Dying, Dementia & Law

Pursuing Legal Responsibility at the End of Life

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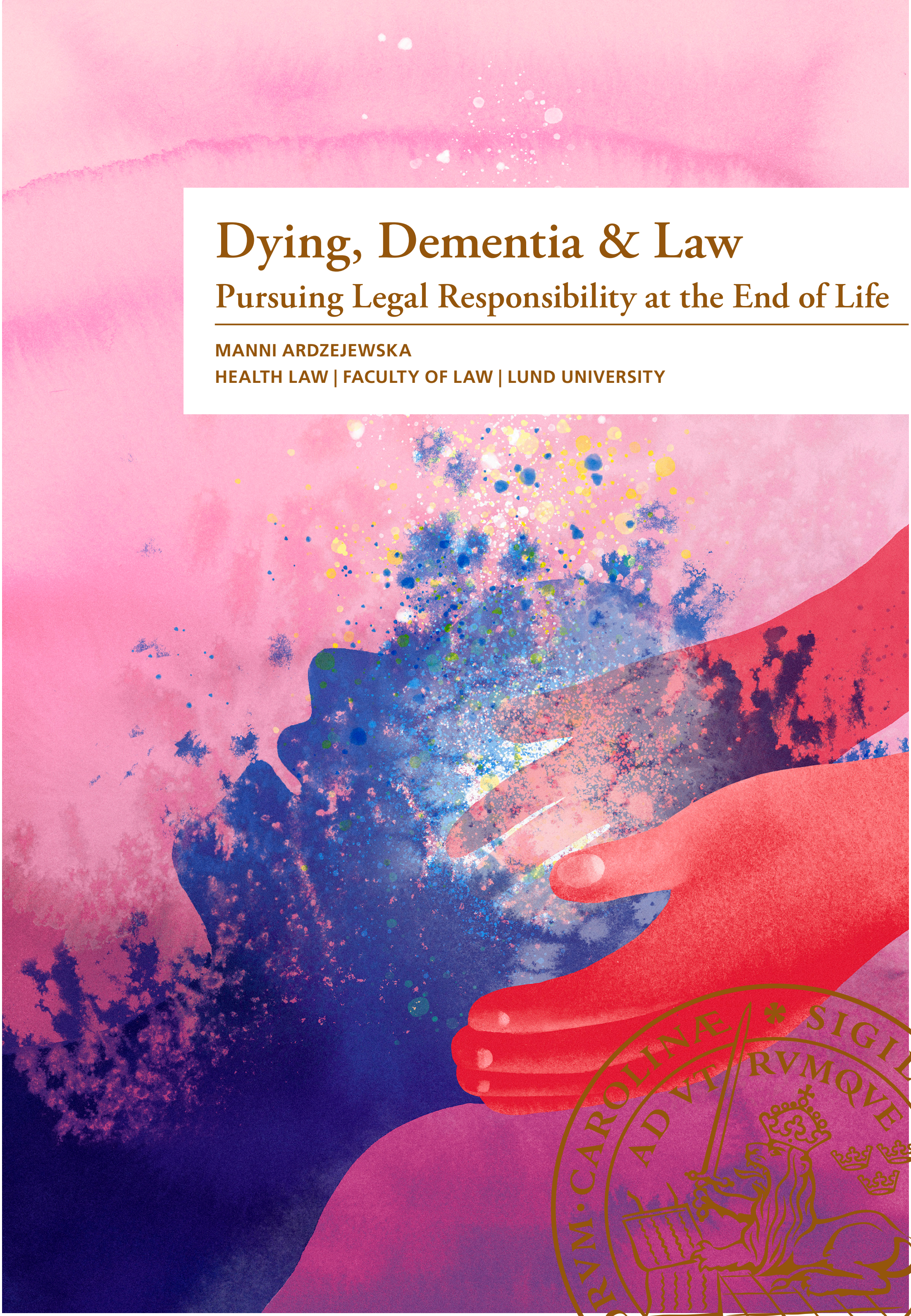
MANNI ARDZEJEWSKA

HEALTH LAW | FACULTY OF LAW | LUND UNIVERSITY



Dying, Dementia & Law

Pursuing Legal Responsibility at the End of Life

Manni Ardzejewska

DOCTORAL DISSERTATION

Doctoral dissertation for the degree of Doctor of Philosophy (PhD) at the Faculty of Law at Lund University to be publicly defended on the 9th of May 2025 at 10.15 in Pufendorfsalen, Faculty of Law, Lilla Gråbrödersgatan 3C Lund

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Abstract:

Dying with dementia is characterised by difficulties with decision-making and limitations as to access to appropriate end-of-life care. Meanwhile, law and society, are predicated on individualism and the medicalisation of death in a way that marginalises physical and cognitive illness. Nevertheless, as a purveyor of rules, norms and values, law arguably has the potential to contribute to collective responsibility for death and dying with dementia. Against this backdrop, this thesis addresses the following question in the interrelated fields of health and elder law in the context of Sweden: What is the role of law in shaping and responding to death and dying with dementia in Sweden? In pursuit of this question, the aim is to critically interrogate the nature and consequences of law in death and dying with dementia in order to better understand, and evaluate, the relationship between law and the end of life. This is connected to the broader aim of improving the experience of dying with dementia To capture law and its consequences for end-of-life decision-making with dementia, this research engages a multi-method approach. This includes semi-structured interviews with physicians informed by legal consciousness theory to account for the everyday experience of law as well as doctrinal and critical analysis through the lens of a feminist approach to vulnerability. In this, individualism, and the related overemphasis on the preservation of life and a non-interference approach to choice is revealed and critiqued to exist at the expense of a commitment to opportunities for both relational empowerment and care as is central to the embodied human reality. Through platforming the vulnerable legal subject, legal responsibility at the end of life is pursued through the recreation of the law as it pertains to end-of-life decision-making with dementia. In grappling with questions of care, empowerment, ethics, law and the everyday, this thesis contributes to legal method and discourse on death and dying beyond the jurisdictional boundaries of Sweden.

Key words: health law, dementia, end of life, vulnerability, everyday

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[1] Caroline O'Donoghue, *Promising Young Women* (Virago 2018) 338–339.

Abbreviations

CRPD	Convention on the Rights of Persons with Disabilities
ECHR	European Convention on Human Rights
ECtHR	European Court of Human Rights
HSAN	Healthcare Responsibility Advisory
HSL	Health Care Act
IoG	Instrument of Government
IVO	Health and Social Care Inspectorate
NBHW	National Board of Health and Welfare

Foreword

Before this book commences in earnest, I would like to reflect on my positionality in this research as a person and researcher. My academic engagement in questions of end-of-life decision-making has its roots in the personal. Growing up, my family was somewhat unusually blessed with what might be described as an easy openness around discussions of death and dying. My grandma was and remains forthright in at times unexpectedly conveying her wishes for abstaining from life-sustaining treatment and her environmentally inclined reflections on her eventual burial. My mum, an extraordinary feminist who engrained in me concern for issues of social justice, fairness and equality, always encouraged healthy debate on issues of politics and ethics. In the case of death and dying, this translated into robust advocacy in the home and beyond for the legalisation of assisted dying. In recent years, the question of assisted dying has become very real for our family. The law has serious implications for the way in which we, and others like us, are safely supported to make such decisions. Interested in examining how the law might offer choice, protection and support for such people, their families and society at large, the dissertation I completed in pursuit of my Juris Doctor degree at Queens University Belfast explored this very issue.

Yet at the conclusion of that research, my work felt unfinished. That we do not do dying well as a society was evidently not an issue that begins or ends with the question of assisted dying alone. Furthermore, the dialogue around questions of death and dying often oscillate around an apparently diametrically opposed debate between choice and protection. Those who present arguments for choice in death like myself are in many ways underdeveloped where the issue of choice becomes more complex, and moreover, fail to account for complex needs for physical care at the end of life. A failure to address this issue felt even more difficult to sustain in light of well-established research that dying with dementia is often marked by particularly poor outcomes due to under treatment of pain and over treatment of non-beneficial interventionist measures. Thus, underpinned by an explicit commitment to the role law can play in achieving the normative goals of social justice, equality and wellbeing at the end of life, at the core of this research is the goal to examine law as both a potential threat and possible tool in the organisation of end-of-life decision-making. In particular, it is interested in how law can contribute to the realisation of a good death that embraces personhood and bodily needs in support of efforts to de-stigmatise and improve the experience of dying and living with dementia.

In undertaking this research, I engage in an explicitly multidisciplinary approach in crossing the boundaries of law, social science and care science. With an undergraduate degree in International and Global Studies with a double major in Gender Studies and Political Economy from the University of Sydney, I began my academic journey embedded in a social science tradition that encouraged critical attention to the socially constructed nature of institutions and the ways in which they exert power. My journey continued as a post graduate student in the field of law. This combination of knowledge in social science and law has equipped me with an interest and capacity to undertake an interdisciplinary approach to law and this dissertation. As a result, I was interested from the outset in embracing the stories of individuals who are engaged with the law and exploring the meaning and influence of law beyond how it applies to a given legal question. Furthermore, although I do not understand dying with dementia solely as a medicalised phenomenon, this research inevitably exists in the space in which medicine and law bleed together in being interested in end-of-life decision-making with dementia as it occurs in the realm of healthcare. As a legal researcher in this space, I have therefore been particularly sensitive to knowledge about health and medicine. Whilst this has been shaped by reading and interviews, it has also been informed by my personal relationships with physicians. Not the least of which is my husband whose generous sharing of his clinical knowledge and experience was formative in understanding the everyday operations of healthcare.

1 Introducing the Investigation

> Once I accept the existence of dying as a life process, who can ever have power over me again? — Audre Lorde[2]

1.1 Introduction

Whilst opportunities to live and thrive with dementia should be promoted,[3] dementia is ultimately a terminal illness that shortens life.[4] As over 55 million people have dementia worldwide,[5] a growing number of people are dying "with or from dementia."[6] In fact, it represents "the seventh leading cause of death" amongst older people globally.[7] Accompanied by difficulties with forming and expressing wishes at the end of life,[8] people with dementia experience particularly poor end-of-life outcomes in the form of overly interventionist measures and inadequate pain relief.[9] Against this backdrop, dying with dementia has been recognised as a public health concern.[10] Whilst

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[2] Audre Lorde, *The Cancer Journals* (Penguin 2020) 18.

[3] Hugh Series, 'The Happy Dementia Patient' in Charles Foster, Jonathan Herring, and Israel Doron (eds), *The Law and Ethics of Dementia* (Bloomsbury Publishing 2014) 109.

[4] Rosie Harding, *Duties to Care: Dementia, Relationality and Law* (Cambridge University Press 2017) 170.

[5] World Health Organisation, 'Dementia' (*Dementia*, 15 March 2023) <https://www.who.int/news-room/fact-sheets/detail/dementia> accessed 13 July 2023.

[6] Gabriele Cipriani and Mario Di Fiorino, 'Euthanasia and Other End of Life in Patients Suffering from Dementia' (2019) 40 Legal Medicine 54, 54.

[7] World Health Organisation (n 5).

[8] Harding, *Duties to Care* (n 4) 170.

[9] Hall and others (eds), 'Palliative Care for Older People: Better Practices' (World Health Organisation: Regional Office for Europe 2011) 24.

[10] ibid.

it has been said that “death and dying are to be everyone’s business and responsibility,”[11] modern, industrialised societies champion one’s personal responsibility to live (in good health) and medicalise dying. Meanwhile, autonomy as manifest in the right to choose without interference, has come to be endorsed as an antidote to protectionist tendencies including those directed at lengthening life. In this context, ageing and dying are marginalised, and collective responsibility for meaningful choice and care at the end of life is undermined.[12]

This dissertation situates itself within the tension between the prevailing values of healthy living and independence, and the importance of attention to care that meets physical and agentic needs at the end of life. In this space, the aim is to critically analyse the relationship between law and end-of-life decision-making with dementia. This is in turn part of a broader effort to understand and improve upon the role of law in pursuit of collective responsibility to death and dying with dementia. Importantly, whilst this research is undertaken in the context of Swedish law, its implications extend beyond jurisdictional boundaries in grappling with universal questions through the application and development of theory and method. What is more, whilst focused on people with dementia, it contributes to the way in which society organises death, care, and decision-making more generally.

This research demonstrates that where law is underpinned by individualism, it is limited in its ability to secure the conditions for end-of-life decision-making with dementia that respects relational and physical needs. However, where death, dying and dementia are embraced as manifestations of embodied vulnerability as a universal condition, new possibilities emerge to secure the legal conditions for care that may help to improve the experience of dying with dementia. This argument is developed through a number of distinct interventions. The first intervention locates law in the everyday to trace the

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[11] Samar Aoun, ‘Supporting the Dying is a Community Responsibility’ (2022) 16 Palliative Care and Social Practice 1, 1.

[12] Aoun (n 11); Libby Sallnow and others, ‘Report of the Lancet Commission on the Value of Death: Bringing Death Back into Life’ (2022) 399 The Lancet 837; Lisette Farias Vera, ‘The (Mis)Shaping of Health: Problematizing Neoliberal Discourses of Individualism and Responsibility’ in SA Hamad Hosseini and others (eds), *The Routledge Handbook of Transformative Global Studies* (Routledge 2020); Julia Lawton, *The Dying Process: Patients’ Experiences of Palliative Care* (Taylor & Francis 2000); Sheila AM McLean, *Old Law, New Medicine: Medical Ethics and Human Rights* (Pandora 1999) 138–139; Jane Österlind and others, ‘A Discourse of Silence: Professional Carers Reasoning about Death and Dying in Nursing Homes’ (2011) 31 Ageing and Society 529, 530.

problem of law in death and dying with dementia as it exists *in society*. Utilising legal consciousness, the way in which law and medicine is experienced by physicians in the navigation of end-of-life decision-making with dementia is explored. As law is embraced and avoided, it represents a mechanism that conveys the preservation of life and promotion of autonomy as universal ideals whilst derogating the responsibility to navigate death and dying with dementia to medicine. This indicates that the force of law has limits in its potential as a resource for encouraging collective responsibility to the realities of death and dying with dementia. This bottom up perspective is the foundation for the exploration of the problem as it exists *in law* itself. In this, formal legality is interrogated via a combination of doctrinal and vulnerability analyses to reveal and analyse the limitations as they are built into the legal framework. Underpinned by the liberal legal subject, law is demonstrably primarily concerned with the protection of life at the juncture of self-determination and medical expertise. As a result, it oscillates between a demand for individualism and paternalism in a way that ultimately threatens to undermine legal opportunities for care that promotes relational self-determination and attends to the physical needs of people with dementia at the end of life. Finally, seeking to bolster the ability of law to promote collective responsibility for wellbeing at the end of life for people with dementia and beyond, the thesis engages a recreation of law via feminist vulnerability perspective. This approach engages the transformative vulnerable subject to replace the struggle against death with the provision of resilience in death that provides for physical and relational needs. This recreation intends to inspire ongoing conversation over how law can be made more attentive to needs for care and relational support in death and dying with dementia.

The foundations for this research will be charted in this introductory chapter which will: set the scene; frame the research; explore the key concepts; situate the contribution of the dissertation in the broader literature; and explain the structure of the book.

1.2 Setting the Scene

This thesis examines the relationship between Swedish law and end-of-life decision-making with dementia in a multi-dimensional context which includes the interlocking themes of life, death, autonomy, capacity and care in the interrelated fields of medicine, ethics and law. First and foremost, this study is embedded in the social and legal context in which death and dying are marginalised. Of course, the "protection of life is basic to any legal order."[13] More than this though, an emphasis on health in the wider public and medical discourse has ultimately obscured the experience of ageing, frailty and dying.[14] In medicine for instance, as death was relocated within the four walls of the hospital, it chaffed against the goal of curing sickness and came to represent a failure.[15] In this context, it has been remarked that the battle against disease has obfuscated care needs in mortality.[16] The medicalisation of death has, for instance, been understood to encourage onerous treatments that are unwarranted and/or ineffectual.[17] Similarly, biomedical advances have introduced the potential that medical technology prolongs life beyond what is valued by the patient.[18]

Yet where medical advances can restore health and extend life, questions regarding the authoritarian preservation of life have also arisen.[19] The fight against death has therefore collided with the rise of choice in death.[20] Whilst decision-making in medicine has been historically underpinned by an ethical framework that champions doing good, avoiding harm and protecting life,[21] autonomy has subsequently emerged as a principle source of regulation in healthcare decision-making.[22] This principle has come to represent liberal notions of individualism and self-governance which are in turn associated with the idea that the legal subject has the relevant capacity to make decisions without coercion.[23] Resulting in the legal and ethical concepts of informed

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[13] Luis Kutner, 'Due Process of Euthanasia: The Living Will, A Proposal Comment' (1968) 44 Indiana Law Journal 539, 539.

[14] Österlind and others (n 12) 530; Aoun (n 11) 1.

[15] Österlind and others (n 12) 530.

[16] Mark J Hanson and Daniel Callahan, *The Goals of Medicine: The Forgotten Issues in Health Care Reform* (Georgetown University Press 2000) 8.

[17] Aoun (n 11) 1.

[18] Carmel Shalev, 'Reclaiming the Patient's Voice and Spirit in Dying: An Insight from Israel: Bioethics' (2010) 24 Bioethics 134, 135.

[19] McLean (n 12) 138.

[20] ibid 138–139.

[21] Mary Donnelly, *Healthcare Decision-Making and the Law: Autonomy, Capacity and the Limits of Liberalism* (Cambridge University Press 2010) 11.

[22] ibid 1.

[23] Rosie Harding, 'Legal Constructions of Dementia: Discourses of Autonomy at the Margins of Capacity' (2012) 34 Journal of Social Welfare and Family Law 425, 427.

consent and refusal, reverence has been enhanced (at least theoretically) for the end-of-life preferences of patients.[24]

This current individualistic framework has evidently not been developed with people with dementia in mind. People with dementia experience cognitive functioning that creates challenges for independent living and medical decision-making with the result that support, and ultimately some form of alternative decision-making processes, are eventually necessary.[25] Furthermore, the current approach to end-of-life care for people with dementia is inadequate and in need of urgent improvement in being characterised by overtreatment in the form of interventionist measures, and undertreatment in the form of limited access to symptom relieving care.[26] Where the disclination to recognise dying collides with obligations of individualistic independence, the need for institutional and interpersonal systems of care that effectively attend to relational decision-making and bodily needs at the end of life for people with dementia is ultimately overlooked.

It has been recognised that where regulatory regimes fail to platform end-of-life care and good death, "we make it harder to live and die with dementia."[27] From this perspective, it is not necessarily self-evident that it is the responsibility of law to facilitate a response to this need for improved end-of-life care and decision-making support. Nevertheless, as Donnelly claims in relation to decision-making with dementia, "legal frameworks are still important."[28] Furthermore, Mclean recognises the particular value of law in ensuring the representation of social values separate to medical ethics and expertise on questions related to death and dying.[29] In accepting the premise of law's relevance, this research is interested in the effect of law on the phenomenon of death and dying with dementia in the midst of the noted tension between the predominant discourse and the reality of dying with dementia. In

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[24] Tom Beauchamp, 'The Right to Die as the Triumph of Autonomy' (2006) 31 Journal of Medicine and Philosophy 643, 643.

[25] Kevin De Sabbata, 'Realising Supported Decision-Making in the Context of Dementia and Treatment Decisions: International Principles and Initiatives from Europe' (PhD, University of Leeds 2019) 5–6.

[26] Hall and others (n 9) 24–25.

[27] Harding, *Duties to Care* (n 4) 192.

[28] Mary Donnelly, 'Deciding in Dementia: The Possibilities and Limits of Supported Decision-Making' (2019) 66 International Journal of Law and Psychiatry 101466, 101468.

[29] McLean (n 12) 146.

focusing on the implications of law for the relationship between healthcare, persons with dementia and questions relating to the end of life, "law" as employed in this work is related to the interrelated research fields[30] of health[31] and elder law.[32]

1.3 Research Scope

1.3.1 Research Aim and Questions

The aim of this dissertation is to examine the relationship between law and death and dying with dementia. The effort to explicate the effects, limits and possibilities of law in this space aligns with the broader ambition to better support people with dementia at the end of life by grounding collective responsibility to death and dying in law. This pursuit is framed by the overarching research question:

What is the role of law in shaping and responding to end-of-life decision-making with dementia in Sweden?

This research question captures multiple points of inquiry. Whilst it engages in legal dogmatics, it also encapsulates sociolegal approaches in order to understand not just the way in which law would apply, but the manifold influence of law on end-of-life decision-making with dementia. Further, the

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[30] Nancy Dowd, 'Conceptualising Elder Law' in Ann Numhauser-Henning (ed), *Introduction to the Norma Elder Law Research Environment: Different Approaches to Elder Law* (The Norma Research Programme 2013) notes that elder law is linked with health law in the common issues of dementia and the end of life at 18.

[31] Kavot Zillen, Titti Mattsson and Santa Slokenberga, 'Introduction [Inledning]' in Kavot Zillen, Titti Mattsson and Santa Slokenberga (eds), *Medical Law [Medicinsk rätt]* (3rd edn, Norstedts Juridik AB 2025) refer to medical law as a legal field that intersects with other legal disciplines like public law and human rights and is further distinguished by the fact it investigates issues that exist in the space between law and medicine such as health and healthcare rights at 28.

[32] Ann Numhauser-Henning, 'An Introduction to Elder Law and the Norma Elder Law Research Environment' in Ann Numhauser-Henning (ed), *Introduction to the Norma Elder Law Research Environment: Different Approaches to Elder Law* (The Norma Research Programme 2013) states that elder law is that which is interested in the relationship between law and "old(er) people" at 27.

question belies a descriptive and critical effort to uncover and evaluate the current effects of law as well as a normative effort to improve upon the legal response. With this in mind, a number of sub-questions have been designed:

1. How is law experienced in the everyday of end-of-life decision-making with dementia from the perspective of physicians?
2. How are legal obligations in healthcare constructed, and what implications does this have for the legal response to dying and end-of-life decision-making?
3. How does law construct and respond to end-of-life decision-making with dementia?
4. How can law be recreated in order to better respond to death and dying with dementia?

1.3.2 Research Design

The starting point for the research design is a commitment to the possibility of law in influencing, and ultimately encouraging collective responsibility to, the social phenomenon of death and dying with dementia. It therefore embraces methodology and theory that allows for the degree and nature of law's influence in society to be mapped, evaluated, and ultimately, transformed, in light of the underpinning assumption of law's potential in this space. In order to illuminate the different dimensions of the relationship between law and society in this pursuit,[33] a concurrent, multi-method research design is employed.[34] This multi-method approach engages interviews, doctrinal analysis and a vulnerability informed critical analysis of law. Firstly, semi-structured interviews are undertaken with physicians engaged in end-of-life decision-making for people with dementia in Sweden. Grounded in the idea that the social practice has implications for the meaning of law,[35] the interviews

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[33] Jennifer C Greene, *Mixed Methods in Social Inquiry* (John Wiley & Sons 2007) 101; Vicki L Plano Clark and Nataliya V Ivankova, *Mixed Methods Research. a Guide to the Field* (SAGE 2016) 20–21.

[34] Plano Clark and Ivankova (n 33) 14; John W Creswell and Vicki L Plano Clark, *Designing and Conducting Mixed Methods Research* (3rd edn, SAGE 2018) 65 & 68.

[35] Simon Halliday, 'After Hegemony: The Varieties of Legal Consciousness Research' (2019) 28 Social & Legal Studies 859, 870.

are informed by legal consciousness[36] to trace law's conceptualisation and influence in the everyday.[37] This snapshot of a co-constructed experience of the relationship between law and medicine in the everyday of end-of-life decision-making with dementia reflects an account of the state of law *in* society. This is the backdrop to the second intervention; the investigation of the role of formal legality in shaping and responding to death and dying with dementia. In this, the research proceeds with an analysis of legal material. This engages doctrinal analysis. However, it also extends beyond what legal dogmatics indicates about how the law applies, to an investigation of what norms are purveyed by the law.[38] In particular, it investigates the norms of liberal individualism and their implications for dying, dementia, and end-of-life decision-making. This is accomplished through the application of a feminist informed approach to vulnerability as a universal embodied and embedded openness to the possibility of change.[39] Thirdly, and finally, a feminist vulnerability perspective will again be drawn upon in a transformative analysis of law which grapples with how law ought to be structured in order to better respond to the realities of vulnerability.[40] In other words, a vulnerability perspective will be applied in the theoretical recreation of law[41] to enhance legal responsiveness, and ultimately, collective responsibility, to death and dying with dementia.

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[36] Patricia Ewick and Susan Silbey, *The Common Place of Law: Stories from Everyday Life* (University of Chicago Press 1998).

[37] Susan Silbey, 'After Legal Consciousness' (2005) 1 Annual Review of Law and Social Science 323, 331; Rosie Harding, *Regulating Sexuality: Legal Consciousness in Lesbian and Gay Lives* (Routledge 2010) 19.

[38] Therése Fridström Montoya, 'Live like Others through Proxies - a Legal and Factual Paradox [Leva som andra genom ställföreträdare: En rättslig och faktisk paradox]' (PhD, Uppsala University 2015) 47–48.

[39] Martha Fineman, 'The Significance of Understanding Vulnerability: Ensuring Individual and Collective Well-Being' (2023) 36 International Journal for the Semiotics of Law 1371, 1378.

[40] Martha Fineman, 'Introduction: Understanding Vulnerability' in Martha Fineman and Laura Spitz (eds), *Law, Vulnerability, and the Responsive State: Beyond Equality and Liberty* (Routledge 2024) explains that vulnerability is constructive in normative evaluations of law at 3.

[41] Titti Mattsson and Lottie Giertz, 'Vulnerability, Law, and Dementia: An Interdisciplinary Discussion of Legislation and Practice' (2020) 21 Theoretical Inquiries in Law 139, 143.

1.3.3 Delimitations

The above interventions are necessarily accompanied by explicit decisions as to what to exclude in the research. Most significantly, although this research traversers scholarship on law and capacity, it ultimately focuses on the sub-speciality of dementia and the law to the exclusion of cognitive differences not related to dementia (for example, Down syndrome, Cerebral palsy with cognitive symptoms, and unconsciousness related to other health events). This follows from the claim people with dementia represent a unique group due to characteristic progressive decline in which their relative cognition and independence across their life-time transitions into greater complications with independence and expressing end-of-life wishes. Ryrstedt, for instance, argues these circumstances demand special consideration for people with dementia.[42] Indeed, given the recognition that people with dementia experience a particular kind of disadvantage in society, they "require special attention in both law and society to ensure that their voices are heard."[43] Nonetheless, the learnings of dementia can have broader meaning and relevance as issues of capacity are a shared human experience that can, for example, manifest in other experiences in healthcare and/or healthcare conditions. To this degree, the focus on dementia does not represent an isolated effort to unravel the role of law at the end of life.

Additionally, scholarship on dementia and law often incorporate subjective experiences of people with dementia, informal caregivers such as family and/or healthcare professionals on issues pertaining to life, death, care and decision-making. Whilst patients, family and other healthcare professionals such as nurses are integral to end-of-life decision-making, the research is focused on the experience of physicians alone.[44]

Finally, in focusing on the experiences of people with dementia, this dissertation is inherently engaging with issues related to marginalisation and discrimination. However, this is achieved without engaging with discrimination law or it's related scholarship. Instead, it elects to develop this important dimension through theory.

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[42] Eva Ryrstedt, 'Dementia and Autonomy' in Ann Numhauser-Henning (ed), *Elder Law: Evolving European Perspectives* (Edward Elgar Publishing Limited 2017) 360.

[43] Harding, 'Legal Constructions of Dementia' (n 23) 425.

[44] The reason for this choice will be elaborated upon in subsection 3.3.1.

1.4 Key Concepts

1.4.1 End-of-Life Decision-Making

The focus on end-of-life decision-making as distinct from what may be (perhaps crudely termed) "regular" decision-making relating to ordinary medical treatment is, of course, not a simple or uncontested distinction. Indeed, the very meaning and nature of death and dying may be disputed. What is more, many medical decisions may have consequences or risks that are intertwined with the possibility of death. Moreover, the medical procedures in which medical impossibility and possibility is investigated and decided upon, are not necessarily distinct in accordance with the life-stage of the patient. Nevertheless, in addressing end-of-life decision-making, this research seeks to explicitly engage with the relationship between law, decision-making and dying as a distinct social (and legal) phenomenon.

In this pursuit, end-of-life decisions are taken in this work to represent those that relate to death and dying in accordance with either contemplation of future or contemporaneous decline/death.[45] Such decisions include: the provision or administration of medication with the purpose of hastening death; the provision or administration of medication for the purpose of pain relief that might hasten death; and the withholding and/or withdrawal of life-sustaining treatment.[46] Relatedly, palliative care is also central to end life decision-making. Palliative care is that which "relieves suffering and promotes quality of life" in the midst of progressive and incurable illness[47] with consideration

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[45] This definition was modified from Michele Y Wiese and Irene Tuffrey-Wijne, 'End-of-Life Choices' in Roger J Stancliffe and others (eds), *Choice, Preference, and Disability: Promoting Self-Determination Across the Lifespan* (Springer International Publishing 2020) who defines end-of-life decisions "as any decision pertaining to the dying and death period. These could be decisions made when the person has a life-limiting illness, or is well but contemplating their future dying and death" at 317.

[46] Life-sustaining treatment can include, for example, cardio-pulmonary resuscitation, medical treatment, provision of hydration and nutrition.

[47] Socialstyrelsen, 'National Knowledge Support for Good Palliative Care at the End of Life: Guidance, Recommendations and Indicators [Nationellt kunskapsstöd för god palliativ vård i livets slutskede: Vägledning, rekommendationer och indikatorer]' (2013) 16; World Health Organisation, 'Palliative Care' (5 August 2020) <https://www.who.int/news-room/fact-sheets/detail/palliative-care> accessed 15 December 2022.

as to patient participation and autonomy.[48] As well as support for physical suffering, it is responsive to “psychological, social and existential needs.”[49] Importantly, palliative care can be instituted earlier or later in the progression of an illness. That which is given at an earlier stage can even be associated with treatment that can lengthen life.[50] However, some palliative care measures also come with the possible effect of shortening life. Palliative sedation for example is a practice of symptom management through the reduction of the patient’s consciousness which is often accompanied by the withdrawal of nutrition and hydration.[51] Whilst it is late-stage palliative care that is the focus of Swedish law,[52] the breadth of palliative care is recognised throughout this research.

1.4.2 Dementia

1.4.2.1 Delineating dementia and its use in this study

“Dementia is an umbrella term”[53] that captures a “clinical state” relating to progressive “decline in cognitive function.”[54] It involves one or more of the following cognitive domains being affected: complex attention, executive function, learning and memory, language, perceptual–motor, or social

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[48] Regionala Cancercentrum, ‘Palliative Care: National Care Program [Palliativ vård: Nationellt vårdprogram]’ (2023) 25.

[49] Socialstyrelsen, ‘National Knowledge Support for Good Palliative Care at the End of Life: Guidance, Recommendations and Indicators [Nationellt kunskapsstöd för god palliativ vård i livets slutskede: Vägledning, rekommendationer och indikatorer]’ (n 47) 16; World Health Organisation (n 47); Regionala Cancercentrum (n 48) 24.

[50] Socialstyrelsen, ‘National Knowledge Support for Good Palliative Care at the End of Life: Guidance, Recommendations and Indicators [Nationellt kunskapsstöd för god palliativ vård i livets slutskede: Vägledning, rekommendationer och indikatorer]’ (n 47) 16.

[51] Titti Mattsson and Lena Wahlberg, ‘Care at the End of Life [Vård i livets slutskede]’ in Kavot Zillen, Titti Mattsson and Santa Slokenberga (eds), *Medical Law [Medicinsk Rätt]* (3rd edn, Norstedts Juridik AB 2025) 306.

[52] Socialstyrelsen, ‘National Knowledge Support for Good Palliative Care at the End of Life: Guidance, Recommendations and Indicators [Nationellt kunskapsstöd för god palliativ vård i livets slutskede: Vägledning, rekommendationer och indikatorer]’ (n 47) 16.

[53] De Sabbata (n 25) 5.

[54] Elissa L Ash, ‘What Is Dementia?’ in Charles Foster and Israel Doron (eds), *The Law and Ethics of Dementia* (Hart Publishing 2014) 3; Donnelly, ‘Deciding in Dementia’ (n 28) 101468.

cognition.[55] Although Alzheimer's disease is the most common form, it can emerge in relation to many other conditions such as vascular dementia, Lewy body and frontotemporal dementias. Dementia may also result due to, among other things, HIV, alcohol misuse, brain injury and nutritional deficiencies. There are no fixed boundaries between these different forms.[56]

In contrast to mild cognitive impairment which represents a state "between normal cognition and dementia, with essentially preserved functional abilities,"[57] dementia refers to the common traits of "loss of memory and other mental abilities severe enough to interfere with daily life, caused by physical changes in the brain."[58] That is, for a formal dementia diagnosis to be made, cognitive decline must become sufficiently severe to represent an impairment that impacts one's work and/or social life.[59] Real-life examples of this impact can include the need for assistance with bill payments and medication management.[60] According to the subtype of dementia, (whether it is for example, Lewy-Body or Alzheimer's), there may be other "mental and physical" symptoms that create increasing dependencies and care needs.[61]

It is important to note that in 2013, the umbrella term "dementia" was replaced with "major neurocognitive disorder" in the Diagnostic and Statistical Manual of Mental Disorders DSM5.[62] This shift was part of an attempt to reduce the stigma attached to the association of dementia with the phrase "demens" which

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[55] Perminder S Sachdev and others, 'Classifying Neurocognitive Disorders: The DSM-5 Approach' (2014) 10 Nature Reviews Neurology 634, 638.

[56] World Health Organisation (n 5).

[57] Julie Hugo and Mary Ganguli, 'Dementia and Cognitive Impairment: Epidemiology, Diagnosis, and Treatment' (2014) 30 Clinics in Geriatric Medicine 421, 421.

[58] Mattsson and Giertz (n 41) 143; Hugo and Ganguli (n 57) 421; Sachdev and others (n 55) 638.

[59] Socialstyrelsen, 'National Guidelines for the Care and Welfare of Dementia: Support for Governance and Management [Nationella riktlinjer för vård och omsorg vid demenssjukdom: Stöd för styrning och ledning]' (2017) 16.

[60] Sachdev and others (n 55) 638.

[61] Jakov Gather and Jochen Vollmann, 'Physician-Assisted Suicide of Patients with Dementia. A Medical Ethical Analysis with a Special Focus on Patient Autonomy' (2013) 36 International Journal of Law and Psychiatry 444, 446.

[62] Donatella Rita Petretto and others, 'Dementia and Major Neurocognitive Disorders: Some Lessons Learned One Century after the First Alois Alzheimer's Clinical Notes' (2021) 6 Geriatrics 1, 1.

in Latin means “without mind.”[63] With this said, this work has principally intended to capture the cognitive challenges associated with a major cognitive disorder with the “mostly synonymous” terminology dementia.[64] As research has indicated that three quarters of people dying with dementia do so at a stage of moderate and advanced stage,[65] such a classification is relevant to research into end-of-life decision-making with dementia.

However, it has also been necessary that issues associated with mild cognitive disorder are also treated in this thesis. One example of this is that people may contemplate and anticipate future cognitive decline in making end-of-life decisions. By way of illustration, a person who has been diagnosed with Alzheimer’s disease at a stage of mild cognitive disorder can participate in forward looking advanced care planning in relation to anticipated decline. Furthermore, over the course of this research, it became clear that end-of-life decision-making with reference to major cognitive disorder give rise to issues of variation and diversity that ultimately run the gauntlet of cognitive challenges. Thus, whilst the focus is on dementia as representative of moderate and major cognitive illness, the term dementia has additionally been used in the broader and more colloquial sense of “an acquired, persistent syndrome or cognitive impairment often, but not always, linked to increasing age” in relation to many forms.[66]

This account of dementia which is inclusive of mild cognitive illness, or early stage dementia, is consistent with the way that the term dementia is mobilised in medicine, society, legal scholarship[67] and policy more generally.[68] Indeed, it has been recognised that dementia will continue to be familiar to the general public and policy makers despite efforts to move away from this terminology.[69] Looked at from this perspective, dementia is clearly not only a medical state, “but a sociocultural phenomenon.” By continuing to use the term dementia, I

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[63] ibid.

[64] Sachdev and others (n 55) 635.

[65] Yvonne Eisenmann and others, ‘Palliative Care in Advanced Dementia’ (2020) 11 Frontiers in Psychiatry 699, 701.

[66] Sachdev and others (n 55) 638.

[67] ibid.

[68] See for example, the Swedish government’s recent publication of the strategy for dementia care entitled ‘National Dementia Strategy [Nationell demensstrategi] 2025–2028,’ Dnr: S2025/00121.

[69] Sachdev and others (n 55) 637–638.

therefore hope to contribute to efforts that seek to undo the stigmatising attitudes and behaviours associated with dementia.[70] In this sense, it is important that a conscious effort is made throughout this research to participate in the reframing people with dementia as full human beings in order to contribute to the dismantling of stereotypes. It is nevertheless acknowledged that in relying on the terminology of dementia, this work is predisposed to be more closely associated with Alzheimer's disease and older people due to the historical associations of the term.[71] To counteract this, the research has been conducted with the diverse constellation of experience under the umbrella of dementia in mind.

1.4.2.2 Living & deciding with dementia

With dementia terminology defined, this section now briefly describes the experience of living and deciding on issues relating to healthcare and medical treatment with dementia. It is essential to emphasise that people with dementia are an extraordinarily heterogenous group.[72] They therefore have diverse "needs and dependencies."[73] Generally speaking though, people with dementia have lived a life which includes having developed complex opinions and relationships.[74] Moreover, people with dementia in the present interact with the outside world and have subjective experiences and desires.[75] Even so, people with advanced dementia may experience difficulties with cognitive functioning that impact decision-making around medical treatment.[76] These vary according to the cognitive domain/s that have been impacted. Importantly, difficulties associated with expressions relating to care are not simply a result of cognitive impairment but are caused by environmental factors including the way in which communication is approached.[77] Stigma, associated with social

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[70] Valerie Keller, 'Failed in Aging? Queering in Living with Dementia' (2023) 8 Frontiers in Sociology 1139271, 1139273.

[71] Sachdev and others (n 55) 638.

[72] Interview with Participant B.

[73] Mattsson and Giertz (n 41) 143.

[74] Donnelly, 'Deciding in Dementia' (n 28) 101468.

[75] Marike E de Boer and others, 'Advance Directives in Dementia: Issues of Validity and Effectiveness' (2010) 22 International Psychogeriatrics 201, 203.

[76] De Sabbata (n 25) 5–6.

[77] Kevin De Sabbata, 'Dementia, Treatment Decisions, and the UN Convention on the Rights of Persons with Disabilities. A New Framework for Old Problems' (2020) 11 Frontiers in Psychiatry 571722, 571727.

exclusion, blanket devaluation of the contributions of people with dementia and a disproportionate focus on impairments,[78] has, for instance, been identified amongst healthcare professionals.[79] This creates an environment that undermines patient cognition and communication and can lead to an implicit association between dementia and incompetence.[80] With this in mind, appropriate support is vital so that persons with dementia are encouraged rather than hindered from participation in decision-making. Against this backdrop, legal and philosophical debate abounds as to the validity of "the opinions of people living with dementia,"[81] and whether alternative approaches to decision-making are required,[82] or, their experiences in the present respected.[83] Legal solutions in the midst of this debate hereto include: decisions based on an objective assessment of best interest;[84] supported decision-making that centres people with dementia;[85] decision-making grounded in the best interpretation of the patient's wishes and preferences;[86] and advanced care directives that contain instructions as to treatment decisions or care goals and/or appoint alternative decision-makers.[87]

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[78] Nicole Batsch and Mary Mittelman (eds), 'World Alzheimer Report 2012: Overcoming the Stigma of Dementia' (Alzheimer's Disease International 2012) 9–10.

[79] Lynn K Herrmann and others, 'A Systematic Review of Dementia-Related Stigma Research: Can We Move the Stigma Dial?' (2018) 26 The American Journal of Geriatric Psychiatry 316.

[80] Leslie Pickering Francis, 'Decision-making at the End of Life: Patients with Alzheimer's or Other Dementias Symposium: Joint Conference on Legal/Ethical Issues in the Progression of Dementia' (2000) 35 Georgia Law Review 539, 542.

[81] De Sabbata (n 25) 41–42.

[82] Ronald Dworkin, *Life's Dominion: An Argument About Abortion, Euthanasia and Individual Freedom* (Knopf 1993) for example argued that people with dementia do not have critical interests, and therefore, ought to have their experiential interests of the present invalidated by the wishes expressed prior to the onset of advanced dementia.

[83] Rebecca Dresser, 'Dworkin on Dementia: Elegant Theory, Questionable Policy' (1995) 25 Hastings Center Report 32, has for instance argued against adherance to previously expressed wishes in favour of responding to the experiential reality of the patient with dementia in the present.

[84] See for example, the Mental Capacity Act (2005) (England & Wales).

[85] Donnelly, 'Deciding in Dementia' (n 28).

[86] 'UN CRPD Committee, General Comment No. 1: Article 12 Equal Recognition before the Law, CRPD/C/GC/1, 11 April 2014' para 21.

[87] For example, Ben P White and others, 'Prevalence of Advance Care Directives in the Community: A Telephone Survey of Three Australian States' (2019) 49 Internal Medicine

1.4.2.3 Dying with dementia

Although it is important that dementia care has in recent times focused on improving care and support services for people with dementia and their families as a redress for the despair correlated with dementia,[88] it is often poorly understood as a condition with a "terminal phase." The result is that the particular needs of end-of-life care are overlooked and unaddressed.[89] As is true in regards to living with dementia, people with dementia at the end of life are also a heterogenous group which means that approaches to end-of-life care cannot be "one-size-fits-all."[90] As such, it is important to be aware of the pitfalls of making generalisations or assumptions about what people with dementia may look like at the end of life. Nevertheless, as with the discussion on living and deciding with dementia, some important points about the end of life with dementia can be made.

As already noted, people can both die with, or from dementia. In this way, while complications associated with end-stage dementia may be the primary cause of death, other illnesses may pre-exist or develop which can be complicated or worsened by dementia.[91] Further, it has been recognised that end-of-life symptoms with dementia commonly include "pain, shortness of breath, anxiety, nausea, confusion, and wheezing." Whilst the identification and treatment of such symptoms is considered important,[92] care at the end of life with dementia has been globally recognised as inadequate with reference to the practice of overly interventionist care that carries too little benefit. By way of illustration, tube feeding, and restraints are used too frequently, whilst

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Journal 1261, note that such regimes are in place in all Australian jurisdictions via legislation or common law at 1262.

[88] Elizabeth Peel and Rosie Harding, 'A Right to "Dying Well" with Dementia? Capacity, "Choice" and Relationality' (2015) 25 Feminism & Psychology 137, 137.

[89] Michael Gordon, 'Ethical Perspectives on End of life Care: Euthanasia, Assisted Suicide and the Refusal of or Withdrawal of Life-Sustaining Treatments in Those Living with Dementia' in Charles Foster, Jonathan Herring and Israel Doron (eds), *The Law and Ethics of Dementi*a (Hart Publishing 2014) 197.

[90] Sarah R Hill and others, 'What is Important at the End of Life for People with Dementia? The Views of People with Dementia and Their Carers: End-of-Life Care for People with Dementia' (2017) 32 International Journal of Geriatric Psychiatry 1037.

[91] Martina Kane, 'My Life Until the End: Dying Well with Dementia' (Alzheimer's Society 2012) 2.

[92] Regionala Cancercentrum (n 48) 123

pain control is not given enough.[93] The importance of this issue is illustrated by the following recognition:

> "Where palliation is appropriate, sympathetic and person-centred, it can ensure a peaceful and dignified death. Where palliative care is poorly carried out, poorly communicated or not used at all, then not only does it mean the dying person experiences more pain and suffering than is necessary, but it also generates further stigma and fear around death and dying with dementia."[94]

In addition, issues of agency arise. There are, for instance, people with dementia who do not wish to live.[95] Such experiences are captured by the story of Sandra Bem who, with Alzheimer's disease, accessed assisted dying with the support of her family in light of the particularly painful prospect of cognitive decline as a person with a rich history in critical thinking.[96] As revealed by Sandra's story of familial support, dementia can create difficulties with independence which requires support to actualise self-determination death as in life. Such complications include "diminishing mental capacity and difficulty with communication, which is particularly problematic when the person is communicating their hunger, thirst, discomfort, pain or other needs."[97] In this context, research has indicated the importance of attention to nonverbal communication including body tension, head movements and breathing frequency where verbal communication is difficult.[98]

1.4.2.4 Dying with dementia in Sweden

In Sweden, figures suggest that between 130,000-150,000 people have dementia with approximately 20,000 new cases every year.[99] Furthermore, in a study of death certificate data in 2012, it was reported that 8349 out of 83712

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[93] Hall and others (n 9) 24.

[94] Harding, *Duties to Care* (n 4) 177.

[95] Peel and Harding (n 88) 137.

[96] Robin Marantz Henig, 'The Last Day of Her Life - The New York Times' *The New York Times Magazine* (14 May 2015) <https://www.nytimes.com/2015/05/17/magazine/the-last-day-of-her-life.html> accessed 6 January 2025.

[97] Kane (n 91) 2.

[98] Eisenmann and others (n 65) 700.

[99] Socialstyrelsen, 'National Guidelines for the Care and Welfare of Dementia: Support for Governance and Management [Nationella riktlinjer för vård och omsorg vid demenssjukdom: Stöd för styrning och ledning]' (n 59) 17.

deaths had dementia as an underlying cause.[100] Dying with dementia often takes place in nursing homes[101] which means that palliative care for people with dementia is largely organised by registered nurses and provided by assistant nurses in nursing homes. Physicians (including geriatricians and primary care physicians) in this environment are largely external actors who consult via telephone and/or visit for period(s) during the week. Nurses therefore have significant responsibility in the provision of end-of-life care.[102] Physicians nevertheless have a primary role ascribed by law as the decision-maker responsible for following and applying law on issues of withdrawing treatment and providing palliative care.[103] What is more, this study itself has demonstrated that physicians understand themselves to play a pivotal role in this decision-making process as part of a team of multi-disciplinary care professionals, family members and the patient.[104]

1.4.3 Bioethics

Bioethics (used interchangeably with "ethics" and "medical ethics" in this book) are inextricably embedded in this investigation on the relationship between law and end-of-life decision-making with dementia. In order to clarify reoccurring concepts such as autonomy, beneficence, non-maleficence and justice, I offer an account of the predominant approach to bioethics as

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[100] Cecilia Håkanson and others, 'A Population-Level Study of Place of Death and Associated Factors in Sweden' (2015) 43 Scandinavian Journal of Public Health 744, 747.

[101] ibid.

[102] Linda Høgsnes and others, 'Healthcare Professionals' Documentation in Nursing Homes When Caring for Patients with Dementia in End of Life – A Retrospective Records Review' (2016) 25 Journal of Clinical Nursing 1663, 1664; Bodil Holmberg, Ingrid Hellström and Jane Österlind, 'End-of-Life Care in a Nursing Home: Assistant Nurses' Perspectives' (2019) 26 Nursing Ethics 1721, 1722; Emma Lundin and Tove Godskesen, 'End-of-Life Care for People with Advanced Dementia and Pain: A Qualitative Study in Swedish Nursing Homes' (2021) 20 BMC Nursing 1, 2.

[103] Life-sustaining treatment [Livsuppehållande behandling] SOSFS 2011:7 2 chap. 3 § stipulates that a licenced physician must be appointed as a fixed care contact in the case of life threatening circumstances. It is either this fixed care contact, or another licenced physician involved in the patient's care in the absence of a fixed care contact (according to 3 chap. 4 § & 4 chap. 5 §) who is responsible for applying the rules as they relate to the withdrawal or withholding of life-sustaining treatment.

[104] See Chapter 3.

contained in Childress and Beauchamp's "principalism."[105] Bioethics in this form are taken to represent standards of conduct or moral norms which provide the foundation of moral reasoning in healthcare.[106] To be unpacked as follows, it is constituted by four overarching ethical principles: autonomy; non-maleficence; beneficence; and justice. Founded upon ideas of "individual freedom and choice," autonomy represents voluntariness, mental capacity and the ability to be free from "external constraint."[107] Respect for autonomy involves respect for the views, decisions and actions of autonomous people with decision-making capacity.[108] In this sense, non-interference is not the be all and end all. Rather, it must also include the construction of opportunities for autonomous action.[109] The second principle of non-maleficence is framed as a requirement to refrain from causing harm.[110] This concept of "do no harm" has historical significance in medicine as the ruling concept over medical practice.[111] In practice, it represents the importance of balancing the benefits with the harm of medical intervention[112] and includes the moral rules that one should not kill or cause suffering.[113] It has also been associated with the ability to withdraw life-sustaining treatment where the "overall burdens outweigh its benefits to the patient" even if the illness is not terminal.[114] Inversely, beneficence relates to a collection of principles associated with harm prevention, acting for others' benefit and balancing costs and benefits.[115] This is framed as the principal obligation in patient care.[116] There is, however, unresolved tension over the issue of the relationship between autonomy and

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[105] Mathew Shea, 'Forty Years of the Four Principles: Enduring Themes from Beauchamp and Childress' (2020) 45 Journal of Medicine and Philosophy 387, 387–388.

[106] Beauchamp (n 24) 3.

[107] ibid 4.

[108] ibid.

[109] Tom Beauchamp and James Childress, *Principles of Biomedical Ethics* (8th edn, Oxford University Press 2019) 104.

[110] Beauchamp (n 24) 4.

[111] ibid.

[112] ibid 5.

[113] Beauchamp and Childress (n 109) 159.

[114] ibid 174.

[115] Beauchamp (n 24) 4–5.

[116] Beauchamp (n 24) 5.

beneficence. In particular, questions as to whether patient autonomy should take precedence[117] in the event of, for example, a non-resuscitation request persist.[118] Finally, the principle of justice was associated with the fair distribution of “benefits, risks and costs.”[119] Common to this concept is the idea that like be treated alike.[120]

1.5 Scholarly Intervention

This research intervenes in dementia and the law as a field which “little sustained attention has been paid.”[121] Specifically, it attends to an underexplored field of Swedish legal scholarship on end-of-life decision-making with dementia which has the dual outcome of furthering both domestic and global dialogue on this issue. It additionally contributes to scholarship that seeks to examine the sociolegal dimensions of law. Finally, this thesis will extend the debate in legal scholarship on individualism, care and relational agency in the context of death and dying. These three contributions, as conceived broadly, will now be situated in the existing scholarship.

Firstly, this research represents a unique opportunity to draw out currently unknown dimensions of Swedish law as it relates to end-of-life decision-making to develop specialised scholarship on the law of death and dying with dementia. This is a distinctive contribution given that Swedish scholarship has not comprehensively canvassed the relationship between the end of life and capacity in the legal regulation of Swedish healthcare. In fact, scholarly engagement with end-of-life questions in Swedish health law has in and of itself been somewhat limited. Review of the literature has uncovered only two publications with Rynning, and more recently, Mattsson and Wahlberg, examining the status of the law in relation to end-of-life decisions.[122] The

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[117] Beauchamp and Childress (n 109) 230.

[118] ibid 231.

[119] Beauchamp (n 24) 4.

[120] ibid 6.

[121] Harding, ‘Legal Constructions of Dementia’ (n 23) 425.

[122] Elisabeth Rynning, ‘Right to Live and Right to Die [Rätt till liv och rätt att dö]’ in Martin Ingvar and others (eds), *Life and Death: Life-Sustaining Treatment from Beginning to End [Liv och död: Livsuppehållande behandling från början till slut]* (Karolinska Institutet University Press 2009); Mattsson and Wahlberg (n 51).

relationship between death and dying is even more unexplored in the context of dementia. Relevant to this is Mattsson and Wahlberg's acknowledgment that Swedish health law is unclear on the question of end-of-life decision-making where there are cognitive difficulties.[123] This thesis makes an explicit effort to develop this existing knowledge with reference to the legal tensions that abound in the context of the end-of-life care with dementia. In doing so, it intersects with Swedish legal scholarship on capacity and somatic care more broadly.[124]

In expanding on legal research in a Swedish context, this work is also intertwined with international efforts to analyse the relationship between law and the end of life in the context of dementia. Advance care planning is a particularly popular topic given the challenging possibility that the person who lived a life prior to cognitive decline can clash with the current person who has their own dementia informed experiences with the world.[125] However, as clarified by Smith, these decisions "are not isolated, but part of a range of possibilities."[126] This insinuates that the breadth of issues associated with end-of-life decision-making with dementia cannot be easily or fairly pigeon holed into any one issue. Indeed, the particularities facing dying with dementia arguably warrant similar focus on a range of decision-making such as withdrawal and withholding of treatment[127] and supported decision-making

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[123] Mattsson and Wahlberg (n 51) 308.

[124] See for example Yana Litins'ka, 'Assessing Capacity to Decide on Medical Treatment: On Human Rights and the Use of Medical Knowledge in the Laws of England, Russia and Sweden' (PhD, Uppsala University 2018); Elisabeth Rynning, 'Consent to Medical Care and Treatment: A Legal Study [Samtycke till medicinsk vård och behandling: En rättsvetenskaplig studie]' (PhD, Uppsala University 1994); Yana Litins'ka, 'To Force or Not to Force: Protecting the Lives of Persons with Dementia Who Refuse Care' in Hans Eklund, Lotts Lerwall and Anna-Sara Lind (eds), *Book for Sverker Scheutz: About Law and Teaching Law [Vänbok till Sverker Scheutz: Om rätt och att undervisa rätt]* (Iustus Förlag 2020).

[125] See for example Andrew Sneddon, 'Indeterminacy of Identity and Advance Directives for Death after Dementia' (2020) 23 Medicine, Health Care and Philosophy 705; Cipriani and Di Fiorino (n 6).

[126] Stephen W Smith, *End-of-Life Decisions in Medical Care: Principles and Policies for Regulating the Dying Process* (Cambridge University Press 2012) 2–3.

[127] Daniel Callahan, 'Terminating Life-Sustaining Treatment of the Demented' (1995) 25 Hastings Center Report 25, for example suggests a 'middle way' in ceasing life-sustaining treatment for people with dementia that embrace the reality of dementia whilst not engaging in stereotypes about the "special horror of the condition"; Jocelyn Downie, Lindy Willmott and Ben White, 'Cutting the Gordian Knot of Futility: A Case for Law Reform on Unilateral Withholding and Withdrawal of Potentially Life-Sustaining Treatment' (2014)

regimes[128] as well as the law as it relates to palliative care.[129] This research purposefully seeks to tackle end-of-life decision-making with dementia in a way that captures the interrelated breadth of the issues. In considering the possibilities together, this research will be able to offer an understanding on how the decisions relate to, and impact on, one another[130] to provide a more comprehensive account of the relationship between law and death and dying with dementia.

Additionally, this dissertation contributes to scholarship interested in the sociolegal dimensions of law in questions of healthcare more generally, and death and dying more specifically. One intervention in this respect is in the area of scholarly accounts of how end-of-life decisions are made in the everyday in relation to law. In his study on the practice of underground euthanasia, Magnusson for example, identifies how responses to requests for euthanasia can involve the mobilisation of ethics and considerations of law.[131] Furthermore, a particularly prominent focus is the identification of gaps between law and the practice of end-of-life decision-making. For instance, Australian scholarship has identified that physicians do not necessarily follow, or are not explicitly influenced by, the relevant laws pertaining to end-of-life decision-making, preferring instead to prioritise clinical and ethical considerations.[132] Even more closely related to this research, Blake et al. discerned a difference in Western Australia between the autonomy driven law of advanced care planning and the practice of end-of-life decision-making with

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26 New Zealand Universities Law Review 24, for example create a core set of values to suggest a new legislative way forward in Australia and New Zealand regarding non-specific patients.

[128] Mary Donnelly, ‘Best Interests in the Mental Capacity Act: Time to Say Goodbye?’ (2016) 24 Medical Law Review 318, reads the Mental Capacity Act through the prism of the CRPD to advocate for the existence of requirements for support; Donnelly, ‘Deciding in Dementia’ (n 28) addresses how support is important in dementia care and argues that this is not yet being fully realised in law.

[129] Harding, *Duties to Care* (n 4) chapter 7.

[130] Smith (n 126) 2–3.

[131] Roger Magnusson, *Angels of Death: Exploring the Euthanasia Underground* (Melbourne University Publishing 2002).

[132] Ben P White and others, ‘Comparing Doctors’ Legal Compliance across Three Australian States for Decisions Whether to Withhold or Withdraw Life-Sustaining Medical Treatment: Does Different Law Lead to Different Decisions?’ (2017) 16 BMC Palliative Care 63; Ben White and others, ‘The Knowledge and Practice of Doctors in Relation to the Law That Governs Withholding and Withdrawing Life-Sustaining Treatment from Adults Who Lack Capacity’ (2016) 24 Journal of Law and Medicine 356.

dementia as informed by the complex realities of dying with dementia.[133] Taking a different approach, Harding captures the experiences of family members in relation to dying with dementia to develop an account of what fundamental changes are needed in law.[134]

A subset of scholarship on everyday decision-making takes place in the field of legal consciousness in which the social practice of law is understood to reveal law and its influence. Similarly to the gap studies described above, Picton-Howell's dissertation was interested in how official state law (professional guidelines and state law) was engaged with and experienced by doctors in making difficult decisions regarding children with disabilities with a view to identifying where law has, and fails to have, influence.[135] Other efforts such as Halliday et al. and Heimer have been directed towards an investigation of how the everyday practices in healthcare determine the influence of law.[136] Largely unexplored in the broader context of Swedish scholarship, especially relevant is Greenbrook's investigation of the legal and medicolegal consciousness of physicians engaged in healthcare for undocumented migrants as liminal patients in Sweden.[137] This research intervenes in the existing milieu by locating a legal consciousness analysis sensitive to the quasi-legal influence of medicine in the hereto unexplored context of end-of-life decision-making with dementia in Sweden. In doing so, it does not seek to replicate gap studies or those which seek to produce universal narratives of the way in which law is socially constructed. Rather, it seeks to interrogate a particular negotiation of legal and medical control in the everyday to reveal the meaning, possibilities and limits of law in the everyday of end-of-life decision-making with dementia.

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[133] Meredith Blake, Olivia Nicole Doray and Craig Sinclair, 'Advance Care Planning for People with Dementia in Western Australia: An Examination of the Fit Between the Law and Practice' (2017) 25 Psychiatry, Psychology, and Law 197.

[134] Harding, *Duties to Care* (n 4) chapter 7.

[135] Zoe Picton-Howell, 'UK Paediatricians' Medical Decision-making for Severely Disabled Children: A Socio-Legal Analysis' (PhD, The University of Edinburgh 2018).

[136] Simon Halliday, Celia Kitzinger and Jenny Kitzinger, 'Law in Everyday Life and Death: A Socio-Legal Study of Chronic Disorders of Consciousness' (2015) 35 Legal Studies 55; Carol Heimer, 'Competing Institutions: Law, Medicine, and Family in Neonatal Intensive Care' (1999) 33 Law & Society Review 17.

[137] Josephine TV Greenbrook, *Liminality and the Lived Experience of Law in Medicine: The Legal Consciousness of Physicians in Encounters with Undocumented Migration* (Brill, forthcoming 2025).

Finally, this thesis will engage with the opportunity to contribute new dimensions to legal scholarship that challenges liberal notions of individualism in the context of death and dying with dementia. Autonomy, framed as self-governance, moral independence,[138] control, and choice,[139] often predominates the focus on assisted dying in death and dying discourse. Perspectives embedded in feminist traditions of relationality and vulnerability have been developed to counteract the trend of individualism in assisted dying. In one instance, relational autonomy is claimed to usefully reveal whether requests for assisted dying are free from external oppressions,[140] and in another, it is encapsulated in an effort to attend to the relational needs of requests for assisted dying.[141] In contributing to efforts to unpack and unravel individualism at the end of life beyond the question of assisted dying, this work joins scholarship that has reimagined opportunities for agency for people with dementia more broadly.[142]

However, it is suggested that even an expanded approach to autonomy may have its limits given the way that death can confound opportunities for

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[138] Marit Karlsson, Anna Milberg and Peter Strang, 'Dying Cancer Patients' Own Opinions on Euthanasia: An Expression of Autonomy? A Qualitative Study' (2012) 26 Palliative Medicine 34, 34–35.

[139] Manne Sjöstrand and others, 'Autonomy-Based Arguments against Physician-Assisted Suicide and Euthanasia: A Critique' (2013) 16 Medicine, Health Care and Philosophy 225, 226.

[140] Jocelyn Downie and Susan Sherwin, 'Bioethics and Law Symposium Deconstructing Traditional Paradigms in Bioethics: Race, Gender, Class and Culture: A Feminist Exploration of Issues around Assisted Death'' (1996) 15 Saint Louis University Public Law Review 303, 326–329.

[141] Manni Ardzejewska, 'Assisted Dying, the Vulnerable Subject and the Responsive State: A Feminist Vulnerability Comparison and Proposal for an Assisted Dying Legal Framework'' (Juris Doctor, Queens University Belfast 2019).

[142] For example, Mary Donnelly, 'A Legal Overview' in Charles Foster, Jonathan Herring, and Israel Doron (eds), *The Law and Ethics of Dementia* (Hart Publishing 2014) follows a critique of capacity as a "blunt instrument" with a proposal that it be replaced with a vulnerability informed understanding of agency to address barriers to empowerment with dementia; Jonathan Herring, 'Entering the Fog: On the Borderlines of Mental Capacity' (2008) 83 Indiana Law Journal 1619, claims that capacity ought to be guided by "principles of dignity and liberty" which requires the views of legally incompetent people to be respected at 1648; Harding, 'Legal Constructions of Dementia' (n 23) promotes a person-centred approach to relational autonomy to account for the complex and relational realities of people with dementia.

choice.[143] Thus, whilst efforts to promote an alternative conceptualisation of autonomy are powerful, and indeed, necessary, I join scholarship that attempts to explicitly carve out the dimensions of care that meet physical as well as agentic needs. In this vein, Swedish scholarship has, for example, addressed the inconsistency between the focus of law on self-determinations with the reality of dementia care through a vulnerability perspective[144] and that which has sought to balance autonomy and protection in Sweden's guardianship regime.[145] In this effort, I, however, will explicitly avoid pitting opportunities for relational agency and care against each other in favour of an investigation into how human interdependency can underpin collective and legal responsibility to care that creates opportunities for both relational choice and the satisfaction of physical needs. This is arguably essential in promoting a comprehensive approach to end-of-life care that curbs stigmatisation, promotes empowerment and meets physical needs for people with dementia.

To achieve this, I will develop and apply a feminist approach to vulnerability to this issue of death and dying with dementia. Beginning with embodied vulnerability as the universal truth of the human condition, vulnerability has been established in the realm of dementia[146] and disability more broadly due to its transformative potential in law.[147] Not all scholarship takes an optimistic view of vulnerability however. Harding, for instance, avoided vulnerability in favour of a relationality approach to identify issues of law spanning physical care and agency in efforts to improve the experience of dying for people with dementia and their families.[148] Justified further in subsection 2.4.4, I will apply vulnerability in recognising the essential role of structural and interpersonal relationships to the human condition, whilst also intentionally engaging with the centrality of bodily vulnerability. In doing so, I intend to position cognitive illness, death and dying as universal rather than exceptional events[149] to work

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[143] Liz Lloyd, 'Mortality and Morality: Ageing and the Ethics of Care' (2004) 24 Ageing & Society 235, 244.

[144] Mattsson and Giertz (n 41).

[145] Ryrstedt (n 42).

[146] De Sabbata (n 25); Donnelly, 'A Legal Overview' (n 142).

[147] Beverley Clough, 'Disability and Vulnerability: Challenging the Capacity/Incapacity Binary' (2017) 16 Social Policy and Society 469.

[148] Harding, *Duties to Care* (n 4).

[149] Ani Satz, 'Disability, Vulnerability, and Public Health Emergencies' in Martha Fineman and Laura Spitz (eds), *Law, Vulnerability, and the Responsive State: Beyond Equality and Liberty* (Routledge 2024) 233; Judith Butler, *Undoing Gender* (Routledge 2004) 21.

towards a transformative critique and reconstruction of law that problematises the normalisation of the struggle against death at all costs and challenges the stigmatisation of dying with dementia.

1.6 Thesis Structure

After establishing the theory, method and material of this research in Chapter 2, the thesis begins substantively in Chapter 3 with an exploration of law in the everyday. The core of this chapter is constituted by an interview study with physicians engaged in end-of-life decision-making with dementia. From these interviews four schemas of legal and quasi-legal medical consciousness are constructed: law as an undercurrent; law as an iron fist; law as a tool; and medicine as a lodestar. These demonstrate an interplay of adherence, instrumentalisation and abandonment of law in which law conveys the significance of autonomy, encourages the maintenance of life, and medicalises death and dying with dementia. In this co-operative network, medicine fills the gaps left by law in working to secure good end-of-life care. This co-constructed snapshot of law in society indicates that whilst law matters, it is limited in regards to its ability to encourage collective responsibility to death and dying with dementia.

Having illustrated the law as it exists in society, Chapter 4 and Chapter 5 explore formal legality's meaning making and response to death and dying with dementia. This is mapped through a comprehensive investigation of Swedish law and its debates as it relates to end-of-life decision-making with dementia via a combination of doctrinal and feminist informed vulnerability analyses. Chapter 4 focuses on the legal construction of dying and decision-making in Swedish healthcare and its implications. In this, Swedish law is identified to hinge upon the individualistic liberal subject. As a result, law is predisposed to encourage the return to good health and the protection of life which is further framed by respect for self-determination, and medical expertise. This system produces a dynamic that oscillates between a potentially harmful demand for individualistic independence in decision-making on the one hand, and paternalistic control in questions of death and dying on the other.

This dynamic is brought into sharp relief by the circumstances of dying with dementia. This is explored in Chapter 5's investigation of the way in which the law constructs and responds to the specific circumstances of end-of-life decision-making with dementia. It demonstrates that, whilst the patient with dementia is generally assigned the status of autonomous legal subject in healthcare, the drive to avoid death collides with a presumption that persons with dementia facing death and dying are neither rational nor self-sufficient legal agents. As a result, the law oscillates between placing inappropriate demands on decision-making agents that overlook opportunities for relational decision-making, and providing for paternalistic control. This has contradictory implications for whose end-of-life wishes are respected as well as access to appropriate end-of-life care that is both self-affirming and attentive to physical wellbeing. Indeed, whilst this is particularly stark in relation to decisions that may hasten death, a system that clouds the possibility of death also arguably creates limitations for palliative care.

Chapter 6 then recreates the law as it relates to the regulation of end-of-life decision-making with dementia. Through the application of a particularly feminist take on vulnerability, the law is reconstructed through the substitution of the liberal subject with the transformative vulnerable subject. This reimagination eschews the focus of individualistic self-determination and the promotion of life in favour of collective care and relational autonomy at the end of life. This is underpinned by the vulnerability informed recognition that responsibilities in healthcare cannot only be directed towards the provision of good health, but must also be concerned with securing opportunities for a good death. By developing and elaborating on key legal dimensions from the perspective of vulnerability, this transformative account of Swedish law demonstrates how collective responsibility to end-of-life wellbeing with dementia can be effectively secured at the core of legal governance. This chapter ultimately represents a call to meaningfully grapple with the boundaries of law in death and dying with dementia as part of broader efforts to improve outcomes at the end of life via relational care and decision-making.

The dissertation concludes in Chapter 7 with the opportunity to reflect on the key findings of this research. As part of this, the contribution of this work to what is known about the relationship between law and death and dying with dementia is made evident, and its limitations acknowledged.

2 Theory, Method & Material

> We must constantly encourage ourselves and each other to attempt the heretical actions that our dreams imply and so many of our old ideas disparage. — Audre Lorde[150]

2.1 Introduction

To investigate the research questions on the intersection of law and society in end-of-life decision-making with dementia, an interdisciplinary approach is necessary. Indeed, it is only through this that this research is able to illuminate and critically interrogate the way in which law informs and responds to death and dying with dementia. With this in mind, ethics approval was sought and received for a multi-method investigation.[151] Chapter 2 is dedicated to the exploration and explanation of the theory, methods and material applied in this multi-method approach. It begins with describing the methodological framework applied in the analysis of law from a bottom up perspective. This includes an explanation of legal consciousness and a brief overview of the approach taken in this research in the thematic narrative analysis of semi-structured interviews. Chapter 2 then moves to outline the nature of doctrinal analysis as applied in this research. This includes a description of the rules and conventions associated with an analysis of Swedish health law. Finally, the chapter explains and examines the use of a vulnerability perspective as the foundation for the critique and recreation of end-of-life law that is responsible for death and dying with dementia.

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[150] Audre Lorde, *Sister Outsider: Essays and Speeches* (revised, Crossing Press 2007) 38–39.

[151] Dnr 2022-01209-01.

2.2 Law in the Everyday

2.2.1 Introducing Legal Consciousness

The account of law in society as one dimension of an analysis of the relationship between law and death and dying with dementia is grounded in an investigation of the experience of law in the everyday. This analysis of law in the everyday is rooted in the legal consciousness tradition which conceptualises law as social action[152] comprised of everyday practices.[153] Law is therefore a material phenomenon socially constructed by individuals, social relationships[154] and ordinary acts.[155] In other words, law does not just regulate social relations, but is entrenched in the practice of social relations.[156] This follows the claim that "everyday transactions and interpersonal encounters are the very stuff of law."[157] Law in this perspective exists in relation to "what people do about the law"[158] and more specifically in the actions and understandings of individuals in "thinking and doing, telling stories, complaining, lumping grievances, [and] working."[159] Ewick and Silbey created the term legality in reference to the way that legal meanings are created in social contexts.[160] The process through which this legality is constructed is termed legal consciousness.[161] In other words, legal consciousness is the process by which social practice makes law.[162] Against this backdrop, this tradition encourages an examination of how everyday practices contribute to

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[152] Ewick and Silbey, *The Common Place of Law* (n 36) 35.

[153] ibid 43.

[154] Silbey (n 37) 327.

[155] Naomi Mezey, 'Out of the Ordinary: Law, Power, Culture, and the Commonplace' (2001) 26 Law & Social Inquiry 145, 146.

[156] Margaret Davies, *Law Unlimited: Materialism, Pluralism and Legal Theory* (Routledge 2017) 41.

[157] Harding, *Duties to Care* (n 4) 18.

[158] Halliday, Kitzinger and Kitzinger (n 136) 69.

[159] Silbey (n 37) 334.

[160] Ewick and Silbey, *The Common Place of Law* (n 36) 22.

[161] ibid 45.

[162] Mezey (n 155) 150.

law and its social meaning.[163] The study of law from this perspective should therefore focus on ordinary people and their everyday behaviour.[164] More than this, stories people tell about their everyday experience of law is where an investigation into the operation of law in society ought to commence.[165]

Importantly, while these manifestations of legality may be narrowly misinterpreted as belonging to the individual alone, legal consciousness is predicated on collectiveness rather than discrete individuals.[166] In this vein, Ewick and Silbey have framed legal consciousness as a "cultural practice."[167] Legal consciousness from this perspective is an amalgamation of both structural conditions and individual agency.[168] It not only constructs, but reflects, broader social structures. That is, legal consciousness is not solely the product of aggregate individual behaviour, as individual behaviour is itself influenced by the social world.[169] As described by Ewick and Silbey,

> "consciousness is understood to be part of a reciprocal process in which the meanings given by individuals to their world become patterned, stabilized, and objectified. These meanings, once institutionalized, become part of the material and discursive systems that limit and constrain future meaning making."[170]

As a result, whilst the world is contingent, it is not "easily undone" as it is bounded by historical and social patterns of behaviour and social organisation.[171] In taking this approach, this thesis reproduces Halliday et al.'s

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[163] Susan Silbey and Austin Sarat, 'Critical Traditions in Law and Society Research' (1987) 21 Law & Society Review 165, 170 & 173.

[164] Mezey (n 155) 146.

[165] Harding, *Regulating Sexuality* (n 37) 9.

[166] David Engel, 'How Does Law Matter in the Constitution of Legal Consciousness?' in Bryant G Garth and Austin Sarat (eds), *How Does Law Matter?* (Northeastern University Press 1998) 111.

[167] Dave Cowan, 'Legal Consciousness: Some Observations' (2004) 67 The Modern Law Review 928, 932.

[168] Simon Halliday and Bronwen Morgan, 'I Fought the Law and the Law Won? Legal Consciousness and the Critical Imagination' (2013) 66 Current Legal Problems 1, 4.

[169] Mezey (n 155) 151; Silbey (n 37) 334.

[170] Ewick and Silbey, *The Common Place of Law* (n 36) 39.

[171] Silbey (n 37) 329–330.

claim that, "although individuals have attitudes, attitudes are not individual. Orientations towards legality are social rather than individual."[172]

2.2.2 Legal Consciousness in the Everyday of End-of-Life Decision-Making with Dementia

This investigation of legal consciousness is framed by an interest in tracing "the social reality of law – law as it is implemented."[173] Halliday identifies that this approach has its origins in the scholarship of Pound who differentiated between law in books on the one hand and law in action on the other.[174] Within this context, the focus is on attempting to draw out the way in which law is constructed as a social practice, in tandem with a focus on the "effects and impact of law."[175] In this way, legal consciousness in this study will be used to explicate the invisible location and saturation of law in the everyday to indicate law's actual influence.[176] It therefore takes up the following mantle:

> "We need to stop trying quite so hard to come to terms with that ineffectiveness and to start studying what legal life is like in the vast interstices of law."[177]

This is possible because in de-centring law, research is able to investigate the various effects of law in society rather just whether or not law has had the intended effect.[178] Where law is understood from the perspective of the legal subject, alternative viewpoints on the role of law than that provided by an investigation of formal legality can be gathered.[179] More than this, a

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[172] Halliday, Kitzinger and Kitzinger (n 136) 69.

[173] Halliday (n 35) 870.

[174] Robert Pound, 'Law in Books and Law in Action' (1910) 44 American Law Review 12.

[175] Harding, *Regulating Sexuality* (n 37) 9.

[176] Silbey (n 37) 331.

[177] Silbey and Sarat (n 163) 173.

[178] Harding, *Regulating Sexuality* (n 37) 32; Silbey (n 37) 328; Austin Sarat and Thomas R Kearns, 'Law in Everyday Life' in Thomas R Kearns and Austin Sarat (eds), *Beyond the Great Divide: Forms of Legal Scholarship and Everyday Life* (University of Michigan Press 2009) 24.

[179] Silbey and Sarat (n 163) 173.

consideration of law in the everyday has been identified as necessary in understanding law itself.[180]

Hertogh cautions that the American tradition of legal consciousness has been unreasonably trained on the question of how official, or state law, is experienced.[181] More recently, Hertogh has argued that people are turning their backs on law. As such, he advocates that the focus on the hegemony of official law should be replaced by an examination of the absence of law in legal consciousness studies.[182] This research however heeds the warning that underestimating the influence of law in society is as risky as overstating it.[183] In doing so, it is influenced by Levine and Mellema's study which warned against overlooking other quasi-legal systems of control that might be present in the consciousness of individuals.[184] Being aware of both official and alternative normative systems ultimately deepens insight into the place law occupies in everyday life[185] and contributes to a better understanding of the role law has in society.[186] As McCann reflects, ignorance of other forms of control muddies the actual significance of law as it is only through the connections between law, law and the everyday, and other sources of control in the everyday, that law's contributions can be identified.[187]

This approach is particularly valuable in a legal analysis of end-of-life decision-making within the context of healthcare in light of established research on the breadth of medical regulation in relation to systems of control more or less readily identified as law. Black for instance engaged in legal pluralism in expanding the concept of legal control in medicine beyond the state to demonstrate that multiple legal orders influence and control physician

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[180] Harding, *Regulating Sexuality* (n 37) 9.

[181] Marc Hertogh, 'A "European" Conception of Legal Consciousness: Rediscovering Eugen Ehrlich' (2004) 31 Journal of Law and Society 457, 474.

[182] Marc Hertogh, *Nobody's Law. Legal Consciousness and Legal Alienation in Everyday Life* (Palgrave Macmillan 2018).

[183] Sarat and Kearns (n 178) 61.

[184] Kay Levine and Virginia Mellema, 'Strategizing the Street: How Law Matters in the Lives of Women in the Street-Level Drug Economy' (2001) 26 Law & Social Inquiry 169, 174.

[185] Harding, *Regulating Sexuality* (n 37) 32.

[186] ibid 29.

[187] Michael McCann, 'On Legal Rights Consciousness: A Challenging Analytical Tradition' in Benjamin Fleury-Steiner and Laura Beth Nielsen (eds), *The New Civil Rights Research: A Constitutive Approach* (Ashgate 2006) xix.

behaviour.[188] Furthermore, Heimer and Tolman have demonstrated that indigenous professional norms create de facto rights in the clinical setting regardless of formal legal rights.[189] Being open to the possibility of a professionally located system of control in end-of-life decision-making with dementia in Sweden is therefore important to develop a deeper understanding of the meaning and influence of law.

In taking on this consideration of alternative systems of control in end-of-life decision-making with dementia, I am inspired by Harding's use of legal pluralism in pursuit of questions about the significance of law in everyday practice.[190] Like Harding, I utilise a combination of Tamanaha's non-essentialist legal pluralism[191] and Kleinhans and Macdonald's critical legal pluralism[192] to underpin a "legal analysis that identifies much more than "official" law as "law.""[193] As a result, the account of law in the everyday in this thesis captures possibly diverse systems of control that might not be captured within the boundaries of the state or formal sources of law.[194] Relatedly, it also usefully facilitates an exploration of the way in which multi-situated regimes constantly interact and mutually influence respective "rules, processes and institutions."[195]

This pluralist approach to legal consciousness takes seriously the fact that legal subjects construct "their own normative standards to shape and symbolize social behaviour and their own institutions to reinforce or apply these

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[188] Lee Black, 'Ethics and Law, and Ethics as Law: Legal Pluralism and the Normative Relationship Between the State and the Medical Profession' (PhD, McGill University 2017) 80–81.

[189] Carol Heimer and Arielle W Tolman, 'Between the Constitution and the Clinic: Formal and de Facto Rights to Healthcare' (2021) 55 Law & Society Review 563.

[190] Harding, *Regulating Sexuality* (n 37) 25.

[191] Brian Z Tamanaha, 'A Non-Essentialist Version of Legal Pluralism' (2000) 27 Journal of Law and Society 296.

[192] Martha-Marie Kleinhans and Roderick A Macdonald, 'What is a Critical Legal Pluralism?' (1997) 12 Canadian Journal of Law and Society 25.

[193] Harding, *Regulating Sexuality* (n 37) 31.

[194] See for example Brian Z Tamanaha, 'The Folly of the "Social Scientific" Concept of Legal Pluralism' (1993) 20 Journal of Law and Society 192, 193.

[195] Roderick A Macdonald, 'Metaphors of Multiplicity: Civil Society, Regimes and Legal Pluralism Part I: General Themes' (1998) 15 Arizona Journal of International and Comparative Law 69, 77.

standards."[196] Thus, following Harding, if legal subjects treat something as related to law and/or regulation, the relevant systems of control will be considered part of a legal consciousness exploration.[197] In this way, where the participants convey attitudes, share practices or report any kind of influence related to law or any other form of guidance or regulation, it is taken to be relevant. An important question nevertheless remains; how ought these distinct systems of control be distinguished? This is key as, on the one hand, locating alternative regimes outside the realm of law risks the reproduction of a simplified narrative of legal hegemony in which medicine is presumed to retain its "non-legal character" which persists "as a residue or supplement to legality" at the same time that it is influenced by, and subjected to, the law.[198] Yet to call these regimes legal runs the risk of artificially subsuming or obscuring medicine under the banner of law. This too may undermine the potential to analyse complex relationships between legal and alternative regimes. This reflects Tamanaha's concern that where law cannot be distinguished from other normative regulation, nuance in regards to the different phenomena is lost.[199] In response to these possible pitfalls, *law* will be identified based on "whatever people identify and treat through their social practices as `law'"[200] as distinct from *quasi-law* that will be identified based on what is treated by legal subjects as distinctly alternative forms of regulation and/or norms. This study therefore seeks to pinpoint legal as well as quasi-legal consciousness.

2.2.3 Thematic Narrative Analysis of Semi-Structured Interviews[201]

Legal consciousness in this research exists in the way that doctors tell stories about law, utilise law and avoid law in the context of end-of-life decision-making with dementia. Furthermore, given the established commitment to quasi-legal regimes, quasi-legal consciousness exists in the way that doctors

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[196] ibid.

[197] Harding, *Regulating Sexuality* (n 37) 31.

[198] Ewick and Silbey, *The Common Place of Law* (n 36) 249.

[199] Tamanaha (n 191) 316.

[200] ibid 313.

[201] For a more in-depth account of the interview methodology see subsection 3.3. For a more detailed account of the strengths, challenges and limitations in order to support an evaluation of the quality of the empirical study, please turn to appendix 1.

think about and use other systems of control in engaging in end-of-life decision-making with dementia. Following the established legal consciousness tradition,[202] narratives understood in this research as the kinds of conversational talk shared in semi-structured interviews[203] are used to elicit this consciousness.[204] The choice of semi-structured interviews with doctors engaged in end-of-life decision-making with dementia, purposefully allows interview questions that are structured yet flexible so that they encompass the research questions as well as allowing for the participants to bring "new meanings" to the study.[205] The questions are trained on

- the nature of the everyday practice of end-of-life decision-making with dementia in the experience of physicians; and
- the experience law and other regulatory regimes in the everyday practice of end-of-life decision-making with people with dementia.

The logic followed here is that when asking questions about "what people do," we are simultaneously asking questions about the nature of law.[206]

Thematic analysis will be used as a tool to analyse these narratives to allow for the systematic identification, analysis and reporting of patterns or themes of legal and quasi-legal consciousness.[207] The analysis takes an intensive rather than extensive approach in which particularity or "authenticity of dailiness" is the focus rather than generality.[208] As such, while some empirical research is geared towards discovering reality, this approach does not seek to position the

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[202] Harding, *Regulating Sexuality* (n 37) 19.

[203] Jaber F Gubrium and James A Holstein, *Analyzing Narrative Reality* (SAGE 2009) xvii-xix describe narratives as talk 'to describe or explain matters of concern to participants.' See subsection 3.3.4 for more on narratives and their application in this study.

[204] Harding, *Regulating Sexuality* (n 37) 82.

[205] Anne Galletta, *Mastering the Semi-Structured Interview and Beyond: From Research Design to Analysis and Publication* (NYU Press 2013) 2 & 24.

[206] Halliday, Kitzinger and Kitzinger (n 136) 69.

[207] Victoria Clarke and Virginia Braun, 'Thematic Analysis' (2017) 12 The Journal of Positive Psychology 297, 297; Virginia Braun and Victoria Clarke, 'Using Thematic Analysis in Psychology' (2006) 3 Qualitative Research in Psychology 77, 79.

[208] Silbey and Sarat (n 163) 173.

findings about the many dimensions of law as universal or objective truths.[209] This approach is illustrated by the following quote:

> "I do not claim that interview accounts are a method of accessing some kind of empirical 'truth' or as a window to some higher 'reality', but rather I see the interview as a place where stories are solicited by the interviewer and told by the interviewee – a space where co-constructed accounts of the relationship between law and everyday life are produced."[210]

In other words, legal consciousness acts as a prism for interpreting individual experiences and narratives[211] with law in end-of-life decision-making with dementia. Thus, in line with critical empirical scholarship which resists "universal scientism,"[212] the intention is not to produce grand theories that account for a generalised experience of law, but rather to employ legal consciousness in the production of a snapshot of law as negotiated in the experiences of the interviewed physicians and drawn out in the interview process.[213]

Nevertheless, this qualitative research approach does draw out rich and contextualised knowledge which is known to be an appropriate method for the extrapolation of "higher-level concepts and theories."[214] The use of narratives is particularly relevant in this context given that individual stories are situated in a broader social context.[215] Indeed, they create a bridge between the daily and the greater institutional structures.[216] As such, the telling of stories is taken in this research not only to indicate the experience of the storyteller alone, but as a process that is reflective of society at large.[217] Taking all of this into

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[209] Silbey and Sarat (n 163), 170; Felicity Bell, 'Empirical Research in Law' (2016) 25 Griffith Law Review 262, 275–276.

[210] Harding, *Regulating Sexuality* (n 37) 111.

[211] ibid.

[212] Mezey (n 155) 164.

[213] Harding, *Regulating Sexuality* (n 37) 111.

[214] Denise F Polit and Cheryl Tatano Beck, 'Generalization in Quantitative and Qualitative Research: Myths and Strategies' (2010) 47 International Journal of Nursing Studies 1451, 1452.

[215] Harding, *Regulating Sexuality* (n 37) 81.

[216] Patricia Ewick and Susan Silbey, 'Narrating Social Structure: Stories of Resistance to Legal Authority' (2003) 108 American Journal of Sociology 1328, 1341.

[217] Harding, *Regulating Sexuality* (n 37) 82.

account, rather than utilising interviews to develop meta-narratives of law, interviews in this research will be used to explore rich, particularised and contextualised knowledge that may also serve as a basis to extrapolate insights into the influence of law and other quasi-legal regimes on end-of-life decision-making with dementia. Furthermore, in addition to the thematic analysis, interview data considered particularly meaningful or useful for the illustration of key issues in this research have been woven into the thesis.

2.3 Doctrinal Analysis

The above account of law does not exclude, but rather exists in relationship to, what can be known about formal law. This investigation of formal legality is guided by the principles of doctrinal analysis (in conjunction with a vulnerability analysis explored in subsection 2.4). Although doctrinal analysis carries with it the possibility for a degree of subjectivity, attention to accepted rules can produce an analysis that is readily identifiable as law.[218] This research adopts the position that doctrinal analysis is made up of sources of law.[219] To this end, various disparate sources of law in the field of end-of-life decision-making will be analysed and synthesised in order to extract general principles and understandings about the law.[220] As this investigation of law takes place in the space between patients and healthcare in Sweden, this subsection provides an account of the accepted sources and their hierarchical status in doctrinal analysis with reference to the rules of Swedish health law, and the Swedish legal order more generally.

The authoritative sources of law that have been applied in order of significance, include, constitutional law, legislative acts of parliament, preparatory works (*förarbetena*), case law and doctrine[221] as constituted by "professional legal

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[218] Moa Dahlin, 'Law on Psychiatry: Interests, Rights & Principles [Psykiatrirätt: Intressen, rättigheter & principer]' (PhD, Uppsala University 2014) 20.

[219] Christopher McCrudden, 'Legal Research and the Social Sciences' (2006) 122 Law Quarterly Review 632, 633–634.

[220] Council of Australian Law Deans, 'Council of Australian Law Deans Statement on the Nature of Legal Research' (2005), 3; McCrudden (n 65), 634.

[221] Ewa Axelsson, 'Patient Safety and Quality Assurance in Swedish Healthcare: A Medical Law Study [Patientsäkerhet och kvalitetssäkring i svensk hälso- och sjukvård: En medicinrättslig studie]' (PhD, Uppsala University 2011) 44; Wiweke Warnling Conradson, *What is Law [Vad är rätt]* (4th edn, Nordstedts Juridik 2023) 57.

writings."[222] The preparatory works to these relevant laws facilitate the interpretation of the legislation in that they contain detailed information about the nature and application of legal norms, general purpose and rationale relevant to the Act.[223] Preparatory works exist in a hierarchical relationship with each other and legislative acts.[224] Propositions occupy the highest status and generally contain information as to the motivations behind the law.[225] These propositions often closely mirror the lesser valued inquiry reports (*Statens offentliga utredningar*)[226] which may be used to provide insight into reasoning not captured in the propositions.[227] This dissertation also draws upon opinions of the Law Council (*Lagrådet*) which operates as a non-binding advisory body that is nevertheless taken seriously in legislative drafting.[228] Finally, although of weaker authority, preparatory works of legislation that have since been updated are used on occasion where useful to illustrate legal meaning.[229]

In addition, case law is applied with reference to the accepted rules that the decisions of the highest courts such as the High Court (*Högsta domstolen*), the Supreme Administrative Court (*Högsta förvaltningsdomstolen*) and

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[222] Aleksander Peczenik, 'A Theory of Legal Doctrine' (2001) 14 Ratio Juris 75, 75.

[223] Thomas Bull and Iain Cameron, 'Legislative Review for Human Rights Compatibility: A View from Sweden' in Murray Hunt, Hayley Hooper and Paul Yowell (eds), *Parliaments and Human Rights: Redressing the Democratic Deficit* (Hart Publishing 2015) 280.

[224] Warnling Conradson (n 221) 61.

[225] Aleksander Peczenik, *What is Law? On Democracy, Legal Certainty, Ethics and Legal Argumentation [Vad är rätt? Om demokrati, rättssäkerhet, etik och juridisk argumentation]* (Norstedts Juridik AB 1995) 241; Litins'ka, 'Assessing Capacity to Decide on Medical Treatment: On Human Rights and the Use of Medical Knowledge in the Laws of England, Russia and Sweden' (n 124) 438.

[226] Thomas Bull, 'Judges Without a Court—Judicial Preview in Sweden' in Tom Campbell, Keith Ewing and Adam Tomkins (eds), *The Legal Protection of Human Rights: Sceptical Essays* (Oxford University Press 2011) 393–394.

[227] Litins'ka, 'Assessing Capacity to Decide on Medical Treatment: On Human Rights and the Use of Medical Knowledge in the Laws of England, Russia and Sweden' (n 124) 439.

[228] Bull and Cameron (n 223) 283–284.

[229] Peczenik *What is Law? On Democracy, Legal Certainty, Ethics and Legal Argumentation [Vad är rätt? Om demokrati, rättssäkerhet, etik och juridisk argumentation]* (n 225) 252–253; Litins'ka, 'Assessing Capacity to Decide on Medical Treatment: On Human Rights and the Use of Medical Knowledge in the Laws of England, Russia and Sweden' (n 124) 439.

administrative courts of appeal are prejudicial[230] and subsequently a source of authority in legal argumentation.[231] It is relevant to note that such decisions are ultimately limited in the context of health law,[232] with opportunities for courts to hear cases on matters of healthcare somewhat restricted.[233] Decisions from lower courts and governmental agencies will therefore also be mobilised as case law.[234] In regards to the latter, decisions resulting from investigations by the Health and Social Care Inspectorate (*Inspektionen för vård och omsorg*, IVO) and the Healthcare Responsibility Advisory (*Hälso- och sjukvårdens ansvarsnämnd*, HSAN) are particularly relevant in light of their supervisory responsibilities in healthcare.[235]

Furthermore, where the legislative regimes provide abstract goals for healthcare,[236] the particularities of healthcare are further navigated and developed by the relevant bodies.[237] Guidelines and general advice developed by governmental agencies in the field of healthcare therefore fulfil an important complementary role in the doctrinal analysis.[238] Such agencies include the National Board of Health and Welfare (*Socialstyrelsen*, NBHW) who have issued a number of guiding documents pertaining to end-of-life

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[230] Peczenik *What is Law? On Democracy, Legal Certainty, Ethics and Legal Argumentation [Vad är rätt? Om demokrati, rättssäkerhet, etik och juridisk argumentation]* (n 225) 232.

[231] ibid 239.

[232] Axelsson (n 221) 44–45.

[233] Litins'ka, 'Assessing Capacity to Decide on Medical Treatment: On Human Rights and the Use of Medical Knowledge in the Laws of England, Russia and Sweden' (n 124) 440.

[234] Axelsson (n 221) 44–45.

[235] Patient Safety Act (2010:659) [Patientsäkerhetslagen] chaps 7 & 8.

[236] Litins'ka, 'Assessing Capacity to Decide on Medical Treatment: On Human Rights and the Use of Medical Knowledge in the Laws of England, Russia and Sweden' (n 124) 470; Axelsson (n 221) 93; Anna Enequist, 'From Abstract Goals to Concrete Rules: Regulating Nursing Home Care in Sweden and the Netherlands' (PhD, University of Groningen 2015) 21.

[237] Rynning, 'Consent to Medical Care and Treatment: A Legal Study [Samtycke till medicinsk vård och behandling: En rättsvetenskaplig studie]' (n 124) 115–116; Litins'ka, 'Assessing Capacity to Decide on Medical Treatment: On Human Rights and the Use of Medical Knowledge in the Laws of England, Russia and Sweden' (n 124) 470; Axelsson (n 221) 89.

[238] Elisabeth Rynning, 'The Law as Guiding Principles [Juridiken som rättesnöre]' in Sven-Olof Andersson and others (eds), *Professional Development in the Medical Profession [Professionell utveckling inom läkaryrket]* (Liber 2012) 278.

decision-making.[239] These include provisions (*föreskrifter*), decisions, general advice (*allmänna råd*), standards (*standarder*) recommendations (*rekommendationer*) and reports.[240] Amongst these, only the provisions are legally binding. Other documents containing instructions for medical practice are therefore more appropriately termed "soft law."[241]

Soft law sources such as these represent norms that are not legally binding.[242] Yet the role of soft law is not necessarily so distinct from that of the formal sources of law outlined above. This follows from Rynning's argument that as the NBHW usually provides advice grounded in "a well-founded interpretation" of the law and its demands for healthcare workers, "one should have good reasons for deviating from the authority's recommendation."[243] Thus, even without being legally binding, soft law sources can offer important guidance.[244] In addition to government agencies, soft law can be produced by actors without formal "norm-setting power." These include domestic interest organisations who may produce policy documents such as the Swedish Society of Medicine (*Svenska Läkaresällskapet*) on issues pertaining to end-of-life decision-making.[245] In addition, ethics[246] represent an important complementary source of law which holds particular relevance where authoritative sources of health law may be unclear or lacking.[247] They emerge as particularly relevant in practice, and are also evident in preparatory works, legislative frameworks and government guidelines.[248] Professional norms

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[239] Axelsson (n 221) 44.

[240] ibid.

[241] Litins'ka, 'Assessing Capacity to Decide on Medical Treatment: On Human Rights and the Use of Medical Knowledge in the Laws of England, Russia and Sweden' (n 124) 435; Dahlin (n 218) 17–18.

[242] Rynning, 'The Law as Guiding Principles [Juridiken som rättesnöre]' (n 238) 277.

[243] ibid.

[244] Thomas Bull and Fredrik Sterzel, *The Instrument of Government: A Commentary [Regeringsformen: En kommentar]* (5th edn, Studentlitteratur 2023) 190.

[245] Rynning, 'The Law as Guiding Principles [Juridiken som rättesnöre]' (n 238) 277; Lotta Wendel, 'Medical Ethics as a Source of Law [Medicinsk etik som rättskälla]' in Titti Mattsson, Thomas Erhag and Therese Bäckman (eds), *Book in Celebration of Lotta Vahlne Westerhäll [Festskrift till Lotta Vahlne Westerhäll]* (Santérus 2011) 473.

[246] Wendel (n 245).

[247] ibid 468–469.

[248] ibid 470.

outside the specific realm of ethics may also come into play. Of particular relevance is where the law grants “indirect legally binding status” to professional norms. For example, the concept of science and proven experience (*vetenskap och beprövad erfarenhet)* as explored more comprehensively in Chapter 4 and Chapter 5 is a central standard in health law that is in fact given meaning by “medical science and practice.”[249] These kinds of sources are particularly relevant because, as health law occupies the space between the fields of medicine and law,[250] it is interdisciplinary, intersecting with care science and medical ethics.[251]

Furthermore, whilst health law is primarily located in national legal frameworks, these frameworks are predicated on values of life and autonomy which are intimately connected with transnational interpretations drawn from traditions of philosophy and religion.[252] With this said, sources of international law will also be applied in this dissertation. In doing so, the treaty conformity principle (*fördragskonform tolkning*) will be followed. The European Convention on Human Rights (ECHR) which has been incorporated in its entirety into domestic legislation[253] will be included. As legislation contravening the ECHR will also be in conflict with the constitutional Instrument of Government (*Regeringsformen*, IoG),[254] legal sources will be read with the intent to harmonise Swedish law with its European obligations.[255] This dissertation will also make use of other public international law documents. First and foremost in this is the Convention on the Rights of People with Disabilities (CRPD) given the claim that dementia falls under the CRPD remit.[256] In doing so, it will also utilise the general comments issued by the

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[249] Rynning, ‘The Law as Guiding Principles [Juridiken som rättesnöre]’ (n 238) 278.

[250] Zillen, Mattsson and Slokenberga (n 31) 28.

[251] ibid 31.

[252] Timothy Stoltzfus Jost, ‘Comparative and International Health Law’ (2004) 14 Health Matrix 141, 143.

[253] Law on the European Convention on the Fundamental Protection of Human Rights and Fundamental Freedoms (1994:1219) [Lag om den europeiska konventionen angående skydd för de mänskliga rättigheterna och de grundläggande friheterna].

[254] Instrument of Government (1974:152) [Regeringsformen] 2 chap. 19 §.

[255] Maria Grahn-Farley, ‘Treaty-Compliant Interpretation of Human Rights Treaties [Fördragskonform tolkning av MR-traktat]’ [2018] Svensk Juristtidning 450, 453.

[256] Peter Mittler, ‘What Can We Learn from Disability Movement’ in Nicole Batsch, Mary Mittelman and Alzheimer’s Disease International (eds), *World Alzheimer Report 2012: Overcoming the Stigma of Dementia* (Alzheimer’s Disease International 2012) 68.

relevant treaty monitoring bodies, such as the Committee in the Rights of People with Disabilities, as authoritative guidance even if they do not constitute "binding, interpretations of treaties."[257] In relation to the CRPD, whilst ratified, it has not been incorporated into domestic law.[258] As a non-ratified treaty, there is no direction that the CRPD ought to be applicable in Swedish law.[259] Indeed, it has been suggested that with the exception of the ECHR, international law has had a limited impact on the practice of Swedish health law, including on questions related to the relationship between patients and healthcare.[260] Nevertheless, in accordance with the treaty conformity principle human rights law is utilised in order to illuminate the meaning of Swedish legal principles in so far as it does not contradict Swedish law.[261]

2.4 Vulnerability Critique

2.4.1 A Feminist Approach to Vulnerability

The research questions demand that an analysis of formal law must also extend beyond an investigation of the way sources of law apply to the way in which sources of law embody and convey particular norms[262] around health, dying,

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[257] Anna Bruce and others, 'Human Rights and Disability: The Current Use and Future Potential of United Nations Human Rights Instruments in the Context of Disability' (United Nations Press 2002) 47.

[258] Yana Litins'ka, 'Implementation of Article 12 of the UN Convention on the Rights of Persons with Disabilities in the Kingdom of Sweden' in Maciej Domanski and Boguslaw Lackoronski (eds), *Models of Implementation of Article 12 of the Convention on the Rights of Persons with Disabilities (CRPD)* (Routledge 2024) 510.

[259] Anna-Sara Lind, 'The Right to Health in Sweden' in Colleen Flood and Aeyal Gross (eds), *The Right to Health at the Public/Private Divide* (Cambridge University Press 2014) 76.

[260] Yana Litins'ka, 'International Law in Swedish Health Law [Folkrätten i svensk medicinsk Rätt]' in Anna-Sara Lind, Rebecca Thorburn Stern and Inger Österdahl (eds), *International Law in Swedish Law: A New Decade [Folkrätten i svensk rätt: Ett nytt decennium]* 287.

[261] Grahn-Farley (n 255) 453; Litins'ka, 'Assessing Capacity to Decide on Medical Treatment: On Human Rights and the Use of Medical Knowledge in the Laws of England, Russia and Sweden' (n 124) 436.

[262] This follows Fridström Montoya, 'Live like Others through Proxies - a Legal and Factual Paradox [Leva som andra genom ställföreträdare: En rättslig och faktisk paradox]' (n 38) who describes the way that she looks for the hidden ways that law conveys what is normal, required and desirable at 47-48.

decision-making and dementia. On this point, this research is aligned with scholarship that recognises the impact of law "beyond its application to a given case" to "its ability to powerfully encourage institutional and interpersonal relationships for choice and care."[263] In addition, implicit to this investigation is a normative interest in how the law can be improved on the issue of end-of-life decision-making with dementia. With this in mind, I apply a feminist informed understanding of vulnerability in a critical analysis of the above mentioned sources of law to facilitate evaluation, and ultimately, the recreation of the law.[264]

As an ambiguous term, vulnerability is subject to diverse interpretations.[265] Chief amongst these is the conceptualisation of vulnerability as individualised weakness that consequently requires specialised protection.[266] On this account, vulnerability comes to be applied in the stigmatisation[267] of particular groups who are considered to be at a higher risk of harm[268] or predisposition to poor health.[269] Framed as a personal failure,[270] vulnerability becomes a condition that should be eradicated, or at the very least, diminished.[271] This conceptualisation of vulnerability has made it difficult to respond to the vulnerabilities and dependencies of groups such as the elderly,[272] and relatedly, people with dementia. In contrast to the individual pathologisation of people

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[263] Jonathan Herring, *Caring and the Law* (Bloomsbury Publishing 2013) 85.

[264] Mattsson and Giertz (n 41) 143.

[265] Fineman, 'The Significance of Understanding Vulnerability' (n 39) 1372.

[266] ibid.

[267] Martha Fineman, 'The Vulnerable Subject: Anchoring Equality in the Human Condition' in Martha Fineman (ed), *Transcending the Boundaries of Law: Generations of Feminism and Legal Theory* (Routledge 2011) 166.

[268] Jonathan Herring, 'Ageing and Universal Beneficial Vulnerability' in Daniel Bedford and Jonathan Herring (eds), *Embracing Vulnerability: The Challenges and Implications for Law* (Routledge 2020) 64; Mary Neal, 'The Idea of Vulnerability in Healthcare Law and Ethics: From the Margins to the Mainstream?' in Daniel Bedford and Jonathan Herring (eds), *Embracing Vulnerability: The Challenges and Implications for Law* (Routledge 2020) 94.

[269] Wendy Rogers, Catriona Mackenzie and Susan Dodds, 'Why Bioethics Needs a Concept of Vulnerability' (2012) 5 International Journal of Feminist Approaches to Bioethics 11, 17.

[270] Herring, 'Ageing and Universal Beneficial Vulnerability' (n 268) 64.

[271] Neal (n 268) 99.

[272] Martha Fineman, 'Elderly as Vulnerable: Rethinking the Nature of Individual and Societal Responsibility' (2012) 20 Elder Law Journal 71, 89.

who are “more” vulnerable, the vulnerability perspective crafted in this thesis is located in a particularly feminist conceptualisation of vulnerability.[273] Whilst not exclusively representative of any single account of vulnerability, it is broadly influenced by a range of key feminist thinkers in this space. These include, Martha Fineman and Judith Butler, feminist bioethicists such as Catriona Mackenzie, Susan Dodds and Wendy Rogers and feminist care ethicists such as Eva Feder Kittay. This feminist iteration approaches vulnerability as a transformative ontology.

This approach starts with the body as an ontological reality[274] to address “questions of justice, responsibility, and care”[275] and ultimately promote “individual and collective wellbeing”[276] for death and dying with dementia. Accepting the inevitability of law in pursuit of an institutional and interpersonal framework that actualises wellbeing,[277] a feminist informed approach to vulnerability allows us to consider what it means for law to be informed by vulnerability as the basic condition of being human.[278] In particular, vulnerability is valuable as a comprehensive scaffold that allows for law to be both evaluated and created.[279] That is, it represents framework for a critique of the state[280] and the development of a counter-discourse[281] that affords the foundation for a more effective state response to vulnerability,[282] and by extension, death and dying with dementia. This subsection now turns

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[273] Catriona Mackenzie, Wendy Rogers and Susan Dodds, ‘Introduction: What is Vulnerability, and Why Does it Matter for Moral Theory?’ in Catriona Mackenzie, Wendy Rogers and Susan Dodds (eds), *Vulnerability: New Essays in Ethics and Feminist Philosophy* (Oxford University Press 2014) 17–18; Vanessa E Munro and Jane Scoular, ‘Abusing Vulnerability? Contemporary Law and Policy Responses to Sex Work in the UK’ (2012) 20 Feminist Legal Studies 189, 190.

[274] Fineman, ‘Introduction: Understanding Vulnerability’ (n 40) 3.

[275] Martha Fineman, ‘Vulnerability in Law and Bioethics’ (2019) 30 Journal of Health Care for the Poor and Underserved 52, 60.

[276] Fineman, ‘Introduction: Understanding Vulnerability’ (n 40) 8.

[277] Fineman, ‘The Significance of Understanding Vulnerability’ (n 39) 1373.

[278] Fineman, ‘Introduction: Understanding Vulnerability’ (n 40) 3.

[279] Mattsson and Giertz (n 41) 143.

[280] Martha Fineman, ‘Vulnerability and Inevitable Inequality’ (2017) 4 Oslo Law Review 133, 148.

[281] ibid 149.

[282] Fineman, ‘The Vulnerable Subject: Anchoring Equality in the Human Condition’ (n 267) 161.

to map the different dimensions of a feminist informed approach to vulnerability and its application to law with attention to its relevance on the issues of death and dying with dementia.

2.4.2 Features of Ontological Vulnerability

A feminist informed account imagines corporeal vulnerability as a function of openness that is integral to the human condition. In doing so, it begins with the stance that corporeality is the essential factor of human existence.[283] The body is therefore positioned as the starting point for any and all reasoning about the human condition.[284] The logic of vulnerability then posits that it is this corporeal materiality of being human that is the source of human vulnerability.[285] Vulnerability is thereby the basic condition of humanity.[286] This is captured by Butler's account of vulnerability as inherent to the emergence of life[287] in connection with the fact that birth is inherently precarious.[288] In accordance with this account, vulnerability precedes the origin of the self to the extent that human existence is impossible without vulnerability.[289] It is therefore a constant, and ever-present reality, as a consequence of our embodiment.[290]

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[283] Fineman, 'Introduction: Understanding Vulnerability' (n 40) 3.

[284] Fineman, 'The Significance of Understanding Vulnerability' (n 39) 1376.

[285] Martha Fineman, 'The Vulnerable Subject and the Responsive State' (2010) 60 Emory Law Journal 251, 267; Catriona Mackenzie, 'The Importance of Relational Autonomy and Capabilities for an Ethics of Vulnerability' in Catriona Mackenzie, Wendy Rogers and Susan Dodds (eds), *Vulnerability: New Essays in Ethics and Feminist Philosophy* (Oxford University Press 2014) 37; Susan Dodds, 'Dependence, Care, and Vulnerability' in Catriona Mackenzie, Wendy Rogers and Susan Dodds (eds), *Vulnerability: New Essays in Ethics and Feminist Philosophy* (OUP 2014) 182; Jonathan Herring, *Vulnerable Adults and the Law* (Oxford University Press 2016) 11; Fineman, 'The Vulnerable Subject: Anchoring Equality in the Human Condition' (n 267) 166.

[286] Judith Butler, *Precarious Life: The Powers of Mourning and Violence* (Verso 2004) 31.

[287] ibid 310.

[288] Judith Butler, *Frames of War: When Is Life Grievable?* (Verso 2009) 14.

[289] Butler, *Precarious Life* (n 286) 31.

[290] Martha Fineman, 'Equality, Autonomy, and the Vulnerable Subject in Law and Politics' in Martha Fineman and Anna Grear (eds), *Vulnerability: Reflections on a New Ethical Foundation for Law and Politics* (Ashgate 2013) 20.

The quality that vests in this unshakable, human condition is a general openness.[291] This openness is not singularly negative but neutral.[292] Where representative of the potential for harm, it is purported that we are universally exposed to the possibility of fluctuations in wellbeing,[293] and ultimately, suffering.[294] The idea that vulnerability engenders a persistent possibility of harm is clearly represented in Fineman's claim that,

> "the idea of the vulnerable subject is anchored in the fact that we all are born, live, and die within a fragile materiality that renders all of us constantly susceptible to destructive external forces and internal disintegration."[295]

Thus, unpredictable outside forces such as disease as well as internal processes outside of human control,[296] such as developmental changes in one's physicality and capacity, are central to vulnerability.[297] In the context of this work, vulnerability indicates that disability is a shared way of being[298] which means that dementia is not exceptional but central to the human condition. Furthermore, taken to its limits, vulnerability usefully captures the fact that the body implies mortality.[299] In other words, vulnerability captures the inevitability of death and dying as the central condition of the human experience. Taken together, this demonstrates the way in which vulnerability can account for and respond to dying with dementia as an essential rather than special or abnormal event.

Yet in addition to being a source of harm, vulnerability is simultaneously a generative[300] and enabling condition.[301] It invests the human experience with

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[291] Judith Butler, *Notes Toward a Performative Theory of Assembly* (Harvard University Press 2015) 149.

[292] Fineman, 'Vulnerability and Inevitable Inequality' (n 280) 142.

[293] ibid.

[294] Rogers, Mackenzie and Dodds (n 269) 19.

[295] Fineman, 'Elderly as Vulnerable' (n 272) 89.

[296] Fineman, 'The Vulnerable Subject and the Responsive State' (n 285) 267.

[297] Fineman, 'Introduction: Understanding Vulnerability' (n 40) 3–4.

[298] Satz (n 149) 233.

[299] Butler, *Undoing Gender* (n 149) 21.

[300] Fineman, 'Elderly as Vulnerable' (n 272) 96.

[301] Erinn Gilson, 'Vulnerability, Ignorance, and Oppression' (2011) 26 Hypatia 308, 310.

the ability to "gain intellectual and emotional skills and experiences,"[302] grow, be creative and feel fulfilled as entities with "physical and emotional needs for love, respect, challenge, amusement and desire."[303] It also drives us to build relationships and institutions.[304] In this way, vulnerability is the source of relationships and structures of care that ensure our needs are fulfilled and provide opportunities for flourishing, including at the end of life.

This description of openness demonstrates that, for better or worse, as vulnerable beings, we are always in the hands of other people.[305] As Butler explains,

> "the body has its invariably public dimensions; constituted as a social phenomenon in the public sphere, my body is and is not mine. Given over from the start to the world of others, bearing their imprint, formed within the crucible of social life."[306]

Thus, in being vulnerably embodied, the human condition is also simultaneously, inevitably embedded[307] in complex relationships of dependency on others, and institutions, from birth until death.[308] In this embeddedness, institutions interpersonal relationships, social structures and organising principles can both cause harm whilst simultaneously offering essential supports such as healthcare.[309]

Importantly, whilst this vulnerability perspective starts with a concept of universality, it also embraces vulnerability as a condition experienced in distinct and asymmetrical ways amongst inherently vulnerable people.[310] The

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[302] Fineman, 'Introduction: Understanding Vulnerability' (n 40) 4.

[303] Fineman, 'Elderly as Vulnerable' (n 272) 96.

[304] ibid.

[305] Butler, *Precarious Life* (n 286) 14.

[306] Butler, *Undoing Gender* (n 149) 21.

[307] Fineman, 'Introduction: Understanding Vulnerability' (n 40) 4.

[308] Fineman, 'Vulnerability and Inevitable Inequality' (n 280) 146; Fineman, 'Introduction: Understanding Vulnerability' (n 40) 4.

[309] De Sabbata (n 25) 77; Fineman, 'The Significance of Understanding Vulnerability' (n 39) 1379.

[310] Munro and Scoular (n 273) 196; Fineman, 'The Vulnerable Subject and the Responsive State' (n 285) 268; Gilson (n 301) 310; Rosie Harding, 'Response: Reflections on Ageing and the Binaries of Vulnerability' in Daniel Bedford and Jonathan Herring (eds), *Embracing Vulnerability: The Challenges and Implications for Law* (Routledge 2020) 82;

claim that vulnerability is a universal condition is therefore not equivalent to a claim that there cannot be difference in kind.[311] Differences in our vulnerability arise due to the fact that we are both embedded and embodied.[312] However, in keeping with the fundamental focus on the body as the core of this vulnerability perspective, I follow Fineman in emphasising the fact that it is the embodied, vertical differences (biological and development distinctions in age, health, physicality and cognitive ability[313]) integral to a body in flux over time which are the most fruitful.[314] In this way, particularised social dependencies are taken to follow from the ontological body's unique susceptibility to generative and degenerative change across the lifespan;[315] that is death and dying in the face of cognitive illness.

2.4.3 Vulnerability & Law: Enshrining Collective Responsibility to Resilience in Death and Dying with Dementia

2.4.3.1 A demand for collective attention to vulnerability

Ultimately, the material reality of bodies as inherently open and subsequently universally situated in relation to that outside the self ultimately demands collective attention.[316] Vulnerability is therefore constitutive of a reliance on

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Fineman, 'Equality, Autonomy, and the Vulnerable Subject in Law and Politics' (n 290) 21; Fineman, 'Vulnerability and Inevitable Inequality' (n 280) 146.

[311] Martha Fineman, 'Reasoning from the Body: Universal Vulnerability and Social Justice' in Chris Dietz, Mitchell Travis and Michael Thomson (eds), *A Jurisprudence of the Body* (Springer International Publishing 2020) 22.

[312] Fineman, 'Vulnerability and Inevitable Inequality' (n 280) 143.

[313] Fineman, 'Reasoning from the Body' (n 311) 24; Fineman, 'Equality, Autonomy, and the Vulnerable Subject in Law and Politics' (n 290) 21; Martha Fineman, 'Equality and Difference - The Restrained State' (2015) 66 Alabama Law Review 609, 613 & 619.

[314] Fineman, 'Vulnerability in Law and Bioethics' (n 275) 56; Fineman, 'Vulnerability and Inevitable Inequality' (n 280) 144.

[315] Fineman, 'The Vulnerable Subject and the Responsive State' (n 285) 268; Fineman, 'Vulnerability in Law and Bioethics' (n 275) 57; Fineman, 'Vulnerability and Inevitable Inequality' (n 280) 134; Fineman, 'The Significance of Understanding Vulnerability' (n 39) 1378; Fineman, 'Equality and Difference - The Restrained State' (n 313) 622; Fineman, 'Reasoning from the Body' (n 311) 24.

[316] Fineman, 'The Significance of Understanding Vulnerability' (n 39) 1372; Fineman, 'Vulnerability and Inevitable Inequality' (n 280) 142; Fineman, 'The Vulnerable Subject: Anchoring Equality in the Human Condition' (n 267) 168; Daniel Engster, 'Care Ethics, Dependency, and Vulnerability' (2019) 13 Ethics and Social Welfare 100, 101.

the other as a need “which any society must attend.”[317] The conceptual power of vulnerability in this regard[318] lies within the fact that the ontological and constant possibility of harm cannot be made invisible.[319] I extend this claim in line with vulnerability as a neutral condition of openness to the fact that vulnerability theory offers a conceptual framework that cannot disregard ontological openness to the conditions of general flourishing. At the core of this is the idea that when we become aware of “our shared vulnerability,” we understand the need to create institutions that respond to this fundamental way of being.[320]

It is the nature of vulnerability itself which determines the necessary response to vulnerability.[321] The key point here is that as an essential quality to human life, vulnerability cannot be eradicated.[322] However, our vulnerable embeddedness means that institutional and interpersonal resources and practices can in fact bolster one’s ability to manage irradicable harmful vulnerabilities.[323] A vulnerability analysis therefore typifies the importance of navigating what can, and must, be done in order to secure opportunities for “resilience necessary to not only survive but thrive in the face of our vulnerability and the inevitability of change.”[324] This is manifest through the institutional provision of resources and practices that augment one’s ability to handle vulnerability and its consequences in the face of misfortune and

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[317] Butler, *Precarious Life* (n 286) 31–32.

[318] Fineman, ‘Equality, Autonomy, and the Vulnerable Subject in Law and Politics’ (n 290) 19.

[319] Fineman, ‘The Vulnerable Subject: Anchoring Equality in the Human Condition’ (n 267) 168; Fineman, ‘Equality, Autonomy, and the Vulnerable Subject in Law and Politics’ (n 290) 19.

[320] Fineman, ‘The Vulnerable Subject: Anchoring Equality in the Human Condition’ (n 267) 169.

[321] Fineman, ‘Vulnerability and Inevitable Inequality’ (n 280) 134.

[322] Fineman, ‘Reasoning from the Body’ (n 311) 21; Fineman, ‘The Vulnerable Subject: Anchoring Equality in the Human Condition’ (n 267) 166.

[323] Fineman, ‘Equality, Autonomy, and the Vulnerable Subject in Law and Politics’ (n 290) 19; Fineman, ‘The Vulnerable Subject and the Responsive State’ (n 285) 269; Rogers, Mackenzie and Dodds (n 269) 32; Titti Mattsson and Sofia Enell, ‘State Provision of Resilience in Social Compulsory Care: A Vulnerability Analysis of Physical Constraint of Children and Youth Without Consent’ (2023) 36 International Journal for the Semiotics of Law 1529, 1531.

[324] Fineman, ‘Introduction: Understanding Vulnerability’ (n 40) 4.

harm.[325] Furthermore, a vulnerability perspective is a reminder of the importance of being attentive to the distinctive manifestations of vulnerability across the lifespan.[326] That is, it obliges accountability to not just respond to the universality of vulnerability, but the differences in the way this shared vulnerability manifests. With this said, some basic premises can be derived in relation to death and dying with dementia.

2.4.3.2 Resilience in death & dying with dementia

From this central assertion that vulnerability is indicative of collective support for resilience that is attentive to differences and diversities in embodied vulnerability across the lifespan, a claim can be made for *resilience building in the face of death and decline with dementia*. That resilience should not only be afforded in relation to thriving in life with dementia but also in relation to thriving in death and dying with dementia is related to a number of overlapping claims. Firstly, representative of embodied, degenerative changes, death and dying with cognitive illness represent dependencies that must be responded to with interpersonal and institutional relationships of care. Secondly, as death and dying with dementia is an expression of vulnerability that therefore cannot be jettisoned, a vulnerability approach should not seek to eliminate death at all costs but rather embrace collective responsibility to creating opportunities for resilience, and quality of life, amongst those who are dying. Whilst this claim does not seek to perpetuate a simplistic abandonment of curative care where this is both possible and desirable, it does seek to challenge systems of care that uncritically mobilises resilience in the struggle against death. This would, in fact, be representative of an inability to grasp embodied developments across the lifespan and a subsequent failure to identify relevant generative interpersonal and institutional relationships.

Thirdly, having established the importance of responding with institutional and interpersonal resources for resilience in the face of death, a vulnerability analysis then encourages attention to the distinct experiences of death and dying. On the one hand, this requires attention to the way in which achieving quality of life at the end of life requires distinctive mechanisms and resources for resilience than that afforded in pursuit of the possibility of health. Indeed, where resources in healthcare are trained on a general idea of equality across

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[325] Fineman, ‘Equality, Autonomy, and the Vulnerable Subject in Law and Politics’ (n 290) 19; Fineman, ‘The Vulnerable Subject and the Responsive State’ (n 285) 269; Rogers, Mackenzie and Dodds (n 269) 32; Mattsson and Enell (n 323) 1531.

[326] Mattsson and Enell (n 323) 1531–1532.

healthcare, there can be a dangerous failure to account for age, decline and the distinctive challenges of the dying process.[327] On the other hand, this position also usefully accounts for diversity at the end of life amongst people who die. The ability to capture and be reflexive of diversity at the end of life is particularly important for people with dementia who in addition to facing shared challenges related to their cognitive illness, are also an extremely heterogeneous group.[328] Whilst a claim has therefore been made for the importance of attending to diverse end-of-life needs rather than avoiding or uncritically seeking the elimination of death, more work is needed to understand the dimensions of resilience once this premise is accepted.

Following in the footsteps of feminist thinkers, vulnerability is indicative of the necessity of "social practices … that can *promote our well-being and capacities for agency*."[329] In regards to the latter a feminist approach to vulnerability holds that autonomy should not be abandoned, but its individualistic credentials reframed so that relationality is recognised as central in decision-making.[330] Relational autonomy is an umbrella term that captures the interrelationship between an individual's social context, their identity and their ability to engage in self-determination [331] In this way, it draws attention to the fact that decision-makers are "emotional, embodied, desiring, creative and feeling,"[332] and understands that it is only "in a relational context" that the capability for self-determination emerges.[333] However, whilst recourse to relational bodily autonomy ought not to be overlooked,[334] the demands of physical vulnerability and dependence must also be taken into account.[335] This is brought to a head in the way that the question of death reveals the tension

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[327] Lloyd (n 143) 251.

[328] Mattsson and Giertz (n 41) 143–144.

[329] Rogers, Mackenzie and Dodds (n 269) 32.

[330] Fineman, 'The Vulnerable Subject and the Responsive State' (n 285) 260.

[331] Catriona Mackenzie and Natalie Stoljar, 'Introduction: Autonomy Refigured' in Catriona Mackenzie and Natalie Stoljar (eds), *Relational Autonomy: Feminist Perspectives on Autonomy, Agency and the Social Self* (Oxford University Press 2000) 4.

[332] ibid 21.

[333] Selma Sevenhuijsen, *Citizenship and the Ethics of Care: Feminist Considerations on Justice, Morality and Politics* (Routledge 1998) 184.

[334] Rogers, Mackenzie and Dodds (n 269) 25; Butler, *Undoing Gender* (n 149) 21.

[335] Butler, *Undoing Gender* (n 149) 22.

between archetype of choice and the bodily and social limits of dying.[336] Thus, a feminist account of vulnerability is mobilised here to advocate for social practices that capture the importance of structures and relationships of care at the end of life whilst not capitulating respect for agency.[337] Recognising "a general responsibility to care"[338] in death and dying with dementia, a vulnerability perspective therefore ultimately represents a call for collective responsibility to provide for resilience in death and dying with dementia that meets bodily needs and promotes relational autonomy rather than stigmatising paternalism. The role of law from a vulnerability perspective in grounding this collective responsibility will now be considered.

2.4.3.3 Situating the role of law

A vulnerability perspective concedes that law is the primary domain through which the state can ensure collective responsibility for resilience[339] in death and dying with dementia. Vulnerability therefore offers a heuristic device[340] to reconstruct law in pursuit of a responsive state[341] that is attentive to the needs of vulnerable persons[342] for care that meets physical and agentic needs at the end of life with dementia. The necessary assumptions embedded in this claim of law's power in undergirding responsibility to end-of-life wellbeing for people with dementia relates to the relationship between law, individuals and the state in pursuit of collective responsibility. They are as follows. Firstly, the state should be understood as a complex entity informed by the interlocking influence of multilevel organisations located across multiple sectors such as governments, transnational bodies, supranational bodies, private bodies, non-

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[336] Lloyd (n 143) 244.

[337] Bruce Jennings, 'Solidarity Near the End of Life: The Promise of Relational Decision-Making in the Care of the Dying' in John Davis (ed), *Ethics at the End of Life* (Routledge 2016) was inspirational in this regard in his use of solidarity to advocate for a relational approach to end of life care based on a medical decision-making model that meets physical needs and avoids "bluntly rejecting … ideals of personal autonomy and respect for [dying] persons" as he describes at 220.

[338] Engster, 'Care Ethics, Dependency, and Vulnerability' (n 316) 109.

[339] Fineman, 'Introduction: Understanding Vulnerability' (n 40) 5–6; Fineman, 'The Significance of Understanding Vulnerability' (n 39) 1373.

[340] Fineman, 'The Vulnerable Subject and the Responsive State' (n 285) 266; Fineman, 'The Vulnerable Subject: Anchoring Equality in the Human Condition' (n 267) 166.

[341] Fineman, 'Vulnerability and Inevitable Inequality' (n 280) 148.

[342] Martha Fineman, 'Vulnerability, Equality and the Human Condition' in Jackie Jones and others (eds), *Gender, Sexualities and Law* (Routledge 2011) 53.

governmental agencies and local authorities.[343] The state has the obligations and means to foster institutional abilities to offer support and manage harm in the face of vulnerability. It does this by "reflecting and shaping public norms and values through law and policy."[344] Thus, where institutions are upheld by the authority of the state,[345] (state) law is the tool through which institutional responsiveness can be constructed[346] and "the means for individual and societal well-being" subsequently provided.[347] In this way, vulnerability provides a lens through which to usefully reconsider the association between individuals, the state and the institutions as constructed in law.[348] In this context, vulnerability therefore amounts to a tool through which the relationship between people with dementia, the institution of healthcare and the state as constructed in law can be analysed in pursuit of collective responsibility for end-of-life resilience and wellbeing.

Whilst vulnerability therefore embraces the role of the state and legal governance as an inevitable influence on our everyday lives that is more appropriate than other alternatives like the market, it does not assume an inherent fairness to the operations of the state.[349] In fact, the failure of the state, law and institutions as vulnerable themselves is an essential point of vulnerability[350] which subsequently calls for systems of monitoring and evaluation.[351] "Corruptions and disruptions," for instance, can result from processes internal or external to the institutions.[352] This is of significant concern given that institutional vulnerability may not only fail to provide

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[343] De Sabbata (n 25) 86–87.

[344] Fineman, 'Equality, Autonomy, and the Vulnerable Subject in Law and Politics' (n 290) 26.

[345] Fineman, 'Vulnerability, Equality and the Human Condition' (n 342) 169.

[346] Fineman, 'The Vulnerable Subject and the Responsive State' (n 285) 255; Martha Fineman, 'Vulnerability and Social Justice' (2018) 53 Valparaiso University Law Review 341, 368.

[347] Fineman, 'Vulnerability and Social Justice' (n 346) 366–367.

[348] ibid 366.

[349] Fineman, 'Introduction: Understanding Vulnerability' (n 40) 6.

[350] Fineman, 'The Vulnerable Subject and the Responsive State' (n 285) 256; Fineman, 'The Vulnerable Subject: Anchoring Equality in the Human Condition' (n 267) 169.

[351] Fineman, 'The Vulnerable Subject and the Responsive State' (n 285) 273; Fineman, 'Equality, Autonomy, and the Vulnerable Subject in Law and Politics' (n 290) 19.

[352] Fineman, 'The Vulnerable Subject and the Responsive State' (n 285) 256 & 273; Fineman, 'The Vulnerable Subject: Anchoring Equality in the Human Condition' (n 267) 169.

resilience, but in fact, exacerbate the vulnerability of individuals.[353] In this space, the concept of pathogenic vulnerability has been coined to indicate that dysfunction within interpersonal relationships and "social and legal institutions" may in fact cause vulnerability.[354] With this in mind, the possibility for the law causing or perpetuating harm rather than resilience at the end of life for people with dementia will be of key importance in the analysis of this book.

2.4.4 Pitfalls & Potentials of Vulnerability in Dying with Dementia

Having set the foundations for a vulnerability analysis in law, it is important to consider the potentials and pitfalls of this theoretical perspective in relation to death and dying with dementia. In many ways, it is a strong match. Firstly, embodied realities are made central under this perspective. As ageing, declining health and dying are situated as the ultimate and certain outcome of our embodiment,[355] vulnerability provides a unique lens through which biological processes such as ageing, cognitive illness, and dying, must be centred as normal to the human condition. Where dying and cognitive illness are presently othered in a system which prioritises individualism and good health to the exclusion of frailty,[356] centring the body in this way challenges the social and cultural power of tropes that stigmatise dementia and position death and dying as the ultimate harm that should therefore always be uncritically struggled against. The inclusion of bodies and their ontological vulnerability in understanding responsibility been identified as particularly useful in the way in which it

> "bring[s] the body back into social approaches to disability, and frame[s] a more refined and inclusive approach which … allows a more inclusive, embodied, interactive social model to develop."[357]

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[353] Fineman, 'The Vulnerable Subject and the Responsive State' (n 285) 273; Fineman, 'The Vulnerable Subject: Anchoring Equality in the Human Condition' (n 267) 169.

[354] Dodds, 'Dependence, Care, and Vulnerability' (n 285) 197; Mackenzie, Rogers and Dodds (n 273) 9.

[355] Fineman, 'The Vulnerable Subject and the Responsive State' (n 285) 267.

[356] See subsection 1.2.

[357] Clough, 'Disability and Vulnerability' (n 147) 476.

Indeed, it is important that the value brought by the ability to account for the body does not come at the expense of attending to the significance of embeddedness on the issue of death and dying with dementia. In fact, the potential of vulnerability lies within the way it connects embodied and embedded vulnerability in an effort to challenge current approaches and forge new forms of redress to death and dying with dementia. As vulnerability embraces institutions and interpersonal relationships as an inevitable backdrop to the human condition, the importance of relationships and structural support in relation to the bodily reality of death and dying with dementia is therefore captured. The ability to embrace embeddedness is vital given concerns within dementia scholarship that vulnerability proceeds as if the individual can be dislocated from their interpersonal relationships in opposition to the realities of interpersonal support and carer vulnerability.[358]

Additionally, this feminist informed account means that vulnerability is usefully understood as constitutive of human life rather than characteristic of any one group.[359] Whilst support is therefore common to the human experience, the need for support that is specific to one's circumstances and needs is recognised. This provides the opportunity for a targeted response to needs for support of people with dementia that is not driven by stigmatisation.[360] It also captures the diversity and variability characteristic of the experience of dementia.[361]

Nevertheless, although this work intends to align with scholars like Fineman who seek to carve out a progressive approach to vulnerability theory away from its traditional stigmatising bent,[362] "norms of recognition" operate to give conceptual meaning to vulnerability.[363] Against this backdrop, it has been suggested that efforts to rehabilitate vulnerability risk a reliance on stereotypical and discriminatory understandings of certain groups which can result in solutions marked by paternalistic intervention rather that solutions that are attentive to the particular needs and contextual harms of marginalised

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[358] Harding, *Duties to Care* (n 4) 21.

[359] Mattsson and Giertz (n 41) 142.

[360] De Sabbata (n 25) 78.

[361] Mattsson and Giertz (n 41) 142; De Sabbata (n 25) 78.

[362] Fineman, 'Vulnerability and Inevitable Inequality' (n 280) 142.

[363] Munro and Scoular (n 273) 201.

groups.[364] In this vein, particular criticism has been directed at the utility of vulnerability in dementia with reference to "difficult conceptual hurdles."[365] Harding has expressed concern for the potential consequences "of foregrounding objective assessments of risk, at the expense of the vulnerable person's subjective experience."[366] Further, she reports that "challenging behaviour[s]" of people with dementia are often met with detrimental efforts at containment and control.[367]

Still, this thesis is supported by scholarship that recognises the validity of such concerns whilst also indicating that such misuse is not inevitable.[368] From this perspective, the final, but by no means the least, valuable contribution of a vulnerability approach is its potential as a transformative power in legal thinking. This perspective is highlighted by Clough, who, working in the space of disability and healthcare, platforms the possibilities of this transformative potential. Indicating that there is "unwarranted and unnecessary preoccupation" with definitional issues surrounding who is vulnerable, she advocates for the focus of scholarly attention on the transformative potential of the call for structural change.[369] Clough recognises that vulnerability is especially valuable in health law where its insertion can operate as a generative mechanism that stretches beyond semantics in substantially altering conceptual understandings and structures.[370] This optimism for the transformative potential of vulnerability in dementia follows Donnelly who advocates for vulnerability's potential in overcoming legal obstacles to agency in dementia[371] and De Sabbata whose doctoral research applied vulnerability in

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[364] ibid 203; Harding, *Duties to Care* (n 4) 21; Rogers, Mackenzie and Dodds (n 269) 16.

[365] Harding, *Duties to Care* (n 4) 20.

[366] ibid.

[367] ibid.

[368] Clough, 'Disability and Vulnerability' (n 147) 475; Herring, *Vulnerable Adults and the Law* (n 285) 35.

[369] Beverley Clough, 'Response: Challenging the Frames of Healthcare Law' in Daniel Bedford and Jonathan Herring (eds), *Embracing Vulnerability: The Challenges and Implications for Law* (Routledge 2020) 116–117.

[370] ibid 117 & 121.

[371] Donnelly, 'A Legal Overview' (n 142) 279.

tandem with the social model of disability in investigating how the right to choose medical treatment can be strengthened for people with dementia.[372]

With this in mind, whilst vulnerability should not necessarily be abandoned, appropriate recognition of these concerns also demands critical attention to the way it is being mobilised. Indeed, the success of vulnerability in this thesis depends upon the extent that the risk of paternalism in the circumstances of dementia can be sufficiently managed in favour of mobilising the transformative potential of the responsive state. This has been executed in this work by eschewing the use of vulnerability "as a loose normative category" in favour of a critical application of a feminist approach to vulnerability that is attentive to its enduring contestability.[373] Furthermore, it heeds Leckey's warning that "if relational theorists stow away their normative commitments, the consequence is that they can find themselves stranded with no tools to contest obviously bad situations."[374] To avoid the possibility that these efforts be misdirected in an inconsistent, stigmatising approach to end-of-life decision-making with dementia, I am also explicit with the normative commitments in this analysis[375] to the goals of social justice, equality, wellbeing and a good death which is defined in this research as a process that is attendant to bodily and social vulnerability in pursuit of improved end-of-life outcomes.[376] I am further committed to the way in which collective responsibility for these goals can be brought into fruition via the law's implementation of just institutional and interpersonal relationships.[377]

2.5 Conclusion

Chapter 2 has set out the theory, method and materials that guide this research. It has explained and justified a multi-method approach that captures different angles in an investigation of the relationship between law and end-of-life

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[372] De Sabbata (n 25).

[373] Munro and Scoular (n 273) 201 & 203.

[374] Robert Leckey, *Contextual Subjects: Family, State and Relational Theory* (University of Toronto Press 2008) 20.

[375] ibid; Harding, *Duties to Care* (n 4) 26.

[376] See subsection 6.3.2 for an elaboration of this concept.

[377] Fineman, 'Vulnerability and Social Justice' (n 346) 342.

decision-making with dementia. It began by describing legal consciousness and its use in a semi-structured interview study of the way in which law and other quasi-legal systems of control as experienced by physicians in the everyday of end-of-life decision-making with people with dementia. It then moved to explain the methodological framework behind the investigation of formal legality. It indicated that doctrinal analysis will be applied according to the rules of Swedish health law. However, with recognition as to the limits of knowledge as to the application of law in an investigation of the relationship between law and society, it also described the use of a vulnerability critique. In particular, it explored the possibilities and pitfalls of a feminist informed vulnerability approach in indicating how vulnerability can be used in evaluating and creating law that is sensitive to collective responsibility to death and dying with dementia. Overall, it has set the scene for the upcoming elucidation and evaluation of the relationship between law and the social phenomenon of death and dying with dementia.

3 Law in the Everyday of Death & Dying with Dementia

> To insist upon the prolongation of life, as nothing more than the coursing of blood and bodily functions, and to do so in circumstances of intractable and irremediable pain, is so offensive to the very purpose of human life that it calls out for relief. The law hesitates on the brink of this decision only because of its fear of the misuse of the power to terminate life. – Michael Kirby[378]

3.1 Introduction

In Chapter 3, the research begins in earnest by investigating physician experience of law in the everyday. This is framed by the following research question:

How is law experienced in the everyday of end-of-life decision-making with dementia from the perspective of physicians?

In this pursuit, the chapter examines the results of a legal consciousness informed, thematic narrative analysis of interviews with physicians on the practice and regulation of end-of-life decision-making with dementia. Four unique legal and quasi-legal medical consciousness schemas were developed in the analysis of the interview data: law as an undercurrent; law as an iron fist; law as a tool; and medicine as a lodestar. These schemas represent a co-constructed snapshot of the issue of law in end-of-life decision-making as it exists in society and allow for reflection as to the role of law in death and dying with dementia.

The analysis demonstrates that as a silent undercurrent in medical practice, law at times bursts forth as it demands compliance and is instrumentalised as a

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[378] Michael Kirby, 'Bioethics: Can Democracy Cope' (1990) 16 Commonwealth Law Bulletin 313, 315.

sometimes-useful tool in healthcare. In this, the role of law as a purveyor of abstract principles relating to protecting life and autonomy within the limits of medicine is made apparent. At the same time, as physicians resist the law where it is understood to lack utility, the limits of law in the realities of end-of-life decision-making with dementia are brought to the fore. In this void, and indeed, with law's acquiescence, physicians turn towards medicine at the coalface of end-of-life decision-making with dementia. Medicine as quasi-law as informed by medical ethics, medical norms and standards of professional practice in which the patient's end-of-life reality rather than an imagined healthy legal subject stands in focus provides particularised guidance. Thus, whilst law matters in the experience of these participants, its influence is related to the protection of life, promotion of individualism and medicalisation of death. As such, its influence in promoting collective responsibility for end-of-life decision-making with dementia is arguably incomplete, if not limited.

This chapter begins with an exploration of relevant, existing schemas of legal consciousness as a foundation for the findings of this research. It then moves to re-establish and elaborate upon the methodological features of this interview study. This is followed by a report of the research findings. This includes general findings related to a commitment to good end-of-life care for patients with dementia and a bottom up conceptualisation of law. It then explores the four schemas extrapolated from the interview data. Chapter 3 then elaborates these findings in order to identify the relationship of the extrapolated schemas to legal consciousness scholarship and their meaning for this investigation on the role of law in end-of-life decision-making with dementia.

3.2 Existing Legal Consciousness Schemas

3.2.1 The Original Legal Consciousness Schemas

This section will canvas the existing legal consciousness schemas that will be drawn upon and developed in relation to the data collected and analysed on the specific question of law in the everyday of end-of-life decision-making. Such an effort cannot begin without attention to Ewick and Silbey's original three schemas: before; with; and against the law. The before the law schema conceives law as a sphere distinct from everyday life.[379] Law is a bounded

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[379] Ewick and Silbey, *The Common Place of Law* (n 36) 47.

regime, housed in formal places of law (i.e. courts) and occupied by formal legal agents (i.e. lawyers).[380] It reflects a reverence for law as an objective, impartial and rational system of rules that are known.[381] In this manner, law is framed as extraordinary and authoritative.[382] People reach out to law to resolve problems that are socially salient, or in other words, problems that have importance for others in addition to the individual[383] in line with a conception of law "as ensuring collective fairness, equality and justice."[384] Hull argues that in addition to appealing to law as a vehicle of fairness and justice, her interviewees attribute power to the ability of law to provide marginalised subjects with legal equality and the status of "socially normal."[385] As revealed in this reflection, before the law stories often emphasise legal power. Judicial power is exemplified in the way that power is transferred from the individual to the law when the law is approached to solve problems.[386] On the one hand, a perceived powerlessness in the face of law may result in expressions of frustration.[387] Indeed, Harding argues that perceived powerless is intensified where law is granted the status of "knowing" how problems can be correctly resolved.[388] On the other hand, narratives in this schema embody a sense of "loyalty and acceptance" toward legal power.[389]

An alternative narrative to that of law as a set of divine principles which people exist before, is law "as an ensemble of legal actors, organizations, rules, and procedures with which they manage their daily lives."[390] This with the law schema does not link law to ideas of justice but rather the concept of a tactical

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[380] Picton-Howell (n 135) 302–303.

[381] Ewick and Silbey, *The Common Place of Law* (n 36) 47.

[382] Levine and Mellema (n 184) 177.

[383] Ewick and Silbey, *The Common Place of Law* (n 36) 47.

[384] Halliday, Kitzinger and Kitzinger (n 136) 70.

[385] Kathleen E Hull, 'The Cultural Power of Law and the Cultural Enactment of Legality: The Case of Same-Sex Marriage' (2003) 28 Law & Social Inquiry 629, 655.

[386] Rosie Harding, 'Dogs Are "Registered", People Shouldn't Be: Legal Consciousness and Lesbian and Gay Rights' (2006) 15 Social & Legal Studies 511, 513.

[387] Ewick and Silbey, *The Common Place of Law* (n 36) 47.

[388] Harding, 'Dogs Are "Registered", People Shouldn't Be' (n 386) 513.

[389] Ewick and Silbey, *The Common Place of Law* (n 36) 47.

[390] ibid 131.

tool in pursuit of individual interest.[391] In this way, it is when formal law offers the opportunity to achieve specific objectives that it is accepted.[392] This schema embodies an understanding of "law as a game." That is, law can be "played" (or not played[393]) to gain advantage.[394] As part of this, legality comes to embody ideas of "engagement and conflict, resource and process"[395] in the midst of law's authority to decide matters.[396] Lawyers remain important legal agents as the mouthpiece and/or translators of the rules of law under the with the law schema.[397] However, they are no longer primary as non-lawyers can take up positions as active agents who can recreate and challenge law.[398] For example, as identified by Hull, with the law schemas can involve the appropriation of legal practice and terminology to define one's activities.[399] From this standpoint, the boundaries between law and society are not distinct. Rather, where law can be utilised in pursuit of self-interest, the boundaries blur.[400] As noted by Levine and Mellema, in this schema people move seamlessly into and out of the language and mechanisms of law without disruption to their lives.[401]

In opposition to this, the against the law schema contains a sense of "being caught within the law or being up against the law."[402] Law appears in this context as an entity that expresses "brute power,"[403] and is considered "untrustworthy,"[404] dangerous" and something that should be evaded.[405] While

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[391] Halliday, Kitzinger and Kitzinger (n 136) 72.

[392] Ewick and Silbey, *The Common Place of Law* (n 36) 48.

[393] ibid 132.

[394] ibid 48; Harding, *Regulating Sexuality* (n 37) 20.

[395] Ewick and Silbey, *The Common Place of Law* (n 36) 131.

[396] ibid.

[397] ibid 153; Picton-Howell (n 135) 305.

[398] Ewick and Silbey, *The Common Place of Law* (n 36) 164; Picton-Howell (n 135) 305.

[399] Hull (n 385) 631–632.

[400] Ewick and Silbey, *The Common Place of Law* (n 36) 48.

[401] Levine and Mellema (n 184) 177.

[402] Ewick and Silbey, *The Common Place of Law* (n 36) 48.

[403] Halliday, Kitzinger and Kitzinger (n 136) 70.

[404] Picton-Howell (n 135) 305.

[405] Ewick and Silbey, *The Common Place of Law* (n 36) 192.

there are similarities in terms of bureaucracy, formality and remoteness with before the law, the against the law schema perceives law as incapable of meaningfully responding to the everyday issues.[406] Resistance is understandably a key theme within this schema. People may resist the law as manifest through behaviours such as “foot dragging, omissions, ploys, small deceits, humor and making scenes”[407] and even gossip.[408] Harding argues that this schema represents a notion of power beyond the boundaries of the judiciary to the way that individuals can use and subvert power.[409]

3.2.2 Legal Consciousness Developments in Healthcare

Considered by Ewick and Silbey to represent the full “range of conventional experiences of the law,”[410] legal consciousness scholarship has been furthered by efforts to situate legality in the specific realm of healthcare. Engaging with Ewick and Silbey’s original schemas, Picton-Howell identified an additional schema in her study of physicians making difficult decisions regarding children with disabilities. The law as kudos schema embodies the perception of legal expertise as prestige. This emerged from narratives that gave way to a sense that a doctor who has expert knowledge in law is afforded kudos amongst colleagues, patients and families. Picton-Howell notes that this additional schema is likely to exist amongst elites who can access legal education and knowledge in addition to the power and respect they have in their own field to further enhances their professional status.[411]

Halliday et al.’s study on the legal consciousness of patient relatives grappling with end-of-life questions transforms Ewick and Silbey’s schemas into law as a sword, shield and barrier. Law as a sword refers to the way that people can “turn to law” in an effort to challenge relations of power, influence medical decisions, combat “unfairness and injustice in the medical system”[412] and be

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[406] ibid 198.

[407] ibid 48–49.

[408] Ewick and Silbey, ‘Narrating Social Structure’ (n 216) 1336.

[409] Harding, *Regulating Sexuality* (n 37) 21.

[410] Ewick and Silbey, *The Common Place of Law* (n 36) 248.

[411] Picton-Howell (n 135) 363–364.

[412] Halliday, Kitzinger and Kitzinger (n 136) 64.

weaponised in private struggle.[413] Law as a shield involves the use of law for self-protection by individuals, or by society to protect vulnerable groups from "reckless" decisions in the withdrawal of artificial nutrition and hydration.[414] Developing the counter-hegemonic credentials of legal consciousness[415] in healthcare, Halliday et al. also produced the law as a barrier schema where law does not embody a higher value system, it is not legitimate and therefore "can be ignored and subverted."[416]

In the context of Swedish healthcare, Greenbrook extends legal consciousness to the experience of physicians in the care of undocumented migrants. In this work, the legal disavowal schema[417] sees law collectively rejected, circumvented and reconstructed in favour of medicine.[418] Part of this schema is "the medical compass" which introduces the concept of medical consciousness as an expression of medicine's social reproduction in the midst of various professional and personal influences.[419] Greenbrook's research also identified that legal disavowal was ultimately secondary to the consciousnesses of medicolegal anomie, and relatedly medicolegal alienation,[420] in which "perceived 'illegality'" associated with the care of undocumented migrants was experienced as "discombobulating, unworkable, and ultimately, suffocating."[421]

Embedded in these existing schemas,[422] Chapter 3 provides an account of consciousness as it emerges in relation to the specific issue of end-of-life law and quasi-law amongst Swedish physicians via the construction of four new

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[413] ibid.

[414] ibid 66.

[415] For example, Harding, *Regulating Sexuality* (n 37) develops schemas of resistance to demonstrate how resistance is a concept of power; Halliday and Morgan (n 168) propose a fourth schema of collective dissent to demonstrate how groups can collectively mobilise against law where it is considered illegitimate, and gamed where considered a tactical tool; Hertogh, *Nobody's Law* (n 182) establishes four schemas of legal alienation to illustrate a spectrum of patterned isolation from law.

[416] Halliday, Kitzinger and Kitzinger (n 136) 68.

[417] Greenbrook (n 137) chapter 5.

[418] ibid 160.

[419] ibid 154.

[420] ibid chapter 6.

[421] ibid 164.

[422] Halliday, Kitzinger and Kitzinger (n 136) 70.

schemas. The following subsection provides a careful elaboration of the nature of the method through which these consciousness schemas were ascertained. This follows Patton's advice that a pragmatic approach to methodology in which methodological decisions are guided by the research aims ought to be accompanied by a report on "what was done, and what the implications are for findings."[423] Whilst the upcoming section is attentive to methodological limitations where applicable, the reader is encouraged to turn to appendix 1 following the reporting of the findings for a more thorough account of the strengths, challenges and limitations of this study. This allows for further elaboration as to the consequences of the methodological choices for the results and facilitates an evaluation of the findings. Appendix 1 will include a detailed consideration of issues of quality (informed by consideration as to transparency, reflexivity, transferability and triangulation), bias, physicians as interview participants, the insider/outsider dichotomy and digital interviews.

3.3 Methodological Considerations in the Legal Consciousness Analysis

3.3.1 Participants

The participants are the first methodological issue to be canvassed. The participants were drawn from the target group of physicians. This target group was identified in relation to their knowledge, experience and formal role in the phenomena being investigated as well as ethical considerations. The possibility of including people with dementia was contemplated. Such consideration was taken to be particularly important in line with the growing recognition as to the way in which protectionist concerns cause research limiting exclusions of so-called vulnerable groups such as people with dementia and the subsequent advocacy of a new approach to research ethics.[424] Indeed, the exclusion of dying persons has been referred to as a blanket approach to gatekeeping which has more recently been questioned on the grounds that it denies the possibility for people to benefit from participation as a therapeutic process, and hinders

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[423] Michael Patton, *Qualitative Research and Evaluation Methods.* (3rd edn, SAGE 2002) 72.

[424] Nola M Ries and Michael Thomson, 'Bioethics and Universal Vulnerability: Exploring the Ethics and Practices of Research Participation' (2020) 28 Medical Law Review 293.

research that could improve end-of-life care.[425] However, the possibility of including people with mild cognitive illness was ultimately set aside with consideration as to my lack of experience and skill in safely navigating the complexities of informed consent with this group as well as the potentially distressing themes being discussed.

The inclusion of carers, be they formal or informal, was then deliberated on. Given that this is a difficult topic which can prove to be emotionally challenging, it was decided that formal healthcare workers rather than family members were more ethically appropriate candidates with consideration as to the relationship between interview participation and harm. In taking this decision, it was not assumed that formal healthcare workers engaged in this space were necessarily immune to the emotional difficulties of end-of-life decision-making. However, it was reasoned that this would be somewhat offset by the fact that the participants would be asked to discuss their daily, routine work practices in which death and dying are regular rather than abnormal. Their experience of death and dying would also not be related to their loved ones which was also thought to lessen the negative emotional impact of their participation. Although no such concerns eventuated, attention was nevertheless maintained as to expressions of discomfort or upset throughout the interviews.

Within this group of healthcare professionals, nurses were considered given the documented significance of nurses in nursing care in end-of-life care for people with dementia in the Swedish context.[426] Ultimately, however, guidelines from the NBHW ascribes physicians the role of primary decision-maker on issues of withdrawing treatment and providing palliative care.[427] This legal role for physicians was the decisive reason in favour of the selection of physicians who have experience with end-of-life decision-making for people with dementia as the target group. In order to enhance the ability for the

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[425] Erna Haraldsdottir, Anna Lloyd and Jan Dewing, ‘Relational Ethics in Palliative Care Research: Including a Person-Centred Approach’ (2019) 13 Palliative Care and Social Practice 2632352419885384, 632352419885387.

[426] See subsection 1.4.2.4 for an exploration of the organisation of care for people with dementia, including end-of-life care.

[427] Life-sustaining treatment [Livsuppehållande behandling] SOSFS 2011:7 2 chap. 3 § indicates a licenced physician must be appointed as a fixed care contact in the case of life threatening circumstances, 3 chap. 4 § & 4 chap. 5 § indicates that in lieu of a fixed care contact, another licenced physician must participate in the patient's care where life-sustaining treatment is not in line with science and proven experience or where a patient does not want life-sustaining treatment.

research participants to make a meaningful contribution, the criteria for inclusion was further limited to those physicians whose field is more closely related to this kind of decision-making to strengthen the significance of their stories. As such, the participants were narrowed to those in geriatrics, general practice and palliative care. They were additionally narrowed to those who had experience with end-of-life decision-making with dementia for at least two years in order to facilitate knowledge and familiarity with the topic.

The participants were selected through purposeful sampling in that they were chosen due to their useful knowledge and/or experience.[428] This guided the initial approach to sampling in which contact was made with workplaces that corresponded with the above mentioned specialities in Southern Sweden. This sampling strategy was paired with convenience sampling which involved the selection of individuals who match the target population based on their particular accessibility.[429] This was executed by taking advantage of existing networks to identify willing/possible participants within the limits of the target group identified above. Participants were also necessarily limited to those who were willing, available, and, provided informed consent.

Eleven participants were interviewed. They were located in three different healthcare settings. The interviews comprised of one group and seven one-on-one interviews. The group interview was with an existing group of physicians who worked in the same workplace environment. One interview was a follow up with one of the group participants. This sample size was guided by qualitative research practices. The number of interviews in interview studies is usually around "15 ± 10."[430] This is in turn underpinned by the fact that qualitative research generally draws on a relatively small sample in pursuit of producing deep understandings.[431] Ultimately, the ground rule is to "interview as many subjects as necessary to find out what to you need to know."[432] Whilst

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[428] Lawrence A Palinkas and others, 'Purposeful Sampling for Qualitative Data Collection and Analysis in Mixed Method Implementation Research' (2015) 42 Administration and Policy in Mental Health and Mental Health Services Research 533, 534.

[429] Ilker Etikan, 'Comparison of Convenience Sampling and Purposive Sampling' (2016) 5 American Journal of Theoretical and Applied Statistics 1, 2.

[430] Steinar Kvale and Svend Brinkman, *Interviews: Learning the Craft of Qualitative Research Interviewing* (3rd edn, SAGE 2015) 140.

[431] Steve Campbell and others, 'Purposive Sampling: Complex or Simple? Research Case Examples' (2020) 25 Journal of Research in Nursing 652, 653.

[432] Kvale and Brinkman (n 430) 140.

this concept of "saturation" lacks specific guidance in qualitative realm,[433] this initiative follows Morse's idea that "saturated data are rich, full and complete. The resulting theory makes sense and does not have gap."[434] This sample size was identified as having met this requirement in the way that the data resulted in consistent analytical discoveries that afforded a comprehensive theoretical framework. In particular, the analysed data provided a logical description of the phenomenon by capturing a complete image of the different elements of end-of-life decision-making and a coherent depiction of the cooperation of regulatory regimes. This was confirmed with reference to scholarship and legal analysis.

The participants were recruited via a multi-step process. For the one-on-one interviews, participants were initially approached with information in the form of an expression of interest letter via email which contained information as to the nature of the project, participation and voluntariness. Upon a positive response, the potential participant was given a participant information form which contained further information about participation including the handling of data. They were additionally provided with a draft copy of the interview schedule and were encouraged to get in contact in case of questions.[435] Where the person was still interested, a time and place to meet was established. The key distinction in this procedure for the group interview was that the interview was necessarily organised with the person in charge of the workplace. Once the interview was confirmed with this person, all participants were distributed the participant information and a draft of the interview schedule.

3.3.2 Interview Schedule

A draft interview schedule that guided the interview process was created and refined throughout the interview process. It contained questions that were designed to encourage discussions around:

- Experiences with end-of-life decision-making for people with dementia; and

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[433] Janice M Morse, 'The Significance of Saturation' (1995) 5 Qualitative Health Research 147, 147.

[434] ibid 149.

[435] See appendix 2 for the expression of interest, participant information, a draft of the interview schedule and the written consent form.

- Experiences, understandings and attitudes to what regulates end-of-life decision-making for people with dementia, including law and other systems of control.

The schedule was developed with reference to the project's research questions, theoretical considerations and relevant subject knowledge. To this end, the questions were formulated in the context of examining law and quasi-law from the perspective of physicians in their everyday experience of end-of-life decision-making with dementia. The questions were subsequently refined by the theoretical strictures of legal consciousness. One particularly important element of theory is the fact that legal consciousness studies generally avoid questions directly related to law[436] as it is from these general discussions rather than specific questioning that ideas of law and legality emerge.[437] Thus, on the whole, the interview schedule attempted to elicit discussions, at least initially, about general activities and regulations in regards to end-of-life decision-making for people with dementia. This was considered particularly valuable as it conceivably allows for plural systems of control to emerge from the perspective of the individual so that the place of law in the everyday may be more accurately ascertained.[438]

Additionally, the questions went through a member checking process. The interview schedule was provided to two members of the target population for review. The process focused on whether the questions were understandable and answerable from the perspective of the target population. One particularly important contribution of this process was the revelation that there was a possibility that a lack of concern or knowledge about law may result in uncertainty, possible resistance and less comprehensive responses where only general questions about regulation were posited.

Considering this in relation to the legal consciousness learnings, it was concluded that whilst much of the interview schedule should be directed to eliciting discussions about activities and regulation some tweaks were necessary. For example, discussion of regulation was prompted with reference to different regulatory regimes: ethics, norms and law. Furthermore, questions that specifically addressed the role of law were included at the end of the interview schedule. This ultimately allowed what might be described as the best of both worlds; the opportunity to primarily allow for legality and quasi-

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[436] Halliday, Kitzinger and Kitzinger (n 136) 61.

[437] ibid 60–61.

[438] Harding, *Regulating Sexuality* (n 37) 25.

legality to emerge from the research participants whilst also avoiding excluding opportunities to examine the everyday place of formal legal structures at the outset. Despite these decisions, it is of course also relevant to note that other factors influenced the kind of legality drawn from the data. For instance, it is accepted that the data gathered through interview is ultimately subjected to the interpretative bias of the researcher.[439] I was therefore also a co-constructer in the emergence of legality. Furthermore, the fact that the participants were aware that I was a lawyer, conducting legal research. In this way, it is understandable that there would be a natural disposition towards discussions of law which was manifest in considerations of legal and quasi-legal legality even prior to direction questioning as to the possible role of law.

Such considerations aside, the interview schedule continued to evolve over the process of conducting interviews in line with the fact that some questions created problems with understandability or did not evoke the intended answers. In addition, opportunities arose during the interview process to pursue alternative questions as new ideas emerged.

3.3.3 Interview Procedure

Informed consent underpinned all interviews and was indicated by the signing a consent form. Participants were informed that they were able to withdraw consent at any stage. Immediately prior to the interviews, participants were again asked if they had questions and were provided with a brief summary about the nature of the research project and the purpose of the interview. This process was refined and strengthened over time as it became apparent that certain elements of the research project and my status as a PhD researcher in law were of more interest and relevance to the participants. The interviews were recorded and lasted between 15 and 45 minutes with the shortest being performed with the follow up interview. Although these may be considered relatively short, their length was not indicative of the lack of fruitful and meaningful conversation as born out in the data and the analysis. It may be result of the relatively routine nature of the subject matter for the participants who engage in these questions and issues in their daily work-life. Furthermore, it is in line with similar research in a Swedish healthcare context.[440] The

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[439] ibid.

[440] See for instance Ingela Beck and others, 'Having to Focus on Doing Rather than Being—Nurse Assistants' Experience of Palliative Care in Municipal Residential Care Settings'

interviews were undertaken at the participant's place of work, the participant's home and over Zoom following agreement. During the transcription process, the data was pseudonymised and participants were ascribed letters i.e. Participant A. The interviews were both undertaken and transcribed verbatim in Swedish.

3.3.4 Thematic Narrative Analysis Through a Legal Consciousness Lens

The analysis of the transcripts was underpinned by the methodological identification of legal and quasi-legal consciousness. Informed by a pluralist account of legal consciousness, the jumping off point was that where legal subjects consider something to be concerned with law and/or regulation, it must be relevant to a legal consciousness study.[441] Following an interest in separating law from quasi-law in the realm of healthcare, I applied the following rule to discern between the two; "whatever people identify and treat through their social practices as 'law'"[442] versus whatever people treated as distinctively alternative forms of regulation and/or norms as "quasi-law."

These two kinds of legal consciousness as they relate to these two distinct forms of legal and quasi-legal control were identified through thematic narrative analysis. This follows from the central role narrative analysis has in legal consciousness research.[443] In this research, narratives are taken to be the kinds of conversational talk shared in the format of a semi-structured interview that describes and explains the practice of end-of-life decision-making and what regulates it. This approach follows Gubrium and Holster's definition of narratives as:

> "spates of talk that are taken to describe or explain matters of concern to participants. This vocabulary implicates descriptive, interactional

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(2012) 49 International Journal of Nursing Studies 455, 25 which held 4 group and 2 individual interviews that had a similar range in length of 23-52 minutes.

[441] Harding, *Regulating Sexuality* (n 37) 31.

[442] Tamanaha (n 191) 313.

[443] Harding, *Regulating Sexuality* (n 37) 82.

> communication of one sort or another, but the length, structure, and content of what is said are notably variable."[444]

Importantly, as narratives depict the outside world as experienced by the narrative teller, the participants are understood to be implicated in its construction.[445]

The narratives were subject to thematic analysis. Thematic analysis is not a fixed method of analysis as despite its widespread use, clear agreement on its nature and procedures is absent.[446] It is nevertheless recognised to be a useful tool in the systematic identification, reporting and analysis of patterns contained in qualitative data[447] from individual and group interviews.[448] Usefully, it is recognised by its key proponents Clarke and Braun to be a method that can be used to reflect the reality of experiences and be mobilised to go beneath the surface in unpacking the socially constituted nature of how meaning is made of such experiences.[449] The procedure begins with the generation of codes. These represent "the smallest units of analysis" which depict notable characteristics in the data. These codes go on to form "building blocks" for the extrapolation of themes which represent "(larger) patterns of meaning." These themes in turn act as the foundations for the report on the key features of data in relation to the research questions.[450]

The data was thematically analysed in relation to research sub-question 1. To this end, the data was analysed to identify codes characteristic of attitudes and behaviours towards law and quasi-law. Themes of legal and medical consciousness were then extrapolated. The analysis was deductive in that it was driven by the theoretical and analytical interest that underlies this book, yet simultaneously inductive as the exact nature of the codes and themes were found within the data set itself.[451] The exact procedure was as followed:

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[444] Gubrium and Holstein (n 203) xviii–xix.

[445] Ewick and Silbey, 'Narrating Social Structure' (n 216) 1341.

[446] Braun and Clarke (n 207) 79.

[447] Clarke and Braun (n 207) 297; Braun and Clarke (n 207) 79.

[448] Clarke and Braun (n 207) 298.

[449] Braun and Clarke (n 207) 81.

[450] Clarke and Braun (n 207) 297.

[451] ibid 298.

Step 1 – The data was coded.

The coding framework was made up of characteristics associated with assumptions, attitudes and uses of law and other regulatory regimes as expressed in the narratives.

The characteristics contained in the codes were both deductive and inductive in that they were driven by the research question, the existing scholarship of legal consciousness as well as the data set itself. More specifically, theory guided the investigation of assumptions, attitudes and uses of law as codes, whilst the exact quality of these codes was inductively informed by the data.

Step 2 – The codes were inductively organised into thematic schemas of legality.

To execute this analysis, each transcript was scoured for codes and overall meaning through multiple readings. There was therefore a possibility to capture specific expressions as well as locate them within the general meanings conveyed in the broader narrative. A reflexive approach to the interview and analytical procedures was undertaken. For instance, whilst the data was initially scoured for characteristics advanced in existing legal consciousness scholarship (e.g. 'gaming/playing law' as linked to the with the law schema), I ultimately discovered that this process did not allow for the attitudes and uses of law and quasi-law shared in this data to be accurately or fully captured. Thus, although the extrapolated codes (e.g. 'law displaced' and 'medicine as transcendent') are not exclusive in that they overlap with existing scholarly accounts of attitudes and uses of law, they were driven by my analysis of the data itself. This in turn allowed for the construction of consciousness schemas unique to this data which also had the benefit of avoiding bloating the existing schemas. Furthermore, the analytical process was subject to an external checking process in two ways. There was an opportunity to present ongoing findings as part of doctoral education processes and conference participation to receive feedback on the themes. The codes were also member checked.

It ought to be noted that "subconsciousness - the unformed, unexpressed and unintended thought processes that feed into our conscious expression of attitudes or ideas" has been recognised to pose a concern with coding legal consciousness.[452] This follows from the postulation that, if something is said

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[452] Harding, *Regulating Sexuality* (n 37) 27.

or performed unconsciously, one cannot know the cultural meaning being employed. As Harding notes, one would need to engage in mind reading to overcome the limitations of understanding complex subjectivities.[453] Moments where law is not mentioned as a system of control even when it could be mentioned, or indeed, even when the regulatory meanings applied coincide with the law, were therefore not coded.

In reporting these findings, quotes that were particularly illustrative or powerful were selected and translated to English in order to provide a data trail. In this, the data was cleaned to enhance meaning. The consequence of this was that phrases such as “umm,” and “like” or word repetition, where participants were searching for words, were only included where it was considered to necessary to maintain or provide meaning.

3.4 Findings

3.4.1 General Findings

3.4.1.1 A collective commitment to care

The central and overriding sentiment in the data was a collective commitment to provide compassionate care for people with dementia:

> As a doctor, you of course also have a responsibility to be humane, to be humane and empathetic. – Participant I

As part of this, the participants were committed to the provision of care that was respectful of, and attentive to, the diverse capabilities and expressions of people with dementia. In this way, there was strong indication in the data that the participants were committed to ensuring that each, individual patient with dementia at the end of life is given care that is not stigmatising, but rather, is respectful of possibilities for inclusion. Perhaps even greater, however, was the overwhelming sentiment that they were responsible for ensuring the needs of the patient were met in a way that minimised suffering and maximised opportunities for quality of life. In this way, the data gave way to a sense that the physicians embraced a professional obligation to mobilise their medical

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[453] ibid.

knowledge and skills in providing medically appropriate treatment and benevolent care for one’s patients.

3.4.1.2 Law from the bottom up

A second general finding relates to the construction of law from the bottom up perspective of the physicians. Participants recognised legal control in the form of recognisably state-based measures of coercion as distinct from medicine as a quasi-legal system of control. This bottom up experience is distinct from the rules of doctrinal analysis. Where formal legality is constituted by a hierarchical relationship between hard and soft sources of law that include ethical and professional norms, the participants differentiate between hard sources of health law as “legal” and systems of control related to the medical profession as “quasi-legal.” In exploring this distinction, new insights can be garnered about the role of state based law, and the relationship between medicine and state-based law, in the governance of death and dying with dementia.

As illustrated in Figure 1, law emerged in the narratives via the participants use of loosely legal language in reference to a particular and distinct regulatory phenomenon. Reference to formal systems of control made up of official documents and rules, was reinforced by language related to “law” in common lexicon and explicit reference to recognised sources of law such as Acts of government. Notably, although recognised as distinct from legislation, guidelines issued by the NBHW were also spoken about. The relationship between this and law was uncovered in one participant’s account that

> it is difficult to distinguish what are laws and what are guidelines from the National Board of Health and Welfare sometimes, but they obviously cross over each other. – Participant J

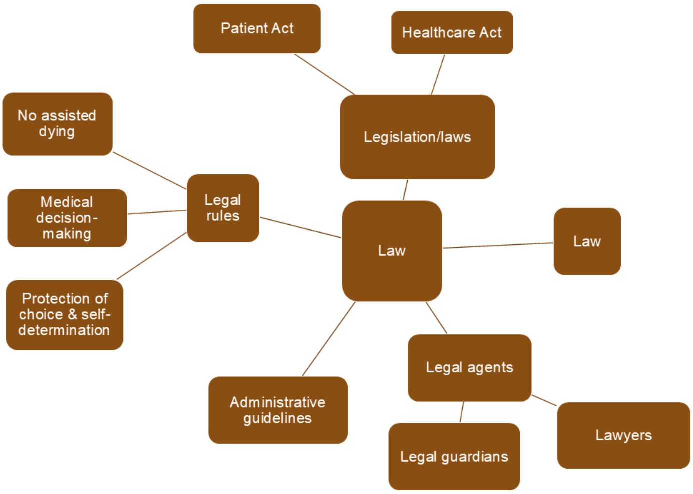

Figure 1: Extrapolations of law from the data.

In turn, quasi-law was identified in the narratives in relation to distinct discussions regarding the regulatory influence of norms evidently indigenous to the medical profession that guide, determine or justify the everyday practice of end-of-life decision-making with dementia. These regulatory customs were captured in standalone, explicitly non-legal discussions in which both loosely and specific medical language was used, as well as comparative talk in which the legal was contrasted with the non-legal. For example, the following participant considered the distinctly different influence of law and ethics:

> I think that, there is some kind of interplay between ethical principles [which] say what I should do and the law [which] says what I should not do. It is kind of like there are sort of push and pull factors … when I think about it, it is the law which says like, nah, you shouldn't practice assisted dying and you cannot take a decision completely against the patient's wishes. … But it is more so ethical principles and such, maybe above all human dignity, which factors in and says what I should do, I think. – Participant J

Although not necessarily clear cut, I identified three manifestations of overlapping medical control as constitutive of quasi-law from the data. As illustrated in Figure 2, quasi-legal medical control is constituted by: medical ethics; clinical practice norms as institutionalised, enculturated ways of doing related to the practice of medicine; and professional standards of practice as evidenced-based principles, policy and clinical protocols.[454]

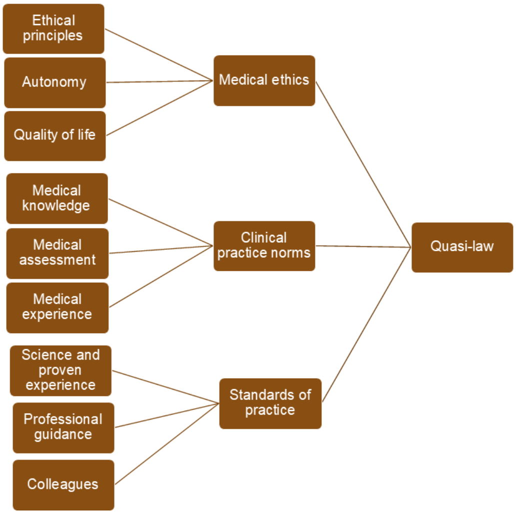

Figure 2: Extrapolations of quasi-law from the data.

Legal and quasi-legal consciousness was subsequently identified in the thoughts, attitudes, reflections as well as stories of doing end-of-life decision-making with dementia and applying these two systems of control.

3.4.2 Legal Consciousness Schemas

3.4.2.1 Law as an undercurrent

Table 1
Codes for legal consciousness theme "law as an undercurrent".

Codes	Theme
Law De-Centred Law as Parameter Setting	Law as an Undercurrent

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[454] This is similar to Greenbrook's (n 137) concept of "the medical compass" as identified in relation to medical need, medical reasoning, medical ethics and medical skill at 141.

The first legal consciousness schema captures the fact that law is always in the shadows of healthcare, and therefore, end-of-life decision-making with dementia. Under *law as an undercurrent*, the physicians demonstrated an awareness that law may have a controlling influence over their practice even whilst it existed in the background. From this perspective, law comes to permeate the practice of end-of-life decision-making with dementia as it works behind the scenes to establish the framework in which healthcare operates. Law in this schema is characterised by the fact that it is *decentred* rather than central or explicit. This refers to the way in which law is acknowledged to be present whilst it is simultaneously not treated as dominant or actively influential. For instance, it was claimed that

> of course [the law] is help[ful] … it regulates what we are allowed to do … Then that we don't reflect … you have it in the back of your mind all the time, and you know like, what, where the line is for what we are allowed to do medically. …. So of course it is helpful, but I don't think that you reflect on it much in the everyday (chuckle), I don't think. – Participant C

In a different vein, another participant reflected that their practice may be bound with law in more subtle ways. In this instance, whilst the obvious presence of law was acknowledged, the possibility that law was more influential as a subtle purveyor of ethical principles that infiltrate one's thought process was also contemplated:

> So it does help that those [laws] exist but they do not affect me so much maybe, or, maybe it [is] because they exist that I think what I think. – Participant J

A sense of law as a norm setting institution that had diffuse implications for the way that healthcare practitioners think, and practice healthcare therefore emerged.

Even whilst law fades into the background of the everyday practice, it is recognised that law

> establishes the *framework* for how we should work. – Participant I

Given this, whilst the law does not always matter directly in end-of-life decision-making with dementia, its implications are diffuse across the practice of medicine. Similarly, when pressed on where law emerges more explicitly to impose guidance, participant K paused before answering:

> Yes, yes, so, generally there are some things that you, above all should adhere to. So, the general legal principles and rules. The things like, uh, yeah, everything around healthcare regarding privacy, eh, yes, the laws around this. – Participant K

In this way, law's influence was located in general organising principles rather than representative of an explicit force in end-of-life decision-making with dementia. Thus, overall, the law as an undercurrent schema indicates that. law operates to set the general boundaries in which healthcare ought to take place. However, this operation leaves law as a background influence whose exact implications on end-of-life decision-making are diffuse rather than specific. As part of this, law might be understood to have a somewhat hidden effect on the everyday.

3.4.2.2 Law as an iron fist

Table 2
Codes for legal consciousness theme "law as an iron fist".

Codes	Theme
Law as Codified Rules in a Distinct Legal Sphere Law as Known Law as Authoritative Law as Influential Law as an Unquestioned Authority Law as Prohibitive	Law as an Iron Fist

At other times, law arrives with a bang. This was captured in the second schema of *law as an iron fist*. This was extrapolated from the way in which participant narratives constructed law as a distinctive and separate set of rules that are brought down upon the everyday practice of end-of-life decision-making. In this way, it is a blunt object that evokes compliance. The first dimension of this schema is that there are rules in end-of-life decision-making that have been *codified* into explicit legislative frameworks that exist in a sphere separate from the everyday practice. The participants described codified rules such as "laws"[455] and "legislation"[456] that provide information about what behaviour is allowed or prohibited. The language is indicative of codified regulations that are contained in the world of law which is separate from the

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[455] Interview with Participant C.

[456] Interview with Participant K.

everyday practice of end-of-life decision-making with dementia. This is explicitly captured by an illustrative account of law as a separate entity that punctures the everyday where questions of death arose:

> When we start to approach death, then the law comes into play. – Participant G

Discussions on legislative frameworks further revealed that the participants *knew* the law. This included being aware of relevant laws such as “the Patient Act” and “the Health Care Act.” Participants further indicated that they were aware of the content of the law. In this way, they reproduced the law as a known factor in questions of death and self-determination. For example, it was stared that,

> there are clear laws, we are not allowed to hasten [death]. – Participant C

It also emerged in relation to the importance and procedures for the participatory involvement of patients such as the provision of information[457] and relatedly, the

> right to say that I do not want to have the information. – Participant K

In a similar vein, it also emerged that the law prevented decision-making in opposition to the position being expressed by the patient:

> We cannot forcibly treat someone who clearly says no. – Participant C

Moreover, these rules were seen to be *authoritative*. This is intimately related to the fact that participants considered that these systems of rules ought to be obeyed. At the crux of the following excerpt from participant G is a sense of deference towards the regulatory power of law as death nears and a fastidiousness to ensure that the rules of law are followed. This reflection was made in relation to situations where death is near, or could be hasted:

> There we of course take care to not to improvise, find our own rules, rather, I discuss with colleagues in every case and try to relieve symptoms through all thinkable ways before we begin palliative sedation. – Participant G

That the everyday practice of law produces and reproduces the ability of formal sources of law to have control over end-of-life decision-making for people with

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[457] Interview with Participant F; Interview with Participant I.

dementia is evident in the way that participants describe the direct *influence* of law over assisted dying:

> Then the law has an immediate effect. – Participant G

Whilst questions of hastening death were perhaps the most prominent situation in which the power of law was brought to bear on physician practice, a number of participants also indicated that the law has a sustained influence over the process of involving patients more generally:

> But [the law] has an effect all the time because I must always relate to the patient, that I could provide them with more information or [they could] participate more in the decision. – Participant I

Significantly, law's *authority was unquestioned*. In other words, respect for the law was not necessarily predicated on agreement or faith in the rightness, usefulness or appropriateness of law. In this way, the simple existence of the law justified adherence, there was no particular quality that underlined this acceptance. The law is accepted simply because it is. Participants, for example, spoke in a matter-of-fact manner about the influence of law:

> We obviously have laws that we need to follow. – Participant K

Laughter was often present in these pragmatic admissions which had the effect of highlighting that, at least on face value, there is absurdity to the suggestion that one would not obey the law. Furthermore, no participant questioned the validity, appropriateness or rightness of the prohibition on assisted dying. Indeed, one participant in fact left the impression that were the law to change, their practice might also change:

> I will never perform assisted dying so long as the possibility to do so is not available. – Participant F

An interesting quality of these rules is that they are often constructed as *prohibitive*:

> The law tells us what I should not do. – Participant J

That is, law works to prevent certain behaviour in the practice of end-of-life decision-making for people with dementia. This is exemplified with phrases such as “we cannot”[458] and it “is of course not allowed.”[459] The law as an iron fist schema is ultimately representative of an experience of law as a discrete system of rules that come down upon physicians in the prohibition of decisions that hasten death, and the demand that treatment be given with reference to the patient’s consent.

3.4.2.3 Law as a tool

Table 3
Codes for legal consciousness theme “law as a tool”.

Codes	Theme
Law Supports Medical Decision-making Law as a Social Good Law Displaced Ambivalence Towards Law Law Unknown Critical of Law Presumed Acting Without Support of Law	Law as a Tool

However, law is not always experienced as an imposing force upon physician practice of end-of-life decision. The schema *law as a tool* captures the way in which law comes to be wielded at the hands of the physician as an instrument. Under this schema, participants shared stories in which loosely legal language was used to describe experiences and understandings of law as a sometimes useful tool that supports or promotes physician practice. Yet this instrumentalisation of law extends to the fact that law is sometimes left behind in the toolbox where it is not considered to be serviceable. This was particularly true with reference to the strictures of law and its promotion of autonomy in distinction to the reality of healthcare and dementia. Law is therefore constructed as an elastic entity that is mobilised on the terms of the physician themselves. This schema consequently embodies the perception that law is not powerful in its own right, but is rather ascribed power by physicians.

The narratives vacillate between contesting law’s relevance and recognising that there is “a large role”[460] for law in medicine. In regard to the latter, law was indeed implicitly *ascribed power*. One way this occurs is through stories

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[458] Interview with Participant C (n 455).

[459] Interview with Participant K (n 456).

[460] Interview with Participant I (n 457).

of law's instrumentalisation as a *support for medical decision-making*. In this, law was considered to provide an overarching framework for delineating what can be done in end-of-life decision-making. For example, hospital lawyers were referenced as a potentially useful resource in indicating "what is forbidden and what is allowed."[461] Lawyers were also considered to be potentially useful, if seldom relied upon, in solving disagreements or uncertainties in healthcare. This includes where relatives and doctors may have different opinions on how to approach medical care, including in relation to questions of life-sustaining treatment and palliation:

> Of course we have access to the hospital lawyers, which I very rarely use, … in patient cases where different wishes go in differing directions … And there we [can] contact the hospital lawyers, about what you are, and are not, allowed to do. – Participant G

Participants were also demonstrably cognisant of the support afforded by law for their ability to make appropriate medical decisions that take medical possibility and patient needs into consideration. This is forcefully captured by participant H who responded that in addition to the central role of law in supporting self-determination, law also protects the ability of doctors to make reasonable medical decisions:

> The role which [law] has is that the patient decides for themselves. … Then it's also that you as a doctor make certain decisions which are like reasonable, that [as a patient] you can't wish to have any particular kind of treatment … as I understand it, rather if the doctor says that this won't work, that this is unreasonable or that you will not be able to manage it. – Participant H

Similarly, law also emerged as a crutch, or backbone, for medical decision-making. In other words, rather than being a system of control that demanded or facilitated certain actions, it provided the physicians with an implicit justification for the way they approached end-of-life decision-making as medical practitioners. For one participant for instance, law was a secondary justification for their practice of overlooking previously expressed wishes on the grounds that they do not coincide with the medical status of the patient in the present:

> If there are previous wishes, which there very rarely are, I try to follow them. Sometimes those wishes are not relevant anymore, rather the patient made them

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[461] Interview with Participant H.

> when they were in another situation when the body and the mind were in a different condition, and such wishes are not actually legally binding. – Participant G

Within this trend, another participant reflected that law supported physicians in their pursuit of good patient care in line with their obligations, even when it might not be explicitly obvious to them and their colleagues:

> To alleviate the patient … as the primary goal … you actually have support, often support, in the law. Even if you might sometimes think that you don't have it. – Participant I

An extension of this is that the protection provided by law to practices that allow for the management of pain and suffering also protects physicians themselves. That is, the law protects the ability of physicians to practice medicine in pursuit of good care by acting as a safety net:

> But obviously you also need to be able find support. It isn't good of course [if] you are condemned regardless of what you do, whatever scenario (laughter). Then that is just, no. Then you are vulnerable in your role [as a doctor]. – Participant I

In this way, there is a consciousness that law is a final arbiter that can defend physicians from criticism or threat from patients, family members and the public at large.

The reproduction of law as medically useful in the practice of physicians also slips into the ascription of law with power as a force to secure *social good*. For one participant, there was an awareness that law has the ability to ensure that medical practice is ordered by a higher set of norms than the values and expertise of an individual doctor. In this way, law was embraced as a tool to prohibit bad behaviour and secure good medical practice. This was evident in the following response to the question of whether there is a role for law in the practice of end-of-life decision-making for people with dementia:

> Oh yes! Eh. Absolutely. Because we cannot have a lawless world in healthcare when it comes to decision-making. Eh, just based on the good or bad judgment of the doctor. – Participant G

For others, law was positioned as a security blanket that protects and promotes social values, particularly the value placed on self-determination. Participant J for example reflected on the role played by law in providing protection to individuals in line with social values:

> But also self-determination is highly valued in society … It is immensely immensely highly valued and that is mirrored in the legislation. In that way, I think that the role of the law, eh, is pretty much to protect the individual from the perspective of social norms about what is important for the individual. – Participant J

Interestingly, there is also a sense that the role of law would be strengthened if it was taken out of the bounded spaces of formal legislated acts of government and placed into the everyday sphere of the physicians. This points to the fact that participants were also involved in *displacing law*. Thus, rather than understanding law as something that comes from above to impose upon physicians as conveyed in the law as an iron fist schema, law as a tool legality conveys a sense that where law can be wrangled into a status consumable by physicians, it has the potential for influence:

> Legislation is just one thing but also to, to communicate the meaning of the laws in an understandable way and to be helpful in making it usable in practice. That [is] where, where I absolutely see a role for the law. – Participant G

Law is therefore transformed into a usable entity when it is overtly communicated to physicians.

The way in which the physicians displaced law arguably comes to a head in stories that relocate law into the realm of healthcare. According to this perspective, the authority of law as an independent arbitrator and protector of rights does not lie in official legal spaces, but in the everyday practice itself. One particularly prominent instance of this was where the role of the lawyer was transformed into the part played by decision-making participants in the everyday. Participant F for example exclaimed that

> I of course know that I'm not a lawyer, but I usually see myself as the patient's lawyer. – Participant F

In such statements, non-legal actors usurp legal actors in the protection and promotion of just outcomes in healthcare. This embodies a sense that medicine in and of itself contains authority over the definitions and protections of justice in healthcare whilst simultaneously recognising the value brought by the tenets of law to healthcare. The significance of using legal language in this way is emphasised with reference to the contrasting account by participant K of themselves as “the patient’s representative” in which comparatively non-legal language was used.[462] This statement should not however be simply dismissed as oppositional to stories of law’s displacement. Rather, it captures the idea that even non-legal actors are engaged in a role traditionally reserved for legal actors and/or legal spaces in working to secure rights. This was particularly prevalent in participant K’s account of how family members were especially important in protecting not only a patient’s right to receive information, but their right to refuse information where the patient is an anxious person who may have otherwise indicated that they were content not knowing the particular of their diagnosis:

> Everyone of course has the right to information, but everyone also has the right to say that I do not want to receive the information. This is, of course, always a much more difficult thing to do when you have a cognitive illness. And even there it is important to involve relatives, it is important to get that feedback. – Participant K

Whilst law was therefore clearly sometimes experienced as a useful tool, at other times the physicians turned away from the law. One way in which law was set aside was through expressions of *ambivalence*. This manifested in a number of different ways in which the law was ultimately positioned as unimportant. For example, law’s possible influence was minimised. By way of illustration, where the law on assisted dying was platformed as the central legal stimulus on the everyday, physicians were quick to move on from discussing the law in expressing the ultimate influence of medical factors:

> We have of course legislation in Sweden that you have to adhere to, above all, for example, assisted dying … is of course not allowed. Um, conversely, we have, a like, the medical ethical principles … What the goal is of the care and how the specific treatment measures that you implement will help the patient. – Participant K

This came to be a common theme across the narratives in which mention of law was swiftly replaced with discussions of medicine.

Ambivalence was also evident in apparently flippant attitudes to law and its possible meaning and function. This was captured in the account that the physicians do not actually take law into consideration in their everyday practice. After reflecting that past wishes are not legally binding in

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[462] Interview with Participant K (n 456).

acknowledging that they attempt to make decisions in relation to the patient's current perception, participant G's story took on a confessional bent in stating,

> I do not think so much about law to be honest. – Participant G

Furthermore, there was a scepticism in regards to the ability of law to effectively support good care for people with dementia. For participant K, for instance, this was the case even if the strong arm of law was reshaped so as to better capture the needs and circumstances of patients with dementia. This reflection was made in the midst of an expression of doubt as to the potential of law as a system of control that was perceived to be predisposed to the provision of fixed rules versus the need to respond to the patient:

> I understand that it is difficult to put [things in], like, black and white … there are many who say that it isn't that way with law either, that it is not black and white either, but rather that there is always a grey zone, and those patients with cognitive impairment … where the autonomy question of course becomes perhaps more difficult, (pause) you might say that it becomes more fuzzy. But still, of course … you have a patient, a person who you need to try and find a good solution for. (pause) … I don't know if we are missing support, I don't know that if we had everything like, things too rigidly aligned, it wouldn't necessarily be better either. – Participant K

Thus, from this perspective, even if the law was able to capture the needs of the patient with dementia, it may still be somewhat inappropriate.

Additionally, the relevance of law was undermined. This was revealed through participant H's humorous representation that whilst they believed that the law allowed them to make a medical decision despite potential disagreement with family members as to whether or not cardio-pulmonary resuscitation should be ruled out as a treatment option, they weren't quite certain of the rule or where it came from. Laughing, the statement gave the impression that this rule was, in and of itself, rather inconsequential to the fact that medical decisions are to be made:

> It is up to the doctor to make such medical decisions … I think, but I, we don't have, I don't know which law it is or whatever. – Participant H

This coincides with law being *unknown* as a manifestation of the experience of law being left behind in the toolbox. Indeed, whilst a majority of the physicians expressed a sense of "knowing" the law, in two interviews, a lack of legal understanding was explicitly mentioned. One physician reported that they were conscious of the fact that they and their colleagues did not know very much about the law. Their expression intimated that physicians do not have a very good sense of the law even though they are aware that there have been efforts to impart legal knowledge:

> We have had a little like medical law, education about it with legislation and such but in general I would say that you as a clinician do not have a strong grasp of it. – Participant H

A second reflected that their lack of familiarity with the law more generally may be contributing to their lack of faith in law's ability to support shared decision-making as the zenith of healthcare practice:

> My personal position is that in healthcare one should reach a higher level of what I now call 'shared decision-making'… but I am maybe a little unsure of if, um, the law, what the law should look like. But this is probably because I don't know the subject well enough. – Participant K

The participants also revealed that they turned away from the law through outright *critical* attitudes that extend from a distrust of law more generally to a specific scepticism of law's consequences and capabilities in relation to dementia care and end-of-life decision-making. Scorn for law is made concrete in reflections that indicate an understanding that medicine is a specialist area that does not easily lend itself to being subject to social control through the blunt force of law. In this vein, one participant expressed the concern that law carries with it a general risk that medicine becomes overly regulated:

> It is not good if it is too governed by rules. – Participant I

There was also a more specific belief in a particular disconnect between law and the nature of end-of-life care:

> The lack of legislation perhaps mirrors the very fact that it can be difficult to create a law that can be appropriate for everyone at the end of life. – Participant D

In this manner, law in and of itself is treated as a system of regulation that cannot begin to grasp the complex realities of end-of-life decision-making.

Misgivings with the nature of law intersect with critical attitudes as to the specific content of the legal regulation of healthcare for patients who are dying with dementia. Prominent amongst these was concern for the strictures of autonomy as written into the law in relation to the realities of dementia. The narratives revealed negative perceptions of what they experienced as an overwhelming focus of the law on the promotion and the protection of autonomous independent decision-making in the midst of efforts to navigate the difficult space of healthcare with dementia. In this regard, one participant described a conflict in which the strict, inflexible rules of law around self-determination were in tension with the more flexible approach to creating possibilities for autonomy for patients with dementia facilitated in medical practice:

> Laws and rules … must be rather concrete … if you say that you don't want to receive help I can't presume that you do want to receive help … Meanwhile the patient group that I care for have difficulties, like maybe they cannot answer yes or no, they cannot really express their will, or express something that I do not believe is their will, and then it becomes like a minor conflict where I, I think anyway, that I proceed based more on like insinuations and what is implied, and previous wishes and such. – Participant J

There was therefore an assumption that the law's hardline approach on autonomy was not appropriate to handle the intricacies of decision-making with dementia. Furthermore, it was recognised that the law is not particularly useful in managing situations where a patient with a cognitive illness refuses care that the physician believes to be beneficial. This was related to the understanding that law demands respect for a patient's refusal even where this may be considered "unreasonable" from a medical perspective:

> We end up at that problem, and there, the law is not particularly helpful. – Participant A

By the same token, law was not seen to support what was reported as important questions related to good care in connection with promoting quality of life where autonomous expressions were at issue. This is expressed in the following quote in which participant A reflected on how the legislative attempts to retain autonomy for people with dementia is understandable, but at the same time, of less significance than conversations around quality of life in the everyday:

> There have been attempts to achieve a situation where autonomy can be upheld. You don't want to regulate away autonomy from these patients. This creates anxiety amongst those who legislate … they don't want to write something that limits someone's autonomy. So, I understand that. Then, for me, the other thing that I usually talk with relatives and patients about is quality of life … and this

> is a matter of ethics. Do we want to give treatment which will extend a quality of life which the patient cannot accept, then it is unethical to give that treatment. – Participant A

At worst, this tension led to the opinion that law was a hindrance to navigating care at the limits of autonomy. To this degree, law was taken by one participant to be representative of a fixed, unflexible system that ultimately placed inappropriate demands on the patients themselves:

> … my experience is often that when it comes to writing law about people with dementia it … places pretty high demands on them to express themselves and make requests … but in practice it is very difficult for them, because they have an illness in their brain which means that they simply can't. – Participant J

It is important to note that participant B seemed to present the opposing position that people with dementia represented a group with many diverse abilities that allowed them to retain autonomy in a way that pushed the way in which law restricted autonomy to its limits:

> [People] with Alzheimer's can actually be fully capable to say that, I don't want my son and that guardian to inherit my money and write a will, … because you can still take a position on things, then that you maybe forget it later is another thing. So this pushes law to its limits. – Participant B

However, this statement was evidently made in relation to a reflection on law as it was understood to apply to the creation of wills for matters of inheritance. This is a different matter than that of healthcare both with reference to the dimensions of this study, and with reference to the fact that such matters are regulated by different regimes than that which governs healthcare. Thus, whilst it is an important reminder that the participants were careful not to preclude the ability of a diverse group of patients to act with autonomy, it is not understood to represent a critique of law as was captured by all other discussions.

Ultimately, the negative perceptions culminate in the observation that law is simply not particularly helpful to rely upon when dealing with this patient group. In this respect, participant I claimed that the law is particularly lacking for the patient group who is most unwell and, correspondingly, conceivably most in need of care:

> So I think that it is easier to find support in law the less sick the patient is. The milder the patient's cognitive illness, the easier it is to find support in

> legislation. … it is the nature of the illness that you lose judgment and cannot give informed consent in the end, so then … maybe the legislation gives less support. – Participant I

The experience of turning away from the law is brought to a head with stories in which physicians presumed they *acted outside the boundaries of law*. Stories of presumed disobedience were particularly prominent in reference to a perception that law's demand for respecting autonomy was at times incongruent with the reality of decision-making with dementia. For instance, it was broadly assumed that the law requires patient consultation. In contradiction to these understandings, the physicians implied or reported that these decisions are sometimes made in the absence of consultation. As an example, referencing the understanding that decisions should be made with patients and relatives, participant H reflected that the law was not followed in the reality of end-of-life decision-making with dementia:

> Because I think that the law is like this, umm, that you must make a decision in consultation with the patient, that the decision should always be made in contact with the patient and relatives. And that doesn't always happen, rather, sometimes you just renew an old decision [to withhold treatment such as CPR] or make a decision without having the time or chance to speak with relatives. So, I think that it's probably not always done correctly. – Participant H

Interestingly, this response implied that there was not necessarily active intent to breach law. Rather, a lack of legal knowledge, or indeed, a lack of opportunity in the workday, underpinned practice that was considered to be "incorrect." Thus, in this instance, the story of presumed disobedience took place incidentally.

Other participants referred explicitly to the pressures of navigating the realities of dementia as a reason for their presumed non-legal practice. To the degree that law was experienced as placing inappropriate demands in regards to patients with dementia, they explained that they engaged in practice that they understood to go beyond the boundaries of the law. In this regard, one participant went so far as to characterise the law as a threatening entity which was the reason for their presumed circumscription of law's rules:

> I know that the legislation is such that the patient should be involved, but I also have experiences where efforts to involve the patient sometimes caused increased suffering rather than being beneficial. – Participant F

In this vein, it was indicated that the requirement to ensure patients were informed of their medical condition would potentially cause significant and unreasonable upset for a patient with dementia. Due to the perceived harm of such legal rules, a willingness to act outside the demands of law was reported. Thus, autonomy as it is written into law, is at once a source of protection and a threat that causes physicians to abandon law. Ultimately, whilst law is a useful tool in facilitating medical practice, where it is considered unsupportive or obstructive to good end-of-life care with dementia it is left in the toolbox. It is therefore at the hands of the physicians that determine the extent to which it is relevant.

3.4.2.4 Medicine as a lodestar

Table 4
Codes for the medical consciousness theme "medicine as a lodestar".

Codes	Theme
Situated in the Profession Medicine as a Guide Grounded in the Patient Related to the Physician Medicine as Transcendent	Medicine as a Lodestar

The *medicine as a lodestar* schema indicates that medicine rushes in to fill the gaps in law's influence. This medical consciousness schema embodies medicine as an underpinning, central system of malleable, particularised guidance in pursuit of fulfilling a professional commitment to patients with dementia at the end of life. Under the control of medicine, the realities of death and dying with dementia are recognised and responded to. This schema captures a quasi-legal medicolegality as the primary guiding force over their practice. Importantly, rather than fixed, determinative rules, the terminology of "lodestar" embodies imagery associated with the fact that medicine affords guidance and inspiration that is not static, or indeed, fixed.

The following excerpt captures the complex intersections at play in medicine's control over end-of-life decision-making with dementia:

> It's of course always, like, an overall assessment. Based on, really, partly on how advanced the patient's dementia illness is and then naturally also what other somatic illnesses they have. It is always an overall assessment from what you believe is of benefit to the patient, and what might potentially cause more harm. It is always an assessment, if relatives are available, together with them,

> um, and what wishes the patient has expressed earlier in life if they cannot express them now. … And then also naturally there is consultation with colleagues on the ward. – Participant C

In this quote, quasi-legal control appears as a multi-pronged system of regulatory *guidance* which is *embedded in the medical profession* itself in that it is informed by clinical norms as enculturated behaviours that are both tacitly and explicitly developed amongst physicians, standards of medical practice and medical ethics. The guidance provided by these norms of control will now be considered in turn so as to allow for a more explorative account on the way in which their influence manifests.

To begin, the physicians are evidently informed by clinical norms of medical decision-making as a dynamic set of clinical behaviours that they have been trained and institutionalised in as medical practitioners. These were articulated in relation to the practice of medical decision-making. In this, medical knowledge is applied in a medical assessment of a patient's specific clinical circumstances and medical possibilities:

> There are of course considerations which are purely a choice of medical treatment – Participant C

in the way that medical factors are weighed in the context of a medical decision.[463] These norms are positioned as exclusive to the medical profession. Indeed, as one participant shared, medicine is something that is accessed through the experience of practicing as a physician:

> You can read up on the pure statistics of which illness will mean that [the treatment] won't go well, but I still believe that you need the practical experience … It is really about experience in relation to what you can read in the books. – Participant F

Whilst medical practice might be considered as implicitly systemic in that it involves knowledge and skills developed over years of enculturation into the medical profession, at other times, medicine was explicitly connected with the professional norms of the broader medical community. In this regard, medicine was at times clearly framed within the boundaries of accepted practice and scientific knowledge with terminology such as "science" and "proven

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[463] Interview with Participant F (n 457).

experience" as a kind of evidence-based standard of medical practice. For example,

> good science on palliative treatment and above all, lots of proven experience and how things stand in terms of what is done in [these] situations. – Participant C

Professional norms were also revealed in accounts of the guidance afforded by collegial discussion and workplace culture:

> You do a bit like colleagues do and what they recommend … you know, what you build up in the clinic … This is how we usually do … and so you ask your colleagues when you are uncertain and then have a discussion and kind of come up with something. – Participant H

The institutional nature of medicine as a system of control became even more apparent in narratives that revealed formal guidance. On some occasions, for instance, these professional norms were recognised as formal. In this regard, it was noted that guidelines developed by the Palliative Development Centre (*Palliativ Utveckling Centrum*) provide physicians with procedures that they can follow:

> We make use of the NVP (National Care Plan for Palliative Care) papers ... I think it is very good that you can have that as a support. – Participant B

Participant C made an overt connection between formal professional guidance and everyday experience by stating that the professional guidelines allow individual physicians to connect with an established way of working:

> Of course we do a lot based on experience as well but it is very nice to be able to tie it together too and also have a structured approach to work. – Participant C

Medical ethics were also experienced as particularly influential:

> I think that we are very guided by ethical principles, or our own, of ethics when we make decisions, serious decisions maybe in general, and it is a serious decision when you decide that now we are nearing the end of life, and yeah, what should we do for this person. – Participant D

Ethics emerged as a complex body of varyingly significant principles that often came into play in relationship to each other. Indeed, it was clear that the ethical considerations undertaken by the physicians were many, and at times, complex:

> In general, it is of course ethics. And then there are many factors, to do right and do good, equal care, we don't exclude patients from our [palliative] care, and we want to also consider using resources in the right way. – Participant G

It was nevertheless clear that autonomy was an integral point of reference as is highlighted in the recognition that "it is always the patient's wishes which are the basis" of decisions regarding care.[464] Autonomy is therefore a relevant navigational star in discerning between medically appropriate decisions that thereby secures opportunities for self-determination even without the explicit force of law. Further still, the value of dignity was mentioned by one participant to be the most prominent source of guidance:

> Ethical principles and such, maybe foremost dignity inserts itself and tells me what I should do. – Participant J

The value of dignity as distinct from autonomy in instead referring to respect for basic human needs and desires, opens to the significance of beneficence and associated issues of quality of life in the data set. As stated by participant A:

> I mean you can extend [life], you can also cause suffering with treatment and so we don't want to give treatment that won't lead to improved quality of life in the future … [if] treatment won't lead to the patient feeling better, it is not ethically defensible. – Participant A

In this sense, beneficence was a lodestar that advised physicians to consider circumstances where life-sustaining treatment should be withdrawn where it threatens the possibility of harm to the patient.

Interestingly, the data suggests that in opposition to law as a rigid set of rules, ethics is a fluid system of norms that bend to the physician and the patient. Unpacking this insight begins with the recognition that there is no comprehensive clarity on which ethical principle is the primary source of guidance. While three participants referred to the autonomy principle as the

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[464] Interview with Participant H (n 461).

most relevant factor in regulating their practice,[465] others explicitly privileged the ethical precedents of beneficence and non-maleficence. In this regard, participant I reflected on the fact that,

> first and foremost, it is to do no harm and to do good – Participant I

when discussing the regulatory control of their practice. The variation in the application of ethics indicate that where the law contains determinative rules, ethics is constructed merely as a point of departure in which accepted ethical values are brought to bear to determine what is appropriate with regard to any particular decision:

> The law must of course by nature be pretty, like, clear while ethics can be a little more, like, implied. – Participant J

Indeed, the role of medicine is not so much a prescriptive, rigid authority but a framework that is responsive to the particular clinical encounter. As medical ethics, clinical norms and standards of practice overlap and interlock to determine what is possible, the patient determines what should be done. Guidance is therefore *grounded in the patient's* complex, multi-dimensional presentation. This throughline in the narratives was made particularly clear in the context of discussions regarding the fact that there are no fixed pathways that determine end-of-life decisions, for people with dementia or otherwise, as the medical decision-making process

> very much depends on the individual situation. – Participant B

My reading of the data suggests that the way in which medicine is grounded in the particular circumstances of the patient also extended to the family unit. That is, family were also positioned as influential factors in the medical decision. Sometimes, the fact that decisions can be made with respect to the consequences for family was also recognised. For instance,

> Ehm, but I usually also think like this … it's the people who are close to the patient who, who live on, so they should actually also have an opportunity to like, reconcile with the progression of the illness. – Participant K

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[465] Interview with Participant C (n 455); Interview with Participant H (n 461); Interview with Participant K (n 456).

However, in addition to being responsive to the patient, a sense that the guidance of medicine is additionally *informed by the physician* themselves also emerged from the data. The malleability of medicine may therefore also be associated with the physician as an interlocuter who determines the way in which the guidelines of medicine are transformed in a given case through the filter of their personal and professional beliefs and experiences. This was evident in the way that the stories at times provided agentic accounts of medicine with reference made to one's own beliefs, positions, practices, ethics and experiences[466] as distinct from references to medicine as a collective practice. It is also clear in the ownership taken over ethical guidance.

Of course, it must be noted that the filtering effect of the physician is not necessarily clearly or exclusively either personal or professional in the data. That is, the distinction is not always clear-cut, or indeed consistent, between personal beliefs and experiences versus those which are professional in association with membership and enculturation into the profession or subspeciality. Either way though, it is apparent that the precise meaning of medicine in end-of-life decision-making with dementia may depend on which physician is presiding over the decision-making process. This was explicitly captured in one participant's reflection in regards to the way in which their own practice of medicine in end-of-life decision-making was distinct from other physicians:

> When I … open the door to the idea that we don't have to treat everything at every cost but we can actually allow one's family to have a dignified end and we will always, regardless of if they are going to die, we will always ensure symptom management … I experience that this is actually often a very big relief [for family]. Because it's not always that my colleagues dare to take up these questions. – Participant F

Having accounted for the distinct ways in which medicine manifests as a system of guidance, this subsection will now drill down into how medicine is mobilised in navigating end-of-life decision-making with dementia. By illustrating the substance of medical control in navigating patient participation and end-of-life decisions, there will be an opportunity to clarify the exact nature of the regulation in the everyday with respect to the specific question of end-of-life decision-making with dementia. The first issue to be addressed is the intersection of medicine with the patient's perceived needs in a

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[466] See for example Interview with Participant A; Interview with Participant K (n 456); Interview with Participant J; Interview with Participant D.

determination of patient participation. Part of this is a determination of whether or not the patient has decision-making capacity. This is not decided through blanket rules regarding presumed capacity or incapacity for a patient with dementia, nor a fixed functional assessment, but the flexible, particularised application of medicine and the particular ethical principle of beneficence in reference to the patient and their cognitive status:

> When you meet the patient, you also get a sense of whether the person seems competent or not. And like we're talking about, there are of course degrees of differences in cognition. – Participant F

Yet even in light of recognised cognitive challenges, the vast majority of participants were guided by the importance of autonomy by attending to the patient's need for support in order to actualise opportunities for self-determination. In this, adjusted communication was frequently mentioned:

> The difficulty is that they maybe, because of cognitive difficulty, can't really understand what they are saying yes to. And then it is often a difficulty which you can, in the best case like, navigate around and it is not impossible, it is just difficult. Simply you talk, explain it as simply as possible or explain it slowly or explain it many times. Then it is of course difficult but not impossible. – Participant J

With reference to the patient's extended family unity, the usefulness of utilising relatives in extending autonomy where communication proves difficult in end-stage dementia where possible was also recognised:

> For the most part it is of course family members who know what the patient would have wanted if they could decide. Eh, it is not everyone who has spoken about these kind of situations … but family members often have an idea about what the patient would have wanted. Would they have wanted to spend their last days at home or do they not want that, what is important, so it becomes like an extension of autonomy, the relatives. – Participant A

Still, in pursuit of autonomy, at other times family was spoken about as a factor to manage in the decision-making process. Stories were shared from this perspective in regards to navigating the wishes and interests of the patient as distinct from what the patient's relatives may want to happen with the patient's care:

> I try to actually go from what I believe is best for them, not what family members want. – Participant F

Medicine also clearly afforded particularised guidance in making treatment decisions. In the data, the principle of beneficence comes to the fore as the physicians seek to navigate the patient's somatic and cognitive condition with respect to what medicine indicates is possible, and what ought to be done in relation to the patient:

> If the situation is obvious, that there is a patient with severe dementia who maybe even has a malignant diagnosis or something else that clearly, from the health carer's perspective, through continued treatment would do harm to the patient or extend their suffering … We therefore explain that this is our medical decision, that this is what is best for the patient. – Participant C

Yet whilst beneficence at the limits of medical possibility is most central, "it is of course about the patient's autonomy."[467] In this, efforts to balance beneficence with opportunities for self-determination as the physicians keep both elements at the forefront of decision-making are revealed:

> Yes, well that's like what I am trying to say, what we think is the actual quality of life, and then also what we think the person has expressed earlier in life. – Participant H

The ethical principle of autonomy therefore remains a key navigational star as the physician attempts to grapple with beneficence and autonomy in coming to a medical decision regarding treatment. This comes to a head in respect for care refusals:

> There are of course some patients who actively like, either maybe pull out their cannulas for example or make it known that they do not want, ehm, and, and often we follow that … then you have to maybe focus, um, on other measures so to say. – Participant K

The guiding force of medicine was *conceptualised as transcendent*. This emerged in the sense that the physicians often spoke about medicine as the primary underpinning principle. They, for instance, described end-of-life decision-making with dementia as, definitionally, a medical decision. This emerged in claims that end-of-life decision-making "is of course a medical decision"[468] and, "in the end it is of course the doctor's decision."[469] It is thus

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[467] Interview with Participant I (n 457).

[468] Interview with Participant H (n 461).

[469] Interview with Participant F (n 457).

within the purview of medicine, not law that these decisions are made. To the degree that this is indicative of an uncomplicated enactment of medical authority, it reaffirms the supreme control of the profession. The transcendence of medicine as a system of control was also revealed in expressions of medical dominance over law. That is, law was de-prioritised in the face of superior medical guidance. One example of this was the postulation that dignity is an ethical principle of such significance that ethics represent a system of control that is of greater weight than the right to self-determination as understood to be contained in law. In this way, ethics granted the physician the explicit approval to go against what was understood to exist within the rights and obligations of law:

> It is a pretty basic human need I think, to experience human dignity … so I put an ethical, shall we say, system of guidance to that, to that need I am trying to satisfy, um, and this is something that carries a lot of weight against that, against like that which pulls in the other direction which is this whole thing with the right to self-determination. – Participant J

Moreover, sometimes law was represented as an after-thought in the wake of medicine. For instance, physician I positioned law as a second-hand feature of the everyday practice of medical decision-making that meets the needs of a patient:

> Of course, there has been situations where easing pain has been clearly the most acutely important and then you think about the law more secondary. – Participant I

In a similar fashion, law was also framed as an entity whose controlling influence was ultimately contingent on medical values. This was conveyed in expressions that legislation is adhered to, to the extent that it is "reasonable."[470] For example, when participant F was asked about the role of law, they replied with some hesitancy,

> Uhh (pause) gosh it is obviously clear that there are lots of legislative frameworks around my job. Uh, which you try to follow to the extent that it is reasonable anyway. – Participant F

The nature of "reasonableness" is not explicit in this statement. It may therefore be representative of personal values rather than the system of control

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[470] ibid; Interview with Participant I (n 457).

informed by medicine. Yet when taken as a whole, the narrative of the participant suggests that reasonableness is in fact related to the ability to provide medically driven, ethical care that is appropriate for the patient at hand and does not cause harm with reference to the patient's health status. This interpretation coheres with Participant I's narrative in which reasonableness was unambiguously associated with the ability to act humanely and empathetically as a physician, and moreover, that law would cease to be applicable where it unreasonably encroached upon this ability:

> The law shouldn't prohibit you from acting with humanity and empathy either … you always make decisions about what might be reasonable. But of course, the law carries the most weight until it feels completely unreasonable (laughter). – Participant I

At other times, where law was recognised as influential, it was simultaneously minimised in expressions indicative of a dismissive attitude towards the role of law in contrast to the role of medicine. For example, participant F reflected that although there were obviously relevant laws to their practice, this was subordinate to the more pressing issues of medicine:

> There are absolutely certain laws. But then it is also a question of experience, and as I said, even science, what we know is compatible with life and the prognosis. – Participant F

Medical consciousness indicates that overlapping professional ethical, norms and standards come to provide overarching guidance in end-of-life decision-making with dementia. Importantly, rather than demanding adherence to universal principles, medicine provides a flexible framework which is ultimately determined by the patient in reference to their condition, needs and social network. Where the law is experienced as a blunt object and useful instrument in promoting autonomy, medicine encourages the ethical principles of autonomy and beneficence to be balanced in conjunction with professional norms of control with the patient with dementia at the centre. Interestingly, the absence of law at the coal face of navigating difficult decisions does therefore not prevent physicians from developing approaches to end-of-life care informed by the profession itself for the good of the individual patient. Thus, in law's wake, medicine steps up to secure opportunities for care.

3.5 Expanding on Legal & Quasi-Legal Consciousness

3.5.1 Discussing the Consciousness Schemas

These overlapping, and at time contradictory, narratives[471] demonstrate that law and medicine are experienced as distinct yet interdependent regulatory regimes that bring different pressures to bare on end-of-life decision-making with dementia. Whilst physicians experience the imposing force of law as a system of formal, state-based regulation, they also work with it, around it, through it and under it as law and medicine are produced as interlocking regulatory regimes. Specifically, law is understood to indicate a responsibility to preserve life, promote autonomy and grant medicine power to make medical decisions at the end of life. Ultimately, medical control is preferred as a more effective mechanism to secure outcomes at the end of life for people with dementia. This elaboration of the legal and quasi-legal consciousness findings begins by considering the ways in which law is experienced as meaningful. It then shifts to consider the how law is instrumentalised, and medicine emerges to regulate the practice of end-of-life decision-making on the ground. Throughout, particular attention will be given to the unique character of the four schemas of consciousness in relation to broader legal consciousness work. This locates these findings so that they not only contribute to what we know about the role of law at the end of life, but also the broader scholarship on law in the everyday. It ends with an exploration of the way in which these findings are indicative of the state of law in the everyday of end-of-life decision-making and explains what this means for this research.

3.5.2 Legal Control in Death & Dying with Dementia

The schemas clearly demonstrate that the attitudes of physicians towards law were varied, and at times, wildly different to the degree that they were contrary even in the space of one interview. To this extent, the physicians' engagement with law might be said to exist on a spectrum. On one end of the spectrum, there was contained optimism for the role that law could have in medicine and end-of-life decision-making with dementia. On the other end of the spectrum, there was almost a sense of resentment for law's inaptitude in this space. For

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[471] Ewick and Silbey, *The Common Place of Law* (n 36) 50.

the most part however, discussions of law seemed to indicate a pragmatic acceptance of law in the practice of medicine. Regardless, of the particular nature of the participant's attitudes, their narratives revealed that law ultimately carries influence in their everyday experiences.

Law as an undercurrent demonstrates that law is sometimes not a bang but a whimper. Thus, even where law is not explicitly recognised, it is nevertheless considered to be working in the background as a parameter setting power. Under this category, physicians identify that whilst they are not entirely sure what the law says or its applicability to the question of end-of-life decision-making with dementia, they believe it to be influential. At first glance, law as an undercurrent appears to coincide with a degree of legal alienation characterised by a loyalty to law in which participants have limited awareness of law, combined with a general identification with law.[472] However, I would suggest that this schema is more suggestive of legal pragmatism. This refers to the fact that although not particularly concerned with the force of law, they are aware of law's role in setting the rules of healthcare. Under this schema, "a transitory and abstract acceptance" of law allows it to shape the everyday practice[473] of decision-making in healthcare.

The strong arm of law is however expressly prevalent under the law as an iron fist schema in which law is reified as a known system of frameworks and rules within formal legal spaces that are accepted as a necessary, and inevitable impingement upon their behaviour. Law was brought to bear on the physicians as a distinct monolith that manifests in specific legal rules that prohibit the hastening of death and promote self-determination via the right to refuse care and receive information. In reifying the law's regulatory status, flesh and meaning is given to law's otherwise abstract force[474] on issues of self-determination and the medicalisation of death. Law as an iron fist's intersection with law as an authoritative source of control from a distinctively legal sphere aligns with a before the law account of law[475] that is present in Picton-Howell's account of courts as a far away and separate location that physicians go before either to protect children or because of threat to their own

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[472] Hertogh, *Nobody's Law* (n 182) 58–59.

[473] Anna-Maria Marshall and Scott Barclay, 'In Their Own Words: How Ordinary People Construct the Legal World' (2003) 28 Law & Social Inquiry 617, 618.

[474] ibid.

[475] Patricia Ewick and Susan Silbey, 'Common Knowledge and Ideological Critique: The Significance of Knowing That the "Haves" Come out Ahead' (1999) 33 Law & Society Review 1025, 1028.

practice.[476] One especially unique factor of the law as an iron fist schema that distinguishes it from before the law accounts is that it does not embrace the sense that law can be a useful anchor for legitimate action.[477] Picton-Howell for instance reflects that the surveyed physicians in her study may have been seeking to lift "the burden, to an extent, on them of having to make life or death decisions," by seeking knowledge of law.[478] Under the iron fist of law however, physicians do not seek a collaborative partnership with law in which the law can be used to lighten the burden of end-of-life decision-making with dementia. Rather, it is limited to its unidirectional force.

Under the law as a tool schema, law is an elastic power whose social and cultural clout can be wielded for advantage in the deft hands of the physician. Law in this way becomes a mechanism given meaning and influence on the level of healthcare where it is considered useful for patients, medical practice and society as conceived more broadly. In capturing the malleability of law at the hands of physicians, this schema provides a unique lens through which to understand the relationship between law and medicine. Where law is mobilised as a tool, it is constructed as a useful instrument in pursuit of healthcare by protecting patients and facilitating end-of-life decision-making with dementia. To this end, there is a marked relationship between this schema and Halliday et al.'s law as a shield and sword schemas. As with Halliday et al.'s family members, physicians in this schema drew upon law to protect the rights of patients and support the decision-making process. However, this interplay between the physicians and the law was not undertaken in a battle like scenario where the power of law was brought to fight against the powerful medical sector.[479] Rather, law emerged as a tool that could be adeptly used to enhance the function of medical practice. Moreover, where Halliday et al.'s identification of law as a sword captured law's use in pursuit of better care for one's own family rather than as a mechanism for collective justice for all patients,[480] it is the latter ideal that undercut the law as a tool consciousness in these narratives in which law was wielded for greater social and medical good. To this degree, the instrumentalisation of law under this schema aligns with Ewick and Silbey's claim that decisions to use law were married with public

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[476] Picton-Howell (n 135) 353–354.

[477] Ewick and Silbey, 'Common Knowledge and Ideological Critique' (n 475) 1029.

[478] Picton-Howell (n 135) 330.

[479] Halliday, Kitzinger and Kitzinger (n 136) 63–67.

[480] ibid 70–71.

interests under a before the law schema[481] rather than a with the law consciousness captured in Picton-Howell's analysis of law's ability to empower a physician "to achieve her aims."[482]

In this way, these findings confirm the existing claim within legal consciousness scholarship that legal and quasi-legal regulation co-exist in a way in which the law retains an important and influential role even whilst it is at times made subordinate to other concerns.[483] Indeed, in regards to the relationship between law and medicine, it follows Heimer's reflection in the context of neonatal care that "the shadow of the law may indeed be long, but long shadows need not be equally dark."[484] In this case, whilst law remains influential, it is made subordinate to the medically framed concern for providing appropriate end-of-life care that meets the diverse needs of people with dementia which is believed to be more effectively fulfilled under the guise of medicine. Indeed, the opposite effect of law's malleability under the law as a tool schema is that law is easily set aside when it threatens rather than supports good outcomes for patients under the gaze of physicians. The reach of law does therefore appear to rely to some extent on the efficaciousness of law and legal agents.[485] However, the reach of law is also connected to its perceived worth. In this fashion, the law as a tool schema also intersects with Halliday et al.'s law as a barrier in which family members demonstrated "considerable scepticism towards the legal regulation of the ending of patients' lives."[486] Further, law could be validly subverted because of its illegitimacy in such matters.[487] Where Halliday et al.'s participants expressed a sense that law was morally inept, the physicians in this work oscillated between the general inappropriateness of law to manage the particularities of medical practice to the more localised reflection that law's principled orientation towards autonomy was sometimes a threat to just care with dementia in life and death. As such, the physicians were not deferential to the authoritative of law but

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[481] Ewick and Silbey, *The Common Place of Law* (n 36) 84.

[482] Picton-Howell (n 135) 362–363.

[483] Ewick and Silbey, *The Common Place of Law* (n 36) 22.

[484] Heimer (n 136) 59.

[485] Heimer (n 136).

[486] Halliday, Kitzinger and Kitzinger (n 136) 67.

[487] ibid.

critiqued it for its failure to meet acceptable standards of care and respect for the human condition.

3.5.3 Medical Control in Death & Dying with Dementia

The medicine as a lodestar schema elucidates medical consciousness in relationship to end-of-life decision-making with dementia. It therefore takes Greenbrook's introduction of the concept of medical consciousness as an expression of medicine's social reproduction in the midst of various professional and personal influences[488] into a new context. That medicine emerges as the lodestar in end-of-life decision-making with patients with dementia is similar to Picton-Howell's conclusion in relation to physicians making difficult decisions for children that, "whilst law is ever present, it seems, however, that it does not provide the doctors with a structure and guidance as to how to make their decisions."[489]

In fact, under this schema, where physicians are guided by medicine in their everyday practice, new de facto legalities are created. In particular, the physicians in this study may be understood to be creating de facto law that is indigenous to medicine in which systematised norms from the profession act to promote practice that secures possibilities for good and appropriate care at the end of life for the benefit of patients with dementia where the law fails to penetrate. This coincides with Heimer and Tolman's account of the emergence of uncodified de facto rights to health in the context of an individualised patient-physician encounter where caregivers use their discretion to mobilise their expertise in the provision of attentive care for patient benefit.[490]

An interesting feature of this de-factor legality is the ease in which the physicians engage with medicine in relationship with law. As opposed to treating the turn towards medicine as something that is wrong or potentially punishable, the physicians demonstrate no concern in their efforts to turn away from law or operate outside the boundaries of law in favour of the guiding hand of medicine. This is similar to Greenbrook's report of a marginalised behaviour amongst Swedish physicians involving engagement in what they perceive as illegality without "fear of repercussion" as part of the process of rejecting the

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[488] Greenbrook (n 137) 154.

[489] Picton-Howell (n 135) 377.

[490] Heimer and Tolman (n 189) 574–575 & 580–581.

common place of law in favour of the bearing of the medical compass.[491] However, it is distinct from other accounts of the physician's experience of law in relation to end-of-life decision-making in which the threat of lawsuits had the potential to inspire physicians to "act contrary to their own recommendations as a safeguard."[492] Furthermore, McCrary et al.'s research demonstrated that physicians may be influenced by a desire to follow what they understand to be law "as a form of psychological, as well as legal, self-protection."[493]

The preference for quasi-legal control in relationship to law on the question of end-of-life decision-making is, however, not a finding unique to this study. As explained by Willmott et al., Australian physicians often integrate terminology of medical facts with medical values in the context of narratives about withdrawing and withholding life-sustaining treatment. They suggest that this constructs a claim that moral expertise in end-of-life decision-making "resides entirely with those with the medical expertise."[494] Willmott et al. however go on to reject this interpretation on the grounds that Australian law has overturned the centrality of "medical expertise in favour of patient values as the sources of decisional authority."[495] Put in legal consciousness terms, Willmott et al. might conceptualise their findings as representative of the way in which the force of law is resisted at the margins of law and medicine as part of an against the law consciousness. This is seemingly alike to Greenbrook's category of legal disavowal in which physicians expressed a preference for the medical compass over law in care for undocumented migrants.[496]

This schema, however, represents a conceptual shift in which medicine does not come to represent a residual, non-legal entity subjected to the hegemonic

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[491] Greenbrook (n 137) 141–142.

[492] Marianne K Bahus and Reidun Føerde, 'Parents as Decision-Makers — Do the Attitudes of Norwegian Doctors Conform to Law?' (2011) 18 European Journal of Health Law 531, 545.

[493] S Van McCrary and others, 'Treatment Decisions for Terminally Ill Patients: Physicians' Legal Defensiveness and Knowledge of Medical Law' (1992) 20 Law, Medicine and Healthcare 364, 373.

[494] Lindy Willmott and others, 'Is There a Role for Law in Medical Practice When Withholding and Withdrawing Life-Sustaining Medical Treatment? Empirical Findings on Attitudes of Doctors' (2016) 24 Journal of Law and Medicine 342, 353.

[495] ibid.

[496] Greenbrook (n 137) 141–143 & 145–147.

power law as suggested by Ewick and Silbey,[497] but rather, a corresponding set of controlling professional norms with its own source of power that complements law in the overarching regulatory milieu. In fact, I suggest that this relationship between law and medicine is a power sharing arrangement which grants both power over death and dying with dementia. This is in line with Smart's reflection that medicine and law are implicated in a co-constitutive relationship in which both reinforce the respective authority and influence of the other.[498] Thus, where law sets the framework of a healthcare practice that promotes autonomy, protects life and medicalises death, medicine is simultaneously empowered to operate at the side of, and at times around law, to provide more particularised guidance that can adapt to patients facing death with dementia. This perspective of legally sanctioned medical control may begin to offer an explanation as to why the physicians appeared to navigate in and out of law without being trapped or concerned by the negative consequences of law's force.[499]

One important issue remains. Others in the field have expressed concern as to the way ethics may actually consist of "the conscience of the individual doctor" rather than the medical profession.[500] This appears similar to Greenbrook's reflection that medical and ethical consciousness were likely informed by many factors including morality, personal beliefs and personal characteristics. In recognising that this may means that physicians may respond differently in healthcare and their "lived experience of law," she suggests that the differences "should be teased out."[501] Whilst teasing out the intricacies of medical consciousness are ultimately beyond the scope of this intervention, this schema does reinforce this burgeoning understanding of this dimension of medical consciousness and its implications for healthcare. Indeed, under the medicine as a lodestar schema, medicine is revealed as a system of control to not be prescriptive or fixed but rather fluid in its influence as it affords guidance in respect to the particular clinical encounter. Whilst such flexibility may usefully

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[497] Ewick and Silbey, *The Common Place of Law* (n 36) 249.

[498] Carol Smart, *Feminism and the Power of Law* (Routledge 1989) 14–15 & 96.

[499] As distinct from Greenbrook's (n 137) account of medicolegal anomie and alienation in chapter 6 amongst Swedish physicians on the issue of undocumented migrant care in which the explicit incursion of the state on medical practice through law evoked. feelings of chaos and powerlessness.

[500] Charles Foster and José Miola, 'Who's in Charge? The Relationship between Medical Law, Medical Ethics, and Medical Morality?' (2015) 23 Medical Law Review 505, 508.

[501] Greenbrook (n 137) 154.

allow for a high degree of specificity in responding to patients, physicians are also given a high degree of latitude. Indeed, exactly what it means to be guided by medicine under this schema may potentially be representative of an arrangement between individual professionals, specialist norms, institutional norms and the specific circumstances of the patient.

3.5.4 The State of Law From a Bottom Up Perspective

Where medicine provides a primary source of control in the navigation of specific clinical encounters involving end-of-life questions with dementia, law persists in its ability to impinge and be instrumentalised in questions of death and dying for patients with dementia. Its force at the end of life consists of upholding autonomy, prohibiting the hastening of death and facilitating the medicalisation of dying by delegating responsibility to medicine. That medicine can, and indeed, does take control in and around the influence of law may be used to claim that there is no need for law in death and dying with dementia. In fact, many of the participants might agree that the realities of end-of-life decision-making should be left up to professional systems of control that are better equipped to deal with the vagaries of life and death. I do not take this, however, as a sign that the investigation of law's role in death and dying with dementia ought to be summarily dismissed in favour of medicine.

Instead, whilst not dismissing the obvious and indeed important, contribution of medicine in relationship to law in the regulation of death and dying with dementia, the intention with this empirical study is to develop an insight into the state of law in the everyday. This is part of an overarching effort to embrace law as a controlling entity that has an important role in the regulation of end-of-life decision-making with dementia which extends to its potential in securing collective responsibility to death and dying with dementia. In this way, knowledge about the use of medicine vis-à-vis law is useful in understanding the issue of legal control in the everyday of end-of-life decision-making with dementia. In this vein, the empirical investigation indicates that the interaction between law and medicine as constructed in this bottom up account demonstrates that law persists as a parameter setting entity that co-signs the medicalisation of death and upholds individualism even as it becomes absent from the realities of end-of-life decision-making with dementia. For now, it is not appropriate to evaluate the nature of these norms. This will be done in relation to the investigation of formal legality in the upcoming chapters. It is nevertheless relevant within the scope of the empirical analysis to conclude that these findings reveal the limitations of law as an influential entity that has the potential to encourage collective responsibility at the end of life for people with dementia where it derogates responsibility for frailty to medicine alone.

3.6 Conclusion

Chapter 3 has demonstrated that multiple forms of regulatory control collide to create a varied tableau of regulation at the coalface of how these physicians engage with end-of-life decision-making with dementia. Notwithstanding the strengths, challenges and limitations of this empirical study as closely unpacked in appendix 1,[502] these findings provide new insights into law in the everyday. In particular, it provides an understanding of the possible constellations of medical and legal control in healthcare as part of a localised account of the role of law in end-of-life decision-making in the context of dementia. A quiet undercurrent to medical practice, law emerges as an iron fist protector and instrument in the protection of life and promotion of self-determination. Despite the possibilities of law's influence, law delegates responsibility for death and dying with dementia to medicine as a quasi-legal regime. This account of a power sharing arrangement between law and medicine is particularly interesting in the way it affords a bottom up perspective of the co-construction of medico-legal power and control over death in which law cosigns the power and influence of medical decision-making at the end of life. To the degree that law allows for medicine to take control of death, law is limited in its potential as a force that could influence end-of-life practice and encourage collective responsibility to death and dying with dementia to issues of independence and the prohibition of death-hastening actions. Having constructed an understanding of law's contribution to the everyday of end-of-life decision-making with dementia, Chapter 3 has set the scene for an investigation of the role of formal legality in constructing and responding to death and dying with dementia. As the upcoming analyses of formal legality in Chapter 4 and Chapter 5 will demonstrate, this construction of law in the everyday is largely mirrored in the law itself.

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[502] Appendix 1 provides a thorough, reflexive account of the strengths, challenges and limitations of this empirical study with reference to issues related to quality, bias, participants and the interview process.

4 The Legal Foundations of Dying & Deciding in Swedish Healthcare

> It is difficult to accept death in this society because it is unfamiliar. In spite of the fact that it happens all the time, we never see it. – Elizabeth Kubler-Ross[503]

4.1 Introduction

Chapter 4 investigates how formal legality constructs and responds to medical decision-making and dying in Swedish healthcare. In critically examining the legal foundations of end-of-life decision-making in Swedish healthcare, it commences the exploration of the limits and possibilities of law in encouraging collective responsibility to death and dying people with dementia. This effort is guided by the following research question:

How are legal obligations in healthcare constructed, and what implications does this have for the legal response to dying and end-of-life decision-making?

The analysis is underpinned by doctrinal analysis and a feminist informed approach to vulnerability whose key principles guide a critique of the ability of law to fulfil basic human needs for agentic support and care at the end of life.

Chapter 4 demonstrates that, off the back of the liberal legal subject, legal obligations in Swedish healthcare are predicated on access to care for good health and non-interference at the limits of medicine. The result is that law largely preserves decision-making as a right and responsibility to be exercised

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[503] Elisabeth Kübler-Ross, *Death* (Simon and Schuster 1975) 5.

with rationality and self-determination. Dying, however, is a marginalised phenomenon that largely prompts avoidance and control wherever possible within the confines medicine. A healthcare regime defined by a return to good health and equal access to healthcare in tandem with the principles of non-interference and science and proven experience produces certain limitations in the legal response to end-of-life decision-making. Whilst a social right to palliative care can be extrapolated to some extent, the principles of self-determination and science and proven experience provide a potentially shaky platform to withdraw and withhold life-sustaining treatment. Moreover, the limits of choice in relation to the presumption that life ought to be maintained is brought into particularly stark relief by the regulation of assisted dying.

The chapter begins by describing and evaluating the nature of the liberal legal subject and its consequences for the legal response to the patient. It then unpacks these implications via an investigation of the legal foundations of Swedish healthcare which includes: the social right to care; the primacy of self-determination; and the principle of science and proven experience. This will be followed by an investigation of how these principles have manifested in relationship to end-of-life decision-making. The regulation of palliative care, withdrawal of treatment and assisted dying are in focus here.

4.2 The Legal Subject

The essential first step in Chapter 4 is to map the legal subject and briefly introduce its implications for law's response to end-of-life decision-making. The legal subject represents "the elementary human subject of law" from which the law is constructed.[504] It is an individual or entity that carries rights and/or responsibilities.[505] In this thesis, it includes individuals as patients and carers within the healthcare system who subsequently have rights and responsibilities in the context of end-of-life decision-making. The focus of this section is largely on the patient who is at the foundation of subsequent responsibilities in healthcare.

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[504] Fineman, 'The Significance of Understanding Vulnerability' (n 39) 1375.

[505] Therése Fridström Montoya, *Homo Juridicus: The Capable Human in Law [Homo juridicus: Den kapabla människan i rätten]* (Iustus förlag 2017) 37.

Presently, the legal subject is constructed within a liberal framework[506] in the western world as self-determining.[507] This accords with the prevailing liberal ideas "of autonomy, self-sufficiency and personal responsibility" in which the individual is considered to be a capable actor who can manage their resources.[508] The subject preferred by law is therefore one that can make "an informed decision" by applying "higher-order reasoning."[509] It has been argued that the liberal imaginings of an abstracted, rational, reasoner minimises the body so that the legal subject is "incidentally, rather than essentially, embodied."[510] That is, the law assumes that humankind operates as decision-making minds, not as bodies.[511] Where a body is assigned to the legal subject, it is physically and cognitively well. This is captured in Naffine's claim that the legal subject

> "seems to be imagined with a rather well-controlled, able and healthy body, which does not pose a problem for the free and effective exercise of reason … Implicitly, his reason is not clouded by sickness or pain; his mind is not impaired by mental illness or disability; he is not pregnant and he is certainly not in labour; he is not a baby or a child (for then he could not reason at a sufficiently sophisticated level); he is not even explicitly sexed."[512]

The nature of this subject occludes human susceptibility to vulnerability[513] and the subsequently natural state of mutability and fragility.[514] In relation to death and dying, where the body of the liberal subject is "constrained, controlled and owned,"[515] the dying body "elude[s] the control both of its own and those

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[506] Fineman, 'The Vulnerable Subject: Anchoring Equality in the Human Condition' (n 267) 167.

[507] Fridström Montoya, *Homo juridicus* (n 505) 38.

[508] Fineman, 'The Vulnerable Subject: Anchoring Equality in the Human Condition' (n 267) 167.

[509] Harding, *Duties to Care* (n 4) 17.

[510] Ngaire Naffine, *Law's Meaning of Life: Philosophy, Religion, Darwin and the Legal Person* (Hart Publishing 2009) 144.

[511] ibid 157.

[512] ibid 144.

[513] Titti Mattsson and Mirjam Katzin, 'Vulnerability and Ageing' in Ann Numhauser-Henning (ed), *Elder Law* (Edward Elgar Publishing 2017) 127.

[514] Herring, 'Ageing and Universal Beneficial Vulnerability' (n 268) 67.

[515] ibid.

participating in a patient's care."[516] Along these lines, the rational, controlled liberal subject as illustrated by Naffine is not dying. Indeed, as the liberal subject is definitionally in control of their body, their death is not even imagined by the law. In this fashion, Lawton argues that where death comes to represent a "terminus" to the self that encased by the body under the tenets of individualism, dying represents a liminality. As a result, it has been said that dying persons are barely perceptible "as members of society."[517]

Where such vulnerabilities are invisible to law, the law is incapable of comprehensively capturing collective responsibility to wellbeing.[518] More accurately, the underpinning liberal subject can be understood to produce two simplistic legal responses. The first avenue is the legal implementation of prohibitions on interference with "autonomy and liberty" due to the assumed rationality and competency of legal subjects.[519] In this way, the disembodied and dis-embedded entity embraces a radical individualism that can be "easily abandoned to legal tools and devices such as consent, … independence, … and rights."[520] Conversely, under the weight of the liberal subject, "those who are not seen as sufficiently autonomous and independent actors are herded together in designated 'vulnerable populations' and are susceptible to monitoring, discipline, and supervision."[521] Fineman has established that that these populations are generally those who are presumed to lack self-sufficiency, like the elderly as well as those who are "profoundly ill or disabled."[522]

I argue that dying persons also arguably fit the bill for protectionism on the same grounds. This follows from the recognition that the "physical and social constraints" experienced by dying persons go against the ideals of autonomy and control.[523] The result is that as the state withdraws from recognising and responding to the needs of the dying person for care and relational support,

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[516] Lawton (n 12) 81; Deborah R Gordon, 'Embodying Illness, Embodying Cancer' (1990) 14 Culture, Medicine and Psychiatry 275, 292.

[517] Lawton (n 12) 173–174; Lloyd (n 143) 239.

[518] Fineman, 'The Significance of Understanding Vulnerability' (n 39) 1375.

[519] Fineman, 'The Vulnerable Subject: Anchoring Equality in the Human Condition' (n 267) 167.

[520] Fineman, 'Introduction: Understanding Vulnerability' (n 40) 5.

[521] Fineman, 'Elderly as Vulnerable' (n 272) 84.

[522] Martha Fineman, 'Elderly as Vulnerable: Rethinking the Nature of Individual and Societal Responsibility' (2012) 20 Elder Law Journal 71, 85.

[523] Lloyd (n 143) 246.

they are simultaneously "conceived as a flawed and incapable chooser" as law seeks to implement restrictive, paternalistic measures to protect dying persons from their impending death, and indeed, themselves.[524] The threat posed by dying to the prototypical human's individualism and bodily control therefore has consequences for the ability of law to perceive and respond to the needs of dying persons beyond protectionist efforts to restore health. The remainder of this chapter considers how this liberal subject manifests in a legal regime that threatens to demand independence until a wish to die is handled with paternalistic overtones rather than agentic support.

4.3 The Legal Foundations of Swedish Healthcare

4.3.1 A Social Right to Healthcare

Chapter 4 now turns to an exploration of the legal principles that form the foundations of Swedish healthcare on the back of this legal subject. First and foremost, it is a social right to healthcare on equal terms, rather than patient rights, which underpins duties in healthcare.[525] This can be traced to the

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[524] Kathy Abrams, 'Three Faces of Privatisation' in Martha Fineman, Titti Mattsson and Ulrika Andersson (eds), *Privatization, Vulnerability, and Social Responsibility: A Comparative Perspective* (Taylor & Francis 2016) at 17-18 makes this claim in relation to the regulation of abortion in America in which the swing to withdraw state support for abortion due to moral concerns related to "a society that aims to manifest respect for life" is accompanied by increasingly restrictive measures in which the state considers the woman seeking a termination to be "a flawed and incapable chooser".

[525] Prop. 2016/17:43 71; Litins'ka, 'Assessing Capacity to Decide on Medical Treatment: On Human Rights and the Use of Medical Knowledge in the Laws of England, Russia and Sweden' (n 124) 470; Elisabeth Rynning, 'The Patients Legal Standing: Two Steps Forward and One Step Back [Patientens rättsliga ställning: Två steg fram och ett tillbaka?]' in Titti Mattsson, Thomas Erhag and Therese Backman (eds), *Book in Celebration of Lotta Vahlne Westerhäll [Festskrift till Lotta Vahlne Westerhäll]* (Santerus Förlag 2011) 309; Lotta Vahlne Westerhäll, *Swedish Patient Legislation: Textbook on Patient 'Rights' in Healthcare [Svensk patientlagstiftning: Lärobok om patienters "rätt" i hälso- och sjukvården]* (3rd edn, Santerus Förlag 2020) 22; Elisabeth Rynning, 'Still No Patients' Act in Sweden - Reasons and Implications' in Elisabeth Rynning and Mette Hartlev (eds), *Nordic Health Law in a European Context: Welfare State Perspectives on Patients' Rights and Biomedicine* (Brill Nijhoff 2011) 124; Anna-Sara Lind, 'The Right to Health and the Medical Law [Rätten till hälsa och den medicinska rätten]' in Kavot Zillén, Titti Mattsson and Santa Slokenberga (eds), *Medical Law [Medicinsk rätt]* (3rd edn, Nordstedts Juridik 2025) 54.

constitutional provisions of the IoG which specify that public institutions are required to promote conditions that are favourable to health.[526] In addition, the Health Care Act (*Hälso och sjukvårdslagen*, HSL) as a goal orientated, framework law,[527] enshrines the abstract healthcare goals[528] of good health (*god hälsa*) and the provision of care on equal grounds for the whole population (*vård på lika villkor för hela befolkningen*).[529] The HSL illustrates the substance of the goal of achieving good health[530] by stipulating that healthcare should: be of good quality; be hygienic; meet patient need for safety and continuity; be built upon respect for patient self-determination and integrity; promote good relationships between healthcare personnel and patients; and be easily accessible.[531] In other words, the HSL indicates that good healthcare should be available to all, and should eliminate differences that arise because of factors such as age.[532] In addition, the definition of healthcare under the HSL is trained on that which prevents, investigates and treats ill-health.[533] Interestingly, whilst the handling of deceased individuals is included,[534] this definition ultimately means that the space between good health and death is limited to the fight towards returning the body to vitality rather than caring for instances of decline. Also determinative for the nature of healthcare are principles contained in the ethical platform.[535] As the primary

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[526] Instrument of Government (1974:152) [Regeringsformen] 1 chap. 2 §.

[527] Rynning, ‘Consent to Medical Care and Treatment: A Legal Study [Samtycke till medicinsk vård och behandling: En rättsvetenskaplig studie]’ (n 124) 115–116; Litins’ka, ‘Assessing Capacity to Decide on Medical Treatment: On Human Rights and the Use of Medical Knowledge in the Laws of England, Russia and Sweden’ (n 124) 470; Axelsson (n 221) 89.

[528] Litins’ka, ‘Assessing Capacity to Decide on Medical Treatment: On Human Rights and the Use of Medical Knowledge in the Laws of England, Russia and Sweden’ (n 124) 470; Axelsson (n 221) 93; Enequist (n 236) 21.

[529] Health Care Act (2017:30) [Hälso och sjukvårdslagen] 3 chap. 1 §.

[530] Litins’ka, ‘Assessing Capacity to Decide on Medical Treatment: On Human Rights and the Use of Medical Knowledge in the Laws of England, Russia and Sweden’ (n 124) 470–471.

[531] Health Care Act (2017:30) [Hälso och sjukvårdslagen] 5 chap. 1 §.

[532] Axelsson (n 221) 101–102.

[533] Health Care Act (2017:30) [Hälso och sjukvårdslagen] 2 chap. § 1.

[534] ibid.

[535] Lind, ‘The Right to Health and the Medical Law [Rätten till hälsa och den medicinska rätten]’ (n 525) 55.

principle, the value of human life (*människovärdeprincipen*)[536] is formulated in the HSL as the requirement that care be given with respect to the equal value of human life and dignity of the individual person.[537] It has been taken to represent the position that patients should not be discriminated against in healthcare regardless of what function they fulfil in society, or their personal characteristics.[538] It is also said to be illustrated by the principles of autonomy, doing good, no harm and justice.[539]

In line with Herring's claim that law should uphold care,[540] the codification of an obligation to provide equal care may be (at least initially) looked upon favourably. There are, however, limitations to a social right intimately bound with the obligation to return to good health,[541] and prevent ill-health[542] for people faced with end-of-life questions. Certainly, Lind recognises the social right to healthcare as instrumental in efforts to ensure that subjects are participating in the welfare state.[543] Although it is of course important to heal and cure in the pursuit of care,[544] the liberal subject's exclusive focus upon those who can be returned to good health and independence[545] means that the preferred focus of law is "on the investment in the future than on the coming

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[536] Also accompanied by the needs and solidarity principle (HSL chap 3. 1 §) and cost effectiveness principle (HSL chap 4. 1 §).

[537] Health Care Act (2017:30) [Hälso och sjukvårdslagen] 3 chap. 1 §.

[538] Axelsson (n 221) 103.

[539] Socialstyrelsen, 'To Give or Not to Give Life-Sustaining Treatment: Handbook for Healthcare Providers, Business Managers and Staff [Om att ge eller inte ge livsuppehållande behandling: Handbok för vårdgivare, verksamhetschefer och personal]' (2011) 25.

[540] Herring, *Vulnerable Adults and the Law* (n 285) 18.

[541] Axelsson (n 221) 101; Litins'ka, 'Assessing Capacity to Decide on Medical Treatment: On Human Rights and the Use of Medical Knowledge in the Laws of England, Russia and Sweden' (n 124) 470; Health Care Act (2017:30) [Hälso och sjukvårdslagen] 3 chap. 1 §.

[542] Health Care Act (2017:30) [Hälso och sjukvårdslagen] 3 chap. 2 §.

[543] Lind, 'The Right to Health and the Medical Law [Rätten till hälsa och den medicinska rätten]' (n 525) 54–55; Anna-Sara Lind, 'Social Rights under Change: A Constitutional Study [Sociala rättigheter i förändring: En konstitutionellrättslig studie]' (PhD, Uppsala University 2009) 25.

[544] Daniel Engster, *Justice, Care, and the Welfare State* (Oxford University Press 2015) 93.

[545] Harding, 'Response: Reflections on Ageing and the Binaries of Vulnerability' (n 310) 85–86.

death of the older person whose contributions are already made."[546] The dying patient is therefore overtly, and indeed, purposefully excluded from the framework that sets out the fundamental obligations of Swedish healthcare. In this milieu, the requirement of equality does not serve to afford equal protections in death as in life. This is because a call for equality in care that does not consider age and problems of dying provides little in the way of support for end-of-life needs.[547] In other words, a focus on what equal care means for preserving and returning good health says little about the kind of care that is required to achieve wellbeing in the face of death and dying. This follows Fineman's claim that formal equality is incapable of dismantling, and can in fact, legitimise "institutional arrangements that privilege some and disadvantage others."[548]

4.3.2 Dignity, Self-Determination & Informed Consent

As briefly noted above, the social right to healthcare is also closely related to a right to care on the grounds of non-interference. That patients are protected via privacy principles that prohibit interference in one's entitlement to liberty is a logical corollary of the liberal account of a legal subject as a competent rational agent.[549] Indeed, this is deeply embedded in the Swedish regulatory regime of healthcare. One way this manifests is through the concept of dignity. The significance of dignity is captured by the IoG's stipulation that public power be exercised with respect to the equal worth of all, dignity and freedom.[550] The Patient Act (*Patientlagen*) as a specific intervention in the regulation of healthcare also requires care to be given with respect to the patient's human value and human dignity.[551] Although the meaning of dignity has been said to lack clear legal meaning,[552] in the legal regulation of healthcare, it has evidently been associated with ideas of equality and

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[546] Mattsson and Katzin (n 513) 121.

[547] Lloyd (n 143) 251.

[548] Fineman, 'The Vulnerable Subject: Anchoring Equality in the Human Condition' (n 267) 162.

[549] ibid 167.

[550] Instrument of Government (1974:152) [Regeringsformen] 1 chap. 2 §.

[551] Patient Act (2014:821) [Patientlagen] 1 chap. 6 §.

[552] Mona Haghgou Strindberg, 'Human Dignity in Sweden' in Paolo Becchi and Klaus Mathis (eds), *Handbook of Human Dignity in Europe* (Springer 2019) 12–13.

integrity.[553] The latter is in turn linked with the preservation of one's wholeness against outside intrusion.[554]

Expressing similar principles, self-determination is also central to the legal regulation of healthcare. The preparatory works to the original iteration of the HSL indicate that self-determination as conceived of in law is seated in a liberal understanding in which the patient is constructed as having both responsibilities and rights to self-determination, integrity and inviolability as an autonomous decision-maker.[555] This was actualised in the position that it was important that patients wields influence over their care through receiving information, making decisions about care and participating in care decisions.[556] Constructed in this form, the government recognised the potential for conflict between self-determination and the value of human life as contained in the ethical platform as illustrated by the following excerpt from the proposition to the ethical platform's inclusion into the HSL:

> "It can be said that not everyone who needs care is aware of their needs, or that those who are aware of their needs do not always have the strength to express them."[557]

With this in mind, they elected to exclude self-determination from the priority setting ethical platform.[558]

Nevertheless, self-determination has only continued to grow in significance.[559] It has replaced the historical centrality of the doctor with specific knowledge and competence[560] to occupy a position of high importance.[561] This has culminated with the Patient Act's demand that healthcare must be respectful

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[553] ibid 9.

[554] Prop. 2009/10:83 15.

[555] Prop. 1981/82:97 48–49.

[556] ibid 48 & 50.

[557] Prop. 1996/97:60 23.

[558] ibid.

[559] Rynning, 'Consent to Medical Care and Treatment: A Legal Study [Samtycke till medicinsk vård och behandling: En rättsvetenskaplig studie]' (n 124) 67–69.

[560] ibid 67.

[561] Mattsson and Giertz (n 41) 144.

of the self-determination and integrity of patients.[562] Indeed, the proposition to the Patient Act indicates that it was intended to strengthen the position of patients as actors rather than objects of care which includes promoting integrity, self-determination and participation in their own healthcare.[563] This demand for autonomy[564] has manifested in the presumption that the patient is an autonomous decision-maker[565] who may rightfully "make their voice heard and to give or withhold their consent."[566]

As the pivotal rule in healthcare,[567] consent is indirectly regulated by the IoG[568] which enshrines protection of bodily integrity against forced physical intrusion by public institutions.[569] This provision should be interpreted as applicable to the vast majority of forced medical interventions within the healthcare context.[570] The preparatory works for instance note that physical intrusion includes health related activities such as examinations by doctors, minor procedures such as vaccinations and blood sampling as well as similar phenomena that are usually denoted by the term bodily inspection.[571] However, the meaning of "forced" as the quality of intervention that the IoG protects patients from[572] has been difficult to interpret[573] resulting in significant

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[562] Patient Act (2014:821) [Patientlagen] 4 chap. 1 §.

[563] Prop. 2013/14:106 41.

[564] Fridström Montoya, *Homo juridicus* (n 505) 39.

[565] Mattsson and Giertz (n 41) 148.

[566] ibid 149.

[567] Yana Litins'ka, 'Consent and Decision-Making Competence in Care [Samtycke och beslutskompetens i vården]' in Kavot Zillén, Titti Mattsson and Santa Slokenberga (eds), *Medical Law [Medicinsk rätt]* (3rd edn, Nordstedts Juridik 2025) 105.

[568] ibid 86.

[569] Instrument of Government (1974:152) [Regeringsformen] 2 chap. 6 §.

[570] Litins'ka, 'To Force or Not to Force: Protecting the Lives of Persons with Dementia Who Refuse Care' (n 124) 467.

[571] Prop. 1975/76:209 147.

[572] Litins'ka, 'Assessing Capacity to Decide on Medical Treatment: On Human Rights and the Use of Medical Knowledge in the Laws of England, Russia and Sweden' (n 124) 458.

[573] Moa Dahlin and Sara Åkerström, 'Coercive and restrictive measures in dementia care: Illegal restriction of rights? [Tvångs- och begränsningsåtgärder inom demensvården: olagliga rättighetsbegränsningar?]' [2012] Förvaltningsrättslig Tidskrift 481, 490.

debate.[574] As no insight has been provided by the preparatory works,[575] a sense of what "forced" may represent must be garnered with reference to scholarly literature. Litins'ka argues that taken literally, explicit refusal or physical resistance indicates that the care is forced.[576] Rynning elaborates that in addition to physical force, "forced" includes threats and the denial of the opportunity to express reluctance or opposition.[577] The defining characteristic of "forced" must, however, hinge upon the understanding and experience of the patient themselves. This follows Dahlin's reasoning that its meaning must account for the perception of the patient in addition to the coercive act itself.[578] Whether or not the individual can be understood to be voluntarily consenting to treatment therefore represents the dividing line in determining whether or not care represents a forced bodily intervention prohibited under the IoG.[579]

Beyond the constitution, the enactment of the Patient Act in 2015 instituted a specific, general requirement of consent to treatment.[580] Central to the requirement of consent is the provision of information. This is encapsulated by chapter 4, section 2 of the Patient Act which stipulates that healthcare must not be given without the patient's consent, unless otherwise provided for in law. A patient may consent in writing, orally or by other means that expresses consent to the care measure. Before consent is obtained, the patient must receive information pursuant to chapter 3 of the Patient Act.[581] Indeed, the preparatory works state that consent will only be valid if preceded by the provision of all information necessary to make the decision.[582] The Patient Act identifies that

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[574] Litins'ka, 'Assessing Capacity to Decide on Medical Treatment: On Human Rights and the Use of Medical Knowledge in the Laws of England, Russia and Sweden' (n 124) 459.

[575] Dahlin and Åkerström (n 573) 490.

[576] Litins'ka, 'To Force or Not to Force: Protecting the Lives of Persons with Dementia Who Refuse Care' (n 124) 467.

[577] Rynning, 'Consent to Medical Care and Treatment: A Legal Study [Samtycke till medicinsk vård och behandling: En rättsvetenskaplig studie]' (n 124) 107.

[578] Dahlin (n 218) 12.

[579] Rynning, 'Consent to Medical Care and Treatment: A Legal Study [Samtycke till medicinsk vård och behandling: En rättsvetenskaplig studie]' (n 124) 108; Litins'ka, 'To Force or Not to Force: Protecting the Lives of Persons with Dementia Who Refuse Care' (n 124) 468; Nils Jareborg, *General Criminal Law [Allmän kriminallrätt]* (Iustus Förlag 2001) 286.

[580] Prop. 2016/17:43 72; Patient Act (2014:821) [Patientlagen] 4 chap. 2 §.

[581] Patient Act (2014:821) [Patientlagen] 4 chap. 2 §.

[582] Prop. 2013/14:106 119.

information should be provided about the state of the patient's health, available methods for investigation, care and treatment, support aids for people with disability, the time frame in which the patient should expect care, the course of treatment, significant risks, complications and side effects, after care and preventative health methods.[583] This list however, should not be approached as a "check-list."[584] Rather, the information should be individualised so as to be appropriate to the unique needs of the patient including, but not limited to, their age, experience, and other individual circumstances.[585] Healthcare providers are obliged to ensure that information is given to the patient, and those in a close relationship[586] where this does not contravene confidentiality and/or non-disclosure provisions.[587] Furthermore, patients who do not wish to receive information must also be respected.[588]

More substance is provided to the requirement of information provision by the stipulation that the person giving the information is required to ensure that the patient has understood the content and meaning of the information as far as possible.[589] This requirement is connected to two important concerns in the context of this study. The first is that this requirement may lead to the "inhumane" situation where a doctor extends this obligation to asking a patient several times if they understand their terminal diagnosis means that they will soon die.[590] The second is that whilst this information must be provided for legally valid consent, the substance of this connection between information and decision-making in healthcare remains legally unclear. It has been argued that the role of the caregiver in the information process includes an active role in guiding and supporting an evaluation of the information.[591] Ultimately however, the legislation does not provide further direction as to the

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[583] Patient Act (2014:821) [Patientlagen] 3 chap. 1 §.

[584] Litins'ka, 'Assessing Capacity to Decide on Medical Treatment: On Human Rights and the Use of Medical Knowledge in the Laws of England, Russia and Sweden' (n 124) 477.

[585] Prop. 2013/14:106 117–118; Patient Act (2014:821) [Patientlagen] 3 chap. 6 §.

[586] Patient Safety Act (2010:659) [Patientsäkerhetslagen] 6 chap. 6 §.

[587] Patient Act (2014:821) [Patientlagen] 3 chap. 5 §.

[588] ibid 3 chap. 6 § para 2.

[589] Patient Safety Act (2010:659) [Patientsäkerhetslagen] 3 chap. 7 §.

[590] Lars-Åke Johnsson, *The New Patient Safety Law and Patient Rights: Handbook for Representatives and Healthcare Workers [Den nya patientsäkerhetslagen och patients rättigheter: Handbok för ombud och vård personal]* (Thomson Reuters 2010) 54–55.

[591] Westerhäll (n 525) 105.

consequences of not understanding information for the legal validity of the consent.[592] Thus, whilst the centrality of information in the consent process evidently departs from the assumption that information is a necessary foundation of self-determination, control and respect for the patient,[593] the approach taken arguably embodies the accepted understanding that carers "make the relevant information available, then … adopt a stance of non-interference in the patient's decision-making."[594]

Rynning argues that consultation is also an implicit element of informed consent.[595] The basic concept behind consultation is to reduce the risk that the patient is positioned as a purely passive object in favour of promoting joint planning and decision-making between patient and caregiver.[596] This is captured in the legislative requirement that care be planned and implemented in collaboration with the patient to the greatest extent possible.[597] The implementation of consultation is explicitly extended to those in a close relationship with the patient who are legislatively provided a role in the design and implementation of care where appropriate under the principles of confidentiality and non-disclosure.[598]

The centrality of self-determination is brought to a head with the fact that Swedish law does not allow for patients to be declared legally incompetent in relation to issues of healthcare.[599] In other words, all patients are expected to act with responsibility and self-sufficiency on matters of care in the Swedish

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[592] Litins'ka, 'Assessing Capacity to Decide on Medical Treatment: On Human Rights and the Use of Medical Knowledge in the Laws of England, Russia and Sweden' (n 124) 474; Prop. 2013/14:106 for example canvasses the information provision at 48 & 52-57 but neglects to consider issues relating to comprehension.

[593] Prop. 2013/14:106 47; Westerhäll (n 525) 99.

[594] Natalie Stoljar, 'Informed Consent and Relational Conceptions of Autonomy' (2011) 36 The Journal of Medicine and Philosophy 375, 375–376.

[595] Rynning, 'Right to Live and Right to Die [Rätt till liv och rätt att dö]' (n 122) 93.

[596] Westerhäll (n 525) 102.

[597] Patient Act (2014:821) [Patientlagen] 5 chap. 1 §; Patient Safety Act (2010:659) [Patientsäkerhetslagen] 6 chap. 1 §.

[598] Patient Act (2014:821) [Patientlagen] 5 chap. 3 §.

[599] Litins'ka, 'Assessing Capacity to Decide on Medical Treatment: On Human Rights and the Use of Medical Knowledge in the Laws of England, Russia and Sweden' (n 124) 448; Prop. 1987/88:124 1; Therése Fridström Montoya, 'Consent to Care: A Matter of Legal Capacity and Agency [Samtycke till vård: En fråga om rättshandlingsförmåga och ställföreträdarskap]' (2020) 1 Ny Juridik 43, 46.

state.[600] In fact, scholarship has long confirmed that an analysis of the relevant constitutional and legislative frameworks indicate that capacity has no bearing on the ability and obligation to provide legal consent in healthcare.[601] The implications for a system predicated upon an individualistic approach to decision-making in healthcare for people with dementia will be developed more fully in the next chapter. It nevertheless bears re-emphasising for now that a system of healthcare based on the general ideals of "independence and personal responsibility" may not only result in misplaced paternalism," but can also result in the inappropriate imposition of individual responsibility.[602] In the case of access to healthcare more generally, the influence of the liberal subject has clearly led to the latter where informed consent is actualised through the provision of information is a right and obligation of every patient that is protected in law.

4.3.3 Science & Proven Experience

Alongside the promotion and protection of self-determination is the principle of science and proven experience. Referred to as the "gold standard" of healthcare decision-making, [603] science and proven experience is central to the regulation of Swedish healthcare.[604] It is enshrined in the stipulation that patients must be afforded health care that is expert, caring, good quality and representative of science and proven experience.[605] On the one hand, it establishes the standard for healthcare practice. It requires, for instance, that

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[600] Mattsson and Katzin (n 513) 121.

[601] SOU 1988:7 105–106; Rynning, 'Consent to Medical Care and Treatment: A Legal Study [Samtycke till medicinsk vård och behandling: En rättsvetenskaplig studie]' (n 124) 110; Litins'ka, 'To Force or Not to Force: Protecting the Lives of Persons with Dementia Who Refuse Care' (n 124) 468; Litins'ka, 'Assessing Capacity to Decide on Medical Treatment: On Human Rights and the Use of Medical Knowledge in the Laws of England, Russia and Sweden' (n 124) 490.

[602] Dodds, 'Dependence, Care, and Vulnerability' (n 285) 198.

[603] Lena Wahlberg and Johannes Persson, 'Importing Notions in Health Law: Science and Proven Experience' (2017) 24 European Journal of Health Law 565, 565.

[604] Lena Wahlberg and Nils-Eric Sahlin, 'On Non-Acceptable Treatment Methods and the Requirement for Science and Proven Experience [Om icke vedertagna behandlingsmetoder och kravet på vetenskap och beprövad erfarenhet]' [2017] Förvaltningsrättslig Tidskrift 45, 47.

[605] Patient Act (2014:821) [Patientlagen] 1 chap. 7 §; Patient Safety Act (2010:659) [Patientsäkerhetslagen] 6 chap. 1–2 §§.

the regulations and general advice of the NBHW are known and adhered to.[606] Where healthcare fails to meet this standard, legal consequences are possible. For example, a failure to comply can result in formal legal consequences for healthcare personnel such as critique from IVO.[607] That care meets the threshold of science and proven experience is also the line between legal healthcare and criminal behaviour.[608] Besides this, patient choice is also delimited by the fact that only treatment that accords with standard of science and proven experience can be requested.[609]

Yet in spite of the significance of science and proven experience, it has been described as a "notoriously vague" concept[610] which is not defined in law,[611] and whose applicability may hinge upon the way it is applied by particular interpreters.[612] Furthermore, its meaning evidently shifts overtime in relation to medical and social developments.[613] Notwithstanding these difficulties, it is adequate for the purpose of this research to draw on Wahlberg and Sahlin whose analysis helpfully concludes that the concept intends "to promote the safety of the individual patient and the effectiveness of the treatment in the concrete treatment situation."[614] It is therefore evidently bound to the realities and practicalities surrounding each instance of medical practice even whilst the concept arguably has a legal dimension.[615] In this way, it can be understood to represent a medical standard of acceptable practice that has been imported into law.[616] It is also, however, important to highlight that science and proven experience might be interpreted as encompassing ethical dimensions in

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[606] Westerhäll (n 525) 81.

[607] Patient Safety Act (2010:659) [Patientsäkerhetslagen] 8 chap.

[608] Prop. 1993/94:130 43–44.

[609] Patient Act (2014:821) [Patientlagen] 7 chap. 1 §.

[610] Wahlberg and Persson (n 603) 565.

[611] Axelsson (n 221) 230; Wahlberg and Sahlin (n 604) 53.

[612] Wahlberg and Persson (n 603) 590.

[613] Axelsson (n 221) 241.

[614] Wahlberg and Sahlin (n 604) 54–56.

[615] Lena Wahlberg, 'Conceptual Challenges for Legal Certainty on the Border between Law and Medicine [Konceptuella utmaningar för rättssäkerheten i gränslandet mellan juridik och medicin]' in Nils-Eric Sahlin (ed), *Science and Proven Experience: Law [Vetenskap och beprövad erfarenhet: Juridik]* (Media Tryck 2016).

[616] Wahlberg and Persson (n 603) 566–567.

determining medical futility and relevant treatment for dying persons.[617] To the degree that it is understood to encompass ethics, it has also been interpreted as enshrining the principles of beneficence and non-maleficence.[618] The particular relevance of both the best practice and ethical dimensions of science and proven experience to end-of-life decisions will be developed as the analysis progresses over the next two chapters.

4.4 End-of-Life Law

4.4.1 Palliative Care

A liberal legal regime underpinned by equal access to a return to good health based on a non-interference conceptualisation of self-determination and science and proven experience produces a peculiar effect on the legal response to end-of-life decision-making. In regards to palliative care, the minimisation of the dying subject poses a sustained threat to the possibility of identifying and pursuing appropriate end-of-life care. Indeed, the NBHW has interpreted science and proven experience so that the first duty of healthcare is to protect life, treat and cure illness as far as possible.[619] Furthermore, the goal of good health in healthcare has been recognised as distinct from goal to improve quality of life in palliative care.[620] Nevertheless, the NBHW has acknowledged that science and proven experience also demands the provision of comfort and relief in the absence of curative possibilities.[621] This is echoed in the scholarly

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[617] Rynning, ‘Consent to Medical Care and Treatment: A Legal Study [Samtycke till medicinsk vård och behandling: En rättsvetenskaplig studie]’ (n 124) 137.

[618] Rynning, ‘The Law as Guiding Principles [Juridiken som rättesnöre]’ (n 238) 275.

[619] Socialstyrelsen, ‘To Give or Not to Give Life-Sustaining Treatment: Handbook for Healthcare Providers, Business Managers and Staff [Om att ge eller inte ge livsuppehållande behandling: Handbok för vårdgivare, verksamhetschefer och personal]’ (n 539) 24–25.

[620] Socialstyrelsen, ‘National Knowledge Support for Good Palliative Care at the End of Life: Guidance, Recommendations and Indicators [Nationellt kunskapsstöd för god palliativ vård i livets slutskede: Vägledning, rekommendationer och indikatorer]’ (n 47) 72.

[621] Socialstyrelsen, ‘To Give or Not to Give Life-Sustaining Treatment: Handbook for Healthcare Providers, Business Managers and Staff [Om att ge eller inte ge livsuppehållande behandling: Handbok för vårdgivare, verksamhetschefer och personal]’ (n 539) 24–25.

recognition that where the possibility for curative treatment is excluded, good care must continue in the form of palliative interventions.[622]

Indeed, a social right to palliative care is arguably embedded in a regime that protects and promotes access to healthcare via a social right to healthcare more generally. This follows Brennan's argument that a right to palliative care can be implied from the human right to health[623] as palliative care constitutes a dimension of healthcare.[624] This is also captured by the General Committee of the International Convention on Economic and Social Rights which has recognised the right to health as an inclusive right that obliges states to refrain "from denying or limiting equal access for all persons to … preventative, curative and palliative health services."[625] More recently, the European Court of Human Rights (ECtHR) recognised the importance of a humane approach to end-of-life suffering which "must necessarily include palliative care that is guided by compassion and high medical standard."[626]

Domestically, legal guidance as provided by the NBHW and soft law sources produced by professional medical bodies have given substance to the nature of palliative care in Sweden. Four pillars of palliative care have been developed with reference to the World Health Organisation's principles of palliative care and the principle of human dignity. These are: symptom management; multi-professional cooperation; communication and interrelationships to secure life quality; and support for relatives.[627] In regards to symptom management, palliative care involves a holistic approach to managing pain and distressing symptoms including physical, psychological, social and existential pain[628] and is connected to promoting quality of life without extending life or hastening

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[622] ibid 40; Rynning, 'Right to Live and Right to Die [Rätt till liv och rätt att dö]' (n 122) 100.

[623] See for example the International Covenant on Economic, Social and Cultural Rights article 12(1) right to the highest attainable standard of health; the European Social Charter article 11 right to benefit from measures enabling the highest possible attainable standard of health; and Charter of Fundamental Rights of the European Union article 35 right to benefit from medical treatment.

[624] Frank Brennan, 'Palliative Care as an International Human Right' (2007) 33 Journal of Pain and Symptom Management 494, 495.

[625] 'Committee on Economic, Social and Cultural Rights, General Comment No. 14: Article 12 The Right to the Highest Attainable Standard of Health, E/C. 12/2000/4, 11 August' paras 11 & 34.

[626] Karsai v Hungary [2024] ECtHR App no. 32312/23 para 158.

[627] SOU 2001:6 55–56; Regionala Cancercentrum (n 48) 24–25.

[628] SOU 2001:6 55; Regionala Cancercentrum (n 48) 23–24.

death in the context of affirming life and recognising dying as normal.[629] According to the NBHW, it can include medication for pain management, fatigue, confusion and anxiety as well as alternative treatment options such as acupuncture to reduce symptoms.[630] As per multi-professional co-operation, healthcare workers are encouraged to engage ensure appropriate planning within the care team. This includes the provision of information to the team as to what to expect at the very end of life and early planning to promptly follow up on symptom management.[631]

Furthermore, good communication with the patient as well as family is encouraged and recognised as central to appropriate end-of-life care.[632] Communication is formally framed by the *brytpunktssamtal* or goals of care conversation which distinguishes the transition to the final phase of palliative care characterised by efforts to manage suffering and enhance quality of life for the patient and their family.[633] In this conversation, the patient, their family and the doctor discuss the shift from curative to palliative treatment as well as the content of that palliative care.[634] This may take the form of one or several conversations[635] which should involve the exchange of information about the

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[629] SOU 2001:6 55.

[630] Rynning, 'Right to Live and Right to Die [Rätt till liv och rätt att dö]' (n 122) 100; Socialstyrelsen, 'To Give or Not to Give Life-sustaining Treatment: Handbook for Healthcare Providers, Business Managers and Staff [Om att ge eller inte ge livsuppehållande behandling: Handbok för vårdgivare, verksamhetschefer och personal]' (n 539) 40; Socialstyrelsen, 'National Knowledge Support for Good Palliative Care at the End of Life: Guidance, Recommendations and Indicators [Nationellt kunskapsstöd för god palliativ vård i livets slutskede: Vägledning, rekommendationer och indikatorer]' (n 47) 41 & 47–51.

[631] Socialstyrelsen, 'Symptom Management at the End of Life: Drug Treatment in Palliative Care for Covid-19 [Symtomlindring i livets slutskede: Läkemedelsbehandling i palliativ vård vid Covid-19]' (2020) 5.

[632] Ibid.

[633] Socialstyrelsen, 'National Knowledge Support for Good Palliative Care at the End of Life: Guidance, Recommendations and Indicators [Nationellt kunskapsstöd för god palliativ vård i livets slutskede: Vägledning, rekommendationer och indikatorer]' (n 47) 18.

[634] Regionala Cancercentrum (n 48) 39; Socialstyrelsen, 'National Knowledge Support for Good Palliative Care at the End of Life: Guidance, Recommendations and Indicators [Nationellt kunskapsstöd för god palliativ vård i livets slutskede: Vägledning, rekommendationer och indikatorer]' (n 47) 19.

[635] Socialstyrelsen, 'National Knowledge Support for Good Palliative Care at the End of Life: Guidance, Recommendations and Indicators [Nationellt kunskapsstöd för god palliativ vård i livets slutskede: Vägledning, rekommendationer och indikatorer]' (n 47) 53.

purpose of care being to “promote quality of life and relieve symptoms.” That there are few to no opportunities to extend the patient’s short remaining lifespan should also be communicated. In this, “clear and individually tailored information” and active listening to encourage patient participation is essential.[636] This is recognised as an important process given that poor communication with patients has been found to result in “excess mortality and unnecessary treatment in inpatient care.”[637] Finally, on the question of family, they are recognised as affording integral support for the patient[638] as well as loved ones in need of support in the midst of the illness and post death themselves.[639]

Ethics are central to the guidance of palliative care provision. Autonomy, for instance, as manifest through self-determination and patient participation in palliative care decisions, has been constructed as central to palliative care in Swedish policy and guidelines.[640] To this end, the multi-disciplinary team are guided to consult with the patient so that their wishes and needs are attended to in line with sections 1, 6 and 7 of the Patient Safety Act.[641] However, while the patient can request to abstain from treatment, they cannot demand any palliative care treatment they wish where such treatment is not commensurate with science and proven experience.[642] In addition, the principle of do no harm emphasises the obligation to reduce harm and suffering through palliative care.[643] In encouraging sensitivity to the effects of possible treatments on

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[636] ibid 52–53.

[637] Prop. 2013/14:106 47; Westerhäll (n 525) 99.

[638] Regionala Cancercentrum (n 48) 15.

[639] SOU 2001:6 55.

[640] Regionala Cancercentrum (n 48) 27–28; Axel Ågren and others, ‘Policy Narratives on Palliative Care in Sweden 1974–2018’ (2023) 31 Health Care Analysis: An International Journal of Health, Philosophy and Policy 99, 107.

[641] Socialstyrelsen, ‘National Knowledge Support for Good Palliative Care at the End of Life: Guidance, Recommendations and Indicators [Nationellt kunskapsstöd för god palliativ vård i livets slutskede: Vägledning, rekommendationer och indikatorer]’ (n 47) 37.

[642] ibid.

[643] Socialstyrelsen, ‘To Give or Not to Give Life-Sustaining Treatment: Handbook for Healthcare Providers, Business Managers and Staff [Om att ge eller inte ge livsuppehållande behandling: Handbok för vårdgivare, verksamhetschefer och personal]’ (n 539) 25; Socialstyrelsen, ‘National Knowledge Support for Good Palliative Care at the End of Life: Guidance, Recommendations and Indicators [Nationellt kunskapsstöd för god palliativ vård i livets slutskede: Vägledning, rekommendationer och indikatorer]’ (n 47) 71–72.

quality of life with consideration to what would provide the most benefit to the patient, the Regional Cancer Centre's (*Regionala Cancercentrum)* National Palliative Care Program sets out the following guiding questions: "what can we do; what should we do; for whose sake are we doing it for?"[644] Thus, whilst this necessarily requires medical knowledge and expertise, it also demands that the patient, their needs and their reactions, lie at the centre of care.[645] End-of-life decision-making may therefore be guided to consider both the medical realities (for example medical futility) as well as the patient's perspective to produce a mutual understanding of care options. For example, to maintain life-sustaining treatment for a short period of time where it does not cause undue harm to the patient but allows for them to say goodbye to family. Furthermore, the principle of justice as contained in the value of human life undergirds the importance of equal treatment to palliative care.[646]

An important consideration in an investigation of palliative care is the fact that palliative treatment can have side effects. The foreseeable benefits of any treatment must be balanced against the consequences of possible risks. This is cosigned by the principles of beneficence and non-maleficence which establish that the side-effects of palliative care, may be acceptable when they are outweighed by its possible benefits.[647] However, the relationship between benefits and risks comes to a head where the possible risk of managing suffering and enhancing life quality goes hand in hand with the risk that death is hastened.[648] Palliative care that shortens life is only legally possible under the following conditions:

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[644] Regionala Cancercentrum (n 48) 27.

[645] Socialstyrelsen, 'To Give or Not to Give Life-Sustaining Treatment: Handbook for Healthcare Providers, Business Managers and Staff [Om att ge eller inte ge livsuppehållande behandling: Handbok för vårdgivare, verksamhetschefer och personal]' (n 539) 25; Socialstyrelsen, 'National Knowledge Support for Good Palliative Care at the End of Life: Guidance, Recommendations and Indicators [Nationellt kunskapsstöd för god palliativ vård i livets slutskede: Vägledning, rekommendationer och indikatorer]' (n 47) 71–72.

[646] Regionala Cancercentrum (n 48) 28.

[647] Socialstyrelsen, 'To Give or Not to Give Life-Sustaining Treatment: Handbook for Healthcare Providers, Business Managers and Staff [Om att ge eller inte ge livsuppehållande behandling: Handbok för vårdgivare, verksamhetschefer och personal]' (n 539) 25.

[648] Mattsson and Wahlberg (n 51) 306.

- The purpose cannot be to shorten life in order to reduce suffering. Rather, the hastening of death must be an unintended side effect of measures taken to reduce suffering.[649]
- On balance, the treatment is considered to contribute to pain relief and enhance quality of life to a greater extent than it risks hastening death. This is determined through an assessment of the extent to which the benefits are expected on the one hand, and how great the risk of hastening death on the other.
- The reduction of suffering and enhancement of quality of life cannot be achieved through other, less risky, measures.[650]

Continuous palliative sedation offers an example through which the practical problems and limits of these conditions become evident. Palliative sedation involves the

> "intermittent or continuous administration of sedative and anti-anxiety drugs in the dose sufficient to induce such a lowering of the level of consciousness that the patient no longer perceives severe symptoms."[651]

The degree of sedation may contribute to the weakening of life-sustaining functions, and therefore, may hasten death.[652] Furthermore, in connection with continuous palliative in which consciousness is reduced until death, fluid and nutrition is not considered meaningful and is therefore routinely withdrawn.[653] If not performed in close proximity to death, continual palliative sedation may therefore significantly hasten death.[654] The NBHW has noted that continuous palliative sedation is legally valid where it adheres to the requirements of good

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[649] Rynning, 'Right to Live and Right to Die [Rätt till liv och rätt att dö]' (n 122) 113.

[650] Mattsson and Wahlberg (n 51) 306.

[651] Socialstyrelsen, 'To Give or Not to Give Life-Sustaining Treatment: Handbook for Healthcare Providers, Business Managers and Staff [Om att ge eller inte ge livsuppehållande behandling: Handbok för vårdgivare, verksamhetschefer och personal]' (n 539) 8.

[652] ibid 42–43.

[653] Statens Medicinsk-Etiska Råd, 'Assisted Dying: A Knowledge Compilation [Dödshjälp: En kunskapssammanställning]' (2017:2) 68.

[654] ibid.

care as contained in the principle of science and proven experience.[655] However, the extent to which death may be hastened causes complicated legal questions to arise.

Ultimately, how close a patient must be to death in order to constitute legally acceptable circumstances is uncertain.[656] Mattsson and Wahlberg note that legal acceptability may hinge upon whether or not the patient is already near death because of their illness, or, their death is "significantly" hastened by these measures.[657] In this vein, Rynning states that continuous palliative sedation involving the removal of artificial nutrition and hydration under circumstances where death is not "judged to be near," may be taken to represent an intentional act to end a patient's life.[658] However, according to the State Medical-Ethics Advisory (*Statens medicinsk-etiska råd*),[659] there are many different views on the timing of palliative sedation from health bodies. Advice from the Medical Products Agency (*Läkemedelsverket*) for instance is that continual palliative sedation is only possible where a patient is judged to have "hours to days" before death.[660] A different position is forwarded by the Swedish Society of Medicine in their palliative sedation guidelines which set out two slightly separate conditions. Whilst palliative sedation is considered possible where the expected life expectantly is "very short, usually at the most one to two weeks," continual palliative sedation is appropriate where "the patient's expected survival is judged to be short."[661] In a different formulation again, the NBHW suggests that continual palliative sedation may be provided over "a longer or shorter time dependent on the patient's wishes, condition and

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[655] Socialstyrelsen, 'Clarification on Palliative Sedation [Tydliggörande om palliativ sedering]' (2010) Meddelandeblad nr 10/2010 2.

[656] Mattsson and Wahlberg (n 51) 313.

[657] ibid.

[658] Elisabeth Rynning, 'Statement Concerning the Legal Prerequisites for the Application of Sedation Therapy in the Swedish Health Care System [Utlåtande rörande de rättsliga förutsättningarna för tillämpning av sederingsterapi i den svenska hälso- och sjukvården]' (Smer 2013) dnr 27/12 6.

[659] Statens Medicinsk-Etiska Råd (n 653) 68–69.

[660] Läkemedelsverket, 'Pain Relief at the End of Life - New Recommendation. Information from the Swedish Medical Products Agency [Smärtlindring i livets slutskede – Ny rekommendation. Information från Läkemedelsverket]' (2010) 22.

[661] Svenska Läkaresällskapet, 'Ethical Guidelines for Palliative Sedation at the End of Life [Etiska riktlinjer för palliativ sedering i livets slutskede]' (2010 6:2).

need of symptom management" where such symptoms are permanently present.[662]

From a criminal law perspective, there is a similar lack of clarity where actions taken in healthcare for the purpose of symptom management have the attendant effect of hastening death.[663] Certainly, the circumstances under which palliative sedation is considered legal, or conversely, constitutive of manslaughter under chapter 3, section 2 of the Criminal Code, are unresolved.[664] This is in line with Leijonhuvfud and Lynøe's argument that "whether a prosecutor would perceive the [palliative sedation] measures as murder or good care in the final stages of life" is unknown.[665] Indeed, whilst Lejonhufvud and Lynøe have argued that hastening death ought to be recognised as an exemption from liability under the Criminal Code's doctrine of necessity (*nödrätten*)[666] where there is no other approach to manage unbearable suffering,[667] Rynning claims that neither patient consent nor the doctrine of necessity should be applicable under the law where a treatment results in death.[668] That there is much uncertainty in regards to the legality of palliative care measures that hasten death is not necessarily surprising. Indeed, whilst a legal right to palliative care can ultimately be drawn from the law, the liberal subject serves to undergird an impulse to sustain life wherever possible. The extent to which the law can be understood to encourage appropriate end-

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[662] Socialstyrelsen, 'Clarification on Palliative Sedation [Tydliggörande om palliativ sedering]' (n 655) 2.

[663] Madeleine Leijonhufvud and Niels Lynøe, 'The Law Makes the Roll of the Doctor Unclear [Lagen gör läkarens roll oklar]' Svenska Dagsbladet (15 October 2012) <https://www.svd.se/a/9621f1d0-feac-30e4-b578-5d41a7039fc9/lagen-gor-lakarens-roll-oklar> accessed 18 February 2023.

[664] Mattsson and Wahlberg (n 51) 307.

[665] Leijonhufvud and Lynøe (n 663).

[666] Criminal Code (1962:700) [Brottsbalken] 24 chap. 4 §.

[667] Madeleine Leijonhufvud and Niels Lynøe, 'Sedation Therapy Which Shortens Life - Manslaughter or Adequate Treatment? [Sederingsterapi som förkortar livet – Dråp eller adekvat behandling?]' Läkartidningen (9 November 2010) <https://lakartidningen.se/lt-debatt/2010/11/sederingsterapi-som-forkortar-livet-drap-eller-adekvat-behandlingae/ and lejonhuvudt article> accessed 25 February 2023.

[668] Rynning, 'Statement Concerning the Legal Prerequisites for the Application of Sedation Therapy in the Swedish Health Care System [Utlåtande rörande de rättsliga förutsättningarna för tillämpning av sederingsterapi i den svenska hälso- och sjukvården]' (n 658) 7.

of-life practices, whether or not they hasten death, is therefore ultimately diluted.

4.4.2 Withholding & Withdrawing Life-Sustaining Treatment

In tandem with palliative care are decisions relating to the withdrawal and/or withholding of potentially life-sustaining treatment. These can include no resuscitation orders as well as decisions to withhold more advanced care[669] such as that available at hospital in contrast to care homes or, that available in the intensive care unit in contrast to regular medicine wards where the care is less interventionist. It is a physician who, in consultation with at least one other licensed professional,[670] decides on the possibility of life-sustaining treatment with reference to legislative principles, professional rules and guidelines.[671] Although fundamentally organised by the law's general principles of self-determination and science and proven experience, the NBHW's regulations and general advice on life-sustaining treatment as well as the accompanying Handbook provide particularised guidance on this issue. Central to this guidance is that the patient should be consulted to the greatest extent possible so that they have the opportunity to impact decision-making relating to the withdrawal or withholding of treatment.[672] Within the framework of consultation, two pathways are made available for the withdrawal or withholding of life-sustaining treatment: a medical assessment as informed by science and proven experience; and the wishes of the patient.

In regards to the former, where continued curative treatment is considered to be inconsistent with science and proven experience,[673] the primary duty to protect life and cure illness under science and proven experience[674] gives way to the obligation to not provide treatment where it conflicts with good care and

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[669] Interview with Participant K (n 456).

[670] Life-sustaining treatment [Livsuppehållande behandling] SOSFS 2011:7 3 chap. 2 § & 4 chap. 2 §.

[671] Dahlin (n 218) 163.

[672] Socialstyrelsen, 'To Give or Not to Give Life-Sustaining Treatment: Handbook for Healthcare Providers, Business Managers and Staff [Om att ge eller inte ge livsuppehållande behandling: Handbok för vårdgivare, verksamhetschefer och personal]' (n 539) 29.

[673] ibid 32.

[674] ibid 24–25.

is medically futile.[675] This is manifest through an assessment procedure in which the advantages are weighed against the disadvantages of life-sustaining treatment.[676] For example,

> "it may be that the treatment lacks the conditions to produce a medical effect and causes discomfort, pain and complications that involve suffering for the patient."[677]

Although this decision can be made by a physician (who is the fixed care contact or other licensed physician involved in the patient's care) in consultation with another licensed care professional independent of the patient's wish to continue treatment,[678] this assessment can differ depending upon the perspective applied to the evaluation.[679] For instance, the Handbook cautions that treatment judged to be medically meaninglessness may not necessarily be experienced by the patient themselves as meaningless. There is therefore a possibility to continue medically ineffectual treatment to allow the patient and their loved one's time to accept and process[680] where the treatment will not cause unacceptable side effects or suffering for the patient.[681] Nevertheless, it is relevant to note that similarly to the concerns identified with palliative care, a system predicated on the return to good health to the exclusion of death and dying may hinder the degree to which science and proven experience might encourage careful reflection over whether potentially life-sustaining treatment can be withdrawn.

Alternatively, withdrawal and withholding treatment can be triggered by the patient themselves. The NBHW's Handbook states that, "treatment should not

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[675] ibid 32.

[676] ibid.

[677] ibid.

[678] Life-sustaining treatment [Livsuppehållande behandling] SOSFS 2011:7 3 chap. 2 & 4 §§.

[679] Mattsson and Wahlberg (n 51) 305.

[680] Socialstyrelsen, 'To Give or Not to Give Life-Sustaining Treatment: Handbook for Healthcare Providers, Business Managers and Staff [Om att ge eller inte ge livsuppehållande behandling: Handbok för vårdgivare, verksamhetschefer och personal]' (n 539) 34; Rynning, 'Right to Live and Right to Die [Rätt till liv och rätt att dö]' (n 122) 108.

[681] Socialstyrelsen, 'To Give or Not to Give Life-Sustaining Treatment: Handbook for Healthcare Providers, Business Managers and Staff [Om att ge eller inte ge livsuppehållande behandling: Handbok för vårdgivare, verksamhetschefer och personal]' (n 539) 34.

be given … so long as the patient considers that treatment as duress,"[682] and, that "a patient cannot be forced to undergo treatment that he or she does not want to have."[683] This right to decline all treatment, including that which may maintain or lengthen life, is protected in the IoG and Patient Act.[684] Ultimately however, the interpretation of the rules on the refusal of life-sustaining treatment is far from settled. In fact, a number of inconsistencies are apparent that reveal the underlying tension between individualism and death and dying. From this tension, protectionist efforts emerge. This is especially apparent than the inconsistent interpretations of which patients are entitled to have their refusals of potentially life-sustaining treatment respected.

The constitutional and legislative protection ought to apply regardless of decision-making competency.[685] However, the right to refuse potentially life-sustaining treatment is protected by the ECtHR only for "mentally competent" patients:

> "The imposition of medical treatment, without the consent of a mentally competent adult patient, would interfere with a person's physical integrity in a manner capable of engaging the rights protected under Article 8 § 1 of the Convention"

even where this would result in a fatal outcome.[686] This dividing line has been replicated in domestic sources of law. For instance, in response to a request from a person with complete paralysis to withdraw a ventilator in 2010, the NBHW emphasised the protection afforded by the IoG from forced intervention, and moreover, claimed that the law requires doctors to respect the decision to withdraw or withhold life-sustaining by a competent patient who is

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[682] ibid 37.

[683] ibid 20.

[684] Instrument of Government (1974:152) [Regeringsformen] 2 chap. 6 §; Patient Act (2014:821) [Patientlagen] 4 chap. 1-2 §§.

[685] SOU 1988:7 105–106; Rynning, 'Consent to Medical Care and Treatment: A Legal Study [Samtycke till medicinsk vård och behandling: En rättsvetenskaplig studie]' (n 124) 110; Litins'ka, 'To Force or Not to Force: Protecting the Lives of Persons with Dementia Who Refuse Care' (n 124) 468; Litins'ka, 'Assessing Capacity to Decide on Medical Treatment: On Human Rights and the Use of Medical Knowledge in the Laws of England, Russia and Sweden' (n 124) 490.

[686] Pretty v United Kingdom [2002] ECtHR Application no. 2346/02 para 63.

well-informed about aspects of care such as different possible treatments and their consequences.[687]

This position has been further perpetuated in chapter 4 of the NBHW regulations in regards to patient requests to withdraw or withhold treatment. The guidelines establish that the doctor must ensure that individually appropriate information has been given to the patient before they take a position on the request.[688] This mirrors the legislative conditions for consent.[689] However, where legislation does not stipulate a capacity limit for respect of one's self-determination,[690] and relatedly, provides no legal guidance as to what constitutes the necessary competency to make medical decisions,[691] the NBHW stipulates conditions of decision-making capacity in the case of life-sustaining treatment refusals.[692] This is present in the requirement that the physician assess the patient's psychiatric status and ascertain that they:

- can understand the information;
- can recognise and consider the consequences of ending or not beginning life-sustaining treatment;
- have had sufficient time to deliberate; and
- are persistent with their wish.[693]

Citing the NBHW, preparatory works to the Criminal Code have stated that it is not punishable for a doctor to accede to a patient's request to withdraw or withhold life-sustaining treatment "under certain circumstances."[694] With

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[687] Statens Medicinsk-Etiska Råd (n 653) 66 referring to Dnr 6367/2010 & Dnr 10821/2010.

[688] Life-sustaining treatment [Livsuppehållande behandling] SOSFS 2011:7 4 chap. 1 §.

[689] Patient Act (2014:821) [Patientlagen] 4 chap. 2 §.

[690] Litins'ka, 'Assessing Capacity to Decide on Medical Treatment: On Human Rights and the Use of Medical Knowledge in the Laws of England, Russia and Sweden' (n 124) states at 485-486 that there are no legislative conditions for refusal.

[691] Litins'ka, 'Consent and Decision-Making Competence in Care [Samtycke och beslutskompetens i vården]' (n 567) 114.

[692] Socialstyrelsen, 'To Give or Not to Give Life-Sustaining Treatment: Handbook for Healthcare Providers, Business Managers and Staff [Om att ge eller inte ge livsuppehållande behandling: Handbok för vårdgivare, verksamhetschefer och personal]' (n 539) 21

[693] Life-sustaining treatment [Livsuppehållande behandling] SOSFS 2011:7 4 chap. 1 §.

[694] Prop. 2020/21:74 17.

reference to the NBHW's treatment of capacity, it may be that the preparatory works imagined the possibility of criminal consequences where the capacity requirements outlined by the NBHW are not fulfilled.

Although issues related to capacity, dementia and the withdrawal of life-sustaining treatment will be considered more fully in subsection 5.5.2, the centrality of capacity is of broader relevance to the question of withdrawing and withholding potentially life-sustaining treatment. Indeed, as this capacity threshold has been developed specifically in relation to life-sustaining treatment refusals where it otherwise does not exist, questions of death and dying when driven by the patient evidently spark elevated standards of competence in law. This can be read as an effort to apply an augmented standard of rationality to death. Whilst decisions informed by notions of medical futility under science and proven experience legally mark a justifiable end-of-life decision, the law frames people who make decisions that may hasten their death in the absence of the treating doctor/healthcare team's own identification of the medical limits of continuing treatment as teetering on the edge of irrationality. In other words, people who act outside of the possibilities and limits of medicine in the face of death and dying are cast as potentially irrational. From this perspective, rational people are largely expected to resist death until the moment that medicine indicates otherwise. A decision to the contrary must be accompanied by additional proof of rationality. This is ultimately a patriarchal response to an irrational subject[695] who requires guidance and support to reveal the natural urge to remain life.[696] Of course, it may be countered that there are good reasons to enact such boundaries in order to afford protection against situations where people may otherwise have their mental health successfully treated and supported. Nevertheless, it also overlooks the fact people may experience what may be considered an adequate death wish:

> Of course there can be depression also and those you can treat, but many of my older patients have actually more of a, what I call, an adequate death wish. When you have turned 95 and all of your friends are dead and maybe even your children are dead and you feel like, I have pain everywhere, I have many illnesses and like, I am satisfied with the life I have had. It's been great but now

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[695] Fineman, 'Elderly as Vulnerable' (n 522) 84.

[696] Abrams (n 524) at 18 makes the same claim in relation to abortion in which restrictive measures to termination requests are informed by the belief that a woman making such a request "requires guidance to help her uncover the natural maternal urges that connect her with her unborn child".

> it's like, now it would be good if it ended. These are pretty normal thoughts which I hear as well … there are nuances. – Participant F

In the midst of these conflicting interpretations on the legal availability of treatment withdrawal, certain limits emerge as to the ability of law to encourage collective responsibility for practices that promote rather than hinder end-of-life wellbeing. Indeed, constitutional and legislative protection of elderly patients at the end of life has, and can continue to be, curtailed.[697] For example, an IVO decision found that the patient consented to the diagnostic and potentially life lengthening treatment at the end of their life despite the patient's files recording sustained verbal and physical communication as to a wish to only be given pain and anxiety managing treatment.[698] Following from this decision, Schiratzki argues that this regime depends upon individual carers "to interpret and respect" the preferences of dying persons which leaves open the possibility for mixed results; end-of-life care may be respectful and comprehensive or overlook preferences with harmful results.[699] Certainly, as detailed in Chapter 3, in the absence of law in death and dying, medicine takes control as a system of flexible control that can, to some extent, depend on various factors such as the physician themselves.[700] Furthermore, as medical research has indicated, older patients are "exposed to various types of overtreatment near the end of life," "generally against their wishes," which raises concerns from the perspective of self-determination and quality of life.[701] From this perspective, the medicalisation of dying in the absence of comprehensive legal support for death and dying carries with it the risk that opportunities for relational autonomy and physical wellbeing are overlooked within healthcare. The point here is not, however, that medicine should necessarily be prevented from navigating the complexities of care at the end of life as an inherently inappropriate entity. Rather, the takeaway message is that law fails to provide an anchor point for values of care and relational choice at the end of life for a collective practice of end-of-life care that addresses persistent concerns with the way that society

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[697] Johanna Schiratzki, 'We Must Have the Right to Die in Peace [Vi Måste Ha Rätt Att Få Dö i Fred]' *Svenska Dagsbladet* (13 January 2024) <https://www.svd.se/a/wAWpEL/johanna-schiratzki-vi-maste-ha-ratt-att-fa-do-i-fred> accessed 25 August 2024.

[698] ibid referring to the IVO decision dnr 3.4.1-14804/2021–73 on 8 november 2023.

[699] Schiratzki (n 697).

[700] See subsection 3.4.3.4 and 3.5.3.

[701] Máté Szilcz, 'Potential Overtreatment during Life-Limiting Illness and End of Life in Older Adults' (PhD, Karolinska Institutet 2023) 83.

(of which medicine is one component) organises and responds to death and dying. This has implications for which patients are granted respect and support for appropriate end-of-life care that values one's wish to refuse potentially life-sustaining treatment.

4.4.3 Assisted Dying

Questions regarding the legal response to death and dying extend to the issue of assisted dying. Human rights law has developed to provide a rights-based possibility for assisted dying within the limits of autonomous decision-making. In this regard, the Human Rights Committee evidently balances the right to life contained under article 6 of the International Covenant on Civil and Political Rights with choice at the end of life in the context of informed consent and vigorous safeguards that protect "patients from pressure and abuse."[702] Similarly, in ECtHR jurisprudence, autonomy has been leveraged as a counter-interest against which the right to life as contained under article 2 can be balanced[703] in developing jurisprudence that explicitly allows states to provide for measures that allow autonomous decisions to die with assistance. In Pretty v UK, the ECtHR located autonomy at the end of life under the umbrella of article 8's right to private.[704] The Court stated that whilst there was no right to assisted dying,[705] it was "not prepared to exclude" that preventing the applicant to undertake the choice "to avoid what she considers will be an undignified and distressing end to her life" interfered with her article 8(1) rights to a private

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[702] 'HRC, General Comment No. 36: Article 6 Right to Life, CCPR/C/GC/36, 30 October 2018' para 9.

[703] Diego Zannoni, 'Right Or Duty to Live? Euthanasia and Assisted Suicide from the Perspective of the European Convention on Human Rights' (2020) 12 European Journal of Legal Studies 181, 195; Daria Sartori, 'End-of-Life Issues and the European Court of Human Rights. The Value of Personal Autonomy within a "Proceduralized" Review' (2018) 52 Questions of International Law 23, 41.

[704] David Orentlicher and Judit Sándor, 'Decisions at the End of Life' in David Orentlicher and Tamara K Hervey (eds), David Orentlicher and Judit Sándor, *The Oxford Handbook of Comparative Health Law* (Oxford University Press 2021) 109.

[705] *Pretty v United Kingdom* (n 686) para 40.

life.[706] Haas v Switzerland progressed the issue by recognising not just a “choice” but a “right” to decide on one’s death:[707]

> “The Court considers that an individual’s right to decide by what means and at what point his or her life will end, provided he or she is capable of freely reaching a decision on this question and acting in consequence, is one of the aspects of the right to respect for private life.”[708]

Connecting this right to a free and “full understanding of what is involved,”[709] the right to life only gives way to a mentally competent individual who expresses well informed wishes.[710] Furthermore, the Court has determined that the decision to prohibit assisted dying by individual states can be justified with reference to what is “necessary in a democratic society for the protection of rights of others” under article 8(2).[711] In this vein, the Court has granted states a considerable margin of appreciation to determine how they will regulate assisted dying.[712] This was given substance in Koch v Germany in which the Court found that whilst state’s would not be required to facilitate assisted dying under the Convention, it did require states to justify their refusal in accordance with paragraph two.[713]

Despite the possibilities available in human rights law, Sweden’s approach to assisted dying can ultimately be described as limited, particularly within the strictures of healthcare. The result is that limited assistance or support can be discerned in terms of providing support for agency for those who wish to

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[706] ibid para 67.

[707] Gregor Puppinck and Claire De La Hougue, ‘The Right to Assisted Suicide in the Case Law of the European Court of Human Rights’ (2014) 18 The International Journal of Human Rights 735, 739; Orentlicher and Sándor (n 704) 109.

[708] *Haas v Switzerland* [2011] ECtHR App no. 31322/07 para 51.

[709] ibid para 54.

[710] Arend Cornelis Hendriks, ‘End-of-Life Decisions. Recent Jurisprudence of the European Court of Human Rights’ (2019) 19 ERA Forum 561, 569.

[711] *Pretty v United Kingdom* (n 686) paras 74-78 concluded that the prohibition on assisted dying was justified as a means to uphold the right to life "by protecting the weak and vulnerable and especially those who are not in a condition to take informed decisions"; *Haas v Switzerland* (n 708) para 49 concluded that the prohibition on non-prescription access to a lethal substance was "necessary for the protection of life, health and safety".

[712] *Haas v Switzerland* (n 708) para 55.

[713] Koch v Germany [2012] ECtHR App no. 497/09 paras 67 & 72.

access assisted dying as a way to exercise choice over their death. Assisted dying in Sweden is regulated differently according to whether the assistance involves: the performance of the decisive life ending act (i.e. the administration of a substance); or the provision of the necessary means for the life ending act (i.e. the procurement and provision of a substance). This distinction was actualised by the Supreme Court case in which someone consented to assisted dying through the consumption of tablets and an injection of insulin. The Court concluded that whilst the individual participated through the act of swallowing the tablets, the insulin injection by the defendant "characterised by such a degree of independent action" that the assisting person perpetrated the death. The actions can therefore be regarded as killing with consent rather than aiding and abetting suicide.[714]

In relation to the former, performing a decisive life ending act at the request of the other person is a criminal act regulated by the Swedish Criminal Code.[715] This interpretation captures the idea that the prohibition of crimes against life and health under chapter 3 is about "protecting the general respect for life and health."[716] Similarly, it has been said that the principle of self-determination was never intended to be mobilised under the circumstances of assisted dying.[717] Although the wishes of the deceased person do not constitute an exemption from criminal responsibility, consent to the act can have bearing on the classification of the crime and penalties.[718] In particular, where consent meets the standards set out in the Criminal Code,[719] the classification becomes manslaughter rather than murder.[720] Further, sentencing regulations hold that a crime prompted by strong human compassion and undertaken with consent

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[714] NJA 1979 s 802 (Högsta Domstolen).

[715] Criminal Code (1962:700) [Brottsbalken] 3 chap; Lena Holmqvist, 'Assisted Dying [Dödshjälp]' in Petter Asp, Stefan Lindskog and Catharina Månsson (eds), *Book in Celebration of Martin Borgeke [Vänbok till Martin Borgeke]* (Jure 2022) 63.

[716] Holmqvist (n 715) 63.

[717] Prop. 1981/82:97 118.

[718] Mattsson and Wahlberg (n 51) 310; LJ Materstvedt and S Kaasa, 'Euthanasia and Physician-Assisted Suicide in Scandinavia - with a Conceptual Suggestion Regarding International Research in Relation to the Phenomena' (2002) 16 Palliative Medicine 17, 26; Petter Asp, Magnus Ulväng and Nils Jareborg, *The Foundations of Criminal Law [Kriminalrättens grunder]* (Iustus Förlag 2010) 233.

[719] Criminal Code (1962:700) [Brottsbalken] as defined in 24 chap. 7 §.

[720] The distinction between murder and manslaughter is set out in ibid 3 chap. 1 & 2 §§; Holmqvist (n 715) 63.

can impact upon the severity of the penalty.[721] This has been affirmed in the judiciary.[722] By way of illustration, a man who ended the life of his sick partner was found guilty of manslaughter after his actions, including the preparation and injection of a deadly substance, were found to be sufficiently independent and active in causing her death. In sentencing him to a one year and six-month prison sentence, the court considered that there were mitigating factors[723] as his actions were prompted by compassion for the suffering of his partner and her wish to die.[724]

On the flipside, where the action is classified as assistance to suicide, there is no crime. This is because as suicide itself is not a crime[725] following its decriminalisation in 1864,[726] participation in another's suicide does not constitute aiding and abetting a crime.[727] Illustrative of this is the case in which a supporter was not convicted due to the fact that their involvement was limited to the provision of a deadly dose of tablets to the person who then willingly swallowed.[728] Whilst this suggests that private persons are not criminally prohibited from engaging in assisted dying, it is important to consider the consequences of the recent adjustment to the Criminal Code. In 2021, the new crimes of incitement of suicide and negligent incitement of suicide were added to the Criminal Code.[729] In relation to the former, it criminalises attempts to encourage or exert psychological influence over someone to end their life. It only pertains to the act of encouragement itself, and therefore, can be punishable regardless of whether or not it causes someone to attempt to end their life. Whilst this could conceivably have consequences for assisted dying, the proposition states that

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[721] Criminal Code (1962:700) [Brottsbalken] 29 chap. 3 §.

[722] *B 2887-18* (Ystad tingsrätts); *B 593-19* (Ångermanlands Tingsrätt).

[723] Criminal Code (1962:700) [Brottsbalken] 29 chap. 3 §.

[724] *B 593-19* (n 722); *B 1705-19* (Hovrätten för Nedre Norrland) upheld the decision but further reduced the sentence to one year imprisonment.

[725] Mattsson and Wahlberg (n 51) 309; Holmqvist (n 715) 62.

[726] Anders Ekström, The Example of Death [Dödens exempel] (Atlantis 2000) 155.

[727] As prohibited under the Criminal Code (1962:700) [Brottsbalken] 23 chap.; Holmqvist (n 715) 62.

[728] RH 1996:69 (Svea hörätt).

[729] Criminal Code (1962:700) [Brottsbalken] 4 chap. 7a §.

> "it cannot normally be considered psychological influence to provide pain-relieving medication out of compassion that, in a high dose, can lead to the death of a close relative who has already made an independent and unequivocal decision to end their life."[730]

Thus, it can be concluded that the recent changes will not alter the status of private persons providing assistance in death in Swedish law.

Where the assistance is afforded by healthcare professionals however, the legal situation is different again with the rules of healthcare interpreted so as to prohibit medically assisted dying. As with all healthcare, medically assisted dying falls under the general regulatory provisions that care must be expert, caring, good quality and commensurate with science and proven experience as contained in chapter 1, section 7, of the Patient Act.[731] Currently, the Handbook on life-sustaining treatment embraces an understanding that participation in assisted dying in the healthcare sector goes against the requirement that healthcare be directed towards the relief and curing of illness as required by science and proven experience.[732] Where assisted dying is determined to breach the demands of good care within the remit of science and proven experience, legal consequences include critique by IVO and the probation or revocation of one's medical licence by HSAN.[733]

This position is reflected in the progression of the case of a doctor who helped a man with amyotrophic lateral sclerosis (commonly known as ALS) to die through the provision of a deadly dose of the sleeping medication pentobarbital that the man consumed himself. Whilst manslaughter charges were abandoned in line with the rules assisted dying,[734] IVO found that in acting with the intent to assist the patient to end his life, the requirements of care that meets science and proven experience were contravened, and the practice was not

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[730] Prop. 2020/21:74 16.

[731] Mattsson and Wahlberg (n 51) 309–310.

[732] Socialstyrelsen, 'To Give or Not to Give Life-sustaining Treatment: Handbook for Healthcare Providers, Business Managers and Staff [Om att ge eller inte ge livsuppehållande behandling: Handbok för vårdgivare, verksamhetschefer och personal]' (n 539) 37–38.

[733] Patient Safety Act (2010:659) [Patientsäkerhetslagen] chap 8.

[734] Joakim Andersson, 'Staffan Bergström Ready to Fight for His Licence [Staffan Bergström redo att ta strid för sin legitimation]' *Läkartidningen* (22 March 2021) <https://lakartidningen.se/aktuellt/nyheter/2021/03/staffan-bergstrom-redo-att-ta-strid-for-sin-legitimation/> accessed 8 August 2024.

commensurate with healthcare according to chapter 2, section 1 of the HSL.[735] The decision was upheld by HSAN in revoking the doctor's licence[736] and was in turn reaffirmed by the Administrative Court.[737] This interpretation of Swedish health law on the case of medically assisted dying has since been replicated in a further HSAN decision relating to another doctor who (at the request of a colleague) made available Pentobarbital prescribed to himself to two patients with the knowledge that this would be used to end their lives.[738]

It is relevant to interrogate the way in which the law has been applied to invalidate medically assisted dying. Science and proven experience, for one, was not applied in an assessment of actual care practice,[739] but rather as a quality requirement that applies to the "vales and assessments" of the physician's medical practice.[740] This application has been criticised on the grounds that science and proven experience is interpreted too broadly to include ethics to the detriment of legal certainty.[741] However, in addition to this, the abandonment of science and proven experience to a value assessment throws up important concerns in relation to what values are being perpetuated by the law, how they are being perpetuated, and who is perpetuating them. Ultimately, this approach to science and proven experience affords medicine norm setting power in law and society. Thus, where the law is already deeply implicated in efforts to sustain life, it invites medicine in as an authoritative partner to ward off death. The inclusion of a value assessment therefore serves to manifest a power sharing arrangement in which medicine and law bolster each other's authority[742] in issues of life and death. This arguably serves to

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[735] Dnr 361-28734/2020-15 (IVO).

[736] Dnr 241-11166/2021 (HSAN).

[737] *B 20746-22* (Förvaltningsrätten).

[738] Dnr 241-84281/2023 (HSAN).

[739] An example of where science and proven experience has been applied solely as a requirement that medical practice be supported by the field of knowledge is the criminal conviction of a physician for transplantation practices in *B 9036-22* (Svea Hovrätt) 6; *B 10553-18* (Solna Tingsrätt) 39.

[740] *B 20746-22* (Förvaltningsrättens) 10.

[741] Lena Wahlberg, 'Science and Proven Experience: the Meaning and Limits of a Legal Concept [Vetenskap och beprövad erfarenhet: Ett rättslig begrepps innebörd och gränser]' in Nils-Eric Sahlin (ed), *Science and Proven Experience [Vetenskap och beprövad erfarenhet]* (Media Tryck 2021) 92–93.

[742] Smart (n 498) 14–15 & 96.

solidify the moral correctness of preserving life as the unproblematic default of healthcare, and indeed, society at large.

Wahlberg argues that whether or not assisted dying is understood as expert, caring, good quality and commensurate with science and proven experience is a normative question whose answer can change over time. The example of the Hippocratic Oath shows the possibility for shifting understandings of responsibilities in healthcare as the Oath's claim against abortion has evidently lost significance, and indeed, legitimacy in Sweden over time.[743] The same development could of course happen in the context of assisted dying. This is perhaps particularly relevant to consider in the midst of an increasing number of jurisdictions taking the decision to legalise doctor participation in assisted dying[744] and the public debate that has been prominent in Sweden in recent years.[745] However, where science and proven experience is applied with reference to an arguably narrow understanding of medical ethics, law and medicine are bound together in a self-perpetuating cycle to the exclusion of alternative considerations, concerns, values and ideals relating to good care at the end of life. To this degree, the reliance on science and proven experience as a value assessment may serve to impede debate and change on the question of medically assisted dying.

The decision to prohibit medically assisted dying is arguably more persistent in regards to the claim that affording access to deadly doses does not meet the purpose of healthcare restricted under the HSL to the medical prevention, investigation and treatment of disease and injury, medical transport and care of the deceased.[746] The inconsistency between Swedish healthcare and assisted dying is further confirmed by the physician's conviction under the Control of Narcotics Act in which the provision of the drug via a prescription not written in the name of the doctor or the patient was found to not constitute a medical

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[743] Wahlberg (n 741) 93–94.

[744] See for example, Oregon's Death with Dignity Act (1998), the Netherland's Termination of Life on Request and Assisted Suicide Act (2002), Canada's Medical Assistance in Dying Act (2016), and Spain's Organic Law of the Regulation of Euthanasia (2021)

[745] Ingemar Engström and Mikael Sandlund, 'Assisted Dying is an Extremely Difficult Ethical Issue [Assisterat döende är en synnerligen svår etisk fråga]' Läkartidningen (24 January 2022) <https://lakartidningen.se/opinion/debatt/2022/01/assisterat-doende-ar-en-synnerligen-svar-etisk-fraga/> accessed 28 November 2023; Mattsson and Wahlberg (n 51) 310.

[746] Health Care Act (2017:30) [Hälso och sjukvårdslagen] 2 chap. 1 §.

purpose, and therefore, was not an exemption[747] to the offence.[748] It also is broadly in line with the argument crafted in this chapter; that Swedish law is concerned with saving lives rather than facilitating care at the end of life. In this way, whilst more appealing on the grounds of legal certainty, the application of the legal rules of what constitutes Swedish healthcare fails to be responsive to issues of autonomy at the end of life as manifest in requests for assisted dying.

Where medical assistance in dying remains prohibited, there is the possibility that Swedish patients can gain access to assisted dying abroad. In this context, Switzerland emerges as a distinct location in which assisted dying can be sought given the unique Swiss phenomenon of “suicide tourism”[749] in which citizens of countries without legal access to assisted dying seek the service of official, voluntary right-to-die organisations that offer assistance to those who are not citizens or residents of Switzerland.[750] Switzerland is home to clinics who can legally offer assisted dying where a health certificate from a doctor is provided. However, the legal consequences for Swedish physicians who provide the relevant certification is unknown. This, and the fact that only people with sufficient resources can take this path, means that it remains a marginal practice.[751]

4.5 Conclusion

Chapter 4 has accounted for how law has constructed obligations in Swedish healthcare and analysed the consequences this has for dying and end-of-life decision-making. In doing so, it has demonstrated that law has been powerfully influenced by the liberalisation of the legal subject in the regulation of

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[747] As contained under Control of Narcotics Act [Narkotikastrafflag] (1968:64) 2 §.

[748] *B 8127-20* (Attunda tingsrätt).

[749] Saskia Gauthier and others, ‘Suicide Tourism: A Pilot Study on the Swiss Phenomenon’ (2015) 41 Journal of Medical Ethics 611, 616.

[750] ibid 611.

[751] Nicklas Juth, Titti Mattsson and Lynøe Niels, ‘Certificates of Assisted Dying in Switzerland Raise Difficult Questions: Investigating the Patient’s Rights at the End of Life [Intyg för assisterat döende i Schweiz väcker svåra frågor: Utred patientens rättigheter i livets slut]’ *Läkartidningen* (7 September 2020) <https://lakartidningen.se/klinik-och-vetenskap-1/artiklar-1/etik-och-lakarroll/2020/09/intyg-for-assisterat-doende-i-schweiz-vacker-svara-fragor/> accessed 27 January 2021.

healthcare. As a result, legal obligations have come to hinge upon equal access to care that returns patients to good health and is respectful of self-determination within the limits of medicine. Whilst legal subjects are generally presumed to be rational and are subsequently principally afforded and obliged to take up opportunities for privacy and non-interference, dying individuals pull at the seams of this subject in epitomising loss of bodily control. Where death and dying are excluded in favour of life promoting activities under the framework of legal individualism, dying cannot be fully captured in the law. As dying persons become ambiguous to law's protections, paternalistic control over bodies which threaten decline and death are instituted. In the midst of this, medicine's own interest in resisting death as a failure of medicine is facilitated if not bolstered by the legal predisposition to preserve life. This has concrete implications for access to care and choice at the end of life.

Importantly, the law can be interpreted so as to allow for legal responsiveness to the need for palliative care. However, in the midst of the overarching marginalisation of death and dying in pursuit of maintaining life, the ability of law to secure such access is arguably more muted than what may otherwise be afforded in a regime that proactively embraces end-of-life obligations. Certainly, that patients are no longer granted the same protections when they reach, or indeed, wish to reach, the liminal status of dying subjects is evident with the replacement of self-determination protections with paternalism. This is manifest in the prohibition of medically assisted dying and the shaky protection of the right to withdraw life-sustaining treatment, especially where questions of capacity arise. With Chapter 4 affording the necessary foundations, the next chapter turns to address how this framework responds to people with dementia who are faced questions of death and dying.

5 Deciding & Dying with Dementia in Law

> What I want … is to die on my own timetable and in my own nonviolent way.
> – Sandra Bem[752]

5.1 Introduction

Chapter 5 begins where the previous chapter leaves off by narrowing the investigation into the legal context of people with dementia confronted with end-of-life decisions. In this, it follows a similar format to Chapter 4 in investigating sources of law against the backdrop of a feminist informed approach to vulnerability that is critical of how law responds to universal needs for relational agency and care at the end of life to answer the following research question:

How does law construct and respond to end-of-life decision-making with dementia?

This chapter demonstrates that end-of-life decision-making with dementia is not fully captured by a legal framework predicated on a self-determining agent who makes rational end-of-life decisions. Individuals with diverse decision-making abilities are largely expected to traverse healthcare, including end-of-life decisions, with rational independence. While they are offered supportive measures, these are aimed at uncovering (or reconstructing) pre-existing preferences, and therefore largely fail to platform universal needs for comprehensive support in the decision-making process. Within this individualistic framework, people with dementia are however simultaneously threatened by the paternalistic drive to maintain life which is only heightened at the limits of a perfect decision-taking patient. This framework ultimately has

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[752] As recorded by Marantz Henig (n 96).

implications for who has access to end-of-life care that is not stigmatising or paternalistic but rather accounts for both one's relational autonomy and bodily needs.

Chapter 5 begins by explicating the status of cognitive variance in the context of a regime predicated on perfect decision-making agents. It then considers the foundational rules of legal decision-making with dementia in the context of Swedish healthcare. This begins with an account of people with dementia as legally valid decision-makers. It then moves to establish how legally valid decisions are predicated on the patient's wishes which can be extrapolated through mechanisms of support. This subsection concludes with a consideration as to the challenge of identifying wishes. Following this, a critical perspective is applied to these rules of decision-making to evaluate what this individualistic approach means for people with dementia in terms of hyper-individualism and paternalism. Next, the focus is narrowed to specific questions of end-of-life law in the case of dementia including palliative care, withdrawal of potentially life-sustaining treatment and assisted dying. Finally, the chapter ends by considering what exemptions exist in law for alternative decision-makers in the realm of healthcare to further interrogate the limitations and possibilities for end-of-life care that promotes opportunities for relational agency and meets physical needs.

5.2 Cognitive Variance in a Regime of Perfect Decision-Making Agents

This initial section addresses the basic decision-making framework ascribed by law as it would apply to end-of-life decision-making with dementia. It begins by locating people with dementia and their diverse decision-making abilities and needs in relation to the liberal decision-making subject as imagined in law.[753] Living with dementia is representative of a diverse state of cognition marked by variance in degree and kind. On the one hand, some patients with dementia may share thoughts, feelings and attitudes that are relevant in decisions to limit life-sustaining treatment:

> Even if one is pretty cognitively impaired, it might also come up that, they have lived in a care home for a while now and find it pretty boring. It might even

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[753] This account of the liberal legal subject in the legal regulation of Swedish healthcare is unpacked in subsection 4.2.

> come up that the patient has mentioned thoughts that “it would be better if I was dead” and such things. – Participant F

On the other hand, people with dementia can experience challenges with forming and expressing wishes at the end of life.[754] In fact,

> the normal progression of a dementia illness is that near the end you will not be able to communicate. – Participant F

In this regard, living and dying with dementia is marked by diverse cognitive functioning, which in turn, must be met with variable and reflexive decision-making opportunities such as support, and indeed, alternative decision-makers where necessary.[755]

Although the NBHW recognises that people with dementia may not be able to formulate or express their wishes,[756] the liberal subject is constructed as a perfect decision-maker who can and must receive and use information to express themselves in the context of welfare-state institutions.[757] These qualities have been increasingly extended to older people, as they too have come to be represented “as active, responsible, self-sufficient and autonomous” subjects.[758] Thus, even though law is tasked with the regulation of the increasingly growing population of people with dementia,[759] the liberal subject only recognises an adulthood that is disconnected from “the passage of time and human experience.”[760] In this vein, it has been acknowledged that the

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[754] Kethakie Lamahewa and others, ‘A Qualitative Study Exploring the Difficulties Influencing Decision-making at the End of Life for People with Dementia’ (2018) 21 Health Expectations 118, 124; Simone A Hendriks and others, ‘End-of-Life Treatment Decisions in Nursing Home Residents Dying with Dementia in the Netherlands’ (2017) 32 International Journal of Geriatric Psychiatry e43, 44; Harding, *Duties to Care* (n 4) 170.

[755] De Sabbata (n 25) 5–6.

[756] Socialstyrelsen, ‘National Knowledge Support for Good Palliative Care at the End of Life: Guidance, Recommendations and Indicators [Nationellt kunskapsstöd för god palliativ vård i livets slutskede: Vägledning, rekommendationer och indikatorer]’ (n 47) 38.

[757] Ann-Charlotte Nedlund and Annika Taghizadeh Larsson, ‘To Protect and to Support: How Citizenship and Self-Determination Are Legally Constructed and Managed in Practice for People Living with Dementia in Sweden’ (2016) 15 Dementia 343, 346.

[758] Mattsson and Katzin (n 513) 121.

[759] Naffine (n 510) 81.

[760] Fineman, ‘The Vulnerable Subject: Anchoring Equality in the Human Condition’ (n 267) 168.

legislative regime is silent on what to do where capacity is at issue,[761] and moreover, provides no guidance where patients are unable to express their wishes for end-of-life care.[762] For instance, the preparatory works for the Patient Act stated that

> "there are people who lack the ability to give expression to their self-determination, by for example giving consent to care. … In the absence of legal provisions in the area, healthcare and healthcare personnel lack clear guidance on which grounds care can still be provided to these people."[763]

In addition, the NBHW has itself recognised that the absence of legislative guidance in regards to competency means that law becomes particularly limited where a patient does not want to continue or begin life-sustaining treatment given that competency is often an issue at the end of life.[764]

Thus, from this standpoint, the law is therefore unable to capture the "range of differing and interdependent abilities over the span of a lifetime" that are inherent to the human condition.[765] As will be developed in this chapter, the way in which legal sources fail to recognise the experience of dying with dementia as a universal possibility has significant implications for the role of law at the end of life with dementia. Where competence, individualism and rationality prevail as the baseline assumption, patients with dementia are given the rights and responsibilities of hyper-independent decision-making agents. Where this baseline assumption is undone by stereotypes, stigma and the perceived threat of dying bodies, paternalism is unveiled. This has implications for the ability of law to provide a framework for genuine and authentic care that accounts for both bodily needs and personhood of people with dementia at the end of life.

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[761] Fridström Montoya, 'Samtycke till vård' (n 599) 54.

[762] Malin Eneslätt, 'Death Talk: Methods and Tools for Conversations about Dying, Death and Future End-of-Life Care [Dödsnack: Metoder och verktyg för samtal om döende, död och framtida vård i livets slutskede]' (PhD, Karolinska Institutet 2021) 12.

[763] Prop. 2013/14:106 59.

[764] Socialstyrelsen, 'To Give or Not to Give Life-sustaining Treatment: Handbook for Healthcare Providers, Business Managers and Staff [Om att ge eller inte ge livsuppehållande behandling: Handbok för vårdgivare, verksamhetschefer och personal]' (n 539) 20.

[765] Fineman, 'The Vulnerable Subject: Anchoring Equality in the Human Condition' (n 267) 168.

5.3 The Fundamentals: Legal Decision-Making with Dementia in Healthcare

5.3.1 People with Dementia as Valid Decision-Makers

In the midst of the baseline assumption of the rational, independent decision-maker, the fundamental principles of Swedish law stipulate that people with dementia are legally valid decision-makers in healthcare. This follows from the fact that capacity is not understood to interfere with one's ability to consent to medical treatment in the context of the IoG's prohibition on force.[766] Indeed, the right to be free from forced treatment extends to people with dementia is confirmed by a "literal interpretation of the [IoG which] emphasises that every person, regardless of his or her mental abilities, should receive the protection."[767] The Patient Act also does not distinguish valid decisions with reference to decision-making abilities.[768] In fact, a patient with dementia cannot be declared legally incompetent,[769] nor does the legislative regime provide guidance on the level of competency necessary to make legal decisions as to medical treatment.[770] Instead, the Patient Act stipulates that treatment cannot be given without the patient demonstrating consent in whatever means available to them unless provided for by an exemption in law.[771] A failure to provide palliative care that accords with science and proven experience where assent is expressed by someone with diverse decision-making abilities would also arguably come up against chapter 3, section 1 of the HSL which establishes that healthcare be accessible to all on equal terms.

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[766] SOU 1988:7 105–106; Rynning, 'Consent to Medical Care and Treatment: A Legal Study [Samtycke till medicinsk vård och behandling: En rättsvetenskaplig studie]' (n 124) 110; Litins'ka, 'To Force or Not to Force: Protecting the Lives of Persons with Dementia Who Refuse Care' (n 124) 468.

[767] Litins'ka, 'To Force or Not to Force: Protecting the Lives of Persons with Dementia Who Refuse Care' (n 124) 468.

[768] Litins'ka, 'Assessing Capacity to Decide on Medical Treatment: On Human Rights and the Use of Medical Knowledge in the Laws of England, Russia and Sweden' (n 124) 490.

[769] ibid 448; Prop. 1987/88:124 1; Fridström Montoya, 'Samtycke till vård' (n 599) 46.

[770] Litins'ka, 'Consent and Decision-Making Competence in Care [Samtycke och beslutskompetens i vården]' (n 567) 115.

[771] Patient Safety Act (2010:659) [Patientsäkerhetslagen] 4 chap. 2 §.

This analysis is reinforced via the treaty conformity principle. Similarly to domestic sources of law, the CRPD promotes the right of people with dementia to be respected as decision-making subjects in healthcare. A key provision in this regard is the CRPD's article 12 equal recognition of people with disabilities. Article 12(2) enshrines the right of persons with disabilities to enjoy legal capacity on an equal basis with others in all aspects of life.[772] This grants equal protection of autonomy regardless of capacity,[773] and effectively constructs the principle of "universal legal capacity."[774] Furthermore, the CRPD's right to health under article 25 stipulates that states shall require healthcare professionals to provide care of the same quality to persons with disabilities as to others, including on the basis of free and informed consent.[775] In recognising a connection between articles 25 and 12, the CRPD Committee indicated that the provision for universal legal capacity requires that states do not allow for consent to be provided for people with disabilities via a substitute decision-maker, and also, that healthcare professionals must appropriately consult with persons with disability.[776] Informed consent is also arguably protected in combination with articles 17, 15 and 16 which protect personal integrity, freedom from torture and freedom from violence, exploitation and abuse.[777] Article 17 for example, has been connected to the prohibition of forced medical intervention[778] in stipulating that every person with disabilities has a right to respect for his or her physical and mental integrity on an equal

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[772] Convention on the Rights of Persons with Disabilities art 12(2).

[773] Jonathan Herring, *The Right to Be Protected from Committing Suicide* (Hart Publishing 2022) 134.

[774] Eilionoir Flynn and Anna Arstein-Kerslake, 'Legislating Personhood: Realising the Right to Support in Exercising Legal Capacity' (2014) 10 International Journal of Law in Context 81, 89.

[775] CRPD art 25(d).

[776] 'UN CRPD Committee, General Comment No. 1: Article 12 Equal Recognition before the Law, CRPD/C/GC/1, 11 April 2014' (n 86) para 37.

[777] Tina Minkowitz, 'The United Nations Convention on the Rights of Persons with Disabilities and the Right to Be Free from Nonconsensual Psychiatric Interventions' (2007) 34 Syracuse Journal of International Law & Commerce 405, 405; 'Committee on the Rights of Persons with Disabilities Draft General Comment on Article 12 of the Convention – Equal Recognition before the Law, Advanced Unedited Version, 11th Session 10th Session, 2014. CRPD/C/11/4.' para 38.

[778] Sascha Mira Callaghan and Christopher Ryan, 'Is There a Future for Involuntary Treatment in Rights-Based Mental Health Law?' (2014) 21 Psychiatry, Psychology and Law 747, 749.

basis with others.[779] Thus, people with dementia are principally valid decision-makers who can, and must, engage in decision regarding end-of-life care. In this respect, people with dementia should therefore be able to legally refuse life-sustaining treatment and consent to palliative care.

5.3.2 Valid Decision-Making with Dementia

5.3.2.1 Contextualising decision-making with dementia

In considering what constitutes a valid decision by a person with dementia as valid decision-making agents, the first step is to contextualise the possibilities and challenges in decision-making with dementia. Often, verbal communication with dementia can be marked by expressive difficulties including "difficulty finding words, reduced fluency and difficulty producing sounds." A related point is that verbal communication can be difficult to understand.[780] Alzheimer's disease for instance, is accompanied by challenges with understanding and verbal communication even as non-verbal communication is largely retained such as gestures and facial expressions.[781] In the case of semantic dementia, clinical features include impairment with the expression and comprehension of words.[782] In regards to non-verbal communication, behavioural changes "such as agitation, hostility and physical aggression, are usually attempts to communicate." Importantly, such "negative" (sic) behaviours as a form of communication may increase in response to inadequate pain treatment.[783] In addition, loss of communication is typical at the end of life. As one physician reported, it can happen that despite all efforts of support, patients with dementia

> quite simply don't really understand what you say, they have lost speech and linguistic ability. – Participant J

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[779] CRPD art 17.

[780] Murna Downs and Lindsey Collins, 'Person-Centred Communication in Dementia Care' (2015) 30 Nursing Standard 37, 38–40.

[781] Silva Banovic, Lejla Junuzovic Zunic and Osman Sinanovic, 'Communication Difficulties as a Result of Dementia' (2018) 30 Materia Socio-Medica 221, 222.

[782] John Hodges and Karalyn Patterson, 'Semantic Dementia: A Unique Clinicopathological Syndrome' (2007) 6 The Lancet Neurology 1004, 1005.

[783] Downs and Collins (n 780) 38–40.

Given this, it is important that the Patient Act stipulates that patients can consent in writing, orally or other means indicative of consent.[784] However, this does not indicate whether there is a requirement as to the quality of these expressions. For example, what is the legal status of a verbal utterance that does not seem to be related to external factors? Further, what does the physical expression of a struggle against pain relieving treatment constitute in law?

5.3.2.2 Valid decisions distinguished by patient wishes

Litins'ka usefully proposes that valid decisions are distinguishable on the basis of whether or not the expressions can be taken to indicate the patient's wishes.[785] This position is forwarded with reference to the preparatory works for the Patient Act's emergency treatment provision[786] which holds that emergency treatment is possible when the wishes of the person are not discoverable.[787] Reading Swedish law through the prism of the CRPD confirms that it is the true wishes of the patient that should be respected and adhered to by healthcare professionals.[788] Recognising that access to legal capacity requires support,[789] article 12(4) of the CRPD explains that supportive measures must safeguard the exercise of legal capacity by ensuring that the rights, wills and preferences of people with dementia are respected and abuse prevented.[790] Despite a lack of clarity on the exact definition of the phrase "will and preferences,"[791] Quinn et al. reflect that

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[784] Patient Act (2014:821) [Patientlagen] 4 chap. 2 §.

[785] Litins'ka, 'To Force or Not to Force: Protecting the Lives of Persons with Dementia Who Refuse Care' (n 124) 474.

[786] A comprehensive analysis of the emergency treatment provision will be provided in subsection 5.6.1.

[787] Prop. 2013/14:106 60; Litins'ka, 'To Force or Not to Force: Protecting the Lives of Persons with Dementia Who Refuse Care' (n 124) 493.

[788] Litins'ka, 'To Force or Not to Force: Protecting the Lives of Persons with Dementia Who Refuse Care' (n 124) 474.

[789] CRPD art 12(3).

[790] ibid art 12(4).

[791] Eilionóir Flynn, 'Legal Capacity for People with Dementia: A Human Rights Approach' in Suzanne Cahill (ed), *Dementia and Human Rights* (Bristol University Press 2018) 164; Anna Arstein-Kerslake and Eilionóir Flynn, 'The General Comment on Article 12 of the Convention on the Rights of Persons with Disabilities: A Roadmap for Equality before the Law' (2016) 20 The International Journal of Human Rights 471, 483-484 stipulated that "will" refers to what a person might hold as their "long-term" vision for their life whilst "preferences" refer to the way they might prioritise options or what they like and dislike;

> "most people rightly use the term "will and preferences" as a term of art that refers essentially to the choice of the person (howsoever formed) as distinct from choices imposed upon the person by a third party and even with their "best interests" in mind."[792]

Thus, regardless of the uncertainty around meaning, it can be concluded that article 12 demands supportive measures that actualise decision-making based on will and preferences rather than best interest decision-making.[793]

Importantly, excavating the patient's wishes as the basis for legally valid end-of-life decisions does not rely upon the ability of people with dementia to be able to express themselves. This follows Rynning's explanation that a person cannot be required to express refusal in order for it to be accepted as such, nor must the absence of expressions of consent mean that it is forced. Rather, under the IoG, it is whether the individual has personally experienced the care as a physical infringement.[794] In this way, it has been suggested that "if there are good reasons to assume that a person would have refused an intervention, it is deemed forced."[795] Similarly, IVO has claimed that where someone is unable to give express consent, the implication is not always necessarily that it is in opposition to their will.[796] In order to actualise opportunities for self-

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George Szmukler, '"Capacity", "Best Interests", "Will and Preferences" and the UN Convention on the Rights of Persons with Disabilities' (2019) 18 World Psychiatry 34, 38 conceptualises "will" in the framework of higher-order self-governance representative of "deeply held, reasonably stable and coherent personal beliefs, values, commitments and conception of the good" in distinction to "preferences" as a presently expressed desire or inclination.

[792] Gerard Quinn, Ayelet Gur and Joanne Watson, 'Ageism, Moral Agency and Autonomy: Getting Beyond Guardianship in the 21st Century' in Israel Doron and Nena Georgantzi (eds), *Ageing, Ageism and the Law: European Perspectives on the Rights of Older Persons* (Edward Elgar Publishing 2018) 57.

[793] 'UN CRPD Committee, General Comment No. 1: Article 12 Equal Recognition before the Law, CRPD/C/GC/1, 11 April 2014' (n 86) para 29; Cliona de Bhailis and Eilionóir Flynn, 'Recognising Legal Capacity: Commentary and Analysis of Article 12 CRPD' (2017) 13 International Journal of Law in Context 6, 14.

[794] Rynning, 'Consent to Medical Care and Treatment: A Legal Study [Samtycke till medicinsk vård och behandling: En rättsvetenskaplig studie]' (n 124) 107.

[795] Litins'ka, 'To Force or Not to Force: Protecting the Lives of Persons with Dementia Who Refuse Care' (n 124) 468.

[796] Inspektionen för Vård och Omsorg, 'Creating Safety without Coercion: Report on Supervisory Efforts in Workplaces Where People with Reduced Decision-Making Ability Live or Stay [Skapa Trygghet Utan Tvång: Rapport om tillsynsinsats vid verksamheter där

determination as manifest in access to healthcare based on one's wishes, the law provides various mechanisms of support.

5.3.3 Mechanisms of Support

5.3.3.1 A legal basis for support

Litins'ka indicates that "all necessary efforts to investigate the wishes and preferences of a particular person" as part of the responsibility to provide supportive measures and an environment "to reasonably accommodate the expression of the person's wishes."[797] Such an obligation is underlined by a network of legal guidance. The NBHW Guidelines on care for people with dementia for instance outlines that carers are under particularly heavy demands where a patient has dementia to be adaptive, responsive and communicative.[798] As part of this, the importance of enhancing competence through the mobilisation of supportive measures that are appropriate to the individual, their environment and their wishes and capabilities is recognised.[799] For example, it encourages consideration of the patient's understanding and experience of their illness and circumstances.[800] The NBHW has also recognised that decision-making capacity is not static, and moreover, that time for consideration and discussion of alternatives with relatives is important.[801] Furthermore, the soft law publication Zero Vision by the Swedish Dementia Centre calls for person-centred care.[802] This idea is that care be responsive to particular and

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personer med nedsatt beslutsförmåga bor eller vistas]' (2015) (Regeringsuppdrag S2013/4269/SAM, S2013/9047/SAM, delvis) 12.

[797] Litins'ka, 'Assessing Capacity to Decide on Medical Treatment: On Human Rights and the Use of Medical Knowledge in the Laws of England, Russia and Sweden' (n 124) 485.

[798] Socialstyrelsen, 'National Guidelines for the Care and Welfare of Dementia: Support for Governance and Management [Nationella riktlinjer för vård och omsorg vid demenssjukdom: Stöd för styrning och ledning]' (n 59) 87.

[799] ibid 43.

[800] Socialstyrelsen, 'Your Obligation to Inform and Involve the Patient: Handbook for Healthcare Providers, Business Managers and Staff [Din skyldighet att informera och göra patienten delaktig: Handbok för vårdgivare, chefer och personal]' (2015) 19.

[801] Socialstyrelsen, 'National Guidelines for the Care and Welfare of Dementia: Support for Governance and Management [Nationella riktlinjer för vård och omsorg vid demenssjukdom: Stöd för styrning och ledning]' (n 59) 88.

[802] Svenskt Demenscentrum, 'Zero Vision for Dementia Care without Coercion or Limitations [Nollvision för en demensvård utan tvång och begränsningar]' (2015) 11 & 14.

individualised needs, wishes, circumstances, values and experiences.[803] This is echoed by the NBHW whose documentation similarly notes the centrality of person-centred dementia care in ensuring that the individual is in focus, and holistic care is made available.[804] The person with dementia is clarified from this perspective to be someone whose experiences and possibilities for self- and "co-determination" should be incorporated and supported in opportunities for participatory interactions with health and social care.[805]

5.3.3.2 The supportive role of those in a close relationship with the patient

The involvement of those in a close relationship with the patient is encouraged[806] in recognition of their supportive contribution to decision-making with dementia. Prior to investigating their role, it is relevant to consider who constitutes a person who has a close relationship with the patient. The proposition to the Patient Act indicated that this group includes, but is not limited to, guardians, children, family members and others who the patient is close to, including for example very close friends.[807] Exactly who may fall within this group is a case-by-case basis consideration.[808] The legislation states that information can be disclosed to those in a close relationship where information cannot be provided to the patient.[809] Such situations include where the patient is unconscious or have reduced decision-making capacities.[810] The possibility to receive information and participate in the healthcare of a patient with dementia in this way is further limited to situations where it is appropriate and not contrary to the principles of privacy and confidentiality.[811]

Interestingly, on the one hand, the NBHW considers those in a close relationship with the patient as grieving loved ones who should receive

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[803] ibid 14–19.

[804] Socialstyrelsen, 'National Guidelines for the Care and Welfare of Dementia: Support for Governance and Management [Nationella riktlinjer för vård och omsorg vid demenssjukdom: Stöd för styrning och ledning]' (n 59) 41.

[805] ibid 20–21.

[806] ibid.

[807] Prop. 2013/14:106 67.

[808] Prop. 1993/94:149 69.

[809] Patient Act (2014:821) [Patientlagen] 3 chap. 4 §; Patient Safety Act (2010:659) [Patientsäkerhetslagen] 6 chap. 6 §.

[810] Prop. 1993/94:149 68.

[811] Patient Act (2014:821) [Patientlagen] 5 chap. 3 § & 3 chap. 5 §.

information in this respect.[812] In this way, it is stipulated that the doctor should provide "next of kin as much time as possible to realise and accept the situation, before taking any measures."[813] On the flipside, it is recognised that those close to the patient also occupy an essential role in relation to the patient themselves in the process of decision-making.[814] This follows the position that well-informed relatives have the potential to work together with caregivers in order to provide good support[815] where they participate in discussions, help to evaluate information[816] and provide valuable information about the circumstances and needs of the patient to healthcare staff.[817]

As forced care cannot be provided against one's will in the absence of legal support,[818] those in a close relationship with the patient cannot provide valid consent to care where the person with dementia expresses their opposition.[819] As such, people in a close relationship with the patient cannot take up the role of deputy decision-maker[820] nor take over the patient's inherent right to decision-making. This is confirmed by Rynning's claim in the context of the legislation that predates the current HSL that the requirement that information be given to someone with a close relationship to the patient is not accompanied by any formal rights to make decision for an incompetent patient.[821] The

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[812] Socialstyrelsen, 'To Give or Not to Give Life-Sustaining Treatment: Handbook for Healthcare Providers, Business Managers and Staff [Om att ge eller inte ge livsuppehållande behandling: Handbok för vårdgivare, verksamhetschefer och personal]' (n 539) 46.

[813] ibid

[814] ibid.

[815] ibid.

[816] Socialstyrelsen, 'National Guidelines for the Care and Welfare of Dementia: Support for Governance and Management [Nationella riktlinjer för vård och omsorg vid demenssjukdom: Stöd för styrning och ledning]' (n 59) 88.

[817] Prop. 2013/14:106 61.

[818] Instrument of Government (1974:152) [Regeringsformen] 2 chap. 20 §; Patient Act (2014:821) [Patientlagen] 4 chap. 2 §; Socialstyrelsen, 'Coercive and Protective Measures in Health and Social Care for Adults [Tvångs- och skyddsåtgärder inom vård och omsorg för vuxna]' (2013) 6.

[819] Socialstyrelsen, 'Coercive and Protective Measures in Health and Social Care for Adults [Tvångs- och skyddsåtgärder inom vård och omsorg för vuxna]' (n 818) 6; SOU 2004:112 625–626.

[820] SOU 2015:80 412.

[821] Rynning, 'Right to Live and Right to Die [Rätt till liv och rätt att dö]' (n 122) 101.

effectiveness of the role imagined for loved ones is potentially undermined by the fact that there are no mechanisms to ensure that such relationships are necessarily capable of facilitating good communication,[822] nor is there a system to ensure that such relationships are not exploitative or otherwise negative, thereby undermining the possibility that it centres the patient's wishes.

5.3.3.3 Past wishes

Although not without limitations, past wishes are a further avenue for affording support for decisions based on the patient's wishes. Advanced care planning has been recognised as providing a form of relational decision-making in which the person with dementia is enabled to prepare for the future.[823] However, there is no legal provision for the formal documentation of one's wishes for future healthcare and/or medical treatment (often referred to as advanced care directives) in Swedish law.[824] In fact, the introduction of legal measures to institute an alternative decision-maker in circumstances of incapacity via the Future Power of Attorney Act in 2017[825] did not extend to the possibility of a future power of attorney in the realm of healthcare as defined in the HSL.[826] Indeed, the preparatory works explicitly stated that a person granted a future power of attorney "should not be allowed to consent or otherwise take a position on the content of measures within health and medicine."[827] This absence has been purposefully crafted on the grounds that advanced care planning through alternative decision-makers in healthcare intersects with particularly challenging legal questions including the protection of freedom from forced bodily intervention provided by the IoG as well as ethical dimensions.[828]

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[822] Litins'ka, 'Assessing Capacity to Decide on Medical Treatment: On Human Rights and the Use of Medical Knowledge in the Laws of England, Russia and Sweden' (n 124) 479.

[823] Harding, *Duties to Care* (n 4) 178.

[824] Carol Tishelman and others, 'Developing and Using a Structured, Conversation-Based Intervention for Clarifying Values and Preferences for End of life in the Advance Care Planning-Naïve Swedish Context: Action Research within the DöBra Research Program' (2022) 46 Death Studies 803, 803; Eneslätt (n 762) 12.

[825] Future Power of Attorney Act [Lag om framtids fullmakter] (2017:310) 1 §.

[826] ibid 2 §.

[827] Prop. 2016/17:30 29.

[828] ibid.

Whilst there are therefore legal limitations to the role of advance care planning in issues pertaining to healthcare,[829] legally non-binding "living wills" are recognised as a meaningful source of information in investigating the attitude of a patient.[830] In this regard, it has been noted by the NBHW that where a patient cannot participate in palliative care, healthcare workers can apply information as to previously expressed wishes and even draw information about previous attitudes through conversations with loved ones.[831] In fact, early communication as a basis for action in future care scenarios is encouraged in soft law. For example, the National Care Program for Palliative Care developed by the Regional Cancer Centre recognises the importance of undertaking conversations early in the progression of cognitive impairment to ascertain what is important for the patient on the question of end-of-life care. Such discussions can allow for wishes for future care and preferences for who might represent the patient past the time they can express themselves to be documented.[832] Similarly, the direction by the NBHW on the issue of person-centred care states that healthcare providers should encourage people with dementia and their families to share stories about the patient which then become a point of departure to understand their "values and preferences" in the provision of care.[833]

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[829] It is nevertheless important to consider how current developments may ultimately bring about change in legal measures in advanced care planning. In addition to the introduction of future power of attorney measures in economic and personal matters, Malin Eneslätt, Gert Helgesson and Carol Tishelman, 'Dissemination, Use, and Impact of a Community-Based, Conversational Advance Care Planning Intervention: Ripple Effects of the Swedish DöBra Cards' (2021) 15 Palliative Care and Social Practice 26323524211032983 for example, discuss how community-based initiatives to introduce advanced care planning have had ongoing impacts with the result of broad dissemination of advanced care planning practices beyond the initial interventions.

[830] Socialstyrelsen, 'To Give or Not to Give Life-Sustaining Treatment: Handbook for Healthcare Providers, Business Managers and Staff [Om att ge eller inte ge livsuppehållande behandling: Handbok för vårdgivare, verksamhetschefer och personal]' (n 539) 46.

[831] Socialstyrelsen, 'National Knowledge Support for Good Palliative Care at the End of Life: Guidance, Recommendations and Indicators [Nationellt kunskapsstöd för god palliativ vård i livets slutskede: Vägledning, rekommendationer och indikatorer]' (n 47) 38.

[832] Regionala Cancercentrum (n 48) 123.

[833] Socialstyrelsen, 'National Guidelines for the Care and Welfare of Dementia: Support for Governance and Management [Nationella riktlinjer för vård och omsorg vid demenssjukdom: Stöd för styrning och ledning]' (n 59) 21.

However, whilst the NBHW recognises the utility of past expressions in the context of a patient who cannot participate in decision-making in the present,[834] concern is also expressed as to the possibility that wishes may evolve. Indeed, government investigations have concluded that advanced care planning ought to be avoided in law as a patient's opinion may have changed, or, have been different when faced with the reality.[835] Against the backdrop of such concerns, the physician is directed to investigate whether the previous writings encapsulate the patient's current position by, for example, gathering information from people close to the patient and other healthcare personnel.[836] The role of documented wishes is therefore evidently secondary to consultation as to the present situation of the patient. If this consultation does not allow a conclusion on the current wishes of the patient, the Handbook directs the physician to proceed with the treatment as if the patient's wishes are unknown. This involves proceeding with a decision on the basis of good care that is commensurate with science and proven experience in the context of the patient's health status.[837] Importantly, whilst science and proven experience can include a consideration as to the patient's perspective, the NBHW Handbook is structured so as to suggest that there is a point in which autonomy becomes irrelevant, and medical decisions can be made solely with regards to patient safety. This, however, goes against the legal rule that legally valid care is predicated on respect of the patient's wishes as explored in subsection 5.3.2.2, even if the patient is unable to communicate this themselves. That such varying guidance exists has the potential to undermine the provision of opportunities for extended agency in suggesting the physicians can proceed on the basis of a medical, objective, decision alone. This can have implications for the degree to which people with dementia may be summarily excluded from participation in the context of well-documented stigmatisation.

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[834] Socialstyrelsen, 'National Knowledge Support for Good Palliative Care at the End of Life: Guidance, Recommendations and Indicators [Nationellt kunskapsstöd för god palliativ vård i livets slutskede: Vägledning, rekommendationer och indikatorer]' (n 47) 38.

[835] SOU 2004:112 580.

[836] Socialstyrelsen, 'To Give or Not to Give Life-Sustaining Treatment: Handbook for Healthcare Providers, Business Managers and Staff [Om att ge eller inte ge livsuppehållande behandling: Handbok för vårdgivare, verksamhetschefer och personal]' (n 539) 38.

[837] ibid.

5.3.3.4 Hypothetical consent as a mechanism to construct wishes

Arguably more appropriate than directing physicians to science and proven experience alone is the doctrine of hypothetical consent as a measure that allows for valid decisions based on the construction of a patient's wishes. This doctrine is not representative of "real" consent but rather constructed consent under specified conditions as a substitute foundation for the provision of legal treatment.[838] Hypothetical consent describes a process in which a patient does not actually consent, but "would have consented if she/he had the opportunity to take a position."[839] Rynning establishes three conditions under which hypothetical consent in healthcare can be valid. Firstly, hypothetical consent can only become relevant in the absence of "reasonable opportunities to obtain valid consent."[840] Secondly, there should not be a reason to think that the patient would oppose the measures. In this context, Rynning notes that whilst previous articulations are relevant, they may not necessarily be decisive.[841] Finally, hypothetical consent can only be acceptable where, on balance, the provision of the treatment is preferable to non-provision.[842] In addition to what is known about what the patient would have chosen, this balancing process includes other considerations such as urgency and the nature of the intervention,[843] with smaller measures more likely to be acceptable than more extensive measures.[844]

This concept was replicated in a government proposal where it was noted that hypothetical consent can actualise where a patient cannot give informed consent, yet the care personnel are aware that the patient would have consented if they were capable.[845] Further, in acknowledging the difficulties in obtaining

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[838] Rynning, 'Consent to Medical Care and Treatment: A Legal Study [Samtycke till medicinsk vård och behandling: En rättsvetenskaplig studie]' (n 124) 385; Dahlin and Åkerström (n 573) 498.

[839] Rynning, 'Consent to Medical Care and Treatment: A Legal Study [Samtycke till medicinsk vård och behandling: En rättsvetenskaplig studie]' (n 124) 385; Jareborg (n 579) 286; Asp, Ulväng and Jareborg (n 718) 235.

[840] Rynning, 'Consent to Medical Care and Treatment: A Legal Study [Samtycke till medicinsk vård och behandling: En rättsvetenskaplig studie]' (n 124) 390.

[841] ibid 391.

[842] ibid 392.

[843] ibid.

[844] ibid 393–394.

[845] Prop. 2013/14:202 12.

consent in some circumstances, IVO noted that there can be a form of presumed consent in which a care worker can assume that a measure is consistent with the patient's will without the expression of consent.[846] Parallel to hypothetical consent, Rynning also employs an understanding that can be labelled hypothetical refusal. This captures the idea that there may be grounds to assume that a person with a rough understanding of the intervention would have refused it.[847]

More substance to the concept of hypothetical consent can be provided with reference to the work of the General Committee of the CRPD in light of the reflection that will and preferences cannot always be known even despite investigative efforts.[848] They have stipulated that where significant efforts to determine a person's will and preferences have failed, a best interpretation of their will and preferences should be made.[849] In this process, the wishes of the patient are reconstructed in a "good faith effort" to come to a decision most indicative of the person's wishes.[850] This includes mobilising everything that is known about what the person wants, including what is being said by "trusted supporters,"[851] and with reference to what supporters know about the patient's life, past decisions, beliefs and values.[852] This can employ consideration of the person's behaviour, "statements, contextual elements or logical/presumptive reasoning."[853] It may, for instance, involve investigating whether supporters can shed light on the nature of their previous engagement with healthcare. For example, has the patient previously elected to avoid going to hospital? It could also involve investigating the patient's values and beliefs in regards to end-of-life experiences. For instance, would they have wanted to be in pain and experience anxiety?

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[846] Inspektionen för Vård och Omsorg (n 796) 12.

[847] Rynning, 'Consent to Medical Care and Treatment: A Legal Study [Samtycke till medicinsk vård och behandling: En rättsvetenskaplig studie]' (n 124) 107–108.

[848] Flynn (n 791) 164–165.

[849] 'UN CRPD Committee, General Comment No. 1: Article 12 Equal Recognition before the Law, CRPD/C/GC/1, 11 April 2014' (n 86) para 21.

[850] Arstein-Kerslake and Flynn, 'The General Comment on Article 12 of the Convention on the Rights of Persons with Disabilities' (n 791) 484; De Sabbata (n 77) 571725.

[851] Arstein-Kerslake and Flynn, 'The General Comment on Article 12 of the Convention on the Rights of Persons with Disabilities' (n 791) 484.

[852] Flynn (n 791) 165.

[853] De Sabbata (n 77) 571725.

CRPD scholarship has suggested that in the absence of information about personal preferences, external decision-makers are likely to conduct their best interpretation approach through the use of "baseline assumptions."[854] Rynning too recognised that where hypothetical consent/refusal can be informed by subjective understandings relating to what is known about the individual's personal views, it may also rely on objective understandings related to what attitudes "people would generally have in similar situations."[855] In this context, it has been said that such assumptions may include that people commonly wish to be alive but not be in pain.[856] However, I argue that the claim that a wish to be alive is an easy presumption stands on shaky ground given the fact that the reality of death is not always a fact to be struggled against. In other words, it may also be said that people at the end of life may, in fact, be accepting of, or even looking forward to death after having lived a long, happy and fulfilled life. Which position is adopted however, is arguably closely related to the norms perpetuated by the law which, as has been demonstrated so far, are largely aligned with the rightness of preserving life and the irrationality of a desire for death.

Nevertheless, when followed to the letter, the doctrine of hypothetical consent should encourage careful reflection that goes beyond assumptions as to the value one places on life and death. With consideration as to the need to balance the provision of care versus the withholding of care under the hypothetical consent doctrine, the nature of the intervention should also be contemplated in addition to what can be known about the patient's position. By way of illustration, pronounced cognitive impairment, difficulties swallowing and repeat infections are recognised as signs of end-stage dementia that should be taken into account in a decision to shift to palliation.[857] Where a life-threatening lung infection results, for example, the use of antibiotics as a curative rather than palliative measure in light of natural decline would require a higher degree of intervention. This is because it requires further procedures including blood work and blood pressure checks not indicated in palliative care. Consequently, in the absence of information that the patient's personal

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[854] Flynn (n 791) 165.

[855] Rynning, 'Consent to Medical Care and Treatment: A Legal Study [Samtycke till medicinsk vård och behandling: En rättsvetenskaplig studie]' (n 124) 107–108.

[856] Flynn (n 791) 165.

[857] Regionala Cancercentrum (n 48) 122.

preference suggests otherwise, palliative treatment would be acceptable where other curative measures would not under the doctrine of hypothetical consent.

Thus, following Litins'ka's claims in relation to healthcare treatment more broadly, palliative treatment for patients who "cannot communicate and do not resist treatment" "may be unproblematic."[858] However, it is nevertheless reasonable to be wary of any efforts to reconstruct someone's wishes as to end-of-life care. Indeed, given the significant implications of such practices for end-of-life care, the following interpretation is important:

> "If a patient cannot express their wills and it is not possible to assume whether they would agree or refuse, it is problematic either to determine that intervention is forced, or, voluntary."[859]

To assume otherwise risks the application of stigmatising, discriminatory and/or paternalistic assumptions as to what wishes one may hold at the end of life.

5.3.4 Challenges with Identifying Wishes

Despite the possibilities for uncovering wishes as a basis for legally valid decisions predicated on self-determination, some concern persists in regards to the way in which one's true wishes can be identified. One issue in this regard is the possibility for conflicting wishes across time or in the present.[860] Temporal conflict, for example, may emerge in circumstances where a person prior to a diagnosis of cognitive illness or decline in advanced dementia has expressed that they do not wish to live past the time they recognise their loved ones. Yet, the person in the present may express content and happiness with their current situation when they are otherwise physically healthy. As accounted for in subsection 5.3.3.3's exploration of past wishes, this is largely solved in domestic sources through preferencing the opinions of the person in the present.

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[858] Litins'ka, 'Assessing Capacity to Decide on Medical Treatment: On Human Rights and the Use of Medical Knowledge in the Laws of England, Russia and Sweden' (n 124) 487.

[859] ibid 460.

[860] Lucy Series and Anna Nilsson, 'Article 12 CRPD: Equal Recognition before the Law' in Bantekas Ilias, Michael Ashley Stein and Dimitris Anastasiou (eds), *The Convention on the Rights of Persons with Disabilities: A Commentary* (Oxford University Press 2018) 30.

In regards to present conflict, one may not want to be in pain but because of behavioural and psychological symptoms of dementia resist pain relief treatment. This situation was explored in the interviews:

> The difficulty there is that they, maybe because of cognitive impairment, don't really understand what it is you say yes to and then, often it is a difficulty which you in the best case scenario can like, come to find that it is not impossible, but just difficult … then there is situations where it is, in principle impossible, it feels as if the patient either refuses something that, from what you know about them and how they have spoken earlier and how their family talk about it, appears to be an inadequate response, actually is not what you expect they would say. – Participant J

It is difficult to see how domestic sources of law support a resolution on this issue where supportive measures are unable to overcome these concerns. A best interpretation of conflicting will and preferences indicated by the General Committee and illuminated by Arstein-Kerslake and Flynn may be useful in what might be described as the "hard case" of conflicting wishes.[861] However, the above procedure does comes with the risk identified by Saks as "choosing selves."[862] Where authenticity is placed into question, issues of understanding or sufficient evaluation based on one's authentic beliefs are raised. An analysis of one's intentionality is subsequently incited. This shares similarities with functional tests for mental capacity[863] which have been criticised by the Committee on the grounds that it assumes that the mind's internal machinations can be accurately assessed resulting in the denial of the human right of equal recognition in law.[864]

Whilst this of significant concern where wishes conflict, it does raise concern as to the process of extrapolating wishes from expressions more broadly. In relation to the pursuit of identifying one's true wishes, Series and Nilsson explain that the transition from a standard of rationality to one of authenticity contains a sustained possibility for coercion.[865] In this context for instance, it

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[861] Arstein-Kerslake and Flynn, 'The General Comment on Article 12 of the Convention on the Rights of Persons with Disabilities' (n 791) 482.

[862] Elyn R Saks, Refusing Care: Forced Treatment and the Rights of the Mentally Ill (University of Chicago Press 2010) 11–12.

[863] Series and Nilsson (n 860) 370.

[864] 'UN CRPD Committee, General Comment No. 1: Article 12 Equal Recognition before the Law, CRPD/C/GC/1, 11 April 2014' (n 86) para 15.

[865] Series and Nilsson (n 860) 370.

may involve coercive or forceful action in order to satisfy what has been constructed as the "true" wish. In light of this, the suggestion has been to engage in "minimalist constructions" of one's intention that locates their will and reference in their present expressions.[866] This is confirmed by Arstein-Kerslake and Flynn who argue that in the case of doubt, intention should be assumed in action.[867] Thus, although supportive measures can be utilised to create the conditions for expressions of assent, it is the expression itself that should often be taken as indicative of valid expressions of refusal or consent of life-sustaining treatment and palliative care. Consent can therefore not be assumed in opposition to these expressions.

5.4 The Consequences of Individualism

5.4.1 Support for What?

Certainly, on the face of it at least, the Swedish framework so conceived arguably follows Clough's vulnerability analysis in which the binary demarcation of capacity is problematised,[868] and the importance of networks of support that respond to a patient's needs in decision-making is recognised.[869] As outlined above, the legal regime does not allow for a declaration of legal incompetence, but rather necessitates an understanding of whether the patient understands the intervention in question to represent force, or, whether they wish to have medical treatment. This is reinforced by the availability of supportive measures to actualise this right to self-determination for people with dementia. Along these lines, Hall's argument that the CRPD implicitly captures a demand for effective responses to vulnerability in

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[866] ibid.

[867] Anna Arstein-Kerslake and Eilionóir Flynn, 'The Right to Legal Agency: Domination, Disability and the Protections of Article 12 of the Convention on the Rights of Persons with Disabilities' (2017) 13 International Journal of Law in Context 22, 26.

[868] Clough, 'Disability and Vulnerability' (n 147) 473 & 477.

[869] Beverley Clough, 'Vulnerability and Capacity to Consent to Sex - Asking the Right Questions' (2014) 26 Child and Family Law Quarterly 371, 389.

decision-making for people with dementia[870] may also be applied to the Swedish system.

Of course, as Pritchard-Jones reflects in relation to the CRPD, respecting the wishes of people with dementia is a welcome opportunity in midst of the experience of discrimination due to disability and age.[871] However, as she goes on to argue, article 12 and General Comment 1 have largely been narrowly interpreted through an "overly-individualistic" lens where support is merely "a conduit to the enactment of a person's already pre-defined 'will and preferences.'"[872] Following Pritchard-Jones' description in relation to article 12,[873] the backdrop of non-interference in Swedish law presumes that the wishes of the patient as the absolute decision-maker already exist, and should be followed, with support therefore existing as a mechanism to reveal the person's pre-existing or true wishes by affording explanations of information and interpretation of wishes. For example, it has been argued that the approach to supportive loved ones as outlined in subsection 5.3.3.2 reflects the presumption of an autonomous and rational subject. In particular, it constructs the role of relatives in relation to people conceived of as incapable decision-makers "as persons with wishes but with an inability to express them."[874]

A vulnerability analysis warns that where efforts to promote autonomy continue to rely on the ideals of "independence and personal responsibility," "unrealistic and inappropriate expectations of autonomy" are promoted.[875] In fact, in a system predicated on a liberal decision-making agent who has pre-

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[870] Margaret Isabel Hall, 'Dementia, Autonomy and Guardianship for the Old' in Charles Foster, Jonathan Herring and Israel Doron (eds), *The Law and Ethics of Dementia* (Hart Publishing 2014) 347.

[871] Laura Pritchard-Jones, 'Exploring the Potential and the Pitfalls of the United Nations Convention on the Rights of Persons with Disabilities and General Comment No. 1 for People with Dementia' (2019) 66 International Journal of Law and Psychiatry 101467, 101469.

[872] ibid 101468.

[873] ibid 101470 explains that article 12 of the CRPD indicates a requirement for support in the context of "a permanent presumption in favour of the will and preferences of the individual" who "is the decision-maker." The role played by supporters is framed as one limited to providing explanations of the decision and interpretations of the individual's wishes.

[874] Elisabeth Dahlborg Lyckhage, Sandra Pennbrant and Åse Boman, '"The Emperor's New Clothes": Discourse Analysis on How the Patient is Constructed in the New Swedish Patient Act' (2017) 24 Nursing Inquiry e12162, 12167.

[875] Dodds, 'Dependence, Care, and Vulnerability' (n 285) 198.

existing wishes, even the scope of support afforded to uphold these rights and obligations is narrowed to the extent that it ultimately threatens to overlook the complex systems of support and relationality. Indeed, for people with dementia, decision-making is not a discovery of pre-existing wishes that exist in a vacuum inherent to the patient, but rather a dialogic process in which support, and supporters themselves, may be the very thing that underlies the ultimate decision.[876] Furthermore, approaches to autonomy that extend beyond an individualistic framework have been recognised as most appropriate for fulfilling the central role of self-determination in palliative care.[877]

Such recognition of the importance of non-individualistic, relational approaches to care affirm that the law presently represents an anaemic portrayal of the patient's position and the responsibilities of healthcare. Ultimately, individualistic informed expectations of a hidden yet implicit rationality that can be uncovered threatens to undermine access to appropriate, person-centred end-of-life care. A concrete example of this inbuilt limitation is the fact that this framework is unable to grapple with the issue of conflicting wishes as canvassed above.[878] The exact implications of the relationship between the presumption of individualism and obligations to navigate end-of-life issues with rationality in order to secure access to physical and self-affirming care at the end of life will be unpacked further in sections 5.5 and 5.6. These implications are closely related to the fact that, where such relational supports are lacking, the turn to paternalism is never far away.

5.4.2 Dementia as an Exception? The Looming Threat of Paternalism

In fact, where patients with dementia are perceived to have failed to actualise the requisite rationality of the legal subject, the underpinning current of individualism manifests in "misplaced paternalism."[879] The turn to paternalism in the midst of an individualistic regime is evident in the legal discourse on whether people with dementia are exempt from the aforementioned description

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[876] Pritchard-Jones (n 871) 101470–101471.

[877] Fiona Wilson and others, 'Autonomy and Choice in Palliative Care: Time for a New Model?' (2014) 70 Journal of Advanced Nursing 1020.

[878] Pritchard-Jones (n 871) 101470 in fact claims that the CRPD's best interpretation rule cannot apply in the face of oppositional preferences.

[879] Dodds, 'Dependence, Care, and Vulnerability' (n 285) 198.

of the right to freedom from interference. In a government report in 2006, a law for coercive medical care where necessary in light of the patient's health status was proposed.[880] The IoG arguably requires the passage of such a law in accordance with the provision that the protection against bodily intrusion can only be limited by law.[881] The Council on Legislation however, argued that a law to exempt healthcare professionals from the IoG‘s prohibition on state infliction of bodily violence was only relevant when said violence was not available to ordinary citizens. The Council subsequently claimed that the use of force against people with dementia was a measure available within private caring arrangements, and therefore, concluded that such legislative provisions were not necessary.[882] On the Council's reading, people with dementia are therefore evidently exempt from the IoG's protection from forced care.

As already accounted for in section 5.3, there are clearly strong reasons to overturn this claim. As pointed to by Litins'ka, overlooking the provision of the legislative exemption of state violence would arguably contravene the intent behind the IoG as well as "the principle of legality, where fundamental rights must receive the strongest protection."[883] Although the IoG is a higher order source of law, it is relevant to point out that such an interpretation would be contrary to the thrust of healthcare regulation in legislative frameworks. In particular, such an approach would be in opposition to the obligation that care be provided on the basis of consent for all people, regardless of decision-making ability or disability. This is provided for by the Patient Act's stipulation that care be provided on the grounds of consent under the Patient Act without consideration as to capacity,[884] and is re-affirmed when read in conjunction with the obligation to provide equal opportunities in healthcare under the HSL.[885] Soft law instruments supplement the conclusion that force should be avoided in dementia care. For example, IVO has discouraged the use of force

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[880] SOU 2006:110.

[881] Instrument of Government (1974:152) [Regeringsformen] 2 chap. 20 §.

[882] Lagrådet, 'Good Care for People with Dementia as Well as Rules for Protection and Legal Certainty [God vård och omsorg om personer med demenssjukdom samt regler för skydd och rättssäkerhet]' (2012); Dahlin (n 218) 161.

[883] Litins'ka, 'To Force or Not to Force: Protecting the Lives of Persons with Dementia Who Refuse Care' (n 124) 478.

[884] Patient Act (2014:821) [Patientlagen] 4 chap. 2 §.

[885] Health Care Act (2017:30) [Hälso och sjukvårdslagen] 3 chap. 1 §.

upon people with dementia.[886] In addition, the guidance produced by the Swedish Dementia Centre also departs from the understanding that coercive measures should be avoided unless it is a last resort in their Zero Vision for coercive dementia care document.[887]

It is therefore ultimately difficult to see the possibility for forced treatment without specific legal exemption despite the claims of the Council of Law to the contrary. However, Dahlin expresses the concern in relation to healthcare more generally that whilst Swedish law lacks regulations outlining the possible circumstances under which care can be forced upon a patient with dementia, there will be uncertainty for patients and practitioners.[888] This uncertainty means that the manifestation of force in practice is a strong possibility. As will be explicitly addressed in the remainder of Chapter 5, given the pressures of individualism on death and dying, this paternalism is arguably only heightened where persons facing death with dementia are presumed to be doubly irrational due to their cognitive illness and proximity to death.

5.5 End-of-Life Decision-Making with Dementia

5.5.1 Palliative Care with Dementia

Although end-of-life decisions have been incorporated in the foregoing analysis of the fundamental features of legal decision-making with dementia, this section pays specific attention to the regulations as they pertain to end-of-life decision-making with dementia. Beginning with palliative care, that consent and refusals by people with dementia are constitutionally and legislatively protected has been taken to mean that there is no legal support for the provision of life-sustaining or palliative treatment without consent.[889] Important in this respect is the Regional Cancer Centre's National Palliative Care Program clarification that respect for self-determination is "not

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[886] Inspektionen för Vård och Omsorg (n 796).

[887] Svenskt Demenscentrum (n 802) 11, 48 & 72.

[888] Dahlin (n 218) 162.

[889] Titti Mattsson, 'Autonomy, Capacity, and Vulnerability: Making Decisions on Social Services for Persons with Dementia in Sweden' in Mary Donnelly, Rosie Harding and Ezgi Tascioglu (eds), *Supporting Legal Capacity in Socio-Legal Context* (Hart Publishing 2022) 309.

conditional on the capacity to exercise one's autonomy."[890] Thus, whilst the ideal situation is that a person can give consent, it is recognised that dignity and integrity can also be safeguarded by family and healthcare workers when opportunities for self-determination (as clearly conceived of in an individualistic sense) is more limited.[891] Furthermore, the NBHW indicated that even where a patient with dementia may have difficulties in comprehending all of the aspects associated with palliative care, one should be cognisant of the fact that they may have some understanding which should be incorporated into palliative conversations.[892]

Indeed, whilst not overlooking the concerns canvassed in 5.4.1, drawing upon the supportive measures afforded by law does undergird a promising starting point to promoting both agency and physical wellbeing in palliative care. For example, rather than allowing for force, the legal framework indicates that expressions of refusal of palliative care judged medically necessary should first be combatted with supportive measures. Supportive measures can, and indeed should, be provided to enhance the possibility for assent to palliative treatment considered to be in line with science and proven experience. This is in fact central given that a failure to provide a platform to encourage assent where cognition may be at issue threatens to undermine the equal rights of people with dementia to palliative care as provided for by chapter 3, section 1 of the HSL.

Nevertheless, embedded in an individualistic regime, an apparent trade-off also looms in the legal guidance. For instance, in stipulating that respect for a patient's autonomy increases in difficulty in tandem with the progression of the dementia illness, the NBHW explains that deciding with dementia at the end of life is not always a clear cut question of respecting autonomous wishes.[893] Indeed, the NBHW suggests that, as serious illness can threaten autonomy, attempts to promote self-determination must be undertaken in

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[890] Regionala Cancercentrum (n 48) 26.

[891] SOU 2001:6 49.

[892] Socialstyrelsen, 'National Knowledge Support for Good Palliative Care at the End of Life: Guidance, Recommendations and Indicators [Nationellt kunskapsstöd för god palliativ vård i livets slutskede: Vägledning, rekommendationer och indikatorer]' (n 47) 38.

[893] Socialstyrelsen, 'Your Obligation to Inform and Involve the Patient: Handbook for Healthcare Providers, Business Managers and Staff [Din skyldighet att informera och göra patienten delaktig: Handbok för vårdgivare, chefer och personal]' (n 800) 19.

balance with “other ethical principles, for example to do no harm.”[894] They recognise that this balance is particularly challenging where a patient refuses treatment.[895] Along these lines, a state investigation into dying indicated that palliative care is about securing quality of life for all at the end of life, especially given the reality of declining self-determination.[896] Such advice is indicative of a sort of dividing line between palliative care that embraces opportunities for self-determination and that which must instead be based on physical needs. Of course, there may be limits to the degree to which a person with dementia can actualise individualistic autonomy in the present as the illness progresses. However, where palliative care is “appropriate, sympathetic and person centred” afford opportunities for “a peaceful and dignified death” where and prevents the stigmatisation of “death and dying with dementia.”[897] With this in mind, the individualistic system under which palliative care operates may serve to undermine potential for genuine support for relational personhood despite recognition as to the importance of autonomy and self-determination at the end of life for all patients.

5.5.2 Refusal of Life-Sustaining Treatment with Dementia

Of greater concern is the regulatory framework of refusals of life-sustaining treatment by people with dementia. Certainly, whilst a physician may unilaterally withdraw or withhold treatment on the basis of science and proven experience,[898] the threat posed by paternalism due to a framework predicated on individualistic rationality creates serious issues. Like palliative care, the respect for the wishes of patients with dementia as written into the relevant sources of law should arguably allow for the refusals of life-sustaining treatment even where they are made by persons with dementia who may have challenges with decision-making competence. However, as canvassed in subsection 4.4.2, the law is far from clear on whose wishes receive legal protection on this question.

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[894] Socialstyrelsen, ‘National Guidelines for the Care and Welfare of Dementia: Support for Governance and Management [Nationella riktlinjer för vård och omsorg vid demenssjukdom: Stöd för styrning och ledning]’ (n 59) 90.

[895] ibid.

[896] SOU 2001:6 54.

[897] Harding, *Duties to Care* (n 4) 177.

[898] See subsection 4.4.2.

For instance, the guidelines and general advice on life-sustaining treatment by the NBHW place an explicit, supplementary demand on the quality of self-determination in the context of a decision to refuse treatment that can lead to death. Arguably, a person with dementia could face particular difficulties regarding the capacity demands which include the requirement that the person understands the information.[899] The Handbook does direct physicians to remedy barriers to an informed refusal before returning to allow the patient to make an informed request.[900] This may indicate the possibility for supportive measures in order to actualise true, informed wishes so conceived by the criteria. However, I would suggest that such opportunities in the case of people with dementia who may be experiencing more sustained or serious issues with decision-making is not imagined or intended by these guidelines. Rather, there is a clear attempt to set limits for autonomy in the face of the primary desire to protect and maintain life.

Adopting a different approach, the Swedish Society of Medicine as an independent professional body instead stipulates respect for the wishes of the patient with dementia on the withdrawal of treatment even where decision-making competence is found lacking. The guidelines hold that, where a patient lacks decision-making competence, verbal or written directives can be applied in favour of the withdrawal of treatment.[901] Further, in the absence of such directives the guidelines direct healthcare professionals to attempt to understand "what the patient would have wanted if they had been competent." This can be achieved through dialogue with those who have a professional or personal relationship with the patient. The guidance concludes that where this reconstruction of the patient's wishes settles that the patient would not have wanted to treatment, this should be respected.[902] It is important that decision incompetency is not related to an inability to have one's personhood respected in the removal of potentially life-sustaining treatment. However, at the same time, these guidelines are operating under principle of a dividing line between

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[899] Life-sustaining treatment [Livsuppehållande behandling] SOSFS 2011:7 4 chap. 1§.

[900] Socialstyrelsen, 'To Give or Not to Give Life-Sustaining Treatment: Handbook for Healthcare Providers, Business Managers and Staff [Om att ge eller inte ge livsuppehållande behandling: Handbok för vårdgivare, verksamhetschefer och personal]' (n 539) 37.

[901] Svenska Läkaresällskapet and Svensk sjuksköterskeförening, 'Ethical Guidelines When Deciding to Withhold and/or Discontinue Life-Sustaining Treatment [Etiska riktlinjer vid ställningstagande till att avstå från och/eller avbryta livsuppehållande behandling]' (2018) art 5.

[902] ibid art 6.

the person with dementia who is capable and the person who is incapable of decision-making. To this degree, it risks overriding the person in the present based on the wishes of the person in the past. This arguably runs afoul of Swedish regulatory principles whilst also leaving unanswered questions as to what to do when the person considered incompetent in the present is otherwise expressing a wish to live.

The logical corollary of legal advice as to whose wishes to withdraw treatment can be respected is a consideration of whether treatment can in fact legally provided against the express wishes of the person with dementia. The NBHW Guideline's cannot in isolation allow for the provision of forced life-sustaining treatment where there are expressions of refusal by a patient with dementia who may not meet the threshold, capacity criteria. As demonstrated above, the Swedish legal system hinges upon the ability of all people to be free from forced treatment. Furthermore, the jurisprudence of the ECtHR also does not indicate that forced care must be provided for in domestic law in the face of possible death. In relation to the ECHR, the freedom afforded to people with normal decision-making abilities to determine the way in which their life ends is not replicated where competency is considered to be an issue. For example, the Court in Pretty emphasised mental competence as a central component of end-of-life choice under article 8.[903] Moreover in Haas, the Court constructed an explicit obligation under article 8(2) "to prevent an individual from taking his or her own life if the decision has not been taken freely and with full understanding of what is involved."[904] Incapacity, in fact, triggers the obligations of the state to prevent people with diverse decision-making capabilities to make such decisions in favour of the right to life:

> "Article 2 of the Convention enshrines the principle of sanctity of life, which is especially evident in the case of a doctor, who exercises his or her skills to save lives and should act in the best interests of his or her patients. The Court has therefore held that this Article obliges the national authorities to prevent an individual from taking his or her own life if the decision has not been taken freely and with full understanding of what is involved. It follows that one of the central issues in determining the validity of a refusal to undergo medical treatment by a patient is the issue of his or her decision-making capacity."[905]

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[903] *Pretty v United Kingdom* (n 686) para 63.

[904] *Haas v Switzerland* (n 708) para 54.

[905] *Arskaya v Ukraine* [2013] ECtHR App no. 45076/05 para 69.

However, although the Court has allowed for force,[906] it has also cautioned against excessive restriction with reference to the fact that States should fulfil, their positive obligations in line with respect for individual rights and freedoms and therefore, should not infringe upon personal autonomy.[907] In respect to this idea, the Court has also held that measures other than force "ought to be available to dimmish the opportunities for self-harm, without infringing personal autonomy"[908] and have referred to the "least restrictive regime" as appropriate.[909]

Further consideration of what this means in the circumstances of dementia is nevertheless required. It is important to note that these cases were considered in the midst of suicidal behaviour in non-dementia psychosocial illness rather than in the context of dementia as a terminal diagnosis. Whilst people with dementia can live a long life after diagnosis, all people with a dementia diagnosis will die with or from dementia. What measures would be appropriate where a treatment refusal or an assisted dying request is expressed by someone in the context of a life-ending illness? Are these different to the stipulation that the measures be required to prevent suicide? Further, may there be other considerations where such a refusal is in line with what is known about the person's life-long wishes regarding quality of life and death? It is difficult to say for certain what the Court would determine in the face of such a case. They have, for instance, made it clear that the right to die regardless of the circumstances is circumscribed to people with decision-making ability. The best available conclusion is therefore that, whilst not requiring force, the current interpretation of the ECHR does encourage states to adopt measures that ward off choice that threaten death for patients with dementia.

A more balanced account that does not unfairly protect choice or protection in death is captured through the CRPD which may apply on the rules of a treaty conformity interpretation. Enshrining the inherent right to life for people with

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[906] *Herczegfalvy v Austria* [1992] ECtHR App no. 10533/83 para 82: article 3's protection of inhuman and degrading treatment will not be infringed where forced treatment is considered therapeutically necessary for the preservation of health under the rules of medical science; *VC v Slovakia* [2011] ECtHR App no. 18968/07 para 110 associates therapeutic necessity with life-sustaining treatment; *Nevmerzhitsky v Ukraine* [2005] ECtHR App no. 54825/00 para 76-77 also links medically necessary treatment with life-sustaining treatment on the issue of forced feeding of competent detainees.

[907] *Fernandes de Oliveira v Portuga*l [2019] ECtHR App no. 78103/14 para 112.

[908] *Trubnikov v Russia* [2005] ECtHR App no. 49790/99 para 70.

[909] *Fernandes de Oliveira v Portugal* (n 907) para 121.

disabilities on equal standards with others,[910] negotiations on the content of article 10 included discussion over the extent to which common understandings about the life quality of people with disabilities should be accounted for.[911] This was reflective of the concern that there is a risk that death for people with disabilities may result from stigmatising beliefs about the low values of such lives.[912] Concerns regarding the connection between disability and the termination of life were in fact ultimately recognised under article 25[913] which requires that States prevent discriminatory denial of health care or health services or food and fluids on the basis of disability.[914] To this extent, the state ought to be cautious to avoid a legal framework that might threaten the right to life by allowing for unequal practices in the withholding of life-sustaining treatment. In a similar vein, Herring is clear that articles 10 and 25 can in fact be mobilised as part of a claim for a right that suicide be prevented.[915] Furthermore, certain readings of the CRPD have positioned the right to life so favourably to the extent that autonomy can be circumscribed. In this vein, Flynn draws attention to the way in which the inclusion of rights in the phrase "rights, will and preferences" contained in article 12(4) has been mobilised to claim that the right to life can eclipse the will and preferences of the patient.[916]

Conversely, the CRPD has also been understood to require that individuals with disability are not to be constructed as passive objects of charity to the extent that their opportunities for self-determination are excluded in contradistinction to the opportunities afforded to people without disability.[917] In other words, there is a concurrent duty to not presume that dementia is necessarily associated with a lack of autonomy that should subsequently be

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[910] CRPD art 10.

[911] Anna Bruce, 'Which Entitlements and for Whom? The Convention on the Rights of Persons with Disabilities and Its Ideological Antecedents' (PhD, Lund University 2014) 169.

[912] ibid 172.

[913] ibid 171.

[914] CRPD art 25(f).

[915] Herring, *The Right to Be Protected from Committing Suicide* (n 773) 134.

[916] Flynn (n 791) 165.

[917] Litins'ka, 'Assessing Capacity to Decide on Medical Treatment: On Human Rights and the Use of Medical Knowledge in the Laws of England, Russia and Sweden' (n 124) 154–155.

met with enhanced life lengthening measures.[918] Thus, as Bruce has claimed, the CRPD does not suggest that life is always preferable, but rather that, disability in and of itself cannot be the basis for deciding that another's life is not worth living.[919] This interpretation is arguably important as it honours the commitment of Swedish law to a patient's wishes in direct relationship to end-of-life decisions. In this way, it goes some way to resisting the predisposition towards a paternalistic prevention of death for people with dementia to the degree that it facilitates overtreatment and reduced quality of life in death and dying.

Despite this, the inconsistent nature of the law gives rise to serious concerns regarding the practice of withdrawing life-sustaining treatment for people with dementia. On the one hand, care practitioners are potentially operating under uncertainty on account of conflicting rules. On the other hand, concerns arise in regards to patients with dementia who refuse life-sustaining care. In particular, whose wishes will be respected and under what conditions whilst others may be ignored? Can supportive measures overcome the requirement for capacity or will the spectre of forced care emerge as a real possibility in care for people with dementia? Due to the law's inconsistency on this matter, it appears presently limited in its ability to constructive collective responsibility to respect and institute end-of-life wishes to withhold and withdraw treatment. Instead, it ultimately undermines the ability of people with a diagnosis of a cognitive illness to exercise control over their death. Such paternalism may arguably arise even in the early stages where the cognitive illness is mild.

5.5.3 Assisted Dying with Dementia

A review of end-of-life decision-making with dementia cannot overlook the specific circumstances of a wish to die with assistance which similarly demonstrates significant limitations on end-of-life choices. Considering assisted dying in this context may be particularly relevant for those in an early stage of cognitive illness who would like the possibility of access to assistance as the illness progresses,[920] or, who would like to die with assistance in the

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[918] Herring, *The Right to Be Protected from Committing Suicide* (n 773) 134.

[919] Bruce (n 911) 171.

[920] Jocelyn Downie and Georgia Lloyd-Smith, 'Assisted Dying for Individuals with Dementia: Challenges for Translating Ethical Positions into Law' in Michael Cholbi and Jukka

present, prior to the onset of major neurocognitive disorder. Indeed, some patients with dementia who experience suffering related to their cognitive decline which "cannot be alleviated even with optimal medical treatment and psychosocial care" subsequently wish to decide on their death whilst still cognitively capable.[921] As indicated in subsection 4.4.3, medically assisted dying is currently not possible under the current interpretation of Swedish law for anyone. The possibility for assistance from a private person in which the consequential death causing act is caused by the dying person themselves in the case of dementia also appears unlikely. In fact, whilst untested on the specific question of persons with dementia, the state of the law in these circumstances may be indicated by jurisprudence relating to the death of a person with reduced decision-making competency.

In this particular case, the defendant's claim that they provided an assisted death was dismissed, and a criminal conviction laid. It involved a man whose disability was considered to mean that he had the competence of a child. He was offered a deadly dose of tablets that he then took himself as part of his regular nighttime medication regime. Although the person who gave him the tablets argued that he had communicated a decision to die, the court declared that the man had not decided to end his life.[922] Most important however, was the court's opinion that even if he had made the decision to end his life, his level of capacity meant that "he acted less rationally and was also not competent to make such a decision." Thus, even if the court agreed that a wish to die had been communicated, the provision of the tablets would have found to have represented a criminal act due to the presumed incapacity of the requesting person.[923] In this way, the general rules of assistance in dying in which the primary death causing act is performed by the person who dies[924] do not apply in circumstances of presumed incapacity.

Questions remain, however, in regards to what degree of incapacity will spark such a protective response. Whilst people at an advanced stage of dementia would certainly be prevented from access to assisted dying according to the court's reasoning in this case, it is unknown whether individuals at an early

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Varelius (eds), *New Directions in the Ethics of Assisted Suicide and Euthanasia* (Springer International Publishing 2015) 104.

[921] Gather and Vollmann (n 61) 446.

[922] *B 1100-22* (Göta Hovrätt) 7–8.

[923] ibid 9.

[924] See subsection 4.4.3.

stage of cognitive illness may be treated with similar protectionist tendencies. Nevertheless, this case suggests that even outside the context of healthcare, the possibility for autonomy at the end of life as manifest through the decriminalisation of suicide and subsequent access to assisted dying where the primary death causing act is by the dying person themselves, will be narrowed in the circumstances of dementia. This approach is arguably seated in a paternalistic response to the presumably irrational subject.

5.6 Alternative Legal Agents for End-of-Life Decision-Making with Dementia

5.6.1 Emergency Care

Chapter 5 has hereto detailed how people with dementia are conceived of as independent decision-making agents subject to responsibilities to navigate healthcare until the spectre of irrationality emerges either through stigmatising beliefs associated with cognitive variance and/or the physical fragility of a dying body. These include issues with the degree to which possible relational decision-making support is comprehensive in the navigation of end-of-life decisions, gaps in the palliative care framework and limitations in regards to treatment decisions that may hasten one's death. With this in mind, this final substantive section considers what legal opportunities exist to navigate end-of-life decision-making outside of the purview of the person with dementia as the primary decision-making agent. In doing so, the analysis is attentive to the way in which alternative decision-making regimes either promote agency or facilitate paternalism. In this, I am particularly concerned with identifying opportunities to remove life-sustaining treatment that may prolong life beyond what the person with dementia may have otherwise wished and provide palliative care with respect to the relational self-hood of the person with dementia.

The first consideration regards possibilities of providing emergency palliative care without consent. Relevant in this context is the Criminal Code's doctrine of necessity which stipulates that emergency situations can represent an exemption from criminal liability.[925] As it applies to actions characterised as

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[925] Criminal Code (1962:700) [Brottsbalken] 24 chap. 4 §.

emergent and temporary,[926] it is only applicable in exceptional cases,[927] not in relation to recurring or regular care measures such as belting or daily medicine routines.[928] Life saving measures as well as temporary palliative care at the last stages of life may therefore be viable. However, as Litins'ka rightly points out, "the fact that certain actions might not lead to criminal responsibility does not mean that such actions are lawful."[929]

The more relevant emergency provision therefore exists under the Patient Act which manages the provision of emergency treatment where the patient's wishes are unknown. It stipulates that the patient shall receive health care which is necessary to avert danger that is an acute and serious threat to the patients' life or health, even if, their wishes cannot be investigated because of unconsciousness or other reasons.[930] This provision is formulated as a temporary measure only applicable in the absence of other avenues to ascertain the patient's wishes in these circumstances.[931] Four inquiries related to whether dementia patients in circumstances necessitating life-sustaining treatment and/or palliative care are necessary to determine the extent to which this provision can apply. These inquiries will be largely informed by the following excerpt from the proposition to the Patient Act which holds that emergency care can be provided where necessary

> "to avert danger that is an acute threat to the patient's life or health even if his or her will, due to unconsciousness or for another reason, cannot be investigated. It is therefore about necessary care that cannot wait for the patient to take a position themselves on the measure. It can be about both those who only temporarily lack the ability to express their will as well as those who for various more lasting reasons may be considered to lack decision-making competence and are in an emergency situation. According to the investigation,

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[926] Rynning, 'Consent to Medical Care and Treatment: A Legal Study [Samtycke till medicinsk vård och behandling: En rättsvetenskaplig studie]' (n 124) 379.

[927] Prop. 1993/94:130 35; SOU 2006:110 173.

[928] Litins'ka, 'To Force or Not to Force: Protecting the Lives of Persons with Dementia Who Refuse Care' (n 124) 475; Dahlin and Åkerström (n 573) 495.

[929] Litins'ka, 'Assessing Capacity to Decide on Medical Treatment: On Human Rights and the Use of Medical Knowledge in the Laws of England, Russia and Sweden' (n 124) 483.

[930] Patient Act (2014:821) [Patientlagen] 4 chap. 4 §.

[931] Prop. 2013/14:106 60–61; Litins'ka, 'To Force or Not to Force: Protecting the Lives of Persons with Dementia Who Refuse Care' (n 124) 473; Litins'ka, 'Assessing Capacity to Decide on Medical Treatment: On Human Rights and the Use of Medical Knowledge in the Laws of England, Russia and Sweden' (n 124) 481.

> "other reason" means i.e. that the patient, without being unconscious, is so affected by the circumstances which in the individual case may be said to constitute the emergency, that he or she cannot express their will. It can about the patient being uncontactable due to shock, or is heading into unconsciousness. Furthermore, the patient can for example be so affected by narcotic preparations or the like that it is impossible to find out the patient's perception."[932]

The first question is, to what degree does this provision capture people with dementia? The proposition indicates that emergency care can be made available to those who are both temporarily or more permanently unable to express their wishes.[933] The latter captures the long-term and progressively worsening issues with decision-making abilities. People with cognitive illness who are experiencing an acute case of delirium and therefore face temporary difficulties with expressing their wishes may also fall within this framework. People with dementia can therefore arguably fall under the dimensions of this provision.

The second question is, to what degree may the emergency provision cover care related to end of life? The preparatory works make it clear that the emergency provision is associated with treatment immediately required to save life or avoid serious consequences for health, not for providing general care for patients who lack decision-making capacity.[934] Certain treatment decisions may more clearly fall under this definition of emergency. For example, treatment for pneumonia or hip surgery may be consider acute. In relation to palliative care, palliative treatment can be instituted far before death as part of a gradual transition from curative care to that which aims at the provision of holistic end-of-life care. This may include for instance, numerous rounds of palliative chemotherapy which may be provided with the consequence of improving quality of life for a significant time period before death. In fact, palliative care can be implemented significantly earlier than that in the immediate lead up to death.[935] Such care would arguably be excluded from the remit of the emergency provision, leaving only that which applies in the very final stage of life available.

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[932] Prop. 2013/14:106 60.

[933] ibid.

[934] ibid.

[935] Interview with Participant K (n 456).

The third question regards whether or not the emergency exemption applies in the absence of expression by the person with dementia. According to the proposition, the emergency exemption captures people when their wishes “cannot be investigated” because of emergency circumstances in which they cannot express their will in addition to where people have more long-term issues with capacity.[936] Thus, people with dementia who cannot express their wishes can have end-of-life decisions made and implemented for them. In this way, the emergency provision provides a way to secure access to emergent care without the need to engage in potentially complex and problematic constructions of one’s wishes under the doctrine of hypothetical consent.

This leads to the fourth and final question; does the emergency provision capture people with dementia who may express wishes even though they have reduced decision-making abilities? In answering this, I draw attention to the way in which the proposition expresses that the emergency provision includes a patient who is “so affected by the circumstances which in the individual case may be said to constitute the emergency itself, that he or she cannot express their will.”[937] Fridström Montoya argues that this framing leads to the inclusion of situations where someone’s expressions are so affected that their perceptions cannot be ascertained.[938] This provision arguably covers situations where expressions in and of themselves are not certain to be reflective of the wishes of the patient in the context of an emergent need for palliative care. For example, where the patient does not appear to be responsive to the circumstances at hand, or perhaps, where the actual expression conflicts with what is otherwise known about what the person wants. Ultimately, where the treatment is considered emergent, the possibility to overlook these expressions are provided.

The emergency care provision under the Patient Act may therefore be understood to offer the opportunity to provide palliative care in the final days of life. However, the way that it facilitates such an opportunity may overlook possibilities for self-determination, and indeed, respect for relational personhood in favour of care that is only interested in physical wellbeing. In fact, it may actually facilitate stigmatising behaviours in which the patient with dementia is treated as an object. Emergency palliative treatment under this provision may be less controversial or difficult to sustain where the person in

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[936] Prop. 2013/14:106 60.

[937] ibid.

[938] Fridström Montoya, ‘Samtycke till vård’ (n 599) 56.

the present is unable to express themselves. However, even under these circumstances, it is somewhat short sighted to overlook the possibility for affording extended, relational self-determination. Even more concerning, however, is the possibility that care be legally forced against someone's expressions. This side steps the possibility and importance of providing comprehensive relational decision-making resources and support to respect personhood and protect opportunities for self-determination in palliative care. More than this, the applicability of the emergency provision also arguably threatens physical wellbeing. How, for instance, can care that a person physically struggles against be represented as in their benefit? It seems to me that such practices should not just be considered as an infringement of one's integrity, but of their overall wellbeing as harm results from force. That this legal option may be too quickly applied in the case of dementia, and subsequently overlook agentic opportunities, is reinforced by the understanding of the turn to paternalism for patients presumed to be irrational under the weight of the liberal subject.

5.6.2 The (Im)Possibility of Guardianship in Healthcare

Although perhaps not immediately apparent, there is arguably an avenue through a progressive interpretation of Sweden's guardianship regime that shakes off the shackles of both hyper-independence and paternalism. In this, relationally autonomous opportunities for palliative care, if not withdrawal of life-sustaining treatment, can be secured. The Child and Parents Code does provide for guardianship[939] in the form of a limited guardian (*god man*) who supports the person in their decision-making and a legal administrator (*förvaltare*) who operates as a substitute decision-maker by adopting decision-making power in areas determined by the court.[940] The remit of their appointment is rather broad[941] in that they are responsible for guarding the rights, managing the assets and providing for their representee.[942] In relation to questions of healthcare, the predominant interpretation holds that guardianship is not generally available. This position stems from the preparatory works to the guardianship legislation from the late 1980s. In this, it was stated that a legal administrator "should not normally represent the

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[939] Child and Parents Code (1949:381) [Föräldrabalken] 11 chap.

[940] Mattsson and Giertz (n 41) 151.

[941] Fridström Montoya, 'Samtycke till vård' (n 599) 59.

[942] Child and Parents Code (1949:381) [Föräldrabalken] 12 chap. 2 §.

principal in matters of consent to, for example, operative procedures."[943] This has been replicated in doctrine where Rynning has clarified that guardians are not legally able to perform their duties in the context of healthcare.[944] Government investigations also appear to accept the view that guardianship is limited in issues of health broadly, and end of life more specifically. For instance, a government investigation into end-of-life care examined what was taken to be an absence of recourse to guardianship in the context of limited capacity at the end of life.[945] Furthermore, in a 2015 government investigation into proposals for regulating decision-making for adults who experience decision-making difficulties, it was made clear that the guardianship regime did not give guardians or legal administrators a role in healthcare:

> "Guardians or legal administrators have also not been given any special role within the general regulatory framework of health and dental care. People who do not have the ability to consent to care should therefore, according to law, seldom receive the help of a guardian or legal administrator in these matters."[946]

This same investigation proposed a hereto unfulfilled proposal to develop legislative clarity and support for people who have diverse abilities.[947] This proposal advocated for legislative change to actualise necessary support and resources for people to take decisions for themselves. It notes that where they remain unable to do so, they should be involved in the decision-making process according to their "conditions, wishes and needs."[948]

The lack of access to guardianship in healthcare may be read as existing hand-in-hand with the retention of persons with dementia as legally valid decision-making agents who can receive support to actualise their pre-existing wishes. From this perspective, it can be understood as an important legal response that prevents the swing to paternalism. However, on the flipside, it may be considered to exclude or limit access to healthcare to those at the limits of an individualistic expression of autonomy. Along these lines, efforts have been made to argue for the possibility of guardianship in Swedish healthcare.

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[943] Prop. 1987/88:124 172.

[944] Rynning, 'Right to Live and Right to Die [Rätt till liv och rätt att dö]' (n 122) 101.

[945] SOU 2001:6 67.

[946] SOU 2015:80 411.

[947] ibid 34.

[948] ibid 34 & 39.

Indeed, an analysis of guardianship law and some of its more ambitious interpretations suggests that it may provide the foundations for the provision of palliative care for people with dementia who cannot express their wishes. However, it unfortunately appears more limited in regards to withholding and withdrawing life-sustaining treatment in the context of dementia.

This effort to map the possibility and limits of guardianship in relation to end-of-life decision-making with dementia begins with Fridström Montoya's progressive interpretation of the guardianship regime which develops the possibility of guardianship within a healthcare context. Locating guardianship possibilities in Swedish healthcare begins with the recognition that whilst certain limitations have been stipulated, and no legislation has been developed to make the possibility of guardianship in healthcare clear, a possibility for certain opportunities for guardianship can be carved out:

> "A guardian or legal administrator however can be authorised to consent to care in the represented person's name, but this depends partly on what his or her appointment covers, and partly the character of the care measure in question."[949]

Importantly, this interpretation recognises that guardians cannot consent to treatment against the express will of their trustee.[950] To this degree, this interpretation of guardianship rules may arguably be relevant in the case of a person with dementia who is unable to express their wishes.

Against the backdrop of this fundamental rule, Fridström Montoya draws upon the excerpt from the preparatory work to the 1980's guardianship legislation in which guardians were described as not "normally" allowed to consent on behalf of a patient in the case of healthcare treatment such as operative procedures.[951] In doing so, she persuasively concludes that this evidences the fact that the legislator ultimately recognised the possibility of guardian consent to healthcare, even if it that was not normal practice. Additionally, she argues that healthcare involves many treatment measures that are less invasive than

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[949] Fridström Montoya, 'Samtycke till vård' (n 599) 62–63.

[950] Socialstyrelsen, 'Coercive and Protective Measures in Health and Social Care for Adults [Tvångs- och skyddsåtgärder inom vård och omsorg för vuxna]' (n 820) 6; Fridström Montoya, 'Samtycke till vård' (n 818) 64; Rynning, 'Consent to Medical Care and Treatment: A Legal Study [Samtycke till medicinsk vård och behandling: En rättsvetenskaplig studie]' (n 124) 110.

[951] Prop. 1987/88:124 172.

that characterised by operative procedures.[952] Relevant to understanding what kind treatment may be eligible for guardian intervention is provided by the Child and Parents Code which stipulates that personal measures are excluded from the remit of guardianship.[953] Such measures have been found to include issues such as sterilisation and abortion.[954] While further guidance on what might be similarly personal is absent, a 2004 Government investigation suggested that a situation which carries serious consequences is one in which guardianship ought not to be accepted.[955]

How might end-of-life decision-making be treated in light of these reflections? The concept of "serious consequences" in a regime that considers death and dying to be the most serious of consequences for human life in the context of individualism would arguably exclude the possibility that guardians be able to withdraw or withhold life-sustaining treatment for the person they represent in the absence of a physician's assessment based on science and proven experience. This conclusion is bolstered by the fact that the 2015 government investigation proposed that representatives be prohibited from opposing life-sustaining treatment.[956] Although this is disappointing, this broad reading of guardianship in healthcare arguably does offer the opportunity to imagine possibilities for guardian consent to palliative measures. It may especially allow for non-invasive palliative treatments such as the provision of pain or anxiety relieving medication through the alternative of guardian consent where a patient may be unable to express their wishes.

Of course, the provision of such a regime may be read through the lens of paternalistic guardianship. Indeed, this appears to be Fridström Montoya's intention given her claim that "most people should probably agree that people should not be left without care which they need with reference to a right to self-determination which they cannot enjoy."[957] Furthermore, although the Committee wrote that article 12 required that substitute decision-making

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[952] Fridström Montoya, 'Samtycke till vård' (n 599) 63–64.

[953] Child and Parents Code (1949:381) [Föräldrabalken] 12 chap. 2 §; Fridström Montoya, 'Samtycke till vård' (n 599) 63.

[954] Prop. 2016/17:30 135.

[955] SOU 2004:112 451.

[956] SOU 2015:80 57.

[957] Fridström Montoya, 'Samtycke till vård' (n 599) 64–65.

regimes be abolished,[958] this interpretation has not been unanimously supported.[959] In fact, a common position is that the CRPD has failed to address the potential that supportive arrangements fail to actualise rights.[960] One aspect is that where support does not provide people with the ability to understand, deliberate or intentionally express preferences for treatment, other rights may be set aside.[961] In this way, it may be suggested that the right to autonomy ought to be set aside where it interferes with other rights of the patient such as those to health and life in accordance with article 12(4) reference to “rights, will and preferences.”[962] Another is the suggestion that it is important to reckon with the reality that, for some people, supported decision-making is stretched to the point that “decisions are being made ‘for’ a person, rather than ‘by’ a person.”[963]

However, such a position arguably fails to recognise the possibility for decision-making that may stretch relational autonomy even past the time in which a person may be able to actively participate in decision-making in the present, as well as account for physical needs. From this perspective, the limited opportunities for guardianship in the Swedish regime are in fact a demand for hyper-independence that undermines opportunities for relational autonomy. With this said, I argue in line with scholarship that sees opportunities for guardianship to be an extension of supportive measures suitable for the progressive nature of dementia. De Sabbata, for instance, has argued that an approach to substitute decision-making which seeks alternatives to paternalism, actually has the ability to manifest support for decision-making for people with dementia.[964] It therefore goes beyond what is made available by the emergency care provision where people with dementia reach a stage of cognitive limitations that leave them unable to express themselves. Furthermore, in contrast to the individualistic approach afforded by

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[958] ‘UN CRPD Committee, General Comment No. 1: Article 12 Equal Recognition before the Law, CRPD/C/GC/1, 11 April 2014’ (n 86) para 28.

[959] Series and Nilsson (n 774) 347.

[960] Peter Bartlett, ‘The United Nations Convention on the Rights of Persons with Disabilities and Mental Health Law’ (2012) 75 The Modern Law Review 752, 759.

[961] Callaghan and Ryan (n 778) 752.

[962] Flynn (n 791) 165.

[963] P Gooding, ‘Navigating the “Flashing Amber Lights” of the Right to Legal Capacity in the United Nations Convention on the Rights of Persons with Disabilities: Responding to Major Concerns’ (2015) 15 Human Rights Law Review 45, 53–54.

[964] De Sabbata (n 25) 12.

hypothetical consent, it sets the scene for comprehensive relational decision-making in which interactions and exchange exist overtime between persons with dementia and their legally valid supporters. An approach that frames guardianship within relationally agentic rather than paternalistic terms is also in line with the fact that the preparatory work to the Patient Act rejected a proposal[965] to institute specific regulations allowing decisions to be made on the basis of what is in their "best interest."[966] In addition to the fact that this is a progressive interpretation not currently representative of the predominant understanding and application of the meaning of guardianship in Sweden today, the remaining downside is that the most accurate account of this progressive interpretation would continue to exclude opportunities for extending autonomy in the case of refusing potentially life-sustaining treatment in the same manner.

5.7 Conclusion

Chapter 5 has developed a comprehensive analysis of Swedish law and its debates in order to unravel the legal construction, response and implications for end-of-life decision-making with dementia. It has demonstrated that the law is largely not fit for purpose in managing the diverse and complex realities of end-of-life decision-making and promoting end-of-life wellbeing. This issue lies in the foundations of the legal regulation of healthcare itself. Under the weight of the liberal subject, people with dementia are expected to have the characteristics of a self-determining, rational, agentic legal subject capable of manifesting their independent, pre-existing wishes for end-of-life care. However, people with dementia, like all people, are not perfect, self-sustaining decision-making agents. They rely on relational supports to make and enact end-of-life decisions. Whilst this regime usefully affords support, this is ultimately arguably based on individualistic principles. The law therefore ultimately represents a sustained demand for hyper-independence that fails to capture the relational complexity necessary in relational autonomy, whilst also simultaneously threatening paternalism. This is made more complex in light of the legal presumption that life be maintained. Indeed, in this context, people with dementia are at risk of paternalistic measures due to stigmatising beliefs

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[965] Prop. 2013/14:106 61.

[966] SOU 2013:2 14–15.

in law, medicine and society associated with cognitive variance and bodily decline in the face of death.

The result is that the threat of paternalism looms particularly large in regards to decisions by people with dementia that may hasten death. By extension, opportunities to develop and maintain relational agency where a person with dementia may have decided (as expressed by the patient or through supportive measures) to eschew potentially life-sustaining treatment, are weakened. Whilst the blind spot covering death and dying arguably threatens to minimise opportunities for access to palliative care in and of itself, opportunities for palliative care can be usefully extracted from the law to some degree. However, where end-stage palliative care is readily available under the emergency care provision, prospects for respecting both personhood and physical needs may be overlooked. Although this may be resolved by a more progressive interpretation of guardianship, this, unfortunately, is not the predominant understanding of the possibilities for guardianship in healthcare today. From the perspective of a feminist informed understanding of vulnerability, the limits of law as accounted for in the last two chapters threaten to undermine collective responsibility to end-of-life wellbeing with dementia. How this might be improved by capturing the realities of vulnerable subject and their needs for support in pursuit of wellbeing at the end of life is the focus of the final substantive chapter.

6 Embracing Legal Responsibility in Death & Dying with Dementia

> Life is a window of vulnerability. It seems a mistake to close it. The perfection of the fully defended, ‘victorious’ self is a chilling fantasy. – Donna Haraway[967]

6.1 Introduction

Having demonstrated the limits of law in death and dying with dementia, this final substantive chapter seeks to address the following question:

How can law be recreated to better respond to death and dying with dementia?

In pursuit of this question, a feminist informed approach to vulnerability is applied in the recreation of law as it pertains to end-of-life decision-making with dementia. This is part of an attempt to probe the legal regulation of end-of-life decision-making in order to pursue the legal conditions for collective responsibility at the end of life, and ultimately, improve end-of-life opportunities and experiences for people with dementia.[968]

Through the recreation and interrogation of five key dimensions of law, vulnerability, and most importantly, collective responsibility to death and dying as the ultimate expression of vulnerability, will be powerfully institutionalised in law. In the place of the current preoccupation with non-interference-based choice and death avoidance, an approach that acknowledges the realities of death and promotes a public duty to care in death

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[967] Donna Haraway, *Simians, Cyborgs, and Women: The Reinvention of Nature* (Routledge 1991) 224.

[968] Harding, *Duties to Care* (n 4) argues that "we need to think carefully about how we regulate decision-making about death and dying in order to maximise everyone’s opportunities, including those with dementia, to have a ‘good death’" at 172.

and dying will be instituted. Through this, law will account for a contextualised, relational and dialogic approach to end-of-life decision-making that embraces opportunities for physical security as well as choice in death and dying with dementia. In this way, it represents a conceptual shift from the reliance on individualistic rights to collective responsibility for relations of support in pursuit of improved end-of-life outcomes.[969] Whilst it is hoped that this provides a more comprehensive approach to securing end-of-life care, this recreation does not represent a fixed roadmap for legal reform as the ultimate solution to this problem.[970] Rather, I seek to advance an alternative scholarly perspective seated in the vulnerably embodied and embedded subject to contribute to ongoing discourse on how law can be more responsible for death and dying with dementia in pursuit of improved end-of-life outcomes.

The key dimensions of law to be reconstructed pertain to the legislative governance of end-of-life decision-making with dementia. The focus on law as contained in acts of government coheres with a vulnerability approach. Indeed, accepting the inevitability of law in pursuit of collective wellbeing,[971] Fineman has described vulnerability analysis as that which defines “ethical legislative behaviour.”[972] Thus, whilst law and bioethics are allied, they are nevertheless distinct and independent professional fields who have different roles “in addressing persistent questions of justice, responsibility, and care.”[973] Further, as articulated in the opening of this thesis,[974] there is reason to presume that legislative input on the question of end-of-life decision-making is important. In this, I follow Mclean’s argument that law must necessarily retain a stake in dying so long as end-of-life decision-making and death remain in the purview of medicine[975] as it is the responsibility of law to afford elements of

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[969] Jennings (n 337) at 219 identifies that "an emphasis on rights and an emphasis on relationships are conceptually distinct, but substantively they point toward many of the same ends" which is the goal of the good death.

[970] Donnelly, ‘Deciding in Dementia’ (n 28) at 101471 for example reflects in relation to supported decision-making for people with dementia that "it may take several iterations to establish appropriate legal frameworks." Whilst this reflection is made in regards to jurisdictions who have a recent history of capacity-based assessments, it arguably remains relevant in the Swedish context given the individualistic credentials of the law.

[971] Fineman, ‘The Significance of Understanding Vulnerability’ (n 39) 1373.

[972] Fineman, ‘Equality, Autonomy, and the Vulnerable Subject in Law and Politics’ (n 290) 27.

[973] Fineman, ‘Vulnerability in Law and Bioethics’ (n 275) 60.

[974] See subsection 1.2.

[975] McLean (n 12) 144.

regulatory influence that extend beyond issues of medical ethics and expertise to broader social values.[976] In reimagining the legislative governance of end-of-life decision-making as it pertains to people with dementia in Sweden, I am also in line with Swedish scholarship that has flagged the potential importance of legislative change in a system that is presently failing to protect people at the end of life.[977]

Chapter 6 begins by establishing the foundations for a vulnerability informed reconstruction of law. This includes a consideration of the vulnerable legal subject whose transformative potential will be harnessed at the core of the reconstitution of law’s response to death and dying with dementia. The way in which this subject demands a legal framework that affords resilience in death and dying will then be addressed. Central to this account of vulnerability is a lifespan perspective that highlights the subsequent importance of providing resilience in death as well as in life. The chapter goes on to establish the centrality of care that meets needs for one’s physical wellbeing and relational agency in responding to end-of-life decision-making with dementia. Next, this vulnerability perspective will be read into the law via a recreation of five key dimensions of legal regulation as it pertains to death and dying with dementia: dignity; a good death; decision-making; medical governance; and assisted dying.

6.2 The Vulnerability Foundations of a Reconstructed Law

6.2.1 A Transformative Vulnerable Subject

Where the legal subject in Swedish healthcare is imagined to have a body that is cognitively and physically well,[978] a vulnerability approach argues in favour of the vulnerable subject who embraces the embodied realities of human nature in the construction of legal responsiveness.[979] This vulnerable subject incorporates a lifespan perspective that captures variations in capacity and

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[976] ibid 146.

[977] Schiratzki (n 697).

[978] See subsection 4.2 for an exploration of the legal subject in Swedish healthcare.

[979] Fineman, ‘Equality, Autonomy, and the Vulnerable Subject in Law and Politics’ (n 290) 17.

ability as inherent to the human experience[980] as well as the unshakable implication of death and dying.[981] In doing so, it integrates vulnerability and inherent dependencies, as well as state responsibility for these vulnerabilities, into law.[982] Thus, where the liberal subject demands little in the way of collective responsibility for wellbeing,[983] by instead focusing on individual failure, the vulnerable subject redirects the focus onto institutions and what the state must do to address disadvantage.[984] The vulnerable subject therefore requires an alternative legal response[985] defined by responsiveness and responsibility to vulnerability.[986] As an agentic source of legal change,[987] the vulnerable subject has been recognised to hold particular value in the context of healthcare in encouraging structural change that better responds to universal vulnerability and need.[988]

6.2.2 Resilience in Death & Dying

The legal response required by the vulnerable subject in the context of healthcare is that which affords resilience in death and dying. The starting point for this response is the nature of vulnerability itself.[989] The central idea is that, as vulnerability is an essential dimension of human existence, we cannot persist without being vulnerable. Thus, as vulnerability can never be bested,[990] resilience must be directed towards the promotion of opportunities for thriving

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[980] Fineman, 'Reasoning from the Body' (n 311) 24.

[981] Butler, *Undoing Gender* (n 149) 21.

[982] Fineman, 'Reasoning from the Body' (n 311) 27.

[983] Fineman, 'The Significance of Understanding Vulnerability' (n 39) 1375.

[984] Mackenzie, Rogers and Dodds (n 273) 5–6.

[985] Clough, 'Response: Challenging the Frames of Healthcare Law' (n 369) 117.

[986] Fineman, 'The Vulnerable Subject: Anchoring Equality in the Human Condition' (n 267) 161.

[987] Clough, 'Response: Challenging the Frames of Healthcare Law' (n 369) 121.

[988] Fineman, 'Vulnerability in Law and Bioethics' (n 275) 59–60.

[989] Fineman, 'Vulnerability and Inevitable Inequality' (n 280) 134.

[990] Fineman, 'Reasoning from the Body' (n 311) 21; Fineman, 'The Vulnerable Subject: Anchoring Equality in the Human Condition' (n 267) 166; Butler, *Precarious Life* (n 286) 31.

in the face of vulnerable circumstances.[991] Institutional support to assist people in their dependencies and frailties rather than non-interference is therefore a requisite of a vulnerability approach.[992] Healthcare can certainly be a resource that affords opportunities for resilience in the way it provides for health, or at least, improved health outcomes.[993] Along these lines, it might be said that as a Nordic welfare state, the Swedish state inherently provides health creating and maintaining resources via "universal health coverage."[994] However, as has been demonstrated in the foregoing chapters, a claim for equality in healthcare that overlooks age and ignores issues with protracted dying does little to support people facing death and dying.[995] That is, where Swedish law is preoccupied with equality in resources for good health for the liberal subject who is disembodied and can manifest decisions based on pre-existing wishes, it remains limited in its ability to engage with diverse capabilities, relationality and the reality of bodily decline at the end of life.

However, where vulnerability implies the need for resources to be provided with reference to a lifespan perspective that embraces diversity in bodily vulnerability,[996] an opportunity emerges to grapple with how resilience can be fostered to enhance not just health, but wellbeing at the end of life for people with dementia. Indeed, as initially explored in subsection 2.4.3.2, where vulnerability infers death, a lifespan perspective does not just demand resource provision in pursuit of good health. Rather, challenges and experiences associated with the end of life must also be recognised and attended to. Significantly, as death is an inevitably of vulnerability that cannot be extinguished, these efforts cannot be uncritically directed towards the prevention of death at all costs, but must rather be sensitive to facilitating resilience in death and dying.

What is more, vulnerability also usefully calls for the creation of equal opportunities amongst those faced with the inevitable prospect of death and

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[991] Fineman, 'Vulnerability and Social Justice' (n 346) 363.

[992] De Sabbata (n 25) 82.

[993] Fineman, 'The Vulnerable Subject: Anchoring Equality in the Human Condition' (n 267) 170.

[994] Mikaela Heikkilä, Hisayo Katsui and Maija Mustaniemi-Laakso, 'Disability and Vulnerability: A Human Rights Reading of the Responsive State' (2020) 24 The International Journal of Human Rights 1180, 1187.

[995] Lloyd (n 143) 251.

[996] Mattsson and Enell (n 323) 1531–1532; see also subsections 2.4.3.1.

dying. This is associated with the fact that vulnerability embraces the potential for embodied resilience not only through structural responsiveness that attends to the universal reality of vulnerability, but individualised support that accounts for the distinctive manifestation of vulnerability in each person.[997] In this vein, rather than demanding sameness, a vulnerability approach usefully points to the fact that different kinds of resources must be afforded in order to offer equal opportunities for people facing end-of-life decisions. This is a useful reference point from which to grapple with the diverse needs of people with dementia at the end of life.[998] Furthermore, given the preexisting concern that the death of elderly persons are normalised to the exclusion of palliative resources for this group,[999] the way in which vulnerability encourages distinctive attention to the needs of people with dementia at the end of life is especially important in ensuring that this group is not overlooked.

6.2.3 Care & Relational Agency in Death & Dying with Dementia

Having established the importance of providing for resilience in death that recognises the diversity of end-of-life needs, this subsection turns to consider the qualities of this resilience. Chief to a feminist informed vulnerability account of resilience is arguably the provision of social practices that promote physical wellbeing as well as agentic capacities.[1000] Responsiveness through care and relational agency in the face of death and dying will therefore now be addressed in turn before concluding with an explanation of the importance of bringing both of them together in an effort to promote end-of-life resilience, and ultimately, improve end-of-life experiences for people with dementia.

Vulnerability clearly establishes a public duty to care in death and dying. Central to this is the idea that, as an enabling condition,[1001] vulnerability is inextricably related to the formation of caring relationships characterised by

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[997] Clough, ‘Vulnerability and Capacity to Consent to Sex - Asking the Right Questions’ (n 869) 389.

[998] Mattsson and Giertz (n 41) 143–144.

[999] Österlind and others (n 12) 540.

[1000] Rogers, Mackenzie and Dodds (n 269) 32.

[1001] Gilson (n 301) 310.

happiness and compassion[1002] which we are reliant on from birth.[1003] Importantly, as this approach to vulnerability emphasises the ontological reality of an indelible and inherent openness to that outside the self, collective attention to the formation and maintenance of these relationships is necessitated.[1004] Along these lines, vulnerability facilitates a wider conception of care so that it is not located solely in individual relations of dependency, but "a general responsibility to care."[1005] In this way, the embodied and embedded reality of vulnerability across the lifespan grounds a collective claim for beneficence.[1006] Doing good is thus not solely located in the physician-patient relationship as manifest in decision-taking in the best interest of the patient, but rather, must be attended to at the macro level. From a legal perspective, I take this as indicative of a call for law to mandate and encourage institutional and interpersonal relationships of care. This aligns with the care and vulnerability scholarship of Herring which forwards the argument that vulnerability and dependency require that "law and society should above all be seeking to uphold and maintain caring relationships."[1007]

Yet, these relationships of care cannot be solely directed towards meeting physical needs. Following feminist scholarship, autonomy should not be rejected outright given the significance of agency for oppressed groups, but rather, have its liberal, individualist credentials abjured.[1008] In its place, relational theorists argue for a relational autonomy that is reflective of a system of capacity building through constructive relationships rather than one of informed consent on the basis of non-interference which considers capacity to be inevitable and static.[1009] Intervention is therefore recast not as a paternalistic

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[1002] Fineman, 'Vulnerability and Social Justice' (n 346) 358.

[1003] Butler, *Frames of War: When Is Life Grievable?* (n 288) 14.

[1004] Fineman, 'The Significance of Understanding Vulnerability' (n 39) 1372; Fineman, 'Vulnerability and Inevitable Inequality' (n 280) 142; Fineman, 'The Vulnerable Subject: Anchoring Equality in the Human Condition' (n 267) 168; Engster, 'Care Ethics, Dependency, and Vulnerability' (n 316) 101; Fineman, 'Equality, Autonomy, and the Vulnerable Subject in Law and Politics' (n 290) 19.

[1005] Engster, 'Care Ethics, Dependency, and Vulnerability' (n 316) 109.

[1006] ibid 111.

[1007] Herring, *Caring and the Law* (n 263) 53.

[1008] Mackenzie (n 285) 42; Jennifer Nedelsky, *Law's Relations: A Relational Theory of Self, Autonomy, and Law* (Oxford University Press 2011) 123.

[1009] Susan Dodds, 'Choice and Control in Feminist Bioethics' in Catriona Mackenzie and Natalie Stoljar (eds), *Relational Autonomy: Feminist Perspectives on Autonomy, Agency* opposition to empowerment, but as a necessary condition where it is crafted appropriately.[1010] The implication for legal theory is therefore a consideration of how law can facilitate structures and relationships that "foster rather than undermine autonomy."[1011] In this research, it requires a consideration of comprehensive measures that promote the agency of the person with dementia in the present, but also, a conscientious effort to consider legal mechanisms that can extend the agency of the person with dementia who may have challenges in experiencing meaningful opportunities for agency on the issue of end-of-life decision-making in end-stage dementia.

In seeking to bring opportunities for relational agency and care in the face of physical need together in the legal response to dying with dementia, this work attempts to actualise the efforts of feminist moral philosophy to recognise how care can meet physical dependencies and relational selfhood.[1012] In doing this, I join Jennings who uses the concept of solidarity to advance a relational approach to end-of-life care that is predicated on "a relational interpretation of autonomy focusing on contextualized, dialogic judgment and self-affirmation in and through mutuality."[1013] As argued by Jenning's this conceptualisation has the benefit of allowing for decision-making that meets the needs in pursuit of "greater patient well-being" without jettisoning "patient agency and personhood."[1014]

In this pursuit, I distinguish myself from other feminist scholars working in the realm of vulnerability who seeks to emphasise the relational autonomy credentials of the theory to the degree that the ability to recognise the universal value of both care and relationality is arguably undermined. This is apparent, for example, where Mackenzie appears to pay only lip service to care needs at the limits of autonomy:

> "It is important to acknowledge that in some situations, such as incapacitating illness, this sense of powerlessness cannot necessarily be remediated, nor is it always possible to restore or enable agency, for example, if the vulnerable

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and the Social Self (Oxford University Press 2000) 226–227; Jennifer Nedelsky, 'Law, Boundaries, and the Bounded Self' [1990] Representations 162, 168.

[1010] Clough, 'Disability and Vulnerability' (n 147) 478.

[1011] Nedelsky (n 1009) 168.

[1012] Sevenhuijsen (n 333) 143.

[1013] Jennings, (n 337) 219.

[1014] ibid 220.

> person has a profound cognitive impairment. In such situations, responses to vulnerability should focus primarily on meeting the person's physical, social, and affective needs and providing appropriate care rather than on fostering agency."[1015]

It is not that I disagree with the importance of acknowledging and understanding the limits of autonomy. Rather, my issue is that I believe that the dual concepts of embodied vulnerability and resilience necessarily demand that both are comprehensively considered. Failing to do so arguably carries with it the risk of overlooking universal needs for care and simultaneously undermining respect for relational selfhood at the limits of individualism.

This amalgamation of relational agency and care for physical dependency under the transformative vulnerable subject is especially important on the question of end-of-life decision-making with dementia. Firstly, it has been said that issues of autonomy alone are insufficient to determine what care is necessary."[1016] This is particularly prominent in this issue given that the question of death reveals the tension between the archetype of choice and the bodily and social limits of dying.[1017] This is supported by Hoffmaster's vulnerability informed understanding "that one is controlled by, rather than in control of, the world."[1018] This position was also expressed in the interviews best highlighted by the explanation on the issue of consent and palliative care that, at the end of life,

> we find ourselves in a situation where the patient maybe can't always, certainly can't, change anything. – Participant C

At the same time, an appropriate response to vulnerabilities as manifest at the end of life cannot exclude possibilities for relational agency. Indeed, excluding opportunities for respecting one's personhood in care arguably works to undermine the work done by caring. This is Jenning's concern in his claim that

> "caring that disables agency in the service of contemporaneous comfort and existential interests undermines its own ethical rationale and vitiates its moral potential as a practice of human enrichment. Caring that is only loving and not

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[1015] Mackenzie (n 285) 46.

[1016] Sevenhuijsen (n 333) 143.

[1017] Lloyd (n 143) 244.

[1018] Barry Hoffmaster, 'What Does Vulnerability Mean?' (2006) Hastings Center Report 38, 44.

> discerning and respecting fails in its recognition of the care recipient as a subject." [1019]

This is arguably as true to palliative care as all other caring relationships. In point of fact, an expansive approach to the goals of palliative care go beyond "comfort care and symptom management"[1020] to include considerations of autonomy and patient participation.[1021] Furthermore, platforming possibilities for affirming the relational identity of the person facing end-of-life questions with dementia is notably important in warding off the link between vulnerability and feelings of powerlessness.[1022] Given the relationship between social stigmatisation and dementia, it is especially important to be attentive to, and provide redress for, the possibility that opportunities for autonomy be undermined.

To illustrate how the law can embrace responsibility to relational choice and care, the chapter now shifts to the application of these ideals in the construction and elaboration of five, at times overlapping and interrelated, dimensions of the legislative governance relating to end-of-life decision-making with dementia through a vulnerability perspective.

6.3 A Vulnerability Informed Reconstruction of Key Dimensions of Law

6.3.1 Dignity as Respect for Relationships of Care

Dignity is the first legal dimension to be developed in pursuit of an alternative regime that provides rights, protections and obligations in relation to the needs of the vulnerable subject at the end of life. The reconstruction of dignity via a vulnerability perspective intends to locate the legal provision of care in a respect for vulnerability and dependency rather than a respect for agentic decision-making marked by non-interference as is presently captured in the legal regulation of healthcare. By explicitly instituting vulnerability

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[1019] Jennings (n 337) 434.

[1020] ibid.

[1021] Regionala Cancercentrum (n 48) 25.

[1022] Rogers, Mackenzie and Dodds (n 269) 25.

dimensions in the existing concept of dignity, I am inspired by Kittay's work on dignity under the framework of feminist ethics of care. For Kittay, dignity does not lie within choice, but an understanding of humanity based on "care and connection."[1023] According to Kittay, this shift in the characterisation of dignity prevents dehumanisation in the case of varied capacity for rationality by locating human value in caring relationships.[1024] Refined through a vulnerability lens, the concept of dignity comes to be seated in an understanding of humanity defined through corporeal vulnerability and dependency upon that outside the self.

In capturing the fact that "individuals are anchored at each end of their lives by dependency and the absence of capacity,"[1025] this approach to dignity demands access to resources and relations that mitigate harm and generate benefit. Through this, respect for dignity becomes more reflexive than the current conceptualisation in which individuals are expected to rationally engage with healthcare. Rather than relating to non-interference-based choice, a vulnerability conceptualisation of dignity comes to be associated with respect for diverse needs for both relational agency and care. A richer account of dignity is therefore afforded so that it retains relevance and influence in pursuit of personhood and physical needs even where the possibility of a more individualistic approach choice is more limited, and the need for physical care becomes increasingly apparent in line with bodily decline. As a result, the precarious position in which people with dementia are either abandoned with little or ineffective support in a framework of non-interference, or faced with force, is overturned. In its place, legally protected access to resources for care that values the universal human need for assistance is instituted. People with dementia are therefore not stigmatised nor given ineffectual protection on the grounds of substantive equality, but rather, receive legal protection of their universal human needs for autonomy and care that limits harm and does good.

[1023] Eva Feder Kittay, 'Equality, Dignity and Disability' in Mary Ann Lyons and Fionnuala Waldron (eds), *Perspectives on Equality: The Second Seamus Heaney Lectures* (The Liffey Press 2005) 116–117.

[1024] ibid 117.

[1025] Fineman, 'The Vulnerable Subject: Anchoring Equality in the Human Condition' (n 267) 168.

6.3.2 A Good Death

Secondly, guided by a vulnerability perspective, law must institutionalise respect for, and pursuit of, a good death. Where the liberal subject frames healthcare as a means through which agentic beings recover bodily control,[1026] law obliges healthcare to work towards the prevention of ill-health[1027] and enshrines good health as a goal in healthcare.[1028] The claim that law focuses on the provision support for people who can successfully maintain good health and independence even into old age[1029] is therefore accurate in the Swedish context. Against this backdrop, the significance of care and opportunities for relational agency at the end of life are at best, made invisible, and at worst, paternalistically compromised by a system that privileges curative care. Embracing vulnerability as a universal openness to both harm and support, however, demands sensitivity to the fact that death and dying is a reality to respond to, rather than one to be unquestionably struggled against.

The introduction of a good death as a part of the content, and goals of Swedish, healthcare will help to afford the requisite stronger foundations for wellbeing at the end of life. Lloyd describes the good death as a concept that enables an understanding of "how deaths can be made as good as possible under today's cultural and social conditions."[1030] Through a vulnerability lens, the notion of a good death is located in the embodied and embedded reality of end-of-life vulnerability as the broader context through which efforts are made to make death as good as it can be. Conceptualised in this way, the good death draws attention to what kind of resilience can be afforded via institutions and relationships to provide opportunities for wellbeing even in death. The inclusion of the good death therefore secures a framework which is richer and more attentive to the realities of bodily decline. The potential effect of the inclusion of the good death is multi-fold.

The first set of possible consequences relate to the way in which the inclusion of the good death brings forth responsibility not only in life, but in death. In this vein, whilst a legal basis for palliative care is evident through legal

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[1026] Susan Dodds, 'Depending on Care: Recognition of Vulnerability and the Social Contribution of Care Provision' (2007) 21 Bioethics 500, 502.

[1027] Health Care Act (2017:30) [Hälso och sjukvårdslagen] 3 chap. 2 §.

[1028] ibid 3 chap. 1 §.

[1029] Harding, 'Response: Reflections on Ageing and the Binaries of Vulnerability' (n 310) 85–86.

[1030] Lloyd (n 143) 253.

analysis, the inclusion of the good death affords an incontrovertible basis for end-of-life care that would arguably strengthen the status of palliative care as a valued and normal practice. Importantly, the inclusion of the good death in support of a stronger basis for palliative care should not, however, be read as undermining opportunities for care in life as well as death. Indeed, as Österlind et al. have argued in relation to nursing homes in Sweden, a palliative care framework can be usefully introduced so that "life and death are intertwined and equally supported." This means that whilst emphasis continues to be placed on promoting living, life is also understood to include death.[1031] This is essential as care must include that which attends to "pain and suffering — even when survival, good health, and normal species functioning are not realistic goals."[1032]

Furthermore, there may be implications for the interpretation and influence of law. In particular, the inclusion of the good death principle has the potential to encourage deeper reflection in regards to the relationship between science and proven experience (and the related ethical principles of do good and do no harm) and the degree to which this framework may support the continuation of life rather than end-of-life care. The good death may especially offer an important reframing that wards against the possibility that science and proven experience be co-opted in uncritical efforts to maintain life at all costs. The result is that whilst a good death would not necessarily disqualify life-lengthening treatment, nor does it necessarily advocate for the global availability of assisted dying in and of itself, it would arguably facilitate more appropriate and considerate deliberations about healthcare where the spectre of end-of-life decision-making emerges more clearly than is currently achieved.

In addition, the explicit vulnerability characteristics of this conceptualisation of the good death also provide a basis for work to ensure opportunities for autonomy not just in life, but in death. Where opportunities for relational autonomy at the end of life is promoted, the possibility for paternalism in end-of-life decision-making is reduced. Thus, even where cultural norms around death and dying change to become more accepting of death, science and proven experience could not just be mobilised without consideration as to the views

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[1031] Österlind and others (n 12) 541.

[1032] Engster, *Justice, Care, and the Welfare State* (n 544) 93–94.

of patients who may wish for more to be done to ward off death.[1033] In the case of end-of-life decision-making with dementia, this is especially important in undoing paternalistic tendencies due to the stigmatising perception that people dying with dementia are unable to make rational, self-sufficient decisions for themselves. In this way, (as will be further developed in 6.3.3) people with dementia would be less likely to be excluded from opportunities to have their personhood and participatory possibilities extended, even as their cognitive capacities become potentially more limited.

The importance of providing relationality for people with dementia is captured by de Beaufort and van de Vathorst's reflection that whilst caring for people with dementia is necessary so that

> "their lives [are] as good and comfortable as possible … it can be morally acceptable for those who do not want to continue their life with dementia to choose to die."[1034]

Indeed, the incorporation of the good death may also have the consequence as to the legal regulation of medically assisted dying. The administrative court has been able to uphold the probation on treatment that intentionally brings about death on the grounds that it goes against the definition of healthcare[1035] as presently contained in the HSL's exclusive focus on curative and restorative treatment. Where such interpretations are consistent with the law as it exists today, instituting the good death within the obligations of healthcare would mean that this prohibitive stance would no longer be as obvious or clear cut. In fact, it would arguably serve to complicate the resistance to medically assisted dying. In doing so, it also has the potential to open up new conversations as to the problems and possibilities of a medically assisted dying regime in a Swedish context.

Furthermore, the inclusion of a good death as a goal in healthcare may also have the potential to encourage potentially more diffuse normative change. This is because the legislative inclusion of a good death brings with it the potential to increase the social value placed on care in death and dying in

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[1033] Jocelyn Downie, 'The Value of a Feminist Approach in the Ethics of End-of-Life Care' in Wendy Rogers and others (eds), *The Routledge Handbook of Feminist Bioethics* (Routledge 2023) 440.

[1034] Inez D de Beaufort and Suzanne van de Vathorst, 'Dementia and Assisted Suicide and Euthanasia' (2016) 263 Journal of Neurology 1463, 1466.

[1035] *B 20746-22* (n 737).

opposition to the current value placed on fighting death at all costs. That is, the goal of a good death would also be an impetus for a radical reconsideration of society's attitudes towards death and the development and use of medical technology in the defeat of disease. For example, the removal of the autonomous subject can potentially inform contextualised deliberation as to what kinds of medicine, "knowledge and technology," is of social value.[1036] In other words, it may usefully result in the pursuit of life lengthening technology being questioned and considered against the realities of dying, death and the value of a good death.

6.3.3 A Process of Relational Decision-Making

6.3.3.1 Introducing a vulnerability approach to decision-making

The third legal dimension concerns the way in which patients can be supported in a decision-making process that embraces personhood, mutuality and the body. This recreation represents an overt effort to shift away from the legal tool of consent as an avenue to distinguish between legal and illegal medical treatment, and instead, take law in a direction that encourages the provision of resources so as to readily facilitate "autonomy in a thicker and more meaningful sense."[1037] This initiative will be primarily directed by vulnerability norms in combination with allied learnings from dementia and relational theorists. It will account for how embodied vulnerability intersects with embedded reliance on relationships of care which can afford mutual decision-making that respects physical and relational needs. To develop this dimension, I present and develop five interrelated sub-principles. These guide decision-making processes to account for the social and medical resources that can be usefully mobilised in response to the needs and experiences of persons with dementia. These principles represent obligations for informal and formal supporters as well as healthcare professionals who are engaged in decision-making in healthcare, and at the end of life. Whilst it has been developed with people with dementia in mind, it is intended to capture decision-making in healthcare more broadly due to the universality of relationality and dependency that underpins this decision-making framework.

[1036] Sevenhuijsen (n 333) 144.

[1037] Clough, 'Disability and Vulnerability' (n 147) 478.

6.3.3.2 Principle 1: As the primary decision-maker, the patient must be given support to participate in the decision-making process

The first principle indicates that the patient, who retains the status of the primary decision-maker, must be given support to participate in the decision-making process. In emphasising the importance of support in participation, this principle intends to increase opportunities for input in the decision-making process, thereby centring people with dementia as individuals "with continuing needs, wants, beliefs and values."[1038] This provision of support is informed by Clough's mobilisation of vulnerability in claiming that the focus of decision-making regulation should be on providing appropriate responses and resources with regard to the contextual needs of the patients.[1039] All possible practical measures of support must therefore be afforded to each patient to secure their participation in end-of-life decision-making. Importantly, this support should not merely seek to reproduce pre-existing wishes, but rather embrace the way in which resources allow for decisions to be made in order to capture the complexity of support inherent to a dialogic process.[1040] From this perspective, assistance and support are essential factors in "creat[ing] options and mak[ing] choices."[1041] Indeed, the comprehensive, vulnerability informed approach to decision-making arguably imagined by scholars such as Clough and De Sabbata is one that demands that the focus of law should be on the construction of the conditions required to determine one's life rather than upholding the mistruth that people are "a solitary artificer of their destiny."[1042]

This interpretation is not necessarily impossible within the current legal framework. Indeed, Pritchard-Jones recognises that the academic literature on the CRPD oscillates between claims that support helps in the decision-making process on the one hand, and that support should give effect to will and preferences on the other.[1043] However, as a vulnerability approach recognises

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[1038] Hope Davidson, 'The Assisted Decision-making (Capacity) Act 2015: Interrogating the Guiding Principles for a Person with Dementia' (2022) 84 International Journal of Law and Psychiatry 101819, 101822.

[1039] Clough, 'Vulnerability and Capacity to Consent to Sex - Asking the Right Questions' (n 869) 389 & 395.

[1040] Pritchard-Jones (n 871) 101470–101471.

[1041] Fineman, 'The Vulnerable Subject and the Responsive State' (n 285) 260.

[1042] De Sabbata (n 25) 85.

[1043] Pritchard-Jones (n 871) 5.

that we come into being from the very beginning in relation to others,[1044] the myth of autonomy as independent self-sufficiency[1045] can never be upheld where the vulnerable subject underpins the legal regulation of decision-making. The more comprehensive account of support in the decision-making process would therefore arguably become inevitable and necessary rather than incidentally afforded by certain contested interpretations. Accompanied by the reconceptualisation of dignity as discussed above in subsection 6.3.1, the concern is no longer with non-interference in pursuit of revealing pre-existing wishes, but with providing support through which wishes and preferences come into being. The resulting obligation to understand values, social contexts and supporters as well as provide for support in relational decision-making will arguably utilise support networks more effectively than a rights approach situated in an individualist understanding of the self and what constitutes "my decisions."[1046]

6.3.3.3 Principle 2: Support should recognise opportunities for care that benefits agentic & physical needs

The second principle recognises that vulnerability is inextricably related to an embedded dependency on social and interpersonal arrangements for both agency and healthcare.[1047] This principle seeks to encourage an integrative and collaborative effort in which support provides for both physical and agentic needs as two inherent dimensions of relational decision-making. This follows Jennings' use of solidarity in end-of-life care in which he claims that "the obligation to respect the self-determination of a relational agent will embrace the obligation to provide care and to promote the person's well-being."[1048] This account is also in line with the clinical skills and practices associated with

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[1044] Butler, *Undoing Gender* (n 149) 21.

[1045] Martha Fineman, *The Autonomy Myth: A Theory of Dependency* (The New Press 2004) 22.

[1046] Craig Sinclair and others, '"A Real Bucket of Worms": Views of People Living with Dementia and Family Members on Supported Decision-making' (2019) 16 Journal of Bioethical Inquiry 587, 601.

[1047] Fineman, 'Reasoning from the Body' (n 311) 18; Fineman, 'Vulnerability in Law and Bioethics' (n 275) 57; Fineman, 'Vulnerability and Social Justice' (n 346) 360; Fineman, 'Vulnerability and Inevitable Inequality' (n 280) 142; Rogers, Mackenzie and Dodds (n 269) 30; Dodds, 'Dependence, Care, and Vulnerability' (n 285) 182; Fineman, 'The Significance of Understanding Vulnerability' (n 39) 1379.

[1048] Jennings (n 337) 231.

"shared decision-making;" a collaborative process[1049] which aims to respect autonomy and afford opportunities for beneficence and non-maleficence.[1050] Agency is therefore understood to be symbiotically developed through mutual adjustment and shared engagement "within a framework of reflective judgment."[1051] By embracing the contextual realities of end-of-life decisions, insight into the actual agentic possibilities in effective end-of-life care can be afforded to patients.[1052] The inclusion of the concept of "benefit" to physical and relational needs is an explicit attempt to marry the importance of healthcare that positively meets bodily needs without abandoning the importance of respect for personhood. In this, it is inspired by the Irish Mental Capacity Act's effort to avoid the patriarchal overtones of "best interests" whilst retaining the idea of the importance of beneficence and non-maleficence.[1053] As Davidson reflects, an active refusal of treatment that may be objectively conceptualised as in their best interest could arguably not be understood to represent a benefit to their overall wellbeing.[1054]

6.3.3.4 Principle 3: The past and present self must be balanced

The third principle obliges that the past and present self be balanced in the process of decision-making. Perhaps the only principle most closely related to the circumstances of cognitive decline, I seek to account for the idea that carers of people with dementia attempt to afford support so that decisions are reflective of "both their past and present selves."[1055] This captures the fact that we are inextricably reliant upon the way that others constitute our very being from birth until death[1056] within the distinctive context of progressive cognitive illness. Jennings, for instance, engages with the concept of carers "reminding"

[1049] Magenta Simmons and Piers Gooding, 'Spot the Difference: Shared Decision-Making and Supported Decision-Making in Mental Health' (2017) 34 Irish Journal of Psychological Medicine 275, 276.

[1050] Anne Stiggelbout and others, 'Shared Decision-making: Really Putting Patients at the Centre of Healthcare' (2012) 344 BMJ e256, 256.

[1051] Jennings (n 337) 230–231.

[1052] ibid 230.

[1053] Assisted Decision-making (Capacity) Act 2015 (Ireland) s.8(7)(e) states that an intervener shall act at all times in good faith and for the benefit of the relevant person.

[1054] Davidson (n 1038) 101813.

[1055] Donnelly, 'Deciding in Dementia' (n 28) 101468.

[1056] Butler, *Frames of War: When Is Life Grievable?* (n 288) 14; Butler, *Undoing Gender* (n 149) 21.

to capture the reality of efforts to rediscover and refashion “the self and among selves” so that the person with dementia is sustained “as a relational human subject, person, [and] agent.”[1057] In a similar fashion, Lindemann speaks of “holding the person in her identity to capture the reality and possibility for evolution in the person with dementia.[1058] By way of a relevant example, a person with dementia in the very final stages of life would be “held badly” where stories of miraculous cures are projected onto this person.[1059] Thus, it is only through attention to the past and present experience of embodied vulnerability in which good end-of-life decisions can be made.

6.3.3.5 Principle 4: Support should exist on a continuum that extends to substitute decision-making arrangements facilitated by advanced care directives

This fourth principle captures the idea that support is a process that shifts overtime and ultimately embraces possibilities for a form of substitute decision-making that retains relational agency. First and foremost, the right support can promote meaningful communication even as dementia progresses.[1060] More than this however, support for relational agency in dementia is possible even when the ability to form and communicate one’s wishes has been lost via a less paternalistic approach to substitute decision-making.[1061] In fact, these different kinds of support “may exist and overlap on a continuum.”[1062] As explored in Chapter 5, the current legal framework does certainly extend to some possibility for substitute decision-making via the doctrine of hypothetical consent and the CRPD’s best interpretation of wishes and preferences. The degree to which substitute decision-making is available is, however, limited with reference to the legal restriction on advanced care planning and guardianship (particularly in relation to the withdrawal or

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[1057] Bruce Jennings, ‘Agency and Moral Relationship in Dementia’ (2009) 40 Metaphilosophy 425, 427.

[1058] Hilde Lindemann, ‘Holding One Another (Well, Wrongly, Clumsily) in a Time of Dementia’ (2009) 40 Metaphilosophy 416, 417.

[1059] ibid 421.

[1060] Megan S Wright, ‘Dementia, Healthcare Decision-making, and Disability Law’ (2019) 47 Journal of Law, Medicine & Ethics 25, 30–31.

[1061] De Sabbata (n 25) 12.

[1062] Brenna M Rosen, ‘Supported Decision-making and Merciful Health Care Access: Respecting Autonomy at End of Life for Individuals with Cognitive Disabilities Student Notes Colloquium’ (2023) 80 Washington and Lee Law Review 555, 584.

withholding of potentially life-sustaining treatment). Furthermore, the spectre of emergency treatment serves to represent a lingering possibility for substitute decision-making based in paternalism rather than an autonomy strengthening framework. Principle four therefore serves to bolster and improve upon what may already be possible in terms of agentic care at the end of life by exploring how decisions can be made through legal tools that allow for contextualised decision-making processes that accounts for cognitive change overtime.

To do so, this subsection will explore how advanced care directives as a legitimate substitute decision-making tool may allow for an approach to decision-making via the provision of instructions and/or guardian appointment that promotes autonomy more meaningfully in the present and into the future on questions of death and dying. Embracing a relational autonomy approach via advanced care planning is important as it has been found to secure positive end-of-life experiences for people with dementia[1063] by: reducing burdensome interventions; increasing palliative care uptake; increasing a sense of control; and improving outcomes for those in a relationship with the patient.[1064] In seeking to comprehensively map and strengthen the possibility of advanced care planning through a vulnerability lens, CRPD and vulnerability scholarship have proved particularly useful.

Like Morrissey's reflection on advanced care directives under the CRPD,[1065] I argue that advanced care directives cannot be enacted in the wake of a declaration of incapacity, nor is there a fixed line that separates a time at which the advanced care directive applies over the person in the present. To suggest otherwise would be inconsistent with Clough's vulnerability informed claim that the universality of human reliance on "relationships of care and support" problematises the binary demarcation of those who have, and those who do not have, capacity.[1066] Instead, advanced care directives are better understood from a vulnerability perspective as an evolving process "followed by the supporter and accounted for in the advance directive" which is "used, when and insofar this is necessary, to integrate the indications the person cannot directly express

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[1063] Harding, *Duties to Care* (n 4) 178.

[1064] Eisenmann and others (n 65) 705; Deborah Carr and Elizabeth A Luth, 'Advance Care Planning: Contemporary Issues and Future Directions' (2017) 1 Innovation in Aging 1, 3.

[1065] Fiona Morrissey, 'The Introduction of a Legal Framework for Advance Directives in the UN CRPD Era: The Views of Irish Service Users and Consultant Psychiatrists' (2015) 1 Ethics, Medicine and Public Health 325, 330.

[1066] Clough, 'Disability and Vulnerability' (n 147) 473 & 477.

due to their deteriorated condition."[1067] In this way, advanced directives become a tool to develop capacity, support expressions, recover one's wishes and communicate preferences.[1068] The integration of this support mechanism can be determined by the person themselves by outlining the conditions under which the directive, and alternative decision-makers enshrined therein, should become active. Such conditions may include, for instance, when the patient finds themselves in crisis or is admitted to hospital.[1069] Under this approach, substitute decision-making via advanced directives is ultimately positioned more usefully as a tool embedded in the collaborative relationship that evolves overtime between supporters and the supported.[1070] Thus, as Rosen claims, "the supporter would understand her (the patient's) wishes at each step and be able to track those wishes relationally to apply them appropriately in context" of evolution in capacity and interests.[1071]

The implementation of a directive must nevertheless necessarily be conditional. In particular, where moments of lucidity give way to alternative opinions via verbal expressions or behaviour, such opinions will also need to be reflexively responded to.[1072] This is particularly important to note in the context of death and dying with dementia in light of research identifying paradoxical lucidity amongst patients with dementia in the hours or days before their death.[1073] A remaining challenge to this approach may be where a patient is not lucid but nevertheless refuses pain relieving care contrary to their well-established wishes as contained and reaffirmed in the directive. Whilst no clear cut solution can be provided to effortlessly overcome such difficulties, reference to the interlocking decision-making principles does provide a methodological framework that is useful in navigating this kind of conflict. Force must be avoided, instead, a mutual approach to decision-making would arguably necessitate a negotiation between the patient, their environment, their supporters and medical possibilities. By way of illustration, healthcare workers

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[1067] De Sabbata (n 25) 12–13.

[1068] Morrissey (n 1065) 326 & 330.

[1069] ibid 330.

[1070] De Sabbata (n 25) 12.

[1071] Rosen (n 1062) 587.

[1072] De Sabbata (n 25) 112.

[1073] Alexander Batthyány and Bruce Greyson, 'Spontaneous Remission of Dementia before Death: Results from a Study on Paradoxical Lucidity.' (2021) 8 Psychology of Consciousness: Theory, Research, and Practice 1.

might return to the patient in an hour when they are calmer. Alternatively, transdermal patches may be applied to the patient's skin rather than the usual approach of pain relief via subcutaneous injections.

Where the role of advanced care directives are unclear in the current legal regime when the person with dementia can no longer express themselves, advanced care directives structured in this way would more explicitly protect the wishes of this person as developed overtime with reference to their changing physical and cognitive realities. Furthermore, it may provide subtle encouragement as to the importance of integrating the patient's personhood even as they pass their limits to engage in individualistic autonomous practices in the present. With this, the possibility that decisions are made without consideration as to personhood would hopefully be reduced. Of course, giving legal meaning to advanced care planning will not necessarily overcome some of the recognised challenges to the implementation of advanced care directives. For example, people with dementia and their carers may remain unwilling to discuss advanced care planning.[1074] Nevertheless, it may serve to encourage enhanced uptake in a jurisdiction that currently lacks a legislative basis in the context of growing advanced care planning community initiatives.[1075]

6.3.3.6 Principle 5: Family must be accounted for in the decision-making process

The fifth principle of relational decision-making in a vulnerability framework recognises family as integral relational figures in the decision-making process. Family is, of course, already recognised in the current Swedish framework as central legal figures in the exchange of information, and as people with a vested interest in the decision-making process.[1076] Similarly to the definition of those in a close relationship with the patient in Swedish law, family is used here to broadly encompass relationships of emotional or psychological closeness which includes, biological families, adopted families as well as other

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[1074] Nathan Davies and others, 'Quality End-of-Life Care for Dementia: What Have Family Carers Told Us So Far? A Narrative Synthesis' (2014) 28 Palliative Medicine 919, 920.

[1075] See for example the DöBra Research Program as reported on in, for example, Olav Lindqvist and Carol Tishelman, 'Going Public: Reflections on Developing the DöBra Research Program for Health-Promoting Palliative Care in Sweden' (2016) 24 Progress in Palliative Care 19.

[1076] Subsection 5.3.3.2.

relationships that are of domestic or intimate nature.[1077] Driven by an interest in recognising the inherent interconnectedness of the vulnerable subject to interpersonal relationships, this account of relational decision-making, however, seeks to incorporate the family as principle decision-making participants who are not merely conduits and translators to uncover the existing preferences of the patient.[1078] Instead, they will be embedded participants in the decision-making process. In doing so, end-of-life decisions are situated as a process that exists between the individual and their family. By approaching decision-making as a familial phenomenon, the patient's clinical, interpersonal and multidimensional needs can be usefully addressed.[1079]

To be sure, end-of-life decisions can be made with reference to the possible impact such decisions may have on loved ones.[1080] This includes people with dementia,[1081] who, as research has found, rely upon relationships in decision-making.[1082] In fact, incorporating family into the decision-making process can promote agency and a "sense of integrity and worth."[1083] Along these lines, the advice and needs of family members, as well as mutual interests, constitute a feature of the patient's agency, and supports the construction of decisions that embrace the patient's relational identity.[1084] On this point, Ho fruitfully explains that familial relations are a dimension of individual identity, and are indicative of the fact that patients are "not a mere collection of dysfunctional body parts that require professional intervention, but a moral agent with full histories and important relationships."[1085] Furthermore, relationality is also central to good, symptom relieving palliative care given that relational support from friends as well as care providers have been found to alleviate pain as well

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[1077] Anita Ho, 'Relational Autonomy or Undue Pressure? Family's Role in Medical Decision-making' (2008) 22 Scandinavian Journal of Caring Sciences 128, 129.

[1078] Dahlborg Lyckhage, Pennbrant and Boman (n 874) 6.

[1079] Anita Ho, 'Taking Family-Centered Care Seriously' (2020) 20 The American Journal of Bioethics 65, 67.

[1080] Ho, 'Relational Autonomy or Undue Pressure?' (n 1077) 132.

[1081] Wright (n 1060) 31.

[1082] Sinclair and others (n 1046) 600; Pritchard-Jones (n 871) 4–5.

[1083] Ho, 'Relational Autonomy or Undue Pressure?' (n 1077) 129–130.

[1084] Anita Ho, 'Relational Autonomy or Undue Pressure? Family's Role in Medical Decision-Making' (2008) 22 Scandinavian Journal of Caring Sciences 128, 132.

[1085] Ho, 'Relational Autonomy or Undue Pressure?' (n 1077) 131.

as fear and other end-of-life symptoms.[1086] This is in line with the vulnerable possibility of compassionate and joyful caring relationships.[1087] Indeed, the process of shared decision-making in which the relational autonomy of patients is contextualised in opportunities for beneficence has been understood to function through attentiveness to the caregiver and "the communication between caregiver and patient."[1088]

Ultimately, a communal approach to decision-making is indicative of a group endeavour to account for the mutual interests of both patient and family.[1089] Ensuring the family are embedded participants in the decision-making process is therefore also important for family members who are significant in and of themselves. This captures the fact that as integral participants in patient care, they might experience fluctuations in their "well-being and identity" given that the experience of illness is relational and has consequences for the future of the family unit.[1090] The inclusion of family is also an important aspect of the feminist informed vulnerability approach given what the concept of derivative dependency reveals about the phenomenon that those who do the caring are also reliant upon others and structures to meet the needs of those who are cared for.[1091] That is, where family are accounted for, their ability to maintain fruitful caring relationships as carers for their loved ones at the end of life is also enhanced.

As the essential condition of vulnerability, openness to that outside the self is also associated with the potential that intimate relationships can cause harm.[1092] It is therefore of course relevant for care professionals to discern whether relational decisions have come about due to "undue pressure," neglect or abuse. This may arise, for example, in a failure to account for patient

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[1086] Harding, *Duties to Care* (n 4) 178.

[1087] Fineman, 'Vulnerability and Social Justice' (n 346) 358.

[1088] Wiesje M van der Flier and others, 'Diagnostic Dilemmas in Alzheimer's Disease: Room for Shared Decision-making' (2017) 3 Alzheimer's & Dementia: Translational Research & Clinical Interventions 301, 302.

[1089] Ho, 'Relational Autonomy or Undue Pressure?' (n 1077) 132.

[1090] Ho, 'Taking Family-Centered Care Seriously' (n 1079) 65.

[1091] Eva Feder Kittay, 'A Feminist Public Ethic of Care Meets the New Communitarian Family Policy' (2001) 111 Ethics 523, 527; Fineman, 'Reasoning from the Body' (n 311) 28–29; Fineman, 'Vulnerability and Social Justice' (n 346) 361; Fineman, 'Equality, Autonomy, and the Vulnerable Subject in Law and Politics' (n 290) 18.

[1092] Dodds, 'Dependence, Care, and Vulnerability' (n 285) 197; Mackenzie, Rogers and Dodds (n 273) 9.

wellbeing or in consistent displays of disregard for the expressed wishes of the patient.[1093] With this said, the option of advance care directives offers a concrete solution for particular loved one's to be included or excluded from the decision-making process. Furthermore, like Ho suggests, it is important to proceed on the basis families do not usually use healthcare as a vehicle for familial abuse. This means that signs of conflict ought to be viewed as a relational event which requires a consideration of motives and efforts to resolve tension.[1094] Such circumstances may arise for example where family may cause what might be described as well-meaning harm by seeking to keep their loved one alive which may be resolved through the careful explanation of the medical situation and the patient's quality of life as well as facilitation of the exchange of what is known about the values and wishes of the patient.

6.3.4 Medical Governance as Evidenced-Based Practice

The inclusion of medical governance as a dimension of law intends to embrace a system of shared responsibility between law and medicine. Indeed, following a concern for institutional vulnerability,[1095] De Sabbata advocates for the distribution of "the resilience building function of the state across different levels and autonomous bodies" in order to allow for cross institutional control and support in securing resources for people to manage their vulnerabilities.[1096] Furthermore, there is value in allowing for medicine to operate on the ground level where it can be responsive and reflexive to the interplay between the particular clinical situation, scientific evidence and clinical experience in relation to the structural norms dispersed by law. This follows from the fact that a vulnerability perspective points to the importance of both structural and individual resilience.[1097]

Central in this arrangement is science and proven experience as the primary mechanism in law that provides a legal role for medicine in demarcating not only what end-of-life decision-making practices are legal, but also what

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[1093] Ho, 'Relational Autonomy or Undue Pressure?' (n 1077) 132.

[1094] ibid 133.

[1095] Fineman, 'The Vulnerable Subject and the Responsive State' (n 285) 256; Fineman, 'The Vulnerable Subject: Anchoring Equality in the Human Condition' (n 267) 169.

[1096] De Sabbata (n 25) 88.

[1097] Clough, 'Vulnerability and Capacity to Consent to Sex - Asking the Right Questions' (n 869) 389.

practices are encouraged. As has been established over the course of Chapter 4 and Chapter 5, science and proven experience presently represents a vague concept that is mobilised both in the evaluation of care practices with consideration as to patient safety, as well as in the assessment of the ethical values inherent to certain medical practices. The problem in the case of death and dying with dementia is the extent to which science and proven experience has been readily interpreted as including this latter, ethics-based assessment of values. Indeed, it has been understood to threaten legal certainty.[1098] More than this though, if maintained in the context of the reformed account of law, it would arguably also allow for institutional vulnerability in which long standing values in medical ethics around the prevention of death at all costs are able to find a backdoor entrance into a legal regime that is otherwise attempting to overturn such harmful principles based on the values brought to light by vulnerability. With this in mind, rather than abandoning science and proven experience, it should instead be exclusively applied as a requirement for end-of-life care practice to be supported by the relevant field of knowledge.[1099]

Where retained in this narrower conceptualisation, science and proven experience may help to promote evidenced based standards in end-of-life care. This is important given the understanding that “consensus driven best-practice approaches” in medical governance promote improved end-of-life experiences with dementia.[1100] Poignant in this regard are the consensus-based, dementia specific recommendations by the European Association for Palliative Care. They indicate that palliative care with dementia involves consideration as to comorbid disease, behavioural problems, management of “physical and cognitive problems,” communication “with patients and families” as well as family support as carers and decision-makers.[1101] Palliative care with dementia was subsequently adapted into a three-goal model to capture the evolution of care goals in the face of cognitive decline; “prolongation of life, maintenance of function and comfort.”[1102] They also developed 11 domains of palliative care that include, but are not limited to; person-centred-care, advance planning,

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[1098] Wahlberg (n 741) 92–93.

[1099] As it was applied in *B 9036-22* 6 & *B 10553-18* 39.

[1100] Harding, *Duties to Care* (n 4) 178.

[1101] Jenny T van der Steen and others, ‘White Paper Defining Optimal Palliative Care in Older People with Dementia: A Delphi Study and Recommendations from the European Association for Palliative Care’ (2014) 28 Palliative Medicine 197, 198.

[1102] ibid 206.

avoiding overly aggressive burdensome or futile treatment, family care and involvement and optimal symptom treatment.[1103]

Moreover, stripped back to the bones of best practice by removing the dimension of values and the associate idea that death should be avoided at all costs, science and proven experience may have a different meaning in regards to practices that may hasten death. For example, science and proven experience would be detached from the established culture in which death is taken to represent a failure of medicine,[1104] and instead, only represent what is appropriate according to indications of medical possibility. In addition, science and proven experience would no longer be able to be used to hamstring democratic debate on the possibility of medically assisted dying as has been achieved so far with the application of the concept in an assessment of the ethical value of assisted dying practice in healthcare.

6.3.5 Assisted Dying From a Vulnerability Perspective

Of course, an investigation into the law on end-of-life decision-making with dementia would not be complete with consideration as to assisted dying. This section represents an opportunity to canvass the specific issues and challenges of assisted dying as it relates to people with dementia from a vulnerability perspective. In doing so, it does not seek to provide "a definitive normative answer" to the issue of assisted dying with dementia.[1105] Instead, it intends to provide a platform from which to wrestle with the obligations, possibilities and limits of assisted dying for people with dementia in law from a vulnerability perspective. Ultimately, it argues that whilst inherently difficult, and demanding of caution, a vulnerability perspective indicates the importance of open consideration as to the possibility of legalisation for assisted dying with dementia.

As a springboard for this discussion, the Dutch model as one of the few jurisdictions that allow and provide guidance for assisted dying with dementia, will be briefly addressed to consider how law can construct access to assisted dying with dementia. In the Netherlands, there is a possibility to access medically assisted dying both at an early stage of cognitive illness as well as at a later stage through an advanced euthanasia directive. The Termination of

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[1103] ibid 200–202.

[1104] Österlind and others (n 12) 530.

[1105] This follows Harding, *Duties to Care* (n 4) 185.

Life on Request and Assisted Suicide Act sets out due care criteria which must be fulfilled for physician assistance in dying to be legal. It holds that the attending physician must:

> (a) be satisfied that the patient has made a voluntary and carefully considered request;
>
> (b) be satisfied that the patient's suffering was unbearable, and that there was no prospect of improvement;
>
> (c) have informed the patient about their situation and prospects;
>
> (d) have come to the conclusion, together with the patient, that there is no reasonable alternative in the light of the patient's situation;
>
> (e) have consulted at least one other, independent physician, who must have seen the patient and given a written opinion on the due care criteria referred to in (a)–(d) above; and
>
> (f) have terminated the patient's life or provided assistance with suicide with due medical care and attention.[1106]

The 2018 Euthanasia Code produced by the Regional Euthanasia Review Committees indicates the need for "particular caution" in regards to assessing the legality of assisted dying requests relating to dementia.[1107] The Code indicates that a significant majority of cases of assisted dying for people with dementia reported to the Committee involve patients at an early stage of cognitive illness. The Code considers that this group often has an adequate understanding of the condition and decisional competence in making the request. Unbearable suffering in this instance is reported to include cognitive decline but also fear of unavoidable future decline and resultant consequences for dignity and autonomy.[1108]

Nevertheless, in the Netherlands, where a consultant concludes that a patient with late stage dementia does not have decision-making competence, advanced

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[1106] Termination of Life on Request and Assisted Suicide (Review Procedures) Act (2002) art 2(1).

[1107] Regional Euthanasia Review Committees, 'Regional Euthanasia Review Committees, Euthanasia Code 2018' (2018) 44.

[1108] ibid.

euthanasia directives can become relevant.[1109] Created when the patient is considered to be capable, advanced euthanasia directives can apply when the due care requirements contained in article 2(1) are fulfilled mutatis mutandis.[1110] An assessment that finds that the patient is not suffering unbearably in the present means that euthanasia will not be performed.[1111] This should be determined with reference to the behaviour of the patient and established medical opinion as to a disease's effects.[1112] In this, special attention to "utterances or gestures" where communication is compromised is required.[1113] The assessment of unbearable suffering should be further supported by reference to the advanced directive which contains, "as clearly as possible the specific circumstances" of unbearable suffering at which they wish the directive to be realised.[1114] Further, the Euthanasia Code considers an advance directive to carry greater weight where it has been updated or the content has been orally reaffirmed.[1115] This is similar to scholarship that argues that advanced euthanasia directives may have "greater moral force" where they are: reiterated when capacity is retained; reflective of enduring values; and informed by knowledge about dementia and the associate quality of life.[1116] Ultimately, while early to end stage dementia is covered under the Termination Act, it is difficult for the legislative criteria to be met with the result that "the practice is uncommon for early dementia and very rare for end stage dementia.[1117] Thus, issues associated with the legalisation of assisted dying with dementia cannot be easily overcome.

However, whether the approach to the legal regulation of assisted dying for people with dementia embraces criminalisation or some form of legalisation, a

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[1109] ibid 45.

[1110] Downie and Lloyd-Smith (n 920) 106; Termination of Life on Request and Assisted Suicide (Review Procedures) Act (2002) (The Netherlands) art 2(2).

[1111] Radboud M Marijnissen, Kenneth Chambaere and Richard C Oude Voshaar, 'Euthanasia in Dementia: A Narrative Review of Legislation and Practices in the Netherlands and Belgium' (2022) 13 Frontiers in Psychiatry 857131, 857137.

[1112] Regional Euthanasia Review Committees (n 1107) 38.

[1113] ibid 44–45.

[1114] ibid 38.

[1115] ibid.

[1116] Paul T Menzel and Bonnie Steinbock, 'Advance Directives, Dementia, and Physician-Assisted Death' (2013) 41 Journal of Law, Medicine & Ethics 484, 494.

[1117] Downie and Lloyd-Smith (n 920) 107.

vulnerability perspective draws attention to the consequences of this decision for the community and the individuals who exist within it. While Harding makes this demand in the context of an investigation of law's relational consequences,[1118] the concept of pathogenic vulnerability as a representation of the way in which institutional dysfunction can cause vulnerability[1119] is also particularly useful in this endeavour. Applied in this context, pathogenic vulnerability highlights the importance of concern for the correlation between predominant social and institutional values, and the consequences of assisted dying law for people with dementia. In this respect, it is important to take the suggestion that assisted dying is increasingly viewed as a morally appropriate solution to the fear of living with dementia seriously.[1120] Along similar lines, Shildrick, is ultimately convinced "that people with disabilities will be targeted for death" given the neoliberal climate.[1121] Relatedly, it is claimed that the prevailing idea that acquiring a disability would be "unbearable" often does not match the actual experience which many find to not be as negative as originally assumed.[1122]

However, as feminist approaches such as the ne applied here call into question the relationship between medically assisted dying, the absence of social support for people with disability and the possibility of internalised oppression, they also point to the bias that undermines the decision-making abilities of people with disabilities.[1123] With this said, whilst it is of vital importance to be aware of such realities, and work against the possibility that they may come to fruition, it is similarly important to consider the possibility that even well-intended legal responses can produce vulnerability in the form of paternalism.[1124] In this vein, Shildrick acknowledges that

> "what begins as an ethically and politically necessary analysis of potential wrongs (limiting disability through death) swiftly solidifies into an uncritical

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[1118] Harding, *Duties to Care* (n 4) 191.

[1119] Dodds, 'Dependence, Care, and Vulnerability' (n 285) 197; Mackenzie, Rogers and Dodds (n 273) 9.

[1120] Ofra G Golan, 'End-of-Life Care' in Charles Foster, Jonathan Herring and Israel Doron (eds), *The Law and Ethics of Dementia* (Hart Publishing 2014) 395.

[1121] Margrit Shildrick, 'XI. Death, Debility and Disability' (2015) 25 Feminism & Psychology 155, 157.

[1122] Menzel and Steinbock (n 1116) 487.

[1123] Downie (n 1033) 445.

[1124] Dodds, 'Dependence, Care, and Vulnerability' (n 285) 198.

> condemnation of all practices – whether externally or self operationalised – that shorten the lives of disabled people in apparent suffering or distress."[1125]

Indeed, it is not just ignorance and a failure to imagine possibilities of adaption that drive requests for assisted dying in the context of dementia. Rather, requests for assisted dying due to dementia may be related to deep convictions as to what gives one's own life meaning.[1126] In addition, dementia can be framed as a unique condition given the impact it can have on selfhood.[1127] This reality, is captured by de Beaufort and van de Vathorst's reflection that:

> "of course, there are people suffering from dementia who seem to be happy, or at least do not seem to suffer. The problem is that for some, an important element of the notion of suffering is precisely the idea that one might become a shadow of oneself ... This is, however, a very personal evaluation, some do not dread such a perspective at all, but others find it horrifying and contrary to their idea of dignity. … Both views, albeit opposing, are personal views that deserve respect as they reflect core personal values regarding what matters."[1128]

A failure to secure equal legal opportunities for assisted dying for people with dementia may therefore see people exercising their choice earlier than they otherwise would have decided if this possibility was available to them.[1129] Pathogenic vulnerability therefore requires awareness of the consequences of both a permissive and restrictive approach to managing assisted dying.

A vulnerability perspective also makes evident the implicit significance of interpersonal relationships in assisted dying, and the subsequent importance of attending to the familial dimensions and implications of assisted dying in any legislative effort. As with their role in upholding opportunities for identity and autonomy, family has been recognised as important in assisted dying discussions where the family member has dementia.[1130] Indeed, people with dementia rely on support, including physical assistance, in making and

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[1125] Shildrick (n 1121) 155–156.

[1126] Menzel and Steinbock (n 1116) 487.

[1127] ibid.

[1128] de Beaufort and van de Vathorst (n 1034) 1465.

[1129] Peel and Harding (n 88) 140; Kathy Davis, 'IX. Dying, Self-Determination, and the (Im)Possibilities of a "Good Death"' (2015) 25 Feminism & Psychology 143, 146.

[1130] Trijntje M Scheeres-Feitsma and others, 'Family Involvement in Euthanasia or Physician Assisted Suicide and Dementia: A Systematic Review' (2023) 19 Alzheimer's & Dementia 3688, 3689.

implementing a decision of when to end their life.[1131] The roles undertaken by family members include: the carer who feels responsible for good care; the advocate who acts as the voice in assisted dying; the supporter who provides active support; and the performer who plays an active role in the death.[1132] In being integral to possibilities for agency and care, family are also inevitably implicated as agents in a way that has implications for themselves. Where a formal legal procedure is lacking, for example, such individuals may be faced with criminal consequences.

With the possible effects of assisted dying regulation explored, this subsection concludes with a consideration as to what a vulnerability approach says about the possibility of legalisation for people with dementia. Ultimately, with careful regard to the consequences explored above, a vulnerability approach would arguably speak to some form of legalisation. The initial basis of this argument lies with the connection between vulnerability and the importance of facilitating relational autonomy. The argument is as follows. Central to assisted dying, autonomy should not be perceived as inevitably out of reach for people with dementia.[1133] In fact, the inherent nature of relationality to human life confirms the fact that opportunities for relational agency at the end of life as manifest through access to assisted dying for people with dementia ought to be taken seriously. This is Wright's argument in which she claims that a relational understanding of autonomy underlies the possibility that assisted dying decisions can be made "intentionally, voluntarily, and with understanding" through a supportive decision-making framework. From this perspective, embracing relationality provides hereto unsecured opportunities for equality at the end of life for differing cognitive abilities.[1134] However, with reference to the possibility of pathogenic vulnerability, a permissive system might be usefully limited to situations of contemporaneous decision-making in order to reduce possibilities of discrimination and abuse from external influences. This position is evident in Harding's argument that this is the only valid approach as it allows for people "to end their lives sooner than they otherwise would" as

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[1131] Harding, *Duties to Care* (n 4) 190.

[1132] Scheeres-Feitsma and others (n 1130) 3697.

[1133] Gather and Vollmann (n 61) 447.

[1134] Megan S Wright, 'Equality of Autonomy? Physician Aid in Dying and Supported Decision-Making' (2021) 63 Arizona Law Review 157, 196. Although Wright is speaking in relation to the United States, Chapter 4 indicates that these reflections are also relevant to Sweden.

well as protecting against the possibility that people are pressured to do so by a fear that they will be a burden.[1135]

Potentially less obvious in a debate saturated by claims for autonomy is the link between ontological vulnerability and a public duty of beneficence and non-maleficence as a basis for assisted dying. In one way, a policy of regulated access to medically assisted dying has the potential to represent efforts to alleviate suffering.[1136] From this angle, a legal framework that provides for assisted dying may be conceptualised as a foundation through which doing good, and doing no harm, is protected and promoted at the end of life. From this perspective, making assisted dying available to some extent for people with dementia represents a kind of palliative care in which symptom management to alleviate end-of-life suffering is allied with choice. Similarly, it can also be understood as a form of harm minimisation in which the dangers of "underground practice" are balanced, potentially through "statutory protocol."[1137] Indeed, as Harding and Peel reflect, the absence of formal networks to die with assistance may bring uncontrolled harm to those who are in a particularly precarious position socially or are otherwise fearful of a future with dementia.[1138]

The focus of this contribution to assisted dying has been a broad brush stroke approach to identify the relationship between vulnerability and a legalisation of assisted dying that provides some kind of access to people with dementia. I conclude this subsection with the suggestion that the careful consideration of opportunities and avenues for legalisation is necessary under a vulnerability approach. In this discourse, law, medicine, ethics and society ought to work together in developing a response to assisted dying requests. Where such a regime is carefully considered, the present harms may be ameliorated, or at least, more fully appreciated, and opportunities for relational autonomy strengthened and potential harm reduced. This process necessarily invites

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[1135] Harding, *Duties to Care* (n 4) 191.

[1136] This was, for example, the claim made in the case of the physician described in subsection 4.4.3 in which the provision of access to deadly substance was described as having the main goal of palliative sedation to alleviate suffering related to anxiety and dyspnoea (that is, shortness of breath) given that the patient removed their life-sustaining treatment. See *B 20746-22* 3.

[1137] Roger S Magnusson, 'Underground Euthanasia and the Harm Minimization Debate Independent Article' (2004) 32 Journal of Law, Medicine and Ethics 486, 493.

[1138] Peel and Harding (n 88) 140.

future interrogation as to the specifics of how this might best manifest in the law making process.[1139]

6.4 Conclusion

Chapter 6 has undertaken a feminist vulnerability recreation of Swedish law as it pertains to death and dying with dementia. Through a feminist informed perspective on vulnerability that specifically embraces the inherent nature of death and dying to the vulnerable subject, it has illustrated how the legislative regime that underpins the governance of healthcare can, and ought to, be reconstituted. Key to this is the transformative vulnerable subject who demands a different kind of response in law. Rather than implying resistance to death, the inevitability of mortality obliges the provision of opportunities for resilience in death via access to care and relational agency. The implications of this for legislative change was elaborated via the development and interrogation of five key dimensions of law. These embrace dependency, interdependency, the reality of mortality, embodied vulnerability and relational agency and demand a legal response attentive to the complex interrelationship between personhood, relationships, medicine and the vulnerable body. The excavation of these dimensions set the scene for how the law can provide resources of resilience rather than non-interference, responsibilities to good end-of-life care, a comprehensive mutual decision-making process and a governance arrangement with medicine that works to secure rather than undermine the possibilities available under this framework. They also demonstrate the importance of further dialogue on the possibility of assisted dying.

Through this approach, the law was conceptually reimagined so as to depart from relational and collective responsibility to vulnerable needs rather than individualistic rights. In this, death becomes an unshakable reality that cannot be uncritically fought against or occluded, but rather, must be met with a collective commitment to care at the end of life. Furthermore, not only is the importance of choice maintained, but strengthened, in connection with comprehensive, relational decision-making processes that also accounts for

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[1139] See for example Downie and Lloyd-Smith (n 920) who analyse how assisted dying legislation relates to the specific circumstances of dementia, concluding that these relationships must be taken into consideration in legislative drafting to the desired effect of the law.

physical needs. Thus, with these revisions, the law can be made more responsible for providing the conditions for end-of-life care that does not stigmatise dying with dementia, but rather encourages responsiveness to physical and relational needs. Indeed, as explored through Chapter 6, this reconstruction offers enhanced opportunities for palliative care comprehensively understood as relating to both physical needs and relational selfhood and greater respect for withdrawal and withholding of potentially life-sustaining treatment. It also opens the door for further discussion on the issue of assisted dying. Importantly, rather than providing a fixed pathway for legal reform, this recreation offers a unique perspective on how the law on the issue of end-of-life decision-making can be improved so as to improve end-of-life opportunities for people with dementia beyond what is currently afforded. This contributes to the wider debate on this issue and encourages further dialogue as to the role of law in the complex and interconnected issues of choice, care, and death. It is therefore not a conclusion to the investigation begun in this thesis, but an open door that other scholars are invited to walk through.

7 Concluding Remarks

It kills me how some people die. – Markus Zusak[1140]

7.1 Summarising the Intervention

Although attention must continue to be directed towards the necessary conditions for thriving in a life with dementia,[1141] it is similarly important to recognise the terminal nature of dementia.[1142] Increasingly prevalent,[1143] dying with dementia is often characterised by complications with forming and expressing wishes[1144] as well as poor end-of-life care characterised by a high rate of overly interventionist measures, and a low rate of care that effectively manages symptoms.[1145] Although it has been claimed that "death and dying are … everyone's business and responsibility,"[1146] these challenges in death and dying with dementia take place within the broader context of the proliferation of individualism, the principles of healthy ageing and the medicalisation of death. The circulation of these norms obscure issues of frailty and dying and even create the possibility for harm at the end of life.[1147] Indeed, where regulatory regimes fail to recognise and value care, end-of-life care and

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[1140] Markus Zusak, *The Book Thief* (Black Swan 2016) 456.

[1141] Series (n 3) 109.

[1142] Harding, *Duties to Care* (n 4) 170.

[1143] Cipriani and Di Fiorino (n 6) 54.

[1144] Harding, *Duties to Care* (n 4) 170.

[1145] Hall and others (n 9) 24.

[1146] Aoun (n 11) 1.

[1147] Lawton (n 12) 173–174; Österlind and others (n 12) 530; Aoun (n 11) 1.

“a ‘good death,’” both living and dying with dementia is made more difficult.[1148]

This research begins with the premise that law has a particularly important role to play, in end-of-life decision-making with dementia. To unravel, and indeed improve, the relationship between law and dying with dementia in the Swedish context, this central research question was crafted:

What is the role of law in shaping and responding to end-of-life decision-making with dementia in Sweden?

This research question underpins a multi-pronged inquiry that describes, evaluates and recreates law in relation to the practice of end-of-life decision-making with dementia. In doing so, this research reveals that the liberal legal subject at the heart of Swedish law leads law to eschew death and dying in favour of legal protections for living with independence and good health at the limits of medicine. This has implications for the ability of people with dementia to access end-of-life care that is respectful of relational selfhood as well as bodily needs. However, where the liberal subject is substituted for the vulnerable subject, law can more effectively promote a public duty to care not only in life, but in death. Although focused on the context of Sweden, this research deals with cross-jurisdictional issues, questions and concerns which means that the analysis presented here has key learnings that extend beyond jurisdictional boundaries.

In these concluding remarks, I will present the key interlocking findings and contributions of this effort to locate the law through empirical, doctrinal theoretical endeavours. In doing so, it restates the findings as to: the everyday meaning and influence of law; the influence and application of formal legality; and the role of a vulnerability in reshaping the role of law. In the closing words, I will consider how this research can transform our understanding of the role of law in death and dying with dementia as well as its limitations in the context of broader scholarly efforts in this field.

[1148] Harding, *Duties to Care* (n 4) 192.

7.2 Outlining the Contributions

7.2.1 Law in the Everyday of End-of-Life Decision-Making with Dementia

In exploring law from the bottom up, a snapshot of the way in which law matters in the everyday legality of end-of-life decision-making with dementia is co-constructed. Undertaken in the context of a legal consciousness study, a thematic narrative analysis of interviews with physicians engaged in end-of-life decision-making with dementia is performed. This analysis results in the construction and elaboration of a legal and quasi-legal consciousness framework that reveals the intersection of medicine and law in the everyday of healthcare: law as an undercurrent; law as an iron fist; law as a tool; and medicine as a lodestar. Law is a silent undercurrent in healthcare more generally in the way that it sets the underlying framework of healthcare, even whilst it is decentred in the everyday minds and practices of the physicians. Notwithstanding this, law also bursts to the fore in end-of-life decision-making as an iron fist protector of life and self-determination via known, authoritative codified rules. At the same time however, law also becomes malleable in the hands of the physicians as they take advantage of law's instrumentality. In this, where law is sometimes useful as a social and medical good, it is relied upon in medical care. Law is also abandoned where it represents a complicating factor in pursuit of medical purposes. In the gap left by law, medicine rushes into provide guidance in end-of-life decision-making with dementia. It is ultimately medicine that guides physicians to navigate issues of selfhood, care and bodily decline.

Thus, whilst law always matters, its influence on the question of end-of-life decision-making with dementia is understood to relate to individualism, the preservation of life and the medicalisation of death and dying. As the physicians work under, alongside and around law, medicine simultaneously provides for particularised guidance that allows for the navigation of the complex reality of decision-making with dementia at the end of life. It is therefore medicine that offers the opportunity for good end-of-life care. In depicting the co-operation between law and medicine, these schemas demonstrate that whilst medicine has an important role to play, law is limited beyond the boundaries of a struggle against death and individualism in ultimately co-signing the medicalisation of death. This framework also contribute to legal consciousness scholarship more broadly in offering a new perspective located in the physician experience of end-of-life decision-making with dementia in Sweden on the social construction of law in healthcare practice.

7.2.2 Formal Legality in Death & Dying with Dementia

A comprehensive analysis of Swedish legal doctrine and its related debates through the lens of a feminist informed approach to vulnerability largely mirrors this account of law in society. In exploring the doctrinal regulation of Swedish healthcare and end-of-life decision-making in relation to people with dementia, this research represents a hereto unexplored opportunity to bring different dimensions of Swedish health law scholarship together; end-of-life law and law as it relates to capacity. It demonstrates the specific ways that law can apply to the circumstances of end-of-life decision-making with dementia. However, by undertaking this analysis through the lens of feminist vulnerability, the otherwise hidden meanings of law are also usefully revealed. This combination of doctrine and theory provides a comprehensive insight into law's construction and response to end-of-life decision-making with dementia. In particular, it reveals that the individualistic liberal legal subject at the core of the regime demands independent rationality, supports the return of patients to good health and ultimately occludes death. As dying with dementia pulls at the seams of this construct, the law provides for a complex and at times contradictory arrangement that both demands rationality and seeks containment and control of death via paternalistic measures. As will now be briefly outlined, this has consequences for access to end-of-life care that meets both relational and physical needs.

Legal support for palliative care can arguably be extrapolated from the more general social right to healthcare. Opportunities for palliative care, as well as the possibility for the withdrawal of potentially life-lengthening treatment, ought to be based on the wishes of the patient in a system that constitutionally and legislatively protects self-determination and bodily integrity. This is extended to people with dementia through systems of support that allow for pre-existing wishes to be actualised. Such support includes adaptive communication, consideration of past wishes and the doctrinal tool of hypothetical consent. Whilst self-determination is therefore made legally available, the legal system continues to perpetuate an idea of individualistic decision-making which undermines opportunities for the ongoing exchange of information in pursuit of mutual decision-making. This is arguably manifest through the rules on guardianship which, whilst evidently crafted so as to avoid paternalism, also excludes opportunities to enshrine opportunities for relational autonomy in law. Whilst a progressive interpretation of guardianship ought to allow for some possibility to secure relational access to palliative care, withdrawal of life-sustaining treatment remains limited.

Furthermore, as the spectre of irrationality emerges in the form of cognitive diversity and declining physical health, paternalism develops. Conflicting interpretations of the protection of self-determination as it applies to people with dementia as well as tension around the value law assigns to good health and the preservation of life produces an uncertain legal milieu. For instance, the values of protecting, promoting and restoring good health as expounded by law threatens to undermine the degree to which science and proven experience (a concept that has been understood to promote patient safety) can be effectively and consistently mobilised in reducing overly interventionist treatment and increasing effective care at the end of life. Further still, stigmatising attitudes in sources of law and society at large may undermine access to end-of-life care that is respectful of opportunities for relational autonomy and bodily needs. As part of this, the law creates uncertainty as to whose wishes in the refusal of potentially life-lengthening treatment will be respected. Further still, the emergency provision is available to provide for emergency palliative care without consideration as to opportunities to respect and respond to relational personhood. In this space, people with dementia may be stigmatised as doubly “vulnerable” in mind and body and subsequently face the threat of paternalistic measures that may, at worst, be overly interventionist at the end of life, and at best, be ignorant of opportunities for respecting personhood in palliative care.

Finally, respect for self-determination was not intended to allow for assisted dying under Swedish law. A patchwork system does nevertheless offer some opportunities to access the assistance of private persons when the dying person themselves performs the decisive death causing act (i.e. through swallowing a deadly dose of medication). Medically assisted dying, however, is presently prohibited as an expression of health law’s overarching concern with the preservation of life and return to good health. The private avenues open for cognitively well people, are, nevertheless, arguably not extended to people with dementia on the grounds that cognitive difference would lead to a presumption of incapacity in the courts.

7.2.3 Recreating Law From a Vulnerability Perspective

Having accounted for the way in which the law’s predication on individualism hampers access to end-of-life care for people with dementia, a feminist informed vulnerability perspective is mobilised in recreating the law through the development of five key dimensions of legislative governance. Here, a vulnerability perspective is pushed to its limits as a powerful tool on the issue of death and dying. Central to this mobilisation of vulnerability is the claim that the core feature of humanity is bodily vulnerability that leaves us open to the possibility of positive and negative change. Such change can result from biological processes. From this perspective, cognitive illness should be understood as normal, and dying, a natural and inevitable result of our embodiment. Importantly, our vulnerable bodies leave us open to that outside the self. Bodily vulnerability therefore also means that we are necessarily and inevitably both at risk from, and simultaneously reliant on, institutional and inter-personal relationships and structures. From this perspective, vulnerability underpins a transformative claim for collective responsibility to vulnerability which it understands to be best realised through the strictures of law.

Whilst universal vulnerability can never be occluded, law can underlie the provision of resilience that allows for people with dementia to thrive. Importantly however, as death and dying are the ultimate consequence of vulnerability, the provision of support to relational beings cannot merely be directed to resilience in life, but rather, must also be provided in death. In this way, a more comprehensive claim for recognising and revising the tendency to fight against death at all costs is provided. Furthermore, in being attentive to different kinds of bodily vulnerability, this approach to vulnerability does not result in the stigmatisation of cognitive illness, but rather, attention to the various and unique needs of people with dementia. Relatedly, the feminist influence on this vulnerability perspective requires, opportunities for resilience to be as attentive to physical needs as it is to opportunities for relational autonomy. This underpins a legal response that explores opportunities for end-of-life care for people with dementia that is neither stigmatising nor ignorant of the importance of appropriate palliative care.

These learnings transform the law's responsiveness to death and dying with dementia. Through the insertion of the vulnerable legal subject, the foundations for a legislative framework that embraces rather than overlooks collective obligations in death and dying with dementia are provided. This is manifest through the development and elaboration of five key dimensions of law which are intended to underpin end-of-life decision-making with dementia. In reimaging dignity from a vulnerability perspective, dignity represents that which is respectful of our inherent need for institutional and interpersonal support. Secondly, introducing the principle of a good death provides an important anchor for efforts to encourage responsibility at the end of life as distinct from that encouraged in pursuit of good health. Conceptualised through a vulnerability lens, a good death is informed by relationships of physical and relational support in pursuit better end-of-life experiences. Thirdly, as opposed to consent as the determinative factor of legal medical treatment, a vulnerability approach encourages a process of decision-making marked by a mutual exchange between the patient, their family and healthcare overtime. This process aims at promoting personhood whilst also addressing the physical needs of the dying body. Fourthly, a vulnerability approach recognises the importance of cross-institutional co-operation to strengthen the provision of resilience and ward off institutional vulnerability. With this in mind, it allows for the contribution of medicine in delineating and encouraging best practice in end-of-life care. This follows the recognition that "consensus driven best-practice approaches" promote improved end-of-life experiences with dementia.[1149] Finally, this vulnerability reconstruction of law is attentive to the consequences of assisted dying for people with dementia, their families and the disabled community at large. It considers that. in light of these challenges, a vulnerability perspective does undergird the careful and considered claim that some form of relational access to assisted dying for people with dementia ought to be discussed in order to manage physical suffering and promote relational autonomy. In doing so, it sets the scene for further debate as to the possibilities and issues of enacting legislative change on the issue of medically assisted dying for people with dementia.

Importantly, this recreation does not intend to provide a fixed roadmap, but rather is an illustrative demonstration of how collective responsibility for death and dying with dementia can be better secured in law. The intention is to join the broader discourse attempting to grapple with dying with dementia as a public health concern marked by issues of paternalistic intervention and insufficient palliative care.

7.3 Closing Words

Against the backdrop of individualism and the medicalisation of death to the exclusion of the realities of physical and cognitive frailty, the discourse around dying has largely settled upon debate over the legalisation of assisted dying as per liberal ideas of self-determination. This, however, does very little to capture the issues at hand in dying with dementia in which challenges with

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[1149] ibid 178.

forming and expressing opinions collides with poor end of life treatment. As a purveyor of rules, norms and values, law arguably has a role in responding to this public health issue. However, as it stands, the ability of law to contribute to collective responsibility to death and dying with dementia is limited. This is arguably a result of the preponderance of the underpinning liberal legal subject which causes the law to oscillate between demands for independence and paternalism and overlook caring relationships. Paternalism is especially magnified in the case of people facing death and dying with dementia where stigmatisation exists due to the way that society marginalises cognitive difference and dying. In pursuit of legal responsibility at the end of life, I propose that law can be transformed. In doing so, law would be subject to a conceptual shift that embraces collective responsibility to the universal possibility of death and dying with dementia. This recognises the role of structural and interpersonal relationships of care that embrace physical and relational needs at the end of life. In unpacking and advocating for greater attention to the consequences and possibilities of the relationship between law, care and dementia at the end of life, this work contributes to efforts to empower people with dementia and improve end-of-life experiences.

The research nevertheless carries limitations that represent important learnings and opportunities for contributions in future scholarly endeavours. For instance, an overly loaded emphasis on the terminal phase of dementia threatens to create difficulties in living "well with dementia."[1150] As such, whilst this research has been undertaken with the explicit purpose of improving the experience with dementia at the end of life, this focus may have the unintended effect of contributing to stigma associated with living with dementia. Whilst it has therefore been essential that this work has explicitly attempted to reduce the stigma and objectification of people dying with dementia, future efforts would do well to remain open as to how insights developed in this work might be pursued in the context of law, care and living with dementia more generally. Additionally, this research is limited in the way that it is situated in a western context. It also champions a view of death and dying that may exist in opposition to other cultural practices. As a result, it provides an account of responsibility to death and dying that is not universal. Being attentive to this cultural bias, and open to explore its meanings in relationship to other cultural ideas, is therefore significant in order to understand how legal responsibility may look in different social and cultural contexts. Furthermore, when investigating law in the everyday, this research

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[1150] ibid 191.

only considers the perspectives of physicians, and a specific group of physicians at that. As the pursuit of an everyday account of law was framed as an essential attendant to an investigation of formal legality in understanding law in end-of-life decision-making with dementia, this is arguably an incomplete account. It is therefore important for future research to be attentive to other important voices in this phenomenon such as people with dementia, their family and other healthcare staff such as nurses. Ultimately, dealing with an issue that goes to the very core of the human experience in modern society, this work is ultimately located within a collective effort to reframe the role of law in society more broadly. Thus, whilst limited to the issue of death and dying with dementia in a western context, this research represents an open invitation to continued and future effort to grapple with the role of law in social phenomena more broadly.

Sammanfattning

Denna avhandling fokuserar på rättens roll i livets slutskede för personer med demenssjukdom. I västerländska rättssystem är individen utgångspunkten i dessa relationer. Konsekvensen blir att skörhet, åldrande och döende utesluts till förmån för idealet som utgörs av ett rationellt rättssubjekt med god hälsa. Samtidigt har döden blivit medikaliserad, vilket inneburit att död och döende gömts undan inom medicinska ramar. På så sätt hamnar fokus på diagnostik och bot, varigenom döden betraktas som ett misslyckande. Oundvikligen kolliderar då individen och medikaliseringen med kampen mot sjukdom och död, vilket ger upphov till onödigt lidande i samband med döden. Till exempel kan paternalistisk förlängning av livet i strid med individers värderingar resultera i inadekvat behandling av smärta och andra vanliga symtom vid livets slut. Den dominerande synen på hur man ska bekämpa de problem som uppstår vid denna kollision har varit att ställa individers val i centrum. I hälso- och sjukvården tillförsäkras detta genom informerat samtycke. Det saknas idag ett kollektivt ansvar för döden och de döende, vilket får till följd att individen förväntas ta ansvar, inte bara för att leva med god hälsa, utan även för att agera autonomt vid den egna döden.

Dessa frågor blir än mer komplicerade i relation till människor med demenssjukdom. Samtidigt som man kan leva, och ibland till och med leva ett gott liv, med en demenssjukdom, är detta oundvikligen en kronisk sjukdom som man antingen kommer att dö med eller av. Att den demenssjukes död präglas av bristande och otillräcklig vård i livets slutskede är så pass välkänt och utbrett att en sådan död kan ses som en folkhälsofråga. Den bristande och otillräckliga vården karaktäriseras av överbehandling med kurativt inriktade och ofta alltför ingripande åtgärder, parallellt med underbehandling av ren symtomlindring. Vidare upplever människor med demenssjukdom i livets slutskede ofta svårigheter med att utrycka önskemål om hur de vill att deras återstående tid ska hanteras av vård och omsorg. Det finns därför ett behov av stöd vid beslutsfattande i livets slutskeende, vilket kan behöva inkludera ställföreträdande beslutsfattare.

Denna avhandling utforskar rättens roll i beslutsfattande för människor med demenssjukdom. En grundläggande utgångspunkt i avhandlingen är att rätten är ett system som förmedlar vad som är normalt och önskvärt. På så sätt kan den påverka hur människor med demenssjukdom dör, och därigenom användas i strävan att förbättra döden för dessa personer. Genom att utforska rättens roll i beslutsfattande för människor med demenssjukdom kartlägger forskningen möjligheter och begränsningar gällande rättsligt ansvar i frågan. Sett ur ett vidare perspektiv bidrar avhandlingen till ett kollektivt ansvar för upplevelser kring död och döende för personer med demens. Den grundläggande frågan är:

> Vad är rättens roll gällande ansvaret för och utformningen av beslutsfattande i livets slutskede för personer med demenssjukdom i Sverige?

Denna fråga öppnar för en multidimensionell ansats för att få fram inte bara vad som gäller rättsligt, utan även rättens bredare inflytande över beslutsfattande vid livets slutskede för personer med demenssjukdom. Frågan tillåter också en normativ analys av begränsningar och möjligheter i strävan att förbättra livets slutskede för personer med demens.

Följaktligen används i arbetet empirisk och kritisk analys (informerad av ett feministiskt förhållningssätt till sårbarhetsteori) av gällanderätt. Forskningen börjar med en empirisk undersökning av hur rätten är konstruerad och hur den påverkar beslutsfattande vid livets slutskede i vardaglig praxis. Utifrån insikten i hur rätten existerar i samhället intervjuas läkare som fattar beslut vid livets slutskede för patienter med demenssjukdom. Den empiriska delen ligger till grund för den efterföljande utredningen av den rättsliga doktrinens roll vid döende med demenssjukdom. Förutom analys av rättsligt material undersöks också vilka normer som förmedlas av rätten kring döden och demenssjukdom. Undersökningen av normer sker genom en analys som använder konceptet kroppslig sårbarhet, något som innebär en grundläggande potentiell förändring. Avhandlingen avslutas med en transformativ analys av rätten genom prövning av hur lagstiftningen, ur ett sårbarhetsperspektiv, bör struktureras för att bättre kunna bemöta omständigheter kring döden hos personer med demens.

Utredningen av hur rätten upplevs i vardagen av läkare engagerade i beslutsfattande i livets slutskede med demenssjukdom visar att rätten främjar autonomi, skydd av liv och medikalisering av döden. Vidare är rätten tydligt kopplad till det liberala rättssubjekt vars individualism ger upphov till ett rättssystem som växlar mellan hyperindividualism och paternalism, i försök att hålla personer vid liv. Detta påverkar människor med demenssjukdom vid livets slutskede, då de kan mötas av stigmatisering på grund av deras varierande grad av mental kompetens, kroppsliga förfall och annalkande död. Detta får konsekvenser för vems önskemål som respekteras och vem som får tillgång till god vård i livets slutskede.

Genom applicering av ett feministiskt förhållningssätt till sårbarhet kan rättssystemet rekonstrueras mot ett bättre anpassat rättsligt ansvar för döden när det gäller personer med demenssjukdom. I synnerhet blir döden inte längre något som alltid och okritiskt bekämpas. Snarare bör döden förstås som en oundviklig och universell del av att vara människa. Man bör därför försöka skapa resiliens hos personer med demens för att tillåta dem att möta död och döende på ett sätt som möjliggör välmående. Ur ett feministiskt sårbarhetsperspektiv innebär detta att skapa förutsättningar för vård som säkerhetsställer möjligheter till relationell autonomi och kroppsligt välmående. Genom denna inriktning kan rätten bidra till en attityd till döende med demens som inte baseras på stigmatisering utan snarare på respekt för såväl personligheten som kroppen.

Avhandlingen är tydligt förankrad i svensk rätt och kommer därför att bidra med nya och viktiga insikter om förhållandet mellan rätten, döden och demens. Likaså berör forskningen stora teman kopplade till kärnan av vad det innebär att vara människa. Samtidigt är forskningen kopplad till normer i västvärlden kring individualism och döden. Därför bidrar avhandlingen till att förbättra rättsligt och kollektivt ansvar för döden och livets slutskede hos personer med demens även inom andra jurisdiktioner.

Appendix 1: Strengths, Challenges & Limitations of the Empirical Study

Assessing Quality

In this appendix, a close consideration of the strengths, challenges and limitations of the interview study will be provided so as to allow for reflections as to its quality and contributions. This begins with a consideration as to how the quality of this investigation can be assessed. Importantly, the quality of this qualitative study should not be measured by the common concepts of reliability and validity. Where these are used in quantitative research,[1151] they are not appropriate for qualitative research which does not intend to generalise to populations but rather draw conclusions on experiences and meanings of law.[1152] The measurement of quality in this research is instead informed by Treharne and Riggs framework made up of the following dimensions: transparency; reflexivity; transferability and triangulation.[1153] Whilst these dimensions have been embedded throughout this book, I pay particular attention to each of these in turn to emphasise the quality of the inferences I have drawn.

[1151] Lisa Webley, 'Qualitative Approaches to Empirical Legal Research' in Peter Cane and Herbert M Kritzer (eds), *The Oxford Handbook of Empirical Legal Research* (Oxford University Press 2010) 933.

[1152] Mareike Persson, 'Caught in the Middle? Young Offenders in the Swedish and German Criminal Justice Systems' (PhD, Lund University 2017) 372; Webley (n 1151) 948.

[1153] Gareth Treharne and Damien Rigg, 'Ensuring Quality in Qualitative Research' in Poul Rohleder and Antonia Lyons (eds), *Qualitative Research in Clinical and Health Psychology* (Palgrave Macmillan 2015) 59.

Firstly, transparency is considered by Treharne and Riggs to be an important, overarching facet in securing research quality in qualitative research.[1154] I have systematically planned and mapped the progression of the qualitative research process from the development of the project through to the extrapolation and reporting of the findings.[1155] I have illustrated this process in this book in a number of important ways, not the least of which is through chapters 1-3 in which the rationale for the research question and choice of methods were made clear. The processes related to the empirical component of the research have also been made transparent in the way that the interview and analytical procedures have been brought to life in the reporting. For example, in addition to detailing the methodological process, I have made extensive use of relevant data excerpts to demonstrate a data trail in reporting the findings.

Secondly, reflexivity requires awareness of my own personal influence on the research. Formally, I made clear the key dimensions of myself as an individual and researcher in the foreword. However, reflexivity has been an ongoing process of reflection. For example, in undertaking the thematic analysis I carefully considered the influence of personal bias and prior knowledge of law and legal consciousness in relation to the data. Through this, rather than replicating existing legal consciousness codes and schemas, I ultimately sought the creation of unique codes that were more appropriate in relation to the data set. Yet reflexivity is also outward facing in the sense of requiring attention to the community of participants through consultation[1156] This has been actualised through member-checking in the production of the interview schedule and sensitivity and adaption of the interview schedule during the interview process. The codes and themes that were extrapolated from the data were also member checked. This was considered to be particularly important in relation to the schema relating to medical consciousness which captured dimensions of professional guidance that I do not have personal or professional experience of.

Thirdly, transferability relates to a consideration of whether or not the findings may transfer to other sources of data. Given the focus of this study, I propose that the issue of transferability relates to whether or not the findings can transfer to sources of data collected from other healthcare professional communities or other locations. Whilst this is something that is ultimately to

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[1154] ibid 70.

[1155] ibid 59.

[1156] ibid 59–62.

be judged by you as the reader,[1157] there are a number of important reflections to be made to indicate the degree to which this research may be transferable. Bound by the parameters of ethics approval, this research was unable to provide identifying features beyond the specialisms of the participants and their broad location. With that said, as enculturated members of the Swedish medical profession, they arguably embody features of all licenced practitioners in the Swedish context such as those imparted through mandatory education and through norms of practice dispersed through the cultural practice of medicine. However, it is reasonable to consider that as they represent specific specialities, the possibility of transferability may be best understood as limited to those physicians within the same group of subspecialities within the Swedish jurisdiction. Whilst this may impede widespread transferability, it is important to recall that the key purpose was to garner insights into particular experiences of the intersection between law and medicine on the question of end-of-life decision-making with dementia in the Swedish jurisdiction.

Finally, as a mixed-methods study, this research has engaged in a form of triangulation to identify convergences, complements and divergences.[1158] This is achieved through the application of doctrinal and qualitative analysis as well as the incorporation of existing scholarship on the relationship between law and the everyday practice of healthcare more generally, and law and the everyday end-of-life care more specifically. This process has confirmed that the findings do not unreasonably or disproportionately diverge from other similar research efforts and the legal context in which this study took place.

Considering Bias

Throughout this research, I have identified, and been attentive to, possible biases. Firstly, the research explicitly sought after physicians who have specialised experience of end-of-life decisions for people with dementia. This may represent professional biases that are distinct from other specialisms and may therefore not necessarily reflect the conditions of all physicians making end-of-life decision for people with dementia in Sweden who may be differently involved in end-of-life decision-making for with people with dementia. For example, emergency or infectious disease specialists may

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[1157] ibid 59 & 62–63.

[1158] ibid 59 & 64–65.

reasonably have alternative practices to those who work in geriatrics and palliative care. In spite of this, the fact that this study is explicit about the fact that the primary intervention is to understand subjective experiences serves to offset the negative consequences of this bias that may emerge from attempts to produce abstract generalisations on the nature of Swedish law more broadly. Secondly, as all participants consented to participation, they may be understood to hold a special interest in the area. This may produce bias in terms of knowledge and attitudes in contrast to the broader community where interest in these issues may be mixed, if not more limited. Thirdly, there is the possibility that some participants were cautious to present an optimistic narrative of end-of-life decision-making so as not to contribute to discrimination and stereotyping of patients with dementia.. Finally, as explored above, bias may also be present in terms of the subject of law. Whilst I did not seek to encourage any particular perspective on the nature of law either in terms of content or quality, the participants were aware that I was a PhD candidate in law undertaking a legal research project. This may have had the effect of encouraging discussions of law or legal matters where they would otherwise not have arisen, or offering certain perspectives on the utility or otherwise of law that would not otherwise have been considered.

Physicians as Participants: An Elite Group?

A number of poignant reflections are relevant in relation to the participants in this study. Firstly, 11 participants may be considered a low participation rate. It is, however, in line with what other research has identified as a normal rate of participation in studies of healthcare professionals. Beck et al. for instance reflect on how their 10 participants in a study of healthcare professional experience with advanced care planning in Sweden represents a low participation rate that is nevertheless in accordance with the common occurrence of low uptake of research participation amongst healthcare professionals.[1159] Additionally, as accounted for in subsection 3.3.1, this participant rate was conducive with saturation. What is more, the possibility that an objectively low participation rate may have a negative on the research is further offset by the fact that this study was not undertaken with the intent

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[1159] Simon Beck and others, ‘Implementing Advance Care Planning in Swedish Healthcare Settings – A Qualitative Study of Professionals’ Experiences’ (2023) 41 Scandinavian Journal of Primary Health Care 23, 30–31.

to provide a grand narrative of law, but instead to interrogate a co-constructed account of a contextualised experience of law in the everyday as a platform for reflections as to the meaning and influence of law in this space.

Of additional interest is the inclusion of physicians as participants in the first instance. Although justified with reference to ethical considerations and the primary legal role afforded to physicians in end-of-life decision-making, it is relevant to note that the selection of physicians as interview participants may be considered a methodological quirk of this research. Legal consciousness research has traditionally overlooked the examination of more powerful groups in favour of marginalised subjects[1160] given that ordinariness has often coincided with the idea of "relative powerlessness."[1161] In contrast, physicians might be described as members of an elite group[1162] that has power[1163] and social status[1164] in society as well in relation to other healthcare professionals, patients and families.[1165] However, following Hertogh, limiting legal consciousness scholarship to marginalised groups leaves many dimensions of the relationship between law and society unattended.[1166] Along these lines, there has been a push to move legal consciousness scholarship to incorporate all kinds of social actors.[1167] This research therefore takes up this mantle by joining other legal consciousness scholarship that is interested in investigating physicians.[1168] Nevertheless, future research may do well to consider alternative voices including the more marginalised groups of people with dementia, their family, and even nurses.

[1160] Picton-Howell (n 135) 288.

[1161] McCann, 'Expanding the Horizons of Horizontal Inquiry into Rights Consciousness: An Engagement with David Engel' (2012) 19 Indiana Journal of Global Legal Studies 467, 474.

[1162] Howard S Becker, 'How I Learned What a Crock Was' in Rosanna Hertz and Jonathan Imber (eds), *Studying Elites Using Qualitative Methods* (SAGE 1995); Picton-Howell (n 135) 98.

[1163] Katherine E Smith, 'Problematising Power Relations in "Elite" Interviews' (2006) 37 Geoforum 643, 646.

[1164] Neil Stephens, 'Collecting Data from Elites and Ultra Elites: Telephone and Face-to-Face Interviews with Macroeconomists' (2007) 7 Qualitative Research 203, 205.

[1165] Picton-Howell (n 135) 99.

[1166] Hertogh, *Nobody's Law* (n 182) 72.

[1167] McCann (n 1161) 474.

[1168] Halliday, Kitzinger and Kitzinger (n 136); Greenbrook (n 137).

Challenges nevertheless emerged in terms of researching physicians as a group with elite membership. I am not alone in this challenge as is highlighted by the following quote:

> "It is clear that the 'doing of research' is not simply a matter of getting out there, armed with a questionnaire, asking some questions and interpreting answers. Rather, the process is bound up with analytical notions of the field, its constitution and attendant methodological challenges. This process becomes complicated when the research is conducted up to an elite set of actors where power differentials can affect access and cooperation."[1169]

Awareness of power differentials between the physicians as elite actors and myself, as well as the consequences this had for the research process, was therefore important.[1170] Particular difficulties include securing access and attempts by research participants "to seek control the agenda."[1171] The literature has also identified the probability of "gate-keeping questions" given the relationship between the elite status and expertise and status.[1172] This resonates with the experience in this research. For example, there were difficulties in gaining access to possible research participants. This manifested in the form of nonresponses to requests to distribute expression of interests forms as well as the establishment of extra requirements to gain access to participants. In addition, on one occasion the appropriateness of the parameters of the research were challenged during an interview. I experienced this event as related to some extent to the fact that I was not a medical professional myself.

However, whilst a relatively powerful group, research has pointed to the fact that the discourse around elites replicates a simplistic dichotomy between the power of elites and the powerlessness of others.[1173] For example, whilst potentially relatively powerful in the workplace and society more broadly, physicians do not necessarily occupy an uncomplicated position of power in relation to the law. Along these lines, the use of the term elite should not

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[1169] Margaret Desmond, 'Methodological Challenges Posed in Studying an Elite in the Field' (2004) 36 Area 262, 268.

[1170] ibid 265.

[1171] Zoë Slote Morris, 'The Truth about Interviewing Elites' (2009) 29 Politics 209, 209.

[1172] Stephens (n 1164) 206.

[1173] Smith (n 1163) 645.

exclude the possibility of vulnerability during the interview process.[1174] This was evident for instance in the way that knowledge and authority over law was recognised as distinct from the knowledge and authority they have over the practice of medicine. Furthermore, whilst questions of dying are part of these physicians' everyday professional lives, the fact that they were being asked to reflect on this has the potential to create unease. Similarly, many participants expressed an understanding that the law was sometimes a challenge for the nature of dementia care. Whilst the possibility for unease might be anticipated, it was not evident in these interviews. Additionally, it remains important to acknowledge that the interview process including the analysis and interpretation of transcripts places the ultimate authority in the hands of the researcher.

Insider/Outsider Dichotomy

Reflecting on my position as a researcher of elites brings to light the further challenge of the insider/outsider dichotomy. This concept refers to the extent to which the researcher is or is not a member of the group to which the research participants belong.[1175] It is clear that based on this dichotomy, I belong to the outsider group. However, it has been suggested that this dichotomy is too simplistic and does not always capture the experience of researchers.[1176] From this perspective, it might be more appropriate to speak of occupying "a third space, a space between, a space of paradox, ambiguity, and ambivalence, as well as conjunction and disjunction."[1177] In occupying this third space, I experienced the consequences of being both an insider and outsider.[1178] In the realm of outsider, I experienced the challenge of speaking across the gap between physicians and lawyers. This created difficulties in finding common language, ensuring that we were speaking about the same thing, and promoting

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[1174] ibid 646.

[1175] Susan Gair, 'Feeling Their Stories: Contemplating Empathy, Insider/Outsider Positionings, and Enriching Qualitative Research' (2012) 22 Qualitative Health Research 134, 137.

[1176] Lauren J Breen, 'The Researcher "in the Middle": Negotiating the Insider/Outsider Dichotomy' (2007) 19 The Australian Community Psychologist 163, 165.

[1177] Sonya Corbin Dwyer and Jennifer L Buckle, 'The Space Between: On Being an Insider-Outsider in Qualitative Research' (2009) 8 International Journal of Qualitative Methods 54, 60.

[1178] ibid 61.

trust. Stephens argues that where the interviewer and the interview participants understand their differences and similarities, the interview process is enhanced.[1179] Overtime, the understanding that there were differences between myself and the participants was specifically inserted into the interview script. In particular, I acknowledged the differences between us as lawyers and doctor. I also made clear the intention and meaning behind the terminology. This recognition was often met with good humour as both parties realised our differing positionalities.

Nonetheless, despite efforts to grapple with my outsider positionality, I have never been truly external to this research and its subject. In this way, Dwyer and Buckle speak of how the ongoing role of the researcher in the research process demands that "we cannot retreat to a distant 'researcher' role." [1180] Indeed, I have embedded myself in this topic as a researcher.[1181] For one, in working with the stories contained within the transcripts, I both impact and am impacted by the analysis.[1182] Further, I can relate to what is being said due to extensive research. Additionally, I have a personal perspective on these issues due to personal relationships with people who make end-of-life decisions. Moreover, as Dwyer and Buckle's reflect; "as a human being faced with mortality, can one ever truly be an outsider when researching death, dying, loss, and grieving?"[1183]

Digital/In-Person Interview Considerations

An additional challenge is that related to the distinction between in person and digital interviews. Face-to-face interviews have long been recognised as the "gold standard."[1184] However, technology has undergone significant

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[1179] Stephens (n 1164) 207.

[1180] Dwyer and Buckle (n 1177) 61.

[1181] ibid.

[1182] ibid.

[1183] ibid.

[1184] Judith LM McCoyd and Toba Schwaber Kerson, 'Conducting Intensive Interviews Using Email: A Serendipitous Comparative Opportunity' (2006) 5 Qualitative Social Work 389, 400.

development in the midst of the Covid-19 pandemic.[1185] Given the idea that technological advances shape research and that researchers should grapple with how technology "fits in the lives of potential respondents,"[1186] digital interviews through the medium of Zoom became a reality in this research. Technological failure or difficulty did not prove a problem in my interviews which perhaps mirrors the findings of Archibald et al. that groups within the health-care sector who have experience with similar technology may experience fewer difficulties.[1187] Further, in spite of conflicting literature regarding the impact of a digital environment on relationship building,[1188] no problems were immediately obvious in this research. Furthermore, whilst digital security is understandably a concern, security issues with the use of Zoom was not experienced in reported studies[1189] or in this study. This may be related to the fact that Zoom has useful security features such as selective invitation mechanisms and the ability to control the supply of information relating to access.[1190] In this study for instance, a passcode was established for each interview. Additionally, as identified in the literature, a digital medium was useful for enhancing access and flexibility in the interview, particularly in the case of geographic distance.[1191] Moreover, whilst concerns may be raised in regards to the potentially sensitive nature of this research, digital approaches have been identified as useful where there are sensitive or personal topics at play as in the way that it allows people to access to interview from a place of choice that does not disrupt schedules and allows the easy possibility to end an interview whenever they want.[1192]

[1185] Sara Thunberg and Linda Arnell, 'Pioneering the Use of Technologies in Qualitative Research – A Research Review of the Use of Digital Interviews' (2022) 25 International Journal of Social Research Methodology 757, 765.

[1186] Judith E Sturges and Kathleen J Hanrahan, 'Comparing Telephone and Face-to-Face Qualitative Interviewing: A Research Note' (2004) 4 Qualitative Research 107, 116.

[1187] Mandy Archibald and others, 'Using Zoom Videoconferencing for Qualitative Data Collection: Perceptions and Experiences of Researchers and Participants' (2019) 18 International Journal of Qualitative Methods 1, 5.

[1188] ibid.

[1189] ibid 6.

[1190] ibid.

[1191] Lisa M Gray and others, 'Expanding Qualitative Research Interviewing Strategies: Zoom Video Communications' (2020) 25 The Qualitative Report 1292, 1297; Thunberg and Arnell (n 1185) 761.

[1192] Gray and others (n 1191) 1297.

A further consideration is digital interviews without video. This was the case in one of the interviews where the participant did not/could not turn on their camera. Drawing on research regarding telephone interviews, the most pressing concern is related to the complete absence of visual cues. As highlighted by Sturges and Hanrahan, the severity of this concern is attached to the degree to which visual cues are important to the quality of the data, and moreover, whether a telephone interview has any features that compensate for any negative effect.[1193] It is concluded that in this context, the most important consideration is whether moments of discomfort can be appropriately identified in the absence of visual cues. Special attention was therefore paid to moments of hesitation or audible consent. Ultimately, while there are mixed findings on the impact of the telephone medium on interview data,[1194] this research is on the side of those which conclude that there are no marked differences in the depth and quality of responses through telephone interview data collection.[1195] This is confirmed by this study where a comparison of transcripts showed no difference in the quality of the data collected between digital and face to face interviews.

[1193] Sturges and Hanrahan (n 1186) 114.

[1194] ibid 111.

[1195] ibid 112.

Appendix 2

Draft of the semi-structured interview schedules:

Jag skulle börja med dina reflektioner om hur beslutsfattande vid livets slutskede för patienter med demenssjukdom i praktiken utövas.

1. Hur fattar du dessa beslut?
2. Kan du berätta om samspelet mellan vårdgivare-patient-närstående i beslutsfattande?
3. Hur beaktas patienten med demenssjukdom i beslutfattandet? T.ex. tidigare önskemål, hur de är/uttrycker sig i sitt nuvarande tillstånd, samråd med närstående?
4. Hur bedömer du om patienten har beslutskapacitet?
5. Finns det utmaningar att sätta in palliativa behandlingar till denna patientgrupp med tänker på demenspatienters svårigheter att samtycka till vård och aktivt delta i beslut?
6. Har du erfarenhet av patienter med demenssjukdom, alternativt närstående, som frågat om dödshjälp som du skulle vara villig att dela med dig om?

Jag skulle nu vilja diskutera de faktorer som reglerar dessa beslut

1. Vad tycker du reglerar ditt beslutsfattande? T.ex. finns där specifika etiska principer, lagar, institutionella normer
2. Vilken roll anser du att lagar, förordningar och rättigheter har för beslutsfattande?
3. Tycker du att juridik är viktig för beslutsfattande vid livets slutskede för patienter med demens?

Tack för din medverkan. Innan vi slutar, är det någonting annat som du skulle vilja dela med dig om?

Request for participation:

Vill du delta i ett forskningsprojekt om beslutande vid livets slutskede?

Projektet inkluderar en fallstudie om läkares perspektiv på beslutande vid livets slutskede för patienter med demenssjukdom

Projektet vid Lunds universitet intresserar sig i juridikens roll vid beslutande vid livets slutskede. Stort fokus ligger på läkares dagliga (kliniska) praxis av beslutsfattande vid livets slutskede för patienter med demenssjukdom samt rollen av juridiken i dessa praxis.

I projektet kommer forskare att bedriva **intervjuer** med läkare som har minst 2 års erfarenhet med arbete som involverar beslutfattande vid livets slutskede för patienter med demenssjukdom. **Vi kommer att ställa frågor bl.a. om hur beslutande vid livets slutskede för patienter med demenssjukdom utförs i praxis samt uppfattningen av faktorerna som reglerar dessa praxis.**

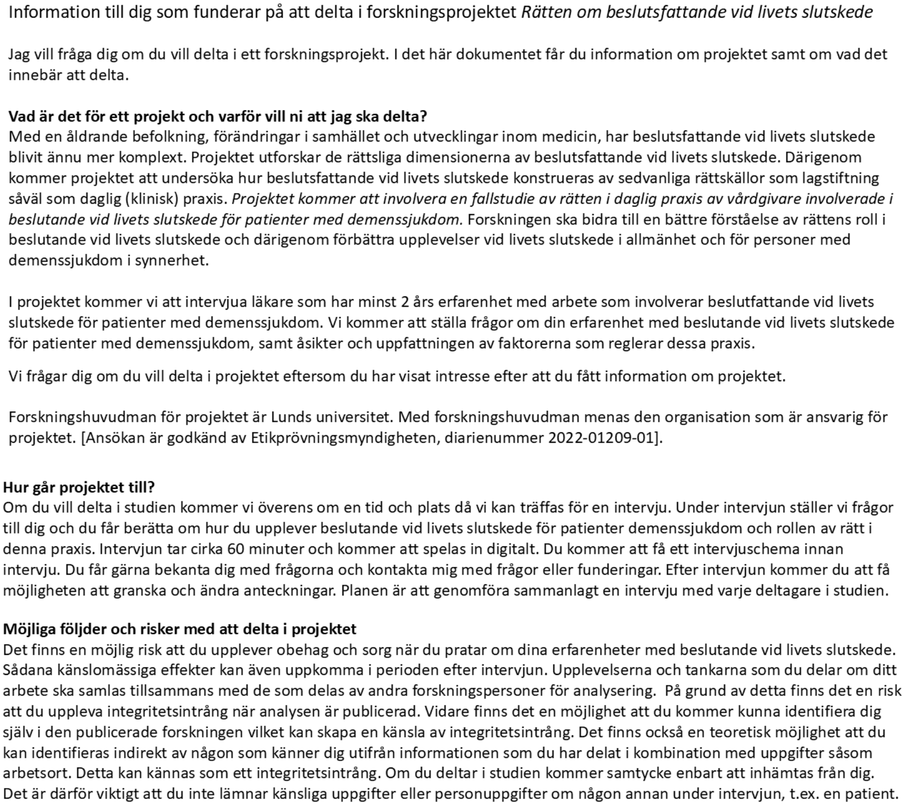
Intervjun tar cirka 45-60 minuter.

Stämmer du in på beskrivningen ovan och vill du veta mer om hur man deltar?

I sådana fall får du gärna kontakta:
Manni Ardzejewska (doktorand i social rätt och medicinsk rätt)
Telefonnummer: +46 707672508
E-post: manni.ardzejewska@jur.lu.se
Adress: Box 207, 221 00 Lund

Att delta i studien är **frivilligt** och personer som väljer att delta kan **när som helst välja att avbryta deltagandet**. Om du väljer att inte delta eller vill avbryta ditt deltagande behöver du inte uppge varför.

Participant information:



Information till dig som funderar på att delta i forskningsprojektet *Rätten om beslutsfattande vid livets slutskede*

Jag vill fråga dig om du vill delta i ett forskningsprojekt. I det här dokumentet får du information om projektet samt om vad det innebär att delta.

Vad är det för ett projekt och varför vill ni att jag ska delta?
Med en åldrande befolkning, förändringar i samhället och utvecklingar inom medicin, har beslutsfattande vid livets slutskede blivit ännu mer komplext. Projektet utforskar de rättsliga dimensionerna av beslutsfattande vid livets slutskede. Därigenom kommer projektet att undersöka hur beslutsfattande vid livets slutskede konstrueras av sedvanliga rättskällor som lagstiftning såväl som daglig (klinisk) praxis. *Projektet kommer att involvera en fallstudie av rätten i daglig praxis av vårdgivare involverade i beslutande vid livets slutskede för patienter med demenssjukdom.* Forskningen ska bidra till en bättre förståelse av rättens roll i beslutande vid livets slutskede och därigenom förbättra upplevelser vid livets slutskede i allmänhet och för personer med demenssjukdom i synnerhet.

I projektet kommer vi att intervjua läkare som har minst 2 års erfarenhet med arbete som involverar beslutfattande vid livets slutskede för patienter med demenssjukdom. Vi kommer att ställa frågor om din erfarenhet med beslutande vid livets slutskede för patienter med demenssjukdom, samt åsikter och uppfattningen av faktorerna som reglerar dessa praxis.

Vi frågar dig om du vill delta i projektet eftersom du har visat intresse efter att du fått information om projektet.

Forskningshuvudman för projektet är Lunds universitet. Med forskningshuvudman menas den organisation som är ansvarig för projektet. [Ansökan är godkänd av Etikprövningsmyndigheten, diarienummer 2022-01209-01].

Hur går projektet till?
Om du vill delta i studien kommer vi överens om en tid och plats då vi kan träffas för en intervju. Under intervjun ställer vi frågor till dig och du får berätta om hur du upplever beslutande vid livets slutskede för patienter demenssjukdom och rollen av rätt i denna praxis. Intervjun tar cirka 60 minuter och kommer att spelas in digitalt. Du kommer att få ett intervjuschema innan intervju. Du får gärna bekanta dig med frågorna och kontakta mig med frågor eller funderingar. Efter intervjun kommer du att få möjligheten att granska och ändra anteckningar. Planen är att genomföra sammanlagt en intervju med varje deltagare i studien.

Möjliga följder och risker med att delta i projektet
Det finns en möjlig risk att du upplever obehag och sorg när du pratar om dina erfarenheter med beslutande vid livets slutskede. Sådana känslomässiga effekter kan även uppkomma i perioden efter intervjun. Upplevelserna och tankarna som du delar om ditt arbete ska samlas tillsammans med de som delas av andra forskningspersoner för analysering. På grund av detta finns det en risk att du uppleva integritetsintrång när analysen är publicerad. Vidare finns det en möjlighet att du kommer kunna identifiera dig själv i den publicerade forskningen vilket kan skapa en känsla av integritetsintrång. Det finns också en teoretisk möjlighet att du kan identifieras indirekt av någon som känner dig utifrån informationen som du har delat i kombination med uppgifter såsom arbetsort. Detta kan kännas som ett integritetsintrång. Om du deltar i studien kommer samtycke enbart att inhämtas från dig. Det är därför viktigt att du inte lämnar känsliga uppgifter eller personuppgifter om någon annan under intervjun, t.ex. en patient.

Vad händer med mina uppgifter?
Projektet kommer att samla in och registrera information om dig. Den information som kommer att samlas in ut gör personuppgifter (namn, specialisering, arbetsgivare), ljudinspelningen från intervjun och avskrifter av intervjun. Behandlingen av dinapersonuppgifter är nödvändigt för attutföra forskning som är av allmänt intresse (GDPR, Art 6, p.1e).

Intervjuerna kommer att spelas in på en inspelningsenhet som inte är anslutna till internet. Därefter transkriberas intervjuerna på plattformen LUSEC, en plattform som är i enlighet med GDPR. Avskriften ska förvaras och hanteras på LUSEC. I samband med transkribering kommer det att ske en så kallad pseudonymisering. Det innebär att din identitet enbart kommer att kunna identifieras med hjälp av ett separat dokument när man läser det transkriberade materialet. Efter att ljudinspelningen har transkriberats ska inspelningen förstöras.

Personuppgifter och blankett med ditt samtycke kommer att förvaras i ett låst skåp i Lunds universitetslokaler.

Studiens resultat kommer att ingå i en avhandling och eventuellt publiceras i en vetenskaplig publikation. Den som läser publiceringen kommer inte att kunna se vad en enskild person har svarat. Inga personuppgifter eller känsliga uppgifter om dig kommer att publiceras.

Dina svar och dina resultat kommer att behandlas så att obehöriga inte kan ta del av dem.
Ansvarig för dina personuppgifter är Lunds universitet. Informationen från de som deltar i studien lagras i minst 10 år. Efter 10 år görs en bedömning om informationen ska gallras i enlighet med riktlinjer från Lunds universitet.

Enligt EU:s dataskyddsförordning har du rätt att kostnadsfritt få ta del av de uppgifter om dig som hanteras i projektet, och vid behov få eventuella fel rättade. Du kan också begära att uppgifter om dig raderas samt att behandlingen av dina personuppgifter begränsas. Rätten till radering och till begränsning av behandling av personuppgifter gäller dock inte när uppgifterna är nödvändiga för den aktuella forskningen.

Om du vill ta del av uppgifterna ska du kontakta:
Titti Mattsson, titti.mattsson@jur.lu.se, +46 46 222 10 24.
Dataskyddsombud nås på dataskyddsombud@lu.se.

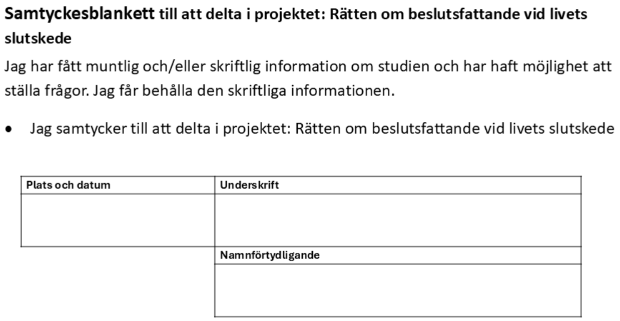
Om du är missnöjd med hur dina personuppgifter behandlas har du rätt att ge in klagomål till Integritetsskyddsmyndigheten, som är tillsynsmyndighet.

Hur får jag information om resultatet av projektet?
Om du i framtiden är intresserad av dina individuella data eller studiens resultat är du välkommen att kontakta någon av nedanstående personer. Du bestämmer själv om du vill ta del av resultaten.

Deltagandet är frivilligt
Ditt deltagande är frivilligt och du har rätt att avbryta deltagandet när som helst. Om du väljer att inte delta eller vill avbryta ditt deltagande behöver du inte uppge varför. Om du vill avbryta ditt deltagande ska du kontakta de ansvariga för projektet (se nedan).

Ansvariga för projektet
Ansvarig för projektet är
Titti Mattsson (professor i offentlig rätt och huvudansvarig för projektet) +46 46 222 10 24, titti.mattsson@jur.lu.se, Box 207, 221 00 Lund.
Ulrika Andersson (professor i straffrätt) +46 46 222 11 14, Ulrika.Andersson@jur.lu.se, Box 207, 221 00 Lund.
Manni Ardzejewska (doktorand i social rätt och medicinsk rätt) +46 707672508 manni.ardzejewska@jur.lu.se, Box 207, 221 00 Lund.

Consent form:



Samtyckesblankett till att delta i projektet: Rätten om beslutsfattande vid livets slutskede

Jag har fått muntlig och/eller skriftlig information om studien och har haft möjlighet att ställa frågor. Jag får behålla den skriftliga informationen.

- Jag samtycker till att delta i projektet: Rätten om beslutsfattande vid livets slutskede

Plats och datum	**Underskrift**
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Interviews

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Interview with Participant C

Interview with Participant D

Interview with Participant F

Interview with Participant G

Interview with Participant H

Interview with Participant I

Interview with Participant K

Dying, Dementia & Law

Death and dying exist at the core of what it is to be human. Despite this, in a world that prioritises individualism, law has co-signed the medicalisation of death and the struggle against dying at all costs. Meanwhile, 'choice' has emerged in society and law as the way in which to secure the so-called 'good death.' This eclipses important discussions about the role of institutional and interpersonal relationships in improving our experience of death and dying. This has significant implications for the ability of law to launch a successful response to the public health issue of dying with dementia where resolutions to support relational personhood and physical wellbeing are desperately required.

Whilst increasing effort has been crucially directed towards what is needed to live well with dementia, far less recognition has been extended to what is necessary in relation to the inevitable reality of dying with dementia. This thesis intervenes in this space by examining what role law has in shaping and responding to death and dying with dementia in Sweden. In doing so, it joins transformative efforts in legal scholarship to map and reimagine the relationship between law and the end of life. In embracing embodied and embedded vulnerability, collective responsibility to physical and relational needs in death and dying with dementia is advanced in law. This contributes to the broader effort to provide the necessary conditions for dying well with dementia.

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