To force or not to force: protecting the lives of persons with dementia who refuse care

Litins'ka, Yana

Published in:
Vänbok till Sverker Scheutz: om rätt – och att undervisa rätt

2020

Document Version:
Publisher's PDF, also known as Version of record

Vänbok till Sverker Scheutz

Om rätt och att undervisa rätt

iUSTUS
FÖRLAG

Redaktörer

Hans Eklund
Lotta Lerwall
Anna-Sara Lind

Upplaga 1:1
ISBN 978-91-7737-110-6
Produktion: eddy.se ab, Visby 2020
Omslag: John Persson
Foto: Mikael Wallerstedt
Förlagets adress: Box 1994, 751 49 Uppsala
Tfn: 018-65 03 30
Webbadress: www.iustus.se, e-post: kundtjanst@iustus.se

Printed by Dimograf, Poland 2020

Innehåll

Yana Litins'ka

To force or not to force: protecting the lives of persons with dementia who refuse care

Introduction

Sverker Scheutz has taught on the issues related to the realisation of the constitutional rights for many years. One of his areas of interest has been how the provisions of public law reflect the reality of care for persons with dementia. In this contribution, I will reflect on the issues of the use of force and the protection of the fundamental rights of persons with dementia.

It is estimated that between 130.000 and 150.000 people in Sweden suffer from dementia, a number that is expected to rise significantly in the near future.[1] This condition is especially common among older persons.[2] Dementia results in the decline of memory and cognitive functions. People with dementia sometimes forget where they are, what they planned to do, have mood swings or depression, and may experience a deterioration in their ability to communicate. The condition represents a challenge for health and social care as people with dementia sometimes resist treatment or medica-

[1] Socialstyrelsen, Nationella riktlinjer 2017 – vård och omsorg vid demenssjukdom – stöd för styrning och ledning, Åtta.45 Tryckeri AB 2017, p. 19.
[2] Statens beredning för medicinsk och social utvärdering, Demenssjukdomar: En systematisk litteraturöversikt, March 2006, pp. 21–22.

tion necessary to save their lives or refuse to undergo hygienic procedures and as a result develop sores and sepsis. Furthermore, those suffering from dementia sometimes wander away from their homes or social care facilities and are not able to find their way back, and in many cases are not dressed appropriately for cold weather when they do so. In the media, healthcare personnel and social workers have described their dissatisfaction with the relevant legislation. They view it as an obstacle to the protection of the lives of persons with dementia. The reason for the dissatisfaction is that the legislation does not allow health and social care personnel to use force on persons with dementia in order to save their lives.[3] This has motivated Swedish health and social care professionals to raise human rights concerns.

The aim of this contribution is to evaluate whether Swedish law on caring for persons with dementia who refuse interventions, or want to leave their homes or care facilities unsupervised is compliant with the obligation to protect life under the Convention for the Protection of Human Rights and Fundamental Freedoms (hereafter – the ECHR). The division between Swedish national law and the ECHR is, to a degree, artificial; the Convention is also a domestic law. To achieve the aim, I will start with the analysis the possibilities within Swedish law for providing life-saving medical treatment to those who refuse care or depriving the liberty to protect the lives of persons with dementia. I will then investigate the methods used by the ECtHR for assessing whether a state is compliant with the positive obligations to protect life. Finally, I will evaluate whether Swedish law is in fact compliant with the ECHR.

Constitutional protection of bodily integrity and liberty

Chapter 2 Articles 6 and 8 of the Instrument of Government (hereafter – the IoG) set forth that everyone is protected in their relations with public institutions against forced bodily interventions and deprivation of liberty. These rights may be limited if the conditions that are listed in Chapter 2 Articles 20 and 21 of the IoG are satisfied. These are: the limitations must be prescribed by an act of Parliament, they must have a purpose acceptable in a democratic society, and they must be limited to what is necessary for this purpose. In this section, I will analyse whether the refusal of a person with dementia to

[3] DN Debatt, Otydliga regler tvingar vårdpersonal bli lagbrytare, Dagens Nyhet 14/8 2013; Olsson, H, and Thuresson, K, Personer med nedsatt autonomi och beslutsförmåga – IVO bör ta ställning, Lakartidningen.se 18/2 2014; Björkstén, K S, and Fälldin, K, Dementa utan rättsligt skydd, SVD.se 14/8 2009.

undergo care should be considered a forced bodily intervention in the meaning of the IoG. Then, I will evaluate whether limiting the ability to leave a home or health or social care facility by locking doors is considered to be a deprivation of liberty in the context of Chapter 2 Article 8 of the IoG.

Chapter 2 Article 6 of the IoG establishes that everyone is protected from forced bodily interventions by public authorities. Its preparatory works suggest that the term "bodily intervention" includes, in particular, medical examinations, blood tests, vaccinations and other injurious medical interventions.[4] In the case law and the decisions of the Parliamentary Ombudsman (hereafter the JO) even non-injurious interventions, such as DNA-testing, urine testing and psychiatric examination, have been considered bodily interventions.[5] Therefore, the provisions of the Article should be interpreted as applicable to the vast majority of forced medical interventions within the health and social care context. Interventions covered by the Article include any examination, hygienic procedures, such as showering or shaving, as well as medication, if these are forced.

The term "forced" was not sufficiently clarified in the preparatory works for the IoG. The literal interpretation leaves no doubt that interventions in cases where the patient explicitly refuses care or physically resists it should be considered forced. The JO has confirmed that forced interventions include those when a person is under threat of any sanctions or reasonably perceives that he or she does not have a choice to refuse a procedure due to the behaviour of the public authority representative.[6] Whether interventions in a person who does not explicitly refuse medication but receives it without knowing are to be considered forced has also been discussed by the Swedish authorities. Back in 1982, the Chancellor of Justice decided on a case that concerned tranquilising a person to prevent a suicide attempt. The person unknowingly consumed the tranquiliser in a drink. Giving medication in

[4] Prop. 1973:90 p. 242.

[5] JO 2929-1983 beslut den 9 augusti 1984; JO 3236-2016 beslut den 12 juni 2017; JO 6442-2014 beslut den 30 juni 2016; JO 2089-2016 beslut den 27 februari 2018; JO 4746-2015 beslut den 25 maj 2018; AD 1984:94; NJA 2016 p. 1157; MÖD dom den 12 september 2011 mål nr UM3793-11; SOU 1975:75 pp. 358–359; SOU 2013:2 p. 174; Warnling-Nerep, W, *"Påtvingat kroppsligt ingrepp" (RF 2:6) och JO:s rättsvägledande funktion*, Förvaltningsrättslig tidskrift, no 1, 2002, pp. 28, *34–37*; Rynning, E, *Samtycke till medicinsk vård och behandling. En rättsvetenskaplig studie*, Iustus Förlag AB 1994, p. 100; Åkerström, S, and Kindström Dahlin, M, *Tvångs- och begränsningsåtgärder inom demensvården – olagliga rättighetsbegränsningar?*, Förvaltningsrättslig tidskrift, no 4, 2012, pp. 489–490.

[6] JO 2089-2016 beslut den 27 februari 2018; JO 5705-2014 beslut den 30 juni 2016; JO 6442-2014 beslut den 30 juni 2016; JO 38-2015 beslut den 23 mars 2016; JO 6823-2009 2196-2010 beslut den 30 juni 2011; JO 479-2010 beslut den 26 april 2010; JO 696-2001 beslut den 29 november 2002; see also JK 2418-16-41 beslut den 16 december 2016.

such a way is common practice in the care of persons with dementia. The Chancellor of Justice decided that forced intervention did not take place as the person did not object to taking the drink containing the medication.[7] However, in more recent case law of the Chancellor of Justice such conclusions have not been repeated.[8] The decision of the Chancellor of Justice received criticism.[9] Some legal scholars argue that if there are good reasons to presume that a patient would have chosen to consent to a treatment, the latter cannot be considered forced.[10] Yet, if there are good reasons to assume that a person would have refused an intervention, it is deemed forced. Other authorities, such as the National Board for Health and Welfare, also support the approach taken in the doctrine as to what interventions should be considered forced.[11]

The other important issue for understanding the scope of Chapter 2 Article 6 of the IoG is whether protection from being forced to receive treatment is also provided to persons with dementia, who may be also mentally incapable to refuse the interventions. The literal interpretation of the IoG emphasises that every person, regardless of his or her mental abilities, should receive the protection. The inquiry report to the IoG explains that in cases where a person with diminished mental abilities consents to a medical treatment without appreciating or fully understanding it, such an intervention shall not be viewed as forced.[12] The sources therefore do not exclude persons with reduced decision-making abilities from the scope of the protection. The refusal of a person with reduced decision-making abilities to undergo care should be considered a forced bodily intervention in the mean-

[7] JK 850-82-22 beslut den 29 april 1982.

[8] JK 1690-16-28, beslut den 22 april 2016; JK 4243-13-40 beslut den 17 juni 2014. In 2016 the Chancellor of Justice considered the question as to *forced* deprivation of liberty. The case concerned an underage person who was arrested on suspicion of committing a crime. Furthermore, the person concerned provided consent to being placed in the residential care home with various limitation of his freedom of movement and communication. The Chancellor of Justice decided that placement was forced, in particular, because the full and accurate information concerning the options that the person had, and consequences of his choice was not provided. The approach seems to be sufficiently different from the practice of 1982 as to what *forced* means, yet the case does not directly relate to forced bodily interventions. JK 2418-16-41 beslut den 16 december 2016.

[9] Kindström Dahlin, M, *Psykiatrirätt: intressen, rättigheter & principer*, Jure Förlag 2014, p. 12; Warnling-Nerep supra note 5 p. 33 f.; see also JO 6442-2014 beslut den 30 juni 2016.

[10] Rynning supra note 5 p. 108; see also Jareborg, N, *Allmän kriminalrätt*, Iustus Förlag AB 2001, p. 286.

[11] Socialstyrelsen, Tvångs- och skyddsåtgärder inom vård och omsorg för vuxna, socialstyrelsen.se nr 12/2013, December 2013.

[12] SOU 1988:7 pp. 105–106.

ing of the IoG. This conclusion is also supported in the doctrine and the soft law documents of the National Board for Health and Welfare.[13]

The discussion in this section indicates that when adult patients with reduced decision-making abilities, in particular due to dementia, refuse care, physically resist care, or consent to care under the threat of sanctions, they are entitled to protection under Chapter 2 Article 6 of the IoG. I will now turn to an analysis of the scope of protection under Chapter 2 Article 8 of the IoG.

The preparatory works explain that deprivation of liberty should be understood as a measure that factually hinders a person from leaving a room or other limited space via confinement, monitoring or other similar means.[14] This broad approach has been further supported by the practice of the authorities. The JO states that use of locks, when it can be assumed that a person with dementia would not be able to open them, should be perceived as deprivation of liberty.[15] Therefore, preparatory works and practice are unanimous in that common measures used in caring for persons with dementia such as codes on doors, keeping a key separate from its lock and the need to receive permission to leave are deemed as deprivation of liberty. Similar to Chapter 2 Article 6 the language of Chapter 2 Article 8 provides protection to every person, including persons with dementia or reduced decision-making abilities. This interpretation has been confirmed by the practice of the JO and accepted in the doctrine.[16]

The IoG protects persons against actions of authorities. To understand the scope of the protection, it is necessary to clarify whether the IoG is applicable when providing medical and social care. The preparatory works explain that the scope of the IoG should be limited to the relations between the authorities themselves or between authorities and citizens. However, the notion of public authorities should be understood in a rather broad sense. Public authorities include various administrative agencies as well as legal entities or individuals that exercise public powers.[17] The exercise of public powers may also be delegated to the private subjects, but only if prescribed by an act of Parliament.[18] Only those actions that lead to decisions consti-

[13] Rynning, supra note 5 p. 110; Socialstyrelsen, supra note 11.
[14] Prop. 1975/76:209 p. 52.
[15] JO 1989/90 p. 207 dnr 837-1987.
[16] JO 1989/90 p. 207 dnr 837-1987; Rynning, supra note 5 p. 114.
[17] SOU 1975:75 pp. 77 and 97; see also Bull, T, and Sterzel, F, *Regeringsformen: en kommentar*, 4 edn, Studentlitteratur AB 2019, pp. 58–59.
[18] SOU 1975:75 pp. 77 and 97; see also Bull, T, *Mötes- och demonstrationsfriheten: en statsrättslig studie av mötes- och demonstrationsfrihetens innehåll och gränser i Sverige, Tyskland och USA*, Skrifter från Juridiska fakulteten i Uppsala 61 Series, Iustus 1997, pp. 358–363.

tute the exercise of public powers. Decisions are statements that influence rights, obligations and benefits or impose administrative punishment; they also clarify how a question is to be resolved.[19] Decisions are contrasted with factual actions – something that happens in the everyday life of authorities.[20] The government and JO also consider that in practice decisions may be "hidden" in factual actions. Those "hidden" decisions that are lengthy in duration and have severe consequences for the individuals concerned should be considered to be exercises of public powers.[21] Should providing a medical treatment against a patient's wishes or through the deprivation of their liberty be considered a decision? In my view, these actions significantly impact the rights of a person with dementia; they clarify that the wishes of these persons will be overridden. If health or social care providers or practitioners take these actions, it is logical to consider them as decisions in the public law sense. Therefore, if health or social care institutions provide care against patients' wishes or deprive them of their liberty, and the powers to decide on these issues are prescribed by the law, health and social care providers should be viewed as public authorities in the meaning of the IoG.

Psychiatric care for persons with dementia

In this section, I will elaborate on the possibilities of providing compulsory psychiatric care to persons with dementia. Before 1992, psychiatric care was provided in accordance with the Act on Compulsory Psychiatric Care in a Certain Situation (1966:293, hereafter – the LSPV). The Act stated that psychiatric care could be provided irrespective of whether persons consent to it if they were in need of care that was indispensable and they did not have insights into their own healthcare situation or were not able to take care of themselves. The broad formulation of the criteria for compulsory psychiatric treatment allowed a significant number of persons with dementia to be hospitalized. In fact, before the 1980s, dementia was one of the three most common diagnoses among psychiatric care patients; a quarter of residents of psychiatric care institutions were persons with dementia.[22] Treating such a number of patients within psychiatric care was considered problematic,

[19] SOU 2010:29 p. 97; prop. 2016/17:180 p. 24; Scheutz, S, *När börjar ett betygsärende?: Till skillnaden mellan faktiskt handlande och handläggning av ärenden*. In: Allmänt och enskilt – offentlig rätt i omvandling: festskrift till Lena Marcusson, Bull, T, Lundin, O, and Rynning E, (eds), Iustus Förlag AB 2013, p. 319.
[20] Prop. 2016/17:180 p. 23.
[21] SOU 2010:29 p. 97; JO 5877-2011 beslut den 6 december 2013 pp. 8–10.
[22] SoU 1982/83:15 p. 18; JO 1989/90 p. 207 dnr 837-1987.

especially in relation to the goal of reducing the numbers in psychiatric care. Moreover, the government considered that caring for persons with dementia in psychiatric hospitals often brought about a deterioration in their mental health as these were often located far from their homes.[23] In 1992, the new Compulsory Psychiatric Care Act (1991:1128, hereafter – the LPT) came into force. As will be discussed below, compared to the LSPV under the LPT, admitting persons with dementia into compulsory psychiatric care is more problematic.

The LPT differs from the LSPV, in particular, in its formulation of the purpose of admission to psychiatric care. This purpose of psychiatric care is expressed in the LPT as a means to empower a patient to voluntarily participate in the necessary care and to receive the support needed. This wording emphasises that the measures must be temporary and that, after achieving the purpose, the need in compulsory care will cease to exist.[24] Yet, if we reflect on potential for effective treatments of persons with dementia in compulsory care, this purpose can be rarely achieved. In its National Guidelines for 2018, the National Board of Health and Welfare clarified that effective treatment for the different types of dementia is currently unavailable. Only for Alzheimer's disease is there a medicine that allows a certain level of cognition to be preserved for a period of time. For other types of dementia, such as vascular dementia, frontotemporal dementia and mild cognitive impairment, effective medication does not currently exist.[25] Since the treatment that will enable a patient with dementia to voluntarily participate in the necessary care is currently unavailable, achieving the aim of compulsory care is problematic. The current state of medical science and practical development therefore means that limiting the rights of persons with dementia by providing compulsory psychiatric care is not appropriate.[26] However, if a person with dementia has also been diagnosed with other serious mental health problems, such as depression or schizophrenia, the purpose of the Act may be achieved by providing this type of care.

Apart from the purpose discussed above, the LPT lays down admission criteria for compulsory care. For admission to closed psychiatric care, in

[23] SOU 1987:21 pp. 99 and 15; prop. 1990/91:58 p. 78.

[24] Prop. 1990/91:58 pp. 70–71; Larsson, M, and Lundberg, G, *Mötet mellan psykiatri och somatik: En intervjustudie om sjuksköterskors upplevelser*, Malmö högskola 2010, p. 127; Gustafsson, E, *Psykiatrisk tvångsvård och rättssäkerhet: en rättsvetenskaplig monografi om LPT*, 1 st edn, Studentlitteratur AB 2010, p. 127.

[25] Socialstyrelsen, Nationella riktlinjer – Utvärdering 2018 – vård och omsorg vid demenssjukdom 2018 – Indikatorer och underlag för bedömningar, socialstyrelsen.se, March 2018, p. 64.

[26] See also similar discussion on the exclusion of the intellectual disabilities from the scope of the act. Prop. 1990/91:58 p. 85.

accordance with Article 3 LPT, a person must suffer from a serious mental disorder, have an indispensable need for psychiatric care and this need must be one that cannot be satisfied by means other than admission to a mental health hospital with qualified 24-hour care. Furthermore, the person must object to treatment or be unable to provide consent. In this contribution it is important to review whether serious mental disorder may include dementia, and what kind of care is indispensable in the meaning of the Act.

The preparatory works for LPT emphasise that serious mental disorder is not just a diagnostic term but is in fact a more complicated concept.[27] Some disorders are always excluded from the scope of compulsory mental health treatment. To these excluded disorders belong intellectual disabilities and all somatic disorders. As to dementia, the preparatory works specifically indicate that sometimes a disorder may have such a strong manifestation that it cannot be excluded from the scope of the LPT.[28]

The wording of the Act stresses that an admission to compulsory care is possible if a patient needs *psychiatric* care. The language also indicates that the legislator wished to draw a boundary between psychiatric and other types of care. The need for other types of care (somatic or social) cannot be the ground for admission under the LPT.[29] However, the exact meaning of psychiatric care is not explicitly laid down in the sources of law. Some types of somatic procedure may still be provided in accordance with the LPT. However, admission to compulsory care cannot be justified by somatic care needs.[30] Put differently, if a person forgets to take medication for a somatic disorder, this cannot indicate an indispensable need for psychiatric treatment. Yet, it is not regulated whether a patient may be administered medication for somatic treatment when he or she is admitted to psychiatric care. The formulation of the law may lead to ambiguity in the applicable rules on whether involuntary somatic procedures are allowed in compulsory psychiatric care.

The discussion in this section indicates that the opportunities for providing compulsory psychiatric care for persons with dementia are not clearly set out in Swedish law. On the one hand, psychiatric care of persons with dementia may often not fulfil the purpose of the LPT because the existing treatments for dementia are unlikely to enable a patient to voluntarily consent to necessary treatment. Persons with dementia are also often in need

[27] Prop. 1990/91:58 p. 85.
[28] Prop. 1990/91:58 p. 86.
[29] See similar conclusions made in Kindström Dahlin, supra note 9 p. 184.
[30] Kammarrätten i Stockholm dom den 9 mars 2011 mål nr 7326-09.

of somatic rather than psychiatric care. The criteria for admission seem to indicate that only psychiatric care should be allowed. On the other hand, the preparatory works specifically indicate that treatment for persons with dementia may be provided in accordance with the Act. Whether somatic care can be provided when a person has been admitted for compulsory psychiatric care is also unclear.

Non-psychiatric care for persons with dementia

As explained above, if an intervention is provided when a person refuses or resists it, such an intervention is seen as forced under the IoG. Interventions can be imposed only in accordance with an act of Parliament that specifically authorises them. In this section, I will explore whether forced interventions or deprivation of liberty are possible within the current health or social legislation. I will also consider how lives of persons with dementia should be saved when they refuse necessary interventions or deprivation of liberty appears to be necessary.

The conditions for lawful provision of medical care in Sweden are regulated inter alia in Patient Act (2014:821). According to the Patient Act, a patient may be treated without consent only in cases prescribed by law. The exception to the general rule of consent is enshrined in Chapter 4 Section 4 of the Patient Act which reads: "the patient should receive the healthcare needed to eliminate any danger that is acute and seriously threatens the patient's life or health, if his or her will cannot be investigated because of unconsciousness or for other reasons". I shall subsequently refer to the situation described in the quotation as an emergency treatment. The preparatory works explain that providing emergency treatment is a temporary measure of last resort that is to be applied when there are no other available ways for making the *wishes* of the patient known under the given circumstances.[31] The knowledge about the wishes of the patient is the focus of the Act, not the decision-making abilities. The important question is whether the resistance or other factual actions should be interpreted as a refusal of treatment. The preparatory works and current practice do not provide a straightforward answer to this question. In this case, the interpretation in light of international treaties may be helpful. Article 12 of the United Nations Convention on the Rights of Persons with Disabilities emphasises the need to provide care in accordance with the wishes and preferences of the patient and ensure that undue influence and abuse are eliminated when

[31] Prop. 2013/14:106 pp. 60–61.

making a decision.[32] The interpretation of Swedish law in light of the Convention seems to imply that personnel must investigate what the patient's true wishes are. If the patient indeed means to refuse treatment (instead of shouting "no", for instance, out of pain), care with the support of Chapter 4 Section 4 of the Patient Act cannot be provided.

The Patient Act does not contain any explicit rules on the treatment of patients who refuse care, whether on patients who are competent to decide or not. In the inquiry report to the Patient Act it was suggested that treatment to patients unable to consent should be provided based on an assessment of the patient's best interests.[33] In the government bill, this proposition was rejected; subsequently, the Patient Act did not contain provisions about treatment in the patient's best interests. In the bill the government emphasised the complexity of the issue and decided to leave the question about possible regulation until the results of a special investigation became available.[34] The Patient Act therefore does not regulate how the validity of the patient's decisions are affected by the patient's mental competence. Inquiry report 2015:80, to which the government referred to in the bill and which was produced later in 2015, does not suggest possibilities to force patients into care but only considers voluntary treatments when patients are not able to decide.[35] The duty of care for adult patients who refuse treatment is not explicitly stated in the current national legislation.[36] Therefore, the means for forcing a patient with dementia who refuses treatment into care is limited under the Patient Act.

The provision of social care in Sweden is regulated in particular by the Act on Social Care (2001:453) and the Act on Support and Service for Some

[32] UN CRPD Committee, General Comment No. 1 Article 12 Equal Recognition before the Law, CRPD/C/GC/1, 19 May 2014, para 21; Arstein-Kerslake, A, and Flynn, E, *The General Comment on Article 12 of the Convention on the Rights of Persons with Disabilities*, The International Journal of Human Rights, vol 20, no 4, 2015, p. 484.

[33] SOU 2013:2 pp. 13–14.

[34] Prop. 2013/14:106 p. 61.

[35] SOU 2015:80 pp. 29, 35, 43–44, 51 and 60.

[36] It may be disputed whether this duty derives from the provisions of the criminal law. In Swedish criminal law it is considered that some persons have a responsibility to act in cases where there is a danger to life or health (*garantställning*) and the person concerned is in a special position that assumes responsibility for such actions. However, to the best of my knowledge, the Swedish Supreme Court or the preparatory works do not acknowledge that healthcare personnel in somatic care have a duty to protect an adult patient's life or health in cases where the patient refuses treatment. The known case practice usually concerns situations where there is the one clear interest of a third party. Those situations where the actions of a guarantor may damage one or other protected interest may be sufficiently different. NJA 2013 p. 588; NJA 1987 p. 222; NJA 1973 p. 141; Svea hovrätt dom den 27 mars 2015 mål nr B 4641–14; Svea hovrätt dom den 11 april 2013 mål nr B 10810–11; SOU 2011:16 p. 26.

Disabled People (1993:387). Both of the Acts are based on the principle of voluntariness. The principle emphasises that a person who receives care should be able to choose the kind of care he or she wants. The possibility of forcing a person into care or depriving a person of liberty is not foreseen by the Acts. The limitation of the constitutional rights cannot be made on the basis of the existing social care legislation.

The discussion in this section indicates that the current legislation does not regulate the limitation of the rights to bodily integrity or liberty of persons with dementia. This means that the health and social care personnel as representatives of public authorities cannot force a person into care. The provisions of the IoG and the Acts mentioned above regulate the obligations of the public authorities or their representatives. If health or social care workers violate the provisions, they might be held liable. It is important to note that the provisions of Chapter 24 Section 4 of the Penal Code may release health or social care personnel from criminal liability if the care is provided without consent in case of emergency. In criminal law an emergency is described as an acute and temporary situation where there is a conflict between two protected interests and, in order to avoid danger to one of those protected interests, harm to the other needs to be inflicted.[37] The acute and temporary criteria indicate that providing care on a regular basis, such as showering, administering daily medication and locking doors to protect the lives of patients, is unlikely to fall within the definition of an emergency under the Penal Code. This leads to the conclusion that the options for using force are not foreseen in national laws, and therefore care that uses force should be viewed as a violation of the constitutional rights of a person.

If the option to use force is limited, what is the current view on the obligation of health and social care personnel to care for persons with dementia? The National Board of Health and Welfare does not encourage the use of force on persons with dementia to protect their lives in its soft law instruments. The government also gave the Swedish Dementia Centrum the task of providing guidance on the care of persons with dementia. The Swedish Dementia Centrum provides methodological support for the care of persons with dementia, an online free-of-charge course for professionals, and a mobile app; all these instruments are called "Zero-vision – for dementia care without force and limitation". The working method of "Zero-vision" is based on the acceptance that care to persons with dementia should be provided without force and, if force is applied, it should be reported as

[37] Asp, P, Ulväng, M, and Jareborg, N, *Kriminalrättens grunder,* Svensk straffrätt 1 Series, Iustus Förlag AB 2010, pp. 241 f.; Jareborg, supra note 10 p. 263.

inappropriate to the Health and Social Care Inspectorate.[38] The reason for the use of force should be properly investigated so that there is no need to apply force again. The method described in "Zero-vision" is rooted in the idea of person-centred care and that it is possible to prevent patients from becoming confused, restless or angry with appropriate support.[39] The course and the guideline consider that it is important to investigate what makes a specific person confused or uncomfortable and find individualised means to calm him or her down, and feel better or understand the problem. What these means are depends on the situation and person; in some cases it may be a piece of music or a dance that the person really enjoys, in others, a walk together with personnel. Similar views are also held by the Health and Social Care Inspectorate. In the report on security without the use of force, the Inspectorate emphasised the need for care providers to create routines to prevent it and deal with difficult situations. It also posed the question why a unified vision on the impermissibility of using force and the methods of avoiding is absent in Sweden and why care is provided differently in different parts of the country.[40]

To summarise, the analysis in this section suggests that the national legislation does not consider that using force is appropriate while delivering health or social care services. The current guidance recommends the minimization of force through increasing the possibilities of support of persons with dementia.

Non-regulated limitations of constitutional rights

In the previous sections, it was argued that force should be used in relation to persons with dementia only in cases of emergency in the criminal law sense. In this section, I will review the argument on permissibility of infringement of the constitutional rights enshrined in Chapter 2 Articles 6 and 8 of the IoG without support from the law.

In 2006 the government considered that the Swedish legislation on the care of persons with dementia was unclear and suggested allowing the use of protective measures that involved force in social care.[41] The protective

[38] Svenskt Demenscentrum Nollvision – för en demensvård utan tvång och begränsningar, Demenscentrum.se 12/8 2019, pp. 48, 72.
[39] Ibid., p. 14 ff.
[40] Kull, K R, et al., Inspektionen för vård och omsorg. Rapport Skapa trygghet utan tvång om tillsynsinsats vid verksamheter där personer med nedsatt beslutsförmåga bor eller vistas (Regeringsuppdrag S2013/4269/SAM, S2013/9047/SAM, delvis) IVO 2015, pp. 6–7.
[41] SOU 2006:110 p. 21.

measures could involve forced bodily intervention or deprivation of liberty, along with constraints on other rights. In its review to the inquiry report, the Council of Legislation commented that the rules of the IoG that allowed for limitations on rights only to be possible in the form of an act of Parliament was not applicable to persons with dementia. The Council of Legislation also reminded that in criminal law emergency releases from responsibility each and everyone, disregarding whether a person who committed actions in emergency situation represents authorities. In addition to emergency situations in the criminal law sense, a person may also be released from criminal liability because his or her actions were socially adequate. The Council of Legislation further considered that the use of force by private persons on persons with dementia is allowed. The use of force by private persons on persons with dementia is considered socially adequate. Because this is allowed to private persons, the Council of Legislation stated that there was no need to create a new act for public authorities. In opinion of the Council of Legislation, if the authorities do not have a monopoly on the use of force, the need to regulate infringements of rights by an act of Parliament (Chapter 20 Article 20 of the IoG) is lacking.[42] After the comments of the Council of Legislation were received, the government did not proceed with creating a legislative proposal.

In 2018 the Supreme Court adjudicated on criminal charges against a nurse who had locked a person with dementia in a room with the help of an armchair. The Supreme Court reasoning reiterates what the Council of Legislation stated in 2012. The Court considered that because other people may apply force in relation to persons with dementia, the ability of the authorities to use force should not be reduced in comparison.[43] Therefore, the rules enshrined in Chapter 2 Article 20 of the IoG on the need to regulate infringements in Acts of Parliament were not applied in the case.

The reasoning of the Supreme Court and the Council of Legislation is not entirely straightforward. As discussed above, the use of force to save life can be legitimate in criminal law, for instance, in an emergency. However, if the situation does not amount to an emergency, the criminal law must also protect persons with dementia against the use of force on an equal basis with others.[44] Yet, the Supreme Court seemed to come to the

[42] Lagrådets yttrande 2012-12-18, God vård och omsorg om personer med demenssjukdom samt regler för skydd och rättssäkerhet.

[43] NJA 2018 p. 1051.

[44] From human rights law perspective, states also have positive obligations in relations to vulnerable persons. This means that if private persons violate a right, the state has the duty to act in order to protect the right, in particular, via imposing sanctions. See X and Y v. the

opposite conclusion – that the protection of criminal law is not granted to persons with dementia because it is socially acceptable for everyone to use force against them. In my view, forcing persons with dementia into care in other situations than prescribed by law promotes discrimination of this vulnerable group. Persons with dementia are also persons with disabilities in the meaning of the Discrimination Act (2008:567). The Act defines direct discrimination as less favourable treatment in comparison with others, if that person has a protected characteristic such as disability. Forcing persons to take treatment or depriving them of their liberty are considered to be less favourable treatment.[45] If a person with a disability, such as dementia, is forced into treatment while refusing or is deprived of liberty when the legislation does not allow for such actions, this should be regarded as direct discrimination. These actions should therefore be prohibited.

The Supreme Court also has not concluded that the IoG is not applicable in relations between health or social care providers, on the one hand, and persons with dementia, on the other. Locking doors or forcing medication is considered to be a limitation of the rights. Yet, in the opinion of the Supreme Court and the Council of Legislation, as long as each and every carer can apply force, then the public authorities may do so as well. It is important to remember that the purpose of the IoG was to clarify what should be considered normal in the course of exercising public powers.[46] Non-application of Chapter 2 Article 20 of the IoG appears to go against the purpose of the IoG and the principle of legality, where fundamental rights must receive the strongest protection.[47]

The reasoning of the Supreme Court and the Council of Legislation is therefore difficult to reconcile with the principle of legality and its direct expression in Chapter 2 Article 20 of the IoG, as well as in the obligation not to discriminate against persons with disabilities. The reasoning in my opin-

---

Netherlands, application number 8978/80, Judgment of 26 March 1985, para 23; see also Tysiąc v. Poland, application number 5410/03, Judgment of 20 March 2007, para 110; Bédat v. Switzerland, application number 56925/08, Judgment of 29 March 2016, para 73; Airey v. Ireland, application number 6289/73, Judgment of 9 October 1979, para 32; Evans v. The United Kingdom, application number 6339/05, Judgment of 10 April 2007, para 75; Storck v. Germany, application number 61603/00, Judgment of 16 June 2005, paras 149–150; Söderman v. Sweden, application number 5786/08, Judgment of 12 November 2013, paras 78–81.

[45] Prop. 2007/08:95 pp. 486–487; see also Hellborg, S, *Diskrimineringsansvar: En civilrättslig undersökning av förutsättningarna för ansvar och ersättning vid diskriminering*, Iustus Förlag AB 2018, pp. 247–248.

[46] SOU 1972:15 p. 154; prop. 1973:90 p. 131; SOU 1975:75 pp. 75 and 95–96; SOU 2008:3 p. 245. See also Bull, supra note 18 p. 355.

[47] Sterzel, F, *Legalitetsprincipen*. In: Offentligrättsliga principer 2nd edn, Marcusson, L, (ed), Iustus Förlag AB 2012, p. 74.

ion blurs the understanding of the borders for the use of force and should not be accepted as part of the practice of public authorities.

Obligations to protect the life of persons with dementia in the case law of the European Court of Human Rights

After the analysis of the Swedish rules on the application of force to persons with dementia, I now turn to the reasoning of the ECtHR on positive obligations to protect life. Article 2 of the ECHR prohibits intentional killing and declares that everyone's right to life shall be protected. The ECtHR considers that states must fulfil not only negative obligations such as not to kill people but also positive obligations.[48] These positive obligations include substantive and procedural ones. The substantial positive obligations generally mean the commitment to take appropriate steps to safeguard the lives of people within the jurisdiction.[49] By procedural obligations the Court means the duty to investigate or otherwise ensure accountability for death.[50] The aim of this contribution means that substantive positive obligations should be its focus.

The ECtHR has not yet decided on the merits of positive substantive obligations to ensure the right to life of persons with dementia.[51] Due to this, I shall analyse the approach of the Court in the adjudication of substantive positive obligations in general and with a specific focus on protecting persons from self-harm. When the Court investigates if a state has violated substantive positive obligations of the right to life, it starts with the question whether a state *knew or ought to have known* about the risk to life.[52] By the

[48] Airey v. Ireland, application number 6289/73, Judgment of 9 October 1979, para 24.

[49] Elena Cojocaru v. Romania, application number 74114/12, Judgment of 22 March 2016, para 99; Mihu v. Romania, application number 36903/13, Judgment of 1 March 2016, para 63; L.C.B. v. the United Kingdom, application number 4/1997/798/1001, Judgment of 9 June 1998, para 36; Osman v. the United Kingdom, application number 87/1997/871/1083, Judgment of 28 October 1998, para 115; see also Wicks, E, *The Right to Life and Conflicting Interests*, Oxford University Press 2010, pp. 62 ff.; Weekes, R, *Focus on ECHR*, Article 2, Judicial Review, vol 10, no 1, 2005, pp. 19–22.

[50] Paul and Audrey Edwards v. the United Kingdom, application number 46477/99, Judgment of 14 March 2002, para 69; Jasinskis v. Latvia, application number 45744/08, Judgment of 21 December 2010, para 72.

[51] The search at the Court's database *hudoc* indicates 30 cases where the word "dementia" and 6 judgments where the word "Alzheimer's" was mentioned. Only 1 of the cases concerns the right to life of the person diagnosed with dementia, namely Dodov v. Bulgaria, application number 59548/00, Judgment of 17 January 2008. The court, however adjudicated on the procedural positive obligations in that case. The data were obtained on 1st of September 2019.

[52] Fernandes de Oliveira v. Portugal, application number 78103/14, Judgment of 31 January 2019, paras 109–110, 115; Osman v. the United Kingdom, application number

term "state" the Court means not only public authorities but also public and private health and social care facilities.[53] It is considered that a state knew or ought to have known about the risk to life not only when the risk was reported to the authorities but also when a vulnerable person was under the care or supervision of the state.[54] Persons with disabilities, including persons with dementia, that receive services from health and social care without doubt would be regarded by the Court as a vulnerable group.[55] Not every risk to life gives rise to positive obligations: the risks must be *real* and *immediate*.[56] Certain factors have been considered as indicators of this type of risk. They include the history and gravity of mental health conditions, previous experience of self-harm and even signs of physical or mental distress. These factors give rise to the positive obligation to protect life and all these factors may be relevant for persons with dementia, depending on the stage of the disease.[57] These considerations allow it to be stated that states have the positive obligation to protect the life of persons with dementia who receive health and/or social services, especially those who are at advanced stages of the disease.

87/1997/871/1083, Judgment of 28 October 1998, para 116; Centre for Legal Resources on behalf of Valentin Câmpeanu v. Romania, application number 47848/08, Judgment of 17 July 2014, para 130; Giuliani and Gaggio v. Italy, application number 23458/02, Judgment of 24 March 2011, paras 246 and 248.

[53] Mehmet Şentürk and Bekir Şentürk v. Turkey, application number 13423/09, Judgment of 9 April 2013, para 81; Dodov v. Bulgaria, application number 59548/00, Judgment of 17 January 2008, para 80; lbeyi Kemaloğlu and Meriye Kemaloğlu v. Turkey, application number 19986/06, Judgment of 10 April 2012, para 35.

[54] Opuz v. Turkey, application number 33401/02, Judgment of 9 June 2009, para 129; Keenan v. the United Kingdom, application number 27229/95, Judgment of 3 April 2001, para 91; Beker v. Turkey, application number 27866/03, Judgment of 24 March 2009 paras 41–42; Mosendz v. Ukraine, application number 52013/08, Judgment of 12 January 2013, para 92.

[55] Fernandes de Oliveira v. Portugal, application number 78103/14, Judgment of 31 January 2019, para 113; Hiller v. Austria, application number 1967/14, Judgment of 22 November 2016, para 52; Jasinskis v. Latvia, application number 45744/08, Judgment of 21 December 2010, para 59; Keenan v. the United Kingdom, application number 27229/95, Judgment of 3 April 2001, paras 91 and 96; Renolde v. France, application number 5608/05, Judgment of 16 October 2008, paras 82–84, 109; see also Dodov v. Bulgaria, application number 59548/00, Judgment of 17 January 2008, para 101.

[56] Berü c. Turquie, requête nombre 47304/07, arrêt du 11 janvier 2011, para 42; Keenan v. the United Kingdom, application number 27229/95, Judgment of 3 April 2001, para 101.

[57] Fernandes de Oliveira v. Portugal, application number 78103/14, Judgment of 31 January 2019, para 115; Volk v. Slovenia, application number 62120/09, Judgment of 13 December 2012, para 86; De Donder and De Clippel v. Belgium, application number 8595/06, Judgment of 6 December 2011, para 75; Renolde v. France, application number 5608/05, Judgment of 16 October 2008, para 86; Çoşelav v. Turkey, application number 1413/07, Judgment of 9 October 2012, para 57.

The next question that the ECtHR has considered is whether the authorities *had powers* to avoid the risk to life. This question can be paraphrased as checking whether the obligation to establish an effective regulatory framework had been implemented.[58] The Court as a general rule does not state what are the exact powers that the authorities should have because states have a broad margin of appreciation in this area.[59] Failure to legislate on a specific power of authority does not necessarily mean that a violation took place because the state may realise the positive obligation through other means. For the purposes of fulfilling the positive obligations under Article 2, it is not crucial that the powers are formulated explicitly in a written law (as opposed to the negative obligations, for instance, under Article 5 or 8 of the ECHR). However, states must ensure that the powers are implemented into practice.[60] To prove that a state failed in the duty to create an appropriate legislative framework, it must be shown that the authorities knew about the risk but omitted to take preventive measures which jeopardised the lives of these people.[61] The ECtHR has stressed the need to analyse whether the national regulatory framework grants concrete possibilities to protect life in a specific (rather than an abstract) situation.[62]

At the beginning of this contribution, I described the issues that are of major concern for Swedish health and social care: persons with dementia refusing to take medication or undergo hygienic procedures, and leaving their place of residence or other facilities when confused. As discussed above, Swedish health and social care professionals have very limited powers to use force on persons under their care – the ability to do this emanates only from the criminal law provisions that release them from liability in case of emergency. Applying the ECtHR reasoning to these situations

[58] Lopes de Sousa Fernandes v. Portugal, application number 56080/13, Judgment of 19 December 2017, para 189.

[59] Lopes de Sousa Fernandes v. Portugal, application number 56080/13, Judgment of 19 December 2017, para 216; Ciechońska v. Poland, application number 19776/04, Judgment of 14 June 2011, para 65; Lambert and Others v. France, application number 46043/14, Judgment of 5 June 2015, para 146; Fadeyeva v. Russia, application number 55723/00, Judgment of 9 June 2005, para 96.

[60] Fernandes de Oliveira v. Portugal, application number 78103/14, Judgment of 31 January 2019, para 119; Lopes de Sousa Fernandes v. Portugal, application number 56080/13, Judgment of 19 December 2017, para 189.

[61] Aydoğdu c. Turkey requête nombre 40448/06, arrêt du 30 août 2016, para 87; Osman v. the United Kingdom, application number 87/1997/871/1083, Judgment of 28 October 1998, para 116.

[62] Z v. Poland, application number 46132/08, Judgment of 13 November 2012, para 111; Brogan and Others v. the United Kingdom, application numbers 11209/84, 11234/84, 11266/84, 11386/85, Judgment of 29 November 1988, para 53.

would require Sweden to show that its regulation empowers health and social professionals to effectively protect life when a person with dementia refuses treatment or decides to leave home or other facility. Will Sweden fail to comply with substantive positive obligations if the authorities continue to have no powers to force a person into care against their will to save his or her life? The case law of the Court does not provide a consistent answer on whether the authorities shall have powers to force a person into care. In one of the cases decided by the Chamber of the Court, the ECtHR criticises states for not forcing persons unable to decide into care.[63] In other case law of the Chamber, the Court considers that application of force is not mandatory as the positive obligations can be realised through monitoring or other means.[64] In the recent judgement in *Lopes de Sousa Fernandes v. Portugal*, the Grand Chamber emphasised the need to realise positive duties in a way that minimised infringement of person's private life.[65] The Court also considers that the legislation that allowed use of force in relation to persons with mental health issues only as a last resort corresponded to the modern international standards.[66] It is possible to conclude that the Grand Chamber of the ECtHR is likely to consider that the realisation of the positive obligation to protect the life of persons with dementia does not necessarily require the use of force and may be realised through other means.

If the Court finds that the obligation to protect life has arisen and that the state has effective regulation, it moves to the next question, namely whether the state applied measures to avoid the risk that could be reasonably expected.[67] The ECtHR reiterated that measures shall be reasonable, not impose a disproportionate burden and be applied in a manner that respects the rights of others. By reasonableness, the Court means that it could be expected that the measures applied could prevent death.[68] When discussing

[63] Arskaya v. Ukraine, application number 45076/05, Judgment of 5 December 2013, para 69.
[64] Horoz c. Turquie, requête nombre 1639/03, arrêt du 31 mars 2009, para 28; see also Harris, D J, O'Boyle, M, and Warbrick, C, (eds), *Harris, O'Boyle & Warbrick: Law of the European Convention on Human Rights,* 3rd edn, Oxford University Press 2014, p. 212. See also Keenan v. the United Kingdom, application number 27229/95, Judgment of 3 April 2001, para 91; Trubnikov v. Russia, application number 49790/99, Judgment of 5 July 2005, para 70.
[65] Fernandes de Oliveira v. Portugal, application number 78103/14, Judgment of 31 January 2019, para 112.
[66] Fernandes de Oliveira v. Portugal, application number 78103/14, Judgment of 31 January 2019, paras 117 and 122.
[67] Osman v. the United Kingdom, application number 87/1997/871/1083, Judgment of 28 October 1998, para 116.
[68] Keenan v. the United Kingdom, application number 27229/95, Judgment of 3 April 2001, para 93; Fernandes de Oliveira v. Portugal, application number 78103/14, Judgment of 31 January 2019, para 125.

what measures constitute a disproportionate burden the ECtHR stated that the resources that authorities have are limited and prioritisation needs to occur.[69] Therefore, answering the question as to what measures can be reasonably expected depends on the actual situation, and in particular, on the resources that health and social facilities have, the behaviour of the person whose life needs to be protected, etc.

To summarise, states have positive obligations to protect the life of persons with dementia. The positive obligations should be realised in particular by creating an effective regulatory framework and taking preventive operative measures. In its current practice, the ECtHR considers that states have a wide margin of appreciation in deciding upon the design of a regulatory framework. This means that the regulation may empower authorities to use force that is necessary for saving life or attempt to save life via other means, such as by giving various forms of support. A state will fulfil its duty to create an effective regulatory framework even if the legal framework is not foreseeable for persons whose life needs to be saved, yet is functional and implemented into practice by the authorities. The most important requirement is that the authorities are able to plan effectively and implement the measures prescribed by law as to how the lives of vulnerable persons will be saved when there is a real risk.

Concluding remarks: Swedish law under test

At the start of this article I described three common instances when health and social practitioners face difficulties in caring for persons with dementia. These are when administering medication or other medical procedures, hygenic procedures when persons with dementia refuse care, and also situations when a confused persons is leaving a building or room. Swedish constitutional law requires that authorities limit the right to bodily integrity or liberty only if there is an act of Parliament authorising this action. As it stands, the use of force is authorised in accordance with the LPT when providing psychiatric care. Yet, the treatment of persons with dementia in compulsory psychiatric care is problematic due to two reasons. Firstly, the aim of compulsory care is unlikely to be achieved due to the absence of available treatment. Secondly, the patient must have a critical need for psychiatric, rather than somatic, care, which is often not the case for persons with dementia. Other health and social care acts do not authorise depriva-

[69] Fernandes de Oliveira v. Portugal, application number 78103/14, Judgment of 31 January 2019, para 125.

tion of liberty or use of force when persons refuse interventions. The main principle adopted in Swedish law is that the wishes of the person shall be respected. At the moment, the national legal system provides three pathways for the protection of the life of persons with dementia. The first is based on the principles set out in the legislation and methodological guidelines but these have a rather vague status. This pathway means that health and social care personnel should focus on providing support and prevent situations of distress and confusion for persons with disabilities. The second pathway means that in cases of criminal law emergency the life of a person can be saved without the threat of criminal sanctions. The first and second pathways are compatible and complement each other. The first pathway represents the desirable routine of care for persons with dementia whereas the second is about extreme and rare situations when the measures implemented did not work out. The limited possibility to qualify the situation as an emergency in the criminal law meaning emphasises the importance of establishing good routines and investigations of the available forms of better support. The third pathway, which was suggested by the Council of Legislation and Supreme Court of Sweden, is that application of force with respect to persons with dementia should be viewed as acceptable because it is in principle allowed to everyone. I consider this pathway to be problematic due to it not following the constitutional principle of legality and legal foreseeability, as well as its promotion of discrimination against persons with dementia.

If we put the national legislation under the ECtHR test, it is possible to conclude that Sweden has the obligation to protect the lives of persons with dementia as long as the state (including the health and social care providers) is aware about the vulnerability of those persons and the existing risk to life. The calculation as to whether the risk to life is real and immediate will depend on the gravity of conditions in the individual case as well as previous experience of harm or presence of mental or physical distress. It is not possible to conclude that a lack of powers held by health and medical personnel to apply force or deprive persons with dementia of their liberty will be seen as a violation of the ECHR. In fact, in recent jurisprudence the Court emphasised that voluntary measures are not only acceptable but also desirable. The member states of the Convention have a wide margin of appreciation in relation to the means that can be applied to save life. It is therefore unlikely that the Swedish law will receive criticism for the absence of powers to force a patient. The ECtHR also considers that the measures that should be used to protect life do not necessarily have to be straightforward and foreseeable to persons unless they also include interference with

their rights. Yet, it is extremely important that the personnel are aware of the measures that should be applied. Therefore, the fact that Swedish law does not have common guidance in the form of a regulation as to how to prevent the usage of force is not a problem *per se* for ECHR compliance. The soft law guidance "Zero-vision" on prevention of force and support in decision-making is available; health and social care professionals also have access to free education on the means for supporting a person with dementia. However, the Court has reaffirmed that the state must ensure that the powers to protect life are implemented in practice and omitting to do so may lead to a violation of the Convention.[70] The binding national regulation as well as supervision of how the measures are to be fulfilled by the authorities may be appropriate means for fulfilling the obligations to protect the right to life in Sweden.

Contrary to the popular opinion among health and social care workers, I therefore conclude that the absence of powers to force patients into care does not constitute a violation of the right to life in the meaning of the ECtHR. The problem that Sweden might face in Strasbourg, in my view, is predominantly related to possible failures to implement the principle of person-centred care into practice, i.e. to listen to persons with dementia and plan the least invasive way to deliver care. The approach chosen by Sweden in relation to treatment of persons with dementia is time- and resource-consuming but is compliant with the Convention if the means for support are in fact provided in practice.

[70] Fernandes de Oliveira v. Portugal, application number 78103/14, Judgment of 31 January 2019, para 119; Lopes de Sousa Fernandes v. Portugal, application number 56080/13, Judgment of 19 December 2017, para 189.