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# **AUTONOMY AND DECISION- MAKING CAPACITY**

**Studies on the Ethics of Self-Determination in  
Healthcare**

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**Karolinska  
Institutet**

Stockholm 2013

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Published by Karolinska Institutet. Printed by Åtta.45 Tryckeri AB.

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ISBN 978-91-7549-435-7

## **ABSTRACT**

The thesis discusses the concepts of autonomy and decision-making capacity and their normative relevance in healthcare. It is based on five studies.

The first study discusses autonomy and the ethics of compulsory treatment in psychiatry. Different lines of reasoning regarding the justification of compulsory treatment are discussed. It is argued that autonomous healthcare refusals should be respected in psychiatry, just as in physical care. When a patient refuses care but is unable to make an autonomous treatment decision, treatment should be given if this is in the patient's presumed best interests. It is argued that non-competent persons may also have reasons, rooted in deeply set and authentic values, that should be taken into account when making treatment decisions. However, the concept of authenticity is problematic and its normative relevance is further discussed in the following studies. The second study discusses the normative implications of conceiving of autonomy as a value to promote or protect in healthcare, focusing on situations where promotion of autonomy clashes with respect for patients' choices. It is argued that if autonomy is valuable, then paternalism for the sake of autonomy can be justified in principle. However, on a policy level autonomy is best promoted by respect for autonomous decisions, as policies allowing for paternalism for the sake of autonomy may become self-defeating. The third study discusses the implications of conceiving of autonomy as a value in end-of-life care. Respect for autonomy is typically considered a key reason for the legalisation of euthanasia and physician-assisted suicide. However, in recent bioethical debate it has been argued that if autonomy is valuable, these practices should not be accepted. The underlying rationale is that euthanasia and assisted suicide are detrimental to autonomy. The article discusses the argument from the point of view of different ideas of autonomy's value and maintains that the argument is untenable. The fourth study discusses the concept of authenticity, understood as the autonomy of personal preferences, focusing on the question of whether lack of authenticity in certain cases may justify overriding a patient's treatment refusal. The paper discusses different notions of authenticity that have been proposed in bioethical debate and concludes that none of them seems to be both a reasonable account of authenticity and provide action-guidance in healthcare. The fifth study is an interview study with Swedish psychiatrists on ethical issues relating to decision-making capacity in psychiatric care. Different ideas and notions of decision-making capacity were raised in the interviews, but there was no consensus on the concept. Decision-making capacity was rarely brought up directly as relevant to decisions about compulsory psychiatric treatment. In line with Swedish law, such decisions were primarily swayed by the patients' perceived need of care and risk of self-harm. Ethical deliberations typically focused on consequences related to treatment outcomes and maintaining patients' trust in psychiatry in the long term.

## LIST OF PUBLICATIONS

This thesis is based on the following papers, which will be referred to by their Roman numerals:

- I. **Coercive treatment and autonomy in psychiatry.** Sjöstrand M, Helgesson G. *Bioethics* 2008;22:113–120.
- II. **Paternalism in the name of autonomy.** Sjöstrand M, Eriksson S, Juth N, Helgesson G. *Journal of Medicine and Philosophy* 2013;38:710-24.
- III. **Autonomy-based arguments against physician-assisted suicide and euthanasia: a critique.** Sjöstrand M, Helgesson G, Eriksson S, Juth N. *Medicine, Health Care and Philosophy* 2013;16:225-230.
- IV. **Authenticity and psychiatric disorder: does autonomy of personal preferences matter?** Sjöstrand M, Juth N. *Medicine, Healthcare and Philosophy*. 2013 Sep 26. [Epub ahead of print]
- V. **The normative (ir)relevance of decision-making capacity: interviews with Swedish psychiatrists.** Sjöstrand M, Karlsson P, Helgesson G, Eriksson S, Juth N. *Manuscript*.

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# 1 BACKGROUND

## 1.1 INTRODUCTION

This thesis is intended as a contribution to the field of medical ethics. It is based on five studies that investigate the concepts of autonomy and decision-making capacity and their normative relevance in healthcare. The main focus is on psychiatry and, to a lesser extent, on end-of-life care. The first four papers are normative philosophical papers and discuss implications of different views of the value of autonomy, focusing on the relevance of autonomy to the issue of whether, and if so when, it may be justifiable to override patients' healthcare decisions. The fifth study is an empirical study of psychiatrists' perceptions of the concept of decision-making capacity and its relevance in healthcare.

In the following I will present the subject of medical ethics and the methods used in the thesis. I will also give a brief outline of the central concepts as well as a brief historical overview of the role of patient autonomy in medical ethics. After that I will present and discuss the papers included.

## 1.2 MEDICAL ETHICS

Medical ethics is an interdisciplinary subject that critically, analytically, empirically and historically examines ethical issues in healthcare and biomedical research (Lynöe & Juth 2009, p. 235).<sup>1</sup> Sometimes the label 'bioethics' is used for a slightly broader field of studies that also includes the ethics of the biological sciences and animal ethics. I will use the two terms interchangeably through the thesis. Philosophical medical ethics is a branch of applied ethics – the philosophical area where concrete and particular ethical problems are discussed. The aim is typically to discuss and find solutions to normative problems, problems about what to do in, or how to regulate, a certain situation in healthcare. Empirical medical ethics, on the other hand, investigates empirical issues relating to biomedical ethics. It does not primarily engage in normative or conceptual reasoning but tries to describe the empirical context regarding ethical issues. In this, it may be seen as a branch of medical sociology or psychology. Yet, to be empirical ethics it should be explicit about the connection between the empirical material and the ethical issues to which it is relevant. The present thesis includes four normative studies and one empirical study, an interview study using a qualitative approach.

### 1.2.1 Normative theories

Normative theories aim to give answers to questions concerning general ethical issues, such as what makes actions right or wrong, or what is valuable or desirable. Applied ethics and normative theoretical ethics are closely intertwined. Normative theories are used to justify particular moral standpoints but individual cases are also

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<sup>1</sup> Ethics discusses issues such as which actions are right, what we ought to strive for and what is (finally) valuable. Ethics, or moral philosophy, also includes conceptual issues about the meaning of the terms used in ethical reasoning (Blackburn 1996, p. 126).

used to test and evaluate more general theories and principles. I will return to this shortly.

One way of distinguishing between different normative theories is to distinguish between *consequentialist* and *deontological* moral theories. Very briefly, consequentialist theories say that the moral status of an action is entirely determined by the value of its consequences (Kagan 1998, pp. 60-61). This means that consequentialist theories need to identify what is valuable or good as an end, what is of *final* or *intrinsic* value.<sup>2</sup> To say that something is a (positive) value amounts to claiming that we have a reason to promote it. Instrumental value concerns things or features that are merely valuable as a means to an end, whereas final value refers to things that are valuable as ends in themselves. We do not have reason to promote what is of instrumental value unless it leads to what is of final value. Classic utilitarianism, the most well-known consequentialist theory, holds that pleasure or happiness is the only thing that is valuable. Moreover, it says that happiness should be maximised. Thus, according to utilitarianism, an action is right if and only if there is no other action with better outcome in terms of total happiness (Kagan 1998, pp. 61-61).<sup>3</sup> Other consequentialist theories might recognise other values such as satisfaction of individual preferences or desires, knowledge, friendship, or aesthetic beauty (Kagan 1998, pp. 59-68; Moore 1903).

Deontological theories depart from consequentialism in that they reject the assumption that the outcome of an action is the *only* thing that matter. Shelly Kagan (1998, pp. 72-73) defines deontological theories as theories that recognise moral constraints. To give an example: utilitarianism holds that no specific act, or kind of act, can be ruled out as wrong if it leads to the best overall outcomes. Thus, actions that common morality would consider horrible (such as torture, killings of innocent persons, or slavery) may be justified if they produce good enough consequences on the whole. Deontological theories on the other hand hold that there are indeed certain actions that are wrong no matter the consequences brought about by the action. Thus, there are constraints on what we are allowed to do in order to achieve what is good.

Deontological, or non-consequentialist, theories may recognise several different ways to take value into account in decision-making. They may recognise that what is valuable should be promoted (for instance happiness), however they would reject that this is the only thing relevant for determining whether or not an action is right. Typically, constraints are formulated in terms of rights or duties. Rights concern obligations to others, to say that I have a right to something means that other people have an obligation to act in certain ways so that my right is respected. A distinction is

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<sup>2</sup> Sometimes a distinction is made between final value and intrinsic value. Korsgaard sees 'intrinsic value' as the value that something has in itself, non-dependent on its relations to other things, final value concerns the value something has for its own sake and not as a means to other things valuable (Korsgaard 1983). The distinction is not important for the purposes of this thesis. I will use the concepts 'intrinsic value', 'value in itself', and 'valuable in its own right' in a corresponding notion to 'final value' – a value that always has normative force (Juth 2005, p. 176; Tännsjö 1998, p. 119).



often made between *positive* and *negative* rights. Roughly speaking, negative rights concern duties on the part of others to refrain from interfering with the right-holder, whereas positive rights concern duties on the part of other people to do or provide things for the right-holder. Duties are moral obligations towards ourselves or others. One distinction between rights and duties can be made in that rights may be waived by the right-holder. This means that I can justifiably choose not to exercise or claim my rights in a certain situation. However, I cannot in the same way choose to relieve myself of my duties.

W D Ross's (1930) theory of basic *prima facie* principles is a prominent deontological theory in current ethics. Ross argues that we have a set of basic duties and obligations towards each other: obligations to promote what is good, not to harm others, to repair or compensate harms or damage we have caused others, keep promises and to improve our character. Each principle is *prima facie*, meaning that it must be fulfilled or respected unless it conflicts with equal or stronger obligations. Ross's theory has inspired the most influential textbook on medical ethics, Tom Beauchamp's and James Childress's *Principles of Biomedical Ethics* (1979, 2009). Beauchamp and Childress present the four principles: respect for autonomy, non-maleficence, beneficence and justice, to guide the ethics of healthcare and the biomedical sciences. According to Beauchamp and Childress (2009, p. 15), ethical deliberation consists in recognising the relevant principles and determining the greatest balance of right over wrong. Another influential duty-based approach that will be discussed in the thesis is Kantian ethics. According to the Kantian approach, an action's rightness depends on whether it conforms to universalisable (descriptions of) acts (Johnson 2013, Kant 1785).

Although there are important differences between consequentialist and non-consequentialist approaches, this is not always apparent when the theories are applied to everyday decision-making. For instance, deontological theories also typically recognise some obligation to promote what is good, whereas consequentialist theories typically recognise the need for certain rules (or rules of thumb) in order to address everyday moral issues efficiently (Hare 1981). The rationale here is that it is very difficult to predict and calculate outcomes of individual actions. In order to function as a society, we need certain rules which enable us to predict how others will behave (for instance, we need to trust that people will keep promises etc.) and we need predictable legal institutions. As utilitarians in the tradition of John Stuart Mill (1859) would argue, the recognition of a set of basic legal rights (such as a right to life) will promote overall utility (for instance in terms of happiness) in a society. This means that consequentialist approaches to applied ethics typically discuss cases and outcomes in relation to general rules and policies (which may include personal and professional duties and legal rights).

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3 Classic utilitarianism is a universalistic theory: it holds that the total amount of happiness is what counts. One could, however, also imagine consequentialist theories with a more narrow scope.

Before going into more details regarding methodology I will make some remarks on metaethics. Metaethics is the field that investigates the concepts and methods used in normative reasoning. This includes issues such as whether there is moral truth, what moral terms mean, and whether it is possible to justify normative standpoints (Lynöe & Juth 2009, pp. 241-242). Although I will remain uncommitted to metaethical positions on issues like truth and semantics, there is one position that seems almost impossible to avoid committing oneself to in the context of applied ethics. Writing a thesis on applied normative ethics seems pretty pointless without acknowledging that moral standpoints can be more or less well founded.<sup>4</sup> In short: I believe that it is possible to argue rationally in ethics. How is this then done?

### **1.2.2 Normative intuitions: justification and reasoning**

Ethical problems trigger moral intuitions, pre-theoretical opinions concerning right or wrong that involve emotions as well as beliefs.<sup>5</sup> We may for instance believe that lying or stealing is wrong, that we should not harm other people, that we should be faithful to our partners, and that we should assist people in need. Moral intuitions can involve a strong emotional component. Behaviour that violates our moral beliefs triggers indignation and behaviour that goes beyond the demands of everyday morality excite admiration. Moral intuitions are also the starting point for most ethical reasoning in everyday healthcare. We have intuitions about doing what is good for our patients, intuitions about justice, about rights, and about truth-telling. However, our moral intuitions are often imprecise and many situations raise different, sometimes conflicting, moral intuitions. Moreover, our intuitions may reflect bias, self-interest or even prejudice. Thus, moral intuitions need scrutiny.

Moral standpoints can be criticised from the point of view of logical coherence. This means for instance that it cannot be true that an action is both right and wrong at the same time. Similarly, general normative standpoints such as “it is always wrong to lie” have implications for the evaluation of particular cases of lying. Thus, a minimal requirement for an ethical argument is that it be logically coherent – it must not rely on or lead to logical inconsistencies. However, logical coherence is in itself insufficient for justifying moral positions.<sup>6</sup> Thus, we also need to test the reasonableness of moral standpoints.

Reflective equilibrium, the predominant method for reasoning and justification in normative ethics, uses scrutinised moral intuitions, i.e. considered moral judgments, as an important part of justification of moral judgments (Daniels 2011).<sup>7</sup> As a standard for justification in ethics, it says that a moral judgment is justified when it is

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4 This position seems possible to take without committing oneself to the belief that moral standpoints can be true, as justification and truth are different concepts. I may have well-founded beliefs that may not be true and I may believe things that are in fact true, without having any good reasons for holding these beliefs.

5 Walter Sinnott-Armstrong (2008) defines moral intuitions as strong immediate moral beliefs.

6 It seems possible, for instance, to imagine someone who is coherently evil.

7 This is widely, but far from uniformly, agreed upon. Peter Singer (2005), for instance, has criticised the idea that a reflective equilibrium has justificatory force in normative ethics.

part of a set of beliefs where the different judgments, particular as well as general, support and explain each other (Juth 2005, p. 12). As a method for ethical reasoning, it uses considered judgments to evaluate or test general normative principles, and general principles are used to evaluate particular considered judgments. If, for example, we believe that lying is wrong but are in a situation where telling a lie is necessary in order to save another person from imminent danger, we might feel that lying in this particular case is in fact justified. If so, we may need to revise our general position to something like “lying is mostly wrong, but may be permitted in order to save innocent people from harm”. Other cases or theoretical assumptions may cause us to revise the position further.<sup>8</sup> Thus, we go back and forth between particular cases and general principles in order to find a coherent system of beliefs, a reflective equilibrium. It is important to note that the idea of a reflective equilibrium rejects the notion of stable substantive foundational fix points or self-evident ethical truths (Daniels 2011). When there is a conflict between different moral judgments, e.g. between general principles and intuitions concerning particular cases, the conflict can be resolved either by revising the general belief or by rejecting the judgment concerning the particular case. The solution then needs to be tested on other cases and with other principles. The best solution must be determined by considerations within the system. In this way, the method of reflective equilibrium may be described as a process where one’s ethical standpoints need to be constantly open for revisions and calibrations.

### **1.2.3 Empirical and normative medical ethics**

Ethical reasoning needs normative as well as empirical premises. The first step in any ethical discussion is to try to get the empirical facts right. First, facts are needed in order to establish a correct description of the situation; we need to answer “the ‘reality-revealing questions’ of what, why, how, who, where and when” (Borry, Schotsmans and Dierickx 2004). For instance: is doctor A’s information to patient B an intentional lie, or has A only drawn the wrong conclusion from the examinations and the laboratory tests? Many concepts used in ethical reasoning also include empirical as well as normative components.<sup>9</sup>

Second, assumptions about consequences are often used to motivate certain courses of action: whether or not the doctor should perform an operation or prescribe a drug depends to a great extent on the outcome of the different alternatives at hand. For a consequentialist theory, this is of course crucial. Predictions about consequences are moreover often used in cost-benefit analyses for healthcare prioritisations, etc. Some important arguments in medical ethics may rest more or less solely on assumptions about consequences. For instance, it has been argued that euthanasia should not be legal since this would erode trust in the healthcare system. This argument seems to rest on two premises: (1) that we should not do something that will undermine trust in the healthcare system, and (2) legalising euthanasia would lead to such erosion of

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<sup>8</sup> This may include real life cases as well as so-called thought experiments, cases constructed to test a certain theory or principle against our intuitions (see pp. 30-34).

<sup>9</sup> In this, they are so-called ‘thick terms’ (Blackburn 1996, p. 376).

trust. If we agree with the first normative premise we also need to test the second premise to see whether the argument is sound (Lindblad 2013).

Third, we also need empirical research to understand the actual ethical problems healthcare personnel, researchers and patients face. In order for ethics to be able to give action-guidance we need to understand how staff and patients' perceive situations, how they make decisions, and what their preferences and needs are.

The above three points are not meant as an exhaustive description of all cases when empirical facts are needed for ethical analysis.<sup>10</sup> However, I think these are the most important examples for the present thesis and they show that empirical questions are highly relevant to bioethical discussions.

#### **1.2.4 Qualitative empirical research in medical ethics**

Empirical research methodologies in medical ethics can be broadly categorised into either qualitative or quantitative. Quantitative research focuses on the use of standardised methods to collect information, which is then transformed into numbers to enable statistical analysis. In medical ethics, this is typically done through questionnaires (Lindblad 2013, pp. 34-35). The aim of qualitative research is typically to study complex behaviours, ways of reasoning, personal experiences, or attitudes, that are not easily quantifiable in this way (Pope & Mays 1995). Study V in the present thesis aims at such an investigation of psychiatrists' experiences and reasoning concerning ethical issues related to the concept of decision-making capacity and its normative relevance for psychiatry.

There are a number of approaches to gather qualitative data, but the most well-known approach is probably the research interview, which also is the method used in study V. In general, research interviews can be described as structured, semi-structured, or in-depth (sometimes also referred to as unstructured interviews) (Meadows 2003). In structured interviews questions should be asked in a standardised way in a pre-determined order, without qualifying questions or follow-up questions. The data obtained from structured interviews are typically also amenable to quantitative analysis. Semi-structured interviews are less structured and may use open-ended questions for the respondent to answer in his or her own words. The interviewer may ask follow-up questions, and the order of questions is flexible. In-depth interviews are the least structured form of research interviews. The questions are open-ended and intended to encourage respondents to provide detailed responses in their own words. Rather than a strict interview guide with pre-determined questions, the interview is facilitated through a list of (limited) topics or themes to be explored. The interviewer can phrase different questions to make the conversations as fruitful as possible. If new

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<sup>10</sup> A recent field of research uses empirical results to undermine or debunk normative standpoints. For instance, empirical findings in neuroscience and social psychology have been used to argue that common moral intuitions merely reflect emotional responses that have been selected by evolution; the reason we have them would then be that they have been useful for the survival and procreation of our ancestors, not that they reflect an independent moral truth (Greene 2003).

topics emerge during the interview, the interviewer may well decide to explore them (Meadows 2003).

Both semi-structured and in-depth interviews rely on flexible interview guides and allow follow-up questions, discussions and clarifications during the interview. Rather than different kinds, they could be described as representing different degrees of flexibility. For instance, the study carried out in the present project uses a semi-structured manual, but the actual interviews may more correctly be described as in-depth interviews, due to the amount of follow-up questions and discussions that emerged during the interviews.

There are a number of different theoretical approaches for analysis of qualitative data. Study V relies on what may be labelled as descriptive content analysis, where the analysis aims to stay close to the manifest descriptions of words and events found in the material (Sandelowski 2000). The material collected during the research process is first reduced to units of meaning and then re-organised into categories and themes. The categories can be pre-determined or constructed during the analysis, the first approach is sometimes referred to as deductive and the latter as inductive.<sup>11</sup> Elo and Kyngäs (2008), write that in inductive analysis the concepts are derived from the data, whereas deductive analysis means the analysis is operationalised on the basis of previous knowledge. It has, however, been argued that there is no theoretical rationale for making such a sharp distinction between these approaches (Malterud 2001). A theoretical framework is needed both in order to formulate research questions and for fruitful analysis of the data. Thus, different interpretations and categorisations of the material may be seen as hypotheses that are tested against the data throughout the research process. This means that there is a basic similarity between this approach and the reasoning process of the reflective equilibrium where ethical theories and intuitions are tested against each other.<sup>12</sup>

### **1.3 THE CONCEPT OF AUTONOMY**

The thesis will mainly discuss normative issues related to respect for patient autonomy in healthcare. In order to discuss this we need first to have some basic conceptual understanding of the term autonomy. In medical ethics the term autonomy is used both as a descriptive and as a normative concept that could refer to persons, actions, decisions or lives. I take as a starting point the basic idea that autonomy is concerned with self-determination or self-governance. I will not attempt any definition of autonomy in terms of necessary and sufficient conditions, and neither here nor in any of the papers will I try to pin down what autonomy 'really is'.<sup>13</sup> In line with Gerald Dworkin (1988, pp. 7-9), I assume that there are some basic

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11 I find these labels a bit disturbing, since all empirical research is inductive in the sense that true premises may nevertheless lead to wrong conclusions (Blackburn 1996, p. 192).

12 It may be argued that philosophical normative inquiry and empirical research (qualitative as well as quantitative) all share a similar basic approach for reasoning (Føllesdal, Wallö & Elster 2001).

13 For a fruitful ethical discussion it is often better to focus on questions such as what is valuable and what ought to be done (Juth 2005, p. 123).

desiderata regarding what an account of autonomy should entail. Most importantly, the account should be useful for normative discussions. As a minimum this means that it must be logically consistent, empirically possible, and - in this context - compatible with different views of its normative relevance that are commonly employed in bioethical discourse. I will draw on standard conceptions of autonomy in contemporary debate in order to give a characterisation of the concept that is useful for the normative discussion that will follow.

I will distinguish between autonomous wants (preferences or desires), autonomous decisions, and autonomous actions. The outline of the concept of autonomy follows Niklas Juth's (2005) account used in his *Genetic Information Values and Rights*. In line with Juth, I will assume that in order for an act to be autonomous there has to be a causal relation between desires, decisions and actions, so that the decision is caused by the desire and the action is caused by the decision (Juth 2005, p. 126). I will discuss the autonomy of desires in terms of 'authenticity'; the autonomy of decisions in terms of 'competence', and the autonomy of acts in terms of 'efficiency' (Juth 2005, chapter III). These components are all matters of degree, a person may thus be more or less autonomous with regard to one or more of the three components. However, there might be a certain threshold level of these abilities that is of normative relevance, I will return to this when discussing the normative relevance of autonomy.

### **1.3.1 Authenticity**

As noted previously, autonomy is concerned with self-governance, leading a life in accordance with one's own will and decisions. From the point of view of my autonomy it may be argued that the wants or desires that I act upon should be in a substantial sense *my own*. I will refer to such wants (including preferences and desires) as *authentic*. The concept of authenticity has, however, proved difficult to pin down in more detail, and several theories have been proposed. It is sometimes supposed that desires are autonomous or authentic depending on their cause (Elster 1983). Examples of desires or preferences that typically are considered as *inauthentic* in this sense are desires originating from causes such as manipulation, oppression, or brainwashing. However, our desires are in many important aspects caused by factors outside our control, factors such as social background, upbringing, cultural ideals and our biology. This, in itself cannot be seen as undermining autonomy – otherwise autonomy would be unattainable. What we need is a theory that explains why certain causes of desires are incompatible with autonomy. The issue is discussed at greater length in paper IV. Here I will briefly present two further suggestions as to what this can mean.

One influential idea is that authenticity consists in consistency between levels of desires. Thus, we have first-order desires – what we want – and we (may) also have second-order desires: what we want to want.<sup>14</sup> A person can have a desire for a drink,

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<sup>14</sup> It is of course also possible to have desires of a third, fourth, fifth order – and so on.

but at the same time, for a variety of reasons, desire not to have this desire. Acting on the first-order desire would then be non-autonomous, since this want is in conflict with higher-order wants. This is Harry Frankfurt's idea of freedom of the will (Frankfurt 1971), which Dworkin (1988) uses as a general conception of personal autonomy. However, the idea has some significant problems. Most importantly, there seem to be no good arguments regarding why we should accept that higher-level desires are more autonomous than lower-level ones. Imagine, for instance, the case of a homosexual man who lives in a bigoted religious environment where homosexuality is condemned and thus tries to repress his first-order sexual desire for men (Juth 2005, pp. 137-138). In such a case I think many would find it hard to accept that the second-order desire to repress his homosexuality should be seen as more authentic or autonomous *per se* than the first-order desire. Rather the case seems to illustrate that higher-order desires may be just as inauthentic as first-order ones.

One idea that has gained traction in recent debate says that authentic desires are the desires that a person approves of, or would approve of, if they had full knowledge of why they had the desire in question (Juth 2005, p. 142). John Christman (2009, p. 145) argues similarly that a person is autonomous relative to a characteristic if, were they to reflect on it in the light of the history of the factor's development, they would not feel deeply alienated from the characteristic.<sup>15</sup> The idea shares assumptions with the two previous mentioned suggestions. First, it agrees with the idea that the history of how we have come to have our desires is important. Second, it agrees with the idea that our attitudes towards our desires are of central importance. This links the account more closely to the idea of autonomy as self-governance and therefore, in my view, provides a more theoretically appealing account of authenticity for the concept of personal autonomy.

However, little in the argument of the thesis hinges on accepting this or indeed any particular idea of authenticity. Rather, implications of different ideas of authenticity are tried out and though some ideas are discarded as unreasonable (see paper IV), no particular view on authenticity is defended in this thesis.

### **1.3.2 Competence**

In this context competence (decision-making competence or decision-making capacity) refers to the ability to make decisions from one's goals or desires, which includes having the necessary cognitive abilities for means-end deliberation (Juth 2005, p. 152). In order to be competent in this regard, people must be able to understand information and to see and understand different outcomes of their decisions. Moreover they must be able to make an estimation of how likely the different outcomes are and how desirable they are. Finally people must be able to use these insights in order to come to a decision. It may also be added that a competent person must see themselves as an agent responsible for their own actions and decisions (and not just as an instrument in the hands of some external 'powers'), as

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<sup>15</sup> See also David DeGrazia (2005).

well as be able to revise and modify their beliefs in the light of new arguments or information (Tännsjö 1999, pp. 11-12).

Competence (decision-making competence or decision-making capacity) is also used as a normative or a legal concept that serves to determine, for instance, whether or not a patient has certain rights. As such it will be presented in relation to the discussion of the normative relevance of autonomy.

### **1.3.3 Efficiency**

In order to *act* autonomously a person must also be able to bring about what he or she decides to do (Juth 2005, pp. 156-160). This means that in order to be autonomous, people need access to relevant information as how to achieve what they want.

Moreover, they must have the available means to carry out their decisions, including both internal and external factors. For instance, a quadriplegic person may have authentic desires and be able to make competent decisions; however, they will be unable to act on certain decisions. Another example would be a person with weakness of will who would fail to carry out what he or she has decided and therefore fails to act autonomously.

The extent to which we are able to realise our decisions partly hinges on factors beyond our control. Some writers would see external factors that prevent persons' from acting, such as physical restraints, as infringements of freedom rather than of autonomy (Christman 2011). However, as the concept will be used in the thesis, a person's autonomy may be affected by both internal and external factors (Juth 2005, p. 128).<sup>16</sup>

### **1.3.4 Relational autonomy**

The predominant conception of autonomy in bioethics relies on certain procedural rather than substantial criteria. Thus, whether or not a person is autonomous depends not on the actual decisions or actions taken or on the external circumstances, but on the underlying processes for desire formation, decision-making, and action. This idea of autonomy has been criticised by ethicists who have argued that external factors, related to personal relations and interdependence are necessary for our autonomy. The core of the critique is that the standard conception of autonomy is too individualistic and fails to acknowledge the essentiality of human relations to our self-conception.

Catriona Mackenzie and Natalie Stoljar (2000, p. 8) write that the concept of 'relational autonomy' refers to views of autonomy that share the assumption that agents' identities are formed within the context of social relationships and shaped by a complex of intersecting social determinants, such as class, gender, and ethnicity. This empirical fact seems quite compatible with the account of autonomy presented earlier. However, many critics go further than just pointing out the relevance of

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<sup>16</sup> Perhaps needless to say, regardless of the conceptual issue, it is an open question whether there is a *normative* difference between different kinds of restrictions of autonomy.



interpersonal relations to individual development. It has been argued that certain external factors, such as relationships, are *conceptually necessary* for autonomy or that certain kinds of relationships are inherently detrimental to autonomy.

One example of this reasoning has been put forth by Mariana Oshana (1998). Oshana criticises what she sees as purely ‘internalist’ accounts of autonomy that only discuss psychological features of a person. She argues that internalist accounts fail to correctly address situations where persons accept conditions that deny them dignity and self-determination. Oshana argues that in certain situations people cannot be considered as autonomous if they live in oppressive structures that seriously limit their options. In order to be autonomous, people must not only have certain psychological qualities, but also be free from certain restrictions and have access to a range of relevant options. Thus, Oshana argues, in order to be autonomous, personal choices must not be dictated by things as economic, emotional and bodily needs. Moreover, autonomy requires social safety so that people are able to defend themselves against physical and psychological assault in order to be autonomous. This critique is discussed by Christman (2009, ch. 8). As argued by Christman, it seems obvious that oppressive structures have an adverse effect on the development of personal autonomy. However, this is not the same thing as to say that a person cannot, by definition, live autonomously within such structures. Moreover, having a certain set of viable options may be important for personal autonomy, if the choices are necessary in order to fulfil one’s plans and goals. From the point of view of self-determination, the reason why those options are important must be related to a person’s own perspective and judgment. It seems an unnecessarily strict view of self-governance that rules out certain goals, commitments and relationships *as such* as being non-autonomous. Rather than a conception of self-governance, the concept presented by Oshana may better be seen as an ideal about what constitutes a good life.

One problem about Oshana’s account in the context of healthcare is that it seems to declare as non-autonomous many people whom we would usually consider autonomous. Many patients are in a vulnerable position, regarding physical as well as social aspects, nonetheless, we would presume most of them autonomous enough to have the right to decide which health care interventions to accept and not accept.

#### **1.4 THE NORMATIVE RELEVANCE OF AUTONOMY**

The notion of valuable autonomy can be given several different interpretations. As noted previously, different ethical theories have different answers to the question of how values should be taken into account in decision-making. Consequentialist theories argue that we have an obligation to bring about valuable state of affairs, thus what is valuable should be promoted. Deontological theories may argue that values may imply certain constraints that are unrelated to the overall consequences of our actions. This also applies to the idea of autonomy as a value. In the following I will make a distinction between three main ideas of autonomy’s normative relevance in healthcare: a) autonomy as a right, b) autonomy as a positive value, and c) autonomy as a personal duty.

### **1.4.1 A right to have one's autonomy respected**

The idea of autonomy as basis for a right to self-determination is probably the most influential view of autonomy's relevance in contemporary bioethics (Beauchamp & Childress 2009). A negative right to have my autonomy respected means that other people have an obligation not to restrict my autonomy. This can be understood in terms of a right to a certain personal sphere of decision-making, a sphere in which other people have an obligation not to interfere (Wilson 2007; Mill 1859). My right to have my autonomy respected does not include a right to violate other persons' rights. This means that if I act in certain ways so that other people's rights are violated I can justifiably be stopped from doing so. One question that needs to be addressed for a theory that holds autonomy as a right in this sense is just how wide the sphere of personal decision-making should be. It is obvious that many actions I perform and decisions I make have an impact on other people. This is also important in health care, where issues about my health and life may have enormous impact on the persons close to me. Even though most health care decisions typically are regarded as coming within this sphere, there are a number of instances where this may be questioned. One such instance is treatment of contagious diseases; another is treatment of mental disorders giving rise to violent behaviour.

A positive right to autonomy may entail obligations for health care personnel to involve patients in decision-making, to provide information and make certain choices available (Beauchamp & Childress 2009, p. 104). It may also include duties to strengthen the autonomy of less than fully autonomous individuals (The British Medical Association 2004, p. 107; 2012 p. 107). The idea is in these aspects equivalent to the idea of autonomy as a positive value. That is, autonomy is something we ought to (or have reason to) promote (Juth 2005, p. 198).

The right to have one's autonomy respected may be held as absolute or *prima facie*. As noted earlier, an absolute right can never justifiably be overridden, whereas a *prima-facie* right may be trumped by other concerns. It is also important to note that a legal right to have one's autonomy respected could also be motivated on a consequentialist ground. A hedonistic utilitarian, for instance, may argue that a right to have one's autonomy respected should be acknowledged in healthcare if this would lead to better outcomes in terms of total happiness than not acknowledging this right (Tännsjö 1999).

### **1.4.2 Autonomy as a positive value**

The idea that autonomy is a positive value has become more common in the bioethical debate. Innovations, such as new medical technologies and procedures, for instance in genetic counselling and reproductive health, have been prompted by concern for the promotion of personal autonomy (Juth 2005). As noted, it is also argued that healthcare staff should act so as to promote patients' autonomy so that they can be involved in decision-making (The British Medical Association 2004, p. 107). An underlying idea here seems to be that possession of autonomy is valuable, or

good, for us. The idea can be supported by considerations of autonomy as an instrumental value or as something of final value.

The idea that autonomy is a positive value is also prominent in political philosophy. Isaiah Berlin (1958, p. 131) writes about positive liberty as an ideal of self-realisation, to live a life according to one's own plans, values and goals.

I wish to be somebody, not nobody; a doer — deciding, not being decided for, self-directed and not acted upon by external nature or by other men as if I were a thing, or an animal, or a slave incapable of playing a human role, that is, of conceiving goals and policies of my own and realising them.

In line with the conception of autonomy outlined previously, an explication of the ideal would say that it is valuable to live in accordance with one's authentic desires, when these are realised through one's own decisions and actions.<sup>17</sup> According to this ideal of self-realisation, actually realising one's desires and goals is what is valuable. However, another possible ideal would say that *having* authentic desires and *being able* to realising them through one's actions and decisions is what is valuable. This ideal would instead concern autonomy as a *capacity*. The ideals can be combined, so that both being autonomous and actually exercising autonomy is what is valuable (Juth 2005, pp. 176-180; Lindley 1986, ch. 5). The normative difference between these two ideals is discussed to a greater extent in paper III. It is important to note that whether or not a person is successful in achieving autonomy (both in terms of self-realisation and in terms of being capable of autonomous acting) is dependent on external factors beyond that person's control. Illnesses, accidents or other person's actions may interfere with our capacities, plans, or goals.

The idea of autonomy as a positive value is also found in discussions of narrative identity. Narrative identity is a conception of personal identity, described as a mental autobiography, an inner story of our lives that includes plans, goals and anticipations of future events (DeGrazia 2005, pp. 80-82). The self-narrative is created by us as we lead our lives according to our goals and values. In this way, narrative identity is about self-realisation or self-creation. DeGrazia writes that autonomy and narrative identity are related in two ways. Self-creation concerns autonomous writing of a self-narrative, and acting autonomously means to act in line with the values and goals that we want to pursue in our narrative. Our self-narratives may be instrumentally valuable in that they guide us towards making decisions that benefit us. However, DeGrazia also argues that autonomy in this way is of intrinsic value (DeGrazia 2005, p. 81).

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<sup>17</sup> The ideal can be further specified in different ways. For instance, there is a difference between realising an absolute amount of authentic desires and a higher quota of desires (see Juth 2005, pp. 177-178).

### 1.4.3 Kantian ethics: autonomy as a duty

Beauchamp and Childress (2009, pp. 103-104) write that the principle of respect for autonomy has its roots in Immanuel Kant's ethics as well as in JS Mill's writings on liberty. However, the two approaches to the normative relevance of autonomy are quite different.<sup>18</sup> For Mill (1859), what is important is respect for the right to have one's actual decisions respected. According to Kant (1785), autonomy is about morality as such. Acting autonomously means acting in accordance with principles that can be universalised according to the *categorical imperative*.<sup>19</sup> Kant's conception ties morality to autonomy in that acting autonomously means acting morally right. This also means that autonomy concerns duties rather than rights.

In Kantian medical ethics respect for autonomy is typically seen as implied by the version of the categorical imperative which says that we must treat persons not merely as means to an end but also as ends in themselves (Kant 1785, pp. 46-47). Beauchamp and Childress (2009, p. 103) write that doing something to another person without that person's consent is to fail to respect that person's autonomy; it fails to respect them as ends in themselves. It is important to note that, for Kant, autonomy also means that we have duties towards ourselves (Johnson 2013, Kant 1785). For instance, Kant argued that it is immoral to end one's own life. Contemporary Kantian bioethicists have similarly argued that respect for autonomy is a reason against euthanasia and physician-assisted suicide. This line of reasoning is discussed in greater detail in paper III.

### 1.4.4 The principle of respect for autonomy

The most important formulation of the normative relevance of autonomy for contemporary bioethics comes from Beauchamp's and Childress's seminal *Principles of Biomedical Ethics* (2009), where respect for autonomy is held to be one of four *prima-facie* ethical principles.<sup>20</sup> They write that respect for an autonomous agent involves, at a minimum, acknowledging that person's right to hold views, to make choices and act according to their values and beliefs. This means both non-interference regarding personal decisions, but also obligations to support capacities for autonomous choice. Thus, respect for autonomy involves the negative obligation that autonomous actions should not be subjected to other people's constraints and positive obligations relating to information disclosure, promotion of autonomous decision-making, and (sometimes) to increasing the options available for patients (Beauchamp & Childress 2009, pp. 104-105). In this the principle seems to include both the notion of autonomy as a value to promote (or a positive right) and as a negative right. As noted, according to the principlist approach, not respecting a person's autonomy is *prima facie* wrong. However, there might be situations where the relevance of respect for autonomy is trumped by other concerns.

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18 The term 'autonomy' is not used by Mill (1859) but the term 'liberty' is used in a corresponding sense.

19 The categorical imperative is stated in different forms in Kant's writings, the most famous statement of the formula says "Act only in accordance with the maxim through which you can at the same time will that it become a universal law" (Kant 1785, p. 37).

20 Beauchamp and Childress argue that the principles are not hierarchical, however for instance Raanan Gillon (2003) has argued that respect for autonomy is more important than the other principles.

### 1.4.5 Autonomy and paternalism

The question of whether, and if so, when, paternalism is justifiable is one of the central issues discussed in medical ethics. Paternalism refers to decision-making on behalf of a person, without that person's informed consent, in order to protect them from harms or to promote their good. Typically it is defined as involving the intentional overriding of a person's actions, decisions or preferences for the sake of their beneficence (Dworkin 2010). In healthcare this might occur when healthcare staff withhold or manipulate information for patients, or when decisions are made in the presumed interest of the patients but without the patients' consent.

Often a distinction is made between paternalism directed against substantially non-autonomous patients or decisions, labelled as *soft* or *weak paternalism*, and paternalism directed against autonomous patients - typically labelled as *hard* or *strong paternalism* (Beauchamp & Childress 2001, pp. 181-182; Feinberg 1986, pp. 12-16). Soft paternalism is typically not seen as involving a real conflict between the beneficence (wellbeing) and autonomy. The controversial issue concerns strong (hard) paternalism (Beauchamp & Childress 2009, p. 210).<sup>21</sup>

The answer of whether paternalism can be justified depends on the normative status of autonomy. According to the idea that autonomy is an absolute right, (strong) paternalism cannot be justifiable. According to the principlism presented by Beauchamp and Childress, strong paternalism is justifiable in health care when beneficence or non-maleficence are more important than respect for autonomy. They offer the following conditions for this: (1) a patient is in danger of sustaining a significant, preventable harm, (2) the paternalistic action will probably prevent the harm, (3) the projected benefits to the patient of the paternalistic action outweigh its risks to the patient, and (4) the least autonomy-restrictive alternative that will secure the intended outcome is adopted (Beauchamp & Childress 2001, pp. 186-187).

For consequentialist theories, paternalistic acts are justified if they lead to the best consequences overall. However, paternalism may nevertheless be instrumentally problematic. If there is reason to believe that paternalistic principles and regulations in healthcare lead to worse outcomes than principles that respect patient autonomy, we should favour the latter. Thus, a consequentialist may argue that, even though paternalism does not matter in principle, it should be avoided as a matter of practice (Tännsjö 1999). If autonomy is seen as a final value in a consequentialist theory, we may have intrinsic reasons to respect autonomy in terms of promoting autonomy. As discussed in paper II, such a theory may allow strong paternalism for the sake of autonomy.

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<sup>21</sup> Sometimes it is argued that so-called soft paternalism should not really be labeled as paternalism at all (see Feinberg 1986, pp. 15-16).

#### **1.4.6 The normative concept of decision-making competence**

The term competence (or decision-making capacity) is often held as a normative concept for the purpose of deciding whether or not a person fulfils criteria for having certain autonomy-related rights, such as the right to have a specific healthcare decision respected. Buchanan and Brock (1986) write that the function of competence judgments is to sort patients into two categories: those whose decisions are morally and legally binding, and those for whom alternative methods of decision-making must be sought. Beauchamp and Childress (2009, p. 113) write that judgments about whether a person is competent to decide about treatment should be based on whether that person is able to choose autonomously in the particular circumstances. Thus, they write that patients are competent to make a decision if they have capacity to understand the material information, can make a judgment about it in light of their values, can intend a certain outcome and are able to communicate this to their caregivers. Although the basic abilities for competence are matters of degree, what is important for the purpose of healthcare is to determine a threshold to decide whether or not a person is competent enough to make a certain healthcare decision.

In their criteria of competence, some ethicists include aspects relating to efficiency, such as the ability to communicate one's decisions, or aspects related to authenticity. Regarding the latter, Buchanan and Brock (1986), for instance, write that competence entails a person having an idea of what is good that is consistent and, to some degree, stable over time. I will return to the normative concept of competence and the issue of authenticity in paper IV and the final discussion.

#### **1.4.7 Decision-making for non-competent patients**

One of the questions discussed in this thesis is what relevance (if any) autonomy has for patients who are unable to make autonomous decisions regarding certain aspects of their care. The issue is discussed in paper I and to a certain extent in paper II. I will also return to the issue in the final discussion of the thesis. Here I will briefly present the three main ideas concerning decision-making on behalf of non-autonomous or (non-competent) patients that recur in the bioethical discourse.

The idea that autonomy is valuable is reflected in the view that precedent autonomy should determine treatment decisions for non-competent patients. Beauchamp and Childress (2009, p. 137) refer to this idea as the 'pure autonomy standard'. The standard says that if a non-competent patient has stated his or her healthcare preferences while autonomous, these should be respected. One example of this would be advance directives ('living wills') which may be used to express refusals of life-sustaining treatment in circumstances such as permanent unconsciousness or advanced dementia (Buchanan and Brock 1986; Furberg 2012).

Ronald Dworkin (1993, pp. 220-230) is a famous proponent of the view that precedent autonomy matters. According to Dworkin persons may still have critical interests in life after a permanent loss of their abilities for autonomous decision-making, and advance directives can help to protect such interests. One problem with

advance directives is that it may be questioned whether the person who issued the directive in some instances is really the same person as the later non-competent person (Dresser 1995). The critique rests on the assumption that psychological continuity is necessary for personal identity and that this may be lacking in, for instance, cases of advanced dementia. If this is correct, autonomy, or self-governance, cannot be used as a reason to support adherence to advance directives in such cases. Respect for *my* autonomy in healthcare cannot give me authority to refuse treatment for *another* individual, or so it is typically argued.<sup>22</sup> It is important to note that the argument is only valid for cases where psychological continuity is lost, such as instances of severe dementia, total memory loss, or permanent unconsciousness. It would not be an argument against the use of advance directives in other situations of non-competency, possible instances being cases of less severe dementia or certain episodes of psychiatric disorders.

Another idea of how autonomy should be respected for non-competent persons is the so-called ‘substituted judgment standard’. The standard says that decisions for non-competent patients should be made according to the patient’s hypothetical autonomous decision – the decision the patient would have made, had they only been competent (Broström 2007, Buchanan & Brock 1986). However, the idea has some theoretical problems. Linus Broström (2007, pp. 29-30) argues that the substituted judgment standard is without justification as typically formulated. First, the standard is “underdetermined”, i.e. it does not describe the conditions for the hypothetical decision. For instance, it does not say how competent we should imagine the patient to be for the decision, nor are any other circumstances spelled out. A second problem that Broström points out is that the reasons typically put forth to respect competent patients’ actual choices (instrumental reasons for respect for autonomy as well as intrinsic reasons related to the value of autonomy) do not seem to imply respect for hypothetical choices. Beauchamp and Childress (2009, p. 137) argue that the standard is only valid for previously autonomous patients whose relevant previous preferences are known. This would make the substituted judgment indistinguishable from the autonomy standard described above. The important question is then not the hypothetical question of what the patient would have wanted, but what the patient *actually* wanted.

The third idea, the best-interest standard, says that the decision-maker should choose whatever has the best outcomes for the patient. The outcomes are typically understood in terms of wellbeing or health (Beauchamp & Childress 2009, pp. 138-139). However, also aspects to autonomy may be incorporated in the concept. The British Medical Association (2012, p. 107), for instance, writes that best interests involve more than just medical aspects and that a person’s known wishes and values also should be considered. Beauchamp and Childress (2009, p. 140) argue that

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22 Note that this criticism only concerns a specific argument for personal directives. There are other reasons for supporting such directives, e.g. utility-based reasons (Furberg 2012, ch. 6). Another important point is that Dresser’s view on personal identity is contested: many ethicists would rather

precedent autonomy should be the primary guide for decisions about non-autonomous patients. If there are no reliable traces of the patient's wishes, decision-makers should make decisions according to a best interest standard. A similar view of the importance of autonomy for non-competent patients is taken by Buchanan and Brock (1986).

#### **1.4.8 Autonomy and involuntary treatment in psychiatry**

As noted previously, in discussions of autonomy in bioethics, lack of autonomy or decision-making capacity is often held to be a necessary criterion for justifiably overriding patients' healthcare decisions. This is reflected in many regulations concerning physical care.<sup>23</sup> However, laws concerning compulsory treatment in psychiatry typically focus on the gravity of a person's mental disorder, his or her need for treatment, or potential danger to the patient themselves or to other persons (Wallsten 2008, p. 10; Testa & West 2010; The British Medical Association 2012, ch. 3). It has, however, been argued that lack of decision-making capacity should be a necessary criterion also for compulsory treatment in psychiatry, the underlying rationale being that treatment should not be imposed on autonomous persons and that patients in psychiatric care and physical care should be treated according to the same standards and principles (Doyal & Sheather 2005; Tännsjö 1999, pp. 5-6, 95). Recent debate on compulsory treatment in psychiatry has also focused on the use of advance directives (Henderson et al 2008; Swanson et al 2008). The reason for accepting such directives would be precisely the same in psychiatry as in physical care: autonomy is to be respected and decisions for non-autonomous patients should be made in line with their autonomously founded preferences. Thus it has been argued that advance directives could protect patients' authentic interests or help them to maintain their personal narrative and personal values during episodes with reduced capacity for decision-making (van Willigenburg & Delaere 2005; Widdershoven & Berghmans 2001).

### **1.5 PATIENT AUTONOMY: A BRIEF HISTORICAL OVERVIEW**

In the following sections I will give a brief overview of the normative status of respect for autonomy in the history of medical ethics. The historical roots of autonomy's role help us to understand why autonomy is held to be of such importance in contemporary bioethics. It is also important in order to understand some points of criticism that have been put forth in recent debate. The overview will present respect for autonomy in terms of disclosure of information and respect for patients' personal healthcare decisions in clinical medicine and research. It is not an attempt to give a philosophical historical overview of the concept of autonomy. The overview is limited to western medicine, since this is the context in where the concept has taken shape. The overview is based on secondary literature, primarily on the works of Ruth Faden and Tom Beauchamp (1986) and Albert Jonsen (2000).

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argue that physical continuity is what matters (see Johansson (2005) for an extensive discussion of this issue).

<sup>23</sup> See for instance the England and Wales Mental Capacity Act (The British Medical Association 2012, ch. 3).



When assessing the status of respect for autonomy in the history of medicine, it is important to bear in mind the historical circumstances in which physicians have practiced. Issues relating to truth-telling and manipulation have been discussed ever since the beginning of western medicine. Physicians may have been able to persuade, pressure or manipulate patients, but they have rarely been able to impose treatment upon patients who did not want it. The patients' support and acceptance of proposed treatments have been necessary in order to provide care and in order for the physicians to get paid for their services (Koch 2012, p. 227).

### **1.5.1 The Hippocratic tradition**

The writing that has been most influential through the history of clinical medical ethics is probably the Oath from the Hippocratic physicians in ancient Greece. The central values promoted in the Hippocratic writings are medical beneficence and non-maleficence. Physicians should act in the interests of their patients so that the patients' health is improved and refrain from interventions that would harm the patient. Regarding questions about disclosure of information and respect for patients' decisions, the Hippocratic writings are quite silent (O'Shea 2011). The physician is told to uphold confidentiality regarding personal information shared by the patient. But apart from this it rarely addresses issues related to communication. The Oath depicts an ideal of an authoritarian but benevolent physician. It cannot, however, be seen as representative of medical ethics in ancient Greece in general (Faden & Beauchamp 1986, pp. 62-62). The influence of the Hippocratic writings was more apparent in medieval Europe, where they were incorporated in Christian religious ethics. The tradition prevailed in Renaissance European thought (Jonsen 2000, pp. 49-52). The Hippocratic Oath is still today put forth as a universal and timeless ideal for medical ethics (Koch 2012).

### **1.5.2 Patient autonomy in early modern medicine**

The 18th century brought with it a critique of previous authoritative systems with a belief in reasoning and social progress known as the Enlightenment. This also had effects on medical ethics. Faden and Beauchamp (1986, pp. 64-67) refer to the writings of the Scottish physician John Gregory and his student, the physician and philosopher Benjamin Rush as examples in point. Rush argued that physicians should share information with their patients, that patients should be educated about their conditions, and that the public should learn about medicine and science. This was probably in part prompted by Rush's belief that health as causally dependent on happiness and freedom of choice. In the spirit of enlightenment thinking, the patient was supposed to be both informed and reasonable (meaning that the patient would also trust the physician expert). According to Faden and Beauchamp the concern for autonomy was nevertheless secondary to promotion of health. Patients should have a say about unimportant matters in order to make motivated to comply with the physician's recommendations, but the physician should maintain his authority when it came to issues relating to life and death. For uneducated patients, deception was justified in order to reach desired outcomes. Faden and Beauchamp argue that a main difference between Rush and many of his contemporary colleagues was his empirical

belief that truth-telling was beneficial rather than harmful, not that self-determination was of importance in itself (Faden & Beauchamp 1986, pp. 65-66).

Rush's teacher John Gregory, a professor at the University of Edinburgh, published his influential "Lectures on the duties and qualifications of a physician" in 1772. In line with the prevailing Hippocratic tradition, he saw the physician's primary role in promoting the patient's health and wellbeing (Mendelson 1996). Gregory did, however, argue, that in some situations patients need to know about a bad prognosis so that they will be able to plan and settle affairs (Faden & Beauchamp 1986, p. 66). This might be grounded in concern for self-determination as an instrumental value, but it may also be seen as recognition of personal autonomy as a value in itself. During this time in England a legal right of informed consent is also recognised in the case of *Slater vs. Baker and Stapleton* 1767. After surgeons had reset a femoral fracture without the patient's consent, a court ruled that the physicians had been negligent, since they had failed to inform the patient of the experimental procedure (Mendelson 1996).

One of the most important writings in the modern history of professional medical ethics is Thomas Percival's *Medical ethics* (1803) (Lynöe & Juth 2009, p. 292). Faden and Beauchamp describe the text as a return to the Hippocratic ideal and a reaction to the writings of Rush and Gregory. Although Percival writes about an alleged right to information, that right is always outweighed by concerns of medical beneficence. Percival shared the belief that negative information is harmful to a person. This belief, combined with the normative principle that patients always should be protected from what may be detrimental to their health, led to the conclusion that to reveal a negative truth to a patient who asks for information is "a gross and unfeeling wrong" (Jonsen 2000, p. 60). Lying was nevertheless seen as something problematic. Thus, according to Percival, physicians do not really lie when they deceive patients with the objective of benefiting their patients (Faden & Beauchamp 1986, p. 69).

Percival's book served as a template for the American Medical Association's (AMA) first "Code of medical ethics" in 1847 (AMA 1847; Lynöe & Juth 2009, p. 292). The code was in parts directly identical to Percival's text, it maintains his views on the role of the physician and the subordinate interest of respect for patients' personal autonomy (Faden & Beauchamp 1986, pp. 69-70). The code's view of truth-telling was however not without dissenters. The physician Worthington Hooker, professor of medicine at Yale University, commented critically on the code in his book *Physician and patient* (1849) and in subsequent works and lectures (Jonsen 2000, p. 72). Hooker argued that although deception may have good consequences in some cases, it does evil in most cases. Strict adherence to truth in interactions with patients must be upheld. The alternative – a system where deception is generally condoned – is unacceptable. Nevertheless, the AMA code prevailed. It was revised numerous times between 1847 and 1980, but the views on the patient-doctor relationship remained largely unchanged until 1980 (Faden & Beauchamp 1986, p. 74).

### **1.5.3 Informed consent and patient autonomy in the 20th century**

Before the 1950s, ethical codes, policies and guidelines in medicine were almost entirely developed by the medical profession. In the US, there are however a number of legal cases from the early 20th century where physicians were held liable for performing medical procedures on patients without first obtaining adequate consent. These cases did not, however, lead to the establishment of any thoroughgoing right of self-determination in medicine (Faden & Beauchamp 1986, pp. 199-201). During the mid-20th century this started to change, at the same time as medical ethics started to develop as an independent research subject. With this, there was a shift of focus from physicians' duties to patient rights (Jonsen 2000, p. 95). From the 1960s and until today, issues relating to patient autonomy have become central to medical ethics and medical policy. It is tempting to speculate about the causes of this change. It seems, at least, related to two things: (1) a general democratisation of western societies, where issues related to individual rights have become more prominent and traditional hierarchies have been questioned and sometimes dissolved and (2) medical scandals, in research as well as clinical practice, which have revealed the possibility of abuse of the medical profession's power. A possible third factor related to the first one is the rise of the consumer society and a consumerist way of life where services (including medical services) are bought and sold in an open market. I will not go into any more detailed discussion of the societal changes. I will, however, give a brief account of some medical research scandals of the mid-20th century, as these are closely related to the development of international guidelines for medical research and clinical practice where informed consent and respect for autonomy are cornerstones.

One important reason behind the drive towards autonomy is the Nuremberg 'Doctors' Trial' of the physicians who had taken part in the medical experiments carried out in the German concentration camps during the Second World War. In it, a central role was allotted to the issues of voluntariness and consent. The trial judges based their ruling in part on a set of basic ethical principles for research on human subjects that was worked out during the trial (Lynöe & Juth 2009, pp. 269-279). The first principle of the 'Nuremberg Code' (1947) states that the primary ethical concern in human research is the subject's voluntary consent.<sup>24</sup> The code does, however, not address the issue of justification for consent and does not specify in any detail how its principles should be applied. It did nevertheless inspire other professional and governmental codes during the subsequent decades (Faden & Beauchamp 1986, p. 156). Most importantly, the World Medical Association drafted a first code of ethical medical research that was adopted at a meeting in Helsinki 1964. In the Helsinki Declaration too, consent was held to be a central prerequisite of ethical research. The Declaration requires the consent of all participants in non-therapeutic research and asks for a guardian to consent if the subject is non-competent. The Declaration was the first significant attempt at self-regulation by the international medical research community

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<sup>24</sup> Interestingly enough, Germany had in 1931 endorsed what Faden and Beauchamp describe as world-unique guidelines for human research, which included strict requirements for consent as well as safeguards for vulnerable research subjects (Faden & Beauchamp 1986, p. 154).

and is generally seen as a landmark document in the history of research ethics (Beauchamp and Childress, 2001, p. 157).

Medical scandals did not only occur in Nazi Germany. In 1972 the New York Times revealed a study that had been started by a group of researchers in Tuskegee in the American south 40 years earlier. The study aimed to investigate the natural cause of syphilis and included infected and uninfected African American men who were not informed about the study or if they had a disease. They were subjected to yearly blood tests and spinal taps which were described as a 'special treatment'; active treatment was withheld (Lynøe & Juth, 2009, pp. 367-368). The revelation of the study, together with other scandals in the 50s and 60s,<sup>25</sup> made the American public aware that abuse of research subjects was not confined to totalitarian states, and a debate followed concerning discrimination, medical abuse and the rights of research subjects (Jonsen 2000, pp. 108-109). In response, the American Congress created the National Commission for the Protection of Research Subjects in 1974. Its tasks included investigating the ethics of research involving vulnerable groups, examining standards and procedures for informed consent and proposing guidelines to ensure adherence to basic ethical principles in American research. The Commission (1979) presented the three ethical principles of respect for persons, beneficence and justice. The principle of respect for persons entails a requirement of consent to research participation. It is argued that the purpose of consent was not merely protection from risk, but protection of autonomy and personal dignity as such (Faden & Beauchamp 1986, p. 216). With this, the independent value of autonomy was established in formal research guidelines. Tom Beauchamp, who was one of the writers of the report, and James Childress published the first major American textbook on medical ethics, *Principles of Biomedical Ethics*, in 1979.

As has already been remarked, the textbook and its principles, and perhaps particularly the principle of respect for autonomy, have become widely influential in bioethical debate. It is, however, not without its critics, and many debaters argue that autonomy is given too large a role in modern society and bioethics (Gaylin & Jennings 1996) and calls for a more Hippocratic approach are constantly recurring in the larger bioethical debate (see for instance Koch 2012).

#### **1.5.4 Autonomy in psychiatric care**

In the 18th and 19th centuries asylums for patients with mental disorders were established in Europe and the US. Porter (2000, ch. 5) writes that asylums often became long-term homes for chronic patients whose care mainly consisted of physical restraints or medical sedation. There was no distinction between voluntary and involuntary admissions and coercive (ineffective) medication was commonplace. During the beginning of the 19th century, a non-restraint movement became

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<sup>25</sup> See Faden & Beauchamp (1986, pp. 161-167) for an overview of other important cases. Similar cases occurred in a European setting as well. In Sweden the 'Vipeholm Study' makes a partly similar case (see Juth & Lynøe 2009, pp. 386-389), but that case has not had any major impact on Swedish or international bioethical debate.

influential and ‘moral therapies’ were introduced. Instead of confinement and restraint, moral therapies involved engaging patients in activities such as communal life, work, craft and physical exercise with the aim of helping the patients to regain reason and self-control (O’Shea 2011; Porter 2000, pp. 106-107). However, the results were limited and the asylums grew larger toward the end of the 19th century (Porter 2000, pp. 119-120). During the 20th century, psychiatry has been radically transformed. New medications have been invented that challenged the previously held assumption that institutional confinement was necessary in order to care for persons with serious psychiatric disorders. In addition to this, the civil rights movement in the mid-20th century also brought with it calls for abandonment of mental institutions in favour of other forms of psychiatric care (Testa & West 2010). Outpatient treatment is now also standard practice for patients with severe mental disorders (Testa & West 2010; Wetterberg 2012).

The ethical discourse of psychiatry has become part of the same discourse as the other medical specialties. This is reflected in the World Psychiatric Association’s declaration of psychiatric ethics, the Declaration of Hawaii (1977). Its first paragraph states that the general goal of psychiatry is the promotion of mental health and to treat mental illness in the best interests of the patients. However, it also tells the psychiatrist to inform the patient of the nature of the condition and therapeutic procedures and states that the patient must be given the opportunity to choose between appropriate and available methods for treatment. Moreover it specifies that no treatment or procedure shall be given against a patient’s will, unless the patient, due to mental illness, is unable to form a judgment as to what is in his or her best interests. However, as noted, the issue of autonomy’s relevance for decision-making and involuntary treatment in psychiatry is still a topic of debate.

## 2 AIMS AND SCOPE

The aim of the thesis is to investigate the concept of autonomy and its normative relevance in healthcare. The main focus is on psychiatry and, to a lesser extent, on end-of-life care. The studies included discuss (1) the ethics of compulsory treatment in psychiatry and the normative relevance of autonomy for overriding a patient's healthcare refusal, (2) the implications of perceiving autonomy as a value in healthcare, with particular focus on the issue of whether it may be justifiable to override a patient's healthcare decision for the sake of their own autonomy, (3) whether the value of autonomy may provide a basis for arguments against euthanasia, assisted suicide and palliative sedation at the end of life, (4) what bearing authenticity, understood as the autonomy of personal preferences, should have on the issue of whether a patient is competent to make consequential decisions about their care, and (5) how Swedish psychiatrists perceive of the concept of decision-making capacity and its relevance in healthcare.

## **3 SUMMARY OF THE PAPERS**

### **3.1 PAPER I**

#### **Autonomy and coercive treatment in psychiatry**

The question of whether patients' self-determination should be respected is especially pressing when seriously ill patients refuse care. In psychiatry the question of treatment refusal is even more complicated, since mental disorders may distort a person's comprehension of reality in such a way that the ill person fails to realise the nature and cause of their suffering. However, the paper argues that this does not necessarily imply that autonomy considerations do not matter or that there are no autonomous preferences to consider. Three principal lines of argumentation in defence of compulsory psychiatric treatment are investigated. The arguments could concern (1) societal interests in protecting others, (2) the patients' own health interests, and (3) patient autonomy. The paper argues, as a general principle, that healthcare should be provided in the interests of the particular patient and that coercive treatment cannot be defended solely for the sake of protecting others. It is also argued that if a patient autonomously refuses treatment, this should be respected. When a patient is not autonomous, the default position should be that treatment should be given in the patient's presumed best interests. It is reasonable to assume that most people, if mentally ill and not competent to decide about their care, would like to receive effective treatment. However, there might also be autonomy related reasons to respect concerns and values for patients who are temporarily non-autonomous. The article uses a case where a patient is not competent, since lacking insight into his illness, he cannot fully realise the cause of his distress. The patient nevertheless claims to have reasons, rooted in deeply set values, to renounce treatment. If such reasons are indeed authentic and of central importance to a person's overall life, it is argued that they should be taken into account when making decisions about treatment. The value and relevance of authenticity is, however, questioned in studies II and IV, and the argument is re-examined in the concluding discussion.

### **3.2 PAPER II**

#### **Paternalism in the name of autonomy**

In the paper "Paternalism in the name of autonomy" the normative implications of conceiving autonomy as a positive value in healthcare are examined with focus on situations where promotion of autonomy clashes with respect for patients' choices. The paper makes a distinction between weak paternalism for the sake of autonomy, paternalism aimed at strengthening autonomy for patients who may be regarded as substantially non-autonomous, and strong paternalism for the sake of autonomy. It is argued that if autonomy is valuable, then paternalism for the sake of autonomy can be justified in principle.

The argument builds on the distinction between competence, authenticity and efficiency as laid out in the introduction. It is argued that promotion of capacity for the non-competent is in many cases uncontroversial and in line with standard health-

related treatment goals. The issue of promoting autonomous choices by imposing information on patients is also discussed. Although sometimes information may be necessary in order to prevent people from making choices with disastrous consequences, it is argued that imposing unwanted information on a competent patient is difficult to justify. It has also been argued in bioethical debate that aspects of autonomy related to authenticity should be promoted. The paper argues that paternalism for the sake of authenticity is problematic. The value of authenticity is controversial and the concept is vaguely defined. The most controversial idea of paternalistic autonomy promotion is what is labelled as strong paternalism for the sake of autonomy. It has, for instance, been proposed that patients, for the sake of their own autonomy, should not be allowed to delegate choices in healthcare or that patients should not be allowed to make choices that would affect their future autonomy adversely.

The paper argues that if autonomy is valuable in itself, even strong paternalism for the sake of autonomy may be justified in principle; however, this does not necessarily imply that such policies should be adopted in healthcare. On the contrary, based on general consequentialist assumptions regarding the promotion of autonomy as a value, it is argued that its value is best promoted by letting competent persons make their own decisions about their health and their lives.

### **3.3 PAPER III**

#### **Autonomy-based arguments against physician-assisted suicide and euthanasia**

The paper discusses the implications of conceiving of autonomy as a value in end-of-life care. Respect for autonomy is typically considered a key reason for the legalisation of euthanasia and physician-assisted suicide (PAS). However, as noted, in recent debate this has been challenged by arguments claiming that autonomy is primarily a value that needs to be promoted or protected. This may imply, or so it has been argued, that euthanasia and physician-assisted suicide (PAS) are impermissible since they destroy the autonomy of the patient. Thus, it has been maintained that autonomy-based arguments in favour of euthanasia are in fact self-contradictory or that respect for autonomy never can be used as a reason in favour of euthanasia. The idea of autonomy as a value has also been taken as a reason for not offering palliative, continuous, deep sedation in end-of-life care. The underlying assumption is that if autonomy is valuable, certain decisions should never be allowed because they are intrinsically detrimental to autonomy.

The paper investigates the rationale behind these claims. Two different interpretations of the idea that autonomy is valuable is presented: a personal prudential value, i.e. something that benefits us in that it makes our lives better, and an unconditional value in a Kantian sense. The idea of autonomy as a prudential value can provide reasons that autonomy is to be promoted and, as argued in paper II, reasons in favour of paternalistic interferences for the sake of autonomy. However, according to this view, the value of autonomy cannot be seen merely as valuable in the sense of having a



capacity for autonomy. If autonomy is valuable, then this value must be connected to actual exercise. It is further argued that the real concern must be with making choices that actually matter. This means that this account cannot conclude that euthanasia or PAS is always wrong. On the contrary, in situations relevant to end-of-life care, there might be reasons based on this view of autonomy's value to allow these practices.

The Kantian argument does not imply that autonomy should be promoted but tries to establish absolute constraints regarding patients' options in healthcare. Kant argued that suicide is inconsistent with respect for our own autonomy and dignity and therefore it is immoral. The idea has been taken also as a reason against euthanasia in contemporary bioethics. Using arguments from contemporary philosophers in the Kantian tradition, the paper argues that respect for autonomy in the Kantian sense may indeed be held as a reason in favour of allowing certain instances of euthanasia, for instance in cases where a patient is suffering terribly and is about to lose future autonomy.

It is argued that, on both accounts of autonomy as a value, some instances of PAS and euthanasia may be wrong, but the argument cannot show that all instances are wrong. The general argument that autonomy is incompatible with PAS or euthanasia therefore fails.

### **3.4 PAPER IV**

#### **Authenticity and psychiatric disorder**

The paper discusses the normative relevance of the concept of authenticity and whether lack of authenticity in certain cases may justify overriding a patient's treatment refusal. The paper takes its starting point from recent empirical studies on patients with anorexia nervosa where questions relating to self-identity and authenticity are discussed. One problem raised in the studies is that patients with anorexia may identify with their disorder and value their thinness. They may therefore refuse treatment despite understanding and awareness of the risks. The standard view of decision-making competence in healthcare does not capture this kind of alleged irrationality. It has been argued that the problem in such cases is not that patients lack decision-making capacity (as specified in standard criteria) but that they value things wrongly. Thus, it has been argued that such decisions may be justifiably overridden because of lack of autonomy of values or preferences, i.e. authenticity rather than decision-making capacity.

The article discusses various interpretations of authenticity or rationality of desires that may be used as an account to explain why such decisions are lacking autonomy. First it may be argued that desires caused by mental disorders are *ipso facto* inauthentic. The problem with this account is that it fails to explain why mental disorders are detrimental to autonomy, since all desires are caused one way or another. What seems interesting from the point of view of autonomy is why some causes are valid but others not. Moreover, in the case of anorexia for instance, the route of causation is far from clear. Is the desire caused by the disorder, is the

disorder (partly) caused by the desire or is the desire part of what it means to have the disorder in question?

The article then discusses other proposals from the bioethical debate: that inauthenticity concerns lack of congruence between different levels of desires, that certain beliefs and desires are compulsory and therefore non-autonomous, the idea that certain desires are inherently irrational because of their content, and the idea that inauthenticity consists in instability of personal desires over time. There are problems with all these ideas, and it is argued that they fail to give a reasonable explanation of why certain desires are not autonomous. It is argued that the most theoretically attractive idea of authenticity, the idea of hypothetical approval, i.e., that a desire is authentic insofar as it would sustain first-person scrutiny in the light of how it is caused, fails to give adequate action guidance in healthcare. It is suggested that rather than rely on autonomy, arguments for paternalistic interference of these kinds of decisions may be better justified out of concerns for beneficence. The problem, then, is to find a policy that says exactly when such paternalism would be acceptable. This issue is not resolved in the article.

### **3.5 PAPER V**

#### **Decision-making capacity, interviews with Swedish psychiatrists**

The fifth study is an interview study with Swedish psychiatrists on issues relating to decision-making capacity in psychiatric care. The legal status and normative role of the concept in Swedish healthcare is unclear. The Swedish Compulsory Mental Care Act focuses on the patient's need for treatment rather than decision-making capacity. In order to investigate how the concept is understood in Swedish psychiatric care, eight psychiatrists were interviewed concerning their views and experiences on the subject. The study was approved by the Ethical Review Board in Stockholm.

The focus of the interviews was on the psychiatrists' experiences of and views on issues relating to the concept of decision-making capacity, its relation to psychiatric disorders, and when it is justifiable to override patients' healthcare decisions. The questions were posed in an open way with several follow-up questions. The analysis was done according to inductive qualitative content analysis, focusing on the manifest content of the interviews.

The interviews presented no common understanding of the concept of decision-making capacity, but characteristics such as ability to understand information and insight in one's illness were commonly referred to. Factors that were seen as impairing decision-making capacity were strong emotions such as fear or anxiety and depressions rendering patients totally bereft of motivation. Aspects relating to outcomes of decisions were also seen as factors to be taken into account. Here, a difference was noted between cases mentioned from psychiatric care and cases from physical care. Patients in physical care who rejected treatment were commonly seen as imprudent but capable of decision-making, whereas psychiatric patients were seen as lacking capacity in such cases.

Compulsory psychiatric care was typically seen as justified when patients were deemed in need of treatment and rejected this or when they posed a threat towards themselves. The main counter-reason to compulsory care in such cases was the risk of damaging a patient's trust in psychiatric services. Considerations of decision-making capacity played little role in determinations about compulsory treatment – which also is in line with Swedish legislation on the subject. The Swedish Compulsory Mental Care Act was generally commended by the interviewees, but it was generally argued that the law was quite flexible and that decisions about compulsory treatment in many situations were up to the individual physician. Even though risk of suicide was seen by the interviewees as a major reason for compulsory treatment, it was also generally argued that suicidal thoughts and plans were not always caused by psychiatric disorders.

## 4 DISCUSSION

The papers included discuss different aspects of the relevance of autonomy to healthcare decisions. However, they also leave important questions unanswered. In the light of papers II-IV, one of the arguments of paper I also needs to be revisited. I will not be able to solve all remaining issues, but I think there is room to make a few points regarding the value of autonomy and how to formulate policies for respect for self-determination in healthcare.

### 4.1 IS AUTONOMY VALUABLE IN ITSELF?

The idea that autonomy is valuable is shared by several theorists in bioethics and political philosophy (see for instance Beauchamp & Childress 2009; Brock & Buchanan 1986; Dworkin 1988; Dworkin 1993; Glover 1990; Lindley 1986). Many argue, along the lines of autonomy as a positive value, that self-creation and leading our lives according to our own wishes and decisions are valuable. The idea may also provide a rationale for individual rights to self-determination (Dworkin 1993, p 224).

The value of autonomy, however, is far from undisputed. It has been argued that the perceived value of autonomy may be fully explained by its role as an instrumental value. For instance, we would not want other people to decide for us because we are afraid that they will make the wrong choices for us. Moreover, we are negatively disposed towards having our wants frustrated – we simply do not like it when other people make decisions for us against our will. Thus, even though we are inclined to give weight to autonomy, it might be plausible that respect for autonomy is not of value as such – it is merely a means to ends that are valuable in themselves, such as happiness or preference satisfaction. Therefore, when testing our intuitions on the subject, we have to find cases that do not raise these kinds of questions. This means that we need to find cases that are as ‘pure’ from such other concerns as possible. Such cases may not arise in clinical practice, so in order to discuss the issue we may need to use thought experiments, examples constructed for the purpose of testing our sometimes conflicting intuitions.

#### 4.1.1 Arguments for the value of autonomy

As noted earlier, many ethicists have assumed that autonomy has an intrinsic value. However, there are few direct arguments for this. Constructing a direct argument as to whether and why something is intrinsically valuable is difficult; often we have to rely on our intuitions. Arguments in favour of autonomy being valuable in itself aim to show that a life without autonomy is less valuable or good for us than a life with autonomy. Arguments against the idea that autonomy is valuable try to show the reverse and that other values, for instance happiness, always outweigh the relevance of autonomy.

One famous argument that has been used to show that autonomy is valuable in itself is the thought experiment of the ‘experience machine’ presented by Robert Nozick (1974, p. 42). Nozick asks us to imagine that we were invited to give up our

autonomy and instead plug in to a machine that stimulates our brain and guarantees a life full of pleasurable experiences. Many people would probably agree with Nozick in that we would choose not to plug in to the machine. A reasonable explanation why this is so would be because of the value we attach to autonomy (Lindley 1986, p. 58). However, we may also have other intuitions on why not to plug in. For instance, perhaps we value contact with reality in itself rather than autonomy, or we may not trust the machine to actually work, or we may be irrationally attached to a *status quo* that we want to preserve.

Another argument for autonomy being valuable in itself is based on Aldous Huxley's (1932) novel *Brave New World*. In it, people lead happy lives in a totalitarian society (almost) without suffering or any kind of unhappiness. To the reader, however, that society seems frightening rather than ideal. The novel might be seen as a *reductio ad absurdum* of classic utilitarianism (Lindley 1986, pp. 44-46). The citizens of the Brave New World are indoctrinated from the beginning of their lives to embrace the society they live in and their predetermined role in it. Whenever they feel the slightest degree of anxiety they resort to the drug Soma which lifts them out of their concerns without any negative side-effects. It is claimed that a central problem with the people of the Brave New World is that their autonomy is undermined (Lindley pp. 44-45; Glover 1990, p. 81). Although decisionally competent in some respects, their desires and preferences are the results of indoctrination and brainwashing. Moreover, as argued by Lindley, they do not engage in theoretical rationality – they do not question their values or beliefs. If happiness is the only thing that is morally relevant, then the Brave New World would probably be a better world than ours. However, if other things, such as autonomy, are also valuable, the Brave New World would be far from ideal.<sup>26</sup>

Yet another argument is that many of the things we value in life, such as relationships or achievements, seem to require (or at least involve) autonomy (Tännsjö 1998, p. 96). Were we to find out that achievements that we took great pride in were not really the result of our own actions and decisions, we would probably value them less. Likewise, if it turned out that important relationships were based on mistaken trust or falsehoods, we would value them less (if at all).

However, it might be that we are wrong to value these things, or that our intuitions are better explained by other factors than that autonomy is valuable. The question that we need to answer is not what we actually value, but what is valuable, or put in another way, what we should value. I will now instead consider some arguments intended to show the limits of the value of autonomy.

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<sup>26</sup> This depends on what ideal of autonomy is employed, as different ideals might lead to different conclusions, for instance as to why and how autonomy of desires matters and whether certain societal factors or relationships may be inherently non-autonomous.

#### 4.1.2 Is paternalism justifiable?

First, it could be asked whether it sometimes may be justified to override a person's autonomous decisions for that person's own good. That is, could (strong) paternalism *ever* be justified (i.e. not respecting someone's *autonomous* decision)? This question is answered in the affirmative even by many ethicists who believe that autonomy is valuable in itself (see for instance Beauchamp & Childress 2001, pp. 186-187; Glover 1990, pp. 75-76). Glover writes that it may be permissible to act paternalistically to prevent persons from causing suffering to themselves if: (1) the suffering is very great, (2) it is very likely to occur, and (3) the outcome of the decision is not easily reversible. Different cases can be constructed to test this intuition, but even if people might have different intuitions about different cases, I believe that most people could imagine at least some possible instance where paternalistic interference would seem justified, for instance if a person we cared deeply for was about to voluntarily inflict great and irreversible suffering on themselves without any apparent reason for it (see Tännsjö 1998, pp. 103-104, or Glover 1990, ch. 5 for a further discussion).

Even if we recognise that autonomy may sometimes justifiably be overruled for the sake of other values, we may nevertheless maintain the idea that autonomy is valuable in itself. However, in order to be worthy of consideration as a theory of final value, the value of autonomy must, at least on some occasions, outweigh other plausible values. If classic utilitarianism is correct, then autonomy should always be sacrificed if this leads to an increase in total hedonic wellbeing, no matter how slight. In order to show this, Tännsjö presents two thought experiments.

The first case tells of a retired man who is happy and contented with his life. He only misses one thing, he would like to see his children more often, but each child only visits him once a year. He could travel to see them and he would be welcome to do so, but he does not dare to do this out of fear of being killed in an accident. Although he knows that the risk of being killed is in fact very small if he were to make such a trip, he nevertheless believes that *any* risk of being killed is too great – no matter what or how. A friend of the man offers him a drug that would cause him to care just a little less about risks to make him able to go and see his children. The man refuses even though he realises that taking it would increase the quality of his life. The friend then secretly administers the drug, with great success. The man does not mind his personality having changed. "I, speaking as the person you have turned me into, have no objections. Now, I am capable of living a life that is slightly better than the one I, the person that used to be me, used to live" (Tännsjö 1998, p. 104). Tännsjö concludes that even though the increase in wellbeing is slight, the paternalistic act of giving the drug without the man's approval was right. Autonomy has no intrinsic value, it is concluded.

However, the argument has some problems. First, it is important to point out that the man's subsequent approval seems quite irrelevant to the main thrust of the

argument.<sup>27</sup> What Tännsjö aims to show is that autonomy is without value in itself. Thus, we should regard the friend's action as justified regardless of consent as long as his happiness is promoted. If instead we were to modify the case so that the man would not consent to the act, it is likely to have a looser intuitive grip. Second, one might well reject the conclusion and stick to the idea that the value of autonomy overrides a slight increase in happiness. For one, it does not fulfil the criteria of justified paternalism presented by either Glover or Beauchamp and Childress, discussed earlier (see pp. 14, 32). Third, one may well accept the conclusion and yet disagree with Tännsjö's rationale as to why the act is justified. In fact, there also seem to be an autonomy-based explanation for why the interference may be justifiable. The man has a desire to see his children more often; nonetheless, he is unable to act upon this desire. In this regard, he is not able to live the life he actually wants to live. This means that the man's evaluation of risks makes him not only less happy but also less able to realise his personal goals. The friend's action means that one aspect of autonomy (i.e. his decision and desire not to take the medication) is traded against an increase in another aspect of autonomy, namely self-realisation. Hence, there is an autonomy-based argument for the case that the friend did the right thing. With these points in mind, I do not think that the case provides sufficient reason for discarding the intuition that autonomy is valuable.

#### **4.1.3 Is it valuable to live an autonomous life?**

In the second of Tännsjö's thought experiments, a case is presented where a man has freely accepted a procedure that has totally deprived him of his autonomy (Tännsjö 1998, pp. 110-111). Although he has desires, his decisions and actions are completely controlled from the outside. The decisions are, however, good for him and in each and every case he will be made to approve of the decision afterwards. He is in this way happy with his life (happier than before the procedure). However, since he is not in control of his actions, he is not autonomous. The question is then, is this in any way bad for him? Tännsjö argues that it is not. As with the former case, all that matters is subjective wellbeing; the fact that the man is not autonomous does not make life in any way worse for him, or so Tännsjö argues. Here I think intuitions differ, and many people would find the man's lack of control of his life quite disturbing. I for one do not share Tännsjö's intuition here. In fact this seems as much as a possible argument against hedonism as an argument in favour of it.

Another recent thought experiment from the bioethical debate aimed at showing autonomy to be of no value in itself is presented by Jukka Varelius (2006). Varelius tells the story of a woman, A, who is offered the chance of delegating every important decision in life to experts but who rejects this. Instead, she goes on to lead a life according to her own decisions, which, however, leads to despair and misery. A wants to find a partner, and marries several times, but her marriages end in divorce. She fails in her career and is frustrated with her work. She becomes depressed and turns to alcohol for consolation. However, as the case is described, all that has

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<sup>27</sup> It is however important for the argument that the action did not have any negative side-effects.

happened to A follows from her own autonomous choices. When A complains to her friend about her situation, the friend asks if there is not anything that is good in her life. A then answers “It is true that I have completely messed up my life, but there is one thing that I can be proud of, one thing that is definitely of value to me: it is I who have brought about this disaster!” Varelius concludes that A’s answer seems absurd to us, her autonomy seems to offer no compensation to relieve her misery. The fact that she made the decisions autonomously does not make the situation better at all, or so he argues.

First, I think that it is possible to question the intuition that we do not ascribe value to autonomous failures. Would it really not be better to autonomously try to fulfil one’s desires and goals but fail to achieve this, than to be coerced or manipulated into failures? Second, as with Tännsjö’s case, there is also an autonomy-based reason to explain the intuition that the woman’s life is not going well for her. As noted, self-realisation is not only dependent on actually making autonomous choices but also on succeeding in realising one’s own goals and plans. Thus, according to the ideal of autonomy as self-realisation as spelled out previously, A’s life is not very successful. Varelius describes a person who, despite her capacity for autonomy, has failed to be the person she wants to be. She wants a partner, but fails to establish any long-lasting relationship, she fails in her career and finally becomes an alcoholic. The case, or so it may be argued, does not only tell of a life with little happiness but also of a person who has failed in self-realisation. The intuition that the woman’s life is bad may then also be explained in terms of autonomy.

Even though there may be no compelling arguments in favour of the idea that autonomy is of intrinsic value, I have not found any knock-down arguments against the idea either. I think that the reflected intuition that autonomy has value in itself is reasonable and I think we are justified in maintaining the intuition until proven wrong. Thus, I will tentatively conclude that autonomy has value in itself, but that its value is not absolute.

#### **4.2 DOES AUTONOMY MATTER FOR NON-COMPETENT PATIENTS?**

I will now return to the issue of autonomy’s value to patients typically considered non-autonomous. There seem to be three main kinds of cases where a person may be considered non-autonomous or non-competent in relation to a certain decision but where considerations relating to autonomy yet may play a role in healthcare: (1) patients who have not yet developed autonomy, i.e. children (2) patients who have been autonomous but who have permanently lost their capacity for autonomous decision-making, and (3) cases where autonomy is lost but may be restored. I will take it for granted that autonomy is of no relevance in cases where a person has never been nor ever will be autonomous.

The issue of children’s developing autonomy is not discussed in the papers, and I will only make a few remarks here. Suffice it to say that if autonomy is valuable, we have reason to promote its development. In general in care for children this is well in line



with standard medical goals related to health and wellbeing. The value of respecting children's and adolescents' healthcare decisions is more complicated and a more detailed discussion is beyond the scope of this thesis.

#### **4.2.1 Precedent autonomy**

As noted previously, many ethicists argue that respect for autonomy also demands respect for previously held autonomous interests and preferences. I will here return to Dworkin's argument for respecting critical interests in end-of-life care. Dworkin illustrates his argument with the case of Margo. Margo is a person with advanced dementia who is happy and contented with her situation and her everyday enjoyments. Due to her dementia, she has no recollections of her previous life. However, before the onset of her dementia she wrote an advance directive stating that she rejects any life-saving treatment if she comes to be in a situation like this. Dworkin argues that her critical interests expressed in the directive have precedence over her everyday enjoyments, or experiential interests. Hence, when Margo contracts a life-threatening pneumonia, no life-sustaining treatment should be given (Dworkin 1993, p. 226). Dresser's (1995) argument about personal identity mentioned earlier is a response to this argument. As noted, Dresser argues that if psychological continuity is lost, personal identity is also lost. If so, autonomy cannot be a reason to adhere to the directive since it refers to a different person. However, even if we acknowledge that the directive concerns the same person, there are nevertheless reasons to question the idea that advance treatment refusals should have the same authority as contemporaneous autonomous refusals (Davis 2002).

I think there are many plausible cases where our intuitions diverge between contemporaneous and precedent autonomous healthcare refusals. The case of Margo may be such a case, but there are examples that seem even more problematic. Assume for instance that a demented patient had previously written a directive that rejects treatment aimed at symptom relief, such as sedatives, anxiolytics or analgesic substances. Her directive is based on some idiosyncratic, but autonomous, moral or religious belief such that we would honour it if she were competent. However, when demented, she has no real recollection of her previous values or the reasons which formed them. Should we then adhere to the refusal in a case where she is in ever-increasing but treatable pain? Here, I think, many people would have the intuition that it would be justifiable to override the previously stated preference for the sake of her current wellbeing.<sup>28</sup> Respecting advance directives regarding life-sustaining treatment in cases where they seem in line with a non-competent person's best interests or when a patient does not have experiential interests (such as when a person is permanently unconscious) does not seem controversial, and many ethicists and clinicians would be ready to accept advance directives that express preferences to forego treatment in such cases. However, the idea that precedent autonomy matters has far less intuitive force in cases of imprudent healthcare refusals.

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<sup>28</sup> The British Medical Association (2012, pp. 114-115, 138) for instance writes that advance directives should not include a right to refuse basic care (including pain and symptom relief).

As argued previously, even if autonomy is valuable in its own right, it must nevertheless be balanced against other values. Although it may be reasonable to suppose that competent patients are themselves best suited to make decisions about their values and interests, this cannot easily be extended to advance refusals. Even if we have certain deeply held values, we might well change them when facing suffering or debilitating disease. Being able to revise beliefs and values is part of what it means to be autonomous. A non-competent person cannot rationally re-evaluate previous standpoints or expressed desires. A case can also be made that a competent refusal of pain relief would not lead to the same degree of suffering for the patient making the decision, since the patient would be aware of the rationale for the decision and would know that he or she could reverse the decision anytime. This, however, would not be the case with a person having no recollection of the reason as to why treatment was rejected in the first place. Here, the pain would only represent suffering. With this in mind, I think it is justifiable to place less value on precedent autonomy when it conflicts with individual wellbeing.

#### **4.2.2 When autonomy can be restored**

As argued in paper II, there are cases when autonomy can be restored through medical interventions. The paper argues that restoration of decision-making competence in many cases should be seen as uncontroversial and in line with standard treatment goals. However, promotion of autonomy may conflict with other values. In paper I a case is described where a patient with diminished abilities for decision-making claims important personal values as a reason against treatment. It is argued that temporarily non-competent patients may have deeply held values and beliefs that may provide reasons against treatment. However, as noted in paper I and II, if autonomy is valuable, its value may sometimes best be respected by promoting and protecting the capacity for autonomy. According to this line of reasoning, we cannot *a priori* conclude that the value of respecting a right to autonomous decisions always outweighs the value of future autonomy – or vice versa.

The case of the non-competent patient described in paper I represents a conflict between autonomy, in terms of authentic, or critical, interests, and the value of having a capacity for autonomous decision-making, and wellbeing. The conflict is not easily resolved. First, the value of authenticity is unclear. Second, if autonomy is a positive value it is nevertheless far from clear which course of action better promotes the patient's autonomy: restoring autonomy or respecting authentic precedent autonomy? The patient is unable to critically revise his standpoint and, as argued in paper IV, there is no reliable way for healthcare personnel to tell whether or not a certain desire or preference really is authentic. These concerns provide a rationale for a paternalistic interference being justifiable, at least in order to relieve symptoms that preclude autonomous decision-making. The case for interference is even stronger if we modify the case so as to render Glover's criteria applicable. If the patient would be about to enter a chronic psychotic illness which is likely to be detrimental to autonomy and

wellbeing,<sup>29</sup> we have good autonomy-related reasons as well as reasons directly related to wellbeing for treating and trying to alleviate the disorder.

This, however, is not to say that authenticity or precedent autonomy should be ignored completely. The basic argument for paternalistic interference is no different from the argument for paternalism regarding standard competent decisions presented earlier. However, in terms of how a healthcare policy should be designed, the difference may be of great importance.

#### **4.3 RESPECT FOR AUTONOMY IN HEALTHCARE: SOME THOUGHTS ON POLICY**

In line with the standard view in bioethics, the present thesis argues that there are good reasons to respect patients' decisions in healthcare when these are sufficiently autonomous. However, also other considerations are deemed important. One remaining question is how policies in healthcare should be designed in order to distinguish between healthcare decisions that should be respected and those that need not be respected.

As noted earlier, different normative theories provide different rationales as to why and how respect for autonomy matters. This also has a bearing on the issue of what policies for decision-making and respect for self-determination should be adopted in healthcare. For rights-based theories, the aim of such a policy is to make sure that no rights are violated. If negative rights were the *only thing* of moral importance, it could be argued that any healthcare refusal from any patient might as well be respected.<sup>30</sup> This would be an extreme way to 'err on the side of autonomy'. If a positive right to healthcare exists for non-autonomous patients, we would need a policy to identify patients whose refusals are insufficiently autonomous and to ensure that they get the care they need, while on the other hand making sure that a negative right to self-determination is not violated. A pluralist theory, such as Beauchamp's and Childress's four principles, would strive for a standard that adequately balances the relevant values, for instance beneficence and respect for autonomy. To a utilitarian, there is no intrinsic reason for respecting any decision. However, a reasonable case can be made for there being indirect reasons for adhering to certain rules and standards in healthcare that respect sufficiently competent decisions (Tännsjö 1999).

Since there is no consensus regarding ethical theory, a policy should ideally be compatible with shared normative assumptions from different theories; at least, it should try to avoid relying on controversial ethical assumptions. However, despite disagreements, there are several issues where common theoretical ground can be found between reasonable normative theories. First, I will propose that a reasonable

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31 Or if the case would involve a direct risk of self-harm.

30 A libertarian might, however, argue that if an individual had previously made a contract agreement with her healthcare provider about treatment when she is no longer competent, capacity is relevant in order to establish whether treatment should be given.

theory should recognise that promotion of health and wellbeing matters.<sup>31</sup> Second, a reasonable theory should recognise a basic principle of justice, that equal cases are to be treated equally. If two cases are to be treated differently, there must be some normatively relevant difference between them. Third, the theory should recognise that autonomy, or self-determination, matters in healthcare. As noted, to recognise this we need not assume that autonomy is an intrinsic value. It is sufficient to recognise its role as an instrumental value (Tännsjö 1999). Starting out from these three assumptions, I will propose some desiderata of how to formulate a policy or a standard of respect for self-determination in healthcare.

The standard should be *internally consistent*. It should not involve any internal inconsistency such as logical contradictions. This is a minimal requirement for all theories scientific or philosophical.

The standard should cohere with *general ethical intuitions* and theories as outlined above. As noted, it should take into account the idea of respect for *autonomy*, it should be coherent with the general goal of promoting *health and wellbeing*, and it should take into account considerations of *justice*.

The standard should cohere with reflected *intuitions about particular cases*. This means that it should be coherent with considered moral judgments regarding intuitions as to whether or not to respect a certain decision. This is most important for real-life cases, but imaginary cases could also be of relevance. However, fanciful thought experiments seem to be of lesser importance for policy purposes than actual healthcare cases.

As noted earlier, conflicts typically arise between health and other values. Different people prioritise and value different goals. Our society consists of people with different values, goals and aims. Healthcare policies should recognise and *respect pluralism*. This may be motivated out of concerns for all three of the principles mentioned above: self-determination, wellbeing and justice.

The standard should be possible to use in practice. Thus, it should be *specific and reliable*. The standard should be able to tell us whether or not a particular decision should be respected. Different persons using the same standard should come to similar conclusions and it should leave little room for arbitrary decisions. This has to do with justice as well as promotion of wellbeing. It is likely that arbitrariness regarding how self-determination is handled would erode trust in the healthcare system and lead to adverse overall consequences.

The standard should be *acceptable* to the parties involved, most importantly patients. This is not to say that each patient needs to agree with an assessment of whether or

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<sup>31</sup> This means that a radical libertarian position that only negative rights have moral importance will be rejected. I will not argue for this here, since it has been convincingly argued for elsewhere (see, e.g. Juth 2005; Tännsjö 1998).

not her decision should be respected, but that people in general should find the standard and its purpose acceptable. For instance, most people would find it reasonable that, if confused or psychotic, they would still receive the treatment they need.

The standard should also be *coherent with regulations* in different areas of healthcare and regulations outside of healthcare. This is not to say that regulations about personal decision-making need to be identical in all walks of society. However, if regulations regarding respect for self-determination diverge on important issues, there should be a reason for this. This also applies to different areas of healthcare. It is possible that there are good reasons for having different standards on how to respect self-determination in healthcare, but, if so, there should be a rationale for this. This criterion is related to the ideas of justice but it seems also be relevant from the standpoint of trust.

Moreover it may be argued that a standard should be able to explain why certain decisions should be respected and others not. That is, it should not merely give a list of disorders, symptoms or situations where treatment refusals may or should be overridden – it should be able to provide a rationale for this.

#### **4.3.1 Is there an ideal standard to be found?**

The criteria outlined here may be fulfilled to a greater or lesser extent and they might in some situations conflict with each other. It is unlikely that we could arrive at a standard that does equally well in relation to all criteria, and this may not be desirable, as different criteria may be of differing importance. Thus, it is possible that we will end up with a standard or a policy that in some cases will provide answers that may seem less than ideal. The task of finding a reasonable standard on when to respect a patient's decisions then boils down to finding a reflective equilibrium where considered intuitions concerning ethical principles match with theoretical considerations and intuitions about particular cases. An important issue is to find a standard that actually is useful and applicable in healthcare.

I think a standard that is both normatively reasonable and practically applicable may be constructed starting out from the idea of competence (decision-making capacity) discussed previously. A recent regulatory example of such a standard is found in the England and Wales Mental Capacity Act, which states that in order to have decision-making capacity a person must (1) comprehend the information relevant to the decision, (2) retain this information long enough to make the decision, (3) use and weigh the information to arrive at a choice, and (4) be able to communicate the decision (The British Medical Association 2012, p. 106). The criteria need to be spelled out in more detail. However, the standard nevertheless leaves some important issues unanswered.

Some debaters have argued that considerations of risk or medical benefits should be part of a standard for capacity, so that decisions that carry low risk require a low

degree of competence whereas decisions that carry great risk require a higher degree of competence (Buchanan & Brock 1986). This is one way to incorporate ideas about wellbeing in a standard for respect for self-determination, but it has some drawbacks. First, there is nothing to say that risky decisions are necessarily more complicated than less risky ones decide (Beauchamp & Childress 2009, p. 117). Second, decisions that involve a risk are typically also decisions that are of great importance to a person. This means that such a standard might be used as a pretext for only allowing patients to make trivial healthcare decisions, while important decisions are left to other persons to decide. Third, the risk-relative standard of competency also seems to preclude the normative discussion of whether paternalistic intervention would be justifiable. Rather than motivating interference with a risky decision out of concern for a patient's wellbeing, the standard would say that the patient is not autonomous or competent enough to make such a decision. This seems like an unnecessary conflation of two important and distinct concepts. Instead of incorporating a notion of wellbeing or risk in the definition of capacity, I think a better way of reconciling these two values is to hold aspects of wellbeing to be important for evaluating a certain standard. Thus, if a policy or a standard of decision-making capacity in healthcare would lead to negative consequences related to health and wellbeing, this would be a reason against it.

The question of authenticity's relevance to respect for autonomy is discussed throughout the thesis. One main problem is that there are several mutually incompatible conceptions of authenticity. Moreover, some conceptions are vaguely defined, while others are defined in such a way that they cannot be used for action guidance in healthcare. As argued in paper IV, even though the idea of authenticity as hypothetical approval of desires may be theoretically attractive, it nevertheless fails to provide much action guidance. Moreover, the value of authenticity is controversial. Here I think it is enough to conclude that if we have no way of assessing authenticity reliably, it should not be part of a standard of respect for autonomy in healthcare. The problem with letting go of this notion is that it might conflict with intuitions in many particular cases. As noted in study IV and V, many problematic decisions seem to be the result of distorted values and goals, rather than distorted abilities for understanding and reasoning. It might be that a criterion such as Buchanan's and Brock's (1986) suggestion that competence requires a concept of what is good for a person that is minimally consistent and stable could be useful to distinguish the problematic cases. Another possible suggestion is Tännsjö's (1999, p. 11) that decision-making ability requires the ability to reflect on and revise values, not only beliefs. However, it is hard to tell what to make of this in a clinical setting. Although it can be argued that healthcare personnel should discuss values and goals as well as beliefs when they assess capacity, it remains an unanswered question in this thesis whether, and if so when, a decision should be reckoned non-autonomous due to the basic desire which motivates it.

The issue of whether psychiatric and somatic care should use the same standard concerning when to override treatment refusals needs further discussion. It may be

argued that decision-making capacity is a vague concept and that it is more reliable to base decisions about involuntary treatment in psychiatry on criteria related to concepts such as serious psychiatric disorder, risk, and need for care. However, these concepts seem to be just as problematic to define. This issue was also discussed by several of the interviewees in study V, who argued that Swedish law with regard to the above-mentioned concepts were somewhat unclear and open for different interpretations and personal judgment.

Psychiatric disorders tend to affect persons' abilities for decision-making, their emotions and their self-identity, but this is also true of many somatic disorders, and the consequences of a healthcare refusal may be just as serious in both areas. What is relevant in this context is what values are at stake, such as whether and to what extent a decision is autonomous, what interests the patient has and what the consequences of respecting or overriding the decision in question are – not how a certain disorder or treatment is classified. However, the question is whether a standard can be constructed that covers all the problematic instances.

#### **4.4 CONCLUDING REMARKS**

The thesis discusses the normative relevance of autonomy in healthcare. Autonomy is typically seen as a ground for the right to make personal decisions in healthcare. However, it may also be seen as something that is valuable in the sense that it should be protected or promoted. This idea of autonomy's relevance may conflict with the idea of autonomy as a right to be respected, for instance when patients make decisions that are likely to be detrimental to their future autonomy. Thus, if autonomy is valuable, paternalism for the sake of autonomy may be justifiable. For healthcare policy, however, it is reasonable to assume that autonomy is best promoted by respecting patients' autonomous decisions. In relation to this, the thesis also discusses recent bioethical arguments that respect for autonomy in terms of a value makes autonomy incompatible with respect for decisions about euthanasia and palliative sedation at the end of life. It is maintained that such arguments are untenable.

Concerns for the value of autonomy might be used to motivate policies for restoration of autonomy in non-competent patients. Here again, however, different aspects of autonomy may clash. It is argued that although patients may lack the capacity for autonomous decision-making in a certain situation, they may nevertheless have interests which are grounded in authentic values. It is proposed that such interests should be taken into account when making decisions about treatment. This idea, however, presents several problems when applied to critical healthcare decisions. The concept of authenticity is hard to define and its value is disputed. Even though there are theoretically appealing ideas of authenticity, these provide little action-guidance in healthcare. Thus, there are good reasons for a policy of respect for autonomy in healthcare to focus on actual capacity for autonomous decision-making rather than authenticity.

One remaining problematic issue is what role the autonomy of personal values and goals should play for assessments of decision-making capacity. As noted, authenticity is a problematic concept, but relevance of personal values to decision-making capacity needs further analysis. The issue of advance directives, especially in psychiatric care, is highly interesting but is only briefly discussed in the thesis. The topic would benefit from further empirical investigations of patients' preferences and experiences as well as from further normative discussion regarding the scope of such directives.

The thesis focuses on controversial questions regarding respect for treatment refusals and issues relating to assisted dying in end-of-life care. Much remains to be said regarding these issues. However, most decisions in healthcare are not of this kind. Respect for autonomy in everyday healthcare is a complex issue and further research would also benefit from normative as well as empirical investigations of everyday decision-making and interactions between patients and caregivers. The concept of autonomy and questions about its value and relevance are likely to continue to be of central interest to the bioethical debate.



## 5 SVENSK SAMMANFATTNING

Autonomi anses vara ett centralt värde i samtida medicinetisk diskussion. Vanligen förstås autonomi som förmågan att styra sig själv och leva sitt liv i enlighet med sina egna önskemål och planer. I hälso- och sjukvårdsetik talas det ofta om respekt för autonomi som en grundläggande etisk princip. Detta förstås vanligen i termer av vissa rättigheter, exempelvis rätten att få information om sitt hälsotillstånd, rätten att få välja mellan likvärdiga behandlingar och rätten att avböja erbjuden vård. Ibland har det förts fram att patientens autonomi även ligger till grund för att erbjuda vissa sorters behandlingar eller åtgärder, framför allt har detta argument förts fram i frågor gällande reproduktiv hälsa samt vård i livets slut. Ofta ställs respekt för autonomi mot paternalism. Paternalism innebär att beslut fattas åt en person, i dennes tänkta intresse men utan dennes samtycke. I senare års medicinetisk debatt har det även förts fram argument för att autonomi är ett värde som bör främjas och skyddas utifrån antagandet att autonomi är något som är bra för oss. Detta synsätt kan ha radikalt andra följder än den traditionella uppfattningen om autonomi som grund för rättigheter.

Avhandlingen diskuterar autonomins roll i hälso- och sjukvårdsetik med inriktning på frågor om autonomins betydelse i psykiatrisk vård och vård i livets slut. Metoden som används är filosofisk normativ analys. Målet för analysen är att finna en reflekterande jämvikt (reflektivt ekvilibrium), alltså en koherens mellan teoretiska antaganden, generella etiska principer och omdömen om enskilda fall. Ett av delarbetena är empiriskt och består av intervjuer med läkare i psykiatrin om etiska frågeställningar relaterade till avhandlingens filosofiska delar.

Avhandlingens första delarbete diskuterar frågan om när det är etiskt motiverat att vårda en person mot sin vilja i psykiatrisk vård. Mot bakgrund av ett fiktivt fall diskuteras tre principiella etiska försvar för tvångsvård: patientens vårdbehov, samhällsskydd och autonomibaserade skäl. Artikeln argumenterar för att tvångsvård är etiskt motiverat när det finns ett starkt vårdbehov men där patienten inte själv har förmåga att förstå och ta ställning till detta. Artikeln argumenterar för att tvångsvård primärt ska ges utifrån patientens eget behov. Artikeln argumenterar också för att även patienter som tillfälligt ej är förmögna att fatta beslut om sin vård på grund av nedsatt sjukdomsinsikt ändå kan ha autonomt grundade och autentiska värderingar, som bör tas i beaktande då vården utformas. Begreppet autenticitet och dess relevans för vården är dock problematiskt och ifrågasätts i de följande delarbetena.

I det andra delarbetet undersöks följder av olika tolkningar av autonomins etiska relevans. I enlighet med idén om autonomi som ett värde har argument förts fram att sjukvården bör agera för att främja och skydda patienters autonomi snarare än att respektera autonoma val. Detta kan motivera paternalism för att skydda patienters autonomi. I artikeln undersöks olika exempel på argument för sådan paternalism som har förts fram i medicinetisk debatt. I fall där patienter har nedsatt beslutskapacitet, men där denna kan återställas med hjälp av behandling, verkar sådan paternalism i

många situationer okontroversiell. Det har dock argumenterats för paternalism i autonomins namn som ter sig betydligt mer kontroversiella. Det har exempelvis förts fram argument för att beslut som inte är grundade i en persons "verkliga" autonoma vilja och önsknings inte behöver respekteras. Denna idé är problematisk eftersom den verkar kunna ge upphov till godtyckliga beslut från sjukvården för vilka beslut som ska respekteras. Ett annat exempel som tas upp är argument för att patienter inte ska få delegera beslut till sjukvårdspersonal eller att patienter måste ta till sig information om sitt tillstånd. I vård i livets slut har idén om autonomins värde förts fram som ett skäl för att patienter inte ska få göra vissa val som riskerar hota deras förmåga till autonomt beslutsfattande. Artikeln argumenterar för att paternalism för autonomins skull riskerar att vara kontraproduktiv som grund för sjukvårdspolicy. Autonomi främjas bäst av att sjukvården respekterar patienters autonoma beslut och därför finns det goda skäl för att hålla kvar vid tolkningen om autonomi som grund för en rättighet även om man antar att autonomi är ett värde som bör främjas.

Frågor om dödshjälp och läkarassisterat självmord hör till de mest omdiskuterade i medicinsk etik. Utifrån idén om autonomi som grund för en rättighet anses respekt för autonomi vanligen vara ett argument för att ge patienter makt att fatta sådana beslut. Det har dock hävdats i den medicinetiska debatten att autonomi är ett värde som bör skyddas och att dödshjälp därför inte är moraliskt acceptabelt. I det tredje delarbetet undersöks om autonomi enligt detta resonemang kan anföras som ett argument mot dödshjälp och läkarassisterat självmord. Resonemanget undersöks utifrån två olika idéer om autonomins värde. Först undersöks argumentet utifrån idén att autonomi är något som bör befrämjas för att autonomi är bra för oss. Utifrån detta synsätt så är det rimligt att anta att vad som är värdefullt är att verkligen kunna utöva vår autonomi i enlighet med våra mål och värderingar. I så fall verkar det rimligt att anta att själv ha makt över centrala livsfrågor faktiskt är något som gynnar en persons autonomi. Att ha en kapacitet för autonomi om detta endast innebär makt över triviala beslut verkar inte vara lika värdefullt för en person. Denna syn på autonomins värde verkar därför inte kunna användas som ett generellt argument mot självvalt livsslut. Den andra idén om autonomins värde som undersöks är ett antagande att vi har en plikt att vara autonoma, vilket ofta antas i den tradition som stammar från den tyska 1700-talsfilosofen Immanuel Kant. Här har autonomi en något annorlunda innebörd än vad som vanligen avses i samtida medicinetisk debatt. Att vara autonom innebär inte bara att handla i enlighet med egna önsknings och vilja, det handlar om att handla moraliskt rätt. Kant menade dessutom att vi som autonoma varelser har plikter mot oss själva, exempelvis plikten att inte ta våra liv. Artikeln argumenterar för att det i vissa fall verkar vara i enlighet även med en Kantiansk etik att respektera en persons önskan om att få dö, exempelvis då personen står inför ett outhärdligt lidande som riskerar att ta ifrån personen sin förmåga till autonomt handlande. Utan att ta ställning till frågan om dödshjälp bör tillåtas i sjukvården så argumenterar artikeln för att autonomihänsyn inte kan ses som ett övergripande principiellt skäl mot detta.

I det fjärde delarbetet diskuteras värderingars betydelse för begreppet beslutskompetens. Vanligen förstås beslutskompetens som en i huvudsak kognitiv

förmåga, nämligen att förstå information och olika alternativ och dess konsekvenser. Ett möjligt problem med denna modell är att den verkar kunna acceptera att en patient kan ha vilka mål och värderingar som helst men ändå anses som beslutskompetent. Modellen ställer alltså inga krav på vilka mål som ska anses acceptabla eller autonoma. Ett problem med detta är att det vid vissa psykiatriska sjukdomstillstånd, exempelvis fall av ätstörningar och depressioner, verkar som att problemet är att patienters mål och värderingar är störda, snarare än deras kognitiva förmåga. Artikeln diskuterar nyligen publicerade empiriska studier om patienter med anorexia. I dessa studier hävdas att även patienter med mycket svåra ätstörningar kan uppfylla standardkrav på beslutskompetens (i termer av förmåga att förstå information och att inse konsekvenser av sina beslut) men vägra vård utifrån motiveringen att de värderar sitt tillstånd och inte önskar att gå upp i vikt. Ett argument som förts fram i den medicinetiska debatten om varför det kan vara rättfärdigat att ändå ge behandling i sådana fall är att patientens önskningar skulle vara icke-autonoma, eller *inautentiska*. I artikeln diskuteras olika förslag från medicinetisk debatt för att förklara vad inautenticitet är. Alla förslagen har dock brister, antingen verkar de inte kunna kopplas till autonomi som självbestämmande eller så är de normativt orimliga. Ett förslag är exempelvis att betrakta önskningar orsakade av psykisk sjukdom som icke-autonoma. Problemet med denna idé är dock att alla önskningar orsakas av något, en teori om autenticitet behöver ge en förklaring om varför just vissa orsaker ska anses diskvalificerade ur autonomisynpunkt. Det finns ingen enhetlig definition på psykisk sjukdom som skulle kunna förklara detta. Den teori som i artikeln bedöms som mest teoretiskt attraktiv säger att en önskan är autentisk om personen i fråga skulle acceptera (eller åtminstone ej avfärda) önskan om personen fick en full förklaring till varför han eller hon har önskan i fråga. Ett problem med detta är dock att det inte verkar gå att dra några slutsatser i konkreta fall om vad en sådan hypotetisk reflektion ska mynna ut i. Idén verkar därmed inte kunna ge någon konkret vägledning i sjukvården. Istället för att försöka förklara varför vissa värden och mål är icke-autonoma föreslås att det kanske är mer fruktbart att finna kriterier relaterade till välbefinnande eller hälsa om man vill förklara varför paternalism kan vara motiverat i de problematiska fall som diskuteras. Artikeln ger dock inget förslag på hur sådana kriterier skulle kunna se ut.

Det femte och sista delarbetet är en empirisk studie där svenska psykiatriker intervjuats om begreppet beslutskompetens och om deras erfarenheter och reflektioner kring etiska problem rörande patienter med nedsatt förmåga att fatta kompetenta beslut om sin vård. Sammanlagt intervjuades åtta psykiatriker med olika bakgrund och erfarenhet. Vad gäller begreppet beslutskompetens så fanns en kärna som de intervjuade generellt var överens om i det att sjukdomsinsikt och förmåga att förstå information sågs som centrala faktorer. Det fanns bland de intervjuade dock inget samförstånd om hur beslutskompetens skulle definieras. De intervjuade menade alla att psykiska sjukdomar, såsom psykoser, depressioner och stark ångest kan påverka personers beslutskompetens. Antingen, som i psykossjukdomar, genom att påverka verklighetsuppfattning, eller genom att påverka förmåga att resonera och förstå information och olika argument. Flera av de intervjuade menade att brist på

insikt i att vård behövdes eller det faktum att patienten tackade nej till föreslagen vård var kriterium på avsaknad av beslutskompetens. Här fanns det en skillnad mellan exempel från somatisk vård och psykiatrisk vård. Patienter i somatisk vård som avböjde föreslagen behandling ansågs ofta okloka men beslutskompetenta, medan detta sågs som ett tecken på att en patient saknade beslutskompetens i fall som handlade om psykiatrisk vård. Vad gäller beslut om tvångsvård så var de intervjuades resonemang i överrensstämmelse med svensk lagstiftning på området. Tvångsvård ansågs vara motiverat i fall där patienter hade en psykisk störning med ett stort psykiatriskt vårdbehov eller då de var farliga för sig själva eller andra. De intervjuade var dock överens om att det fanns utrymme för olika tolkningar av lagen och därmed ett visst utrymme för läkaren att fatta beslut i enlighet med egna uppfattningar. Risk för självmord ansågs vara ett av de viktigaste skälen till tvångsvård, samtidigt menade dock de flesta att suicidalitet inte måste vara associerat med psykisk sjukdom. Beslutskompetens nämndes ej som ett direkt kriterium för när tvångsvård är motiverat. Vid direkt fråga så var det en allmänt hållen uppfattning att begreppen allvarlig psykisk störning var distinkt från begreppet beslutskompetens och att även patienter med allvarliga psykisk sjukdomar kan vara beslutskompetenta. Omvänt menade de flesta också att en person kan vara oförmögen att fatta kompetenta beslut utan att för den skull ha ett psykiatriskt sjukdomstillstånd.

I den avslutande diskussionen lyfts frågorna om autonomins värde och hur en policy om respekt för autonomi i vården bör se ut. Avhandlingen argumenterar för att även om autonomi hålls som ett egenvärde bör detta dock ej ses som absolut. Det finns tillfällen då andra intressen eller värden som välbefinnande och hälsa gör att paternalistiska interventioner kan vara etiskt motiverade. Vad gäller en generell *policy* för respekt för självbestämmande finns dock goda skäl för att respektera autonomi i vården. För icke-beslutskompetenta patienter bör det finnas möjlighet till intervention för att ge vård enligt behov. Även om inget konkret förslag för hur en vårdövergripande policy gällande dessa frågor ska se ut så föreslås ett antal kriterier för grundläggande krav på en sådan policy. En sådan policy ska vara normativt rimlig och helst undvika kontroversiella etiska antaganden men också tillämpbar och säker. Ett problem med idén om autenticitet som tidigare nämndes är just att det inte verkar finnas något sätt för olika personer att avgöra huruvida en önskan är autentisk, vilket riskerar att leda till godtycke i frågan om hur patienters självbestämmande ska hanteras. Avslutningsvis diskuteras också skillnaden i regelverk för hur patienters självbestämmande respekteras i psykiatrisk och somatisk vård. Utifrån antagandet att lika fall ska behandlas lika så verkar det finnas goda skäl för att hantera konflikter mellan autonomi och självbestämmande på liknande sätt i olika delar av vården. I de fall där en patient vägrar vård är den grundläggande konflikten mellan autonomi, hälsa och välbefinnande samma oavsett vårdområde. Den centrala frågan är huruvida en patient är beslutskapabel och vilka konsekvenserna av olika handlingsalternativ är.

## 6 ACKNOWLEDGEMENTS

First and foremost, I would like to express my deepest gratitude to my supervisors Gert Helgesson, Niklas Juth and Stefan Eriksson for encouraging me, for patiently discussing my ideas and for constantly making me improve my arguments and writing. I would especially like to thank Gert, my main supervisor, for believing in me when I was a medical student back in 2006 and for making this possible. A huge thank you also to Petter Karlsson, who joined our team for the last project and helped out with interviews and writing for the final paper.

I would like to thank all bioethical colleagues, past and present, at Karolinska Institutet and Stockholm University. Particularly I would like to thank Henrik Ahlenius, Daniela Cutas, Lisa Furberg, Emma Karlsson, Anna Lindblad, Niels Lynöe, Erik Malmqvist, Tomas Månsson, Torbjörn Tännsjö, and Maja Wessel for support and for valuable comments on the manuscripts. Anna and Maja, my fellow doctoral students: thank you for making these years so enjoyable. Also, a big thank you to Roger Tanner for help with language revisions. For all remaining faults and weaknesses, the author of the thesis remains solely responsible.

I am very grateful to Södersjukhuset and Psykiatri Södra Stockholm for making it possible for me to do research in parallel to my clinical work. Special thanks must go to Residency Programme Director Karin Sparring Björkstén at Psykiatri Södra Stockholm.

I was fortunate enough to spend the last semester of my doctoral studies as a fellow at the Division of Medical Ethics, Harvard Medical School. A huge thank you to Nir Eyal, Mildred Solomon and the 2013-2014 ethics fellows for making this such a rewarding time. I would also like to thank Forte, the Swedish Medical Association, and the Swedish Society for Medicine for funding support during the stay.

My psychiatry colleagues Klara Askegård, Johan Eriksson and Joar Guterstam. Thank you for friendship and discussions about research, ethics and everything that really matters in the world of psychiatry and elsewhere.

My brilliant friends Magnus Kusoffsky and Holger Rosencrantz, for thought experiments since 1999 and for valuable comments on early (and very late) drafts: *allt är salt!*

Axel Englund, for valuable comments on the texts and for conversations about research, philosophy and life: thank you, my friend!

To my mother and my father, thank you for your support, encouragement, and, particularly to you Dad: thank you for introducing me to the world of philosophy.

Karin, my love, my friend, my most valued critic and reader; Siri and Arvid, I know you could not care less about this thesis, but I cannot help putting your names here anyway. Words are not enough. Thank you for being here!

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