Canadian Resources to Support Patients Making Decisions about Medical Assistance in Dying (MAID)

Alda Greta Kiss

Thesis submitted to the University of Ottawa
in partial Fulfillment of the requirements for the
Masters of Science degree in Nursing.

School of Nursing
Faculty of Health Sciences
University of Ottawa

Preface

Contributions of Collaborators

Elements	Chapter One	Chapter Two	Chapter Three
Protocol/conceptualization, design and review	N/A	DS	DS, KL, LW
Assisted with search strategy	N/A	MCD	MCD
Quality appraisal of studies by second reviewer	N/A	N/A	LPB
Third reviewer consensus	N/A	N/A	DS
Revisions of manuscript	N/A	N/A	DS, KL, LW
Approval of final version	DS, KL, LW	DS, KL, LW	DS, KL, LW

DS: Dr. Dawn Stacey – Professor University of Ottawa

KL: Dr. Krystina B. Lewis – Professor University of Ottawa

LW: Laura Wilding – Advanced Practice Nurse The Ottawa Hospital

MCD: Marie-Cecile Dominique – Health Sciences Research Liaison Librarian

LPB: Lissa Pacheco-Brosseau – PhD Student University of Ottawa

Thesis Abstract

Introduction

Medical Assistance in Dying (MAID) was legalized in Canada in 2016. In 2021, an update in legislation included changes to MAID eligibility and procedural safeguards.

Purpose

Guided by the Ottawa Decision Support Framework (ODSF), the overall aim was to describe how Canadian patients considering MAID are being supported in making the decision about end-of-life care.

Literature Review

Eleven articles were included in the literature review. ODSF themes are evident in MAID literature. Nurses play key roles in end-of-life decision-making.

Environmental Scan

Environmental scan of publicly available MAID resources identified 58 eligible resources. Sixty-nine percent of MAID resources were updated with 2021 legislation. None met the International Patient Decision Aid Standards criteria. Thirty met Patient Education Materials Assessment standard for adequate understandability and 11 for actionability.

Conclusions

Although patient decision aids are effective for supporting health care decisions, none exist for MAID and current resources are inadequate for supporting people of lower health literacy.

Acknowledgements

I would like to give the sincerest of thanks to my supervisor, Dr. Dawn Stacey. Thank you for believing in me as an academic and as a nurse from the very beginning. I cannot be more thankful that you have pushed me to my full capacity time and time again. I am especially appreciative for your guidance and critique of my research throughout this process. Your dedication and enthusiasm for your work is truly inspiring. To my committee members, Dr. Krystina Lewis and Ms. Laura Wilding, thank you for your expertise and guidance throughout. You have encouraged me to think open-mindedly about the research process, for that I am eternally grateful.

I would like to acknowledge Lissa Pacheco-Brosseau and Meg Carley. Thank you for your support and guidance during my thesis. I have learned valuable lessons on the research process that I will keep with me forever.

Thank you to the Thesis is Progress (TIPs) group that met virtually every Thursday. Although I was not able to join every week, you made me feel welcome and appreciated. The sharing of our personal anecdotes was always enjoyable and inspiring. I am so thankful to have met all of you and wish you the best of luck in your future endeavours.

Finally, my deepest gratitude to my family. Anya, thank you for your unconditional love and support during my Master's. Anna, thank you for always listening to me when I had a difficult day. Joe, thank you for your unwavering support and encouragement throughout these past few years, I can't thank you enough. Thank you all for the love you have given me. I am forever grateful.

Table of Contents

List of Tables

List of Figures

List of Abbreviations

APN	Advanced Practice Nurse
CO	Conscientious Objection
EOL	End-of-life
HCP	Health Care Provider
IPDAS	International Patient Decision Aid Standards
IQR	Interquartile Range
MAID	Medical Assistance in Dying
N/A	Not Applicable
NP	Nurse Practitioner
ODSF	Ottawa Decision Support Framework
OPDG	Ottawa Personal Decision Guide
PAS	Physician-Assisted Suicide
PEMAT	Patient Education Material Assessment Tool
PtDA	Patient Decision Aid
SDM	Shared Decision Making
VE	Voluntary Euthanasia

Chapter One

Introduction

Introduction

Introduction to Medical Assistance in Dying

In June 2016, Canada joined the growing list of countries that have legalized voluntary euthanasia (VE) and physician-assisted suicide (PAS). VE is the practice in which a physician administers medications that intentionally end a person's life at their explicit request to relieve suffering; while PAS is the practice in which a person receives a prescription for life-ending medications that are self-administered (Elmore et al., 2018). Under the Canadian *Criminal Code* (i.e., Bill C-14), VE and PAS are collectively referred to as medical assistance in dying (MAID) (Government of Canada, 2021b; Suva et al., 2019). MAID involves the administration of medications to both safely and intentionally end the life of an eligible adult who has specifically requested MAID (Government of Canada, 2021a; Ontario Ministry of Health and Longterm Care, 2021). Health Canada outlines two forms of MAID that are currently available. Health care providers (HCPs) such as a physician or nurse practitioner (NP) may: (a) directly administer a substance that causes death, or (b) prescribe a drug that the eligible person takes themselves to cause their own death (Government of Canada, 2021b).

Eligibility for MAID expanded when Bill C-7, passed in 2021, *An Act to amend the Criminal Code (medical assistance in dying)* (Department of Justice, 2021) included individuals whose natural death is not reasonably foreseeable (Government of Canada, 2021a; Pesut et al., 2021). Since then, current eligibility criteria include: (a) being 18 years of age or older and able to make health care decisions for oneself; (b) being eligible for publicly funded health coverage in Canada; (c) having a grievous and irremediable health condition; (d) making a voluntary request for MAID; and (e) giving informed consent to receive MAID (Government of Canada, 2021b). The updated MAID legislation introduces a two-track system whereby safeguards are lessened for individuals whose natural death is reasonably foreseeable, while additional

safeguards are added for those whose death is not reasonably foreseeable. Those whose death is not reasonably foreseeable must wait 90 days between the request and the provision of MAID (Mills et al., 2020; Health Canada, 2021). These new safeguards are designed to help HCPs carry out MAID in a way that protects patients from abuse or misuse of the service (Government of Canada, 2021b).

Since its enactment in 2016, MAID has become an increasingly well-known end-of-life (EOL) option to many Canadians (Health Canada, 2021). In fact, there have been 21,589 cases of MAID reported in Canada from the enactment of legislation to the end of 2020 (Health Canada, 2021). Furthermore, the annual growth of MAID cases has been steadily increasing with MAID deaths as a proportion of overall deaths accounting for 2.5% of deaths in Canada in 2020. There is wide variability of overall MAID deaths across Canadian jurisdictions, ranging from 0.9% in Newfoundland and Labrador to 4.0% in British Columbia in 2020 (Health Canada, 2021). This may be because of the greater acceptance of MAID in British Columbia (Health Canada, 2021). An increasing number of Canadians see MAID as an ideal of patient-centered care and a concrete means to alleviate intolerable suffering (Pesut et al., 2020). Although many patients who are suffering from a grievous and irremediable health condition request an assisted death, not everyone receives MAID (Health Canada, 2021; Wiebe et al., 2018). In 2020, 9,375 written requests for MAID were reported and 7,595 (78.8%) had resulted in MAID (Health Canada, 2021). Of the requests in 2020 that did not result in MAID, reasons for which MAID did not occur include patients: (a) dying prior to receiving MAID (12.7% of requests), (b) were found to be ineligible (6.0%); and (c) withdrew their request (2.5% of requests). The total number of MAID deaths includes formal reports completed by HCPs and received by Health Canada (7,384

cases) and additional MAID deaths that were provided by provinces and territories for cases where a formal report was not yet received by Health Canada (211 cases).

The following data is an analysis of the 7,384 formal reports of MAID that were provided to Health Canada in 2020. This does not include the 211 cases that were not received by Health Canada (Health Canada, 2021). There are some variations in the underlying medical conditions of individuals who receive MAID (Table 1.1) and they are consistent with the leading causes of death in Canada (Statistics Canada, 2020).

Table 1.1 MAID by Main Condition, 2020

Condition	**Percentage* (n)**
Cancer	69.1 (5087)
Lung	24.2
Colon	12.2
Pancreas	8.0
Hematologic	7.5
Breast	6.9
Prostate	6.6
Ovary	4.2
Esophagus	3.9
Other	30.5
Cardiovascular conditions	13.8 (1015)
Congestive Heart Failure	42.2
Respiratory conditions	11.3 (826)
Neurological conditions	10.2 (743)
Amyotrophic Lateral Sclerosis	35.2
Parkinson's Disease	18.1
Multiple Sclerosis	9.7
Progressive Supranuclear Palsy	4.4
Other	33.6
Other conditions	8.7 (622)
Multiple comorbidities	7.8 (562)
Other organ failure	6.6 (472)
Renal Failure	41.7
Cirrhosis	13.8
Bowel Obstruction	9.3

*Providers were able to choose more than one medical condition when reporting their cases therefore, the total exceeds 100%.

The decision to request and receive MAID may not be so straightforward given the finality of the choice in the presence of other options requiring personal trade-offs between benefits and potential harms across options. Other reasonable EOL options include palliative care, counselling services, mental health, and disability support services (Government of Canada, 2021b). Ideally, patients making these difficult EOL decisions should be achieving good quality decisions. A quality decision is defined as being informed with the best available evidence and selecting an option that is consistent with patients informed values for outcomes of options (Stacey et al., 2020).

Patient preferences for EOL options

Patients are known to have different preferences for EOL decisions. Decisions about EOL are personal and often complex (Ward et al., 2021). Factors influencing EOL decisions may include: (a) the desire to alleviate suffering; (b) wanting to have a "good death"; (c) an individual's previous experience with death and dying; and (c) the individual's values and/or the perceived values of their loved ones. Factors that lead patients to pursue MAID, include avoiding loss of dignity, a feeling that they cannot engage in what makes life worth living, loss of an ability to perform activities of daily living, worry about being a burden on others, and a feeling of hopelessness (Health Canada, 2021; Wiebe et al., 2018). For some, having MAID as an option provides a much needed sense of autonomy and independence near the end of their lives and allows their family to be part of their loved one's EOL choices (Variath et al., 2020). However, it is unclear the extent to which patients are supported to make quality decisions when they submit a written request and provide verbal consent to have MAID. To be eligible for MAID in Canada, an individual must give informed consent for MAID. An individual may choose to revoke their consent at any time in the MAID process (Government of Canada, 2021b). In the context of MAID, the individual who made the request must be informed that they have a grievous and

irremediable condition and be informed of other available options before consenting (Government of Canada, 2021a).

Patient decision aids (PtDAs) were created to guide patients to make a quality decision when faced with multiple healthcare options (Stacey & Volk, 2021). PtDAs describe the health condition or problem, make explicit the decision, provide information on options, benefits, and harms, and help patients clarify which benefits and harms matter most to them. Evidence shows that compared to usual care, patients who use a PtDA are more knowledgeable, have more realistic expectations, feel less decisional conflict, and are more likely to make a decision that matches their values (Stacey et al., 2020). In a regularly updated inventory of over 300 PtDAs, nine are focused on EOL decisions including advanced care planning and use of mechanical ventilation (Patient Decision Aids Research Group, 2022). None discuss the option of MAID.

In summary, the decision to receive MAID is very personal and difficult decision given the need to weigh benefits and potential harms across all options, including palliative care. Little is known about the availability and quality of resources targeting people who are considering MAID and whether the resources are intended to support them in making a quality decision.

Conceptual Framework

A review of 15 frameworks relevant to patient involvement in decision-making depicts the Ottawa Decision Support Framework (ODSF) (Figure 1.1) as the only conceptual framework that considers the decisional needs for all health and social decisions (Stacey et al., 2010). The ODSF is a shared decision making (SDM) model that is specific for use with decisions created by new circumstances which require careful deliberation, including EOL decision-making (Stacey et al., 2010). SDM is defined as a collaborative approach between patients and their HCPs that is based on the patients' values and the best possible evidence, with the goal of reaching a quality decision (Elwyn et al., 2017).

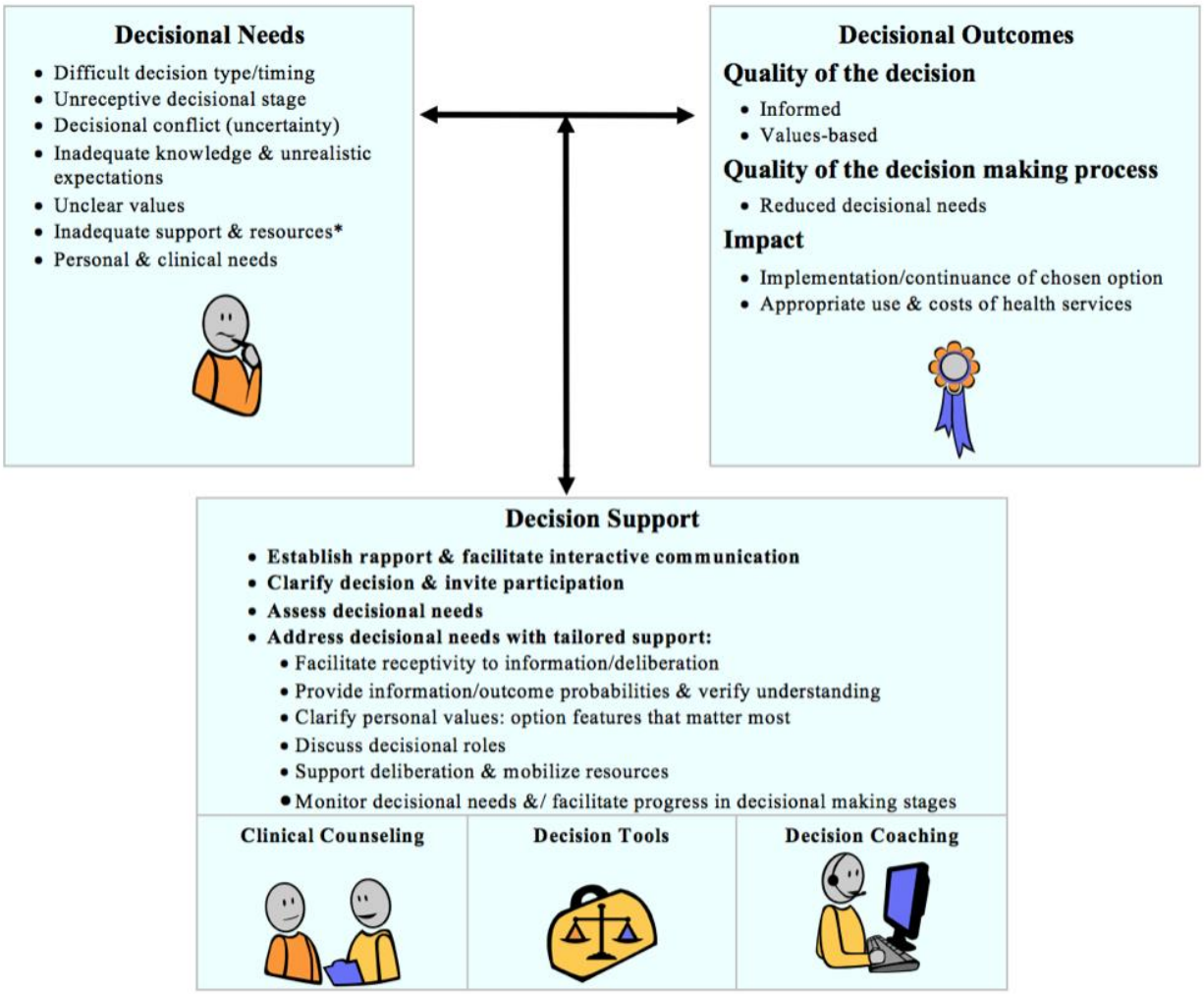


Figure 1.1 Ottawa Decision Support Framework (ODSF) model (revised 2020). Based on Stacey et al. (2020). *Ottawa decision support framework*, Ottawa Hospital Research Institute. Retrieved from https://decisionaid.ohri.ca/odsf.html

The ODSF was originally published by an interprofessional team in 1998 and has been one of the most commonly used frameworks to guide HCPs and patients in making complex health and social decisions over the last 20 years (O'Connor et al., 1998; Stacey et al., 2020). The conceptual framework guides users to support decision-making through assessing patients' decisional needs, providing decision support interventions (clinical counselling, decision tools, and decision coaching), and evaluating the quality and the outcomes of their decision and their decision-making process (O'Connor et al., 1998; Stacey et al., 2020). It is based on theories from

decisional analysis (Keeney & Raiffa, 1976), general psychology (Tversky & Kahneman, 1981), social psychology (Ajzen & Fishbein, 1980), self-efficacy (Bandura, 1982), and social support (Orem, 1995). According to the ODSF, people decide about options based on their knowledge of the options, personal judgement of outcomes that are likely and important, beliefs regarding the opinions of important others, personal uncertainty about the best course of action, and support and resources to make the decisions (Stacey et al., 2020). The framework hypothesizes that when these determinants are unmet, patients achieve suboptimal decisions. The main hypothesis underlying this framework is interventions that address patient's suboptimal decisional needs improve the quality of decision-making by addressing the patient's suboptimal decisional needs (O'Connor et al., 1998). Quality decisions are informed with the best available evidence and are consistent with the patient's values (Stacey et al., 2020). The ODSF proposes that various decision support interventions can be used to address these decisional needs and lead to improved decisional outcomes such as decision quality. Decisions are more difficult when the timing of deliberation is urgent (e.g., minutes, hours) or delayed (e.g., months) (Hoefel et al., 2020b). Clinical counselling, decision tools, and decision coaching are all strategies that may lead to improved decisional outcomes. A detailed description of the ODSF definitions is in Appendix A.

Positioning myself within the Thesis

The idea for this thesis originates from my personal clinical experience. When I started nursing, I worked on an inpatient oncology unit. I had the opportunity to care for many people throughout their cancer journey including those at the most vulnerable stages of their lives, at the end of their life. The following narrative was a defining moment in my career, it helped me realize that MAID is a valuable option for those suffering from a grievous and irremediable health condition.

In 2019, five months into my nursing career, I worked as a nurse on a busy inpatient oncology unit. One shift, I was caring for a lovely patient named Mary (pseudonym). Mary was admitted with advanced cancer and had been on our unit for approximately three weeks. One night, she was crying about her cancer diagnosis and I tried to comfort her as best as I could; although, I wish I could have spent more time with her. Mary became more dependent upon the nurses and other HCPs for her basic needs and would apologize for 'being a bother.' When her level of care was changed to comfort care, she made a formal written request for MAID and received MAID a few days later.

I reflected on her decision often during the next couple of weeks. I heard her words of 'being a bother' and wondered if I had made her feel that way. This was the first patient that I had cared for who requested MAID, and I wondered if I had missed the cues of her wanting to discuss MAID when I comforted her. Although many patients on the unit received palliative care, few had received MAID. As most nurses on the unit had less than two years of nursing experience, we did not have regular experiences with MAID. We were often surprised when a patient requested information about the MAID process and were afraid to provide them with false information. In turn, we advocated for the patient and physician to have a conversation about the patients' goals of care.

It was through providing care to Mary that I began to see MAID as a compassionate option to end the suffering of those diagnosed with grievous and irremediable health conditions. I also recognized that MAID provided family members and friends an opportunity to grieve and to be part of their loved ones EOL decisions. After this experience, I wanted to be more sensitive to others at EOL who may be considering their options including MAID. I wondered how I could better support them with this EOL decision.

Research Aims & Objectives

The overall purpose of this thesis was to investigate how Canadian patients who are considering MAID are being supported in making this EOL decision. The content and structure of this manuscript-based thesis is found in Table 1.2. In Chapter Two, I provide a comprehensive review of the literature on MAID in the context of decision-making using the ODSF and assess the current state of the literature on how nurses support patients who are considering MAID. This chapter also identifies knowledge gaps that my thesis seeks to address. Chapter Three, the article for this article-based thesis is titled, "Appraising resources to support patients considering decisions about Medical Assistance in Dying in Canada: An online environmental scan". The aim of this study was to identify and quality appraise Canadian MAID patient-targeted resources to support patients facing this decision. Specific objectives were to determine if available resources for patients and families: (a) were up-to-date with the 2021 legislative changes; (b) presented information to support quality decisions; and (c) written in plain language to ensure patients and families could understand the information and take action. In Chapter Four, I provide an integrated discussion of the findings of the thesis within the broader literature and discuss implications for nursing practice, education, leadership, collaboration, consultation, and research.

Table 1.2 Manuscript-based Thesis Structure and Content

Chapter	Chapter Title	Objective	Study Design	Manuscript
1	Introduction	Describe the rationale, research problem, and structure for this manuscript-based thesis.	-	-
2	Literature Review	Assess the current state of literature in the context of decision-making. Introduce the theoretical framework.	-	-
3	Appraising resources to support patients	Identify and quality appraise Canadian MAID	Environmental scan	Manuscript formatted for submission to the

	considering decisions about Medical Assistance in Dying in Canada: An online environmental scan	patient-targeted resources to support patients facing this decision.		*Canadian Medical Association Journal Open.*
4	Integrated Discussion	To integrate the thesis findings and identify implications for nursing practice, education, leadership, consultation, collaboration, and research.	-	-

References

Adams, J. A., Bailey, D. E., Anderson, R. A., & Docherty, S. L. (2011). Nursing Roles and Strategies in End-of-Life Decision Making in Acute Care: A Systematic Review of the Literature. *Nursing Research and Practice*, *2011*, 1–15. https://doi.org/10.1155/2011/527834

Ajzen, I., & Fishbein, M. (1980). *Understanding attitudes and predicting social behaviour*. Prentice Hall.

Bandura, A. (1982). Self-efficacy mechanism in human agency. *American Psychologist*, *37*(2), 122–147. https://doi.org/10.1037/0003-066X.37.2.122

Banner, D., Schiller, C. J., & Freeman, S. (2019). Medical assistance in dying: A political issue for nurses and nursing in Canada. *Nursing Philosophy*, *20*(4). https://doi.org/10.1111/nup.12281

Beuthin, R., Bruce, A., & Scaia, M. (2018). Medical assistance in dying (MAiD): Canadian nurses' experiences. *Nursing Forum*, *53*(4), 511–520. https://doi.org/10.1111/nuf.12280

Brooks, L. (2019). Health Care Provider Experiences of and Perspectives on Medical Assistance in Dying: A Scoping Review of Qualitative Studies. *Canadian Journal on Aging / La Revue Canadienne Du Vieillissement*, *38*(03), 384–396. https://doi.org/10.1017/S0714980818000600

Bruce, A., & Beuthin, R. (2019). Medically Assisted Dying in Canada: "Beautiful Death" Is Transforming Nurses' Experiences of Suffering. *Canadian Journal of Nursing Research*, 084456211985623. https://doi.org/10.1177/0844562119856234

Canadian Nurses Association. (2019). *Advanced Practice Nursing: A Pan-Canadian Framework.*

Charlton, P., Doucet, S., Azar, R., Nagel, D. A., Boulos, L., Luke, A., Mears, K., Kelly, K. J., & Montelpare, W. J. (2019). The use of the environmental scan in health services delivery

research: a scoping review protocol. *BMJ Open*, *9*(9), e029805. https://doi.org/10.1136/bmjopen-2019-029805

College of Nurses of Ontario. (2021). *Guidance on Nurses' Roles in Medical Assistance in Dying*.

Coulter, A., Entwistle, V., & Gilbert, D. (1999). Sharing decisions with patients: is the information good enough? *BMJ*, *318*(7179), 318–322. https://doi.org/10.1136/bmj.318.7179.318

Department of Justice. (2021). *Medical Assistance in Dying*. https://www.justice.gc.ca/eng/cj-jp/ad-am/index.html

Durand, M. A., Carpenter, L., Dolan, H., Bravo, P., Mann, M., Bunn, F., & Elwyn, G. (2014). Do interventions designed to support shared decision- making reduce health inequalities? A systematic review and meta-analysis. *PLoS ONE*, *9*(4). https://doi.org/10.1371/journal.pone.0094670

El-Jawahri, A., Podgurski, L. M., Eichler, A. F., Plotkin, S. R., Temel, J. S., Mitchell, S. L., Chang, Y., Barry, M. J., & Volandes, A. E. (2010). Use of Video to Facilitate End-of-Life Discussions With Patients With Cancer: A Randomized Controlled Trial. *Journal of Clinical Oncology*, *28*(2), 305–310. https://doi.org/10.1200/JCO.2009.24.7502

Elmore, J., Wright, D. K., & Paradis, M. (2018). Nurses' moral experiences of assisted death: A meta-synthesis of qualitative research. *Nursing Ethics*, *25*(8), 955–972. https://doi.org/10.1177/0969733016679468

Elwyn, G., Durand, M. A., Song, J., Aarts, J., Barr, P. J., Berger, Z., Cochran, N., Frosch, D., Galasiński, D., Gulbrandsen, P., Han, P. K. J., Härter, M., Kinnersley, P., Lloyd, A., Mishra, M., Perestelo-Perez, L., Scholl, I., Tomori, K., Trevena, L., … Van der Weijden, T.

(2017). A three-talk model for shared decision making: multistage consultation process. *BMJ*, j4891. https://doi.org/10.1136/bmj.j4891

Fajardo, M. A., Balthazaar, G., Zalums, A., Trevena, L., & Bonner, C. (2019). Favourable understandability, but poor actionability: An evaluation of online type 2 diabetes risk calculators. *Patient Education and Counseling*, *102*(3), 467–473. https://doi.org/10.1016/j.pec.2018.10.014

Feenstra, B., Lawson, M. L., Harrison, D., Boland, L., & Stacey, D. (2015). Decision coaching using the Ottawa family decision guide with parents and their children: a field testing study. *BMC Medical Informatics and Decision Making*, *15*(1), 5. https://doi.org/10.1186/s12911-014-0126-2

Fujioka, J. K., Mirza, R. M., McDonald, P. L., & Klinger, C. A. (2018). Implementation of Medical Assistance in Dying: A Scoping Review of Health Care Providers' Perspectives. *Journal of Pain and Symptom Management*, *55*(6), 1564-1576.e9. https://doi.org/10.1016/j.jpainsymman.2018.02.011

Government of Canada. (2017). *Annual Report on the Operation of the Canadian Multiculturalism Act 2015-2016*.

Government of Canada. (2021a). *Canada's new medical assistance in dying (MAiD) law*. https://www.justice.gc.ca/eng/cj-jp/ad-am/bk-di.html

Government of Canada. (2021b). *Medical assistance in dying - Canada. ca*. https://www.canada.ca/en/health-canada/services/medical-assistance-dying.html

Graham, P., Evitts, T., & Thomas-MacLean, R. (2008). Environmental scans: how useful are they for primary care research? *Canadian Family Physician Medecin de Famille Canadien*, *54*(7), 1022–1023. http://www.ncbi.nlm.nih.gov/pubmed/18625830

Hatch, T. F., & Pearson, T. G. (1998). Using environmental scans in educational needs assessment. *Journal of Continuing Education in the Health Professions*, *18*(3), 179–184. https://doi.org/10.1002/chp.1340180308

Health Canada. (2021). *Second Annual Report on Medical Assistance in Dying in Canada, 2020*.

Ho, A., Joolaee, S., Jameson, K., & Ng, C. (2021). The Seismic Shift in End-of-Life Care: Palliative Care Challenges in the Era of Medical Assistance in Dying. *Journal of Palliative Medicine*, *24*(2), 189–194. https://doi.org/10.1089/jpm.2020.0185

Ho, A., Norman, J. S., Joolaee, S., Serota, K., Twells, L., & William, L. (2021). How does Medical Assistance in Dying affect end-of-life care planning discussions? Experiences of Canadian multidisciplinary palliative care providers. *Palliative Care and Social Practice*, *15*, 263235242110459. https://doi.org/10.1177/26323524211045996

Hoefel, L., Lewis, K. B., O'Connor, A., & Stacey, D. (2020). 20th Anniversary Update of the Ottawa Decision Support Framework: Part 2 Subanalysis of a Systematic Review of Patient Decision Aids. *Medical Decision Making*, *40*(4), 522–539. https://doi.org/10.1177/0272989X20924645

Hoefel, L., O'Connor, A. M., Lewis, K. B., Boland, L., Sikora, L., Hu, J., & Stacey, D. (2020). 20th Anniversary Update of the Ottawa Decision Support Framework Part 1: A Systematic Review of the Decisional Needs of People Making Health or Social Decisions. *Medical Decision Making*, *40*(5), 555–581. https://doi.org/10.1177/0272989X20936209

Jolicoeur, L. J. A., O'Connor, A. M., Hopkins, L., & Graham, I. D. (2009). Women's decision-making needs related to treatment for recurrent ovarian cancer: A pilot study. *Canadian Oncology Nursing Journal*, *19*(3), 117–121. https://doi.org/10.5737/1181912x193117121

Joseph-Williams, N., Elwyn, G., & Edwards, A. (2014). Knowledge is not power for patients: A

systematic review and thematic synthesis of patient-reported barriers and facilitators to shared decision making. *Patient Education and Counseling*, *94*(3), 291–309. https://doi.org/10.1016/j.pec.2013.10.031

Joseph-Williams, N., Newcombe, R., Politi, M., Durand, M. A., Sivell, S., Stacey, D., O'Connor, A., Volk, R. J., Edwards, A., Bennett, C., Pignone, M., Thomson, R., & Elwyn, G. (2014). Toward minimum standards for certifying patient decision aids: A modified delphi consensus process. *Medical Decision Making*, *34*(6), 699–710. https://doi.org/10.1177/0272989X13501721

Jull, J., Köpke, S., Boland, L., Coulter, A., Dunn, S., Graham, I. D., Hutton, B., Kasper, J., Kienlin, S. M., Légaré, F., Lewis, K. B., Lyddiatt, A., Osaka, W., Rader, T., Rahn, A. C., Rutherford, C., Smith, M., & Stacey, D. (2019). Decision coaching for people making healthcare decisions. *Cochrane Database of Systematic Reviews*. https://doi.org/10.1002/14651858.CD013385

Keeney, R. L., & Raiffa, H. (1976). *Decisions with Multiple Objectives: Preferences and Value Tradeoffs*. John Wiley and Sons.

Lamb, A., Martin-Misener, R., Bryant-Lukosius, D., & Latimer, M. (2018). Describing the leadership capabilities of advanced practice nurses using a qualitative descriptive study. *Nursing Open*, *5*(3), 400–413. https://doi.org/10.1002/nop2.150

Lawson, M. L., Shephard, A. L., Feenstra, B., Boland, L., Sourial, N., & Stacey, D. (2020). Decision coaching using a patient decision aid for youth and parents considering insulin delivery methods for type 1 diabetes: a pre/post study. *BMC Pediatrics*, *20*(1), 1. https://doi.org/10.1186/s12887-019-1898-4

Lipari, M., Berlie, H., Saleh, Y., Hang, P., & Moser, L. (2019). Understandability, actionability,

and readability of online patient education materials about diabetes mellitus. *American Journal of Health-System Pharmacy*, *76*(3), 182–186. https://doi.org/10.1093/ajhp/zxy021

Maddah-Ali, M. A., & Niesen, U. (2014). Fundamental Limits of Caching. *IEEE Transactions on Information Theory*, *60*(5), 2856–2867. https://doi.org/10.1109/TIT.2014.2306938

Martin, R. W., Brogård Andersen, S., O'Brien, M. A., Bravo, P., Hoffmann, T., Olling, K., Shepherd, H. L., Dankl, K., Stacey, D., & Dahl Steffensen, K. (2021). Providing Balanced Information about Options in Patient Decision Aids: An Update from the International Patient Decision Aid Standards. *Medical Decision Making*, *41*(7), 780–800. https://doi.org/10.1177/0272989X211021397

Maurer, M., Siegel, J. E., Firminger, K. B., Lowers, J., Dutta, T., & Chang, J. S. (2021). Lessons Learned from Developing Plain Language Summaries of Research Studies. *HLRP: Health Literacy Research and Practice*, *5*(2). https://doi.org/10.3928/24748307-20210524-01

Mills, A., Wortzman, R., Bean, S., & Selby, D. (2020). Allied Health Care Providers Participating in Medical Assistance in Dying. *Journal of Hospice & Palliative Nursing*, *22*(3), 220–228. https://doi.org/10.1097/NJH.0000000000000646

Murray, M.-A. (2010). *When you need extra care, should you receive it at home or in a facility? A decision aid to prepare you to discuss the options*.

Murray, M. A., Stacey, D., Wilson, K., & O'Connor, A. (2010). Skills training to support patients considering place of end-of-life care: a randomized control trial. *Journal of Palliative Care*, *26*(2), 112–121.

Muscat, D. M., Smith, J., Mac, O., Cadet, T., Giguere, A., Housten, A. J., Langford, A. T., Smith, S. K., Durand, M.-A., & McCaffery, K. (2021). Addressing Health Literacy in Patient Decision Aids: An Update from the International Patient Decision Aid Standards.

Medical Decision Making, *41*(7), 848–869. https://doi.org/10.1177/0272989X211011101

Nuhn, A., Holmes, S., Kelly, M., Just, A., Shaw, J., & Wiebe, E. (2018). Experiences and perspectives of people who pursued medical assistance in dying: Qualitative study in Vancouver, BC. *Canadian Family Physician Medecin de Famille Canadien*, *64*(9), e380–e386. http://www.ncbi.nlm.nih.gov/pubmed/30209111

O'Connor, A. M., Drake, E. R., Wells, G. A., Tugwell, P., Laupacis, A., & Elmslie, T. (2003). A survey of the decision-making needs of Canadians faced with complex health decisions. *Health Expectations*, *6*(2), 97–109. https://doi.org/10.1046/j.1369-6513.2003.00215.x

O'Connor, A. M., Tugwell, P., Wells, G. A., Elmslie, T., Jolly, E., Hollingworth, G., McPherson, R., Bunn, H., Graham, I., & Drake, E. (1998). A decision aid for women considering hormone therapy after menopause: decision support framework and evaluation. *Patient Education and Counseling*, *33*(3), 267–279. https://doi.org/10.1016/S0738-3991(98)00026-3

O'Connor, A., Stacey, D., & Boland, L. (2015). *Introduction to the Ottawa Decision Support Tutorial*.

Ontario Ministry of Health and Longterm Care. (2021). *Medical Assistance in Dying - Health Care Professionals - MOH*. https://www.health.gov.on.ca/en/pro/programs/maid/#maid

Orem, D. . (1995). *Nursing: Concepts of practice* (5th ed.). Mosby.

Page, M. J., McKenzie, J. E., Bossuyt, P. M., Boutron, I., Hoffmann, T. C., Mulrow, C. D., Shamseer, L., Tetzlaff, J. M., Akl, E. A., Brennan, S. E., Chou, R., Glanville, J., Grimshaw, J. M., Hróbjartsson, A., Lalu, M. M., Li, T., Loder, E. W., Mayo-Wilson, E., McDonald, S., … Moher, D. (2021). The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. *BMJ (Clinical Research Ed.)*, *372*, n71. https://doi.org/10.1136/bmj.n71

Patient Decision Aids Research Group. (2022). *A to Z Inventory - Patient Decision Aids - Ottawa Hospital Research Institute*. https://decisionaid.ohri.ca/AZinvent.php

Pellisé, F., & Sell, P. (2009). Patient information and education with modern media: the Spine Society of Europe Patient Line. *European Spine Journal*, *18*(S3), 395–401. https://doi.org/10.1007/s00586-009-0973-1

Pesut, B., Thorne, S., Schiller, C., Greig, M., Roussel, J., & Tishelman, C. (2020). Constructing Good Nursing Practice for Medical Assistance in Dying in Canada: An Interpretive Descriptive Study. *Global Qualitative Nursing Research*, *7*. https://doi.org/10.1177/2333393620938686

Pesut, B., Thorne, S., Wright, D. K., Schiller, C., Huggins, M., Puurveen, G., & Chambaere, K. (2021). Navigating medical assistance in dying from Bill C-14 to Bill C-7: a qualitative study. *BMC Health Services Research*, *21*(1), 1–16. https://doi.org/10.1186/s12913-021-07222-5

Rahn, A. C., Jull, J., Boland, L., Finderup, J., Loiselle, M.-C., Smith, M., Köpke, S., & Stacey, D. (2021). Guidance and/or Decision Coaching with Patient Decision Aids: Scoping Reviews to Inform the International Patient Decision Aid Standards (IPDAS). *Medical Decision Making*, *41*(7), 938–953. https://doi.org/10.1177/0272989X21997330

Shoemaker, S. J., Wolf, M. S., & Brach, C. (2014). Development of the Patient Education Materials Assessment Tool (PEMAT): A new measure of understandability and actionability for print and audiovisual patient information. *Patient Education and Counseling*, *96*(3), 395–403. https://doi.org/10.1016/j.pec.2014.05.027

Stacey, D., Légaré, F., Boland, L., Lewis, K. B., Loiselle, M.-C., Hoefel, L., Garvelink, M., & O'Connor, A. (2020). 20th Anniversary Ottawa Decision Support Framework: Part 3

Overview of Systematic Reviews and Updated Framework. *Medical Decision Making*, *40*(3), 379–398. https://doi.org/10.1177/0272989X20911870

Stacey, D., Légaré, F., Lewis, K., Barry, M. J., Bennett, C. L., Eden, K. B., Holmes-Rovner, M., Llewellyn-Thomas, H., Lyddiatt, A., Thomson, R., & Trevena, L. (2017). Decision aids for people facing health treatment or screening decisions. *Cochrane Database of Systematic Reviews*. https://doi.org/10.1002/14651858.CD001431.pub5

Stacey, D., Légaré, F., Pouliot, S., Kryworuchko, J., & Dunn, S. (2010). Shared decision making models to inform an interprofessional perspective on decision making: A theory analysis. *Patient Education and Counseling*, *80*(2), 164–172. https://doi.org/10.1016/j.pec.2009.10.015

Stacey, D., Ludwig, C., Archambault, P., Smith, M., Carley, M., Plourde, K., Boland, L., Gogovor, A., Graham, I. D., Kobewka, D., McLean, R., Nelson, M., Taljaard, M., Vanderspank, B., & Legare, F. (2022). *Decisions and decision making needs of Canadians during the COVID-19 pandemic: A national survey*.

Stacey, D., Suwalska, V., Boland, L., Lewis, K. B., Presseau, J., & Thomson, R. (2019). Are Patient Decision Aids Used in Clinical Practice after Rigorous Evaluation? A Survey of Trial Authors. *Medical Decision Making*, *39*(7), 805–815. https://doi.org/10.1177/0272989X19868193

Stacey, D., & Volk, R. J. (2021). The International Patient Decision Aid Standards (IPDAS) Collaboration: Evidence Update 2.0. *Medical Decision Making*, *41*(7), 729–733. https://doi.org/10.1177/0272989X211035681

Statistics Canada. (2020). *Deaths, 2019*.

Statistics Canada. (2022). *Increasing diversity of languages, other than English or French,*

spoken at home.

Stein, R. A., Sharpe, L., Bell, M. L., Boyle, F. M., Dunn, S. M., & Clarke, S. J. (2013). Randomized Controlled Trial of a Structured Intervention to Facilitate End-of-Life Decision Making in Patients With Advanced Cancer. *Journal of Clinical Oncology*, *31*(27), 3403–3410. https://doi.org/10.1200/JCO.2011.40.8872

Suva, G., Penney, T., & McPherson, C. J. (2019). Medical Assistance in Dying: A Scoping Review to Inform Nurses' Practice. *Journal of Hospice and Palliative Nursing*, *21*(1), 46–53. https://doi.org/10.1097/NJH.0000000000000486

Thiele, T., & Dunsford, J. (2019). Nurse leaders' role in medical assistance in dying: A relational ethics approach. *Nursing Ethics*, *26*(4), 993–999. https://doi.org/10.1177/0969733017730684

Tversky, A., & Kahneman, D. (1981). *The framing of decisions and the psychology of choice*. Science.

Variath, C., Peter, E., Cranley, L., Godkin, D., & Just, D. (2020). Relational influences on experiences with assisted dying: A scoping review. *Nursing Ethics*, *27*(7), 1501–1516. https://doi.org/10.1177/0969733020921493

Vishnevetsky, J., Walters, C. B., & Tan, K. S. (2018). Interrater reliability of the Patient Education Materials Assessment Tool (PEMAT). *Patient Education and Counseling*, *101*(3), 490–496. https://doi.org/10.1016/j.pec.2017.09.003

Ward, V., Freeman, S., Callander, T., & Xiong, B. (2021). Professional experiences of formal healthcare providers in the provision of medical assistance in dying (MAiD): A scoping review. *Palliative and Supportive Care*, *19*(6), 744–758. https://doi.org/10.1017/S1478951521000146

Wiebe, E., Shaw, J., Green, S., Trouton, K., & Kelly, M. (2018). Reasons for requesting medical assistance in dying. *Canadian Family Physician Medecin de Famille Canadien*, *64*(9), 674–679. http://www.ncbi.nlm.nih.gov/pubmed/30209101

Wu, J. S. Y., Pinilla, J., Watson, M., Verma, S., & Olivotto, I. A. (2018). Medical Assistance in Dying for Cancer Patients One Year After Legalization: A Collaborative Approach at a Comprehensive Cancer Centre. *Current Oncology*, *25*(5), 486–489. https://doi.org/10.3747/co.25.4118

Yen, R. W., Smith, J., Engel, J., Muscat, D. M., Smith, S. K., Mancini, J., Perestelo-Pérez, L., Elwyn, G., O'Malley, A. J., Leyenaar, J. K., Mac, O., Cadet, T., Giguere, A., Housten, A. J., Langford, A., McCaffery, K., & Durand, M.-A. (2021). A Systematic Review and Meta-Analysis of Patient Decision Aids for Socially Disadvantaged Populations: Update from the International Patient Decision Aid Standards (IDPAS). *Medical Decision Making*, *41*(7), 870–896. https://doi.org/10.1177/0272989X211020317

Yiu, A., Ng, K. K., Lee, V. W., & Bajorek, B. V. (2020). Evaluating the Understandability and Actionability of Web-Based Education Materials for Patients Taking Non–vitamin K Oral Anticoagulants. *Therapeutic Innovation & Regulatory Science*, *54*(2), 476–483. https://doi.org/10.1007/s43441-019-00079-1

Yun, Y. H., Lee, M. K., Park, S., Lee, J. L., Park, J., Choi, Y. S., Lim, Y. K., Kim, S. Y., Jeong, H. S., Kang, J. H., Oh, H.-S., Park, J. C., Kim, S.-Y., Song, H. S., Ro, J., Lee, K. S., Heo, D. S., & Hong, Y. S. (2011). Use of a Decision Aid to Help Caregivers Discuss Terminal Disease Status With a Family Member With Cancer: A Randomized Controlled Trial. *Journal of Clinical Oncology*, *29*(36), 4811–4819. https://doi.org/10.1200/JCO.2011.35.3870

Chapter Two

Literature Review

Literature Review

The purpose of this literature review is to assess the current state of the literature on how nurses can support patients who are considering medical assistance in dying (MAID). The Ottawa Decision Support Framework (ODSF) (O'Connor et al., 1998; Stacey et al., 2020) was used to organize the synthesis of the evidence.

Literature Review Process

Collaborating with a research librarian (MCD), we created the search strategy. I searched four electronic databases (Cumulative Index to Nursing and Allied Health Research [CINAHL], MEDLINE, Embase, and Scopus) in July 2021 using the search terms: (a) "medical assistance in dying" AND conflict and (b) "medical assistance in dying" AND decision making or decision-making or decision-making process or decision-making process AND nurse or nurses or nursing. The search strategy included all research study designs (e.g., scoping reviews, primary studies, quantitative, and qualitative). Personal statements, including editorials, commentaries, or blogs, were excluded. Studies on conscientious objection (CO) and questioning the legality of MAID were excluded. I excluded citations pertaining to other end-of-life (EOL) practices, such as palliative sedation. See Table 2.1 for the characteristics of included studies

Table 2.1 Characteristics of included studies

Authors (year)	Study design	Purpose	Participants	Findings	Limitations
Beuthin et al. (2018)	Qualitative semi-structured interviews	Understand the range of nurses' experience in providing care for someone choosing MAID.	17 nurses	- Concepts such as profession of nursing, personal impact, and practice of nursing.	- Unable to generalize findings. - Participants are from one geographical area.
Brooks (2019)	Scoping review	Summarize existing qualitative literature focused on provider experiences in the MAID process.	21 articles	- Supporting patients through MAID is a complex process. - Important to have a therapeutic relationship with the patient.	- No grey literature included. - Limited to English-language articles.
Bruce & Beuthin (2019)	Qualitative secondary analysis using narrative inquiry and thematic analysis	Explore how nurses' overall experience of suffering is shaped by participating in MAID.	15 Registered Nurses, 1 Nurse Practitioner, 1 Licensed Practical Nurse	- Participating in MAID positively affects nurses and their ideas of suffering.	- Unable to generalize findings.
Fujioka et al. (2018)	Scoping review	Map the existing literature on health care providers' perspectives of their involvement in MAID.	33 articles	- Nurses and other HCPs are paramount in the MAID process.	- Did not capture regional variation between perspectives.
Ho et al. (2021a)	Qualitative thematic analysis of semi-structured interviews	Explore hospice and palliative care provider's experiences with MAID.	26 HCPs	- Resources to improve training, debriefing, and tailored bereavement may support HCPs.	- Participants were not diverse.
Ho et al. (2021b)	Qualitative thematic analysis of semi-structured interviews.	Explore how the Canadian MAID legislation affects EOL care discussions between patients and multidisciplinary specialist palliative care providers.	48 palliative care providers	- MAID discussions require education and support to enable compassionate communication.	- Unable to generalize findings.
Nuhn et al. (2018)	Qualitative study using semi-structured interviews	Explore the experiences, wishes, fears, and beliefs of people who requested and were eligible for	23 participants requesting MAID	- Reasons for requesting MAID were loss of autonomy, loss of independence, loss of	- Participants volunteered for this study.

		MAID in Canada in the first year after legalization.		purpose and enjoyment, loss of physical and communication abilities, and suffering or fear of future suffering.	- Participants were recruited from a single clinic, unable to generalize.
Suva et al. (2019)	Scoping review	Synthesize evidence on nurses' roles and responsibilities in relation to MAID and to identify gaps in literature.	24 articles	- HCPs' effective engagement with the individual in the decision-making process is important.	- Majority of included studies are from outside of Canada.
Thangarasa et al. (2021)	Qualitative semi-structured interviews	To better understand the caregiver experience of MAID within the Canadian legal landscape following Bill C-14.	22 caregivers	- The caregiver experience of MAID was found to be understood as a "race to the end."	- Findings are not generalizable.
Variath et al. (2020)	Scoping review	Identify influences on the experiences of family members and HCPs of those who had MAID and of those unable to access MAID.	36 articles	- Experiences are influenced by relational contexts including personal and societal.	- Excluded grey literature. - Eliminated non-English literature.
Ward et al. (2021)	Scoping review	Describes nurses' experiences with MAID.	30 articles	- Nurses' experiences with MAID are individualized.	- Excluded grey literature.

To synthesize the literature, I will first discuss the MAID literature as it relates to the three pillars of the ODSF: decisional needs, decision support interventions, and decisional outcomes (O'Connor et al., 1998; Stacey et al., 2020). Next, I synthesize the literature focused on the nurse's role in supporting patients making health-care decisions.

Pillar 1: Decisional Needs

Patients experience decisional needs when faced with decisions that have more than one option, undetermined outcomes, or known outcomes which people value differently (Stacey et al., 2020). In general, most common examples of decisional needs include inadequate knowledge and information, feeling unclear about personal values, feeling uncertain about the best choice, and feeling unsupported in the decision-making process (Stacey et al., 2020). Other examples of decisional needs include being at an unreceptive decisional stage, having decisional conflict, having unrealistic expectations, and the decision having complex decision characteristics. Decisional needs may be modifiable or non-modifiable. Non-modifiable decisional needs (such as clinical needs, difficult decision timing, personal needs, and difficult decision type) must be considered when tailoring decision support interventions to the patient (Stacey et al., 2020).

A recently published systematic review of 45 decisional needs studies included three studies on EOL decisions with adults; none of which were about patients considering MAID (Hoefel et al., 2020b). One of the three studies was a cross-sectional telephone survey of the decision-making needs of 635 Canadian adults faced with complex health decisions. While most of these decisions were related to sterilization and birth control, cessation of life support was a complex decision that two participants faced (O'Connor et al., 2003). Fifty-nine percent of participants indicated having decisional conflict, reporting that they were unsure of which option to choose. These participants experienced physical stress and decision delay. Most participants (77%) had unclear values, questioning what was important to them while making the decision.

Approximately 17-19% of participants reported deficits in their readiness for decision-making. The factors associated with lower decisional conflict included making a decision regarding birth control and being 70 years of age or older. These participants wanted more information on the available options from their physician and through educational resources (e.g., booklets, pamphlets, Internet, videos) (O'Connor et al., 2003). A study on EOL care preferences and needs of Canadians with chronic kidney disease found that most participants get information to make a health decision from their nephrologist (79.5%) or family physician (65.8%) (Davison, 2010). The same study found that 25.7% of participants gathered information from paper resources, 16.1% from the Internet, and 12.8% from television or media.

Another qualitative retrospective, cross-sectional needs assessment of 13 Canadian women with recurrent ovarian cancer identified inadequate knowledge about the options and the benefits and potential harms of the options provided as their main decisional needs (Jolicoeur et al., 2009). These women wanted to be presented with more than one treatment option and to have counselling in the decision by nurses, as they are perceived to have more time, seem to have better skills in providing information, and know the patient better. Interestingly, 11 of 13 women did not experience decisional conflict which is a common decisional need in other studies. One of the participants who experienced difficulty making the decision reported that she felt like she was expected to make the decision immediately. Few women participants in the study believed that they were presented with treatment options to consider (Jolicoeur et al., 2009). No study reported on how patients considering MAID identified or used educational information on the topic.

Interestingly, in the context of MAID, patients described the importance of features of options, indicating that they did not have unclear values (Nuhn et al., 2018; Variath et al., 2020).

A scoping review on the experiences of family members and healthcare providers (HCPs) of those who have pursued MAID identified a strong desire for patients to control their own death in 11 of 36 included studies (Variath et al., 2020). An additional descriptive qualitative study of the experiences of people who pursued MAID indicated main themes including the importance of autonomy and the desire for patients to control their own end-of-life decisions (Nuhn et al., 2018). Only one study identified focused on the decision making needs of nurses (Beuthin et al., 2018). This qualitative study of Canadian nurses' experiences of providing clinical support in MAID indicated that nurses' experienced decisional conflict and their religious beliefs were often the reason underlying this decisional conflict.

Pillar 2: Decision Support Interventions

According to the ODSF, decision support interventions include clinical counselling, patient decision aids (PtDAs), and decision coaching. These interventions must be tailored to the patient's decisional needs and used in an approach that includes establishing rapport, clarifying the decision, facilitating communication, and supporting deliberation (O'Connor et al., 2003).

Clinical counselling is provided by practitioners who have competence, legal authority, and accountability to identify problems and offer support to their patients (O'Connor et al., 2003). Practitioners engage in clinical counselling by: (a) identifying/diagnosing a problem or health condition; (b) identifying the patient's options; (c) providing decision support (including referring patients to PtDAs and/or decision coaching); and (d) facilitating implementation of a final decision by making a referral, writing a prescription, ordering screening/diagnostic tests, performing surgery, and/or providing care or therapy. The HCP who provides clinical counselling depends on the decision and may include audiologists, nurses, nurse practitioners, occupational therapists, pharmacists, physicians, physiotherapists, psychologists, medical social workers, and speech language pathologists (O'Connor et al., 2015).

Physicians, nurses, and social workers are HCPs that engage in aspects of clinical counseling related to MAID (Variath et al., 2020; Ward et al., 2021). Multiple scoping reviews stress the importance of establishing good rapport and nurturing a therapeutic relationship between patient and nurse (Suva et al., 2019; Variath et al., 2020). In a scoping review of 24 research studies, 3 articles stress that effective communication and strong relationships between the patient, family, and HCP are paramount in the decision-making process (Suva et al., 2019). Finally, in a qualitative secondary analysis including 15 Registered Nurses' stories who participated directly or indirectly in MAID, nurses provide information on the MAID process and EOL options available to the patient (Bruce & Beuthin, 2019).

PtDAs are another example of a decision support intervention. They are supplementary, evidence-based tools (i.e., booklets, video, online applications) used to prepare a patient to participate in decision-making and to increase the likelihood of reaching a decision that is well-informed and consistent with the patient's personal values for features and outcomes of options (Stacey & Volk, 2021). A typical PtDA: (a) makes explicit the decision: (b) provides information about the condition, (c) discusses available options including the option of doing nothing, (d) provides benefits and harms for each option, and (e) helps patients clarify their values by providing detailed descriptions of the options or including an explicit values clarification exercise (Stacey & Volk, 2021). To minimize patients making biased decisions, they provide balanced, information on the benefits and harms of relevant options to help the patient identify and reflect on their personal preferences (Hoefel et al., 2020b).

A systematic review of 24 randomized controlled trials evaluating patient decision aids created based on the ODSF reported that PtDAs had favourable impacts on both the quality of the decision made (e.g., improved knowledge, realistic expectations, fit between the option

chosen and patients' values for outcomes of options) and the decision-making process (e.g., lower decisional conflict, improved participation in decision-making, fewer undecided patients) (Hoefel et al., 2020b). None of the PtDAs focused on any EOL decision, including MAID. These findings were consistent with the 105 randomized controlled trials included in the Cochrane Review of PtDAs of which none were focused on EOL decisions or MAID (Stacey et al., 2017). Although one study evaluated a PtDA that did not specifically mention MAID, it addressed issues regarding the place of EOL care which is a relevant decision for people considering MAID as an EOL option (Murray et al., 2010). A pre-/post-test study, based on the ODSF, evaluated a PtDA titled *"When you need extra care, should you receive it at home or in a facility?"*. This PtDA is intended for patients who are living with an incurable illness, would like to plan where they receive EOL care, and wish to share their views with others. Findings showed that the study participants rated the PtDA as acceptable and clinically useful. Twenty-five of 38 participants (66%) who used the PtDA reported that they would recommend the PtDA to others.

The International A to Z Inventory provides a link to publicly accessible PtDAs. Each of the PtDAs are evaluated against the International Patient Decision Aid Standards (IPDAS) criteria (Patient Decision Aids Research Group, 2022). Within this inventory, there are 9 PtDAs for advanced care planning and EOL care, none of which included the decision of MAID. All 9 PtDAs met the IPDAS qualifying criteria for being defined as a decision aid (7 of 7 defining criteria met).

Decision coaching is the third intervention to address decisional needs in the ODSF and can be used to guide patients in making difficult choices consistent with their personal values and beliefs (Stacey et al., 2020). It is defined as non-directive guidance given by trained healthcare professionals in an attempt to develop patients' decision-making and implementation

skills and to prepare them for discussing their decisions (Stacey et al., 2020). Different professionals including nurses, psychologists, and social workers, can provide decision coaching in-person or using communication technologies (telephone, Internet), either individually or in a group session with a leader. Decision tools including specific PtDAs or generic personal decision guides may be utilized during decision coaching (Jull et al., 2019). Used internationally, the Ottawa Personal Decision Guide (OPDG) was created for use between adult patients and their practitioners to help make difficult decisions. When used with decision coaching, the OPDG decreases decisional conflict (Feenstra et al., 2015). When populated with evidence from a clinical practice guideline it was shown to lower decisional conflict and improve knowledge of the decision (Feenstra et al., 2015; Lawson et al., 2020).

One qualitative study involving 48 palliative care providers in Toronto and Vancouver indicated that nurses and other HCPs asked their patients to clarify their values and motivations regarding MAID (Ho et al., 2021a). A nurse asked "If you're dying naturally, how important is it for you that you die from MAiD? Or are you ok for us to allow you to die naturally if it's clear that's what's happening?" Findings revealed that this intervention confirmed if MAID is an end or a means to an end for the patient. In a scoping review on family members' and HCPs' experiences with MAID, nurses would ask patients who had requested MAID to clarify what they truly meant by asking open-ended questions (Variath et al., 2020). Findings showed that this was critical in addressing patients' and family members' questions, expectations, and fears.

Pillar 3: Decision Outcomes

The final pillar of the ODSF is the concept of decision outcomes (Stacey et al., 2020). Decision outcomes include the quality of the decision, the quality of the decision-making process, and the impact of the decision. The quality of a decision is based on whether that decision is: (a) informed (i.e., the patient has essential knowledge for making their decision, and

possesses realistic expectations of the possible outcomes) and (b) values-based (i.e., the person's choice is congruent with the features that matter most to them) (O'Connor et al., 1998; Stacey et al., 2020). The decision-making process is of high quality when there is a reduction in the decisional needs, reduction in proportions who are undecided, and a reduction of perceptions of feeling uninformed, having unclear values, and feeling unsupported (O'Connor et al., 1998; Stacey et al., 2020). Based on the current evidence for interventions to support patients' decisional needs, PtDAs have been the most evaluated intervention and demonstrated to improve both the quality of the decision and the decision-making process (Stacey et al., 2020). Decision impact is measured by the implementation of the chosen option and the appropriate use of health services (Stacey et al., 2020).

Little is reported on the outcomes of decisions about MAID. Although MAID deaths accounted for 2.5% of total Canadian deaths in 2020 (Health Canada, 2021), it is impossible to know the exact number of people who considered MAID. One participant in a qualitative study about family caregivers' experiences with their loved ones' MAID process shared that the patients' decision to pursue MAID was consistent with their personality and values system (Nuhn et al., 2018). Another caregiver, in the same study, felt decisional regret about the patient's choice to proceed with MAID as an EOL option.

Nurses' role in supporting people considering EOL decisions

Although there is an increasing body of literature outlining the development of MAID programs and patient characteristics, much less explored is the role of HCPs supporting patients in making this decision. As nurses are the HCPs that spend the most time close to patients, they develop trusting relationships both with patients and their loved ones. Therefore, nurses play a crucial role in EOL decision-making processes which embraces a collective inclusive approach (Adams et al., 2011; Brooks, 2019; Ward et al., 2021).

Three key roles nurses play in EOL decision-making are: (a) *information broker*, (b) *supporter*, and (c) *advocate* (Adams et al., 2011). As *information brokers* regarding the decision in question, nurses provide information to the patients and their loved ones and relay the patients' personal values and opinions to the interprofessional team. Multiple studies on the experiences of HCPs role in MAID suggest that nurses answer patient and family questions about the process of MAID as an EOL option (Brooks, 2019; Ward et al., 2021). Nurses act as *supporters* to patients and their loved ones throughout the EOL process by demonstrating empathy and compassion for their patients and their family members. Nurses found that compassionate listening and asking open-minded questions were critical to their role as a supporter (Beuthin et al., 2018; Bruce & Beuthin, 2019; Ward et al., 2021). This role includes providing decisional support. The final role nurses undertake while caring for patients at the EOL is one of an *advocate* (Adams et al., 2011). Nurses pride themselves on advocating for their patient's wishes to other members of the interprofessional team (Variath et al., 2020). They speak to the physicians, social workers, and other allied health professionals on behalf of the patient or family (Stacey et al., 2017). These roles are consistent with those identified by patients in a systematic review of 45 studies reporting patient perspectives on facilitators to overcome barriers to patient/family involvement in decision-making (Hoefel et al., 2020b). Patients in these studies identified nurses as key mediators who explain information, provide support by listening to patients' preferences, and provide physicians with information on patient preferences. Hence, for patients considering MAID as an EOL option, nurses can be knowledge brokers, provide decision support, and advocate for patient preferences.

In summary, patients will face difficult decisions in their lifetime, including EOL decisions. The ODSF had been used for over 20 years to guide HCPs and patients in making

these complex decisions. The ODSF can be used by HCPs to assess decisional needs, select and provide decision support interventions, and monitor decisional outcomes. While the ODSF has been used to guide decisions regarding EOL about location of care, no studies have been identified that focused on supporting patients making decisions about MAID. To date, there were no PtDAs specifically that include the option of MAID identified in the literature and none were found in the International A to Z inventory (Patient Decision Aids Research Group, 2022).

References

Adams, J. A., Bailey, D. E., Anderson, R. A., & Docherty, S. L. (2011). Nursing Roles and Strategies in End-of-Life Decision Making in Acute Care: A Systematic Review of the Literature. *Nursing Research and Practice*, *2011*, 1–15. https://doi.org/10.1155/2011/527834

Ajzen, I., & Fishbein, M. (1980). *Understanding attitudes and predicting social behaviour*. Prentice Hall.

Bandura, A. (1982). Self-efficacy mechanism in human agency. *American Psychologist*, *37*(2), 122–147. https://doi.org/10.1037/0003-066X.37.2.122

Banner, D., Schiller, C. J., & Freeman, S. (2019). Medical assistance in dying: A political issue for nurses and nursing in Canada. *Nursing Philosophy*, *20*(4). https://doi.org/10.1111/nup.12281

Beuthin, R., Bruce, A., & Scaia, M. (2018). Medical assistance in dying (MAiD): Canadian nurses' experiences. *Nursing Forum*, *53*(4), 511–520. https://doi.org/10.1111/nuf.12280

Brooks, L. (2019). Health Care Provider Experiences of and Perspectives on Medical Assistance in Dying: A Scoping Review of Qualitative Studies. *Canadian Journal on Aging / La Revue Canadienne Du Vieillissement*, *38*(03), 384–396. https://doi.org/10.1017/S0714980818000600

Bruce, A., & Beuthin, R. (2019). Medically Assisted Dying in Canada: "Beautiful Death" Is Transforming Nurses' Experiences of Suffering. *Canadian Journal of Nursing Research*, 084456211985623. https://doi.org/10.1177/0844562119856234

Canadian Nurses Association. (2019). *Advanced Practice Nursing: A Pan-Canadian Framework.*

Charlton, P., Doucet, S., Azar, R., Nagel, D. A., Boulos, L., Luke, A., Mears, K., Kelly, K. J., & Montelpare, W. J. (2019). The use of the environmental scan in health services delivery

research: a scoping review protocol. *BMJ Open*, *9*(9), e029805. https://doi.org/10.1136/bmjopen-2019-029805

College of Nurses of Ontario. (2021). *Guidance on Nurses' Roles in Medical Assistance in Dying*.

Coulter, A., Entwistle, V., & Gilbert, D. (1999). Sharing decisions with patients: is the information good enough? *BMJ*, *318*(7179), 318–322. https://doi.org/10.1136/bmj.318.7179.318

Department of Justice. (2021). *Medical Assistance in Dying*. https://www.justice.gc.ca/eng/cj-jp/ad-am/index.html

Durand, M. A., Carpenter, L., Dolan, H., Bravo, P., Mann, M., Bunn, F., & Elwyn, G. (2014). Do interventions designed to support shared decision- making reduce health inequalities? A systematic review and meta-analysis. *PLoS ONE*, *9*(4). https://doi.org/10.1371/journal.pone.0094670

El-Jawahri, A., Podgurski, L. M., Eichler, A. F., Plotkin, S. R., Temel, J. S., Mitchell, S. L., Chang, Y., Barry, M. J., & Volandes, A. E. (2010). Use of Video to Facilitate End-of-Life Discussions With Patients With Cancer: A Randomized Controlled Trial. *Journal of Clinical Oncology*, *28*(2), 305–310. https://doi.org/10.1200/JCO.2009.24.7502

Elmore, J., Wright, D. K., & Paradis, M. (2018). Nurses' moral experiences of assisted death: A meta-synthesis of qualitative research. *Nursing Ethics*, *25*(8), 955–972. https://doi.org/10.1177/0969733016679468

Elwyn, G., Durand, M. A., Song, J., Aarts, J., Barr, P. J., Berger, Z., Cochran, N., Frosch, D., Galasiński, D., Gulbrandsen, P., Han, P. K. J., Härter, M., Kinnersley, P., Lloyd, A., Mishra, M., Perestelo-Perez, L., Scholl, I., Tomori, K., Trevena, L., … Van der Weijden, T.

(2017). A three-talk model for shared decision making: multistage consultation process. *BMJ*, j4891. https://doi.org/10.1136/bmj.j4891

Fajardo, M. A., Balthazaar, G., Zalums, A., Trevena, L., & Bonner, C. (2019). Favourable understandability, but poor actionability: An evaluation of online type 2 diabetes risk calculators. *Patient Education and Counseling*, *102*(3), 467–473. https://doi.org/10.1016/j.pec.2018.10.014

Feenstra, B., Lawson, M. L., Harrison, D., Boland, L., & Stacey, D. (2015). Decision coaching using the Ottawa family decision guide with parents and their children: a field testing study. *BMC Medical Informatics and Decision Making*, *15*(1), 5. https://doi.org/10.1186/s12911-014-0126-2

Fujioka, J. K., Mirza, R. M., McDonald, P. L., & Klinger, C. A. (2018). Implementation of Medical Assistance in Dying: A Scoping Review of Health Care Providers' Perspectives. *Journal of Pain and Symptom Management*, *55*(6), 1564-1576.e9. https://doi.org/10.1016/j.jpainsymman.2018.02.011

Government of Canada. (2017). *Annual Report on the Operation of the Canadian Multiculturalism Act 2015-2016*.

Government of Canada. (2021a). *Canada's new medical assistance in dying (MAiD) law*. https://www.justice.gc.ca/eng/cj-jp/ad-am/bk-di.html

Government of Canada. (2021b). *Medical assistance in dying - Canada. ca*. https://www.canada.ca/en/health-canada/services/medical-assistance-dying.html

Graham, P., Evitts, T., & Thomas-MacLean, R. (2008). Environmental scans: how useful are they for primary care research? *Canadian Family Physician Medecin de Famille Canadien*, *54*(7), 1022–1023. http://www.ncbi.nlm.nih.gov/pubmed/18625830

Hatch, T. F., & Pearson, T. G. (1998). Using environmental scans in educational needs assessment. *Journal of Continuing Education in the Health Professions*, *18*(3), 179–184. https://doi.org/10.1002/chp.1340180308

Health Canada. (2021). *Second Annual Report on Medical Assistance in Dying in Canada, 2020*.

Ho, A., Joolaee, S., Jameson, K., & Ng, C. (2021). The Seismic Shift in End-of-Life Care: Palliative Care Challenges in the Era of Medical Assistance in Dying. *Journal of Palliative Medicine*, *24*(2), 189–194. https://doi.org/10.1089/jpm.2020.0185

Ho, A., Norman, J. S., Joolaee, S., Serota, K., Twells, L., & William, L. (2021). How does Medical Assistance in Dying affect end-of-life care planning discussions? Experiences of Canadian multidisciplinary palliative care providers. *Palliative Care and Social Practice, 15,* 263235242110459. https://doi.org/10.1177/26323524211045996

Hoefel, L., Lewis, K. B., O'Connor, A., & Stacey, D. (2020). 20th Anniversary Update of the Ottawa Decision Support Framework: Part 2 Subanalysis of a Systematic Review of Patient Decision Aids. *Medical Decision Making*, *40*(4), 522–539. https://doi.org/10.1177/0272989X20924645

Hoefel, L., O'Connor, A. M., Lewis, K. B., Boland, L., Sikora, L., Hu, J., & Stacey, D. (2020). 20th Anniversary Update of the Ottawa Decision Support Framework Part 1: A Systematic Review of the Decisional Needs of People Making Health or Social Decisions. *Medical Decision Making*, *40*(5), 555–581. https://doi.org/10.1177/0272989X20936209

Jolicoeur, L. J. A., O'Connor, A. M., Hopkins, L., & Graham, I. D. (2009). Women's decision-making needs related to treatment for recurrent ovarian cancer: A pilot study. *Canadian Oncology Nursing Journal*, *19*(3), 117–121. https://doi.org/10.5737/1181912x193117121

Joseph-Williams, N., Elwyn, G., & Edwards, A. (2014). Knowledge is not power for patients: A

systematic review and thematic synthesis of patient-reported barriers and facilitators to shared decision making. *Patient Education and Counseling*, *94*(3), 291–309. https://doi.org/10.1016/j.pec.2013.10.031

Joseph-Williams, N., Newcombe, R., Politi, M., Durand, M. A., Sivell, S., Stacey, D., O'Connor, A., Volk, R. J., Edwards, A., Bennett, C., Pignone, M., Thomson, R., & Elwyn, G. (2014). Toward minimum standards for certifying patient decision aids: A modified delphi consensus process. *Medical Decision Making*, *34*(6), 699–710. https://doi.org/10.1177/0272989X13501721

Jull, J., Köpke, S., Boland, L., Coulter, A., Dunn, S., Graham, I. D., Hutton, B., Kasper, J., Kienlin, S. M., Légaré, F., Lewis, K. B., Lyddiatt, A., Osaka, W., Rader, T., Rahn, A. C., Rutherford, C., Smith, M., & Stacey, D. (2019). Decision coaching for people making healthcare decisions. *Cochrane Database of Systematic Reviews*. https://doi.org/10.1002/14651858.CD013385

Keeney, R. L., & Raiffa, H. (1976). *Decisions with Multiple Objectives: Preferences and Value Tradeoffs*. John Wiley and Sons.

Lamb, A., Martin-Misener, R., Bryant-Lukosius, D., & Latimer, M. (2018). Describing the leadership capabilities of advanced practice nurses using a qualitative descriptive study. *Nursing Open*, *5*(3), 400–413. https://doi.org/10.1002/nop2.150

Lawson, M. L., Shephard, A. L., Feenstra, B., Boland, L., Sourial, N., & Stacey, D. (2020). Decision coaching using a patient decision aid for youth and parents considering insulin delivery methods for type 1 diabetes: a pre/post study. *BMC Pediatrics*, *20*(1), 1. https://doi.org/10.1186/s12887-019-1898-4

Lipari, M., Berlie, H., Saleh, Y., Hang, P., & Moser, L. (2019). Understandability, actionability,

and readability of online patient education materials about diabetes mellitus. *American Journal of Health-System Pharmacy*, *76*(3), 182–186. https://doi.org/10.1093/ajhp/zxy021

Maddah-Ali, M. A., & Niesen, U. (2014). Fundamental Limits of Caching. *IEEE Transactions on Information Theory*, *60*(5), 2856–2867. https://doi.org/10.1109/TIT.2014.2306938

Martin, R. W., Brogård Andersen, S., O'Brien, M. A., Bravo, P., Hoffmann, T., Olling, K., Shepherd, H. L., Dankl, K., Stacey, D., & Dahl Steffensen, K. (2021). Providing Balanced Information about Options in Patient Decision Aids: An Update from the International Patient Decision Aid Standards. *Medical Decision Making*, *41*(7), 780–800. https://doi.org/10.1177/0272989X211021397

Maurer, M., Siegel, J. E., Firminger, K. B., Lowers, J., Dutta, T., & Chang, J. S. (2021). Lessons Learned from Developing Plain Language Summaries of Research Studies. *HLRP: Health Literacy Research and Practice*, *5*(2). https://doi.org/10.3928/24748307-20210524-01

Mills, A., Wortzman, R., Bean, S., & Selby, D. (2020). Allied Health Care Providers Participating in Medical Assistance in Dying. *Journal of Hospice & Palliative Nursing*, *22*(3), 220–228. https://doi.org/10.1097/NJH.0000000000000646

Murray, M.-A. (2010). *When you need extra care, should you receive it at home or in a facility? A decision aid to prepare you to discuss the options*.

Murray, M. A., Stacey, D., Wilson, K., & O'Connor, A. (2010). Skills training to support patients considering place of end-of-life care: a randomized control trial. *Journal of Palliative Care*, *26*(2), 112–121.

Muscat, D. M., Smith, J., Mac, O., Cadet, T., Giguere, A., Housten, A. J., Langford, A. T., Smith, S. K., Durand, M.-A., & McCaffery, K. (2021). Addressing Health Literacy in Patient Decision Aids: An Update from the International Patient Decision Aid Standards.

Medical Decision Making, *41*(7), 848–869. https://doi.org/10.1177/0272989X211011101

Nuhn, A., Holmes, S., Kelly, M., Just, A., Shaw, J., & Wiebe, E. (2018). Experiences and perspectives of people who pursued medical assistance in dying: Qualitative study in Vancouver, BC. *Canadian Family Physician Medecin de Famille Canadien*, *64*(9), e380–e386. http://www.ncbi.nlm.nih.gov/pubmed/30209111

O'Connor, A. M., Drake, E. R., Wells, G. A., Tugwell, P., Laupacis, A., & Elmslie, T. (2003). A survey of the decision-making needs of Canadians faced with complex health decisions. *Health Expectations*, *6*(2), 97–109. https://doi.org/10.1046/j.1369-6513.2003.00215.x

O'Connor, A. M., Tugwell, P., Wells, G. A., Elmslie, T., Jolly, E., Hollingworth, G., McPherson, R., Bunn, H., Graham, I., & Drake, E. (1998). A decision aid for women considering hormone therapy after menopause: decision support framework and evaluation. *Patient Education and Counseling*, *33*(3), 267–279. https://doi.org/10.1016/S0738-3991(98)00026-3

O'Connor, A., Stacey, D., & Boland, L. (2015). *Introduction to the Ottawa Decision Support Tutorial*.

Ontario Ministry of Health and Longterm Care. (2021). *Medical Assistance in Dying - Health Care Professionals - MOH*. https://www.health.gov.on.ca/en/pro/programs/maid/#maid

Orem, D. . (1995). *Nursing: Concepts of practice* (5th ed.). Mosby.

Page, M. J., McKenzie, J. E., Bossuyt, P. M., Boutron, I., Hoffmann, T. C., Mulrow, C. D., Shamseer, L., Tetzlaff, J. M., Akl, E. A., Brennan, S. E., Chou, R., Glanville, J., Grimshaw, J. M., Hróbjartsson, A., Lalu, M. M., Li, T., Loder, E. W., Mayo-Wilson, E., McDonald, S., … Moher, D. (2021). The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. *BMJ (Clinical Research Ed.)*, *372*, n71. https://doi.org/10.1136/bmj.n71

Patient Decision Aids Research Group. (2022). *A to Z Inventory - Patient Decision Aids - Ottawa Hospital Research Institute*. https://decisionaid.ohri.ca/AZinvent.php

Pellisé, F., & Sell, P. (2009). Patient information and education with modern media: the Spine Society of Europe Patient Line. *European Spine Journal*, *18*(S3), 395–401. https://doi.org/10.1007/s00586-009-0973-1

Pesut, B., Thorne, S., Schiller, C., Greig, M., Roussel, J., & Tishelman, C. (2020). Constructing Good Nursing Practice for Medical Assistance in Dying in Canada: An Interpretive Descriptive Study. *Global Qualitative Nursing Research*, *7*. https://doi.org/10.1177/2333393620938686

Pesut, B., Thorne, S., Wright, D. K., Schiller, C., Huggins, M., Puurveen, G., & Chambaere, K. (2021). Navigating medical assistance in dying from Bill C-14 to Bill C-7: a qualitative study. *BMC Health Services Research*, *21*(1), 1–16. https://doi.org/10.1186/s12913-021-07222-5

Rahn, A. C., Jull, J., Boland, L., Finderup, J., Loiselle, M.-C., Smith, M., Köpke, S., & Stacey, D. (2021). Guidance and/or Decision Coaching with Patient Decision Aids: Scoping Reviews to Inform the International Patient Decision Aid Standards (IPDAS). *Medical Decision Making*, *41*(7), 938–953. https://doi.org/10.1177/0272989X21997330

Shoemaker, S. J., Wolf, M. S., & Brach, C. (2014). Development of the Patient Education Materials Assessment Tool (PEMAT): A new measure of understandability and actionability for print and audiovisual patient information. *Patient Education and Counseling*, *96*(3), 395–403. https://doi.org/10.1016/j.pec.2014.05.027

Stacey, D., Légaré, F., Boland, L., Lewis, K. B., Loiselle, M.-C., Hoefel, L., Garvelink, M., & O'Connor, A. (2020). 20th Anniversary Ottawa Decision Support Framework: Part 3

Overview of Systematic Reviews and Updated Framework. *Medical Decision Making*, *40*(3), 379–398. https://doi.org/10.1177/0272989X20911870

Stacey, D., Légaré, F., Lewis, K., Barry, M. J., Bennett, C. L., Eden, K. B., Holmes-Rovner, M., Llewellyn-Thomas, H., Lyddiatt, A., Thomson, R., & Trevena, L. (2017). Decision aids for people facing health treatment or screening decisions. *Cochrane Database of Systematic Reviews*. https://doi.org/10.1002/14651858.CD001431.pub5

Stacey, D., Légaré, F., Pouliot, S., Kryworuchko, J., & Dunn, S. (2010). Shared decision making models to inform an interprofessional perspective on decision making: A theory analysis. *Patient Education and Counseling*, *80*(2), 164–172. https://doi.org/10.1016/j.pec.2009.10.015

Stacey, D., Ludwig, C., Archambault, P., Smith, M., Carley, M., Plourde, K., Boland, L., Gogovor, A., Graham, I. D., Kobewka, D., McLean, R., Nelson, M., Taljaard, M., Vanderspank, B., & Legare, F. (2022). *Decisions and decision making needs of Canadians during the COVID-19 pandemic: A national survey*.

Stacey, D., Suwalska, V., Boland, L., Lewis, K. B., Presseau, J., & Thomson, R. (2019). Are Patient Decision Aids Used in Clinical Practice after Rigorous Evaluation? A Survey of Trial Authors. *Medical Decision Making*, *39*(7), 805–815. https://doi.org/10.1177/0272989X19868193

Stacey, D., & Volk, R. J. (2021). The International Patient Decision Aid Standards (IPDAS) Collaboration: Evidence Update 2.0. *Medical Decision Making*, *41*(7), 729–733. https://doi.org/10.1177/0272989X211035681

Statistics Canada. (2020). *Deaths, 2019*.

Statistics Canada. (2022). *Increasing diversity of languages, other than English or French,*

spoken at home.

Stein, R. A., Sharpe, L., Bell, M. L., Boyle, F. M., Dunn, S. M., & Clarke, S. J. (2013). Randomized Controlled Trial of a Structured Intervention to Facilitate End-of-Life Decision Making in Patients With Advanced Cancer. *Journal of Clinical Oncology*, *31*(27), 3403–3410. https://doi.org/10.1200/JCO.2011.40.8872

Suva, G., Penney, T., & McPherson, C. J. (2019). Medical Assistance in Dying: A Scoping Review to Inform Nurses' Practice. *Journal of Hospice and Palliative Nursing*, *21*(1), 46–53. https://doi.org/10.1097/NJH.0000000000000486

Thiele, T., & Dunsford, J. (2019). Nurse leaders' role in medical assistance in dying: A relational ethics approach. *Nursing Ethics*, *26*(4), 993–999. https://doi.org/10.1177/0969733017730684

Tversky, A., & Kahneman, D. (1981). *The framing of decisions and the psychology of choice*. Science.

Variath, C., Peter, E., Cranley, L., Godkin, D., & Just, D. (2020). Relational influences on experiences with assisted dying: A scoping review. *Nursing Ethics*, *27*(7), 1501–1516. https://doi.org/10.1177/0969733020921493

Vishnevetsky, J., Walters, C. B., & Tan, K. S. (2018). Interrater reliability of the Patient Education Materials Assessment Tool (PEMAT). *Patient Education and Counseling*, *101*(3), 490–496. https://doi.org/10.1016/j.pec.2017.09.003

Ward, V., Freeman, S., Callander, T., & Xiong, B. (2021). Professional experiences of formal healthcare providers in the provision of medical assistance in dying (MAiD): A scoping review. *Palliative and Supportive Care*, *19*(6), 744–758. https://doi.org/10.1017/S1478951521000146

Wiebe, E., Shaw, J., Green, S., Trouton, K., & Kelly, M. (2018). Reasons for requesting medical assistance in dying. *Canadian Family Physician Medecin de Famille Canadien*, *64*(9), 674–679. http://www.ncbi.nlm.nih.gov/pubmed/30209101

Wu, J. S. Y., Pinilla, J., Watson, M., Verma, S., & Olivotto, I. A. (2018). Medical Assistance in Dying for Cancer Patients One Year After Legalization: A Collaborative Approach at a Comprehensive Cancer Centre. *Current Oncology*, *25*(5), 486–489. https://doi.org/10.3747/co.25.4118

Yen, R. W., Smith, J., Engel, J., Muscat, D. M., Smith, S. K., Mancini, J., Perestelo-Pérez, L., Elwyn, G., O'Malley, A. J., Leyenaar, J. K., Mac, O., Cadet, T., Giguere, A., Housten, A. J., Langford, A., McCaffery, K., & Durand, M.-A. (2021). A Systematic Review and Meta-Analysis of Patient Decision Aids for Socially Disadvantaged Populations: Update from the International Patient Decision Aid Standards (IDPAS). *Medical Decision Making*, *41*(7), 870–896. https://doi.org/10.1177/0272989X211020317

Yiu, A., Ng, K. K., Lee, V. W., & Bajorek, B. V. (2020). Evaluating the Understandability and Actionability of Web-Based Education Materials for Patients Taking Non–vitamin K Oral Anticoagulants. *Therapeutic Innovation & Regulatory Science*, *54*(2), 476–483. https://doi.org/10.1007/s43441-019-00079-1

Yun, Y. H., Lee, M. K., Park, S., Lee, J. L., Park, J., Choi, Y. S., Lim, Y. K., Kim, S. Y., Jeong, H. S., Kang, J. H., Oh, H.-S., Park, J. C., Kim, S.-Y., Song, H. S., Ro, J., Lee, K. S., Heo, D. S., & Hong, Y. S. (2011). Use of a Decision Aid to Help Caregivers Discuss Terminal Disease Status With a Family Member With Cancer: A Randomized Controlled Trial. *Journal of Clinical Oncology*, *29*(36), 4811–4819. https://doi.org/10.1200/JCO.2011.35.3870

Chapter Three

Appraising resources to support patients considering decisions about Medical Assistance In Dying in Canada: An online environmental scan

This chapter was written in accordance with the Canadian Journal of Medicine Open requirements.

Abstract

Background: Medical Assistance in Dying (MAID) was legalized in Canada in 2016 with legislation updated in 2021. Patients contemplating MAID must make this decision without coercion or external influence. It is unclear whether specific resources are available to help patients make this difficult decision. We sought to identify and quality appraise Canadian MAID resources suitable for supporting patients making this decision.

Methods: Environmental scan of MAID resources using Canadian websites. Inclusion criteria: published after 2016 initial MAID legislation, MAID-focused, patient-targeted, publicly accessible, and able to inform decisions about MAID in Canada. Exclusion criteria: resources targeting healthcare professionals and policymakers, service protocols, and personal narratives. Two reviewers appraised resources using the International Patient Decision Aids Standards (IPDAS) criteria and the Patient Education Materials Assessment Tool (PEMAT). Descriptive analysis was conducted. Resources were patient decision aids if 7 IPDAS defining criteria were met and adequate for health literacy if $\geq$70% on PEMAT.

Results: Fifty-eight MAID resources were identified. Of 58 resources, 41 (71%) provided updated eligibility criteria updated with 2021 legislation and 4 did not discuss eligibility criteria. The median IPDAS score was 3 out of 7; none provided benefits or potential harms of options. The proportion of resources with adequate PEMAT understandability score was 52%, and adequate PEMAT actionability score was 19%.

Interpretations: Although many resources on MAID were updated with 2021 legislation, few were adequate to support patients with lower health literacy. There is a need to determine if a patient decision aid would be appropriate for patients contemplating MAID.

Keywords: medical assistance in dying, end of life, patient decision aids, IPDAS, PEMAT

Background

In June 2016, Canada legalized Medical Assistance in Dying (MAID; Bill C-14) which allowed the safe and intentional end of life of patients suffering from grievous, incurable diseases, whose death is reasonably foreseeable (Government of Canada, 2021b). MAID involves the administration of medications to safely and intentionally end the life of an adult who is eligible for MAID and specifically requested it (Government of Canada, 2021b). In March 2021, an amendment to the legislation (Bill C-7) broadened the eligibility criteria for MAID to include patients whose death is not reasonably foreseeable, but this requires a 90-day waiting period (Government of Canada, 2021b). The new regulation aimed to assist healthcare professionals to carry out MAID, while protecting patients from abuse or misuse (Government of Canada, 2021a).

Although patients requesting MAID are supposed to receive information about all options available to them, as per the legislation (Government of Canada, 2021b), it is unclear the extent to which patients actively making the decision about MAID are supported in considering alternative end-of-life (EOL) care options (Government of Canada, 2021b). When making a decision with multiple options requiring trade-offs among benefits and potential harms, patients are likely to experience decisional conflict, a state described as uncertainty about the best course of action (Stacey et al., 2020). EOL decisions, including MAID, were identified in a recent Canadian survey of difficult decisions during the first year of the pandemic that is currently under review (Stacey et al., 2022).

Patient decision aids are evidence-based resources proven to reduce decisional conflict, improve knowledge, and support patients to participate in decisions (Stacey & Volk, 2021). As compared to those who did not use a decision aid, patients with lower health literacy and socio-

economic status who used a decision aid had higher gains in knowledge, informed choice, participation in decision-making, decision self-efficacy, preference for shared decision-making, and reduced decisional conflict (Durand et al., 2014). At a minimum, patient decision aids make explicit the decision, provide information on options (including benefits, harms), and help clarify values for outcomes of options (Durand et al., 2014).

Although there are many Canadian MAID resources available for patients, it is not clear the extent to which they use effective approaches to support decision-making and whether they are adequate for people with lower health literacy. Further, it is not clear if they can be identified as patient decision aids, the gold standard of decision support tools, to ensure informed values congruent decisions (Stacey & Volk, 2021). Therefore, we sought to identify Canadian MAID resources for patients and appraise their quality.

Methods

Study design

We conducted an environmental scan by seeking, gathering, and interpreting information to inform decision-making (Charlton et al., 2019; Graham et al., 2008; Hatch & Pearson, 1998). The interpretation was informed by quality appraisal. As there are no specific guidelines used to report environmental scans, we adapted the PRISMA reporting guidelines to write this article (Page et al., 2021).

Search strategy

We conducted the environmental scan using Google searches and hand searching Canadian government and organization websites. We limited the search to Canadian websites given that the resources identified would also need to reflect the Canadian MAID legislation (Government of Canada, 2021a). One person (AK) conducted the searches using popular

searched keywords according to the Google Trend. Key search terms, used independently, were: medical assistance in dying, assisted suicide, voluntary euthanasia, MAID and dying, and physician assisted suicide.

We conducted the searches in new private window in the internet browser Safari to prevent caching of results from previous searches (Maddah-Ali & Niesen, 2014). We discontinued the searches when no new resources were identified within the next 50 internet hits. We searched the Canadian federal, provincial, and territorial governments websites, as well as relevant Canadian organizations' websites (i.e., Dying with Dignity, Canadian MAID Assessors and Providers) using the same search terms. Additionally, we reviewed Google Advanced Search using the same keywords.

Eligibility of resources

All identified MAID resources were reviewed against our eligibility criteria. Eligible resources were published after the 2016 MAID legislation, MAID-focused, able to inform decisions about MAID, patient-targeted, and publicly accessible. To determine whether the resource could inform decisions, it had to provide information on MAID as an EOL option, including details about the procedure. We excluded resources if they were: exclusively targeted to healthcare providers or policymakers, personal narratives (i.e., personal websites, blogs, public forums), or healthcare service protocols (i.e., request forms, instructions for completion of healthcare providers roles). We documented non-eligible MAID resources with reasons for exclusion.

Data extraction

We extracted information on eligible resources using a standardized data extraction spreadsheet in Excel Version 16.48 (Microsoft, Redmond, WA). One researcher (AK) extracted the data, and it was verified by others (DS, LBP). The following were collected: resource title,

target audience, author/developer, year of last update, languages in which the resource is available, URL, pathway to the resource, and dates accessed.

Quality appraisal

Two reviewers (AK, LPB) independently appraised the eligible resources. Discrepancies were resolved through consensus or consultation with an arbitrator (DS) as necessary.

Accuracy of MAID information on eligibility criteria was compared to the 2021 Bill C-7: *An Act to amend the Criminal Code (MAID)* at 5 months and 13 months after legislation passed. We scored it as yes (updated), no (not updated), or not applicable if eligibility was not discussed.

We used the 6 International Patient Decision Aids (IPDAS) defining criteria to determine whether the resource qualified as a patient decision aid (Joseph-Williams et al., 2014). We included a 7th criteria of 'target audience' as proposed in 2021 (Martin et al., 2021) (Appendix B). We scored the IPDAS criteria as present (yes) or absent (no).

To assess health literacy, we used the Patient Education Material Assessment Tool for Printable Materials (PEMAT-P) or Audiovisual Materials (PEMAT-AV) (Appendix C). The PEMAT assesses resources on two domains: (a) understandability (PEMAT-P includes 17 items; PEMAT-AV includes 13 items) and (b) actionability (PEMAT-P 7 includes items, PEMAT-AV includes 4 items) (Shoemaker et al., 2014). We scored the items as 0 (disagree), 1 (agree), or N/A (not applicable) according to the PEMAT User's Guide (Shoemaker et al., 2014). PEMAT scores were calculated as percentages of total possible points (excluding not applicable) (Shoemaker et al., 2014; Vishnevetsky et al., 2018). According to the PEMAT, materials are considered understandable when consumers of diverse backgrounds and varying levels of health literacy can process and explain the key messages and resources are actionable when consumers of diverse backgrounds and varying levels of health literacy can identify what to do based on the information provided. The PEMAT individual scores were standardized on a scale out of 100.

Data analysis

We used descriptive statistics to report characteristics of the resources. As data was not normally distributed, we analyzed findings using median, interquartile range (IQR), and range. Resources had to meet all 7 criteria to be defined as a patient decision aid (Stacey & Volk, 2021). An overall score of ≥70% indicated the resource was adequate for being understandable or actionable (Shoemaker et al., 2014; Vishnevetsky et al., 2018).

Results

Main characteristics of resources

Of 530 Google results searched in August 2021, 58 were included and analyzed (Figure 3.1). Google Trend indicated that MAID was a common topic in Canadian Healthcare in 2020 to 2021 as evidenced by the number of search hits (Figures 3.2-3.4). Resources were available in French and/or English, and one resource was available in English, Chinese Traditional, Chinese Simplified, Punjabi, Spanish, and Vietnamese. Developers varied, with 3 developed by the federal government, 10 by national organizations, 41 by provinces and 4 by the Canadian Territories (Table 3.1). Fifty-three resources were in print and five were videos. None were available in both formats.

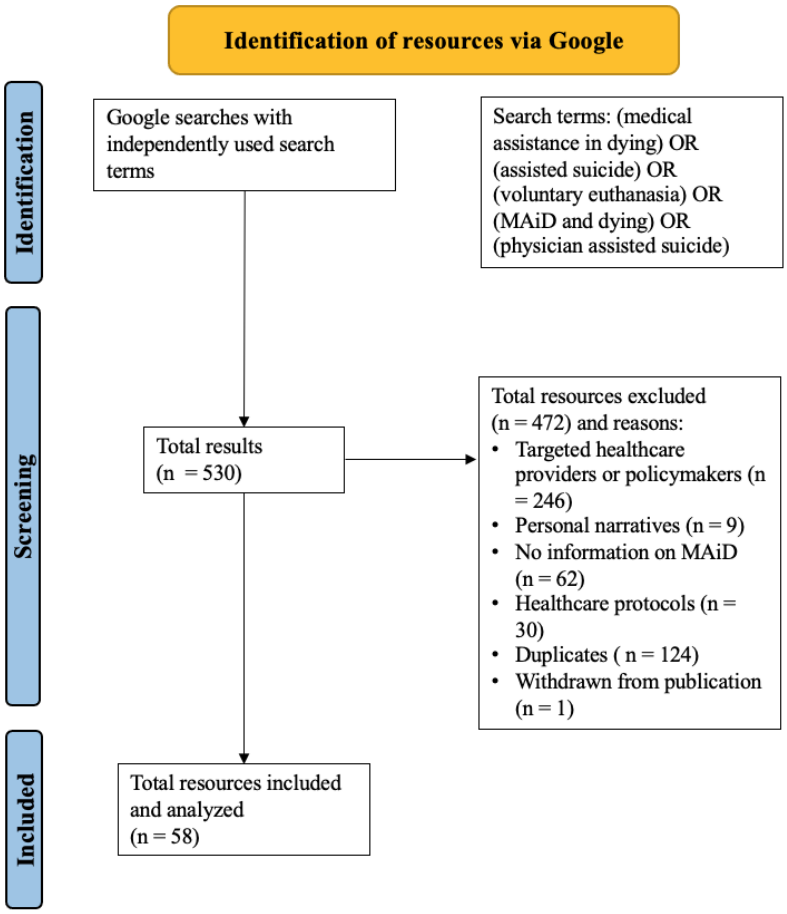


Figure 3.1. PRISMA Diagram of search results

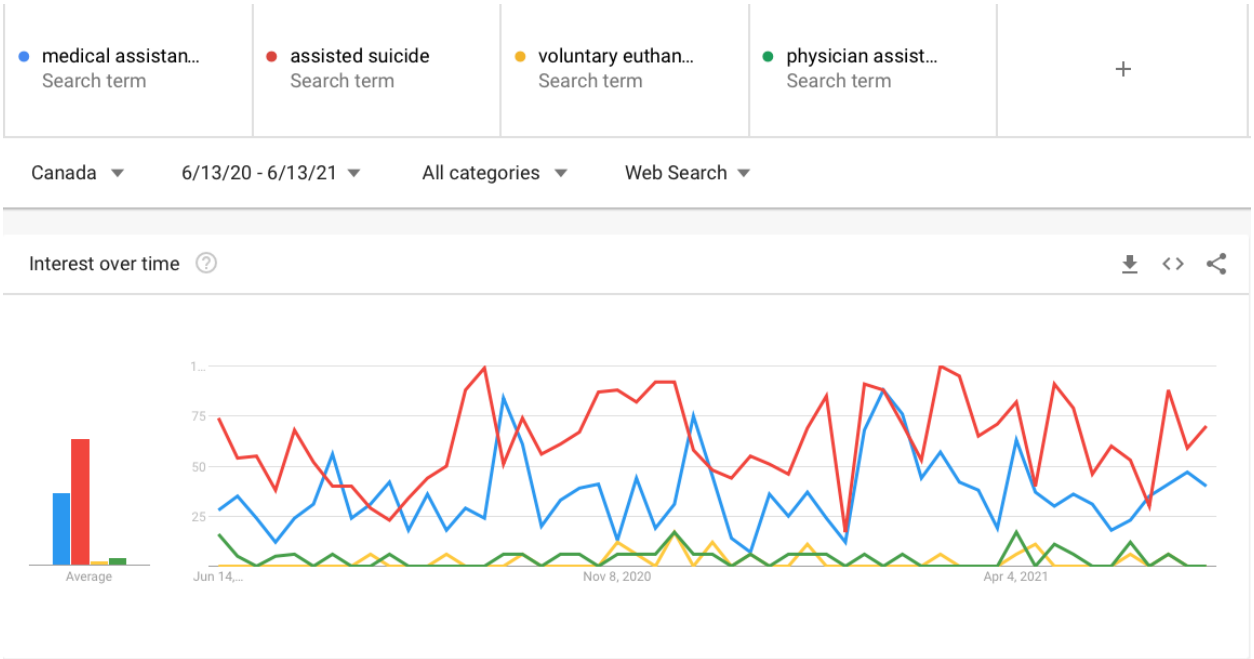


Figure 3.2 Google Trends of key words graph

*Figure 3.3 Google Trends results for key words of subregions 1-5**

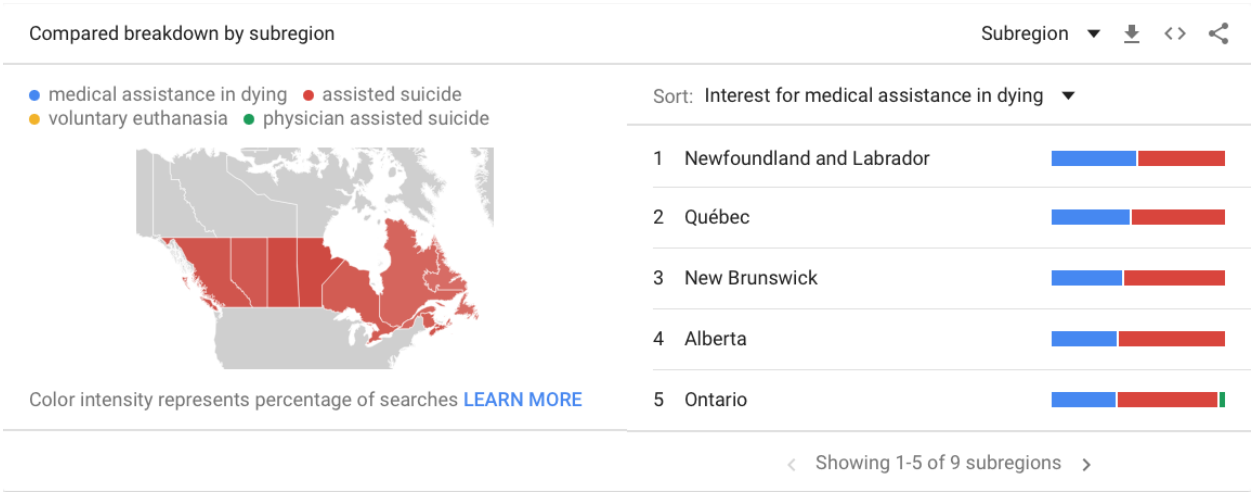
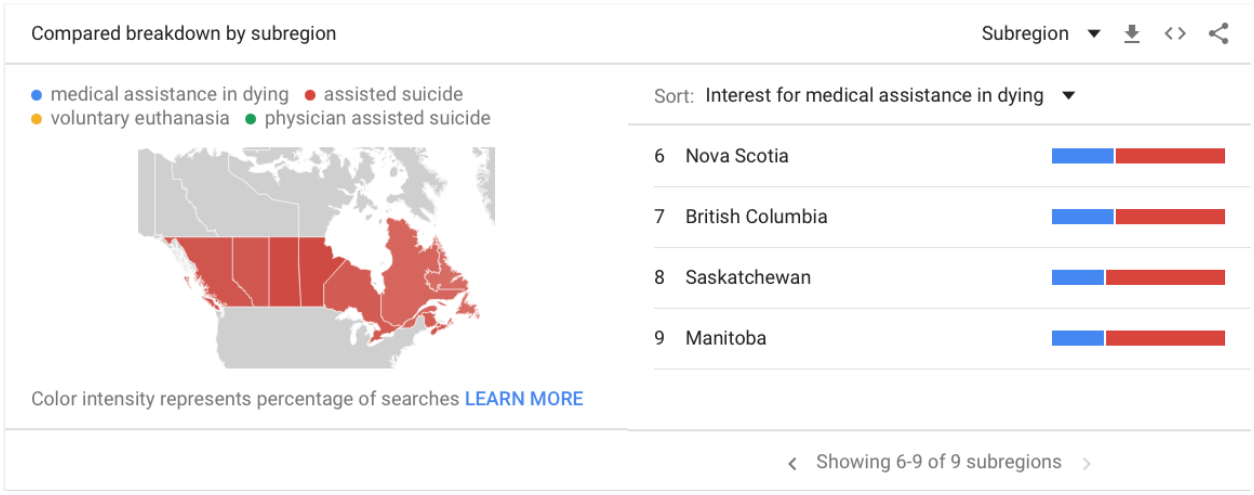


*Figure 3.4 Google Trends results for key words of subregions 6-9**



*Coloured bars show the prevalence of which search term was used in which subregion

Table 3.1. Main characteristics of publicly available MAID resources

ID	Developer	Year last updated	Resource name	Format	Languages available	Eligibility criteria based on 2021 legislation at 5 mos.	Eligibility criteria based on 2021 legislation at 13 mos.
Canada							
1	Government of Canada	2021	MAID	Webpage	English, French	Yes	Yes
2	Government of Canada	2021	Canada's new MAID law	Webpage	English, French	Yes	Yes
3	Government of Canada	2021	Canada's New MAID Law (Infographic)	Webpage, paper, PDF	English, French	Yes	Yes
4	Dying with Dignity Canada	2021	Get the Facts: Canada's MAID law	Webpage	English, French	Yes	Yes
5	Dying with Dignity Canada	2021	A legal overview of MAID	Video	English	Yes	Yes
6	Dying with Dignity Canada	2021	From Bill C-14 to Bill C-7: A legal update on MAID in Canada	Video	English	Yes	Yes
7	LegalLine	NR	MAID	Webpage	English	Yes	Yes
8	Alzheimer Society of Canada	NR	MAID	Webpage	English, French	Yes	Yes
9	Canadian Virtual Hospice	2019	How MAID is administered	Video	English	No	No
10	CAMAP Canada	2018	MAID in Canada	Video	English	No	No

11	Canadian Virtual Hospice	NR	Explaining MAID	Webpage	English, French	No	No
12	Canadian Virtual Hospice	2018	Tara Noble MSW, RSW on explaining MAID to children	Video	English	NA	NA
13	Centre for Suicide Prevention	NR	Physician-Assisted Death/MAID and Suicide	Webpage, paper, PDF	English	NA	NA
Alberta							
14	Alberta Health Services	2021	MAID: How does Bill C-7 affect me?	Webpage, paper, PDF	English	Yes	Yes
15	Alberta Health Services	2021	MAID: How Do I Access MAID Services in Alberta?	Webpage, paper, PDF	English	Yes	Yes
16	Alberta Health Services	2021	How do I make a formal request for MAID in Alberta?	Webpage, paper, PDF	English	Yes	Yes
17	Alberta Health Services	NR	Patients or Family Members: MAID	Webpage	English	Yes	Yes
18	Alberta Health Services	2017	MAID: Getting More Information	Webpage, paper, PDF	English	No	No
British Columbia							
19	Fraser Health	2021	MAID fact sheet	Webpage, paper, PDF	English	Yes	Yes
20	Fraser Health	2021	MAID	Webpage, paper, PDF	English	Yes	Yes
21	Fraser Health	NR	MAID	Webpage	English	Yes	Yes
22	BC Cancer	NR	MAID	Webpage	English	No	Yes
23	BC Cancer	2017	MAID: Q & A Information for patients of Provincial Health Services Authority	Webpage, paper, PDF	English	No	No

24	Government of British Columbia	2021	MAID	Webpage	English	Yes	Yes
25	Island Health	2021	MAID Information for Island Health patients and families	Webpage, paper, PDF	English	Yes	Yes
26	Island Health	2021	MAID; A Guide to Support Patients & Families	Webpage, paper, PDF	English	Yes	Yes
27	Interior Health Authority	2021	A Shared Journey: A Resource for Individuals, Families and Loved Ones about MAID	Webpage, paper, PDF	English	Yes	Yes
28	Fraser Health	2021	A Guide to Support People Requesting MAID	Webpage, paper, PDF	English	Yes	Yes
29	Vancouver Coastal Health	2021	MAID patient pamphlet	Webpage, paper, PDF	English, Chinese Traditional, Chinese Simplified, Punjabi, Spanish, Vietnamese	Yes	Yes
30	Island Health	NR	MAID	Webpage	English	Yes	Yes
31	Interior Health Authority	2019	MAID pamphlet for individuals and families	Webpage, paper, PDF	English	No	Yes
32	Vancouver Coastal Health	NR	MAID frequently asked questions	Webpage	English	No	Yes
Saskatchewan							
33	Saskatchewan Health Authority	2021	Provincial MAID Program Frequently Asked Questions	Webpage, paper, PDF	English	Yes	Yes

			for Patients and Families Foreseeable Death				
34	Saskatchewan Health Authority	2021	Provincial MAID Program Frequently Asked Questions for Patients and Families Non-Foreseeable Death	Webpage, paper, PDF	English	Yes	Yes
35	Government of Saskatchewan	NR	MAID Information for the Public	Webpage	English	Yes	Yes
36	Saskatchewan Health Authority	2021	Provincial MAID Program; Information for Patients and Families	Webpage, paper, PDF	English	NA	NA
37	Saskatchewan Health Authority	2021	Provincial MAID Program; Preparing for Provision Day	Webpage, paper, PDF	English	NA	NA
Manitoba							
38	Shared Health Manitoba	2021	MAID in Manitoba	Webpage, paper, PDF	English	Yes	Yes
39	Government of Manitoba	NR	Questions and answers about MAID	Webpage	English, French	No	No
Ontario							
40	Government of Ontario	NR	MAID: Information for Patients	Webpage, paper, PDF	English, French	Yes	Yes
41	University Health Network	NR	MAID	Webpage	English	No	No
42	Government of Ontario	2021	MAID and EOL decisions	Webpage	English, French	Yes	Yes
43	Ontario Ministry of Health	2021	MAID	Webpage	English, French	Yes	Yes
44	The Ottawa Hospital	2021	MAID: Information for patients and families	Webpage, paper, PDF	English, French	Yes	Yes

45	The Ottawa Hospital	2021	MAID: Information for patients and loved ones	Webpage	English, French	Yes	Yes
46	Waterloo Wellington Integrated Hospice Palliative Medicine	2017	Waterloo Wellington MAID Frequently Asked Questions (FAQs)	Webpage, paper, PDF	English	No	No
47	Home and Community Care Support Services South West	NR	MAID	Webpage	English	No	No
Québec							
48	Government of Québec	2020	MAID	Webpage	English, French	No	Yes
Eastern Provinces							
49	Nova Scotia Health Authority	2021	Patient & Family Guide; MAID Patient and Family Guide	Webpage, paper, PDF	English, French	Yes	Yes
50	Horizon Health Network, New Brunswick	NR	Patient Information: MAID	Webpage, paper, PDF	English	Yes	Yes
51	Government of New Brunswick	NR	MAID	Webpage	English, French	No	No
52	Government of Newfoundland and Labrador	NR	MAID frequently asked questions	Webpage, paper, PDF	English, French	No	No

53	Government of Prince Edward Island	2021	MAID	Webpage	English, French	No	No
54	Nova Scotia Health Authority	NR	MAID	Webpage	English, French	No	No
Canadian Territories							
55	Government of Northwest Territories	2021	MAID– Information for Patients and Families	Webpage, paper, PDF	English, French	Yes	Yes
56	Government of Northwest Territories	2021	MAID– Questions and Answers for Patients and Families	Webpage, paper, PDF	English, French	Yes	Yes
57	Government of Northwest Territories	NR	MAID	Webpage	English, French	Yes	Yes
58	Government of Yukon	NR	Find information about MAID	Webpage	English, French	Yes	Yes

NR= not reported; NA= not applicable; *shaded results indicate adequate scores for understandability and actionability*

Quality appraisal of resources

By five months after Bill C-7 was passed, 37 of 54 (68.5%) were updated with eligibility criteria that reflected the new legislation and 4 did not discuss eligibility criteria for MAID. Thirteen months after Bill C-7 was passed, 41 of 54 (75.9%) of resources discussing eligibility criteria had been updated.

None of the 58 eligible resources met the criteria to be defined as patient decision aids (Table 3.2). The median number of IPDAS defining criteria was 3 out of 7 (IQR 2, range 0-5) (Figure 3.5). Of 58 resources, more common IPDAS criteria met were: information on the target audience (n=49; 84.5%), describes the health condition (n=45; 77.6%); and states the decision to be made (n=34; 58.6%). Although 18 out of 58 (31.0%) resources provided options, none provided information on the potential benefits or potential harms of the options.

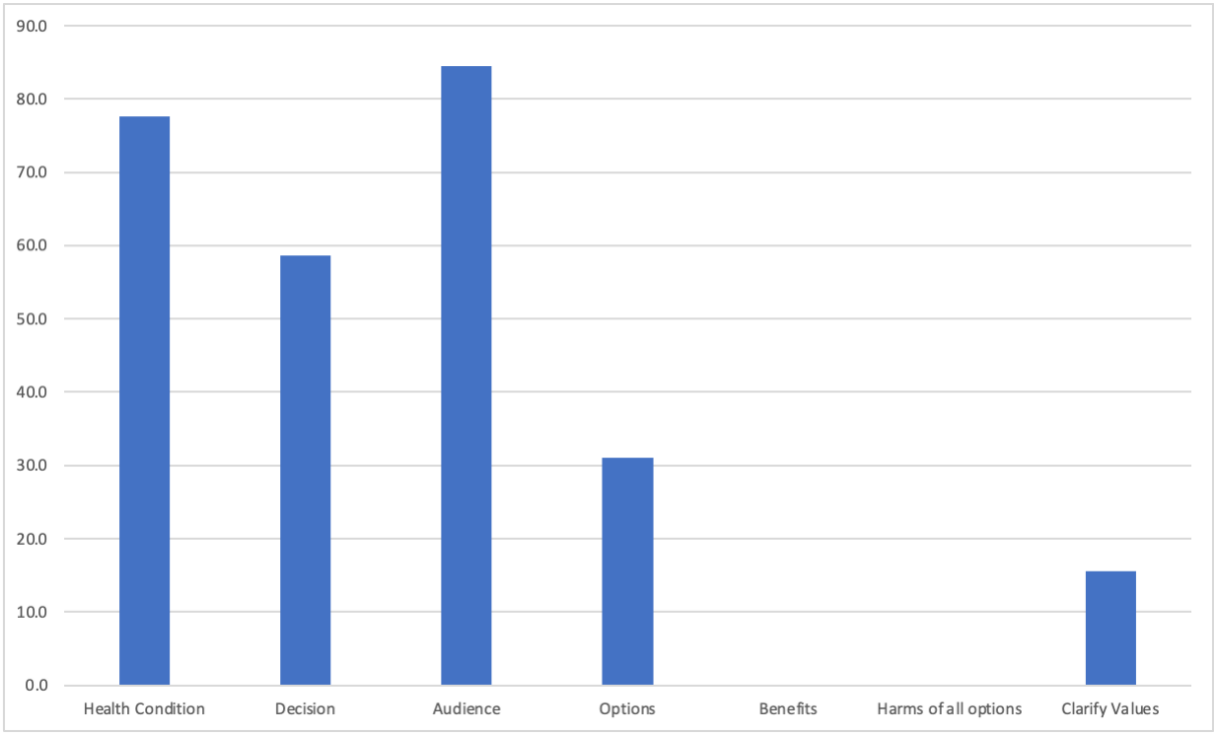


Figure 3.5 MAID resources for patients compared to IPDAS defining criteria (n=58)

Table 3.2. Appraisal results using IPDAS defining criteria and PEMAT scores

Resource ID	IPDAS								PEMAT	
	Describes health condition	Decision to be made	Target audience	List all available options	Benefits of all options	Harms of all options	Explicit values clarification	Total (/7)	Understandability (%)	Actionability (%)
1	√	√	√	√				4	75	60
2	√			√				2	67	20
3	√							1	54	33
4	√	√	√					3	67	20
5	√	√	√					3	64	0
6	√	√	√					3	73	0
7	√	√	√	√				4	67	40
8	√							1	54	40
9	√						√	2	56	0
10	√	√	√				√	4	70	67
11	√	√	√					3	69	40
12								0	50	0
13	√	√						2	50	0
14			√					1	**70**	**80**
15			√					1	91	60
16			√					1	69	60
17			√					1	67	40
18	√		√	√				3	60	40
19	√	√	√					3	**92**	**80**
20			√					1	**83**	**86**
21	√	√	√					3	**83**	**80**
22	√	√	√	√				4	**83**	**80**
23	√		√	√				3	**85**	**80**
24	√	√	√					3	67	60
25	√	√	√	√				4	60	40
26			√				√	2	63	40
27	√	√	√				√	4	67	40

28			√				√	2	69	40
29	√	√	√	√				4	67	60
30	√		√					2	60	80
31	√	√	√					3	60	60
32	√	√	√	√			√	5	75	60
33	√	√	√	√				4	83	20
34	√	√	√					3	85	20
35	√	√	√					3	63	40
36		√	√					2	83	60
37			√				√	2	92	60
38								0	78	60
39	√	√	√					3	75	60
40	√	√	√	√				4	**75**	**80**
41	√	√	√				√	4	**83**	**80**
42	√	√	√	√				4	92	60
43	√		√					2	69	17
44	√	√	√	√				4	84	60
45	√		√					2	82	60
46	√	√	√					3	92	60
47			√					1	50	20
48	√							1	50	20
49	√	√	√				√	4	**92**	**80**
50	√	√	√	√				4	69	60
51	√		√					2	47	20
52	√	√	√	√				4	53	40
53	√	√	√	√				4	83	20
54	√	√						2	82	60
55	√	√	√	√				4	**92**	**80**
56	√	√	√	√				4	83	60
57			√					1	91	60
58	√		√					2	100	60
TOTAL	77%	59%	84%	31%	0%	0%	16%	3	70%	60%

** Legend: "√" = present, " " = not present; light shaded results indicate adequate scores for understandability or actionability; bolded and dark shaded results indicate adequate scores for both understandability and actionability*

The median PEMAT understandability score was 70.0% (IQR 20, range 47-100) (Figure 3.6). Of 58 resources, 30 (51.7%) achieved an adequate understandability rating of ≥70%. The applicable PEMAT understandability items met by most resources were: does not expect the user to perform calculations (52 of 53; 98.1%), breaks down information into short sections (53 of 56; 94.6%), uses visual cues to draw attention to key points (48 of 55; 87.3%), and presents information in a logical sequence (47 of 58; 81.0%). PEMAT understandability items met by few resources were: provides a summary (8 of 47; 17.0%), visual aids reinforce rather than distract from the content (1 of 15; 6.7%), and visual aids have clear titles or captions (1 of 14; 7.1%).

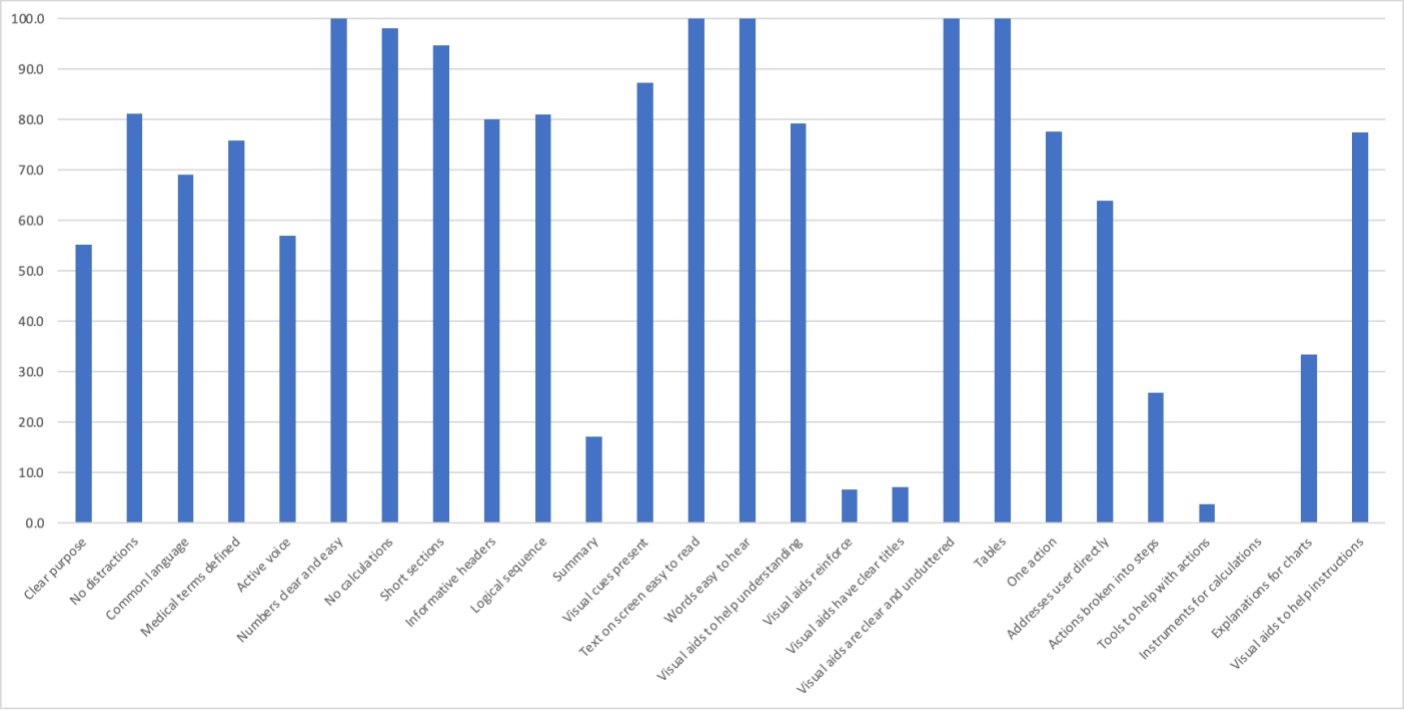


Figure 3.6 MAID resources for patients PEMAT scores (n=58)

The median PEMAT actionability score was 60.0% (IQR 25, range 0-86). Of 58 resources, 11 (19.0%) achieved an adequate actionability rating of ≥70%. Appropriate PEMAT actionability items mostly met were: clearly identifies at least one action the user can take (45 of 58; 77.6%), uses visual aids to make it easier to act on instructions (41 of 53; 77.4%), and addresses the user directly when describing actions (37 of 58; 63.8%). PEMAT actionability

items rarely met were: explains how to use the charts, graphs, tables, or diagrams to take actions (1 of 3; 33.3%), breaks down the action into manageable, explicit steps (15 of 58; 25.9%), and provides a tangible tool whenever it could help the user take actions (2 of 53; 3.8%). For example, one resource that expected the user to perform calculations did not provide simple instructions for how to perform the calculation.

Interpretations

Of 58 publicly available resources on MAID in Canada, most reported on 2021 updated eligibility criteria according to Bill C-7 and none were patient decision aids. According to the PEMAT, approximately half of the resources were understandable and few were actionable. These findings lead to the following discussion points.

First, many MAID resources were updated at five and thirteen months after the new 2021 Bill C-7 legislation expanded those who were eligible for MAID (Government of Canada, 2021b). This is reassuring given the increased complexity with this revised legislation and challenges with ensuring educational resources are up-to-date as new evidence emerges (Stacey et al., 2019). If publicly available MAID resources are outdated, newly eligible individuals may be deterred from seeking more information about MAID or may seek access to MAID based on unrealistic expectations. With the finality and legal aspects of MAID, it is essential that MAID resources for patients are continually updated as legislation changes (Coulter et al., 1999; Pellisé & Sell, 2009).

Second, most MAID resources for patients were produced by governments and organizations. Nevertheless, none of the 58 resources met the IPDAS criteria to be defined as a patient decision aid; the gold standard for achieving informed values-congruent decisions (Stacey & Volk, 2021). Our findings revealed that the least met IPDAS defining criteria were a description of the options including the potential benefits and harms, and explicit guidance for

clarifying values. Few resources listed alternative options, despite there being other treatments that could be considered for relieving or easing unbearable suffering apart from MAID, including palliative care, counselling services, mental health care, disability support services, and community services (Government of Canada, 2021a). Previous studies reported that patients who used patient decision aids for end of life decisions about their goals of care, often experienced less decisional conflict and were more comfortable discussing the decision (El-Jawahri et al., 2010; Stein et al., 2013; Yun et al., 2011). However, our findings cause us to reflect on the unusual nature of patient decision aids for people considering MAID. Some health providers and allied healthcare staff are uneasy with supporting decision-making in which one of the options presented involves death of the patient. In a pilot project to obtain feedback on a draft patient decision aid developed to guide pastoral workers providing nondirective discussion of EOL care options, some pastoral workers were reluctant to consider using it as they were morally and religiously against MAID (Louisa Blair, DPTh, e-mail correspondence).

Lastly, there is a need to improve both the understandability and actionability of MAID patient education resources. Strategies for improving understandability include providing a summary of key points, presenting resources in an active voice, and using visual images or diagrams (Fajardo et al., 2019; Shoemaker et al., 2014; Yiu et al., 2020). Actionability of decision support resources may be improved by breaking down actions into manageable steps and providing a tangible tool to help the user take action (Lipari et al., 2019; Shoemaker et al., 2014). Tools, such as checklists, improve understanding and recall when provided in decision support resources (Yiu et al., 2020). Many patient decision aids are structured in a series of steps to guide the process of deliberating and communicating with others (Rahn et al., 2021).

Our environmental scan has strengths and limitations to consider when interpreting the findings. The search strategy was comprehensive for Canadian federal, provincial, and territorial governments, as well as relevant Canadian organizations' websites. However, given the changing nature of websites, it is possible that previously published resources may no longer be available or be moved to different webpages making them harder to locate. Another strength was that the appraisal of resources using IPDAS and PEMAT was done independently by two authors. Finally, given the search was done in English and once an English resource was identified we looked for its availability in other languages, it is possible that we missed some non-English resources.

Our environmental scan identified and quality appraised 58 Canadian resources about MAID for patients, of which most accurately reflect the 2021 legislation on eligibility criteria and none were patient decision aids. Only about half met the adequate PEMAT health literacy scores for understandability and few for actionability. Therefore, current MAID resources are more limited for guiding decision-making or for supporting Canadians. The quality of MAID resources for patients should be improved so that Canadians can understand the MAID process and make a values-based, informed decision. Given the difficult and preference-sensitive nature of MAID decisions, future research should also investigate if a patient decision aid could support people considering MAID decisions.

References

Adams, J. A., Bailey, D. E., Anderson, R. A., & Docherty, S. L. (2011). Nursing Roles and Strategies in End-of-Life Decision Making in Acute Care: A Systematic Review of the Literature. *Nursing Research and Practice*, *2011*, 1–15. https://doi.org/10.1155/2011/527834

Ajzen, I., & Fishbein, M. (1980). *Understanding attitudes and predicting social behaviour*. Prentice Hall.

Bandura, A. (1982). Self-efficacy mechanism in human agency. *American Psychologist*, *37*(2), 122–147. https://doi.org/10.1037/0003-066X.37.2.122

Banner, D., Schiller, C. J., & Freeman, S. (2019). Medical assistance in dying: A political issue for nurses and nursing in Canada. *Nursing Philosophy*, *20*(4). https://doi.org/10.1111/nup.12281

Beuthin, R., Bruce, A., & Scaia, M. (2018). Medical assistance in dying (MAiD): Canadian nurses' experiences. *Nursing Forum*, *53*(4), 511–520. https://doi.org/10.1111/nuf.12280

Brooks, L. (2019). Health Care Provider Experiences of and Perspectives on Medical Assistance in Dying: A Scoping Review of Qualitative Studies. *Canadian Journal on Aging / La Revue Canadienne Du Vieillissement*, *38*(03), 384–396. https://doi.org/10.1017/S0714980818000600

Bruce, A., & Beuthin, R. (2019). Medically Assisted Dying in Canada: "Beautiful Death" Is Transforming Nurses' Experiences of Suffering. *Canadian Journal of Nursing Research*, 084456211985623. https://doi.org/10.1177/0844562119856234

Canadian Nurses Association. (2019). *Advanced Practice Nursing: A Pan-Canadian Framework.*

Charlton, P., Doucet, S., Azar, R., Nagel, D. A., Boulos, L., Luke, A., Mears, K., Kelly, K. J., & Montelpare, W. J. (2019). The use of the environmental scan in health services delivery

research: a scoping review protocol. *BMJ Open*, *9*(9), e029805. https://doi.org/10.1136/bmjopen-2019-029805

College of Nurses of Ontario. (2021). *Guidance on Nurses' Roles in Medical Assistance in Dying*.

Coulter, A., Entwistle, V., & Gilbert, D. (1999). Sharing decisions with patients: is the information good enough? *BMJ*, *318*(7179), 318–322. https://doi.org/10.1136/bmj.318.7179.318

Department of Justice. (2021). *Medical Assistance in Dying*. https://www.justice.gc.ca/eng/cj-jp/ad-am/index.html

Durand, M. A., Carpenter, L., Dolan, H., Bravo, P., Mann, M., Bunn, F., & Elwyn, G. (2014). Do interventions designed to support shared decision- making reduce health inequalities? A systematic review and meta-analysis. *PLoS ONE*, *9*(4). https://doi.org/10.1371/journal.pone.0094670

El-Jawahri, A., Podgurski, L. M., Eichler, A. F., Plotkin, S. R., Temel, J. S., Mitchell, S. L., Chang, Y., Barry, M. J., & Volandes, A. E. (2010). Use of Video to Facilitate End-of-Life Discussions With Patients With Cancer: A Randomized Controlled Trial. *Journal of Clinical Oncology*, *28*(2), 305–310. https://doi.org/10.1200/JCO.2009.24.7502

Elmore, J., Wright, D. K., & Paradis, M. (2018). Nurses' moral experiences of assisted death: A meta-synthesis of qualitative research. *Nursing Ethics*, *25*(8), 955–972. https://doi.org/10.1177/0969733016679468

Elwyn, G., Durand, M. A., Song, J., Aarts, J., Barr, P. J., Berger, Z., Cochran, N., Frosch, D., Galasiński, D., Gulbrandsen, P., Han, P. K. J., Härter, M., Kinnersley, P., Lloyd, A., Mishra, M., Perestelo-Perez, L., Scholl, I., Tomori, K., Trevena, L., … Van der Weijden, T.

(2017). A three-talk model for shared decision making: multistage consultation process. *BMJ*, j4891. https://doi.org/10.1136/bmj.j4891

Fajardo, M. A., Balthazaar, G., Zalums, A., Trevena, L., & Bonner, C. (2019). Favourable understandability, but poor actionability: An evaluation of online type 2 diabetes risk calculators. *Patient Education and Counseling*, *102*(3), 467–473. https://doi.org/10.1016/j.pec.2018.10.014

Feenstra, B., Lawson, M. L., Harrison, D., Boland, L., & Stacey, D. (2015). Decision coaching using the Ottawa family decision guide with parents and their children: a field testing study. *BMC Medical Informatics and Decision Making*, *15*(1), 5. https://doi.org/10.1186/s12911-014-0126-2

Fujioka, J. K., Mirza, R. M., McDonald, P. L., & Klinger, C. A. (2018). Implementation of Medical Assistance in Dying: A Scoping Review of Health Care Providers' Perspectives. *Journal of Pain and Symptom Management*, *55*(6), 1564-1576.e9. https://doi.org/10.1016/j.jpainsymman.2018.02.011

Government of Canada. (2017). *Annual Report on the Operation of the Canadian Multiculturalism Act 2015-2016*.

Government of Canada. (2021a). *Canada's new medical assistance in dying (MAiD) law*. https://www.justice.gc.ca/eng/cj-jp/ad-am/bk-di.html

Government of Canada. (2021b). *Medical assistance in dying - Canada. ca*. https://www.canada.ca/en/health-canada/services/medical-assistance-dying.html

Graham, P., Evitts, T., & Thomas-MacLean, R. (2008). Environmental scans: how useful are they for primary care research? *Canadian Family Physician Medecin de Famille Canadien*, *54*(7), 1022–1023. http://www.ncbi.nlm.nih.gov/pubmed/18625830

Hatch, T. F., & Pearson, T. G. (1998). Using environmental scans in educational needs assessment. *Journal of Continuing Education in the Health Professions*, *18*(3), 179–184. https://doi.org/10.1002/chp.1340180308

Health Canada. (2021). *Second Annual Report on Medical Assistance in Dying in Canada, 2020*.

Ho, A., Joolaee, S., Jameson, K., & Ng, C. (2021). The Seismic Shift in End-of-Life Care: Palliative Care Challenges in the Era of Medical Assistance in Dying. *Journal of Palliative Medicine*, *24*(2), 189–194. https://doi.org/10.1089/jpm.2020.0185

Ho, A., Norman, J. S., Joolaee, S., Serota, K., Twells, L., & William, L. (2021). How does Medical Assistance in Dying affect end-of-life care planning discussions? Experiences of Canadian multidisciplinary palliative care providers. *Palliative Care and Social Practice, 15,* 263235242110459. https://doi.org/10.1177/26323524211045996

Hoefel, L., Lewis, K. B., O'Connor, A., & Stacey, D. (2020). 20th Anniversary Update of the Ottawa Decision Support Framework: Part 2 Subanalysis of a Systematic Review of Patient Decision Aids. *Medical Decision Making*, *40*(4), 522–539. https://doi.org/10.1177/0272989X20924645

Hoefel, L., O'Connor, A. M., Lewis, K. B., Boland, L., Sikora, L., Hu, J., & Stacey, D. (2020). 20th Anniversary Update of the Ottawa Decision Support Framework Part 1: A Systematic Review of the Decisional Needs of People Making Health or Social Decisions. *Medical Decision Making*, *40*(5), 555–581. https://doi.org/10.1177/0272989X20936209

Jolicoeur, L. J. A., O'Connor, A. M., Hopkins, L., & Graham, I. D. (2009). Women's decision-making needs related to treatment for recurrent ovarian cancer: A pilot study. *Canadian Oncology Nursing Journal*, *19*(3), 117–121. https://doi.org/10.5737/1181912x193117121

Joseph-Williams, N., Elwyn, G., & Edwards, A. (2014). Knowledge is not power for patients: A

systematic review and thematic synthesis of patient-reported barriers and facilitators to shared decision making. *Patient Education and Counseling*, *94*(3), 291–309. https://doi.org/10.1016/j.pec.2013.10.031

Joseph-Williams, N., Newcombe, R., Politi, M., Durand, M. A., Sivell, S., Stacey, D., O'Connor, A., Volk, R. J., Edwards, A., Bennett, C., Pignone, M., Thomson, R., & Elwyn, G. (2014). Toward minimum standards for certifying patient decision aids: A modified delphi consensus process. *Medical Decision Making*, *34*(6), 699–710. https://doi.org/10.1177/0272989X13501721

Jull, J., Köpke, S., Boland, L., Coulter, A., Dunn, S., Graham, I. D., Hutton, B., Kasper, J., Kienlin, S. M., Légaré, F., Lewis, K. B., Lyddiatt, A., Osaka, W., Rader, T., Rahn, A. C., Rutherford, C., Smith, M., & Stacey, D. (2019). Decision coaching for people making healthcare decisions. *Cochrane Database of Systematic Reviews*. https://doi.org/10.1002/14651858.CD013385

Keeney, R. L., & Raiffa, H. (1976). *Decisions with Multiple Objectives: Preferences and Value Tradeoffs*. John Wiley and Sons.

Lamb, A., Martin-Misener, R., Bryant-Lukosius, D., & Latimer, M. (2018). Describing the leadership capabilities of advanced practice nurses using a qualitative descriptive study. *Nursing Open*, *5*(3), 400–413. https://doi.org/10.1002/nop2.150

Lawson, M. L., Shephard, A. L., Feenstra, B., Boland, L., Sourial, N., & Stacey, D. (2020). Decision coaching using a patient decision aid for youth and parents considering insulin delivery methods for type 1 diabetes: a pre/post study. *BMC Pediatrics*, *20*(1), 1. https://doi.org/10.1186/s12887-019-1898-4

Lipari, M., Berlie, H., Saleh, Y., Hang, P., & Moser, L. (2019). Understandability, actionability,

and readability of online patient education materials about diabetes mellitus. *American Journal of Health-System Pharmacy*, *76*(3), 182–186. https://doi.org/10.1093/ajhp/zxy021

Maddah-Ali, M. A., & Niesen, U. (2014). Fundamental Limits of Caching. *IEEE Transactions on Information Theory*, *60*(5), 2856–2867. https://doi.org/10.1109/TIT.2014.2306938

Martin, R. W., Brogård Andersen, S., O'Brien, M. A., Bravo, P., Hoffmann, T., Olling, K., Shepherd, H. L., Dankl, K., Stacey, D., & Dahl Steffensen, K. (2021). Providing Balanced Information about Options in Patient Decision Aids: An Update from the International Patient Decision Aid Standards. *Medical Decision Making*, *41*(7), 780–800. https://doi.org/10.1177/0272989X211021397

Maurer, M., Siegel, J. E., Firminger, K. B., Lowers, J., Dutta, T., & Chang, J. S. (2021). Lessons Learned from Developing Plain Language Summaries of Research Studies. *HLRP: Health Literacy Research and Practice*, *5*(2). https://doi.org/10.3928/24748307-20210524-01

Mills, A., Wortzman, R., Bean, S., & Selby, D. (2020). Allied Health Care Providers Participating in Medical Assistance in Dying. *Journal of Hospice & Palliative Nursing*, *22*(3), 220–228. https://doi.org/10.1097/NJH.0000000000000646

Murray, M.-A. (2010). *When you need extra care, should you receive it at home or in a facility? A decision aid to prepare you to discuss the options*.

Murray, M. A., Stacey, D., Wilson, K., & O'Connor, A. (2010). Skills training to support patients considering place of end-of-life care: a randomized control trial. *Journal of Palliative Care*, *26*(2), 112–121.

Muscat, D. M., Smith, J., Mac, O., Cadet, T., Giguere, A., Housten, A. J., Langford, A. T., Smith, S. K., Durand, M.-A., & McCaffery, K. (2021). Addressing Health Literacy in Patient Decision Aids: An Update from the International Patient Decision Aid Standards.

Medical Decision Making, *41*(7), 848–869. https://doi.org/10.1177/0272989X211011101

Nuhn, A., Holmes, S., Kelly, M., Just, A., Shaw, J., & Wiebe, E. (2018). Experiences and perspectives of people who pursued medical assistance in dying: Qualitative study in Vancouver, BC. *Canadian Family Physician Medecin de Famille Canadien*, *64*(9), e380–e386. http://www.ncbi.nlm.nih.gov/pubmed/30209111

O'Connor, A. M., Drake, E. R., Wells, G. A., Tugwell, P., Laupacis, A., & Elmslie, T. (2003). A survey of the decision-making needs of Canadians faced with complex health decisions. *Health Expectations*, *6*(2), 97–109. https://doi.org/10.1046/j.1369-6513.2003.00215.x

O'Connor, A. M., Tugwell, P., Wells, G. A., Elmslie, T., Jolly, E., Hollingworth, G., McPherson, R., Bunn, H., Graham, I., & Drake, E. (1998). A decision aid for women considering hormone therapy after menopause: decision support framework and evaluation. *Patient Education and Counseling*, *33*(3), 267–279. https://doi.org/10.1016/S0738-3991(98)00026-3

O'Connor, A., Stacey, D., & Boland, L. (2015). *Introduction to the Ottawa Decision Support Tutorial*.

Ontario Ministry of Health and Longterm Care. (2021). *Medical Assistance in Dying - Health Care Professionals - MOH*. https://www.health.gov.on.ca/en/pro/programs/maid/#maid

Orem, D. . (1995). *Nursing: Concepts of practice* (5th ed.). Mosby.

Page, M. J., McKenzie, J. E., Bossuyt, P. M., Boutron, I., Hoffmann, T. C., Mulrow, C. D., Shamseer, L., Tetzlaff, J. M., Akl, E. A., Brennan, S. E., Chou, R., Glanville, J., Grimshaw, J. M., Hróbjartsson, A., Lalu, M. M., Li, T., Loder, E. W., Mayo-Wilson, E., McDonald, S., … Moher, D. (2021). The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. *BMJ (Clinical Research Ed.)*, *372*, n71. https://doi.org/10.1136/bmj.n71

Patient Decision Aids Research Group. (2022). *A to Z Inventory - Patient Decision Aids - Ottawa Hospital Research Institute*. https://decisionaid.ohri.ca/AZinvent.php

Pellisé, F., & Sell, P. (2009). Patient information and education with modern media: the Spine Society of Europe Patient Line. *European Spine Journal*, *18*(S3), 395–401. https://doi.org/10.1007/s00586-009-0973-1

Pesut, B., Thorne, S., Schiller, C., Greig, M., Roussel, J., & Tishelman, C. (2020). Constructing Good Nursing Practice for Medical Assistance in Dying in Canada: An Interpretive Descriptive Study. *Global Qualitative Nursing Research*, *7*. https://doi.org/10.1177/2333393620938686

Pesut, B., Thorne, S., Wright, D. K., Schiller, C., Huggins, M., Puurveen, G., & Chambaere, K. (2021). Navigating medical assistance in dying from Bill C-14 to Bill C-7: a qualitative study. *BMC Health Services Research*, *21*(1), 1–16. https://doi.org/10.1186/s12913-021-07222-5

Rahn, A. C., Jull, J., Boland, L., Finderup, J., Loiselle, M.-C., Smith, M., Köpke, S., & Stacey, D. (2021). Guidance and/or Decision Coaching with Patient Decision Aids: Scoping Reviews to Inform the International Patient Decision Aid Standards (IPDAS). *Medical Decision Making*, *41*(7), 938–953. https://doi.org/10.1177/0272989X21997330

Shoemaker, S. J., Wolf, M. S., & Brach, C. (2014). Development of the Patient Education Materials Assessment Tool (PEMAT): A new measure of understandability and actionability for print and audiovisual patient information. *Patient Education and Counseling*, *96*(3), 395–403. https://doi.org/10.1016/j.pec.2014.05.027

Stacey, D., Légaré, F., Boland, L., Lewis, K. B., Loiselle, M.-C., Hoefel, L., Garvelink, M., & O'Connor, A. (2020). 20th Anniversary Ottawa Decision Support Framework: Part 3

Overview of Systematic Reviews and Updated Framework. *Medical Decision Making*, *40*(3), 379–398. https://doi.org/10.1177/0272989X20911870

Stacey, D., Légaré, F., Lewis, K., Barry, M. J., Bennett, C. L., Eden, K. B., Holmes-Rovner, M., Llewellyn-Thomas, H., Lyddiatt, A., Thomson, R., & Trevena, L. (2017). Decision aids for people facing health treatment or screening decisions. *Cochrane Database of Systematic Reviews*. https://doi.org/10.1002/14651858.CD001431.pub5

Stacey, D., Légaré, F., Pouliot, S., Kryworuchko, J., & Dunn, S. (2010). Shared decision making models to inform an interprofessional perspective on decision making: A theory analysis. *Patient Education and Counseling*, *80*(2), 164–172. https://doi.org/10.1016/j.pec.2009.10.015

Stacey, D., Ludwig, C., Archambault, P., Smith, M., Carley, M., Plourde, K., Boland, L., Gogovor, A., Graham, I. D., Kobewka, D., McLean, R., Nelson, M., Taljaard, M., Vanderspank, B., & Legare, F. (2022). *Decisions and decision making needs of Canadians during the COVID-19 pandemic: A national survey*.

Stacey, D., Suwalska, V., Boland, L., Lewis, K. B., Presseau, J., & Thomson, R. (2019). Are Patient Decision Aids Used in Clinical Practice after Rigorous Evaluation? A Survey of Trial Authors. *Medical Decision Making*, *39*(7), 805–815. https://doi.org/10.1177/0272989X19868193

Stacey, D., & Volk, R. J. (2021). The International Patient Decision Aid Standards (IPDAS) Collaboration: Evidence Update 2.0. *Medical Decision Making*, *41*(7), 729–733. https://doi.org/10.1177/0272989X211035681

Statistics Canada. (2020). *Deaths, 2019*.

Statistics Canada. (2022). *Increasing diversity of languages, other than English or French,*

spoken at home.

Stein, R. A., Sharpe, L., Bell, M. L., Boyle, F. M., Dunn, S. M., & Clarke, S. J. (2013). Randomized Controlled Trial of a Structured Intervention to Facilitate End-of-Life Decision Making in Patients With Advanced Cancer. *Journal of Clinical Oncology*, *31*(27), 3403–3410. https://doi.org/10.1200/JCO.2011.40.8872

Suva, G., Penney, T., & McPherson, C. J. (2019). Medical Assistance in Dying: A Scoping Review to Inform Nurses' Practice. *Journal of Hospice and Palliative Nursing*, *21*(1), 46–53. https://doi.org/10.1097/NJH.0000000000000486

Thiele, T., & Dunsford, J. (2019). Nurse leaders' role in medical assistance in dying: A relational ethics approach. *Nursing Ethics*, *26*(4), 993–999. https://doi.org/10.1177/0969733017730684

Tversky, A., & Kahneman, D. (1981). *The framing of decisions and the psychology of choice*. Science.

Variath, C., Peter, E., Cranley, L., Godkin, D., & Just, D. (2020). Relational influences on experiences with assisted dying: A scoping review. *Nursing Ethics*, *27*(7), 1501–1516. https://doi.org/10.1177/0969733020921493

Vishnevetsky, J., Walters, C. B., & Tan, K. S. (2018). Interrater reliability of the Patient Education Materials Assessment Tool (PEMAT). *Patient Education and Counseling*, *101*(3), 490–496. https://doi.org/10.1016/j.pec.2017.09.003

Ward, V., Freeman, S., Callander, T., & Xiong, B. (2021). Professional experiences of formal healthcare providers in the provision of medical assistance in dying (MAiD): A scoping review. *Palliative and Supportive Care*, *19*(6), 744–758. https://doi.org/10.1017/S1478951521000146

Wiebe, E., Shaw, J., Green, S., Trouton, K., & Kelly, M. (2018). Reasons for requesting medical assistance in dying. *Canadian Family Physician Medecin de Famille Canadien*, *64*(9), 674–679. http://www.ncbi.nlm.nih.gov/pubmed/30209101

Wu, J. S. Y., Pinilla, J., Watson, M., Verma, S., & Olivotto, I. A. (2018). Medical Assistance in Dying for Cancer Patients One Year After Legalization: A Collaborative Approach at a Comprehensive Cancer Centre. *Current Oncology*, *25*(5), 486–489. https://doi.org/10.3747/co.25.4118

Yen, R. W., Smith, J., Engel, J., Muscat, D. M., Smith, S. K., Mancini, J., Perestelo-Pérez, L., Elwyn, G., O'Malley, A. J., Leyenaar, J. K., Mac, O., Cadet, T., Giguere, A., Housten, A. J., Langford, A., McCaffery, K., & Durand, M.-A. (2021). A Systematic Review and Meta-Analysis of Patient Decision Aids for Socially Disadvantaged Populations: Update from the International Patient Decision Aid Standards (IDPAS). *Medical Decision Making*, *41*(7), 870–896. https://doi.org/10.1177/0272989X211020317

Yiu, A., Ng, K. K., Lee, V. W., & Bajorek, B. V. (2020). Evaluating the Understandability and Actionability of Web-Based Education Materials for Patients Taking Non–vitamin K Oral Anticoagulants. *Therapeutic Innovation & Regulatory Science*, *54*(2), 476–483. https://doi.org/10.1007/s43441-019-00079-1

Yun, Y. H., Lee, M. K., Park, S., Lee, J. L., Park, J., Choi, Y. S., Lim, Y. K., Kim, S. Y., Jeong, H. S., Kang, J. H., Oh, H.-S., Park, J. C., Kim, S.-Y., Song, H. S., Ro, J., Lee, K. S., Heo, D. S., & Hong, Y. S. (2011). Use of a Decision Aid to Help Caregivers Discuss Terminal Disease Status With a Family Member With Cancer: A Randomized Controlled Trial. *Journal of Clinical Oncology*, *29*(36), 4811–4819. https://doi.org/10.1200/JCO.2011.35.3870

Chapter Four

Integrated Discussion

Introduction

The overarching aim of this thesis was to investigate how Canadian patients who are receiving Medical Assistance in Dying (MAID) are supported in their decision-making. This thesis was guided by the Ottawa Decision Support Framework (ODSF), a theoretical framework that structures a supported decision-making process. The ODSF guides health care practitioners (HCPs) and researchers in assessing the decisional needs of participants, providing decision support interventions such as patient decision aids (PtDAs), and evaluating the effects of decision support on decisional outcomes (Stacey et al., 2020). The ODSF framework was used to organize the evidence of the literature review (Chapter 2). I will briefly provide a summary from the literature review (Chapter 2) and the study that identified and appraised the quality of Canadian MAID resources for patients and families (Chapter 3). Then, I will provide an integrated discussion with the broader literature on MAID. Finally, I will discuss the implications of this research for nurses.

In Chapter Two, I described the current state of literature on how nurses support their patients who are considering MAID decisions at their end-of-life (EOL). Using narrative literature review methods, I searched multiple electronic databases (CINAHL, MEDLINE, Embase, and Scopus) using predefined search terms. Findings were structured according to the three key elements in the ODSF: (a) decisional needs; (b) interventions to support decision-making; and (c) decisional outcomes (O'Connor et al., 1998; Stacey et al., 2020). The literature review identified systematic reviews, scoping reviews, surveys, and studies about decisional needs of patients and family at EOL.

Interventions to support EOL decisions were providing information on EOL options, supporting the patient in their decisions, and advocating for the patient's preferences (Adams et al., 2011; Variath et al., 2020). Although there were studies evaluating PtDAs to support patients

and families making EOL decisions such as location of care, none were conducted in the setting of MAID decisions. Nurses were found to play three key roles in EOL decision-making. Nurses act as information brokers, supporters, and advocates to their patients who engage in EOL decisions, including MAID (Adams et al., 2011; Brooks, 2019; Variath et al., 2020). In summary, little is known about patients and their families' decisional needs about MAID decisions, there are no known PtDAs to support patients making these decisions, and it is unclear the extent to which MAID resources for patients are adequate for addressing their decisional needs.

To determine the quality of MAID resources, I conducted an environmental scan which identified publicly accessible resources about MAID in Canada for patients and their families (Chapter 3). I appraised each resource to determine if they were up to date with 2021 legislation, met standards to be identified as a PtDA using International Patient Decision Aids Standards (IPDAS) defining criteria, and met standards for health literacy using the Patient Education Material Assessment Tool (PEMAT). Of 58 identified resources, 41 (75.9%) provided eligibility information consistent with the 2021 MAID legislation and four resources did not discuss eligibility. None met the criteria to be defined as a PtDA, the gold standard of decision support tools (Stacey & Volk, 2021). While the mean PEMAT understandability score was 70.0%, only 30 of 58 resources (51.7%) achieved an adequate score of ≥70%. The mean PEMAT actionability score was 60.0%; 11 of 58 resources (19.0%) achieved an adequate actionability score of ≥70%. The study found that there is a need to improve both the understandability and actionability of MAID patient education resources. In summary, Canadian publicly available MAID resources are mostly up to date but could be improved for those with lower health literacy and be better structured to support decision-making.

Integrated Discussion

MAID resources should be accessible to all Canadians. The environmental scan of MAID resources (Chapter 3) revealed numerous MAID resources that are publicly accessible, but they are not necessarily fully accessible to Canadians who have lower health literacy. In the literature review (Chapter 2), one strategy to make scientific resources more accessible to Canadians of varying health literacy is by using plain language (Maurer et al., 2021). Both the IPDAS and PEMAT stress the importance of plain, everyday language in their guidelines (Maurer et al., 2021; Shoemaker et al., 2014). For example, IPDAS requires an 8th grade or less reading level as a metric for encouraging plain language (Muscat et al., 2021). Plain language is not only helpful for people of lower literacy levels, but it is often beneficial for all readers, including people with disabilities and those who are not experts in a topic (Maurer et al., 2021; Muscat et al., 2021).

Although PtDAs are more likely to benefit patients of lower health literacy (Chapter 2), no PtDAs were identified in the environmental scan (Chapter 3). Systematic reviews of 19 studies on interventions designed to support decision-making and of 25 PtDAs and other shared decision-making interventions for socially disadvantaged populations suggest that PtDAs are beneficial for people of lower socioeconomic status backgrounds (Durand et al., 2014; Yen et al., 2021).

Another method to improve accessibility is to create resources in the different languages for the target population. However, most MAID resources were written solely in English, with few being available in both of Canada's national languages, English and French. Only one resource from British Columbia was available in six languages (Chapter 3). As Canada prides itself in being multicultural with a large number of immigrants (Government of Canada, 2017), this lack of language variety of MAID resources is surprising. As of 2022, 4.6 million Canadians (12.7%) speak a language other than English and French predominately at home (Statistics

Canada, 2022). This has increased from 9.7% of Canadians in 2001. MAID resources would better support all Canadians if they were available in the most common languages spoken in Canada including, Chinese languages, Punjabi, Spanish, Italian, German, Tagalog, Arabic, Portuguese, Polish, Urdu, and Indigenous languages.

Nurses have various roles that can support EOL decision-making. Nurses are the healthcare professionals that spend the most time with their patients; they have frequent and regular contact which allows them to develop special, trusting relationships at their EOL (Brooks, 2019; Ward et al., 2021). Therefore, nurses continue to play various roles in their patients' EOL decision-making, including (a) information broker, (b) supporter, and (c) advocate (Adams et al., 2011; Variath et al., 2020). More specifically, at the patient's EOL, nurses help patients understand the EOL process, demonstrate compassion and empathy to their patients, and communicate with the medical team on behalf of the patient (Variath et al., 2020).

Nurses help patients understand the EOL options and processes at EOL by providing them with information resources on palliative care and MAID. However, none of the resources identified in the literature review (Chapter 2) or environmental scan (Chapter 3) discuss both palliative care and MAID together. When patients are considering EOL care options, quality resources to support decision-making need to present all options in a balanced format to facilitate patients making trade-offs across options. According to the ODSF (Stacey et al., 2020), evidence-informed resources that are not designed to as PtDAs can be delivered by decision coaches. Decision coaching is non-directive and includes assessing the patient's decisional needs, providing information about the options available, verifying the patient's understanding, and clarifying their values. Decision coaching is tailored to support each patient's situation (O'Connor et al., 1998; Stacey et al., 2020). This involves nurses establishing rapport with their

patients, providing information on their options for EOL care (including palliative care and MAID), and asking patients about the personal importance associated with the different features and outcomes of their options (Rahn et al., 2021). However, nurses work in busy clinical environments, particularly since the COVID-19 pandemic, with little time for patient teaching. However, if nurses defer to the publicly available patient resources (Chapter 3), they are likely to be inadequate given their limitations related to understandability, actionability, and decision support; thereby increasing demands on nurses to discuss their content, answer patients' questions, and support them in meeting their decision-making needs.

Specialized or generalist nurses can support MAID decisions. Although MAID has been legal in Canada since 2016, there continues to be confusion about the specific role of nurses in MAID and many Canadian nurses are uncertain about their scope of practice related to MAID (Banner et al., 2019; Thiele & Dunsford, 2019). However, EOL care is within the scope of nursing practice across most clinical areas and nurses have varying degrees of expertise based on their education and practice. For example, Canadian nurses can become certified in hospice and palliative care with the Canadian Nurses Association by way of a written examination (Canadian Nurses Association, 2022) and, to maintain certification, nurses are required to accumulate 100 hours of related clinical learning over a five year term. The hospice palliative care nurse who earns this certification must understand the ethics and legality of MAID. Although the Canadian Nurses Association offered a MAID Learning Certificate, the learning certificate has not been updated to reflect Bill C-7 and has been removed from the website (Personal Communication, Professional Development, Canadian Nurses Association). Whether or not nurses achieve this advanced level of education, registered nurses are clinicians who are expected to provide safe, competent, and evidence-informed care to patients throughout their lives, including EOL that

may involve MAID (Health Canada, 2021). Hence, nurses can benefit from having access to evidence-informed resources providing information on EOL care options inclusive of MAID. Therefore, no matter their level of expertise, it is crucial for nurses in all specialties to understand MAID, their role in the process, and where to find evidence-informed quality information resources.

There are multiple roles for nurses as part of the MAID process. Nurse practitioners (NPs) may assess and provide MAID in Canada depending on the province where they live and hold a nursing license (Government of Canada, 2021a). Registered nurses and registered practical nurses may participate in MAID by providing nursing care during the procedure and assisting a MAID provider (College of Nurses of Ontario, 2021). MAID navigators may be nurses who specialize in the MAID process and work as part of an interprofessional team to coordinate the necessary functions of MAID for healthcare providers and patients (Wu et al., 2018). Part of the MAID navigator role includes: (a) educating patients and their families on MAID and providing available evidence-informed educational resources; and (b) educating generalist nurses about MAID. As MAID undergoes legislation changes, these MAID navigators continue to provide up-to-date education.

Implications for Nursing

The results from this thesis have several implications for nursing. In Table 4.1, I discuss the implications for advanced practice nurses (APNs) through the following core competencies: (a) direct clinical practice, (b) consultation and collaboration, (c) leadership, (d) research, and (e) education.

Table 4.1. Implications of findings for APNs

APN Competency	**Implications of thesis findings for APNs**
Direct Clinical Practice	- Verifies understanding and answer questions about the MAID process

	- Identifies available resources for patients and caregivers - Supports patients and families through the decision-making process - Supplements resources with guidance in decision-making - Attends MAID cases to provide clinical support
Consultation and Collaboration	- Collaborates with individuals, families, and healthcare providers regarding EOL care options - Provides clinical consultation for difficult cases
Leadership (clinical, professional, systems)	- Continues education through professional development courses - Engages in leadership and managerial roles to their team in their organization, provincially, and nationally
Education	- Educates patients and their families on MAID - Educates generalist nurses on the MAID process - Develops MAID resources for patients and families
Research	- Engages in research regarding MAID, nurses' role in MAID, and the experiences of patients who consider MAID

Direct clinical practice

Clinical practice is the central core of APN roles (Lamb et al., 2018). APNs provide specialized clinical practice using a patient-centered care approach that is holistic and integrative (Canadian Nurses Association, 2019). More specifically, APNs engage in advanced assessments, analyze the patients complex lived experiences, and disseminate knowledge to their patients (Canadian Nurses Association, 2019). Within the speciality of MAID, the APN completes the intake assessment for complex patients who considers MAID, helps them understand the MAID process using their specialized knowledge and various delivery methods including pamphlets and publications, and supports the patient and their loved ones through the decision-making process, Given the quality and readability of publicly available Canadian MAID resources (Chapter 3), APNs verify patients' understanding and guide them the process of making an informed, values-based decisions (Canadian Nurses Association, 2019). Finally,

APNs attend MAID cases and provide clinical support to the patient (e.g., ensuring that their intravenous line is patent and documenting during the procedure).

Consultation and collaboration

Another core competency of APNs is consultation and collaboration. It is necessary for APNs to both consult and collaborate with their colleagues across professions and at the national level (Canadian Nurses Association, 2019). They coordinate interprofessional teams and work with their colleagues to gather information about their patients. APNs specializing in MAID are well positioned to advocate for the patients' values throughout the MAID process during discussions with the interprofessional team. They may also provide clinical consultation for complex MAID cases regionally and nationally.

Leadership

APNs are clinical leaders in their specialized areas (Lamb et al., 2018). Furthermore, APNs are agents of change involved in identifying and addressing issues that promote high-quality patient centered care. For example, the MAID APN can provide leadership within educational and quality improvement committees to enhance the quality of MAID services within their organization. Nursing leadership activities can also support the enhancement of nursing practice, education of nurses, and supporting research (Canadian Nurses Association, 2019).

Education

The APN is committed to the professional growth of all HCPs, patients, and their families related to their area of expertise (Canadian Nurses Association, 2019). APNs continue their lifelong learning by enrolling in professional development courses, which includes being up to date as MAID legislation changes. Through providing information and training sessions on

MAID and the use of MAID resources, APNs educate patients, their families, and HCPs (e.g., physicians, social workers, physiotherapists, and occupational therapists) on the current context of MAID. APNs act as mentors and role models for nursing students, novice nurses, and/or other members of the interprofessional health team. This includes precepting and mentoring graduate students and sharing their vast knowledge on the MAID legislation and process.

Research

APNs are committed to creating, synthesizing, critiquing, and applying research evidence to their practice (Canadian Nurses Association, 2019). This may involve participating in upcoming research related to their specialty area. APNs work with the interprofessional research team to support research as a primary investigator, collaborator, or knowledge user. They may also disseminate evidence-based research to their colleagues and peers through developing evidence-based clinical programs to help enhance nursing practice, or present at nursing conferences, and publish in peer-reviewed journals. The results from this thesis have provided direction for future research in decision-making in EOL decisions. An example of a research project for the APN could be to engage in qualitative interviews to determine the registered nurses' roles in supporting decision-making for patients who are considering MAID (Appendix D).

Conclusion

This thesis aspired to investigate how Canadian patients who are considering MAID are being supported in making this decision. The literature review (Chapter Two) identified gaps in knowledge, while the environmental scan (Chapter Three) appraised Canadian MAID resources that are publicly available to support patients facing this decision. There are 58 Canadian MAID resources, mostly updated with the latest 2021 legislation for eligibility but these resources are limited in their ability to support people of lower health literacy and those experiencing difficulty

making this decision. Guided by the ODSF, the thesis findings suggest that nurses are paramount in the involvement of MAID decision-making.

References

Adams, J. A., Bailey, D. E., Anderson, R. A., & Docherty, S. L. (2011). Nursing Roles and Strategies in End-of-Life Decision Making in Acute Care: A Systematic Review of the Literature. *Nursing Research and Practice, 2011*, 1–15. https://doi.org/10.1155/2011/527834

Ajzen, I., & Fishbein, M. (1980). *Understanding attitudes and predicting social behaviour*. Prentice Hall.

Bandura, A. (1982). Self-efficacy mechanism in human agency. *American Psychologist*, *37*(2), 122–147. https://doi.org/10.1037/0003-066X.37.2.122

Banner, D., Schiller, C. J., & Freeman, S. (2019). Medical assistance in dying: A political issue for nurses and nursing in Canada. *Nursing Philosophy*, *20*(4). https://doi.org/10.1111/nup.12281

Beuthin, R., Bruce, A., & Scaia, M. (2018). Medical assistance in dying (MAiD): Canadian nurses' experiences. *Nursing Forum*, *53*(4), 511–520. https://doi.org/10.1111/nuf.12280

Brooks, L. (2019). Health Care Provider Experiences of and Perspectives on Medical Assistance in Dying: A Scoping Review of Qualitative Studies. *Canadian Journal on Aging / La Revue Canadienne Du Vieillissement*, *38*(03), 384–396. https://doi.org/10.1017/S0714980818000600

Bruce, A., & Beuthin, R. (2019). Medically Assisted Dying in Canada: "Beautiful Death" Is Transforming Nurses' Experiences of Suffering. *Canadian Journal of Nursing Research*, 084456211985623. https://doi.org/10.1177/0844562119856234

Canadian Nurses Association. (2019). *Advanced Practice Nursing: A Pan-Canadian Framework.*

Charlton, P., Doucet, S., Azar, R., Nagel, D. A., Boulos, L., Luke, A., Mears, K., Kelly, K. J., & Montelpare, W. J. (2019). The use of the environmental scan in health services delivery

research: a scoping review protocol. *BMJ Open*, *9*(9), e029805. https://doi.org/10.1136/bmjopen-2019-029805

College of Nurses of Ontario. (2021). *Guidance on Nurses' Roles in Medical Assistance in Dying*.

Coulter, A., Entwistle, V., & Gilbert, D. (1999). Sharing decisions with patients: is the information good enough? *BMJ*, *318*(7179), 318–322. https://doi.org/10.1136/bmj.318.7179.318

Department of Justice. (2021). *Medical Assistance in Dying*. https://www.justice.gc.ca/eng/cj-jp/ad-am/index.html

Durand, M. A., Carpenter, L., Dolan, H., Bravo, P., Mann, M., Bunn, F., & Elwyn, G. (2014). Do interventions designed to support shared decision- making reduce health inequalities? A systematic review and meta-analysis. *PLoS ONE*, *9*(4). https://doi.org/10.1371/journal.pone.0094670

El-Jawahri, A., Podgurski, L. M., Eichler, A. F., Plotkin, S. R., Temel, J. S., Mitchell, S. L., Chang, Y., Barry, M. J., & Volandes, A. E. (2010). Use of Video to Facilitate End-of-Life Discussions With Patients With Cancer: A Randomized Controlled Trial. *Journal of Clinical Oncology*, *28*(2), 305–310. https://doi.org/10.1200/JCO.2009.24.7502

Elmore, J., Wright, D. K., & Paradis, M. (2018). Nurses' moral experiences of assisted death: A meta-synthesis of qualitative research. *Nursing Ethics*, *25*(8), 955–972. https://doi.org/10.1177/0969733016679468

Elwyn, G., Durand, M. A., Song, J., Aarts, J., Barr, P. J., Berger, Z., Cochran, N., Frosch, D., Galasiński, D., Gulbrandsen, P., Han, P. K. J., Härter, M., Kinnersley, P., Lloyd, A., Mishra, M., Perestelo-Perez, L., Scholl, I., Tomori, K., Trevena, L., … Van der Weijden, T.

(2017). A three-talk model for shared decision making: multistage consultation process. *BMJ*, j4891. https://doi.org/10.1136/bmj.j4891

Fajardo, M. A., Balthazaar, G., Zalums, A., Trevena, L., & Bonner, C. (2019). Favourable understandability, but poor actionability: An evaluation of online type 2 diabetes risk calculators. *Patient Education and Counseling*, *102*(3), 467–473. https://doi.org/10.1016/j.pec.2018.10.014

Feenstra, B., Lawson, M. L., Harrison, D., Boland, L., & Stacey, D. (2015). Decision coaching using the Ottawa family decision guide with parents and their children: a field testing study. *BMC Medical Informatics and Decision Making*, *15*(1), 5. https://doi.org/10.1186/s12911-014-0126-2

Fujioka, J. K., Mirza, R. M., McDonald, P. L., & Klinger, C. A. (2018). Implementation of Medical Assistance in Dying: A Scoping Review of Health Care Providers' Perspectives. *Journal of Pain and Symptom Management*, *55*(6), 1564-1576.e9. https://doi.org/10.1016/j.jpainsymman.2018.02.011

Government of Canada. (2017). *Annual Report on the Operation of the Canadian Multiculturalism Act 2015-2016*.

Government of Canada. (2021a). *Canada's new medical assistance in dying (MAiD) law*. https://www.justice.gc.ca/eng/cj-jp/ad-am/bk-di.html

Government of Canada. (2021b). *Medical assistance in dying - Canada. ca*. https://www.canada.ca/en/health-canada/services/medical-assistance-dying.html

Graham, P., Evitts, T., & Thomas-MacLean, R. (2008). Environmental scans: how useful are they for primary care research? *Canadian Family Physician Medecin de Famille Canadien*, *54*(7), 1022–1023. http://www.ncbi.nlm.nih.gov/pubmed/18625830

Hatch, T. F., & Pearson, T. G. (1998). Using environmental scans in educational needs assessment. *Journal of Continuing Education in the Health Professions*, *18*(3), 179–184. https://doi.org/10.1002/chp.1340180308

Health Canada. (2021). *Second Annual Report on Medical Assistance in Dying in Canada, 2020*.

Ho, A., Joolaee, S., Jameson, K., & Ng, C. (2021). The Seismic Shift in End-of-Life Care: Palliative Care Challenges in the Era of Medical Assistance in Dying. *Journal of Palliative Medicine*, *24*(2), 189–194. https://doi.org/10.1089/jpm.2020.0185

Ho, A., Norman, J. S., Joolaee, S., Serota, K., Twells, L., & William, L. (2021). How does Medical Assistance in Dying affect end-of-life care planning discussions? Experiences of Canadian multidisciplinary palliative care providers. *Palliative Care and Social Practice, 15,* 263235242110459. https://doi.org/10.1177/26323524211045996

Hoefel, L., Lewis, K. B., O'Connor, A., & Stacey, D. (2020). 20th Anniversary Update of the Ottawa Decision Support Framework: Part 2 Subanalysis of a Systematic Review of Patient Decision Aids. *Medical Decision Making*, *40*(4), 522–539. https://doi.org/10.1177/0272989X20924645

Hoefel, L., O'Connor, A. M., Lewis, K. B., Boland, L., Sikora, L., Hu, J., & Stacey, D. (2020). 20th Anniversary Update of the Ottawa Decision Support Framework Part 1: A Systematic Review of the Decisional Needs of People Making Health or Social Decisions. *Medical Decision Making*, *40*(5), 555–581. https://doi.org/10.1177/0272989X20936209

Jolicoeur, L. J. A., O'Connor, A. M., Hopkins, L., & Graham, I. D. (2009). Women's decision-making needs related to treatment for recurrent ovarian cancer: A pilot study. *Canadian Oncology Nursing Journal*, *19*(3), 117–121. https://doi.org/10.5737/1181912x193117121

Joseph-Williams, N., Elwyn, G., & Edwards, A. (2014). Knowledge is not power for patients: A

systematic review and thematic synthesis of patient-reported barriers and facilitators to shared decision making. *Patient Education and Counseling*, *94*(3), 291–309. https://doi.org/10.1016/j.pec.2013.10.031

Joseph-Williams, N., Newcombe, R., Politi, M., Durand, M. A., Sivell, S., Stacey, D., O'Connor, A., Volk, R. J., Edwards, A., Bennett, C., Pignone, M., Thomson, R., & Elwyn, G. (2014). Toward minimum standards for certifying patient decision aids: A modified delphi consensus process. *Medical Decision Making*, *34*(6), 699–710. https://doi.org/10.1177/0272989X13501721

Jull, J., Köpke, S., Boland, L., Coulter, A., Dunn, S., Graham, I. D., Hutton, B., Kasper, J., Kienlin, S. M., Légaré, F., Lewis, K. B., Lyddiatt, A., Osaka, W., Rader, T., Rahn, A. C., Rutherford, C., Smith, M., & Stacey, D. (2019). Decision coaching for people making healthcare decisions. *Cochrane Database of Systematic Reviews*. https://doi.org/10.1002/14651858.CD013385

Keeney, R. L., & Raiffa, H. (1976). *Decisions with Multiple Objectives: Preferences and Value Tradeoffs*. John Wiley and Sons.

Lamb, A., Martin-Misener, R., Bryant-Lukosius, D., & Latimer, M. (2018). Describing the leadership capabilities of advanced practice nurses using a qualitative descriptive study. *Nursing Open*, *5*(3), 400–413. https://doi.org/10.1002/nop2.150

Lawson, M. L., Shephard, A. L., Feenstra, B., Boland, L., Sourial, N., & Stacey, D. (2020). Decision coaching using a patient decision aid for youth and parents considering insulin delivery methods for type 1 diabetes: a pre/post study. *BMC Pediatrics*, *20*(1), 1. https://doi.org/10.1186/s12887-019-1898-4

Lipari, M., Berlie, H., Saleh, Y., Hang, P., & Moser, L. (2019). Understandability, actionability,

and readability of online patient education materials about diabetes mellitus. *American Journal of Health-System Pharmacy*, *76*(3), 182–186. https://doi.org/10.1093/ajhp/zxy021

Maddah-Ali, M. A., & Niesen, U. (2014). Fundamental Limits of Caching. *IEEE Transactions on Information Theory*, *60*(5), 2856–2867. https://doi.org/10.1109/TIT.2014.2306938

Martin, R. W., Brogård Andersen, S., O'Brien, M. A., Bravo, P., Hoffmann, T., Olling, K., Shepherd, H. L., Dankl, K., Stacey, D., & Dahl Steffensen, K. (2021). Providing Balanced Information about Options in Patient Decision Aids: An Update from the International Patient Decision Aid Standards. *Medical Decision Making*, *41*(7), 780–800. https://doi.org/10.1177/0272989X211021397

Maurer, M., Siegel, J. E., Firminger, K. B., Lowers, J., Dutta, T., & Chang, J. S. (2021). Lessons Learned from Developing Plain Language Summaries of Research Studies. *HLRP: Health Literacy Research and Practice*, *5*(2). https://doi.org/10.3928/24748307-20210524-01

Mills, A., Wortzman, R., Bean, S., & Selby, D. (2020). Allied Health Care Providers Participating in Medical Assistance in Dying. *Journal of Hospice & Palliative Nursing*, *22*(3), 220–228. https://doi.org/10.1097/NJH.0000000000000646

Murray, M.-A. (2010). *When you need extra care, should you receive it at home or in a facility? A decision aid to prepare you to discuss the options*.

Murray, M. A., Stacey, D., Wilson, K., & O'Connor, A. (2010). Skills training to support patients considering place of end-of-life care: a randomized control trial. *Journal of Palliative Care*, *26*(2), 112–121.

Muscat, D. M., Smith, J., Mac, O., Cadet, T., Giguere, A., Housten, A. J., Langford, A. T., Smith, S. K., Durand, M.-A., & McCaffery, K. (2021). Addressing Health Literacy in Patient Decision Aids: An Update from the International Patient Decision Aid Standards.

Medical Decision Making, *41*(7), 848–869. https://doi.org/10.1177/0272989X211011101

Nuhn, A., Holmes, S., Kelly, M., Just, A., Shaw, J., & Wiebe, E. (2018). Experiences and perspectives of people who pursued medical assistance in dying: Qualitative study in Vancouver, BC. *Canadian Family Physician Medecin de Famille Canadien*, *64*(9), e380–e386. http://www.ncbi.nlm.nih.gov/pubmed/30209111

O'Connor, A. M., Drake, E. R., Wells, G. A., Tugwell, P., Laupacis, A., & Elmslie, T. (2003). A survey of the decision-making needs of Canadians faced with complex health decisions. *Health Expectations*, *6*(2), 97–109. https://doi.org/10.1046/j.1369-6513.2003.00215.x

O'Connor, A. M., Tugwell, P., Wells, G. A., Elmslie, T., Jolly, E., Hollingworth, G., McPherson, R., Bunn, H., Graham, I., & Drake, E. (1998). A decision aid for women considering hormone therapy after menopause: decision support framework and evaluation. *Patient Education and Counseling*, *33*(3), 267–279. https://doi.org/10.1016/S0738-3991(98)00026-3

O'Connor, A., Stacey, D., & Boland, L. (2015). *Introduction to the Ottawa Decision Support Tutorial*.

Ontario Ministry of Health and Longterm Care. (2021). *Medical Assistance in Dying - Health Care Professionals - MOH*. https://www.health.gov.on.ca/en/pro/programs/maid/#maid

Orem, D. . (1995). *Nursing: Concepts of practice* (5th ed.). Mosby.

Page, M. J., McKenzie, J. E., Bossuyt, P. M., Boutron, I., Hoffmann, T. C., Mulrow, C. D., Shamseer, L., Tetzlaff, J. M., Akl, E. A., Brennan, S. E., Chou, R., Glanville, J., Grimshaw, J. M., Hróbjartsson, A., Lalu, M. M., Li, T., Loder, E. W., Mayo-Wilson, E., McDonald, S., … Moher, D. (2021). The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. *BMJ (Clinical Research Ed.)*, *372*, n71. https://doi.org/10.1136/bmj.n71

Patient Decision Aids Research Group. (2022). *A to Z Inventory - Patient Decision Aids - Ottawa Hospital Research Institute*. https://decisionaid.ohri.ca/AZinvent.php

Pellisé, F., & Sell, P. (2009). Patient information and education with modern media: the Spine Society of Europe Patient Line. *European Spine Journal*, *18*(S3), 395–401. https://doi.org/10.1007/s00586-009-0973-1

Pesut, B., Thorne, S., Schiller, C., Greig, M., Roussel, J., & Tishelman, C. (2020). Constructing Good Nursing Practice for Medical Assistance in Dying in Canada: An Interpretive Descriptive Study. *Global Qualitative Nursing Research*, *7*. https://doi.org/10.1177/2333393620938686

Pesut, B., Thorne, S., Wright, D. K., Schiller, C., Huggins, M., Puurveen, G., & Chambaere, K. (2021). Navigating medical assistance in dying from Bill C-14 to Bill C-7: a qualitative study. *BMC Health Services Research*, *21*(1), 1–16. https://doi.org/10.1186/s12913-021-07222-5

Rahn, A. C., Jull, J., Boland, L., Finderup, J., Loiselle, M.-C., Smith, M., Köpke, S., & Stacey, D. (2021). Guidance and/or Decision Coaching with Patient Decision Aids: Scoping Reviews to Inform the International Patient Decision Aid Standards (IPDAS). *Medical Decision Making*, *41*(7), 938–953. https://doi.org/10.1177/0272989X21997330

Shoemaker, S. J., Wolf, M. S., & Brach, C. (2014). Development of the Patient Education Materials Assessment Tool (PEMAT): A new measure of understandability and actionability for print and audiovisual patient information. *Patient Education and Counseling*, *96*(3), 395–403. https://doi.org/10.1016/j.pec.2014.05.027

Stacey, D., Légaré, F., Boland, L., Lewis, K. B., Loiselle, M.-C., Hoefel, L., Garvelink, M., & O'Connor, A. (2020). 20th Anniversary Ottawa Decision Support Framework: Part 3

Overview of Systematic Reviews and Updated Framework. *Medical Decision Making*, *40*(3), 379–398. https://doi.org/10.1177/0272989X20911870

Stacey, D., Légaré, F., Lewis, K., Barry, M. J., Bennett, C. L., Eden, K. B., Holmes-Rovner, M., Llewellyn-Thomas, H., Lyddiatt, A., Thomson, R., & Trevena, L. (2017). Decision aids for people facing health treatment or screening decisions. *Cochrane Database of Systematic Reviews*. https://doi.org/10.1002/14651858.CD001431.pub5

Stacey, D., Légaré, F., Pouliot, S., Kryworuchko, J., & Dunn, S. (2010). Shared decision making models to inform an interprofessional perspective on decision making: A theory analysis. *Patient Education and Counseling*, *80*(2), 164–172. https://doi.org/10.1016/j.pec.2009.10.015

Stacey, D., Ludwig, C., Archambault, P., Smith, M., Carley, M., Plourde, K., Boland, L., Gogovor, A., Graham, I. D., Kobewka, D., McLean, R., Nelson, M., Taljaard, M., Vanderspank, B., & Legare, F. (2022). *Decisions and decision making needs of Canadians during the COVID-19 pandemic: A national survey*.

Stacey, D., Suwalska, V., Boland, L., Lewis, K. B., Presseau, J., & Thomson, R. (2019). Are Patient Decision Aids Used in Clinical Practice after Rigorous Evaluation? A Survey of Trial Authors. *Medical Decision Making*, *39*(7), 805–815. https://doi.org/10.1177/0272989X19868193

Stacey, D., & Volk, R. J. (2021). The International Patient Decision Aid Standards (IPDAS) Collaboration: Evidence Update 2.0. *Medical Decision Making*, *41*(7), 729–733. https://doi.org/10.1177/0272989X211035681

Statistics Canada. (2020). *Deaths, 2019*.

Statistics Canada. (2022). *Increasing diversity of languages, other than English or French,*

spoken at home.

Stein, R. A., Sharpe, L., Bell, M. L., Boyle, F. M., Dunn, S. M., & Clarke, S. J. (2013). Randomized Controlled Trial of a Structured Intervention to Facilitate End-of-Life Decision Making in Patients With Advanced Cancer. *Journal of Clinical Oncology*, *31*(27), 3403–3410. https://doi.org/10.1200/JCO.2011.40.8872

Suva, G., Penney, T., & McPherson, C. J. (2019). Medical Assistance in Dying: A Scoping Review to Inform Nurses' Practice. *Journal of Hospice and Palliative Nursing*, *21*(1), 46–53. https://doi.org/10.1097/NJH.0000000000000486

Thiele, T., & Dunsford, J. (2019). Nurse leaders' role in medical assistance in dying: A relational ethics approach. *Nursing Ethics*, *26*(4), 993–999. https://doi.org/10.1177/0969733017730684

Tversky, A., & Kahneman, D. (1981). *The framing of decisions and the psychology of choice*. Science.

Variath, C., Peter, E., Cranley, L., Godkin, D., & Just, D. (2020). Relational influences on experiences with assisted dying: A scoping review. *Nursing Ethics*, *27*(7), 1501–1516. https://doi.org/10.1177/0969733020921493

Vishnevetsky, J., Walters, C. B., & Tan, K. S. (2018). Interrater reliability of the Patient Education Materials Assessment Tool (PEMAT). *Patient Education and Counseling*, *101*(3), 490–496. https://doi.org/10.1016/j.pec.2017.09.003

Ward, V., Freeman, S., Callander, T., & Xiong, B. (2021). Professional experiences of formal healthcare providers in the provision of medical assistance in dying (MAiD): A scoping review. *Palliative and Supportive Care*, *19*(6), 744–758. https://doi.org/10.1017/S1478951521000146

Wiebe, E., Shaw, J., Green, S., Trouton, K., & Kelly, M. (2018). Reasons for requesting medical assistance in dying. *Canadian Family Physician Medecin de Famille Canadien*, *64*(9), 674–679. http://www.ncbi.nlm.nih.gov/pubmed/30209101

Wu, J. S. Y., Pinilla, J., Watson, M., Verma, S., & Olivotto, I. A. (2018). Medical Assistance in Dying for Cancer Patients One Year After Legalization: A Collaborative Approach at a Comprehensive Cancer Centre. *Current Oncology*, *25*(5), 486–489. https://doi.org/10.3747/co.25.4118

Yen, R. W., Smith, J., Engel, J., Muscat, D. M., Smith, S. K., Mancini, J., Perestelo-Pérez, L., Elwyn, G., O'Malley, A. J., Leyenaar, J. K., Mac, O., Cadet, T., Giguere, A., Housten, A. J., Langford, A., McCaffery, K., & Durand, M.-A. (2021). A Systematic Review and Meta-Analysis of Patient Decision Aids for Socially Disadvantaged Populations: Update from the International Patient Decision Aid Standards (IDPAS). *Medical Decision Making*, *41*(7), 870–896. https://doi.org/10.1177/0272989X211020317

Yiu, A., Ng, K. K., Lee, V. W., & Bajorek, B. V. (2020). Evaluating the Understandability and Actionability of Web-Based Education Materials for Patients Taking Non–vitamin K Oral Anticoagulants. *Therapeutic Innovation & Regulatory Science*, *54*(2), 476–483. https://doi.org/10.1007/s43441-019-00079-1

Yun, Y. H., Lee, M. K., Park, S., Lee, J. L., Park, J., Choi, Y. S., Lim, Y. K., Kim, S. Y., Jeong, H. S., Kang, J. H., Oh, H.-S., Park, J. C., Kim, S.-Y., Song, H. S., Ro, J., Lee, K. S., Heo, D. S., & Hong, Y. S. (2011). Use of a Decision Aid to Help Caregivers Discuss Terminal Disease Status With a Family Member With Cancer: A Randomized Controlled Trial. *Journal of Clinical Oncology*, *29*(36), 4811–4819. https://doi.org/10.1200/JCO.2011.35.3870

Appendices

Appendix A: Ottawa Decision Support Framework Definitions

Table 1 Ottawa Decision Support Framework Definitions (Revised 2020)

1.0 DECISIONAL NEED Deficit that can adversely affect the quality of a decision (informed, match most valued features) and require tailored decision support. Each need below describes their manifestations (and quantitative measures[28]).

1.1 DIFFICULT DECISIONAL TYPE & TIMING Special characteristics that affect the quality of the decision and require tailored decision support interventions. For example, interventions may need to be tailored according to:

a. Difficult Decisional Type: class or features of a decision that make decision making more difficult, e.g., multiple options; scientifically uncertain outcomes; known outcomes and other features that patients value differently.
b. Difficult Decisional Timing: features of the time frame for deliberation that makes decision making more difficult, e.g., urgent, delayed, or unpredictable (NEW 1).

1.2 UNRECEPTIVE DECISIONAL STAGE: lacks openness to receive information and/or to deliberate in their current stage of decision making about options (not thinking about, actively considering, close to choosing, taking steps toward/already implemented). Contributing factors may include: denial, hasty decision making, premature closure, powerful emotions affecting information processing (NEW 2), lack of acceptance of condition or need for treatment (NEW 3), being unmotivated, e.g., because decision too far off in the future or unpredictable (NEW 4).

1.3 DECISIONAL CONFLICT A state of personal uncertainty about which course of action to take when choice among options involve risk, loss, regret, or challenge to one's personal values[63] (measured by DCS Uncertainty subscale; SURE test item).
The hallmark behavioral manifestation is verbalized uncertainty. Other manifestations while making a decision include: worrying what could go wrong/concerned about undesired outcomes, wanting to delay the decision, questioning what is important to them, feeling distressed or upset while attempting decision, wavering between options, feeling like they cannot get the decision off their minds, feeling physically stressed (e.g., tense muscles, a racing heartbeat, difficulty sleeping). Although personal uncertainty arises from the inherent nature of the difficult decision, modifiable decisional needs can exacerbate it: inadequate knowledge, unrealistic expectations, unclear values, and inadequate support.

1.4 INADEQUATE KNOWLEDGE Unaware or lacks cognizance of essential relevant facts to make a decision: health problem/condition; options; features of options (known benefits, harms, and other outcomes and features; scientifically uncertain outcomes). (Measured by knowledge test: % inaccurate; DCS Uninformed subscale; SURE test item).

1.5 UNREALISTIC EXPECTATIONS

a. Unaware of one's chances or probabilities of outcomes (e.g., benefits, harms, other) for each option.
b. Perceptions of one's likelihood of outcomes are not aligned with the current evidence for similar patients.
c. Difficulty believing that the outcome probabilities apply to them (NEW 5).

(Measured by % unrealistic expectations: perceived outcome probabilities that are not aligned with evidence for similar patients.)

1.6 UNCLEAR VALUES Lacks clarity regarding desirability or personal importance of the features of options: known benefits, harms, other outcomes and features; scientifically uncertain outcomes. (Measured by DCS unclear values subscale; SURE test item.)

1.7 INADEQUATE SUPPORT & RESOURCES TO MAKE AND IMPLEMENT THE DECISION Lacks the quality, appropriate quantity, and/or timely access to support and resources needed to make and implement the decision. (Measured by DCS unsupported subscale; SURE test item.)

a. Information inadequacy/overload: lacks the quality, appropriate quantity, and/or timely access to essential relevant information for decision making: health problem/condition, available options and their features. Examples include: known benefits, harms, other outcomes and features, outcome probabilities; scientifically uncertain outcomes, others' experiences with options, e.g., procedures, side effects, outcomes (NEW 6), information overload (NEW 7).
b. Inadequate perceptions: others' views/practices: unaware of, misperceives, or lacks clarity about what others decide or what important others think is the appropriate choice (e.g., spouse, family, peers, health professional[s]). Receives conflicting recommendations from others.
c. Social pressure: perception of persuasion, influence, coercion from important others (e.g., spouse, family, health professionals, or society) to choose a specific option.
d. Difficult decisional roles: problematic involvement in decision making about options. Manifestations may include:
    i. unclear decisional role (shared with important other[s]; patient-led after considering important other[s] views; delegated after important other[s] considers patient's views). ii. mismatch between an informed person's preferred decisional role and actual role.
    iii. difficulty deliberating with practitioner (NEW 8). Examples of contributing factors are: the patient/family has not yet established a relationship with health professional or does not perceive they have positive relationship with the health professional (e.g., trust, mutual respect, empathy, compassion, honesty, clear communication).
    iv. difficult shared family deliberation (NEW 9). Examples of contributing factors may include different information needs, different values, communication barriers, pre-existing social/family dysfunction (see personal needs).
    v. difficulty involving family in deliberations (NEW 10), e.g., because patient does not want to worry family, family lacks knowledge.
e. Inadequate experience, self-efficacy (measured by Decision Self-efficacy Scale), motivation, skills to decide/implement a decision.
f. Inadequate emotional support, advice, instrumental help (e.g., transportation), financial assistance, health and social services to make/implement a decision.

1.8 PERSONAL & CLINICAL NEEDS Special personal and clinical characteristics that affect the quality of the decision and require tailored decision support interventions. For example, interventions may need to be tailored according to patient characteristics listed below.

a. Patient: age, gender, education, marital status, ethnicity, socioeconomic status, occupation, locale, diagnosis & duration of condition, health status (physical, emotional, cognitive, social limitations), religion/spirituality (NEW 11).
b. Practitioner: age, gender, ethnicity, clinical education, specialty, clinical practice locale, experience, counseling style.

Appendix B: IPDAS Defining Criteria

The decision aid describes the condition (health or other) related to the decision.
The decision aid describes the decision that needs to be considered (the index decision).
The decision aid identifies the target audience.
The decision aid lists the options (health care or other).
The decision aid has information about the positive features of the options (e.g. benefits, advantages).
The decision aid has information about negative features of the options (e.g. harms, side effects, disadvantages).
The decision aid helps patients clarify their values for outcomes of options by: a) asking people to think about which positive and negative features of the options matter most to them AND/OR b) describing each option to help patients imagine the physical, social, and /or psychological effect.

Appendix C: PEMAT User's Guide Items

Domain	Understandability
Item 1	The material makes its purpose completely evident (P and A/V)
Item 2	The material does not include information or content that distracts from its purpose (P)
Item 3	The material uses common, everyday language (P and A/V)
Item 4	Medical terms are used only to familiarize audience with the terms. When used, medical terms are defined (P and A/V)
Item 5	The material uses the active voice (P and A/V)
Item 6	Numbers appearing in the material are clear and easy to understand (P)
Item 7	The material does not expect the user to perform calculations (P)
Item 8	The material breaks or "chunks" information into short sections (P and A/V)
Item 9	The material's sections have informative headers (P and A/V)
Item 10	The material presents information in a logical sequence (P and A/V)
Item 11	The material provides a summary (P and A/V)
Item 12	The material uses visual cues (e.g., arrows, boxes, bullets, bold, larger font, highlighting) to draw attention to key points (P and A/V)
Item 13	Text on the screen is easy to read (A/V)
Item 14	The material allows the user to hear the words clearly (e.g., not too fast, not garbled) (A/V)
Item 15	The material uses visual aids whenever they could make content more easily understood (e.g., illustration of healthy portion size) (P)
Item 16	The material's visual aids reinforce rather than distract from the content (P)
Item 17	The material's visual aids have clear titles or captions (P)
Item 18	The material uses illustrations and photographs that are clear and uncluttered (P and A/V)
Item 19	The material uses simple tables with short and clear row and column headings (P and A/V)
Domain	**Actionability**
Item 20	The material clearly identifies at least one action the user can take (P and A/V)

Item 21	The material addresses the user directly when describing actions (P and A/V)
Item 22	The material breaks down any action into manageable, explicit steps (P and A/V)
Item 23	The material provides a tangible tool (e.g., menu planners, checklists) whenever it could help the user take action (P)
Item 24	The material provides simple instructions or examples of how to perform calculations (P)
Item 25	The material explains how to use the charts, graphs, tables, or diagrams to take actions (P and A/V)
Item 26	The material uses visual aids whenever they could make it easier to act on the instructions (P)

Appendix D: Abstract of the Exploration of Ways to Support Patients Facing the Decision About Medical Assistance in Dying (MAID)

Background	Medical Assistance in Dying (MAID) is becoming a more well-known end-of-life option for Canadians. Oncology and palliative care nurses have the most experience with patients asking about MAID. Little is known about the MAID experiences of nurses working in non-oncology settings.
Purpose	The aim of this study is to explore how inpatient nurses in non-oncology settings respond to their patients asking about Medical Assistance in Dying (MAID). Specific objectives include: 1. To identify the decisional needs of inpatient nurses to be able to provide decision support to patients considering MAID. 2. To discover the barriers and facilitators to nurses providing decision support about MAID.
Methods	An interpretive description design of semi-structured interviews guided by the Ottawa Decision Support Framework. Eligible participants will include RNs who: (a) are working on one of the following inpatient units: medicine, surgery, neurology, cardiology, thoracics, urology, and adult intensive care units, (b) have directly cared for patients who do not have cancer for at least 1 year at the study site, and (c) who have received requests for information on MAiD from their patients and/or family members. Exclusion criteria include: (a) RNs working in neonatal intensive care, maternity, mental health, and oncology units, and (b) RNs in a managerial or educator role, Advanced Practice Nurses, Nurse Practitioners and Registered Practical Nurses. These roles will be excluded as they all have differing levels of specialization and interaction with patients who are considering MAID.