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Refusing Medical Treatment due to Mental Capacity

A Study of the Concept of a Valid Consent and What the Healthcare
Personnel's Obligations are When the Patient has not Given an
Informed Consent

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Summary

This essay has two purposes: to examine how much the patient has to understand to be able to consent to medical treatment and what the healthcare personnel's obligations are when the consent is not informed. Regarding the first purpose I concluded that there is no explicit requirement of a certain mental capacity to consent but that if one considered an uninformed consent to constitute a forced bodily intervention, which is prohibited in Chapter 2 Section 6 Instrument of the Government, then medical treatment can be refused. Regarding the essay's second purpose I examined this both in relation to Swedish and international law. With Swedish law I, firstly, studied the healthcare personnel's obligations to provide a good, patient-oriented, care and care with equal opportunity. I concluded that since these obligations are vague it is unclear if the healthcare personnel would contravene these obligations if they refused to give medical treatment. Secondly, I examined if refusal to give medical treatment due to mental capacity could constitute discrimination and I studied this in relation to indirect discrimination and inadequate accessibility. I concluded that there are uncertainties if patients with reduced decision-making capabilities would be regarded as disabled within the meaning of DiskL. I also concluded that it could constitute indirect discrimination but that the refusal could be allowed if there was a risk of the patient being harmed. Additionally, I concluded that it was hard to assess if it could constitute inadequate accessibility, partly since one has to consider the financial and practical aspects, partly since it is unclear if individual adjustments are included. Secondly, I examined international law, specifically the ECHR and the CRPD. Regarding the ECHR I concluded that it is possible to claim that there has been an interference with the convention but that an individual assessment must be made. Regarding the CRPD I concluded that it would interfere with the right to legal capacity to refuse medical treatment. I also stated that Sweden has an obligation to provide reasonable accommodation and that it constitutes inappropriate influence to refuse medical treatment due to mental capacity. Lastly, I analysed and discussed, once again, if an uninformed consent could constitute a forced bodily intervention. I also discussed this issue in relation to what risks persons with reduced decision-making capabilities are allowed to take. Finally, by using a bridge-metaphor I illustrated the dangers of having unclear obligations for the healthcare personnel as it creates opportunity for personal interpretations.

Sammanfattning

Denna uppsats har två syften: att undersöka hur mycket patienten måste förstå för att kunna samtycka till medicinsk behandling samt vad hälso- och sjukvårdspersonalens skyldigheter är när samtycket inte är informerat. Angående det första syftet kom jag fram till att det inte finns ett uttryckligt krav på att patienten ska ha en viss mental nivå för att samtycka men att om man anser att ett oinformerat samtycke skulle utgöra ett påtvingat kroppsligt ingrepp, som förbjuds i regeringsformen 2 kap. 6 §, kan en medicinsk behandling nekas. Angående uppsatsens andra syfte undersökte jag detta i svensk och i internationell rätt. Med svensk rätt tittade jag på först på hälso- och sjukvårdspersonalens skyldigheter att ge en god och patientcentrerad vård och en vård på lika villkor. Jag kom fram till att då dessa skyldigheter är så vagt formulerade är det svårt att hävda att hälso- och sjukvårdspersonalen skulle gå emot dessa skyldigheter om de nekade medicinsk behandling på grund av mental kapacitet. Därefter undersökte jag om nekande av medicinsk behandling skulle kunna utgöra diskriminering och jag undersökte specifikt indirekt diskriminering och bristande tillgänglighet. Jag kom fram till att det först och främst finns oklarheter om beslutsoförmögna patienter skulle falla in under diskrimineringslagens förståelse av funktionsnedsättning. Vad gäller indirekt diskriminering kom jag fram till att det kan utgöra indirekt diskriminering men att det eventuellt kan tillåtas om det finns en risk för patientens hälsa. Vad gäller bristande tillgänglighet kom jag fram till att det är svårt att bedöma om det skulle utgöra diskriminering dels då man ska beakta ekonomiska och praktiska möjligheter, dels då det är oklart om det inkluderas individuella anpassningar. När jag undersökte internationell rätt tittade jag på EKMR eller CRPD. Vad gäller EKMR kommer jag fram till att det finns en möjlighet att hävda att det skulle strida mot EKMR att neka men att individuella bedömningar kommer göras här. Vad gäller CRPD konstaterar jag att det skulle strida mot rätten till rättshandlingsförmåga att neka medicinsk behandling. Jag konstaterade även Sverige har skyldighet att ha skäliga anpassningsåtgärder samt att det utgör otillbörlig påverkan att neka medicinsk behandling. Slutligen hade jag en analys där jag återigen diskuterade om ett oinformerat samtycke ska anses utgöra ett påtvingat kroppsligt ingrepp. Jag diskuterade detta även i relation till vilka risker beslutsoförmögna tillåts ta. Slutligen använde jag en bro-metafor för att illustrera faran i att hälso- och sjukvårdspersonalens skyldigheter är otydliga och hur det skapas utrymme till personliga tolkningar.

Preface

How does one eat an elephant? One bite at a time. How does one obtain a law degree? One course at a time. And now all the courses are finally done.

The road to obtaining my law degree would have been a lot harder without the support and friendship from others. So, thank you to my family, my friends and my fiancée for all that you have done for me.

Thérèse Bennshagen
25th of May 2021, Malmö, Sweden.

Abbreviations

CRPD	Convention on the Rights of Persons with Disabilities
the CRPD Committee	The Committee on the Rights of Persons with Disabilities
DiskL	Diskrimineringslag (2008:567) [Discrimination Act (2008:567)]
DO	Diskrimineringsombudsmannen [The Equality Ombudsman]
ECHR	The Convention for the Protection of Human Rights and Fundamental Freedoms
The European Court	The European Court of Human Rights
FL	Förvaltningslagen (2017:900 [the Administrative Act (2017:900)]
HSAN	Hälso- och sjukvårdens ansvarsnämnd [the Medical Responsibility Board]
HSL	Hälso- och sjukvårdslag (2017:30) [Health and Medical Service Act (2017:30)]
IoG	Regeringsformen (1974:152) [the Instrument of Government (1974:152)]
IVO	Inspektionen för vård och omsorg [the National Board of Health and Welfare]
JK	Justitiekansler [Chancellor of Justice]
JO	Justitieombudsmannen [the Parliamentary Ombudsmen]
PL	Patientlag (2014:821) [Patient Act (2014:821)]
PSL	Patientsäkerhetslag (2010:659) [Patient Safety Act (2010:659)]
Prop.	Proposition [bill of the Government]
SOU	Statens offentliga utredningar [inquiry report]

1 Introduction

1.1 Background

One of the fundamental principles of Swedish law is that a patient has to consent to medical treatment. Prior to obtaining the consent, it is stated that the healthcare personnel are obliged to disclose a list of information and that they have to ensure that the patient, as far as possible, understands the information given. However, it is not stated in law what the consequences are when the patient understands only parts, or nothing, of the information. This raises the questions of how much the patient has to understand of the information given in order to give a valid consent to medical treatment and what the obligations are for the healthcare personnel when the consent is not truly informed. The issue of a consent's validity and the obligations of healthcare personnel are even more complex in regard to patients who for various reasons, such as intellectual or psychosocial disability, have a reduced decision-making capability.¹ To illustrate with an example: a patient with an intellectual disability wishes to receive medical treatment for their acne. However, this medication is highly potent and leaves the skin very sensitive to the sun. Furthermore, this medication cannot be used while pregnant as it may harm the foetus and the patient should also avoid alcohol as the medication is metabolised in the liver. Additional to there being a care need for the acne medication, the patient may also suffer emotionally because of the skin condition. The healthcare personnel will have to face a dilemma of whether to give care without having a valid consent from the patient, with the risk of complications that might harm the patient, or to refuse the care that the patient needs. This example illustrates that there is a need for legal research into how Swedish law should deal with situations when patients with a reduced decision-making capability consents to medical treatment. This is the question this thesis addresses.

There are various principles and legal norms that the healthcare personnel have to respect and fulfil when they are meeting a patient. When deciding whether or not to give medical treatment to a patient with a reduced decision-making capability the principles and legal norms that arise are the principle of legality, the obligation stated in Swedish health law that they are obliged to give good care and care with equal opportunities for the population as well as the prohibition to discriminate according to the Discrimination Act (hereinafter referred to as the DiskL). Moreover,

¹ In Swedish the term "beslutsoförmögen" is often used for these cases.

Sweden is also bound by the international treaties such as the European Convention on Human Rights (hereinafter referred to as the ECHR), which prohibits discrimination on persons with disabilities in their right to respect for private life, as well as the United Nations Convention on the Rights of Persons with Disabilities (hereinafter referred to as the CRPD), which stipulates that disabled persons have a right to health on an equal basis to others. These international obligations may also influence if the health care personnel can refuse to give medical treatment due to mental capacity and what their obligations are to those patients.

1.2 Purpose and Research Questions

The overall purposes of this essay are to examine how much the patient has to understand in order to give a valid consent and what the healthcare personnel's obligations are in relation to a patient who wishes to receive a medical treatment but who has not given a valid consent. To achieve this goal, I will analyse the following sub questions:

1. What constitutes a valid consent within the Swedish healthcare and can a patient with reduced decision-making capability consent?
2. If a healthcare personnel refused a patient medical treatment due to the patient having a reduced decision-making capability, would it interfere with the principle of legality?
3. If a medical treatment was refused on the basis of the patient lacking mental capacity to give a valid consent, would the healthcare personnel still fulfil their obligation of providing "good care" and would this contravene the principle of care with equal opportunities for the population?
4. If a medical treatment was refused on the basis of the patient lacking mental capacity to give a valid consent, would it constitute discrimination according to the DiskL?
5. If a medical treatment was refused on the basis of the patient lacking mental capacity to give a valid consent, would it interfere with Sweden's obligations in the ECHR, specifically Article 8 and 14?
6. If a medical treatment was refused on the basis of the patient lacking mental capacity to give a valid consent, would it interfere with Sweden's obligations in the CRPD, specifically Article 5, 12 and 25?

1.3 The Concept of Patients with Reduced Decision-Making Capabilities

When I use the term "patient with a reduced decision-making capability" in this thesis, what is referred to are patients who for various reasons, such as intellectual or psychosocial disability, cannot fully comprehend the meaning and the consequences of the information given to them. I make no distinction of whether this is temporary or permanent or what the causes behind it may be. However, in this thesis I assume that it is clear that the patient is consenting to the medical treatment but that it is doubtful whether they understand what they are consenting to.

1.4 Method and Material

1.4.1 Method

To answer my research questions, I have adopted a legal dogmatic method. This method uses accepted legal sources to answer what the applicable law is and how a legal rule should be perceived in a given context.² The method describes, systematizes and interprets the applicable law and does this principally from a judge's perspective.³ The legal dogmatic method attains its specific character from the relationship between an often abstract legal rule and the concrete situation where it is applicable.⁴ In my essay the main abstract legal rules that I study are Chapter 2 Section 6 of the Instrument of Government (hereinafter referred to as the IoG), which states the protection from forced bodily intervention, Chapter 4 Section 2 of the Patients Act (hereinafter referred to as the PL), which states that the patient has to consent to medical treatment, Chapter 3 Section 1 PL, which lists what information the healthcare personnel has to give, the legality principle in Section 5 of the Administrative Act (hereinafter referred to as the FL), the concept of "good care" that is found in Chapter 5 Section 1 of the Health and Medical Service Act (hereinafter referred to as the HSL) and the prohibition of discrimination found in DiskL. The international legal sources are primarily Article 8 and 14 of the ECHR (the right to respect for private life and the prohibition of discrimination) and Article 5, 12 and 25 of the CRPD (the prohibition of discrimination, the recognition of persons with disability having legal capacity and the right to health). All of the mentioned

² Korling & Zamboni (2013) p. 26.

³ Olsen (2004), pp. 111 & 113.

⁴ Ibid.

legal rules appear at first glance to be empowering from a patient's perspective, but do they really specify what the patient can expect from the healthcare personnel? The reason why I have chosen the legal dogmatic method is because the essay deals with concepts and obligations that are abstract by nature and the purpose of this essay is to break down these obligations in order to see what the healthcare personnel's obligations actually are and what the consequences are if they refuse to give a patient treatment on the basis of mental capacity.

However, the legal dogmatic method has been criticised for being too observant and focused on applying the law no matter if the result is ethical or not. The method is not interested in what the actual reality is like.⁵ In this essay I do not only describe the law, I also keep in mind what the actual, physical world is like and criticise the applicable law and to some extent discuss what the law should be, *de lege feranda*. The legal dogmatic method is not interested in *de lege feranda* which may cause troubles when the applicable law is complicated and hard to discern, as it is in some of the areas that this thesis examines.⁶ Therefore I will additionally adopt a legal analytical method. This method has been described as a continuation of the legal dogmatic method. It is focused on describing the applicable law but it is broader than the traditional legal dogmatic method as it allows one to analyse, and possibly criticise, the applicable law.⁷ In this essay I will criticise how the applicable law is sometimes too vague and creates room for personal interpretation.

1.4.2 Material

To answer the essay's questions, I study the legal norms by examining the legal sources that are considered as authoritative. These include statutes, preparatory works and precedents.⁸ I will also study legal doctrine which can give guidance when other legal sources are scarce. In Sweden, legal doctrine is not binding but can gain importance by its argumentation and it is not uncommon that it is referenced in rulings from the higher courts.⁹ The foremost of legal sources are the statutes¹⁰ and of these, the thesis will study the IoG and relevant health law, particularly the HSL and the PL. Additionally, I will also study the previous Health and Medical Service Act, which has been revoked, since many of the provisions in the current HSL

⁵ Olsen (2004), pp. 112, 116 & 117.

⁶ Olsen (2004), p. 117.

⁷ Sandgren (2018), pp. 50–51.

⁸ Lehrberg (2020) p. 101.

⁹ Bernitz (2020) p. 32.

¹⁰ Bernitz (2020) p. 30.

that I examine derive from this law and the preparatory works relating to this are relevant. I will also examine the FL and the DiskL. In order to understand and analyse the relevant provisions in the legal acts I will study relevant preparatory works, such as *propositioner* (bills of the Government) and *SOU reports* (inquiry reports). From an international perspective, Sweden attaches great importance and legal weight to these sources and one reason for this is that Sweden often uses a legislation technique where the provisions are relatively short and sometimes even vague but are complemented by explanations in the preparatory works.¹¹ The preparatory works in Sweden are therefore traditionally comprehensive.¹² However, the statements in these documents are not binding and can never substitute the meaning of a statute that is clear.¹³

Moreover, I will analyse the practices of various courts. A precedent from a higher court is not binding but is generally followed by other courts, especially if derived from The Supreme Court, The Supreme Administrative Court or the Labour Court.¹⁴ If a legal question has not been tried by the highest courts, a ruling from a court of appeal may have significance and I have studied some of these for further clarification.¹⁵ I have also examined decisions from the Parliamentary Ombudsmen (hereinafter referred to as the JO), from the Chancellor of Justice (hereinafter referred to as the JK), from the Health and Social Care Inspectorate (hereinafter referred to as the IVO), from the Medical Responsibility Board (hereinafter referred to as the HSAN) and from the Equality Ombudsman (hereinafter referred to as the DO). The JO is appointed by the Swedish parliament and their main task is to ensure that public authorities comply with the law. Their investigations are documented in a decision or protocol and although it is not legally binding, in practice the public authorities usually comply.¹⁶ The JK is a Swedish government agency that, inter alia, supervises authorities and civil servants. The IVO is a government agency responsible for, inter alia, supervising the healthcare sector and the healthcare personnel. The IVO handles complaints in the healthcare sector and can issue a non-appealable decision where they inform whether the healthcare personnel followed the law or other relevant regulations. The HSAN decides on matters of licensing and certification to practice medicine. The DO is a governmental agency that supervises compliance with DiskL and individuals can leave complaints to them which may result in a decision. It is important to stress here that the decisions from the JO, the JK, the IVO, the HSAN and the DO are not really

¹¹ Bernitz (2020) p. 31.

¹² Lehrberg (2020) p. 149.

¹³ Bernitz (2020) p. 31.

¹⁴ Lehrberg (2020) pp. 165 & 173.

¹⁵ Lehrberg (2020) p. 173.

¹⁶ Bernitz (2020) p. 158.

legal sources but they give us some insight as to how to understand the provisions that this thesis analyses.

When examining the thesis's sub question 5 I have analysed case law from the European Court of Human Rights (hereinafter referred to as the European Court). Sweden ratified the ECHR in 1952 and it is also stated in Chapter 2 Section 19 IoG that no act of law or other provision may be adopted which contravenes Sweden's undertakings under the ECHR. The member states are obliged to comply with the European Court's rulings and their case law has over the years grown exponentially and the ECHR is considered to be a living document that evolves its practices with the changing of the society.¹⁷ To study this thesis sub question 6 I have analysed preparatory works of the CRPD and jurisprudence from the Committee on the Rights of Persons with Disabilities (hereinafter referred to as the CRPD Committee). Sweden ratified the CRPD in 2008. The CRPD is a document of interest since it marks the point where human rights law, which has grown significantly since the end of the Second World War, started to take the rights of disabled persons seriously.¹⁸ Furthermore, the CRPD creates legally enforceable rights for disabled individuals and puts the focus on this as an entitlement of the individual rather than the State acting benevolently.¹⁹

1.5 Previous Research

The purposes of this thesis extend over several fields where similar research has been done. In 1994 Elisabeth Rynning wrote her dissertation on what constitutes consent from a legal perspective and when medical treatment can lawfully be given without the consent of the patient.²⁰ Rynning has also written about the demographic changes in Europe with a widening group of elderly patients, which will lead to a higher share of patients with declining cognitive functions.²¹ In one article she writes that there is a need for supportive measures for this demographic that aims to safeguard their medical treatment.²² Titti Mattson has also researched the group of elderly people with dementia and their autonomy.²³ Titti Mattson has also co-authored, with Linus Boström and Mats Johansson, an article which examines consent from patients with reduced decision-making capabilities

¹⁷ Bernitz (2020) p. 81.

¹⁸ Quinn, G. and Arnadóttir, O.M. (2009) p. 163.

¹⁹ Quinn, G. and Arnadóttir, O.M. (2009) pp. 165-166.

²⁰ Rynning (1994).

²¹ Rynning (2008).

²² Rynning (2008) p. 305.

²³ Mattson, T. and Giertz L (2020); Mattson, Titti (2013).

to participate in medical research.²⁴ The legislation that regulates medical research on humans does allow research to be done to patients who have not given a valid consent if certain conditions are met. The article shows that it is not clear which patients fall under the category of having a reduced decision-making capability in this legislation. Moreover, Yana Litins'ka has researched patients with reduced decision-making capabilities in her dissertation “Assessing capacity to decide on medical treatment: On human rights and the use of medical knowledge in the laws of England, Russia and Sweden”.²⁵ The dissertation evaluates and compares when the assessment of mental abilities to refuse, or consent to, somatic medical intervention is required in England, Russia and Sweden and what criteria must be applied to assess the ability to decide about somatic medical interventions in the legal orders of these countries.

In addition, this thesis studies whether refusing medical treatment due to the patient's mental capacity would interfere with the obligation to provide good care. Kavot Zillén has analysed another perspective of the obligation to provide good care, namely the obligation to provide good care while respecting the healthcare personnel's religious rights or freedoms.²⁶ One of Zillén's central questions is whether the healthcare personnel's conscientious objections could jeopardize the patient's right to the highest attainable care, specifically in regard to women's right to sexual and reproductive health. Furthermore, my thesis studies if refusing medical treatment could constitute discrimination. Discrimination due to disability has been studied by Andreas Inghammar in relation to work²⁷ and by Richard Sahlin in relation to education.²⁸ Sabina Hellborg has also written about discrimination in her dissertation, where she focuses on liability and compensation.²⁹

1.6 Delimitations

This thesis focuses only on adults who have a reduced decision-making capacity. Weighing in age and maturity, children have a more limited decision-making capability and the parents have a right to decide on issues regarding the child's personal matters, including healthcare.³⁰ Secondly, this thesis studies obligations that arise for the healthcare personnel when the

²⁴ Broström, L., Johansson, M. and Mattson, T. (2014)

²⁵ Litins'ka (2018).

²⁶ Zillén (2016).

²⁷ Inghammar (2007).

²⁸ Sahlin (2004).

²⁹ Hellborg (2018).

³⁰ See Chapter 6 Section 11 Föräldrabalk (1949:381) [The Children and Parental Code].

patient *has* consented to a medical treatment. Many of the provisions and principles that I examine also relate to negative autonomy, i.e. the right to refuse medical treatment, which I will not examine in this thesis. Thirdly, I will only focus on somatic healthcare and have consequently excluded psychiatric care and dental care. Fourthly, I will not study cases where the will of the patient cannot be determined.³¹ Fifthly, I will only examine healthcare that is covered within HSL. For example, plastic surgeries for aesthetic purposes are generally not included.³² Sixthly, another factor that is relevant when determining whether a patient has a right to medical treatment, and which I will not examine, is whether it is in accordance with "science and proven experience".³³

Lastly, I had to make delimitations in regard to international sources due to the scope of this thesis and the purpose of it. I decided to examine the ECHR because it has a central standing in Swedish law as no act of law or other provision may be adopted which contravenes Sweden's undertakings under the ECHR.³⁴ Furthermore, I decided to study the CRPD since its concept of legal capacity, and what shall be included in the concept, has been debated and the CRPD Committee has made statements in this regard that are a departure from how persons with disability have historically been viewed. However, there are other legal sources that enshrines a right to health, such as the European Social Charter (article 11 and 13), the European Code of Social Security (article 7 to 12) and the International Covenant on Economic, Social and Cultural Rights (article 12). Moreover, the Council of Europe has issued the Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine. This convention is the first internationally legally binding instrument that formalised the rule that medical intervention cannot be carried out on a person without that person's prior consent. However, Sweden has signed it but not ratified it.

³¹ See for example Chapter 4 Section 4 PL which allows the healthcare personnel to give medical treatment when the wishes of the patient cannot be established, in order to ward off immediate and serious danger that threatens the patient's life or health.

³² For more information on this, note particularly prop. 2020/21:57, which the government handed over to the Parliament in December 2020.

³³ Prop. 1981/82:97 p. 116; Chapter 6 Section 1 Patientsäkerhetslag (2010:659) [Patient Safety Act]; Chapter 1 Section 7 PL. This concept has been discussed in academic writing due to it not always being easy to define. For further reading on this issue: Wahlberg, L. and Sahlin, N.-E. (2017); Persson, J., Anttila, S. and Sahlin, N.-E. (2018).

³⁴ See Chapter 2 Section 19 IoG.

1.7 Outline

In Chapter 2 of this thesis I will answer sub question one and two, i.e. what constitutes valid consent and would refusing medical treatment due to mental capacity interfere with the principle of legality? In Chapter 3 I will answer the third sub question, i.e. if the healthcare personnel would still fulfil their obligation to provide good care and care with equal opportunities if they refused medical treatment due to mental capacity. Chapter 4 of the thesis will examine discrimination law in Sweden in order to answer the fourth sub question. In Chapter five I will study if refusing medical treatment due to mental capacity would interfere with Sweden's obligations in the ECHR and the CRPD and thus answering the fifth and sixth sub questions. In Chapter 6 I will give an analysis on the conclusions that I have made and relate it to the dilemma of the healthcare personnel mentioned in Section 1.1 as well as I will relate it to the interests of the patients with reduced decision-making capabilities. Lastly, I will have a conclusion in Chapter 7.

2 A Valid Informed Consent

2.1 Introduction

In this chapter I am going to address the thesis first sub question, i.e. what constitutes a valid consent within the Swedish healthcare and if a patient with a reduced decision-making capability can consent to medical treatment. Firstly, I will investigate the concept of consent within the healthcare sector by examining Chapter 2 Section 6 IoG and Chapter 4 Section 2 PL. In order for a consent to be considered as valid it has to be preceded by information and I will therefore in Section 2.3 explain what kind of information that has to be given and how it must be adjusted to the recipient. In this section I will also examine Chapter 3 Section 7 PL, which stipulates that the healthcare personnel must ensure, as far as possible, that the patient understands the information given to them. In this essay's chapter I will additionally address the thesis second sub question: if a healthcare personnel refused medical treatment due to the patient having a reduced decision-making capability, would it interfere with the principle of legality? The principle of legality entails that interventions against an individual must be based on law and I will study this in Section 2.4. Lastly, in Section 2.5 I will outline what conclusions I have made regarding the essay's sub questions 1 and 2 and have a discussion on consequences of requiring a certain level of mental capacity in order to give a valid consent.

2.2 Consent

2.2.1 Chapter 2 Section 6 IoG

The obligation to obtain consent before a medical procedure is essentially derived from Chapter 2 Section 6 IoG, which stipulates that everyone shall be protected in their relations with the public institutions against any physical violation to their person. The right to be protected from forced bodily interventions may be limited if it is prescribed by law and only to satisfy a purpose acceptable in a democratic society and if the limitations never go beyond what is necessary with regard to the purpose which occasioned it. Furthermore, the limitation must not constitute a threat to the free shaping of opinions and the limitations cannot be imposed solely on grounds of political, religious, cultural or other such opinion.³⁵ *Bodily*

³⁵ See Chapter 2 Sections 20 and 21 IoG.

interventions included in Chapter 2 Section 6 IoG do not only include torture and whipping but also vaccination, blood sampling and other forced medical examinations.³⁶ Other bodily interventions that have also been included are urine samples,³⁷ rectal- or vaginal examinations,³⁸ submitting to drug tests³⁹ and leaving saliva for DNA-testing.⁴⁰ Reiterating my example from the essay's first chapter of taking strong medication for acne, this would probably also be considered as a form of bodily intervention.

Moreover, for an intervention to be prohibited it has to be *forced*. An intervention is considered forced if the public institutions use violence for enforcement, threats of sanctions, or if the person representing the public institution acts in a manner that leads the person to feel pressured to submit.⁴¹ However, in regard to some interventions, such as being restrained to a bed with belts, the JO has expressed that even though the patient consents to it, there has to be support for it in the law.⁴² The opposite of forced is voluntary, but when is a bodily intervention considered to be voluntary? When it is uncertain if the intervention is voluntary it has been expressed in doctrine and by the JO that one must consider the specific situation, the information that the individual has received about their possible courses of action, and the individual's ability to make an informed decision about the issue in question.⁴³

The JO has addressed the issue of voluntariness in regard to Chapter 2 Section 6 IoG in their decisions. In one of these, regarding leaving urine samples, the JO states that whether or not someone has given consent to bodily intervention that is based on authentic voluntariness might be hard to assess but that it is important to provide clear information so that the individual truly understands the prerequisites and terms of what they consent to and the options that the person has.⁴⁴ In another decision from the JO, regarding requiring all patients to leave urine samples in order to get medication for ADHD, the JO expresses that even if the patient consents to the bodily intervention it might still under some circumstances be considered as not voluntary.⁴⁵ In this case, the JO uses as an example underlying threats or the governmental agent acting in a threatening manner.

³⁶ Prop. 1973:90 p. 242; prop. 1975/76:209 p. 147; AD 1984 nr 94.

³⁷ JO 2009/10 p. 39; JO 2011/12 p. 471; JO beslut den 7 april 2021, dnr. 603–2020; JO 2020/21 p. 115.

³⁸ JO 1984/85 p. 227.

³⁹ JO 2016/17 p. 548.

⁴⁰ JK 5263-09-21, beslut den 10 november 2010.

⁴¹ JO 2010/11 p. 509; JO 2011/12 p. 471; JO 2003/04 p. 72; JO 2020/21 p. 115.

⁴² JO 2008/09 p. 338.

⁴³ Bull & Sterzel (2019) p. 72; JO 2020/21 s. 115.

⁴⁴ JO 2016/17 s. 500.

⁴⁵ JO 2020/21 s. 115.

Furthermore, the JO writes that in order for the intervention to be considered as authentically voluntary then the individual has to have been given information, in a manner that is understandable for them, about the intervention so that it is clear to the individual what their options are and so they can make a well-founded decision. The JO has also expressed in one of their decisions that when someone is at a disadvantage then the bar must be set high to ensure that the consent to bodily intervention is voluntary.⁴⁶

Chapter 2 Section 6 IoG is mainly focused on the negative autonomy, i.e. the right to be protected *from* bodily interventions. But should a medical intervention be considered as forced if the consent derives from a patient with a reduced decision-making capability who may not have understood what they consented to? Rynning has argued that this should not be considered as being forced.⁴⁷ She considers that the situation of an individual who does not have the ability to understand enough information and survey the consequences is not in an equal situation to an individual who, because of the actions of other people, is not given the opportunity to decide for themselves.⁴⁸ Litins'ka has also discussed this but in relation to when capacity assessments can be considered as forced.⁴⁹ Litins'ka concludes that capacity assessment procedures may be seen as forced bodily interventions not only when a patient refuses to undergo them but also when the patient feels that they do not have a choice to refuse or when they are threatened with sanctions if they do refuse. However, if there is explicit consent to undergo capacity assessment it is very unlikely, according to Litins'ka, that it would be considered to be forced.⁵⁰

The issue of whether or not to refusing medical treatment due to mental capacity would constitute a forced medical intervention is hard to give a definite answer to. On the one hand, Chapter 2 Section 6 IoG is a fundamental right and it should therefore not be easily circumvented. Furthermore, one can understand the reasoning of being able to understand in order to consent, and if the patient has not understood to a certain degree then surely it cannot be considered as a valid consent and it thus constitutes forced bodily intervention. On the other hand, is not the purpose of Chapter 2 Section 6 IoG mainly to protect individuals from having to, inter alia, be subject to medical treatments against their wishes, and that the objective in the provision is not to possibly undermine the wishes of people with

⁴⁶ JO 2018/19 p. 681.

⁴⁷ Rynning (1994), p. 110.

⁴⁸ Rynning (1994), p. 110.

⁴⁹ Litins'ka (2018), pp. 458-461.

⁵⁰ Litins'ka (2018) pp. 460-461.

reduced decision-making capabilities? Furthermore, if we conclude that it would be considered as forced bodily intervention, then we would also remove the legal capacity of the patient. On this issue, Sweden has international obligations that they must respect, which I will discuss further in Chapter 5. Furthermore, if we conclude that it may be forced, then we would additionally have to answer at what point the patient has sufficient understanding so it will not be considered as forced bodily intervention.

2.2.2 Chapter 4 Section 2 PL

When PL came into force in 2015 the requirement for the patient's consent was explicitly stated for the first time in Chapter 4 Section 2. Although the concept of consent was by no means new and in a proposition from the 1980s it was expressed that it was essential with regard to results in healthcare that the care was given in an atmosphere of mutual understanding and collaboration between the healthcare personnel and the patient. It was also noted that if the patient wishes to refrain from undergoing medical treatment this has to be respected.⁵¹ However, the patient's autonomy and integrity, according to the preparatory works of the older HSL, was not by any means absolute and it was expressed that it was not possible for the patient to decide the content and the extent of the healthcare.⁵²

According to Chapter 4 Section 2 paragraph 2 PL consent can be given in writing, orally or if the patient acts in a manner that shows that they consent to the procedure in question. The patient can show their consent by, inter alia, facilitating a blood test or asking when a medical procedure is to be taken place.⁵³ In order to consent to medical treatment it has to be based on real voluntariness and medical treatment cannot be performed if there are threats of sanctions or other forms of pressures. Before the patient can give a valid consent, they have to be given information about different options of treatments.⁵⁴ The healthcare personnel must also inform the patient of the purpose of medical testing, if one is to take place.⁵⁵ A patient has a basically unlimited right to abstain from getting medical treatment, even though it is medically necessary.⁵⁶ A form of pressure that may render a consent to be considered as forced is requiring the patient to consent to the caregiver gathering information from other government agencies in order to obtain

⁵¹ Prop. 1981/82:97 p. 118.

⁵² Ibid.

⁵³ Prop. 2013/14:106 p. 57; SOU 1984:64 p. 176

⁵⁴ JO 2016/17 p. 110; prop. 2013/14:106 p. 57.

⁵⁵ HSAN 643/82, LT 1984:472; HSAN 125/83:1, ref. 4:37/1984; HSAN 864/88, LT 1990:4241.

⁵⁶ HFD dom den 20 februari 2017 i mål nr. 2310–16.

medical treatment.⁵⁷ Another form of pressure that may question the voluntariness of the consent is having to accept rules such as not leaving the health facility in order to receive voluntary psychiatric care.⁵⁸ However, it must also be possible to prove that the patient gave their consent because they were pressured.⁵⁹

In some cases, the patient can be conflicted when expressing their will. The preparatory works do not give much clarity on what the healthcare personnel's obligation are in these instances. However, it has been suggested in legal doctrine that it is within the healthcare personnel's obligations to investigate further the patient's will and possibly give the patient more time and/or information.⁶⁰ In addition to various ways to show consent, the consent has to be given freely and can be revoked at any moment.⁶¹ One area that may render uncertainties is the issue on what the patient actually consents to. A patient will, normally, never fully understand a treatment or a surgery due to lack of medical education and experience. So, what can the patient actually consent to? Rynning discusses this in her dissertation and concludes that some procedures must be considered covered by the general consent to a certain treatment. In the case of an appendix surgery the general consent would include, inter alia, the opening of the abdomen, the removal of the appendix, stitching up the abdomen, the occurrence of scarring and the risk of complications such as fever.⁶² The Supreme Court has also discussed the issue of what the patient consents to in one case where the doctors cut off a nerve fibre during a surgery without informing the patient about the possibility of this complication prior to the surgery.⁶³ The court wrote that a patient consenting to a certain surgery does not mean that the patient also has consented to all the medical procedures with the purpose of curing the patients disease. However, the court also writes that some medical interventions must be able to be undertaken with the support of consent to the surgery in question. The court did not specify this further.

In Chapter 4 Section 2 PL it is written that healthcare cannot be given without the *patient's* consent. Furthermore, Chapter 2 Section 6 IoG writes that "everyone" is protected from forced bodily interventions. Thus, the

⁵⁷ JO 2017/18 p. 99.

⁵⁸ JO 2019/20 p. 132.

⁵⁹ See HSAN 2008/1207:A3 beslut den 5 maj 2009, where a man complained that he had been forced to participate in a study in order to obtain care for his diverticulitis. The HSAN only stated that in this case it was word against word and the complaint was left without action.

⁶⁰ Rynning (1994) pp. 323–324.

⁶¹ See Chapter 4 Section 2 paragraph 3 PL; HSAN 2008/1036:B6 beslut den 19 september 2008.

⁶² Rynning (1994) pp. 327–328.

⁶³ NJA 1990 s. 442.

consent must derive from the person who is being subjected to a bodily intervention. SOU 2015:80 introduced a bill that would allow the use of guardianship when the patient does not have the ability to decide on matters relating to their healthcare. Although it is emphasized in the SOU that the patient, as far as possible, should be given individually adjusted information and support in order for them to safeguard their own right to decide on health matters and only when this is insufficient shall a guardian be appointed.⁶⁴ The SOU also included a list of criteria when assessing whether the patient lacks decision-making capability.⁶⁵ This SOU has not however resulted in a bill.

2.3 Information

Before the healthcare personnel obtain the consent from the patient, they have to give the patient adequate information.⁶⁶ The information that is given has to be objective, clear and comprehensive enough in order for the patient to be able to make a well-founded decision.⁶⁷ Unfortunately a lot of patients report that they have not been given sufficient information.⁶⁸ The obligation to provide information has only been statutory since 1999, although it was described before in the preparatory works.⁶⁹ The responsibility to disclose information to the patient lies, firstly, with whoever has the direct responsibility for the care situation that the information refers to.⁷⁰ However, it is the caregivers responsibility to organize the healthcare in a manner that enables the healthcare workers to give the information.⁷¹ To give information about the patient's state of health and the planned medical procedures is a way to ensure that the requirement for the patient's consent has a de facto meaning.⁷² It is also mentioned that giving the patient information will have a decisive impact on the patient's opportunity to exercise their autonomy and to be part of their care. In gaining a deeper understanding from the information given, the patient has the possibility to analyse and make active choices between

⁶⁴ SOU 2015:80 p. 37.

⁶⁵ SOU 2015:80 pp. 370–382.

⁶⁶ See Chapter 4 Section 2 PL; Chapter 6 Section 6 Patientsäkerhetslag (2010:659) [Patient Safety Act].

⁶⁷ JO 2016/17 p. 110.

⁶⁸ *Lag utan genomslag; utvärdering av patientlagen 2014–2017* (2017), Stockholm: Myndigheten för vård och omsorgsanalys, p. 54–59.

⁶⁹ Prop. 1998/99:4 pp. 24.

⁷⁰ Ibid.

⁷¹ Prop. 2013/14:106 pp. 47–48.

⁷² Prop. 1978/79:220 p. 44.

different medical procedures.⁷³ Something that is mentioned in an older inquiry report and that Rynning discusses is that the information is not given in order for the patient to be able to make a *medical* decision, rather for the patient to be able to make a *personal* decision. The patient does not have to understand advanced medical-technical procedures to understand their practical consequences and what procedures and risks they are willing to be subjected to.⁷⁴

The sort of information that the healthcare personnel has to give is regulated in the third chapter of PL. The first section offers some examples, such as informing about existing methods for treatment, but these examples are not exhaustive. It is also stressed in the preparatory works that the information given should be adapted to the current situation.⁷⁵ The need for information may vary depending on the patient, the patient's state of health, the character and degree of difficulty of the disease, and other factors. The extent of the information given may therefore differ between patients. In the case of prescribing strong medication for acne relevant information would include the importance of taking it routinely for it to have effect and the recommendation to avoid sun, alcohol and getting pregnant. The obligation to provide information about essential risks for complications has been tried by the Appeal Court of Lower Norrland in a case where a man suffered from problems with regurgitation after a surgery and complained about lack of information.⁷⁶ The appeal court found that the patient had not received enough information to have given a valid consent since it was only noted in the patient's medical records that he had been informed about the procedure and that it would hurt in the future and because the doctor in question told that this complication was *generally* disclosed.

When giving the information it should not be given routine-like but rather adjusted for the recipients age, maturity, experience, language knowledge and other individual conditions. The latter includes factors such as disabilities, education, gender identification and other circumstances that may affect how information should be given.⁷⁷ According to Chapter 3 Section 7 paragraph 2 PL information shall be given in writing to the patient if it is necessary considering the recipients individual conditions or if the patient ask for it. The JO has even stated that it might be possible to record the meeting.⁷⁸ With regard to patients with reduced decision-making

⁷³ Prop. 2013/14:106 pp. 37 & 47; SOU 2013:2 p. 65; prop. 1998/99:4 pp. 23 and 49; Rynning (1994) p. 185.

⁷⁴ SOU 1977:66 pp. 93-94; Rynning (1994) p. 187.

⁷⁵ Prop. 2013/14:106 p. 114.

⁷⁶ Hovrätten för nedre Norrland dom den 3 mars 1999 mål nr. T 239/96.

⁷⁷ See Chapter 3 Section 6 PL; prop. 2013/14:106 p. 53.

⁷⁸ JO 2016/17 p. 107.

capabilities, this means that healthcare personnel have to adjust the information in regard to the *specifics* of why the patient is considered to have a reduced decision-making capability. For example, if the patient is considered to have a reduced decision-making capability due to them having some sort of diagnosis that makes it hard for them to concentrate, this would mean that the healthcare professionals should give the information in a room with fewer distractions, writing down the information and giving it to the patient more than one time with pauses in between.

The healthcare personnel do not only have an obligation to give information to the patient but also, according to PL Chapter 3 Section 7, an obligation to ensure that the patient, as far as possible, *understands* the information. Whoever gives information to the patient must ensure that the recipient can evaluate the information and is obligated to give active guidance and to ensure that the patient has enough information to be able to exercise their autonomy.⁷⁹ However, what this actually entails is unclear and neither the preparatory works nor the JO give much insight. The IVO has found in their decisions that the caregiver has disregarded the obligation to ensure that the patient understands the information but these decisions are generally very short and do not give us much insight on the extent of Chapter 3 Section 7 PL. The IVO is also somewhat contradictory when it comes to situations where it is unclear what information the patient was given. In some cases, they conclude that they struggle to judge whether a breach of Chapter 3 Section 7 PL has occurred because of lack of information in the medical records.⁸⁰ In other cases, the IVO concludes that despite the lack of clarification it is still clear that the patient had not understood.⁸¹ In one case the IVO criticized a doctor for not fulfilling Chapter 3 Section 7 PL because he had given the information to the patient when they had received anaesthetic.⁸² In another case, the IVO criticized the doctor for putting the patient through an extensive test that demanded knowledge in Swedish, even though the doctor had pointed out that it was unclear if the patient needed an interpreter.⁸³ The IVO has also stated that it is even more important to ensure that the patient understands the information given when an unexpected complication has occurred.⁸⁴ The HSAN has also discussed the issue of understanding the information, in relation to language

⁷⁹ Prop. 2013/14:106 p. 53.

⁸⁰ IVO Dnr. 8.2–6128/2016–20 beslut den 20 september 2017; IVO Dnr. 8.2.1–39462/2019–32 beslut den 2 december 2020.

⁸¹ IVO Dnr. 8.2–18076/2017–20 beslut den 10 augusti 2018; IVO Dnr. 8.2.1–41785/2018–17 beslut den 10 juli 2019.

⁸² IVO Dnr. 8.2–18083/2016–12 beslut den 12 september 2016.

⁸³ IVO Dnr. 8.2–18981/2017–17 beslut den 3 september 2018.

⁸⁴ IVO Dnr. 8.2–23972/2017–13 beslut den 12 december 2017.

proficiency.⁸⁵ In this case the HSAN noted the risks of misunderstandings when the patient does not really understand Swedish and that under these circumstances it is paramount to make sure that the patient understands.

Lastly, there is also a provision in PL that outlines that the patient has a right to not be informed.⁸⁶ This follows from the obligation to provide individually adjusted information.⁸⁷ However, it is not expressed in the proposition or the SOU⁸⁸ to PL how this affects the validity of the consent. Neither does the JO, the JK, the IVO or the HSAN give us any insight on this.

2.4 The Principle of Legality

In this section I am going to answer the question of whether or not a healthcare personnel refusing medical treatment due to mental capacity would go against the principle of legality. I will discuss this both in relation to inappropriate influence and forced bodily intervention. I will also briefly discuss the principle of objectivity. The assessment of whether the patient can give a valid consent or not should be viewed as a decision within the public law meaning and thus the principle of legality expressed in Section 5 FL and Chapter 1 Section 1 paragraph 3 IoG is relevant.⁸⁹ Moreover, it is expressed in Chapter 2 Section 20 IoG that forced bodily interventions are allowed if it is prescribed by law. The principle of legality is generally defined as a requirement that interventions against individuals have to be based on law.⁹⁰ The principle of legality is also expressed in Article 8(2) of the ECHR which stipulates that interferences in the enjoyment of the right to respect for private life are allowed if it is in accordance with the law.

Regarding Chapter 2 Section 6 IoG it would go against the principle of legality to force a patient to undergo a medical treatment against their wishes. But is there legal support to refuse to give a medical treatment due to the patient having a reduced decision-making capability? To answer this question, we have to examine what influence from the healthcare personnel that can be allowed. The healthcare professionals will normally influence the patient and their opinion will often carry great weight. The question is to what extent the healthcare personnel may influence a patient before there is

⁸⁵ HSAN 906/86, LT 1988:1077.

⁸⁶ See Chapter 3 Section 6 paragraph 2 PL.

⁸⁷ Prop. 2013/14:106 p. 53.

⁸⁸ SOU 2013:2.

⁸⁹ Litins'ka (2018) pp. 452-455; prop. 2016/17:180 pp. 33ff; Lotta Vahlne Westerhäll (2019).

⁹⁰ Prop. 2016/17:180 p. 57.

an issue of whether or not the patient is still expressing their own consent. None of the provisions in HSL or PL tells us how to answer this question. The JO has not tried the principle of legality in relation to the healthcare personnel influencing the care in an inappropriate manner. Most of the decisions from the JO relating to the principle of legality in the healthcare sector deals with restricting the possession of personal items in psychiatric wards.⁹¹ When researching what the IVO has expressed in relation to the principle of legality, nothing shows up.

Rynning distinguishes in her dissertation between influence that is acceptable and influence that is inappropriate. A healthcare personnel may try to impel the patient to consent to a certain procedure by explaining the negative consequences that occur if they avoid the procedure or the disadvantages if they chose an alternative procedure. As long as the information is not deceptive and is given with respect to the patient's autonomy such influence is acceptable.⁹² By contrast, a consent preceded by fake information or pressures in the form of threats or other unacceptable sanctions can never be valid. Neither is the consent acceptable if the patient is under the erroneous impression that they have to submit to the procedure.⁹³ If the healthcare professional however influence to the extent that the patient is refused the medical treatment that they desire, then this has to be considered as inappropriate influence because the patient has been stripped of their autonomy.

To answer the question of whether or not refusing medical treatment due to the patient having a reduced decision-making capability would interfere with the principle of legality we have to discuss if giving medical treatment without an informed consent would constitute forced bodily intervention. If we consider that giving medical treatment without an informed consent would constitute forced bodily intervention then Chapter 2 Section 6 IoG is clear that it is not allowed and it would not contravene the principle of legality to refuse medical treatment. But if we do not consider that giving medical treatment without an informed consent would constitute forced bodily intervention, then the legal sources regarding the patient's consent are clear that there is no requirement that the patient has to have a certain mental capacity. Thus, it may then interfere with the principle of legality to refuse to give medical treatment to them.

⁹¹ See for example in JO 2021/21 p. 77; JO 2015/16 s. 498; JO beslut den 18 mars 2021, Dnr. 4225–2019.

⁹² Rynning (1994) p. 332.

⁹³ Rynning (1994) p. 341–342.

Furthermore, refusal of medical treatment may also go against the principle of objectivity. The principle of objectivity is found in Section 5 FL as well as in Chapter 1 Section 9 IoG. This principle entails an obligation to act objectively and impartially and to respect that everyone is equal before the law.⁹⁴ The principle of objectivity stresses that discriminatory treatment is not allowed. Thus, the healthcare personnel have an obligation to not treat patients with reduced decision-making capabilities differently according to this principle. Included in this principle is not only the processing of the matter or the reasons behind a governmental decision but also how the government's acting was perceived. It is enough if there are objective objections, based on how it is perceived from the outside, in order for the principle of objectivity to be applicable.⁹⁵ It is also enough that there is a risk it not being handled objectively.⁹⁶

2.5 Discussion

Regarding the question of what constitutes a valid consent I have explained that it derives from Chapter 2 Section 6 IoG and is expressed in Chapter 4 Section 2 PL. I explained that it can be given in writing, orally or if the patient acts in a manner that shows that they consent. I also stated that it may be revoked at any time. Additionally, I explained the importance of individually adjusted information before obtaining the consent. Regarding the question of if a patient with a reduced decision-making capability can consent, none of the legal sources I have examined has answered this question specifically. Even if the healthcare personnel have an obligation to ensure that the patient understands the information, it is unclear what this actually entails. It is however, nowhere stated that there is a threshold of a certain level of mental capacity in order to give a valid consent. It is stated in PL that the healthcare personnel have to ensure that the patient, as far as possible, understands the information given. However, the healthcare system in Sweden is based on obligations for the healthcare personnel and thus this should be interpreted as an obligation for the healthcare personnel and not a requirement of consent for the patient. In this chapter I have thus concluded that a patient with a reduced decision-making capability should be able to give a valid consent and that *only* if we considered that giving medical treatment without a valid consent would constitute a forced bodily intervention would we come to the conclusion that they cannot consent. Furthermore, if we assumed that it would constitute a forced medical

⁹⁴ Prop. 2016/17:180 pp. 50-60.

⁹⁵ Bull & Sterzel (2019) pp. 54-55; JO beslut den 7 september 2020, Dnr. 4141-2018.

⁹⁶ Bull & Sterzel (2019) p. 55; JO beslut den 7 september 2020, Dnr. 4141-2018; JO 2015/16 p. 456.

intervention, then it would not go against the principle of legality to refuse to give medical treatment.

When discussing the issue of a valid consent, we must also examine what we consider to be a valid, informed consent. If we concluded that it would constitute forced bodily intervention to give medical treatment without a valid consent, then we would also have to answer at what point the consent is considered to be valid. This question is difficult to answer considering that there is not much guidance on the level of understanding that the patient has to have for the consent to be valid. A patient will normally not have the same medical knowledge and experience as a healthcare professional or possibly an individual with a profound medical interest. The question is how much the patient has to understand? Let me illustrate with the following scale:

Completely understands ————— Understands nothing

In some circumstances the patient is a heart surgeon who has to undergo heart surgery and they will be on the far-left side of the line. But this is not the case for most patients. Here I want to reiterate that Rynning outlined in her dissertation that the purpose of giving information is to ensure that the patient can make a *personal* decision and not a *medical* decision. Thus, the question of whether the patient gives a valid consent should not be based on whether they understand all the medical technicalities but rather whether the patient understands the risks, benefits and consequences of the medical intervention on their personal life. Thus, if we concluded that the patient has to reach a certain level of mental capacity in order give a valid consent then we would have to decide where on the scale we place a valid informed consent. This would probably also change depending on the medical treatment in question. This is a legal question that is highly influenced by society and the norms that are prevalent in that society.

Lastly, I want to return to an article by Titti Mattson, Linus Boström and Mats Johansson that I mentioned under "Previous Research" regarding consent to medical research from patients with reduced decision-making capabilities. In the article it is mentioned that the purpose of allowing medical research on these patients is that otherwise medical research would be defective and it would complicate the care of these patients.⁹⁷ This illustrates that there might be other interests at stake when determining whether one should simply rule out a consent as invalid. In regard to

⁹⁷ Broström L., Johansson, M. and Mattson, T. (2014) p. 172–174; prop. 2002/03:50 pp. 141–142.

patients with reduced decision-making capability desiring acne treatment one such interest is obviously their self-determination. In the article, the authors write that the assessment of if the patient can make a competent decision may vary depending on the situation and that the society's choice of criteria will be determined by what mistakes are considered to be least serious to commit, whether it be overprotectiveness (and potentially violation) these persons or to not adequately protect them.⁹⁸ This is also an interesting factor in if it is possible to refuse to give medical treatment due to mental capacity. What mistakes are we willing to let people, and particularly people with disabilities, make?

⁹⁸ Broström L., Johansson, M. and Mattson, T. (2014) p. 181.

3 Good Care With Equal Opportunities

3.1 Introduction

In this chapter I am going to answer the following question: if a medical treatment was refused on the basis of the patient lacking mental capacity to give a valid consent, would the healthcare personnel still fulfil their obligation to provide good care and would it contravene the principle of care with equal opportunities for the population?⁹⁹ In order to do this, I am first going to explain how the concept of "good care" is described and I will mainly focus on the concept of patient-oriented care. Secondly, I will study what the concept of care with equal opportunities for the population entails. Care with equal opportunities is pertinent to examine since the essay's overall purpose is to examine whether people with reduced decision-making capabilities has access to the same care as others. Lastly, I will provide a conclusion in Section 3.4. With both the obligation to provide good care that is patient-oriented and the obligation to provide care with equal opportunities for the population there is one aspect that weakens the patient's position: the fact that these are not enforceable rights the patient can invoke in court but are instead obligations for the healthcare personnel. This means that the Swedish courts have not tried these provisions.¹⁰⁰ The IVO exercises supervision over the healthcare sector and has discussed good care and care with equal opportunities for the population in their decisions. However, in their decisions, these obligations are generally only stated but not specified further. The JO does mention the obligation to provide good care in some of their decisions but does never really describe what this entails.¹⁰¹ Therefore, in this section the legal sources mainly emanate from the preparatory works.

⁹⁹ In Swedish the terms used are "god vård" and "vård på lika villkor för hela befolkningen".

¹⁰⁰ In SOU 2013:2 p. 159 the pros and cons of having enforceable rights are discussed. In *Lag utan genomslag: utvärdering av patientlagen 2014-2017* (2017) it is suggested to include at least some enforceable rights.

¹⁰¹ Some decisions where JO mentions "good care" but does not explain it: JO beslut 4 juni 2020, Dnr. 2050-2018; JO 2018/19 p. 98; JO 2017/18 p. 99

3.2 The Obligation to Provide Good Care

3.2.1 In General

The obligation to provide good care is stated in Chapter 5 Section 1 HSL, which stipulates that healthcare activities shall be conducted in a manner that ensures that the requirement to provide good care is satisfied. Section 1 further lists the five aspects this entails, which can be divided into two categories. The first category covers the healthcare provider's obligation to provide healthcare of a certain level of quality. This requires a certain personnel standard (e.g. requiring applying to obtain the title of physician) and a certain material standard (e.g. technical equipment and proper facilities).¹⁰² It also includes the requirement that all medical care is in accordance with science and proven experience and that it is of good hygienic standard.¹⁰³ The second category of good care is that it is patient-oriented and I will discuss this below in order to examine the balancing act of refusing a medical treatment after an inspection of the patient's mental capacity, while at the same time having a responsibility to provide a patient-oriented care.

3.2.2 Patient-Oriented Care

In an SOU preceding the current HSL, having a list of what good care entails was discouraged as the definition of good care may vary over time and that a list would risk resulting in a narrow interpretation.¹⁰⁴ However, in the proposition to the current HSL it was described that these concerns would not be a problem since the list is not exhaustive and that it is clear for the parties concerned that the requirements of good care are complex.¹⁰⁵ The list of good care was included already in the older HSL, first as an obligation directed at specifically the county council¹⁰⁶ but since 1985 as an obligation for everyone that offers healthcare in Sweden.¹⁰⁷ With the introduction of the current HSL the provision was transferred with only linguistic and editorial changes. Chapter 5 Section 1 HSL introduces different aspects of patient-oriented care. The first aspects of patient-oriented care are meeting the patient's needs for security, continuity and

¹⁰² Prop. 1981/82:97 p. 116; prop. 1984/85:181 pp. 94–95.

¹⁰³ See Chapter 5 Section 1 paragraph 1 HSL. For more information on demanding a certain hygienic standard in order to prevent the occurrence and proliferation of antibiotic resistant bacteria see proposition 2005/06:50.

¹⁰⁴ SOU 2013:44 p. 103; prop. 2016/17:43 pp. 94–95.

¹⁰⁵ Prop. 2016/17:43 p. 95.

¹⁰⁶ In prop. 1981/82:97 it is included in the third paragraph, see p. 114.

¹⁰⁷ See Paragraph 2 § in prop. 1984/85:181.

safety, as well as promoting good relations between the patient and the healthcare personnel. Two examples of this are ensuring that the patient meets the same healthcare personnel as much as possible and the obligation to keep patient records.¹⁰⁸ Another aspect of patient-oriented care is that it is easily accessible. This does not only relate to geographic distances but other examples are the opening hours, the queueing system, on-call duty and direct phone calls.¹⁰⁹

The aspect of a patient-oriented care that is most relevant to this essay's purposes is that it is built on respect for the patient's autonomy and integrity. As described in the previous chapter the whole basis of giving medical treatment is that the patient has consented to it. However, some patients feel that this is not the case and it is therefore expressed in the proposition to the older HSL that it is urgent to ensure that the patient is aware of their autonomy.¹¹⁰ In line with respecting the patient's autonomy and integrity, and a way for the patient to exercise this, is the healthcare personnel's obligation to provide healthcare in consultation with the patient. In order for healthcare to be given in consultation with the patient, the healthcare professionals have to give as thorough information as is necessary and stimulate the patient to earnestly seek information, scrutinize it and then adapt the information to their individual situation.¹¹¹ However, a recent report disclosed that the patient does not always have a participatory role, as was described in the preparatory works.¹¹² The respect for the patient's autonomy and integrity is not absolute, unless with reference to the right to abstain from getting medical treatment. The patient does not have an absolute right to determine the content and extent of the care given and can, for example, never use this provision as an argument to get euthanasia.¹¹³ The healthcare professional does not have an unconditional duty to offer the patient the treatment or examination that they desire. It is the healthcare professional who judges if a certain examination or treatment is necessary and they can refuse to give this if they consider that it is not necessary or does not have purpose.¹¹⁴ For example, a healthcare personnel cannot perform an insemination if a woman's medical conditions are not suited for this.¹¹⁵

¹⁰⁸ Chapter 3 Sections 1 and 2 Patientdatalagen (2008:355) [the Patient Data Act].

¹⁰⁹ Prop. 1981/82:97 pp. 57 & 117; prop. 1984/85:181 p. 18.

¹¹⁰ Prop. 1981/82:97 p. 58; *Lag utan genomslag; utvärdering av patientlagen 2014-2017* (2017), Stockholm: Myndigheten för vård och omsorgsanalys, p. 61.

¹¹¹ Prop. 1981/82:97 pp. 58–59.

¹¹² *Lag utan genomslag; utvärdering av patientlagen 2014–2017* (2017), Stockholm: Myndigheten för vård och omsorgsanalys, pp. 64–65.

¹¹³ Prop. 1981/82:97 pp. 117–118.

¹¹⁴ Prop. 1981/82:97 p. 54.

¹¹⁵ Prop. 1984/85:2 p. 30.

In regard to persons with disabilities it is stated in one proposition that it is of particular importance that they have an active role. Furthermore, it is written that the individual's ability or inability to speak for their cause can never be a determining factor in whether the patient has a participatory role in their medical treatment and that this requires that the healthcare personnel are more attentive to the patient's wishes and to be more informed about the disability.¹¹⁶ The IVO also emphasises this in one of their cases concerning a man who stated that he struggled with communicating and to be assertive and demand what he wants.¹¹⁷ The man sought medical help for his need to frequently urinate and was scheduled for surgery for this. When the man was hospitalized, the day before the surgery, he was informed by a nurse that they would also operate his prostate. The man got in contact with the physician only just before the surgery, who assured the man that he had control of the operation. The patient kept asking questions as the anaesthesia kicked in and he fell asleep. The IVO criticized the way the patient was informed and the lack of involvement. The IVO also stated in that case that when the healthcare sector meets patients with disabilities it is important that they base the care that is given on the specifics of the disability of the patient in question. What this entails is however unclear.

One could argue that it would mean that when the healthcare personnel meet a patient who, for example, has autism that results in the patient struggling to process when there is a lot of stimuli, then this obligation could mean that they would try to convey the information in a room with fewer distractions and to leave the information in writing. One could also argue that it means that when the healthcare personnel encounter a patient with an intellectual disability wishing to receive acne medication they are obliged to, inter alia, give the information in a stress-free environment with as easy explanations as possible. But what about situations where the reason for the patient's struggle or inability to process information cannot be fixed as easily? The preparatory works and decisions from the IVO do not give us any insights on how far the healthcare personnel's obligations are in relation to giving healthcare in consultation with the patient and with respect for the patient's autonomy. It only informs us that the patient does not have an absolute right to demand a specific care and that respect for the patient's autonomy means that medical treatment cannot be given against the patient's wishes. It does not give us much guidance on situations where a patient with a reduced decision-making capability is refused, for example, the desired acne treatment while another patient, who is not considered to have a reduced decision-making capability, is offered the same acne treatment. The latter

¹¹⁶ Prop. 1984/85:181 p. 82.

¹¹⁷ IVO Dnr. 8.2-26191/2013 beslut den 7 februari 2014.

patient will surely feel that they have had a say in what care they receive and that it has been done with respect for their autonomy. The patient with the reduced decision-making capacity will probably feel the opposite. The ambiguity of the patient's self-determination is also something that is identified by the Swedish Agency for Health and Care Services Analysis in one report where they conclude that there is a need for clarification on what this entails so they can have a real effect and so it is clear how the healthcare personnel should act.¹¹⁸

3.3 Care With Equal Opportunities for the Population

The obligation to provide care with equal opportunities for the population is one of the two overall aims of the Swedish healthcare.¹¹⁹ This obligation is found in Chapter 3 Section 1 HSL and Chapter 1 Section 6 PL. Both provisions further note that the care shall be given with respect for the equal value of everyone and that the patient with the greatest need of healthcare is given priority. The obligation to provide care with equal opportunities for the population means in principle that it should be possible for everyone to take part in healthcare services when they are in need and to do this on equal terms. Financial, social, linguistic, religious, cultural and geographic conditions shall not impede the individual from obtaining healthcare.¹²⁰ Neither shall age, gender, nationality, place of residence, education, financial ability, ethnicity, cultural differences, the ability to take the initiative, or the character and duration of the disease affect the possibility to obtain good care.¹²¹ Furthermore, in order to ensure care with equal opportunities for the population, the healthcare sector must strive to even out the differences emanating from disparities in age, gender, income and education and give equal opportunity to understand a diagnosis or understand the implications of a certain medical procedure.¹²² It is further addressed in one proposition that certain groups of patients are more vulnerable, such as people with a disability who might have difficulties in accessing the healthcare facility which will hinder their right to equal opportunity.¹²³

¹¹⁸ *Lag utan genomslag. Utvärdering av patientlagen 2014-2017* (2017:2), Myndigheten för vård- och omsorgsanalys, pp. 121-122.

¹¹⁹ The second overall aim is to promote good health for all of the population; prop. 1981/82:97 pp. 26–28.

¹²⁰ Prop. 1981/82:97 p. 27.

¹²¹ Prop. 1984/85:97 p. 13.

¹²² Prop. 1981/82:97 p. 113.

¹²³ Prop. 1981/82:97 p. 28.

In ensuring care with equal opportunities for the population the decision of who receives healthcare shall be based on the needs of the patients.¹²⁴ This is often referred to as the principle of solidarity.¹²⁵ This principle of solidarity means that the resources shall be focused on the areas and the individuals most in need.¹²⁶ The principle also entails an obligation to pay particular attention to patients who are considered weaker. These are the patients who do not have the same abilities to safeguard their rights and included here are children, people suffering from senile dementia, people who are unconscious and other people who for various reasons struggle to communicate with others.¹²⁷ The principle of solidarity entails an obligation to place resources in the areas where the needs are the greatest and to especially consider the needs of the groups of people who have less opportunities than others to make their voices heard and to exercise their rights.¹²⁸

The JO does mention the obligation to provide care with equal opportunities but does never explain it in depth. The IVO gives us a bit more insight on how to interpret this obligation. In one of their decisions a healthcare provider refused to give opioid replacement therapy to people who suffered from opioid addictions since this treatment was only for addiction that had not been caused by the healthcare.¹²⁹ The IVO stressed in their decision that there is an obligation to provide care with equal opportunities and that the assessment should be based on the needs and not the type of addiction. In another one of their decisions an individual complained that the patient's symptoms were neglected because of the patient's mental health.¹³⁰ The IVO however explained that they cannot judge whether this was true but stressed the obligation to provide care with equal opportunities. The IVO has also expressed that the obligation to provide care with equal opportunity and that the care should be provided in consultation with the patient, does not mean that the patient has a final say in what care is given and when it is given, but that no discrimination is allowed to occur.¹³¹ Lastly, the IVO has expressed that care with equal opportunity entails an obligation to make an individual assessment when estimating the patient's need of care.¹³²

¹²⁴ Prop. 1981/82:97 pp. 27–28; prop. 1984/85:181 p. 13.

¹²⁵ Johnsson (2020) p. 48.

¹²⁶ Prop. 1996/97:60 p. 20.

¹²⁷ Ibid.

¹²⁸ Prop. 1996/97:60 p. 53.

¹²⁹ IVO Dnr. 8.2–32250/2017–18 beslut den 3 december 2018.

¹³⁰ IVO Dnr. 8.2-44433/2017-18 beslut den 26 mars 2018.

¹³¹ IVO Dnr. 9.2-47612/2012-18 beslut den 12 januari 2015.

¹³² IVO Dnr. 8.2–27788/2017–10 beslut den 16 november 2018.

With my example of receiving acne treatment the principle of care with equal opportunities and the principle of solidarity tells us that this treatment should be based on the needs of the patient and not on the patient's mental capacity. It further specifically addresses vulnerable groups, and patients with reduced decision-making capability should be considered included here, and that extra resources shall be placed on them. Though, what these resources are is not specified but it does entail an obligation for the healthcare personnel to give extra attention when ensuring that patients with reduced decision-making capabilities have equal opportunity to access medical treatment. Furthermore, the obligation to make an individual assessment when estimating the patient's need of care means that the healthcare personnel cannot rely on assumptions but need to make individual assessments of the need for care. I argue that this entails, *inter alia*, to not rely on an assumption that a patient with an intellectual disability would feel a lesser need for receiving treatment for their acne.

3.4 Conclusions

If a medical procedure was refused on the basis of the patient lacking mental capacity to give a valid consent, would the healthcare personnel still fulfil their obligations to provide good care and would it contravene the principle of good care with equal opportunities for the population? The responsibility to provide good care entails respecting the patient's autonomy and integrity and requires that the care given should be in consultation with the patient. Respect for a patient's autonomy and integrity is not absolute in the sense of determining the extent and content of one's care. Regarding patients with reduced decision-making capabilities it is stated that it is of particular importance that patients with disabilities have an active role and that in these circumstances the healthcare professionals need to be *more* attentive to the patient's wishes. What having an active role actually entails is however unclear. The requirement for the healthcare professional to provide good care is vague as it is never really specified what actions are required of them to respect the patient's self-determination and it is therefore hard to draw conclusions on how this applies specifically to patients with reduced decision-making skills. Thus, we cannot conclude in general that refusing medical treatment would interfere with the principle of good care. It would have to be an assessment based on the individual circumstances of the situation. However, I want to argue that the healthcare personnel should not in general be considered to have fulfilled their obligation to provide good care that is patient-oriented because otherwise this obligation would be ineffective in practice. Moreover, it is important to note that the Swedish healthcare system is based on duties for the healthcare personnel and not on

the patient having rights that they can claim in court. Thus, if a patient is refused a certain treatment due to mental capacity and wants to complain that their self-determinacy has not been respected, they can complain to the IVO. However, the main function of the IVO is to supervise the healthcare sector and it is stated that the responsibility to provide good care lies with the healthcare provider.¹³³ Thus, the patient can complain to the IVO who can criticize the healthcare personnel for not respecting the patients autonomy, but this will not ensure that the patient will actually receive the care that they want. For example, a patient with a reduced decision-making capability who has been refused acne treatment can complain to the IVO that their autonomy has not been respected. If the patient is lucky, the IVO will criticise the healthcare personnel who then reconsiders, but this is never guaranteed. Receiving a specific treatment, such as acne medication, is never something that the patient can demand.

But can the patient demand a certain medical treatment on the basis that another patient with the same problem received it? Care with equal opportunities for the population means that it should be possible for everyone to equally take part in healthcare services, no matter e.g. financial or linguistic conditions nor gender or ethnicity. It is closely related to the principle of solidarity, which entails that healthcare shall be based on the care needs of the patients and that there is an obligation to pay particular attention to patients who are considered weaker and who may have less opportunities than others to exercise their rights. I mentioned before a decision where the IVO criticized a caregiver for only offering opioid replacement therapy to people who suffered opioid addictions. However, this decision does not mean that the patient is able to demand a certain treatment. It only illustrates that when the healthcare personnel provide a certain treatment, they cannot base their decision on who receives the care on other factors than who are in need of the care. This case illustrates that basing a decision on the mental capacity of the patient and not on the need for a treatment, such as needing medication for one's acne, may interfere with the principle of care with equal opportunity for the population. As with the obligation to provide a patient-oriented care, it is unclear when the obligation to provide equal care for the population can be considered to have been fulfilled. However, with care with equal opportunities for the population it is clearer that this provision is not being realized when a patient is refused a certain treatment solely because they are considered to not have given valid consent. However, as with the obligation to provide good care, the provision that obliges the healthcare professionals to provide care with equal opportunities for the population is not something that the

¹³³ Prop. 2013/14:106 p. 30.

patient can invoke in a court. This means that the patient will have to rely on the healthcare personnel making an effort to organise the care in consultation with the patient and to respect their autonomy. This will result in a more arbitrary healthcare for patients with reduced decision-making capabilities in regard to their participation in care and whether their wish for a certain medical treatment, such as acne medication, is satisfied. Luckily there is another way for the patient to be able to exercise their rights in court, which I will illustrate in the next chapter.

4 Discrimination

4.1 Introduction

In this chapter I am going to answer the question of whether or not it would constitute discrimination if a patient with a reduced decision-making capability was refused medical treatment. The main Swedish legislation act regarding discrimination is the Discrimination Act which entered into force in 2009. If an individual has been subject to discrimination, they can go to court and possibly receive compensation. The provision that prohibits discrimination in the healthcare sector is found in Chapter 2 Section 13. This provision is applicable to healthcare activities that are covered by HSL.¹³⁴ The prohibition to discrimination include, inter alia, the right to access to medical care or treatment.¹³⁵ Regarding healthcare activities that are not included in HSL, Chapter 2 Section 12 of DiskL might be applicable. The provision prohibits discriminating in the distribution of goods, services and housing that occurs outside private and family life. Also note Chapter 1 Section 2 IoG where it is recognized that the "Public power shall be exercised *with respect for the equal worth of all* and the liberty and dignity of the individual" (emphasis added) and the principle of objectivity that I mentioned in Section 2.4.

DiskL includes seven protected grounds of discrimination and I will in this essay focus on disability.¹³⁶ DiskL also covers six forms of discrimination but I will in this essay only focus on indirect discrimination and inadequate accessibility.¹³⁷ I have chosen indirect discrimination, and not direct discrimination, since the requirement of a valid consent may seem neutral but will be harder to fulfil for some patients, such as patients with intellectual disabilities. Inadequate accessibility as a form of discrimination is similar to the healthcare personnel's obligation to adjust the information that they give, which I discussed in Chapter 2.3, but there are differences. Since inadequate accessibility partly shares prerequisites with indirect discrimination it is practical to examine these jointly in this chapter. Both inadequate accessibility and indirect discrimination require that the individual has suffered a *disadvantage* which has to be related to one of the

¹³⁴ Prop. 2007/08:95 p. 254.

¹³⁵ Prop. 2007/08:95 p. 522.

¹³⁶ The other protected grounds for discrimination are sex, transgender identity or expression, ethnicity, religion or other belief, sexual orientation and age.

¹³⁷ The other forms of discrimination are direct discrimination, harassment, sexual harassment and instructions to discriminate.

grounds of discrimination and that the individual can be put in a *comparable situation* to someone who did not suffer the disadvantage. Furthermore, indirect discrimination can sometimes be justifiable and I will investigate this further in Section 4.5. Additionally, inadequate accessibility requires that the accessibility measures are considered as reasonable and I will examine this in Section 4.6.

In order to answer the question of whether or not it would constitute discrimination if a patient was refused a medical treatment due to mental capacity, I will in this chapter answer five questions (see below) and then end the chapter with a conclusion.

- I. Will a patient with a reduced decision-making capability be regarded as disabled within the meaning of DiskL?
- II. Does a refusal to give medical treatment constitute a disadvantage?
- III. Is there a comparable situation and what could it be?
- IV. If the refusal to give medical treatment would constitute indirect discrimination, could the difference in treatment be considered as justifiable with means that are appropriate and necessary?
- V. Are there any reasonable accessibility measures that the healthcare personnel must adopt?

4.2 Disability

Will a patient with a reduced decision-making capability be regarded as disabled within the meaning of DiskL? As mentioned above, discriminatory treatment has to be related to one of the protected grounds of discrimination, such as disability. Disability differs from some of the other grounds of discrimination since a person either has a disability or does not have disability.¹³⁸ In Chapter 1 Section 5 paragraph 4 DiskL the term disabilities refer to lasting physical, mental or intellectual limitations of a person's functional capacity that as a consequence of injury or illness existed at birth, has emerged since or can be expected to appear. The terms "physical, mental or intellectual" illustrates that the concept of disability is to be interpreted broadly.¹³⁹ Note that disabilities only refer to conditions that are *lasting* and not limitations from illnesses or diseases that are transient.¹⁴⁰ Even though a fractured arm may render a person physically hindered it is not included in DiskL since it is of temporary nature. Neither will a person

¹³⁸ Hellborg (2018) pp. 165-166.

¹³⁹ Inghammar (2007) p. 283.

¹⁴⁰ SOU 2006:22 p. 312; prop. 1997/98:179 p. 33.

be included in DiskL who has been recovered or rehabilitated.¹⁴¹ However, a person who carries a disease that will worsen over time will eventually be included in DiskL. This applies e.g. to people who are HIV-positive, who have cancer or who have multiple sclerosis.¹⁴² Case law has additionally included in the list of disabilities dyslexia, ADHD and narcolepsy,¹⁴³ and chronic asthma.¹⁴⁴ As has been pointed out by Andreas Inghammar, even though *lasting* is a key element there has not been suggested a time frame for when this is considered fulfilled.¹⁴⁵

With regard to the patients that this essay focuses on, an important factor is if their reduced decision-making capability will be considered as lasting as only these people will be considered as disabled within the meaning of DiskL. In this essay the concept of patients with reduced decision-making capabilities does not specify whether this inability is lasting or temporary. In some cases, for example when the patient has Down's syndrome, this requirement will be fulfilled. In other cases, for example patients who have bipolar disorder, this requirement may not be fulfilled since the disorder will lead them to have some periods where they feel overly happy and energized, some periods where they feel sad or depressed and some periods where they feel neither of these extremes.

Moreover, case law is clear that it is important to make an individual assessment in each case on if there is a disability and to not rely on general risks of a certain condition.¹⁴⁶ This was emphasized in one case where a man applied for a job at a petroleum refinery but was denied this on the basis of his diabetes and the fact that the job included working alone, at high altitudes and at night time, which are working conditions that are *generally* not recommended if one has diabetes.¹⁴⁷ Hence, the healthcare professional has to make sure they make an individual assessment and cannot assume that a patient cannot consent simply because of a certain diagnosis or condition. As Richard Sahlin has illustrated, categorizing someone as disabled can be beneficial as it may result in material justice for them, but there is also a danger of stereotyping.¹⁴⁸ The material justice in this case would be possibly getting compensation for having been discriminated against when they were refused a medical treatment. The danger of

¹⁴¹ Prop. 1997/98:179 p. 33.

¹⁴² SOU 2006:22 pp. 312–313; prop. 1997/98:179 pp. 33–34.

¹⁴³ AD 2005 nr 32; AD 2015 nr 57.

¹⁴⁴ AD 2020 nr 9.

¹⁴⁵ Inghammar (2007) p. 282.

¹⁴⁶ AD 2006 nr 97; AD 2003 nr 47; Svea hovrätt dom den 11 april 2014 mål nr. T 5095–13.

¹⁴⁷ AD 2003 nr 47. In the case the man was considered to have been discriminated against since he had his diabetes well under control.

¹⁴⁸ Sahlin (2004) p. 29.

stereotyping is that it might lead to their consent being regarded as not valid due to, *inter alia*, an established intellectual diagnosis.

4.3 A Disadvantage

Does a refusal of medical treatment constitute a disadvantage? A disadvantage is when a person is put in a worse position or misses out on an improvement, benefit or service.¹⁴⁹ For example, a court found in two cases that there had been a disadvantage since a doctor had made pejorative statements relating to the patients' ethnicity in the medical certificates which had led to the patients being denied sickness benefit.¹⁵⁰ In regard to indirect discrimination the disadvantage can occur when a certain group of people has more difficulty in fulfilling a requirement or provision.¹⁵¹ In regard to inadequate accessibility a woman, with severely impaired vision, was considered by the Svea Court of Appeal to have been disadvantaged since she could not apply for parental benefits online because a screen reader would not work on the website.¹⁵² A disadvantage is not, according to DiskL, the same as special treatment.¹⁵³ The determining factor on if a disadvantage has occurred is not the underlying *causes*, but rather if a negative *effect* arises.¹⁵⁴ It has been expressed in case law that the concept of disadvantage requires that the treatment *objectively* can be said to lead to a negative experience or harm.¹⁵⁵ This means that even though the intentions for the differential treatment may be well-meaning it does not matter. This has been emphasized by the Supreme Court in a case where a woman was initially denied to make an appointment at her local health centre to undergo the base inquiry for assisted insemination and was instead referred to a facility that specialised in lesbian and bisexual women.¹⁵⁶ The patient complained and was eventually able to undergo the base inquiry at the local health centre. The Supreme Court found that the woman had been subject to a disadvantage.¹⁵⁷ This case illustrates that even though the woman was

¹⁴⁹ Prop. 2002/03:65 p. 87; prop. 2007/08:95, p. 486-487; Inghammar (2007) p. 289.

¹⁵⁰ Stockholms tingsrätt dom den 10 december 2009 mål nr. T 16183-06; Stockholms tingsrätt den 10 december 2009 mål nr. T 25395-06; see also AD 2005 nr 87 where an employer required their employees to be of a certain height.

¹⁵¹ Prop. 2007/08:95 p. 490; Hellborg (2018) p. 125.

¹⁵² Svea hovrätt dom den 12 mars 2021 mål nr. T 9308-18.

¹⁵³ Hellborg (2018) p. 243.

¹⁵⁴ Prop. 2002/03:65 p. 87; prop. 2007/08:95 pp. 486-487; prop. 2013/14:198 p. 63; Hellborg (2018) p. 242.

¹⁵⁵ NJA 2008 s. 915; Hovrätten för Övre Norrland dom den 9 januari 2008 mål nr. T 441-07 (RH 2008:62).

¹⁵⁶ NJA 2014 s. 499 II.

¹⁵⁷ However, two of the judges of the Supreme Court had a dissenting opinion. They were of the view that the woman had not been disadvantaged because she could get the inquiry at another facility.

initially referred to what was believed to be a better facility, the negative effect arose because she was rejected.¹⁵⁸ Another case that shows that a disadvantage is at hand even if the person has received the benefit, is a case where the court found that a Roma woman had been disadvantaged when she was questioned several times by staff at a hotel when she was getting coffee during a conference.¹⁵⁹

The analysis of the legal sources provided in this section, indicates that if a patient was refused a medical treatment, for example acne medication, then they will miss out on a service and the requirement of there being a disadvantage is fulfilled. The cases with assisted insemination and the Roma woman also open up the possibility that even though the patient may *first* be refused medical treatment and then granted it, it could still constitute discrimination. The case with assisted insemination also illustrates that even though a refusal is well-meaning it could still constitute discrimination.

4.4 A Comparable Situation

Is there a comparable situation and what could it be? With indirect discrimination the comparison is between those who can or those who cannot fulfil the requirement in question.¹⁶⁰ Since the discrimination form inadequate accessibility deals with situations where there is a lack of active measures, the assessment will be of if there exist measures to place the disabled person in a comparable situation.¹⁶¹ The Svea Court of Appeal has stated that "comparable situation" does not mean the *same* situation and that the goal is to ensure that the person with a disability can access the business or the activity. It is therefore accepted that the way a disabled person accesses a business or activity may differ from the way a person without a disability gains access.¹⁶² When assessing whether the person has been subject to a different treatment then the treatment must be compared to what the "normal" treatment would be.¹⁶³ In the case of refusal of acne treatment due to mental capacity the normal situation would be obtaining the acne treatment due to the patient having severe acne.

In an inquiry report it was expressed that within the healthcare sector, the comparable situation may be between a patient with a disability and a

¹⁵⁸ Hellborg (2018) pp. 248-249.

¹⁵⁹ Göta hovrätt dom den 19 maj 2010 i mål nr T 3065-09. However, one of the judges was dissident and claimed that since she received coffee she had not been disadvantaged.

¹⁶⁰ Prop. 2002/03:65 p. 93; prop. 2007/08:95 p. 490.

¹⁶¹ Hellborg (2018) p. 262.

¹⁶² Svea hovrätt dom den 12 mars 2021 mål nr. T 9308-18.

¹⁶³ Hellborg (2018) p. 264.

patient without a disability, or between patients with the same or different kinds of disabilities.¹⁶⁴ Although, in the healthcare sector the assessment of a comparable situation shall initially be on the needs of care of the patients.¹⁶⁵ A patient who is *not* in need of care is not in a comparable situation to a patient who is.¹⁶⁶ The comparable situation will therefore essentially be in regards to the *care needs*.¹⁶⁷ In one case a homosexual couple claimed that they had been discriminated against because they had to pay to undergo three insemination treatments before it would be paid for by the county council.¹⁶⁸ On the issue of a comparable situation, the court stated that the homosexual couple would only be in a comparable situation to a heterosexual couple if they also could not get pregnant for medical reasons. Regarding medication for acne one can conclude from this that a patient with a reduced decision-making capability and a patient who does not have a reduced decision-making capability would be in a comparable situation since the cause for both of their acne is medical.

Swedish case law has not dealt explicitly with refusal to give medical treatment for a disabled person but the preparatory works have expressed that a comparable situation may be between a patient with a disability and a patient without a disability.¹⁶⁹ Note however that, as Andreas Inghammar points out, the group of disabled persons is large and heterogeneous and the comparable groups should therefore be based on the specific disability, and not on disabilities in general.¹⁷⁰ Assuming that there is a need for care, one could argue that a comparable situation would be between a patient with an intellectual or psychosocial disability, and who does not fully understand the information given, and a patient who have not been diagnosed with an intellectual or psychosocial disability, and who also does not fully understand the information given. Since neither of them fully understands the information, the issue of the existence of informed consent arises. However, a consent from a patient with an intellectual or psychosocial disability to receive acne treatment may be judged differently due to prejudices even though the patient lacking an intellectual or psychosocial disability also, for various reasons, struggle to understand the information given.

¹⁶⁴ SOU 2006:22 p. 549.

¹⁶⁵ Prop. 2013/14:198 p. 126; Hellborg (2018) p. 281.

¹⁶⁶ SOU 2006:22 p. 549.

¹⁶⁷ SOU 2006:22 pp. 352 & 550.

¹⁶⁸ Umeås tingsrätt dom den 6 november 2009 mål nr. T 1795–08.

¹⁶⁹ Prop. 2007/08:95 p. 488.

¹⁷⁰ Inghammar (2007) p. 289.

4.5 A Balance of Interests

If the refusal to give medical treatment could constitute discrimination, could the difference in treatment be considered as justifiable with means that are appropriate and necessary? Indirect discrimination may be allowed if two prerequisites are met. The first prerequisite is that the purpose of the provision or treatment is justified, meaning that it has to be worth protection in itself and to be sufficiently important to motivate it being granted priority over the principle of non-discrimination. The second prerequisite is that the means to reach the purpose must be appropriate and necessary, which means that there cannot exist other options that are non-discriminatory.¹⁷¹

There are no pre-determined purposes mentioned in DiskL or the preparatory works that will be considered as justifiable but there has emerged case law.¹⁷² The Labour Court has for examples established that providing good care is a justifiable purpose and that not offering a job for this reason is appropriate and necessary. In that case a midwife claimed that she had been discriminated against when she was denied work due to her refusal, for religious reasons, to perform abortions.¹⁷³ The Labour Court has also found patient security as a justifiable purpose in one case where a dental worker wanted to use disposable sleeves in her practice in order to conceal her arms for men.¹⁷⁴ In this case it was also considered as appropriate and necessary, even though there does not exist any scientific studies that show that disposable sleeves either increase or decrease the risk of spreading infections. The court motivated this with reference to there being serious risks that could endanger the patient's health or life, and stated that a lot of measures with negative effects would be proportionate since "what is vital is paramount to a lot of other things".¹⁷⁵ However, a similar case was tried by the Stockholm District Court in 2016 where they found that disposable sleeves were a lesser interference that would still ensure the patient security and the denial of allowing this was indirect discrimination.¹⁷⁶ The Labour Court has also stated in two of their rulings that omitting to hire a disabled person due to the fact that the work assignments would lead to exposing the person's health to a serious risk, does not constitute discrimination.¹⁷⁷

¹⁷¹ Prop. 2002/03:65 p. 94; prop. 2007/08:95 p. 491.

¹⁷² Hellborg (2018) p. 323.

¹⁷³ AD 2017 nr 23.

¹⁷⁴ AD 2017 nr 65.

¹⁷⁵ The Swedish expression used was: "det som är livsviktigt är viktigare än mycket annat"

¹⁷⁶ Stockholms tingsrätt dom 16 november 2016 mål nr. T 3905–05.

¹⁷⁷ AD 2003 nr 47; AD 2006 nr 97.

As illustrated by case law, providing good care and ensuring patient's, as well as future employee's, safety are purposes that may render an indirect discrimination as justifiable. Therefore, if a healthcare personnel would refuse to give a medical treatment on the basis of the patient not being able to give valid consent because they cannot understand the implications *and* this could threaten patient security, the healthcare professional would not necessarily be guilty of discrimination. However, note that this is only clear in cases where the lack of a valid consent would lead to danger to the patient's health. In cases where there is not an issue of patient safety, it is uncertain whether it would be justifiable and those cases could thus constitute discrimination. For example, strong acne medication will not threaten the patient's life but will result in complications, such as dry skin for example, and potentially more severe complications if the patient's skin would be exposed to too much sun, if the patient got pregnant or the patient drank too much alcohol. Would it in these cases be justifiable to refuse to give medical treatment such as acne medication? Neither legislation, preparatory works or case law has dealt with this specific issue. However, I consider that one should be mindful regarding what purposes should be justifiable in these cases since it would weaken not only the prohibition of discrimination in DiskL but also the principle of objectivity and the principles that stipulate that the healthcare should be patient-oriented and that care shall be given on an equal basis. With these in mind the threshold should be high of what discrimination is allowed. Not least when one considers that neurotypical people may also at times not understand the information given, and thus be at risk to be harmed, but they are still normally given the medication.

4.6 Reasonable Accessibility Measures

Are there any reasonable accessibility measures that the healthcare personnel must adopt? Inadequate accessibility as a form of discrimination was legislated six years after the DiskL entered into force and the purpose of it was to attain participation and equality by enhancing the accessibility for people with disabilities.¹⁷⁸ The legislator found no reason to establish any legal definition of the concept "accessibility" but noted that the obligations arising principally adhere to support or personal service, information and communication, and the physical environment.¹⁷⁹ Inadequate accessibility requires an omission to take measures to prevent that persons with disabilities are disadvantaged but it will only be considered as

¹⁷⁸ Prop. 2013/14:198 p. 51.

¹⁷⁹ Prop. 2013/14:198 pp. 56–57.

discriminatory if there exists reasonable accessibility measures. Which accessibility measures that are deemed as reasonable will vary depending on the individual circumstances and it has been expressed in one proposition that to enumerate the criteria to consider in such assessment would risk it being regarded as exhaustive.¹⁸⁰ The measures should though be considered as simple.¹⁸¹ One such example is reading aloud a decision instead of sending it in a letter to a person.¹⁸² Furthermore it is expressed in the same proposition that this does not mean that a person may access a service in the same way as others.¹⁸³ For example, in one decision from the DO it was not considered as reasonable that a food store would replace doors so people in wheelchairs could access refrigerated goods since a customer could instead ask someone for their help.¹⁸⁴ Additionally, a measure of accessibility will only be considered as reasonable if it is possible to reduce or eliminate the effects of the disability.¹⁸⁵ Examples of measures relating to information and communication could be to offer the information in certain customized formats such as using DAISY¹⁸⁶, to make the information easier to read or to have the communication through emails and personal service.¹⁸⁷ The DO has for example stated in three of their decisions that in the healthcare sector, omission to book a sign language interpreter might constitute inadequate accessibility.¹⁸⁸ Chapter 1 Section 4 paragraph 3 DiskL declares that when assessing what is a reasonable accessibility measure one should take into consideration the financial and practical conditions, the duration and scope of the relationship or the contact between the parties concerned, and other relevant circumstances.¹⁸⁹

In the preparatory works the healthcare sector is specifically addressed and it is mentioned that the discrimination from inadequate accessibility should be applicable in order to ensure that people with disabilities have the same opportunity to access healthcare as others.¹⁹⁰ It is stated that this does not

¹⁸⁰ Prop. 2013/14:198 p. 61.

¹⁸¹ Prop. 2013/14:198 p. 64.

¹⁸² DO GRA 2017/68 handling 44, beslut den 20 februari 2018

¹⁸³ Prop. 2013/14:198 p. 63–64.

¹⁸⁴ DO GRA 2016/150 handling 6, beslut den 20 januari 2017.

¹⁸⁵ Prop. 2013/14:198 p. 69.

¹⁸⁶ Stands for "Digital accessible information system" and is a technical standard for digital audiobooks and computerized text designed for people who have impaired vision or dyslexia.

¹⁸⁷ Prop. 2013/14:198 p. 65.

¹⁸⁸ DO GRA 2016/20 handling 24, beslut den 30 november 2016; DO GRA 2016/20 handling 22, beslut den 30 november 2016; DO GRA 2016/20 handling 23, beslut den 30 november 2016.

¹⁸⁹ See AD 2017 nr 51 where it was judged that a cost of 500 000 SEK (around 46 000 €) in order to employ a deaf person was not reasonable; or AD 2010 nr 13 where it was not reasonable to require a governmental agency to employ a woman with severely impaired vision since it would in practice require them to hire another person to accomplish the work of one person.

¹⁹⁰ Prop. 2013/14:198 pp. 98–99.

entail a right to invoke a benefit that otherwise is not included in the current systems. Neither is it applicable to question an assessment on the need for care that is based on science and proven experience.¹⁹¹ Accessibility measures in the healthcare sector can include making the information accessible, different measures to ensure that a person with a disability can communicate with the one in charge and measures to make the facilities accessible.¹⁹²

As Yana Litins'ka points out, the preparatory works focus mainly on measures that makes the environment accessible for the *groups* of people, such as having some staff provide easy-to-read printed formats, and it is therefore not clear if tailor-made measures are also included. She argues that if the individual adjustments do not fit into those composed for the groups, then the healthcare provider does not have an obligation to provide it, although disclosure of information about proposed medical treatment may be seen as an exception.¹⁹³ Furthermore, as Litins'ka also identifies,¹⁹⁴ Chapter 1 Section 4 paragraph 3 DiskL also states that a measure is not reasonable if it would be a financial, practical or other burden.

Moreover, inadequate accessibility as a form of discrimination is similar to the obligation to provide individually adjusted information, which is found in Chapter 3 PL and which I studied in Chapter 2 of this thesis. The difference from the obligation in PL, is that if it falls within the scope of the DiskL the patient can have its case taken to court. However, the court would not in those circumstances try if the refusal to give treatment constitute discrimination, but could only try whether the healthcare professional made sure to adjust the information given to the patient. When examining the case law of inadequate inaccessibility there are many cases regarding adapting work assignments,¹⁹⁵ but none are about the obligation to adjust the information given. One of the most important accessibility measures regarding patients with reduced decision-making capability is the way information is conveyed. If given properly, adjusted and without stress, then the patient has the best opportunity to give an informed consent. The analysis of the legal sources in this section illustrates that accessibility measures such as making the information more accessible are highlighted but that there are also restrictions as it is stated that when assessing if a measure is reasonable one should take into account the financial and practical conditions. In practice, if the healthcare personnel are under a lot

¹⁹¹ Prop. 2013/14:198 p. 99.

¹⁹² Ibid.

¹⁹³ Litins'ka (2018) pp. 527-529.

¹⁹⁴ Ibid.

¹⁹⁵ E.g. AD 2010 nr 13; AD 2011 nr 25; AD 2012 nr 51; AD 2013 nr 78; AD 2017 nr 51; AD 2020 nr 3.

of pressure regarding time, does this mean that they do not have to explain it properly? It does open up the possibility for this and makes the extent of the healthcare personnel's obligations uncertain. In conclusion, there are accessibility measures that the healthcare personnel can, and should adopt, most notably regarding how the information is given, but the scope of their obligations is uncertain.

4.7 Conclusions

In this chapter my aim was to answer the question of whether or not refusing medical treatment on the basis of the patient lacking decision-making capability would constitute discrimination. I concluded that, firstly, to even be covered by DiskL, the disability has to be lasting, which may exclude some of the patients that this essay focuses on. Secondly, I established that refusal of medical treatment would constitute a disadvantage, even though it may be well-meaning. Thirdly, regarding comparable situation I stated that, firstly, it must be based on the needs of the patients, and, secondly, that it would be between a patient with an intellectual or psychosocial disability and who does not understand the information and a patient without an intellectual or psychosocial disability who does not understand the information.

Fourthly, I discussed if refusing medical treatment could constitute a justifiable purpose with necessary and proportionate means and would thus be discrimination that is allowed. I studied case law that stated that when there is a threat to patient security then discrimination is allowed. Furthermore, I found case law that stated that providing good care may also be a justifiable purpose. However, as regards refusing medical treatments that are not a threat to the patient's life, such as acne medication, I stated that the legal sources are silent, but that I consider that the threshold should be high as it would otherwise weaken the prohibition of discrimination, the principle of objectivity and principles that state that healthcare shall be patient-oriented and given on an equal basis.

Lastly, I analysed if there are reasonable accessibility measures that the healthcare personnel must adopt in order to not be guilty of the discrimination form inadequate accessibility. A refusal of medical treatment would never in itself constitute inadequate accessibility. However, the measures leading up to a refusal may constitute the discrimination form inadequate accessibility. I came to the conclusion that the most important accessibility measure is conveying the information properly in order to ensure that the patient has the best possibility to give an informed consent,

but that the extent of the healthcare personnel's obligations is uncertain as it is also expressed that one must consider the financial and practical conditions. Furthermore, I also stated that the preparatory works focus mainly on measures that are focused on the group and that it is therefore not clear if tailor-made adjustments are included.

5 Sweden's Obligations in the ECHR and the CRPD

5.1 Introduction

In this chapter I am going to answer the question of whether or not refusing medical treatment to a patient with reduced decision-making capability would interfere with Sweden's obligations in the ECHR or the CRPD. The ECHR has a particular position in Swedish law and was incorporated in 1995 through a specific incorporation law¹⁹⁶ with the purpose of allowing the individual to be able to invoke the ECHR if it gave a stronger protection than the Swedish law.¹⁹⁷ With the ECHR, I will mainly focus on the right to respect for private life, which is enshrined in Article 8, and the prohibition of discrimination, which is found in Article 14. The European Court has in its case law shown that both negative¹⁹⁸ and positive¹⁹⁹ obligations arising from Article 8 are relevant for persons with disabilities. The ECHR does not expressly guarantee a right to healthcare or a right to be healthy and it has been expressed in doctrine that this is not likely to change.²⁰⁰ In Section 5.2 I will, first, discuss what the European Court has stated regarding informed consent in healthcare and, secondly, whether refusal to give medical treatment due to mental capacity would contravene Article 8. Regarding Article 8 I will discuss this regarding a right to self-determination and a right to not have one's legal capacity removed. Thirdly I will also study if refusing medical treatment due to mental capacity would interfere with Article 14.

In Section 5.3 I will study the CRPD and Article 5, which prohibits discrimination, Article 12, which enshrines a right to legal capacity, and Article 25, which stipulates a right to health. I will first have a brief introduction on what has been said on the concepts of disability and mental capacity in relation to the CRPD. Secondly, I will discuss Article 12 and 25 and if refusing medical treatment due to mental capacity would interfere with the right to legal capacity. Thirdly, I will study if refusal to give medical treatment could constitute discrimination and what the CRPD states

¹⁹⁶ Before it was only stated that Swedish law was compatible with the ECHR, see Sahlin (2004) p. 100.

¹⁹⁷ Prop. 1993/94:117 p. 39.

¹⁹⁸ *Nasri v. France*, no. 19465/92, Judgement of 13 July 1995.

¹⁹⁹ *X and others v. Austria* [GC], no. 19010/07, Judgement of 19 February 2013.

²⁰⁰ Bartlett, Thorold & Lewis (2007) p. 113.

regarding the obligation to provide reasonable accommodation. Fourthly, I will study whether refusal to give medical treatment would constitute a form of substitute decision-making and what Sweden's obligations are in this regard. I will end the chapter with my conclusions on whether or not refusing medical treatment due to mental capacity would contravene Sweden's obligations in the ECHR or the CRPD.

5.2 The ECHR

5.2.1 Informed Consent

According to the European Court a medical intervention without the subject's free, informed and expressed consent is an interference to the individual's private life according to Article 8 of the ECHR.²⁰¹ This has been illustrated in both *Konovalova v. Russia* and *V.C. v. Slovakia*. In *Konovalova v. Russia* the European Court criticized a member State that it was unclear whether a woman had been capable of making an informed decision about allowing medical students to observe the birth of her baby since the information she was given was vague, presented in a manner that suggested that it was mandatory and given while the patient was between two sessions of drug-induced sleep.²⁰² In *V.C. v. Slovakia* the European Court criticized a member State for lack of a clear consent since the woman was not informed prior about her health status, the proposed procedure and the alternatives to it, she was not given time to reflect on the implications and to discuss it with her partner and had to make a decision while she was in labour.²⁰³ *Konovalova v. Russia* focuses on a general right to not be subject to an interference with one's private life without giving a valid consent. *V.C. v. Slovakia* focuses on the right to negative autonomy, i.e. the right to not be subject to a bodily intervention without having given a valid consent. The two cases illustrate that a consent is considered valid if the patient is given information prior that is clear, on the patient's health status, the procedure and the alternatives to it, and if the patient is given time to reflect on it, by themselves or with someone else. Furthermore, a consent is not valid if it is given when the patient is in a vulnerable position or if the patient feels forced to consent. The Swedish regulation is similar to the ECHR regarding the right to negative autonomy and what constitutes a valid consent.

²⁰¹ *Glass v. the United Kingdom*, no. 61827/00, Judgement of 9 March 2004, para. 81; *Juhnke v. Turkey*, no. 52515/99, Judgement of 13 May 2008, para. 76.

²⁰² *Konovalova v. Russia*, no. 37873/04, Judgement of 9 October 2014, paras 46 and 47.

²⁰³ *V.C. v. Slovakia*, no. 18968/07, Judgement of 8 November 2011 paras 112 and 117.

5.2.2 Self-Determination and Legal Capacity

Does Article 8 include the right to medical treatment? The European Court has expressed in case law that the concept of "private life" enshrined in Article 8 is a broad term that is not susceptible to an exhaustive definition.²⁰⁴ Included in the right to respect for private life are, inter alia, the physical and psychological integrity of a person as well as a right to personal development.²⁰⁵ The European Court has also in one case stated that even though no previous case has established a right to self-determination as being contained in Article 8, "the notion of personal autonomy is an important principle underlying the interpretation of its guarantees".²⁰⁶ Furthermore, the European Court has stated the importance of persons with disabilities being able to live autonomously.²⁰⁷ Thus, Article 8 states a right to personal development, that self-determination is an important principle and that it is important for persons with disabilities to be able to live autonomously. Article 8 does not state clearly that refusing medical treatment due to mental capacity would interfere with the article. However, one can argue those statements indicate that the rights of disabled persons to undergo medical treatment should generally be respected. But there is one reservation to this: Article 8(2) which allows limitations if it is prescribed in law and if it is necessary in a democratic society in the interests of protecting health. Whether "protecting health" requires a life or death situation or other medical cases is unclear.

The issue of refusing a patient with a mental illness a desired treatment was discussed in *Haas v. Switzerland* where a man suffering from bipolar disorder was not prescribed a lethal substance due to his mental disorder. The European Court noted that Article 8 encompasses a right to decide by what means and when to end one's life, *provided that* the person is capable of freely reaching a decision on this question and acting in consequence of this.²⁰⁸ The European Court notes that as regards prescribing lethal substances, it is in line with the ECHR to require a psychiatric assessment.²⁰⁹ The European Court does not however answer the question of what the requirements are for a valid consent in relation to a patient who has a mental illness nor whether member states can refuse *any* medical treatment due to mental capacity. The European Court has in another case regarding assisted suicide noted that "the ability to conduct one's life in a

²⁰⁴ *Pretty v. the United Kingdom*, no. 2346/02, Judgement of 29 April 2002, para 61.

²⁰⁵ *Pretty v. the United Kingdom*, no. 2346/02, Judgement of 29 April 2002, para 61.

²⁰⁶ *Ibid.*

²⁰⁷ *Enver Sahin v. Turkey*, no. 23065/12, Judgement of 30 January 2018, para 63.

²⁰⁸ *Haas v. Switzerland*, no. 31322/07, Judgement of 20 January 2011, para. 51.

²⁰⁹ *Haas v. Switzerland*, no. 31322/07, Judgement of 20 January 2011, para. 58.

manner of one's own choosing may also include the opportunity to pursue activities perceived to be of a physically or morally harmful or dangerous nature for the individual concerned". That illustrates that one should be afforded the right to choose activities that may be harmful to one. It does not however tell us, whether *anyone* shall be afforded this right. It does not really guarantee a right for a patient with a reduced decision-making capability the right to acne treatment, which may have harmful consequences.

Additionally, the European Court has stated that removing from someone their legal capacity may interfere with the right to respect for private life in Article 8.²¹⁰ The European Court has stated that the existence of mental disorder, even a serious one, cannot be the sole reason to justify a full incapacitation.²¹¹ Note however the possibility for allowing interferences to Article 8 and the European Court has expressed that under Article 8 the authorities must strike a fair balance between the interests of a "person of unsound mind" and other legitimate interests concerned.²¹² However, when determining somebody's mental capacity, the authorities shall enjoy a wide margin of appreciation, but that strict scrutiny is called for when measures have such adverse effect on an individual's personal autonomy, as removal of legal capacity, is at stake.²¹³ Moreover the European Court has also stated that when restrictions on fundamental rights apply to a particularly vulnerable group in society, such as persons with mental disabilities, then the state's margin of appreciation is narrower and there must be very weighty reasons for the restrictions in question. The reason for this, the European Court notes, is that such groups were historically subject to prejudices that could entail legislative stereotyping that did not allow the individualised evaluation of their capacities and needs.²¹⁴

Would refusing acne treatment due to mental capacity interfere with the ECHR in regard to legal capacity? Refusing medical treatment such as acne medication is a way to remove legal capacity. However, the European Court has stated that removing legal capacity due to mental disorder is allowed but

²¹⁰ *Shtukaturov v. Russia*, no. 44009/05, Judgement of 27 March 2008; *Ivinovic v. Croatia*, no. 13006/13, Judgement of 18 September 2014; *A.N. v. Lithuania*, no. 17280/08, Judgement of 31 May 2016.

²¹¹ *Shtukaturov v. Russia*, no. 44009/05, Judgement of 27 March 2008, para 94; *A.N. v. Lithuania*, no. 17280/08, Judgement of 31 May 2016, para 123.

²¹² *Shtukaturov v. Russia*, no. 44009/05, Judgement of 27 March 2008, para 87; *A.N. v. Lithuania*, no. 17280/08, Judgement of 31 May 2016, para. 116.

²¹³ *Shtukaturov v. Russia*, no. 44009/05, Judgement of 27 March 2008, para 87; *A.N. v. Lithuania*, no. 17280/08, Judgement of 31 May 2016, para. 116; *Ivinovic v. Croatia*, no. 13006/13, Judgement of 18 September 2014, para. 37.

²¹⁴ *A.N. v. Lithuania*, no. 17280/08, Judgement of 31 May 2016, para. 125; *Alajos Kiss v. Hungary*, no. 38832/06, Judgement of 20 May 2010, para 42.

that there must be weighty reasons for denying a fundamental right. A right to health is not included in the ECHR, but so is the prohibition against discrimination as well as a right to respect for private life, which includes, as an underlying principle, a right to self-determination. Thus, one can argue that refusal to give medical treatment due to mental capacity may contravene Article 8 as it removes legal capacity, but as interferences are allowed, the assessment will be based on the individual circumstances.

5.2.3 Prohibition of Discrimination and Reasonable Accommodation

Article 14 of the ECHR prohibits discrimination in the enjoyment of the rights set forth in the ECHR. Article 14 does not presuppose a breach of those provisions but the facts in issue must fall within the ambit of at least one of them.²¹⁵ This means that even though a right to medical treatment is not included, as long as the issue falls within the ambit of Article 8, in this case the right to live autonomously or to have one's legal capacity respected, Article 14 is applicable. Even though not explicitly stated as one of the examples in the article of the grounds of discrimination, disability is considered to be covered in the article.²¹⁶ For an issue to arise under Article 14 there has to be a difference of treatment of persons in analogous or relevantly similar situations.²¹⁷ In *Cînta v. Romania* the European Court found a breach of Article 14 in conjunction with Article 8 because a domestic court had not taken into consideration the concrete circumstances but relied on assumptions of a person's mental illness. This case illustrates, once again, that refusing medical treatment requires, at least, to not make general assumptions of a person's illness. To some extent, one could argue that Article 14 taken in conjunction with Article 8 includes a prohibition against denying someone their right to self-determination or to have their legal capacity respected due to their mental capacity. But as the scope of self-determination in Article 8 is not articulated more specifically, that the removal of legal capacity may be allowed to some extent and under some circumstances and since Article 8(2) allows interferences, it is not clear if

²¹⁵ *X and others v. Austria* [GC], no. 19010/07, Judgement of 19 February 2013, para 94.

²¹⁶ Support that disability is covered within the meaning of "other status" is found in *Glor v. Switzerland*, no. 13444/04, Judgement of 30 April 2009, para 82; *G.N. and others v. Italy*, no. 43134/05, Judgement of 1 December 2009, para. 126; *Kiyutin v. Russia*, no. 2700/10, Judgement of 10 March 2011, para. 57.

²¹⁷ *Cînta v. Romania*, no. 3891/19, Judgement of 18 February 2020; *Konstantin Markin v. Russia* [GC], no. 30078/06, Judgement of 22 March 2012; *X and others v. Austria* [GC], no. 19010/07, Judgement of 19 February 2013; *Khamtokhu and Aksenchik v. Russia* [GC], no. 60367/09 and 961/11, Judgement of 24 January 2017.

refusing medical treatment such as acne medication would interfere with the ECHR.

Additionally, the European Court has stated that there is an obligation for the states to ensure reasonable accommodation to allow persons with disabilities the opportunity to fully realise their rights and that a failure to do so may amount to discrimination.²¹⁸ This was clearly stated in *Çam v. Turkey* where a person was refused to enrol at a Music Academy due to their blindness. The European Court states in the case that Article 14 must be read in the light of texts regarding reasonable accommodation and references the CRPD (more of this in Section 5.3.3.).²¹⁹ Furthermore, *Çam v. Turkey* notes that this obligations also extends to situations where discrimination is encountered not only by a group of individuals but also encountered by one individual.²²⁰

5.3 The CRPD

5.3.1 Disability and Mental Capacity

In the CRPD Preamble para. e it is written that "[...] disability is an evolving concept and that disability results from the interactions between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others". The existence of a disability often results in an assumption of incapacitation and that the individual's affairs are taken over allowing others to make decisions based on the "best interests" approach.²²¹ Mental capacity is not the same as *legal capacity*, although many legal systems couple restrictions on legal capacity to some formulation of mental capacity.²²² The CRPD Committee has defined mental capacity as the decision-making skills of a person and stated that this will vary from one person to another and may also be different for a person depending on different factors, such as environmental and social factors.²²³ The CRPD Committee has also expressed that mental capacity is contingent on social and political context

²¹⁸ *Enver Sahin v. Turkey*, no. 23065/12, Judgement of 30 January 2018, paras 67-69; *Cam v. Turkey*, no. 51500/08, Judgement of 23 February 2016 paras 65-67; *G.L. v. Italy*, no. 59751/15, Judgement of 10 September 2020, paras 60-66.

²¹⁹ *Cam v. Turkey*, no. 51500/08, Judgement of 23 February 2016, para. 65.

²²⁰ See also *D.H. v. Czech Republic*.

²²¹ Della Fina, Cera & Palmisano (2017) p. 268.

²²² Bantekes, Stein & Anastasiou (2018) p. 352; Della Fina, Cera & Palmisano (2017) p. 269.

²²³ General Comment No. 1 Article 12 Equal Recognition before the Law, CRPD/C/GC/1, 19 May 2014, para 13.

and not an objective, scientific and naturally occurring phenomenon.²²⁴ The CRPD Committee has clearly stated that denying someone legal capacity on the basis of mental capacity is not permitted according to Article 12 of the CRPD and that all persons with disabilities have full legal capacity.²²⁵

5.3.2 Legal Capacity

In order to answer the question of whether or not refusing a patient medical treatment due to mental capacity would infringe on their rights as persons with legal capacity I will first investigate what legal capacity means. Article 12(2) acknowledges that "persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life", although, what the term legal capacity entails has been contested.²²⁶ At the final Ad Hoc Committee meeting which preceded the CRPD a footnote appeared in the consensus text that stated that "In Arabic, Chinese and Russian, the term 'legal capacity' refers to 'legal capacity for rights', rather than 'legal capacity to act'".²²⁷ This footnote was however removed after heated negotiations.²²⁸ The CRPD Committee has since declared that legal capacity is the ability to hold rights and duties (i.e. legal standing) but also the ability to *exercise* those rights and duties (i.e. legal agency).²²⁹ This view has also been supported in academia.²³⁰ Another definition of legal capacity is whether a person's acts and decisions are treated as legally effective within a particular legal system.²³¹ A systematic interpretation of Article 12(2) does also support the idea that legal agency should be included in the concept of legal capacity since Article 25, the right to health, would otherwise have little meaning if a patient with a reduced decision-making capability could not act on this right.²³² According to Article 25 of the CRPD people with

²²⁴ Ibid, para. 14.

²²⁵ Ibid, paras 8 & 15

²²⁶ Caivano, N (2014) p. 2; Della Fina, Cera & Palmisano (2017) p. 268; this was also discussed by the fifth meeting of the ad hoc committee: *Ad Hoc Committee on a Comprehensive and Integral International Convention on Protection and Promotion of the Rights and Dignity of Persons with Disabilities*, Daily Summary of Discussion at the Fifth Session, 25 January 2005.

²²⁷ UN Enable, 'Interim report of the Ad Hoc Committee on a Comprehensive and Integral International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities on its eight session' UN Doc A/AC265/2006/4, 1 September 2006.

²²⁸ Bantekes, Stein & Anastasiou (2018) p. 346.

²²⁹ General Comment No. 1 Article 12 Equal Recognition before the Law, CRPD/C/GC/1, 19 May 2014, para. 15.

²³⁰ Fallon-Kund, M. & Bickenbach, J.E. (2017); Morrissey, F. (2012); Dhanda, A. (2008).

²³¹ Bantekes, Stein & Anastasiou (2018) p. 352.

²³² A systematic method is one of the general methods that is described in Article 31 of the Vienna Convention on the Law of Treaties. As Litins'ka (2018), p. 122, points out this method means interpreting an article in the context of other provisions of the convention and/or other human rights treaties. Furthermore Litins'ka also supports the idea that a

disabilities have a right to the enjoyment of the highest attainable standard of health. Furthermore, in Art. 25(d) it is stated that healthcare professionals are required to provide care of the same quality to persons with disabilities as to others and that this care is based on the free and informed consent.²³³ Hence, in this essay it will be assumed that the right to legal capacity enshrined in Article 12(2) means not only possessing the ability to have rights but also that people with disabilities have a right to *act* on the rights in the CRPD. This means that a patient with a reduced decision-making capability shall be able to exercise their right to health on an equal basis of others, i.e. have the same possibility to request acne treatment as patients without reduced decision-making capabilities. Refusing them this means ignoring their legal capacity and would interfere with Article 12 and 25 of the CRPD.

5.3.3 Non-Discrimination and Reasonable Accommodation

Article 12(2) also establishes that persons with disabilities shall enjoy their legal capacity *on an equal basis with others*. Moreover, Art. 25(f) obliges the State Parties to prevent discriminatory refusal of healthcare. Additionally, Article 5 of the CRPD stipulates the prohibition of discrimination on the basis of disability. Discrimination on the basis of disabilities means, according to the CRPD Article 2, any distinction, exclusion or restriction on the basis of disability which has the purpose or effect of impairing or nullifying the recognition, enjoyment or exercise, on an equal basis with others, of all human rights and fundamental freedoms in the political, economic, social, cultural, civil or any other field. The CRPD Committee has in one of their cases tried a complaint where a Swedish woman, who had not been able to stand or walk for the last eight years and had difficulties sitting and lying down, was denied planning permission to build a pool, which would benefit her health.²³⁴ The CRPD Committee

systematic interpretation points out that legal capacity includes a right to exercise rights, see p. 122.

²³³ This is also mentioned in General Comment No. 6 on Equality and Non-Discrimination, CRPD/C/GC/6, 9 March 2018, para. 66 i relation till diskriminering; In several of their concluding observations they recommend issuing health protocols that ensure the realization of a free and informed consent to medical treatment, e.g: Concluding Observations on the Initial Report of Sudan, CRPD/C/SDN/CO/1, 10 April 2018; Concluding Observations on the Initial Report of the Kingdom Morocco, CRPD/CO/MAR/CO/1, 25 September 2017; Concluding Observations on the Initial Report of Montenegro, CRPD/C/MNE/CO/1, 22 September 2017; Concluding Observations on the Initial Report of United Arab Emirates, CRPD/C/ARE/CO/1, 3 October 2016.

²³⁴ UN CRPD Committee. H.M. v. Sweden (003/2011), CRPD/C/7/D/3/2011, 19 April 2012.

reiterated Article 25 and stated that when Sweden rejected the application they did not address the specific circumstances of the woman's disability and the related needs. This decision was considered disproportionate and had a discriminatory effect on the woman's right to the healthcare that she needed.²³⁵ Regarding this essay's purpose, refusing medical treatment due to mental capacity, this case demonstrates that when a governmental agency denies a benefit that a person with a disability has requested then it has to be proportionate. With regard to acne treatment my belief is that refusing the treatment would not be considered as proportionate when weighing in the risks of complications against refusing treatment for a skin condition, which would render the refusal as discriminatory. In particular, if the refusal was based on assumptions regarding the patient's mental capacity and not the individual circumstances.

Moreover, Article 5(3) obliges State Parties to take necessary steps to ensure that *reasonable accommodation* is provided. In several of the CRPD Committee's concluding observations they criticize the state for not including this as a form of discrimination.²³⁶ Article 2 of the CRPD defines reasonable accommodation as: "necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden, where needed in a particular case, to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms". As Yana Litins'ka points out in her dissertation, the definition indicates a requirement to make *case-specific* adjustments.²³⁷ Examples of this regarding healthcare are accessibility in regards to physical environment (for example for people living in rural areas)²³⁸ and providing information in accessible formats such as Braille, sign language and Easy read formats,²³⁹

²³⁵ UN CRPD Committee. H.M. v. Sweden (003/2011), CRPD/C/7/D/3/2011, 19 April 2012, para. 8.8.

²³⁶ See for example Concluding Observations on the Initial Report of Turkey, CRPD/C/TUR/CO/1, 1 October 2019; Concluding Observations on the second third periodic reports of El Salvador, CRPD/C/SLV/CO/2-3, 1 October 2019; Concluding Observations on the Initial Report of Vanuatu, CRPD/C/VUT/CO/1, 13 May 2019; Concluding Observations on the Initial Report of Oman, CRPD/C/OMN/CO/1, 17 April 2018; Concluding Observations on the Initial Report of Panama, CRPD/C/PAN/CO/1, 29 September 2017.

²³⁷ Litins'ka (2018) p. 147.

²³⁸ See for example Concluding Observations on the Initial Report of Iraq (Advance Unedited Version), CRPD/C/IRQ/CO/1, 23 October 2019; Concluding Observations on the second third periodic reports of Ecuador, CRPD/C/EQU/CO/2-3, 21 October 2019; Concluding Observations on the second third periodic reports of Australia (Advance Unedited Version), CRPD/C/AUS/CO/2-3, 15 October 2019.

²³⁹ See for example Concluding Observations on the Initial Report of Senegal, CRPD/C/SEN/CO/1, 13 May 2019; Concluding Observations on the combined second third periodic reports of Spain, CRPD/C/ESP/CO/2-3, 13 May 2019; Concluding Observations on the Initial Report of Norway, CRPD/C/NOR/CO/1, 7 May 2019; Concluding Observations on the Initial Report of Niger, CRPD/C/NER/CO/1, 1 May 2019; Concluding Observations on the Initial Report of Oman, CRPD/C/OMN/CO/1, 17 April 2018.

As is clear from Article 2, limitations in providing accessibility measures are if it would be disproportionate or undue. Furthermore, when assessing the reasonableness and proportionality the states enjoy a wide margin of appreciation.²⁴⁰ The CRPD Committee has in one of its cases, regarding a woman who was denied a job due to her visual impairment, considered that paying 2 percent of the governmental agency's IT budget on a special program, installing programs converting text to Braille and hiring another employee to help the woman, would constitute an undue burden.²⁴¹ In the previous section I mentioned a case where a woman was denied planning permission to build a pool.²⁴² The CRPD Committee considered in that case that the state Party had not proven that allowing this would constitute an undue or disproportionate burden.²⁴³

In the case of refusing acne treatment due to the patient having a reduced decision-making capability, reasonable accommodation should, as I described in Section 4.6 of the thesis, primarily be focused on how the information is given as it will influence if the consent will be considered as valid. With the example of acne treatment this means that the healthcare personnel in contact with a patient with reduced decision-making capability should have the time to properly explain, and to adjust the information to the specific patient, what the complications of the medication are, such as sensitive skin, and what complications can arise if one is exposed to too much sun, gets pregnant or drink alcohol. The limitations that the CRPD poses are that it has to be necessary and appropriate and that it cannot impose a disproportionate or undue burden. Obligating the healthcare personnel to take the time to properly explain in order for a patient with reduced decision-making capability to have a right to health on an *equal basis* with others should be considered as necessary and appropriate. Given the two cases that I mentioned in this section, it shall neither be considered as imposing a disproportionate or undue burden.

5.3.4 Reasonable Support

The CRPD Committee has stated that respecting the legal capacity of persons with disabilities means not permitting substitute decisions-making,

²⁴⁰ UN CRPD Committee, Marie-Louise Jüngelin v. Sweden (5/2011), CRPD/C/12/D/5/2011, 2 October 2014, para 10.5.

²⁴¹ UN CRPD Committee, Marie-Louise Jüngelin v. Sweden (5/2011), CRPD/C/12/D/5/2011, 2 October 2014.

²⁴² UN CRPD Committee. H.M. v. Sweden (003/2011), CRPD/C/7/D/3/2011, 19 April 2012.

²⁴³ *Ibid*, para 8.5.

i.e. persons making the decision for them.²⁴⁴ Here I want to remind the reader of Section 2.2.2 of the thesis where I mentioned SOU 2015:80 which proposed a bill that would allow the use of guardianship when the patient does not have the ability to decide on issues relating to their healthcare and Section 2.4 where I discussed how the healthcare personnel will influence the patient but how this influence must be considered as unjustifiable if they refuse to give medical treatment against the patient's wishes. Article 12(3) of the CRPD stipulates that State Parties shall take appropriate measures to offer persons with disabilities access to the support they might need in order to exercise their legal capacity. How this support is to take form was up for discussion at the fifth session of the Ad Hoc Meeting that preceded the CRPD, where many parties expressed that supported decision-making will not be sufficient in every situation.²⁴⁵ Furthermore, many State Parties upon ratifying the CRPD made reservations in relation to Article 12.²⁴⁶ However, the CRPD Committee has later emphasized that State Parties must provide systems of *supported* decision-making that do not amount to *substitute* decision-making.²⁴⁷ Supported decision-making regimes can take many different forms but the most important factor is that it respects the rights, will and preference of the person and not on what is believed to be the objective "best interest" of the person concerned.²⁴⁸ The CRPD Committee criticized Sweden for this in 2014 and emphasized the obligation to provide a wide range of measures which respect the individual's autonomy, will and preferences, including with respect to the individual's right to give and withdraw informed consent for medical treatment.²⁴⁹ As regards the form of the supported decision-making regimes, the CRPD Committee has given the example of developing support mechanisms at the community level to promote choices, autonomy and inclusion for adults with disabilities.²⁵⁰

While Article 12(3) stipulates that State Parties must have a system of support in the exercise of legal capacity, Article 12(4) stipulates that there

²⁴⁴ General Comment No. 1 Article 12 Equal Recognition before the Law, CRPD/C/GC/1, 19 May 2014, para. 41; Della Fina, Cera & Palmisano (2017) p. 269-270

²⁴⁵ *Ad Hoc Committee on a Comprehensive and Integral International Convention on Protection and Promotion of the Rights and Dignity of Persons with Disabilities*, Daily Summary of Discussion at the Fifth Session, 25 January 2005.

²⁴⁶ Fallon-Kund, M. & Bickenbach, J.E. (2017) p. 287.

²⁴⁷ General Comment No. 1 Article 12 Equal Recognition before the Law, CRPD/C/GC/1, 19 May 2014, para 16; see also, inter alia: Concluding Observations on the Initial Report of Ethiopia, CRPD/C/ETH/CO/1, 4 November 2016; Concluding Observation on the Initial Report of India (Advanced Unedited Version), CRPD/C/IND/CO/1, 29 October 2019.

²⁴⁸ Della Fina, Cera & Palmisano (2017) p. 270; General Comment No. 1 Article 12 Equal Recognition before the Law, CRPD/C/GC/1, 19 May 2014, para. 27.

²⁴⁹ Concluding Observations on the Initial Report of Sweden, CRPD/C/SWE/CO/1, 12 May 2014; this was also emphasized in Concluding Observations on the Initial Report of Croatia, CRPD/C/HRV/CO/1, 15 May 2015

²⁵⁰ Concluding Observations on the Initial Report of Cook Islands, CRPD/C/COK/1, 15 May 2015.

must be safeguards in these systems. This paragraph has been described as an uneasy compromise between those who wanted to abolish substitute decision-making under the CRPD and those who considered that some form of guardianship is inevitable but that it needs safeguards.²⁵¹ Article 12(4) stipulates that measures relating to the exercise of legal capacity shall provide for safeguards to prevent abuse and that these safeguards shall ensure that these measures respect the rights, will and preferences of the person and are free of conflict of interests and inappropriate influence. The CRPD Committee has also mentioned that the protection against inappropriate influence includes the right to take risks and make mistakes.²⁵² In some of the CRPD Committee's concluding observations they note that the state Party should establish safeguards but does not specify this further.²⁵³ However, the CRPD Committee has expressed that the safeguards shall be transparent²⁵⁴ and free from inappropriate influence.²⁵⁵ In their recently issued concluding observation to Norway the CRPD Committee wrote that they recommend to them to conduct capacity-building activities for public officials on the right to supported decision-making arrangements and that those in need of support shall also receive support in deciding when they need less support, or when they do not need support at all.²⁵⁶

In conclusion, if a healthcare professional would refuse a patient an acne treatment, they would make the decision for the patient against that patient's wishes, which would constitute substituted decision-making. Instead there has to be systems of support where patients with reduced decision-making capabilities are given the best opportunity to give a valid consent. These will mainly be focused on the giving of information. Here I want to reiterate that the CRPD Committee has expressed that the protection against inappropriate influence includes allowing the individual to take risks and make mistakes. When a healthcare professional prescribes a certain medication that may have complications if the patient, for example, exposes their skin to the sun, then there will always be a risk that the patient does not understand the risks. However, patients without a reduced decision-making

²⁵¹ Bantekes, Stein & Anastasiou (2018) p. 368.

²⁵² General Comment No. 1 Article 12 Equal Recognition before the Law, CRPD/C/GC/1, 19 May 2014, para. 22.

²⁵³ See for example Concluding Observations on the Initial Report of Paraguay, CRPD/C/PRY/CO/1, 15 May 2013; Concluding Observations on the Initial Report of Costa Rica, CRPD/C/CRI/CO/1, 12 May 2014.

²⁵⁴ Concluding Observations on the Initial Report of Turkmenistan, CRPD/C/TKM/CO/1, 13 May 2015; Concluding Observations on the Initial Report of Serbia, CRPD/C/SRB/CO/1, 23 May 2016

²⁵⁵ Concluding Observations on the Initial Report of Ethiopia, CRPD/C/ETH/CO/1, 4 November 2016; Concluding Observations on the Initial Report of Norway, CRPD/C/NOR/CO/1, 7 May 2019

²⁵⁶ Concluding Observations on the Initial Report of Norway, CRPD/C/NOR/CO/1, 7 May 2019.

capability are normally allowed to take these risks, while some feel a need to act in the "best interest" for persons with reduced decision-making capabilities and not allow them to take the risks.

5.4 Conclusions

If a patient with a reduced decision-making capability was refused medical treatment, such as acne medication, would it interfere with Sweden's obligations in the ECHR? As the ECHR has not dealt explicitly with the situation of refusal of medical treatment that is not as severe as a lethal substance, we can only speculate what the European Court would think regarding, for example, acne medication. In *Haas v. Switzerland* it is stated that requiring a psychiatric treatment before prescribing a lethal substance is not an interference with the ECHR. The European Court does not specify if *other* medical treatments that are not as severe should require psychiatric assessment, with the possible result of being refused after the assessment, and this is possibly something that would fall within the member States margin of appreciation. However, it is my view, given the cases I have mentioned that stipulate that self-determination is an important principle in Article 8 and that legal capacity may not be completely removed due solely to mental capacity, that there is a possibility to argue that a violation of Article 14 taken in conjunction with Article 8 has occurred when a patient with a reduced decision-making capability is refused a medical treatment such as acne medication. This is further supported by the statement from the European Court that when restrictions on fundamental rights apply to a particularly vulnerable group then there must be weighty reasons for the restrictions. I interpret this statement that there has to exist a serious threat to the patient's health. However, the assessment of whether or not a violation of Article 14 taken in conjunction with Article 8 has occurred will be based on the individual circumstances.

If a patient with a reduced decision-making capability was refused medical treatment, such as acne medication, would it interfere with Sweden's obligations in the CRPD? I concluded that legal capacity shall be included in Article 12(2) and that refusing medical treatment due to mental capacity is a way to remove legal capacity. Furthermore, the CRPD states that a patient with a reduced decision-making ability should not be discriminated against in their enjoyment of their right to health, i.e. that a patient with a reduced decision-making capability should be able to act on their right to acne treatment on an equal basis of patients without reduced decision-making capabilities. Furthermore, the protection against inappropriate influence also includes a right to take risks and to make mistakes. Thus, it

would interfere with Sweden's obligations in the CRPD if a patient was refused medical treatment due to mental capacity. Additionally, I argued that with regard to providing reasonable accommodation, Sweden are obliged to give properly explained and individually adjusted information. Lastly, I argued that deciding against receiving medical treatment such as acne medication against the patient's wishes is a form of substitute decision-making which is not allowed according to the CRPD. This does not mean, though, that patients with reduced decision-making capabilities should be left on their own. A patient is normally in a vulnerable position while seeking medical help and a patient with a reduced decision-making capability is often even more in a vulnerable position. For these situations a supported decision-making regime can be of great assistance, especially if the patient does not have other close relations that help them. However, a system of supported decision-making should not remove the obligation for the healthcare personnel to leave individually adjusted information and to give the patient a proper chance to decide if they wish to receive the medical treatment.

6 Analysis

In the beginning of this thesis I wrote that it is not stated in law what the consequences are if a patient only understands parts, or nothing, of the information given by a healthcare personnel before obtaining medical treatment. As I stated previously, this raises two questions: how much does the patient have to understand in order to give a valid consent and what are the obligations for the healthcare personnel when the consent is not considered to be informed. I also wrote that these questions are even more complex in regard to patients who for various reasons, such as an intellectual or psychosocial disability, have a reduced decision-making capability. In this chapter I will analyse the conclusions that I have drawn in this thesis regarding these two questions.

6.1 A Valid Consent

How much does the patient have to understand in order to give a valid consent? Chapter 3 Section 1 PL lists examples of what type of information the patient has to be given. It is also stated in Chapter 3 Section 7 PL that the person who gives the information has to ensure "as far as possible" that the patient has understood the content and meaning of the information. It is, however, nowhere stated how much the patient actually has to understand in order to give a valid consent nor that a consent can be considered as not valid due to mental capacity.

As I discussed in Chapter 2, the question of how much the patient has to understand is difficult to reply to since the legal sources I examined do not give a clear answer. In this thesis I have discussed both the concept of mental capacity and legal capacity and how these are sometimes coupled together, i.e. requiring mental capacity in order to have legal capacity. Swedish law does not say whether mental capacity is a threshold in order to have legal capacity regarding health matters, i.e. being able to give a valid consent to medical treatment. Thus, from this it is possible to conclude that a patient with a reduced decision-making capability can consent to medical treatment. However, I have also discussed that the question of whether or not a lack of mental capacity will result in a removal of legal capacity may be dependent on if we consider that a medical intervention without a valid consent is considered as forced within the meaning of Chapter 2 Section 6 IoG. If we consider that a consent from a patient with a reduced decision-making capability should be invalid as it would constitute a forced bodily

intervention, then a lack of mental capacity would result in a removal of legal capacity. As I mentioned in Chapter 2, it is important that the fundamental freedoms in the second chapter of the IoG are not easily circumvented. However, if we conclude that because they cannot give a valid consent it constitutes a forced medical intervention, then we remove their legal capacity, which is an interference to their right to respect for private life and their right to not be discriminated against due to mental disability. These are also vital rights that should be respected. Furthermore, if we conclude that an uninformed consent would constitute a forced bodily intervention, then we would ignore the need to make individual assessments and the healthcare personnel's obligations to provide a patient-oriented care in consultation with the patient and with individually adjusted information.

Related to the question of how much a patient has to understand in order to give a valid consent is the question of what risks a person should be allowed to take. The European Court stated in both *Haaz v. Switzerland* and *Shtukaturov v. Russia* that included in the right to live one's life as one wishes is allowing people to do harmful activities. However, the European Court also expresses that this includes that the person is capable of freely reaching a decision on the question and acting in consequences of this. So how should patients with reduced decision-making capabilities be protected from being harmed as a result of them not understanding while not being patronizing and acting according to, what is believed to be, their "best interest"? In the scenario of a patient wishing to receive medication for their acne, the medication does include a side effect of dry skin and may also result in more serious complications if the patient is exposed to too much sun, gets pregnant or drinks alcohol. In this scenario, it is important therefore that the patient not only understand the side-effect but also the more serious possible complications. The reason why it is important, and why a valid consent is important, is to ensure that the patient will not be harmed. The essence of being a healthcare worker is to do no harm, as is illustrated by, inter alia, the Hippocratic Oath. Note however that a patient will normally take risks when obtaining medical treatment: the risks of complications from the treatment as well as risks of other complications if the patient does not follow, or misunderstands, the healthcare personnel's recommendations. Normally, the patient is still offered the medical treatment even though there are always risks. Note also that this type of medication is often given to teenagers. Thus, when discussing how much the patient has to understand in order to give a valid consent, we also have to discuss what risks people are allowed to take, in order to respect their right to live autonomously on an equal basis of others.

The result of the current Swedish legal order concerning this issue is that there are no clear guidelines but that the healthcare personnel still have to face this dilemma. Furthermore, the healthcare personnel have not been given authority from the Parliament to decide on matters of decision-making capacity. Additionally, this decision is not really medical but rather legal. The solution to the current situation is not necessarily that patients with reduced decision-making capacity should automatically be given the medical treatment that they wish, this is not afforded to anyone. But the uncertainty of how much the patient has to understand in order to give a valid consent creates a grey area where no one has authority to decide but where decisions still have to be taken.

6.2 The Obligations of the Healthcare Personnel

The second purpose of this thesis was to examine what the obligations are for the healthcare personnel when the consent is not informed. I examined this in relation to providing individually adjusted information, providing good, patient-oriented care with equal opportunities for the population, providing care without discrimination and if the ECHR and the CRPD poses further obligations for the healthcare personnel. In this thesis, I have illustrated that in practice their obligations are unclear. The healthcare personnel are obliged to provide individually adjusted information and to provide "good care" that is patient-oriented, but as it is never explained in the statutes, the preparatory works nor in the decisions from the governmental agencies the extent of the obligations, it is unclear what the healthcare personnel's obligations really entail. It may appear empowering for the patient but as these are not rights that the patient can invoke and because of the uncertainty of their extent, it does not have as much substance as it may at first appear. Furthermore, the healthcare personnel are obliged to provide care with equal opportunities. This means that everyone should access healthcare when they are in need and that the healthcare personnel should strive to even out differences. It means that a patient with severe acne should be able to receive treatment for it. It also entails an obligation to make individual assessments and is related to the principle of solidarity which entails an obligation to pay particular attention to vulnerable patients and to place resources where the needs are the greatest. Care with equal opportunity is a fundamental principle in Swedish law. It does not carry reservations stipulating a requirement for mental capacity. As opposed to providing individually adjusted information and good care, I consider this obligation much clearer. However, it is still not a right the

patient can invoke. One consequence of these being obligations for the healthcare personnel and not rights for the patient is that the patient has to depend on the healthcare provider creating a possibility for the healthcare personnel to fulfil these obligations and that the healthcare personnel then carries them out. This opens up the possibility for unequal care.

Moreover, the healthcare personnel are obliged to not discriminate. The DiskL can be a powerful tool as it is focused on whether a negative effect arises, and not on the underlying causes, and because it can constitute discrimination even if the motive is well-meaning. Additionally, it can constitute discrimination even if the patient later receives the treatment if they were first refused it. However, discrimination may be allowed if it has a justifiable purpose and is necessary. Patient security has been considered as a justifiable purpose but it is unclear what situations may amount to "patient security" and consequently be allowed. Furthermore in regards to the discrimination form inadequate accessibility the DiskL, the ECHR and the CRPD stipulates that the healthcare personnel are obliged to provide measures that will ensure that persons with disability are not discriminated against and have an equal opportunity to exercise their rights. However, they are only obliged to take these measures if it is considered as reasonable. The measure that I argue is the most important regarding patients with reduced decision-making capabilities is *how* information is provided. This does not only include adjusting the language and the format, but also the setting in which information is disclosed. Furthermore, for these to have effect in real life it is important that these measures are tailored to the individual. It is not enough to only provide easy-to-read formats as the reasons behind the patient's struggle to understand will vary. However, it is also unclear in this regard what the healthcare personnel's obligations are and what measures will be considered as reasonable and what measures will be considered an undue burden. These questions are more complex when faced with a healthcare sector that is overworked. Not least do these concerns have greater impact when the healthcare sector is particularly overworked, such as when a pandemic hits.

In conclusion, the obligations for the healthcare personnel when the patient has not given an informed consent are unclear. This is dangerous as it creates a vulnerability in the system that may affect individuals who could be considered to be particularly vulnerable. If it is unclear how laws and rules should be applied then it is reasonable to conclude that this will particularly affect the individuals who struggle to process information and express their needs and expectations. Let me illustrate with a metaphor. A clear system is like a bridge over water with high and solid fences. An individual with visual impairment crossing it will know the way forward

and the risk of them falling in the water are microscopic. Of course, there is always a risk that the individual climbs over the fences and falls over but generally there is a smaller risk of them being hurt. With an unclear system the fences of the bridge are brittle and are lacking in some areas. The individual with the visual impairment crossing this bridge can still walk forward but there is a greater risk that they will fall in the water. The current Swedish system is unclear for both the patient and for the healthcare personnel. If laws and rules are not clear, we create room for personal interpretations, which will result in different care depending on which healthcare personnel the patient meets. It may also result in the patient falling in the water.

7 Conclusions

The overall purposes of this essay are to examine how much the patient has to understand in order to give a valid consent and what the healthcare personnel's obligations are in relation to a patient who wishes to receive a medical treatment but has not given an informed consent. To achieve this goal, I chose six sub questions.

The first sub question was what constitutes a valid consent within the Swedish healthcare and whether a patient with a reduced decision-making capability can consent. I began by explaining that the requirement of obtaining a consent to medical treatment derives from Chapter 2 Section 6 IoG, which stipulates that everyone shall be protected in their relations with the public institutions against any physical violation to their person. Thereafter, I explained that within the healthcare sector there is no requirement regarding the form of the consent and that it may be revoked whenever. I stated that the patient has an absolute right to refrain from medical treatment, even if it is medically necessary, but that the patient does not have an absolute right to decide the content and extent of their healthcare. Furthermore, I also explained that consent has to be preceded by information that is not given in a routine-like manner but instead tailored to the individual patient. In Chapter 2 I illustrated that it is difficult to answer whether a patient with a reduced decision-making capability can give a valid consent since the legal sources never specifically address it. However, no sort of threshold regarding mental capacity is mentioned that would render the consent to be considered as valid. It is stated in PL that the healthcare personnel have to ensure that the patient, as far as possible, understands the information given. However, the healthcare system in Sweden is based on obligations for the healthcare personnel and thus this should be interpreted as an obligation for the healthcare personnel and not a requirement of consent for the patient. Thus, I came to the conclusion in Chapter 2 that the only way to argue that a patient with a reduced decision-making capability could not consent to medical treatment is if we assumed that it would constitute a forced bodily intervention.

The issue of whether or not giving medical treatment without an informed consent would constitute a forced bodily intervention also answers the thesis second sub question: would refusing medical treatment due to the patient having a reduced decision-making capability interfere with the principle of legality? In this section I began by discussing what influence may be allowed from the healthcare personnel and I argued that refusing medical

treatment due to mental capacity would constitute inappropriate influence. Furthermore, I highlighted that the principle objectivity, enshrined in both FL and IoG, does not allow discriminatory treatment. I concluded that if we consider that giving medical treatment without informed consent to constitute a forced bodily intervention, then there would be support in law to refuse medical treatment. Lastly, I ended Chapter 2 with a discussion on when consent would be considered as valid, if there was such a requirement. I also mentioned that this issue is dependent on what mistakes we are willing to allow people, and in particular people with reduced decision-making capabilities, to make.

The third sub question of this thesis was if refusing medical treatment due to the patient having a reduced decision-making capability would interfere with the healthcare personnel's obligations to provide good care and care with equal opportunities for the population. Providing good care is an obligation for the healthcare personnel that, *inter alia*, requires it to be patient-oriented. However, as I stated, this does not entail an absolute right to receive the medical treatment one wishes. Additionally, it is nowhere stated the extent of the obligation to provide healthcare that is patient-oriented and we can thus not conclude in general that refusing medical treatment would interfere with the principle of good care. It would have to be an assessment based on the individual circumstances of the situation. However, I argued that they should in general not be considered to have fulfilled this obligation as it would otherwise be ineffective in practice. Care with equal opportunities for the population means that everyone shall be able to take part in healthcare services when they are in need and to do this on equal terms. It is related to the principle of solidarity which states, *inter alia*, that particular attention needs to be placed on those who are considered as weaker. Unlike the obligations to provide individually adjusted information and to provide good care that is patient-oriented, I argue that it is clearer with the obligation to provide care with equal opportunities that this obligation is not being met if the patient is refused a medical treatment due to mental capacity. However, none of these three obligations are rights that the patient can invoke and it is thus hard to establish with certainty that the healthcare personnel would not fulfil their obligations if they refused medical treatment. This uncertainty will also result in a more unequal care as the patient has to rely on the healthcare personnel fulfilling these obligations.

The thesis fourth sub question was if refusing medical treatment to patients with reduced decision-making capabilities would constitute discrimination. I examined this in relation to disability and to two forms of discrimination: indirect discrimination and inadequate accessibility. As opposed to the

obligations I studied in Chapter 3, if a patient had been discriminated against according to DiskL, they could go to court and possibly receive compensation. In Chapter 4, I concluded that refusal of medical treatment would constitute a disadvantage and that the comparable situation must, firstly, be based on the needs of the patients, and, secondly, would be between a patient with an intellectual or psychosocial disability and who does not understand the information and a patient without an intellectual or psychosocial disability who does not understand the information. I came to the conclusion that the question of if refusal of medical treatment would constitute discrimination is, firstly, dependent on if the patient's reduced decision-making capability would fall within the meaning of disability in the DiskL, mainly that it is considered as lasting. I stated that some of the patients that this essay focuses on may not fall within the scope of disability in DiskL. Secondly, I came to the conclusion that it may only constitute indirect discrimination if the refusal of medical treatment is not because of a threat to patient security. However, as regards refusing medical treatments which are not a threat to the patient's life, such as acne medication, I stated that the legal sources are silent but that I consider that the threshold should be high as it would otherwise weaken the prohibition against discrimination, the principle of objectivity and principles that state that healthcare shall be patient-oriented and given on an equal basis. Thirdly, I concluded that it is hard to assess if it could constitute inadequate accessibility, partly since one has to consider the financial and practical aspects, partly since it is unclear if individual adjustments are included. I also stated that the most important accessibility measure is conveying the information in a manner that is tailored to the patient in order to ensure that the patient has the best possibility to give an informed consent.

The thesis fifth sub question was if a refusal of medical treatment on the basis of the patient lacking mental capacity to give a valid consent would interfere with Sweden's obligations in the ECHR. The ECHR does not include a right to health but I examined the question in relation to Article 8 and the right to self-determination and to not have one's legal capacity removed. I also examined Article 14 which prohibits discrimination on the grounds of, inter alia, disability. I stated that the European Court has in its case law established that a consent is considered as valid if the patient is given information prior that is clear, on the patient's health status, the procedure and the alternatives to it, and if the patient is given time to reflect on it, by themselves or with someone close. Furthermore, a consent is not valid if it is given when the patient is in a vulnerable position or if the patient feels forced to consent. This is similar to the Swedish regulations, which I outlined in Chapter 2.

As the European Court has not dealt explicitly with the situation of refusal of medical treatment that is not as severe as lethal substances, we can only speculate what the European Court would consider regarding refusal to give less severe treatments such as acne medication due to mental capacity. However, the European Court has stated that Article 8 article includes a right to personal development, that self-determination is an important principle underlying the interpretation of its guarantees and that it is important for persons with disabilities to live autonomously. Given these statements one could argue that the rights of patients with reduced decision-making capability to undergo medical treatment should generally be respected. Furthermore, the European Court has stated that mental disorder cannot be the sole reason to justify a full incapacitation and that when restrictions on fundamental freedoms apply to a particularly vulnerable group then there must be weighty reasons. Thus, it is allowed to remove the legal capacity from patients with reduced decision-making capabilities, i.e. not allow them to make a valid consent to medical treatment, but there must be significant reasons behind it. I interpret this as meaning, regarding the situation that this thesis focuses on, serious threats to the patient's health. Regarding Article 14, as the extent of self-determinacy and legal capacity is not clearly defined it is also hard to answer at what point it would interfere with Article 14 and the refusal would constitute discrimination. Lastly, the European Court has stated that with regard to patients with disabilities it is important to not rely on general assumptions and thus, the assessment of if a violation of Article 14 taken in conjunction with Article 8 has occurred will have to be based on the specific situation and the specific patient.

Lastly, the thesis sixth sub question was if a refusal to give medical treatment on the basis of the patient lacking mental capacity to give a valid consent would interfere with Sweden's obligations in the CRPD and I focused particularly on Article 5, 12 and 25. I argued that legal capacity should entail a right to act on the rights in the CRPD which means that refusal of medical treatment would mean interfering with the patient's legal capacity. Furthermore, I discussed the right to not be discriminated against and mentioned one case where the CRPD Committee stressed the importance of making individual assessment with regard to persons with disabilities. I established that refusing a medical treatment such as acne medication would not be considered as proportionate or an undue burden in relation to receiving the care that the patient needs. Moreover, I discussed the obligation to provide reasonable accommodation and I highlighted, as I did in Chapter 2, that the most important measure for patients with reduced decision-making capability wishing to receive acne medication, is information that in its communication is tailored to the patient. Lastly, I discussed the obligation to provide regimes of supported decision-making

enshrined in Article 12(3) and to provide safeguards in these regimes to avoid abuse. I argued that refusing medical treatment would constitute substitute decision-making and is thus not allowed according to the CRPD. I wrote that the CRPD Committee obliges the State Parties to have supported decision-making regimes and that they have expressed that the protection against inappropriate influence includes the right to take risks and make mistakes.

In my analysis I returned to the overall purposes of this thesis: how much does the patient have to understand in order to give a valid consent and what the healthcare personnel's obligations are when the consent is not informed. Concerning how much the patient has to understand in order to give a valid consent I argued that the question of if a reduced mental capacity should result in legal incapacity is dependent on if we consider an uninformed consent to medical treatment to constitute a forced bodily intervention. I also argued that the question of how much a patient has to understand is related to the question of what risks we allow as there is nearly always a risk concerning medication. Lastly, I stated that there is a grey area as the healthcare personnel does not have authority to decide on mental capacity but decisions still need to be taken. Regarding the second overall purpose I concluded in my analysis that many of the healthcare obligations are vague. I argued, by using a metaphor of a bridge, that these uncertainties create a vulnerability which may affect individuals who could be considered to be particularly vulnerable. I also argued that when the laws and rules are not clear then we allow room for personal interpretations, which will result in different care depending on which healthcare personnel the patient meets. The purpose of this thesis was not to provide a solution for this problem. It is also important to stress that finding a solution is not an easy task as there are several interests competing such as the right to decide over one's own life, the right to be able to get the same healthcare as others and that patients with reduced decision-making capabilities should not be harmed. However, this thesis has illustrated that there is a need for even more research in this field, particularly regarding how the interests and voices of patients with reduced decision-making capabilities are best heard and respected. The research will greatly benefit from being interdisciplinary, not least offering a medical perspective as it is the field that tackles these issues in day to day practice. Lastly, the obligations of the healthcare personnel have to be more clearly defined so that the patient knows what to expect and so the healthcare personnel knows more in depth what is expected of them. This will result in a more equal care.

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