Respect for Patient Self-Determination: Ambiguities, Barriers, and Possibilities

Lindberg, Jenny

2025

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

Link to publication

Citation for published version (APA):
Lindberg, J. (2025). *Respect for Patient Self-Determination: Ambiguities, Barriers, and Possibilities*. [Doctoral Thesis (compilation), Department of Clinical Sciences, Lund]. Lund University, Faculty of Medicine.

Respect for Patient Self-Determination

Ambiguities, Barriers, and Possibilities

JENNY LINDBERG
DEPARTMENT OF CLINICAL SCIENCES, LUND | FACULTY OF MEDICINE | LUND UNIVERSITY

Printed by Media-Tryck, Lund 2025 NORDIC SWAN ECOLABEL 3041 0903

LUND UNIVERSITY

FACULTY OF MEDICINE

Department of Clinical Sciences, Lund

Lund University, Faculty of Medicine
Doctoral Dissertation Series 2025:123
ISBN 978-91-8021-776-7
ISSN 1652-8220

9 789180 217767

Respect for Patient Self-Determination: Ambiguities, Barriers and Possibilities

Respect for Patient Self-Determination

Ambiguities, Barriers, and Possibilities

Jenny Lindberg

LUND
UNIVERSITY

DOCTORAL DISSERTATION

Doctoral dissertation for the degree of Doctor of Philosophy (PhD) at the Faculty of Medicine at Lund University to be publicly defended on 13th of November 2025 at 10.00 in Belfrage Hall, Department of Clinical Sciences, Lund, Klinikgatan 32, Lund.

Faculty opponent
Tove Godskesen

Organization: LUND UNIVERSITY

Document name: Doctoral thesis **Date of issue 13th November 2025**

Author(s): Jenny Lindberg **Sponsoring organization: Newman Institute**

Title and subtitle: Respect for Patient Self-Determination: Ambiguities, Barriers, and Possibilities

Abstract:

The principle of patient self-determination is central to contemporary medical ethics. However, many uncertainties remain regarding its implementation in healthcare. This thesis explores, from an ethical perspective, situations in nephrology care that reveal barriers to patient self-determination or where the requirements of the principle are unclear. The thesis includes three published articles and one manuscript. Paper I examines the ethics of delaying (temporizing) communication with patients about decisions that need to be made. Temporizing may result in patients losing decision-making capacity before the decision is presented to them, or circumstances may change to such an extent that the decision is essentially no longer the same. This calls for caution, as it risks violating patient self-determination. Paper II analyzes the ethics of healthcare professionals withholding information from patients regarding healthcare priorities or similar considerations - relevant to which treatments are offered or recommended. Suggesting that an egalitarian moral perspective should be adopted calls for transparency with patients regarding e.g. healthcare prioritization. This perspective shifts the burden of proof from determining what information should be included to determining what information could be excluded without compromising moral values. Paper III explores the experiences and views of Swedish nephrologists on informing and preparing patients for future decisions regarding treatment options for kidney failure. Several conflicting goals in this process are identified, as well as important barriers to, and strategies for, achieving a common understanding of the situation and the available options. The nephrologists expressed a tension between enabling patients to make their own decisions and make decisions that align with what they, as nephrologists, identify as the best for the patient. They also reported adjusting the timing and framing of the information based on their perception of the patient's needs. Paper IV explores the ethical challenges of respecting a competent patient's wish to not receive information when approaching the end of life. Ethical, practical, and epistemic challenges are identified through the lens of a hypothetical clinical scenario. In summary, this thesis highlights the challenges of respecting patient self-determination, related to temporizing, withholding information (either at the healthcare professional's initiative or at the patient's request), and framing. Failing to address these issues could result in patients' self-determination not being adequately honored.

Key words: Self-determination, nephrology care

Language **English** **Number of pages**: 97

ISSN: 1652-8220

ISBN: 978-91-8021-776-7

Signature Date 2025-09-30

Respect for Patient Self-Determination

Ambiguities, Barriers, and Possibilities

Jenny Lindberg

LUND
UNIVERSITY

Department of Clinical Sciences, Lund
Faculty of Medicine
Lund University
Lund 2025

ISSN 1652-8220
ISBN 978-91-8021-776-7 (print)
Lund University, Faculty of Medicine Doctoral Dissertation Series 2025:123

Printed in Sweden by Media-Tryck, Lund University, Lund, 2025

Printed matter
3041 0903

Media-Tryck is a Nordic Swan Ecolabel
certified provider of printed material.
Read more about our environmental
work at www.mediatryck.lu.se

MADE IN SWEDEN

To my family

“What does have intrinsic value is not having choices but being recognized as the kind of creature who is capable of making choices. That capacity grounds our idea of what it is to be a person and a moral agent equally worthy of respect by all” (Dworkin, G., 1988, p. 80).

“One of the realities of illness is the gap in information that separates the patient and the physician. Certainly one of the physician’s obligations is to close that gap, to enhance the patient’s capability to act and make truly human decisions. Therefore, the patient needs to understand the nature of the illness and the alternatives being offered - to understand them well enough to be able to make an authentic personal decision” (Pellegrino, E.D., 2006, p. 68).

Nu Jenny Lindberg stod på scenen, och det presenteras
hur patientens självbestämmande ska respekteras.
Och alla här i salen denna stunden nu begriper:
Vi alla måste följa vissa etiska principer,
som rättvisa och "göra gott" sa Jenny i sin svada,
samt folks autonomi och att undvika skada.
Och patient som ej begriper, slipper förebråelse,
men dock är viktigt att dom får substantiell förståelse,
och har man det som patient, så hörde alla vi,
då har man rätt att faktiskt ha en viss autonomi.
Och säg, hur ska man formulera det som kan va skrämmande,
och därmed ge en möjlighet till vettigt självbestämmande?
Jag kanske där kan hjälpa till, så det blir tjo och tjim
och formulera all information som ges - på rim…
Och givetvis det skiljer mellan varje individ,
beslutsförmåga även varierar över tid.
Och vilken info bör man ge, och säg på vilket sätt?
Man vill dom ska bestämma själv, men helst bestämma rätt.
Och givetvis kan kompromissen också va' besvärlig
emellan att man vill va' snäll och även vara ärlig.
Och hur kan man hantera dom problemen, rent konkreta,
när patienten säger tydligt: "Jag vill inte veta!"
För kanske det för stunden ökar nåns livskvalitet
att inte veta det som doktorn vet dom inte vet…
Ja, det är inte lätt att formulera den repliken
som utmanar etiken på kliniken i praktiken.

Jacke Sjödin Njurmedicinskt vårmöte, Uppsala 2025

Table of Contents

1 Preface

My background in clinical nephrology has inspired this project. In a previous PhD project, which I completed in 2010 at Karolinska Institutet, I studied the effects of chronic kidney disease and dialysis on the immune system. The project was primarily laboratory-based, yet clinically focused. In 2014, I received a scholarship from the Newman Institute to begin a new PhD project in medical ethics, which I decided should focus on the ethical aspects of caring for patients with chronic kidney disease. I have always been interested in medical ethics and in reflecting on the ethical aspects of everyday clinical situations, such as encounters between patients and healthcare professionals, and medical decision-making. In healthcare, there are many ethical dilemmas and value conflicts, partly due to discrepancies between patients' goals of care and life preferences, and healthcare professionals' goals of care. These goals are often not sufficiently communicated.

Ethics is fundamental to healthcare, and caring for chronically ill patients often comes with complex and profound ethical challenges. Healthcare professionals are expected to provide care and to improve patients’ health-related quality of life. Time constraints, stress, and too much focus on medical aspects may cause them to overlook important ethical issues. In my experience, nephrology patients are not always involved in decisions regarding their own treatment. In fact, some dialysis patients appear regrettably unaware that they have the right to discontinue medical treatment, as well as of the potential consequences of different courses of action. Decisions whether to initiate dialysis, and which form of dialysis to choose, are not always adequately communicated to patients, let alone reached together with them.

In my clinical work, I have observed that healthcare professionals may hesitate to burden patients with information that they consider to be unwarranted or potentially distressing. This could lead to framing, or withholding, of information to steer patient decision-making. Patients may in turn be reluctant to receive information or engage in advance care planning. Consequently, they may not have the information they need to make decisions about their care. Healthcare professionals often recognize their obligation to share information with patients so they can make informed decisions. However, they may have difficulty fulfilling this obligation due to the complexity of the clinical reality or their lack of awareness regarding what patient self-determination requires in specific situations. They may also be disinclined to adapt their information-sharing efforts to overcome existing barriers.

These experiences sparked my interest in studying value conflicts in nephrology care, eventually leading me to focus on patient self-determination. This concept largely encompasses patients’ right to make decisions and exert some influence over their care. This thesis identifies areas of ambiguity regarding the principle of patient self-determination and areas where patients may face barriers to participating in decisions about their care. This identification is a crucial first step in understanding how to adhere to the principle of patient self-determination in clinical practice.

2 List of Papers

Paper I

Lindberg, J., Johansson, M. & Broström, L. Temporising and Respect for Patient Self-Determination, *Journal of Medical Ethics* 2019;45(3),161–167. https://doi.org/10.1136/medethics-2018-104851

Paper II

Lindberg, J., Broström, L. & Johansson, M. An Egalitarian Perspective on Information Sharing: The Example of Health Care Priorities. *Health Care Analysis* 2024;32, 126–140. https://doi.org/10.1007/s10728-023-00475-7

Paper III

Lindberg, J., Johansson, M. & Broström, L. In Search of Common Ground - Nephrologists' Experiences in Preparing and Informing Patients on the Path to End-stage Kidney Disease. *BMC Nephrology* 2025;26, 106. https://doi.org/10.1186/s12882-025-04023-4

Paper IV

Lindberg, J. Navigating Patients' Refusal of Information in Clinical Practice - A Clinical Scenario. *Manuscript (unsubmitted).*

3 Introduction

Curative treatment is rarely an option for diseases affecting the kidneys. Much of nephrology care therefore aims to slow down the progression of chronic kidney disease, prolonging life, and eventually replacing kidney function with dialysis or a kidney transplant, unless conservative kidney management is considered more appropriate (Davison et al., 2024; KDIGO, 2024).

As in many other areas of healthcare, conflicts between different values or interests can arise in nephrology, of which some have been extensively studied. Some of these conflicts could make it difficult to decide whether to start, withhold, continue or withdraw dialysis, taking into account both patients' survival expectancy and expected quality of life (Ashby et al., 2005; Brown et al., 2017; Eiser, 1996; Elliott et al., 2014; Ladin, Pandya, et al., 2018; Martin et al., 2020). These decisions are of particular importance in a patient population characterized by increasing frailty, cognitive impairment, and multiple comorbidities (Davison & Holley, 2008; Del Vecchio & Locatelli, 2012; Kennard et al., 2023; Schmidt & Moss, 2014; Swidler, 2013). For many patients, supportive or palliative care must also be considered (Axelsson et al., 2012; Davison, 2012; Davison et al., 2015; Davison et al., 2024).

One potential conflict is the one between respecting patient self-determination and healthcare professionals' desire to benefit their patients. Another such conflict is the one between respecting patients' privacy - here largely understood as their right to being protected from undue physical and psychological interference - and requiring patients to adhere to treatment plans that can imply restrictions on their life. Nonadherence has been identified as prevalent among nephrology patients (Chan et al., 2014; Ghimire et al., 2015). Previous research has extensively focused on the value conflicts of organ donation and kidney transplantation (Ehtuish, 2024; Lewis & Gardiner, 2023; Reese et al., 2015). There are several other examples of significant value conflicts in nephrology care as well. Needless to say, in order to properly address these ethical issues, one must first be aware of them and know how to navigate conflicting interests. Otherwise, healthcare might do wrong to or even harm their patients. Additionally, healthcare professionals may experience moral distress, which has been shown to be common among nephrologists (Ducharlet et al., 2020; Gronlund et al., 2011; Saeed et al., 2021).

Several topics relevant to ethics in nephrology remain understudied. This thesis focuses on potential challenges to respecting patient self-determination in the context of routine nephrology care, within publicly funded healthcare systems comparable to Sweden's. A selection of situations is examined to particularly address concerns about postponing decisions, withholding information, either at the patient's own request or for other reasons, and how information to patients is framed. Identifying the challenges of reaching common epistemic ground with patients regarding their situation, options, and care goals, can serve to find strategies to improve patients' understanding of, and decision-making regarding, their care.

Unless otherwise specified, the patients discussed in this thesis are assumed to be adults with sufficient decision-making capacity in relation to the decision at hand. While issues related to the nature of decision-making competence or capacity are undoubtedly important in their own right[1], they are of limited relevance to this thesis. Another key delimitation is that the thesis does not address ethical issues specific to organ donation, transplantation, or clinical research. It should also be noted that when the issues are described from a normative perspective, it is the moral dimension and not the legal normativity that is referred to. References to law are provided where it is necessary to understand the context, but the thesis focuses on ethical issues. Full accounts of the legal regulation surrounding patient rights (which, of course, also differs from one country to another) are therefore not provided. The decisions discussed in the thesis, if not otherwise specified, concern the patient's own situation (i.e., they are not decisions regarding a whole patient population, or about national guidelines, etc.), which does not rule out that it has an impact on others as well. Despite this specific scope, the analyses may be relevant to sufficiently similar settings.

The following sections will describe the thesis's aims, methodology, and major findings in more detail. First, however, a background will be provided to situate the reader in the ethical and clinical context of the thesis.

---

[1] Key questions concern when a person counts as unable to make a decision, who then should make the decision, and on what basis this should be done (Buchanan & Brock, 1990).

4 Background

To understand the challenges explored in this thesis, some contextual information is needed. This section will therefore outline the key ethical considerations with relevance for the thesis, with particular emphasis on the principle of patient self-determination. Ways in which this principle is implemented in practice will be explained. In connection with this, a brief introduction will be given to paternalism, as paternalism may undermine respect for patient self-determination. Additionally, a brief overview will be provided of topics related to some other relevant ethical principles in healthcare, concerning such things as quality of life and welfare, as well as priority considerations, to demonstrate the values that healthcare should strive to uphold. Thereafter, the reader will be introduced to the clinical setting of nephrology care, and then to advance care planning and palliative care, both in general and specifically in nephrology.

4.1 Key ethical considerations

Today, Western medical ethics largely leans on moral principles derived from common morality and applicable to healthcare, where clinical decision-making and patient care occur. According to the influential work by Tom L. Beauchamp and James F. Childress, respect for autonomy, beneficence, nonmaleficence, and justice form the four key *prima facie* principles, or clusters of principles, of medical ethics (Beauchamp & Childress, 2019). Although these principles have been contested, they contribute to positioning the issues discussed in thesis. The principles in question are briefly outlined below, and some will be further elaborated and illustrated in subsequent sections as needed.

> **Respect for autonomy:** The obligation to protect and acknowledge patients' right to make informed, voluntary decisions about their own care. Healthcare professionals should support and respect these decisions, even if they differ from what the clinicians would recommend.
>
> **Beneficence:** Healthcare professionals have a duty to actively promote patients' well-being. This includes providing them with medically effective care and rehabilitation, or otherwise improving their health-related quality of life.
>
> **Nonmaleficence:** The duty to avoid causing harm to the patient, whether by action or omission. It includes minimizing risks and complications associated with medical interventions.

> **Justice:** Healthcare resources should be distributed fairly and equitably, without discrimination. Similar cases should be treated similarly, and resources should be spent according to an estimation of patients' need and benefit of the interventions that imply the spending of resources.

These four principles are highly relevant in nephrology, where decisions about life-sustaining treatments, such as kidney replacement therapy, and issues of resource allocation are common. Following Beauchamp and Childress, they are to be proportioned in medical decision-making to ensure fair, patient-centered care and a balance between treatment benefits and potential harm (Beauchamp & Childress, 2019, pp. 20-22). However, when conflicts occur, or there is a tension between the principles, it is not always easy to know which of the principles should be prioritized - something that, among others, Raanan Gillon has pointed out. Gillon suggests that the principles must be combined with an attention to scope, concretizing in which way the principles are to be understood in specific situations, for healthcare professionals to adhere to a common moral commitment and use the same language to reflect on ethical issues (Gillon, 1994). Guidance on how to adequately adhere to the principles, realize their underlying moral values and specify them into guiding rules for specific settings is needed (Beauchamp & Childress, 2019, pp. 17-19), and nephrology care is no exception (Ducharlet et al., 2020; Martin et al., 2020).

This project mainly focuses on one of the four principles mentioned above, namely that of patient autonomy, or self-determination. Historically, patient self-determination was not given the role it plays today. In the past, physicians and other healthcare professionals mostly acknowledged patients' vulnerability and accepted the power asymmetry between themselves and their patients. Recently, this position has been defended again, partly in response to the perceived exaggerated focus on patient autonomy (Carlberg, 2009, pp. 82-93; O'Neill, 2002; Pellegrino, 2006). Traditionally, accepting, or even enforcing, the asymmetry between patients and healthcare professionals has been part of what is denominated medical paternalism (hereafter: paternalism). For the purposes of this thesis, paternalism is broadly defined as attitudes or actions of healthcare professionals that aim to benefit patients while disregarding their personal values, preferences, and priorities. This definition aligns with how paternalism has been understood in the literature (Beauchamp et al., 2019, pp. 231-232; Buchanan, 1978, p. 372; Dworkin, 1972, p. 65). In contrast with some of these accounts, it is important to note that a paternalistic act, as it is understood here, need not contradict a patient's values, preferences, or priorities. Rather, those are simply not considered when making the decision, in line with the distinction made by Daniel Groll (Groll, 2012). The patient may, for example, not have a clear opinion about the matter at hand, or there may be an accidental (not intentional) alignment between the patient's wishes and the healthcare professional's decision. Another core component of a paternalistic approach, of importance for this thesis, is that paternalists generally consider their judgment to be more qualified than that of the person being paternalized, as noted by Seana V. Shiffrin (Shiffrin, 2000). The arguments for and against paternalism have been extensively accounted for by Jessica Begon (Begon, 2016).

Patient self-determination is emphasized as an ideal in modern healthcare, as evident from the request for informed consent, shared decision-making, and patient- or person-centered care - concepts that will be further explained in the subsequent sections. While recognizing that there are several ways to conceptualize self-determination, this project starts from the fairly non-committal understanding that patients with sufficient decision-making capacity have the right to make informed decisions about their healthcare. This is widely accepted by law and social practice, as described by Allen E. Buchanan and Dan W. Brock (Buchanan & Brock, 1990, p. 21).

The emphasis of patient self-determination in modern healthcare raises the question of why it is deemed important for patients to make their own decisions about their care. The answer is open to discussion. Self-determination can be considered a fundamental right in healthcare, which obligates health care professionals to respect patients' decisions about their health, as described in the literature (Beauchamp & Childress, 2019, pp. 400-404; Darwall, 2006; Hill, 1991, pp. 31-32; Molyneux, 2009). However, there may be other reasons to respect patient self-determination. It could be argued that, in general, people themselves are best suited to make the kinds of decisions under discussion here. The idea is that most people act in their own best interest, an idea discussed among others by Buchanan and Brock, Jay Katz and Brian McKinstry (Buchanan & Brock, 1990, pp. 22, 29; Katz, 1994; McKinstry, 1992). Not respecting patient self-determination would potentially therefore deprive patients of the opportunity to pursue their own welfare, as also suggested by John Stuart Mill (Mill, 2011, ch. 3). However, according to Stephen Darwall, and further developed by David Molyneux, the reason to respect a person's autonomy is grounded not only in welfare considerations, but also in the idea that autonomy is a value in itself, the respect for which is a legitimate demand one can place on others (Darwall, 2006b; Molyneux, 2009).

The right to self-determination is only granted to those who possess sufficient decision-making capacity.[2] There has been a debate about what counts as sufficient decision-making capacity, and how it is to be assessed, which will not be further commented here (Bruine de Bruin et al., 2007; Delaney et al., 2015; Finucane & Gullion, 2010; Fischhoff, 2008; Palmer & Harmell, 2016; Worthy et al., 2014). In this thesis, the focus is on ethical issues that arise when the patients' decision-making capacity exceeds the relevant threshold, wherever that might be set. According to one influential account, self-determination rests on the absence of external control, and the presence of certain internal conditions such as intentionality and understanding (Beauchamp & Childress, 2019, pp. 102-103). According to Buchanan and Brock, autonomy or self-determination more specifically builds on the capacity for understanding, reasoning, deliberation, and communication, as well as possessing a set of personal values to pursue in decision-making (Buchanan & Brock, 1990, p. 23). It has also been suggested that self-determination requires that the person is able to picture the probable outcomes, given

---

[2] This is not to say that decisions made by patients lacking sufficient capacity should not be respected. Rather, they should be involved in the decision-making process to the extent possible. However, these aspects fall outside the scope of this project.

the options, and forming an opinion of their value (Tännsjö, 1998, pp. 140-141). More specifically, it requires understanding the relevant information, considering the risks and benefits, and making a decision based on one's priorities, values, and preferences. In other words, it means acting according to one's beliefs (Dretske, 1989) and in some sense being authentic, or true to oneself (Taylor, 1991, p. 15). Even when patients *de facto* make decisions that do not serve their own interest, the general view is that they should be granted that kind of self-governance, if there are reasons to believe that they have sufficient decision-making capacity, which is practically the case with adult patients without evidence of cognitive or severe psychiatric disorder.[3] This is true also regarding decisions that might be controversial, or even considered detrimental for the patient as judged from the outside, as suggested by Julian Savulescu (Savulescu, 2007).

As highlighted by for example Buchanan and Brock, patients' decision-making capacity is regarded relative to particular decisions (Buchanan & Brock, 1990, pp. 18-19). This means that the capacity may be sufficient for certain kinds of decisions, but not for others, such as complex ones requiring medical expertise and experience. Decision-making capacity may vary over time, both in general and in relation to a particular decision, exceeding the threshold at some points in time but not at others, as also discussed in the literature (Buchanan & Brock, 1990, pp. 19-20). Additionally, a potential difference has been suggested between having borderline decision-making capacity and having clear, obvious decision-making capacity (Buchanan & Brock, 1990, pp. 27-28). In other words, a patient can be more or less high above the relevant threshold. Again, in this project, the situations studied concern patients deemed capable of making the relevant decisions at hand, at least to a threshold level. They are considered to have substantial autonomy as described by Ruth Faden and Tom L. Beauchamp (Faden & Beauchamp, 1986, p. 240)

The judgment whether a patient is sufficiently autonomous is, among other things, relevant for the distinction between hard and soft paternalism, as described by Beauchamp and Childress (Beauchamp & Childress, 2019, p. 233). Hard paternalism in healthcare involves interfering with voluntary, informed decisions with the intention of benefiting the patient. In contrast, soft paternalism interferes with a person's decision when that decision is not fully voluntary or informed. For instance, healthcare professionals might use soft paternalism and decide for patients in the case patients act out of ignorance or impaired judgment (Beauchamp & Childress, 2019, p. 233). In such cases, the intervention may be justified to protect individuals from harm that they would have avoided had they been fully aware or competent.[4]

---

[3] In Swedish healthcare, obviously self-destructive actions might need to be prevented by compulsory care if they originate from a severe psychiatric disorder and the patient refuses voluntary care (Socialdepartementet, 1991).

[4] Critics argue that the line between hard and soft paternalism can be difficult to draw in practice, as assessing voluntariness and informed consent is often complex and controversial, and some suggest that the distinction may not always be morally significant or intuitively satisfying (Hanna, 2018).

Patients need not justify, or explain, their decisions to the healthcare professional. Respect for self-determination is furthermore not conditioned on there being an agreement between patients and healthcare professionals. Additionally, given that human decision-making is influenced by both rational deliberation and emotional responses or intuitions (Evans, 2008; Finucane et al., 2003; Kahneman, 2011) it is hardly realistic to require fully rational decisions in every healthcare situation. What is generally required is substantial understanding, which according to Faden and Beauchamp implies understanding *that* one is authorizing (something) and *what* one is authorizing (Faden & Beauchamp, 1986, pp. 300-304).

In Sweden, as in other comparable healthcare systems, patients do not have the right to freely choose a treatment. In these systems, where patients only pay a small portion of the total cost of their care[5], self-determination is ultimately limited to deciding whether to consent to, or decline, suggested treatment or care as described in the literature on informed consent in healthcare (Faden & Beauchamp, 1986, Rynning, 1994). Informed consent has legal, ethical and administrative underpinnings (Hall et al., 2012). One important aspect is that patients' explicit acceptance of healthcare interventions shares legal accountability for these interventions between patients and healthcare professionals (Faden & Beauchamp, 1986, pp. 26-30). Obtaining informed consent can also serve to make cooperation with the patient possible, setting common goals and making a patient adhere to a treatment plan (Eyal, 2025).

The core idea underlying the requirement of informed consent is that care is usually voluntary and that patients have the right to refuse treatment (Rynning, 1994, p. 233). According to international literature and Swedish legislation, informed consent must be both voluntary and competent to be legally valid (Cocanour, 2017; Eyal, 2025; Faden & Beauchamp, 1986, pp. 274-275; Litins'ka, 2022, pp. 121, 127-128; Rynning, 1994, pp. 233, 282). When above the minimum threshold for decision-making competence, it is widely accepted that patients' decisions are generally to be respected regarding consent or dissent to treatment (Buchanan & Brock, 1990, p. 21; Faden & Beauchamp, 1986, pp. 240-241). Additionally, the absence of external control is considered an essential condition for valid informed consent (Faden & Beauchamp, 1986, pp. 256, 262).

Before choosing whether to receive treatment, the patient must be adequately informed about the relevant details concerning the decision at hand. The question arises as to what constitutes relevant information. Disclosure standards vary among codes and contexts. These standards include the *professional practice standard*, the *reasonable person standard* and the *subjective standard* (Beauchamp & Childress, 2019, pp. 124-125; Faden & Beauchamp, 1986, pp. 30-34). Elisabeth Rynning reports four standards of disclosure: the *subjective professional standard*, the *objective professional standard*, the *objective patient standard* and the *subjective patient standard* (Rynning, 1994, pp. 198-201). However, these standards by themselves do not explain what kind of information

---

[5] The focus here is on the fee. In fact, most Swedish patients may over the course of their lifetime fund their own care though taxes.

that should be disclosed. Codes of medical ethics and the Swedish Patient Act require the disclosure of basic information about for instance diagnosis, prognosis, treatment alternatives and their risks and benefits (Cocanour, 2017; Katz, 1994; Paterick et al., 2008; Socialdepartementet, 2014). Ideally, the information should be adapted to each individual patient (Rynning, 1994, pp. 200-201). The information arguably has objective and subjective components. When choosing whether to receive dialysis, it is important for the patient to know not only about dialysis in general, but also what life on dialysis is expected to be like for the patient personally.

The endeavors to respect patient self-determination nowadays go beyond mere consent or dissent to treatment. The narrow focus of not harming patients, and of protecting patients' privacy by preventing unwarranted interference has been widened to encompass patient-centered care. Patient-centered care is tailored to each patient and emphasizes communication between patients and healthcare professionals, as well as partnership in care, care coordination, patient empowerment, and a biopsychosocial approach as has been described in the literature (Grover et al., 2021; Langberg et al., 2019). It encompasses several key aspects, including viewing the patient as a person, sharing power and responsibility, and maintaining a therapeutic alliance (Mead & Bower, 2000). It shares connotations with the more demanding ideal of person-centered care (Coulter & Oldham, 2016; Ekman et al., 2011; El-Alti et al., 2019). In a sense, patient-centered care promotes patient self-determination, but it may also lead to compromises between what healthcare professionals judge beneficial for the patient and what the patient desires.

Part of, or an instrument to, patient-centered care is shared decision-making (Hall et al., 2012; Paterick et al., 2008; Spatz et al., 2016). Shared decision-making is a widely accepted ideal in modern healthcare, and it relates to patient self-determination. However, there is variability in how it is understood and practiced, ranging from narrow to broad conceptions, as has been highlighted by Alan Cribb and Vikki A. Entwistle (Cribb & Entwistle, 2011; Entwistle et al., 2012). Though shared decision-making has been defined in various ways, the underlying idea is that decisions regarding care should ideally be made jointly by healthcare professionals and patients, as suggested by various authors (Elwyn et al., 2012; Montori et al., 2023; Sandman & Munthe, 2009, 2010). In this joint decision-making process, as described, healthcare professionals contribute with medical knowledge that patients lack, and patients contribute with information about personal values and priorities that healthcare professionals lack (Montori et al., 2023). After receiving the necessary medical information, patients should ideally be given the time and opportunity to participate in a shared, rational, deliberative, joint decision-making process as suggested by Lars Sandman and Christian Munthe (Sandman & Munthe, 2009, 2010).

As Coos Engelsma has pointed out, there is a difference to be made between the process of shared decision-making and the intended product of it, that is, a shared decision (Engelsma, 2024). Not all shared decision-making processes would, according to this view, result in a shared decision (Engelsma, 2024). Although shared decision-making is intended to increase patient autonomy in healthcare decisions, it can also represent a compromise between paternalistic and patient-driven approaches to decision-making, as has been described in the literature (Kon, 2010; Sandman & Munthe, 2009, 2010). Shared decision-making involves negotiation and balancing different values as judged by healthcare professionals and patients (Sandman, 2009). In that sense, it supports patient self-determination, but it may also encourage patients to align with the goals of healthcare professionals and adhere to the established healthcare framework, for instance through adhering to specific treatment plans, which has been discussed by Sandman (Sandman et al., 2012). Therefore, it does not necessarily promote patient self-determination. Additionally, shared decision-making as part of patient-centered care can come into conflict with other values, such as for instance treatment quality, patient safety, avoiding harm to others and equality considerations, as pointed out by Sven O. Hansson and Barbro Fröding (Hansson & Fröding, 2021).

There is a push to promote shared decision-making both in healthcare in general (Barry, 2012; Barry & Edgman-Levitan, 2012; Stiggelbout et al., 2015) and in specific areas of healthcare (Austin et al., 2015; Birchley, 2014; Ernst et al., 2013; Kim et al., 2001; Rocque et al., 2018). This includes nephrology (Andersen-Hollekim et al., 2021; Finderup et al., 2021; Finderup et al., 2020; Frazier et al., 2022; Gordon et al., 2013; Moss, 2001; Yu et al., 2022). However, there are still barriers to its implementation. These include adapting to different cultural and ethnic expectations regarding healthcare, handling prognostic difficulties and other uncertainties, addressing health illiteracy, and clarifying the role of healthcare professionals in decision-making (Cassidy et al., 2018; Hawley & Morris, 2017; Katz, 1994, p. 81; Kim et al., 2001; Orsino et al., 2003; Verberne et al., 2019).

Another important concept, or phenomenon, relevant to this project is patient health literacy which has been identified as an important public health goal, to promote health and well-being (Santana et al., 2021). Health literacy is a multifaceted concept that has been defined by different patient characteristics, such as knowledge about health and the healthcare organization, the ability to process health-related information, and the capacity to maintain health, participate in decision-making, and carry out healthcare interventions aimed at improving health (Liu et al., 2020). It can be understood as an important part both of informed consent, shared decision-making, and patient-centered care since the incapacity to understand and orientate oneself in the language and organization of healthcare is a significant barrier to participating in healthcare decisions (Liu et al., 2020). Limited health literacy is prevalent and has been identified as a barrier to patient involvement in nephrology care (Ladin, Buttafarro, et al., 2018; Muscat et al., 2018). Health literacy is considered important for patients' ability to make decisions about their healthcare. However, it can also be understood as a patient's ability to adhere to health interventions presented by healthcare providers (Santana et al., 2021). This focus on health and well-being could serve to downplay the importance of patients' preferences if patients prioritize other values.

As previously mentioned, self-determination is not the only important aspect of healthcare. Challenges may arise when trying to fulfill different goals. The primary mission of healthcare is to promote health-related quality of life and welfare in the population (Tengland, 2006). However, this only concerns one aspect of quality of life. There is no consensus on what quality of life entails in a broader sense. According to one reasonable account, quality of life consists of several categories containing elements of well-being, pleasure, and the fulfillment of one's life plans and wishes. In line with this comprehensive view, quality of life encompasses both subjective and objective components (Brülde, 2003; Brülde, 1998) and can be understood as overall subjective life satisfaction (Hurka, 2011, p. 20). This is consistent with a person having a high quality of life while not experiencing pleasure. For instance, someone may endure hardship to achieve an important life goal as explained by various authors (Brülde, 2003, pp. 41, 45; Sumner, 1996, p. 87). It also means that even though information can cause emotional distress, it may be important for quality of life in the sense of enabling prudential living, fulfilling one's preferences, etc. as has been suggested in the literature (Sumner, 1996, pp. 43, 65, 139, 143). At the same time, it opens for the possibility that, in important respects, patients can better define their own quality of life than anyone else can, especially those who do not know them well. Attempting to benefit patients without knowing their personal values, preferences and priorities is unlikely to succeed.

Ensuring good and equitable healthcare for the entire population is closely related to the necessity of establishing priorities, since healthcare in Sweden, like in many other countries, is publicly funded. In Sweden, such priorities should adhere to ethical principles established by the Swedish Parliament (Regeringen, 1996), principles that have since been further specified and operationalized (Broqvist et al., 2011). The overarching ethical principles focus on human dignity, needs and solidarity, and cost-effectiveness (Broqvist et al., 2011). In addition to referencing these ethical principles, the Swedish Parliament stated that priority setting should be transparent to society and patients. It has further been suggested that the public should have the opportunity to influence decisions regarding priorities (Broqvist et al., 2011, pp. 11-12). The National Center for Priority Setting in Health Care is committed to interpreting and presenting these principles, as well as addressing the challenges of their interpretation and implementation. While the principle of cost-effectiveness is described as subordinate to the other principles, the recommendation is to balance the severity of the condition with patient benefit and cost-effectiveness (Broqvist et al., 2011). These guidelines aim to direct the distribution of resources in both regional and local healthcare.

As mentioned above, citizens should be informed about healthcare priorities. However, this is not always done (Broqvist & Garpenby, 2014). In a healthcare setting, this lack of transparency can be viewed as not showing sufficient respect for patients, and in that sense be ethically problematic. And there are other reasons for being transparent. Honestly declaring resource limitations and priority considerations could potentially improve trust in healthcare. It could lead to acceptance of rationing, though it could also cause distress, which must be addressed, as described in the literature (Broqvist & Garpenby, 2014; Owen-Smith et al., 2010a, 2010b). In addition to priority considerations, other frameworks may impact the care offered to patients. For instance, standardized care processes and adherence to scientific evidence and proven experience are critical, as outlined in regional and local guidelines. While patients may not be fully aware of these factors, knowing about them would help patients grasp the basis for considerations regarding treatment options that are offered to them.

As previously mentioned, medical paternalism is when healthcare professionals promote patients' well-being while disregarding their values, preferences, and priorities. This can be done through coercion or deception. However, acting paternalistically does not always entail directly and openly overriding the patient's preferences. It may also consist of withholding information to which the patient is entitled (Buchanan, 1978). Whether it is ethically acceptable to withhold information from patients to reduce their choices and assist them in decision-making has been debated (Cox & Fritz, 2016; Levy, 2014; Palmboom et al., 2007; Rees, 2023). From this perspective, withholding certain information could be considered safeguarding the patient's best interests, though it disregards the patient's preferences regarding the information to be shared.

Using, for example, specific wording of information to influence patient decision-making is referred to as framing. Framing is prevalent in healthcare (Menichetti et al., 2024) and could have an impact on patient decision-making, at least under some conditions (Gong et al., 2013). Nudging, also known as libertarian paternalism, is a more recent, but nonetheless highly debated, conceptualization of paternalism first suggested by Richard H. Thaler and Cass R. Sunstein (Sunstein, 2016; Thaler & Sunstein, 2008; Thaler, 2003). Nudging aims to help people make decisions that align with their deeper preferences or what is in their best interest - what they "should want", or what benefits society or a group of persons. It is achieved by modifying how options are presented, supposedly without restricting them, as described by the defenders of nudging (Leonard, 2008; Levy, 2017, 2018; Sunstein, 2016; Thaler & Sunstein, 2008). Others see nudging as problematic, among other things since it stands for a kind of manipulation which conflicts with self-determination (Hausman & Welch, 2010; Keeling, 2018; Schmidt & Engelen, 2020; Simkulet, 2018, 2019). It has also been argued that it is more problematic to influence decision-making through nonrational means, rather than rational explanations, as occurs in nudging (Ploug, 2018). Examples of nudging in healthcare have been taken to include measures intended to help patients choose treatments, adhere to prescriptions and recommendations, and adopt a healthy lifestyle (Aggarwal et al., 2014; Blumenthal-Barby & Ubel, 2018; Blumenthal-Barby et al., 2013; Methven & Caskey, 2014; Schiavone et al., 2014; Wheeler et al., 2011). In healthcare, decision aids and other forms of support for patient decision-making could be seen as a way to nudge patients toward the "best" choice for them (Blumenthal-Barby et al., 2013) but the extent of the "nudging effect" would obviously depend on how they are designed.

A special situation emerges when patients themselves want to opt out of their right to self-determination, expressing a wish not to receive information about their disease, prognosis, treatment options, etc., and leaving treatment decisions entirely to healthcare professionals. Whether patients have the right not to know has been debated (Berkman et al., 2015; Harris & Keywood, 2001; Laurie, 2014). This question has been extensively discussed in the context of genetic screening, where patients may only want to receive some or none of the information about the risk of future diseases (Andorno, 2004; Takala, 2001) as well as in other areas of healthcare (Andorno, 2016; Björk, 2025; Bortolotti & Widdows, 2011; Youngs & Simmonds, 2016). Those who argue that there is such a right not to know have done so out of respect for patient privacy (Laurie, 2014), or because of the potential harm that information could cause the recipient (Wilson, 2005). Additionally, some have emphasized that potential negative consequences for patients or others should be considered before honoring a patient's wish to remain uninformed, as these consequences could supersede the respect healthcare professionals owe to a patient’s desire for privacy (Bullock, 2015; Davies, 2020). Furthermore, some argue that the right not to know cannot be justified from an autonomy perspective, since while the patient’s current autonomous wish is respected, her future autonomy will be restricted by not knowing. This has been named the incoherence objection (Harris & Keywood, 2001; Malpas, 2005). Thus, there is a wide range of different positions, attitudes and recommendations regarding the right not to know.

After this introduction to key ethical principles, and especially to patient self-determination, what it generally requires, and different ways to ensure it in healthcare, as well as commenting on different forms of paternalism, including withholding information, framing and nudging, we will turn to the clinical context of nephrology care that is the focus of this thesis.

4.2 Clinical setting - nephrology care

Most patients with progressive chronic kidney disease will ultimately have to consider kidney replacement therapy, such as dialysis and transplantation. Transplantation is, however, not available for all patients, often because of a high comorbidity and increased frailty (Abramowicz et al., 2015). This reduces the available options to life-long dialysis treatment or conservative kidney management which means optimal medical treatment without dialysis (Chanouzas et al., 2012; Davison et al., 2024).

Dialysis is a life-supportive therapy which replaces some of the kidney functions, but not all. It filtrates uremic toxins from the blood and removes excess fluid but can only compensate for the loss of kidney function to a limited degree. There are mainly two dialysis treatment options: hemodialysis and peritoneal dialysis (Chan et al., 2019). In hemodialysis, the blood passes through a filter in a dialysis machine. In peritoneal dialysis, the peritoneum acts as a filter, and the abdomen is filled with two liters of dialysis fluid. Most patients receive hemodialysis at a hospital three times a week for four to five hours per session, while peritoneal dialysis is a home-based treatment that involves changing the dialysis fluid in the abdomen several times a day. For some patients, peritoneal dialysis can be administered through a machine, often during the night. Some patients manage their hemodialysis at home. The differences in outcomes and complications between the two treatment modalities are uncertain (Ethier et al., 2024). The survival with conservative kidney management is statistically shorter than with dialysis (Da Silva-Gane et al., 2012), but might still be a good alternative for frail patients with severe comorbidity (Brown et al., 2017; Ladin, Pandya, et al., 2018; Smith et al., 2003) since it should be related to patient quality of life and the benefit (or harm) with living longer (Foote et al., 2016).

Individualized treatment is the ideal in current nephrology care, aligning with the preferences and goals of the patient (Chan et al., 2019; Tong et al., 2017). However, there is discrepancy between patient and healthcare expectation concerning their prognosis (Beckwith et al., 2023). There might also be divergence in how healthcare professionals and patients view the goals and expected effects of the treatment, where healthcare professionals often give priority to dialysis efficacy and survival while patients may give priority to other values (Morton, Devitt, et al., 2010; Morton, Tong, et al., 2010; Ramer et al., 2018; Schmidt & Moss, 2014; Tweed & Ceaser, 2005; Visser et al., 2009). Patients may prioritize freedom and autonomy, as well as treatment that has the least impact on their lifestyle, allowing them to be more independent. However, they may also want to stay alive and get symptom relief (Morton, Devitt, et al., 2010; Ramer et al., 2018). All these divergent goals of care and discrepancies in expectations may make it difficult to attain a common ground between healthcare professionals and patients when it comes to the perspectives of the disease, prognosis and expected outcomes of different care interventions.

Over the last few decades, the patient population with kidney failure has grown and now includes a large proportion of elderly patients. This population experiences progressive loss of physical and psychological function, as well as low life expectancy, high hospitalization rates, and low self-reported quality of life (Axelsson et al., 2018; Chambers et al., 2018; Chesnaye et al., 2023; Hall et al., 2020; Kennard et al., 2023; Montez-Rath et al., 2017; Schrauben et al., 2020; Tonelli et al., 2015). They also need several medications (Letts et al., 2024). Patients with chronic kidney disease display a successive increase in comorbidities and symptoms as the disease proceeds (Davison et al., 2015; Davison et al., 2024; MacRae et al., 2021; Mehrotra et al., 2023; Tonelli et al., 2015). The most common comorbidities include diabetes, hypertension and cardiovascular disease (Fraser et al., 2015). Symptoms are multiple and patients present for instance variably with fatigue, pain, depression, itching, muscle cramps, and sleep disorders (Mehrotra et al., 2023).

Conservative kidney management can be chosen by the patient or suggested by the healthcare professionals when dialysis is not expected to provide any significant benefit to the patient (Davison et al., 2024; Martin et al., 2020). However, it has been shown that nephrologists may be reluctant to offer conservative kidney management to patients (Hamroun et al., 2022). In some situations, there is a need for transition from one dialysis modality to another (Lanot et al., 2022), and these transitions have been associated with worse health-related quality of life (Dumaine et al., 2023). Accordingly, there are several things to consider for healthcare professionals and patients in deciding which treatment will be best on the trajectory towards kidney failure and while on dialysis.

Given these different perspectives, the question arises as to how the principle of patient self-determination plays out specifically in nephrology care, while sharing common practices with the rest of healthcare. It is generally considered to be advantageous for patients to be prepared in due time for dialysis treatment and presented with different treatment options at an early stage (KDIGO, 2024). On the trajectory leading to kidney failure and the decision regarding starting long-term dialysis, patients need information, mental preparation and the possibility to communicate their own preferences and wishes. For this to be obtainable it is crucial to provide patients with information that they can understand. Research indicates that patients with chronic kidney disease, who face the decision whether to start dialysis treatment, receive less information than ideally expected about the reasons for choosing one therapy over another, and this makes them not completely prepared for the decision (Morton, Tong, et al., 2010; Song et al., 2013). This could be due to time and resource constraints as well as lack of capacity to detect and compensate for educational barriers in the patient (Cassidy et al., 2018).

4.3 Palliative care and advance care planning

One central part of the relevant information is that dialysis will not reduce all the symptoms that patients experience. Some symptoms will rather increase with the time on dialysis, affecting the patients' quality of life (Amro et al., 2014; Culp et al., 2016; Hall et al., 2020; Mehrotra et al., 2023). These symptoms are not always adequately alleviated (Axelsson et al., 2018; Culp et al., 2016). Dialysis itself can be a burdensome treatment (Brown et al., 2017). In an elderly population with severe comorbidity and frailty, dialysis might cause several complications and repeated hospital admissions (Chesnaye et al., 2023; Hall et al., 2020). Although dialysis is effective in clearing the blood of uremic toxins, it can be considered futile in these situations (Martin et al., 2020). Then, the most reasonable option would be either not to start dialysis or, when the patient is on dialysis, withdraw it and intensify palliative care (Arellano-Mendez & Ladin, 2024). This decision is often made at a point when the patient is too affected by the disease to fully participate in decision-making. Therefore, advance care planning is recommended at an earlier stage.

Advance care planning for patients with chronic diseases such as chronic kidney disease is considered crucial for aligning treatment with patient preferences (Amro et al., 2016; Luckett et al., 2014; O'Halloran et al., 2018, Adenwalla et al., 2024; Bristowe et al., 2015; Rietjens et al., 2017). The idea of preparing patients in advance for potential situations and decisions by exploring their current values, preferences and priorities is highly relevant. One of the reasons for recommending advance care planning is the variability and potential decline of patients' cognitive functions over time. Advance care planning allows patients to decide what should be done when they lack the necessary decision-making capacity, which is a risk as the disease proceeds (Bobot & Burtey, 2024; Burn & Bates, 1998; Dixit et al., 2013; Drew et al., 2019; Murray et al., 2006; Thimmaiah et al., 2012).

It is widely acknowledged that palliative or supportive care needs to be integrated in nephrology care during the whole disease trajectory according to the needs of the patient (Davison et al., 2015; Grubbs et al., 2014; Lanini et al., 2022; Leiva-Santos et al., 2012; Levy et al., 2004; Lu & Blinderman, 2019; Moss, 2017). The decision to initiate palliative care early can be a way to ensure patient values during the whole trajectory, in parallel with dialysis or conservative kidney management. Palliative care is then successively intensified as the end of life is approaching and the patient's need for symptom relief increases. In the situation described above when dialysis is considered futile, a decision should be made whether to withhold or withdraw it. There is also a need to identify patients approaching the end of life to enable end-of-life conversations and planning together with the patients (Chesnaye 2023; Lazenby 2017). However, healthcare professionals can experience difficulties in initiating conversations about withholding or withdrawal of dialysis and about intensifying a palliative approach to care (Axelsson et al., 2019, 2020; Ducharlet et al., 2021). Patients also sometimes hesitate to bring up the question, either thinking it is inappropriate or fearing that they will be misunderstood as not appreciating the care or wanting to end their life (Axelsson et al., 2012).

Several factors have been shown to influence the implementation and effectiveness of advance care planning (Brighton & Bristowe, 2016; Brinkman-Stoppelenburg et al., 2014). Barriers to advance care planning include differing views on survival and expected quality of life, and reluctance from patients, families, or healthcare professionals to initiate discussions about end-of-life care (Brighton & Bristowe, 2016; Chewning et al., 2012; Phillips et al., 2018). When roles are ambiguous, it might not be clear to nephrologists that it is their responsibility to initiate advance care planning (O'Hare et al., 2016). In elderly patients with chronic kidney disease, the ability to engage in advance care planning might be reduced because of several different factors such as health illiteracy, reduced cognitive functions and increased frailty (Ladin, Buttafarro, et al., 2018; Ladin et al., 2021). Patients and their families might have different perspectives on advance care planning, which also can complicate the process.

Effective advance care planning requires training and preparation of healthcare professionals (Goff et al., 2019; O'Halloran et al., 2018). It is also more successful when it is culturally appropriate and tailored to the needs of individual patients (Goff et al., 2015; Holley, 2012). Clear communication between patients, families, and healthcare professionals is necessary, and tailored documentation processes can ensure that patients' wishes are respected (Holley, 2012; O'Halloran et al., 2018). The ideal seems to be to integrate advance care planning into routine clinical care and provide healthcare professionals with the necessary resources and support to conduct it (Luckett et al., 2014; Lupu et al., 2021). Several interventions have been suggested to increase and improve advance care planning in general (Houben et al., 2014) and in patients with chronic kidney disease in particular (Amro et al., 2016; Song et al., 2024; Song et al., 2025).

One way to identify patients' values, preferences, and priorities throughout the disease trajectory is to initiate serious illness conversations with them (Mandel et al., 2017). These conversations do not necessarily involve making specific decisions or speaking about end-of-life issues. Therefore, it may be easier to initiate these kinds of conversations than advance care planning conversations, which focus more on future decisions. Serious illness conversations can be initiated by several different healthcare professionals. Various tools have been used to determine when to initiate them, among others the *surprise question,* which is a question answered intuitively by the healthcare professionals regarding whether they would be surprised if the patient died within 6 or 12 months (Downar et al., 2017). The *surprise question* has been evaluated as a tool also in nephrology care (Forzley et al., 2018; Javier et al., 2017; Moss et al., 2008; Schmidt et al., 2019). Interprofessional communication is necessary, since different healthcare professionals may have different views about the patient's prognosis (Wallin et al., 2023) and it is important to identify patients in time with a need for serious illness conversation. It is also important to understand how patients experience their subjective quality of life, which the healthcare professionals might not always grasp (Wallin et al., 2024).

In summary, the complexities of the patient population and the clinical setting in which patients with chronic kidney disease are cared for present many challenges to ethical decision-making. Decisions such as whether to start dialysis, receive conservative kidney management, withdraw dialysis, and initiate supportive and palliative care carry high stakes. These decisions can lead to significant consequences both for patients, families, healthcare professionals, and potentially other patients or healthcare in general. Therefore, many factors must be considered to ensure patient quality of life, respect patient self-determination, and address other aspects that influence medical decision-making, such as healthcare priorities and guidelines. Proper deliberation before decisions are made requires information sharing between healthcare professionals and patients, and between different healthcare professionals. Taking all this into account, it is now time to in more detail present the aims of the project.

5 The overall aim of the thesis

This thesis aims to critically explore the implications and challenges of respecting the principle of patient self-determination in clinical practice, particularly in the context of routine nephrology care. Specifically, it focuses on what information should be provided to patients and when, as well as the challenges involved in sharing information with patients in a manner that upholds this principle.

5.1 Aims of the studies

Paper I

From the moment a physician or other healthcare professional concludes that a patient faces a certain decision, to the moment this is communicated to the patient, time may pass. This postponement may or may not be intentional on the part of the healthcare professional. In this project, however, temporizing refers to the deliberate postponement of presenting a decision to a patient who has sufficient decision-making capacity. This paper explores the ethical implications of temporizing in a nephrology care setting. It examines under what circumstances, if any, temporizing could be ethically acceptable, especially in the light of the principle of patient self-determination, when the patient has substantial decision-making capacity regarding the decision at hand.

Paper II

In healthcare, providing pertinent information to patients is a moral and legal obligation. Codes of medical ethics and the Swedish Patient Act require healthcare professionals to provide relevant information to patients, as described in the background. This information primarily concerns the potential benefits and risks of the offered treatment options. However, other kinds of information may at least in part explain why the patient is offered or recommended one treatment but not another. In publicly funded healthcare systems, this could involve information about underlying priority considerations. Here, healthcare priorities are defined as those that directly impact decision-making for an individual patient and do not apply to a more general or political level. Conventional perspectives do not consider this an obligatory part of information to share with patients. This study aims to analyze whether there are moral reasons for informing patients about healthcare priorities and similar considerations underlying what treatment options are offered or recommended to patients.

Paper III

Effective communication between healthcare professionals and patients is essential for planning future treatment strategies for those with progressive chronic kidney disease. In order to educate, prepare, and support patients in their decision-making process, information must be provided in an understandable way. The timing, content, and format of this information may influence patients and the decisions they make. It is important to understand nephrologists' perspectives on their role in sharing information with patients in order to evaluate patients' epistemic and moral positions in nephrology care. This study explores how Swedish nephrologists view the goals of information sharing, the associated challenges, and the strategies employed in treatment planning to promote mutual understanding of the patient's situation and available decision-making options.

Paper IV

Patients may express a wish not to be informed about their disease, prognosis, treatment, or related facts. Although healthcare professionals are expected to respect this wish, it is unclear to what extent this should be done. Based on a hypothetical yet realistic clinical scenario, this study aims to analyze the ethical challenges associated with honoring such requests, with a special focus on patients approaching the end of life, and the potential impact on patient self-determination.

6 Methods

A combination of theoretical and empirical methods was employed. In addition to methods borrowing from analytical philosophy, which are necessary for exploring normative issues, empirical research in the form of qualitative content analysis was used to examine the views of practicing nephrologists. Unlike in empirical research, analytical methods are usually not explicitly articulated in non-empirical medical ethics publications. Therefore, it should be noted that these methods are not described in Papers I, II, and IV. The rationale for the methods employed, whether empirical or theoretical, is outlined below. The limitations will be addressed in a subsequent section.

6.1 Theoretical methods

The theoretical methods employed in this thesis are primarily analysis of arguments and normative analysis. While these methods are used in combination, it is useful to distinguish their respective roles in this context. Essentially, analysis of arguments employs logic to break down reasoning - to understand concepts and identify possible ambiguities; to understand claims and assumptions; to assess their soundness; and evaluate overall argumentative strength. Normative analysis, on the other hand, deserves more attention. In this context, normative issues refer to questions about what ought to be done, what constitutes the right course of action, what is valuable, and related matters. The normative method used in this project combines the principle of self-determination as part of a theoretical framework, with moral reasoning and moral intuitions regarding the application of this principle in clinical situations. This method, which aims to justify, and reach coherence between, moral practices, ethical principles and ethical reasoning falls under what is commonly termed reflective equilibrium (Daniels, 1996; Rawls, 1971; Tersman, 2018). Although it has been critically debated, a debate accounted for by Carl Knight (Knight, 2025), reflective equilibrium is a widely accepted method of justification in medical ethics. Essentially, it is an iterative process of adjusting beliefs and principles to reach a stable, coherent ethical stance to guide decision-making in complex medical contexts (Schmidt, 2024). The coherence objective imposes normative demands on existing practices, requiring them to align with moral standards. It can also lead to the refinement of ethical principles so that they can be applied to real-world scenarios.

In this thesis, identifying situations where there seems to be some conflict between these different levels of reasoning - particularly between the principle of patient self-determination and how it plays out in clinical situations - can be seen as one first step in the process of reaching reflective equilibrium. Identifying situations where there is ambiguity regarding the implementation of the principle of patient self-determination, or where it is not fully respected, provides input for the subsequent process of harmonizing the theoretical level of reasoning with the practical implications of the principle. It is important to note that the project did not aim to “go the whole way” and achieve equilibrium. In fact, achieving such equilibrium in a project of this nature seems unrealistic. It would require an extensive program in this field, as both the principle of self-determination and its implementation in clinical practice can take many different forms. Nevertheless, the findings may contribute to the collective effort to achieve equilibrium between the principle of patient self-determination, and how it is understood and practiced in nephrology care. Further research is necessary to translate the findings into specific practical rules and strategies, which would be the ultimate goal of the research (Kuehlmeyer et al., 2024).

6.2 Qualitative content analysis from interviews

One empirical study has been conducted within this project. This qualitative study was based on data from semi-structured interviews with 14 practicing Swedish nephrologists, consecutively recruited after answering an invitation to participate via the mailing list of the Swedish Society of Nephrology member registry. No purposive sampling was employed, i.e., participants were not approached based on their particular background or characteristics. This kind of sampling is otherwise prevalent in qualitative phenomenological research (Gentles, 2015). However, after analyzing the contexts and experiences of the participants, it was assumed that they were fairly representative of the population that we aimed to study: Swedish nephrologists with experience of preparing patients on their trajectory towards kidney failure and the decision whether to start dialysis. The participants worked in various hospitals, both in cities and smaller towns. They all had experience providing information to patients approaching the need for dialysis, but they had different levels of experience, both in the medical profession and in nephrology.

Some interviews were conducted on site, while others were conducted digitally. The use of interviews is an established method in qualitative research, including digitally conducted interviews (Peters & Halcomb, 2015). The interviews were recorded, transcribed *verbatim*, and then pseudonymized. Once data saturation was reached, according to the definition of saturation in previous work in the field (Rahimi & Khatooni, 2024), the data were analyzed using qualitative content analysis with an inductive, phenomenological approach to explore the lived experience of the participants. This approach is one of the primary methods of qualitative research (Elo & Kyngas, 2008; Graneheim & Lundman, 2004; Korstjens & Moser, 2017). Meaning units were condensed and sampled as codes. Then, these codes were sorted into categories and abstracted to form overarching themes. This process followed the method of qualitative content analysis as it has been described by, among others, Ulla H. Graneheim and Berit Lundman (Graneheim & Lundman, 2004).

A qualitative content analysis was chosen for its potential to explore a complex phenomenon with fragmented background knowledge, such as the process of informing and preparing patients for a decision whether to receive dialysis. This method has been used to study similar phenomena (Elo & Kyngas, 2008; Graneheim et al., 2017; Kyngäs, 2020). This approach helps to identify, describe, and interpret both explicit and latent values and meanings within the data (Graneheim & Lundman, 2004). In this study, it was used to analyze responses, and associated reflections, to preformulated interview questions. (The interview guide is presented in the appendix). To grasp the experiences of the nephrologists we interviewed as they were expressed by themselves, a process of iterative abstraction and interpretation was conducted, as previously explained in the methodological literature on qualitative research (Assarroudi et al., 2018; Lindgren et al., 2020; Mayring, 2015). Since the transcriptions were written *verbatim* and the interviews were listened to several times, also the latent content could be analyzed, which has been previously recommended in using qualitative content analysis (Assarroudi et al., 2018; Graneheim et al., 2017; Lindgren et al., 2020). As explained above, the study primarily employed an inductive approach to analyze the data. This approach served to understand the challenges nephrologists face in their own words without oversimplifying their experiences or seeking to validate the researchers' preconceptions. The findings and process were reported transparently, as is widely recommended (Lindgren et al., 2020). Before publication, the COREQ (COnsolidated criteria for REporting Qualitative research) checklist was used to confirm that all steps in the process had been completed properly.

Unlike in quantitative research, qualitative research findings are not intended to be generalized or replicable in other contexts. However, like quantitative research, qualitative research aims to produce trustworthy, applicable, and consistent evidence (Frambach et al., 2013). Regardless of the approach used, the research should not be biased by the researcher's preconceptions. However, in qualitative research, there is a wider acceptance of the fact that researchers cannot be completely objective when interpreting results since they are part of the research process (Malterud, 2016). The conception and operationalization of quality criteria differ between the two methods. Quantitative research uses internal and external validity, reliability, and objectivity as quality criteria, while qualitative research uses credibility, transferability, dependability, and confirmability (Frambach et al., 2013).

To ensure credibility, careful data collection and analysis were performed, keeping the analysis close to the transcriptions. All members of the research group participated in interpreting the data. To ensure transferability, the context of the interviewed nephrologists was described in detail and the sampling strategy that was used was compared with those in previously published research in the field. To achieve dependability, data collection continued until data saturation was reached, meaning no new substantial data emerged from the interviews. Since the transcriptions were made consecutively during the process, iterative data collection occurred. Furthermore, the data were analyzed multiple times to identify latent meanings and ensure the correct extraction of categories and themes. The data were not intentionally adjusted to fit the researchers' preconceptions. To achieve confirmability, the analysis was based on the findings, and the results were discussed within the research group. Short notes were taken during the interviews to record the interviewers' initial impressions.

6.3 Combining theoretical and empirical methods

In applied medical ethics, as in this project, combining theoretical analysis with empirical data is valuable because it reveals how general ethical principles are interpreted in and applied to specific medical situations (Birnbacher, 1999; Davies et al., 2015; Huxtable & Ives, 2019; Kon, 2009; Mihailov et al., 2022). After completing the first theoretical part of the project, which led to Papers I and II, it became clear that more knowledge was needed about the understudied area at the heart of the project. The empirical data obtained in Paper III served as anchors to real-life situations. These data confirmed the assumptions about situations occurring in practice by providing real-world information about current opinions and practices among nephrologists. With the results from the empirical study in the back, the normative approach was again employed regarding how the ideal of patient self-determination plays out and should play out in practice. Integrating empirical and theoretical research, through its connection with real-life situations in nephrology care, provided important insights into areas where the ethical principle of patient self-determination may not be observed and the potential reasons for this lack of compliance. This information can be used to further improve ethical practices. Exploring the application of ethical principles using either method in isolation would be less fruitful. Therefore, descriptive and normative data were combined in a context-dependent manner. According to the literature on the subject, this context-dependent approach has the advantage of applying theory to ordinary, common clinical situations and vice versa (Musschenga, 2005).

It is important to note that the challenges identified in the project are not intended to be used as justification for adopting a particularist approach to normativity in clinical situations. Particularism is here broadly understood as defending the view that there are no general moral principles to guide action (Shiu-Hwa Tsu, 2025). Although ethical judgments are to a certain extent situation-based, what is assumed in the thesis is that there indeed are specific general principles to guide action, and that actions can be judged within a framework in which patient self-determination is a central principle, among other ethical principles. Therefore, identifying challenges and thresholds for applying this principle in clinical practice is not intended as a reason to downplay the importance of patient self-determination. Rather, it is a reason to search for strategies to overcome these challenges.

7 Contribution

This section specifies my contributions to each paper included in the thesis and demonstrates my developing independence in the research process.

For Paper I, my supervisors and I decided to focus on temporizing. I contributed by situating the topic within a clinical context and focusing on the care of patients with chronic kidney disease. I participated in the analysis and wrote the first draft. My main supervisor was the corresponding author when we submitted the paper to the scientific journal. I revised the paper with my supervisors and responded to comments from the editor and reviewers.

For Paper II, I came up with the idea to examine healthcare priorities as part of the information provided to patients. I was prompted to propose this topic because, according to my experience by then, information about priority considerations is seldom provided to patients even though they are obviously present in my work as a nephrologist when making decisions regarding dialysis care. I wrote the first draft with input from my supervisors, who actively participated in revisions before and after submitting the paper to a scientific journal. As the corresponding author, I was responsible for the entire publication process, including revisions and correspondence with the scientific journal, with help from my supervisors.

For Paper III, I decided together with my supervisors that I would conduct an empirical study including a qualitative content analysis of interviews with nephrologists. Together, we formulated interview questions focusing on areas where knowledge about current practices and experiences among nephrologists was lacking. With the help from my supervisors, I prepared the application for the ethics review. After receiving ethics approval, I wrote a recruitment letter containing the necessary information and sent it via the mailing list of the Swedish Society of Nephrology through my contact with the chairman of the Society. I recruited the participants and conducted all the recorded interviews. I transcribed the data manually, performed the initial condensation, coding and abstraction into categories, and proposed preliminary overarching themes. Together in the research group, we analyzed the data and successively modified some categories and themes as needed to better align with the data. I wrote the first draft of the paper and participated in subsequent revisions, both before and after submitting it to a scientific journal. As the corresponding author, I communicated with the editor and reviewers, also incorporating my supervisors' suggestions, until the paper was accepted. I previously presented selected results from the study at two international conferences: the European Society for the Philosophy of Medicine and Healthcare (ESPMH) conference in Frankfurt and the Uppsala Medical Ethics Conference (UMEC), both in 2024. These presentations focused on framing information in a healthcare context.

For Paper IV, I decided to write about patients who do not want to receive information from healthcare professionals when they are approaching the end of their lives. I presented my initial ideas on the subject at the ESPMH International Conference in Riga in 2023. Afterward, I began writing the manuscript and revised it several times based on feedback from my supervisors and colleagues in the Medical Ethics Unit. I received general feedback from seminars, as well as more specific feedback on the manuscript itself. I am the sole author of this paper.

8 Limitations

This work is subject to certain limitations. Importantly, in one sense the results are inconclusive. The results indicate challenges in clinical practice that may conflict with honoring patient self-determination, and they illustrate how such conflicts can arise. However, uncertainties remain regarding the extent to which practices such as temporizing, withholding information at the initiative of the healthcare professional or the patient, or framing information to influence decision-making, can be considered acceptable in the light of patient self-determination. While this may seem unsatisfactory, these uncertainties underscore the fact that the requirements of this principle in clinical practice are still unclear, a fact that is easily overlooked and therefore deserves attention.

One should further note that the findings may be context-sensitive and not directly transferable to other settings. There may be clinical contexts, both nationally and internationally, that differ in their conditions and practices, which have not been considered in this work. In an even broader sense, the relationship between patient self-determination and the information provided by healthcare professionals to patients has been the subject of extensive academic discussion and literature of which only a selection is provided in this thesis.

While practices such as temporizing, framing, and withholding information undoubtedly occur, their exact prevalence has not been studied specifically in this thesis. However, the absence of quantification does not significantly impact the applicability of the findings. The analysis is valid even without specifying how often temporizing occurs in nephrology care, since the analysis did not intend to answer the question of prevalence but rather to analyze it from an ethical perspective. The qualitative data from the empirical part of the project speaks to the prevalence of uncertainties and barriers to involving patients and honoring their self-determination, which supports the preconception that these are areas of concern that need to be further analyzed.

In qualitative content analysis, including the approach adopted in this project, the researcher's preconceived notions about the subject can influence the questions in the interview guide, and the subsequent interpretation and construction of categories and themes. In this thesis specifically, my personal experience as a nephrologist may have influenced my interpretation of categories and themes in Paper III. This is acknowledged to be inevitable to some extent in qualitative research, as explained in the methodology section above. Thus, theory influences the design of the study, the construction of interview questions, and the interpretation of data. However, an inductive approach was used to limit the extent to which preconceptions or other kinds of researcher bias could affect the analysis, and to remain open to the participants' own stories. During the interviews, care was taken to clarify that the interviewer was a researcher, not a fellow nephrologist. Participants were instructed to express themselves as if the interviewer had no knowledge of or experience in the clinical setting. When participants inadvertently did so anyway, I, as the interviewer, asked clarifying questions to delve deeper into the subject. To avoid steering the analysis toward findings based on my preconceptions as a clinician, my supervisors - who do not have the same clinical experience - contributed to the analysis of the findings and those were compared with previous research in the area.

The sampling strategy included participants who signed up for the study after receiving the initial email invitation. This may have introduced a bias toward recruiting mostly nephrologists with a special interest in the topic. However, the interviews revealed a wide variety of experiences. Therefore, it is believed that the data largely represent the experiences of Swedish nephrologists. The participants' backgrounds (place of work, experience, age, and position) also varied greatly. Another challenge when using qualitative content analysis is handling extensive material without compromising the depth of the analysis. For example, one could include a lot of data while only superficially analyzing it, which is akin to not seeing the forest for the trees (Graneheim et al., 2017; Lindgren et al., 2020). At the same time, there is a challenge in ensuring that all relevant data is included in the analysis. The data were analyzed several times, and the process of abstraction was done close to the transcriptions to minimize both these risks.

When interviewing nephrologists, the focus was clearly on the medical perspective and from the physicians' point of view, which may have led to overlooking other viewpoints such as those of nurses and physiotherapists, etc. While the interprofessional team responsible for the patient's care was mentioned in the interviews, the project did not examine the experiences of other healthcare professionals. Much of the information to patients, both before and after starting dialysis is provided by specialized nurses, whose perspectives were not explored. The empirical part of the project also lacks a patient perspective, as patients were not interviewed. However, including several professions, as well as patients, would have made the project significantly more extensive.

9 On the use of Artificial Intelligence

According to the applicable local guidelines of the Faculty of Medicine at Lund University (Lund University, 2024), the national guidelines of the Swedish Research Council (Vetenskapsrådet, 2024, pp. 56-57), and the European Code of Conduct for Research Integrity (ALLEA, 2023), any use of artificial intelligence (AI) must be disclosed. In this project, AI was used for editing and proofreading (deepl.com/write). Additionally, AI (Consensus.app) was used to facilitate a literature review of some of the themes in the thesis summary. AI was not used for transcribing interviews, for analyzing and discussing empirical findings, or for conducting ethical analyses. Generative AI was not used to produce content or generate text. In compliance with the above guidelines, I take full accountability for the content.

10 Ethical considerations

The empirical part of the thesis raises some ethical considerations that require attention. No patient data were collected or analyzed, but Paper III included interview data from nephrologists. This study was conducted in accordance with relevant guidelines and regulations. It was approved by The Swedish Ethical Review Authority (Dnr 2022-00652-01). Participants received written information about the study before agreeing to participate. They were also provided with written and oral information when they met the interviewer for the first time. Participants were informed about the study's purpose and procedures, as well as their right to choose not to answer a question, to respect their privacy. They were also informed that the interviews would be recorded and that the data would be kept confidential and stored according to Lund University guidelines. Written and oral informed consent was obtained from all participants. The results are presented with consideration for the complexities reported by the participants. The aim was not to emphasize any professional shortcomings on their behalf, but rather to identify areas in need of further reflection and to find solutions to support healthcare professionals in the future.

This project examined clinical nephrology practices involving patients, their families, and healthcare professionals. Consequently, ethical issues arise when clarifying situations in nephrology care where there may be ambiguities or barriers regarding the principle of self-determination. Highlighting problems with respecting patient self-determination could give patients and families the impression that such practices are accepted, something which might negatively impact their trust in healthcare. Eliminating the risk of such reactions is impossible without allowing this concern to influence the analysis and presentation, which in turn would deviate from good research practice. While the latter is clearly unacceptable, measures have been taken to present the findings in a nuanced and respectful manner, thereby minimizing these risks. The intention was to identify challenges to the principle of patient self-determination in order to highlight areas where improvement can be made. The results may help to establish better routines and provide healthcare professionals with more support to involve patients in decisions regarding their care. Ultimately, the project is therefore intended to benefit patients, their families, and healthcare professionals.

11 Major findings

The studies in this thesis have identified several ambiguities and barriers to respecting self-determination in the clinical context of routine nephrology care. Below follows an outline of the major findings.

Decision-making has temporal aspects. In this thesis, these are primarily addressed in the form of temporizing, as explained above. The analysis concluded that temporizing is associated with uncertainty whether it will or will not align with patient self-determination. It may imply an unacceptable risk of not respecting the principle of self-determination in at least two ways. First, the patient may miss an opportunity to participate in decision-making due to a reduced capacity for autonomous decision-making by the time the patient is invited to participate. Second, the relevant decision may no longer be possible to make by the time the patient is invited to participate. The characteristics of the decision, including for instance available options, expected outcomes, patient preferences or priorities, and consequences of the decision may change over time, resulting in a different decision than if it had been made earlier. (In the nephrology patient population, both of these risks are significant).

Attempting to optimize decision-making through temporizing could be problematic in a situation where patients exceed the threshold for decision-making capacity that society has established. If the right to self-determination is to be respected, patients should arguably be allowed to participate in the decision-making process, which begins by realizing that a decision needs to be made. Obviously, temporizing would always conflict with the principle of patient self-determination if it required patients to be informed immediately and without further consideration. However, it would be difficult to comply with such a conception of the principle since providing all the information at once and with all patients is practically impossible. If patient self-determination is instead considered an ideal to pursue over time, competing with other ethical considerations, and if there are strong reasons to temporize the decision to improve decision-making, then it may be more acceptable to do so. Temporizing can therefore be problematic, but it is not always wrong, or so it seems. While a short period is often considered less problematic than a long one, the issue is not only the length of time but above all the risk that something could happen during that time to interfere with the patient's self-determination regarding the decision.

Referring to a general conception of self-determination alone may not be sufficient for deciding which risks of lost decision-making opportunities are acceptable. There might obviously be differences among individuals in how they judge the acceptability of risk. Some might be more risk-averse than others. One part of the problem is that healthcare professionals decide whether to temporize, disregarding patients' preferences regarding the timing of information, and patients' own risk assessment. Doing so indicates a paternalistic attitude, which in turn raises ethical concerns.

The interviews with nephrologists also covered temporal aspects. For example, the participants discussed the importance of allocating enough time to speak with patients and prepare them gradually for the decision of whether to start dialysis. The nephrologists expressed concern about overwhelming patients with information and preferred to space it out over several appointments. They therefore saw value in having enough time to prepare patients. According to their experience, decision-making is sometimes temporized to better suit the patient or family, at the nephrologist's discretion. However, they also reported that preparing patients is not always possible. When urgent decisions have to be made, the nephrologists said they feel strained because they do not feel that the patients are adequately prepared.

The thesis also addresses questions about the type and amount of information that should be provided to patients. As mentioned earlier, guidelines and legal regulations tend not to, in detail, specify what information needs to be provided and why. However, certain types of information are recommended to be provided to patients as part of the requirements for informed consent or dissent to treatment, as outlined in the background. If the aim is to increase patients' understanding of, for example, the treatment options presented to them, then other potential information might also be relevant. This includes information about priority considerations, but it is applicable also to other kinds of information, such as national guidelines and local routines, which can impact the treatment options offered to the patient.

Patient information can be regarded important for various reasons – reasons which in different ways can influence what information is considered important. First, the information may be intended to help patients make decisions that result in them becoming, at least partially, accountable for the decisions. If this were the primary reason for providing information, then details about priorities would perhaps be considered optional. Second, patient information can be regarded useful (actionable) for patients who, through decision-making, aim to promote their own health and well-being. However, priority considerations are likely not useful to patients in the sense that it helps them to exert influence over their care. Patients are typically not (and should in most cases not be) invited to question or negotiate these priorities. The information might be useful in other ways, for instance by opening a possibility for patients to publicly protest against these priorities, to vote for a different political party, and so on. These actions will, however, not affect the range of options presented to the patient. And it is not clinically useful unless patients can turn to other clinics, either within or outside the country, should another treatment option be available there.

If the focus is on actionability or clinical utility, it therefore makes sense to exclude information about priorities and similar information. But then there is a risk that other moral concerns will be neglected. These include that patients and healthcare professionals are essentially moral equals, and that patients (as well as, of course, professionals) deserve respect as persons. Such respect may require healthcare professionals to minimize power imbalances and to be honest with patients. And it can be argued that healthcare professionals are not fully honest when they withhold information from patients, such as about certain reasons for recommending a treatment, including priority considerations. Without honesty, patients will not be helped to develop sufficient understanding of their situation. Of course, it should be acknowledged that the information provided to patients must be somewhat limited. This may be for practical reasons, such as time constraints on conversations between healthcare professionals and patients. However, rather than justifying what information to communicate to patients, the suggestion is that the burden of proof lies in demonstrating what information can safely be excluded without compromising patient self-determination. Hence, healthcare professionals should be able to justify excluding information about healthcare priorities from patients. Another way to put it is that the default should be to provide all the information needed for patients to understand their own situation also in a wider context of acknowledging other patients' needs and, thus, the need for prioritization. This default should of course be contrasted with other values at stake.

In the empirical part of this thesis, nephrologists were interviewed and, among other things, asked if they believe information about priority considerations should be shared with patients. Most replied that such information is irrelevant to patients. Furthermore, they said that the available treatment options (restricted by priority considerations) are sometimes described as those that will benefit the patient. Even if this is partly true, it can be misleading because the information only partially explains why these alternatives are offered and not others. According to the nephrologists interviewed, patients should not have to deal with such information, emphasizing that it is the nephrologist's responsibility to take these factors into account. This reflects a paternalistic attitude that may prevent patients from exercising their right to self-determination. And, even if the information does not promote patient self-determination, it risks perpetuating or increasing the epistemic asymmetry in the relationship between patients and healthcare professionals.

Related to the situation where information is withheld at the healthcare professionals' initiative, is the question of patients who do not want to know about their disease, prognosis, treatment options, etc. The clinical case presented in Paper IV shows how this can be problematic, especially at the end of life, when many factors must be considered, and patients' priorities may change. First, respecting a patient's wish not to know can conflict with the requirement of informed consent. In most cases, appealing to the patient's right to self-determination supports providing information rather than withholding it. Not being informed would result in an uninformed decision to opt out of information and, thereby, opt out of self-determination. Not knowing relevant information can affect current and future decision-making regarding matters of which the patient is currently unaware. Furthermore, since dialysis requires significant patient collaboration, it is essential that patients have a basic understanding of their disease in order to make informed decisions about their treatment. This includes decisions about withdrawing dialysis and initiating intensified palliative care as death approaches. It can be difficult to achieve if patients refuse this information. Advance care planning will be difficult. This process involves discussing patients' preferences in the early stages of the disease and planning for situations when decisions must be made. Respecting patients' wishes not to know might, through lack of relevant knowledge, prevent them from making authentic choices during the time they have left in life. Not knowing relevant facts about their remaining life might further make them vulnerable to domination or to being deferential to the preferences of others.

Not knowing can harm the patient in other ways. Without the necessary information, it is unreasonable to expect adherence to treatment. Adherence requires an understanding of the disease state and the consequences of treatment, as well as open communication between the healthcare professional and the patient regarding symptoms and interventions. Without this communication, it will therefore be difficult to provide the patient with good care, which is an important goal for healthcare professionals.

Respecting a patient's wish not to know can negatively impact others as well, including family members, healthcare professionals, and potentially other patients. It creates morally challenging situations for family members and healthcare professionals, such as withholding important information and, in certain cases, lying to the patient. This creates a double standard regarding truthfulness in healthcare that will be difficult to maintain. Others will be held accountable for decisions, which may burden them, knowing the patient could have participated in the decision-making process if she had been given information. Decisions to withdraw burdensome treatment may be postponed. Besides harming the patient by providing futile treatment with a high risk of complications, this could also affect other patients' access to care through displacement effects. All these consequences must be weighed against honoring the right not to know.

A patient's desire to remain uninformed may stem from various motives, including rational beliefs, emotional reactions such as fear, and misunderstandings. The question is therefore what exactly is expected to be honored, and how. There is also uncertainty as to the kind and amount of information that is to be excluded, which is difficult to judge without knowing about the underlying motives. Furthermore, it is unclear for how long relevant information should be withheld, since it is difficult to ask the patient without revealing that there is something to know about.

In summary, cases where information is withheld, either on the healthcare professional's or the patient's initiative, raise questions of epistemic, moral, and practical character. These questions must be answered before deciding whether withholding pertinent information is ethically acceptable, especially in relation to the principle of patient self-determination, but also other moral values that must be considered. There is no safe way to ensure that withholding information will not be detrimental to patients, either by reducing their self-determination or in other ways. While these concerns must be taken seriously, it must also be acknowledged that respecting a patient's wish not to be informed is sometimes an important aspect of honoring patient self-determination in healthcare.

The qualitative content analysis of the interview study resulted in themes including objectives, content, challenges, and strategies. The interviews revealed uncertainties about both the appropriate scope and the intended purpose of information sharing. One of these reported uncertainties was how to balance the objective of enabling patients to make their own decisions with the objective of helping them make decisions that are in their best interest, as understood by the nephrologist. The nephrologists said that in some cases, they take on the responsibility of making decisions when patients indicate that they prefer not to participate in the decision-making process. However, some participants said they found this responsibility too heavy due to the high stakes involved in deciding whether to start dialysis. Nephrologists reported that decision-making is easier when they decide in line with patients' wishes because it relieves them of some of the perceived responsibility for the decisions. They said information is sometimes withheld or presented in a way that softens its impact and influences patient decision-making. This reveals a tension between being transparent and gentle when providing information.

Participants also mentioned that it is challenging to handle other sources of information, such as information from other patients or social media, because this information is sometimes perceived as misleading. Interprofessional collaboration was viewed as both an asset and a challenge. While information from multiple sources or different professionals can provide a more complete picture, differences in communication made the nephrologists worry that patients would be unsure of what to rely on. Family was considered a double-edged sword because, although family members often support patients, ensuring patient autonomy with regard to family members was reported to be difficult at times. Apart from the previously mentioned challenges, adapting to patients' lack of preparedness, proactivity, health illiteracy, and unrealistic expectations about the future was reported to be difficult. Additionally, the risk of information overload was described as challenging. Strategies were implemented to improve patient understanding, empower patients, and prevent misunderstandings. Strategies were also implemented to steer patient decision-making and improve the way patients feel about their situation.

In summary, temporizing, withholding information from patients, either on the healthcare professional's or the patient's initiative, and framing information are practices where healthcare professionals might not sufficiently honor the principle of patient self-determination. The analyses point out which considerations can be relevant to judge these situations from an ethical perspective. The interview study showed that nephrologists face additional communicative challenges relevant to patient self-determination.

12 Discussion

Over the years, healthcare has taken many steps to strengthen patients' self-determination. The move from a paternalistic model to informed consent, and the development of patient-centered care, shared decision-making, and health literacy have advanced the respect for autonomy. At first, it might seem that patient self-determination has already been achieved. However, when confronted with concrete clinical situations, it becomes clear that uncertainty remains regarding how to honor the principle of self-determination, and that barriers remain.

Previous research has highlighted the various challenges that healthcare professionals in nephrology care encounter when sharing information with patients. For example, value conflicts that might be difficult to manage arise when discussing the choice between dialysis and conservative kidney management (Chan et al., 2019; Chanouzas et al., 2012; Davison et al., 2024; Ho et al., 2022; Ladin, Pandya, et al., 2018; Mathur et al., 2022; Muthalagappan et al., 2013; Visser et al., 2009; Walker et al., 2016). Value conflicts and other challenges have also been identified in advance care planning and in preparing patients for the possibility of withdrawing dialysis and intensifying palliative care (Axelsson et al., 2019, 2020; Chesnaye et al., 2023; Mandel et al., 2017). In many of these situations, there is a conflict between respecting patient self-determination and benefiting the patient in other ways. However, there are challenges and ambiguities present in other situations of routine nephrology care as well. Identifying areas where the principle of patient self-determination risks not being sufficiently honored can help develop strategies that empower patients and enable them to participate in decisions about their care, which is generally recommended in Western societies. It can also clarify situations in which fully respecting self-determination is not feasible or reasonable.

Honoring patients' self-determination requires special care, as their situation may make them more vulnerable. Patients may be ill and find themselves in unfamiliar surroundings with different routines in an inpatient hospital unit. This makes them more dependent on healthcare professionals to provide services that meet their needs (O'Neill, 2002, p. 38). Balancing this sense of dependency with self-determination may be challenging for healthcare professionals, but also for patients. Asking them to participate in decision-making and in their own care may be difficult. Nevertheless, it is important to strike a balance and prevent patients from assuming a too deferential attitude toward healthcare professionals, either on their own account or due to the attitudes and actions of the professionals. This deferential attitude can be detrimental to patients even if they themselves have chosen to adopt it (Garnett, 2023). Respecting a patient's self-determination can be viewed as an interpersonal claim that the patient has against the healthcare professional (Darwall, 2006a). A responsibility for a person's welfare may arise in the relationship between healthcare professionals and patients insofar as the professionals care for the patients (Darwall, 2002, p. 4, 8-9). In this relationship, patients trust that healthcare professionals will strive to promote their welfare (O'Neill, 2002, p. 38). Balancing these objectives means benefiting patients while being sensitive to their own values, preferences, and priorities. This is arguably even more important because of the vulnerability mentioned above. Therefore, healthcare professionals are particularly responsible for how and when information is presented to patients to ensure they can make decisions according to their preferences. The information provided, as well as how and when it is presented, may influence patients' choices.

One area of concern in this thesis was the timing of information, with a special focus on temporizing. Temporizing is prevalent in dialysis care. For example, decisions to reduce or withdraw dialysis are sometimes temporized (Axelsson et al., 2020; Schmidt & Moss, 2014). Motives for temporizing could, among others, include respecting the patient's privacy, achieving greater medical certainty, allowing the patient to have a richer experience with the disease and treatment, enforcing self-determination, ensuring social support, and making decisions that reflect the patient's personal goals and values (Lazenby et al., 2017). In other words, temporizing may be motivated by a desire to optimize decision-making beyond the threshold of decision-making capacity, enabling patients to decide under better conditions. However, it also runs the risk of patients ultimately not participating in decision-making, for the reasons explained above. There is an underlying potential paternalistic attitude in this kind of temporizing. Healthcare professionals interpret patients' informational preferences from their own perspective, which may differ from what patients want or need. Temporizing implies that patients, for some time, lack information about pertinent decisions that is in their interest to receive, and that can be more or less problematic. Epistemic and moral uncertainties must be resolved before temporizing can be safely accepted, i.e. without compromising the principle of patient self-determination. The safest approach appears to be to avoid temporizing altogether to minimize the associated risks to patient self-determination. In analogy with temporizing on the healthcare professional's initiative, patients who opt out of decision-making in the present moment run the risk of being unable to participate later or of having their decisions significantly restricted in the future. In this situation, honoring the patient's request is, in a sense, acting according to the patient's expressed preference. However, the risks for the patient's future self-determination must be considered.

Another issue raised in this project is the withholding of information on the healthcare professional's initiative, for instance about priority considerations. Several of the nephrologists we interviewed expressed that they thought patients should not have to deal with these questions and assumed that patients did not need to be informed about them. However, the judgment of what information is necessary for patients should arguably be made by the patients themselves. If healthcare professionals filter out information that they consider irrelevant for patients, it may reflect a paternalistic attitude that disregards the patients' informational preferences and needs. This is a crucial point because it potentially impedes both respecting patient self-determination and treating patients as equals. According to the most influential accounts on informed consent, information should be tailored to patients' needs and wishes, at least meeting the request of the *reasonable person standard* (Beauchamp & Childress, 2019, pp. 124-125; Faden & Beauchamp, 1986, pp. 32-33). Following that standard, the information provided should not be based solely on what healthcare professionals deem important. It becomes particularly problematic in case the *subjective professional standard* is followed instead, making it up to each individual physician to decide what information to share with their patients (Rynning, 1994, p. 198). To some extent, information should also be adapted to each individual patient. An egalitarian approach, as suggested in this project, implies that relevant information should be shared with patients rather than being owned and dispensed by healthcare professionals.

All relationships, including those between patients and healthcare professionals, carry an inherent probability of influencing the individuals involved in them. However, this influence may or may not be undue in the sense of counteracting the individuals' self-determination (Faden & Beauchamp, 1986, pp. 256-262). In healthcare, the probability of such controlling influence might be higher than in other relationships, because of the asymmetry in the relationship between healthcare professionals and patients. Instances of influence range from persuasion, which essentially appeals to reason and is non-controlling, to coercion, which is essentially controlling and strong (Faden & Beauchamp, 1986, p. 259). Influence from others is especially problematic when it involves deception, lying, manipulation, or nondisclosure of highly relevant information, coercion, or direct refusal to carry out a patient's legitimate wishes (Beauchamp & Childress, 2019, pp. 136-139). Besides being paternalistic, practices that mislead patients can negatively impact trust in the relationship (O'Neill, 2002, pp. 38-39, 151-152, 192; Robins et al., 2011) and potentially also harm the patient. Telling patients that a treatment option was chosen based on clinical benefits rather than priority considerations, as was sometimes the case for the nephrologists we interviewed, might mislead patients by providing only a partial explanation of why one treatment option was chosen over another. According to Abram Brummett and Erica K. Salter, several factors affect the moral evaluation of misleading patients. Depending on the patient's capacity, the nature of the information and the deceptive act, and contextual factors, stronger justification is required in some cases (Brummett & Salter, 2023). Undoubtedly, some instances may be considered seriously misleading, even if based solely on withholding information, as has been described (Cox & Fritz, 2016). Such cases would arguably include instances similar to those exemplified in this thesis where patients have the capacity to understand the information, yet certain relevant information is withheld, causing patients to have false beliefs about their situation.

In addition to the potential risks of not respecting patients as persons when not being honest about for instance prioritization information, focusing solely on clinical utility or actionability for judging the relevance of information to patients may amount to treating patients unfairly. While information about priorities may be actionable for wealthy, health-literate patients, it may not be so for those who lack the means to seek care outside the publicly funded system. It could lead to the unfortunate conclusion that this information is to be provided to those who can act on it while it would be acceptable to withhold it from others that do not have the same resources or capacities.

Considering other values at stake when information about priorities is shared, it is important to consider the risk that patients will become upset or lose trust in the healthcare system, as has been previously discussed (Owen-Smith et al., 2010b). However, in many cases, the importance of being transparent with patients outweighs the potential negative consequences, meaning information should still be provided. Furthermore, in modern society, there is no such thing as an information vacuum (Perry, 2007). Patients may learn about healthcare prioritization elsewhere, such as from other patients, the media, or social media. Learning about priority considerations from sources other than healthcare professionals could damage trust further and negatively impact patient well-being in the long term. Withholding this information can also hinder patients from making certain altruistic choices. Autonomous choices are not necessarily choices that benefit oneself; rather, they could also benefit others, as has been previously discussed (Doukas & Hardwig, 2014). In a scenario where resources are scarce, a patient may choose to forgo treatment in order to benefit someone else. However, making such choices requires having sufficient information to judge the consequences for oneself and for others of the choices to be made. For instance, to make this kind of altruistic decisions, patients must understand the prioritization principles and considerations in their healthcare setting. Withholding this information could interfere with that possibility.

Once the amount of information to be provided has been considered, the question of how to present it arises. The conflicting goals of respecting patient self-determination and providing good care may result in attempts to present information in a way that aligns patients with the treatment goals established by healthcare professionals. In nephrology, healthcare professionals may for example prioritize interventions that improve survival, postpone the need for dialysis, and enhance long-term quality of life. Patients may prioritize other goals over a longer life or preventing the negative effects of a disease, especially if the treatment carries a risk of complications or if the restrictions imposed are difficult to adhere to. According to the nephrologists we interviewed, information is sometimes framed to either influence decision-making or to avoid distressing patients. Framing information in a certain way could help patients feel better about their situation or the chosen treatment option than if the information had been presented more straightforwardly. As revealed in the interviews, this could be achieved by making it seem as if life will continue as usual and decisions are not set in stone (even though some actually are). The question is whether it is acceptable for healthcare professionals to frame information in this way to influence patient decision-making. This approach is paternalistic because it disregards patients' actual values, preferences, and priorities. It can also be misleading because it provides only a partial or distorted picture of what to expect.

The framing of information both in general (Tversky & Kahneman, 1981) and between healthcare professionals and patients has been discussed in the literature (Gerend & Shepherd, 2013; Gong et al., 2013; Heisig et al., 2015; Menichetti et al., 2024; Ploug, 2018). Besides steering decision-making and minimizing potentially distressing information, the nephrologists we interviewed reported using framing also to encourage patients to participate in their care, such as through self-managed dialysis and home dialysis. Healthcare professionals tend to view patients' active involvement in care as the ultimate form of autonomy. However, not all patients desire to collaborate to the same degree (Arestedt et al., 2019). Following Manne Sjöstrand et al., this attitude among healthcare professionals may be an example of paternalism in the name of autonomy (Sjöstrand et al., 2013). To a certain extent, framing is unavoidable in the communication between healthcare professionals and patients. For example, it might be strictly impossible to keep total neutrality when sharing information about a treatment option while having a clear idea as to whether it will benefit or harm the patient (Avitzour et al., 2019). But as suggested in this thesis, there is a line to be drawn between acceptable and unacceptable framing as judged by the impact on patient self-determination.

The desire to improve patients' decision-making can lead healthcare professionals to postpone decisions (temporizing), or steer patients through framing, or shield patients from information that the healthcare professionals deem unwarranted or harmful. This may make moral sense, given that the principle of self-determination in one sense aims to facilitate decisions that align with the patient's underlying deeper or more authentic preferences. It serves an overall idea of promoting the ideal of patient self-determination although by not following the principle at each point in time (Conly, 2012). However, this aim to improve patient decision-making could also be driven by the idea of achieving what is considered to be objectively the best consequences for the patient. This approach involves controlling the information patients receive and how they understand it, in order to help them make, according to some accounts, "better" decisions. Temporizing, framing and withholding information with the aim of either focusing on patients' supposedly more authentic preferences or what they should ideally care about (according to others) may represent examples of nudging as explained in the background (Sunstein, 2016; Thaler & Sunstein, 2008; Thaler, 2003).

The extent to which nudging is compatible with respecting patient self-determination is an open question. Even if the intention is to help patients make good decisions, nudging them may be problematic because it goes against their right to self-determination. This right implies respect for value pluralism among individuals, something that must be acknowledged for the principle to be observed. If nudging is used to assist patients in decision-making, the decision architect must make judgments about patients' preferences without knowing about their personal values and priorities, even when patients have sufficient decision-making capacity. The difference between nudging and hard paternalism thus remains unclear, as does the acceptability of nudging patients to help them make decisions. The issue becomes even more problematic when nudging aims to serve objectives other than assisting patients in making decisions, such as benefiting a group of patients or society as a whole.

The claim that nudging does not restrict the availability of different choice options makes unwarranted assumptions about patients. For example, it presumes that patients are relatively resistant to external influence and capable of making free choices. Depending on the strength of the nudge, this will not always be the case, especially considering patients' vulnerability in healthcare situations, which risks reducing their capacity to make decisions that go against the nudger's intentions (Dworkin, 2013; Simkulet, 2019). It is reasonable to assume that nudging could negatively impact the trust between patients and physicians if the nudging is made known to patients afterwards. Furthermore, patients may have different attitudes toward it, and since it affects patient decision-making, the patient should be enabled to take part in deciding whether it is acceptable or not, as suggested by David Avitzour et al. (Avitzour et al., 2019). However, patients are normally neither invited nor involved in these forms of nudging; healthcare professionals take the initiative and control the nudge. There is an obvious risk here of not respecting patient self-determination. At the same time, one must acknowledge that patients can have difficulties in handling all information and choosing between all the available options. Nudging might therefore to some extent meet a need in the patient as a form of decisional support. However, uncertainty remains regarding the acceptable form and extent of nudging, and whether it responds to a patient's needs or if it is rather another expression of undue paternalism in healthcare.

There might be a difference between having a paternalistic attitude and acting paternalistically. Not all attitudes lead to actions, or so it may be argued. Yet, paternalistic attitudes are likely to result in paternalistic actions, which can be more or less subtle. This thesis highlights examples such as temporizing, framing, and withholding information. In cases involving patients with limited capacity who cannot pursue their own well-being or recognize potential harm, acting paternalistically may be necessary (Beauchamp & Childress, 2019, p. 233). However, this is arguably not applicable in situations where patients have sufficient decision-making capacity, which was the context of the present work. In some cases, paternalistic attitudes and actions may stem from uncertainty about patients' ability to make complex treatment decisions. Furthermore, according to Niels Lynöe et al., a form of disguised paternalism can arise when physicians interpret hard paternalism as soft paternalism by questioning patients' decision-making capacity (Lynøe et al., 2021). Considering patients as in need of being steered even when they have sufficient decision-making capacity, and maintaining a state of superiority on the part of healthcare professionals touches on the issue of epistemic asymmetry or injustice.

Temporizing, withholding and framing information not only risk preventing patients from making decisions or acting on the information. These practices may lead to other problems. The mere fact that patients know little and healthcare professionals know much more about the disease, prognosis, and treatment options might be problematic when the knowledge gap is disproportionate and maintained by healthcare professionals. Withholding or framing information could create or exacerbate an already existing epistemic asymmetry in the relationship. This asymmetry of knowledge and power between patients and healthcare professionals can be considered a form of epistemic injustice as explained further below. Blindfolded self-paternalism also becomes problematic for instance when patients prefer not to receive important information. In cases where patients want to maintain or increase epistemic asymmetry in this way, the question remains: Are healthcare professionals obligated to respect such wishes, or must other values be considered? In any case, respecting such a patient wish is more complicated than it seems at first glance, as previously suggested.

It is difficult to argue for full epistemic symmetry in the professional relationship between patients and physicians. Therefore, accepting a certain degree of asymmetry is not necessarily wrongdoing; it may even be necessary, as long as the patient is respected as a person, and the relationship is built on reciprocity and honesty (Surbone & Lowenstein, 2003). In some cases, medical expertise must guide medical decision-making. It is often not possible to inform patients to the same degree that healthcare professionals are informed. In many cases, it is not even desirable: as noted above, it could lead to information overload, alarm, or it could unnecessarily confuse the patient. However, at a certain level, epistemic asymmetry becomes problematic in the sense of not providing patients with the means to meaningfully participate in decision-making regarding their care. Epistemic injustice has been used to describe situations where someone's testimony is not acknowledged as valid, or where there is a lack of necessary terminology to be able to communicate one's experience in a certain context (Fricker, 2007, pp. 20, 43, 116, 147). Transferred to healthcare settings, these two kinds of epistemic injustice might occur when healthcare professionals do not take into account what patients tell them about their own experience of their illness, or when patients are not enabled to make themselves understood since they cannot use the language employed in healthcare (Carel & Kidd, 2014, 2017, pp. 338, 340, 343). A third conception of epistemic injustice is one that stems from malformation, such as when patients are misled about the reasons for a decision (Nikolaidis, 2021). This third form of epistemic injustice might stem from temporizing, framing and withholding information as explained in this thesis.

Patients in an epistemically inferior position are at risk of being dominated by others. Patients might be vulnerable to domination by for example healthcare professionals who withhold or frame information in a way that negatively affects the patient's understanding. This can be negative even if the patients are not harmed as a result, or whether domination actually occurs or not. The mere vulnerability to domination which is maintained in this asymmetric relationship might be problematic. It might even be the result of a situation where patients are not viewed as moral equals by healthcare professionals. One step in overcoming this problem is to inform patients about the things that are relevant for them to know in order to understand their situation. Levelling out the different forms of epistemic asymmetry requires both listening and paying attention to patients, and providing them with sufficient information. However, the question remains as to where the line should be drawn to minimize unmotivated or unacceptable epistemic asymmetry. This may depend on several factors, such as patient characteristics, previous experience, knowledge, and personal preferences, as well as situational factors, such as the healthcare area and level of complexity (Nimmon & Stenfors-Hayes, 2016). While the findings of this thesis do not conclusively answer the question where the line should be drawn, the principle of patient self-determination arguably suggests that epistemic asymmetry should be reduced whenever it is necessary and feasible. This allows patients to participate more fully in decision-making and prevents them from being vulnerable to domination.

In nephrology, as in most other areas of healthcare, an interprofessional team is in place to address patients' various medical, nursing, rehabilitation, nutritional, and emotional needs. This interprofessional collaboration is essential for effective healthcare (Kreps, 2025). Establishing common ground for health evaluations and effective communication can be challenging for people with different competencies, as demonstrated by the empirical part of the project. Different perspectives on patient needs may affect the information given to patients. The challenge identified by the nephrologists we interviewed when patients receive information from different sources, including other healthcare professionals, may reflect a paternalistic attitude of wanting to control the information patients receive. However, as we have seen, patients do not live in an information vacuum (Perry, 2007) and it is important to acknowledge that the patient may be informed from different sources. Furthermore, information from nephrologists might not always lead to increased understanding. The barriers that the nephrologists identified during the interviews can make it difficult to achieve patient understanding. Effective communication between healthcare professionals regarding patient care is essential both for interprofessional collaboration and for informing patients about different care perspectives. This multiplicity of professionals and the need for interprofessional communication is also relevant to address in cases where patients express a wish not to be informed. It is not as simple as the relationship between one patient and one healthcare professional, such as a nephrologist. Rather, what makes it complex is the large number of people who are expected to act without transparency in many different situations or even lie to the patient. Keeping a promise to the patient of not providing information might also affect communication between healthcare professionals when the patient is present. This can lead to misunderstandings and medical risks.

If we are to take the patient's whole situation into account, other relationships must be considered as well. One challenge that the nephrologists we interviewed experienced was ensuring patient autonomy in relation to their families. This involves considering the relational aspects of autonomy (Sledge et al., 2023; Walter & Ross, 2014). Autonomy focuses on individuals and their decisions, choices, and actions. One important aspect is precisely not being controlled by others. However, a complete lack of influence from others is unrealistic and undesirable in many non-professional relationships, such as those within families. People are interdependent and affected by different social commitments and relationships. Many of the choices one makes affect the people one cares about. So called relational autonomy considers this, acknowledging the relational and social origins of all of our choices and actions, and pointing out the interdependence of people in decision-making (Walter & Ross, 2014). Nevertheless, according to the principle of patient self-determination, decisions regarding treatment ultimately rest with the patients themselves, not their families, at least not in Western countries. Family considerations also arise in cases where patients express a wish not to know. As the findings of this project describe, there may be negative consequences for family members that should be considered before respecting such a wish from the patient.

The information patients are given for making personal decisions should be as complete as possible. Healthcare professionals should provide information about what life is expected to be like, e.g., on dialysis. This was reported as a challenge for the nephrologists interviewed. Both patients and healthcare professionals may lack the knowledge necessary for making treatment decisions due to epistemic uncertainty, which negatively affects decision-making. Previous research has addressed how to handle uncertainty in advance care planning, suggesting, for instance, that one should be honest, clarify goals over time, respect patients' personal decisions, and be willing to readdress them together in the light of new knowledge (Berger, 2015). Recognizing that there is mutual uncertainty about the outcomes of healthcare decisions is the first step in developing strategies to address it. Acknowledging uncertainty means accepting that decisions will not be "perfect", because neither the patient nor the healthcare professional will know if a decision will eventually benefit the patient. However, the goal should be to make the decision as informed as possible. This will be far from the case if patients are misled about their disease and prognosis, the treatment options that are available, and other pertinent information.

In summary, the timing, amount, and type of information shared, as well as how it is shared, can impact patient self-determination. Healthcare professionals play an important role in adhering to the principle of patient self-determination. Nonadherence could be partly due to the complexity of real-life clinical situations and to time constraints. However, accepting this situation as normal raises concerns. Identifying areas of potential paternalism, like the ones highlighted in this thesis, can contribute to a greater understanding of how to support healthcare professionals and develop tools that ensure patients' self-determination is respected. While it is unclear how to overcome the challenges and barriers identified in this thesis, awareness of these issues could facilitate the development of strategies to adhere to the principle in practice.

13 Conclusion

On the broadly accepted assumption that patient self-determination is important, this thesis has explored various challenges in ensuring that patients are not deprived of the chance to exercise self-determination, with a particular focus on nephrology care. Adhering to the principle of patient self-determination generally requires healthcare professionals to first share relevant information with patients. However, it is unclear exactly what patients should be informed about, when the information should be provided, and how it should be provided for healthcare professionals to live up to this principle. Several challenges to sharing information with patients, at the right time and in the right way are identified in this thesis, and these may result in patient self-determination not being fully honored, or at least they point to the need to have the principle of self-determination clarified. Examples of practices raising these questions include temporizing, framing, and withholding information at the patient's request or for other reasons.

Temporizing risks depriving patients of the chance to make some of the decisions they have the right to make, but it also points to the need for greater clarity when it comes to temporal aspects of the right to self-determination. The choice not to share information about prioritization considerations and similar reasons for offering patients certain options, on the basis that such information is not relevant to the patients' deliberations, may not remove choices from these patients. It may nonetheless conflict with the spirit of the principle of self-determination, in that proceeding with assumptions about what is not relevant to patients may reflect a paternalistic attitude. And when patients' wishes to not know are respected and information is withheld at their request, there is an obvious sense in which their right to self-determination is respected, but at the same time, these patients are allowed to put themselves in an epistemically inferior position, with several potential negative consequences for themselves and others, including worse chances of exercising *future* self-determination. Further potential barriers to fully respecting patient self-determination were identified by the nephrologists interviewed.

The challenges identified in this project ought to be addressed if one wants to ensure that the respect for the principle of patient self-determination in healthcare, including routine nephrology, is not merely nominal. The findings can provide healthcare professionals (and patients) with guidance on how to better adhere to the relevant principle - when they should - but also inform future research and be of help in the continuing efforts of bioethicists to clarify just what respect for patient self-determination requires.

14 Future research

During the course of this project, ideas for future research emerged, partly in response to the limitations mentioned above. One such idea is to expand the focus beyond nephrologists to include other team members since the entire interprofessional team is responsible for providing patients with information about decisions regarding the initiation or withholding of dialysis, as well as end-of-life decisions. One method of conducting such research would be focus group studies with recorded interviews and qualitative data analysis. Future research could also examine patients' experiences with receiving information about dialysis during the progression towards kidney failure and the associated decision-making process. Additionally, it would be interesting to explore the experiences of patients who do not want to receive information at the end of their lives. Assuming it would be permissible from a research ethics perspective, a qualitative or quantitative study could be designed to address this issue while considering the complex nature of this desire and the obvious difficulty of obtaining informed consent. Other areas where patient self-determination might be marginalized could be identified. Analogous to the analyses in this thesis, the practical problems can be contrasted with the principle of patient self-determination to further increase the understanding of what the principle requires in different situations. The research could also take a broader approach by including global or transcultural dimensions and differences in patient self-determination. Findings from this project could help identify situations where there is need for more support to healthcare professionals and to patients, designing decision aids and other support tools. The implementation of such tools is then to be preceded by feasibility studies.

15 Lessons learned

If I were starting my PhD project today, what would I do differently? After spending years working on my thesis, I often think about how I could have been more efficient. As I recall, I spent the first few years studying relevant, and also less relevant, literature and deciding what I should study more closely. This time was necessary since it was a new field, and I needed background knowledge to formulate research questions. However, since it usually takes me longer to study a subject than to focus on a specific question, I could have tried to formulate more concrete questions from the beginning. This is not to say that I did not have research questions in my initial project plan. They were just very general: patient autonomy, other ethical principles in choosing treatment (including withdrawing from dialysis and initiating palliative care), patient liberty versus adherence, and how physicians experience their role in making decisions for their patients.

The methodology was not outlined from the beginning, either. In my initial project plan, I considered conducting empirical research using quantitative (questionnaires) and qualitative (interviews) methods with participants including patients, their family members, physicians, and other healthcare professionals. Ultimately, though, the thesis ended up being theoretical and empirical, with most of it being theoretical. I would not change that, though, because I think it is a strength to have delved deeply into the theory. Given my background in laboratory work, statistics, and quantitative research, conducting an empirical project would have been much easier, but I would not have enriched my theoretical understanding of ethical principles, especially the principle of patient self-determination. According to my opinion, this is needed to continue conducting research in medical ethics, as well as for teaching.

If I had planned more in advance, I probably would have started the empirical part of the thesis earlier. However, I am not sure that it would have been better overall since I needed the background from Papers I and II to develop the interview guide for Paper III. The theoretical and empirical parts of the thesis are intertwined, so it is hard to say if starting in a different order would have been better. Reflecting on the thesis and how it developed, I think it evolved creatively and without haste, which is what research, according to my view, should be all about. Other research projects and collaborations that I have had over the years were also a great source of inspiration, as well as teaching students and working in the clinic.

16 Popular summary of the thesis

Respect for patients’ own decisions about whether to accept or refuse offered care (hereafter: the principle of patient self-determination), is a strongly emphasized ideal in modern Western healthcare. However, there are situations and practices in healthcare where it is difficult to understand or follow the principle. This thesis studies a selection of such practices in kidney care with a special focus on the challenges they imply for respecting patient self-determination.

One study examines intentionally postponing information to the patient about the fact that a decision must be made, such as changing, starting, or withdrawing a treatment (hereafter: temporizing). There could be different motives behind not informing the patient at once that a decision ought to be made. Motives may include helping patients make good decisions, waiting for a better moment, waiting until patients have their family present, or waiting until healthcare professionals have greater certainty, e.g., about the expected effects of a treatment. However, temporizing may also pose a risk that patients lose the capacity needed to participate in decision-making or that the decision significantly changes over time, so they are unable to make that specific decision. In that case, temporizing would not respect patient self-determination since the patient cannot participate in decision-making.

Another study is about excluding information from patients that healthcare professionals might deem irrelevant, such as about healthcare priorities. There is a lot of information to give patients, and it is often impossible to cover all the details. A common criterion for deciding which kind of information to include is that the patient can use the information to make choices of treatments or lifestyle interventions. However, other kinds of information may be important to the patient as well. Any exclusion of relevant information runs the risk of limiting patients' knowledge about their own situation, and healthcare priorities might be one such kind of information. Excluding relevant information to the patient might imply not respecting patient self-determination. Furthermore, if a situation is accepted where patients are significantly less informed than healthcare professionals, then they are not treated as equals. This approach makes it a matter of honesty to provide patients with relevant information. Considering patients as equals requires healthcare professionals to be able to explain why it is the case that certain information to the patient is being excluded, whenever that happens.

In an empirical part of the project, 14 Swedish kidney physicians were interviewed regarding their experiences from informing and preparing patients with chronic kidney disease for a decision about whether to start dialysis. The physicians reported difficulty finding common ground with patients regarding their understanding of the disease and available treatment options. They also reported difficulty in respecting patients' decisions while feeling the need to steer them to choose what the physicians think is the best option for them. Another expressed challenge was to inform patients honestly without causing distress or sadness. The physicians also wanted to support the patients' independence from their families while ensuring the families would support the patients as needed. The physicians said that they used various strategies to address these challenges, among others, ways of wording or framing the information.

The fourth study focuses on patients that approach the end of life who wish not to receive information from healthcare professionals. Respecting this wish could have negative consequences for patients themselves, their families, other patients, and healthcare professionals. The reasons for not wanting to be informed and the extent to which patients do not want to be informed may be unclear. Without information, patients will be unable to make important end-of-life choices, thus being unable to exercise self-determination and give informed consent or dissent to treatment. Then, decisions will be made by others (family or healthcare professionals), which is problematic since these decisions will not reflect the patient's wishes. This also obligates healthcare professionals to act with a lack of transparency toward patients and to assume full accountability for important decisions with many consequences for the patient.

In summary, the timing and framing of information, as well as withholding information, either on the healthcare professional's or the patient's initiative might be detrimental to patient self-determination in nephrology care.

17 Sammanfattning på svenska

Patienters utrymme att bestämma själva och ge sitt informerade samtycke eller nekande till vård är en stark princip inom hälso- och sjukvården. Men det finns områden där denna självbestämmandeprincip är otydlig eller svår att tillämpa. Ett urval av olika områden har behandlats i det här avhandlingsarbetet med särskilt fokus på njursjukvården. Det rör exempelvis frågor kring att skjuta upp information, utesluta viss information eller formulera information på ett visst sätt.

En delstudie handlar om att skjuta upp information. Detta kan aktualiseras när ett beslut måste fattas i samråd med patienten om att ändra inriktning på vården eller att påbörja en annan behandlingsform. Att det finns skäl för att ett sådant beslut behöver fattas kan vara känt för hälso- och sjukvårdspersonalen men inte för patienten. Det kan finnas vissa motiv för att skjuta upp sådan information till när patienten är mer beslutskapabel, eller har sina närstående med sig, eller att hälso- och sjukvårdpersonalen har en större säkerhet kring vilka alternativ som ska föreslås patienten o.s.v. Men att skjuta upp information kan också innebära antingen att patienten under tiden förlorar en del eller hela sin beslutskapacitet och därmed inte kan delta i beslutet. Det kan också innebära att beslutet inte längre är detsamma, eftersom situationen har förändrats så att alternativen har ändrat karaktär, eller patientens önskemål har förändrats. Då ställs inte patienten inför det ursprungliga beslutet och berövas på så sätt möjligheten att fatta ett beslut. I dessa fall är uppskjutande av information inte förenlig med patientens självbestämmande.

En annan delstudie handlar om att avgränsa information, till exempel om prioriteringar inom hälso- och sjukvården med betydelse för de behandlingsalternativ patienten får presenterade för sig. Det kan finnas mycket information att förmedla till patienten och en viss avgränsning är i princip alltid nödvändig. Men frågan är hur den avgränsningen ska ske. Ofta har det betraktats som acceptabelt att undanhålla information som inte bidrar till patientens beslutsfattande eller handlingsval. Men all avgränsning löper risken att begränsa patientens kunskap om sitt eget tillstånd och de möjligheter som finns till behandling, och på så sätt respekteras inte patientens självbestämmande. Genom att acceptera en kunskapsklyfta mellan patient och hälso- och sjukvårdspersonal betraktas patienten inte som en jämbördig person som har rätt till kunskap om sin egen situation. Om patienten betraktas som en jämbördig person så kräver det basal uppriktighet och ett sådant perspektiv kan även vända på frågan till att det är valen kring vad patienten inte informeras om som ska kunna försvaras, snarare än valet av information som inkluderas.

I en empirisk studie som ingår i avhandlingen intervjuades 14 njurmedicinska specialistläkare om deras erfarenheter av att informera och förbereda patienter med kronisk njursvikt inför ett beslut att påbörja dialys eller inte. I den studien kom det fram att läkarna upplevde många utmaningar i detta, varav några exemplifieras här. En utmaning som de nämnde bestod i att hitta en gemensam kunskapsgrund och grund för förståelse med patienterna. En annan utmaning de identifierade var att informera patienter ärligt samtidigt som informationen inte skulle orsaka negativa känslor hos patienten. Ytterligare en utmaning låg enligt njurläkarna i att respektera patientens egna beslut rörande sin behandling samtidigt som läkarna ville främja det som de ansåg vara bäst för patienten utifrån sitt eget perspektiv. Patienternas självbestämmande i förhållande till familjen var också något som läkarna uttryckte att de ville främja, samtidigt som de ville att familjen skulle finnas där och stötta patienten. Läkarna identifierade olika strategier som de använder för att möta dessa utmaningar.

Fjärde delstudien handlar om patienter som inte vill ta emot information från hälso- och sjukvårdspersonal när de befinner sig nära livets slut. Patienter har en laglig rätt att slippa information, men detta kan innebära stora konsekvenser både för dem själva och för andra, såsom närstående och sjukvårdspersonal. Det finns en osäkerhet rörande vad önskemålet bottnar i att inte bli informerad. Det finns också en osäkerhet rörande exakt vilken typ av information patienten inte vill ha, och under hur lång tid. Patienten kommer inte att kunna få sina önskemål igenom rörande den sista tiden i livet eller ge informerat samtycke eller nekande till behandling. Att respektera patientens önskan tvingar fram en brist på transparens hos sjukvårdspersonalen. Besluten skjuts över till andra (läkare och närstående) som får ta hela ansvaret för dem. Det är svårt för patienten att överblicka konsekvenserna av att inte få information, då patienten inte vet vad informationen innehåller, och därmed är beslutet att inte ta emot information oinformerat. Patientens framtida självbestämmande påverkas i hög grad. Dessa konsekvenser behöver beaktas innan patientens önskan att inte veta respekteras av hälso- och sjukvårdspersonal.

18 Acknowledgements

First, I would like to thank my main supervisor, Mats Johansson. You dedicated many hours to supervising and contributing to the project. Sometimes, you had to make me slow down in my urge to proceed. This greatly contributed to my development since patience and revision are necessary components of research - not settling for second best but always striving for perfection. During our meetings, I often wished I had a recorder to capture the precise wording of certain things to include in the manuscripts. However, when sitting in front of the computer, I lost the trace of it, something which I regretted. Thank you for your patience with my failures and successes. I hope to continue discussing the ethical issues that arise in clinical practice with you.

Second, I would like to thank my co-supervisor, Linus Broström. Your intriguing questions that I had difficulty answering greatly contributed to my understanding of the field and how much I had left to study. Thank you also for your great patience with all the numerous revisions. Your advice to start a new text for each early revision really helped me avoid getting stuck in previous “favorite” formulations. Now, I have much less of a problem erasing and replacing text, knowing that nothing valuable will be lost. I look forward to continuing our interesting conversations. You have opened my eyes to the fact that there is more to an argument than what meets the eye. This has deepened my analysis and strengthened my critical thinking skills.

I would also like to thank my previous main supervisor, Nils-Eric Sahlin. I remember when we first discussed the project and the various ethical issues that could be explored. That conversation opened my eyes to the vast field of ethical inquiries in nephrology. You made pursuing a second PhD in medical ethics sound like the best decision.

I also want to thank my colleagues in the Department of Clinical Sciences, Lund, Medical Ethics (Daniela Cutas, Kristina Hug, Göran Hermerén, Niklas Vareman, and Eva Sjöstrand) for inviting me to be part of your excellent research team for over ten years. In different ways, you have all contributed to my research, and I am very thankful for that. I have learned a great deal from you all, and I have truly enjoyed our meetings, retreats, and social activities outside of work. You have all enriched my reflections on the subject. Daniela and Kristina, our walks and dinners during international conferences were wonderful!

I want to thank Carin Wallquist, Gustav Lund, Kerstin Westman, and Anders Christensson, as well as all my other colleagues at the Department of Nephrology at Skåne University Hospital in Malmö, for accepting me into your department during all these years, even though I could not support you as much in the clinical work. This research project began and ended in nephrology. You were a great inspiration for the work. Your challenges and strategies to meet them were central to the project.

I also want to thank my colleagues at the Transplantation Unit at Skåne University Hospital in Malmö: Clara Paul, Alireza Biglarnia, Carl Raihle, Oleg Slivca, and the younger physicians in training. You have opened a new field of ethical inquiry for my future research. Our collaboration in caring for patients who have received kidney transplants is outstanding.

I would like to thank Nils H. Persson, the former head of the Nephrology and Transplantation Clinic in Malmö, whom I met during my first months working in Skåne. For a couple of years now, your first question was always: "How is it going with your second PhD project?" That meant a lot to me. You also taught me what caring for patients and being professionally engaged means in practice while maintaining a critical view of ethical concerns in the clinic.

I want to thank my former colleague, Sigrid Lundberg, who now works at Danderyd Hospital, for mentioning that the nephrology department should also receive credit for my research. This clarified that the clinic and the university are both involved in the project. Your dedication to research has always been a great inspiration.

My thanks are also due to my wonderful research team at Sophiahemmet University in Stockholm: Jeanette Wallin, Lena Axelsson, Agneta Wennman-Larsen, and Carina Persson. Thank you for helping me understand the importance of interprofessional research collaborations and broadening my perspective on research. Jeanette, I followed your journey from recent PhD student to dissertation completion - such a wonderful journey! I would also like to thank Jenny Stenberg from the Nephrology Clinic at Uppsala University Hospital. After one of our meetings, you asked me, "How does this kind of medical ethics research really work when there's no statistical or qualitative data to analyze?" Your question forced me to think about how to explain the interaction between the theoretical part of the project and its practical implications.

I want to thank Lars Sandman, for explaining the practical application of the principles of prioritization in Sweden. Even though it was for a different purpose, it helped me formulate part of the background of the thesis. I would like to express my gratitude to Niklas Juth and all the other medical ethicists I have had the privilege to meet during meetings and conferences. Your insights always provide me with new thoughts and perspectives related to medical ethics. I look forward to discussing further subjects with you!

I would like to thank Lotta Wendel, for sharing your insights on health law with me both for teaching and research purposes. Your experiences and clarity of thought and speech have been valuable to me.

I also want to thank Sam Polesie at the University of Gothenburg. Speaking with you always sparked new ideas for research. I hope to have more time after finishing this thesis to start working on some of our ideas for further research.

I would also like to thank Magnus Torstensson, a friend and colleague throughout these years. Thank you for your patience while I balanced teaching with research. Your less academic perspective on my research was very helpful.

I would like to express my deepest gratitude to my lovely family: Jonas, Sebastian, and Alexander. You were always supportive and accepted my late nights and weekends at work as well as my periodic frustration when things did not go as planned. Thank you for keeping our home in order while I was away at conferences and meetings.

I would also like to express my gratitude to my supporting parents and in-laws, who passed away during my PhD studies. I am also grateful to my dear friends Marianne and Sebastian, who also passed away during this time, leaving me feeling doubly orphaned. You were such a great support.

19 Appendix

19.1 Interview guide

The interview guide is written in Swedish as the original language since the interviews were conducted in Swedish.

Njurläkares information till patienter inför dialys

Intervjuguide:

Hur länge har du arbetat inom njurmedicin?

Hur ser det ut på den klinik där du arbetar? Hur många läkare är ni? Har ni både vårdavdelning, dialys och mottagning?

Hur länge har du haft patienter med njursjukdom i slutstadiet och som står inför ett beslut om livslång dialysbehandling?

Det är en hel del att samtala om med patienter och deras närstående inför eventuell dialys. Du har säkert varit med om sådana samtal. Hur brukar de gå till?

Lägger du upp en plan för dessa samtal eller sker de mer spontant?

Om du har en plan, hur brukar den se ut?

Vad tycker du är viktigt för att samtalet ska bli bra?

Finns det några utmaningar med denna typ av samtal, tycker du?

Vad tycker du är viktigt att berätta för patienter som står inför att eventuellt påbörja dialysbehandling?

Finns det saker som patienter ibland frågar om men som du inte brukar ta upp om du inte blir tillfrågad?

Brukar du (på något annat sätt) anpassa informationen till patient och närstående och vilka faktorer påverkar i så fall vad du tar upp eller hur du formulerar dig? (Händer det t.ex. att du väljer att formulera dig på vissa sätt för att göra det lättare för patienten att fatta ett, enligt dig, bra beslut?)

Har du samtalat med patienter som på något sätt ger uttryck för att de inte vill veta så mycket om sin sjukdom eller den förestående dialysbehandlingen? Hur förhåller du dig till det?

Om du eller nära anhörig skulle stå inför valet att börja i dialysbehandling, vad hade du själv velat veta, tror du?

Olika slags överväganden kan ju påverka vilka behandlingsalternativ man erbjuder eller rekommenderar; (inte bara vad man tror gagnar patienten). Vissa av dessa brukar patienter kanske inte känna till, exempelvis lokala rutiner, eller överväganden kring prioriteringar och resursfördelning. Berör du sådana överväganden i dina samtal med patienter? (Exempelvis antal dialysplatser, tillgängliga dialysformer, vilka praktiska detaljer som styr behandlingen?)

(Följdfrågor av typen: Kan du ge exempel? Berätta mer. etc. kan förekomma i förtydligande syfte.)

20 References

Abramowicz, D., Cochat, P., Claas, F. H., Heemann, U., Pascual, J., Dudley, C., Harden, P., Hourmant, M., Maggiore, U., Salvadori, M., Spasovski, G., Squifflet, J. P., Steiger, J., Torres, A., Viklicky, O., Zeier, M., Vanholder, R., Van Biesen, W., & Nagler, E. (2015). European Renal Best Practice Guideline on kidney donor and recipient evaluation and perioperative care. Nephrol Dial Transplant, 30(11), 1790-1797. https://doi.org/10.1093/ndt/gfu216

Adenwalla, S. F., O'Halloran, P., Faull, C., Murtagh, F. E. M., & Graham-Brown, M. P. M. (2024). Advance care planning for patients with end-stage kidney disease on dialysis: narrative review of the current evidence, and future considerations. J Nephrol, 37(3), 547-560. https://doi.org/10.1007/s40620-023-01841-3

Aggarwal, A., Davies, J., & Sullivan, R. (2014). “Nudge” in the clinical consultation – an acceptable form of medical paternalism? BMC Med Ethics, 15(1), 31. https://doi.org/10.1186/1472-6939-15-31

ALLEA. (2023). All European Academies: The European Code of Conduct for Research Integrity - Revised Edition. Retrieved from https://allea.org/wp-content/uploads/2023/06/European-Code-of-Conduct-Revised-Edition-2023.pdf

Amro, A., Waldum, B., Dammen, T., Miaskowski, C., & Os, I. (2014). Symptom clusters in patients on dialysis and their association with quality-of-life outcomes. J Ren Care, 40(1), 23-33. https://doi.org/10.1111/jorc.12051

Amro, O., Ramasamy, M., Strom, J., Weiner, D., & Jaber, B. (2016). Nephrologist-Facilitated Advance Care Planning for Hemodialysis Patients: A Quality Improvement Project. Am J Kidney Dis, 68 1, 103-109. https://doi.org/10.1053/j.ajkd.2015.11.024

Andersen-Hollekim, T., Landstad, B. J., Solbjor, M., Kvangarsnes, M., & Hole, T. (2021). Nephrologists' experiences with patient participation when long-term dialysis is required. BMC Nephrol, 22(1), 58. https://doi.org/10.1186/s12882-021-02261-w

Andorno, R. (2004). The right not to know: an autonomy based approach. J Med Ethics, 30(5), 435-439; discussion 439-440. https://doi.org/10.1136/jme.2002.001578

Andorno, R. (2016). The right not to know does not apply to HIV testing. J Med Ethics, 42(2), 104-105. https://doi.org/10.1136/medethics-2015-103210

Arellano-Mendez, D., & Ladin, K. (2024). Dialysis Discontinuation, Prognosis, and Shared Decision-Making. Kidney Int Rep, 9(7), 1963-1965. https://doi.org/10.1016/j.ekir.2024.05.030

Arestedt, L., Martinsson, C., Hjelm, C., Uhlin, F., & Eldh, A. C. (2019). Patient participation in dialysis care-A qualitative study of patients' and health professionals' perspectives. Health Expect, 22(6), 1285-1293. https://doi.org/10.1111/hex.12966

Ashby, M., op't Hoog, C., Kellehear, A., Kerr, P. G., Brooks, D., Nicholls, K., & Forrest, M. (2005). Renal dialysis abatement: lessons from a social study. Palliat Med, 19(5), 389-396. https://doi.org/10.1191/0269216305pm1043oa

Assarroudi, A., Heshmati Nabavi, F., Armat, M. R., Ebadi, A., & Vaismoradi, M. (2018). Directed qualitative content analysis: the description and elaboration of its underpinning methods and data analysis process. J Res Nurs, 23(1), 42-55. https://doi.org/10.1177/1744987117741667

Austin, C. A., Mohottige, D., Sudore, R. L., Smith, A. K., & Hanson, L. C. (2015). Tools to Promote Shared Decision Making in Serious Illness: A Systematic Review. JAMA Intern Med, 175(7), 1213-1221. https://doi.org/10.1001/jamainternmed.2015.1679

Avitzour, D., Barnea, R., Avitzour, E., Cohen, H., & Nissan-Rozen, I. (2019). Nudging in the clinic: the ethical implications of differences in doctors' and patients' point of view. J Med Ethics, 45(3), 183-189. https://doi.org/10.1136/medethics-2018-104978

Axelsson, L., Alvariza, A., Lindberg, J., Ohlen, J., Hakanson, C., Reimertz, H., Furst, C. J., & Arestedt, K. (2018). Unmet Palliative Care Needs Among Patients With End-Stage Kidney Disease: A National Registry Study About the Last Week of Life. J Pain Symptom Manage, 55(2), 236-244. https://doi.org/10.1016/j.jpainsymman.2017.09.015

Axelsson, L., Benzein, E., Lindberg, J., & Persson, C. (2019). End-of-life and palliative care of patients on maintenance hemodialysis treatment: a focus group study. BMC Palliat Care, 18(1), 89. https://doi.org/10.1186/s12904-019-0481-y

Axelsson, L., Benzein, E., Lindberg, J., & Persson, C. (2020). Processes toward the end of life and dialysis withdrawal Physicians' and nurses' perspectives. Nurs Ethics, 27(2), 419-432. https://doi.org/10.1177/0969733019848050

Axelsson, L., Randers, I., Jacobson, S. H., & Klang, B. (2012). Living with haemodialysis when nearing end of life. Scand J Caring Sci, 26(1), 45-52. https://doi.org/https://doi.org/10.1111/j.1471-6712.2011.00902.x

Barry, M. J. (2012). Shared decision making: informing and involving patients to do the right thing in health care. J Ambul Care Manage, 35(2), 90-98. https://doi.org/10.1097/JAC.0b013e318249482f

Barry, M. J., & Edgman-Levitan, S. (2012). Shared decision making--pinnacle of patient-centered care. N Engl J Med, 366(9), 780-781. https://doi.org/10.1056/NEJMp1109283

Beauchamp, T. L., & Childress, J. F. (2019). Principles of biomedical ethics (8th ed.). Oxford University Press.

Beckwith, H., Thind, A., & Brown, E. A. (2023). Perceived Life Expectancy Among Dialysis Recipients: A Scoping Review. Kidney Med, 5(8), 100687. https://doi.org/10.1016/j.xkme.2023.100687

Begon, J. (2016). Paternalism. Analysis, 76(3), 355-373.

Berger, Z. (2015). Navigating the unknown: shared decision-making in the face of uncertainty. J Gen Intern Med, 30(5), 675-678. https://doi.org/10.1007/s11606-014-3074-8

Berkman, B. E., Hull, S. C., & Biesecker, L. G. (2015). Scrutinizing the Right Not to Know. Am J Bioeth, 15(7), 17-19. https://doi.org/10.1080/15265161.2015.1039733

Birchley, G. (2014). Deciding together? Best interests and shared decision-making in paediatric intensive care. Health Care Anal, 22(3), 203-222. https://doi.org/10.1007/s10728-013-0267-y

Birnbacher, D. (1999). Ethics and Social Science: Which Kind of Co-operation? Ethical Theory and Moral Practice, 2(4), 319-336. https://doi.org/10.1023/A:1009903815157

Björk, J. (2025). Ethical reflection: The palliative care ethos and patients who refuse information. Palliative Care and Social Practice, 19, 1-8. https://doi.org/10.1177/26323524251355287

Blumenthal-Barby, J., & Ubel, P. A. (2018). Truth be told: not all nudging is bullshit. J Med Ethics, 44(8), 547. https://doi.org/10.1136/medethics-2017-104317

Blumenthal-Barby, J. S., Cantor, S. B., Russell, H. V., Naik, A. D., & Volk, R. J. (2013). Decision aids: when 'nudging' patients to make a particular choice is more ethical than balanced, nondirective content. Health Aff (Millwood), 32(2), 303-310. https://doi.org/10.1377/hlthaff.2012.0761

Bobot, M., & Burtey, S. (2024). New insights into mechanisms underlying cognitive impairment in chronic kidney disease. Kidney Int, 106(6), 1020-1022. https://doi.org/10.1016/j.kint.2024.09.008

Bortolotti, L., & Widdows, H. (2011). The right not to know: the case of psychiatric disorders. J Med Ethics, 37(11), 673-676. https://doi.org/10.1136/jme.2010.041111

Brighton, L. J., & Bristowe, K. (2016). Communication in palliative care: talking about the end of life, before the end of life. Postgrad Med J, 92(1090), 466-470. https://doi.org/10.1136/postgradmedj-2015-133368

Brinkman-Stoppelenburg, A., Rietjens, J. A., & van der Heide, A. (2014). The effects of advance care planning on end-of-life care: a systematic review. Palliat Med, 28(8), 1000-1025. https://doi.org/10.1177/0269216314526272

Bristowe, K., Horsley, H. L., Shepherd, K., Brown, H., Carey, I., Matthews, B., O'Donoghue, D., Vinen, K., & Murtagh, F. E. (2015). Thinking ahead--the need for early Advance Care Planning for people on haemodialysis: A qualitative interview study. Palliat Med, 29(5), 443-450. https://doi.org/10.1177/0269216314560209

Broqvist, M., Branting Elgstrand, M., Carlsson, P., Eklund, K., & Jakobsson, A. (2011). National Centre for Priority Setting in Health Care. National Model for Transparent Prioritisation in Swedish Health Care. Revised Version. 2011:14.

Broqvist, M., & Garpenby, P. (2014). To accept, or not to accept, that is the question: citizen reactions to rationing. Health Expect, 17(1), 82-92. https://doi.org/10.1111/j.1369-7625.2011.00734.x

Brown, E. A., Finkelstein, F. O., Iyasere, O. U., & Kliger, A. S. (2017). Peritoneal or hemodialysis for the frail elderly patient, the choice of 2 evils? Kidney Int, 91(2), 294-303. https://doi.org/10.1016/j.kint.2016.08.026

Bruine de Bruin, W., Parker, A. M., & Fischhoff, B. (2007). Individual differences in adult decision-making competence. J Pers Soc Psychol, 92(5), 938-956. https://doi.org/10.1037/0022-3514.92.5.938

Brummett, A., & Salter, E. K. (2023). Mapping the Moral Terrain of Clinical Deception. Hastings Cent Rep, 53(1), 17-25. https://doi.org/10.1002/hast.1454

Brülde, B. (2003). Teorier om livskvalitet. Studentlitteratur.

Brülde, B. (1998). The human good. Acta Universitatis Gothoburgensis.

Buchanan, A. (1978). Medical Paternalism. Philosophy & Public Affairs, 7(4), 370-390. http://www.jstor.org.ludwig.lub.lu.se/stable/2264963

Buchanan, A. E., & Brock, D. W. (1990). Deciding for Others: The Ethics of Surrogate Decision Making. Cambridge University Press. https://doi.org/DOI: 10.1017/CBO9781139171946

Bullock, E. C. (2015). Mandatory Disclosure and Medical Paternalism. Ethical Theory Moral Pract, 19(2), 409-424. https://doi.org/10.1007/s10677-015-9632-2

Burn, D. J., & Bates, D. (1998). Neurology and the kidney. J Neurol Neurosurg Psychiatry, 65(6), 810-821. http://www.ncbi.nlm.nih.gov/pubmed/9854955

Carel, H., & Kidd, I. J. (2014). Epistemic injustice in healthcare: a philosophial analysis. Med Health Care Philos, 17(4), 529-540. https://doi.org/10.1007/s11019-014-9560-2

Carel, H., & Kidd, I. J. (2017). Epistemic Injustice in Medicine and Healthcare. In I. J. Kidd, J. Medina, & G. J. Pohlhaus (Eds.), The Routledge Handbook of Epistemic Injustice. Routledge.

Carlberg, A. (2009). Patientens bästa. En kritisk introduktion till läkaretiken. Nordic Academic Press. https://books.google.se/books?id=9ZOSGcyQszMC

Cassidy, B. P., Getchell, L. E., Harwood, L., Hemmett, J., & Moist, L. M. (2018). Barriers to Education and Shared Decision Making in the Chronic Kidney Disease Population: A Narrative Review. Can J Kidney Health Dis, 5, 2054358118803322. https://doi.org/10.1177/2054358118803322

Chambers, S., Healy, H., Hoy, W. E., Kark, A., Ratanjee, S., Mitchell, G., Douglas, C., Yates, P., & Bonner, A. (2018). Health service utilisation during the last year of life: a prospective, longitudinal study of the pathways of patients with chronic kidney disease stages 3-5. BMC Palliat Care, 17(1), 57. https://doi.org/10.1186/s12904-018-0310-8

Chan, C. T., Blankestijn, P. J., Dember, L. M., Gallieni, M., Harris, D. C. H., Lok, C. E., Mehrotra, R., Stevens, P. E., Wang, A. Y., Cheung, M., Wheeler, D. C., Winkelmayer, W. C., Pollock, C. A., & Conference, P. (2019). Dialysis initiation, modality choice, access, and prescription: conclusions from a Kidney Disease: Improving Global Outcomes (KDIGO) Controversies Conference. Kidney Int, 96(1), 37-47. https://doi.org/10.1016/j.kint.2019.01.017

Chan, K. E., Thadhani, R. I., & Maddux, F. W. (2014). Adherence Barriers to Chronic Dialysis in the United States. J Am Soc Nephrol, 25(11), 2642-2648. https://doi.org/10.1681/asn.2013111160

Chanouzas, D., Ng, K. P., Fallouh, B., & Baharani, J. (2012). What influences patient choice of treatment modality at the pre-dialysis stage? Nephrol Dial Transplant, 27(4), 1542-1547. https://doi.org/10.1093/ndt/gfr452

Chesnaye, N. C., Caskey, F. J., Dekker, F. W., de Rooij, E. N. M., Evans, M., Heimburger, O., Pippias, M., Torino, C., Porto, G., Szymczak, M., Drechsler, C., Wanner, C., Jager, K. J., & investigators, t. E. s. (2023). Clinical and patient-reported trajectories at end-of-life in older patients with advanced CKD. Nephrol Dial Transplant, 38(11), 2494-2502. https://doi.org/10.1093/ndt/gfad091

Chewning, B., Bylund, C. L., Shah, B., Arora, N. K., Gueguen, J. A., & Makoul, G. (2012). Patient preferences for shared decisions: a systematic review. Patient Educ Couns, 86(1), 9-18. https://doi.org/10.1016/j.pec.2011.02.004

Cocanour, C. S. (2017). Informed consent-It's more than a signature on a piece of paper. Am J Surg, 214(6), 993-997. https://doi.org/10.1016/j.amjsurg.2017.09.015

Conly, S. (2012). Against Autonomy: Justifying coercive paternalism. Cambridge University Press. https://www.cambridge.org/core/product/076138B2B57DF6799625F264481A1B3D

Coulter, A., & Oldham, J. (2016). Person-centred care: what is it and how do we get there? Future Hosp J, 3(2), 114-116. https://doi.org/10.7861/futurehosp.3-2-114

Cox, C. L., & Fritz, Z. (2016). Should non-disclosures be considered as morally equivalent to lies within the doctor-patient relationship? J Med Ethics, 42(10), 632-635. https://doi.org/10.1136/medethics-2015-103014

Cribb, A., & Entwistle, V. A. (2011). Shared decision making: trade-offs between narrower and broader conceptions. Health Expect, 14(2), 210-219. https://doi.org/10.1111/j.1369-7625.2011.00694.x

Culp, S., Lupu, D., Arenella, C., Armistead, N., & Moss, A. H. (2016). Unmet Supportive Care Needs in U.S. Dialysis Centers and Lack of Knowledge of Available Resources to Address Them. J Pain Symptom Manage, 51(4), 756-761 e752. https://doi.org/10.1016/j.jpainsymman.2015.11.017

Da Silva-Gane, M., Wellsted, D., Greenshields, H., Norton, S., Chandna, S. M., & Farrington, K. (2012). Quality of life and survival in patients with advanced kidney failure managed conservatively or by dialysis. Clin J Am Soc Nephrol, 7(12), 2002-2009. https://doi.org/10.2215/CJN.01130112

Daniels, N. (1996). Justice and Justification: Reflective Equilibrium in Theory and Practice. Cambridge University Press. https://doi.org/DOI: 10.1017/CBO9780511624988

Darwall, S. (2002). Welfare and Rational Care. Princeton University Press.

Darwall, S. (2006a). The Second-Person Standpoint: Morality, Respect, and Accountability. Harvard University Press. https://doi.org/10.2307/j.ctv1bzfp0f

Darwall, S. (2006b). The Value of Autonomy and Autonomy of the Will. Ethics, 116(2), 263-284. https://doi.org/10.1086/498461

Davies, B. (2020). 'The right not to know and the obligation to know', response to commentaries. J Med Ethics, 46(5), 309-310. https://doi.org/10.1136/medethics-2020-106261

Davies, R., Ives, J., & Dunn, M. (2015). A systematic review of empirical bioethics methodologies. BMC Med Ethics, 16(1), 15. https://doi.org/10.1186/s12910-015-0010-3

Davison, S. N. (2012). The ethics of end-of-life care for patients with ESRD. Clin J Am Soc Nephrol, 7(12), 2049-2057. https://doi.org/10.2215/CJN.03900412

Davison, S. N., & Holley, J. L. (2008). Ethical issues in the care of vulnerable chronic kidney disease patients: the elderly, cognitively impaired, and those from different cultural backgrounds. Adv Chronic Kidney Dis, 15(2), 177-185. https://doi.org/10.1053/j.ackd.2008.01.004

Davison, S. N., Levin, A., Moss, A. H., Jha, V., Brown, E. A., Brennan, F., Murtagh, F. E., Naicker, S., Germain, M. J., O'Donoghue, D. J., Morton, R. L., Obrador, G. T., & Kidney Disease: Improving Global, O. (2015). Executive summary of the KDIGO Controversies Conference on Supportive Care in Chronic Kidney Disease: developing a roadmap to improving quality care. Kidney Int, 88(3), 447-459. https://doi.org/10.1038/ki.2015.110

Davison, S. N., Pommer, W., Brown, M. A., Douglas, C. A., Gelfand, S. L., Gueco, I. P., Hole, B. D., Homma, S., Kazancioglu, R. T., Kitamura, H., Koubar, S. H., Krause, R., Li, K. C., Lowney, A. C., Nagaraju, S. P., Niang, A., Obrador, G. T., Ohtake, Y., Schell, J. O., Scherer, J. S., Smyth, B., Tamba, K., Vallath, N., Wearne, N., Zakharova, E., Zuniga, C., & Brennan, F. P. (2024). Conservative kidney management and kidney supportive care: core components of integrated care for people with kidney failure. Kidney Int, 105(1), 35-45. https://doi.org/10.1016/j.kint.2023.10.001

Del Vecchio, L., & Locatelli, F. (2012). Ethical considerations in nephro-geriatrics. J Nephrol, 25 Suppl 19, S6-10. https://doi.org/10.5301/jn.5000165

Delaney, R., Strough, J., Parker, A. M., & de Bruin, W. B. (2015). Variations in Decision-Making Profiles by Age and Gender: A Cluster-Analytic Approach. Pers Individ Dif, 85, 19-24. https://doi.org/10.1016/j.paid.2015.04.034

Dixit, A., Dhawan, S., Raizada, A., Yadav, A., Vaney, N., & Kalra, O. P. (2013). Attention and information processing in end stage renal disease and effect of hemodialysis: a bedside study. Ren Fail, 35(9), 1246-1250. https://doi.org/10.3109/0886022X.2013.819768

Doukas, D. J., & Hardwig, J. (2014). Patient Informed Choice for Altruism. Cambridge Quarterly of Healthcare Ethics, 23(4), 397-402. https://doi.org/10.1017/S0963180114000073

Downar, J., Goldman, R., Pinto, R., Englesakis, M., & Adhikari, N. K. (2017). The "surprise question" for predicting death in seriously ill patients: a systematic review and meta-analysis. CMAJ, 189(13), E484-E493. https://doi.org/10.1503/cmaj.160775

Dretske, F. (1989). Reasons and causes. Philosophical Perspectives, 3, 1-15.

Drew, D. A., Weiner, D. E., & Sarnak, M. J. (2019). Cognitive Impairment in CKD: Pathophysiology, Management, and Prevention. Am J Kidney Dis, 74(6), 782-790. https://doi.org/10.1053/j.ajkd.2019.05.017

Ducharlet, K., Philip, J., Gock, H., Brown, M., Gelfand, S. L., Josland, E. A., & Brennan, F. (2020). Moral Distress in Nephrology: Perceived Barriers to Ethical Clinical Care. Am J Kidney Dis, 76(2), 248-254. https://doi.org/10.1053/j.ajkd.2019.09.018

Ducharlet, K., Philip, J., Kiburg, K., & Gock, H. (2021). Renal supportive care, palliative care and end-of-life care: Perceptions of similarities, differences and challenges across Australia and New Zealand. Nephrology (Carlton), 26(1), 15-22. https://doi.org/10.1111/nep.13787

Dumaine, C. S., Fox, D. E., Ravani, P., Santana, M. J., & MacRae, J. M. (2023). Health related quality of life during dialysis modality transitions: a qualitative study. BMC Nephrol, 24(1), 282. https://doi.org/10.1186/s12882-023-03330-y

Dworkin, G. (1970). Acting Freely. Noûs, 4(4), 367-383. https://doi.org/10.2307/2214680

Dworkin, G. (1988). The Theory and Practice of Autonomy. Cambridge University Press.

Dworkin, G. (2013). Lying and nudging. J Med Ethics, 39(8), 496-497. https://doi.org/10.1136/medethics-2012-101060

Ehtuish, E. F. A. (2024). Ethics of Organ Donation and Transplantation: Toward Self-Sufficiency. Exp Clin Transplant, 22(Suppl 5), 30-34. https://doi.org/10.6002/ect.pedsymp2024.O1

Eiser, A. R. (1996). Withdrawal from dialysis: the role of autonomy and community-based values. Am J Kidney Dis, 27(3), 451-457. http://www.ncbi.nlm.nih.gov/pubmed/8604719

Ekman, I., Swedberg, K., Taft, C., Lindseth, A., Norberg, A., Brink, E., Carlsson, J., Dahlin-Ivanoff, S., Johansson, I. L., Kjellgren, K., Liden, E., Ohlen, J., Olsson, L. E., Rosen, H., Rydmark, M., & Sunnerhagen, K. S. (2011). Person-centered care--ready for prime time. Eur J Cardiovasc Nurs, 10(4), 248-251. https://doi.org/10.1016/j.ejcnurse.2011.06.008

El-Alti, L., Sandman, L., & Munthe, C. (2019). Person Centered Care and Personalized Medicine: Irreconcilable Opposites or Potential Companions? Health Care Anal, 27(1), 45-59. https://doi.org/10.1007/s10728-017-0347-5

Elliott, B. A., Gessert, C. E., Larson, P. M., & Russ, T. E. (2014). Shifting responses in quality of life: people living with dialysis. Qual Life Res, 23(5), 1497-1504. https://doi.org/10.1007/s11136-013-0600-9

Elo, S., & Kyngas, H. (2008). The qualitative content analysis process. J Adv Nurs, 62(1), 107-115. https://doi.org/10.1111/j.1365-2648.2007.04569.x

Elwyn, G., Frosch, D., Thomson, R., Joseph-Williams, N., Lloyd, A., Kinnersley, P., Cording, E., Tomson, D., Dodd, C., Rollnick, S., Edwards, A., & Barry, M. (2012). Shared decision making: a model for clinical practice. J Gen Intern Med, 27(10), 1361-1367. https://doi.org/10.1007/s11606-012-2077-6

Engelsma, C. (2024). Sharing a medical decision. Med Health Care Philos, 27(1), 3-14. https://doi.org/10.1007/s11019-023-10179-3

Entwistle, V. A., Cribb, A., & Watt, I. S. (2012). Shared decision-making: enhancing the clinical relevance. J R Soc Med, 105(10), 416-421. https://doi.org/10.1258/jrsm.2012.120039

Ernst, J., Berger, S., Weissflog, G., Schroder, C., Korner, A., Niederwieser, D., Brahler, E., & Singer, S. (2013). Patient participation in the medical decision-making process in haemato-oncology--a qualitative study. Eur J Cancer Care (Engl), 22(5), 684-690. https://doi.org/10.1111/ecc.12077

Ethier, I., Hayat, A., Pei, J., Hawley, C. M., Francis, R. S., Wong, G., Craig, J. C., Viecelli, A. K., Htay, H., Ng, S., & et al. (2024). Peritoneal dialysis versus haemodialysis for people commencing dialysis. Cochrane Database of Systematic Reviews (6). https://doi.org/10.1002/14651858.CD013800.pub2

Evans, J. S. B. T. (2008). Dual-Processing Accounts of Reasoning, Judgment, and Social Cognition. Ann Rev Psychol, 59, 255-278. https://doi.org/https://doi.org/10.1146/annurev.psych.59.103006.093629

Eyal, N. (2025). Informed Consent. In E. N. Zalta & U. Nodelman (Eds.), The Stanford Encyclopedia of Philosophy (Spring 2025 ed.). Metaphysics Research Lab, Stanford University. https://plato.stanford.edu/archives/spr2025/entries/informed-consent/

Faden, R., & Beauchamp, T. L. (1986). A History and Theory of Informed Consent. Oxford University Press.

Finderup, J., Jensen, J. D., & Lomborg, K. (2021). Shared decision-making in dialysis choice has potential to improve self-management in people with kidney disease: A qualitative follow-up study. J Adv Nurs, 77(4), 1878-1887. https://doi.org/10.1111/jan.14726

Finderup, J., Lomborg, K., Jensen, J. D., & Stacey, D. (2020). Choice of dialysis modality: patients' experiences and quality of decision after shared decision-making. BMC Nephrol, 21(1), 330. https://doi.org/10.1186/s12882-020-01956-w

Finucane, M. L., Peters, E., & Slovic, P. (2003). Judgment and Decision Making: The Dance of Affect and Reason. In S. L. Schneider & J. Shanteau (Eds.), Emerging Perspectives on Judgment and Decision Research (pp. 327-364). Cambridge University Press. https://doi.org/DOI: 10.1017/CBO9780511609978.012

Finucane, M. L., & Gullion, C. M. (2010). Developing a tool for measuring the decision-making competence of older adults. Psychol Aging, 25(2), 271-288. https://doi.org/10.1037/a0019106

Fischhoff, B. (2008). Assessing adolescent decision-making competence. Developmental Review, 28(1), 12-28. https://doi.org/10.1016/j.dr.2007.08.001

Foote, C., Kotwal, S., Gallagher, M., Cass, A., Brown, M., & Jardine, M. (2016). Survival outcomes of supportive care versus dialysis therapies for elderly patients with end-stage kidney disease: A systematic review and meta-analysis. Nephrology (Carlton), 21(3), 241-253. https://doi.org/10.1111/nep.12586

Forzley, B., Er, L., Chiu, H. H. L., Djurdjev, O., Martinusen, D., Carson, R. C., Hargrove, G., Levin, A., & Karim, M. (2018). External validation and clinical utility of a prediction model for 6-month mortality in patients undergoing hemodialysis for end-stage kidney disease. Palliat Med, *32*(2), 395-403. https://doi.org/10.1177/0269216317720832

Frambach, J. M., van der Vleuten, C. P., & Durning, S. J. (2013). AM last page. Quality criteria in qualitative and quantitative research. Acad Med, 88(4), 552. https://doi.org/10.1097/ACM.0b013e31828abf7f

Fraser, S. D. S., Roderick, P. J., May, C. R., McIntyre, N., McIntyre, C., Fluck, R. J., Shardlow, A., & Taal, M. W. (2015). The burden of comorbidity in people with chronic kidney disease stage 3: a cohort study. BMC Nephrol, 16(1), 193. https://doi.org/10.1186/s12882-015-0189-z

Frazier, R., Levine, S., Porteny, T., Tighiouart, H., Wong, J. B., Isakova, T., Koch-Weser, S., Gordon, E. J., Weiner, D. E., & Ladin, K. (2022). Shared Decision Making Among Older Adults With Advanced CKD. Am J Kidney Dis, 80(5), 599-609. https://doi.org/10.1053/j.ajkd.2022.02.017

Fricker, M. (2007). Epistemic Injustice: Power and the Ethics of Knowing. Oxford University Press. https://doi.org/10.1093/acprof:oso/9780198237907.001.0001

Garnett, M. (2023). Ghostwritten Lives: Autonomy, Deference, and Self-Authorship. Ethics, 133(2), 189-215. https://doi.org/10.1086/722126

Gentles, S. J., Charles, C., Ploeg, J., & McKibbon, K. (2015). Sampling in Qualitative Research: Insights from an Overview of the Methods Literature. The Qualitative Report, 20(11), 1772-1789. https://doi.org/ https://doi.org/10.46743/2160-3715/2015.2373

Gerend, M. A., & Shepherd, M. A. (2013). Message framing, it does a body good: effects of message framing and motivational orientation on young women's calcium consumption. J Health Psychol, 18(10), 1296-1306. https://doi.org/10.1177/1359105312463587

Ghimire, S., Castelino, R. L., Lioufas, N. M., Peterson, G. M., & Zaidi, S. T. R. (2015). Nonadherence to Medication Therapy in Haemodialysis Patients: A Systematic Review. PLoS One, 10(12), e0144119. https://doi.org/10.1371/journal.pone.0144119

Gillon, R. (1994). Medical ethics: four principles plus attention to scope. BMJ, 309(6948), 184-188. https://doi.org/10.1136/bmj.309.6948.184

Goff, S. L., Eneanya, N. D., Feinberg, R., Germain, M. J., Marr, L., Berzoff, J., Cohen, L. M., & Unruh, M. (2015). Advance care planning: a qualitative study of dialysis patients and families. Clin J Am Soc Nephrol, 10(3), 390-400. https://doi.org/10.2215/cjn.07490714

Goff, S. L., Unruh, M. L., Klingensmith, J., Eneanya, N. D., Garvey, C., Germain, M. J., & Cohen, L. M. (2019). Advance care planning with patients on hemodialysis: an implementation study. BMC Palliat Care, 18(1), 64. https://doi.org/10.1186/s12904-019-0437-2

Gong, J., Zhang, Y., Yang, Z., Huang, Y., Feng, J., & Zhang, W. (2013). The framing effect in medical decision-making: a review of the literature. Psychology, Health & Medicine, 18(6), 645-653. https://doi.org/10.1080/13548506.2013.766352

Gordon, E. J., Butt, Z., Jensen, S. E., Lok-Ming Lehr, A., Franklin, J., Becker, Y., Sherman, L., Chon, W. J., Beauvais, N., Hanneman, J., Penrod, D., Ison, M. G., & Abecassis, M. M. (2013). Opportunities for shared decision making in kidney transplantation. Am J Transplant, 13(5), 1149-1158. https://doi.org/10.1111/ajt.12195

Graneheim, U. H., Lindgren, B. M., & Lundman, B. (2017). Methodological challenges in qualitative content analysis: A discussion paper. Nurse Educ Today, 56, 29-34. https://doi.org/10.1016/j.nedt.2017.06.002

Graneheim, U. H., & Lundman, B. (2004). Qualitative content analysis in nursing research: concepts, procedures and measures to achieve trustworthiness. Nurse Educ Today, 24(2), 105-112. https://doi.org/10.1016/j.nedt.2003.10.001

Groll, D. (2012). Paternalism, Respect, and the Will. Ethics, 122(4), 692-720.

Gronlund, C. E., Dahlqvist, V., & Soderberg, A. I. (2011). Feeling trapped and being torn: physicians' narratives about ethical dilemmas in hemodialysis care that evoke a troubled conscience. BMC Med Ethics, 12, 8. https://doi.org/10.1186/1472-6939-12-8

Grover, S., Fitzpatrick, A., Azim, F., Ariza-Vega, P., Bellwood, P., Burns, J., Burton, E., Fleig, L., Clemson, L., Hoppmann, C., Madden, K., Price, M., Langford, D., & Ashe, M. (2021). Defining and implementing patient-centered care: An umbrella review. Patient education and counseling. https://doi.org/10.1016/j.pec.2021.11.004

Grubbs, V., Moss, A. H., Cohen, L. M., Fischer, M. J., Germain, M. J., Jassal, S. V., Perl, J., Weiner, D. E., Mehrotra, R., & Dialysis Advisory Group of the American Society of, N. (2014). A palliative approach to dialysis care: a patient-centered transition to the end of life. Clin J Am Soc Nephrol, 9(12), 2203-2209. https://doi.org/10.2215/CJN.00650114

Hall, D. E., Prochazka, A. V., & Fink, A. S. (2012). Informed consent for clinical treatment. CMAJ, 184(5), 533-540. https://doi.org/10.1503/cmaj.112120

Hall, R. K., Cary, M. P., Jr., Washington, T. R., & Colon-Emeric, C. S. (2020). Quality of life in older adults receiving hemodialysis: a qualitative study. Qual Life Res, 29(3), 655-663. https://doi.org/10.1007/s11136-019-02349-9

Hamroun, A., Speyer, E., Ayav, C., Combe, C., Fouque, D., Jacquelinet, C., Laville, M., Liabeuf, S., Massy, Z. A., Pecoits-Filho, R., Robinson, B. M., Glowacki, F., Stengel, B., Frimat, L., & Collaborators, C.-R. s. (2022). Barriers to conservative care from patients' and nephrologists' perspectives: the CKD-REIN study. Nephrol Dial Transplant, 37(12), 2438-2448. https://doi.org/10.1093/ndt/gfac009

Hanna, J. (2018). Soft Paternalism II. Oxford Scholarship Online. https://doi.org/10.1093/oso/9780190877132.003.0007

Hansson, S. O., & Fröding, B. (2021). Ethical conflicts in patient-centred care. Clinical Ethics, 16(2), 55-66. https://doi.org/10.1177/1477750920962356

Harris, J., & Keywood, K. (2001). Ignorance, information and autonomy. Theor Med Bioeth, 22(5), 415-436. https://doi.org/10.1023/a:1013058801622

Hausman, D. M., & Welch, B. (2010). Debate: To Nudge or Not to Nudge. J Political Philosophy, 18(1), 123-136. https://doi.org/10.1111/j.1467-9760.2009.00351.x

Hawley, S. T., & Morris, A. M. (2017). Cultural challenges to engaging patients in shared decision making. Patient Educ Couns, 100(1), 18-24. https://doi.org/10.1016/j.pec.2016.07.008

Heisig, S. R., Shedden-Mora, M. C., Hidalgo, P., & Nestoriuc, Y. (2015). Framing and personalizing informed consent to prevent negative expectations: An experimental pilot study. Health Psychol, 34(10), 1033-1037. https://doi.org/10.1037/hea0000217

Hill, J. T. E. (1991). *Autonomy and Self-Respect*. Cambridge University Press. https://doi.org/DOI: 10.1017/CBO9780511609237

Ho, Y. F., Hsu, P. T., & Yang, K. L. (2022). Peritoneal dialysis after shared decision-making: the disparity between reality and patient expectations. BMC Nurs, 21(1), 268. https://doi.org/10.1186/s12912-022-01043-5

Holley, J. L. (2012). Advance care planning in CKD/ESRD: an evolving process. Clin J Am Soc Nephrol, 7(6), 1033-1038. https://doi.org/10.2215/cjn.00580112

Houben, C. H. M., Spruit, M. A., Groenen, M. T. J., Wouters, E. F. M., & Janssen, D. J. A. (2014). Efficacy of advance care planning: a systematic review and meta-analysis. J Am Med Dir Assoc, 15(7), 477-489. https://doi.org/10.1016/j.jamda.2014.01.008

Hurka, T. (2011). The Best Things In Life - A Guide To What Really Matters. Oxford University Press.

Huxtable, R., & Ives, J. (2019). Mapping, framing, shaping: a framework for empirical bioethics research projects. BMC Med Ethics, 20(1), 86. https://doi.org/10.1186/s12910-019-0428-0

Javier, A. D., Figueroa, R., Siew, E. D., Salat, H., Morse, J., Stewart, T. G., Malhotra, R., Jhamb, M., Schell, J. O., Cardona, C. Y., Maxwell, C. A., Ikizler, T. A., & Abdel-Kader, K. (2017). Reliability and Utility of the Surprise Question in CKD Stages 4 to 5. Am J Kidney Dis, 70(1), 93-101. https://doi.org/10.1053/j.ajkd.2016.11.025

Kahneman, D. (2011). Thinking, fast and slow. Farrar, Straus and Giroux. https://ludwig.lub.lu.se/login?url=https://search.ebscohost.com/login.aspx?direct=true&AuthType=ip,uid&db=cat07147a&AN=lub.2160043&site=eds-live&scope=site

Katz, J. (1994). Informed consent--must it remain a fairy tale? J Contemp Health Law Policy, 10, 69-91. https://www.ncbi.nlm.nih.gov/pubmed/10134817

KDIGO. (2024). Clinical Practice Guideline for the Evaluation and Management of Chronic Kidney Disease. Kidney Int, 105(4s), S117-s314. https://doi.org/10.1016/j.kint.2023.10.018

Keeling, G. (2018). Autonomy, nudging and post-truth politics. J Med Ethics, 44(10), 721-722. https://doi.org/10.1136/medethics-2017-104616

Kennard, A., Glasgow, N., Rainsford, S., & Talaulikar, G. (2023). Frailty in chronic kidney disease: challenges in nephrology practice. A review of current literature. Int Med J, 53(4), 465-472. https://doi.org/https://doi.org/10.1111/imj.15759

Kim, S. P., Knight, S. J., Tomori, C., Colella, K. M., Schoor, R. A., Shih, L., Kuzel, T. M., Nadler, R. B., & Bennett, C. L. (2001). Health literacy and shared decision making for prostate cancer patients with low socioeconomic status. Cancer Invest, 19(7), 684-691. https://doi.org/10.1081/cnv-100106143

Knight, C. (2025). Reflective Equilibrium (Spring 2025 Edition). <https://plato.stanford.edu/archives/spr2025/entries/reflective-equilibrium/>.

Kon, A. A. (2009). The Role of Empirical Research in Bioethics. Am J Bioethics, 9(6-7), 59-65. https://doi.org/10.1080/15265160902874320

Kon, A. A. (2010). The shared decision-making continuum. JAMA, 304(8), 903-904. https://doi.org/10.1001/jama.2010.1208

Korstjens, I., & Moser, A. (2017). Series: Practical guidance to qualitative research. Part 2: Context, research questions and designs. Eur J Gen Pract, 23(1), 274-279. https://doi.org/10.1080/13814788.2017.1375090

Kreps, G. L. (2025). Communication and Effective Interprofessional Healthcare Teams. In S. Fox, K. McAllum, & L. Mikkola (Eds.), Interprofessional Communication in Health and Social Care: Theoretical Perspectives on Practical Realities (pp. 25-40). Springer Nature Switzerland. https://doi.org/10.1007/978-3-031-70106-1_2

Kuehlmeyer, K., Jansky, B., Mertz, M., & Marckmann, G. (2024). Transformative medical ethics: A framework for changing practice according to normative–ethical requirements. Bioethics, 38(3), 241-251. https://doi.org/https://doi.org/10.1111/bioe.13185

Kyngäs, H. (2020). Qualitative Research and Content Analysis. In H. Kyngäs, K. Mikkonen, & M. Kääriäinen (Eds.), The Application of Content Analysis in Nursing Science Research (pp. 3-11). Springer International Publishing. https://doi.org/10.1007/978-3-030-30199-6_1

Ladin, K., Buttafarro, K., Hahn, E., Koch-Weser, S., & Weiner, D. E. (2018). "End-of-Life Care? I'm not Going to Worry About That Yet." Health Literacy Gaps and End-of-Life Planning Among Elderly Dialysis Patients. Gerontologist, 58(2), 290-299. https://doi.org/10.1093/geront/gnw267

Ladin, K., Neckermann, I., D'Arcangelo, N., Koch-Weser, S., Wong, J., Gordon, E., Rossi, A., Rifkin, D., Isakova, T., & Weiner, D. (2021). Advance Care Planning in Older Adults with CKD: Patient, Care Partner, and Clinician Perspectives. JASN, 32, 1527-1535. https://doi.org/10.1681/ASN.2020091298

Ladin, K., Pandya, R., Perrone, R. D., Meyer, K. B., Kannam, A., Loke, R., Oskoui, T., Weiner, D. E., & Wong, J. B. (2018). Characterizing Approaches to Dialysis Decision Making with Older Adults: A Qualitative Study of Nephrologists. Clin J Am Soc Nephrol, 13(8), 1188-1196. https://doi.org/10.2215/CJN.01740218

Langberg, E. M., Dyhr, L., & Davidsen, A. (2019). Development of the concept of patient-centredness - A systematic review. Patient Education and Counseling, 102 7, 1228-1236. https://doi.org/10.1016/j.pec.2019.02.023

Lanini, I., Samoni, S., Husain-Syed, F., Fabbri, S., Canzani, F., Messeri, A., Mediati, R. D., Ricci, Z., Romagnoli, S., & Villa, G. (2022). Palliative Care for Patients with Kidney Disease. J Clin Med, 11(13). https://doi.org/10.3390/jcm11133923

Lanot, A., Bechade, C., Boyer, A., & Lobbedez, T. (2022). Transitions between dialysis modalities. J Nephrol, 35(9), 2411-2415. https://doi.org/10.1007/s40620-022-01397-8

Laurie, G. (2014). Recognizing the Right Not to Know: Conceptual, Professional, and Legal Implications. J Law Med Ethics, 42(1), 53-63. https://doi.org/10.1111/jlme.12118

Lazenby, S., Edwards, A., Samuriwo, R., Riley, S., Murray, M. A., & Carson-Stevens, A. (2017). End-of-life care decisions for haemodialysis patients - 'We only tend to have that discussion with them when they start deteriorating'. Health Expect, 20(2), 260-273. https://doi.org/10.1111/hex.12454

Leiva-Santos, J. P., Sanchez-Hernandez, R., Garcia-Llana, H., Fernandez-Reyes, M. J., Heras-Benito, M., Molina-Ordas, A., Rodriguez, A., & Alvarez-Ude, F. (2012). Renal supportive care and palliative care: revision and proposal in kidney replacement therapy. Nefrologia, 32(1), 20-27. https://doi.org/10.3265/Nefrologia.pre2011.Nov.11065

Leonard, T. C. (2008). Richard H. Thaler, Cass R. Sunstein, Nudge: Improving decisions about health, wealth, and happiness. Constitutional Political Economy, 19(4), 356-360. https://doi.org/10.1007/s10602-008-9056-2

Letts, M., Chesnaye, N. C., Pippias, M., Caskey, F., Jager, K. J., Dekker, F. W., van Diepen, M., Evans, M., Torino, C., Vilasi, A., Szymczak, M., Drechsler, C., Wanner, C., Hole, B., Hayward, S., & investigators, E. s. (2024). Prescribing patterns in older people with advanced chronic kidney disease towards the end of life. Clin Kidney J, 17(11), sfae301. https://doi.org/10.1093/ckj/sfae301

Levy, J. B., Chambers, E. J., & Brown, E. A. (2004). Supportive care for the renal patient. Nephrol Dial Transplant, 19(6), 1357-1360. https://doi.org/10.1093/ndt/gfh178

Levy, N. (2014). Forced to be free? Increasing patient autonomy by constraining it. J Med Ethics, 40(5), 293-300. https://doi.org/10.1136/medethics-2011-100207

Levy, N. (2017). Nudges in a post-truth world. J Med Ethics, 43(8), 495-500. https://doi.org/10.1136/medethics-2017-104153

Levy, N. (2018). Nudges to reason: not guilty. J Med Ethics, 44(10), 723. https://doi.org/10.1136/medethics-2017-104639

Lewis, J., & Gardiner, D. (2023). Ethical and legal issues associated with organ donation and transplantation. Surgery (Oxford), 41(9), 552-558. https://doi.org/https://doi.org/10.1016/j.mpsur.2023.06.010

Lindgren, B. M., Lundman, B., & Graneheim, U. H. (2020). Abstraction and interpretation during the qualitative content analysis process. Int J Nurs Stud, 108, 103632. https://doi.org/10.1016/j.ijnurstu.2020.103632

Litins'ka, Y. (2022). Samtycke och beslutskompetens i vården. In K. Zillén, Mattsson, Titti & Slokenberga, Santa (Ed.), Medicinsk rätt (2 ed., pp. 119-134), Norstedts Juridik.

Liu, C., Wang, D., Liu, C., Jiang, J., Wang, X., Chen, H., Ju, X., & Zhang, X. (2020). What is the meaning of health literacy? A systematic review and qualitative synthesis. Fam Med Community Health, 8(2). https://doi.org/10.1136/fmch-2020-000351

Lund University (2024). Faculty of Medicine: Riktlinjer avseende användningen av generativ AI inom forskarutbildningen. https://www.intramed.lu.se/sites/intramed.lu.se/files/2025-02/AI-policy.pdf

Lu, E., & Blinderman, C. D. (2019). Palliative Care for Patients With Advanced CKD: Moving Beyond the Status Quo. Kidney Med, 1(6), 335-337. https://doi.org/10.1016/j.xkme.2019.09.003

Luckett, T., Sellars, M., Tieman, J., Pollock, C., Silvester, W., Butow, P., Detering, K., Brennan, F., & Clayton, J. (2014). Advance care planning for adults with CKD: a systematic integrative review. Am J Kidney Dis, 63 5, 761-770. https://doi.org/10.1053/j.ajkd.2013.12.007

Lupu, D. E., Aldous, A., Anderson, E., Schell, J. O., Groninger, H., Sherman, M. J., Aiello, J. R., & Simmens, S. J. (2022). Advance Care Planning Coaching in CKD Clinics: A Pragmatic Randomized Clinical Trial. Am J Kidney Dis, 79(5), 699-708.e691. https://doi.org/10.1053/j.ajkd.2021.08.019

Lynøe, N., Engström, I., & Juth, N. (2021). How to reveal disguised paternalism: version 2.0. BMC Med Ethics, 22(1), 170. https://doi.org/10.1186/s12910-021-00739-8

MacRae, C., Mercer, S. W., Guthrie, B., & Henderson, D. (2021). Comorbidity in chronic kidney disease: a large cross-sectional study of prevalence in Scottish primary care. Br J Gen Pract, 71(704), e243-e249. https://doi.org/10.3399/bjgp20X714125

Malpas, P. (2005). The right to remain in ignorance about genetic information--can such a right be defended in the name of autonomy? N Z Med J, 118(1220), U1611.

Malterud, K. (2016). Theory and interpretation in qualitative studies from general practice: Why and how? Scand J Public Health, 44(2), 120-129. https://doi.org/10.1177/1403494815621181

Mandel, E. I., Bernacki, R. E., & Block, S. D. (2017). Serious Illness Conversations in ESRD. Clin J Am Soc Nephrol, 12(5), 854-863. https://doi.org/10.2215/CJN.05760516

Martin, D. E., Harris, D. C. H., Jha, V., Segantini, L., Demme, R. A., Le, T. H., McCann, L., Sands, J. M., Vong, G., Wolpe, P. R., Fontana, M., London, G. M., Vanderhaegen, B., Vanholder, R., Martin, D. E., Harris, D. C. H., Jha, V., Segantini, L., Demme, R. A. et al. (2020). Ethical challenges in nephrology: a call for action. Nat Rev Nephrol, 16(10), 603-613. https://doi.org/10.1038/s41581-020-0295-4

Mathur, V. S., Wesson, D. E., Li, E., & Tangri, N. (2022). Factors Affecting the Decision to Initiate Dialysis: A National Survey of United States Nephrologists. Am J Nephrol, 53(10), 722-729. https://doi.org/10.1159/000528167

Mayring, P. (2015). Qualitative Content Analysis: Theoretical Background and Procedures. In A. Bikner-Ahsbahs, C. Knipping, & N. Presmeg (Eds.), Approaches to Qualitative Research in Mathematics Education: Examples of Methodology and Methods (pp. 365-380). Springer Netherlands. https://doi.org/10.1007/978-94-017-9181-6_13

McKinstry, B. (1992). Paternalism and the doctor-patient relationship in general practice. Br J Gen Pract, 42(361), 340-342.

Mead, N., & Bower, P. (2000). Patient-centredness: a conceptual framework and review of the empirical literature. Soc Science & Medicine, 51(7), 1087-1110. https://doi.org/https://doi.org/10.1016/S0277-9536(00)00098-8

Mehrotra, R., Davison, S. N., Farrington, K., Flythe, J. E., Foo, M., Madero, M., Morton, R. L., Tsukamoto, Y., Unruh, M. L., Cheung, M., Jadoul, M., Winkelmayer, W. C., Brown, E. A., & Conference, P. (2023). Managing the symptom burden associated with maintenance dialysis: conclusions from a Kidney Disease: Improving Global Outcomes (KDIGO) Controversies Conference. Kidney Int, 104(3), 441-454. https://doi.org/10.1016/j.kint.2023.05.019

Menichetti, J., Gulbrandsen, P., Landmark, A. M., Lie, H. C., & Gerwing, J. (2024). How Do Physicians Frame Medical Information in Talks With Their Patients? An Inductive Microanalysis. Qualitative Health Research, 34(1-2), 101-113. https://doi.org/10.1177/10497323231205152

Methven, S., & Caskey, F. (2014). Putting the patient first: should we nudge them or shove them? Nephrol Dial Transplant, 29(5), 941-943. https://doi.org/10.1093/ndt/gft504

Mihailov, E., Provoost, V., & Wangmo, T. (2022). Acceptable objectives of empirical research in bioethics: a qualitative exploration of researchers' views. BMC Med Ethics, 23(1), 140. https://doi.org/10.1186/s12910-022-00845-1

Mill, J. S. (2011). On Liberty. Cambridge University Press. https://doi.org/DOI: 10.1017/CBO9781139149785 (1859)

Molyneux, D. (2009). Should healthcare professionals respect autonomy just because it promotes welfare? J Med Ethics, 35(4), 245-250. https://doi.org/10.1136/jme.2008.024968

Montez-Rath, M. E., Zheng, Y., Tamura, M. K., Grubbs, V., Winkelmayer, W. C., & Chang, T. I. (2017). Hospitalizations and Nursing Facility Stays During the Transition from CKD to ESRD on Dialysis: An Observational Study. J Gen Intern Med, 32(11), 1220-1227. https://doi.org/10.1007/s11606-017-4151-6

Montori, V. M., Ruissen, M. M., Hargraves, I. G., Brito, J. P., & Kunneman, M. (2023). Shared decision-making as a method of care. BMJ Evid Based Med, 28(4), 213-217. https://doi.org/10.1136/bmjebm-2022-112068

Morton, R. L., Devitt, J., Howard, K., Anderson, K., Snelling, P., & Cass, A. (2010). Patient views about treatment of stage 5 CKD: a qualitative analysis of semistructured interviews. Am J Kidney Dis, 55(3), 431-440. https://doi.org/10.1053/j.ajkd.2009.11.011

Morton, R. L., Tong, A., Howard, K., Snelling, P., & Webster, A. C. (2010). The views of patients and carers in treatment decision making for chronic kidney disease: systematic review and thematic synthesis of qualitative studies. BMJ, 340, c112. https://doi.org/10.1136/bmj.c112

Moss, A. H. (2001). Shared decision-making in dialysis: the new RPA/ASN guideline on appropriate initiation and withdrawal of treatment. Am J Kidney Dis, 37(5), 1081-1091. http://www.ncbi.nlm.nih.gov/pubmed/11325693

Moss, A. H., Ganjoo, J., Sharma, S., Gansor, J., Senft, S., Weaner, B., Dalton, C., MacKay, K., Pellegrino, B., Anantharaman, P., & Schmidt, R. (2008). Utility of the "surprise" question to identify dialysis patients with high mortality. Clin J Am Soc Nephrol, 3(5), 1379-1384. https://doi.org/10.2215/cjn.00940208

Moss, A. H. (2017). Integrating Supportive Care Principles Into Dialysis Decision Making: A Primer for Palliative Medicine Providers. J Pain Symptom Manage, 53(3), 656-662 e651. https://doi.org/10.1016/j.jpainsymman.2016.10.371

Murray, A. M., Tupper, D. E., Knopman, D. S., Gilbertson, D. T., Pederson, S. L., Li, S., Smith, G. E., Hochhalter, A. K., Collins, A. J., & Kane, R. L. (2006). Cognitive impairment in hemodialysis patients is common. Neurology, 67(2), 216-223. https://doi.org/10.1212/01.wnl.0000225182.15532.40

Muscat, D. M., Kanagaratnam, R., Shepherd, H. L., Sud, K., McCaffery, K., & Webster, A. (2018). Beyond dialysis decisions: a qualitative exploration of decision-making among culturally and linguistically diverse adults with chronic kidney disease on haemodialysis. BMC Nephrol, 19(1), 339. https://doi.org/10.1186/s12882-018-1131-y

Musschenga, A. W. (2005). Empirical Ethics, Context-Sensitivity, and Contextualism. J Medicine and Philosophy, 30(5), 467-490. https://doi.org/10.1080/03605310500253030

Muthalagappan, S., Johansson, L., Kong, W. M., & Brown, E. A. (2013). Dialysis or conservative care for frail older patients: ethics of shared decision-making. Nephrol Dial Transplant, 28(11), 2717-2722. https://doi.org/10.1093/ndt/gft245

Nikolaidis, A. C. (2021). A Third Conception of Epistemic Injustice. Studies in Philosophy and Education, 40(4), 381-398. https://doi.org/10.1007/s11217-021-09760-1

Nimmon, L., & Stenfors-Hayes, T. (2016). The "Handling" of power in the physician-patient encounter: perceptions from experienced physicians. BMC Med Educ, 16, 114. https://doi.org/10.1186/s12909-016-0634-0

O'Halloran, P., Noble, H., Norwood, K., Maxwell, P., Shields, J., Fogarty, D., Murtagh, F., Morton, R., & Brazil, K. (2018). Advance Care Planning With Patients Who Have End-Stage Kidney Disease: A Systematic Realist Review. J Pain Symptom Manage, 56, 795-807. https://doi.org/10.1016/j.jpainsymman.2018.07.008

O'Hare, A. M., Szarka, J., McFarland, L. V., Taylor, J. S., Sudore, R. L., Trivedi, R., Reinke, L. F., & Vig, E. K. (2016). Provider Perspectives on Advance Care Planning for Patients with Kidney Disease: Whose Job Is It Anyway? Clin J Am Soc Nephrol, 11(5), 855-866. https://doi.org/10.2215/cjn.11351015

O'Neill, O. (2002). Autonomy and Trust in Bioethics. Cambridge University Press. https://doi.org/DOI: 10.1017/CBO9780511606250

Orsino, A., Cameron, J. I., Seidl, M., Mendelssohn, D., & Stewart, D. E. (2003). Medical decision-making and information needs in end-stage renal disease patients. Gen Hosp Psychiatry, 25(5), 324-331. https://doi.org/10.1016/s0163-8343(03)00069-0

Owen-Smith, A., Coast, J., & Donovan, J. (2010a). Are patients receiving enough information about healthcare rationing? A qualitative study. J Med Ethics, 36(2), 88-92. https://doi.org/10.1136/jme.2009.033241

Owen-Smith, A., Coast, J., & Donovan, J. (2010b). The desirability of being open about health care rationing decisions: findings from a qualitative study of patients and clinical professionals. J Health Serv Res Policy, 15(1), 14-20. https://doi.org/10.1258/jhsrp.2009.009045

Palmboom, G. G., Willems, D. L., Janssen, N. B., & de Haes, J. C. (2007). Doctor's views on disclosing or withholding information on low risks of complication. J Med Ethics, 33(2), 67-70. https://doi.org/10.1136/jme.2005.014936

Palmer, B. W., & Harmell, A. L. (2016). Assessment of Healthcare Decision-making Capacity. Arch Clin Neuropsychol, 31(6), 530-540. https://doi.org/10.1093/arclin/acw051

Paterick, T. J., Carson, G. V., Allen, M. C., & Paterick, T. E. (2008). Medical informed consent: general considerations for physicians. Mayo Clin Proc, 83(3), 313-319. https://doi.org/10.4065/83.3.313

Pellegrino, E. D. (2006). Toward a reconstruction of medical morality. Am J Bioeth, 6(2), 65-71. https://doi.org/10.1080/15265160500508601

Perry, J. (2007). Patients do not live in an information vacuum. BMJ, 334(7600), 915. https://doi.org/10.1136/bmj.39199.465648.3A

Peters, K., & Halcomb, E. (2015). Interviews in qualitative research. Nurse Res, 22(4), 6-7. https://doi.org/10.7748/nr.22.4.6.s2

Phillips, C. R., MacNab, C. J., & Loewen, L. M. (2018). Advance Care Planning and Chronic Kidney Disease: What Do Patients Know and What Do They Want? Nephrol Nurs J, 45(6), 513-523. https://www.ncbi.nlm.nih.gov/pubmed/30585708

Ploug, T. (2018). Physicians' framing and recommendations. Are they nudging? And do they violate the requirements of informed consent? J Med Ethics, 44(8), 543-544. https://doi.org/10.1136/medethics-2017-104653

Rahimi, S., & Khatooni, M. (2024). Saturation in qualitative research: An evolutionary concept analysis. Int J Nurs Stud Adv, 6, 100174. https://doi.org/10.1016/j.ijnsa.2024.100174

Ramer, S. J., McCall, N. N., Robinson-Cohen, C., Siew, E. D., Salat, H., Bian, A., Stewart, T. G., El-Sourady, M. H., Karlekar, M., Lipworth, L., Ikizler, T. A., & Abdel-Kader, K. (2018). Health Outcome Priorities of Older Adults with Advanced CKD and Concordance with Their Nephrology Providers' Perceptions. J Am Soc Nephrol, 29(12), 2870-2878. https://doi.org/10.1681/asn.2018060657

Rawls, J. (1971). A Theory of Justice. Original Edition. Harvard University Press. https://doi.org/10.2307/j.ctvjf9z6v

Rees, M. (2023). Patient autonomy and withholding information. Bioethics, 37(3), 256-264. https://doi.org/10.1111/bioe.13130

Reese, P. P., Boudville, N., & Garg, A. X. (2015). Living kidney donation: outcomes, ethics, and uncertainty. Lancet, 385(9981), 2003-2013. https://doi.org/10.1016/s0140-6736(14)62484-3

Regeringen. (1996). Swedish Government, Ministry of Health and Social Affairs, proposition Priorities in Health Care 1996/97:60.

Rietjens, J. A. C., Sudore, R. L., Connolly, M., van Delden, J. J., Drickamer, M. A., Droger, M., van der Heide, A., Heyland, D. K., Houttekier, D., Janssen, D. J. A., Orsi, L., Payne, S., Seymour, J., Jox, R. J., Korfage, I. J., & European Association for Palliative, C. (2017). Definition and recommendations for advance care planning: an international consensus supported by the European Association for Palliative Care. Lancet Oncol, 18(9), e543-e551. https://doi.org/10.1016/S1470-2045(17)30582-X

Robins, L., Witteborn, S., Miner, L., Mauksch, L., Edwards, K., & Brock, D. (2011). Identifying transparency in physician communication. Patient Educ Couns, 83(1), 73-79. https://doi.org/10.1016/j.pec.2010.05.004

Rocque, G. B., Williams, C. P., Halilova, K. I., Borate, U., Jackson, B. E., Van Laar, E. S., Pisu, M., Butler, T. W., Davis, R. S., Mehta, A., Knight, S. J., & Safford, M. M. (2018). Improving shared decision-making in chronic lymphocytic leukemia through multidisciplinary education. Transl Behav Med, 8(2), 175-182. https://doi.org/10.1093/tbm/ibx034

Rynning, E. (1994). Samtycke till medicinsk vård och behandling: En rättsvetenskaplig studie, Uppsala university.

Saeed, F., Duberstein, P. R., Epstein, R. M., Lang, V. J., & Liebman, S. E. (2021). Frequency and Severity of Moral Distress in Nephrology Fellows: A National Survey. Am J Nephrol, 52(6), 487-495. https://doi.org/10.1159/000516575

Sandman, L. (2009). The concept of negotiation in shared decision making. Health Care Anal, 17(3), 236-243. https://doi.org/10.1007/s10728-008-0103-y

Sandman, L., Granger, B. B., Ekman, I., & Munthe, C. (2012). Adherence, shared decision-making and patient autonomy. Med Health Care Philos, 15(2), 115-127. https://doi.org/10.1007/s11019-011-9336-x

Sandman, L., & Munthe, C. (2009). Shared decision-making and patient autonomy. Theor Med Bioeth, 30(4), 289-310. https://doi.org/10.1007/s11017-009-9114-4

Sandman, L., & Munthe, C. (2010). Shared decision making, paternalism and patient choice. Health Care Anal, 18(1), 60-84. https://doi.org/10.1007/s10728-008-0108-6

Santana, S., Brach, C., Harris, L., Ochiai, E., Blakey, C., Bevington, F., Kleinman, D., & Pronk, N. (2021). Updating Health Literacy for Healthy People 2030: Defining Its Importance for a New Decade in Public Health. J Public Health Manag Pract. https://doi.org/10.1097/PHH.0000000000001324

Savulescu, J. (2007). Autonomy, the Good Life, and Controversial Choices. In The Blackwell Guide to Medical Ethics (pp. 17-37). https://doi.org/https://doi.org/10.1002/9780470690932.ch1

Schiavone, G., De Anna, G., Mameli, M., Rebba, V., & Boniolo, G. (2014). Libertarian paternalism and health care policy: a deliberative proposal. Med Health Care Philos, 17(1), 103-113. https://doi.org/10.1007/s11019-013-9502-4

Schmidt, A. T., & Engelen, B. (2020). The ethics of nudging: An overview. Philosophy Compass, 15(4). https://doi.org/10.1111/phc3.12658

Schmidt, M. W. (2024). Defining the method of reflective equilibrium. Synthese, 203(5), 170. https://doi.org/10.1007/s11229-024-04571-6

Schmidt, R. J., & Moss, A. H. (2014). Dying on dialysis: the case for a dignified withdrawal. Clin J Am Soc Nephrol, 9(1), 174-180. https://doi.org/10.2215/CJN.05730513

Schmidt, R. J., Landry, D. L., Cohen, L., Moss, A. H., Dalton, C., Nathanson, B. H., & Germain, M. J. (2019). Derivation and validation of a prognostic model to predict mortality in patients with advanced chronic kidney disease. Nephrol Dial Transplant, 34(9), 1517-1525. https://doi.org/10.1093/ndt/gfy305

Schrauben, S. J., Chen, H. Y., Lin, E., Jepson, C., Yang, W., Scialla, J. J., Fischer, M. J., Lash, J. P., Fink, J. C., Hamm, L. L., Kanthety, R., Rahman, M., Feldman, H. I., & Anderson, A. H. (2020). Hospitalizations among adults with chronic kidney disease in the United States: A cohort study. PLoS Med, 17(12), e1003470. https://doi.org/10.1371/journal.pmed.1003470

Shiffrin, S. V. (2000). Paternalism, Unconscionability Doctrine, and Accommodation. Philosophy & Public Affairs, 29(3), 205-250. http://www.jstor.org.ludwig.lub.lu.se/stable/2672846

Shiu-Hwa Tsu, P. (2025). "Moral Particularism", Internet Encyclopedia of Philosophy. https://iep.utm.edu/morlpat/

Simkulet, W. (2018). Nudging, informed consent and bullshit. J Med Ethics, 44(8), 536-542. https://doi.org/10.1136/medethics-2017-104480

Simkulet, W. (2019). Informed consent and nudging. Bioethics, 33(1), 169-184. https://doi.org/10.1111/bioe.12449

Sjöstrand, M., Eriksson, S., Juth, N., & Helgesson, G. (2013). Paternalism in the Name of Autonomy. J Med Philos, 38(6), 710-724. https://doi.org/10.1093/jmp/jht049

Sledge, R., Meyer, D., Heiden-Rootes, K., Zubatsky, M., Browne, T., & Philipneri, M. (2023). Dyadic shared decision-making in dialysis: An interpretive phenomenological inquiry. Fam Syst Health, 41(1), 7-15. https://doi.org/10.1037/fsh0000718

Smith, C., Da Silva-Gane, M., Chandna, S., Warwicker, P., Greenwood, R., & Farrington, K. (2003). Choosing not to dialyse: evaluation of planned non-dialytic management in a cohort of patients with end-stage renal failure. Nephron Clin Pract, 95(2), c40-46. https://doi.org/73708

Socialdepartementet. (1991). Swedish Parliament, The Compulsory Psychiatric Care Act (Lagen om psykiatrisk tvångsvård 1991:1128).

Socialdepartementet. (2014). Swedish Parliament, Swedish Patient Act (Patientlagen 2014:821).

Song, M.-K., Manatunga, A., Plantinga, L., Metzger, M., Kshirsagar, A. V., Lea, J., Abdel-Rahman, E. M., Jhamb, M., Wu, E., Englert, J., & Ward, S. E. (2024). Effectiveness of an Advance Care Planning Intervention in Adults Receiving Dialysis and Their Families: A Cluster Randomized Clinical Trial. JAMA Network Open, 7(1), e2351511-e2351511. https://doi.org/10.1001/jamanetworkopen.2023.51511

Song, M. K., Lin, F. C., Gilet, C. A., Arnold, R. M., Bridgman, J. C., & Ward, S. E. (2013). Patient perspectives on informed decision-making surrounding dialysis initiation. Nephrol Dial Transplant, 28(11), 2815-2823. https://doi.org/10.1093/ndt/gft238

Song, M. K., Plantinga, L., Metzger, M., Noorani, N., Lea, J., Kshirsagar, A. V., Jhamb, M., Abdel-Rahman, E. M., Laszlo, M., Wu, E., Englert, J., Manatunga, A., Benloukil, S., Timmons, W., Turberville-Trujillo, L., & Ward, S. E. (2025). Implementation of An Advance Care Planning Intervention in Dialysis Clinics. Am J Kidney Dis. https://doi.org/10.1053/j.ajkd.2024.12.003

Spatz, E. S., Krumholz, H. M., & Moulton, B. W. (2016). The New Era of Informed Consent: Getting to a Reasonable-Patient Standard Through Shared Decision Making. JAMA, 315(19), 2063-2064. https://doi.org/10.1001/jama.2016.3070

Stiggelbout, A. M., Pieterse, A. H., & De Haes, J. C. (2015). Shared decision making: Concepts, evidence, and practice. Patient Educ Couns, 98(10), 1172-1179. https://doi.org/10.1016/j.pec.2015.06.022

Sumner, L. W. (1996). Welfare, Happiness & Ethics. Oxford University Press.

Sunstein, C. R. (2016). The Ethics of Influence - Government in the Age of Behavioral Science. Cambridge University Press.

Surbone, A., & Lowenstein, J. (2003). Exploring asymmetry in the relationship between patients and physicians. J Clin Ethics, 14(3), 183-188.

Swidler, M. (2013). Considerations in starting a patient with advanced frailty on dialysis: complex biology meets challenging ethics. Clin J Am Soc Nephrol, 8(8), 1421-1428. https://doi.org/10.2215/CJN.12121112

Takala, T. (2001). Genetic ignorance and reasonable paternalism. Theor Med Bioeth, 22(5), 485-491. https://doi.org/10.1023/a:1013019120277

Taylor, C. (1991). The Ethics of Authenticity. Harvard University Press. https://doi.org/10.2307/j.ctvv41887

Taylor, T. E. (2013). Well-being and Prudential Value. Philosophy & Public Policy Quarterly, 31(2), 10-17.

Tengland, P. A. (2006). The goals of health work: Quality of life, health and welfare. Med Health Care Philos, 9(2), 155-167. https://doi.org/10.1007/s11019-005-5642-5

Tersman, F. (2018). Recent work on reflective equilibrium and method in ethics. Philosophy Compass, 13(6), e12493. https://doi.org/https://doi.org/10.1111/phc3.12493

Thaler, R. H., & Sunstein, C. R. (2008). Nudge: Improving decisions about health, wealth, and happiness. Yale University Press.

Thaler, R. H. S., Cass R. (2003). Libertarian Paternalism. AEA Papers and Proceedings, Behavioral Economics, Public Policy, and Paternalism, 175-179.

Thimmaiah, R., Murthy, K. K., & Pinto, D. (2012). Cognitive dysfunction in patients with renal failure requiring hemodialysis. Indian J Psychol Med, 34(3), 237-241. https://doi.org/10.4103/0253-7176.106019

Tonelli, M., Wiebe, N., Guthrie, B., James, M. T., Quan, H., Fortin, M., Klarenbach, S. W., Sargious, P., Straus, S., Lewanczuk, R., Ronksley, P. E., Manns, B. J., & Hemmelgarn, B. R. (2015). Comorbidity as a driver of adverse outcomes in people with chronic kidney disease. Kidney Int, 88(4), 859-866. https://doi.org/10.1038/ki.2015.228

Tong, A., Winkelmayer, W. C., Wheeler, D. C., van Biesen, W., Tugwell, P., Manns, B., Hemmelgarn, B., Harris, T., Crowe, S., Ju, A., O'Lone, E., Evangelidis, N., Craig, J. C., & Initiative, S.-H. (2017). Nephrologists' Perspectives on Defining and Applying Patient-Centered Outcomes in Hemodialysis. Clin J Am Soc Nephrol, 12(3), 454-466. https://doi.org/10.2215/CJN.08370816

Tversky, A., & Kahneman, D. (1981). The framing of decisions and the psychology of choice. Science, 211(4481), 453-458. http://www.ncbi.nlm.nih.gov/pubmed/7455683

Tweed, A. E., & Ceaser, K. (2005). Renal replacement therapy choices for pre-dialysis renal patients. Br J Nurs, 14(12), 659-664. https://doi.org/10.12968/bjon.2005.14.12.18287

Tännsjö, T. (1998). Vårdetik (3 ed.). Thales.

Verberne, W. R., Konijn, W. S., Prantl, K., Dijkers, J., Roskam, M. T., van Delden, J. J. M., & Bos, W. J. W. (2019). Older patients' experiences with a shared decision-making process on choosing dialysis or conservative care for advanced chronic kidney disease: a survey study. BMC Nephrol, 20(1), 264. https://doi.org/10.1186/s12882-019-1423-x

Vetenskapsrådet. (2024). Swedish Research Council: Good Research Practice. Retrieved from https://www.vr.se/english/analysis/reports/our-reports/2025-07-03-good-research-practice-2024.html

Visser, A., Dijkstra, G. J., Kuiper, D., de Jong, P. E., Franssen, C. F., Gansevoort, R. T., Izaks, G. J., Jager, K. J., & Reijneveld, S. A. (2009). Accepting or declining dialysis: considerations taken into account by elderly patients with end-stage renal disease. J Nephrol, 22(6), 794-799. http://www.ncbi.nlm.nih.gov/pubmed/19967659

Walker, R. C., Howard, K., & Morton, R. L. (2016). Patient Education and Choice of Peritoneal Dialysis. Am J Kidney Dis, 68(3), 341-343. https://doi.org/10.1053/j.ajkd.2016.06.007

Wallin, J. M., Jacobson, S. H., Axelsson, L., Lindberg, J., Persson, C. I., Stenberg, J., & Wennman-Larsen, A. (2023). Discrepancy in responses to the surprise question between hemodialysis nurses and physicians, with focus on patient clinical characteristics: A comparative study. Hemodial Int, 27(4), 454-464. https://doi.org/10.1111/hdi.13103

Wallin, J. M., Jacobson, S. H., Axelsson, L., Lindberg, J., Persson, C. I., Stenberg, J., & Wennman-Larsen, A. (2024). The Surprise Question and Health-Related Quality of Life in Patients on Hemodialysis: A Cross-Sectional Multicenter Study. Palliat Med Rep, 5(1), 306-315. https://doi.org/10.1089/pmr.2023.0093

Walter, J. K., & Ross, L. F. (2014). Relational autonomy: moving beyond the limits of isolated individualism. Pediatrics, 133 Suppl 1, S16-23. https://doi.org/10.1542/peds.2013-3608D

Wheeler, D. C., Szymanski, K. M., Black, A., & Nelson, D. E. (2011). Applying strategies from libertarian paternalism to decision making for prostate specific antigen (PSA) screening. BMC Cancer, 11, 148. https://doi.org/10.1186/1471-2407-11-148

Wilson, J. (2005). To know or not to know? Genetic ignorance, autonomy and paternalism. Bioethics, 19(5-6), 492-504. https://doi.org/10.1111/j.1467-8519.2005.00460.x

Worthy, D. A., Byrne, K. A., & Fields, S. (2014). Effects of emotion on prospection during decision-making. Front Psychol, 5, 591. https://doi.org/10.3389/fpsyg.2014.00591

Youngs, J., & Simmonds, J. (2016). HIV and the right not to know. J Med Ethics, 42(2), 95-99. https://doi.org/10.1136/medethics-2015-102956

Yu, X., Nakayama, M., Wu, M. S., Kim, Y. L., Mushahar, L., Szeto, C. C., Schatell, D., Finkelstein, F. O., Quinn, R. R., & Duddington, M. (2022). Shared Decision-Making for a Dialysis Modality. Kidney Int Rep, 7(1), 15-27. https://doi.org/10.1016/j.ekir.2021.10.019