looks all right in the ultrasound I can go visit my children. I don't want to do anything that will make Madam change her mind about letting me go home for a day or two. (Pande, 2010, p. 982)

Everything has to go well in order for this mother to be permitted to go home and visit her own children. She has to be the perfect surrogate and behave accordingly. Although, I do not realize whether I am in any way capable of understanding the feelings and choices of these women, I find their voices disturbing.

It is important to emphasize two things. First, these voices should not be generalized in any way. As mentioned above, there are other studies based on interviews with gestating women in Canada that focus on other issues (Yee et al., 2020). Secondly, surrogacy does not respect borders; it is a global praxis as can be seen from the fact that Icelandic parents, like many other parents in the more affluent parts of the world, have used the service of Indian surrogates. This gives these voices global relevance. Hence, it is important for the ethical discussion on surrogacy everywhere to pay special attention to surrogacy procedures in the poorer parts of the world because this is where the women are most vulnerable.

In spite of this, I do not bring these stories into light primarily to criticize these practices. I am highlighting them to give further examples of marginalized voices of women in a vulnerable position where the use of modern technology in medicine marginalizes them even further and makes them more vulnerable. That is what makes them interesting in the current discussion. I also want to highlight the importance of using a wide lens where situations and circumstances are given ethical relevance.

In general, those who are already marginalized and vulnerable within the medical system seem to be prone to becoming more marginalized and vulnerable when medicine evolves into new fields. I will discuss this further in the next chapter.

4.3.3 Why Does the Practice of Medicine Deviate From its Ends and Inherent Values?

All of the voices above are reactions to medicine. The voices indicate a power imbalance, a medical oppression where the patients are structured as objects of medicine, are no longer in control of their lives, and are no longer accepted as experts in their own lives. Instead, their lives and the way they should be and live is medically structured and not always to their own benefit.

Again, we are faced with a type of medicine that seems to have difficulties accepting humanity in all its diversity, i.e. to a humanity that is characterized by the imperfection and mortality of every human being, the very imperfection that unites us (Weil, 1986). The descriptions from the voices above are a response to the sort of medicine that generalizes them and reduces them as persons even to a collection of organs or biomedical processes. What further characterizes the marginalized voices in this thesis is the fact that they are often from women, from those who are poor, and from those who have a low status in society.

To notice the marginalized voices and gain a better understanding of their situation, knowledge from mainstream empirical science is not enough. These voices are sometimes invisible unless we search for them as marginalized voices are easy to miss with conventional research methods. (Morimoto et al., 2014; Stefánsdóttir et al., 2015). Therefore, to tease out these experiences, alternative methods of qualitative research, like narrative inquiry and inclusive research are necessary (Atkinson, 2004; Clandinin, 2013; Nin, 2917). Thesemethodological approaches are specifically designed to address marginalized voices. They have repeatedly come up within research in critical sociology. Examples of these critical approaches that are specifically aimed at examining medicine, often by criticizing mainstream views in medicine on their lives are: Deaf studies, Mad studies, Fat studies and Disability studies. All these disciplines have roots in feminist ideas. All are formed as a reaction to an oppressive state of affairs. They frequently describe voices of people who have become more oppressed and whose position in life has worsened due to medical attention. Their reaction is a demonstration of medicine's influence on their lives. Knowledge and awareness of their experiences is necessary if we are to prevent harm towards people in this position as medicine enters new grounds.

At this stage, I want to clarify two things. The first is that I have so far discussed contradictory descriptions of medicine. Medicine has been described as a humanitarian endeavor that focuses on the patient, caring for and curing those who suffer, those who are vulnerable, and those who need help. This is the medical doctor described earlier by Pellegrino (1999) and

Jonsen (1990). Such a doctor works within a tradition that listens and is sensitive to the patient's vulnerability. There has also been reference to medicine described as a profession that primarily refers to the biomedical view of the human body where the patient as a person seems to be lost. The oppressed voices above seem to reflect and criticize this latter type of medicine which is heavily influenced by empirical science and technology where the patient seems to be a mere body almost without a soul. It is not my intention to claim that medicine is primarily of this type, and is mainly concerned with biomedical descriptions of the body, forgetting the person inhabiting it. On the contrary, medicine is much more, as this thesis repeatedly states. It also needs to be acknowledged that many subdivisions and fields within medicine are grounded in views derived from the premise that human beings were not best described through biomedical processes. Hence, this thesis does not emphasize that medicine is only based on biomedical science; rather, it emphasizes that these tendencies within medical theorizing to oversimplify and restructure the patient primarily as the subject of biomedical science and technology have the potential to undermine the patient's humanity as well as the ends of medicine. Fortunately, this does not describe what happens in all medical encounters but it has happened in the cases the voices above describe and that is of concern.

My latter clarification is that it is now helpful to recall that the three key examples in paper I–III that this thesis is based on are chosen because they reflect examples where medicine enters new grounds. In this discussion, we are focusing on new grounds where developments in medicine are driven by constructional forces like new technological means, market and public demands, and ideas of human enhancement. These constructional forces can and do in the cases of the key examples cause medicine to deviate from its ends and inherent values. What happens in all of them, and has been described under the discussion on the themes above is: Firstly, there is a drift where the gap between the patient's narrative and subjective experience (illness) and the doctor's professional perspective (disease), based on science, widens. Secondly, biomedical science becomes the dominant drive in medical thinking, and the feelings and narrative of the patient stay in the shadows. This lack of insight into the patient's reality can undermine their importance and humanity. The ethical understanding, emphasizing the well-being of those most vulnerable in the given situations, is no longer at the center. Thirdly, the voices described above demonstrate how this can make medicine oppressive. These processes can occur when medicine, influenced by constructional forces, enters new grounds. I am not claiming that this is generally what happens when medicine progresses and takes on new tasks, neither am I saying that this only happens when medicine enters new ground. I am only highlighting that this is what these key examples in the papers show us can happen when medicine enters new grounds. What we can now add to the discussion in the papers is that, by looking at these three examples together, we get a clearer picture of how this can be seen as an oppressive process that repeats itself. This process described through the discussion of the first, second and third theme, summarized above, forms a flow of connected processes. As such it outlines how the progress of medicine where the ends and inherent values of medicine are not respected and as a consequence it can harm vulnerable patients.

Now we can turn to the question: Why does medicine deviate from its ends and inherent values if we ignore these voices? Medicine is not best described as being biomedical or scientific since we are not only biological beings (Kirkengen et al., 2016). Although these elements are a part of medicine, medicine is something more. Apart from being mere bodies, we are persons, individuals with feelings and aims in life. If medicine evolves in such a way that it becomes primarily a technical and scientific endeavor the medical doctor loses her ability to listen closely, even listen to that which is unspoken, listen to the voices of the weak, vulnerable, and oppressed. This is a description of medicine not being true to its ends. In all three key examples of this thesis, the medical ear is not catching all the tunes. To be able to do this, the medical doctor has to listen to each and every patient but also to look up, use a wider lens, and see the patient not only in the consulting room but also through the web of human connections that has taken part in forming each person's character and life story. Hence, medical doctors need to be able to see each patient for what he is and be able to contextually reflect upon the patient. Here, the doctor has to rely on now marginalized research methods within the field of medicine, and rely on the approaches used by philosophy, anthropology, and the social sciences. Hence, it is not enough for doctors to improve their interactive skills with patients; medical knowledge has to include this as a part of its knowledge base. These fields are helpful in getting a better picture of life conditions and in understanding the patient's point of view as well as detecting vulnerable groups in need of special attention. If this view is left out, the inherent values of medicine are not guarded, and medicine can actually harm the vulnerable patient.

This leads us to the last theme we can see in the three papers: "The relational view," acknowledging that we are not only biological and personal, but are also contextual beings. Feminist health care ethics or feminist bioethics emphasize the importance of viewing ethical issues in health care through a wider lens than is usually applied in mainstream bioethics (Sherwin, 1999). The basis for this is the description of the human condition through a web of persons rather than being constructed of distributed atomic selves (Donchin & Scully, 2015; Sherwin, 1992, 1999; Willett et al., 2016). Incorporating this view in medical thinking is helpful, not only to notice the weak and vulnerable, but also to gain a firm ground when considering questions regarding medicine and social justice.

4.4 The Fourth Theme: Using a Relational Lens to Detect Oppression

> Since our identities, values, opportunities, and choices are shaped and constrained by the personal and public relations into which we are born and from which our characters develop, the sort of beings we are calls for a relational lens to interpret all of our ethical concepts. And, we insist, that relational lens must be a feminist one; that is, it must be one that is consciously attentive to the political dimensions of one's relational status as it is influenced by factors such as race, gender, socio-economic class, ability status, age, and ethnicity. (Sherwin & Stockdale, 2017, p. 15)

The voices of fat people, disabled people, and pregnant women described in the chapter above were not expressed in the consultation room. Hence, the clinical doctor can easily miss them. Although their voices are difficult to detect, they give a very important insight into the issues discussed in the key examples in the papers. Under the fourth theme, I address how we can gain a better insight into their relevance as well as how the pain they describe might be prevented.

To be able to adequately understand many bioethical questions, it is not enough to focus on the interaction between the doctor and patient. The social and political context in which patients, doctors, and policy-makers are situated also needs to be considered (Sherwin & Stockdale, 2017). This wider lens is what Sherwin and Stockdale (2017) refer to as the relational lens. This view has been applied in all of the articles discussing the key examples in this thesis. Political questions have been asked and their relevance acknowledged in order to gain a proper understanding of the issues under discussion and to find acceptable solutions. In paper I, on surrogacy, it is necessary to see the process not only as involving the gestating mother, the intended parents, and the medical doctor. This process has to be viewed as a social matter where we must evaluate our common understanding and the meaning of roles like motherhood, not just privately but also publicly. We further need to evaluate the status and relation of all of those participating in the process. Are people in general under a social pressure to have children? How and why? Does new technology commodify children? Does the possibility of surrogacy pose a new threat to poor women where the offer to become a surrogate is something they cannot deny because of their unacceptable circumstances? All of these issues have already been discussed. Paper III, on obesity emphasizes the importance of seeing it as a public issue rather than a private problem. Public policy and the environment create a great influence on the average weight of those inhabiting it. I also discussed the stigma that fat people face and how that restricts their options in life. Finally, in paper III, when discussion fetal diagnosis, the wider lens was used to highlight the difficulty of the choices that prospective parents face regarding fetal diagnosis. The political aspect further forces us to reflect upon the policy to offer this choice and ask ourselves to honestly determine what this choice means and whether and why this choice is relevant, as well as considering who has and what constitutes a good and worthy life.

These questions, some of which have been discussed more thoroughly than others, all comprise a part of the wider picture. They concern oppression as well as ideas surrounding social justice. They are meant to throw light on how injustice can manifest itself. To fight injustice and to promote not only a good but also a just health care, medical doctors have an important role. They are partly responsible for structuring the health care system as well as driving the processes discussed in the papers of the thesis.

Under this theme, I will discuss this view and argue for its importance. When we are evaluating whether current changes in our health service are good or bad, this is one perspective we need to consider. The former three themes showed us how the changes discussed in the articles could undermine the inherent values and ends of medicine. This last theme—the need to acknowledge this wider perspective—has the same purpose. If we do not acknowledge it, medicine can become oppressive without us noticing it, and then the practice of medicine deviates away from its ends and inherent values. To follow this thread, I will use insights from feminist bioethics (Collier & Haliburton, 2015; Flynn, 2021; Sherwin, 1992). The feminist approach pays special attention to women's experiences and, as such, is of interest when the key examples that form this particular thesis are under discussion. Further, feminist bioethics focuses on oppression and marginalized groups. It aims at expressing insights into the lives and experiences of those most disadvantaged in society (Flynn, 2021). What characterizes feminist ethics cannot described in terms of conflicts between individuals, but in "focusing on the larger political, institutional, and social contexts within which these conflicts occur" (Collier & Haliburton, 2015, p. 50).

The next sections will outline the basis for this way of thinking about ethical dilemmas and show how this approach can be beneficial in medical work. I begin by outlining the feminist approach to which I am referring. This view is rooted in ideas based on the social self and relational theory (Mackenzie & Stoljar, 2000b). I will then connect this way of theorizing about bioethics to the key examples by arguing for the importance of including the wider picture and by acknowledging the importance of our diversity. Both approaches are aimed at making us more sensitive to the marginal voices in our society and thus better able to resist oppression in medical work.

4.4.1 What is Relational Approach Within Feminist Ethics?

In their article, "Whither bioethics now? The promise of relational theory," Sherwin and Stockdale say, "Feminist bioethicists have made significant achievements using relational theory to shape the notion of autonomy, bringing to light the relevance of patients' social circumstances and where they are situated within systems of privilege and oppression" (Sherwin & Stockdale, 2017, p. 7). To understand their claim, it is necessary to explain what they mean by referring to relational theory and how that approach has shaped the notion of autonomy.

The term "relational theory" comes from the discussion on relational autonomy within feminist theory (Mackenzie & Stoljar, 2000b). There, relational autonomy is an umbrella term referring to autonomy definitions with a range of perspectives based on the ideas of the social self, thus emphasizing a rich account of the autonomous agent:

> These perspectives are premised on a shared conviction, the conviction that persons are socially embedded and that agents' identities are formed within the context of social relationships and shaped by a complex of intersecting social determinants, such as race, class, gender, and ethnicity. (Mackenzie & Stoljar, 2000a, p. 4)

Relational theories have drawn our attention to the influence of context on autonomy, where the focus is on the relation between the agent's self-understanding, her social surroundings, and her abilities that are necessary to be autonomous (Mackenzie & Stoljar, 2000a). This approach views autonomy as a capacity that can be developed and held up to a degree. The more that the individual possesses this ability, the better. It is further believed that we all have the potential to develop these capacities and that we are entitled to support in doing so.

According to these ideas, the context influences and shapes the way we understand ourselves at every moment. The main emphasis in autonomy research is here to describe and analyze the social sphere's influence on the self. For instance, how other people, culture, and gender affect personal autonomy and political activity (Mackenzie & Stoljar, 2000a). This can, for example, be done by investigating the relation between autonomy and self-respect, on the one hand, and self-trust on the other, and then seek to understand how this influences autonomy (Mackenzie & Stoljar, 2000a; McLeod & Sherwin, 2000). Here, the significance of others in shaping our lives has gained ethical importance as well as the influence of our social context, in general (Mackenzie & Stoljar, 2000a). As a result, it also becomes the purpose of relational approaches to analyze the specific ways in which oppressive socialization and oppressive social relationships can impede autonomous agency (Mackenzie & Stoljar, 2000a).

What makes these feminist ideas interesting for the approach of this thesis is this potential to detect oppression and notice and respond to people in a marginalized position. By using the perspectives of relational autonomy, we need to take into account the influence of the surroundings in a wide sense. We are thus forced to consider political views when evaluating people's options and choices and when we determine who is responsible for these choices. This shapes our ideas of where the actual ethical problem is located as well as the focus on solutions to the ethical problems. Therefore, this view sharpens our sensitivity towards oppression and enhances our means to be more aware of invisible trends in society strengthening the position of those in power.

To illustrate how this approach can be used in ethical discussion, it is helpful to regard the example of internal oppression. By using the notion of relational autonomy, it is possible to draw attention to the context in which the person lives and how the circumstances of her life may influence her personal autonomy. Willett et al. (2016) define internal oppression as when a person accepts a situation that is not acceptable. She refers to examples of women who view themselves as less worthy than men and, hence, expect less for themselves than men. Women are then internalizing the values of the patriarchy where they are commonly regarded as objects and not valued fully as self-governing agents. When these ideas are internalized, they diminish their self-worth and undermine their self-respect. This limits their options and diminishes their autonomy. It has even been argued that women as a group are less autonomous than men because of diminished self-respect, and consequently claimed that this has undermined their equality of opportunity. Consequently, this has revealed an example of serious systematic injustice in society (Meyers, 1989). When we focus on the agent in isolation and ignore the social context, we fail to detect internal oppression because it is already internalized in the longings and desires of the individual and what she expects for herself. If we do not see and react to this, certain groups continue to suffer from a systematic lack of equal access to benefits in society.

In the next two sections, I will use this relational approach to reflect upon the key examples described in paper I–III and in medical work. My aim is to show why it is necessary to identify marginalization and oppression within the health care system.

4.4.2 The Ethical Relevance of the Big Picture

When we use the relational lens to reflect upon these perspectives on autonomy, it is possible to see how they can be helpful in analyzing the situation of different participants involved in the key examples of the thesis. This opens up possibilities for an ethical reflection where we can shift the emphasis regarding choices, duties, and responsibilities.

The contextual approach of the fourth theme is about ways to detect and analyze the ethical situation of fat people. It emphasizes the importance of seeing them as socially embedded and viewing their choices and responsibilities differently. Instead of localizing the real problem within the person herself, thereby placing the responsibility for the "obesity problem" only on fat people, it can be seen also as an environmental and social problem and as a political project. This will shape the emphasis on different solutions rather than just drugs, behavior modification, and surgery. Including environmental influence, as well as ideas on who are responsible for creating such an environment, gives way for a new type of discussion. It opens up the possibility to discuss political actions that influence public health and assign responsibility to those decisions. As it becomes acknowledged that increased obesity is not only due to personal decisions, this view gives way to a more shared responsibility for why people gain weight and a resultant relief from stigma.

The same can be said for the approach to the surrogacy process. If we recall the stories of the women in Pande's research, we can easily see why it is necessary to regard their options and choices in a political light (2010). Their position in life leaves them with limited choices and it may even be said that they have internalized their situation which prevents them from expecting better for themselves as they have accepted their role as well as their limited choices. This highlights the marginalized position of the woman carrying the child and her vulnerability towards further marginalization. Although the option to define surrogacy as an adoption does not completely change that, it is nevertheless an attempt to give her a more central position in this process. When reflecting upon the process of surrogacy and the need to have a child, we can also pose the question of whether there is undue pressure on people to have children and if and how that pressure is connected to new technological options.

Finally, this contextual approach gives us an opportunity to discuss and evaluate in a different way the options and choices of parents and women, in particular, when deciding whether to accept an offer of a prenatal test like NIPT as well as facing results from prenatal diagnosis. We can use this approach to theorize on how the view on the lives of disabled people influences personal choices as well as policy-making regarding fetal diagnosis. To answer this question, it is necessary to reflect upon it by using a wider lens, i.e., to regard the relational perspective where we are aware of culture, gender, class, etc.

When we do an ethical evaluation of these questions about choices and responsibilities, it is not enough to focus on what happens in the interaction between the doctor and the patient. We also need to reflect upon the underlying reasons for the options given, as well as question the location of the problem. These are political questions as well as policy decisions. I discuss them in all of the key examples and they play a major role in my conclusion in all of the papers. In the case of surrogacy, I focus on the process itself and suggest that we rethink it and restructure our way of conceptualizing it. In the discussion on obesity, I emphasize the need to see this as a political problem, not just a lifestyle disease where the fat person is often assumed to bear all the responsibility. The real ethical problem here is not necessarily the fact that many people gain too much weight, but rather the potential violence against fat people, through stigmatization as well as marginalization within the health sector. This potential violence can never be the responsibility of fat people themselves; this is a much more deep-rooted problem ingrained in our culture. Finally, when discussing fetal diagnosis, I claim we also need to step back, ask where the problem is located, and why are we offering these choices.

In this discussion, I am not claiming that the choices we make inside the consultation room should always be doubted as being inauthentic. Far from it. The most important choice is the one coming from the person herself. But, to only regard the personal choice in isolation and give the larger picture no ethical relevance is nevertheless a very limited view. These limitations are especially problematic when we consider responsibilities and solutions. If we omit the political picture from the discussion on obesity—the structure of the environment and people's lack of access to good living conditions—we will never bring any true solution to the particular problem of people gaining too much weight. The reason for that happening is not and cannot be the existence of fat people as is indicated in public health propaganda phrases mentioned earlier like "War on obesity". If there is a culprit in this case, it is to be situated in the surroundings and the fact that our living conditions are not adequate. The responsibility for people gaining too much weight is therefore primarily political. The reason why I take this clear stance on the issue is partly pragmatic—since this stance is more likely to give good results—and partly ethical, because it does not involve oppression towards fat people (Kleinert & Horton, 2015).

This shows that the broader view considering the person as contextually situated gives us an opportunity to ask questions about how we define problems and whether the solutions given are solving real problems or pseudo-problems. As in the discussion of obesity, we can use this broader view to rethink fetal diagnosis. When structuring health policy, offering choices to parents within health care and defining fetal diagnosis as a solution to a problem begs the question: Solution to what problem? Why is there a given preconception that the birth of a baby with a disability is a problem? The relational view makes us consider these questions not only as personal choices or health issues but also as political questions and as questions of social justice, where the importance and meaning of the life of disabled people is not automatically deemed of lesser worth than the life of those who are not with disability.

A part of the process necessary to enhance social justice is to give space and attention to alternative voices. We need these voices to give everyone, especially those currently in a marginalized and stigmatized position, an opportunity to gain a healthy self-image and self-respect. An example of important views necessary for such a reflection are the activists speaking for fat people and disabled people, who have gained strength to rise above the oppression facing those in a marginalized position by describing their own lives. By doing this, they have inspired others to do the same (Friedman, 2000). Through public appearances, fat women, as well as people with Down syndrome, have served as role models to others in a similar situation. Their voices have the potential to make changes through different norms that others can use to reflect upon themselves and help them create a self-image where they can realize their self-worth and enhance their self-respect. The only way to acknowledge this as ethically important is to accept the individual as a relational being and to view the self as socially embedded.

It is very important to reflect upon the marginalized voices in surrogacy. These voices show us how oppressive surroundings can and do hinder their speech. We need to ask what it means if they are participating in a socially unacceptable process out of need. When the deed itself is also stigmatizing, it is hard to speak up and almost impossible to do that of your own accord (Pande, 2009). This is why qualitative research describing the voices of Indian women participating in the process, like the one by Pande, is so important. It does not tell us in general what all women carrying a child for another couple feel. It uncovers the voices of those most vulnerable and marginalized in the surrogacy process. That is important knowledge since we gain a wider picture and better knowledge of what this process can mean and how it can possibly cause harm. It helps pave the way for real solutions: political solutions, such as structuring laws and public processes that protect them against the violence from which they have no means to protect themselves. It further opens our eyes to the necessity of restructuring and rethinking the surrogacy process where there is less chance of oppression towards those participating in it.

I have so far focused on the wider view, the relational lens reveals to us when regarding questions in medical ethics like those posed in the key examples of the thesis. The importance of the relational view goes beyond that. It is a view that reminds us of our situatedness, our contextuality, and as such, our particularities. This approach highlights the importance of acknowledging these aspects as ethically important. This type of knowledge is not just about describing the general and being able to draw general conclusions, we must also acknowledge particularities and the uniqueness of everyone. If not, we pave the way for further social injustice in a systematic way. Such an injustice can occur due to a lack of understanding and general ignorance towards the situation of those sharing different living conditions than ourselves. We will now reflect upon that.

4.4.3 The Importance of Understanding Diversity to Avoid Oppression

Why is it important to understand diversity? How can a doctor's ignorance of human diversity interfere with her work? How can such ignorance be oppressive? In this scenario, it is necessary to recall that oppression is here interpreted as a "series of restrictions and barriers that reduce the options available to people on the basis of their membership in a group" (Sherwin, 1992, p. 13). To illustrate how ignorance in health care settings can form these barriers towards certain groups and how that can be oppressive, I will outline three examples from the everyday clinical work of the medical doctor.

The first example is the manifestation of clinical signs. There are gender specific variations in clinical signs, e.g. heart and coronary diseases do not manifest in the same way in women as in men (Maas & Appelman, 2010). If this is not acknowledged and the way these diseases are represented in men becomes the true way of seeing these signs, we will be blind to the clinical signs of heart and coronary diseases in women. As a consequence, women will be systematically excluded from receiving adequate treatment. This can result in a form of barrier hindering them from receiving service when needed. That would be a sign of systematic injustice in health care.

Another example where lack of knowledge of marginalized groups can serve as a barrier to service is when doctors are ignorant regarding skin color. In Nelson's Textbook of Paediatrics 12th edition from 1983, there are 18 color palates for different skin outbreaks and rashes. Seventeen of them show white children, with only one palate demonstrating a rash on a black child (Behrman & Vaughan, 1983). This represents the education of doctors learning pediatrics 30 or 40 years ago. Some of them are currently at the peak of their careers. This demonstration gave them the unspoken idea that being white was the norm whereas being black was not. Teaching doctors how to notice and interpret these rashes with a strong focus on white skin could easily undermine their sensitivity to skin rash and how it manifests itself on black skin. This marginalizes the black child, through ignorance and lack of knowledge about how skin diseases manifest themselves. We only have to hope that these currently practicing specialists have corrected this flaw in their medical education. These examples show how omission or simply blindness towards certain groups—in this case, women and people of color—are examples of systemic blindness that hinders access to good services. This is a form of oppression within the system. The relational approach is based on awareness of how issues like gender, race, and color influence our situations. It is, therefore, helpful to alert us and hinder systematic blindness towards certain groups.

Finally, I would like to mention, as an example of the importance of relational thinking in the doctor's practice, a recent personal story. This story shows how hindrances in the lives of disabled people manifest themselves when they try to use health care services. A friend of mine has an adult son that uses a wheelchair. He broke his leg and, as a consequence, had a large cast on his leg. When he was due for a check-up at the hospital, it seemed almost impossible to make the scheduled appointment. My friend explained to me how being in a wheelchair and with a cast on his leg made it difficult for her son to travel around as he normally did. He had real problems leaving his apartment and he could not properly fit into his car; furthermore, because the cast was so heavy, his personal assistant was unable to help him access the car. The doctors treating him at the emergency clinic gave this no consideration when treating his broken leg and putting on this type of cast. They did not regard it as their responsibility to get him to the hospital, or even let the means he had for transport influence the type of cast used to treat him. It took many phone calls and negotiations, as well as the involvement of several influential persons within the health care system, to arrange for a suitable transfer. This shows us how important it is to regard the relational view and remember that we are different, we have different needs, and there are invisible hindrances systematically marginalizing certain groups by not giving them adequate service as well as preventing them from receiving this service. This might seem like a minor incident, but when barriers of this type are met again and again in every encounter with the health care system, they systematically marginalize some patients and establish a form of social injustice.

To notice that these systemic faults can lead to oppression, we need diverse types of research methods grounding the knowledge necessary in order to be able to deliver good health care services. But we also need different types of health care workers (Sherwin, 1992). We need diverse professionals with varying origins, backgrounds, and personal experience to understand diverse patients and their specific situations. Nothing is as illustrative when trying to understand hindrances as first-hand experience. Hence, we need doctors of all genders and colors and we need those coming from all classes of society as well as doctors with and without disabilities. All of this is necessary to increase the understanding of different ways of life in order to avoid systemic oppression and marginalization to help us create a more just health care system.

The feminist ethical discussion around the idea of relational autonomy has revealed some pitfalls in mainstream medical ethics. These show how we can unwillingly be blind to the oppression of marginalized groups and how important it is to uncover their experiences and voices, especially of those who are in a weaker position in life. Here, I refer to the experience of women, people of color, and disabled people, to name a few. Further, they show how mainstream ideology can serve to enhance the power of those who have it while marginalizing further those who are in a vulnerable position.

Under the fourth theme, I have outlined the relational view and argued for its importance when we evaluate ethical changes in medicine. The key examples discussed in this thesis focus on changes in medicine related to surrogacy, medicalization of fat people, and the use of NIPT in fetal diagnosis. Although the examples of medicine’s expansion addressed here affect all genders, the experiences of women still seem to be at the core of them. Hence, we cannot ignore the need to look at them in a gender-specific way and accept that our differences and context matter ethically. Further, we need to evaluate changes in medicine relationally and acknowledge that the wider view that recognizes our situatedness by noticing our gender, culture, class, and political background matters ethically. If we turn a blind eye towards our social embeddedness and our contextuality, we do not hear the marginalized voices. That omission results in medicine that does not adequately serve the most vulnerable members of society, and so medicine is then no longer true to its ends and inherent values.

4.4.4 The Themes and the Meaning of Medicine

I have now outlined the themes common to all of the three examples discussed in paper I–III. First, I discussed the influence of disease and the power of the diagnosis on the patient's life. I pointed out the tension formed between illness and disease when the connection is lost between the patient's narrative on the one hand, and the acknowledgement and knowledge of the doctor using the diagnosis, on the other. The former, i.e. the illness, is based on the patient's subjective experience, whereas the latter, the diagnosed disease, is characterized as a physiological dysfunction and, as such, is often objectively measurable. This led to the second theme where the humanistic thread and the scientific thread of medicine were outlined. I explored ways where the delicate balance between these two threads can go astray. I discussed the possible danger occurring when the doctor identifies primarily with medicine as a scientific conduct, focusing on the objectively described disease which can overshadow the patient as a person. Here, I specifically recalled the Christian root of medicine, emphasizing the importance of the doctor keeping her focus not only on the patient, but on the vulnerable patient. I concluded by saying that, within medicine, it is especially important to focus on the weakest call coming from those most vulnerable. That led us to the third theme, the marginalized voices. Under the third theme, I examined the personal voices of patients in a marginalized position within the health care system. Some have criticized the impact the diagnostic label has had on their lives and the way their voices are systematically ignored in theory and policy-making within medicine. To change this and give these voices full hearing, doctors need to accept research methods that are now marginalized within the field of medicine such as the approaches used by philosophy, anthropology, and the social sciences. These fields are helpful in gaining a better understanding of diverse life conditions and personal narratives from patients as well as detecting vulnerable groups in need of special attention within the health care system. This conclusion led to the last theme which reflects on feminist bioethics and relational theory. This theme illustrates the importance of viewing ethical issues in health care through a relational lens. According to the relational approach, our social context is given ethical importance as it affects our choices and responsibilities on all levels.

The themes from the articles show how medicine can deviate from its ends and inherent values when entering new grounds. What characterizes new grounds is the fact that social constructional forces influence medicine. Originally, I regarded the themes as reflecting separate issues in each of the key example in the articles, but when I regarded them together I noticed that the themes are connected and intertwined. Saying that, and although I have kept the thread of continuity when describing them above, they are not to be interpreted as an argumentation culminating in the fourth theme.

As illustrated in the beginning of this thesis, my primary intention in writing the papers was to address and shed light on the tension outlined in the international report that the Hastings Center published regarding the constructional forces of society or sources of stress and the aim and inherent values of medicine. Through three selected key examples, I wanted to pay special attention to what happens when medicine enters new grounds and takes on new responsibilities. The themes I have outlined are not to be viewed in the same manner as the constructional forces or sources of stress on contemporary medicine that are mentioned in the Hastings Center Report (Callahan & Hanson, 1999). They are patterns repeating themselves in all of the key examples, visible when medicine is strained, as demonstrated in the papers. After having studied them, I see them as reflecting some essential insight into the meaning of medicine. I fear these are insights that we, in our daily lives, tend to ignore. What are these insights to which I am referring?

First, they involve the inherent uncertainty of empirical medicine. It is collecting information about human beings, but they can never be more accurate than man himself. Human beings vary in their biology as well as in their thoughts, will, and intentions. We all live in uncertainty and, even if we use the very narrow description of medicine where the human aspects of medicine are subordinated to the natural sciences, even medicine understood in this narrow sense would never deal with accurate figures. Medical tests, diagnostic procedures, and medical treatments are based on probabilities and must be interpreted contextually. Therefore, even medicine in the purest scientific sense is uncertain where it has more in common with meteorology as a science than with mathematics. This uncertainty shapes medical theory and defines what medicine is and how it works. The medical doctor can never promise results, like a computer program can. She can only promise to choose what she thinks is best (and what has the best probability) and that she will work in the patient's interest as best she can.

Secondly, human interactions within medicine are always about dependence and power. Medicine influences people's lives in a profound way. It has the power to have good and bad effects on people's quality of life. The patient is in a vulnerable position and thus is dependent on the doctor. Hence, medicine will always bring with it a power imbalance. It is neither good nor bad per se; this imbalance is just inevitably a part of what medicine is and does. The medical doctor needs to be aware of this and be trained to work in these situations. That is the reason for codex ethicus where the doctor promises to do no harm and to always act in the patient's interests.

Finally, the concepts and the language influence the way we think and comprehend the world. Disease is the core concept of medicine. We have difficulties in understanding and defining this concept (Hofmann, 2001, 2010, 2021). We cannot phrase its precise meaning and we will never be able to do so. This relates to the complicated duty of the physician to respond to a person's need and answer questions like: What is a relevant need? What is medical suffering? When is a human condition a disease and when does a health related issue fall under the doctor's domain? These questions are real, but there is no definite answer to them. Although the meaning behind the word is elusive, we still need to refer to the concept of disease. We are bound to this concept, and our understanding and definition of it will always influence the way we think and act as patients, doctors, and policy-makers in health care.

The themes from the articles reflect these insights that I here want to call ontological characteristics of medicine and as such, they also partly tell us what medicine is. The discussion under these four themes has revealed how medicine can be ethically led astray. It has outlined examples where medicine has deviated from its ends and inherent values and as a consequence has caused harm to patients. The key examples discussed in the papers show us how, to whom and under what circumstances this can happen. The discussion on the themes in this chapter has deepened the discussion in the papers and explained this process in more detail.

If the potential harm described under these four themes is not acknowledged and addressed, it can enhance ethically damaging trends in medicine as medicine progresses. The benefit of spelling them out, as well as acknowledging the harm they can lead to, helps us in trying to avoid harm in medicine. That has been the purpose of describing them.

We can now recall the research question: "When medicine enters new grounds, as described in papers I–III, it can deviate from its ends and inherent values. What characterizes this deviation and how can that knowledge be used to interpret the meaning of medicine?" At this point, I have shown how medicine can deviate from its ends and inherent values and what characterizes this deviation. In the next chapter I will turn to the question: "How can that knowledge be used to interpret the meaning of medicine?" I approach it by focusing on how it is possible to interpret and preserve the ends and inherent values of medicine as medicine develops and enters new grounds. To do this, I will spell out a three-dimensional view of medicine that can be used as a frame of reference when evaluating its expansion. Each of these three dimensions refer to different facades of medicine. I will argue that all of them need to be acknowledged if we are to gain a proper understanding of medicine’s meaning. Through gaining a deeper knowledge of the meaning of medicine, as well as its ends and inherent values, we are better prepared and in a better position to avoid the possible harm medicine can cause.

5 A Three- dimensional View on Medicine: The Science, the Vocation, and the Values.

5.1 The Dimensions

This chapter will sketch up a three-dimensional understanding of medicine and outline what medicine is and ought to be. The first dimension emphasizes the need to ground medicine in validated knowledge, the second describes the vocation which must be alive as a way to remind us of the ends of medicine, and the third spells out the important values inherent in medicine.

5.1.1 The Grounding Knowledge and the Science

Medicine’s greatest advances in the last century are based on scientific knowledge on new biomedical information about how humans are as natural beings and how they might be threatened by diseases or accidents. The discovery of microorganisms, the chemistry behind the drug industry and the genome, are to name a few groundbreaking scientific fields, contemporary medicine relies on. Advanced techniques, both in diagnosing diseases as well as in curing patients, have transformed medicine and medical work. This progress has, without a doubt, enhanced our lives.

Most of this new evidence-based knowledge is grounded in the view that we are biological beings and is described through the impersonal models of anatomy and physiology. Much of the empirical knowledge of medicine is also detected and described through numbers often extracted from large databases, like in epidemiology. This gives medicine an important and objective ground on which to stand. This type of knowledge is a necessary part of medicine, but is nevertheless a limited description of what it means to be a human being. This empirical description often lacks insight into the variations in life and is blind to our thoughts, will, and intention. It is mainly concerned with us as objects, not as subjects (Kirkengen et al., 2016).

Greenhalgh et al. (2014) have outlined some of the difficulties with which evidence-based medicine is confronted. Here, “evidence-based medicine” is referred to as an important paradigm for teaching and practicing clinical medicine (Bensing, 2000; Guyatt et al., 1992). This approach of evidence-based medicine is aimed at making medicine “more scientific and empirically grounded and thereby achieving safer, more consistent, and more cost effective care” (Greenhalgh et al., 2014, p. 1 of 7). This in itself is a good aim, although challenging because this type of evidence is sometimes difficult to apply. Scientific research and its relevance can be hard to interpret and explain and it sometimes lacks relevance to the lives of real patients. As a response to these difficulties in making medicine evidence-based, Greenhalgh et al. (2014) emphasize the importance of acknowledging the patient as being at the center of evidence-based medicine. As a consequence, they introduce actions to deliver what they call "real evidence-based medicine". One of these recommendations is that "[t]he research agenda must become broader and more interdisciplinary, embracing the experience of illness, the psychology of evidence interpretation, the negotiation and sharing of evidence by clinicians and patients, and how to prevent harm from overdiagnosis" (Greenhalgh et al., 2014, p. 4 of 7).

This shows a discussion within medicine that underlines the importance of understanding ourselves as biomedical beings as well as agents, thinkers, and creators. This is done by drawing attention to other research methods than empirical sciences and acknowledging their importance as a contribution to medicine. These include research methods based on social sciences and anthropology where it might be possible to give a more detailed description of the person and the human condition and thereby widen medicine's knowledge base. The main benefit in adding descriptions from other fields like the social sciences and even the humanities would be to better understand what it means to be a human being. These approaches could further increase understanding and help to come to terms with the inevitability of the uncertainty of the human condition.

As mentioned above, there is a variation within human beings; we are of different genders, different colors, and different classes. All of this can influence our anatomy, our physiology, and our likelihood of getting certain diseases. This means that the empirical results of medicine need to be interpreted contextually. The meaning of a positive HIV test in a person with no known risk factors of HIV does not necessarily have the same meaning as a positive test result in a person having a high risk of getting HIV. This test result might need to be interpreted with a clear knowledge of probability and compared against the risk of false negative and positive results (Mukherjee, 2015). The difficulty of interpreting the results of medical tests does in no way undermine their importance, but highlights the complexity of medicine since it is a science that seeks certainty but is inherently uncertain (Montgomery, 2006; Mukherjee, 2015).

To summarize this, it can be said that medicine needs to be grounded in evidence-based knowledge, and to rely on empirical science and the scientific method, in general. Nevertheless, we need to realize that being scientific it is not necessarily always accurate. This is because we are not mechanical or mathematical, but biological beings. The science describing us will always reflect that. Further, we have to interpret the probabilistic figures and the context we get from the life sciences in order to gain some sort of a meaning, thereby providing additional knowledge from other disciplines than empirical biomedical sciences and broadening the base that medical knowledge is grounded on in the attempt to make the medical knowledge meaningful. The next step in describing medicine is to explore how this is done, i.e., how we use the medical knowledge described. This leads us to the second dimension: the discussion on the ends of medicine and the vocation.

5.1.2 The Vocation and the Ends of Medicine

Katheryn Montgomery describes two pillars of medicine: the scientific pillar and the clinical pillar in her book, *How Doctors Think: Clinical Judgement and Practice of Medicine* (2006). She draws attention to how medicine is based on science in a positivist sense, but is also based on clinical judgment. Clinical judgment, being how that scientific knowledge is used for the benefit of the patient (Montgomery, 2006). I have already discussed her approach in the article on fetal diagnosis. She criticizes the tendency to emphasize the scientific aspect out of proportion and view medicine only as an academic science and forgetting that medicine is a clinical practice. Although it is based on the empirical knowledge of science, it has to be remembered that this knowledge must serve a clinical purpose, or it becomes “medically meaningless” (Montgomery, 2006, p. 206). She is making a very important point. I agree with her that this has not received due attention in the discussion on medicine. Ignorance of this interpretive task of medical knowledge can be dangerous for the patient, the health care system, and the medical profession.

To know the ends of medicine is to understand the purpose of medical work and to have a deep sense of what it means to be a medical doctor. This is the teleological dimension of medicine. It describes its ends. Pellegrino talks about the “need of sick persons for care, cure, help, and healing” as making up the ends of medicine (1999, p. 60). Pellegrino describes the core of the ethos of medicine when he talks about “the healing end of medicine in the context of patient vulnerability” (p. 63). This means that all medical work has this end built into it, in order to answer the sick patient’s need. This also marks the position of the doctor; she is always in her work addressing those who are vulnerable and in need.

This entails looking more closely at how we can interpret the ends of medicine. Daryl Koehn writes on professional ethics and describes the vocation of medicine. She talks about the meaning of the word “profession”, derived from the Greek verb “prophaino” meaning “to declare publicly”. According to Koehn, the professional is “an agent who freely makes a public promise to serve persons (e.g., “the sick” to use Pellegrino’s phrasing) who are distinguished by a specific desire for a particular good (e.g. health)” (Koehn, 1994, p. 59). The profession promises to answer the call of those in need. In the case of the doctor, this addresses the needs of those who are sick (Koehn, 1994). This is the calling, the vocation of the doctor. One aspect of the vocation of medicine can be traced back to the parable of the good Samaritan in the New Testament (Luke 10:25-37), where every patient is the doctor´s “neighbor” in the sense of the parable (Jonsen, 1990; Montgomery, 2006). This describes well the foundation and meaning of the doctor-patient relationship. To be aware of why we practice medicine is inherent in the physician’s clinical judgement. The vocation is always towards the patient as a human being so the doctor attends to the person in need, not the disease per se.

What gives medical knowledge meaning is its relevance to the patient. With the patient in the center, not the scientific description of the disease, we see why awareness of uncertainty, mortality, and vulnerability needs to be at the core. Hence, the aim of the profession—reflecting on those ends—is not to eliminate imperfection or promote some sort of a disease-free existence, but to accept us as we are and support us in our inescapably imperfect lives. This is what the medical doctor following her calling needs to hear. This is why she is not primarily on a quest for truth and knowledge, in the empirical sense, but is following a vocation to care for and cure those who are sick.

I will now turn to what I see Pellegrino referring to when he speaks about “the context of patient vulnerability” (1999, p.63). The patient’s vulnerability characterizes the doctor’s vocation. It also characterizes the doctor’s position. She has to be aware of the patient’s vulnerability at all times and this above all else has to shape the self-identification of the medical doctor. Due to the patient’s inherent vulnerability, the doctor in medieval Christian medicine was described as the servant of the sick (Jonsen, 1990). This shows why doctors need to always know their place. They are to advise, help, and support, not control and dominate. That is why the doctor always needs to be reverent towards her work and has to work with insight and understanding of the particular patient and his life. The patient in his vulnerable condition needs assurance he can trust his doctor. This assurance rests on the doctor’s promise to care and cure the patient (Koehn, 1994). Hence, we can say that the proper relationship between the doctor and patient is based on the premise that it is always the patient that matters most:

this particular human being, his life, not his disease. This is the core of ethical thinking in clinical medicine.

There are good reasons for discussing these ideas in this context. With medical knowledge comes power and with diseases comes vulnerability. This inevitable combination can easily cause harm if the ends are not clear and strict protocols regarding the doctor's position are not respected. This explains why we need to always remember that medicine may never be defined as being merely science; it is a vocation, a calling that uses the knowledge of science for the patient's benefit.

Clinical judgement, giving meaning to medical science, can be described as the tacit knowledge of medicine. We need to lift this dimension of medicine and take care that it is mainstream in the professional discussion and not seen merely as an afterthought. Medical doctors must be true to their vocation at all times. If this reflection and awareness is not practiced and exercised, medical doctors can lose their integrity and identity as well as their ability to do the necessary interpretation of the scientific facts where their clinical relevance is evaluated.

Medicine is a profession that participates in a moral contract between the doctor and the patient as well as between the medical profession and society. What this contract entails is not discussed much within medicine. When working as a doctor, it is more or less assumed that doctors understand the moral importance of this contract. This relative silence about the ends of medicine and the vocation of the profession can undermine medical work. Awareness and insight into this dimension versus neglect towards it can easily be the defining difference between a good doctor and a bad doctor and between a good health care system and a bad one.

This teleological insight revealing the ends of medicine and the awareness of its inherent power imbalance is what constitutes the second dimension. Montgomery describes two pillars of medicine, where the former is grounded in scientific knowledge and the latter in clinical judgement, i.e., on how to use that knowledge for the patient's benefit. This clinical judgement is rooted in the teleological dimension described above, but it also relies on the third dimension: the inherent values, describing medicine as being true, good, and just. That will be discussed in the next chapter.

5.1.3 The Inherent Values: On Medicine Being True, Good, and Just.

Drawing up this three-dimensional view is an attempt to describe the core of medicine. I have already described the evidence based scientific foundation, as well as the ends of medicine which give it its inner direction. The last dimension describes the inherent values of medicine.

It describes medicine through value judgements. When referring to the inherent values in medicine, the focus is on the values that help us understand and describe what medicine is and what it ought to be. I am not grounding my statements on sophisticated value theories, rather I am using the reference to inherent values to describe what makes medicine good and worthy, as something we would not want to be without or lose.

I approach this discussion by referring to *beneficence*, *justice* and *truth*. Here it is also necessary to clarify that I do not see these descriptions as "principles" or as describing "virtues" in medicine rather, these references are used to approach important normative ideas describing why medicine is valuable.

Firstly, we can name beneficence. This word stems from Latin, the word "bene" meaning "well" and "facere" meaning "to do" (Skeat, 2007). Hence, this value describes the will to promote goods, such as health, well-being, welfare, and life itself. To be able to guard this value, the medical doctor needs some understanding of what a good life amounts to. I have here no intention of claiming that there needs to be some sort of strict unity behind our understanding of the notion of a good life. There is ample space for diversity as there needs to be in pluralistic societies. Nevertheless, medical doctors need to be familiar with and even participate in this discussion. Otherwise, they are not familiar with the reference to which judgement claims about well-being and health are made. An understanding of beneficence and a good life is the unspoken background upon which all medical decisions are evaluated and decided. Some might ask, why not refer to health, well-being, welfare, and life as basic values in medicine rather than beneficence? The answer is that while these are important values in medicine, they are all an integral part of a more profound value of that which is good. We need this more foundational idea to evaluate the deep questions of how and why to practice medicine and to be able to give all of the decisions in medicine their clinical meaning. There are moments in medicine when questions can be asked about the goodness of things such as prolonging life or promoting health. When facing these hard questions, we need this idea of goodness or beneficence to help us, as well as the importance to do no harm. Therefore, health, well-being, welfare, and life are important ways to describe what beneficence in medicine entails.

The importance of not doing harm or what often is referred to as the principle of non-maleficence is "Primum non nocere." This statement can be regarded as an important part of guarding the value of beneficence. Although it may not be referred to as a value in itself, this should be remembered as a special and primary concern. That is because of the nature of the bond between the physician and the patient: a doctor who holds power and a patient who is vulnerable. This combination demands medical professionals be reverent towards their work. If not, medicine can easily do harm and turn a cure into wrongdoing.

The second value inherent in medicine is justice. Justice is derived from the word “ius,” meaning “that which is right,” “that which is fitting” (Skeat, 2007). Justice is here referred to as having two fundamental meanings. First, the notion of distributive justice is described as fair distribution of resources (Beauchamp & Childress, 2001; Rawls, 2009). Second, there is the idea of justice understood as being able to attend to the voices of those who are weak and vulnerable. This connection to justice is described in Simone Weil’s article: Human Personality (Weil, 1986). This latter idea has a deep connection with medicine where justice serves as the value that reminds us that those who are weak and vulnerable are not to be left out. Medicine is participating in a social contract that serves the community. It promotes health and distributes service that is good in itself. In the discussion above on the themes of the articles, I claim that medicine has a duty to listen to the voices of those who are ill and those who suffer, and the duty is strongest towards those who are most weak, most vulnerable, and who suffer the most. The third theme on marginalized voices provides an example of how these voices are and explain why it may be difficult to hear them in ordinary medical work. The voices there described only became visible when new methodological approaches were used outside the clinical setting. This idea to attend to those more vulnerable first, is intrinsic in most health systems, visible in things such as the discussion on allocation of health care where it is to be distributed based on need, where those in most need are to be served first. Therefore, medical service is not to be seen as a commodity to be bought and sold at will or at random.

Third, truth is a grounding value of medicine. Truth here refers to that which is true, meaning “firm” or “certain,” but also connected to the idea of “believing” or “trusting” (Skeat, 2007). This value reminds us of the need to base medicine on research in order for it to be effective. It also considers medicine as a profession of truthfulness, where we can rely on its honesty and integrity. Since medicine is in high demand and has promised to help, it needs to ground its statements, its advice, and its doings in a reality that is honest and evidence-based. It is also necessary to discuss and evaluate what sort of knowledge should be the basis for medical work (Greenhalgh et al., 2014). The guiding value in this quest is truth, so medicine can be effective in acquiring its aims.

These three core values—beneficence, justice, and truth—are what I call the inherent values of medicine. They are the properties of medicine describing how medicine is and how it ought to be. They should be reflected in the doctor's work and in the promise to the patient outlined above. This promise outlined under the discussion of the vocation is the basis for the patient's trust (Koehn, 1994). Trust has not been included as an inherent value of medicine although it is a basic value in the practice of medicine. Here, it is necessary to make a distinction. On the one hand, trust is an important value that the profession needs to guard, i.e., by being trustworthy. On the other hand, trust is not something that doctors have the power to give, although it may follow if the doctor works in accordance with the inherent values of medicine. Trust in that case is coming from the patient towards the doctor and as such, it is an elementary value for which any profession strives. That is different from being a value that is inherent in medicine.

Finally, it might be asked, what about autonomy? Has autonomy no place in this discussion on values in medicine? There is no doubt that autonomy has a central place in the ethos of medical work. Autonomy, however, has to be distinguished from being an inherent value in medicine. Although medicine has clear ends and characteristics, it is not like a self-governing person and as such, not inherently autonomous. I claim medicine to be characterized as being inherently good, just and true but reference to autonomy is in this discussion better described as the medical doctor's duty to respect the patient's autonomy.

The values I claim are inherent in medicine are the values that help us to understand what medicine is and as such they are helpful in outlining the limits of medicine. Consequently, acts that are not truthful, good or just are not in line with what medicine is and ought to be. Trust is not marking this boundary, it is a value that follows if the doctor is doing her work accordingly. Same goes for autonomy, it is not characterizing medicine, it is an important value for the patient and the medical doctor needs to respect it in her work.

5.2 Why the Three-dimensional View?

The novelty of this description of medicine lies in how these three dimensions are viewed together as an inseparable whole where the vocation is seen as the origin and inner direction of medicine. Medicine is most often described too narrowly. Here, using this three-dimensional view emphasizes the depth of medicine and its complexity. This description outlines the equal importance of all of these views and the need to see them as an inseparable whole. Medicine's ends and inherent values can be undermined in many ways as described in the discussion of the themes from the papers. This happens because we are not nurturing all of these three dimensions together. To neglect any of them increases the probability of making mistakes and causing harm in medicine's use.

We are now in a position to reconsider the harm described under the themes from the articles and reflect upon how this description of the three-dimensional view of medicine can help us address and prevent it. First, I discussed the possible harm of the diagnostic label, outlining the possible danger when the doctor's professional perspective mediated through the classification by diagnosis and the patient's subjective experience are separated. To be able to tolerate this gap without harming the patient, it is necessary to remember and be aware of the vocation and inherent values of medicine and use that insight as guidance. The ends help the doctor keep the patient in focus as the core of her work and hinders her from being carried away with the diagnosis in her hand. If the diagnosed disease or health related issue acquires a life of its own and loses connection to the personal dimension, i.e. the patient's illness, then the doctor has lost sight of the ends and might act with the wrong aim in mind. Consequently, the diagnostic label must always be related to medicine's ends and values.

Secondly, I discussed the overemphasis on science where it can take the lead as the sole drive of medicine's progress, whereas the patient as a person loses centrality. By recalling all three dimensions, it is possible to see the need for strengthening the doctor's awareness of the vocation and the inherent values of medicine. The vocation and the inherent values help the medical doctor evaluate what does and does not matter when interpreting scientific evidence and giving them medical meaning to use the reference from Montgomery (2006). From the second and third dimensions, we gain insight into why certain factors matter medically and why they do not.

Paper III addresses how science and the diagnostic label cast a shadow on the importance of the lives of people with Down syndrome, regardless of how they feel. The vocation and the values connected to the search for fetuses with Down syndrome are generally hidden in the mainstream medical discussion on when to offer tests like NIPT. I am here referring to questions like: Whom do these tests serve and why? Are the lives of people with Down syndrome of less worth than the lives of others? What makes life worthy? How can these tests harm? These questions are central when deciding upon the relevance of their use. Medicine grounds its policy and treatments on judgements regarding these questions but rarely discusses or questions them. These are value judgements but are nevertheless inherent in medicine and failing to address them is a serious oversight. Only disabled people themselves and their families are speaking out in questioning the value judgements underlying the use of NIPT. The relevance of these questions should be acknowledged and debated within medicine. Of course, this does not mean that doctors are the only people capable of discussing them, like oncologists discussing what medicines to use for cancer. It simply means that medicine should acknowledge that these questions and the way we answer them influences medical decisions, and medical doctors should listen, participate, and try to comprehend. When these value judgements are not discussed, there are unspoken biases hidden under the cloak of neutrality. That has been interpreted as a form of oppression towards people with disability, especially towards people with Down syndrome. This interpretation is based on the fact that screening is seen as discriminating towards this particular group of people so that they and their families feel the need to justify their existence (Dixon, 2008; Diaz, 2019).

In the discussion on the third theme, the marginalized voices were described. In all of the key examples discussed in the papers there was emphasis on the need for the doctor to situate herself beside the patient and on trying to understand the possible barriers the patient might meet within the health system. When discussing the third theme, examples of personal experiences of those marginalized within the health system were highlighted to gain a better understanding of their specific position. Again, the two additional dimensions describing the vocation and the inherent values are helpful. The doctor who knows the ends of medicine is aware of the duty to listen and tries to understand the position of the patient, especially the weak and vulnerable patient. The doctor also knows that a primary concern of medicine is to do no harm. She realizes the importance of recognizing stigma and marginalization and does her best to prevent medicine from enhancing those tendencies when infiltrating her service.

Under the fourth theme, the importance of the relational lens to avoid oppression was discussed. It outlined the need to use the wide lens and keep in mind the relational view. This view reveals why it is necessary to note hidden biases and social injustice and helps to phrase the discussion so that we can avoid stigma and search for better solutions. A medical doctor who recognizes her duty to listen to the voices of all, including the marginalized, the weak, and the vulnerable, accepts justice as one of medicine's inherent values. Hence, she is more capable of preventing the possible harm described in the fourth theme.

Finally, I want to mention the importance of both understanding the vocation and the inherent values in helping to demarcate medicine's boundaries. The vocation is to answer the needs of those who suffer. Suffering clearly plays a central role in demarcating the limits of health and disease, and as such, the doctor's attention (Hofmann, 2021). To gain a better insight into what it means to say that medicine's vocation is to answer the calls of those who suffer, we need to rephrase the problem more precisely, i.e., finding that medicine is not answering human suffering, in general, but rather to what we might label as medical suffering, in particular. Here, we are facing the difficulties coming with the third ontological characterization of medicine mentioned above, i.e., the dynamic concept of disease. The medical doctor does not need to note and react to all suffering. We suffer when we grieve, but it would not be helpful to medicalize e.g. a loss of a child. That could undermine or even trivialize the importance and meaning of such a loss. We suffer from poverty, but this is not cured by medical means and neither is suffering due to loneliness. There is a reason to set limits to what types of suffering medicine reacts to and that boundary is not always clear. This is reflected in the difficulty of defining and demarcating the core concept of medicine, that of "disease" as has already been mentioned. In this thesis these difficulties are acknowledged. Insight into the inherent values further helps to draw this line demarcating medicine. The medical doctor has promised his patient to do him good and avoid harm. The doctor has also promised to act in a just and truthful manner. If the doctor is not following these ends and does not guard these values, she is not working in accordance with what is and ought to be medicine.

The vocation, as well as the inherent values of medicine, is not well-represented in formal medical education. Neither is it reflected in their peer reviewed journals nor in their scientific work. This shows neglect of important elements of medicine, the very part that guards its aim, meaning, and value.

6 Conclusion

In this thesis, I explore the meaning of medicine as well as the possible harm when medicine evolves and enters new grounds. The first part of the thesis is three peer reviewed articles that describe and ethically evaluate the discussion of three key examples. This is represented in papers I–III. The examples discussed in the papers were chosen because they originated in ethical discussions in Iceland in the last decade and reflected upon issues at medicine's limits. In all the examples, medicine was entering new grounds and was influenced by constructional forces in contemporary society. In the second part of the thesis, I concentrate on four themes binding the papers together. These themes are common to the discussion in all of the key examples and by investigating them it is possible to strengthen the argumentation in the papers. The research question for the second part of the thesis is: "When medicine enters new grounds, as described in paper I–III, it can deviate from its ends and inherent values. What characterizes this deviation and how can that knowledge be used to interpret the meaning of medicine?"

First, I want to focus on the former half of the research question above, i.e., what characterizes this deviation of medicine from its ends and inherent values. To answer that, I have described the four themes that repeat themselves in the discussions in papers I–III. When these themes are investigated further, it is possible to see a connection between them forming a pattern that flows from the first theme to the fourth theme and can be described as follows: The first theme shows that, when medicine evolves and enters new grounds as described in the examples in the papers, the diagnostic label has gained a separate existence without clear connection to the patient's subjective feeling and experience of illness. This diverging dichotomy undermines the patient's humanity as he is no longer in the center of the doctor's attention since that has turned to the description of the medical pathology and the diagnostic label. The second theme describes how this can further be enhanced by science's influence as being the essence of medicine at the cost of the focus on the vulnerable patient. The third theme shows how this is especially prone to happen if the patient is in a marginalized position. Finally, the fourth theme emphasizes the need to evaluate and regard the patient as a relational being; otherwise, medicine can lead to oppression where justice is not respected.

How can the changes referred to in the key examples cause medicine to deviate from its ends? The reference to the ends of medicine reminds us of the vocation of medicine. In the discussion on the first and second themes, it was shown how the aim of medicine can change when medicine loses its focus on the patient´s illness and primarily works with reference to the disease perspective, then medicine has deviated from its ends. As was discussed under the headings of the third and the fourth themes, this is especially threatening to marginalized and vulnerable patients.

Further, how can these processes described under the four themes from the papers affect medicine’s inherent values? I specifically defined three values inherent to medicine: beneficence, justice, and truth. When discussing medical ethics in general, additional values that are not included in what I call the inherent values of medicine are also in focus. These additional values are trust and autonomy. Both very important values to know and guard in medical work. What characterizes the inherent values of medicine, i.e., beneficence, justice, and truth, is that they describe why medicine is important and worthy as well as being descriptive of what medicine is and ought to be. The harm described shows examples of how these inherent values are not guarded as they should be in medicine. This can occur when it is not properly evaluated whether the work performed has clinical meaning for the patient. Medical work also needs to be grounded in evidence-based knowledge, has to improve the patient’s quality of life, and has to respect justice. Examples of neglect of these towards these inherent values are visible in the reactions by certain groups of patients. In this thesis, I have reflected upon reactions of fat people, disabled people, as well as vulnerable women serving as surrogates. For these groups of people, medical attention is very important to enhance their quality of life, but it also has the potential to make their position in life worse, where it can be oppressive and harmful.

The themes that repeatedly occur in the three papers are to be interpreted not as descriptions of what generally happens but rather as signs of ethical concerns, visible in the dynamic evolution of medicine. It is necessary to recognize them in order to be able to both prevent harm towards individual patients in health care as well as be aware of potential harm towards certain groups of people that are stigmatized as well as marginalized in society. The themes describe ways in which the ends and the inherent values of medicine are not respected. I believe the tendencies that the themes describe cannot be escaped since they are there because of how medicine is. These characteristics of medicine that can lead to the harm are the uncertainty of medicine, the power imbalance between the doctor and the patient, and the difficulty in deciding what is a disease and what is not. They are addressed as ontological because I wanted to underline that I see them as inevitable. They are inherent parts of what medicine is. Further, I now hesitate to call these characteristics “a weakness” because they are also the reason for medicine being an art and for being both caring and dynamic. That makes these characteristics the origin of both interest and beauty. Nevertheless, they are the reason for why medicine can be led astray when its limits are tested.

We can now turn to the latter half of the research question which focuses on how this knowledge can be used to interpret the meaning of medicine. As a reply to that, I sketched a three-dimensional view of medicine that describes it as based on science, with clear ends and inherent values. Here, I am searching for a common core of medicine that can give us a frame of reference when distinguishing between what is medical and what is not as well as gaining a deeper sense of what to guard as medicine develops. I propose an interpretation of medicine as holding three dimensions that form an inseparable whole. This is done to counteract the marginalization of the vocation of medicine as well as keeping the attention on medicine’s inherent values in mainstream medical discussions. If physicians are not familiar with all these dimensions of their profession and keep them in mind, it can lead to an emphasis on the wrong things, and medicine can then cause harm.

Primarily and fundamentally, medicine is a calling; it is an answer to the needs of those who suffer from medical conditions. The medical doctor has to constantly listen and follow the patients’ voices in order to be able to serve them. This provides an inner direction. Deeds that do not meet these ends are not in line with what ought to be medicine. Secondly, it is based on a science that is constantly evolving where we see progress both in its knowledge and technology. The dynamic evolution of medicine is necessary to meet the challenge of searching for new and better ways to meet the vocation. This makes up the direction, the drive, and the moving force of medicine. What helps demarcate the limits of medicine is both the ends, and the third dimension describing the inherent values. Firstly, we can reflect upon beneficence. Medicine is based on the calling to meet the patient’s needs and to do him good, here the will to promote life, health, well-being and welfare. This further refers to the goal not to harm the patient. What guides us in understanding beneficence are insights into discussions on what is a worthy life and what is a good life. Secondly, we have justice; medicine is to serve those who are vulnerable and most in need. It has to notice the marginalized voices and be aware of possible oppression in order to be able to avoid it. Thirdly, we have the value of truth where medicine has to be truthful and evidence-based as a necessary ground for medicine to be effective. These core values as well as the ends of medicine do not change. Everything done within the scope of medicine has to have this inner direction and include these values. So, now we have the drives, the direction and the limits. When evaluating the evolution of medicine as it enters new grounds, this can be used as a frame of reference, since it describes a core that does not change. What is done within the scope of medicine has this inner direction and includes these values.

To reflect upon the ends and inherent values of medicine is as important for medical work as the evaluation that needs to done when scientific evidence is accepted. The additional teleological and normative evaluations discussed above are not to be only conducted by professors in medical ethics classes in universities, but primarily by medical doctors meeting patients and medical scientists as well as health authorities implementing new health policies. These reflections should be ingrained into all medical work. If this reflection and evaluation is not done properly as medicine evolves, three things can happen. First, medical doctors can cause harm to patients. Second, the health care system can lose its correct focus and end up using its resources in an unjust manner. Third, doctors lose their professional identity. To prevent that, the holistic view—a three-dimensional concept of medicine—is helpful.

When reflecting upon this thesis, I want to highlight what I take from this work.

First, the common themes of the papers brought to me a new knowledge. They revealed a pattern that could be described as flowing from the first theme to the fourth theme. By drawing attention to this, a new insight is gained into how medicine can cause harm to certain patients as well as groups of people. Those most likely to experience this harm are patients who are in a marginalized position in society. It is important to highlight that these experiences are usually not expressed in the consultation room nor are they visible in general empirical research done within health care. As was pointed out in Chapter 4.3., Sherwin (1992) claims that: “One of the central insights of feminist work is that the greatest danger of oppression lies where bias is so pervasive as to be invisible” (p.10). These voices are invisible unless we search for them.

Second, by drawing attention to the three ontological characteristics of medicine, I gained a deeper understanding of how medicine is. Here, I refer to the description of medicine as being uncertain, with an inherent power imbalance and based on a dynamic disease concept. This description has ethical importance since it serves as a reminder for medical doctors to be reverent in their work. In many ways, medicine might be better described as a blunt instrument rather than as a sharp one, and it should be remembered that medicine as a profession has the potential to bring both good and bad things for the patient as well as for society.

Third, this thesis is an attempt to phrase what medicine is. It tries to locate and describe a common understanding of medicine that can endure the dynamic forces of time and social construction. It searches for a common core that can serve as a frame of reference for doctors and patients when speaking and thinking about medicine.

Finally, I see this thesis as an example of how we can discuss and evaluate changes as medicine enters new grounds. The value of applied ethics is in its relevance to our daily lives, to what is happening here and now. The problems we face touch us personally, and they are confusing and loaded with feelings where it is difficult to realize what is of relevance. In this context, it can be difficult to phrase and conceptualize our thoughts and actions. When I had to construct a theoretical discussion in the field of applied ethics, it was clear in my mind that the discussion had to originate in such problems, in an actual discussion that is alive here and now. By grounding this work in the key examples represented in each paper and then through a deeper reflection focus is on a common pattern in them I have been able to theorize on the same issues in a new way. This structure has given me the opportunity to ground my discussion in real life events but, at the same time, search for new theoretical insights through repeated reflection.

This research has focused on, examples of when medical attention can cause harm and the question: What is the core of medicine? In searching for this core, it has been important to describe a common nominator as well as to outline what makes medicine worthy and what is it in medicine that we do not want to lose. I find both of these focuses important and they have been neglected in medical discussions. This thesis does not provide final answers, but proposes an attempt to keep this discussion going.

My discussion also shows the need for further research. There are other examples in line with the key examples in this thesis that need to be investigated. I can name the discussion on cochlear implants and the responses of the Deaf[6] community toward these operations. It is also necessary to take seriously the voices of those now founding “Mad studies” and see how they might influence the approach of medicine in the field of psychiatry. There are further examples where I suspect we might see the same patterns in need of ethical attention as those described in this thesis. All of these examples need to be investigated and brought into the daylight. I have argued above that the type of harm described in this thesis is more prone to happen to patients already in a marginalized position within society. This needs to be better

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[6] Deaf with a capital letter refers to a cultural minority group that uses sign language and shares a history and a complex culture, transmitted across generations. See Padden, C. A., & Humphries, T. (1988).

confirmed and ways in which medicine is better equipped to serve vulnerable populations need to be developed. One way of doing that is to listen to the users of the service and for this group in particular it is helpful to use insights gained from e.g. critical sociology and anthropology. The knowledge these disciplines have be helpful in making medicine better aware of social injustice in relation to health care services and develop better ways to hinder that.

I have in the 5th chapter sketched a three dimensional model of medicine. These are rough outlines that need to be refined. To finish this description of the core of medicine, more research is needed. In this discussion the aim is primarily to show that medicine has defined ends and inherent values that are important. Further, to advocate for the view that medicine is based on a common core that is valuable and ought to be guarded.

Medicine as a human endeavor is something that has to be reflected upon constantly and cannot be allowed to evolve and progress without concern and without paying attention. I say this because medicine is powerful and can therefore be dangerous, but medicine also guards something immensely important for our life, well-being, and welfare. This research is an attempt to address this. The discussion on what medicine is, what it should be, and what its place in society should be must continue.

References

Adami, H.-O., Kalager, M., Valdimarsdottir, U., Bretthauer, M., & Ioannidis, J. P. A. (2019). Time to abandon early detection cancer screening. *European Journal of Clinical Investigation*, *49*(3), e13062. https://doi.org/10.1111/eci.13062

Atkinson, D. (2004). Research and empowerment: Involving people with learning difficulties in oral and life history research. *Disability & Society*, 19(7), 691–703. https://doi.org/10.1080/0968759042000284187

Allert, G., Blasszauer, B., Boyd, K., Callahan, D., Gillon, R., Glasa, J., Gracia, D., Lolas, F., Mori, M., Nordenfelt, L., Payne, J., Rossel, P., Suwandono A., ten Have, H., & Weibo, L. (1996). The goals of medicine: Setting new priorities. *The Hastings Center Report*, *26*(6), S1-27. https://search.proquest.com/docview/222381801?accountid=28822

Anonymous One. (2014). My story: Evolving obesities. *Narrative Inquiry in Bioethics*, *4*(2), 96-98. https://doi.org/10.1353/nib.2014.0046

Autier, P., Boniol, M., Koechlin, A., Pizot, C., & Boniol, M. (2017). Effectiveness of and overdiagnosis from mammography screening in the Netherlands: Population based study. *BMJ: British Medical Journal*, *359*, j5224. https://doi.org/10.1136/bmj.j5224

Árnason, V., & Hjörleifsson, S. (2016). The person in state of sickness. The doctor-patient relationship reconsidered. *Cambridge Quarterly of Health care Ethics*, *25*(2), 209-218. https://doi.org/10.1017/S0963180115000511

Basu, P., Ponti, A., Anttila, A., Ronco, G., Senore, C., Vale, D. B., Segnan, N., Tomatis, M., Soerjomataram, I., Primic Žakelj, M., Dillner, J., Elfström, K. M., Lönnberg, S., & Sankaranarayanan, R. (2018). Status of implementation and organization of cancer screening in The European union member states – Summary results from the second European screening report. *International Journal of Cancer*, *142*(1), 44-56. https://doi.org/10.1002/ijc.31043

Beauchamp, T. L., & Childress, J. F. (2001). *Principles of biomedical ethics*. Oxford University Press.

Behrman, R. E., & Vaughan, V. C. (1983). *Nelson textbook of pediatrics* (W. E. Nelson, Ed., 12th ed.). W. B. Saunders.

Bensing, J. (2000). Bridging the gap: The separate worlds of evidence-based medicine and patient-centered medicine. *Patient Education and Counseling*, *39*(1), 17-25. https://doi.org/https://doi.org/10.1016/S0738-3991(99)00087-7

Birmingham, S. (2013). Uniquely my own: One woman’s experience of living with a physical disability. *Narrative Inquiry in Bioethics*, *3*(3), 186-189.

Bishop, J., & Sunderland, N. (2013). Living with the label “disability”: Personal narrative as a resource for responsive and informed practice in biomedicine and bioethics. *Narrative Inquiry in Bioethics*, *3*(3). https://muse.jhu.edu/article/530464

Bjarnason, D. (2001). Af sjónarhóli félagsfræði og fötlunarfræða. Er lífið þess virði að lifa því fatlaður? *Læknablaðið. Fylgirit 42 – Kerfisbundin leit að fósturgöllum*, 30-35. https://www.laeknabladid.is/2001/fylgirit/1/fraedigreinar/nr/1226/

Björnsdóttir, K., Stefánsdóttir, Á., & Stefánsdóttir, G. V. (2017). People with intellectual disabilities negotiate autonomy, gender and sexuality. *Sexuality and Disability*, *35,* 295-311. https://doi.org/10.1007/s11195-017-9492-x

Björnsson, I. (2001). Viðhorf og reynsla foreldris til fósturgreininga og Downs heilkenni. *Læknablaðið. Fylgirit 42 – Kerfisbundin leit að fósturgöllum*, 20-23. http://www.laeknabladid.is/2001/fylgirit/1/fraedigreinar/nr/1229

Brass, C. R. (2014). Experiences of an obese patient. *Narrative Inquiry in Bioethics*, *4*(2), 88-91. https://muse.jhu.edu/article/552034/pdf

Bryant, L.D., Shakespeare, T. (2022). The Impact of Prenatal Screening on Disability Communities and the Meaning of Disability. In: Allyse, M.A., Michie, M. (eds) Born Well: Prenatal Genetics and the Future of Having Children. The International Library of Bioethics, vol 88. Springer, Cham. https://doi.org/10.1007/978-3-030-82536-2_4

Bruk, J. (2014). Shame is not an effective diet plan. *Narrative Inquiry in Bioethics*, *4*(2), 91-93.

Callahan, D., & Hanson, M. J. (Eds.). (1999). *The goals of medicine: The forgotten issues in health care reform*. Georgetown University Press.

Calman, K. C. (2007). *Medical education: Past, present and future*. Churchill Livingstone; Elsevier.

Clandinin J. D. (2013). *Engaging in Narrative Inquiry*. Left Coast Press.

Cockerham, W. C. (2016). *Medical sociology*. Routledge. (Original work published 2009).

Collier, C., & Haliburton, R. (2015). *Bioethics in Canada: A philosophical introduction* (2nd ed.). Canadian Scholars' Press.

COVID-19: Learning from experience. (2020). *The Lancet*, *395*(10229), 1011. https://doi.org/10.1016/S0140-6736(20)30686-3

David, E.J.R., Derthick, A.O. (2014). What is Internalized Oppression, and so what? In: E.J.R David (Ed.), *Internalized Oppression; The psychology of marginalized groups* (pp.1-30). Springer Publishing Company.

Dixon, D.P. (2008). Informed consent or institutionalized eugenics? How the medical profession encourages abortion of fetuses with Down syndrome. *Issues Law Med.* 24(1): 3–59.

Díaz, R.B. (2019). Mission Impossible? Preventing discrimination on grounds of disability of foetuses with Down syndrome in Spain after the emergence of non-invasive prenatal testing. *International Journal of Discrimination and the Law*, *19*(3–4), 178–199. https://doi.org/10.1177/1358229120902654

Donchin, A., & Scully, J. (2015). Feminist bioethics. In E. N. Zalta (Ed.), *The Stanford encyclopedia of philosophy* (Winter 2015 ed.). https://plato.stanford.edu/archives/win2015/entries/feminist-bioethics/

Drainoni, M.-L., Lee-Hood, E., Tobias, C., Bachman, S. S., Andrew, J., & Maisels, L. (2006). Cross-disability experiences of barriers to health-care access: Consumer perspectives. *Journal of Disability Policy Studies*, *17*(2), 101-115. https://doi.org/10.1177/10442073060170020101

DuBois, J. M., Ilitis, A. S., & DuBois, S. G. (2014). Editors' note. *Narrative Inquiry in Bioethics 4*(2), v-vi.

Esterberg, K. G. (2002). *Qualitative methods in social research*. McGraw-Hill Higher Education.

Flynn, J. (2021). Theory and bioethics. In E. N. Zalta (Ed.), *The Stanford encyclopedia of philosophy* (Spring 2021 ed.). https://plato.stanford.edu/archives/spr2021/entries/theory-bioethics/

Friedman, M. (2000). Autonomy, social disruption and women. In C. Mackenzie & N. Stoljar (Eds.), *Relational autonomy: Feminist perspectives on autonomy, agency, and the social self* (pp. 35-51). Oxford University Press.

Gaita, R. (2002). *A common humanity thinking about love and truth and justice*. Routledge.

Garand, L., Lingler, J. H., Conner, K. O., & Dew, M. A. (2009). Diagnostic labels, stigma, and participation in research related to dementia and mild cognitive impairment. *Research in gerontological nursing*, *2*(2), 112–121. https://doi.org/10.3928/19404921-20090401-04

Goodley, D. (2016). *Disability Studies: An Interdisciplinary Introduction.* 2nd ed. Sage.

Greenhalgh, T., Howick, J., & Maskrey, N. (2014). Evidence based medicine: A movement in crisis? *BMJ: British Medical Journal*, *348*, g3725. https://doi.org/10.1136/bmj.g3725

Gunnarsson Payne, J., Korolczuk, E., & Mezinska, S. (2020). Surrogacy relationships: A critical interpretative review. *Upsala Journal of Medical Sciences, 125*(2), 183-191. https://doi.org/10.1080/03009734.2020.1725935

Guyatt, G., Cairns, J., Churchill, D., Cook, D., Haynes, B., Hirsh, J., Irvine, J., Levine, M., Levine, M., Nishikawa, J., Sackett, D., Brill-Edwards, P., Gerstein, H., Gibson, J., Jaeschke, R., Kerigan, A., Neville, A., Panju, A., Detsky, A., … Tugwell, P. (1992). Evidence-based medicine. A new approach to teaching the practice of medicine. *Jama*, *268*(17), 2420-2425. https://doi.org/10.1001/jama.1992.03490170092032

Hansen, J. (2014). Explode and die! A fat woman's perspective on prenatal care and the fat panic epidemic. *Narrative Inquiry in Bioethics*, *4*(2), 99-101. https://muse.jhu.edu/article/552038/pdf

Hawthorne, N. (1987). The birthmark. In J. McIntosh (Ed.), *A Norton critical edition, Nathaniel Hawthorne's tales: Authoritative texts, backgrounds, criticism* (pp.118- 131). W.W. Norton. (Original work published 1843)

Hippocrates. (2008). *The corpus.* Kaplan Publishing.

Hofmann, B. (2001). Complexity of the concept of disease as shown through rival theoretical frameworks. *Theoretical Medicine and Bioethics*, *22*(3), 211-236. https://doi.org/10.1023/A:1011416302494

Hofmann, B. (2010). The concept of disease – vague, complex, or just indefinable? *Medicine, Health Care and Philosophy*, *13*(1), 3-10. https://doi.org/10.1007/s11019-009-9198-7

Hofmann, B. (2017). ‘You are inferior!’ Revisiting the expressivist argument. *Bioethics*, *31*(7), 505-514. https://doi.org/10.1111/bioe.12365

Hofmann, B. (2021). How to draw the line between health and disease? Start with suffering. *Health Care Analysis*, *29*(2), 127-143. https://doi.org/10.1007/s10728-021-00434-0

Jonsen, A. R. (1990). *The new medicine and the old ethics*. Harvard University Press.

Jonsen, A. R., & Toulmin, S. (1988). *The abuse of casuistry: A history of moral reasoning*. University of California Press.

Jutel, A. (2009). Sociology of diagnosis: A preliminary review. *Sociology of Health & Illness*, *31*(2), 278-299. https://doi.org/10.1111/j.1467-9566.2008.01152.x

Kirkengen, A. L., Ekeland, T.-J., Getz, L., Hetlevik, I., Schei, E., Ulvestad, E., & Vetlesen, A. J. (2016). Medicine’s perception of reality – a split picture: Critical reflections on apparent anomalies within the biomedical theory of science. *Journal of Evaluation in Clinical Practice*, *22*(4), 496-501. https://doi.org/https://doi.org/10.1111/jep.12369

Kleinert, S., & Horton, R. (2015). Rethinking and reframing obesity. *The Lancet*, *385*(9985), 2326-2328. https://doi.org/10.1016/S0140-6736(15)60163-5

Koehn, D. (1994). *The ground of professional ethics*. Routledge.

Kristjansdottir, H., & Gottfredsdottir, H. (2014). Making sense of the situation: Women’s reflection of positive fetal screening 11-21 months after giving birth. *Midwifery*, *30*(6), 643-649. https://doi.org/https://doi.org/10.1016/j.midw.2013.10.024

LeFrançois, B. A. (2016). Foreword. In J. Russo & A. Sweeney (Eds.), *Searching for a rose garden: Challenging psychiatry, fostering mad studies* (pp. v-viii). PCCS Books.

Lord, J.E. (2013). Screened out of existence: the convention on the rights of persons with disabilities and selective screening policies [Internet]. *Int J Disabil Community Rehabil.* 12(2). http://www.ijdcr.ca/VOL12_02/articles/lord.shtml

Maas, A. H. E. M., & Appelman, Y. E. A. (2010). Gender differences in coronary heart disease. *Netherlands Heart Journal*, *18*(12), 598-603. https://doi.org/10.1007/s12471-010-0841-y

Mackenzie, C., & Stoljar, N. (2000a). Introduction: Autonomy refigured. In C. Mackenzie & N. Stoljar (Eds.), *Relational autonomy: Feminist perspectives on autonomy, agency, and the social self* (pp. 3-34). Oxford University Press.

Mackenzie, C., & Stoljar, N. (Eds.). (2000b). *Relational autonomy: Feminist perspectives on autonomy, agency, and the social self*. Oxford University Press.

McGann, P., Hutson, D., & Rothman, B. K. (2011). *Sociology of diagnosis*. Emerald Group Publishing.

McLeod, C., & Sherwin, S. (2000). Relational autonomy, self-trust, and health care for patients who are oppressed. In C. Mackenzie & N. Stoljar (Eds.), *Relational autonomy: Feminist perspectives on autonomy, agency, and the social self* (pp. 259-269). Oxford University Press.

McMurray, R. J., Clarke, O. W., Barrasso, J. A., Clohan, D. B., Epps, C. H., Glasson, J., McQuillan, R., Plows, C. W., Puzak, M. A., & Orentlicher, D. (1991). Gender disparities in clinical decision making. *Jama*, *266*(4), 559-562.

Meyers, D. T. (1989). *Self, society, and personal choice*. Columbia University Press.

Michael, E. K. (2013). Surprised by disability. *Narrative Inquiry in Bioethics*, *3*(3), 207-210.

Minicozzi, A. (2013). Let me pay taxes! *Narrative Inquiry in Bioethics*, *3*(3), 210-213.

Montgomery, K. (2006). *How doctors think: Clinical judgement and practice of medicine*. Oxford University Press.

Moore, L. (2014). I'm your patient, not a problem. *Narrative Inquiry in Bioethics*, *4*(2), 110-112.

Morimoto, S. A., & Zajicek, A. (2014). Dismantling the 'Master's House': Feminist Reflections on Institutional Transformation. *Critical Sociology*, *40*(1), 135–150. https://doi.org/10.1177/0896920512460063

Moynihan, R., Doust, J., & Henry, D. (2012). Preventing overdiagnosis: How to stop harming the healthy. *BMJ: British Medical Journal*, *344*. https://doi.org/10.1136/bmj.e3502

Mukherjee, S. (2015). *The laws of medicine. Field notes from an uncertain science*. TED Books.

Nin, M. (2017). The practical wisdom of inclusive research. *Qualitative Research*. Vol. 17(3) 278–288. https://doi.org/10.1177/1468794117708123

Nizar, S. (2016). *The Contradiction in Disability Law: Selective Abortions and Rights*. Oxford University Press

Njor, S. H., Olsen, A. H., Blichert-Toft, M., Schwartz, W., Vejborg, I., & Lynge, E. (2013). Overdiagnosis in screening mammography in Denmark: Population based cohort study. *BMJ: British Medical Journal*, *346*. https://doi.org/10.1136/bmj.f1064

Nuland, S. B. (1995). *Doctors: The biography of medicine*. Vintage Books; Random House.

Padden, C. A., & Humphries, T. (1988). *Deaf in America: voices from a culture*. Harvard University Press.

Pande, A. (2009). Not an 'angel', not a 'whore': Surrogates as 'dirty' workers in India. *Indian Journal of Gender Studies*, *16*(2), 141-173. https://doi.org/10.1177/097152150901600201

Pande, A. (2010). Commercial surrogacy in India: Manufacturing a perfect mother-worker. *Signs*, *35*(4), 969-992. https://doi.org/10.1086/651043

Pande, A. (2011). Transnational commercial surrogacy in India: Gifts for global sisters? *Reproductive BioMedicine Online*, *23*(5), 618-625. https://doi.org/10.1016/j.rbmo.2011.07.007

Parsons, T. (1975). The sick role and the role of the physician reconsidered. *The Milbank Memorial Fund Quarterly. Health and Society*, *53*(3), 257-278. https://doi.org/10.2307/3349493

Parsons, T. (1991). *The social system*. Psychology Press. (Original work published 1951)

Patterson, M., & Johnston, J. (2012). Theorizing the obesity epidemic: Health crisis, moral panic and emerging hybrids. *Social Theory & Health*, *10*(3), 265-291. https://doi.org/10.1057/sth.2012.4

Pausé, C. (2014). Die another day: The obstacles facing fat people in accessing quality health care. *Narrative Inquiry in Bioethics, 4*, 135-141. https://doi.org/10.1353/nib.2014.0039

Pellegrino, E. D. (1999). The goals and ends of medicine: How are they to be defined? In M. J. Hanson & D. Callahan (Eds.), *The goals of medicine: The forgotten issue in health care reform* (pp. 55-68). Georgetown University Press.

Pineda, P. [Pablo Pineda] (2015, August 30). *Down syndrome is not an illness* [Video]. YouTube. https://www.youtube.com/watch?v=uqqVa4t5Jg8

Pineda, P. (2018, April 27). *Down's syndrome does not define me nor conditions me*. Universitat de Barcelona. https://www.ub.edu/web/ub/en/menu_eines/noticies/2018/04/066.html

Rawls, J. (2009). *A theory of justice*. Harvard University Press.

Rhees, R. (2000). *Discussions of Simone Weil* (D. Z. Phillips, Ed.). State University of New York Press.

Rothblum, E., & Solovay, S. (Eds.). (2009). *The fat studies reader*. New York University Press.

Russo, J., & Sweeney, A. (Eds.). (2016). *Searching for a rose garden: Challenging psychiatry, fostering mad studies*. PCCS Books.

Sacristán, J. A. (2013). Patient-centered medicine and patient-oriented research: Improving health outcomes for individual patients. *BMC Medical Informatics and Decision Making*, *13*, 6. https://doi.org/10.1186/1472-6947-13-6

Sandel, M. J. (2009). *The case against perfection*. Harvard University Press.

Sangster SL, DeLucry KJ, Lawson KL.(2022). "We're in the same book, but we're in different parts of the book": Dominant and sub-group narratives of life following a Down syndrome determination. *Journal of Intellectual Disabilities*. March 2022. doi:10.1177/17446295221079584

Schramme, T. (2016). Goals of medicine. In T. Schramme & S. Edwards (Eds.), *Handbook of the philosophy of medicine* (pp. 121-128). Springer. https://doi.org/10.1007/978-94-017-8706-2_5-1

Sherwin, S. (1992). *No longer patient: Feminist ethics and health care*. Temple University Press.

Sherwin, S. (1999). Foundations, frameworks, lenses: The role of theories in bioethics. *Bioethics*, *13*(3-4), 198-205. https://doi.org/10.1111/1467-8519.00147

Sherwin, S., & Stockdale, K. (2017). Whither bioethics now? The promise of relational theory. *IJFAB: International Journal of Feminist Approaches to Bioethics*, *10*(1), 7-29. https://doi.org/10.3138/ijfab.10.1.7

Skeat, W. W. (2007). *The concise dictionary of English etymology*. Wordsworth Reference.

Stefansdottir, A. (2009). Fósturgreiningar: Tengslin við læknisfræðina, ófullkomleikann og lífshamingjuna. *Hugur*, *21*, 30-51.

Stefansdottir, A. (2011a). Foreldrahlutverk og fjölskyldutengsl – siðferðilegar vangaveltur. Um gjafaegg, gjafasæði og staðgöngumæðrun. In *Heiðursrit – Ármann Snævarr 1919-2010* (pp. 15-33). Rannsóknastofnun Ármanns Snævarr um fjölskyldumálefni við Háskóla Íslands; Codex.

Stefansdottir, A. (2011b). Offita – sjúkdómur einstaklings eða vandi samfélags? In S. Nordal & V. Árnason (Eds.), *Siðfræði og samfélag* (pp. 143-164). Háskólaútgáfan.

Stefansdottir, A. (2012). Er staðgöngumæðrun heilbrigðisþjónusta? In H. Gottfreðsdóttir, H. Sveinsdóttir, & Ó. Sigurðardóttir (Eds.), *Við góða heilsu? Konur og heilbrigði í nútímasamfélagi* (pp. 121-133). Háskólaútgáfan.

Stefansdottir, A. (2016). Hvers vegna beina læknar í auknum mæli sjónum að feitu fólki? Um sjúkdómsvæðingu offitu. *Sérrit Netlu 2016 – Menntun, mannvit og margbreytileiki.* http://netla.hi.is/serrit/2016/menntun_mannvit_og_margbreytileiki_greinar_fra_menntakviku/001.pdf

Stefansdottir, A. (2017). Is 'surrogacy' an infertility treatment? *Clinical Ethics*, *13*(2), 75-81. https://doi.org/10.1177/1477750917738113

Stefansdottir, A. (2020a). Three positions on the fat body: Evaluating the ethical shortcomings of the obesity discourse. *Clinical Ethics*, *15*(1), 39-48. https://doi.org/10.1177/1477750920903455

Stefansdottir, A. (2020b). 'A world without Down's syndrome' – an evaluation of foetal diagnosis in light of the ethos of medicine. *Disability & Society*, 1-18. https://doi.org/10.1080/09687599.2020.1851171

Stefánsdóttir, G.V. and Traustadóttir, R. (2015). Lifehistories as counter narratives against dominant and negative stereotypes about people with intellectual disabilities. *Disability & Society*, 30(3), 368–380. doi: 10.1080/09687599.2015.1024827

Stewart, M., Brown, J. B., Weston, W., McWhinney, I. R., McWilliam, C. L., & Freeman, T. (2013). *Patient-centered medicine: Transforming the clinical method* (3rd ed.). CRC press; Taylor & Francis Group.

Stoljar, N. (2015). Feminist perspectives on autonomy. In E. N. Zalta (Ed.), *The Stanford encyclopedia of philosophy* (Fall 2015 ed.). https://plato.stanford.edu/archives/fall2015/entries/feminism-autonomy/

Stoner, L., & Cornwall, J. (2014). Did the American Medical Association make the correct decision classifying obesity as a disease? *The Australasian Medical Journal*, *7*(11), 462-464. https://doi.org/10.4066/AMJ.2014.2281

Tolstoy, L. (2015). The Death of Ivan Ilyich (N. P. Slater, Trans.). In *The Death of Ivan Ilyich and Other Stories* (pp. 155-209). Oxford University Press. (Original work published 1886).

Tomiyama, A. J., Carr, D., Granberg, E. M., Major, B., Robinson, E., Sutin, A. R., & Brewis, A. (2018). How and why weight stigma drives the obesity 'epidemic' and harms health. *BMC Medicine*, *16*(1), 123. https://doi.org/10.1186/s12916-018-1116-5

Weil, S. (1986). Human personality. In S. Miles (Ed.), *Simone Weil – An anthology* (pp. 69-98). Grove Press.

Willett, C., Anderson, E., & Meyers, D. (2016). Feminist perspectives on the self. In E. N. Zalta (Ed.), *The Stanford encyclopedia of philosophy* (Winter 2016 ed.). https://plato.stanford.edu/archives/win2016/entries/feminism-self/

Winch, P. (1987). *Trying to make sense.* Basil Blackwell.

World Health Organization. (2011). *World report on disability*. https://www.who.int/publications/i/item/9789241564182

Yee, S., Hemalal, S., & Librach, C. L. (2020). “Not my child to give away”: A qualitative analysis of gestational surrogates’ experiences. *Women Birth, 33*(3):e256-e265. https://doi.org/10.1016/j.wombi.2019.02.003

Paper I

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Is ‘surrogacy’ an infertility treatment?

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Abstract

In this article, it is argued that it is problematic to construe the debate around the process labelled ‘surrogacy’ as a form for infertility treatment. Firstly, this way of defining what happens opens up a new form of medical desire where a growing number of people wish to have children through ‘surrogacy’. This medicalizes childlessness and creates pressure within health services to respond to the desires of an ever-growing group of patients. Secondly, this labels the woman who carries the child as a ‘surrogate’ and defines her as a core element in a ‘treatment method’. This way of phrasing and defining what happens puts the woman carrying the child in an unacceptable moral position within the health system. Thirdly, by viewing the woman carrying the child as a ‘substitute’ for a mother or as a ‘temporary custodian’ ignores the unique relationship between the foetus and the pregnant woman. To keep the ethical issues in focus in the ‘surrogacy’ process, it is necessary for health professionals to always accept the woman who goes through gestation and birth as the mother of the child. This unconditional acceptance shifts the core of the process away from the idea of ‘treatment’ and towards ‘adoption’ as the defining element in the process. Consequently, it will be easier to accept ‘surrogacy’ as a complicated and wide-ranging process as well as to secure the basic human rights of the pregnant woman and the welfare of the child being born.

Keywords

Adoption, healthcare, medicalization, surrogacy, infertility treatment

Introduction

In public debate, ‘surrogacy’[1] has commonly been construed primarily as a form of infertility treatment. ‘Surrogacy’ is then chiefly described as a form for assisted reproductive technology (ART) to be used for the benefit of the intended parents.[2–5] According to this view, ‘surrogacy’ is one possible option, along with technical innovations in medicine, in overcoming fertility problems. What is referred to as ‘surrogacy’ is then implicitly regarded as a form for healthcare service. In this article, I will question this approach and this way of framing the discussion. I believe the words we use to construe the discussion are of great importance since they will influence our understanding of what happens around what is now labelled ‘surrogacy’. An example of how words can influence our understanding and thus our view of the issue is the use of the word ‘surrogate’ instead of referring to the ‘pregnant woman’ or simply the ‘expectant mother’. Each of these phrases describes the situation of a woman about to give birth to a baby, but they have quite different meanings. It is necessary, therefore, to contemplate what is involved and what we are referring to when we discuss ‘surrogacy’. There are difficult ethical issues that need to be dealt with regarding the description of ‘surrogacy’ as a form for ART. In this paper, I will draw attention to some of them and emphasize the importance of taking care how we phrase and categorize our practices.

I begin by considering why we might be tempted to see ‘surrogacy’ primarily as a form of infertility treatment. I will then outline serious challenges facing the health services when ‘surrogacy’ is primarily seen as a treatment option for infertility. Following that, I will compare two ways of categorizing what is labelled as ‘surrogacy’. We can either outline the process as *a way to treat infertility problems* or we can construe it as an *adoption process*. Although ‘surrogacy’ is not a typical example of either of those two, both references have been made in the literature.[6,7] In light of my discussion of that comparison, I conclude that we should rather emphasize the understanding of ‘surrogacy’ as an adoption process since that approach is more likely to reflect the ethical challenges involved as well as

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protecting the interests of those most vulnerable in the situation.

'Surrogacy' as infertility treatment

In the current literature, the aim of 'surrogacy' is often defined as being: '…a means of overcoming childlessness for couples unable to carry their own pregnancies due to infertility, medical conditions, or sexuality' (p. 273).[8] This way of framing the discussion highlights the importance of ART and medical means as the defining element of the 'surrogacy' process. It implies the view that 'surrogacy' should primarily be seen as a form for infertility treatment and the related public administration as healthcare service. Occasionally, 'surrogacy' is directly referred to as a treatment option.[7] This way of viewing the process of 'surrogacy' is quite understandable. It can, e.g., be argued for in the following way: Not being able to have a child when one is wished for is a difficult experience for a couple. As the desire for a child is often very strong, it can deeply impact their relationship and be the cause of life-long suffering.[9] 'Surrogacy' as an infertility treatment can be a way to address such sufferings.

To better understand the perspective of those who view childlessness as being, at least on occasion, a result of lack of health, or even a disease, we can look to Bircher's definition of health:

> Health is a dynamic state of wellbeing characterized by a physical, mental and social potential, which satisfies the demands of a life commensurate with age, culture, and personal responsibility. If the potential is insufficient to satisfy these demands the state is disease. (p. 336)[10]

Bircher's definition admits that health is not tied to physical standards only, but also to mental, social, and even cultural factors. According to Bircher's definition, when an individual cannot do what he or she may be expected to do, the state is disease. For example, a woman of fertile age unable to carry and give birth to a child suffers from a disease according to this definition, since generally it may be assumed that such women can have children. By using Bircher's definition of health, it can be argued that certain instances of childlessness are health problems, to which the health services should respond.

We see from this discussion that it can well be argued that there are instances where the condition of not being able to carry and give birth is viewed as a health concern. When 'surrogacy' is used to meet that problem, we could be tempted to view 'surrogacy' as a form for treatment of infertility. In the following sections, I will focus on the concerns that are raised by this view. I will begin by showing direct challenges facing the healthcare services.

Medicalization: The 'cure' increases the number of 'patients'

In 1985, the U.K. was the first country in the world to have a specific legislation permitting 'surrogacy' (Surrogacy Arrangements Act, 1985).[7,8] 'Surrogacy' was supposed to be the last resource to solve the problem of a very limited number of couples with fertility complications. One could be tempted to assume that when surrogacy had been an accepted practice within healthcare services, for some time, there would be a decline in the cases where 'surrogacy' is meant to address, since the problem had then been solved for many couples. Such views were, e.g., stated in the discussion around the possibility of legalizing 'surrogacy' in Iceland. In a report on the issue written for the Ministry of Health, it is stated that the estimated need is most urgent in the beginning since there are now many couples waiting for a solution to their childlessness, but later the need would probably stabilize.[11] This view does not reflect the experience in the U.K. Since 1985 there has been a steady increase in demand for 'surrogacy' as a form of infertility treatment, and accordingly the number of 'surrogacy' agreements has never been higher.[8]

One possible explanation to this development within the health services is that instead of accepting limitations of life, there is now increased pressure to use new medical innovations whenever possible and almost at whatever cost to meet unfulfilled desires.[12] This happens almost automatically in parallel with technological developments. Now it is possible for everyone, not only heterosexual couples, to have a child. It results in more people feeling their own shortcomings and new demands emerge. A new norm for reproduction evolves. Using new technological solutions to overcome childlessness not only satisfies desires and demands but also increases the pressure to have children. Groups that generally were neither considered to have any health problems nor to have any reason to seek healthcare service due to not having a child, such as childless individuals or two men living together, now experience a need for healthcare service due to new possibilities and a change in the culture of reproductive behaviour.

Here, medical technology is used to solve problems for a constantly growing group of people. Not only infertile women, but also individuals and homosexual men, become 'patients' in the healthcare system and thus their inability to have a child is also conceived as a healthcare problem. We already see both ethical and legislative changes in the U.S. and some European countries giving equal rights to requests for assisted reproduction without regard to sexual orientation or marital status.[13] These techniques are then normalized for everyone on demand since they are regarded as a response to a medical need. This leads to medicalization; that is, it defines human problems, hitherto not regarded as medical in nature, to be identified and treated as medical problems.[14,15] What initially was introduced as a medical solution for a very limited number of couples will be culturally accepted for almost everyone. It might be said that 'surrogacy' evolves from being what was conceived of as a medical necessity to becoming a medical desire.[16] The downside of this is that a great number of people will not be able to live up to the demands of life unless they receive medical assistance for reproduction. These will not always be fulfilled and many go through grief when things do not work out as planned.[17] Furthermore, this new demand will compete for both human resources as well as financial resources which are limited within the health system. As a result, they might marginalize other diseases and health problems that do not receive as much attention.

The ambiguous position of the pregnant woman as a 'surrogate'

What is called altruistic 'surrogacy' is permitted and has been practised for many years in some countries, for example the U.K. and Canada.[8,18] Hence, some deliberation has already taken place about the practice of 'surrogacy' and the experience of healthcare professionals participating in the process. The discussion has emphasized the need to take special precautions to protect the rights of the 'surrogate' during pregnancy.[8,18–20] This sheds light on the problems that emerge when 'surrogacy' is considered a normal part of medical services. Thus a Canadian doctor has said:

> After a busy morning in the office, you have an appointment with a new prenatal patient. This gravida 3, para 2, woman is at 6 weeks' gestation. There are 3 people waiting in the examination room: the patient and the couple whose egg and sperm were used to create the embryo being gestated by the patient. Each person has questions about prenatal care and wishes to be involved in any decision that needs to be made. (p. 483)[20]

This situation is complicated. The regulations that doctors have already put in place for their practice regarding 'surrogacy', e.g., in Canada and the U.K., state the necessity of all professional processes and rules surrounding the pregnancy and birth to be well implemented. These regulations highlight that the 'surrogate' should have full control over her body, including the fate of the unborn child. She should be fully entitled to make all decisions related to the pregnancy by herself, in exactly the same way as any other pregnant woman.[19–22] Medical professionals should therefore meet the 'surrogate' by herself and not with the prospective parents. Furthermore, it is considered important that the doctor caring for the couple dealing with infertility is not the same doctor as the one who is taking care of the 'surrogate'. Decisions made during the pregnancy, for instance related to foetal diagnosis, chorionic villus sampling, ultrasounds and even abortion, should, therefore, be the choice and responsibility of the 'surrogate' and not the intended parents. Finally, all parties must have open access to the services of psychologists and social workers to help them face the emotional pressures related to this, and healthcare professionals are required to be alert to potential oppression or duress in the process.[3,8] These regulations come about as a professional response to ensure that doctors involved in 'surrogacy' work according to the physician's primary duty. They can also be seen as a way of the healthcare system to protect the 'surrogate' as a person.

When these actions are considered, it is interesting that they are framed as being some sort of 'extra means' to take care and prevent the welfare of the 'surrogate'. It might even seem as if her rights were placed higher than the rights of the intended parents by these means. However, if we rephrase our thoughts at this point and use the word 'expectant mother' instead of the 'surrogate', it becomes clear that these rules are not best understood as special means where the 'surrogate' trumps the intended parents. Instead, they are the basic human rights of the woman who is going to give birth to a baby. They are the same basic human rights that women have been fighting for over the last centuries.[23] During the pregnancy process, women are more prone to suffer violence and it can therefore be argued that they need special protection during that time.[24] Besides, there is also a strong tendency in these special circumstances by both the prospective parents and even the medical professionals to want to gain control of the body and daily life of the 'surrogate'.[25] This is done on the grounds that the foetus or child is not only a part of her body; *she* is also a part of the child's body, but the child is not hers. To view the pregnant woman solely as the child's temporary custodian or as a substitute, as the phrase 'surrogate' indicates, has the unfortunate implication within the healthcare services that the pregnant woman becomes 'instrumental' in the sense of being part of the 'medical means' to cure the infertility of the individual or couple at hand. These very regulations are a sign of that danger. Their existence shows that the woman carrying the child is in such a vulnerable position that it becomes necessary to remind us of her basic human rights.

But are these precautions sufficient to ensure the respect and humanity of the 'surrogate'? While these regulations may protect her against potential oppression by healthcare professionals and the intended parents, they are of questionable use when her status within the healthcare services is assessed on a deeper level. We still have not ensured her position as an independent actor in the process. She is not referred to as an 'expectant mother' but labelled as a 'surrogate', and within the healthcare system, the process of 'surrogacy' is recognized as a 'treatment option' for infertility. The 'surrogate' is still at least in healthcare discourse, a part of the 'means' of the health services. This can always develop into a situation where concern for her autonomy and welfare ceases to be in focus. This is especially prone to happen in countries where there is widespread poverty and women's rights are not valued sufficiently. This has already happened in India where the poverty and low social status of women has forced them into making unacceptable choices and taking part, during pregnancy, in services where their basic human rights were broken.[25–27]

'Surrogacy' differs from other remedies available through the healthcare services because a third person is used in a very profound way to reach the treatment goals. The ensuing situation creates a new relationship between medical professionals and the pregnant woman acting as a 'surrogate'. Here it does not matter whether there is always an assumption of her full consent. When a woman agrees to go through gestation for another woman, and does so as healthcare practices, she enters into two different and often conflicting kinds of relationships within the health system. On the one hand, she is a patient who needs care during her pregnancy. On the other hand, she is seen as part of a treatment plan by the health services, where she is either selling or giving service. This situation involves dilemmas which will not be solved as long as 'surrogacy' is accepted within the health system as a treatment for infertility. This is irrespective of whether we have in mind altruistic 'surrogacy' or commercial 'surrogacy'. The situation arises because the pregnancy and birth are regarded as infertility treatment for the intended parents. Healthcare professionals can face contradictory responsibilities in their approach towards the group of women who are taking on these roles, on the one hand, and towards the infertile couples, on the other. This possible conflict of interest can undermine the ethos of the doctor–patient relationship which is the cornerstone of medical service.[28,29]

The 'adoption model' vs. the 'treatment model'

In many countries where 'surrogacy' has been legalized, adoption is part of the 'surrogacy' process.[22,30,31] The woman carrying the child and giving birth is then its legal mother at birth, regardless of intention or the genetic origin of the child.[31] The advantage of this is the certainty of the baby to have at least one legal parent at birth. For the intended mother to become the legal mother of the child, adoption is mandatory. When adoption is a necessary part of what is now labelled 'surrogacy', a ban of commercial 'surrogacy' usually follows.[22,30] Yet, adoption is not always a necessary part of the 'surrogacy' process. In some countries (e.g. Greece), the intended parents become the legal parents of the baby at birth and their names appear on the baby's birth certificate.[31] Often they are also the persons whose sperm and egg were used to conceive the baby. That per se and the fact that they are the ones who initiated this process through their intention is seen as the ground for their parenthood and no adoption is needed. Intended parents are here accepted as the driving force of the process and it is highlighted that because of their wish the baby exists. However, this approach raises some serious issues. Surely, willingness of the intended parents is necessary but not enough. To meet their wishes, they need a woman to carry the baby and give birth to it. From the perspective of the intended parents, this process is labelled and categorized as service or labour on behalf of the 'surrogate'. The service can either be given (altruistic surrogacy) or sold (commercial surrogacy). This terminology and interpretation of the whole process gives rise to questionable talk about compensation or payment. 'Surrogacy' without adoption, accompanied by what is called commercial 'surrogacy', is often criticized, not only for commercializing children but also for being degrading and potentially oppressive towards the 'surrogate'.[32–34]

'Surrogacy' with adoption has also been criticized, for example as being unfair towards the intended parents due to insecurity and also for being both unfair and exploitative towards the woman carrying the child. An alternative approach which is meant to be more fair towards both parties can be seen in the writings of Van Zyl and Walker.[30] They call it 'professional surrogacy'. The authors claim that 'surrogacy' should be paid for on a 'fee-for-service basis' and emphasize the importance of a professional regulatory body for the process. In their words, 'the surrogate would be motivated by a desire to do something worthwhile while still expecting reasonable compensation for her service' (p. 384).[30] They underline the importance of the intended parents being the legal parents of the child right from birth. That would eliminate uncertainty both for the intended parents and for the 'surrogate'. They acknowledge that in the 'professional model', it is important to secure that the surrogate retains all her rights as a pregnant woman. Hence, it would be important to maintain the rule that the intended parents could not require her to undergo any procedures and tests that she does not want. Furthermore, Van Zyl and Walker claim that through this model the surrogate is much better protected from exploitation than in the adoption model where altruistic 'surrogacy' is the rule.

These are important points that need to be addressed. Firstly, I agree with Van Zyl and Walker that it is problematic to define 'surrogacy' primarily as an altruistic deed, but I do not share their belief in payment as being the solution to that problem. What is problematic with this runs deeper. Let us first look at the obvious downside of altruistic 'surrogacy', that is, viewing it as a deed performed primarily by 'good women'. This deed is then driven by the duty to help others in need; others who are viewed as patients. Throughout history, women have been in the position of caring for the sick and those in need. This work has been unpaid and not properly acknowledged. Women have been trying to free themselves from this role and fighting for acceptance as agents where their work is acknowledged, respected and paid for on an equal basis to men. Using women to carry babies for intended parents in need and the sole gain of the process being the 'joy of helping others' could turn into a new way of exploiting women. Arguing, therefore, as Van Zyl and Walker do, that they should be able to charge for their service and thus gain prestige and due compensation should come as no surprise.

Although I do agree with this criticism of altruistic surrogacy, it does not follow that we should accept commercial 'surrogacy' and hence see payment as the solution. What is problematic in Van Zyl's and Walker's argument is their reference to 'surrogacy' as a form of infertility treatment. In contrast to what they label 'the adoption model', I contend that the view they describe should be called 'the treatment model'. The authors see the adoption as a weakness in the process and describe it as degrading for the woman who gives birth to the child that she does not receive compensation for her work. I want to argue that there is something inherently wrong with this view on the state of being pregnant. The connection between the gestating woman and the child to be born is unique. It has a profound and defining effect on the lives of both. This will never be described accurately through the language and laws of labour and business.[35,36] The pregnant woman is neither selling (commercial surrogacy) nor giving (altruistic surrogacy) any type of work or service. She is not to be defined as 'labourer'. During pregnancy she is first and foremost an expectant mother.[36] If we are to keep our attention on the core of the ethical issues in this complicated debate this has to be acknowledged. Health professionals especially need to keep this in mind when establishing relations with the woman carrying the child within the health-care system. My contention is that the only way to acknowledge this is by always accepting the woman who goes through gestation and gives birth as the mother of the child. Taking that seriously shifts the core of our understanding of this process: It becomes hard to view it as a treatment for the intended parents. Instead the adoption becomes the defining element in the process.

Why is adoption so important?

Family units can now be structured in many ways.[37] In this new landscape, the status, role, responsibility, and self-understanding of those involved can become unsteady and complicated. This initiates many difficult moral issues, not only regarding the understanding of concepts like mother and father[32,36] but also other things like the welfare of the child,[9,38] the rights of individuals to know their origin,[39,40] the connection between responsibility and family relations,[22,29] our culture[32] and the foundation of our self-understanding[9] to name a few. The critical issues listed here have been addressed by many and it has not been the purpose of this article to investigate them in any depth. They are only mentioned to draw out how complex the process now labelled 'surrogacy' is and to show how widespread the effects of it can be. These issues are not only health related. They are wide-ranging and complicated.

The main focus in the paper has been on 'surrogacy' within the health system and I have criticized how viewing it principally as a health issue is problematic. When contemplating our policy and our discourse around 'surrogacy', not only health matters, but at least all of the issues mentioned above and many more. They all need to be at the centre of the discussion. The ethos of the health system is primarily based on working privately with patients. By categorizing 'surrogacy' as a treatment for infertility we tend to view it as a private matter of concern mainly to those directly involved, the core of our attention being to meet the needs of the intended parents. This tends to divert the attention away from important ethical concerns regarding this process. This view is therefore too narrow and leads us to marginalize important aspects of the 'surrogacy' debate. Consequently, it is very important to evaluate and think carefully how we construe the discussion around this complicated process.

When the ethical issues involved are contemplated within the health sector, it is important to remember that what really happens involves at least (i) the intention of a couple or an individual to raise a child; (ii) conception, gestation and birth and (iii) the transfer of a baby from the woman who gave birth to it to the people that will raise the child. This is a long process, which can take years and involves many people, not least the baby being born. This is neither an infertility treatment nor is it a simple adoption, although it relates to both. It is of primary importance here what we choose to be the defining element of this process and the discussion around it. In order to understand and define these events, it is very important to keep a close eye on where to place the rights, the duties and the responsibilities. When the whole process is discussed and choices made accordingly, I contend that there are two fundamental points that have to be clearly understood. The first one is the claim that the relation between the child being born and the woman carrying that child cannot simply be described in the terminology of a 'mother substitute' or a 'temporary custodian'. These connections are more profound and special than the term 'surrogate' implies. The second claim I want to draw attention to is the importance of keeping the attention on the gestating woman and the child being born, because they are most vulnerable in this process.

If 'surrogacy' is a treatment option for childless couples, we have circumstances not least in the health system where the child and the pregnant woman tend to be overshadowed in the discussion by the wishes and desires of the intended parents. This is especially prone to happen if the woman giving birth is not recognized as an expectant mother in this process.

Every decision made should be taken with the welfare of the child in mind. The only way to do so is by basing the process on an ethos that acknowledges the needs and the welfare of the child and gives it priority within the discourse. If we compare the aims of *adoption* to the aims of *infertility treatments*, we can note a clear difference: Adoption is about finding parents, guided by the child's welfare, whereas treatment for infertility has only the aim of producing a child, and there is no claim or reference to the capabilities of the parents to raise that child.

To refer to surrogacy as a form of adoption has already been done.[6] As noted before, 'surrogacy' is strictly speaking neither a form for infertility treatment nor is it a conventional adoption. I want to draw attention to the advantage of adoption in this process. If we omit the adoption and ignore the importance of it, we open up for a new way of harming both women and children. We do no longer respect the special relationship that forms between the mother and the child during gestation; we open up for the possibility of commercialization of childbirth and there is no attempt to evaluate whether the welfare of the child will be met by the intended parents.[35] By highlighting adoption as the core of what happens rather than claiming this to be an infertility treatment is a better way to guard for the dangers mentioned above.

Conclusion

In this article, it has been argued that it is profoundly problematic to construe the debate around 'surrogacy' as a form for infertility treatment. Firstly, this medicalizes childlessness and creates pressure within health services to respond to the desires of an ever-growing group of patients. As a result, the medical treatment of 'surrogacy' is not alleviating the problem at hand but increasing it. Secondly, the treatment method of using another woman as a 'surrogate' to carry a child for a couple or an individual dealing with infertility puts the woman carrying the child in an unacceptable moral position within the health system where the doctor's responsibilities towards the patient are no longer clear. And thirdly, by viewing the woman carrying the child not as an expectant mother but rather as a 'substitute' or a 'temporary custodian' of the child, the unique relationship between the foetus and the pregnant woman is ignored. By accepting adoption as a necessary and defining step in this process, as well as giving it an increased importance in the debate, it is easier to secure the basic human rights of the pregnant woman as well as to secure the welfare of the child being born.

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References and notes

1. In this article, I refer to 'surrogacy' as the process when a woman gives birth to a child and hands it over to another individual or a couple to raise. Often the genetic origin of the child is from either of the intended parents or both. I will use quotation marks for the terms 'surrogacy' and 'surrogate' since I share the views described by Overall[35] where she doubts the appropriateness of the words 'surrogacy' and 'surrogate' to capture the meaning of the

status and relationship between the woman carrying the child and the child being born.

2. Söderström-Anttila V, Wennerholm U-B, Loft A, et al. Surrogacy: outcomes for surrogate mothers, children and the resulting families – a systematic review. *Hum Reprod Update* 2016; 22: 260–276.
3. Bhatia K, Martindale EA, Rustamov O, et al. Surrogate pregnancy: an essential guide for clinicians. *Obstet Gynecol* 2009; 11: 49–54.
4. Using a Surrogate Mother: What You Need to Know. *WebMD*. https://www.webmd.com/infertility-and-reproduction/guide/using-surrogate-mother#1 (2017, accessed 16 October 2017).
5. Bologna C. Tearjerking video shows mom feeling her babies kick inside her surrogate. *Huffpost*, 19 January 2017. https://www.huffingtonpost.com/entry/tearjerking-video-shows-mom-feeling-her-babies-kick-inside-her-surrogate_us_5880d451e4b00d44838d5a08 (2017, accessed 16 October 2017).
6. Tong R. The overdue death of a feminist chameleon: taking a stand on surrogacy arrangements. *J Soc Philos* 1990; 21: 40–56.
7. Brinsden PR. Gestational surrogacy. *Hum Reprod Update* 2003; 9: 483–491.
8. Burrell C and Edozien LC. Surrogacy in modern obstetric practice. *Semin Fetal Neonatal Med* 2014; 19: 272–278.
9. Raphael-Leff J. The ‘Kinder Egg’: some intrapsychic, interpersonal, and ethical implications of infertility treatment and gamete donation. In: KWM Fulford, D Dickenson and TH Murray (eds) *Healthcare Ethics and Human Values: An Introductory Text with Readings and Case Studies*. Malden: Blackwell Publishers, 2002.
10. Bircher J. Towards a dynamic definition of health and disease. *Med Health Care Philos* 2005; 8: 335–341.
11. Stefánsdóttir Á þorsteinsdóttir G and Oddsson K. Áfangaskýrsla vinnuhóps heilbrigðisráðherra um staðgöngumæðrun [Working Group on Surrogacy, Status Report], Heilbrigðisráðuneytið [Ministry of Health] 2 May 2010.
12. Callahan D. *Taming the Beloved Beast: How Medical Technology Costs are Destroying Our Health Care System*. Princeton: Princeton University Press, 2009.
13. Golombok S. Families created by reproductive donation: issues and research. *Child Dev Perspect* 2013; 7: 61–65.
14. Sadler JZ, Jotterand F, Lee SC, et al. Can medicalization be good? Situating medicalization within bioethics. *Theor Med Bioeth* 2009; 30: 411–425.
15. Conrad P. Medicalization and social control. *Annu Rev Sociol* 1992; 18: 209–232.
16. Callahan D and Wasunna AA. *Medicine and the Market: Equity v. Choice*. Baltimore: JHU Press, 2008.
17. Berend Z. Surrogate losses: understandings of pregnancy loss and assisted reproduction among surrogate mothers. *Med Anthropol Q* 2010; 24: 240–262.
18. Nakash A and Herdiman J. Surrogacy. *J Obstet Gynaecol* 2007; 27: 246–251.
19. Guichon J. The body, emotions and intentions: challenges of preconception arrangements for health care providers. *CMAJ* 2007; 176: 479–481.
20. Reilly DR. Surrogate pregnancy: a guide for Canadian prenatal health care providers. *CMAJ* 2007; 176: 483–485.
21. Ber R. *Ethical issues in gestational surrogacy*. *Theor Med Bioeth* 2000; 21: 153–169.
22. Jackson E. *Medical Law: Text, Cases, and Materials*. Oxford: Oxford University Press, 2013.
23. Rowbotham S. *Hidden from History: 300 Years of Women’s Oppression and the Fight Against It*. London: Pluto Press, 1977.
24. Bewley CA and Gibbs A. Violence in pregnancy. *Midwifery* 1991; 7: 107–112.
25. Pande A. Transnational commercial surrogacy in India: gifts for global sisters? *Reprod Biomed Online* 2011; 23: 618–625.
26. Palattiyil G, Blyth E, Sidhva D, et al. Globalization and cross-border reproductive services: ethical implications of surrogacy in India for social work. *Int Soc Work* 2010; 53: 686–700.
27. Venkatashivareddy B, Gupta A and Ramesh V. Surrogacy: blessing or curse to poor society in India. *Healthc Low Resour Settings* 2015; 3: 45–47.
28. Pellegrino ED. The goals and ends of medicine: how are they to be defined. In: MJ Hanson and D Callahan (eds) *The Goals of Medicine: The Forgotten Issue in Health Care Reform*. Washington, DC: Georgetown University Press, 1999, pp. 55–68.
29. Rothenberg KH. Gestational surrogacy and the health care provider: put part of the ‘IVF genie’ back into the bottle. *Law Med Health Care* 1990; 18: 345–352.
30. Van Zyl L and Walker R. Surrogacy, compensation, and legal parentage: against the adoption model. *Bioeth Inq* 2015; 12: 383–387.
31. Stoll J. *Surrogacy Arrangements and Legal Parenthood: Swedish Law in a Comparative Context*. Uppsala: Uppsala University, 2013.
32. Callahan S. The ethical challenge of the new reproductive technology. In: EE Morrison (ed.) *Health Care Ethics: Critical Issues for the 21st Century*. 2nd ed. Sudbury: Jones and Bartlett Publishers, 2009, pp. 71–86.
33. Ber R. Ethical issues in gestational surrogacy. *Theor Med Bioeth* 2000; 21: 153–169.
34. Tieu MM. Altruistic surrogacy: the necessary objectification of surrogate mothers. *J Med Ethics* 2009; 35: 171–175.
35. Overall C. Reproductive ‘surrogacy’ and parental licensing. *Bioethics* 2015; 29: 353–361.
36. Bayne T and Kolers A. Toward a pluralist account of parenthood. *Bioethics* 2003; 17: 221–242.
37. van den Akker OBA. Psychosocial aspects of surrogate motherhood. *Hum Reprod Update* 2007; 13: 53–62.
38. Golombok S, Blake L, Casey P, et al. Children born through reproductive donation: a longitudinal study of psychological adjustment. *J Child Psychol Psychiatry* 2013; 54: 653–660.
39. Árnason V. *Dialog und menschenwürde: Ethik im gesundheitswesen* Münster: LIT Verlag, 2005.
40. Jadva V, Freeman T, Kramer W, et al. The experiences of adolescents and adults conceived by sperm donation: comparisons by age of disclosure and family type. *Hum Reprod* 2009; 24: 1909–1919.

Paper II

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Three positions on the fat body: Evaluating the ethical shortcomings of the obesity discourse

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Abstract

This article raises serious ethical concerns regarding the medical discourse on obesity. It offers a description of three alternate positions on the fat body: the scientific approach dominant within medicine, the critical view mainly raised by social scientists, and the voices of fat people themselves. By viewing and comparing the perspectives these positions reveal, it is possible to underline the complexity of the problem labeled as the "obesity epidemic" and draw attention to serious ethical concerns in the mainstream medical discussion. Medicalization of fat people narrows the focus on the "obesity epidemic" where it is framed as private and personal rather than social and political. It is also argued that the hegemonic discourse of medicine omits the social embeddedness of fat people and ignores their own voices and narratives. This undermines the well-being of fat people and hides their humanity as well.

Keywords

Ethics, medicalization, fat people, obesity

Introduction

I, the author of this article, am labeled overweight according to medical terms. I come from a family of fat people. By calling them fat, I am not making any judgment on my family. I am simply using the word in a neutral sense, referring to a certain state of the body. As far as I can remember I have been fat. I have not always been happy about it. I have tried many types of diets or food restriction programs, resulting in short and long term bodily changes. I am in a moderate physical condition and I am able to successfully accomplish difficult long term assignments, as can be seen by my finishing medical school without really being interested in becoming a doctor. As I grow older my acceptance of my fat body grows as well as my love of life itself, with all its joys and wonders, aches and pains.

I am sharing this personal story to explain my position when writing this and to underline the main thread in this article: the need to realize the missing factor in the dominant discussion on the state of being fat, the humanity of fat people. Being a medical doctor myself, I do not deny the fact that more people worldwide are fat today than there were 20 or 30 years ago and I find this to be of concern.[1–3] Nevertheless, in this complicated and for me in many ways personal discussion on the lives and prospects of fat people, it is necessary to highlight certain ethical concerns in the medical narrative.

The narrative I am referring to is framed as being based on objective scientific facts. It uses objectively determined terms when talking about fat people like "overweight," "obesity," and "the obesity epidemic." "Overweight" usually defined as the body mass index (BMI)[1] in the range of 25–30, "obesity" defined as BMI over 30, and the "obesity epidemic" referring to a public health hazard.[4–7] This way of describing the lives of fat people has been criticized by many social scientists who claim that the medical discourse is oppressive toward fat people.[8] They have advocated for the use of the term "fat" as an empowering term in the fight against the oppression of fat people.[9] I will, in this article, use the term fat as a neutral term describing a body with increased body fat, whereas the words

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"overweight," "obesity," and "obesity epidemic" will refer to the medical standpoint that describes the fat individual through biomedical facts mostly relating their lives to diseases and personal suffering.

The main question in this paper is: What are the ethical concerns regarding the mainstream medical discussion on the lives of fat people? I begin by describing and analyzing the objective scientific position that dominates medical discourse. Subsequently, I outline what I call the critical view, coming mainly from social scientists where shortcomings of the medical discourse are outlined. Finally, I draw attention to the importance of the voices of fat people themselves, when trying to understand the complexity of what is labeled "the obesity epidemic." By uncovering these different positions in the discussion on the lives of fat people, it is possible to highlight serious ethical shortcomings in current medical approach and suggest how it could be complemented.

The scientific position

When medical doctors talk and write about the fat body they tend to refer to objective measureable facts that are described as scientifically proven. According to this way of thinking, obesity is one of the most serious health problems of the present day.[2,10–12] This implies that obesity is a condition that leads to diseases, diminishing the quality of life for the person involved. Sometimes obesity is even defined as a disease in and of itself.[13,14]

When we view obesity as a disease it becomes a medical condition that has to be responded to and the fat person becomes a suffering patient. We see this expressed, for example, in the Canadian Clinical Guidelines on how to manage obesity.[7] In the guidelines it is stated that approximately two-thirds of the Canadian population are either overweight or obese. The objective of the guidelines is to: "... provide evidence-based recommendations for structured interventions aimed at preventing weight gain in adults of normal weight and to provide recommendations for behavioral and pharmacologic interventions for weight loss to manage overweight and obesity in adults" (Brauer et al.,[7] p.185). It is further recommended that those in this position should be managed by medical doctors, according to a scheme that addresses the current and imminent problem of overweight and obese patients. This objective to target every single individual, who is according to set definitions overweight or obese, raises serious questions about the approach of medicine. In this paper, I will not pay attention to doubts regarding causal links between obesity and diseases, although such doubts have been raised.[15–17] At this stage my concern is rather: what does it mean to define two-thirds of any nation as chronic patients in need of healthcare intervention and specialist aid? This is troublesome in view of the fact that the majority of these "patients" are currently leading normal and happy lives and do not necessarily suffer, feel sick, or view themselves as unhealthy.

To begin to understand this medical recommendation, it is necessary to realize that the focus of medicine is primarily on the patient and as a consequence being fat is in essence a biological imbalance or deviation situated within the individual. Therefore, it is thought to be crucial to treat this individual in order to "normalize" her[18] and help her to gain the right balance. It is common in medical journals to explain the etiology of obesity in the following way: "obesity develops when unconsumed energy because of excess intake, reduced expenditure, or most likely both, accumulates gradually as fat tissue" (Maziak et al.,[19] p.36). Here the "imbalance" is situated within the individual. She is responsible for her "excess intake" and "reduced expenditure."

This way of placing the problem and locating it in the individual has deep roots within medicine. The medical doctor is trained to focus primarily on the patient. The patient is defined as a person who suffers and needs assistance. She cannot deal with her problems on her own.[8,20,21] She seeks help from the doctor by placing the problem in his hands. The idea of "the Patient" is closely related to the idea of the one who is passive and patient and bears her suffering in silence.[22] The role of the doctor is to use methods that he masters to treat or change the one who suffers and is ill, for example by using medication or surgery. When the doctor focuses on "the disease" obesity he behaves accordingly. The individual is not "normal." The problem is solved by changing this particular individual, by making her undergo the right treatment. Based on these premises, the conclusions of the Canadian Task Force on Preventive Health Care are quite logical.

These and similar clinical guidelines have been in place for decades but we have so far seen little success.[2,23] Worldwide we have seen rising figures in obesity prevalence despite the efforts of medicine.[17,19,24–26] Treatment plans that consist solely of advising people how to change their diet (reduce intake) and exercise more (increase expenditure) are not working.[12,27–29] If nothing else is done during treatment it can be assumed that almost all of those who lose weight on a regular diet will be back to their original weight within a matter of years.[11,29–31] Medication for obesity has been tried but with limited long term success and surgery used as cure for obesity is still controversial and limited to a very small group of persons since it has serious adverse effects.[12,29]

In view of this and in view of the epidemiological statement that figures of overweight or obesity seem to be on the rise globally, it can be said that clinical doctors are making little or no progress in curing the obese patient.[12,26] This has called for a new way of looking at the matter.

Lately medical as well as media attention in the obesity dialogue has shifted toward the "obesogenic environment."[5] This approach acknowledges the causal importance of environmental forces in the "obesity epidemic."[1,32–34] Environment in this sense has reference to open spaces and structures of buildings but more broadly to things in life that we, individually, do not control. They can be the results of political choices or decisions by public institutions or private companies. The environment can comprise food production industries, architecture and design of public places, means of transportation, access to healthy food at work and in schools, and even the acceptance of the attitude that exercise and motion should be a normal part of everyday life in the structure of the school day and in the arrangement of our work facilities.[35]

There is hardly any doubt that our daily living habits, like how we commute and use our leisure time, are undergoing a change that makes people more sedentary. Studies from the U.S. show a clear connection between the opportunities a person has to exercise in daily life and the prevalence of obesity. Those who live in surroundings where the possibilities for motion and outdoor activities are not available tend to be heavier than those who live in neighborhoods where such options are on offer.[19,36] This strengthens the claim that it is more difficult to remain within what is defined as normal weight in some environments than in others.

Medical and public health scholars have advocated for the view that at present we are heavily influenced by the environment we live in and the way it is currently structured directly increases the obesity problem.[10,13,37–39] It has been forecast that in 2030 half of those living in the U.S. will be obese and the only way to prevent that from happening is to make environmental changes.[40]

Although medical scholars do emphasize the importance of environmental changes when fighting the obesity epidemic, the medical view on the fat person is always seen through the eyes of the physician who bases his position on the clinical definition of obesity. As stated above, this view is characterized as an objective science where obesity is a biomedical fact, a health risk, and an epidemic.[8] Accordingly, regardless of cause, fat people are predominantly framed as patients suffering from a disease in the mainstream medical discourse.[7]

What are the consequences of framing the fat person primarily as a patient and as an object of science? I will address this question in the next section.

Consequences of medicalization

Being fat was in former times a sign of prosperity. Later being thin became a sign of health and beauty whereas fatness was assigned to weakness of the will, even sloth. It became a moral issue where the responsibility for this undesirable condition was placed on the fat person.[41] For centuries doctors have attributed fatness to an unhealthy way of life, but it was not until the latter half of last century that the state of "being fat" became an "obesity problem" that should be dealt with by medical means.[41] The responsibility for this condition was no longer personal but instead seen as something that had happened.[42] The manifestation of the medicalization of "obesity" appears, for example, in statements from the World Health Organization, in medical textbooks, countless articles in medical journals addressing the issue, in the fact that there are doctors specializing in obesity and medical clinics that have it as their primary agenda to cure obesity.[41,42] At this point I want to highlight three factors worth considering when reflecting upon the consequences of seeing the fat person as a patient and as such the object of medical science.

First, I will discuss the stigma of being fat. It might seem that medicalizing the fat person and turning her into the obese patient would neutralize and even destigmatize this condition. If being fat is no longer a sign of vice or moral weakness, but a disease, it should free the patient from the blame of obesity. Surprisingly this is not the case. The stigma on obesity manifests itself in many ways in modern society. It is evident in healthcare settings and research has showed considerable stigma and negative views toward obese patients among healthcare professionals. Puhl and Heuer[43] refer to a study where:

> 620 primary care physicians, >50% viewed obese patients as awkward, unattractive, ugly and noncompliant. One-third of the sample further characterized obese patients as weak-willed, sloppy, and lazy. Physicians also viewed obesity as largely a behavioural problem caused by physical inactivity and overeating. (p.944)

This strengthens the view that the medical profession is still blaming the obese patient for their bad results in curing obesity.[30] Thus, medicalization does not destigmatize obesity but quite the reverse.

Second, I want to mention the desire for power or wealth as a driving factor of medicalization.

Here attention is drawn to the self-interest of the medical profession. Sadler et al.[44] refer to Illich and Foucault who both argued that physicians expanded the list of diseases to grant themselves more power and authority. As mentioned earlier, we see claims in medical articles where it is considered very urgent to introduce medical interventions addressing the majority of the population regarding the chronic health risk and disease of overweight and obesity.[2,7,23] As there described, the patients would need imminent attention from doctors and other health personnel who were to influence (and control) their way of life. This medical intervention would last for a long period of time since obesity is a chronic disease that will not be cured in days or weeks but rather in months and years.[2,7,23] I am not saying that medical doctors are consciously trying to gain control over the lives of the majority of the population in Western countries. Nevertheless, this is what they propose by claiming "excess body fat" to be a disease and thus labeling them "patients" in need of healthcare attention.[14] From the perspective of fat people, this disease label can be a very troubling claim. To me, the fat author of this article, it seems more appealing to be addressed and seen in control of my own fate in the "kingdom of the well" than being in the "kingdom of the sick" under the management of healthcare personnel.[45]

The third point I want to highlight is what Sadler et al.[44] refer to as the balance between individual rights and responsibilities, on the one hand, and governmental or societal roles and responsibilities, on the other.[44] They describe the "obesity epidemic" in the following way:

> Partisans have frequently medicalized collective (social) problems in an effort to shift the onus of responsibility from society at large to healthcare services and, ultimately, to individuals. For example, Western societies have recently medicalized "lifestyle habits," particularly diet, exercise, and self-care, in an effort to shift the responsibility for public health and disease reduction away from government/society and more towards individuals. (Sadler et al.,[44] p.416)

There are strong societal forces that want to avoid political interference to promote a healthier lifestyle. For example, the Centre for Consumer Freedom. They represent the food industry and have taken part in the public discussion on obesity.[46] Needless to say they are advocating the consumer's freedom to choose and the freedom of the industry to advertise and sell their products.[47]

This shift in responsibility leads us to depoliticize politically difficult social problems.[44] To further show the need for acceptance of political responsibility and not only personal responsibility for the "obesity epidemic," studies show positive correlation between being of a lower social class and being obese.[19] Studies have also shown positive correlation between inequalities within societies and prevalence of obesity.[48] Inequalities and poverty are here recognized as important causal factors for obesity.

These authors draw our attention to the fact that the "obesity epidemic" needs to be met as a social problem. The danger of medicalization is however that when problems are framed as medical problems, they tend to be seen as primarily private and personal. Hence, when being fat is framed as the medical problem of "obesity" the responsibility for it is mainly viewed in a narrow perspective where the responsibility is situated in the personal life of the fat individual.[34] This happens although a call for a wider view on the responsibility for what is labeled as the "obesity problem" is in general accepted in medical and public health writings.[6,42] Politicians are nevertheless hesitant in taking steps to change the "obesogenic environment."[5,49] Although public health recommendations are clear, the influence of medicalization is not leading to better public health through political and environmental changes but rather to increased medical attention on the fat person, who experiences increased stigma as well as public blame and shame.[43,50]

Those who resist the medicalization of fat people see the medical discourse on "obesity," not as revealing scientific facts and truths about the lives of fat people, but rather as a product of power and oppression. They claim the medical view has a tendency to ignore the social implications of defining the state of being fat as a pathology and thus make it primarily the concern and responsibility of individuals.[8] These critical voices form the second position on the fat body, introduced in this article.

The critical view from the constructionist pole

Patterson and Johnston[8] claim that the academic literature on obesity bifurcates into two poles: the former being the realist pole, expressed within medicine and public health, and the latter, the constructionist pole. The constructionist is critical of the obesity discussion and relates to it as "...a moral panic driven by political interests and cultural values" (Patterson and Johnston,[8] p.265). They are not interested in outlining a cause for rising body weights but try instead to problematize the obesity epidemic as a social construct. The aim of the constructionist is to analyze issues like power interests, beauty norms, and feminine ideologies underlying the discourse.

The realist (medical) discussion is criticized for not being correctly constructed. Instead of focusing on the fat body, research should concentrate on a healthy diet and lifestyle as well as exercise for all body types.[16,51] "Thinness" is a commonly cited value in contemporary Western culture and that in and of itself stigmatizes "fatness." This might explain why medical research is so centrally focused on bodyweight rather than lifestyle. Patterson and Johnston[8] draw attention to the questions asked in medical research on obesity where the studies are dedicated to:

> ... the ill health effects of overweight and obesity ... to justify the pre-existing cultural notion that there must be something wrong with fat people. This would not be the case if the research was more centrally oriented towards the health effects of lifestyle habits. (p.277)

Hence, the studies are asking value laden stigmatizing questions. The results of those studies are therefore no longer objective. They go on to say that describing obesity as a disease of those who cannot control their food intake and balance it with their energy expenditure implies that the thin body is an attribute of the "normal", controlled, healthy and desirable citizen where the "... dominant realist discourse ... creates 'division between active [thin]citizens who can manage their own risks, and "target populations", those who require intervention' ..." (Patterson and Johnston,[8] p.283). These underlying ideas determine the way we feel about our body, whether we get a job or not and they determine who requires medical treatment or intervention.[8]

As a reaction to this criticism of social constructionists, a trans-disciplinary movement called Health at Every Size (HAES) has emerged. Their agenda is to shift the focus from weight management to health promotion. They propose ways to health promotion where the focus is not on physiological measures like BMI but on health behavior and increased general well-being. Psychological health reflected in self-like, self-esteem, and body image as well as body acceptance is important. They criticize mainstream medical approach toward fat people where the main concern is lowered body weight. They advocate for a paradigm shift in the obesity discourse where weight is not the focus but HAES.[52]

This criticism has even entered into mainstream medical journals where there is increased awareness of serious concerns regarding the conventional medical discourse on obesity, based solely on objective science. Ralston et al.[3] ask in a recent comment in *The Lancet* for a new obesity narrative. They go from the premise that obesity is a disease but nevertheless point out that current medical discourse is causing fat people harm. By using a simplistic causal model, the discussion is placing blame on individuals and a "siloed focus" on individual responsibility is hindering necessary political action to prevent obesity.[3] They also call for a more person-centered medical approach toward obesity. They draw attention to the importance of including lived experiences of fat people and call for respect for them while searching for solutions to the problem of obesity.

To better understand the importance of changing the dominant medical narrative on the lives of fat people and include their voice, I will introduce the third position on what it means to be fat. I label it: The personal position.

The personal position

Currently, there are several university departments teaching and studying social forces that are at play in stigmatizing the fat body (fat studies). The root of these movements can be traced to fat women in the 1960s and 1970s. Originally their fight was aimed toward the medical profession and its discrimination and subjection toward fat people.[9] Researchers in fat studies in the 1980s and 1990s were mostly marginalized voices, publishing research articles that undermined mainstream views on obesity and criticizing diets and food restriction programs.[53,54] Now, fat studies are an interdisciplinary study, focusing on the lives of fat people from a wide range of perspectives. These writings are not only focused on criticizing the medical dimension but also on describing social, spiritual, and cultural aspects of the lives of fat people.[9,55]

It is noteworthy in this discussion that it is primarily driven by fat people themselves and they want to change the whole narrative on what it means to be fat. This position in the discourse on the fat person draws attention to the fact that speaking about "energy machines" as in clinical medicine or referring to "communitarian bodies" controlled by environmental forces as in the public health dialogue does not capture the essence of the real lives of fat people.[19,56] They show us that we all desire to be accepted regardless of size or appearance.

These personal voices help us to understand important ethical realities which must be acknowledged when dealing with any human and social issue. A fundamental problem of our ethical and social life is to apprehend that other people are existing in exactly the same sense as I myself am existing. What is problematic with the medical narrative based on the scientific view described above is that by being impersonal it makes it more difficult to recognize the real existence of others. The philosopher and writer Iris Murdoch claims that the essence of ethics is knowledge of the existence of other human beings or in her own words: "Virtue is not essentially or immediately concerned with choosing between actions or rules or reasons... it is concerned with really apprehending that other people exist" (Murdoch and Conradi,[57] p.248). Implied in the above, is this special knowledge, and the fact that other people too are creators of their own lives, like me, every minute.

What does it mean to really apprehend that other people exist? It means to recognize the inner life of others as equal to my own inner life and to understand this reality to be just as meaningful as my own existence. This understanding cannot be taken for granted. The English writer George Orwell demonstrated the point in a powerful essay called "A Hanging." There he describes what goes on in the mind of a soldier who follows a prisoner who is about to be hanged. The man walks with a steady pace. Suddenly, he does the unexpected: he steps aside to avoid a puddle:

> It is curious, but till that moment I had never realized what it meant to destroy a healthy, conscious man. When I saw the prisoner step aside to avoid the puddle, I saw the mystery, the unspeakable wrongness, of cutting a life short when it is in full tide. This man was not dying, he was alive just as we were alive. (Orwell,[58] p.16)

These words capture the moment when Orwell realizes that the prisoner is a human being, that he is a person with thoughts and feelings just like Orwell himself. We can see this as an insight into our common humanity, which is no less of an achievement than the discoveries of science. It is in fact an important part of what makes us human. But this insight can easily be lost; for example, if our "objective scientific language" is dominant in medical and public discourse.

To fully apprehend the existence of others does not only imply recognition of their experiences, it also acknowledges their freedom and power to live their own lives according to their own will. Again, this acknowledgment is not something to be taken for granted. It is part of our moral universe that we can easily lose sight of, especially when we are focused on big problems like what is now labeled as the "obesity epidemic." In search for the good life, also fat people need to believe in the possibility of change, particularly when living in an environment that is not favorable to our health. A necessary prerequisite for those who want to change their lives for the better is to see themselves as creators of their own lives and to believe in the possibility of change. To do so it is necessary to have inner strength, self-confidence, and a clear vision for the future. To quote the philosopher Thoreau[59]: "there are as many ways as there can be drawn radii from one centre" (p.331). Similarly, we should open our eyes to the fact that we should not let others make our choices but choose ourselves our own way toward happiness.

My main criticism of the dominant scientific description on obesity is its blindness toward this personal view and acknowledgment of the uniqueness of each one of us. Mainstream medical articles on obesity are rooted in this discourse. Hence, they have a tendency to objectify the person and reduce her to "a body" or even "a disease" to be eliminated.[19,40,60] I object to this description as the "objective and scientifically true discourse" on what it means to be fat. I further regret that it has become the hegemonic discourse both within medicine and within public discourse describing the lives of fat people.

This does not reflect how the real life of fat people is. Fat people celebrate life in all its forms. For them being fat is woven into their lives. When obesity is discussed it cannot be addressed separately from their existence. Obesity does not exist as a unity in and of itself, but it is only real in the lives of fat people. Furthermore, there are no fat people existing without heads, like many pictures in medical journals regarding obesity express.[61] Such framing of their lives is in a nutshell what I am criticizing. These pictures are likely to exacerbate the stigma, as well as being attempts to rob them of personality and reduce their existence to a disease.[3,62,63]

To help us remember the deep connection which can exist between the individual human person and his figure, I want to quote the preface of the biography of the famous philosopher and author C.K. Chesterton. He was a great thinker and a beautiful personality and by current medical standards he would be labeled as morbidly obese:

> C.K. Chesterton was a giant. In every way. A massive mind in a massive body. He stood at a towering six feet, four inches, and he weighed three hundred pounds. His weight was the subject of many jokes, most of which he told himself. For instance, he said he was one of the most polite people in England. After all, he could stand up and offer his seat to three ladies on a bus.[64]

Chesterton's figure was interwoven with his personality and his philosophy of the wonder and miracle of life. A "thin Chesterton" does not exist. Thus, it would be utterly perverse to reduce his (fat) being to a disease. To eliminate Chesterton's fatness is to eliminate Chesterton. A world without Chesterton is without doubt a poorer world than one with Chesterton in it.

We all have a personal relation to food and to motion. These relations are unique and special because these are core elements of human existence and life itself. This relationship is not best described through a connection with suffering and disease, not even in the lives of fat people. Rather, it is a fundamental aspect of human life which can no less be expressed through creation of art and beauty where it is a source of pleasure and well-being. Obliterating the personal position and the complexity of being human makes the discussion of the lives of fat people shallow and we may question whether it reveals any sort of truth or value.

I have in this discussion underlined the blindness of medicine toward the humanity of those being fat. The core of medicine concerns people and how to make their lives better. Hence, medicine is not primarily about "objective science," it is a profession with a rich ethical dimension.[65,66] That is why medicine needs to take this criticism seriously. They need to realize the missing factor in the medical discourse: they need to include the humanity of fat people.

The way forward

I have now reflected upon three different positions when describing the lives of fat people. The first describing the objective view of science. This is the dominant position in modern medicine. It is impersonal and claims to be factual and true. The second position is the constructive pole of social science demonstrating a critical perspective. These critical voices aim to show how the objective view of science and medicine can be oppressive toward fat people. Third, I want to emphasize the importance of the personal position, revealing the voices of fat people themselves. These voices are highly important to counterbalance the impersonal view of science. It is to remind us of our common humanity shared by all of us, both the thin and the fat.

Medical discourse has approached fat people mainly through the narrow focus of objective science. This narrow focus has undermined the moral status of fat people. This view disregards their personal story, the social embeddedness of fat people, and ignores them as relational beings. Objectification of fat people frames them as passive and it marginalizes them as actors with feelings, ideas, personality, and a voice. Their own view on their own lives is thus not receiving due attention.

Medicalization further narrows the responsibility for what is labeled as "the obesity epidemic" where it diverts attention away from the political and social toward the private and personal. This "siloed focus" nourishes ideas of blame and shame instead of underlining the importance of fundamental changes in our living conditions.

Finally, describing fat people as passive objects, faceless and speechless, as well as ignoring their social embeddedness undermines their humanity. Therefore, it is time to advocate for a change in the medical discourse on the lives of fat people.

I will now outline two standpoints that the medical discourse on fat people needs to acknowledge to meet the ethical concerns introduced above.

First, by medicalizing the lives of fat people, it is omitted that the fat person is socially embedded. She is situated in time and space where culture, gender, and social role matter. This is opposite to most medical approaches where "... food, bodies and eating are disembodied and disengaged from the social contexts in which people live their lives" (Warin et al.,[67] p.98). This needs to be acknowledged. What follows is that by accepting the social embeddedness of fat people, public solutions like fighting inequalities and helping people out of poverty become more obvious than simply viewing the task as "curing" the anonymous "patient." To view the fat person relationally as a socially embedded being further shows the importance of admitting the negative effects of external influences like shame and blame. They can easily undermine their self-esteem, self-worth, and self-respect and consequently their personal autonomy.[68]

Second, as discussed in the previous section, it needs to be acknowledged in a more profound way that other people exist.[57] The lives of fat people should not be seen and defined primarily as "a medical problem" and "a personal tragedy." Focusing on the fat person as "a patient" marginalizes the voice of the fat person herself. Thus, with medicalization the emphasis on the person as the object of science and technology increases.[44] The person herself ceases to be the expert in her own life and as such loses power over her own fate. In fat people's protest we can see similarities with the current fight of disabled people against the medicalization of their lives and the fight of those labeled with a psychiatry diagnoses where they want to reclaim their identity and deny the medicalization of their lives.[69,70] These groups wish to tell their own story of how their lives are and resist the typical story told in scientific medical articles as being the dominant way to describe their lives. This has to be changed; the personal position has to be accepted as a source of important truth and as such given a central place in the dominant narrative of the lives of fat people.

Conclusion

The aim of this article is to draw attention to ethical concerns in the medical discourse on obesity, where the social dimension and the humanity of fat people are undermined. In order to reach this aim, I have outlined three positions on the obesity discourse—demonstrating the view of objective science, the critical voices of social scientists, and the personal perspective. All can contribute to the overall understanding of the lives of fat people. By encompassing these three positions and view together the different perspectives they reveal, the complexity of the problem labeled as the "obesity epidemic" is underlined and the serious ethical concerns in the mainstream medical discourse become visible. Acknowledging and emphasizing that fat people are contextually situated and that they share our common humanity is a good start. Here the medical profession needs to pave the way.

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References and notes

1. Dietz WH, Bland MG, Gortmaker SL, *et al*. Policy tools for the childhood obesity epidemic. *J Law Med Ethics* 2002; 30: 83–87.
2. Lau DC, Douketis JD, Morrison KM, *et al*. 2006 Canadian clinical practice guidelines on the management and prevention of obesity in adults and children [summary]. *CMAJ* 2007; 176: S1–S13.
3. Ralston J, Brinsden H, Buse K, *et al*. Time for a new obesity narrative. *Lancet* 2018; 392: 1384–1386.
4. Kuczmarski RJ and Flegal KM. Criteria for definition of overweight in transition: background and recommendations for the United States. *Am J Clin Nutr* 2000; 72: 1074–1081.
5. Caballero B. The global epidemic of obesity: an overview. *Epidemiol Rev* 2007; 29: 1–5.
6. James PT, Rigby N and Leach R. The obesity epidemic, metabolic syndrome and future prevention strategies. *Eur J Cardiovasc Prev Rehabil* 2004; 11: 3–8.
7. Brauer P, Gorber SC, Shaw E, *et al*. Recommendations for prevention of weight gain and use of behavioural and pharmacologic interventions to manage overweight and obesity in adults in primary care. *CMAJ* 2015; 187: 184–195.
8. Patterson M and Johnston J. Theorizing the obesity epidemic: health crisis, moral panic and emerging hybrids. *Soc Theory Health* 2012; 10: 265–291.
9. Rothblum ED. Why a journal on fat studies? *Fat Studies* 2012; 1: 3–5.
10. Dietz WH, Benken DE and Hunter AS. Public health law and the prevention and control of obesity. *Milbank Q* 2009; 87: 215–227.
11. Noël PH and Pugh JA. Management of overweight and obese adults. *BMJ* 2002; 325: 757–761.
12. Williams EP, Mesidor M, Winters K, *et al*. Overweight and obesity: prevalence, consequences, and causes of a growing public health problem. *Curr Obes Rep* 2015; 4: 363–370.
13. World Health Organization. *Obesity: Preventing and managing the global epidemic; report of a WHO consultation*. Report no. 9241208945. Geneva: World Health Organization, 1999.
14. Allison DB, Downey M, Atkinson RL, *et al*. Obesity as a disease: a white paper on evidence and arguments commissioned by the council of the obesity society. *Obesity* 2008; 16: 1161–1177.
15. Gard M and Wright J. *The Obesity Epidemic: Science, Morality and Ideology*. New York: Routledge, 2005.
16. Campos P, Saguy A, Ernsberger P, *et al*. The epidemiology of overweight and obesity: public health crisis or moral panic? *Int J Epidemiol* 2006; 35: 55–60.
17. Nicholls SG. Standards and classification: a perspective on the 'obesity epidemic'. *Soc Sci Med* 2013; 87: 9–15.
18. In this discussion I use the pronoun *she* for the patient and *he* for the doctor. This is to draw attention to the need for the discussion on the fat body to be relational and gendered, see for example Warin et al.[67]
19. Maziak W, Ward K and Stockton M. Childhood obesity: are we missing the big picture? *Obes Rev* 2008; 9: 35–42.
20. Heshka S and Allison DB. Is obesity a disease? *Int J Obes* 2001; 25: 1401–1404.
21. Pellegrino E. The goals and ends of medicine: how are they to be defined. In: Mark J Hanson and Daniel Callahan (eds) *The Goals of Medicine: The Forgotten Issues in Health Care Reform*. Washington, DC: Georgetown University Press, 1999, pp. 55–68.
22. Britannica World Language Dictionary: "patient: ...1. A person undergoing treatment for disease or injury. 2. Anything passively affected; the object of external impressions or actions: opposed to *agent*... [<OF *pacient* <L *patiens.-entis*, ppr. of *patiri* suffer]."
23. Wechsler JG and Leopold K. Medical management of obesity. *Langenbecks Arch Surg* 2003; 388: 369–374.
24. Have M, Beaufort IDd, Teixeira PJ, *et al*. Ethics and prevention of overweight and obesity: an inventory. *Obes Rev* 2011; 12: 669–679.
25. Abarca-Gómez L, Abdeen ZA, Hamid ZA, *et al*. Worldwide trends in body-mass index, underweight,

overweight, and obesity from 1975 to 2016: a pooled analysis of 2416 population-based measurement studies in 128,9 million children, adolescents, and adults. *Lancet* 390: 2627–2642.

26. WHO. Fact sheet: obesity and overweight, http://www.who. int/news-room/fact-sheets/detail/obesity-and-overweight (2018, accessed 24 October 2018).
27. Bacon L, Stern JS, Loan MDV, *et al*. Size acceptance and intuitive eating improve health for obese, female chronic dieters. *J Am Diet Assoc* 2005; 105: 929–936.
28. Abramson E. On the futility of dieting. *MedGenMed* 2005; 7: 31.
29. Sjöström L. Review of the key results from the Swedish Obese Subjects (SOS) trial – a prospective controlled intervention study of bariatric surgery. *J Intern Med* 2012; 273: 219–234.
30. Wooley C and Garner DM. Controversies in management: dietary treatments for obesity are ineffective. *BMJ* 1994; 309: 655–656.
31. Katan MB. Weight-loss diets for the prevention and treatment of obesity. *N Engl J Med* 2009; 360: 923–925.
32. Kleinert S and Horton R. Rethinking and reframing obesity. *Lancet* 2015; 385: 2326–2328.
33. Hawkes C, Smith TG, Jewell J, *et al*. Smart food policies for obesity prevention. *Lancet* 2015; 385: 2410–2421.
34. Hawkins KW and Linvill DL. Public health framing of news regarding childhood obesity in the United States. *Health Commun* 2010; 25: 709–717.
35. Greener J, Douglas F and van Teijlingen E. More of the same? Conflicting perspectives of obesity causation and intervention amongst overweight people, health professionals and policy makers. *Soc Sci Med* 2010; 70: 1042–1049.
36. Spear BA, Barlow SE, Ervin C, *et al*. Recommendations for treatment of child and adolescent overweight and obesity. *Pediatrics* 2007; 120: S254–S288.
37. Crawford D. Population strategies to prevent obesity. *BMJ* 2002; 325: 728–729.
38. Hill JO and Peters JC. Environmental contributions to the obesity epidemic. *Science* 1998; 280: 1371–1374.
39. Jeffery RW. Public health strategies for obesity treatment and prevention. *Am J Health Behav* 2001; 25: 252–259.
40. Wang Y, Beydoun MA, Liang L, *et al*. Will all Americans become overweight or obese? Estimating the progression and cost of the US obesity epidemic. *Obesity* 2008; 16: 2323–2330.
41. Sobal J. The medicalization and demedicalization of obesity. In: Maurer D and Sobal J (eds) *Eating Agendas: Food and Nutrition as Social Problems*. New York: Walter de Gruyter, Inc., 1995, pp.67–90.
42. Chang VW and Christakis NA. Medical modelling of obesity: a transition from action to experience in a 20th century American medical textbook. *Sociol Health Illn* 2002; 24: 151–177.
43. Puhl RM and Heuer CA. The stigma of obesity: a review and update. *Obesity* 2009; 17: 941–964.
44. Sadler JZ, Jotterand F, Lee S, *et al*. Can medicalization be good? Situating medicalization within bioethics. *Theor Med Bioeth* 2009; 30: 411–425.
45. Sontag S. *Illness as Metaphor and AIDS and Its Metaphors*. New York: Anchor Books Doubleday, 1978.
46. The Center for Consumer Freedom Team. The (obesity) parent trap? https://www.consumerfreedom.com/2007/07/3406-the-obesity-parent-trap/ (2007, accessed 8 November 2018).
47. Kwan S. Framing the fat body: contested meanings between government, activists, and industry. *Sociological Inquiry* 2009; 79: 25–50.
48. Wilkinson R and Pickett K. *The Spirit Level: Why More Equal Societies Almost Always Do Better*. London: Penguin UK, 2009.
49. Callahan D and Wasunna AA. *Medicine and the Market: Equity vs. Choice*. Baltimore, MD: The Johns Hopkins University Press, 2006.
50. Garry A. Medicine and medicalization: A response to Purdy. *Bioethics* 2001; 15: 262–269.
51. Saguy AC and Almeling R. Fat in the fire? Science, the news media, and the "obesity epidemic". *Sociol Forum* 2008; 23: 53–83.
52. Bacon L and Aphramor L. Weight science: evaluating the evidence for a paradigm shift. *Nutr J* 2011; 10: 9.
53. Wooley SC and Wooley OW. Obesity and women – I. A closer look at the facts. *Women's Stud Int Q* 1979; 2: 69–79.
54. Wooley OW, Wooley SC and Dyrenforth SR. Obesity and women – II. A neglected feminist topic. *Women's Stud Int Q* 1979; 2: 81–92.
55. Rothblum E and Solovay S. *The Fat Studies Reader*. New York and London: New York University Press, 2009.
56. Rich E and Evans J. 'Fat ethics' – the obesity discourse and body politics. *Soc Theory Health* 2005; 3: 341–358.
57. Murdoch I and Conradi PJ. *Existentialists and Mystics: Writings on Philosophy and Literature*. New York: Penguin, 1999.
58. Orwell G. *The Penguin Essays of George Orwell*. London: Penguin Books, 1984.
59. Thoreau HD. *A Week on the Concord and Merrimack Rivers; Walden, or, Life in the Woods; the Maine Woods; Cape Cod*. 12th printing ed. New York: Library of America, 1985.
60. Sharma AM and Kushner RF. A proposed clinical staging system for obesity. *Int J Obes* 2009; 33: 289–295.
61. The Lancet. Obesity and diabetes in 2017: a new year. *Lancet* 2017; 389: 1.
62. Evans B. 'Gluttony or sloth': critical geographies of bodies and morality in (anti)obesity policy. *Area* 2006; 38: 259–267.
63. McClure KJ, Puhl RM and Heuer CA. Obesity in the news: do photographic images of obese persons influence antifat attitudes? *J Health Commun* 2011; 16: 359–371.

64. Ahlquist D. *G. K. Chesterton: Apostle of Common Sense (A Kindle Version)*. San Francisco, CA: Ignatius Press, 2003.
65. Tauber AI. *Confessions of a Medicine Man: An Essay in Popular Philosophy*. Cambridge and London: A Bradford Book, the MIT Press, 2000.
66. Montgomery K. *How Doctors Think; Clinical Judgement and Practice of Medicine*. Oxford: Oxford University Press, 2006.
67. Warin M, Turner K, Moore V, *et al*. Bodies, mothers and identities: rethinking obesity and the BMI. *Sociol Health Illn* 2008; 30: 97–111.
68. Mackenzie C and Stoljar N. *Relational Autonomy: Feminist Perspectives on Autonomy, Agency, and the Social Self*. New York and Oxford: Oxford University Press, 2000.
69. Coles S, Keenan S and Diamond B. *Madness Contested; Power and Practice*. Monmouth: PCCS Books, 2013.
70. Barnes C and Mercer G. *Exploring Disability*. 2nd ed. Cambridge: Polity Press, 2010.

Paper III

‘A World without Down’s Syndrome’ – An Evaluation of Foetal Diagnosis in Light of the Ethos of Medicine

Journal:	*Disability & Society*
Manuscript ID	CDSO-2018-0324.R3
Manuscript Type:	Original Article
Keywords:	NIPT, Down´s syndrome, Medicine, Ethics, Foetal diagnosis
Abstract:	This article is an ethical evaluation of two familiar views in the debate on foetal diagnosis; one being the mainstream view in medical texts emphasizing early detection of foetuses with Down´s syndrome so they may be aborted, and the other coming from Down´s syndrome activists claiming that such screening is never acceptable. The core question asked is: What ethical weaknesses in modern medical practice does this discussion reveal? I argue that the marketization of noninvasive prenatal testing (NIPT) and the mainstream discussion in the health sector on its application shows two trends undermining the traditional ethos of medicine. Firstly, that doctors are, in their work, concentrating on diseases as isolated entities, whereas the patient and her life remains in the shadow. Secondly, the emphasis has been on the scientific foundation of medicine where the clinical evaluation of these scientific facts has not received due attention.

Points of interest.

- This article is about how we can evaluate ethically two different views on tests done on foetuses.
- It describes how some medical texts talk about tests done on foetuses to see if they have Down’s syndrome; and secondly, how some people with Down´s syndrome and their families talk about such tests.
- The medical view is criticized for failing to understand the importance of the lives of people with Down´s syndrome and for not taking their views of the value of their lives seriously.
- The medical texts focus on diseases instead of patients. Thus they tend to ignore the life and value of the person having the disease.
- The medical view is mainly about science and facts. It ignores the question of whether and how these facts matter for the patient.
- People with Down´s syndrome and their families have criticized this medical approach. Their criticism is very important.

'A World without Down's Syndrome' – An Evaluation of Foetal Diagnosis in Light of the Ethos of Medicine

Introduction.

In the documentary *A world without Down's Syndrome* (Phillips and Richards 2016), Sally Phillips asks: "What kind of a society would we like to live in, and who do we think should be allowed to live in it?" She interviews doctors, talks to people with Down's syndrome and describes her own views as a mother of a boy with Down's syndrome. The film shows a wide gap between the views of people with Down's syndrome on prenatal testing, on the one hand, and the views of medical doctors on the importance of such tests, on the other. In the documentary, doctors are shown as wanting and aiming for more precise tests to diagnose Down's syndrome in foetuses early in pregnancy, so they may be aborted. People with Down's syndrome and their families resist this approach and find it necessary to justify their existence in public. The film brings these two views into the public sphere, and in her article in *Disability and Society*, Burch (2017) shows how social media keeps this discussion alive, where it continues to echo through a Twitter debate.

Recent techniques in prenatal screening have sparked a rise in the debate over the search for foetuses with Down's syndrome. One such breakthrough is NIPT, non-invasive prenatal testing (Greely 2011). This test can be used to detect the nucleic acids of a foetus in the mother's blood and, on that basis, assess the prospective child's inherited characteristics. In this way, genetic variation that can lead to, for example, disabilities or diseases which can be expected to negatively affect the quality of life of the child and its family may be identified.

Disability studies have criticized what they label the medical model of disability, as opposed to the social model of disability. They claim that the medical model focusses too narrowly on disability as a characteristic of the person or unborn baby, instead of regarding it as being caused both by individual factors, such as bodily impairment and oppressive factors in society (Shakespeare 2014; Hartley et al. 2011). One of the aims of disability studies as a discipline is to sweep away the hindrances that confront disabled people in society (Shakespeare 2014). Disability studies frequently express criticism of the medical profession and its approach to disability, where it has, historically speaking, assumed the power of specialist knowledge, thus contributing to the social isolation and oppression of people with disabilities (Goodley 2016; Barnes and Mercer 2010; Bjarnason 2010).

The debate over using NIPT to diagnose Down's syndrome in pregnancy clearly shows the difference reflected in medical texts, on the one hand, and the views expressed on prenatal testing for Down's syndrome by disability activists, on the other. It is not presupposed in the discussion that these views represent all doctors or all those with Down's syndrome and affiliated families. Life is more nuanced. In both groups, we find diverse views. Nevertheless, these two conflicting views are prominent within each group, as will be demonstrated through examples. The aim of this paper is to examine these polarized views as an example and use them to address important aspects within medical ethics. I will focus on the question of how these different opinions can be interpreted in light of the ethos and aims of medicine and what ethical weaknesses in modern medical practice this discussion reveals.

I begin by describing my understanding of the ethos and ends of medicine. This understanding is a necessary prerequisite for my argument. Next, I will use the discussion on NIPT to show how medical attention has shifted away from the patient to the disease, where the disease seems to be constructed as a separate entity in and of itself. I will then turn to discussing how the emphasis has been on the scientific foundation of medicine, whereas evaluating the relevance of that knowledge to the patient has received insufficient attention.

Understanding medicine and its two pillars

In her book *How Doctors Think***,** Kathryn Montgomery (2006) describes two pillars of medicine. Firstly, she draws attention to medicine being based on science in a positivist sense and, secondly, to what she calls clinical judgement, that is, how to use this scientific knowledge for the benefit of the patient. She criticizes the tendency to disproportionally emphasise the scientific aspect of medicine and view medicine as an academic discipline, thus forgetting that medicine is, first and foremost, a clinical practice. She claims that medicine can never acquire the certainty and accuracy of mathematics or physics, since it is a practice that inevitably has to work with uncertainty and death. Although it is based on scientific facts, all those facts must serve a clinical purpose. Otherwise, they are not important and are, instead, what we might call "medically meaningless" (Montgomery 2006).

To know what has relevance and meaning in medical practice is an assessment every clinical physician must be able to perform to be a good doctor. To achieve this, medical practitioners must see their work not only in relation to scientific figures but also in relation to a particular patient's life. A doctor who lacks the understanding of how a disease relates to a patient's life and circumstances does not understand the art of healing (Montgomery 2006). Tolstoy ([1886] 2004) describes such a doctor in his story about the death of Ivan Ilyich.

> For Ivan Ilyich only one question mattered: was his condition dangerous or not? But the doctor ignored this inappropriate question. From the doctor's point of view, it was an idle question and not to be discussed; there existed only the weighing of probabilities – a floating

> kidney, chronic catarrh, or appendicitis. It was not a question of Ivan Ilyich's life, but an argument between a floating kidney and the appendix (61).

The doctor in the story falls into the trap of seeing a disease while remaining unaware of the connection with the person whose life is at stake. He is not talking to Ivan about what is really happening. Ivan is dying, but that has little bearing on the conversation. Instead, the doctor describes a reality which is alien to the patient and totally irrelevant to how he feels. The doctor appears oblivious to the fact that Ivan is a human being with hopes and fears, not a mere bundle of organs.

This particular notion of seeing the patient has deep roots within medicine. We can first relate it to *kline*, in the writings of Hippocrates. *Kline* means bed and refers to the clinical doctor coming to the patient's bedside. It emphasises the doctor who has to use his knowledge and adapt it to this particular patient. Medicine, in this sense is not only based on general knowledge but also on particular knowledge where the general understanding has to be adapted to a particular patient's life and needs (Hippocrates 2008; Nuland 1995).

Secondly, we can name a different ethical foundation for medicine, one where the doctor sees the patient as a fellow human being and responds to him or her as a person in need. That is the Christian root of medicine which appears in the parable of the Good Samaritan in the New Testament (Luke 10:25-37). The attitude so clearly manifested in this story remains an important undercurrent in the relationship between doctor and patient. Here, suffering is noted and responded to (Winch 1987). The ethical core of the medical profession is that the doctor is called upon to heal and minister to anyone in need. In that sense, every doctor follows in the footsteps of the Samaritan and every patient is his neighbour (Jonsen 1990; Montgomery 2006). In other words, working to heal and alleviate suffering means being concerned about a human being. One sees the person and, through one's work, reveals his or her humanity (Winch 1987; Gaita 2002).

This understanding of the physician-patient relationship was practised in mediaeval cloisters and has shaped the meaning of this connection in modern hospitals (Jonsen 1990). In this reference, the doctor was seen as the human instrument of God and the servant of the patient (Jonsen 1990). The idea of the servant where the sick person is the Lord, illustrates how medicine gains its true meaning through the patient, his cure and care. Medicine does not receive its meaning through the doctor, science or knowledge. The physician exists because of the patient and for the patient. The true value and end of medicine is, therefore, in the care and the cure of the patient (Pellegrino 1999).

Because of the patient's vulnerability, it is important that doctors remember this historical tradition and accept it as an important ethical foundation for their role and their position. Here, I am primarily referring to the doctor seen as the servant of the patient where his role is to help, advise and support, not to rule and control. The patient's trust in the doctor is based on this unspoken promise, and the doctor has to work with concern and understanding for this particular patient and his or her life.

When we read medical textbooks and journals, medicine appears as a branch of the natural sciences. Positivist science gives medicine its necessary grounding in evidence-based truth, but although this is necessary, it is not sufficient. Evaluating the relevance of this positivist knowledge to the patient is also an essential feature of medicine. This evaluation is done by referring to the essential ends of medicine, the care and cure of the patient (Pellegrino 1999). This is the foundation of the doctor's promise to the patient and of the moral contract between medicine and society.

To sum up, physicians rely on a long and well-established professional tradition of not only collecting information on the human body, health and diseases, but primarily of fulfilling a promise to the patient to use this knowledge for the benefit of the patient to care and cure. Ivan's doctor in Tolstoy's story saw only organs and probabilities; he did not see the patient that is Ivan. He was not upholding his professional promise, since what he said had no meaning for Ivan. If the doctor cannot communicate with the patient and does not understand his fears and hopes, there is always the danger of him offering a treatment that does not benefit the patient. In this case meaningless information instead of care and consolation. The doctor's promise is not meant to address organs, or diseases. It can only be made to a human being, that is to the patient.

I will now outline two trends in current medical discourse undermining the ethos of medicine described above. Firstly, I will show how the disease itself can overshadow the patient. To do that, I will present the discourse on using NIPT as a screening tool or a way of making a meaningful reproductive choice with regard to foetuses characterized by Down's syndrome.

When 'the patient' becomes 'the disease' through screening and choosing

The main goals of medicine are sometimes said to be to prevent and cure diseases as well as promoting health (Callahan and Hanson 1999; Calman 2007). One way of reaching this aim is to reduce the incidence of diseases in the community. Since Down's syndrome is defined within medicine as a disease (see: ICD 11: LD40.0 Complete trisomy 21), it might seem appropriate to reduce its incidence by preventing the birth of babies with Down's syndrome. We can see this view expressed in medical articles on screening tests for Down's syndrome. Here is an example:

> Currently, the most effective prenatal screening tests for Down syndrome combine maternal age with information from sonographic measurement of nuchal translucency in the first

> trimester and measurements of several maternal serum screening markers obtained in the first and second trimesters. This approach detects up to 90% of all cases at a false-positive rate of 2%. Given the prevalence of Down syndrome, 1 of every 16 screen positive women offered invasive diagnostic testing (amniocentesis or chorionic villus sampling) will have an affected pregnancy and 15 will not. As many as 1 in 200 such invasive procedures are associated with fetal loss, a major adverse consequence of prenatal diagnosis. (Palomaki et al. 2011, 913)

The phrasing in this text is noteworthy. When the authors refer to foetuses with Down's syndrome, they are described as affected pregnancies and they are to be detected. On the other hand, when a foetus that does not have Down's syndrome is lost because of a medical procedure the text refers to adverse consequence and foetal loss. This avoids addressing the foetus with Down's syndrome as a foetus. The only real foetus in the text is the one that does not have Down's syndrome. In other words, the foetus with Down's syndrome is constructed as a state of disease where 'the pregnancy is affected with Down's syndrome'. Further, to improve public health, it is important to detect and, according to this line of thinking, end the affected pregnancy and thus remove 'the disease'.

Down Syndrome International (DSI) has criticized this attitude on prenatal testing, where it says:

> DSI does not consider Down syndrome in itself a reason for termination. People with Down syndrome can and do lead full and rewarding lives and contribute as valued and equal members of their communities (DSI 2018).

The DSI’s statement rejects the medical view described above and maintains that the diagnosis of Down’s syndrome in the foetus is not to be accepted as a reason for terminating pregnancy. The Convention on the Rights of Persons with Disability (CRPD) has also been interpreted as a Human Rights statement opposed to screening for foetuses on the grounds of them having Down’s syndrome (Lord 2013; "Convention on the Rights of Persons with Disabilities" 2007).

Although we might not accept the view that the birth of people with Down’s syndrome is seen as a public health threat, we might support the idea of having the choice to test foetuses for impairments like Down’s syndrome. We could then claim that it is irrelevant whether or not we regard Down’s syndrome to be a disease. Potential parents should, in any case, have the choice to eliminate a pregnancy of a foetus with Down’s syndrome to avoid the birth of such a child.

When policy makers argue for prenatal testing it is more often referred to in this way; not as health screening but as a reproductive choice (Parens and Asch 2003; Shakespeare 1998; Nijsingh, Juth, and Munthe 2017). We see this view demonstrated in the following medical text on the purpose of foetal diagnosis:

> Enabling meaningful reproductive choice with regard to parenting or avoiding a child with a serious disorder or disability is (or should be) the aim of offering testing for fetal abnormalities. (de Jong et al. 2011, 657)

Is a ‘meaningful reproductive choice’ a valid reason for offering prenatal testing for Down’s syndrome? The screening procedures are meant to prevent future suffering from disease and disability. The reproductive choices, on the other hand, are mainly to be interpreted as the private concern of the prospective parents. Some even go so far as to state that parents should always have the choice of selecting embryos on the basis of their traits, regardless of diseases or impairments. Prospective parents should only be guided by which prospective babies are most likely to have a good life (Savulescu 2001).

However, the argument about the benefit of information and choice is based on the premise that prospective parents’ free choice and autonomy will be increased if they are given sufficient information about the foetus. That is, per se, meant to increase the well-being of the parents and the child. Does such information truly increase parental autonomy and theirs and their child’s well-being? At first sight, it might seem that giving parents more information would increase their autonomy and control over their lives and lead to a better life. In reality, the interpretation and understanding of the meaning of the tests under discussion is complicated and their results can be of limited meaning to the parents. The real challenge for both parents and doctors is not only to understand the figures, the tests sensitivity and specificity in the scientific sense. It is also to understand and interpret what the test results mean in real life. What do they tell us about the child’s life in the future and that of the family? Will she have friends? Will she be happy? Will she suffer? Such an interpretation is at best complicated, if at all possible (Heyman et al. 2006). For the prospective parents to interpret the figures from the tests and try to translate them into meanings about the value of the unborn child’s life, is both complicated and difficult. Interviews with prospective parents have shown that many feel they are not given enough time and support to really face these difficult tasks and choices in maternity support (Nijsingh, Juth, and Munthe 2017; Bjarnason 2010). Therefore, the choices are most often not personal in that they do not necessarily reflect the values, context and character of the prospective parents. Instead, a routine is followed where the woman does what she feels is expected of her (Kristjansdottir and Gottfredsdottir 2014). In spite of the woman’s powerlessness against these choices, she always bears the responsibility for the conclusion (Sandel 2009), which puts her in a very difficult position. Although she has limited means to evaluate this choice it inflicts upon her the responsibility of whether her prospective child lives or dies.

By questioning this reproductive choice, I may be criticized for arguing against the freedom of women. The question of abortion is to be seen solely as the right of women to control their own bodies. The choice is a private decision and needs not be justified. This reflects the mainstream feminist view on abortion, which conflicts with prevailing views expressed by disability activists, as has been shown earlier in an excellent article in *Disability and Society* by Sharp and Earle (2002). Although this tension is accepted, it is nevertheless right to emphasize that there are different types of justifications for reproductive choices. The foetus could, for example, be aborted because of certain circumstances in the life of the mother (or parents). In relation to the use of NIPT, the discussion is about whether the choice to abort a foetus because of its characteristics can be justified. In other words, this is the choice of a woman who wants to become pregnant but not with this foetus/child because of how it is (Lid 2015). This is also a socially accepted, and even encouraged, justification. It could further be said that offering a choice to abort a foetus because it has Down's syndrome sends the messages that not only foetuses with this particular characteristic do not have the same value as other foetuses but also that persons living with Down's syndrome are inferior. This argument is referred to as the 'expressivist argument' (Hofmann 2017).

I realize that this argumentation is controversial. Parens and Asch (2003) have reflected upon this debate and outlined how some people claim, for example, that foetal screening or prenatal testing is not aimed against disabled people. Foetal-screening programs are not to be seen as any kind of statement about the current lives of people with Down's syndrome. Thus, the claim is that the issue of people alive today is totally different and should be clearly distinguished from foetuses.

Although we may differ in our opinion on the logical truth of the expressivist argument, it cannot be denied that many of us regard the use of NIPT to diagnose foetuses with Down’s syndrome to be a way of expressing a certain value judgement, being the idea that the lives of people with Down´s syndrome is of less value than the lives of those who are not with Down´s syndrome. This underlying premise is not discussed openly in medical texts, since the existence or nonexistence of such value judgements is regarded to be outside the scope of medicine. This reflects ignorance and lack of deliberation around the relevance of this test and is further masked by referring to Down’s syndrome as ‘a disease’ in itself or a separate entity instead of seeing it for what it is, a characteristic of a fellow human being.

I want to state that claiming that Down’s syndrome in a foetus is a medical justification for a systematic offer of abortion has implications for the self-identity and self-respect of people with Down’s syndrome and how others see them. I do not ground my statement in logic but in discussions with people with Down’s syndrome and with their friends and families and on public statements from Down’s syndrome activists. We can interpret their voices as a response to the underlying notion that people with Down’s syndrome are not welcome because of how they are. They feel the need to rebut implied judgements about their lives and to justify their existence (Friedersdorf 2017). In public discourse, examples can be found of people with Down’s syndrome who describe how meaningful their lives are; their parents report how thankful they are for having their son or daughter with Down’s syndrome in their lives (Björnsson 2001; Þorbergsdóttir 2012). We read about people with Down’s syndrome who contribute in a meaningful way to society and hear Down’s syndrome activists say that Down’s syndrome is not a disease but a variation to be welcomed in the human spectrum (Pineda 2015; Goksøyr 2012). Those who are categorized as accepted, welcomed and valued do not feel the same need to justify their existence as those who are not. Hence, these voices can be interpreted as an effort to resist and rebut the unspoken judgment value in the medical discourse.

The medical discourse, rebutted by the voices described above, represents a view of people with Down's syndrome as 'a disease' that should have been prevented and that we should choose to prevent. This is apparent when foetal diagnosis is discussed as a public health screening measure and when it is routinely offered within health services as a personal reproductive choice. By singling out foetuses with Down's syndrome, describing them as 'affected pregnancies' or introducing the search for them as 'a meaningful reproductive choice', the danger of conflating the foetus with Down's syndrome with 'a disease' in and of itself is increased.

This last point may seem like a bold ontological claim, but this very claim is present enough to be rebutted by people with Down's syndrome and by disability activists. They have argued against categorizing Down's syndrome as a disease and have particularly stressed the fact that they themselves are people and not 'a disease' (Kikabhai 2014). Their strong reply shows a clear resistance to the dehumanizing attitude expressed through systematic approaches towards foetuses with Down's syndrome within the health care system.

By viewing foetuses with Down's syndrome as something that should either be effectively detected or that people should chose to detect, medicine has undermined the humanity of people with Down's syndrome. By so doing, there is a shift in medical attention away from 'the patient' and to 'the disease'. There are other examples within medical discourse showing the same tendency. The discussion on obesity has, for example, been criticized within fat studies.

They have shown how fat people are, through medical discourse, depersonalized and dehumanized (Rothblum 2012; Ralston et al. 2018). This is a serious trend that undermines the patient's trust in the physician's vocation and word.

I will now turn to the second trend in current medical discourse undermining the ethos of medicine, being the neglect of the importance of the clinical pillar mentioned earlier. Here, I am referring to the emphasis on the scientific foundation of medicine, whereas evaluating the relevance of that knowledge to the patient needs to be addressed more sincerely.

The medical meaning of NIPT

Currently, the discussion on the application of NIPT and the policy around it is regarded as appropriately being in the hands of medical experts. Furthermore, the choice of whether to terminate pregnancy because of a result from NIPT is primarily seen as a private choice for the parents. Although medical experts and health policy makers do not directly decide which foetuses are aborted, they do choose what types of foetuses are singled out and targeted for abortion. They determine when it is justifiable to offer a choice to terminate a pregnancy. The offer itself is probably the single most important issue shaping the choices of the prospective parents. Health care settings are characterized by the ethos of health care professionals. This implies that when this offer is presented by physicians, it can easily be understood as part of the doctor's recommendations and treatment. Because of the inherent ends of medicine and because of the implicit promise to act solely for the benefit of the patient, the parents are inclined to believe that these choices, recommended by their doctor, are for their benefit and for the good of the foetus.

When both offering and interpreting a test like NIPT, physicians are directing people's choices through medical advice. This power brings with it difficult ethical questions that doctors ought to face. I am not referring to complicated interpretations of scientific results like evaluating false-positive or false-negative tests, figures and statistics. Rather, I am referring to hard questions regarding which lives are meaningful and which lives are not. In other words, the doctor needs to evaluate when his actions are of beneficence and when not. These questions are normative but they are nevertheless medical questions about health and disease. To be able to do that, doctors must acknowledge the scientific pillar of medical knowledge and the clinical pillar discussed earlier. Such reflection requires the ability to view scientific knowledge from a personal, ethical and political perspective.

The way reproductive choices are viewed goes hand in hand with how medicine is envisioned. It is, therefore, necessary to point out that medical decisions are taken in a social context. The medical profession is embedded in society and, as such, is influenced by powerful social forces. Marketization and public demand influence medicine, including reproductive choices (Callahan and Hanson 1999). If such choices are to be regarded as personal and offered only because people want them, they seem to be represented as medically neutral. By that I mean that the physician offering them is not restricted by the constitutive values and aims of medicine. Instead, we might tend to regard these decisions as market decisions, mainly influenced by people's personal choices and, as such, their personal responsibility. Accordingly, doctors only have the duty to inform, not to advise.

This double meaning of medical aims can cause, and does sometimes cause, misunderstandings between health professionals and patients. Firstly, offering choices and claiming that they are medically neutral, means that the choice itself is no longer based on considerations regarding the welfare or health of the patient. It shifts responsibility further away from the doctor towards the patient. The medical doctor might even become indifferent to the patient's choice. This change in the relationship between doctor and patient is contrary to the ethical foundation of medicine, where the physician cares for the patient and accepts the responsibility for his treatment (Jonsen 1990; Callahan and Hanson 1999; Calman 2007). This situation can easily create confusion. The general public and patients specifically may still assume that medicine only promotes values and choices beneficial to their health. This may in turn lead them not to evaluate, or even question, medical proposals in the way they would e.g. offers on the market.

Secondly, if prenatal testing were to be regarded as a neutral offer, some health professionals might misinterpret their position in this changed ethos and use nudging to coax the patient towards a certain decision. Nudging in health care might be acceptable in cases where we can be certain of the health benefit of the choices offered, but when the choice is merely based on personal preferences, such pressure from health personnel is not ethically acceptable (Hofmann and Stanak 2018).

This clearly shows why it is insufficient to conduct this debate either in an academic (scientific) discussion within medicine on the one hand or within disability studies on the other. The debate on how and why we use prenatal testing has also to be conducted in the broader community where the aims and goals of medicine in human life are openly discussed. It has to be discussed openly what sort of a choice is being offered, is it based on our traditional understanding of the ethos of medicine or is the nature of this choice different? Is it to be regarded in the same way as commercial choices in the market? If this is not clear to both prospective parents and doctors it can lead to misunderstandings as outlined above.

When we follow public discussion within medicine and read standard texts in medical journals on NIPT, we do not see any true evaluation of the relevance of NIPT (Brady et al. 2016; Buchanan et al. 2014). When I say ‘true evaluation’, I am referring to an evaluation of NIPT founded on both pillars of medicine, not only the scientific pillar. Only when this is done, can medicine uphold its moral contract to society. Articles within medical journals are scientific in nature and, as such, accept unspoken assumptions on the relevance of these tests. They mainly refer to complicated interpretations of scientific results like evaluating false positives or false negative tests, figures and statistics. They systematically avoid hard questions involving fundamental ideas about the meaning and purpose of medicine in the face of ethical challenges as to which lives are meaningful and which lives are not.

If the academic discourse is to take on the task of reflecting upon the clinical pillar with reference to NIPT, it will need to gain basic insights into what it means to have Down’s syndrome. That begs the question of whether doctors can explain this choice to prospective parents having seemingly avoided any research into what it really means to have Down’s syndrome.

What does it mean to have Down’s syndrome?

A doctor talking to a prospective mother with the results of a foetal diagnosis in her hands describes the situation and defines terms in light of medical interests and knowledge. Let us assume that the mother is carrying a child diagnosed with Down’s syndrome. The medical discourse is highly likely to define the unborn child, first and foremost, on the basis of its relation to diseases. The doctor’s description might sound something like the following:

> The child will be born with reduced intelligence, possibly damaged hearing and a heart defect. Besides, it could develop leukaemia and degenerative diseases as it grows older. The average lifespan of this individual will be lower than normal and there is considerable likelihood that the child will require special support in daily life.

The doctor’s interpretation is not wrong, but it is far from being a full description of the life awaiting the mother and child (Lord 2013). Fortunately, our health weaknesses do not form a complete picture of our lives.

To search for a more accurate picture, we need to include the voices of people with Down’s syndrome and their families (Boardman 2014). We would, of course, hear all sorts of stories. We do often hear claims emphasizing the special value of their life. Some parents also describe their experiences as involving a lot of work but nevertheless, say it has also taught them to value life (Björnsson 2001; Þorbergsdóttir 2012). We could interpret such statements as examples of how finding our way through difficulties teaches us to value life and understand how precious it is. The Stoics pointed this out and explicitly advised people to think of all we could lose, so we might learn to appreciate what we have. Life, with all its gifts, should not be taken for granted. Irvine (2009) says in his description of Stoic philosophy:

> Generally, war, disease and natural disasters are tragic inasmuch as they take from us the things we value, but they also have the power to transform those who experience them. Before, these individuals might have been sleepwalking through life; now they are joyously, thankfully alive – as alive as they have felt in decades. (Irvine 2009, 75)

We could say that problems and hardships teach us to value everyday life, being alive and existing. This view is mainly presented to draw attention to the fact that aiming to constantly remove difficulties and relieve pain is not a way to a better life. Such a way of living would convert us into sleepwalkers in our own lives. Disability studies have, by means of research and critical attitudes towards medicine, demonstrated that disability is not first and foremost a personal tragedy. Discourse from people with Down’s syndrome on their own lives and from their families shows that they can, as well as most of us, lead rich and giving lives (Burch 2017; Alderson 2001). Above all, they are thankful for life in all its diverse forms.

In this discussion, I primarily highlight the difficulties in distinguishing unambiguously between lives that are worth living and lives that are not. Furthermore, more information on the foetus through prenatal tests is not automatically related to more autonomy and more happiness. As a matter of fact, the tests and choices are not necessarily helpful in that respect. Life and what gives it value and meaning are much more complicated than that.

When we reflect upon the question of what it means to have Down’s syndrome, we can state that people with Down’s syndrome are the only people with first-hand knowledge of how to answer this question. Family and friends of people with Down’s syndrome are the only ones with first-hand knowledge of what it means to share your life with a person with Down’s syndrome. Hence, their voices are of fundamental importance when interpreting the relevance of a prenatal test to diagnose Down’s syndrome. Their views matter in public debate, in policy making for those taking the tests and, finally, for medical doctors who discuss options with prospective parents at health clinics. Disability activists’ claim of ‘Nothing About Us Without Us’ is fundamental to the discussion on foetal diagnosis (Kikabhai 2014). Ignoring their voices, as is mostly done in today’s health care policy making, is an example of poor clinical reflection. Making offers involving prenatal tests like NIPT look like ‘meaningful reproductive choices’ provided by neutral scientific medical doctors shows insensitivity about what it means to live with Down’s syndrome and ignorance as to the importance of the clinical pillar of medicine.

I have now demonstrated the second ethical weakness in modern medical discourse that this paper illustrates. It highlights the mainstream medical discourse on NIPT and its narrow focus on the scientific pillar of medicine that ignores the importance of careful deliberation of the relevance of this test to the patient. The discussion of NIPT is not the only example of this trend. Medical doctors have, for example, been criticized for not understanding and respecting the culture of deaf people. Without due familiarity with this culture, physicians cannot correctly evaluate the clinical relevance of a cochlear implant as medical treatment. (Sparrow 2005; Gaylor et al. 2013).

These examples show that physicians and those planning health policy need to recognise the interaction between doctor and patient in a social context. Furthermore, medical treatment is an act of beneficence, and thus should be connected to the good life. This asks for ethical reflection and deliberation from doctors as an integral part of their work. To systematically ignore this and promote medical choices as neutral personal preferences can change the purpose of medicine and, as such, undermine its essential values.

Conclusion

In this article, I have used the discussion about NIPT in the medical literature and the discussion conducted by disability activists to reflect upon two serious trends in modern medicine that undermine the ethical foundations of the profession.

The discourse on NIPT shows that medical doctors have given undue attention to the disease as a separate entity. This construct of the discourse undermines the fact that there is no such thing as a separate disease. A disease only exists in relation to a living being. In the case of the foetus, we can debate and disagree on its moral status, but we cannot deny its presence and its potentiality of becoming a person. Such a denial is apparent in medical discourse, for example, where we have reference to ‘the affected pregnancy’, when referring to a foetus with Down’s syndrome as opposed to ‘foetal loss’ when referring to a foetus not having Down’s syndrome. The medical approach and the accompanying discourse occurs frequently under the cloak of science and neutrality. As such, it can undermine the humanity of people with Down’s syndrome. This is contrary to the very essence of medicine, where the patient, not the disease, is always the primary focus.

Secondly, the medical approach shows undue attention to scientific facts and little reflection in medical journals on their relevance to the patient. The medical discourse on NIPT takes for granted that the number of births of children with Down’s syndrome should be lowered. This premise is not discussed within medicine with due sincerity. A real discussion about the relevance and meaning of tests like NIPT does not seem to have a proper place within medical journals. This task is mostly viewed as being outside mainstream medicine, either addressed as an afterthought or downplayed as not being real medicine. That shows serious indifference towards one of the two pillars of medicine; that is, how can the knowledge of science benefit this particular patient?

This critical reflection on the discourse around NIPT highlights the importance of medical doctors knowing their vocation. The discussions reflected upon in this article are not isolated examples of these ethical shortcomings of modern medicine. The medical discourse on obesity and the use of cochlear implants are also examples of the lack of open, ethical deliberation within modern medical practice which needs to be addressed with more sincerity.

Physicians are guardians of important values in society as they are called upon in people’s times of need. They are highly influential in shaping our health policy and should take responsibility for its practice. They need to know what they stand for and why they are practicing medicine. If this is forgotten, physicians can lose their integrity and their primary focus on the patient, as well as the ability to accomplish the necessary interpretation of scientific facts within the frame of clinical relevance. Neglecting this can cause the profession to lose its essential value and fail to uphold the moral contract between the profession and society. Here, the opinion outlined by Sally Philipps in her documentary as well as the criticism of Down's syndrome activists and their families can serve as an important reminder.

References.

Alderson, Priscilla. 2001. "Down's syndrome: cost, quality and value of life." *Social Science & Medicine* 53 (5):627-38. doi: http://dx.doi.org/10.1016/S0277-9536(00)00365-8.

Barnes, Colin, and Geof Mercer. 2010. *Exploring disability*. 2nd ed. Cambridge: Polity Press.

Bjarnason, Dóra. 2010. *Social Policy And Social Capital: Parents And Exceptionality 1974-2007*, *Children's Issues, Laws And Programs*. New York: Nova Science Publishers, Inc.

Björnsson, Indriði. 2001. "Viðhorf og reynsla foreldris til fósturgreininga og Downs heilkenna [Prenatal diagnosis and Down's syndrome. A parent's perspective]." *Læknablaðið [The Icelandic medical Journal]* (Fylgirit 42 - Kerfisbundin leit að fósturgöllum).

Boardman, Felicity K. 2014. "Knowledge is power? The role of experiential knowledge in genetically 'risky' reproductive decisions." *Sociology of Health & Illness* 36 (1):137-50. doi: 10.1111/1467-9566.12048.

Brady, P., N. Brison, K. Van Den Bogaert, T. de Ravel, H. Peeters, H. Van Esch, K. Devriendt, E. Legius, and J.R. Vermeesch. 2016. "Clinical implementation of NIPT – technical and biological challenges." *Clinical Genetics* 89 (5):523-30. doi: 10.1111/cge.12598.

Buchanan, Amanda, Amy Sachs, Tomi Toler, and Judith Tsipis. 2014,. "NIPT: current utilization and implications for the future of prenatal genetic counseling." *Prenatal Diagnosis* 34:850–7.

Burch, Leah. 2017. "A world without Down's syndrome? Online resistance on Twitter: #worldwithoutdowns and #justaboutcoping." *Disability & Society* 32 (7):1085-9. doi: 10.1080/20550340.2017.1330453.

Callahan, D., and M.J. Hanson. 1999. "The Goals of Medicine: The Forgotten Issues in Health Care Reform." In *Hastings Center Studies in Ethics series*. Washington: Georgetown University Press.

Calman, Kenneth C. 2007. *Medical Education; Past, Present and future*. Edinburgh: Churchill Livingstone Elsevier.

"Convention on the Rights of Persons with Disabilities." United Nations. http://www.un.org/disabilities/documents/convention/convoptprot-e.pdf.

de Jong, A., W. J. Dondorp, S. G. Frints, C. E. de Die-Smulders, and G. M. de Wert. 2011. "Advances in prenatal screening: the ethical dimension." *Nat Rev Genet* 12 (9):657-63. doi: 10.1038/nrg3036.

"DSI Position Statement on Prenatal Testing." Accessed 6/11/2018. https://ds-int.org/dsi-position-statement-prenatal-testing.

Friedersdorf, Conor. 2017. "'I Am a Man With Down Syndrome and My Life Is Worth Living'." In *The Atlantic*. Oct. 30. https://www.theatlantic.com/politics/archive/2017/10/i-am-a-man-with-down-syndrome-and-my-life-is-worth-living/544325/

Gaita, Raimond 2002. *A Common Humanity Thinking About Love and Truth and Justice*. London: Routledge.

Gaylor, James M., Gowri Raman, Mei Chung, Jounghee Lee, Madhumathi Rao, Joseph Lau, and Dennis S. Poe. 2013. "Cochlear Implantation in Adults: A Systematic Review and Meta-analysis " *JAMA Otolaryngology–Head & Neck Surgery* 139 (3):265-72. doi: 10.1001/jamaoto.2013.1744.

Goksøyr, Marte Wexelsen. 2012. *Jeg vil leve [I want to live]*. Oslo: Oktober.

Goodley, Dan. 2016. *Disability studies: An interdisciplinary introduction*. 2nd ed. London: Sage.

Greely, Henry T. 2011. "Get ready for the flood of fetal gene screening." *Nature* 469:289. doi: 10.1038/469289a.

Hartley, Sally, Venus Ilagan, Rosamond Madden, Alana Officer, Aleksandra Posarac, Katherine Seelman, Tom Shakespeare, et al. 2011. "World Report on Disability.". Malta: World Health Organization, The World Bank.

Heyman, Bob, Gillian Hundt, Jane Sandall, Kevin Spencer, Clare Williams, Rachel Grellier, and Laura Pitson. 2006. "On being at higher risk: A qualitative study of prenatal screening for chromosomal anomalies." *Social Science & Medicine* 62 (10):2360-72. doi: https://doi.org/10.1016/j.socscimed.2005.10.018.

Hippocrates. 2008. "The Corpus " In *The Corpus.* New York: Kaplan Publishing.

Hofmann, Bjørn, and Michal Stanak. 2018. "Nudging in screening: Literature review and ethical guidance." *Patient Education and Counseling* 101 (9):1561-9. doi: https://doi.org/10.1016/j.pec.2018.03.021.

Irvine, William B. 2009. *A Guide to the Good Life; The Ancient Art of Stoic Joy*. New York: Oxford University Press.

Jonsen, Albert R. 1990. *The New Medicine and the Old Ethics*. Cambridge, Mass.: Harvard University Press.

Kikabhai, Navin. 2014. "'Resistance: Which Way the Future?' A dual-screen installation related to the theme of disability and eugenics." *Disability & Society* 29 (1):143-58. doi: 10.1080/09687599.2013.776489.

Kristjansdottir, Hildur, and Helga Gottfredsdottir. 2014. "Making sense of the situation: Women's reflection of positive fetal screening 11–21 months after giving birth." *Midwifery* 30 (6):643-9. doi: https://doi.org/10.1016/j.midw.2013.10.024.

Lid, Inger Marie. 2015. "Vulnerability and disability: a citizenship perspective." *Disability & Society* 30 (10):1554-67. doi: 10.1080/09687599.2015.1113162.

Lord, Janet E. 2013. "Screened Out of Existence: The Convention on the Rights of Persons with Disabilities and Selective Screening Policies." *International Journal of Disability, Community & Rehabilitation* 12 (2).

Montgomery, Kathryn. 2006. *How Doctors Think; Clinical Judgement and Practice of Medicine*. Oxford: Oxford University Press.

Nijsingh, Niels, Niklas Juth, and Christian Munthe. 2017. "Ethics of Screening." In *The International Encyclopedia of Public Health*, edited by W.C. Cockerham and S.R.Quah, 28-35. Oxford: Academic Press.

Nuland, S.B. 1995. *Doctors; The Biography of Medicine*. New York: Vintage Books a division of Random House, Inc.

Pineda, Pablo.2015. "Down syndrome is not an illness - [video file]." Aug.30. https://www.youtube.com/watch?v=uqqVa4t5Jg8.

Palomaki, Glenn E., Edward M. Kloza, Geralyn M. Lambert-Messerlian, James E. Haddow, Louis M. Neveux, Mathias Ehrich, Dirk van den Boom, et al. 2011. "DNA sequencing of maternal plasma to detect Down syndrome: An international clinical validation study." *Genet Med* 13 (11):913-20.

Parens, Erik, and Adrienne Asch. 2003. "Disability rights critique of prenatal genetic testing: Reflections and recommendations." *Mental Retardation and Developmental Disabilities Research Reviews* 9 (1):40-7. doi: doi:10.1002/mrdd.10056.

Pellegrino, Edmund D. 1999. "The Goals and Ends of Medicine: How Are They to be Defined?" In *The Goals of Medicine: The Forgotten Issue in Health Care Reform*, edited by Mark J Hanson and Daniel Callahan, 55-68. Washington, D.C.: Georgetown University Press.

Phillips, Sally, and Clare Richards. 2016. "A World Without Down’s Syndrome." In. London: BBC two.

Ralston, Johanna, Hannah Brinsden, Kent Buse, Vanessa Candeias, Ian Caterson, Trevor Hassell, Shiriki Kumanyika, et al. 2018. "Time for a new obesity narrative." *The Lancet* 392 (10156):1384-6. doi: 10.1016/S0140-6736(18)32537-6.

Rothblum, Esther D. 2012. "Why a Journal on Fat Studies?" *Fat Studies* 1 (1):3-5. doi: 10.1080/21604851.2012.633469.

Sandel, Michael J. 2009. *The case against perfection*. Cambridge, Mass.: Harvard University Press.

Savulescu, Julian. 2001. "Procreative Beneficence: Why We Should Select the Best Children." *Bioethics* 15 (5-6):413-26. doi: 10.1111/1467-8519.00251.

Shakespeare, Tom. 1998. "Choices and Rights: Eugenics, genetics and disability equality." *Disability & Society* 13 (5):665-81. doi: 10.1080/09687599826452.

———. 2014. *Disability Rights and Wrongs*. Second ed. Oxon and New York: Routledge.

Sharp, Keith, and Sarah Earle. 2002. "Feminism, Abortion and Disability: Irreconcilable differences?" *Disability & Society* 17 (2):137-45. doi: 10.1080/09687590120122297.

Sparrow, Robert. 2005. "Defending Deaf Culture: The Case of Cochlear Implants." *The Journal of Political Philosophy* 13 (2):135-52.

Þorbergsdóttir, Thelma. 2012. "Kristófer Karl." In *Gleðigjafar [Those who bring joy]*, edited by Thelma Þorbergsdóttir and Sigrún Ósk Kristjánsdóttir, 271. Reykjavík: Bókafélagið.

Tolstoy, Leo. 2004. "The Death of Ivan Ilyich." In *The Death of Ivan Ilyich and Other Stories*, edited by Tim Cook, 77-130. London: Wordsworth Classics. (Original work published 1886).

Winch, Peter. 1987. *Trying to Make Sense.* Oxford: Basil Blackwell Ltd.