

**Physicians' Personal End-of-life
Preferences and Their Connection to
Clinical Practice**

An International Multi-Method Study

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Mroz S, Dierickx S, Deliens L, Cohen J, Chambaere K. Assisted dying around the world: a status quaestionis. *Ann Palliat Med*. 2021 Mar;10(3):3540-3553. [2021 SCI impact factor 1.925; journal ranking Q3; ranking n°106/159 in category Health Science & Services].

Mroz S, Deliens L, Cohen J, Chambaere K. Developments Under Assisted Dying Legislation: The Experience in Belgium and Other Countries. *Dtsch Arztebl Int*. 2022 Dec;119(48):829–35.[2023 SCI impact factor 6.5; journal ranking Q1; ranking n°26/329 in category Medicine General & Internal].

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Mroz S, Dierickx S, Chambaere K, Mortier F, De Panfilis L, Downar J, Lapenskie J, Anderson K, Skold A, Campbell C, Campbell T, Feeney R, Willmott L, White B, Deliens L. Physicians' preferences for their own end-of-life: A comparison across North America, Europe, and Australia (In revision with the *Journal of Medical Ethics*).

Chapter 3

Mroz S, Daenen F, Dierickx S, Mortier F, De Panfilis L, Ghirotto L, Campbell T, Deliens L, Chambaere K. What do physicians want at the end? An international qualitative study on physicians' own end-of-life preferences and what influences them (In revision with *Palliative Care and Social Practice*).

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Chapter 5

Mroz S, Daenen F, Dierickx S, Mortier F, De Panfilis L, Ghirotto L, Campbell T, Deliens L, Chambaere K. How do physicians perceive and manage the influence of their personal end-of-life preferences on clinical practice and end-of-life

decision making with patients? PROPEL international qualitative study
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PART I

INTRODUCTION

Chapter 1

Background, research questions and outline of this dissertation

This chapter is based in part on the following:

Mroz S, Dierickx S, Deliens L, Cohen J, Chambaere K. Assisted dying around the world: a status quaestionis. Ann Palliat Med. 2021 Mar;10(3):3540-3553.

Mroz S, Deliens L, Cohen J, Chambaere K. Developments Under Assisted Dying Legislation: The Experience in Belgium and Other Countries. Dtsch Arztebl Int. 2022 Dec;119(48):829–35.

1. Introduction

In developed countries with aging populations, people are living longer and facing unprecedented levels of chronic disease and extended illness trajectories, which underscores the growing clinical and societal importance of improving end-of-life care.¹ Death is foreseeable in two out of three deaths, and in half of all deaths, at least one medical end-of-life decision is required.^{1,2} End-of-life decisions can include withholding or withdrawing treatment, intensification of symptom management using medication, palliative sedation, or assisted dying, which includes euthanasia and physician-assisted suicide (PAS).¹ Palliative sedation is the administration of drugs to a patient to induce sedation to relieve end-of-life suffering.^{1,2} Euthanasia refers to the act of intentionally ending the life of a patient by a health care practitioner by means of active drug administration at that patient's explicit request.³ PAS involves the provision or prescribing of drugs by a health care practitioner for a patient to use to end their own life.³ The term "assisted dying" is used here as an umbrella term referring to both the practice of euthanasia and PAS. These decisions have a significant impact on individuals, families, healthcare systems and society. Physicians play a critical role in initiating and conducting end-of-life conversations and they have considerable influence on the decision-making process.⁴ Research has found that physicians' recommendations significantly impact patients' treatment preferences as well as their attitudes toward treatments.⁵

1.1 Physicians' personal end-of-life decision preferences

Physicians often face confronting medical scenarios and patients frequently seek guidance when making difficult decisions by asking their physician what they would do in their position, so it is expected that physicians would consider what they would want for themselves.^{6,7} Research has indicated that physicians largely wish to forego high-intensity treatments for themselves at the end of life, and physicians with significant levels of exposure to sick patients are unlikely to prefer aggressive treatment if they themselves become terminally ill, demented, or are in a persistent vegetative state.^{8,9} Studies have found that physicians would likely refuse many life-sustaining treatments in a scenario with poor survival prognosis.^{10,11} Research analyzing the resuscitation preferences of a large and

diverse group of younger physicians determined that, like older physicians, they also prefer comfort care for themselves at the end of life.⁹ There is limited information on physicians' personal preferences related to assisted dying, however, one study revealed that nearly 40% of physicians would request physician assisted suicide if they had severely disabling amyotrophic lateral sclerosis (ALS) and a significant number were in support of euthanasia if they had an advanced motor neuron disease.¹¹

It is important to situate end-of-life decisions within the context of medical care and appreciate that they occur within a broader continuum of care. This continuum ranges from early chronic disease management to palliative and terminal care, where physicians' perspectives and preferences may shape patient care decisions at multiple stages. In chronic disease management, physicians influence treatment trajectories by discussing prognosis, assisting in the identification of priorities, shaping expectations about interventions such as CPR, artificial nutrition and hydration, and ventilation, and potentially guiding or facilitating advance care planning.¹² Physicians may also play a pivotal role in the integration of palliative care throughout the care continuum, screening patients for palliative services and reassessing throughout their care trajectory. This allows for the early identification and management of symptoms and addresses psychosocial and spiritual needs. As illnesses progress, physician perspectives can influence how symptoms are managed and the extent to which comfort-focused care is prioritized over life-prolonging measures. These decisions are not made in isolation but are shaped by patient, physician, and institutional factors.¹² Understanding this continuum is critical in recognizing how physicians' personal preferences may subtly or overtly play a role in patient care, particularly in the transition from curative to palliative intent, where ethical considerations and medical judgment intersect.

Various terms are used in this dissertation including preferences, attitudes, beliefs, and values. These are interconnected yet distinct psychological constructs that influence human behavior and decision-making.¹³ Our exploration of physicians' personal end-of-life preferences involved individual physician's evaluative judgments about the desirability of specific theoretical end-of-life options and their perceptions about the connection of their preferences with clinical practice. We understand that since personal preferences are often constructed during the decision-making process and are highly influenced by context,

physicians' preferences may ultimately be different when faced with actual end-of-life situations and decisions. Attitudes refer to enduring evaluations— either positive or negative—guiding responses across various situations.¹³ Beliefs are convictions about the truth of information or propositions, forming the cognitive basis for attitudes and influencing how individuals interpret experiences, and values are deeply held principles that serve as guiding standards for behavior and judgments across contexts.¹³ The terms used in this dissertation were largely selected to reflect the language used by participating physicians to describe their personal end-of-life preferences and perspectives.

1.2 Contextual factors influencing physicians' end-of-life preferences

Various factors influence physicians' end-of-life preferences, including their personal and professional backgrounds, ethical perspectives and legal environment.^{11,14} Studies suggest the factors with the most significant impact on physicians' preferences include religious background, personal values, age, health status, physician specialty, experience, country of origin, and place of training¹⁵⁻¹⁷ Multiple studies have identified religious beliefs as consistently related to end-of-life care attitudes and behaviors and physicians with more strongly held religious beliefs are more likely to object to the withdrawal of life support and assisted dying.^{11,16,18,19} Attitudes towards end-of-life issues have also been shown to be highly connected to location, with the majority of physicians approving of assisted dying in Belgium and the Netherlands and 40-50% in the US and Western Europe.²⁰ The presence or absence of assisted dying legislation is a critical macro-level factor that impacts physicians' end-of-life care options. As we wrote two invited papers on assisted dying practices, we will delve deeper into this topic.

The experiences, personal feelings and clinical practice of physicians is deeply influenced by their environment and those who work in a jurisdiction and institution where assisted dying is allowed may have vastly different ideas about what they would prefer for themselves at the end-of-life than those with limited experience or no exposure.²¹ End-of-life decisions related to assisted dying can be particularly fraught as hastening death has substantial consequences for patients and families and the practices are ethically loaded and remain contested.²² However, research indicates that attitudes about assisted dying change rapidly

once legalization has occurred and physicians practicing in jurisdictions with assisted dying legislation are more accepting of the practices.²¹

1.3 Assisted dying as part of a good death

Leading causes of death, including cancer and cardiovascular disease, can involve long and debilitating trajectories complicated by the use of medical-technological interventions, which can extend life but can also lead to protracted suffering.^{23,24} Disease-associated pain, suffering, functional and cognitive decline, and related losses of dignity and autonomy motivate some people to wish for hastened death.^{23,25} Assisted dying practices have become increasingly important considerations for medical practice, end-of-life care and public health as they are debated and legislation is passed in a growing number of jurisdictions around the world.^{25,26}

Research has explored the evolution of societal views on assisted dying by examining the concept of a "good death" across different philosophical, cultural, and religious frameworks, from ancient beliefs focused on honor in death, to Stoic ideals of acceptance and virtue.²⁷ The spread of Christianity brought a shift in views which emphasized spiritual purity and the afterlife, condemning voluntary death, including suicide, as opposing divine will.²⁷ In modern contexts, assisted dying has developed into a complex ethical and medical debate, often focusing on patient autonomy and quality of life.²⁷ While ancient and modern views share the aim of minimizing suffering, contemporary discussions incorporate specific legal and moral implications that reflect changes in societal values.²⁷ For many, the concept of a "good death" now includes having a planned, peaceful, and dignified end-of-life, at home, surrounded by loved ones.²⁸ For some, assisted dying offers a pathway to achieving such a death. Research exploring contemporary international perspectives on assisted dying, including the views of patients, caregivers, and the public found that autonomy, quality of life, and the avoidance of unbearable suffering are among the primary motivations behind the desire for assisted dying.²⁹ Maintaining personal control and a sense of dignity at the end of life were revealed to be as crucial in dying as they are in life.²⁹ Studies have identified consistent themes across varied demographics, indicating that these perspectives cut across cultural, economic, and healthcare contexts and suggest they are universal considerations.²⁹

1.4 Current legal status

Twenty-nine jurisdictions around the world now allow some form of assisted dying and many more are debating and considering legislation.^{30,31} (Table 1) Currently, euthanasia is legal in fourteen jurisdictions: the Netherlands, Belgium, Luxemburg, Colombia, Canada, New Zealand, six Australian states (Victoria, Western Australia, Northern Territory, Queensland, South Australia, Tasmania), Spain and Portugal.^{3,31} PAS without the option for euthanasia, is legally practiced in Switzerland, Austria and eleven US jurisdictions: Oregon, Washington, Montana, Vermont, California, Colorado, District of Columbia, Hawaii, Maine, New Jersey and New Mexico.^{31,32} More than fifteen other US states have recently introduced or are currently considering death with dignity laws.³³ In Italy and Germany, courts declared the criminalization of assisted suicide unconstitutional, though Italy has extremely narrow eligibility criteria, and the German parliament has not yet finalized legislation.^{3,34} While most assisted dying legislation is limited to those with terminal illness due to somatic disorders, the Benelux countries allow requests with non-terminal conditions; where death is not foreseeable.^{35,36}

1.5 Frequency of assisted dying practices

The frequency of assisted dying practices varies across jurisdictions and is tracked through mandatory reporting and mortality follow-back studies. In the Netherlands, euthanasia cases have increased steadily since legalization in 2002, rising from under 2,000 annually to 9,068 cases (5.4% of total deaths) in 2023.^{31,37} Belgium reported 3,423 euthanasia cases in 2023 (3.1% of deaths), with the majority occurring in the Dutch-speaking population. Applying broader definitions of euthanasia in Flanders suggest a frequency of 4.6% of deaths in 2013, though underreporting is a recognized issue in both countries (data on rates beyond 2013 is unavailable so the current situation is uncertain, but the number is likely higher still).^{20,25,26} Physicians sometimes fail to report cases due to misclassification or procedural barriers.³⁸

Elsewhere, Luxembourg recorded 34 cases in 2022 (0.76% of deaths)³¹, and Canada reported euthanasia in 4.1% of deaths in 2022.³⁶ Switzerland has seen a steady rise in assisted suicide cases, more than doubling from 500 in 2012 to 1,125 in 2022 (1.5% of deaths) and hosting

about 150–200 “suicide tourists” annually.^{39,40} In the U.S. state of Oregon, physician-assisted suicide accounted for less than 0.4% of deaths from 1998 to 2015, with requests steadily increasing over time.^{20,41} Despite variations, underreporting and differences in legal frameworks complicate cross-country comparisons of assisted dying practices. Due to the recent passage of laws in several additional jurisdictions data and information on trends is lacking.

TABLE 1: Jurisdictions with AD laws and frequency of reported euthanasia and assisted suicide

Jurisdiction	Year of law passage or decision	Euth and/or PAS	Type of legislation or decision	Year of latest known number of deaths	Number of annual deaths by euth and/or PAS	Percentage of all deaths
Europe						
Portugal	2023	E-PAS	Legislation	A	a	a
Austria	2021	PAS	Legislation	A	a	a
Germany	2020	PAS	Decriminalisation	A	a	a
Italy	2019	PAS	Decriminalisation	A	a	a
Spain	2021	E-PAS	Legislation	2022	288	.06%
Switzerland	1942	PAS	Decriminalisation	2022	1125	1.5%
Netherlands	2002	E-PAS	Legislation	2023	9068	5.4%
Belgium	2002	E-PAS	Legislation	2023	3423	3.1%
Luxembourg	2009	E-PAS	Legislation	2022	34	a
America						
Canada	2016	E-PAS	Legislation	2022	13,241	4.1%
Colombia	1997	E-PAS	Court ruling	2021	47	a
USA						
Oregon	1997	PAS	Legislation	2023	367	a
Washington	2009	PAS	Legislation	2022	363	a
Montana	2009	PAS	Court ruling	A	a	a
Vermont	2013	PAS	Legislation	2021-2023	72 (b)	a
California	2015	PAS	Legislation	2023	884	a
Colorado	2016	PAS	Legislation	2023	389	a
District of Columbia	2016	PAS	Legislation	2022	8	a
Hawaii	2018	PAS	Legislation	2023	59	a
Maine	2019	PAS	Legislation	2023	53	
New Jersey	2019	PAS	Legislation	2023	101	a
New Mexico	2021	PAS	Legislation	A	a	a
Australia						
Victoria	2017	E-PAS	Legislation	2022-2023	306	a
Western Australia	2019	E-PAS	Legislation	2023-2024	292	1.6%
Northern Territory	1995	E-PAS	Legislation	1996-1997	7	a

Queensland	2021	E-PAS	Legislation	A	a	a
South Australia	2021	E-PAS	Legislation	A	a	a
Tasmania	2021	E-PAS	Legislation	A	a	a
New Zealand	2019		Legislation	2021-2022	257	a
a: Data not (yet) available						
b: number of medical aid in dying cases between July 1, 2021 to June 30, 2023						

1.6 Debates related to assisted dying

The ethical debates around assisted dying are complex and highly polarized and have led to divisions among physician groups.⁴² Proponents emphasize autonomy and self-determination, arguing that these practices offer dignity in dying and relief from unbearable suffering, particularly when other options fail. They advocate for assisted dying as a safer alternative to unregulated suicides, with physicians ensuring the process is controlled and compassionate.^{43,44} Opponents, however, assert that euthanasia and PAS violate the Hippocratic Oath, harm the patient-physician relationship, and undermine public trust in healthcare.³ They argue that suffering can be adequately addressed through palliative care or palliative sedation and warn of potential abuses, particularly against vulnerable populations, invoking the "slippery slope" argument and religious principles such as the sanctity of life.^{43,45,46}

The "slippery slope" argument suggests that legalization inevitably leads to misuse, harm, and broader application to vulnerable populations, such as older individuals, minors, and those with disabilities or psychiatric conditions.³ For instance, critics cite Belgium's 2014 extension of assisted dying to minors as evidence of this slope. However, this amendment included stringent criteria, limiting eligibility to terminally ill minors with physical suffering and capacity for discernment, and resulted in very few cases.⁴⁷ Other concerns include the potential for suicide contagion, where assisted dying might trigger suicidal ideation in vulnerable individuals.³ Yet, evidence from Belgium, where euthanasia was legalized in 2002, shows no significant association between euthanasia legislation and general suicide rates.⁴⁸ Additionally, the practice of life-ending acts without explicit patient requests remains a contentious issue. Critics link this to euthanasia laws, though studies suggest these actions

often align with patient wishes, are primarily aimed at symptom management, and also exist in jurisdictions without assisted dying laws.^{49–51} This is not a counter argument for the critics, but a finding that contradicts proponents of assisted dying.

The most contentious assisted dying debates center on vulnerable groups, including individuals with psychiatric disorders, dementia, or disabilities; socioeconomically disadvantaged people; and minors.^{20,45} Assisted dying for psychiatric conditions or dementia—legal only in Belgium, the Netherlands, Luxembourg, and Canada (*delayed until 2027*)—raises concerns about mental capacity, voluntariness, and the potential emotional burden on healthcare providers.^{35,52} These debates underscore the ethical, legal, and societal tensions surrounding assisted dying practices.

1.7 Evolution of assisted dying practices after legalization

To conceptualize the potential impact of assisted dying legislation on physicians, it is essential to examine the development of such laws in jurisdictions where they have been established for some years. Since the legalization of assisted dying in Belgium, the practice has steadily increased, from 235 cases (0.2% of all deaths) in 2003 to 3,423 cases (3.1% of all deaths) in 2023.^{49,53,54} This growth reflects an initial phase of cautious acceptance, followed by broader implementation as physicians and health systems gained familiarity with the practice. A survey in Flanders, Belgium revealed that both euthanasia requests and granting rates increased significantly between 2007 and 2013, driven by reduced barriers, cultural shifts favoring autonomy, enhanced education and training, and professional support systems (data on rates beyond 2013 is unavailable so the current situation is uncertain).^{21,26,49,55,56} Despite these trends, controversies around the practices remain, including some high-profile legal cases against physicians, though convictions have been rare.^{57–59}

1.8 Impact on palliative care

It is essential to examine the impact assisted dying legislation has on the practice of palliative care and how palliative care physicians might align these practices with the care

they provide. Critics raise important concerns that assisted dying legislation diminishes the focus on the need for adequate palliative care, thwarting its development as a young discipline.⁶⁰ This concern is compounded by perceptions of intrinsic ethical and philosophical incompatibilities.⁶¹ Moreover, many fear that patients would request and receive assisted dying in the absence of good palliative care. Though it is difficult to establish the ripple effects, policy makers in Belgium chose to enact a twin law to boost capacity and ensure universal coverage of palliative care services.⁶² However, this is unique as such a close relationship is not found in other countries implementing assisted dying laws as many palliative care physicians and organizations are firmly in opposition of assisted dying.^{61,63} Nonetheless, data from the Benelux countries suggests that palliative care development has advanced under assisted dying legislation.⁶⁰ In Flanders, the evidence points toward a considerable involvement of palliative care workers in patients receiving assisted dying⁵³: 71% of assisted dying cases took place within or after a palliative care trajectory.⁶⁴ That said, the long-term effects of assisted dying legalization are still unknown.

1.9 Relevance for physicians

The passage of assisted dying laws may have particularly serious implications for the responsibilities of certain physicians as well as the notion of what it means to be a physician.⁶⁵ Every jurisdiction that has enacted assisted dying legislation has implemented similar procedural requirements and safeguards, imposing additional professional responsibilities on physicians.³ For example, in Belgium, euthanasia requests must be evaluated by an attending physician as well as a second consulting physician, and performed cases reported to the Federal Control and Evaluation Commission for Euthanasia (FCECE).⁶⁶ The impact of assisted dying laws on physicians is also influenced by whether euthanasia or PAS is legalized, or both. Although PAS is rarely chosen over euthanasia by patients in jurisdictions where both options are available, it might be preferred because it places less burden on the physician, with the responsibility resting on the patient; moreover, physicians may perceive the two practices differently.⁶⁵ In those jurisdictions where only PAS is legalized, the prevalence and rate of increase is much lower than in those jurisdictions where euthanasia is also an option, e.g. the frequency of PAS in Oregon is significantly less than the assisted dying numbers in the Netherlands.⁶⁷

Assisted dying legislation affects certain groups of physicians more profoundly, with general practitioners being the primary physicians involved in euthanasia or PAS in 93% of cases in the Netherlands, 60% in Belgium, and 71% in Switzerland.⁶⁵ Although physicians may exercise conscientious objection and decline to participate in assisted dying practice, concerns related to the wellbeing of physicians involved in the practices exist as participation can potentially contrast with personal feelings and expectations about professional roles and responsibilities.^{63,68} Research has shown that some physicians experience emotional burden or discomfort, while others experience satisfaction in meeting the needs of patients.⁶⁹ Considering the potential personal, professional, and ethical issues physicians face when engaged in assisted dying practices, it is reasonable to expect these experiences could influence their preferences and decision-making in end-of-life care.

1.10 Connection between physicians' preferences and clinical decision-making

Understanding physicians' preferences for end-of-life decisions is an important goal, however, it is also relevant for patient care since physicians' attitudes have an influence on the opinions of their patients.⁶ Many people turn to their physicians for guidance when faced with difficult treatment decisions and physician recommendations have major impact on how patients consider end-of-life medical care and the decisions they make.^{6,7} Physician and patient treatment preference scores have proven to be highly correlated and patient willingness to withdraw life support appears to be connected to physician beliefs about end-of-life care.⁶ However, research also suggests that physicians exercise caution when giving recommendations in preference-sensitive situations and are cognizant of their influence on patients to avoid hindering informed decision-making.⁵

It has been posited that the tension between what physicians would want for themselves and what they do for their patients poses an emotional burden that may stem from a social situation that requires them to avoid viewing decisions through a personal lens and instead consider what is the right thing to do professionally.⁷⁰ This can result in physicians becoming more detached than empathic in clinical encounters.⁷⁰ Physicians can also experience emotional distress if they provide care that conflicts with their personal preferences or

professional judgement, particularly when they perceive the care as being futile, harmful or inappropriate.⁷¹ This emotional strain can have a negative impact on physicians' psychological and physical well-being and job satisfaction.⁷¹ This burden is an important consideration as research suggests a notable contrast between the care physicians provide to patients and the care physicians would want for themselves at the end of life.⁹

1.11 Incongruity between physicians' preferences and practice

Multiple studies have found that physicians prefer less use of life-sustaining treatments for themselves than they would order for patients in similar medical situations.^{11,70} Research also shows that physicians receive significantly less aggressive treatment at the end of life than the general population, specifically, they are less likely to die in hospitals or to receive intensive interventions like intensive care unit admissions or surgeries during their final months.⁷ This suggests a change in the psychological evaluation process as well as a disconnect between how physicians weigh treatments they would want for themselves and what they recommend to patients.^{7,72} Research has attributed the incongruence to the fact that physicians possess a greater understanding of the burdens associated with intensive medical interventions, which leads them to favor more conservative care options when it comes to their own end-of-life decisions.⁷² It also underscores that physicians' firsthand experiences with healthcare complexities inform their personal preferences, which may differ markedly from their clinical recommendations.⁷²

2. Objectives and research questions

This dissertation has two main objectives, each consisting of several research questions.

2.1. Objective 1: To explore physicians' preferences for end-of-life decisions and the factors that shape them

Physicians' Personal Preferences: Physicians personal preferences for end-of-life decisions are not well understood though research suggests they often prefer less aggressive care at the end of life, especially when prognosis is poor. Various factors including religion, age, specialty, jurisdiction and personal values influence end-of-life preferences.^{16,17}

Understanding the perspectives of physicians, who are at the frontline of end-of-life decision-making, is crucial as physicians' attitudes and experiences impact their approach to end-of-life care and influence their decisions to recommend some treatments over others.¹⁵ Existing studies on physicians' end-of-life preferences are limited in both geographical scope and the range of end-of-life decisions examined so there is a knowledge gap. Developing a broader understanding of physicians' personal preferences across a range of practices, from life-sustaining treatments to assisted dying, and spanning diverse geographic regions, would significantly enrich the knowledge base. Additionally, assisted dying laws vary widely, impacting how physicians view these practices both personally and professionally. Physicians in regions with legal assisted dying may be more accepting of these practices and have different end-of-life preferences compared to those in regions where such practices are illegal. Finally, since physicians sometimes encounter challenges aligning their personal beliefs and preferences with their professional practice, a more thorough understanding of their perspectives is essential.⁸

To address the first objective, the following four research questions are studied in this dissertation:

1. What are physicians' preferences for end-of-life practices including withholding and withdrawing treatment, palliative sedation and assisted dying in hypothetical medical scenarios?
2. What are physicians' considerations about their end-of-life preferences and how deeply have they considered what they would want for themselves at the end of life?
3. To what extent do physicians' preferences for end-of-life practices vary by assisted dying legislative environment, sociodemographic and professional characteristics, and what factors are associated with physicians' end-of-life preferences?
4. How do physicians perceive their end-of-life preferences are impacted by personal, professional, cultural, legislative, social, and religious influences?

2.2. Objective 2: To explore the connection between physicians' end-of-life preferences and their clinical practice

Connection Between Preferences and Clinical Practice: Physicians' personal end-of-life preferences can influence the care and recommendations they provide to patients as well as end-of-life decision-making.^{14,73} Exploring this connection is imperative as it offers deeper insight into the complex factors shaping physicians' attitudes toward end-of-life decisions. Existing studies on the connection between physicians' end-of-life preferences and their clinical practice are generally focused on limited end-of-life decisions (e.g. withholding and withdrawing treatment), a specific influence (e.g. religious beliefs) or are restricted to one geographic region. Therefore, a deeper understanding of physicians' perspectives on how physicians manage the connection between their end-of-life preferences and clinical practice is lacking. By exploring culturally diverse perspectives, we can uncover commonalities and challenges, which lead to more informed, globally relevant evidence to help align clinical care with patient values. Due to the lack of current comprehensive information and the potential significant impact on patient care, it is necessary to further explore the relationship between physicians' personal preferences and their clinical practice.

To address the second objective, the following research questions are studied in this dissertation:

1. To what extent do physicians believe their personal end-of-life preferences impact their own clinical practice and how do they compare across physician groups and jurisdictions?
2. To what extent do physicians' personal treatment option preferences differ from their treatment option preferences for patients in similar health scenarios?
3. How do physicians perceive and manage the impact of their personal preferences on their clinical practice with patients at the end of life and end-of-life decision making?

This structured approach addresses the complexity of physicians' end-of-life preferences and highlights the value of multi-method research in capturing both the measurable trends and nuanced considerations that shape end-of-life decision-making among physicians.

3. Methods used in this dissertation

This section describes the methods used to address the research questions of this dissertation. The PROPEL study employed a multi-method approach combining a quantitative survey design (Chapters 2 and 4), with a qualitative interview study design (Chapters 3 and 5).

We selected a multi-method study design for this research because it allowed for a comprehensive understanding of specific issues along with the quantifiable patterns and the personal, complex factors that shape end-of-life decision-making. Together, this multi-method approach enhanced validity by creating a more nuanced understanding of physicians' end-of-life preferences, the complex interplay between personal and professional influences and their connection to clinical practice.

Our multi-method approach followed a pragmatic research paradigm. Pragmatism focuses on the practical application of research using various sources of data and knowledge and values both objective and subjective perspectives, so it allows for the integration of quantitative and qualitative methods.⁷⁴ Since end-of-life care is particularly complex and this paradigm acknowledges that reality is often complicated and different types of data can provide complementary insights, it was well-suited for our study. By combining a survey to identify broad patterns in physicians' preferences and perspectives with interviews that captured deeper reflections, pragmatism ensured a more comprehensive understanding of both measurable trends and subjective reasoning. This flexibility is particularly valuable for studying context-dependent and value-laden issues like end-of-life care, where physicians' personal beliefs, ethical considerations, cultural background and institutional norms intersect.⁷⁴ Pragmatism allowed for the adaptation of its methods to our research questions, ensuring that findings are both meaningful and applicable to real-world situations.

3.1. Quantitative cross-sectional survey

The quantitative cross-sectional survey allowed us to identify broad trends in physicians' preferences across sociodemographic and legislative contexts, providing a statistically grounded picture of how preferences vary by physician specialty, region, and other factors. This aligns well with objectives to compare physician groups and jurisdictions, offering

insights into the measurable influences on end-of-life preferences.

Study design

Self-administered cross-sectional survey across various countries in North America, Europe, and Australia.

Context and setting

We included jurisdictions in North America (Canada and the US states Oregon, Wisconsin, and Georgia); Europe (Belgium (Flanders), Italy); and Australia (states of Victoria and Queensland). Countries were purposely selected to include physicians with diverse cultural and religious backgrounds and different levels of exposure to and experience with assisted dying practices (Appendix C & D).

Participants

The study population included general practitioners, palliative care physicians and other medical specialists with a high likelihood of seeing patients facing end-of-life issues (i.e. cardiologists, emergency medicine, gastroenterologists, geriatricians, gynecologists, internal medicine, intensivists, nephrologists, neurologists, oncologists, pulmonologists). A convenience sample in each jurisdiction was sought with a participant goal that included a minimum of 60 general practitioners, 30 palliative care physicians, and 60 medical specialists in each jurisdiction, for a minimum total of 150 physicians in each jurisdiction.

Data collection and recruitment

Data were collected between May 2022 – February 2023 using a self-administered web-based questionnaire (Appendix A) on the Qualtrics online survey platform. The survey invitation was shared via email by our international research partners or their professional contacts within physician organizations, medical licensing boards, commercial registries, professional networks and on social media. An initial survey invitation was sent by email, followed by a maximum of three reminders.

Questionnaire

The survey instrument incorporated questions on end-of-life decisions from a validated questionnaire, which were modified to fit the study focus and followed by a phase of pilot testing.⁷⁵ Participants provided consent at the start and the final survey comprised 38 questions, with a total completion time of approximately 10 minutes.

Statistical analysis

We calculated the proportion of physicians that agreed or strongly agreed with each of the items on physicians' perceived connection between their personal end-of-life preferences and clinical practice. To examine congruence between the end-of-life practice preferences of physicians for themselves and what they prefer for patients in scenarios of cancer and Alzheimer's we conducted univariate analyses for each option for both scenarios to report percentages for response options 'a very good/good option for both', 'not a good option for both', 'good for physician, not good for patient', 'not good for physician, good for patient'.

Ethical considerations

The study protocol was approved by the medical ethics committee of the Brussels University Hospital that acts as central ethics committee (BUN:1432021000562, September 29, 2021). Approvals were also obtained from ethics committees in Australia (Queensland University of Technology:20225080, December 17, 2021), Canada (Ottawa Hospital Research Institute:20220217-01H, August 29, 2022), and Italy (AUSL, Comitato Etico dell'Area Vasta Emilia Nord:748EE93B, April 7, 2022). Formal ethics approvals were not required by the other participating consortium partners/institutions.

3.2 Qualitative study

The qualitative study was essential for exploring the nuanced, deeply personal considerations and beliefs influencing end-of-life choices, which are often difficult to capture with quantitative data. Through interviews, we could uncover how individual values, personal and professional experiences, and emotional responses shape physicians' views, including how physicians reconcile personal preferences with professional duties in sensitive clinical scenarios.

Study design

Qualitative study using semi-structured in-depth interviews.

Context and setting

We selected physicians practicing in jurisdictions with diverse cultural environments and varied levels of experience with assisted dying legislation. We included physicians in the US state of Wisconsin, Belgium (Dutch-speaking region of Flanders), and Italy.

Participant recruitment

We used a convenience sample in each country and we sought to include three types of physicians: general practitioners, palliative care physicians, and specified medical specialists. Our goal was a distribution that included a minimum of five general practitioners, five palliative care physicians, and five medical specialists in each jurisdiction, amounting to 15 in each jurisdiction and 45 total physicians. Participants were identified through the networks of our research partners, medical associations and professional societies, and self-identification following participation in the PROPEL online survey. Following initial contact, physicians received an email invitation with information on the study, research team, and eligibility.

Inclusion and exclusion criteria

Currently practicing physicians in the following groups were eligible for participation: general practitioners, specified medical specialists or palliative care physicians. Exclusion criteria were having less than two years of clinical experience and being unable to do the interview in English.

Data collection

Data was collected between January – November 2022 using a semi-structured interview guide. Most interviews were conducted online using a video conferencing platform (Zoom or Teams) due to COVID-19 restrictions; however, five interviews were conducted in person. The interviews varied in length from 30 to 80 minutes and all interviews were conducted by the lead author (SM). A demographics form was completed at the start of each interview.

Data analysis

Interviews were audiotaped and transcribed verbatim. Data collection and analysis were informed using the reflexive thematic analysis approach. This method was an ideal approach for this study as its flexibility allowed for a deep examination of the multifaceted nature of end-of-life preferences without the constraints of rigid frameworks, making it well-suited to capturing the complexity of this topic.⁷⁶

Interview transcripts were imported to NVivo (version 12) for analysis. The lead author (SM) coded all transcripts, and another team member (FD) independently coded four transcripts for comparison. Initial codes were discussed and refined and themes and subthemes were developed. The themes were refined and collapsed and a thematic map was developed and evaluated. Associated interview quotes were then identified, discussed, and selected by the full research team.

4. Outline of this dissertation

All the chapters in this dissertation can be read independently. Chapters 2-5 are based on scientific articles that have been published, accepted or submitted for publication in academic peer-reviewed journals.

Part I provides a general introduction, background, methods and outline of the objectives of this dissertation. Part I also includes an overview of the current state of assisted dying, along with an examination of the complex issues related to the practices and potential impact on physicians.

Part II focuses on understanding the end-of-life preferences of physicians and how their preferences have been influenced and addresses objective 1. Chapter 2 describes the quantitative findings related to what physicians consider as options for themselves at the end of life based on two medical scenarios and how physicians perceive their end-of-life preferences have been impacted by personal, professional, cultural, legislative, social, and religious influences. Chapter 3 presents the qualitative findings exploring more deeply what physicians have considered for their own end-of-life preferences and how they perceive their end-of-life preferences have been impacted by various personal, professional and

socio-cultural influences.

Part III explores the relationship between physicians' end-of-life preferences and their clinical practice and addresses objective 2. Chapter 4 is focused on the quantitative findings related to the degree to which physicians believe their personal end-of-life preferences impact their clinical practice as well as how their preferred treatment options for themselves differ from the options they recommend for patients in similar health scenarios. Chapter 5 describes the qualitative findings centered on how physicians perceive and manage the impact of their personal preferences on their clinical practice and end-of-life decision-making.

Part IV presents a general discussion of the main findings of this dissertation, reflections on the strengths and limitations of the employed study methods, implications of the findings and recommendations for policy, practice and future research.

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PART II

Physicians' end-of-life preference and what shapes them

Chapter 2

Physicians' preferences for their own end-of-life: a comparison across North America, Europe, and Australia

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Abstract

Objective:

To study physicians' personal preferences for end-of-life practices, including life-sustaining and life-shortening practices, and the factors that influence preferences.

Design:

A cross-sectional survey (May 2022 – February 2023).

Setting:

Eight jurisdictions: Belgium, Italy, Canada, USA (Oregon, Wisconsin, and Georgia), Australia (Victoria and Queensland).

Participants:

Three physician types: general practitioners, palliative care physicians, and other medical specialists.

Main outcome measures:

Percentage of physicians who preferred various end-of-life practices and provided information about influence on preferences and demographics.

Results:

We analyzed 1157 survey responses. Physicians rarely considered life-sustaining practices a (very) good option (in cancer and Alzheimer's respectively, CPR, 0.5% and 0.2%; mechanical ventilation, 0.8% and 0.3%; tube feeding, 3.5% and 3.8%). About half of physicians considered euthanasia a (very) good option (respectively, 54.2% and 51.5%). The proportion of physicians considering euthanasia a (very) good option ranged from 37.9% in Italy to 80.8% in Belgium (cancer scenario), and 37.4% in Georgia, USA to 67.4% in Belgium (Alzheimer's scenario). Physicians practicing in a jurisdiction with a legal option for both euthanasia and physician-assisted suicide were more likely to consider euthanasia (very) good option in both cancer (OR=3.1, 95% CI 2.2-4.4) and Alzheimer's (OR=1.9, 95% CI 1.4-2.6).

Conclusion:

Physicians largely prefer to intensify alleviation of symptoms at the end of life and avoid life-sustaining techniques. In a scenario of advanced cancer or Alzheimer's disease, over half of physicians prefer assisted dying. Considerable preference variation exists across jurisdictions and preferences for assisted dying seem to be impacted by legalization of assisted dying within jurisdictions.

INTRODUCTION

Globally, people are living longer than they were 50 years ago. However, higher rates of chronic disease and extended illness trajectories have made the need for improved end-of-life care an issue of growing clinical and societal importance.¹ Physicians play a critical role in initiating and conducting conversations about end of life with their patients whose death is often preceded by decisions about end-of-life practices.² These decisions may include choosing to forego life-prolonging therapies, or treatments that potentially hasten death, which have a significant impact on individuals, families, and healthcare systems.²⁻⁴

Research suggests a link between physicians' consideration of their own end-of-life and their clinical practice. General practitioners (GPs) who have prepared their own advance directive tend to initiate consultation on end-of-life issues more frequently.⁵ Moreover, physicians' perceptions of their patients' treatment wishes are influenced by their own preferences.⁶ Studies suggest most physicians wish to forego high-intensity treatments for themselves, especially those with high exposure to very sick patients.^{7,8} Moreover, most would refuse life-sustaining treatments in a scenario with poor prognosis^{9,10} with nearly 40% expressing a preference for physician-assisted suicide if they had advanced amyotrophic lateral sclerosis.¹⁰

Since physicians have significant influence on patients' end-of-life care, it is important to better understand their personal perspectives about end-of-life care.¹¹ However, existing studies on physicians' preferences for end-of-life practices are outdated and/or focus on a narrow range of end-of-life practices. Additionally, knowledge on whether physicians would consider assisted dying for themselves is limited and no international comparative studies have been conducted.

Various terms are used to refer to assisted dying including euthanasia, physician-assisted suicide, medically assisted suicide, physician-assisted dying, voluntary assisted dying,

and medical aid in dying,¹² though the meaning and use is not consistent or universally agreed upon. In this article, we use “assisted dying” as an umbrella term covering both “euthanasia” and “physician-assisted suicide”. Euthanasia refers to the act of intentionally ending the life of a patient by a physician by active drug administration at that patient’s explicit request and physician-assisted suicide is the provision of or prescribing of drugs by a physician for a patient to use to end their own life.¹² The legality and acceptability of these practices varies greatly, and an international comparison of physicians’ preferences, which are likely impacted by macro-level factors, is lacking.

This study explored physicians’ preferences for end-of-life practices across three continents (North America, Europe, Australia). We address the following research questions:

1. What are physicians’ preferences for end-of-life practices in hypothetical medical scenarios of advanced cancer and Alzheimer’s disease?
2. To what extent do physicians’ preferences for end-of-life practices vary by assisted dying legislative environment, sociodemographic and professional characteristics, and what factors are associated with physicians’ end-of-life preferences?

METHODS

Study design

This study involved a large-scale, self-administered, cross-sectional survey in countries in North America, Europe, and Australia.

Context and setting

Considering assisted dying legislation can have a substantial impact on the role of physicians, medical practice, and end-of-life culture¹³, we intentionally selected physicians practicing in jurisdictions which have diverse cultural environments and varied levels of experience with assisted dying legislation (Appendix D). We included jurisdictions

in North America (Canada and the US states of Oregon, Wisconsin, and Georgia); Europe (Belgium (Flanders), Italy); and Australia (states of Victoria and Queensland).

In North America, Oregon is among the most socially progressive states.¹⁴ It has had the longest standing physician-assisted suicide law (since 1997) and is also among the least religious US states.¹⁵ Wisconsin is largely rural with isolated pockets that are urban and progressive.¹⁴ Death with Dignity legislation has been introduced there numerous times over the past 20 years but remains illegal.¹⁶ Physicians from Georgia offer perspectives from a southern state without assisted dying legislation, which ranks among the most religious US states by the Pew Research Center (79% Christian) and where end-of-life care decisions are influenced by widely held conservative views.¹⁵ Canadian physicians will provide further comparison in a setting which has a national healthcare system (unlike the USA) and allows both physician-assisted suicide and euthanasia (since 2016).

In Europe, physicians in Belgium offer perspectives from a more socially liberal European environment¹⁷ where assisted dying has been legal since 2002 and attitudes about end-of-life care and assisted dying have evolved over time through intense debate and exposure to euthanasia. Italy offers a contrasting viewpoint as one of the most religious countries in Europe where assisted dying remains illegal. Although a Constitutional court ruling in 2019 allows physician-assisted suicide, patients must meet extremely narrow criteria and it is not generally accessible, though there is ongoing social and legal debate.^{15,18,19}

Australia is a secular country with a high level of religious freedom and diversity.²⁰ The Australian state of Victoria implemented assisted dying legislation in June 2019 and offers perspectives from physicians experiencing recent implementation of the Act.²¹ In Queensland, assisted dying legislation was passed in 2021, but had not commenced at the time of data collection for this study.²²

Participants

Due to their varied levels of experience treating patients at the end of life, we sought to include three types of physicians: GPs, palliative care physicians, and other medical specialists with a high likelihood of seeing patients facing end-of-life issues (i.e. cardiologists, emergency medicine, gastroenterologists, geriatricians, gynecologists, internal medicine, intensivists, nephrologists, neurologists, oncologists, pulmonologists). A convenience sample in each jurisdiction was sought. Our goal was a distribution of physician types that included a minimum of 60 general practitioners, 30 palliative care physicians, and 60 medical specialists in each jurisdiction, for a minimum total of 150 physicians in each jurisdiction, which was considered sufficient to make inferences about the population.

Data collection

Data was collected between May 2022 and February 2023 using a self-administered web-based questionnaire (Appendix A) on the Qualtrics online survey platform. The survey was shared via email utilizing physician organizations, medical licensing boards, commercial registries, partners' professional networks and social media. An initial survey invitation was sent by email, followed by a maximum of three reminders.

The survey instrument is an adaptation of a validated questionnaire used in the European End-of-Life (EURELD) study, which explored end-of-life decision-making among physicians from six European countries and Australia.²³ The EURELD study used hypothetical medical scenarios to examine physicians' willingness to make end-of-life decisions, exploring their frequency, cross-country differences, and the influence of both situational and physician characteristics on decision-making. We opted to include similar medical scenarios that made clear participants were to consider themselves (or a patient) in an end-of-life situation with a life expectancy of no more than 2 weeks. However, we understand that if the scenarios had been more nuanced, included different disease conditions, or life expectancies, the survey responses may have varied.

We also reviewed the literature to find and compare other questionnaires on end-of-life decisions. Questions were added to gather information on physicians’ preferences for patients as well as their personal preferences and their perceptions about the connection between their personal preferences and clinical practice. Furthermore, a phase of cognitive testing was conducted with two to four physicians in each jurisdiction to evaluate the questionnaire for length, clarity, question order, appropriateness of terminology, and overall structure. Feedback was received from a total of 22 physicians, incorporated into the survey, and further reviewed by a subset of physicians. The final survey included 38 questions in total, with a completion time of approximately 10 minutes.

To assess physicians’ preferences for end-of-life practices, we used two case vignettes with hypothetical situations – one cancer scenario and one Alzheimer’s disease scenario (Box 1). We asked physicians the extent to which they would consider various end-of-life practices for themselves including: cardiopulmonary resuscitation, mechanical ventilation, artificial nutrition and hydration, intensified alleviation of symptoms, palliative sedation, using available medications to end one’s own life, physician-assisted suicide, and euthanasia. Physicians’ preferences were measured using a 4-point Likert scale. Respondents were asked “Right now, which of the following end-of-life decisions would you consider possible options for yourself (if there were an indication for it and it was a legal option in your jurisdiction)?”, using the following response options: (1) Not at all a good option, (2) Not such a good option, (3) A good option, or (4) A very good option.

Additional questions were included on demographic-, cultural-, and institutional-level factors that may influence physicians’ preferences including gender, age, physician specialty, average number of end-of-life patients annually, ethnicity, and religion.

Box 1. End-of-life scenarios and end-of-life decision preferences included in the PROPEL questionnaire	
Cancer scenario	You have been diagnosed with cancer with extensive lung and bone metastases and your treating oncologist has said no further

	treatments are available. You have an estimated life expectancy of no more than two weeks and are fully competent. You are experiencing ongoing severe pain and agitation. A palliative care provider is involved and palliative care services (e.g. home care, inpatient hospice) are available for you.
Alzheimer's scenario	You are suffering from Alzheimer's dementia in gradual cognitive decline and you no longer recognize your family or friends. You refuse to eat and drink and have become more and more withdrawn. It is no longer possible to communicate with you about medical treatment options. A palliative care provider is involved and palliative care services (e.g. home care, inpatient hospice) are available for you.
Preferences for end-of-life decisions ^a	<p>Right now, which of the following would you consider possible options for yourself (if there were an indication for it)? Response options (1) <i>Not at all a good option</i> (2) <i>Not such a good option</i> (3) <i>A good option</i> (4) <i>A very good option</i></p> <ul style="list-style-type: none"> - the use of cardiopulmonary resuscitation - the use of mechanical ventilation - the use of intravenous hydration - the use of a feeding tube (gastrostomy, jejunostomy, or intravenous) to provide nutrition - to intensify the alleviation of symptoms by using medications, taking into account the probability or certainty that this could hasten your death - to use high doses of medications, such as benzodiazepines or barbiturates, to be kept in deep sedation until death - to request medications from your health care practitioner that would allow you to end your own life, if it is currently legal or were to become a legal option in your jurisdiction - to use medications which are at your disposal as a physician to end your own life - to request assistance from a medical practitioner who could administer a substance to end your life, if it is currently legal, or were to become a legal option in your jurisdiction
^a End-of-life decision preference options were adjusted to fit each scenario	

Statistical analysis

We dichotomized the 4-point Likert scale into ‘not at all/not such a good option’ and ‘a good/very good option’. To examine the association between physicians’ own end-of-life decision preferences in two hypothetical scenarios and the legislative environment or sociodemographic and clinical characteristics, we conducted backward stepwise binomial logistic regression models (one for each scenario). At each step, variables were chosen based on p-values; a threshold of 0.05 was used to set a limit on the total number of variables included in the final model. We report odds ratios and 95% confidence intervals. All analyses were done using SPSS (version 28).

Ethics

The study protocol was approved by the medical ethics committee of the Brussels University Hospital that acts as central ethics committee (BUN:1432021000562, September 29, 2021). Approvals were also obtained from ethics committees in Australia (Queensland University of Technology:20225080, December 17, 2021), Canada (Ottawa Hospital Research Institute:20220217-01H, August 29, 2022), and Italy (AUSL, Comitato Etico dell’Area Vasta Emilia Nord:748EE93B, April 7, 2022). Formal ethics approvals were not required by the other participating consortium partners/institutions. The study protocol, informed consent form, and supporting documents were approved by the appropriate local research ethics committees, prior to participant recruitment.

RESULTS

We received 1408 survey responses. Of those, 251 were excluded because they were ineligible or incomplete, resulting in a final sample of 1157 physicians (Table 1). The overall response reached our minimum goal of 150 participants in all jurisdictions, except in Canada, Georgia, USA, and in both states of Australia. Most physicians were white/European (74%) and identified as either Christian (39%) or non-religious (43%).

Table 1. Characteristics of participating physicians, per jurisdiction									
	OVERALL (N=1157)	USA			CA (N=113)	BE (N=154)	IT (N=196)	AUS^b	
		WI (N=161)	OR (N=169)	GA (N=116)				VIC (N=128)	QLD (N=98)
		%	%	%	%	%	%	%	%
Gender ^a									
Male	523	43.0	45.3	50.9	58.4	37.5	47.4	62.1	51.7
Female	542	57.0	54.7	49.1	41.6	62.5	52.6	37.9	48.3
Age									
<40 years	237	29.4	12.1	21.7	28.7	28.5	22.3	17.2	16.1
40-59 years	569	61.4	57.7	39.6	55.4	59.0	46.1	45.7	58.6
>60 years	264	9.2	30.2	38.7	15.8	12.5	31.6	37.1	25.3
Physician type									
General practitioner	390	32.1	43.0	34.5	1.8	26.6	34.2	37.0	64.6
Palliative care physician	249	13.8	7.9	19.8	41.6	27.3	42.3	8.7	7.3
Other medical specialist	509	54.1	49.1	45.7	56.6	46.1	23.5	54.3	28.1
Average yearly end-of-life patients									
<10	430	39.5	54.3	54.1	22.9	37.1	35.6	39.2	64.9
11-30	197	24.8	18.3	17.1	21.1	27.2	14.4	17.6	3.5
>30	399	35.7	27.4	28.8	56.0	35.8	50.0	43.2	31.6
Religion									
Christian	451	46.8	32.9	60.0	30.7	31.7	61.5	31.0	36.0
Other religion	131	13.0	17.8	25.7	16.8	2.8	3.6	12.9	16.3
Non-religious	481	40.3	49.3	14.3	52.5	65.5	34.9	56.0	47.7
Ethnicity									
White/European	859	82.5	79.3	62.9	74.3	98.6	82.4	83.3	75.6
African/Black	19	0.6	2.1	11.4	0	0.7	0	0.9	1.2
Latino/Hispanic	46	1.3	3.4	4.8	1.0	0	16.1	0	1.2
Asian	79	8.4	10.3	11.4	17.8	0	0	11.4	8.5
Other	56	7.1	4.8	9.5	6.9	0.7	1.6	4.4	13.4
WI=Wisconsin, OR=Oregon, GA=Georgia, CA=Canada, BE=Belgium, IT=Italy, VIC=Victoria, QLD= Queensland									
Missing values: Gender: n=87, Age: n=87; Physician type: n=9; End of life patients: n=131; Religion: n=94; Ethnicity: 98.									
^a Gender percentages exclude n=5 responses of 'other' and 'prefer not to say'.									
^b For n=22 Australian cases jurisdiction is unknown.									

Physicians' personal end-of-life decision preferences

Both scenarios for advanced cancer and Alzheimer's show similar proportions of physicians preferring suggested end-of-life options: CPR (0.5%, 0.2%), mechanical ventilation (0.8%, 0.3%), tube feeding (3.5%, 3.8%), intravenous hydration (21.5, 17.8%) (Table 2). Of all physicians, 93.6% vs 90.9% found intensifying alleviation of symptoms a good or very good option and 58.9% vs 49.9% considered palliative sedation a good or very good option. About half of participating physicians (54.2%, 51.5%) in both scenarios considered euthanasia a good or very good option.

Table 2. Physicians' personal end-of-life preferences: overall results (in % of "good" or "very good" option)

	Life-sustaining practices					Assisted dying practices				Use medications at own disposal to end life
	CPR	Mechanical ventilation	Intravenous hydration	Feeding tube	Intensified alleviation of symptoms	Palliative sedation	Physician-assisted suicide	Euthanasia		
	%	%	%	%	%	%	%	%	%	%
Cancer scenario^a	0.5	0.8	21.5	3.5	93.6	58.9	50.1	54.2		33.5
Alzheimer's scenario^a	0.2	0.3	17.8	3.8	90.9	49.9	^b	51.5		^b

CPR: cardiopulmonary resuscitation

Missing values: cancer: CPR: n=74, mechanical ventilation: n=76, intravenous hydration: n=76, feeding tube: n=76, intensified alleviation of symptoms: n=76, palliative sedation: n=74, physician-assisted suicide: n=77, use medications at own disposal: n=81, euthanasia: n=80; Alzheimer's: CPR: n=78, mechanical ventilation: n=79, intravenous hydration: n=81, feeding tube: n=80, intensified alleviation of symptoms: n=79, palliative sedation: n=82, euthanasia: n=82

^aTwo hypothetical medical scenarios were included –one using advanced cancer and one using Alzheimer's disease

^bThese end-of-life decisions were not appropriate for inclusion in the Alzheimer's scenario

In the cancer scenario, the proportion of physicians considering palliative sedation a good or very good option varied across jurisdictions, from 42.7% in Queensland to 82.0% in Italy (Table 3). Preferences for physician-assisted suicide as an option differed from a minimum of 25.3% in Belgium to a maximum of 71.2% in Oregon. Preferences for euthanasia as a good or very good option differed from a minimum of 37.9% in Italy to a maximum of 80.8% in Belgium. Also, 33.5% of physicians would consider using medications at their disposal to end their own life.

In the Alzheimer’s scenario, preferences for palliative sedation as a good or very good option varied from a minimum of 39.3% in Georgia to a maximum of 66.3% in Italy and physicians who considered euthanasia ranged from 37.4% in Georgia to 67.4% in Belgium.

Table 3. Physicians’ personal end-of-life preferences: results per jurisdiction (in % of “good” or “very good” option)							
		Cancer scenario^a				Alzheimer's scenario^a	
		Assisted-dying practices				Assisted-dying practice	
		Palliative sedation	Physician-assisted suicide	Euthanasia	Use medications at own disposal to end life	Palliative sedation	Euthanasia
	N	%	%	%	%	%	%
OVERALL	1157	58.9	50.1	54.2	33.5	49.9	51.5
North America							
<i>Canada</i>	113	61.4	60.0	67.3	32.7	52.5	61.4
<i>Oregon, USA</i>	169	54.9	71.2	57.5	46.4	46.1	54.6
<i>Wisconsin, USA</i>	161	46.5	49.7	42.2	33.5	44.2	46.1
<i>Georgia, USA</i>	116	46.7	43.9	38.7	33.0	39.3	37.4
Europe							
<i>Belgium</i>	154	77.9	25.3	80.8	15.9	54.2	67.4
<i>Italy</i>	196	82.0	35.4	37.9	31.6	66.3	39.3
Australia ^b							
<i>Victoria</i>	128	43.2	66.7	59.0	40.5	43.2	58.5
<i>Queensland</i>	98	42.7	59.6	57.3	38.2	43.2	51.1
Missing values: Cancer: palliative sedation: n=74, physician-assisted suicide: n=77, use medications at own disposal: n=81, euthanasia: n=80; Alzheimer’s: palliative sedation: n=82, euthanasia: n=82							

^a See Box 2 for the two medical scenarios

^b Excludes n=22 Australian cases with location unknown

Association between physicians' preferences and legislative environment, sociodemographic and professional characteristics

For the cancer scenario, physicians who live in a jurisdiction that allows both euthanasia and physician-assisted suicide (Belgium, Canada and Victoria) were more likely to consider euthanasia a good or very good option than those in jurisdictions without legalized assisted dying (Table 4). Physicians from jurisdictions which allow only physician-assisted suicide (Oregon) were more likely to consider physician-assisted suicide a good or very good option.

Compared to palliative care physicians, GPs and other medical specialists were less likely to consider palliative sedation a good or very good option (GPs: 55.1% vs 70.3%, other medical specialists: 56.2% vs 70.3%), and were more likely to consider euthanasia, physician-assisted suicide, and using available medication to end one's own life (euthanasia: 55.8% vs 39.1%, physician-assisted suicide: 52.6% vs 31.8%), using available medication to end one's own life (35.3% vs 19.0%); other medical specialists vs palliative care physicians (euthanasia: 60.4% vs 39.1%, physician-assisted suicide: 56.8% vs 31.8%), using available medication to end one's own life: 39.0% vs 19.0%. Physicians who see more than five end-of-life patients per year were less likely to consider physician-assisted suicide or euthanasia a preferable option compared to those who see fewer than 5 per year (physician-assisted suicide 44.9% vs 59.0%, euthanasia 50.4% vs 63.1%). Non-religious physicians were more likely to consider physician-assisted suicide or euthanasia a preferable option than religious physicians: physician-assisted suicide (64.6% vs 38.1%), euthanasia (71.8% vs 40.1%).

Table 4. Multivariate binary logistic regression per end-of-life decision with personal preference as dependent variable (1 = a (very) good option, 0 = not such/at all a good option)												
	Cancer scenario						Alzheimer's scenario					
	Palliative sedation		Physician-assisted suicide		Euthanasia		Use medications at own disposal to end life		Palliative sedation		Euthanasia	
	%	OR (95% CI)	%	OR (95% CI)	%	OR (95% CI)	%	OR (95% CI)	%	OR (95% CI)	%	OR (95% CI)
Legislative environment												
Euthanasia & PAS	62.1	*	48.2	NS	70.1	3.1 (2.2-4.4)	28.5	0.6 (0.4-0.8)	50.1	*	62.8	1.9 (1.4-2.6)
Only PAS	54.9	*	71.2	2.6 (1.7-4.1)	57.5	1.6 (1.1-2.4)	46.4	NS	46.1	*	54.6	NS
No assisted dying option	58.5	Ref.	45.1	Ref.	42.5	Ref.	33.5	Ref.	50.8	Ref.	42.8	Ref.
Gender												
Female	61	*	50.5	*	55.2	*	31.6	*	51	*	51.7	*
Male	57.5	Ref.	49.6	Ref.	53.5	Ref.	36	Ref.	48.8	Ref.	52	Ref.
Age												
Younger than 60 years	60.4	*	49.9	*	55.6	*	31.8	*	50.3	*	52.6	*
60 years or older	54.9	Ref.	49.8	Ref.	49.8	Ref.	39.8	Ref.	48.3	Ref.	48.9	Ref.
Physician type												
General practitioner	55.1	0.5 (0.3-0.7)	52.6	NS	55.8	2.1 (1.3-3.1)	35.3	1.9 (1.2-3.0)	46.1	*	51.9	1.6 (1.1-2.5)
Other medical specialist	56.2	0.5 (0.4-0.8)	56.8	2.5 (1.7-3.6)	60.4	2.5 (1.7-3.6)	39	2.7 (1.8-4.0)	51.1	*	58.3	2.5 (1.8-3.6)
Palliative care physician	70.3	Ref.	31.8	Ref.	39.1	Ref.	19	Ref.	52.6	Ref.	36.5	Ref.
Average yearly end-of-life patients												
5 or more patients	60.6	*	44.9	0.6 (0.4-0.8)	50.4	0.7 (0.5-0.9)	30.8	*	50.3	*	47.9	0.7 (0.5-0.9)
< 5 patients	58.1	Ref.	59	Ref.	63.1	Ref.	38.8	Ref.	49.4	Ref.	59.1	Ref.
Religion												
Non-religious	63.7	1.4 (1.1-1.8)	64.6	3.0 (2.2-4.0)	71.8	2.9 (2.1-3.9)	41.2	1.9 (1.4-2.6)	55.3	1.4 (1.1-1.8)	67.4	2.7 (2.0-3.6)
Religious	55.4	Ref.	38.1	Ref.	40.1	Ref.	27.9	Ref.	45.4	Ref.	39.5	Ref.
Ethnicity												
White	59.4	*	49.4	*	55.7	*	33.4	*	49.5	*	52.5	*
Non-white	61	Ref.	54.2	Ref.	49.4	Ref.	36.6	Ref.	53.1	Ref.	50.3	Ref.
Nagelkerke R²		0.031		0.178		0.216		0.1		0.01		0.163

PAS: physician-assisted suicide; NS: not significant
Jurisdictions: Euthanasia & PAS: Canada, Belgium & Victoria, Australia; Only PAS: Oregon; No assisted dying legislation: Italy, Georgia, Wisconsin & Queensland, Australia (legislation passed but implementation pending at time of survey)
*Variable not included in the equation through stepwise selection process; Variables controlled for: jurisdiction, gender, age, physician type, yearly end-of-life patients, religion, ethnicity

For the Alzheimer's scenario, physicians in jurisdictions allowing euthanasia and physician-assisted suicide were more likely to consider euthanasia a good or very good option. Gender, age, and ethnicity did not appear to independently impact physicians' preferences for end-of-life practices.

DISCUSSION

Summary of main findings

Across all participating jurisdictions, our findings indicate that more than 90% of physicians have a personal preference for the intensification of symptom alleviation using medications in both the advanced cancer and Alzheimer's disease scenarios, and more than 95% prefer to avoid life-sustaining techniques like CPR, mechanical ventilation, and tube feeding. Palliative sedation presents a mixed picture across the jurisdictions, with 39% to 66% of physicians considering it for themselves in the Alzheimer's scenario and 43% to 82% in the cancer scenario. In jurisdictions with a legal option for euthanasia at the time of the survey (Belgium, Canada, Victoria) 59% to 81% of physicians considered euthanasia for themselves in an advanced cancer scenario, while 58% to 61% considered it for themselves in an Alzheimer's scenario. Also, in Queensland, where legislation had passed but was not yet implemented at the time of data collection, 51% (Alzheimer's) and 57% (cancer) of physicians considered euthanasia for themselves. Our results also indicate that physician type, average number of end-of-life patients, religiosity and legislative environment is associated with physicians' preferences for end-of-life practices, while physician gender, age and ethnicity did not impact preferences.

Strengths and limitations

A major strength of our study is the inclusion of physicians across three continents, five countries and eight jurisdictions, representing varied legal and cultural environments. This study provides novel evidence on end-of-life preferences by focusing on physicians' preferences for end-of-life options for their own end of life, contrasting jurisdictions with

and without assisted dying legislation, and including three contrasting types of physicians - general practitioners, palliative care physicians and other medical specialists.

The study had certain limitations. The pragmatic choice for convenience sampling does not allow for random selection, meaning the point estimates cannot be considered representative of the sampled populations. There may be selection bias as the survey could have attracted those with a particular interest in end-of-life issues. Though the overall recruitment of respondents was satisfactory in all jurisdictions, there was a low representation of GPs in the Canadian sample. On the other hand, the comparison between the jurisdictions and between three selected categories of physicians generates valid results.

Interpretation of main findings

Our findings show that across all jurisdictions physicians largely prefer intensified alleviation of symptoms and to avoid life-sustaining techniques like CPR, mechanical ventilation, and tube feeding. This finding may also relate to the moral distress some physicians feel about the routine continuation of treatment for their patients at the end of life.²⁴ These findings warrant reflection on current clinical practice since life-prolonging treatment is still widely used with patients²⁵ yet is not preferred by physicians for themselves.

A majority of physicians consider euthanasia and physician-assisted suicide a good or very good option in an advanced cancer scenario for themselves. However, substantial differences across the jurisdictions have been found and much higher support was found in jurisdictions where assisted dying is already legalized. This is consistent with existing research exploring physicians' preferences for end-of-life practices.¹⁰ For these physicians, the legal availability of assisted dying would provide another option for untreatable refractory symptoms and unbearable suffering of their patients and palliative sedation is not the only final end-of-life treatment option. Furthermore, physicians'

jurisdiction is strongly related to their preferences and those who practice in a jurisdiction which allows physician-assisted suicide and euthanasia are much more likely to consider assisted dying practices a good or very good option.²⁶ This may be because these physicians are more familiar and comfortable with the practices and have observed positive clinical outcomes. It also suggests that macro level factors heavily impact personal attitudes and preferences and physicians are likely influenced by what is considered 'normal' practice in their own jurisdiction. In the case of Belgium, assisted dying may be more normalized after more than 20 years of experience, than in Canada or in Australia where legalization came much later. It is worth noting that physicians were asked to consider assisted dying practices 'if they were a legal option' in their jurisdiction, so preferences were not distorted by question phrasing.

The legislative framework and whether assisted dying is administered in a clinical practice setting or is self-administered also has an impact. Some laws specify a preferred form of administration (practice-administration or self-administration), which establishes a normative direction (e.g. euthanasia in Belgium, physician-assisted suicide in Victoria, Australia). It is also noteworthy that in any jurisdiction where euthanasia and physician-assisted suicide are both legal options, euthanasia is preferred.²⁷ The status of legislation also influences preferences and in some jurisdictions the law has been long established, while in others it has been more recently implemented, or is pending. These findings underscore the complex variation of physicians' personal perspectives and the need for further research on physicians' own end-of-life practice preferences, and the influences on those preferences.

It is striking that many physicians would also consider euthanasia in the Alzheimer's disease scenario, despite the progressive status of this disease making it a complex basis for making a competent assisted dying request. In most jurisdictions, the law would not allow physicians to grant this request. It also highlights the need for further discourse on assisted dying, and, in particular, end-of-life practices for complex conditions like

Alzheimer's disease.

Our results indicate there are a variety of influences on physicians' end-of-life practice preferences including practice type and personal characteristics. We found palliative care physicians consider palliative sedation a preferable option than assisted dying. This corroborates other research indicating that palliative care physicians have more negative attitudes toward life-shortening practices.²⁸ The preference for palliative sedation may be because it is better understood by palliative care physicians and is therefore considered more manageable and acceptable.

Additionally, we found physicians with more strongly held religious beliefs are less likely to consider assisted dying a good or very good option. This finding is in line with other studies²⁹ and is likely due to the conflict between religious beliefs about the sanctity of life and the unacceptability of active life-shortening practices.

In conclusion, there is a high level of agreement among physicians who prefer to intensify alleviation of symptoms at the end of life and avoid life-sustaining practices. Considerable variation in preferences exists across jurisdictions and preferences for assisted dying seem to be impacted by the legalization of assisted dying within jurisdictions.

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Chapter 3

What do physicians want at the end? An international qualitative study on physicians' personal end-of-life preferences and what influences them

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ABSTRACT

Background:

Physicians play a key role in end-of-life decision-making. As research suggests a connection between physicians' personal end-of-life preferences and their clinical practice, it is important to understand what physicians want for themselves at the end of life and what has shaped their preferences.

Objective:

To explore what physicians have considered for their end-of-life preferences, including life-sustaining and life-shortening practices, and their perceptions of the socio-cultural factors that influence their preferences.

Design:

Qualitative study using in-depth interviews.

Methods:

Forty-five interviews were conducted from January-November 2022 using a semi-structured interview guide. Participants included three types of physicians: general practitioners, palliative care physicians, and other medical specialists in Belgium (Flanders), Italy and the USA (Wisconsin). Data collection and analysis were informed using the reflexive thematic analysis approach. Audio recordings were transcribed verbatim and NVivo 14 was used for coding and analysis. Consolidated criteria for reporting qualitative research (COREQ) was followed.

Results:

We found physicians, particularly those in palliative care, have reflected on their end-of-life preferences and have ideas about what constitutes a good death and what they hope to avoid. Most physicians prefer to avoid aggressive and life-prolonging treatment, physical and mental suffering, and being a burden. They prioritize being in a peaceful environment and communication with loved ones. Various factors influence preferences including cultural, social

and religious beliefs, and legislative environment but most significant are the deaths of loved ones and clinical practice. Death and dying become normalized the more they are reflected upon and discussed and this process can also provide personal growth and physicians provide better care to patients and families.

Conclusion:

Physicians have reflected on their end-of-life preferences and prefer a peaceful end of life without aggressive and life-prolonging treatment. Physicians' views on end-of-life practices are influenced by evolving cultural and societal norms and legal and ethical factors.

INTRODUCTION

Physicians play a central role in conversations about end-of-life and decision-making for patients nearing death. These conversations often involve highly impactful decisions to limit treatment and focus on comfort or even to hasten death.¹ Research indicates a stark contrast between the care physicians provide to patients and the care they would choose for themselves at the end of life, due in part to their individual approaches to practice.² This discrepancy is significant, as it underscores differences in attitudes as well as the personal and professional dilemmas faced by physicians managing complex end-of-life issues.³ Like many patients, physicians wish to forego high-intensity end-of-life treatments for themselves; this is especially true for physicians who have had high exposure to very sick patients.^{2,4} Moreover, most physicians would refuse life-sustaining treatments in a scenario with a poor prognosis.⁵

Various factors influence physicians' end-of-life preferences, including their personal, professional and ethical backgrounds.^{5,6} The factors found to have the most significant impact on physicians' preferences include religious background, personal values, age, health status, physician specialty, experience, country of origin, and place of training.⁷⁻⁹ For example, physicians generally prefer less aggressive end-of-life treatment, particularly older physicians who are white and practicing in Western countries; younger physicians who have worked in a clinical environment are more comfortable withdrawing life support; and physicians with more strongly held religious beliefs are more likely to object to the withdrawal of life support and assisted dying practices.⁷⁻⁹ The legislative environment's influence on attitudes and end-of-life preferences is another important consideration as assisted dying becomes available in more jurisdictions around the world. Research indicates that use and acceptance of assisted dying practices increases over time due to evolving cultural attitudes that prioritize autonomy and greater acceptance and familiarity among medical professionals and the public.¹⁰ The influence of these complex and often intermingled factors may help explain how some physicians come to prefer one treatment decision for themselves and another for their patients and shed light on the tension that exists for some physicians in reconciling personal convictions and professional responsibility.³

Understanding the perspectives of physicians, who are at the frontline of end-of-life decision-making, is crucial for several reasons. First, physicians' attitudes and experiences impact their approach to end-of-life care and influence their decisions to recommend some treatments over others.⁶ Second, exploring the connection between physicians' end-of-life preferences and their clinical practice can enhance the knowledge base by offering deeper insight into the complex factors shaping physicians' attitudes toward end-of-life decisions. Finally, physicians encounter challenges aligning their personal beliefs with their professional practice so a more thorough understanding of why they think and feel as they do is critical.³

Existing studies on physicians' end-of-life preferences are limited in both geographical scope and the range of end-of-life decisions examined. International comparative research can provide valuable insights into how cultural, social, and system-level differences influence physicians' personal end-of-life preferences. By exploring diverse perspectives, we can uncover commonalities and unique challenges, which lead to more informed, globally relevant evidence to help align clinical care with patient values. To the authors' knowledge, no international comparative studies have been conducted.

In this study, we address the following research questions:

1. What are physicians' considerations about their end-of-life preferences?
2. How do physicians perceive their end-of-life preferences are impacted by personal, professional, cultural, legislative, social, and religious influences?

METHODS

Study design

Qualitative study using semi-structured in-depth interviews.

Context and setting

We selected physicians practicing in jurisdictions with diverse cultural environments and varied levels of experience with assisted dying legislation. We included physicians in Belgium (Flanders), Italy, and the USA (Wisconsin).

Participant recruitment

We used a convenience sample in each country. Due to their varied levels of experience treating patients at the end of life, we sought to include three types of physicians: general practitioners, palliative care physicians, and other medical specialists with a high likelihood of seeing patients facing end-of-life issues (i.e., cardiologists, emergency medicine, gastroenterologists, geriatricians, gynecologists, internal medicine, intensivists, nephrologists, neurologists, oncologists, pulmonologists). Our goal was a distribution of physician types that included a minimum of five general practitioners, five palliative care physicians, and five medical specialists in each jurisdiction, amounting to 15 in each jurisdiction and 45 total physicians. Physician participants were identified through the networks of our research partners in each country, as well as through medical associations and professional societies, and self-identification following participation in the PROPEL online survey. This qualitative exploration is part of a multi-method study called PROPEL: Physician Reported Preferences for End-of-Life Decisions. Following initial contact by email or telephone, physicians received an email invitation detailing the study, information on the research team, and eligibility for participation.

Inclusion and exclusion criteria

Currently practicing physicians in the following groups were eligible for participation: general practitioners, clinical specialists (cardiologists, emergency medicine, gastroenterologists, geriatricians, gynecologists, internal medicine, intensivists, nephrologists, neurologists, oncologists, pulmonologists) or palliative care physicians. Exclusion criteria were having less than two years of clinical experience and being unable to do the interview in English. We originally planned to include only physicians with five or more years of experience. However, since we encountered recruitment challenges, eligibility was expanded. Most of the recruited physicians had 10-40 years of experience.

Data collection

Data was collected between January – November 2022 using a semi-structured interview guide. The interview guide (Appendix B) was pilot tested with three physicians and adjusted for clarity and appropriateness before use. Most interviews were conducted online using a video conferencing platform (Zoom or Teams) due to COVID-19 restrictions. However, five interviews were conducted in person, at the office or home of the participant, and one at a public library. The interviews varied in length from 30 to 80 minutes and no repeat interviews were conducted. Notes were made following each interview. All interviews were conducted by the lead author (SM), a female doctoral researcher with previous experience conducting qualitative research with physicians (credentials-MSc, MPH). SM had no prior relationship with the participants, apart from two Wisconsin physicians who had previously provided care for her mother. Due to the complex nature of the interview topic, participants were offered language support through the attendance of a second researcher who spoke their native language and could explain complex questions or responses. Some European physicians accepted this option (Italy 4, Belgium 1). A demographics form was completed at the start of each interview.

Data analysis

Interviews were audiotaped and transcribed verbatim. Data collection and analysis were informed using the reflexive thematic analysis approach. A reflexivity statement was developed by the lead researcher. Reflexive thematic analysis is an ideal approach for this study as its flexibility allows for a deep examination of the multifaceted nature of end-of-life preferences without the constraints of rigid frameworks, making it well-suited to capture the complexity of this topic.¹¹ It emphasizes personal meaning and perception and aligns with our focus on physicians' subjective experiences and reflections. The iterative, reflexive nature of this method ensures that the researcher's role in interpreting sensitive, personal data is acknowledged, providing room for richer, more nuanced insights.¹¹ It excels in exploring the intersection of broader social and cultural contexts with individual decision-making, making it ideal for understanding the varied influences on physicians' preferences. Identifying patterns across the data helps uncover shared and divergent experiences, facilitating a comprehensive understanding of the study population. Additionally, it is an inductive, data-driven approach,

which allows for open exploration, making it particularly useful for research without predefined categories, enabling the discovery of unexpected themes.¹¹

Interview transcripts were imported to NVivo (version 12) for analysis. Our recruitment goal was met, and thematic saturation was achieved in each jurisdiction. Reaching saturation suggests that the themes generated from the interviews are comprehensive and robust enough to address the central research aims, allowing for a nuanced understanding of the phenomenon being studied without the need for further data collection. The lead author (SM) coded all transcripts, and another team member (FD) independently coded four transcripts for comparison. Transcripts were not shared with participants. Initial codes were discussed and refined (by SM & FD) and themes and subthemes were developed. The themes were then refined and discussed further by the full research team and similar or overlapping themes were collapsed or removed. A thematic map was then developed and evaluated and associated interview quotes were identified, discussed, and selected by the full research team. Participants did not provide feedback on the findings. Consolidated criteria for reporting qualitative research (COREQ) was followed.

Ethics

The study protocol was approved by the medical ethics committee of the Brussels University Hospital, which acts as the central ethics committee (BUN:1432021000562, September 29, 2021). Approvals were also obtained from the ethics committee in Italy (AUSL, Comitato Etico dell'Area Vasta Emilia Nord:748EE93B, April 7, 2022). The other participating institution did not require formal ethics approvals.

RESULTS

We collected data from interviews with 45 physicians, 15 in each country. Participants included 23 female and 22 male physicians (Table 1). Most were white/European (43) and identified as either Christian (23), non-religious (16) or other religion (6) and fell within the age groups < 40 years (18), 40-59 years (22), and > 60 years (5). We nearly achieved our target balance of

selected specialties with 15 general practitioners, 14 palliative care physicians and 16 other medical specialists participating.

Table 1. Characteristics of participating physicians, per jurisdiction				
	OVERALL (N=45)	Wisconsin, USA (N=15)	Belgium (N=15)	Italy (N=15)
Gender				
Male	22	6	7	9
Female	23	9	8	5
Age				
<40 years	18	6	3	9
40-59 years	22	7	11	4
>60 years	5	2	1	2
Physician type				
General practitioner	15	5	5	5
Palliative care physician	14	4	5	5
Other medical specialist	16	6	5	5
Average yearly end of life patients				
≤10	10	4	3	3
10-50	19	7	4	8
50-100	3	0	3	0
≥100	12	4	4	4
Religion				
Christian	23	7	6	10
Other religion	6	2	3	1
Non-religious	16	6	6	4
Ethnicity				
White/European	43	13	15	15
Asian	2	2	0	0
Other	0	0	0	0
Missing values: End of life patients: n=1				

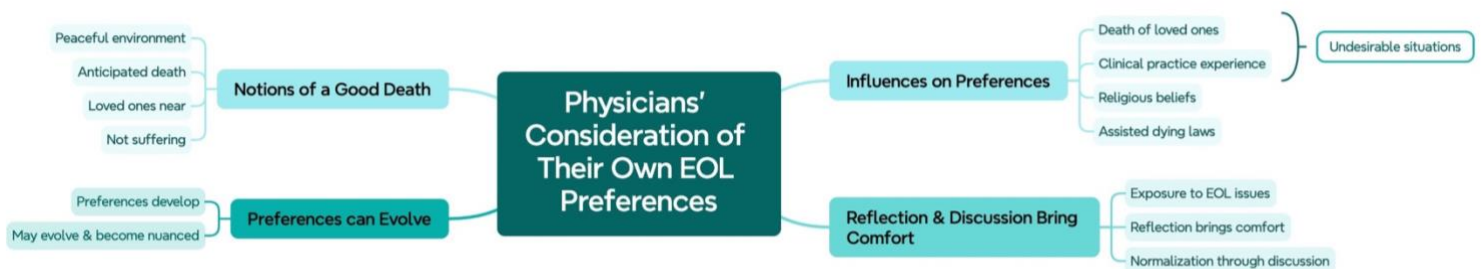
What do physicians consider for their own end of life

The sample reported a wide range of personal preferences related to various end-of-life decisions, shared information about the influences on their preferences, detailed elements they consider important for having a good death, and undesirable scenarios they hope to avoid.

We developed three main themes related to physicians' consideration for their own end-of-life preferences: 1. Notions of a good death – physicians have developed ideas about what a good death would look like for themselves; 2. Preferences can evolve – physicians recognize their preferences could change over time; and 3. Reflection and discussion bring comfort – death and dying become normalized through reflection and discussion (Figure 1).

We found that most physicians have considered their personal end-of-life preferences and for many, their ideas have clarified over time. Many physicians shared that they think regularly or often about their own mortality and have given some consideration to end-of-life issues. Palliative care physicians reported having reflected a lot on their own end-of-life preferences, which was not the case for general practitioners or other medical specialists. Many physicians stated they have formed strong ideas about what constitutes a good death after witnessing experiences with family members or patients they considered peaceful and positive, and, conversely, situations they would prefer to avoid.

Figure 1. Thematic map of physicians’ consideration for their own end-of-life preferences



EOL = End-of-life

Theme 1: Notions of a good death - Many physicians have a strong conception about what they would consider a good death.

Physicians often cited the elements of a good death as being at home or in hospice, anticipating death, loved ones nearby, enough time for goodbyes, not suffering, pain and

symptoms controlled, spiritual and practical affairs in order, a clear mind, and autonomy and dignity preserved.

Physicians largely preferred a death at home or in a peaceful environment. However, a small number said they have become accustomed to medical environments, and they would be fine with dying in a hospital. Many physicians specified that they would prefer to know that death was coming so they could prepare by putting their practical affairs in order and say goodbye to loved ones.

“Ideally, I am a much older man. I have a terminal illness that I see coming, so that way I have time to prepare and do the things that need to be done, say the things that need to be said. Family and people I care about around me, not in the hospital, in my own bed. Fairly free of symptoms, though I think a certain amount of suffering is just inevitable in end of life.” (Palliative care physician/internal medicine, Wisconsin)

Physicians also shared that they would prefer to avoid suffering and uncontrolled pain, and some specified they would like palliative care support and a competent medical team. If suffering could not be controlled many physicians said they would want palliative sedation, and some would request assisted dying.

“I think (palliative sedation) it's in line with the good death . . . I have seen what it can do and how people can say goodbye with more time and I think it's a good alternative. It's a good way of dying if you choose for it. If I would choose for it, I would. I think everything will be okay.” (Medical specialist, Belgium)

Other physicians shared that dignity and autonomy and having the ability to maintain cognitive clarity at the end of life are primary issues of concern to them.

“it's all about what we call dignity. And it's a very broad term, but I think (to) be aware of the situation is very important. Being able to say goodbye to your relatives, to your loved ones, to be as comfortable as possible and to be without fear and without worries. Because it's not because I work in palliative care that I'm not afraid of dying. And I hope that I will be surrounded by people who can give me comfort and who can, because I think I will be very frightened.” (Palliative care physician, Belgium)

For some physicians preserving a level of independence and not being a burden on their families at the end-of-life is a significant concern. Several palliative care physicians stated that part of a good death is that it is not medicalized.

Theme 2: Preferences can evolve- Some physicians shared that although they have a fairly clear idea about their personal preferences for end of life, they realize their preferences can change or become more nuanced over time due to exposure to various situations.

Physicians shared that they have noticed patients and/or family members change their minds and want very different things at the end of life than they might have considered earlier. Personal preferences and what one considers acceptable can evolve as an illness progresses and physicians acknowledge this could also be the case for themselves.

“My intention . . . is to revisit that document every ten years to make sure it's still applicable because, gosh darn it, so many patients I've run into change their mind. Over time you can get acclimated to new baselines you never thought that you could.” (Palliative care physician, Wisconsin)

“How you change in the course of dementia, how you as a person change. And even if you think this will be burdened to me, once you are in that state, that burden often is not that clear anymore just the same as you would think. I don't want to have chemo in my life because see how sick people are. But once you suffer from a cancer, you are willing to get chemo, so things change.” (General practitioner, Belgium)

Physicians expressed a level of acceptance about the fact that they may change their minds in time. In fact, some physicians cite this as the reason they have not yet done an advance directive, which was the case for many participants.

“I think it is much more important at regular times to speak with my family (about) how I'm looking and maybe like I look now to health and to diseases and end of life circumstances. This is a dynamic process. Probably I will change my mind in the next years. That is possible and acceptable.” (Palliative care physician, Belgium)

Other physicians say their preferences have changed due to exposure to specific clinical situations or they have become more nuanced. For example, some physicians described having an opposition to assisted dying as an option for themselves early in their careers but

becoming more open to assisted dying practices after seeing various difficult end-of-life scenarios. Others say their preferences developed early, such as avoiding aggressive life-prolonging measures, and has only deepened over time. Other physicians believe their core preferences have stayed constant over time and their wishes have altered little.

“At least six months of my residency was spent pretty heavily pondering what a good death can look like and what good deaths look like. And then, you know, probably at least monthly something crops up where it makes me reflect on my own mortality. Either at work or at home or in the universe. I don't think I spend more than 30 seconds thinking about it, because I feel like, my opinions aren't changing, my views aren't changing.” (General practitioner, Wisconsin)

Theme 3: Reflection and discussion bring comfort - Physicians shared the belief that death and dying become more comfortable and normalized the more they are reflected upon and when end-of-life issues are discussed with patients, colleagues, family and friends.

Some physicians reported feeling uncomfortable and uncertain during end-of-life conversations early in their careers but after more personal reflection on their own feelings and preferences and more clinical experience they came to feel more at ease initiating and navigating difficult end-of-life conversations with patients and families.

“Thinking about my own end of life preferences has made me, continues to make me more open with discussing different scenarios with my patients. So I think that has helped me, just, I think the more I'm introspective about things the better I'm able to talk about those scenarios with my patients. Not necessarily influence the way I talk about it, but just, you know, makes me more open to those conversations with people.” (Medical specialist, Wisconsin)

Physicians' perceptions of how their own end-of-life preferences have been impacted by personal, professional, cultural, legislative, social and religious influences

When we explored how physicians have reflected on their own end of life and perceive their preferences have been impacted by socio-cultural influences, physicians shared that their personal reflection on end of life is often triggered by a specific catalyst. These motivators include personal interest/curiosity, treating patients of a similar age, patient situations, history of illness in family, getting older, personal/family end-of-life experiences.

From the interview data, we identified four main themes and two sub-themes, including: 1. Death of loved ones – physicians have been significantly impacted by the death of loved ones; 2. Clinical practice experiences (sub-theme: Undesirable situations) – physicians have been influenced by their clinical practice, particularly negative experiences; 3. Assisted dying laws – physicians have been influenced by the existence/absence of assisted dying laws; and 4. Socio-cultural context (sub-theme: Religious beliefs/faith) – physicians have been influenced by a variety of factors including culture, ethnicity, education, social norms, personal/family values, and particularly, religion.

Theme 1: Death of loved ones - Most physicians have been significantly influenced by the death of loved ones.

Many physicians shared experiences of having acted as a caregiver for a loved one or seeing the impactful death of parents, grandparents, family members, or other loved ones. Often the illness trajectory and/or cause of death was mentioned as shaping the experience as positive or negative and influencing their attitudes toward preferring or rejecting certain end-of-life decisions.

Many physicians discussed being strongly influenced by seeing loved ones die after a prolonged illness with dementia or cancer, which sometimes involved choices or treatments they would not prefer for themselves.

“That (mother’s illness) was probably the primary one. I saw her suffer through cancer for almost 18, 19 months and chemo, radiation, everything, and I, I think if I had a terminal diagnosis like that, I probably wouldn’t do anything.” (General practitioner, Wisconsin)

“I think going through it personally was also helpful with my father’s experience, and he actually made choices I would not make for myself. And we respected and supported them . . . personal experience really made me much more comfortable and realizing how important it was to have these conversations.” (Palliative care physician, Wisconsin)

Other physicians discussed the sudden death of family members, especially young family members, as a particularly challenging experience and a significant influence on their lives and personal preferences.

“I would say my child's death in some ways made it more personally difficult for me, but yet also a little bit more of a calling to try to make it be a better experience for, for patients and families.” (General practitioner, Wisconsin)

Theme 2: Clinical practice experiences - Most physicians consider their clinical practice and helping patients at the end of life to be a significant influence on their own preferences.

Seeing difficult end-of-life patient situations and helping patients make end-of-life decisions profoundly impacts what physicians prefer for themselves. Many physicians described challenging end-of-life scenarios that involved prolonged illnesses with high levels of physical or psychological suffering or situations with cognitive impairment and dependency as being influential. Many also described seeing patients receive aggressive or futile treatments that they would strongly prefer to avoid at the end of life. Some physicians described being impacted by treating patients of similar age to themselves. Other physicians described peaceful deaths, or sudden deaths, or assisted deaths they thought might be preferred, or not preferred, for themselves.

“I just vividly remember this, an intensive care unit where every single person was a young man with Aids and pneumocystis pneumonia on a ventilator. None of them would survive, and it just would be one after another die, die, die, die. And, you know, finally . . . a lot of hospitals either said to people, you know, we're not going to put you on a ventilator with this condition because you're not going to survive it. So you're better off just having palliative care or, you know, I think there was a certain amount of assisted, you know, assisted dying going on. You know, maybe sort of under the table, so to speak. But, you know, that was just horrible to see, you know, people just, you know, sort of be kind of bright and perky, get intubated, they're awake at the time, and then that's it, you know, then that's the last moment that they're awake or interacting with anybody. And I just thought, this is just really awful. So that, that I think really influenced me.” (Palliative care physician, Wisconsin)

Some physicians explained that their clinical experience working in an intensive care unit influenced them to prefer another type of environment at the end of life and others shared

that exposure to palliative care teams or receiving palliative care training was influential and exemplified the kind of care they would prefer to receive at the end of life.

“My time in critical care is probably the biggest (influence). Well. And if I could choose a second, I would say my interaction with the palliative and hospice care services, to know that that existed and to kind of get what they do and to think, wow, this feels so comfortable. And, and actually, it's a strangely joyful place to, to spend time. And so my time in critical care showed me a lot of what I don't want. And my time with in working with the palliative and hospice care folks was shorter, but probably equally meaningful.” (General practitioner, Wisconsin)

Sub-theme: Undesirable situations - Physicians described being deeply impacted by seeing situations and deaths they would not want for themselves in both their personal and professional lives. Undesirable situations was interpreted as a cross-cutting sub-theme across Theme 1. the death of loved ones, and Theme 2. clinical practice experiences.

The undesirable situations detailed by physicians in the interviews included: sudden deaths, being in the hospital or intensive care unit at the end of life, having uncontrolled symptoms or severe pain, being on a ventilator long term without the ability to communicate, receiving futile or aggressive treatment, experiencing physical and/or psychological suffering, being alone, being dependent on others for care, being confused or cognitively impaired, and being a burden on their families.

“I hope I will not die alone. That's what we see in some care units or that that there we see patients that have not a lot of family, and we're only the doctors and palliative care personnel is there for the patient, so I think that's very important to me. Another thing is, is that the things you hear a lot like suffocation or a lot of pain that are the two main reasons that I hear a lot and that are also praying for myself that I hope to avoid. And I think we can avoid at the end of life.” (General practitioner, Belgium)

Most physicians expressed the desire to avoid life-prolonging treatment at the end of life including cardiopulmonary resuscitation, artificial nutrition and hydration and mechanical ventilation. The concepts of being dependent and physical and mental suffering also came across as a main concern for physicians considering possible end-of-life scenarios.

“I guess (I hope to avoid) a lot of pain at the end where there's trouble with pain relief. Also, like the physical indignities of the end stage where you are incontinent

and you need to depend on other people. I think also like more the emotional burden, if you would be if I would be very young to die and I would know it in advance. And you see the suffering of your family. I have four children myself so I think that would be horrible to know that I would have to leave my children. So I think it's both the physical suffering as the as the mental suffering.” (General practitioner, Belgium)

Theme 3: Assisted dying laws - Many physicians feel they have been influenced by living in a jurisdiction with or without an assisted dying law.

Some physicians feel assisted dying laws are a positive and important end-of-life option for themselves and patients and are grateful to live in a jurisdiction which allows these options or express a wish to have an assisted dying option available to them. Other physicians are opposed to assisted dying for themselves, or for everyone, and expressed concern and conflict about the notion of having to practice medicine in an environment which allows assisted dying should it become legal where they practice. These beliefs seem to be often aligned with the legal situation in the jurisdiction of the physician.

“I think this (assisted dying law) will influence us as physicians and just in our own personal view, if you can talk about something freely, I think it will alter your way of thinking also. Yeah, but in this way, I'm happy that we can. We don't have to have any fear about this topic.” (Medical specialist, Belgium)

“This can influence you because if nobody among you, nobody in the hospital, nobody among patients, nobody among your friends even have to speak about assisted suicide or something like that, you never start to think about it and you just think implicitly that this is not a solution to consider.” (Medical specialist, Italy)

“I think not only Wisconsin, but, you know, the United States in general. So absolutely, it affects, it limited my scope of thought process because when I was filling out the survey, I thought, oh, wow, I really haven't even thought about this. And it's because it's not it's not an option for me or my patients or my family.” (Medical specialist, Wisconsin) (The ‘survey’ refers to the related PROPEL quantitative survey study)

Some physicians acknowledged feeling undecided or conflicted about assisted dying practices or believe their preferences have not been impacted one way or another by the presence or absence of an assisted dying law. We also found that palliative care physicians strongly preferred palliative sedation to assisted dying at the end of life. Many

general practitioners and other medical specialists said they would consider assisted dying if it were a legal option and all physicians said they would consider palliative sedation an option to relieve suffering at the end of life.

Theme 4: Socio-cultural context - Many physicians feel they have been influenced by their culture, ethnicity, education, social norms, and personal and family values.

Physicians shared personal stories and traditions related to death and dying within their families, often of their parents or grandparents, as well as impactful exposures to films, books, media stories, etc. For example, the books *Being Mortal* by Atul Gawande and *The Death of Ivan Ilyich* by Leo Tolstoy were mentioned as being influential for some physicians as well as exposure to media coverage of patients who remained in a persistent vegetative state for extended periods. These exposures motivated some physicians to reflect on end-of-life issues and influenced their own preferences.

“I traveled a lot for purpose of studying and working, and that really helped me a lot in seeing different perspectives in different relationships with doctors and their patients. The cultural situation and also practical aspects of care and, and I'm sure that they helped me a lot in feeling more comfortable, because I think if I just lived in Italy, probably I would be more narrow minded because I would have I would not have seen so many things. That really impacted the way that I opened the discussion about end of life.” (Palliative care physician, Italy)

“Reading about people dying, even in a fictional setting, or probably more so in a fictional setting, has influenced me. I mean, there's some of the most beautiful and accurate passages about death in literature.” (General practitioner, Wisconsin)

Sub-theme: Religious beliefs/faith - Some physicians feel they have been influenced by their religion/faith, or non-religious views and believe these views have impacted their personal preferences for end-of-life.

Some physicians described having a strong connection with God and/or their faith and a comforting belief that their lives and end-of-life are in the hands of a higher power. Some cite their religious beliefs as the basis for their opposition to assisted dying practices and belief that the end of life should not be hastened. Other physicians describe being influenced by treating patients with strong religious beliefs, who received what the

physician considered overtreatment due to religious objection to ending treatment. This seems to be a key issue as several physicians expressed concern and objection to receiving aggressive or futile treatment at the end of life and this was influential on their personal preferences.

Our study found that physicians with more strongly held religious beliefs were more opposed to assisted dying practices. This was prominent with physicians from Italy but also with the more religious physicians in Belgium and Wisconsin.

“I think that religion influences me only to artificial death . . . I'm against to artificial death. I think because of religion, cultural aspects, really in myself and I think that this aspect could influence.” (General practitioner, Italy)

“And the way you are raised as a child, for example, I've been raised in a rather a very Catholic family, actually. So my, mother and father, they, went to mass every Sunday. We prayed. I had to go there, too. I don't do it anymore now. So I've lost that kind of necessity but I still consider myself a Catholic, so I didn't. I still consider myself as being a Christian, a Christian man. But it all shapes you to what you want also. You . . . have to think about it because it influences, of course, your way of working with people. Which might, which might be a danger because you might want to fill in for the patient like the way you want it to be.” (General practitioner, Belgium)

Other non-religious physicians shared that they held spiritual or other personal beliefs that influenced their preferences. Some non-religious physicians noted that it is hypocritical to argue that medicine should not interfere at the end of life since medicine has developed in significant ways and often intervenes and impacts the beginning of life.

“I'm not religious. So, for me deciding or taking end of life decisions, for me, there is no religious component in or like life is sacred. I think that medicine had already developed. I always think it's a bit hypocritical to say that we can't decide for God, because we do it already. If you see what we do with little children when they're born, when they're 23, 24 weeks, we already play for God. So when we can play for God in the beginning of the life, I don't see why we shouldn't, can't do that at the end of life. Yeah. That's really, so I totally, I respect the religious people but I totally disagree with that because we do it already.” (General practitioner, Belgium)

Discussion

This study found many physicians, particularly those in palliative care, have reflected on what they would want for themselves at the end-of-life and have developed ideas about what they consider a good death and what they hope to avoid. Physicians have notions about what they would prefer but acknowledge their preferences could evolve and become more nuanced. Most physicians prefer to avoid aggressive and life-prolonging treatment, physical and mental suffering, and being a burden. They prioritize being in a peaceful environment and retaining the ability to communicate with loved ones. Physicians' preferences are shaped by various factors, including cultural, social, and religious beliefs, and legislative environment. However, their experiences with the deaths of loved ones and their clinical practice play a particularly significant role. Physicians emphasized that death and dying become more comfortable and normalized the more they are reflected upon and discussed and feel this process can also provide personal growth and help them provide better care to patients and families.

It is not unexpected that physicians with extensive experience caring for end-of-life patients have reflected deeply on the type of care they would desire for themselves at the end of life. However, it is notable that physicians across all specialty groups and countries have developed ideas about what they would prefer for themselves and what constitutes a good death, and many have well-formed opinions about the scenarios they hope to avoid. Physicians' ideas are mainly based on the suffering they have witnessed during the death of a loved one, caring for end-of-life patients with extremely challenging clinical situations or seeing patient choices they would not prefer for themselves. This aligns with research indicating that the emotional challenges of caring for dying patients can influence physicians' thought processes and decision-making.^{12,13} Although some physicians highlighted experiences of observing peaceful and meaningful deaths, the most powerful influence seems to be the end-of-life experiences they found most challenging and hope to avoid.

Personal and professional experiences have considerable effect on physicians' end-of-life preferences. For some physicians, personal experiences including acting as a caregiver,

making end-of-life decisions for family members, or witnessing the death of loved ones, has had a profound impact on their lives and preferences. Seeing a loved one suffer from a prolonged illness and receive intensive treatment has led some physicians to prefer some end-of-life decisions over others, or generally less aggressive treatments for themselves. This finding is in line with research indicating that physicians generally prefer less intensive and life-prolonging treatment, particularly those with high exposure to very sick patients.^{2,4} Professional experiences like caring for patients with challenging end-of-life scenarios or working in intensive care units have also significantly impacted and clarified their personal preferences. This is likely due to observing intensely challenging circumstances firsthand, seeing diverse outcomes, and developing expertise over time through active involvement in patient care. This exposure has led many physicians to prefer a peaceful, non-medical environment at the end of life.

We found striking variation in physicians' end-of-life preferences connected to cultural influence, legislative environment, and physician specialty. Physicians' attitudes about assisted dying seem to vary based on cultural and legal environment and personal beliefs. Physicians in jurisdictions where assisted dying is legal or where laws have been considered (Belgium and Wisconsin) more often view it as a positive and important end-of-life option, while others express discomfort, especially if their cultural or religious beliefs, or the legal framework of their country, opposes it (Italy). Religious beliefs can also contribute to the complex emotions physicians experience, influencing both their personal preferences and their moral interpretation of clinical and personal experiences. Palliative care physicians clearly prefer palliative sedation to assisted dying, which may be a result of their familiarity with the practice and belief that appropriate palliative care can manage suffering at the end of life. This supports previous research which finds variation in attitudes toward end-of-life practices based on medical specialty.¹⁴ Many general practitioners and other medical specialists would consider both palliative sedation and assisted dying for intractable suffering at the end of life. Cultural norms, family traditions and exposures to death through art and media have also clearly played a role in shaping

physicians' normative beliefs and preferences. These findings suggest that physicians' beliefs, including religious and ethical convictions, significantly shape their views on assisted dying and other end-of-life practices, highlighting the complex interplay between individual values and professional practice.

Our findings provide insights into the factors shaping physicians' end-of-life preferences and highlight how these preferences, which may differ from the treatments they provide to patients, are formed. It also raises important questions that warrant further research. For instance, how do physicians' own preferences influence their clinical practice and recommendations to patients? Are physicians effectively separating their personal preferences and deferring to patients' wishes? What supports do physicians have in balancing the tensions that exist between personal values and professional responsibility? How does the reluctance of some physicians to reflect on their own end-of-life or openly discuss such issues with patients, colleagues, or loved ones impact clinical practice? Should personal reflection and training in end-of-life conversations be obligatory in medical education or continuing professional development? Does exposure to assisted dying legislation increase acceptance over time, regardless of personal religious beliefs?

Strengths and limitations

A strength of our study is the cross-national qualitative design, including physicians across three countries representing varied legal and cultural environments and the participation of three groups of physicians - general practitioners, palliative care physicians, and other medical specialists. Our preferred balance of physician groups was successfully recruited and the total sample of 45 physicians was ideal to gather comprehensive insights given our research questions, the diversity within the sample, and our analytical approach. By focusing on how physicians have considered their end-of-life preferences and the factors that influence them, we provide a much-needed addition to the current literature on physicians' end-of-life preferences. The study had certain limitations. Although the final sample included a variety of physician groups in three countries, it was ethnically homogenous, and there may be selection bias as the interview study could have attracted

those with a particular interest in end-of-life issues, resulting in a sample that could have reflected more intensely on the topic.

Policy and practice implications

These study findings suggest several important implications for policy and practice. First, clear policies and ethical guidelines are needed to help physicians manage moral conflicts and maintain professional boundaries to ensure that clinical recommendations are based on patient preferences rather than personal beliefs or biases, particularly in end-of-life care. Second, ethical guidelines would help physicians navigate complex decisions, such as those involving physician-assisted suicide or euthanasia. Third, promoting palliative care training, which fosters a person-centered approach, could help reduce the influence of personal preferences on patient recommendations, making it crucial to integrate palliative care principles into general medical education. Fourth, addressing cultural and religious influences on physician decision-making through cultural competency training is also essential, especially in jurisdictions where strong religious traditions impact patient care.

Conclusion

Many physicians have reflected on their end-of-life preferences, particularly those who work in palliative care. They generally favor less aggressive and life-prolonging treatment and prioritize communication with loved ones and minimizing pain and suffering. Their preferences are largely shaped by experiences, such as the death of a loved one and clinical practice and are also influenced by social, cultural and legal factors including religious beliefs and assistance dying legislation. We found variation in attitudes across physician groups and countries, which suggests that physicians' views on end-of-life practices are evolving, particularly in response to changing cultural and societal norms, legal and ethical factors, and changes in medical practice. Some physicians feel engaging in end-of-life reflection and discussions can foster personal growth and help them provide better care. Further research is needed to gain deeper insight on physicians' personal end-of-life preferences as well as their underlying socio-ethical-cultural basis.

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PART III

The connection between physicians' preferences and practice

Chapter 4

Associations between physicians' personal preferences for end-of-life decisions and their own clinical practice: PROPEL survey study in Europe, North America and Australia

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ABSTRACT

Background:

Physicians have significant influence on end-of-life decisions. Therefore, it is important to understand the connection between physicians' personal end-of-life care preferences and clinical practice, and whether there is congruence between what they prefer for themselves and for patients.

Aim:

Study to what extent physicians believe their personal end-of-life preferences impact their clinical practice and to what extent physicians' personal treatment option preferences differ from what they prefer for their patients.

Design:

A cross-sectional survey was conducted from May 2022 – February 2023.

Setting/participants:

Eight jurisdictions: Belgium, Italy, Canada, USA (Oregon, Wisconsin, and Georgia), Australia (Victoria and Queensland). Three physician types were included: general practitioners, palliative care physicians, and other medical specialists.

Results:

We analyzed 1157 survey responses. Sixty-two percent of physicians acknowledge considering their own preferences when caring for patients at the end of life and 29.7% believe their personal preferences impact the recommendations they make. Palliative care physicians are less likely to consider their own preferences when caring for and making recommendations to patients. Congruence was found between what physicians prefer for patients and themselves with cardiopulmonary resuscitation considered "not a good option for both" by 99.1% of physicians. Incongruence was found with physicians considering some options "not good for

the patient, but good for themselves” - palliative sedation (8.3%), physician-assisted suicide (7.0%) and euthanasia (11.6%).

Conclusion:

Physicians consider their own preferences when providing care and their preferences impact the recommendations they make to patients. Incongruence exists between what physicians prefer for themselves and what they prefer for patients.

INTRODUCTION

Medical decision-making is particularly complex at the end of life and may include withholding or withdrawing life-sustaining treatment, the intensification of symptom management or palliative sedation.^{1,2} In a growing number of countries it also includes assisted dying, an umbrella term covering voluntary assisted dying (VAD), medical aid in dying (MAiD), euthanasia or physician-assisted suicide (PAS). Assisted dying refers to the act of intentionally ending the life of a patient by a clinician by means of active drug administration or the provision or prescribing of drugs at that patient's explicit request.³ It is estimated that up to half of all deaths in Western countries are preceded by at least one end-of-life decision.⁴

Physicians have significant influence on healthcare decisions and various factors influence physicians' clinical decisions and attitudes about end-of-life care.^{2,5} These factors include expertise, medical specialty, level of experience, comfort providing end-of-life care, clinical guidelines, values, religiosity and spirituality.^{2,5} Since patients frequently seek help, advice, or reassurance when making difficult decisions by asking their physician what they would do in their position, it is expected that physicians would consider what they would want for themselves.^{6,7} Consequently, gaining a better understanding of the connection between physicians' own preferences and their practice is of clinical importance.

Existing studies on physicians' attitudes about end-of-life care demonstrate that physicians generally prefer less aggressive care and fewer resuscitative measures at the end of life, though their personal preferences are not always reflected in their clinical practice.⁸⁻¹¹ Research has revealed a discrepancy between what doctors personally desire - comfort over prolonging life - and the care patients often receive.¹² Existing studies of physicians' preferences are outdated and limited in focus, both geographically and regarding the end-of-life practices they investigate. A key gap in this area of research is the disconnect between physicians' personal preferences and their clinical practices, and how these preferences are communicated and respected in real-world medical settings. Additionally, research is needed to explore how

cultural, ethical, and systemic factors influence the discrepancy between physicians' end-of-life care for themselves versus their patients.

This study aims to explore the connection between physicians' personal end-of-life decision preferences and their own clinical end-of-life practice across three continents (North America, Europe, Australia) among three groups of physicians (general practitioners, palliative care physicians, and other medical specialists). Exploring across jurisdictions and specialties is important because the connection between personal preferences and clinical practice may vary between medical specialties and macro-level contexts, due to training, exposure to patients at the end of life, or other factors.

Since assisted dying legislation can have a substantial impact on the role of physicians and medical practice,¹³ we intentionally selected physicians practicing in jurisdictions which have diverse cultural environments and varied levels of experience with assisted dying legislation (Appendix C & D). We address the following research questions:

- To what extent do physicians believe their personal end-of-life preferences impact their own clinical practice and how do they compare across physician groups and jurisdictions?
- To what extent do physicians' personal treatment option preferences differ from their treatment option preferences for patients in similar health scenarios?

METHODS

Study design

We conducted a self-administered cross-sectional survey across various countries in North America, Europe, and Australia.

Context and setting

We included jurisdictions in North America (Canada and the US states Oregon, Wisconsin, and Georgia); Europe (Belgium (Flanders), Italy); and Australia (states of Victoria and Queensland). Countries were purposely selected to obtain perspectives from diverse jurisdictions with varied legal options regarding assisted dying. Our goal was to include physicians with diverse cultural and religious backgrounds and different levels of exposure to and experience with assisted dying practices. (Appendix C & D)

Participants

The study population included currently practicing general practitioners, palliative care physicians and other medical specialists with a high likelihood of seeing patients facing end-of-life issues (i.e. cardiologists, emergency medicine, gastroenterologists, geriatricians, gynecologists, internal medicine, intensivists, nephrologists, neurologists, oncologists, pulmonologists).

A convenience sample of 150-200 physicians in each jurisdiction was sought. Our goal was a distribution of physician groups that included a minimum of 60 general practitioners, 30 palliative care physicians, and 60 medical specialists in each jurisdiction, for a minimum total of 150 physicians in each jurisdiction.

Data collection and recruitment

Data were collected between May 2022 – February 2023 using a self-administered web-based questionnaire (Appendix A) on the Qualtrics online survey platform. To ensure participant privacy, we used an anonymous link and did not collect personal identifiable information. The survey invitation was shared via email by our international research partners or their professional contacts within physician organizations, medical licensing boards, commercial registries, professional networks and on social media. An initial survey invitation was sent by email, followed by a maximum of three reminders.

Questionnaire

The survey instrument is an adaptation of a validated questionnaire, which underwent substantial modification and pilot testing.¹⁴ Cognitive testing was conducted to evaluate the questionnaire for question order, clarity and appropriateness of terminology with two to four physicians in each jurisdiction followed by revision and further testing. Participants provided consent at the start and the final survey comprised 38 questions, with a total completion time of approximately 10 minutes.

We used several items to assess the connection between physicians' own end-of-life preferences and their clinical practice: the extent to which they consider what they would want for themselves when caring for patients at the end of life, whether they believe their personal end-of-life preferences impact the recommendations they make to patients, and whether they feel it is appropriate to consider their own personal end-of-life preferences when caring for a patient, using a 5-point Likert scale from (1) strongly disagree to (5) strongly agree.

To further assess the connection between physicians' own end-of-life decision preferences and clinical practice, we used two case vignettes with hypothetical end-of-life scenarios, one cancer scenario and one Alzheimer's disease scenario, first in reference to a patient, then to the physician themselves (Box 1). Physicians were asked to what extent they would consider various end-of-life practices, including: cardiopulmonary resuscitation, mechanical ventilation, artificial nutrition and hydration, intensified alleviation of symptoms, palliative sedation, using available medications to end one's own life, physician-assisted suicide and euthanasia, first for a patient, and then for themselves. Preferences were measured using a 4-point Likert scale, with physicians asked, "Which of the following would you consider possible options for this particular case (if there is an indication for it)?", using the following response options, "(1) Not at all a good option (2) Not such a good option (3) A good option (4) A very good option".

Additional questions were included on demographic-, cultural-, and institutional-level factors that may influence physicians' end-of-life decision preferences including gender, age, physician specialty, average number of end-of-life patients annually, ethnicity, and religion.

Box 1. End-of-life scenarios and end-of-life decision preferences included in the PROPEL questionnaire	
Cancer scenario*	You have been diagnosed with cancer with extensive lung and bone metastases and your treating oncologist has said no further treatments are available. You have an estimated life expectancy of no more than two weeks and are fully competent. You are experiencing ongoing severe pain and agitation. A palliative care provider is involved and palliative care services (e.g. home care, inpatient hospice) are available for you.
Alzheimer's scenario*	You are suffering from Alzheimer's dementia in gradual cognitive decline and you no longer recognize your family or friends. You refuse to eat and drink and have become more and more withdrawn. It is no longer possible to communicate with you about medical treatment options. A palliative care provider is involved and palliative care services (e.g. home care, inpatient hospice) are available for you.
Preferences for end-of-life decisions*	<p>Right now, which of the following would you consider possible options for yourself (if there were an indication for it)? Response options (1) <i>Not at all a good option</i> (2) <i>Not such a good option</i> (3) <i>A good option</i> (4) <i>A very good option</i></p> <ul style="list-style-type: none"> - the use of cardiopulmonary resuscitation - the use of mechanical ventilation - the use of intravenous hydration - the use of a feeding tube (gastrostomy, jejunostomy, or intravenous) to provide nutrition - to intensify the alleviation of symptoms by using medications, taking into account the probability or certainty that this could hasten your death - to use high doses of medications, such as benzodiazepines or barbiturates, to be kept in deep sedation until death - to request medications from your health care practitioner that would allow you to end your own life, if it is currently legal or were to become a legal option in your jurisdiction - to use medications which are at your disposal as a physician to end your own life - to request assistance from a medical practitioner who could administer a substance to end your life, if it is currently legal, or were to become a legal option in your jurisdiction
	*Scenarios for physician (self) shown here. Patient scenarios for cancer and Alzheimer's were also included and preference options were modified to fit each scenario (physician assisted suicide not presented with the Alzheimer's scenario).

Statistical analysis

We calculated the proportion of physicians that agreed or strongly agreed with each of the items on physicians' perceived connection between their personal end-of-life preferences and clinical practice. To examine congruence between the end-of-life practice preferences of physicians for themselves and what they prefer for patients in scenarios of cancer and

Alzheimer's we conducted univariate analyses for each option for both scenarios to report percentages for response options 'a very good/good option for both', 'not a good option for both', 'good for physician, not good for patient', 'not good for physician, good for patient' (Table 3). All analyses were done using SPSS (version 28). Binary logistic regression analysis was conducted using modeling for each of the three outcomes separately (whether physicians perceive an impact of their personal end-of-life preferences on their clinical practice). Variables analyzed include: jurisdiction, gender, age, physician group, palliative care training, yearly end-of-life patients, and religion. The variable related to years of practice was omitted from Table 2 due to issues of multicollinearity with the variable for age (correlation coefficient .82). Data were reviewed for duplicate responses and none were found. For each jurisdiction and age group included, analysis was calculated against the mean, as opposed to a reference category.

Ethical considerations

The study protocol was approved by the medical ethics committee of the Brussels University Hospital that acts as central ethics committee (BUN:1432021000562, September 29, 2021). Approvals were also obtained from ethics committees in Australia (Queensland University of Technology:20225080, December 17, 2021), Canada (Ottawa Hospital Research Institute:20220217-01H, August 29, 2022), and Italy (AUSL, Comitato Etico dell'Area Vasta Emilia Nord:748EE93B, April 7, 2022). Formal ethics approvals were not required by the other participating consortium partners/institutions.

RESULTS

We received 1408 survey responses. Of those, 251 were excluded because they were ineligible or incomplete, resulting in a final sample of 1157 physicians (Table 1). Responses were considered incomplete if less than 80% of the questions were answered or the response excluded the end-of-life scenario questions. Due to the use of convenience sampling, an exact response rate cannot be determined; however, our interest was on associations between variables more than in point estimates of a given variable (prevalence) and this focus is less prone to bias from low response rates.¹

Responses came from eight jurisdictions including in North America: Canada (N=113), Oregon US (N=169), Wisconsin US (N=161), Georgia US (N=116); in Europe: Belgium (N=154) and Italy (N=196); and in Australia: Victoria (N=128) and Queensland (N=98). Seventy percent of respondents were physicians between 40-59 years old and there was almost equal participation of male and female physicians. The spread of responses came close to our goal with overall 389 general practitioners, 249 palliative care physicians, and 510 other medical specialists with end-of-life experience. Most physicians were White/European (74%) and identified as either non-religious (43%) or Christian (39%). Most physicians reported caring for either approximately <10 end-of-life patients per year (42%), or approximately >30 end-of-life patients per year (38.9%).

Table 1. Characteristics of physicians in the sample, per jurisdiction									
	OVERALL (N=1157)	CA (N=113)	USA			BE (N=154)	IT (N=196)	AUS ^b	
			WI (N=161)	OR (N=169)	GA (N=116)			VIC (N=128)	QLD (N=98)
	N (%)	%	%	%	%	%	%	%	%
Gender^a									
Male	523 (49.1)	58.4	43.0	45.3	50.9	37.5	47.4	62.1	51.7
Female	542 (50.9)	41.6	57.0	54.7	49.1	62.5	52.6	37.9	48.3
Age									
30-39 years	237 (22.1)	28.7	29.4	12.1	21.7	28.5	22.3	17.2	16.1
40-49 years	289 (27.0)	33.7	37.9	24.8	19.8	25.7	24.9	20.7	29.9
50-59 years	280 (26.2)	21.8	23.5	32.9	19.8	33.3	21.2	25.0	28.7
60+ years	264 (24.7)	15.8	9.2	30.2	38.7	12.5	31.6	37.1	25.3
Physician group									
General practitioner	390 (34)	1.8	32.1	43.0	34.5	26.6	33.7	37.0	64.6
Palliative care	249 (21.7)	41.6	13.8	7.9	19.8	27.3	42.3	8.7	7.3
Other medical specialty	509 (44.3)	56.6	54.1	49.1	45.7	46.1	24.0	54.3	28.1
Years of practice									
<5 years	193 (16.9)	20.7	20.1	10.8	16.1	17.6	20.4	13.4	15.6
5-10 years	197 (17.3)	24.3	23.9	15.7	15.2	16.3	15.3	13.4	14.6
11-20 years	319 (28.0)	25.2	34.0	27.1	18.8	26.8	31.6	24.4	33.3
>20 years	432 (37.9)	29.7	22.0	46.4	50.0	39.2	32.7	48.8	36.5
Average yearly end-of-life patients									
<5	255 (24.9)	7.3	16.6	31.1	32.4	21.9	16.5	39.2	64.9
5-10	175 (17.1)	15.6	22.9	23.2	21.6	15.2	19.1	0	0
11-20	122 (11.9)	12.8	15.9	14.6	10.8	20.5	8.2	0	0
21-30	75 (7.3)	8.3	8.9	3.7	6.3	6.6	6.2	17.6	3.5
>30	399 (38.9)	56.0	35.7	27.4	28.8	35.8	50.0	43.2	31.6

Religion									
Christian	451 (42.4)	30.7	46.8	32.9	60.0	31.7	61.5	31.0	36.0
Non-religious	481 (45.2)	52.5	40.3	49.3	14.3	65.5	34.9	56	47.7
Other religion	131 (12.3)	16.8	13.0	17.8	25.7	2.8	3.6	12.9	16.3
Ethnicity									
White/European	859 (81.1)	74.3	82.5	79.3	62.9	98.6	82.4	82.5	75.6
African/Black	19 (1.8)	0	0.6	2.1	11.4	0.7	0	0.9	1.2
Latino/Hispanic	46 (4.3)	1	1.3	3.4	4.8	0	16.1	0	1.2
Asian	79 (7.5)	17.8	8.4	10.3	11.4	0	0	11.4	8.5
Other	56 (5.3)	6.9	7.1	4.8	9.5	0.7	1.6	5.3	13.4
WI=Wisconsin, OR=Oregon, GA=Georgia, CA=Canada, BE=Belgium, IT=Italy, VIC=Victoria, QLD= Queensland									
Missing values: Gender: n=87, Age: n=87; Physician group: n=9; End-of-life patients: n=131; Religion: n=94; Ethnicity: 98.									
^a Gender percentages exclude n=5 responses of 'other' and 'prefer not to say'.									
^b For n=22 Australian cases jurisdiction is unknown.									

Perceived impact of physicians' personal end-of-life preferences on clinical practice

Across the sample, 62% of physicians said they frequently consider their own personal end-of-life preferences when caring for their end-of-life patients. Physician responses varied across jurisdictions, with the highest percentage of physicians who perceive considering their preferences when caring for patients found in Belgium (compared to the mean) (70.8%) (OR 1.7, 95% CI 1.2-2.5), while the lowest percentage of physicians was found in Queensland (52.9%) (OR 0.6, 95% CI 0.3-0.9) (Table 2). Palliative care physicians and physicians who care for a high number of patients with end-of-life issues (>30 per year) least frequently perceive considering their own preferences when caring for patients (respectively, 53.8% and 56.0%) (not significant).

Across the sample, 29.7% of all physicians agree or strongly agree that their personal preferences impact the recommendations they make to patients. Physicians who were more likely to agree include those from Georgia (37.1%) (OR 1.7, 95% CI 1.1-2.6), Belgium (34.7%) (OR 1.6, 95% CI 1.1-2.3) and Italy (31.3%) (OR 1.5, 95% CI 1.0-2.1). Physicians from Victoria were less likely to agree (26.7%) (OR 0.5, 95% CI 0.3-1.0) (than the mean). Those who say their personal preferences impact recommendations to patients was lowest among palliative care physicians

(18.8%) (not significant). General practitioners and other medical specialists were more likely than palliative care physicians to say their personal preferences impact recommendations to patients (32.3%) (OR 2.3, 95% CI 1.3-4.0), and (33.2%) (OR 2.5, 95% CI 1.5-4.1), respectively. Those who identified as religious (not Christian) were less likely than non-religious and Christian physicians to agree that their personal preferences impact recommendations to patients (21.3%) (OR 0.5, 95% CI 0.3-0.9).

	I frequently consider what I would want for myself when caring for patients who are at the end of life		My personal end-of-life preferences impact the recommendations I make to patients		I feel it is appropriate to consider my personal end-of-life preferences when caring for patients	
	% ^a	OR (95% CI)	% ^a	OR (95% CI)	% ^a	OR (95% CI)
Overall	62.0	--	29.7	--	23.9	--
North America						
<i>Canada</i>	57.4	1.0 (0.7-1.5)	19.8	0.7 (0.4-1.2)	21.8	0.9 (0.6-1.4)
<i>Oregon, USA</i>	65.5	1.1 (0.8-1.6)	29.1	1.0 (0.7-1.5)	29.7	1.3 (0.9-1.9)
<i>Wisconsin, USA</i>	68.4	1.3 (0.9-1.8)	32.9	1.2 (0.9-1.7)	21.1	0.8 (0.5-1.2)
<i>Georgia, USA</i>	68.6	1.4 (0.9-2.0)	37.1	1.7 (1.1-2.6)*	30.5	1.3 (0.9-2.0)
Europe						
<i>Belgium</i>	70.8	1.7 (1.2-2.5)*	34.7	1.6 (1.1-2.3)*	23.6	1.1 (0.8-1.7)
<i>Italy</i>	52.1	0.7 (0.5-1.0)	31.3	1.5 (1.0-2.1)*	16.2	0.7 (0.5-1.2)
Australia						
<i>Victoria</i>	59.5	0.7 (0.5-1.1)	26.7	0.5 (0.3-1.0)*	24.1	0.8 (0.5-1.4)
<i>Queensland</i>	52.9	0.6 (0.3-0.9)*	19.5	0.5 (0.3-1.0)	29.9	1.3 (0.7-2.4)
Gender						
Male	61.5	Ref.	31.0	Ref.	26.9	Ref.
Female	62.4	0.9 (0.7-1.2)	28.6	0.8 (0.6-1.1)	21.0	0.7 (0.5-.97)*
Age						
30-39 years	63.4	0.9 (0.7-1.2)	29.7	1.0 (0.8-1.3)	22.4	1.1 (0.8-1.4)
40-49 years	65.7	1.3 (1.0-1.6)*	32.5	1.2 (0.9-1.5)	24.7	1.0 (0.9-1.4)
50-59 years	57.2	0.9 (0.7-1.1)	25.1	0.8 (0.5-1.3)	18.5	0.6 (0.5-0.9)*
60+ years	61.8	1.0 (0.8-1.3)	31.3	0.9 (0.7-1.2)	29.7	1.3 (1.0-1.7)
Physician group						
Palliative care	53.8	Ref.	18.8	Ref.	18.4	Ref.
General practice	66.0	1.5 (0.9-2.6)	32.3	2.3 (1.3-4.0)*	24.8	1.0 (0.5-1.9)
Other medical specialty	63.2	1.1 (0.7-1.7)	33.2	2.5 (1.5-4.1)*	25.9	1.1 (0.6-1.8)
Palliative care training						

Yes	56.7	Ref.	24.6	Ref.	17.7	Ref.
No	65.0	1.2 (0.8-1.7)	32.3	1.2 (0.8-1.8)	27.2	1.6 (1.0-2.5)*
Average yearly end-of-life patients						
<5	65.0	Ref.	29.2	Ref.	24.0	Ref.
5-10	66.5	1.0 (0.6-1.6)	34.1	1.1 (0.7-1.7)	24.0	1.1 (0.7-1.9)
11-20	69.8	1.1 (0.7-1.9)	30.2	1.0 (0.6-1.6)	26.7	1.3 (0.7-2.2)
21-30	58.6	0.8 (0.5-1.5)	31.4	1.1 (0.6-2.1)	24.3	1.2 (0.6-2.3)
>30	56.0	0.9 (0.6-1.4)	27.2	1.2 (0.8-2.0)	21.7	1.2 (0.7-2.0)
Religion						
Christian	61.5	Ref.	32.6	Ref.	24.2	Ref.
Non-religious	61.5	0.9 (0.7-1.3)	29.1	0.9 (0.6-1.2)	23.3	0.9 (0.6-1.3)
Other	66.1	1.1 (0.7-1.7)	21.3	0.5 (0.3-0.9)*	25.2	0.8 (0.5-1.3)
Missing values: Gender: n=87, Age: n=87; Physician group: n=9; End-of-life patients: n=131. ^a Percentage of physicians who agree or strongly agree with the statement * Indicates statistical significance. Binary logistic regression analysis modeled for each of the 3 outcomes separately. For each jurisdiction and age group included, analysis was calculated against the mean, as opposed to a reference category. Variables analyzed include: jurisdiction, gender, age, physician group, palliative care training, yearly end-of-life patients and religion.						

Across the sample, 23.9% of all physicians agree or strongly agree that it is appropriate to consider their own personal preferences when caring for patients. Physicians in the age group 50-59 years responded least often that it is appropriate to consider personal preferences when caring for patients (18.5%) (OR 0.6, CI 95% 0.5-0.9). Women were less likely to feel it is appropriate than men (21%) (OR 0.7, 95% CI 0.5-.9). Palliative care physicians and physicians with palliative care training least often reported that it is appropriate to consider their own preferences when caring for patients (18.4% (not significant)) and (17.7%), respectively.

Congruence of physicians' personal treatment option preferences and preferences for patients in similar health scenarios

The highest congruence in a medical scenario with advanced cancer was for life-sustaining treatments: cardiopulmonary resuscitation was considered not a good option for both themselves and the patient by 99.1% of physicians, mechanical ventilation by 98.8% and tube feeding by 94.4% (Table 3). The intensified alleviation of symptoms with medications was considered a good or very good option for both by 90.5% of physicians.

There was disagreement in responses in the advanced cancer scenario with physicians considering it good for the patient but not good for themselves for intravenous hydration (7.9%), palliative sedation (8.4%), physician-assisted suicide (8.8%) and euthanasia (6.7%). There was disagreement in responses with physicians considering it not good for the patient, but good for themselves for palliative sedation (8.3%), physician-assisted suicide (7.0%) and euthanasia (11.6%). Physician-assisted suicide and euthanasia were considered a good or very good option for both themselves and patients, (respectively, 43.3% and 42.8%).

	Advanced Cancer						Alzheimer's Disease					
	CONGRUENT			INCONGRUENT			CONGRUENT			INCONGRUENT		
	good/very good option for both (%)	not a good option for both (%)	good for physician, not good for patient (%)	not good for physician, good for patient (%)	good/very good option for both (%)	not a good option for both (%)	good for physician, not good for patient (%)	not good for physician, good for patient (%)	good/very good option for both (%)	not a good option for both (%)	good for physician, not good for patient (%)	not good for physician, good for patient (%)
END OF LIFE DECISION												
Cardiopulmonary resuscitation	0.1	99.1	0.4	0.5	0.2	99.3	0.0	0.6	0.2	99.3	0.0	0.6
Mechanical ventilation	0.2	98.8	0.6	0.4	0.2	99.4	0.1	0.4	0.2	99.4	0.1	0.4
Intravenous hydration	18.4	70.7	3.1	7.9	16.0	77.4	1.8	3.1	16.0	77.4	1.8	4.8
Feeding tube	2.3	94.4	1.2	2.1	3.2	93.3	0.6	1.2	3.2	93.3	0.6	2.9
Intensified alleviation of symptoms	90.5	2.0	3.1	4.3	87.8	5.3	4.5	3.1	87.8	5.3	4.5	2.4
Palliative sedation	50.9	32.5	8.3	8.4	32.2	46.0	17.6	8.3	32.2	46.0	17.6	4.2
Physician-assisted suicide	43.3	41.0	7.0	8.8	NA	NA	NA	7.0	NA	NA	NA	NA
Euthanasia	42.8	38.9	11.6	6.7	35.7	44.2	15.8	11.6	35.7	44.2	15.8	4.3

*Scenario: You have been diagnosed with cancer with extensive lung and bone metastases and your treating oncologist has said no further treatments are available. You have an estimated life expectancy of no more than 2 weeks and are fully competent. You are experiencing ongoing severe pain and agitation. A palliative care provider is involved and palliative care services (e.g. home care, inpatient hospice) are available.

*Scenario: You have an 80 year old patient diagnosed with Alzheimer's dementia. It is a typical case with gradual cognitive decline and the patient no longer recognizes family or friends. They now refuse to eat and drink and have become more and more withdrawn. It is no longer possible to communicate with them about medical treatments. A palliative care provider is involved and palliative care services (e.g. home care, inpatient hospice) are available.

Percentages are row percentages. Missing values range from 6.4% to 7.3%.

The Alzheimer's disease scenario showed similar findings with the highest congruence relating to life-sustaining treatments, with cardiopulmonary resuscitation and mechanical ventilation being considered not a good option for both themselves and the patient by 99.3% and 99.4%, respectively. The use of a feeding tube was considered not a good option for both by 93.3% of physicians. The intensified alleviation of symptoms with medications was considered a good or very good option for both by 87.8%. Responses related to the use of intravenous hydration showed disagreement, with 4.8% considering it good for the patient but not good for themselves. Higher levels of discordance were seen for palliative sedation with 17.6% of physicians considering it a good or very good option for themselves but not for the patient.

When asked about assisted dying practices in the Alzheimer's scenario, 35.7% of physicians considered euthanasia a good or very good option for both themselves and patients and 15.8% indicated it would be a good or very good option for themselves but not for the patient.

We also conducted hypothesis-driven analyses exploring the degree to which physicians (dis)agree for themselves and for their patients and whether they would answer more positively or negatively for themselves, but more moderately for their patients but this was unconfirmed.

DISCUSSION

Summary of main findings

Across jurisdictions, our findings indicate nearly two thirds of physicians acknowledge considering their own care preferences when caring for patients at the end of life and almost one third believe the recommendations they make to patients are impacted by their personal preferences. Palliative care physicians and physicians with palliative care training are less likely to consider their own preferences when caring for patients and when making recommendations and are less likely than other physicians to consider it appropriate to consider their own preferences when caring for patients. This finding is in line with research indicating that palliative care physicians sometimes utilize bias management strategies

including self-awareness during end-of-life discussions.¹⁶ Variation was found across jurisdictions and do not appear linked to the existence of assisted dying legislation.

There is notable incongruence between what physicians prefer for patients and what they would want for themselves for certain end-of-life practices. While research is limited, some findings have shown that physicians were more likely to choose a treatment with a higher risk of death for themselves than for a hypothetical patient¹⁷. Studies of physicians have also indicated they want less life-sustaining treatment for themselves than they would order for their older patients, which is also more than the patients would prefer for themselves.¹² We found physicians consider some options “not good for the patient, but good for themselves” - palliative sedation (8.3%), physician-assisted suicide (7.0%) and euthanasia (11.6%). There are interesting similarities between physicians’ preferences for themselves and patients in the cancer and Alzheimer’s scenarios including the preference to intensify alleviation of symptoms and avoid life-prolonging practices. While the differences between the cancer and Alzheimer’s scenarios were not substantial, we found the percentage of incongruence for the Alzheimer’s scenario is larger with physicians finding palliative sedation and euthanasia a good option more strongly for themselves than for patients. This may relate to the difficulty of making these consequential end-of-life decisions for people with cognitive impairment. However, the overall similarity in responses for cancer and Alzheimer’s suggests that variations in these medical conditions may not play a significant role in the congruence of considering something a good option or not for yourself and your patient. Additional research with other medical scenarios could help corroborate this finding.

These study findings both align with and expand on existing literature, showing that many physicians' personal end-of-life preferences have a significant influence on the care they provide to patients. This extends previous research and adds new insights into specific practices, such as palliative sedation and assisted dying. These findings also highlight the role of palliative care training in reducing bias and increase our understanding about the influence of cultural and religious factors on physician decision-making.

Strengths and limitations

A major strength of our study is the inclusion of physicians across five countries and eight jurisdictions, representing varied legal and cultural environments. By focusing on the association between physicians' personal preferences for end-of-life decisions and their clinical practice, contrasting jurisdictions with and without assisted dying legislation, and including our desired spread of three groups of physicians - general practitioners, palliative care physicians and medical specialists, we provide a much-needed addition to the current literature on end-of-life preferences. The study had certain limitations. The pragmatic choice for convenience sampling does not allow for random selection, meaning the point estimates cannot be considered representative of the sampled populations. There may be selection bias as the survey could have attracted those with a particular interest in end-of-life issues, or bias with some physicians considering it more socially acceptable to respond that their personal preferences do not influence their clinical practice. Due to the sampling method, we could not use unique URLs to ensure physicians would not complete the survey multiple times; however, the data were reviewed for duplicate responses. Though the overall recruitment of respondents was satisfactory in all jurisdictions, there was a low representation of general practitioners in the Canadian sample. However, the comparison of groups is not affected as much as point estimates by lack of representativeness in a sample.

Interpretation of main findings

Considering nearly two-thirds of physicians consider their personal preferences when caring for patients, almost a third let their preferences influence the recommendations they make, and nearly a quarter of physicians believe it is appropriate to do so, it is evident that many physicians find it challenging to avoid letting their preferences, consciously or unconsciously, affect their clinical practice. The findings of this study are in line with research suggesting a connection exists between the preferences physicians have for their own end of life and the recommendations they make to patients.² However, these findings are novel as they clearly demonstrate physicians recognize a connection between their personal preferences and clinical practice and offer a more comprehensive comparison of what physicians would choose for

themselves versus their patients in various end-of-life situations. Further research is needed to better understand this connection and its impact on clinical practice. It may also be worthwhile to explore physicians' motivations for considering their own preferences as some may be seeking to heighten their own awareness and manage potential influence on patient decisions. The underlying normative question of whether it is appropriate for physicians' personal preferences to influence the recommendations they make to patients should also be considered.

The finding that palliative care physicians, and those with palliative care training, are less likely to consider their own preferences when caring for patients and much less likely to consider their own preferences when making recommendations, may relate to the fact that palliative care physicians typically take a person-centered approach in their clinical practice and may be able to keep more separation between their personal preferences and patient interactions than general practitioners or other medical specialists.¹⁸ It may also be that palliative care physicians have more end-of-life experience and expertise to draw on when making recommendations to patients.

When evaluating the impact of physicians' personal preferences on patient recommendations, the role of religion and culture is also worth considering. Physicians in jurisdictions with strong religious traditions (Italy and Georgia) show a much stronger connection between personal preferences and the recommendations made to patients. These physicians are undoubtedly guided by professional norms but there may be an important influence of cultural and religious beliefs as well. This may relate to some religious systems holding a firmer belief in what is considered the morally correct path or following what a higher power dictates as good behavior.¹⁹ This connection is also more pronounced in Belgium, which may have to do with the strong historical influence of Catholicism. It could also be that these populations are more homogenous and therefore physicians may be inclined to assume that others prefer what they would want for themselves. These findings are not entirely surprising given that previous research has indicated physicians with more strongly held religious beliefs are more likely to

object to certain end-of-life practices and reinforces the importance of understanding the influence of physicians' personal values on clinical decision-making.²⁰

Policy and practice implications

These study findings suggest several important policy and practice implications. First, clear policies and ethical guidelines are needed to help physicians maintain professional boundaries and ensure that clinical recommendations are based on patient preferences rather than personal beliefs or biases, particularly in end-of-life care. Second, ethical guidelines would help physicians navigate complex decisions, such as those involving physician-assisted suicide or euthanasia. Third, the promotion of palliative care training, which fosters a person-centered approach, could help reduce the influence of personal preferences on patient recommendations, making it crucial to integrate palliative care principles into general medical education. Fourth, addressing cultural and religious influences on physician decision-making through cultural competency training is also essential, especially in jurisdictions where strong religious traditions impact patient care.

Further research is needed to explore how physicians' personal preferences influence patient outcomes across various medical scenarios, which could lead to more evidence-based policies.

In conclusion, many physicians consider their personal end-of-life preferences when caring for patients and believe their preferences impact the recommendations they make to patients. While there is a high level of congruence in what physicians prefer for themselves and recommend to patients for several life-sustaining treatments, there is a notable proportion of physicians whose preferences do not align with what they feel is good for their patients - particularly for certain critical end-of-life options.

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Chapter 5

How do physicians perceive and manage the influence of their personal end-of-life preferences on clinical practice and end-of-life decision making with patients? PROPEL international qualitative study

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Submitted

ABSTRACT

Background:

Physicians are frequently asked what they would do in the position of their patients, and they have significant influence on end-of-life decisions. Therefore, it is crucial to understand the connection between physicians' personal end-of-life preferences and their clinical practice and the impact of this connection on patient care.

Aim:

To explore how physicians perceive and manage the impact of their end-of-life preferences on their clinical practice and end-of-life decision making.

Design:

A qualitative interview survey was conducted from January – November 2022.

Setting/participants:

Three jurisdictions: Belgium, Italy, Wisconsin, USA. Three physician types were included: general practitioners, palliative care physicians, and other medical specialists.

Results:

We analyzed data from 45 interviews. Physicians acknowledge the impact of their personal end-of-life preferences on their clinical practice and emphasize the importance of maintaining objectivity and centering decision-making on patient preferences. Physicians adopt strategies to mitigate potential biases. There is a divergence of opinion about whether it is appropriate to share when asked what they would do in the position of their patients. Most believe focusing on patients' values and priorities is essential and others feel sharing is crucial to maintain trust. Physicians struggle with ethical tensions and moral discomfort, particularly when patients' requests conflict with their beliefs. Physicians experience personal and professional growth through end-of-life discussions and reflection.

Conclusion:

Physicians recognize and attempt to manage the impact of their own end-of-life preferences on their clinical practice. Physicians are not in agreement about sharing when asked what they would do in the situation of their patients.

Physicians are pivotal in guiding patients and shaping healthcare decisions, which are particularly complicated at the end of life. These decisions may involve withholding or withdrawing life-sustaining treatment, palliative sedation, or assisted dying (a term encompassing voluntary assisted dying (VAD), medical aid in dying (MAiD), euthanasia and physician-assisted suicide (PAS)).¹⁻³ Since physicians encounter confronting medical scenarios and are frequently asked by patients for guidance based on what they would do in similar circumstances, it is reasonable to assume that they have reflected on their personal preferences.^{4,5} The extent to which physicians' personal end-of-life preferences and beliefs impact their clinical practice raises important ethical and clinical considerations.

Physicians face challenges balancing their personal end-of-life preferences and beliefs with professional practice, particularly in the context of end-of-life decision-making.⁶ Personal values, emotions, and external pressures can influence their practice, at times making it difficult to maintain full neutrality.⁶ This internal struggle can become more pronounced when physicians' personal treatment preferences unconsciously shape their perceptions of patient desires and preferences, further complicating their ability to remain impartial.⁷ The difficulty of navigating these dilemmas during end-of-life discussions is considerable as personal biases can inadvertently interfere, creating professional hazards and hindering the goal of providing truly patient-centered care.⁸

Physicians also encounter difficulty reconciling their personal ethical integrity and conscience with their professional practice, particularly when confronted with ethically controversial situations or when asked to perform or refer for practices they find morally objectionable.^{9, 10} Some physicians prioritize their moral integrity by refusing to be involved in some end-of-life practices or by referral to colleagues.⁹ There can also be an emotional toll on physicians who provide care that conflicts with their personal preferences or professional judgment, particularly when they perceive the care as being futile, harmful or inappropriate.¹⁰ In some cases, deeply held religious beliefs also shape physicians' approaches to treatment, leading to internal conflict for physicians.¹¹ This emotional strain can have a negative impact on their

psychological and physical well-being and job satisfaction.¹⁰ These challenges illustrate the importance of exploring the complex relationship between physicians' end-of-life attitudes and preferences and the end-of-life care they provide.

Existing research examining the relationship between physicians' end-of-life preferences and their clinical practice are generally focused on limited end-of-life decisions (e.g. withholding and withdrawing treatment), a specific influence (e.g. religious beliefs) or are restricted to one geographic region. Consequently, a comprehensive understanding of how physicians perceive and manage the connection between their end-of-life preferences and clinical practice is lacking. International comparative research provides valuable insights into how cultural, social, and system-level differences influence physicians' personal end-of-life preferences. A qualitative study design allows for a deeper and more nuanced understanding of physicians' diverse perspectives and can shed light on how they perceive and manage the link between their personal preferences and the end-of-life care they provide. Qualitative methods can also reveal important commonalities and challenges faced by physicians enhancing our global understanding and potentially fostering alignment between clinical care and patient values. To the authors' knowledge no international comparative qualitative studies have been conducted in this domain. Due to the lack of current qualitative data and the potential impact on patient end-of-life care, it is crucial to better understand the relationship between physicians' personal end-of-life preferences and their clinical practice.

Our guiding research question was: How do physicians perceive and manage the impact of their personal end-of-life preferences on their clinical practice and end-of-life decision making?

METHODS

Study design

Qualitative study using semi-structured in-depth interviews and analyzed using a reflexive thematic approach.

Context and setting

We selected physicians practicing in jurisdictions with diverse cultural environments and varied levels of experience with assisted dying legislation. We included physicians in Belgium (Flanders), Italy, and the USA (Wisconsin). Belgium has had an assisted dying law in place since 2002, while Italy currently lacks such legislation, and in Wisconsin, despite legislative debates over the past 20 years, assisted dying remains illegal.

Participant recruitment

We used a convenience sample in each country. Due to their varied levels of experience treating patients at the end of life, we sought to include three types of physicians: general practitioners, palliative care physicians, and other medical specialists with a high likelihood of seeing patients facing end-of-life issues (i.e., cardiologists, emergency medicine, gastroenterologists, geriatricians, gynecologists, internal medicine, intensivists, nephrologists, neurologists, oncologists, pulmonologists). Our goal was a distribution of physician types that included a minimum of five general practitioners, five palliative care physicians, and five medical specialists in each jurisdiction, amounting to 15 in each jurisdiction and 45 total physicians. Physician participants were identified through the networks of our research partners in each country, and via outreach through medical associations, professional societies, and self-identification after completing an online survey linked to this study. This qualitative exploration is part of a multi-method international study called PROPEL: Physician Reported Preferences for End-of-Life Decisions. Following initial contact by email or telephone, potential participants received an email invitation detailing the study, information on the research team, and eligibility for participation.

Inclusion and exclusion criteria

Currently practicing physicians in the following groups were eligible for participation: general practitioners, (specified) clinical specialists or palliative care physicians. Participants were excluded if they had less than two years of clinical experience or were unable to do the interview in English. We originally planned to include only physicians with five or more years of

experience. However, since we encountered recruitment challenges and most of the previously recruited physicians had 10-40 years of experience, eligibility was expanded.

Data collection

Data was collected between January – November 2022 using a semi-structured interview guide. The interview guide (Appendix B) was pilot tested with three physicians and adjusted for clarity and appropriateness before use. Most interviews were conducted online using a video conferencing platform (Zoom or Teams) due to COVID-19 restrictions. However, five interviews were conducted in person, at the office or home of the participant, and one at a public library. The interviews varied in length from 30 to 80 minutes and no repeat interviews were conducted. Notes were made following each interview. All interviews were conducted by the lead author (SM), a female doctoral researcher with previous experience conducting qualitative research with physicians (credentials-MSc, MPH). SM had no prior relationship with the participants, apart from two Wisconsin physicians who had previously provided care for her mother. Due to the complex nature of the interview topic, participants were offered language support through the attendance of a second researcher who spoke their native language and could explain complex questions or responses. Some European physicians accepted this option (Italy 4, Belgium 1). A demographics form was completed at the start of each interview.

Data analysis

Interviews were audiotaped and transcribed verbatim. Data collection and analysis were informed using the reflexive thematic analysis approach. A reflexivity statement was developed by the lead researcher (Appendix E). Reflexive thematic analysis is an ideal approach for this study as its flexibility allows for a deep examination of the multifaceted nature of end-of-life preferences without the constraints of rigid frameworks, making it well-suited to capture the complexity of this topic.¹² It emphasizes personal meaning and perception and aligns with our focus on physicians' subjective experiences and reflections. This method's iterative, reflexive nature ensures that the researcher's role in interpreting sensitive, personal data is acknowledged, providing room for richer, more nuanced insights.¹² It excels in exploring the intersection of broader social and cultural contexts with individual decision-making, making it

ideal for understanding the varied influences on physicians' preferences and identifying patterns across the data. Additionally, it is an inductive, data-driven approach, which allows for open exploration, making it particularly useful for research without predefined categories, enabling the discovery of unexpected themes.¹²

Interview transcripts were imported to NVivo (version 12) for analysis. Thematic saturation was achieved in each jurisdiction. Reaching saturation suggests that the themes generated from the interviews were comprehensive and robust enough to address the central research question, allowing for a nuanced understanding of the phenomenon being studied without the need for further data collection. The lead author (SM) coded all transcripts, and another team member (FD) independently coded four transcripts for comparison. Transcripts were not shared with participants. Initial codes were discussed and refined (by SM & FD), and themes and subthemes were developed. The themes were then refined and discussed further by the full research team and similar or overlapping themes were collapsed or removed. A thematic map was then developed and evaluated, and the research team identified, discussed, and selected associated interview quotes. Participants did not provide feedback on the findings. The consolidated criteria for reporting qualitative research (COREQ) checklist was followed.

Ethics

The study protocol was approved by the medical ethics committee of the Brussels University Hospital that acts as central ethics committee (BUN:1432021000562, September 29, 2021). Approvals were also obtained from the ethics committee in Italy (AVEN, Comitato Etico dell'Area Vasta Emilia Nord:748EE93B, April 7, 2022). Formal ethics approvals were not required by the other participating institution.

RESULTS

We collected data from interviews with 45 physicians—15 in each country—reaching our recruitment goal. Participants included 23 female and 22 male physicians (Table 1). Most were white/European (43) identified as either Christian (23), non-religious (16) or another religion (6)

and fell within the age groups < 40 years (18), 40-59 years (22), and > 60 years (5). We nearly achieved our target balance of selected specialties with 15 general practitioners, 14 palliative care physicians, and 16 other medical specialists participating.

Table 1. Characteristics of participating physicians, per jurisdiction				
	OVERALL (N=45)	Wisconsin, USA (N=15)	Belgium (N=15)	Italy (N=15)
Gender				
Male	22	6	7	9
Female	23	9	8	5
Age				
<40 years	18	6	3	9
40-59 years	22	7	11	4
>60 years	5	2	1	2
Physician type				
General practitioner	15	5	5	5
Palliative care physician	14	4	5	5
Other medical specialist	16	6	5	5
Average yearly end of life patients				
≤10	10	4	3	3
10-50	19	7	4	8
50-100	3	0	3	0
≥100	12	4	4	4
Religion				
Christian	23	7	6	10
Other religion	6	2	3	1
Non-religious	16	6	6	4
Ethnicity				
White/European	43	13	15	15
Asian	2	2	0	0
Other	0	0	0	0
Missing values: End of life patients: n=1				

We identified four main themes and two sub-themes related to how physicians perceive and manage the impact of their own end-of-life preferences on their clinical practice (Box 1).

Theme 1: Balancing personal and patient preferences - Physicians feel it is natural and unavoidable to bring their own values and preferences into their practice but try to be cognizant of it and remain objective in order not to impose their own preferences on patients.

Physicians openly acknowledged their own values impact their clinical encounters and say they work to keep patients and patients' priorities at the center of the decision-making process and not provide too much influence or allow their own beliefs and values to direct decisions. They emphasized the importance of being aware of their own preferences and respectful of patients' wishes.

"I hope that I don't push people in any direction because these are my values. But I think it's a little bit normal that you take your own values with you when you have conversations with patients and families. But I hope I give my patients and families enough freedom to make their own decisions." (Medical specialist, Belgium)

Some physicians described it as an ongoing struggle to be conscious of their personal feelings and preferences during clinical encounters without allowing their feelings to interfere with patient decisions.

"It's been challenging for me to set aside my personal beliefs because as a physician, and I didn't realize this until probably my third year in practice, where, how much influence you can have and how to separate the discussion on end of life care from your own personal beliefs. And it's still a struggle, but it's easier to talk about and it's it feels less personal." (General practitioner, Wisconsin)

Physicians work to understand the patients' values and preferences and consider it crucial to ask thoughtful questions and listen carefully to patients to really understand their wishes and remove themselves from the discussion. Physicians reported that even when trying to set aside their own beliefs and values and keep them separate from their clinical interactions, their preferences always infiltrate to some degree.

"I always put up that wall because what I want for myself is probably going to be different than for my patients, right. But I, I think about, I think the general framework of what you think is right, what we all think is right, like shapes, shapes the way we practice in our decision making. But I think, like my number one job is not to do what I want to do, it's to do what my patients want to do. And there is a wall. I think there's not as much of a wall as we think." (Medical specialist, Wisconsin)

“Every time is an effort, of course. The fact I have the, a clear idea for me and the fact I have a way of a point of view about these things. It's not, it doesn't make my work easy, easier. No. Many, many times. It could be . . . that I disagree. But I don't express my disagreement, of course.” (Palliative care physician, Italy)

“Often it's quite easy to lengthen the life of a patient. Adding some days, weeks, months to a patient's life. Often this works, but without the prospect of a normal life, or a life with, with any form of quality in the future and this is a personal opinion, quality of life. We always try to have a view about what would this person's view be on quality of life. So we talk if it's possible, with the patients and with the family, with the general physician to have a little bit an idea of how this person would value quality of life. But still then I think you also have your own values that infiltrate a little bit this this process, I, I think it's not possible to really set this completely aside because you, you get information from many parties, from many persons but I think that your own preferences will always infiltrate a little bit.” (Medical specialist, Belgium)

Nuanced differences in attitudes were identified between physician groups. Some general practitioners emphasized the importance of exercising caution with respect to exerting influence and giving patients room to consider their values and respecting their wishes. Palliative care physicians stressed the importance of personal reflection and understanding their own preferences and shared that doing this allows them to remove themselves during clinical encounters and have less influence. Some medical specialists shared a desire to limit the influence of their preferences on patients by listening and learning about patients' wishes and keeping them at the forefront of the decision-making process. Physicians across all countries shared that they try to keep a separation between their personal preferences and clinical practice and there is sometimes a struggle to do so. Italian physicians, in particular, highlighted the difficulty and occasional struggle of distancing themselves during clinical interactions.

Sub-theme: Collaboration to managing personal influence - Physicians recognize the connection between personal preferences and clinical practice and highlight the importance of actively managing their influence by talking with colleagues and making decisions as a team in order to reduce the impact of personal influence.

Physicians cited discussions and collaboration with colleagues as a way to share responsibility for making important end-of-life decisions, recognize personal bias, reflect collaboratively to

make the best possible decision for patients. This method also allows them to gather diverse perspectives for making future decisions.

“That's one of the benefits of doing this work in a team. So, you know, when your little alarm bell goes off that you're feeling sort of personally, you know, engaged or you wonder if your own beliefs or preferences might be clouding the situation for you, you can ask a team member to, you know, give you feedback and so try to be help you be a bit more objective.” (Palliative care physician, Wisconsin)

“It's very important that you make decisions in a team, because in that way you have a lot of people, a team and every person in the team has this in his or her values. So that's why it's important never to make the decision alone, I think because the decision will be influenced by personal values.” (Medical specialist, Belgium)

Sub-theme: Sharing personal preferences at the request of the patient - Physicians shared that they are frequently asked in clinical encounters what they would do if they were in the position of the patient, or the patient were their loved one.

Most physicians reported that they try to respond to this question by turning the focus of the discussion back to the patients' priorities and offer to evaluate the available options. However, some physicians feel they have a responsibility to be open and honest and share what they would do in the patient's situation. Physician responses varied greatly with some feeling it appropriate to share their own preferences, others very opposed to sharing, and some saying they may share depending on the situation. We found more physicians were opposed to sharing because they felt their preferences, values and priorities may differ from their patients, and they considered it ethically inappropriate to influence their patients in a direction that may not be in line with the patient's own preferences.

“Sometimes people will ask me, what would you do? Or what if this was your father or something like that? And so I think that some separation is definitely important. So I, I try my very best not to just give an answer after a question like that, but to say, well, I would want to talk to my father and see what his wishes are. And then kind of transition it back or reflect that back to the patient and their family to make sure that that we're really focusing on what he or she wants or would want, rather than my projected values onto them. Certainly that's not perfect, but at least try to have some separation.” (Medical specialist, Wisconsin)

The physicians who supported sharing their own preferences do so because they feel it is necessary to maintain a trusting relationship by being open and honest with patients when

asked. Others share because they hold a more informed position due to their medical knowledge and experience and feel they would be in the best position to provide requested counsel. Some also said they share their own preferences as a way to model decision-making for patients.

“I always say to the patients what I would do if they were my father, my mother, my brother or sister, I gave you the advice as if you were my family. And that is really respected by the patients. Many of them followed me in that direction.” (Palliative care physician, Belgium)

General practitioners and palliative care physicians were divided on whether to share their own preferences with patients, while most other medical specialists said they would not. Physicians across all specialties stated they would typically attempt to redirect the conversation to the patients’ priorities in order to minimize their own influence on decisions.

Box 1. Main themes related to physicians' perceptions and management of their personal preferences on clinical practice

Themes:

1. Balancing personal and patient preferences

Subthemes:

- Collaboration to manage personal influence
- Sharing personal preferences at the request of the patient

2. Act according to the golden rule

Subthemes:

- Maintaining personal ethical integrity

3. Personal and professional growth through end-of-life discussions

Theme 2: Personal preferences shaping clinical guidance (Act according to the golden rule) - Physicians say they hold their own preferences as an ideal to guide interactions with patients and some strive to treat others as they would want to be treated themselves.

Many physicians shared that they work to keep a balance and separation between their personal beliefs and preferences and their clinical practice to maintain focus on the patient’s priorities. However, some physicians shared they feel it is a natural response to a situation to

consider what one would want for themselves, and this can be an appropriate starting point for discussions and decision-making, then they focus on the patients' desires.

"I think my own end-of-life preferences probably completely shape my clinical practice for patients who might be in a certain scenario . . . I'm trying to do what I think is best for patients, is in their best interest, and is in their family's best interest. So, since we all think a lot about ourselves, in some ways that's what I operate at if I don't hear anything else, I always ask people what they want first, you know. But the thing generally guides what I think people might like is my own preferences, and then easily guided by whatever someone really wants or needs." (Medical specialist, Wisconsin)

Several physicians, particularly Italian physicians, cited the phrase "treat others as I would want to be treated". This maxim found in many religious and philosophical traditions represents a general moral guideline upholding the principles of empathy and ethical reciprocity, encouraging people to treat others with the same respect and kindness they would wish for themselves. Physicians shared that they try to consider patients' situations also from their own perspective of wanting to avoid futility and suffering. They understand the patient's final decision may be quite different from their own but feel it can be a useful and positive point to begin contemplation.

"I think that generally a physician tries to do his or her best depending on what you think could be the best for himself or herself in the same condition." (Medical specialist, Italy)

"I think I treat my patients as I want people to treat me, or I treat my patients as I want others treated." (Medical specialist, Belgium)

"That's the most reliable way to know that I'm being honest and diligent and fair in my work with patients is to imagine, you know, how I would want to be approached and counseled and guided, offered in that type of decision making knowing that the end result might be a very different decision than I would make. But I think it's, you know, maybe quite natural to want to, you know, to hold as a, as an ideal to extend to our patients what we think might be, the, again, how we would want I said as the health care provider, how I personally would want to be allowed to make decisions. I don't think it's a . . . negative. I guess, I would say I think it can be a positive." (Palliative care physician, Wisconsin)

It is possible that the physicians who said they contemplate the golden rule meant that they would not want their physician to project their own preferences and would prefer to make their

own choices and would therefore treat others as they would like to be treated by not using their own preferences as a guide. However, the responses were shared following a discussion about their specific end-of-life decision preferences and was in response to the question, “What is the relationship between your personal end-of-life preferences and your clinical practice?”, so this may not be the case.

Theme 3: Maintaining personal ethical integrity - Physicians are not comfortable acting against their own values in their clinical practice.

Physicians described a sense of conflict between respecting and honoring patient wishes and acting according to their own convictions and values.

“If you imagine that you're practicing completely the opposite of your own conviction, it would be difficult.” (Palliative care physician, Belgium)

“I think I need to be consistent. This doesn't mean that I have to do to people exactly what I would do to me. But this means for me that I have to, I need to always check my beliefs and think about what I think, . . . what are my beliefs and what I'm doing to see if I am consistent with my values in my, that, and my values influence both my clinical choices and my work are the themes of my work, my values, and also the basis for my choices, . . . of my own preferences.” (Palliative care physician, Italy)

Some physicians said they struggle when asked by patients and families to provide what they consider futile treatment. Physicians have encountered situations where they felt uncomfortable caring for patients with strong personal or religious beliefs that motivated them to request all possible medical efforts to prolong life at a point when the physician felt it was no longer appropriate. Others described situations of patients requesting assisted dying, which, for some physicians, was in conflict with their own beliefs and values. This was most prominent among Italian physicians, several of whom expressed opposition to assisted dying based on personal or religious beliefs. Several physicians said they would not be comfortable or willing to practice in a way that was not in accordance with their personal values.

“An important part of our job, as this might be true in many, many fields. Like check your, check that the two are not putting your vision, your personal values into other people's brain or taking decision for them. And it's part of my value that everyone has the right to express their preferences on their own death. At the same time, it's part of my values that I cannot decide to take their lives.” (Palliative care physician, Italy)

Physicians across all specialties and countries described the importance of aligning their personal values and their clinical practice. Belgian physicians, in particular, discussed issues related to euthanasia as a source of ethical difficulty or discomfort.

“My wife, she finds it difficult to think about me assisting in euthanasia, for example, so you have to balance that also. Your personal relationship with people can also have an influence on your work. Yeah. It can make you less comfortable when someone asks you for euthanasia.” (General practitioner, Belgium)

Theme 4: Personal and professional growth through end-of-life discussions - Physicians reported end-of-life discussions can be rich and help them grow as a person and doctor.

Physicians described the potential for great value in dealing with complex issues and walking alongside patients during the difficult end-of-life phase. Some shared that engaging in end-of-life conversations was initially daunting or uncomfortable but over time the encounters became more comfortable and could be an extremely rewarding part of caring for patients and provided opportunities for growth, beauty and lessons for them personally. Physicians also describe this engagement as a chance for meaningful connection with patients as fellow human beings. This finding also highlights that there is bi-directional impact with physicians' preferences impacting their practice but also the practice impacting physicians.

“If you are quite sound and . . . are happy with your work, and if you are curious and careful with patients, then your ability to cope with this decision and to create moments of discussion with relatives, with the patient becomes a very rich, very, a very rich moment. . . . because over time, you know that you are making yourself better in a certain related, and more able to work in a good way and more able to lead in a good way.” (Medical specialist, Italy)

“I was always very comfortable in difficult conversations but I feel like in the last five years maybe I am, I feel more connected with people and that's a very good thing for me and I hope for my patients.” (Palliative care physician, Italy)

Some palliative care physicians shared that they were particularly drawn to palliative care as a way to be involved in meaningful connections with patients and believe there is a particular connection between the self and the delivery of palliative care that cannot be disconnected. No other clear differences were observed by medical specialty or country related to personal and professional growth through end-of-life discussions.

DISCUSSION

Summary of main findings

This study offers novel insights into the relationship between physicians' personal end-of-life preferences and their clinical practice. Findings reveal that physicians acknowledge the impact of their personal values and beliefs on their end-of-life decisions; however, they emphasize maintaining objectivity and centering patient preference in their clinical decision-making. Some physicians adopt collaborative strategies, consulting with colleagues to mitigate potential biases and strive to balance personal ethical considerations with patient autonomy. A significant finding is that there is a divergence of opinion among physicians about whether it is appropriate to share when asked what they would do in the position of their patients. Most physicians believe focusing on patients' values and priorities is essential. Some physicians feel it is necessary to maintain an open trusting patient-provider relationship. Personal values, including the concept of treating others as you would like to be treated, underlies and guides the clinical interactions of some physicians. Physicians also report grappling with ethical tensions and moral discomfort, particularly when patients' requests conflict with their own beliefs, such as in cases perceived as involving futile treatment or requests for assisted dying. Physicians report experiencing personal and professional growth through reflection and challenging discussions and find value and connection in end-of-life conversations.

Interpretations of main findings

Our findings confirm and expand on research suggesting a connection exists between physicians' personal preferences and their clinical practice.⁷ Physicians acknowledge that their personal values and preferences naturally emerge in clinical practice, particularly during intense end-of-life care situations, and they stress the importance of balancing these forces by maintaining professional distance and prioritizing patients' wishes in decision-making. This balance appears challenging for physicians, as some describe it as an ongoing struggle to prevent their personal beliefs from influencing patient choices. While they manage this with practical strategies, it is important to consider the underlying normative question of whether it

is appropriate for physicians to consider their personal preferences in a professional context. Since physicians also report using their personal preferences as a guide for what might be desirable in a given situation it may be perceived as a natural and appropriate starting point in the decision-making process. However, this finding might be considered against research which suggests that, in practice, physicians often provide end-of-life care for patients, which differs from what they would choose for themselves.^{13,14} While the reasons for this are complex, they may stem from physicians' desire to preserve patient trust, reluctance to extinguish hope, or systemic incentives toward treatment. It also raises important questions, such as: how does the emotional toll on physicians for providing care that is not in line with their own values impact clinical care? Is variability in practice a concern if physicians diverge in the extent to which they incorporate their preferences into their clinical practice? Could physicians frame guidance as provision of their perspective while anchoring it in the values and goals of their patients.

It may also be that in striving to manage the interaction between personal preferences and clinical practice some physicians are employing a skill called decentering, which is maintaining awareness of one's thoughts and feelings and striving to view them as temporary and objective.¹⁵ In this practice, thoughts and feelings are simply observations that can be accepted as they are, and do not define one's self.¹⁵ This technique was not specifically mentioned by physicians, but they may be doing this when revealing their own preferences, taking care not to impose their own hypothetical wishes. Decentering is not a simple practice and the theme of maintaining integrity illustrates that physicians' individual moral rules and guidelines are being considered and some physicians are imposing limits on themselves. These findings must also be considered in terms of their implications for patients. Physicians' personal preferences may not have a limiting effect on patients if physicians do not impose their preferences or share them in a neutral way. However, a more concerning scenario could arise if a physician were to limit a patient's choices due to the influence of their personal preferences.

In comparing our findings across physician groups and countries, we found that most physicians reported striving to separate their personal preferences from clinical practice. Some physician

face challenges doing so, which was particularly emphasized by Italian physicians. Since more Italian physicians also cited the maxim of, 'treating others as I would want to be treated', it may be that a cultural or religious component is associated with this strong connection to personal preferences. Across all specialties and regions, physicians generally try to steer conversations back to patients' priorities to minimize personal influence, which indicates consensus among physicians about the importance of maintaining patient-centered care. This is reflected in existing research that suggests physicians recognize the importance of limiting information that may bias the patient.⁴ Physicians also highlighted the importance of aligning their personal values with their clinical practice. Italian and Belgian physicians especially identified assisted dying as a source of ethical difficulty or discomfort. This finding is in line with literature that indicates more religious physicians and those confronted by requests for assisted dying may experience moral distress when providing care that conflicts with personal values.^{9, 10} The finding that end-of-life discussions can be both professionally and personally enriching was particularly pronounced among palliative care physicians. This may be because palliative care physicians routinely encounter end-of-life scenarios and opportunities for meaningful connection with patients, which is confirmed by existing research.¹⁶

Our findings are also largely consistent with what we learned from the PROPEL online survey, which was conducted alongside this qualitative study.¹⁷ We found that nearly two-thirds of physicians consider their own end-of-life preferences when caring for patients, almost one-third believe the recommendations they make to patients are influenced by their preferences, and nearly a quarter of physicians believe it is appropriate to do so. Palliative care physicians, however, are less likely to let their personal preferences impact patient care. This is relevant for its clinical implications and is confirmed by the physician interviews. The survey also indicated that physicians often prefer less life-sustaining treatment for themselves than they recommend for patients, and they would opt for palliative sedation and assisted dying more for themselves than for their patients. We found culture, religion, practice type, training factors and legislative environment influenced preferences. The results of this qualitative study reinforce our survey findings and add more depth to the connection between physicians' personal beliefs and

preferences and their clinical practice. It is noteworthy that physicians consider it somewhat inevitable that their personal values and preferences enter into clinical encounters. It is also essential to appreciate the methods used by physicians to maintain objectivity and preserve ethical integrity.

Another important finding of this study relates to the moral distress and professional discomfort physicians feel when asked to provide care that does not align with their ethical values. As with existing research, we found this discomfort is especially evident in cases where patients request treatment perceived as futile or assisted dying, which some physicians feel violate their personal or religious beliefs.¹⁸ This may be the case for the Belgian physicians who reported difficulty or discomfort related to euthanasia requests. The complex emotions physicians experience are often influenced by their personal preferences and moral interpretation of clinical and personal experiences, which may also be shaped by their religious beliefs. This internal conflict may sometimes manifest as reluctance to engage in practices such as withdrawing life support or assisted dying. There is also a clear preference among physicians not to continue or initiate life-saving treatment for themselves though this occurs often with patients¹⁹ and presents another potential internal conflict. While the issue of patient autonomy is central, physicians strive to preserve their own ethical integrity, which can lead to internal discord.

This study indicates that end-of-life care is recognized by physicians as a rich environment for personal and professional growth, allowing them to form meaningful connections with patients, confront ethical challenges, and deepen their personal insights and compassion through difficult conversations. This underscores research that emphasizes the clinical significance of conducting realistic and compassionate end-of-life conversations, which enable patients to maintain their autonomy and dignity while enhancing their quality of life as they approach death.²⁰ These conversations need not merely be a way to convey medical information but are also an opportunity to engage with human beings confronting imminent mortality—an experience that can be transformative for everyone involved.²¹

Strengths and limitations

A strength of our study is the inclusion of physicians across three countries representing varied legal and cultural environments, and the participation of three groups of physicians - general practitioners, palliative care physicians, and other medical specialists. Our preferred balance of physician groups was successfully recruited. By focusing on how physicians' personal end-of-life preferences impact their clinical practice, we provide a much-needed addition to the current literature on physicians' end-of-life preferences. The study had certain limitations. Although the final sample included a variety of physician groups in three countries, it was ethnically homogenous, and there may be selection bias as the interview study could have attracted those with a particular interest in end-of-life issues resulting in a sample that could have reflected more intensely on the topic.

Policy and practice implications

These study findings suggest several important policy and practice implications. First, to help physicians manage moral conflicts and maintain professional boundaries, clear ethical guidelines should help ensure that clinical recommendations are based on patient preferences rather than personal beliefs or biases, particularly in end-of-life care. Ethical guidelines can also help physicians navigate complex decisions, such as those involving physician-assisted suicide or euthanasia. Second, the promotion of consultation with local palliative care experts or palliative care training and end-of-life conversation training, which fosters a person-centered approach, could help physicians to manage the influence of their personal preferences on patient recommendations. Third, addressing cultural and religious influences on physician decision-making through cultural competency training is also important, particularly in jurisdictions where strong religious traditions impact patient care.

Conclusion

This study confirms the connection between physicians' personal preferences and their clinical practice. While there is divergence with some physicians striving to keep a separation and

others using their personal preferences as a guide, most physicians stress the need to keep the patient's priorities at the center of decision-making. These findings underscore the complex interplay between physicians' beliefs and preferences, personal ethics, and patient autonomy, highlighting the nuanced decision-making process involved in end-of-life care. Further research is needed to deepen our understanding of how physicians navigate the relationship between their own preferences and clinical practice and its impact on clinical decision-making.

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PART IV

GENERAL DISCUSSION AND CONCLUSIONS

Chapter 6

General discussion and conclusions

1. Introduction

The aim of this dissertation was to explore physicians' preferences for end-of-life decisions and the factors that shape them, and to investigate the connection between physicians' end-of-life preferences and their clinical practice. This dissertation addressed seven research questions.

Four research questions dealt with physicians' preferences for end-of-life decisions and their influences:

1. What are physicians' preferences for end-of-life practices in hypothetical medical scenarios of advanced cancer and Alzheimer's disease?
2. What are physicians' considerations about their end-of-life preferences?
3. To what extent do physicians' preferences for end-of-life practices vary by assisted dying legislative environment, sociodemographic and professional characteristics, and what factors are associated with physicians' end-of-life preferences?
4. How do physicians perceive their end-of-life preferences are impacted by personal, professional, cultural, legislative, social, and religious influences?

Three research questions focused on the connection between physicians' end-of-life preferences and their clinical practice.

5. To what extent do physicians believe their personal end-of-life preferences impact their own clinical practice and how do they compare across physician groups and jurisdictions?
6. To what extent do physicians' personal treatment option preferences differ from their treatment option preferences for patients in similar health scenarios?
7. How do physicians perceive and manage the impact of their personal preferences on their clinical practice with patients at the end of life and end-of-life decision making?

This section of the dissertation examines the primary findings of the studies. It begins with an evaluation of the methodological strengths and limitations, followed by an overview of the key results. A general discussion will then delve into the results in detail, connecting the findings to prior research. Lastly, several implications and recommendations are presented for policy, practice, and future research directions.

2. Methodological strengths and limitations

We used two types of studies to answer our research questions. First, we performed a quantitative study to explore physicians' preferences for end-of-life practices, how preferences for end-of-life practices vary by assisted dying legislative environment, sociodemographic and other characteristics, and how physicians perceive their personal preferences impact their clinical practice. Second, we conducted a qualitative study to gain an in depth understanding of what physicians' have considered for their end-of-life preferences, how they perceive their end-of-life preferences are impacted by various influences and how their preferences are connected with their clinical practice. Both studies have their specific strengths and limitations which will be discussed in this section.

Some methodological limitations apply to both our studies. Our choice of a multi-method design was pragmatic and provided certain benefits; however, a mixed methods approach would have offered a more fully integrated way to study physicians' end-of-life preferences and their connection to practice. By combining the quantitative and qualitative data collection and analysis process, a unified design may have allowed for iterative refinement and provided a richer understanding of how numerical trends align with physicians' perspectives and the socio-cultural influences on their preferences revealed through interviews. Although it was our intention to use a mixed methods design, we were unable to do so due to timing and practical considerations. Our study faced early challenges due to delays in ethical approvals and the COVID-19 pandemic resulted in the loss of research partners and testing participants, which set back our study further. Since we encountered recruitment difficulty for the quantitative study and had to extend the data collection phase and concurrently proceed with the qualitative interview study, we were unable to integrate the quantitative and qualitative studies during data collection. Although a mixed methods approach could have been incorporated after data collection, merging narrative data with numerical data is often time-consuming and methodologically challenging and requires advanced analytical skills and time to ensure rigor. These factors led us to conduct the analyses separately. However, to honor the richness of the data and deepen our understanding of numerical trends alongside nuanced physician perspectives, we have tried to integrate the findings of both studies in a mixed methods format in this Chapter.

Additionally, findings based on predominantly white/European samples may not fully apply to other racial and ethnic groups due to differences in socioeconomic factors, healthcare system differences, and cultural attitudes. Our research approach was limited by its reliance on hypothetical scenarios and self-reported data, which may not fully capture how physicians actually make decisions in real-world clinical settings. Physicians' stated preferences and reported behaviors may differ from their actions when faced with complex, high-stakes situations where personal preferences, institutional policies, and emotional factors also play a role. Additionally, just as individuals' end-of-life preferences may shift when they become

seriously ill, physicians' theoretical considerations may not always align with their real-time decision-making, introducing potential gaps between reported and actual practice. Despite these limitations, the study offers valuable insights into how physicians perceive the role of their personal preferences in patient care and the multi-method design provides both measurable trends and deeper reflections on this issue. The findings highlight a significant self-reported connection between physicians' personal preferences and clinical recommendations, suggesting the need for greater awareness of potential biases. By exploring this underexamined aspect of medical decision-making, the study contributes to broader discussions on promoting patient-centered care while acknowledging the human elements that shape physician judgment.

2.1. Quantitative cross-sectional study of physicians' end of life preferences and perspectives using a self-administered online survey

2.1.1. Strengths of the study

A key strength of our study was the use of a quantitative survey spanning varied legal and cultural contexts and jurisdictions (Canada, USA (Georgia, Wisconsin, Oregon), Belgium, Italy and Australia (Victoria, Queensland)) and multiple physician groups with varying experiences with end-of-life care (general practitioners, palliative care physicians, and other medical specialists). This purposive sampling strategy enabled us to identify broad and generalizable trends in physicians' preferences and perspectives and uncover novel social, cultural and religious variation. We came close, and in some cases, exceeded our goal of gathering responses from a sufficient number of participants in each jurisdiction (150 physicians), which strengthened the statistical power of our results. This target number was determined after consultation with two experienced researchers - an epidemiologist and a demographer - who advised that recruiting a sample of over 100 physicians would be sufficient to make inferences about the population. Using clearly defined research questions allowed us to focus on specific measurable aspects including physician's end-of-life decision preferences. Our cross-sectional

design provided a snapshot of physicians' preferences and perceptions at a specific point in time, which was useful for drawing associations between variables including sociodemographic factors and physicians' preferences.

2.1.2. Limitations of the study

This study design also has some weaknesses. Our choice of purposive sampling did not allow for random selection of physicians. Therefore, the point estimates cannot be considered representative of the specific group of physicians, which limits the external validity of the findings. The vignettes did not capture the important role of the family in end-of-life decision-making. There may have been bias with some physicians considering it more socially acceptable to respond that their personal preferences do not influence their clinical practice or self-selection bias with participants having a particular interest in end-of-life issues. This may have led to skewed point estimates by over- or underrepresenting certain ethnic or religious groups, introducing systematic differences, as the sample may not reflect the true diversity of the target population resulting in reduced generalizability of the findings. Due to the sampling method, we could not use unique URLs to ensure physicians would not complete the survey multiple times; however, the data were reviewed for duplicate responses. The overall recruitment of respondents was satisfactory in all jurisdictions but there was a low representation of general practitioners in the Canadian sample. However, the comparison of groups is not affected as much as point estimates by lack of representativeness in a sample and we have included confidence intervals, which help quantify the uncertainty around estimates derived from the survey data by capturing and expressing the variability in responses among these populations. This also demonstrates transparency and provides context for interpreting the results.

2.2. **Qualitative physician interview study using semi-structured interviews**

2.2.1. Strengths of the study

As in the survey study, a strength of our qualitative study was the cross-national qualitative design, with physicians across three countries and three jurisdictions with varied assisted dying status (Belgium, Italy, USA) representing diverse legal and cultural environments and the participation of three groups of physicians (general practitioners, palliative care physicians, and other medical specialists). Our preferred balance of physician groups was successfully recruited and the total sample of 45 physicians was considered ideal to gather comprehensive insights given our research questions, the diversity within the sample, and our analytical approach. The flexibility of conducting semi-structured interviews allowed us to explore unexpected themes, such as physicians' concepts of a good death and physician-perceived rewards of engaging in difficult conversations, which enhanced the depth of our collected data. The use of reflexive thematic analysis allowed for a nuanced, iterative consideration of the data and the discovery of complex themes in physicians' perspectives, including more subtle cultural and religious influences, which are not easily captured in quantitative measures.¹

2.2.2. Limitations of the study

However, the qualitative study also had certain limitations. The sample was ethnically homogenous and therefore could not adequately capture the diversity of experiences and perspectives across different cultural contexts. Also, a lack of member checking, where participants verify the accuracy of the themes derived from their input, risks a misinterpretation of their views. Self-selection bias may skew the sample toward physicians with more distinct or extreme views, limiting the transferability of the findings. Furthermore, cultural and contextual biases arise from the inclusion of only a few countries, which may not fully reflect the diversity of global perspectives. Our formulation of the interview guide question, "How do you believe you keep your personal preferences from influencing your practice?" assumes that physicians should actively separate their personal preferences from their clinical decisions. This may have limited the depth of responses by framing personal

preferences as something to be managed or excluded, rather than acknowledging that personal values might naturally inform decision-making, even in ways physicians may not always consciously recognize. Had this question been framed more open-endedly, such as “How do you see your personal preferences influencing your clinical practice, if at all?” it may have elicited a more nuanced understanding of the role that personal beliefs play in decision-making and would likely have encouraged physicians to reflect more freely on how their personal preferences intersect with their professional judgments, offering a broader range of insights into the complex relationship between personal preferences and patient care. Combined with the non-random sampling method, these issues reduce the transferability of the study. Nonetheless, we believe these study findings contribute valuable insights to a line of inquiry that has previously been underexplored.

3. Summary of the main findings

The main findings for each research question are summarized below.

3.1. Physicians’ preferences for end-of-life practices

In Chapter 2, we described physicians’ preferences for specific end-of-life practices in hypothetical medical scenarios of advanced cancer and Alzheimer’s disease. This study showed that, across all participating jurisdictions, more than 90% of physicians have a personal preference for the intensification of symptom alleviation using medications in both the advanced cancer and Alzheimer’s disease scenarios, and more than 95% prefer to avoid life-sustaining techniques like CPR, mechanical ventilation, and tube feeding. Palliative sedation presents a mixed picture across the jurisdictions, with 39% to 66% of physicians considering it for themselves in the Alzheimer’s scenario and 43% to 82% in the cancer scenario. About half of participating physicians (54.2%, 51.5%) in both scenarios considered euthanasia a good or very good option.

3.2. Variation of physicians' preferences by personal, professional, cultural, legislative, social, and religious influences

In Chapter 2, we described how physicians perceive their end-of-life preferences are impacted by socio-cultural and legal influences. We found that physicians believe their preferences have been influenced by a variety of factors, including cultural, social, and religious beliefs, and legislative environment. Physicians from jurisdictions with a legal option for assisted dying considered euthanasia for themselves to a much greater extent than those in jurisdictions without a legal option (81% in Belgian versus 38% in Italy). We also found that physicians with more strongly held religious beliefs are less likely to consider assisted dying a preferred option for themselves. Chapter 6 has shown that physicians' experiences with the deaths of loved ones and their clinical practice have a particularly significant impact on their preferences. Seeing a loved one or patient suffer from a prolonged illness, receive intensive treatment, or deal with challenging end-of-life scenarios and has influenced physicians to prefer some end-of-life decisions over others, or generally less aggressive treatments for themselves. Experiences such as culturally- based refusal to speak about death, exposure to death and dying through literature and media coverage of controversial situations such as the extended prolongation of life in a persistent vegetative state have also played a role in shaping physicians' normative beliefs and preferences.

3.3 What physicians have considered for themselves at the end-of-life

In Chapter 3, we described physicians' considerations about their end-of-life preferences. We found that many physicians, particularly those in palliative care, have reflected on what they would want for themselves at the end-of-life and have developed ideas about what they consider a good death and the kind of scenarios they hope to avoid. Physicians have notions about what they would prefer but realize their preferences could evolve and become more nuanced. Most physicians prefer to avoid aggressive, life-prolonging treatments, physical and mental suffering, and the burden their care might place on others. They prioritize being in a

peaceful environment, retaining the ability to communicate with loved ones and maintaining their dignity.

3.4. Impact of physicians' personal end-of-life preferences on patient care

In Chapter 4, we described the extent to which physicians believe their personal end-of-life preferences impact their own clinical practice. This study showed that across jurisdictions, nearly two thirds of physicians acknowledge considering their own preferences when caring for patients at the end of life and almost one third believe the recommendations they make to patients are impacted by their personal preferences. Palliative care physicians and physicians with palliative care training are less likely to consider their own preferences when caring for patients and when making recommendations and are less likely than other physicians to consider it appropriate to consider their own preferences when caring for patients.

3.5. Congruence between physicians' personal treatment option preferences and their treatment option preferences for patients

In Chapter 4, we described the extent to which physicians' personal treatment option preferences differ from their treatment option preferences for patients in a scenario of advanced cancer or Alzheimer's disease. We found notable incongruence between what physicians prefer for patients and what they would want for themselves for certain end-of-life practices. We found physicians consider some options "not good for the patient, but good for themselves" - palliative sedation (8.3%), physician-assisted suicide (7.0%) and euthanasia (11.6%), in the cancer scenario and palliative sedation (17.6%) and euthanasia (15.8%), in the Alzheimer's scenario. There are interesting similarities between physicians' preferences for themselves and patients in the cancer and Alzheimer's scenarios including the preference to intensify alleviation of symptoms and avoid life-prolonging practices. While the differences between the cancer and Alzheimer's scenarios were not substantial, we found the percentage of incongruence for the Alzheimer's scenario is larger with physicians finding palliative sedation

and euthanasia a good option more strongly for themselves than for patients.

3.6. Physicians' perception and management of their personal preferences on clinical practice

In Chapter 5 we described how physicians perceive and manage the impact of their personal preferences on their clinical practice with patients at the end of life and end-of-life decision making. We found that physicians feel their personal preferences influence their clinical practice and to manage this influence, they emphasize maintaining objectivity and keeping patient preferences at the center of decision-making. Some physicians actively collaborate with colleagues to reduce personal bias and attempt to balance personal ethical considerations with patient autonomy. There is disagreement among physicians about whether it is appropriate to share when asked what they would do in the position of their patients. Most believe the focus should remain on the patient's values and priorities while others feel it is important to share to maintain an open trusting relationship. Personal values, including the idea of treating others as you would like to be treated, underlies and guides clinical interactions for some physicians. Physicians sometimes face internal ethical conflict when patient requests clash with their personal beliefs, such as in cases of perceived futile treatment or assisted dying. Physicians also reported experiencing personal and professional growth through reflection and challenging discussions and find value and connection in end-of-life conversations.

4. Discussion of the findings

In this section, the main findings of this dissertation are discussed in-depth and in relation to each other, the research objectives and the relevant literature.

4.1 Physicians' end-of-Life preferences: shaped by experience

This dissertation has shown that many physicians, particularly those in palliative care, have reflected on what they would want for themselves at the end of life and have developed clear

ideas about what they consider a good death (Chapters 2 and 3). There is an overwhelming preference among physicians for non-aggressive, comfort-focused end-of-life care reflecting a strong alignment with the principles of palliative care, which emphasize quality of life and the alleviation of suffering over life-prolonging interventions. Research has indicated physicians prefer less aggressive end-of-life care for themselves including for treatment such as CPR, mechanical ventilation, artificial nutrition and hydration, major and minor surgery, dialysis, chemotherapy, invasive tests, blood transfusions, antibiotics and diagnostic tests.^{2,3} This preference was corroborated by our quantitative study and further confirmed and expanded upon in the qualitative study. We found that more than 90% of physicians surveyed opt for symptom management in terminal scenarios, and more than 95% would reject invasive treatments like CPR, mechanical ventilation, and tube feeding in low-recovery or high-burden circumstances. This trend is consistent across various jurisdictions and aligns with a clear emphasis on retaining autonomy and the avoidance of prolonged dependency. Physicians' preferences indicate a clear appreciation for non-invasive, dignity-preserving care.

Our qualitative findings have shown that physicians' end-of-life preferences are profoundly impacted by personal experiences, particularly the deaths of loved ones involving prolonged suffering and decline. Additionally, their clinical practice and experiences guiding patients through illness and end-of-life play a pivotal role in molding their preferences for themselves. These intimate encounters often lead physicians to favor comfort-oriented approaches over aggressive treatments for themselves, as they aim to avoid scenarios they have witnessed firsthand - such as unmanaged pain, prolonged dependency, invasive treatments or futile interventions. These findings support previous research showing that individuals who have observed painful or protracted deaths are more likely to reject life-sustaining treatments and instead seek options like palliative care or noninvasive interventions.⁴

We found that physicians' deep understanding of the physical and emotional toll of aggressive interventions, coupled with their observations of outcomes in terminal cases, informs a rejection of measures perceived as unlikely to enhance quality of life. This alignment of

personal preferences with less invasive care likely stems not only from emotional resonance but also from physicians' professional exposure to complex end-of-life scenarios. Witnessing suffering, whether in loved ones or patients, heightens awareness of the limitations and potential burdens of aggressive medical interventions. These experiences appear to inform physicians' preferences and result in an emphasis on dignity and comfort at the end of life. While the finding that personal losses have significant impact on physicians is not entirely surprising, it does prompt consideration about how emotional processing from personal loss can be balanced with professional decision-making.

The connection between physicians' clinical experiences and their personal treatment preferences also reflects an important convergence in medical ethics and professional practice. Physicians are not only shaped by their own personal histories but also by the ethical dilemmas they face in clinical practice, where they are often required to make decisions or recommendations about life-sustaining treatments under circumstances that may involve patient suffering, cognitive decline or impairment, or challenging end-of-life trajectories. Our qualitative findings support previous research indicating that the emotional challenges of caring for dying patients - particularly those enduring prolonged suffering - profoundly impact physicians, who are deeply affected by the moral and emotional complexities of these decisions.^{5,6} The strain of direct repeated involvement in challenging end-of-life patient scenarios likely exerts an emotional toll and leads physicians to form strong preferences for their own end-of-life care.

These study findings correspond to our first objective of understanding physicians' preferences for end-of-life decisions and the factors that shape them. They provide a deeper understanding of the psychological and emotional influences that shape physicians' preferences and underscore the significance of personal and professional experiences.

4.2 Legal, structural and cultural factors impact physicians' end-of-life preferences

The findings from our quantitative and qualitative studies show that, among other factors, legislative environment has an influential effect on physicians' attitudes toward end-of-life options (Chapters 2 and 3). These findings address our first objective and offer valuable insights into the factors that shape physicians' preferences. In jurisdictions where euthanasia is legal (e.g., Belgium, Canada, and Australia), there is significantly higher acceptance of these practices. The quantitative survey indicated that 81% of Belgian physicians consider euthanasia for advanced cancer compared to 38% of Italian physicians, which supports this conclusion. This study has shown that familiarity with these practices in legal contexts likely normalizes them, fostering greater comfort and reducing ethical or professional hesitations, which aligns with existing literature suggesting that when assisted dying is integrated into standard medical practice it becomes more accepted.⁷

While legislation directly influences clinical practices, it operates within broader cultural and professional contexts, which also impact physicians' end-of-life preferences. Physicians appear to adapt their preferences based on what is considered normative within their jurisdictions. Our survey findings in Queensland - where legislation was passed but not yet enacted - suggest that even the anticipation of legislative change can influence attitudes and increase acceptance. To understand the variation in our findings, reflecting on cultural attitudes and social contexts may also be necessary. Societal norms and beliefs about death, including religious or spiritual perspectives, shape how physicians view their role in medical situations.⁸ In cultures where autonomy and dignity are prioritized, physicians may feel more aligned with practices that honor patient choice, while in societies where family roles or spiritual considerations dominate, they may lean toward more life-prolonging interventions.⁹ This likely reflects the cultural shift toward postmaterialist values emphasizing self-expression, autonomy, and quality of life. Inglehart's theory of modernization and cultural change underscores how evolving values influence political behavior, social norms, and the priorities of individuals and communities.¹⁰ Historical debates about end-of-life, social exposure to diverse choices and media coverage of extreme cases, such as unauthorized cases of assisted suicide or patients who have lived for prolonged periods in a persistent vegetative state, contribute to the lens through which

physicians view their own end-of-life care. Interview participants also shared that they have been impacted by moving portrayals of death and dying from literature, such as the *Death of Ivan Ilyich* by Leo Tolstoy, illustrating the broad range of social and cultural influences on physicians' preferences.

While assisted dying legislation is expanding, many jurisdictions lack access and must manage refractory suffering at the end of life by other means, often employing palliative sedation. Our findings indicate contrasting levels of acceptance among physicians between assisted dying and palliative sedation, which merits reflection. Assisted dying remains highly divisive, influenced by legislation, controversial terminology and ethical debates, while we found that palliative sedation has much broader consensus and acceptance among physicians across jurisdictions. This was seen in the quantitative study and strongly confirmed by the interviews. This variation may stem from differing ethical and cultural perceptions: palliative sedation aligns with more traditional medical values of relieving suffering without directly hastening death. By contrast, assisted dying challenges longstanding medical and societal boundaries around the role of the physician and sanctity of life. These findings suggest that palliative sedation may provide a middle ground option for the treatment of refractory suffering at the end-of-life, particularly in regions where legal or cultural barriers to assisted dying persist. Our findings also confirm existing research that healthcare providers are more comfortable with palliative sedation – both conceptually and as an end-of-life intervention.¹¹ Limited data from the Netherlands and Canada suggest rates of palliative sedation may have increased following legalization of assisted dying, potentially due to the practice being perceived as a less extreme option.¹¹ This sentiment was prominent in our interview study as physicians expressed more comfort with the idea of palliative sedation due to its objective being symptom control as opposed to the hastening of death. However, there was a distinct difference with Belgian physicians. In both the quantitative study and the interviews, they showed a preference for euthanasia. Many shared that they would consider palliative sedation but since they were comfortable and familiar with euthanasia they would probably prefer it due to its immediate effect.

Jurisdictional differences in physicians' preferences could have significant implications for patient care. For example, physicians in regions where assisted dying is legal may present these options more readily to patients, potentially creating disparities in end-of-life care access and quality, while in restrictive regions, patients may have limited options, with physicians potentially leaning more heavily on palliative sedation or the intensification of symptom management with medications. These potential disparities underscore the need for continued dialogue between physicians, healthcare administrators and policy makers to ensure equitable access to end-of-life care. The findings also raise broader ethical and legislative considerations about how end-of-life practices should be integrated into healthcare systems. For instance, does the legalization of assisted dying inadvertently pressure physicians to align with societal norms, potentially at odds with their personal values, which results in emotional conflict? Conversely, do restrictive laws hinder physicians from offering what they personally consider compassionate care? Research has explored some of these complex issues and found that physicians' participation in assisted dying can potentially contrast with their personal expectations about professional roles and responsibilities and result in emotional burden or discomfort, while other physicians who participate experience satisfaction in meeting the end-of-life needs of patients.^{12,13}

Beyond the influencing factors identified here including socio-culture forces, physician specialty, institutional norms, religiosity, and legislative environment, factors such as broader cultural attitudes toward death and suffering, the strength of palliative care systems, and institutional policies may significantly shape both what physicians choose for themselves and what they recommend to patients. A closer examination of macro-level influences such as palliative care availability, end-of-life care strategies, professional guidelines, and medical training could have provided a more nuanced understanding of the variation in physicians' end-of-life preferences across jurisdictions. We found that identifying macro-level influences through the quantitative survey presented certain challenges as it could not capture the full complexity of systemic and cultural influences while maintaining minimal length to increase likelihood of participation. The qualitative interviews, though rich in detail, do not easily

generalize across diverse settings, and we found that physicians may not always be conscious of how institutional policies, systems, and cultural attitudes shape their perspectives.

4.3 Physicians experience emotional conflict when their religious beliefs and personal values are not aligned with their clinical practice

This dissertation has shown that physicians' religious beliefs and personal values can significantly shape their approaches to end-of-life care, providing moral clarity and emotional grounding while also introducing ethical challenges and potential sources of conflict. In line with abundant existing research in this area, we found in both the quantitative and qualitative studies that physicians with strong religious convictions were less likely to prefer or support practices that hasten death, like assisted dying (Chapters 2 & 3).^{14–18} This alignment with religious principles underscores how deeply held beliefs influence not only personal preferences but also professional decision-making. We heard from some interviewed physicians that these beliefs provide a comforting framework for understanding life and death, enabling them to navigate ethically sensitive decisions with integrity and purpose. However, when clinical practices or patient requests conflict with personal beliefs, we found that physicians may experience emotional and ethical conflict.

The emotional toll of navigating such conflicts can be intense. Physicians in the interview study, like those in previous research, described struggles to reconcile personal conscience with professional responsibilities, especially when concerns were related to treatments they considered futile, harmful or controversial, such as life-sustaining treatments or assisted dying.^{19–22} This illustrates the psychological burden and moral distress some physicians experience, which can ultimately lead to diminished job satisfaction, burnout and suboptimal patient care.^{19,21,23} This internal conflict was especially pronounced in certain cultural contexts, such as Italy, where religious opposition to assisted dying was more common, and Belgium, where interviewed physicians expressed ethical dilemmas related to euthanasia. These issues draw attention to the challenging dual role physicians must balance as individuals with personal

convictions and as professionals committed to patient autonomy and equitable care. This challenge might be addressed by physicians acquiring key competencies using the CanMEDS framework. This approach highlights the importance of role-modeling and experiential learning, where residents learn various roles and skills through observation, reflection, and real-world practice.²⁴ For instance, when senior physicians demonstrate compassionate communication and ethical decision-making in palliative care, they create a supportive environment that guides trainees and enables them to internalize these behaviors, fostering their ability to deliver empathetic, patient-centered care. Physicians can also employ methods for managing their emotional distress and promoting personal well-being. Research has identified various strategies including cultivating supportive relationships (e.g., engaging with family, friends, and colleagues), which serves as a key source of emotional resilience.²³ Religious or spiritual practices were less commonly prioritized but can offer a meaningful coping mechanism.²³ Additionally, self-care practices, such as regular exercise, pursuing hobbies, maintaining self-awareness, setting clear boundaries around work responsibilities, and adopting life philosophies have been identified as fostering well-being among physicians.²³

A major concern related to the conflict between personal values and clinical practice is the potential for physicians' personal or religious beliefs to inadvertently shape patient care in ways that undermine autonomy or create barriers to access. Physicians who frame treatment options based on their own values, rather than those of the patient, risk alienating patients or eroding trust. This challenge is especially acute in culturally diverse settings, where patients' worldviews may differ significantly from those of their physicians. Moreover, systemic disparities in care can arise if conscientious objection leads physicians to opt out of offering certain treatments, such as assisted dying, without adequate provisions for referrals and alternative care. Cultural and societal contexts may further complicate this issue. In regions where religious or cultural opposition to practices like assisted dying is prevalent, societal expectations may amplify physicians' distress, compelling them to reconcile personal, professional, and social pressures.^{25,26} Conversely, in more secular societies, religious physicians might feel isolated or face challenges in reconciling their practices with mainstream medical ethics.^{25,26} These cross-

cultural differences raise broader questions such as, how can healthcare policies accommodate diverse religious and ethical perspectives while maintaining patient access to legal care? What role should institutions play in fostering inclusive dialogues that bridge cultural and religious divides, supporting physicians and ensuring patient-centered care remains paramount? Upon reflection, it seems that healthcare policies could help accommodate physicians' diverse perspectives while assuring access to care by implementing a structured referral system allowing providers who object to certain practices to transfer care to willing colleagues without compromising patient rights. These systems may already exist but ensuring that they are available to all physicians in a comfortable, non-critical environment is essential. Involving diverse stakeholders, including faith leaders, ethicists, and patient advocates, in the healthcare policy-making process could lead to the development of more inclusive guidelines that reflect broader societal values while ensuring equitable access. As for the role of institutions, such as hospitals, healthcare organizations and medical education institutions, they could improve physician support and overall care by prioritizing education and training programs that enhance cultural competence and communication skills, helping providers navigate end-of-life dilemmas with sensitivity and professionalism. The coordination of facilitated intercultural forums about the impact of religious and cultural diversity on end-of-life decisions could also serve to raise awareness and build trust.

This discussion has largely focused on reconciling potential tensions and the need for physicians to balance the impact of their personal beliefs on patient care. It may also be worthwhile to consider whether physicians bringing their personal beliefs into patient care could be justified, or even preferred. First, research indicates that personal beliefs and values shape a physician's ethical framework, guiding them to act with integrity and compassion.²⁷ Ignoring these beliefs could risk moral distress, potentially impairing their ability to provide optimal care.²³ A physician's commitment to authenticity can foster trust with patients, as many patients value understanding the moral and personal perspectives of those providing care and research shows patients may be dissatisfied if physicians withhold their own opinions.²⁸ Second, engaging with personal beliefs does not necessarily mean imposing them; it can serve as a channel to open

dialogue. For example, a physician who is transparent about their values might better collaborate with patients, creating opportunities to explore care pathways that respect both the patient's preferences and the physician's ethical boundaries. This is particularly important in morally complex situations like end-of-life care, where nuanced conversations are key. Finally, maintaining personal beliefs underscores the diversity within the medical profession, which is vital in a pluralistic society. Physicians embody a wide range of worldviews, and this diversity ensures a healthcare system that respects various cultural, religious, and ethical perspectives.²⁶ Patients can benefit from a system where providers' integrity is upheld, as it reinforces the principle of mutual respect in patient-physician relationships.

While it may not be possible, or completely desirable, for physicians to entirely divorce their personal beliefs from their professional practice, these beliefs must not overshadow the principles of evidence-based medicine and respect for patient autonomy. Research indicates that this is precisely what patients want: for their physician to share their personal perspective while also providing evidence-based guidance.²⁹ Physicians must strive for a delicate balance, using their values as a foundation for empathy and moral reasoning while ensuring their recommendations and decisions remain patient centered. These findings relate to our first objective and help illuminate the complex influences on physicians' preferences. They also underscore the need for healthcare systems to provide robust support mechanisms, such as peer networks, referral systems and multidisciplinary team consultations, that respect physicians' moral frameworks while ensuring that patients receive unbiased, high-quality care.

4.4 The contrast between what physicians want for themselves and for their patients

This dissertation has shown that physicians' personal preferences do not align with their preferences for patients for some critical end-of-life decisions (Chapter 4). This incongruence underscores an important aspect of the clinical decision-making process: while physicians may provide more aggressive or life-sustaining treatments for patients, they tend to prefer less intervention for themselves. These quantitative study findings align with prior research showing

that physicians often prefer less life-prolonging treatment compared to what they would recommend for patients, revealing a significant gap between personal and professional decision-making.^{30,31} While it can be beneficial for physicians to adapt their perspectives and set aside personal preferences in patient care, this divergence may also suggest the influence of potential biases. For example, status quo bias may result in physicians favoring established medical norms, such as aggressive life-prolonging treatments, even when they might not align with patients' preferences. This highlights the difference between physicians' personal perspectives and their professional roles and relates to research suggesting that physicians continue treating patients only until further clinical interventions no longer meaningfully contribute to achieving the patient's specific goals (medical futility).³² This finding raises concerns about how biases may shape clinical recommendations and whether they unintentionally perpetuate disparities in care. For example: If physicians see some interventions as "good for themselves but not the patient," are they inadvertently prioritizing professional norms over patients' subjective experiences of suffering? Research has shown that patients frequently receive unwanted invasive, life-extending treatments.² There are complex factors influencing the provision of more aggressive care including: patient and family requests for exhaustive life-saving efforts; the desire to maintain trust by preserving hope; a lack of time, desire or perceived competence to engage in time-consuming end-of-life conversations; fear of litigation; the increasing availability of medical technological treatments; and the default toward maximal interventions. Physicians were not directly asked their reasoning behind recommending treatments for patients that differ from their own preferences, however, it may relate to underlying professional norms, feeling a sense of empathy, and a perceived responsibility to provide comprehensive care. Physicians often feel obligated to provide all options to respect patient autonomy, driven by optimism for better outcomes or fear of regret and liability. Physicians may also project patient desires for life prolongation, view treatment futility differently for patients, or feel a moral duty to preserve life.

This incongruence reflects an ethical tension between physicians' personal end-of-life values and their professional responsibilities. That physicians prefer less invasive interventions is

documented in literature and suggests a desire to prioritize quality of life over prolonged suffering.³¹ However, their professional recommendations often align with preserving life, guided by interpretations of patient autonomy, societal expectations, professional training and institutional norms. This tension invites reflection on how physicians reconcile their personal beliefs with their duty to act in the patient's best interest. It also raises questions about the extent to which external pressures, such as fear of litigation or societal norms, shape their professional decisions. These external pressures were not identified in the physician interviews to be a factor of concern. However, participants did acknowledge that social norms likely play an underlying role. Existing literature has highlighted the struggle physicians face in maintaining neutrality when their personal values conflict with patient care and this was also a theme revealed by our physician interviews.^{30,33} This finding underscores the difficulty physicians face balancing their personal preferences with clinical decision-making that respects patient autonomy.

Our quantitative findings also showed that physicians consider some options not good for the patient, but good for themselves, including palliative sedation, physician-assisted suicide, and euthanasia. This is in line with research showing that physicians are more likely to choose a treatment with a higher risk of death for themselves than for a hypothetical patient.³⁰ While the differences between the cancer and Alzheimer's scenarios were not great, we found the percentage of incongruence for the Alzheimer's scenario is larger, which is understandable as it may relate to the difficulty of making consequential end-of-life decisions for people with cognitive impairment. This may also point to a factor contributing to the broader discrepancy in critical end-of-life decisions. Physicians may feel more morally comfortable, even in the context of a survey, expressing a preference for potentially life-shortening practices for themselves than for their patients. In the case of Alzheimer's, it is possible that physicians consider themselves ill-equipped to judge the effects of cognitive decline on autonomy and subjective well-being among these patients. Other factors including ethical obligations to sustain life, professional norms and assumptions about patients' or families' values may also drive more aggressive treatment recommendations.

These findings indicate that physicians' preferences may diverge from patients' preferences and address our second objective of understanding the connection between physicians' preferences and their clinical practice. This incongruence raises important considerations about the role of physician autonomy and biases in clinical practice, particularly when the decision involves patients' wishes and the physician's moral framework. Given the complicated and compelling influences on treatment decisions, it is understandable that patient care is not aligned with physicians' personal preferences. It should also be considered whether aligned care is, or should be, a goal of clinical practice. Perhaps physicians striving to ensure that patients are well-informed and providing evidence-based, patient-centered care is the most appropriate objective.

4.5 Physicians are divided on sharing their end-of-life preferences with patients

A key finding of this dissertation is that physicians are divided on whether to share their personal preferences when asked by patients what they would do in similar circumstances, highlighting an important ethical and professional dilemma within the broader context of end-of-life care (Chapter 5). This dilemma is rooted in the tension between fostering trust and transparency and maintaining patient-centered care. Physicians in the qualitative study stated that sharing their preferences can help maintain trust, model decision-making, and offer clarity. However, other physicians felt that doing so risks unduly influencing patients, especially when their own values may differ from those of their patients. Our findings confirm previous research that has found physicians are reluctant to provide information they feel will bias the patient and most feel negative or ambivalent about sharing their personal recommendations.²⁹ While both perspectives, to share or not share, are understandable, this divide underscores a deeper ethical tension inherent in the physician's role as both a neutral guide and an experienced expert. Although it wasn't a specific point of exploration for this study, no particular physician or patient profile characteristics were identified as being associated with the likelihood of the

physician sharing. These findings expand our understanding about the connection between physicians' preferences and clinical practice (objective 2).

Both our quantitative and qualitative studies indicate that physicians are aware of the potential for their personal preferences to shape patient decisions, whether intentionally or inadvertently. Most interviewed physicians shared that redirecting end-of-life conversations toward the patient's values and goals was the most ethical approach, as it minimizes the risk of bias and centers the decision-making process on the patient's needs. However, the belief among some physicians that sharing their own preferences can foster trust and provide a model for decision-making highlights the complexity of this issue. Some physicians specified that they would consider sharing their preferences depending on the situation, if, for example, they thought they would choose the same treatment option the patient was considering. It is also possible that a physician's decision to share would be dependent upon the impact of the treatment being considered. If the decision had an immediate life-shortening effect, such as assisted dying, it may increase their reluctance to share. It is also worth considering that research shows patients highly value knowing what their physician would choose in their position.²⁹

The divergence over whether to share personal preferences also reflects broader concerns in medical ethics. Physicians must carefully balance their dual roles as advocates for patient autonomy and providers of professional guidance. The concept of relational autonomy should be taken into account, as the traditional, individualistic approach to autonomy may fail to incorporate the complexities of real-life decision-making, especially in the context of end-of-life care. Relational autonomy recognizes the interconnectedness between individuals and their social contexts and incorporates the perspectives of family, caregivers, and broader social influences.³⁴ This perspective aligns more closely with the realities of end-of-life care, where decisions are often made in a communal context and involve emotional and relational factors. How can physicians ensure their own beliefs do not inadvertently overshadow the values of the patient, their significant others, or family members within the broader interpersonal context?

Also, does sharing preferences inherently blur the line between personal bias and professional expertise, or can it sometimes clarify options for patients? These issues require careful reflection and a commitment to ethical discernment. Transparency is often viewed as an integral part of trust in physician-patient relationships. Some physicians felt that sharing their preferences, when done thoughtfully, can enhance trust and provide valuable context for patients facing difficult choices. However, others shared that the risk of influence is too great, especially in scenarios where patients might defer to their physician's judgment due to perceived authority. These are justifiable concerns which raise critical considerations of how physicians can foster trust without introducing unintended bias. Are there strategies for communicating personal insights that maintain the patient's agency? Some physicians seem to feel it is possible to share their own preferences without inappropriately influencing patients, though they are the minority.

Based on the physician interviews, it seems conceivable that choosing to selectively share one's own preferences based on the specific circumstances of the patient - while carefully considering their emotional and cognitive state - may allow for the preservation of patient trust and maintenance of patient autonomy. Given that patient trust is a foundational component in the patient-provider relationship, it is understandable that physicians would make extreme efforts to preserve it. Ensuring that one's own preferences are presented as a personal opinion and balanced option among all available choices, physicians could attempt to avoid undue influence and empower patients to make informed decisions. Providing an explanation of their reasoning may serve to clarify and deepen the patient's understanding about the range of options and could be appropriate under limited circumstances. This approach would demonstrate respect for the patient's values and needs while fostering a collaborative relationship that supports ethical decision-making.

The context in which end-of-life conversations occur adds another layer of complexity. Sensitive discussions about end-of-life care are often emotionally charged, requiring physicians to consider not only the clinical scenario but also the patient's emotional state, cultural

background, family perspectives and individual circumstances. Sharing personal preferences might be particularly fraught in cases where patients or families hold strong beliefs that differ from the physician's perspective and highlights the culturally and emotionally nuanced issues physicians must navigate while maintaining a focus on patient-centered care.

4.6 Physicians acknowledge the connection between their personal preferences and clinical practice and try to manage it

This dissertation has shown that a significant proportion of physicians (62%) report that they consider their personal end-of-life preferences when caring for patients and nearly one-third acknowledge that these preferences shape the recommendations they make to patients (Chapter 4). This signifies a crucial clinical impact and indicates that many physicians are aware of the interplay between their personal preferences and professional practice. Physicians recognize this link, and some interview participants even described it as inevitable, particularly in emotionally charged scenarios like end-of-life care. Given that physicians are often responsible for guiding patients through complex end-of-life decisions, understanding how their personal perspectives factor into these recommendations is crucial for ensuring that care remains patient-centered rather than physician-influenced. While one could argue that the majority of physicians (around 70%) do not perceive their personal preferences as influencing their recommendations, this does not negate the significance of the findings. Self-reported data may underrepresent the true impact due to social desirability bias—some physicians may not feel comfortable admitting that their personal views play a role in their clinical practice. Moreover, the fact that 62% of respondents frequently consider their own preferences suggests that the potential for influence is greater than the 30% who explicitly acknowledge it. Even subtle, unconscious biases in end-of-life care decision-making can have meaningful consequences for patients, potentially influencing care decisions in ways that extend beyond objective medical considerations. This is a novel finding as previous studies have suggested a connection exists based on the fact that physicians' personal recommendations have been shown to significantly influence how patients make medical decisions³⁵; however, we found

that most physicians in both the quantitative and qualitative studies acknowledge that there is a relationship between their own preferences and clinical practice. These findings address objective 2 and shed light on the connection between physicians' preferences and their practice.

Our findings show variability across regions and specialties including a lower frequency of personal preference consideration among palliative care physicians and those with extensive end-of-life care experience. This finding reinforces the notion that training and exposure may mitigate potential bias in clinical decision-making and aligns with literature that indicates increased levels of clinical experience and specialized training play a role in promoting self-awareness and patient-centered care.³⁶ It also speaks to the patient-centered philosophy inherent in palliative care and the reality that palliative care physicians typically prioritize comfort and quality of life over curative or life-prolonging treatments. Such treatments often involve greater uncertainty regarding success rates and require a different approach to prognostication. Regional differences in the survey showing a higher perception of consideration in some jurisdictions (e.g. 70.8% of Belgian physicians versus 52.9% in Queensland), and the reduced influence of preferences among palliative care physicians reinforces the role of cultural factors, such as emphasis on autonomy, and medical specialty in shaping practice. This variation may also relate to the level of awareness among reporting physicians or their willingness to acknowledge a connection between their personal preferences and clinical practice.

The finding that nearly one-third of physicians acknowledge the influence of their personal preferences on recommendations to patients raises additional considerations. Although a detrimental effect is uncertain, research has shown that trust in the physician-patient relationship relies on transparency and the assurance that care decisions align with patients' goals rather than physicians' values.³⁷ Patients may not always detect the subtle ways in which physicians' preferences influence recommendations, but the risk of eroding trust remains. The extent to which physicians' moral views *should* play a role in end-of-life decision-making should

also be explored, especially in ethically charged situations like withholding or withdrawing treatment or assisted dying. Research has shown that physicians' personal beliefs may impact the treatment options presented to patients or surrogate decision-makers, potentially limiting or excluding choices that do not align with the physician's values, which can undermine shared decision-making.³⁸ However, physicians' personal values can also provide depth and empathy to clinical care.²⁷ Therefore, it is essential to employ ethical frameworks, such as relational autonomy and shared decision-making in the context of end-of-life care, as studies show these emphasize the importance of a collaborative environment where patient values take precedence while allowing physicians to maintain their moral integrity.^{34,39}

We found that managing the intersection of personal beliefs and professional responsibilities is challenging for physicians. Participant interviews illustrate how physicians navigate this delicate balance through collaboration, self-awareness, and patient-centered practices (Chapter 5). We found that physicians employ deliberate strategies to ensure their personal beliefs do not overshadow their professional responsibility to respect patient autonomy. One such approach is collaboration with colleagues, which distributes decision-making responsibility among the medical team. By consulting diverse perspectives, physicians reduce the risk of bias and ensure that care remains focused on the patient's values and goals. However, this approach may add a layer of complexity as more views risks the infiltration of more personal values. That said, this collaborative process reflects broader issues in medical ethics, where transparency and collective deliberation can serve as safeguards against individual biases. As discussed in the literature and confirmed by our findings, teamwork in complex medical decision-making can foster patient-centered care while enabling physicians to navigate the professional and moral tensions of their roles.^{40,41}

Some physicians report using their personal preferences as a reflective starting point for guiding decisions, aligning with the principle of "treating others as I would want to be treated." While this moral framework can prove useful in difficult situations, it is typically balanced by redirecting the focus toward the patient's unique preferences and needs. This approach

demonstrates that physicians make an intentional effort to integrate self-awareness with professional objectivity. These findings raise questions about the ethical boundaries of personal reflection in clinical practice. Using one's own preferences as a guide is considered helpful and appropriate by some physicians and improper and contrasting with the provision of patient-centered care by others. Determining whether it is inherently right or wrong for physicians to incorporate their own preferences when caring for patients is challenging as there are strong arguments supporting both perspectives; however, it is crucial to consider whether physicians' personal reflections can enhance, rather than hinder, the delivery of patient-centered care. It is likely that the successful management of this relationship largely depends on the ability of the individual physician to prioritize their patients' values and preferences above all else.

While physicians' preferences may have an impact, additional non-patient issues might influence physicians' decision-making and should be considered. Factors like hospital bed shortages, institutional norms, economic pressures, or financial incentives can intentionally or unintentionally shape physicians' recommendations. These elements, although external to the patient's immediate care, reflect systemic challenges in balancing individual needs with broader healthcare resource allocation and potentially perverse incentive systems.

Examining the potential extremes of how physicians manage their personal perspectives in clinical practice is also an important consideration. If physicians were to entirely leave their values behind, the risk is a depersonalized approach to care that may overlook the richness of human connection and empathy, both critical in end-of-life decisions. For instance, choices about CPR, withdrawal of life support, or palliative sedation could become purely procedural, potentially alienating patients and families who value relational depth in decision-making. On the other hand, if physicians were to routinely integrate and openly disclose their personal values, there is a risk of undue influence or implicit coercion, especially in decisions like assisted dying, where the stakes are deeply emotional and moral. Such transparency could blur the boundary between professional guidance and personal advocacy, potentially undermining patient autonomy.

For a balanced approach, physicians could aim to acknowledge their values through self-awareness while ensuring their primary focus remains on the patient's preferences and well-being. If this aspect were incorporated into the Hippocratic Oath, it might be phrased as: "I will cultivate self-awareness of my values and biases, ensuring they do not unduly influence my clinical decisions, while respecting and prioritizing the values, preferences, and autonomy of my patients in all aspects of care." This formulation respects the dual responsibilities of ethical self-reflection and patient-centered care, crucial for navigating the complexities of end-of-life decisions.

Physicians' efforts to manage the connection between their personal preferences and clinical practice underscore their commitment to maintaining professionalism and prioritizing patient-centered care. The interplay between personal and professional domains highlights the need for ongoing dialogue about ethics, empathy, and the evolving role of physicians in patient-centered care. Recognizing and navigating this connection thoughtfully is key to providing care that honors both the humanity of the physician and the autonomy of the patient. Our findings indicate that physicians' recognition of their personal preferences also provides opportunities for growth, both as clinicians and as individuals. Physicians shared that by reflecting on their own desires and fears about end-of-life care, they can engage in more meaningful discussions with patients, fostering trust and deeper connections. They described them as transformative experiences, offering lessons in emotional resilience, ethical clarity, and communication, which highlights the bi-directional nature of patient care. Over time, physicians report that engaging in end-of-life discussions becomes increasingly comfortable, rewarding and beneficial, both personally and professionally.

5. Implications and recommendations

As a result of our study findings, a number of recommendations can be formulated to improve support systems for physicians and the management of end-of-life communication and care. In

this section, several implications and recommendations for policy, practice and future research are identified.

5.1. Implications and recommendations for policy, ethics and practice

The findings of this dissertation have revealed a number of ethical challenges and clinical practice issues, which have important implications for policy and practice.

First, to address the difficulty physicians described in balancing their personal and religious beliefs with clinical practice, medical education programs should enhance programs emphasizing self-awareness, cultural humility, and ethical reasoning. Physician training should also improve communication skills for managing difficult conversations, strategies for bias management, and structured reflection exercises to prepare them for navigating the complexities of end-of-life care. Our interview findings clearly demonstrated that improvement of specific trainings which integrate the principles of palliative care would be highly beneficial. Increased emphasis on normalizing discussions about death and dying in medical training could reduce stigma, enhance empathy, and equip physicians to engage patients with greater comfort, transparency and neutrality.

Second, healthcare systems should undertake a variety of policy-related measures to improve support for physicians and address the struggle physicians described to manage the connection between their personal preference and clinical practice. Institutional policies should be evaluated to prioritize clear and empathetic communication, reinforced by robust shared decision-making processes, to uphold patient autonomy and reduce potential biases. This can be accomplished through policies that promote interprofessional collaborative networks and the use of ethical consultations to support physicians in balancing their personal values and their professional practice. Research has shown that ethics consultations can be used effectively through individual consultants providing case-specific guidance, capacity-building consultants training staff in ethical decision-making frameworks, or facilitation teams

addressing complex ethical issues collaboratively.⁴² Ethicists and ethics committees also contribute to organizational policies, such as those governing end-of-life care or routine ethics reviews for prolonged intensive care cases. Practices like weekly ethics rounds in critical care settings can help to mitigate the moral distress physicians encounter.⁴² Ideally, a combination of these efforts would be utilized.

Additionally, healthcare systems can address clinical practice issues by promoting access to palliative care consultation and encouraging palliative care training to improve the capacity of physicians to provide patient-centered end-of-life care. To address the influence of cultural and religious beliefs on physician decision-making, healthcare systems should provide jurisdictionally tailored cultural competency training, particularly in jurisdictions where strong religious traditions may impact patient care. Healthcare systems are well positioned to foster a culture of collaboration, ethical dialogue and teamwork to mitigate potential biases and enhance physician support.

Third, healthcare institutions or physician societies must develop or enhance existing policies and resources that address the emotional and ethical challenges physicians described in managing the influence of their personal values on their clinical practice in the interview study. Research has shown that structured support systems, such as peer discussions, mentorship, and multidisciplinary team consultations, can help physicians build emotional resilience and manage the moral tensions inherent in end-of-life care.^{40,41} Institutions and organizations could provide safe spaces for physicians to reflect on their experiences and engage in discussions about the emotional and ethical dimensions of care. This approach not only supports physician well-being but also promotes equitable, high-quality care. Addressing the challenges identified in this dissertation will require a multifaceted strategy that integrates training, institutional support, and systemic policies to balance physicians' humanity with their professional responsibilities, promoting ethical patient-centered end-of-life care.

5.2. Recommendations for future research

Future research should further investigate the impact of legal, cultural, and ethical factors on physicians' end-of-life preferences, as variations across jurisdictions indicate that external influences such as social norms, cultural traditions, medical training, professional exposure and legislative environment, play a significant role. More extensive information gathered using a mixed-methods or qualitative study design would help clarify the underlying values driving physicians' preferences and impacting their approach to care. One possible research design could utilize vignette-based surveys, where physicians are presented with hypothetical end-of-life scenarios that vary in cultural, legal, and ethical contexts. The vignettes would involve end-of-life decisions including those related to life-prolonging treatment, pain management, palliative sedation and assisted dying. Physicians would select their preferred course of action and explain the factors influencing their decisions, with a focus on how legal frameworks, cultural norms, and medical training affect their responses. Another study design option would be to use moral case deliberation, where groups of physicians engage in structured discussions about real or hypothetical cases that raise ethical conflicts in the context of end-of-life care. Each case could present dilemmas that involve tensions between personal values and professional obligations, with an emphasis on how physicians navigate these conflicts in light of their cultural, legal, and ethical frameworks.

Additional forthcoming studies should explore how personal experiences, such as the death of a loved one, influence physicians' preferences and, in turn, impact their clinical recommendations over time. These studies could shed light on whether and how these profound experiences shape physicians' attitudes toward end-of-life decisions. A longitudinal study could be used to follow a cohort of physicians across multiple years, tracking changes in their attitudes toward decisions, such as withholding or withdrawing treatment, intensification of symptom medication, palliative sedation, and assisted dying, before and after experiencing personal loss. Data could be collected through periodic surveys and interviews, focusing on their moral and ethical perspectives, as well as their clinical decision-making in cases involving terminally ill patients. This approach would allow researchers to examine how personal grief or significant

life events shape professional behavior and whether these changes are sustained or temporary.

Given the significant involvement of family members in end-of-life decision-making, future research should investigate the additional complexities that arise when physicians share their personal perspectives on treatment options within the context of a relational autonomy framework. Investigating how physicians navigate the balance between honoring the patient's preferences, respecting family input, and maintaining professional boundaries could provide valuable insights on the complicated process of shared decision-making. Studies could examine diverse cultural and legislative contexts to gain deeper insights into how varying approaches to complex situations involving relational autonomy shape end-of-life decisions.

Future research should explore the divergence in physicians' attitudes toward allowing their personal end-of-life preference to impact their clinical practice. Since some physicians consider using their own preferences a helpful and appropriate guide and others feel it is improper and contrasting with the provision of patient-centered care, elucidating the basis for these beliefs would be informative. A qualitative research design using focus groups with physicians on both sides of the issue could provide a deeper, more nuanced understanding of their perspectives and ethical reasoning.

The incongruence between physicians' personal end-of-life preferences and what they consider appropriate for patients, particularly for practices like palliative sedation, physician-assisted suicide, and euthanasia also warrants further exploration. Future studies could use an experimental psychology research design to tactfully explore the ethical and psychological factors influencing physicians' preferences for themselves and patients. This research would help clarify how physicians balance their personal beliefs with professional responsibilities in complex end-of-life decision-making situations. Such a study might employ a mixed-methods design, combining a survey with hypothetical case scenarios, and in-depth interviews. Participants, including physicians from various specialties, could first complete a survey assessing their personal preferences for practices including palliative sedation, physician-

assisted suicide, and euthanasia, building on what was learned in this study. They could then evaluate case scenarios requiring treatment recommendations for patients with similar circumstances. Finally, interviews would explore the psychological and ethical reasoning behind the potential discrepancies, digging deeper into the roles of professional norms, personal beliefs, and emotional factors.

Finally, research is needed on the value and feasibility of strategies to support physicians in balancing their personal values with patient autonomy, particularly in the sensitive context of end-of-life care. Randomized controlled trials or simulation-based studies that assess the effectiveness of training programs in ethical decision-making, boundary management, and patient communication could provide practical insights for improving physician preparedness. By examining these areas, future research can contribute to a more nuanced understanding of the complex ethical landscape physicians navigate, ultimately enhancing the quality of end-of-life care for patients across diverse settings by reducing bias and improving end-of-life communication and decision-making.

6. Conclusion

This dissertation has contributed to a deeper understanding of physicians' personal end-of-life preferences and their perceived influence on clinical practice. Most physicians expressed a preference to intensify alleviation of symptoms and are determined to avoid aggressive and life-prolonging treatment at the end of life. Physicians have clear ideas about what would constitute a good death and value being in a peaceful environment, retaining the ability to communicate with loved ones and minimizing pain, suffering and dependency. Although physicians' preferences are highly aligned with the recommendations they make to patients regarding certain life-sustaining treatments, a notable proportion display incongruence - particularly for decisions about assisted dying - where their personal choices diverge from what they believe is best for their patients.

Physicians' end-of-life preferences are largely shaped by experiences, particularly the death of loved ones and clinical practice experiences. They are also influenced by social, cultural and legislative factors, and religious beliefs. Variation in attitudes exists across physician groups and countries, which suggests that physicians' views on end-of-life practices are variable, particularly in response to shifting cultural and societal norms, legislative environment, and changes in medical practice. Our findings underscore the complex interplay between physicians' beliefs and preferences, personal ethics, and patient autonomy, highlighting the nuanced decision-making process involved in end-of-life care.

This dissertation confirms the connection between physicians' personal preferences and their clinical practice. Findings indicate that many physicians consider their personal end-of-life preferences when caring for patients and believe their preferences impact the recommendations they make to patients. While there is significant divergence with some physicians striving to keep a strict separation and others using their personal preferences as a guide, most physicians stress the need for patient centered care and decision making. Physicians find value in engaging in end-of-life reflection and discussions and believe it can foster personal and professional growth.

Healthcare systems face mounting pressure from aging populations and rising levels of chronic disease and must adapt to effectively address the complexities of end-of-life care. This dissertation's findings illustrate that physicians' personal end-of-life preferences can influence clinical encounters and patient recommendations, introducing an element of subjectivity into already complex and emotionally charged medical situations. As demand for palliative and end-of-life services continues to grow, it is crucial for healthcare systems to support physicians in managing ethical dilemmas, balancing personal beliefs with patient autonomy, and ensuring patient-centered decision-making. Strengthening policies, training, and interdisciplinary collaboration will be essential to providing equitable and compassionate end-of-life care amid increasing strains on healthcare systems.

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Curriculum Vitae and list of publications of Sarah Mroz

Sarah Mroz holds a master's degree in Bioethics (2019, KU Leuven) and Public Health (2014, University of Wisconsin-Madison) and a bachelor's degree in Sociology (2007, University of Wisconsin-Madison). In November 2019 she joined the End-of-Life Care Research Group (Vrije Universiteit Brussel & Ghent University) as a doctoral researcher to study the end-of-life preferences of physicians and how their preferences are connected to clinical practice. Prior to working as a researcher at the End-of-Life Care Research Group she worked in cancer prevention for the Carbone Cancer Center at the University of Wisconsin.

List of publications and presentations

Publications - internationally peer reviewed journals

Mroz S, Dierickx S, Chambaere K, Mortier F, De Panfilis L, Downar J, Lapenskie J, Anderson K, Skold A, Campbell C, Campbell T, Feeney R, Willmott L, White B, Deliens L. Physicians' preferences for their own end-of-life: A comparison across North America, Europe, and Australia (*Manuscript in revision with the Journal of Medical Ethics*)

Mroz S, Daenen F, Dierickx S, Mortier F, De Panfilis L, Ghirotto L, Campbell T, Deliens L, Chambaere K. What do physicians want at the end? An international qualitative study on physicians' own end-of-life preferences and what influences them (*Manuscript in revision with Palliative Care and Social Practice*)

Mroz S, Daenen F, Dierickx S, Mortier F, De Panfilis L, Ghirotto L, Campbell T, Deliens L, Chambaere K. How do physicians perceive and manage the influence of their personal end-of-life preferences on clinical practice and end-of-life decision making with patients? PROPEL international qualitative study (*Submitted*)

Mroz S, Daenen F, Dierickx S, Chambaere K, Mortier F, De Panfilis L, Downar J, Lapenskie J, Anderson K, Skold A, Campbell C, Campbell T, Feeney R, Willmott L, White B, Deliens L. Associations between physicians' personal preferences for end-of-life decisions and their own clinical practice: PROPEL survey study in Europe, North America and Australia. *Palliat Med.* 2025;39(2):266-276.

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Mroz S, Zhang X, Williams M, Conlon A, LoConte NK. Working to Increase Vaccination for Human Papillomavirus: A Survey of Wisconsin Stakeholders, 2015. *Preventing Chronic Disease* 2017;14:160610

Presentations at international and national conferences

Physicians' personal preferences for MAID and other end-of-life decisions, and how those preferences impact clinical practice: A mixed methods study in North America, Europe, and Australia, ICEL4: International Conference on End-of-life, Oral presentation, March 2024

Physician Reported End-of-life Decision Preferences (PROPEL): a multinational mixed methods study, XXIX Congresso Nazionale SICP 2022, Oral presentation, November 2022

Addressing Breast Cancer Mortality Disparities, CDC National Cancer Conference 2017, Oral presentation, August 2017

Wisconsin's HPV Environmental Scan, CDC National Cancer Conference 2017, Poster presentation, August 2017

Wisconsin's HPV Environmental Scan, National Cancer Institute Conference, 'Increasing HPV Vaccination in the United States: A Collaboration of NCI-Funded Cancer Centers', Oral presentation, November 2015

Assessing Provider Beliefs and Practices about Breast Cancer Screening to Improve Early Detection Rates in Wisconsin, CDC Cancer Conference, Oral presentation, August 2012

Enhancing collaboration to increase HPV vaccination in Wisconsin, American Public Health Association 143rd Annual Meeting & Expo, Oral presentation, October 2015

PROPEL International Physician End-of-life Preferences Survey - Wisconsin

Start of Block: Default Question Block

JS

Q1 Please note that this survey is part of an international study so some terminology may be different from what you are accustomed to seeing. [Click here](#) to view the consent form then proceed to the survey.

Thank you for your participation!

Page Break

Q1

Specialty and Work Setting

Are you currently working as a practicing physician?

Yes (1)

No (2)

Skip To: End of Survey If Specialty and Work Setting Are you currently working as a practicing physician? = No

Q2 In which of the following clinical specialties do you work? (more than one answer possible)

- Cardiology (1)
- Emergency medicine (2)
- Gastroenterology (3)
- Family medicine/general practice/primary care (4)
- Geriatrics (5)
- Gynecology (6)
- Internal medicine (7)
- Intensive care (8)
- Nephrology (9)
- Neurology (10)
- Nursing home medicine (11)
- Oncology (12)
- Palliative care (13)
- Pulmonology (14)
- Other (15) _____

Page Break

Q3 For how many years have you been practicing in your primary specialty (post-training)?

- < 5 years (1)
 - 5 - 10 years (2)
 - 11 - 20 years (3)
 - > 20 years (4)
-

Q4 In what kind of care setting are you primarily working at this moment? (more than one answer possible)

- General practice/community practice (1)
 - Hospital/ambulatory/outpatient clinic (2)
 - Nursing home/aged care facility (3)
 - Other (4) _____
-

Q5 Have you had any specific formal or accredited training in palliative care?

- Yes (1)
 - No (2)
-

Display This Question:

If Have you had any specific formal or accredited training in palliative care? = Yes

Q6 Please estimate the level of palliative care training you've received (Combined total including medical training, continued professional education and bedside supervision)

- < 1 day (1)
 - 1 - 3 days (2)
 - 4 - 10 days (3)
 - 11 - 20 days (4)
 - > 20 days (5)
-

Q7 Please estimate how many terminally ill or end-of-life patients you cared for during the year 2019 (pre-COVID)

- < 5 (1)
 - 5 - 10 (2)
 - 11 - 20 (3)
 - 21 - 30 (4)
 - > 30 (5)
-

Page Break

Q8 Now we would like you to consider your personal views and your own health and healthcare as you answer the following questions.

Advance Care Planning

To what extent have you spent time reflecting on the care you might prefer to receive at the end of your own life, related to end-of-life decisions like, cardiopulmonary resuscitation, artificial ventilation, artificial nutrition and hydration, palliative sedation, medical assistance in dying?

- A lot (1)
 - A moderate amount (2)
 - A little (3)
 - None (4)
-

Q9 Have you ever consulted with a physician (or had an informal discussion with a physician colleague), about the kind of medical care you would want for yourself if you were so ill or incapacitated that you could not make such decisions?

- Yes, I have discussed these matters with at least one of my physicians/colleagues (1)
 - No, but I intend to do so (2)
 - No, but I have recently considered doing so (3)
 - No, and I am unlikely to do so anytime soon (within the next year) (4)
-

Display This Question:

If Have you ever consulted with a physician (or had an informal discussion with a physician colleagu... = Yes, I have discussed these matters with at least one of my physicians/colleagues

Q10 When was the first time you discussed these matters with a physician/s?

- In the past year (1)
 - 1 - 5 years ago (2)
 - More than 5 years ago (3)
-

Display This Question:

If Have you ever consulted with a physician (or had an informal discussion with a physician colleagu... = Yes, I have discussed these matters with at least one of my physicians/colleagues

Q11 Who initiated the first discussion/s?

- Me (1)
 - A physician/physician colleague (2)
 - Other, please specify relationship to you (3)
-

Display This Question:

If Have you ever consulted with a physician (or had an informal discussion with a physician colleagu... = Yes, I have discussed these matters with at least one of my physicians/colleagues

Q12 What prompted the discussion? (more than one answer possible)

- Having a past serious illness/hospitalization (1)
 - Routine examination (2)
 - Death or serious illness of a family member, friend, or patient (3)
 - Nothing specific (4)
 - Something else, please specify (5)
-

Q13 To what extent has the loss of patients or loved ones influenced your own preferences for end-of-life decisions like, cardiopulmonary resuscitation, artificial ventilation, artificial nutrition and hydration, palliative sedation, medical assistance in dying?

- A lot (1)
 - A moderate amount (2)
 - A little (3)
 - Not at all (4)
-

Q14 Have you discussed your preferences for the kind of medical care you would want if you were so ill or incapacitated that you could not make such decisions for yourself with the significant people in your life (spouse, child, partner, etc)?

- Yes, I have discussed these matters with at least one of the significant people in my life (1)
 - No, but I intend to do so (2)
 - No, but I have recently considered doing so (3)
 - No, and I am unlikely to do so anytime soon (within the next year) (4)
 - No, but I believe they are aware of my preferences (5)
-

Page Break

Q15 Have you established a 'do not resuscitation order' (DNR)* for yourself? *(A DNR is a document which instructs the medical team not to attempt cardiopulmonary resuscitation (CPR) if your breathing stops or if your heart stops beating.

- Yes (1)
 - No, but I am considering establishing one (2)
 - No, I haven't given it much thought (3)
 - No, I have decided not to establish one (4)
-

Q16 Have you established any formal document related to your end-of-life care preferences for yourself?

- Yes (1)
 - No, but I am considering establishing one (2)
 - No, I haven't given it much thought (3)
 - No, I have decided not to establish one (4)
-

Page Break

Display This Question:

If Have you established any formal document related to your end-of-life care preferences for yourself? =
Yes

Q17 Please indicate the type of document**

An **advance directive is a written statement that tells your doctor what form of medical care you would accept or refuse in specific medical circumstances. A **living will** is a particular kind of advance directive that allows life-sustaining therapy to be withdrawn in case one is terminally ill and cannot make healthcare decisions for oneself. A **power of attorney for health care** (or health care proxy) gives someone you designate the legal authority to make decisions if you are unable to do so for yourself. **Physician Orders for Life Sustaining Treatment (POLST)** is a physician's order that outlines a plan of care at the end of life. It is only available in some Wisconsin counties.

- Advance directive (1)
- Living will (2)
- Power of attorney for health care (3)
- POLST (Physician Orders for Life Sustaining Treatment) (4)
- Unsure of the document name (5)
- Other (6) _____

Page Break

Q18 End-of-life Practice and Decisions

Now we would like you to consider **your clinical practice**. In the following questions, which include some hypothetical end-of-life patient scenarios, we are interested in understanding your perspective about certain procedures that are sometimes used to prolong or shorten life in serious illness. Please indicate the answers that most closely reflect your attitude or opinion.

	Always (1)	Usually (2)	Sometimes (3)	Rarely (4)	Never (5)
I feel comfortable discussing end-of-life options with my patients (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I routinely initiate discussions about end-of-life options with my severely ill patients (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I share my personal perspective with patients when asked what I would do in their situation (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Page Break

Q19 PLEASE READ THIS SCENARIO THEN ANSWER THE FOLLOWING QUESTIONS

Scenario: You have a 65 year old patient diagnosed with cancer and extensive lung and bone metastases. According to the treating oncologist, no further treatments are available. This patient has an estimated life expectancy of no more than 2 weeks and they are experiencing ongoing severe pain and agitation but are fully competent. A palliative care provider is involved and palliative care services (e.g. home care, inpatient hospice) are available for this patient.

Which of the following would you consider possible options for this particular case (if there is an indication for it)? Please select one answer for each question.

	Not at all a good option (1)	Not such a good option (2)	A good option (3)	A very good option (4)
the use of cardiopulmonary resuscitation (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
the use of mechanical ventilation (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
the use of intravenous hydration (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
the use of feeding tube (gastrostomy, jejunostomy, or intravenous) to provide nutrition (4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
to intensify the alleviation of symptoms by using medications, taking into account the possibility that this could hasten the end of life (5)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q20 Continued...which of the following would you consider possible options for this particular case (if there is an indication for it)? Please select one answer for each question.

	Not at all a good option (1)	Not such a good option (2)	A good option (3)	A very good option (4)
to use high doses of medications, such as benzodiazepines or barbiturates, to keep the patient in deep sedation until death (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
to prescribe/provide medications for the patient to end their own life at their request, if it is currently legal or were to become a legal option in your jurisdiction (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
to administer a substance to end the patient's life at their request, if it is currently legal or were to become a legal option in your jurisdiction (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Page Break

Q21 PLEASE READ THIS SCENARIO THEN ANSWER THE FOLLOWING QUESTIONS

Scenario: You have an 80 year old patient diagnosed with Alzheimer’s dementia. It is a typical case with gradual cognitive decline and the patient no longer recognizes family or friends. They now refuse to eat and drink and have become more and more withdrawn. It is no longer possible to communicate with them about medical treatments. A palliative care provider is involved and palliative care services (e.g. home care, inpatient hospice) are available for this patient.

Which of the following would you consider possible options for this particular case (if there is an indication for it)? Please select one answer for each question.

	Not at all a good option (1)	Not such a good option (2)	A good option (3)	A very good option (4)
the use of cardiopulmonary resuscitation (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
the use of mechanical ventilation (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
the use of intravenous hydration (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
the use of a feeding tube (gastrostomy, jejunostomy, or intravenous) to provide nutrition (4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q22 Continued...which of the following would you consider possible options for this particular case (if there is an indication for it)?
Please select one answer for each question.

	Not at all a good option (1)	Not such a good option (2)	A good option (3)	A very good option (4)
to intensify the alleviation of symptoms by using medications, taking into account the possibility that this could hasten the end of life (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
to use high doses of medications, such as benzodiazepines or barbiturates, to keep the patient in deep sedation until death (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
to administer a substance to end the patient's life at their request, if it is currently legal within the context of an advance directive , or were to become a legal option in your jurisdiction (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

JS

Q23 Personal end-of-life preferences

The following scenarios are hypothetical about your own end of life. We are interested in assessing your willingness to undergo certain procedures that are sometimes used to prolong or shorten life in serious illness. Please indicate the answers that most closely reflect your attitude or opinion.

Page Break

Q23 PLEASE READ THIS SCENARIO THEN ANSWER THE FOLLOWING QUESTIONS

Scenario: You have been diagnosed with cancer with extensive lung and bone metastases and your treating oncologist has said no further treatments are available. You have an estimated life expectancy of no more than 2 weeks and are fully competent. You are experiencing ongoing severe pain and agitation. A palliative care provider is involved and palliative care services (e.g. home care, inpatient hospice) are available for you.

Right now, which of the following would you consider possible options for yourself (if there were an indication for it)? Please select one answer for each question.

	Not at all a good option (1)	Not such a good option (2)	A good option (3)	A very good option (4)
the use of cardiopulmonary resuscitation (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
the use of mechanical ventilation (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
the use of intravenous hydration (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
the use of a feeding tube (gastrostomy, jejunostomy, or intravenous) to provide nutrition (4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
to intensify the alleviation of symptoms by using medications, taking into account the possibility that this could hasten your death (5)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q24 Continued...Right now, which of the following would you consider possible options for yourself (if there were an indication for it)? Please select one answer for each question.

	Not at all a good option (1)	Not such a good option (2)	A good option (3)	A very good option (4)
<p>to use high doses of medications, such as benzodiazepines or barbiturates, to be kept in deep sedation until death (1)</p>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<p>to request medications from your health care practitioner that would allow you to end your own life, if it is currently legal or were to become a legal option in your jurisdiction (2)</p>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<p>to use medications which are at your disposal as a physician to end your own life (3)</p>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<p>to request assistance from a medical practitioner who could administer a substance to end your life, if it is currently legal, or were to become a legal option in your jurisdiction (4)</p>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q25 PLEASE READ THIS SCENARIO THEN ANSWER THE FOLLOWING QUESTIONS

Scenario: You are suffering from Alzheimer’s dementia in gradual cognitive decline and you no longer recognize your family or friends. You refuse to eat and drink and have become more and more withdrawn. It is no longer possible to communicate with you about medical treatment options. A palliative care provider is involved and palliative care services (e.g. home care, inpatient hospice) are available for you.

Right now, which of the following would you consider possible options for yourself (if there were an indication for it)? Please select one answer for each question.

	Not at all a good option (1)	Not such a good option (2)	A good option (3)	A very good option (4)
the use of cardiopulmonary resuscitation (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
the use of mechanical ventilation (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
the use of intravenous hydration (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
the use of a feeding tube (gastrostomy, jejunostomy, or intravenous) to provide nutrition (4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q26 Continued...Right now, which of the following would you consider possible options for yourself (if there were an indication for it)? Please select one answer for each question.

	Not at all a good option (1)	Not such a good option (2)	A good option (3)	A very good option (4)
to intensify the alleviation of symptoms by using medications, taking into account the probability or certainty that this could hasten the end of life (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
the use of high doses of medications, such as benzodiazepines or barbiturates, to be kept in deep sedation until death (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
to request assistance from a medical practitioner who could administer a substance to end your life, if it is currently legal within the context of an advance directive or were to become a legal option in your jurisdiction (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q27 In any serious illness, there may come a point where the illness related suffering can become distressing and burdensome, even with the best available treatment. If you had a serious illness, please describe the specific point (tipping point) when you would **start theoretically considering consciousness altering palliative sedation**. (more than one answer possible)

- When I have extremely poor quality of life (1)
 - When I require machines/life support to keep me alive (2)
 - When I become severely confused/lose cognitive functioning (3)
 - When I have unbearable physical suffering (4)
 - When I have unbearable psychological suffering (5)
 - When I become a burden to my family (6)
 - When I am not expected to live more than a few days (7)
 - I don't believe I will ever reach a tipping point (8)
 - I don't know (9)
 - Other (10) _____
-

Q28 In any serious illness, there may come a point where the illness related suffering can become distressing and burdensome, even with the best available treatment. If you had a serious illness, please describe the specific point (tipping point) when you would **start**

theoretically considering life shortening procedures (voluntary assisted dying). (more than one answer possible)

- When I have extremely poor quality of life (1)
- When I become permanently unconscious (2)
- When I require machines/life support to keep me alive (3)
- When I become severely confused/lose cognitive functioning (4)
- When I have unbearable physical suffering (5)
- When I have unbearable psychological suffering (6)
- When I become a burden to my family (7)
- When I am not expected to live more than a few days (8)
- I don't believe I will ever reach a tipping point (9)
- I don't know (10)
- Other (11) _____

Page Break

Q29 Please indicate to what extent you agree or disagree with the following statements

	Strongly disagree (1)	Disagree (2)	Neither agree nor disagree (3)	Agree (4)	Strongly agree (5)
My personal end-of-life preferences are influenced by my spiritual views/religious beliefs (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My personal end-of-life preferences have been influenced by my cultural norms/heritage (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My personal end-of-life preferences have been influenced by my clinical experiences (4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q30 Please indicate to what extent you agree or disagree with the following statements

	Strongly disagree (1)	Disagree (2)	Neither agree nor disagree (3)	Agree (4)	Strongly agree (5)
My personal preferences about assisted dying are influenced by my spiritual views/religious beliefs (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My personal preferences about assisted dying have been influenced by my cultural norms/heritage (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My personal preferences about assisted dying have been influenced by my clinical experiences (4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q31 Please indicate to what extent you agree or disagree with the following statements

	Strongly disagree (1)	Disagree (2)	Neither agree nor disagree (3)	Agree (4)	Strongly agree (5)
I frequently consider what I would want for myself when caring for patients who are at the end of life (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My personal end-of-life preferences impact the recommendations I make to patients (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel it is appropriate to consider my personal end-of-life preferences when caring for patients (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Page Break

Q32 Demographic characteristics

Are you?

- Male (1)
 - Female (2)
 - Other (3) _____
 - Prefer not to say (4)
-

Q33 What is your age?

- < 30 years (1)
 - 30 - 39 (2)
 - 40 - 49 (3)
 - 50 - 59 (4)
 - > 60 years (5)
-

Page Break _____

Q34 What ethnicity do you most identify as? *This is an international survey so we have included broad categories for comparability. They may not be what you are accustomed to but please choose the most appropriate response.*

- Arab/Middle Eastern (1)
 - Asian (2)
 - Black/African (3)
 - Latino or Hispanic (4)
 - European (5)
 - Native/Indigenous/aboriginal people (6)
 - White/European (7)
 - Prefer not to say (8)
 - Other (9) _____
-

Q35 How would you identify your world view/religion? *This is an international survey so we have included broad categories for comparability. They may not be what you are accustomed to but please choose the most appropriate response.*

- Buddhist (1)
- Christian (Anglican, Catholic, Orthodox, Protestant...) (2)
- Hindu (3)
- Jewish (4)
- Muslim (5)
- Non-religious (Agnostic/Atheist/Humanist/Spiritual) (6)
- Prefer not to say (7)
- Other (8) _____

Page Break

Q36 I consider myself as having strongly held religious/spiritual beliefs (as described in the previous question)

- Strongly agree (1)
 - Agree (2)
 - Neither agree nor disagree (3)
 - Disagree (4)
 - Strongly disagree (5)
-

Q37 I would describe my level of adherence to my religion as

- Very strict (1)
 - Somewhat strict (2)
 - Somewhat liberal (3)
 - Very liberal (4)
 - Not religious (5)
-

Page Break

Q38 Political parties can be classified by their current social values. Those with LIBERAL values favor expanded personal freedoms, (eg: abortion rights, same-sex marriage, and democratic participation). Those with CONSERVATIVE values favor order, tradition and stability, believing that government should be a firm moral authority on social and cultural issues. How would you describe your own social-political views?

- Very socially liberal (1)
 - Somewhat socially liberal (2)
 - Neutral (3)
 - Somewhat socially conservative (4)
 - Very socially conservative (5)
-

Q39 Please provide here any comments on answers to the previous questions you wish to clarify or expand

Q40 If you would consider doing a qualitative interview as part of this study please contact Lead Researcher, Sarah Mroz, at Sarah.Christine.Mroz@vub.be

End of Block: Default Question Block

Appendix B: PROPEL interview guide

Physicians' Own End-of-life Decision Preferences Study Semi-structured Interview Guide

- Introductions
- Review informed consent form
- Complete demographic questionnaire
- Brief study summary
- Ask about further questions
- Ask for permission to record the interview

Introduction:

The aim of this study is to **explore physicians' personal preferences for end-of-life decisions**, (eg. withholding and withdrawing of treatment, intensification of medication for symptom management, palliative sedation and euthanasia), **examine to what extent these preferences impact clinical decisions** when confronted with patients near the end of life, and **assess the influence of micro and macro level factors**, (eg. personal, cultural, political, legislative, institutional, social and religious influence).

I understand you may or may not have given much thought to these issues and some of these topics are difficult to discuss. I appreciate you agreeing to speak with me about this topic. Do you have any questions before we begin?

Physicians' personal preferences for end-of-life decisions

1. What kind of medicine do you practice?
2. What might a 'good death' look like for yourself?
3. *Which scenarios of dying do you hope to avoid?*
4. To what extent have you spent time reflecting on the care you would want or not want to receive at the end-of-life?
 - *If no, why not?*
 - *Can also ask what scenario they are imagining (locked in syndrome, ALS, end-stage dementia) and what specific circumstances are important to them, (severe suffering, no treatment options, improvement unlikely)*

5. What are your preferences regarding concrete end-of-life decisions/and why?
- *Prompt if needed: CPR, artificial ventilation, artificial nutrition and hydration, hospice care, palliative sedation, physician assisted suicide, suicide, euthanasia?*
 - *Have you discussed preferences with your doctor or partner or someone else?*
 - *Have you formulated your preferences in a specific way (ACP, AD)?*

Influence of micro and macro level factors on physicians' personal preferences

6. What do you believe has influenced your end-of-life preferences?
- *personal worldview or religion, family values and attitudes, cultural norms and/or societal influences, law?*
 - *Personal/professional experiences?*
 - *How/to what extent has living in a jurisdiction which **allows** euthanasia and assisted dying influenced your attitude and personal preferences?*
 - *Has it changed over time?*

Impact of personal preferences on clinical practice

7. What is the relationship between your personal end-of-life preferences and your clinical practice?
- *Can you illustrate an example from your clinical practice?*
 - *If no, how do you believe you keep your personal preferences from influencing your practice?*
 - *Is it difficult for you? Do you consciously feel a need to check yourself when practicing?*
 - *How has your personal reflection (or lack of) changed how you discuss ELDs with patients*

To conclude

8. Is there anything else you would like to share that I have not asked about your EOL care preferences?

Appendix C. PROPEL Jurisdiction selection rationale

In North America, Oregon is among the most socially progressive states.¹ It has had the longest standing physician-assisted suicide law (since 1997) and is also among the least religious US states.² Wisconsin is largely rural with isolated pockets that are urban and progressive.¹ Death with Dignity legislation has been introduced there numerous times over the past 20 years but remains illegal.³ Physicians from Georgia offer perspectives from a southern state without assisted dying legislation, which ranks among the most religious US states by the Pew Research Center (79% Christian) and where end-of-life care discussions and decisions are influenced by widely held conservative views.² Canadian physicians will provide further comparison in a setting which has a national healthcare system (unlike the USA) and allows both physician-assisted suicide and euthanasia (since 2016).

In Europe, physicians in Belgium offer perspectives from a more socially liberal European environment⁴ where assisted dying has been legal since 2002 and attitudes about end-of-life care and assisted dying have evolved over time through intense debate and exposure to euthanasia. Italy offers a contrasting viewpoint as one of the most religious countries in Europe where assisted dying remains illegal. Although a Constitutional court ruling in 2019 allows physician-assisted suicide, patients must meet extremely narrow criteria and it is not generally accessible, though there is ongoing social and legal debate.^{2,5,6}

Australia is a secular country with a high level of religious freedom and diversity.⁷ The Australian state of Victoria implemented assisted dying legislation in June 2019 and offers perspectives from physicians experiencing recent implementation of the Act.⁸ In Queensland, assisted dying legislation was passed in 2021, but had not commenced at the time of data collection for this study.⁹

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Appendix D: Assisted dying status of the PROPEL study jurisdictions

Assisted dying status of the PROPEL study jurisdictions			
Jurisdiction	Year of legislation	Title of legislation	Legalization status
North America			
Canada	2016	Medical Assistance in Dying Law	Euthanasia and Physician-Assisted Suicide (PAS) ^a
Oregon, USA	1997	Death with Dignity Act	PAS
Wisconsin, USA	No existing legislation ^b	None	None
Georgia, USA	No existing legislation	None	None
Europe			
Belgium	2002	Law on Euthanasia	Euthanasia ^c
Italy	No existing legislation ^d	None	<i>Court judgement on PAS^c</i>
Australia			
Victoria	2017 (commenced 2019)	Voluntary Assisted Dying Act	Euthanasia and PAS (Euthanasia only permitted if PAS not possible)
Queensland	2021 (commenced 2023)	Voluntary Assisted Dying Act	Euthanasia and PAS ^e
<p>^a While PAS is legal in Canada, euthanasia is usually requested/administered, and PAS is rarely practiced</p> <p>^b Laws have been introduced in Wisconsin numerous times but never passed</p> <p>^c Belgian law stays silent on the issue of PAS and the status is still unclear after significant legal debate</p> <p>^d Italian Constitutional court ruling in 2019 allows PAS (It has been performed but it is not generally accessible or supported by physicians, and patients must meet very narrow requirements).</p> <p>^e The Queensland law also has a default for Euthanasia ahead of PAS, but because patient choice is a relevant consideration, in practice, euthanasia is widely available to patients who want it. Legislation had passed but was not in effect at the time of the survey.</p>			

Appendix E: Researcher reflexivity statement

As the lead researcher conducting this study, I (Sarah Mroz) recognize that my personal, professional, and cultural background may shape my approach to both data collection and analysis. My prior experiences with healthcare and end-of-life care, particularly as a caregiver for my mother during her cancer treatment, along with my cultural and social beliefs about death, dying, and medical decision-making, have the potential to influence how I interpret the participants' reflections. Specifically, my experience with physicians who appeared uncomfortable or reluctant to discuss end-of-life issues during my mother's illness trajectory reinforced my belief that end-of-life communication should be better incorporated within clinical care. I try to approach qualitative research with an open mind and listen compassionately to anything participants wish to share. I am deeply grateful for the opportunity to do this work and I respect the trust others place in me when they share their personal feelings and stories.

Additionally, I acknowledge that my assumptions about how professional, legislative, and religious influences intersect with personal preferences may affect the themes I emphasize during analysis. I am aware of the need to continuously reflect on how my positionality might impact the research process and I aim to remain open to the diverse ways physicians may consider their end-of-life preferences and to the possibility that their beliefs and influences may diverge from my own. To mitigate the influence of my preconceptions, I will maintain an iterative process of reflection and seek feedback from colleagues to challenge and broaden my interpretations. I will also collaborate closely with my supervisors during the coding phase to moderate the influence of my individual perspective. I aim to ensure that the themes that are developed are grounded in the physicians' voices and experiences rather than my assumptions.