Physician-Perceived Challenges in End of Life Care

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Abstract:

Background: Multiple factors influence end of life care and can lead to barriers in the experience of care for patients and the delivery of care for physicians. It is vital to determine the possible challenges physicians may face in providing end of life care in order to understand and decrease these challenges.

Objective: The purpose of this study was to identify and understand the different challenges physicians face in the provision of quality end of life care.

Methods: First, a scoping review was conducted on five databases to gather knowledge on the current literature on physician-perceived challenges in end of life care. Subsequently, a secondary data analysis was performed from the results of a pan-Canadian study with 1 060 respondents on medical end of life practices to: (1) measure the frequency of physician-perceived challenges based on the last patient who died under their care in the last 12 months, and (2) assess the relationship between the challenges and the physician's or patient's sociodemographic characteristics.

Results: The results of the scoping review on 40 studies identified ten challenges: physician's characteristics, family issues, team conflicts, team and family conflicts, institutional and organizational factors, training and educational factors, religious challenges, ethnicity and value-related challenges, human rights issues, and language challenges. Results from the secondary data analysis revealed that 26.9% of physicians reported at least one challenge, such as family conflicts, in the provision of end of life care with the last patient who died under their care in the last 12 months.

Conclusion: These challenges restrict quality end of life care. As such, targeted strategies should be implemented to mitigate these barriers to end of life care and improve care.

Résumé :

Contexte: Les facteurs qui peuvent influencer la qualité des soins en fin de vie administrée par les médecins, ainsi que l'expérience du patient, sont nombreux et variés. Il est alors primordial de déterminer les obstacles auxquels font face les médecins au cours de l'administration des soins en fin de vie, afin de mieux comprendre ceux-ci.

Objectif : L'objectif de cette thèse est d'identifier et de comprendre les différentes barrières auxquels font face les médecins au cours de la provision des soins en fin de vie.

Méthodes: Au préalable, une revue exploratoire a été menée sur cinq bases de données pour sonder la littérature sur les barrières en soins en fin de vie selon la perspective du médecin. Ensuite, une analyse secondaire de données a été entamée se basant sur les résultats d'une étude pancanadienne visant les pratiques médicales en fin de vie. Cette étude a compris 1060 répondants avec le but de: 1) déterminer la fréquence des barrières, d'après les médecins, basée sur leur dernier patient qui est décédé dans les derniers 12 mois et 2) déterminer la relation entre les barrières et les caractéristiques sociodémographiques des médecins et des patients.

Résultats : Les résultats de l'étude exploratoire, basé sur 40 études, ont identifiés dix barrières : les caractéristiques personnelles du médecin, les problèmes familiaux, les conflits d'équipe, les conflits entre l'équipe médicale et la famille, les facteurs institutionnels et organisationnels, les facteurs éducationnels et de formation, les barrières religieuses, les barrières de valeurs et d'ethnicité, les problèmes de droit humain, et les barrières de langue. Les résultats de l'analyse secondaire des données ont trouvé que 26,9% des médecins ont signalé au moins une barrière avec un patient qui est décédé sous leurs soins au cours des 12 derniers mois.

Conclusion : Les résultats de cette étude peuvent informer les parties prenantes et les analystes de politiques sur l’actualité des barrières auxquelles font face les médecins dans les soins en fin de vie. Les résultats de cette étude peuvent également aider avec la mise en œuvre des stratégies et d’interventions pour améliorer la qualité des soins en fin de vie.

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Summary of Contributions:

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This thesis was written by Carina Stumpf as the primary author. The scoping review was written in its entirety by Carina. The study selection of the articles was done by Carina Stumpf and Daniel Cousineau-Short. Dr. Isabelle Marcoux, the thesis supervisor provided guidance, advice and corrections for the scoping review. She was involved in every aspect of the creation of the article and is the co-author of the review.

The secondary data analysis is based on the data from the study by Dr. Isabelle Marcoux and her team (2016). The article was written by Carina Stumpf, with help by Dr. Isabelle Marcoux, who is the co-author of this article. Dr. Sanni Yaya, the thesis co-supervisor, provided guidance and support for the quantitative data analysis. The data analysis was performed by Carina Stumpf, with guidance and help from Michael Ekholuenetale.

The thesis committee aided in the creation of the thesis objectives and terminology. They also provided advice on the data analysis for this thesis.

1.0 Introduction

1.1 Introduction:

Canada's aging population, combined with numerous terminal conditions that arise in both older and younger adults, have caused end of life care to become a mounting concern for health care providers, policy makers and academics. As the aging Canadian population continues to grow, end of life care has become increasingly important in Canada. By 2036, the number of seniors, aged 65 and older, is estimated to represent between 23% and 25% of the Canadian population (Statistics Canada, 2012), a percentage that will have grown significantly from the current rate of 16.9% of seniors aged 65 and older in Canada (Statistics Canada, 2016). This rising percentage of seniors could represent insurmountable costs on the Canadian healthcare system, as in 2015, the share of health expenditures spent on Canadians, aged 65 and older, was 46% (CIHI, 2018).

Correspondingly, medical advances in technology and health have extended the human lifespan, which has permitted people with illnesses and conditions to live longer (Ontario Health Quality Council, 2007). Nevertheless, seniors are increasingly afflicted with conditions that they otherwise would not have been without the rise in life expectancy (Statistics Canada, 2015). In 2004, patients in end of life made up 1.1% of the Canadian population and consumed 21.3% of the health care costs (Menec, Lix, & Steinbach, 2004). These exorbitant statistics can be linked to the high number of hospitalizations that occur in end of life. Bekelman et al. (2016) reported that Canada had the highest rate of hospital deaths and mean total costs for patients dying with cancer. This is often in contrast to some patients' wishes, who may prefer to spend their end of life in the community or in their homes (Gomes, Calanzani, Gysels, Hall, & Higginson, 2013). Costly and unnecessary transfers to acute care could potentially be prevented by a greater recognition of end of life care needs and an earlier integration of palliative care (DeCaria et al., 2017). Despite the fact that there are high numbers of care costs, the Economist's Intelligence Unit (2010) ranked Canada in the top ten countries across 40 countries in terms of the quality and availability of end of life care in 2010. However, only 16% to 30% of Canadians, depending on where they reside in Canada, currently have access to palliative and end of life care services (Canadian Institutes for Health Information, 2007). In 2018, the vast majority (89%) of Canadian patients who died in a hospital had an unplanned admission on their final hospitalization (Canadian Institutes for Health Information, 2018). In hospitalization cases where patients had primarily received palliative care, 84% were still unplanned cases of palliative care in hospitals (Canadian Institutes for Health Information, 2018). This may indicate the need for earlier integration of palliative care in the community in order for patients to receive the services that they require before their illness gets worse (Canadian Institutes for Health Information, 2018). Estimates suggest that up to 89% of people who die might have benefited from palliative care (Canadian Institutes for Health Information, 2018). If palliative care was more accessible in community settings, these patients could have benefitted from it. In fact, this same Canadian Institutes for Health Information report on palliative care (2018) found that few health care providers in Canada specialize or practise primarily in palliative care. Data from Alberta found that just 1% of physicians practised primarily in palliative care in 2012-2013, and only 2% of licensed practical nurses in Canada in 2016 worked in palliative care (Canadian Institutes for Health Information, 2018). This report also reported that Canadian physicians, on average, feel less prepared to manage care for palliative patients than physicians in 10 other countries (Canadian Institutes for Health Information, 2018). With the advancements of medical care and technology and the rising number of Canadian seniors, it is paramount to ensure better access and distribution of these services, as well as to determine patients' end of life preferences in order to prevent unnecessary and unwanted use of considerable health resources (Murray, Kendall, Boyd, & Sheikh, 2005).

1.2 Background:

The advancements in medicine and the growing, aging population have created further obstacles in the decision-making process with regards to life-sustaining treatment and end of life care between healthcare professionals, patients and their families. Communication in end of life contexts can be a difficult dialogue for physicians to begin, however it is vital that these conversations and decisions take place in order for the highest quality of end of life care to be provided. End of life discussions involve numerous components, such as preferences for care in the event of a life-threatening illness, values, prognosis, fears or concerns, and questions about goals of care (You et al., 2014). As these topics are emotion-laden and take time to properly discuss in order to reach a consensus, adequate time should be taken to have end of life discussions with patients and their loved ones. In fact, patients and families have identified communication with healthcare providers and discussions about goals of care as priorities to improve end of life care in Canada (You et al., 2014). A cross-sectional survey study by Abbott et al. (2001) found that 46% of families experienced conflict with physicians over end of life decision making. Most of those conflicts revolved around poor communication and perceived unprofessional behaviour, such as disregarding the primary caregiver in treatment decisions, between the physician and the family, and many families felt they were not receiving adequate information (Abbott et al., 2001).

These difficult conversations can become even more problematic in the Canadian context, as Canada is becoming a more culturally diverse nation, with increasing heterogeneity in terms of ethnic origins, language and health practices (Schüklenk et al., 2011). In a report published in 2010, Statistics Canada indicated that by 2031, between 25-28% of the population could have been born outside of Canada (Schüklenk et al., 2011). This Canadian diversity requires physicians to be able to provide culturally sensitive end of life care, with an understanding of how to manage differing values and preferences of minority groups. Due to these incredibly and increasingly difficult tasks for physicians and the healthcare system, cultural differences may pose important issues in health settings, such as medical contexts of assistance in dying and end of life decision-making.

End of life conversations can be difficult for both physicians and patients, as they require all parties to understand and accept the patient's condition, as well as to arrive at a consensus on end of life care decisions. End of life decision-making is a process where physicians, patients and the patients' families discuss which treatments will or will not be used to treat and care for a life-threatening illness (Thelen, 2005). Due to the multicultural setting in Canada, these difficulties can be exacerbated by the multiple difficulties, such as language, socio-cultural and religious challenges. It can be incredibly difficult to properly communicate end of life discussions between individuals, such as the patients and physicians, if they do not speak the same language. This can affect the relationship between the physician, the patient, as well as the patient's family due to the fact that these challenges pose additional conflicts and stress on the patient-physician relationship and the physician-family relationship (Abbott et al., 2001). Physicians often feel stress and anxiety related to end of life care without the additional conflicts that can occur. A study on palliative care and end of life care and physicians found that approximately 39% physicians felt unprepared to address patients' fears about death, and nearly 50% felt unprepared to manage their own feelings about it (Patel & Kruczynski, 2015). Problems can also arise in the communication between members of the healthcare team, such as miscommunications between the nurse and the physician on how to proceed with the patient, which can lead to strains in those relationships. These barriers not only complicate relationships, but they also cause unnecessary stress and may negatively affect the patients' mental health, their family and friends, and the multidisciplinary team (Van Keer et al., 2015). Physicians are habitually involved in end of life matters with patients and families, and are often the ones initiating the end of life discussions. As physicians are an integral component in the provision of end of life care, their perspectives on obstacles that could affect this care are incredibly important. Physician-perceived challenges could provide a clearer understanding of the barriers in end of life care. Therefore, it is vital to identify and determine how these possible impediments may affect end of life care in the Canadian context.

1.3 Terminology:

Several terms related to end of life need to be explained and defined in the context of this thesis. These terms are often used synonymously or have differing definitions that define them. Providing a set of definitions for these ambiguous terms will help establish a knowledge base for this subject and help to avoid confusion of terms for the better understanding of this thesis.

End of life care and palliative care are terms that are often used synonymously, however there are important distinctions to be made between the two concepts. Palliative care is "an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual" (World Health Organization, 2018). In comparison, end of life care, as defined by a Canadian Institute for Health Information report, refers "to care for people in decline who are deemed to be terminal or dying in the foreseeable (near) future" (Canadian Institutes for Health Information, 2011, p.xii). End of life care is thus an important part of palliative care, centered specifically on patients who are approaching the end of their life.

Other terms that require explanation are withholding and withdrawing of treatment. Withholding of life-sustaining treatment occurs when there is “no application of medically futile therapy which prolongs the life (and suffering) of the terminally ill patient” (Kuře, 2011, p.27). An example of this could be not providing cardiopulmonary resuscitation to a patient after a cardiac arrest. However, withdrawing life-sustaining treatment is defined as the “termination of medically futile therapy which prolongs life (and suffering) of the terminally ill patient” (Kuře, 2011, p.28). An example of this could be the removal of a ventilator from a patient with a severe head injury with no prospect of improvement. Essentially, withholding treatment occurs when no treatment is given, whereas withdrawing treatment is the discontinuation of medical treatment.

A few other terms that are often misunderstood are advanced care planning, palliative continuous sedation, euthanasia, physician-assisted suicide and medical aid in dying. Advanced care planning is defined as “a process of reflection and communication in which a capable person makes decisions with respect to future health and/or personal care in the event that they become incapable of giving informed consent.” (Canadian Hospice Palliative Care Association, 2011, p.1). Palliative continuous sedation consists of “inducing sleep until death in persons at the end of life who have treatment-resistant symptoms such as pain, respiratory disorders, moral suffering or delirium.” (Marcoux, 2011, p.47). The intent with palliative continuous sedation is to use sedatives for symptoms relief in patients, who are terminally ill, until their death. Euthanasia can be defined as “the administration of drugs with the explicit intention of ending the patient’s life at his/her request” (van Der Maas, van Delden, Pijnenborg, & Looman, 1991, p.670). On the other hand, physician-assisted suicide refers to “a doctor intentionally helping a person to commit suicide by providing drugs for self-administration, at that person’s voluntary and competent request” (Materstvedt et al., 2003, p.98). The important difference between these two concepts is that in physician-assisted suicide, it is the patient who undergoes the action that will lead to their death, while in euthanasia, it is the physician who takes on this responsibility. Medical aid in dying, a new end-of-life practice denomination related to the new laws in Quebec (Gouvernment de Quebec, 2017) and Canada (Government of Canada, 2017), can have different meanings and clinical implications. In the federal context, medical aid in dying is defined in two parts, in that it consists of “the administering by a medical practitioner or nurse practitioner of a substance to a person, at their request, that causes their death” or “the prescribing or providing by a medical practitioner or nurse practitioner of a substance to a person, at their request, so that they may self-administer the substance and in doing so cause their own death” (Government of Canada, 2017). In Quebec, medical aid in dying consists of “a doctor administering medication to patients at the end of life, at their request, in order to relieve their suffering by bringing about their death.” (Gouvernment de Quebec, 2017). Medical aid in dying in Quebec refers more specifically to the practice of euthanasia, while it refers to both euthanasia and physician-assisted suicide by the federal government.

2.0 Rationale

End of life is a challenging time, and it may become even more difficult with the different obstacles that may affect the end of life process. This stage of life can be costly for Canadians and therefore, it is important that this period be properly examined in order to reduce challenges that may create a higher burden on the healthcare system. Conversations can be exacerbated by ethical issues that may occur at any time during the process. Conflicts can occur amongst members of the medical team, amongst members of the family, or between the patient, family and the team. Organizational and institutional challenges, such as a lack of resources, can further complicate the process. As well, the multicultural environment in Canada poses many unique limitations. A positive physician-patient relationship is necessary to build trust with the patient so that the physician can properly and completely inform patients with respect to all their options and support them in their decision-making process. The identified challenges can pose additional conflicts and stress on the patient-physician relationship, and may also affect the relationship between the patient's family and the physician (Bullock, 2011). It is thus important for these relationships to be well developed and positive, as it allows the patient to feel that their wishes are well understood, respected and heard (Bullock, 2011). Barriers that may prevent or limit this medical treatment standard and transmission of medical information need to be countered in order to reduce the complications that may arise during end of life care in the Canadian multicultural context.

This research will fill an important knowledge gap and help to identify potential challenges in end of life care, as studies that focus on challenges in end of life often examine the role played by one aspect out of the multitude of existing obstacles, such as cultural challenges. While these studies provide valuable and in-depth information on these specific challenges, they do not permit a positioning of barriers in relation to one another. Only a few studies have focused on more than one challenge (Breen, Abernethy, Abbott, & Tulsky, 2001; El Sayed, Chan, McAllister, &

Hellmann, 2013; Lamba, Nagurka, Zielinski, & Scott, 2013; Larochelle, Rodriguez, Arnold, & Barnato, 2009; Mpinga, Chastonay, Pellissier, & Rapin, 2006), however many of these studies do not capture a comprehensive comparative analysis of the many challenges. This thesis is thus important, as it will be the first comprehensive study on various challenges in end of life care in Canada. This study takes place within the uniquely multicultural environment of Canada, where many impediments related to this diverse setting occur. Therefore, it is vital to identify and understand which challenges may pose potential problems in end of life care for Canadians.

A physician's perspective was used for this study in order to engage and examine barriers from the perspective of a key member of the end of life process. It is paramount to understand a physician's viewpoint on the challenges related to end of life care, as they are, in collaboration with the healthcare team, the ones administering this care. Death and dying are sensitive research topics (Johnson and Clarke, 2003) and thus, end of life research needs to be sensitive of that when deciding the study population. Pleschberger et al. (2011) identifies bereaved people as a potentially vulnerable population. These vulnerable populations necessitate additional efforts from researchers to protect their rights and interests. Therefore, physicians were selected as the target population for this thesis in order to avoid the potential ethical issues that can arise in end of life research on patients and their families. Focusing on physicians' perspectives first may help inform and further research involving patients and their families on end of life care.

This thesis will attempt to fill the gap in literature by providing a broader view of challenges that affect and impact end of life care. Research outcomes of this study can have important implications for end of life care in Canada, as well as demonstrate the importance of reducing obstacles affecting end of life care.

3.0 General thesis objectives

The objectives of this thesis project were threefold. The first objective was to identify the different ethical challenges related to the provision of end of life care through a scoping review, whereas the second and third objectives focused on a mixed-methods secondary data analysis on a pan-Canadian cross-sectional study by Marcoux et al. (2016). The second objective was to measure the frequency of different ethical challenges related to end of life care between Canadian physicians, patients and their families, as well as to qualitatively describe and understand these challenges. The third objective was to assess the relationship between socio-demographic characteristics of the physicians, as well as the socio-demographic characteristics of patients on the perceived challenges.

4.0 Ethics

Ethics approval was not needed for this thesis study. The scoping review did not require ethics approval, as it was a review of studies. The data from a larger cross-sectional study that was used by the secondary data analysis received ethics approval from the University of Ottawa (ID Number: #H12-16-20). As the secondary data analysis uses fully anonymous data, according to the Article 2.4 of the Tri-Council Policy Statement, "REB review is not required for research that relies exclusively on secondary use of anonymous information, or anonymous human biological materials, so long as the process of data linkage or recording or dissemination of results does not generate identifiable information" (Government of Canada, 2014).

5.0 Methodology

To meet the goals and objectives in this exploration of the various barriers in end of life care, a two-part thesis project was undertaken. Two separate but interlinked articles were designed in order to better understand and identify physician-perceived challenges in end of life care.

5.1 Thesis Layout

This thesis is comprised of two stand-alone article papers that complement one another. Each paper helps to complete the objectives of this thesis. The two articles are presented with complete individual abstracts, introductions, methodologies, discussions and conclusions. Additional detail was added to the methods and results sections of each separate article for clarity and comprehensiveness. The first article is a scoping review on physician-perceived challenges in end of life care. This scoping allowed for the identification of the existing knowledge in current literature on the various barriers in order to better understand them. This article fulfills the first objective of this thesis project.

The second article is a mixed-methods secondary data analysis on the results of a pan-Canadian study on medical end of life practices. This article completes the second and third objective, by measuring and analysing the frequency of the various difficulties in end of life care and by assessing the relationship between socio-demographic characteristics of physicians and patients related to the different challenges in end of life care. This secondary data analysis will follow a sequential explanatory design. The qualitative results will help fulfill the second objective to further explain and interpret the quantitative data on different physician-perceived challenges in end of life care.

Situated between the two articles is a reflection of the findings. Following the two articles is a final discussion on the results of this project and on how they can be used moving forward in research on challenges in end of life care. Finally, this is followed by the general thesis conclusions and a section on the significance of the thesis and future directions.

6.0 A Scoping Review on Physician-Perceived Challenges in End of Life Care

6.1 Abstract:

Background: End of life care is a critical time in a patient's medical journey and can have an impact on the physician, the patient and the patient's family with the limitations that may arise. Therefore, it is vital to properly examine the extent, range and nature of these challenges in order to better understand the scope of these challenges.

Methods: The purpose of this scoping review was to identify the different ethical challenges in end of life care from the physician's perspective. Literature searches were conducted in the fall of 2017 through CINAHL, Embase, PsycInfo, Medline, and Web of Science.

Results: From the 40 studies analyzed, reported challenges were identified and regrouped using Bronfenbrenner's Ecological Systems Theory: the individual system is comprised of the physician's characteristics; the microsystem includes family issues, team conflicts, and team and family conflicts; the exosystem contains institutional and organizational factors, as well as training and educational factors; and the macrosystem is comprised of human rights issues and cultural issues.

Conclusion: Diverse challenges from different systems affect physicians and can impact the quality of end of life care. As this scoping review is the first comprehensive exploration of challenges in end of life care in Canada, these findings are important for the improvement of end of life care.

6.2 Introduction:

End of life care, as defined by a Canadian Institute for Health Information report refers "to care for people in decline who are deemed to be terminal or dying in the foreseeable (near) future" (Canadian Institutes for Health Information, 2011). Many people are involved in end of life care, such as the patient's family, the healthcare team, the patient, and physicians, each playing an important role in this process (Braun, Ford, Beyth, & Mccullough, 2010). With so many different members playing a role in the end of life process, certain obstacles may occur, which can affect the quality of care. Problems can arise from communication among the healthcare team members, such as miscommunication between nurses and physicians. These barriers not only complicate relationships, they also negatively affect the patients' mental health, their family and the healthcare team (Van Keer, Deschepper, Francke, Huyghens, & Bilsen, 2015). Effective communication is important, as it leads to an enhanced rapport with higher feelings of satisfaction from the encounter and thus, improves health care outcomes (Tan & Manca, 2013). There are also cultural and/or social challenges resulting from living in multicultural societies, where physicians increasingly encounter patients from different ethnicities. There are more misunderstandings, less compliance and less satisfaction in intercultural patient-physician meetings, compared with intra-cultural encounters (Schouten & Meeuwesen, 2006). Since there is a scarcity of evidence available that examines barriers perceived by physicians in end of life care, it is important to retain a comprehensive view of these difficulties in order to properly comprehend the importance of the various challenges. To our knowledge, this is the first review on physician-perceived challenges in end of life care. As such, the aim of this scoping review was to explore and identify the various challenges in end of life care, as perceived by physicians.

6.3 Methods:

The method adopted for this scoping review followed Arksey and O'Malley's (2005) framework for scoping reviews. This type of review is best suited for a broad topic that has not yet been studied. This scoping review is aimed at synthesizing and assessing the available literature on ethical challenges that may occur in end of life situations from the physician's perspective.

6.3.1 Search strategy and data sources

Multiple electronic databases were selected in order to touch on a range of academic disciplines; CINAHL, Embase, PsycInfo, Medline and Web of Science. Bibliographies of full-text articles were also reviewed to identify other potential sources of information. These searches were conducted in late fall 2017.

6.3.2 Data selection

Inclusion and exclusion criteria were developed a priori, based on the objectives of this study, and were updated throughout the search, based on the results (see Table 1). Search strategies were adapted for each database (Appendix A), with the help of a research librarian who provided expert advice on search terms. Key search terms included: (MeSH heading) Doctor or physician or family/ or general practioner/ or MD, (MeSH heading) social* or cultur* or religio* or language* or communication* or famil*, (MeSH heading) issue* or barrier* or challeng* or conflict*, (MeSH heading) Ethics, Clinical or Ethics, (MeSH heading) Terminal Care or Palliative Care or end of life. Boolean operators were used to further refine the searches.

6.3.3 Data extraction, analysis and synthesis

The titles and abstracts of all potential papers were read, and all duplicate references were deleted. All remaining titles and abstracts of papers were reviewed for suitability by two independent researchers. Any papers not immediately meeting selection criteria or not focusing on the topic of physician-perceived challenges in end of life contexts were excluded. The abstracts of the remaining papers were retrieved and read for suitability against the inclusion criteria by two independent researchers through the use of Covidence. Any conflicts on the suitability were resolved through discussions. All final papers were read to identify study aims, methodology and findings. Data extraction sheets were completed by one researcher for each paper and were presented as a summary of: author and year of publication, study population, methodology, study findings and commentary (Appendix B). Each data sheet was read, and key areas were collated in order for findings to be thematically analyzed, with central themes, focusing on physician-perceived barriers in end of life care. This conventional content analysis approach enabled a broad exploration of physicians' experiences without being prescribed by any pre-existing theoretical constraints (Hsieh and Shannon, 2005).

6.4 Ethics:

Ethics approval was not required.

6.5 Results:

Of the 2 656 articles identified in the initial search, 38 studies were relevant for inclusion. Two other studies were found by hand-searching the bibliographies, yielding a total of 40 studies included in this scoping review.

A majority of the studies were conducted in North America: 20 originated from the United States, and 5 were from Canada. The other studies were conducted in Europe (n=7), Taiwan (n=1), Israel (n=1) and Australia (n=1). The last 5 studies involved multiple countries and were mostly conducted in the United States and various European countries.

Several themes emerged from the data, centered on different physician-perceived challenges that affect the end of life care process. In order to organize these barriers, Bronfenbrenner's Ecological Systems Theory (Lerner, 2002) was used. This theory, created by Urie Bronfenbrenner, postulates that in order to understand human development, the entire ecological environment as well as genetic and biological aspects of the person need to be understood (Lerner, 2002). This ecological approach recognizes that individuals affected are positioned on different levels, both in macro and micro contexts (Hayes, O'Toole & Halpenny, 2017). These different levels of an individual's environment are known as systems, and they are organised from those closest to the individual to those whose influence is indirect or direct (Hayes, O'Toole & Halpenny, 2017). This model can be applied to difficulties in end of life care, as these obstructions can affect end of life care for physicians at different times, processes and at varying degrees. In understanding how the different systems impact the physician as an individual, this affords a better comprehension and organization of the challenges.

6.5.1 Individual:

6.5.1.1 Physician's Personal Factors:

The first system in Bronfenbrenner's Theory is the individual level, which accounts for the physician's characteristics. This challenge to the provision of end of life care was stated in 18 studies. Many studies mentioned the internal conflict and distress that physicians had over decisions (Beck et al., 2008; Deep et al., 2008; El Sayed, Chan, Mcallister, et al., 2013; Granek et al., 2013; Jensen et al., 2013; Nouvet et al., 2016; Oberle & Hughes, 2001; Ruppe et al., 2012; Tan & Manca, 2013; Torke et al., 2009). Avoidance of end of life discussions causes unnecessary suffering, as physicians agonize over the right decision, leading to distress and feelings of anxiety (Oberle & Hughes, 2001; Torke et al., 2009). However, a study by Ruppe et al. (Ruppe et al., 2012) found that physicians, who were distressed from difficult end of life decisions, felt they often provided futile care. Moreover, there are behaviors that differ according to the physician's personality, such as being direct or outgoing as personality traits in discussions, which may account for some variation in explaining treatment options to patients (M. Larochelle et al., 2009; Yapp, 2012).

6.5.2 Microsystems:

6.5.2.1 Family Conflicts and Issues:

The microsystem focuses on the physician's immediate social and physical environment. This includes family conflicts that occur around the physician, potentially affecting end of life care. Family issues were found to be a common theme for challenges in end of life care, as they were present in 14 of the 40 studies. Intra-familial conflicts hampered the communication and delayed the process of reaching a decision (Breen, Abernethy, Abbott, & Tulsky, 2001; Colman et al., 2013; De Graaff, Francke, Van Den Muijsenbergh, & Van Der Geest, 2012; Hurst et al., 2007; Mpinga et al., 2006; Van Keer et al., 2015). These conflicts habitually centered around difficulty in reaching a consensus (Brooks, Manias, & Nicholson, 2017; Colman et al., 2013; De Graaff et al., 2012; El Sayed, Chan, Mcallister, et al., 2013; Hurst et al., 2007). Most consistently, the family's unrealistic expectations of treatment or the patient's outcome was mentioned in studies (Brooks et al., 2017; Colman et al., 2013; Colón, 2012; El Sayed, Chan, Mcallister, et al., 2013; Granek et al., 2013; Oberle & Hughes, 2001; Tan & Manca, 2013), and resulted in an unwillingness to plan goals of care (Colman et al., 2013) and unreceptiveness to information on options (Tan & Manca, 2013).

6.5.2.2 Team Conflicts:

Another barrier situated in the physician's immediate social and physical environment is team conflicts, as it was identified in 11 studies. This was mostly a central theme in studies that included either more than one physician specialty or other healthcare professionals and physicians. The only two studies that focused on physicians and still reported team conflict as a challenge were the studies by Granek et al. (2013) and Otte et al. (2016). A lack of communication between members of the healthcare team and amongst different medical specialities was a central barrier to the provision of end of life care (Azoulay et al., 2009; De Graaff et al., 2012; Granek et al., 2013; Mpinga et al., 2006; Otte et al., 2016; Smith et al., 2009). This conflict could be due to physicians' variation in receptivity of input from the team (Larochelle et al., 2009). A lack of collaboration also led to team conflicts (Jensen et al., 2013; Larochelle et al., 2009; Otte et al., 2016). As well, this lack in collaboration could be caused by differing opinions of healthcare team members (Jensen et al., 2013; De Graaff et al., 2012; Brooks et al., 2017), and this ambivalence between parties could be due to different value systems (Kabengele et al., 2006). Hospital hierarchy was stated as a possible source of conflict between team members (Breen et al., 2001; Kabengele et al., 2006; Oberle, K & Hughes, D., 2000), as many nurses felt physicians did not consider their opinion or input in decisions. In a cross-sectional study by Azoulay et al. (2009), 25% of respondents believed the conflicts were related to previous conflicts that had not been resolved. This demonstrates that a lack of communication after a conflict can have lasting effects into future situations in end of life care. Many studies found similar amounts of reported conflict amongst team members, ranging from 48% to 66% (Azoulay et al., 2009; Breen et al., 2001; Mpinga et al., 2006).

6.5.2.3 Team and Family Conflicts:

A third challenge that was identified as part of the physician's microsystem is conflicts between family members and the healthcare team, which were identified in 12 studies. Many of the examined studies reported that these conflicts arose from a lack of communication (Breen et al., 2001; Curtis et al., 2005; Mpinga et al., 2006; Torke et al., 2009; Van Keer et al., 2015). Differing opinions between members of the healthcare team and the patient's families about end of life decisions were also a common cause of conflict (Breen et al., 2001; De Graaff et al., 2012; El Sayed, Chan, Mcallister, et al., 2013; Torke et al., 2009; Van Keer et al., 2015; van Tol et al., 2015). Additionally, conflicts between surrogate decision-makers and physicians have been studied. A study by Torke et al. (2009) found that, in 24% of cases, physicians never actually spoke with the surrogate decision-makers, however overt conflict was only reported 5% of the time. Conversely, another study on surrogate decision-makers (Schuster et al., 2014) found that the physicians or the surrogate decision-makers identified conflict in 63% of cases.

6.5.3 Exosystem:

6.5.3.1 Institutional and Organizational Factors:

The exosystem comprises the broader social, political and economic conditions of a physician's environment. The hospital, clinic or office where the physician works may influence the end of life care they provide by posing institutional and organizational challenges. In fact, institutional and organizational factors were mentioned in 19 studies. A shortage of time for end of life discussions was mentioned in several studies as a main challenge, as it made it difficult for physicians to adequately explain the risks and benefits of options (Balboni et al., 2014; Braun et al., 2010; Colman et al., 2013; Dzeng et al., 2015; Oberle & Hughes, 2001; Tan & Manca, 2013). As well, many physicians agreed that end of life discussions should happen as soon as possible, but, in reality, the timing of these discussions is often too late (Bardach et al., 2017; Brooks et al., 2017; Nouvet et al., 2016). Consequently, many physicians expressed a desire for standardised guidelines and protocols for end of life care (Bardach et al., 2017; Braun et al., 2010; El Sayed, Chan, Mcallister, et al., 2013; Granek et al., 2013; Larochelle et al., 2009) to ensure that all patients receive similar information, and to help physicians understand when and how to initiate this conversation (Bardach et al., 2017; Braun et al., 2010; Granek et al., 2013; Jensen et al., 2013; M. Larochelle et al., 2009), as well as to ensure a better and more consistent completion of directives and files (Bardach et al., 2017; M. Larochelle et al., 2009; Smith et al., 2009). Another challenge that can have a detrimental effect on end of life care is the scarcity of resources, such as beds (Hurst et al., 2007; Oberle & Hughes, 2001). It was also reported that a shortage of privacy and private spaces greatly affected the occurrence of end of life discussions (Balboni et al., 2014; Brooks et al., 2017; Dzeng et al., 2015; Lamba et al., 2013).

6.5.3.2 Training and Educational Factors:

Another difficulty in the exosystem is training and educational factors. Of the examined studies, 21 studies made reference for the need of further training and education to better prepare physicians to deal with challenges in end of life care. Younger physicians may perceive situations more intensively than older physicians (Dzeng et al., 2015; Periyakoil et al., 2015). On a similar note, several studies reported that physicians had a lack of experience in communicating end of life news (Brooks et al., 2017; Granek et al., 2013; M. Larochelle et al., 2009; Yapp, 2012). In addition, a few studies demonstrated that physicians may have a poor understanding of certain aspects of end of life care (Bardach et al., 2017; Beck et al., 2008; Liu et al., 2005; Nouvet et al., 2016).

6.5.4 Macrosystem:

6.5.4.1 Ethnicity and Value-Based Issues:

The macrosystem focuses on the cultural values and laws upheld by society. A common and recurrent theme was ethnicity and value-based differences as a barrier for effective end of life care. Ethnicity and value-based issues were found to be prevalent in 15 studies. Many studies reported that a multitude of differing opinions based on cultural grounds impeded the ease of engaging in end of life discussions (Breen et al., 2001; De Graaff et al., 2012; Hurst et al., 2007; Lamba et al., 2013; Larochelle et al., 2009; Mpinga et al., 2006; Yapp, 2012). This was conceivably due to a difference in value systems (Mpinga et al., 2006). Studies reported that physicians require more cross-cultural education (Carrion, 2010; El Sayed, Chan, Mcallister, et al., 2013). As well, ethnic families often have large family circles and physicians are uncertain about how to integrate the entire family in these contexts and discussions (Carrion, 2010; Colón, 2012; Van Keer et al., 2015). Better and more comprehensive guidelines may help dissolve these uncertainties for physicians. Moreover, different ethnicities think that western hospitals have the cure for anything (Carrion, 2010; Van Keer et al., 2015), which may delay end of life discussions. Several physicians also reported that some ethnic families had a culturally-based difference in opinion about truth telling, where the family often do not want to tell the patient about terminal diagnosis to protect patients from bad news (Braun et al., 2010; Colón, 2012; Granek et al., 2013).

6.5.4.2 Language barriers:

Language barriers were also brought up by 7 studies as a challenge to providing end of life care. Some patients requested care from families instead of the healthcare team, as they could not communicate with the team to ask for help (Van Keer et al., 2015). In an American study by Periyakoil et al. (2015), physicians identified language and medical interpretation issues to be the most problematic barrier. The physicians using medical interpreters reported that there was a considerable variation in the quality and accuracy of the medical interpreters (Colón, 2012; Periyakoil et al., 2015). Although medical interpreters may speak the same language as the patients, this does not equate to an understanding of the specific culture (Periyakoil et al., 2015).

6.5.4.3 Religious Issues:

Another common obstacle was religious issues, which was mentioned in 13 studies. Patient disagreement with care options on religious grounds is a common phenomenon (Carter et al., 2006; Colón, 2012; Hurst et al., 2007; Larochelle et al., 2009; Periyakoil et al., 2015). In a study by Carter et al. (2006), 80% of the physicians reported always or sometimes discussing patients' religious and spiritual influences, regarding treatment preferences. Conversely, other studies found that some physicians, particularly Caucasians and less religious physicians, were reluctant to discuss religious beliefs with patients (Balboni et al., 2014; Bateman & Clair, 2015; Braun et al., 2010; Carter et al., 2006). Furthermore, a study by Cohen et al. (2015) found that physicians, who define themselves as religiously non-observant, are more likely to withhold or withdraw treatments.

6.5.4.4 Ethical Principles Issues:

A final challenge situated in the macrosystem is ethical difficulties, mentioned by 10 studies. A few studies discussed physicians not respecting the patient's autonomy (Beck et al., 2008; Bulow et al., 2012; Burkle et al., 2012; El Sayed et al., 2013). Physicians, in a study by Bülow et al. (2012), reported that 80% of them would try to convince a patient against a treatment if they thought that treatment was futile. Many of the trainee physicians, in an American study by El Sayed et al. (2013), came from different countries where a certain amount of paternalism was usual for physicians. As the study by Yapp (2012) states, the patient-physician relationship is full of boundary issues, and physicians need to be aware of the possibility of transference. This entails physicians placing their beliefs and values into the discussions on end of life with patients and families. Other ethical difficulties can occur when there is uncertain or impaired decision-making capacity or a limitation of treatment at end of life (Hurst et al., 2007).

6.6 Discussion:

The results from the 40 studies examined in this scoping review identified various physician-perceived challenges at many stages of the end of life care process. The reported barriers were identified and regrouped using Bronfenbrenner's Ecological Systems Theory (Lerner, 2002). The identified difficulties affect various layers of the physicians' environments, which highlights the complexity in decreasing these challenges.

Notably, the reviewed literature indicated that training and educational factors are the most commonly mentioned challenge. This factor was mentioned in 21 out of the 40 studies examined. Many physicians and trainees reported that they felt they lacked the training and education in end of life communication (Balboni et al., 2014; Bardach et al., 2017; Bateman & Clair, 2015; Beck et al., 2008; Braun et al., 2010; Brooks et al., 2017; Carrion, 2010; Carter et al., 2006; Colman et al., 2013; Colón, 2012; Dzeng et al., 2015; El Sayed, Chan, Mcallister, et al., 2013; Granek et al., 2013; Hurst et al., 2007; Lamba et al., 2013; Larochelle et al., 2009; Liu et al., 2005; Nouvet et al., 2016; Periyakoil et al., 2015; Smith et al., 2009; Yapp, 2012). The study by El Sayed et al. (2013) suggested that simulated case scenarios would help trainees understand how to make these difficult decisions, and gain experience. Providing further training opportunities will further help to ensure physicians receive refresher courses and additional training in end of life care. Additionally, a factor that was mentioned in the institutional and organizational factors was establishing standardized guidelines and protocols for end of life care. Each end of life case is unique; however, guidelines and protocols are imperative in guiding events, such as timely end of life conversations. Implementing these standardised guidelines and protocols may help to combat challenges in end of life related to physicians' characteristics, such as their communication style. A prospective cohort study on end of life care in intensive care units by Heyland et al. (2002) found that the frequency of physician communication was one of the main determinants to families' overall satisfaction. As well, physician communication was seen to have an effect on team conflicts, as many nurses reported that some physicians did not want their input and that after team conflicts occurred, the study by Azoulay et al. (2009) found that up to 25% of conflicts were linked with previous conflicts that had not been resolved. Since many of the obstacles that focused on conflict were centered around a lack of communication or differing opinions (Azoulay et al., 2009; Breen et al., 2001; Brooks et al., 2017; Colman et al., 2013; Curtis et al., 2005; De Graaff et al., 2012; El Sayed, Chan, Mcallister, et al., 2013; Hurst et al., 2007; Mpinga et al., 2006; Torke et al., 2009; Van Keer et al., 2015), frequent meetings with better communication approaches could help reduce these conflicts.

Furthermore, the macrosystem contains the challenges that could be the most difficult to reduce for physicians, as they are situated at a cultural level and are ingrained in the physician's social environment. Studies recommended cross-cultural training (Carrion, 2010; El Sayed et al., 2013) to teach physicians how to improve their awareness and understanding of different cultures. This is similar to the results of an integrative review on U.S. Indigenous populations and culturally relevant palliative and end of life care, which suggested that cultural sensitivity training should be mandated for current and new healthcare providers caring for Indigenous populations (Isaacson & Lynch, 2018). More research is needed to develop a better understanding of the frequencies of each barrier. Further research should also be undertaken in order to learn more about the different perspectives of the challenges, such as the patient's, families' and healthcare team's perspectives. One of the studies that demonstrates the importance of gathering other perspectives on end of life obstructions is the study by Torke et al. (2009), which found that surrogate decision-makers reported more numerous and more severe levels of conflicts than physicians.

Although a substantial volume of literature was identified and summarized to address a critical knowledge gap in challenges in end of life care, this review is not without limitations and findings. First of all, a substantial amount of the studies in this review were based in the United States. This large proportion of American studies indicates that the results may not be generalizable to other countries, especially countries with differing laws and policies concerning end of life care. As well, another limitation to this study is that only one author was involved in the thematic analysis. This review was only intended to provide initial scoping of relevant literature and future research would benefit from conducting a more exhaustive review. Arksey and O'Malley's Framework for Scoping Reviews (2005) also contains an optional sixth step; the consultation phase. This was omitted based on resource and time constraints. Future research could build on this scoping review to include a consultation exercise with physicians on the results of this study. However, this scoping review has several strengths; notably, that this was the first comprehensive review on physician-perceived challenges in end of life care. Another strength of this study rests in its search strategy that was developed in collaboration with a librarian and adapted for each database. This review represents an important step towards undertaking a systematic review, given the findings on the number of barriers in end of life care.

6.7 Conclusion:

This review highlights the numerous difficulties that can affect end of life care experienced by physicians. To our knowledge, this was the first comprehensive review on physician-perceived challenges in end of life care. The results of this review demonstrate that the various layers of challenges affect physicians in many ways. Some challenges, like inter-team conflicts, may be easier to mitigate through enabling consistent inter-team meetings with better communication. Other challenges, like religious challenges, are more complex, as they affect medical care on a broader scale. End of life care can be improved by understanding the systems in which changes are required, following Bronfenbrenner's Ecological Systems Theory (Lerner, 2002). Improving end of life care could begin by targeting barriers based on training, clinical leadership, policies and compassionate care. Therefore, more research is required to properly understand these different difficulties from all perspectives in order to improve end of life care.

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Table 1: Inclusion/Exclusion Criteria

Inclusion Criteria:	**Exclusion Criteria:**
English language/FR	Studies in languages other than EN or FR
Studies involving end of life care	Not focused on EOL/related barriers
Studies involving ethical barriers/challenges in end of life care	Biomedical studies(eg: drug trials)
Physicians	No physicians involved
Studies with quantitative/qualitative data	Articles not involving a study (eg: position article, discussion piece)
	Articles involving a review

Figure 1: Flow Chart of Included Studies

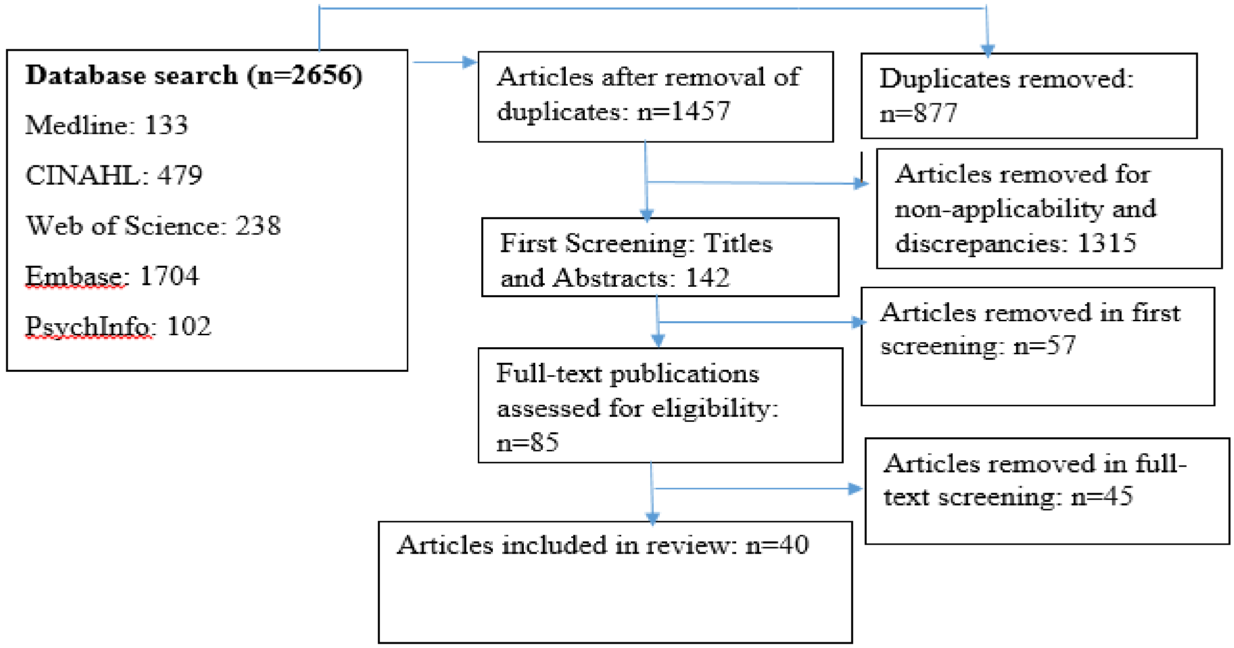

Figure 2: Major Challenges organized using Bronfenbrenner's Ecological Systems Theory

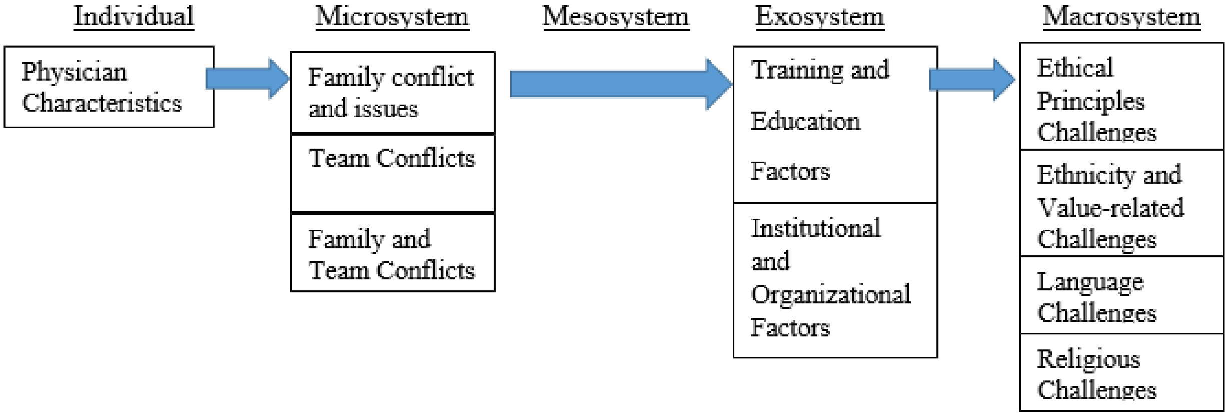

Table 2: Key characteristics from the studies

Authors	Country	Study Population	Methods	Key Findings	Key Themes
1.Azoulay et al., 2009	29 countries in Europe	7,498 ICU staff members	Cross-sectional survey	71.6% of respondents reported conflicts. Factors were personal animosity, mistrust and communication gaps. Sources of conflict were lack of support, no staff meetings and issues with decision-making.	Physician characteristics, Team conflicts, Team and family conflicts, Institutional challenges.
2.Balboni et al., 2014	US	339 oncology nurses and physicians	Survey	Only a minority (40%) provided less spiritual care than they desired. Barriers to providing spiritual care were a lack of time, inadequate training, lack of privacy, spiritual care better offered by others and power inequity with patient.	Institutional and organizational challenges, Training and educational challenges, Religious Challenges.
3. Bardach et al., 2015	US	15 physicians, 48 nurses, 4 social workers and 5 respiratory therapists	Survey with open ended responses	Impediments to following patients' wishes: timing/quality of code status discussions, locating previous stated preferences in medical records, obstacles with expiring DNR* orders and confusion over terminology.	Institutional and organizational challenges, Training and educational challenges.

4.Bateman & Clair, 2015	US	17 physicians	Semi-structured interviews	Most physicians suggested that religion/spirituality played a role in many ways. Many described the significance of religion in EOL** communication with families. Low religious responders felt religion could help in communication but felt religious language may be inappropriate.	Training and educational challenges, Religious challenges.
5.Beck et al., 2008	Germany	28 physicians	Semi-structured interviews with 2 case studies.	Physicians had difficulties in interpreting patient's wishes and best interest. Physicians found it more difficult to withdraw than withhold mechanical ventilation. Judgements were emotionally shaped. There was significant uncertainty over terminology.	Physician characteristics, Institutional and organizational, Training and education, Ethical principles.
6.Braun et al., 2009	US	26 physicians	Semi-structured focus groups	Five themes differed with race/ethnicity: reducing burden of decision-making, responding to requests, racial/ethnic discordance, cultural differences in truth-telling and religious beliefs.	Physician characteristics, Institutional and organizational, Training and education, Ethnicity and value-based, Religion, Language.
7. Breen et al., 2001	US	406 physicians and nurses	Semi-structured interviews	Health providers described conflict in 78% of cases. In 63% of cases, conflict arose over decisions about treatment. In 45% of cases, conflict occurred over communication and pain control. Social issues caused conflict in 19% of cases.	Family conflicts, Team conflicts, Family and team conflicts, Ethnicity and value-based, Language.
8. Brooks et al., 2017	Australia	11 physicians and 17 nurses	Semi-structured focus groups	Barriers to providing EOL care were conflicts with ICU*** team and external teams, education and training and environmental limitations. Enablers were	Family conflicts, Team conflicts, Institutional and organizational, Training and education, Language.

				collaboration and leadership during transitions of care. Challenges were communication, decision-making and expectations of family.	
9.Bülow et al., 2012	Sweden, UK, Israel, Portugal, Netherlands & Czech Republic	304 physicians, 386 nurses, 248 patients and 330 family members	Structured questionnaires	22% professionals compared to 55% patients/family wanted more treatment. Religious respondents wanted more treatment. 80% respondents stated that they would try to convince a patient against a treatment they considered futile.	Physician characteristics, Ethical principles, Religion.
10. Burkle et al., 2012	US	388 physicians	Survey with 3 scenarios and questions	Physicians believed their judgement superseded previous patient instructions. 52% believed the risk of liability was lower in keeping someone alive against wishes than failing to provide resuscitative efforts.	Ethical principles.
11.Carrion, L., 2010	US	10 physicians	Semi-structured face-to-face interviews	Factors impacting communication and hospice referral related to role of family members and decision-making. Language barriers and limited knowledge of cultural factors/beliefs impacted communication. Gaps in training and education were also identified.	Institutional and organizational, Training and education, Ethnicity and value-based.
12.Carter et al., 2006	US	24 African-American physicians and 16 Caucasian physicians	Semi-structured interviews	Physicians perceived racial differences in EOL care between patients. African American physicians were more likely to perceive racial differences in patient preferences for pain medication.	Ethnicity and value-based, Religion, Training and education.

13.Cohen et al., 2014	Israel	112 physicians	Questionnaire	Physicians with liberal social values and are religiously non-observant are more likely to withhold or withdraw treatments. Religion explained 5% variance, and social values 5.3% of the variance.	Religion
14.Colman et al., 2013	21 countries	158 physicians	Survey	Patient/family barriers: unrealistic expectations, unwillingness to plan EOL and disagreements. Physician challenges included competing time demands. Strategies for improvement were advance care planning, access to palliative care specialists and regular meetings with all parties.	Institutional and organizational, Training and educational, Family conflicts.
15. Colón, M., 2012	US	1 oncologist, 2 internists, 1 gerontologist, 2 disease specialists and 2 social workers	Semi structured interviews	Challenges to referring Latinos to hospice included patient/family's resistance, religious beliefs, perception of hospice and patient difficulty in acceptance. Language barriers and family involvement were difficulties for physicians.	Language, Religion, Ethnicity and value-based, Training and education.
16.Curtis et al., 2005	US	221 clinicians, 50 nurses, 25 social workers, 12 chaplains, 227 families	Family/team conferences	29% of family conferences had missed opportunities identified. These opportunities included to listen and respond to family, to acknowledge and address emotions and key principles of ethics and palliative care.	Team and family conflicts, Family conflicts
17.Deep et al., 2008	US	28 physician-decision-maker dyads	Semi-structured interviews	Physicians discussed decisions in a scripted and depersonalized manner. Decision-makers exhibited a poor understanding of the decision. Discussions may have implicitly influenced decision-making.	Physician characteristics, Ethical principles, Family conflicts, Team and family conflicts.

18. De Graaff et al., 2012	Holland	6 patients, 30 relatives,19 nurses, 17 physicians, 5 specialists, 4 social workers and 2 pastoral workers	Semi structured interviews	4 issues identified: agreement with family and care providers, communication issues, lack of communication and agreement among care providers and good communication between all parties.	Family conflicts, Team conflicts, Ethnicity and value-based, Family and team conflicts.
19.Dzeng et al., 2015	US & UK	58 physicians	Semi structured interviews	Institutional culture and policy influenced the way that physician trainees conceptualized patient autonomy. This influenced the recommendations and choices the trainees offered.	Institutional and organizational, Training and education, Ethical principles.
20. El Sayed et al., 2013	Canada	12 physician trainees	Semi-structured interviews	6 challenges: withdrawal of treatment, clarifying DNR orders, providing knowledge, dealing with cultures and internal conflict. Formal training in EOL care was reported as vital, and suggestions were didactic sessions or case scenarios.	Institutional and organizational, Training and education, Ethnicity and value-based, Ethical principles, Religion, Physician characteristics, Family conflicts, Team and family conflicts.
21.Granek, et al., 2013	Canada	20 oncologists	Semi-structured interviews	Strategies to effective EOL discussions: early discussions and balancing hope/reality. Physician factors were personal discomfort, diffusion of responsibility, lack of experience and mentorship. Patient factors were reluctance to discuss EOL, language challenges and younger age.	Team conflicts, Physician characteristics, Language, Ethnicity and value-based, Training and education, Institutional and organizational.
22. Hurst et al., 2007	Norway, Switzerlan	656 general internists	Questionnaire	Common difficulties were impaired decision-making capacity, disagreement among caregivers and limitation of treatment. The types of	Training and education, Institutional and organizational, Ethnicity and value-based, Ethical

	d, Italy, UK			help identified were reassurance on decisions, providing specific advice, help in weighing outcomes and clarification of issues.	principles, Religion, Family conflicts.
23. Jensen et al., 2013	Denmark	11 nurses, 10 intensivists and 8 physicians	Focus groups and interviews	Respondents' found obstacles with interdisciplinary collaboration. Challenges: changes in withholding/withdrawing orders, how/when to identify wishes and suffering caused by treatments.	Institutional and organizational, Team conflicts.
24. Kabengele et al., 2006	Switzerland	227 healthcare professionals	Questionnaire	82.4% of respondents reported conflicts. Conflicts: lack of communication, uncertainty, different values and hierarchy problems. Conflicts occurred among family, team or patient and staff. Possible solutions could be seminars, internal supervision procedure and sharing of experiences.	Ethnicity and value-based, Ethical principles, Family conflicts, Team conflicts, Team and family conflicts, Physician characteristics.
25. Lamba et al., 2012	US	23 residents and 7 faculty members	Questionnaire	Two challenges to emergency department palliative care provision: lack of 24 hour palliative care team and lack of access to medical records. Also, communication issues, environment, education and training and personal beliefs were difficulties.	Training and education, Institutional and organizational, Ethnicity and value-based.
26. Larochelle et al., 2009	US	108 key informants working at 11 hospitals	Observation and semi structured interviews	EOL treatment intensity depended on physician. Physician behaviors were EOL treatment, intensity, communication, timing of discussions and collaboration with team members. The factors of physician behavior included beliefs and attitudes, religion and culture, determination of dying patient,	Training and education, Institutional and organizational, Ethnicity and value-based, Religion, Physician characteristics, Team conflicts.

				quality of life determination and a fear of failing.	
27. Liu et al., 2005	Taiwan	140 physicians	Questionnaire	Most physicians voiced a willingness to provide palliative care, but limited their services to consultation and referral. Although 88.2% physicians had received information on palliative care, only 16.5% could express a clear understanding.	Physician characteristics, Training and education.
28. Nouvet et al., 2016	Canada	30 physicians and nurses	Semi structured interviews	There is an active avoidance of EOL discussions. Key challenges: concerns about the relationship, physicians' uncertainty about EOL and a dominant practice of doing everything. Physicians realised having discussions sooner was vital but rarely enacted this in practice.	Training and education, Institutional and organizational.
29.Oberle & Hughes, 2000	Canada	14 nurses and 7 physicians	Unstructured interviews	All respondents experienced ethical problems around EOL care. Witnessing suffering caused a moral obligation to end it. Uncertainty about best course of action gave moral distress. Competing values, hierarchal processes, scarce resources and communication problems were common.	Institutional and organizational, Ethical principles, Physician characteristics, Family conflicts, Team conflicts.
30. Otte et al., 2016	Switzerland	23 physicians	Semi-structured interviews	Practitioners described collaboration with hospital physicians as poor. They reported a lack of communication. They were concerned about the lack of involvement in decision-making.	Team conflicts.

31.Periyakoil et al. (2015)	US	1040 multi-specialty physicians	Questionnaire	99.99% physicians reported barriers and 85.7% found EOL conversations very challenging with patients of different ethnicities. The biggest barriers were language/medical interpretation, religious/spiritual beliefs, cultural differences, health literacy and mistrust of the system.	Training and education, Ethnicity and value-based, Religion.
32. Ruppe et al., 2013	US	30 physicians, 36 fellow physicians, 298 nurses	Randomized vignette survey	Physicians were more likely to get a court-appointed guardian with families with nonreligious objections. Those who felt personal distress from difficult EOL care, felt they provided futile care.	Physician characteristics, Religion.
33. Schuster et al., 2013	US	230 surrogate decision-makers, 100 physicians	Questionnaire	Either physicians or surrogate decision-makers identified conflict in 63% of cases. Physicians were less likely to report conflicts. The surrogate having felt discriminated against was associated with more conflict while surrogates' satisfaction with physicians' bedside manner had less conflicts.	Team and family conflict.
34. Seale, C., 2010	UK	2923 medical practitioners	Survey	Non-religious physicians were more likely to give deep sedation, taken decisions to end life and discussed with capable patients. Being very religious was associated with less discussions.	Religion
35. Smith et al., 2009	US	14 physicians, 6 nurses, 2 social workers and 4 technicians	Focus groups	Respondents reported that patients often visited the emergency department because family were distressed by EOL symptoms. Lack of communication leads to bad outcomes and troubles in EOL	Training and education, Institutional and organizational, Physician characteristics, Family

				discussions in the emergency department.	conflicts, Team conflicts, Family and team conflicts.
36.Tan & Manca, 2013	Canada	11 family physicians	Semi-structured interviews	Theory emerged that identified the steps: building mutual trust and rapport, understanding and making informed decisions. Key challenges were physicians' internal conflict, denial of illness, lack of relationship, and no planning. Time is the ultimate facilitator and barrier.	Family conflicts, Physician characteristics, Institutional and organizational.
37. Torke et al., 2009	US	281 physicians	Survey	Physicians reported trouble contacting surrogates in 21% of cases. Agreement was more common for older patients, ICU patients and established wishes and less common with difficult to contact surrogates or Asian physicians.	Physician characteristics, Team and family conflicts.
38.Van Keer et al., 2015	Belgium	10 patients and family members, 80 nurses and 12 physicians.	Interactive observation and interviews.	In 9/10 cases one or more conflicts occurred, related to different expectations, emotional involvement, information exchange and EOL decision-making. In the 1 case where no conflict occurred, the patient received less frequent/fewer visitors than the rest.	Team and family conflicts, Ethnicity and value-based, Language, Family conflicts.
39. van Tol et al., 2014	The Netherlands	48 physicians	Semi-structured interviews	Disagreements arise between physician and family concerning dignity of dying process or if patient is suffering. Some reported they hastened dying process to relieve families' suffering.	Team and family conflicts.

40.Yapp, K.A, 2012	US	14 physicians	Semi-structured interviews	Physicians’ personal skills affected communication. Lack of training in palliative care and cultural diversity was identified.	Physician characteristics, Ethical principles, Ethnicity and value-based, Training and education.

*DNR= Do Not Resuscitate

**EOL= End Of Life

***ICU= Intensive Care Unit

7.0 Reflection on the scoping review on physician-perceived challenges in end of life care

The scoping review on physician-perceived challenges in end of life care provides important results that have an impact on the remainder of this thesis project. To our knowledge, this is not only the first scoping review on the various limitations that occur in end of life contexts as perceived by physicians, but also the first scoping review on physician-perceived challenges in end of life care. This paper highlights the complex and numerous barriers in end of life care. These different difficulties can occur at any time during the end of life process, and they can permeate all members and result from all involved environments. Challenges can occur at the physician level, with their communication style, all the way to a more abstract level of cultural issues. Classifying the different categories of challenges by Bronfenbrenner's Ecological Systems Theory demonstrated the variety of barriers and the stark differences between the different influences of the systems of a physician's environment. Conflicts in end of life care can affect any member involved from the physician, specialists, emergency department providers, nurses, family members, patients, and surrogate decision-makers. Institutional and organizational factors can play an important role in affecting quality end of life care. For example, a lack of private rooms to conduct end of life discussions in can affect the quality of these conversations. Training and education can become important factors to enable physicians and nurses with the knowledge and experience on how to approach these medical situations. Before conducting the scoping review, training and educational factors had not been considered as a challenge to end of life care, they and were thus not included in the questionnaire. The scoping review reflected that training and education were still considered as important challenges by physicians in the field of end of life care. This was the obstacle that was mentioned by the highest number of studies (21 studies). The reviewed studies all demonstrated the importance of proper education and continuing training on end of life care. It has been shown that ethical principle barriers can pose significant problems for physicians who exhibit a paternalistic attitude towards their patients. Furthermore, barriers concerning ethnicity and value-based issues are a growing difficulty in multicultural societies.

The results from this study also identify the need for further research on challenges in end of life care. Further research is critically needed for the difficulties in end of life care within a Canadian context. The study by Marcoux et al. (2016) focused on all potential challenges in end of life care; however more in-depth studies are needed to fully grasp the extent of the challenges. This scoping review also found that not many studies exist on physician-perceived challenges in end of life care. The physician’s point of view and position in regard to this topic is invaluable, as they are directly responsible for delivering the care to patients and are often the most involved in the end of life care. While their perspective is important, they may also be biased and may not identify limitations that other members, such as the family, may perceive. Therefore, reviews on patients, families, surrogate decision-makers and nurses are equally instrumental in helping build a comprehensive and precise view of the different challenges in end of life care.

This article identified challenges in end of life care from physicians’ perspectives. With the knowledge of these different barriers, the next part of the thesis project was undertaken in order to understand the frequency of these challenges in end of life situations. As well, the third objective of this thesis was to assess the relationship between the socio-demographic characteristics of the physicians and the patients with the perceived challenges.

8.0 Justification of mixed methods approach:

In order to justify the mixed methods approach used in the next study, the use of mixed methods will be explored in this section. Mixed methods research involves the use of qualitative and quantitative approaches in one study (Johnson & Onwuegbuzie, 2004). The research questions in this secondary data analysis were varied, and consist of a mix of methods that was used to answer these questions. In this study, the frequencies of challenges and the relationships between the barriers and sociodemographic characteristics were examined quantitatively. In order to better understand the identified challenges, the different difficulties were thereafter explored from the physicians' perspectives qualitatively. The strength of mixed methods research is that it combines the advantages of qualitative research of rich, detailed data with the large, representative samples from quantitative research (Denzin, 2009). However, a mixed methods approach does not suit every research question, and this approach requires a wide range of research skills and a large effort (Simons and Lathlean, 2010). Using a mixed methods approach can enrich the understanding of complex health issues (Simon and Lathlean, 2010), such as end of life care. Consequently, a mixed methods approach was used in this thesis, as it better answers the research questions, and qualitative and quantitative data were collected in the original questionnaire. The field of end of life care is complex. The results from the scoping review highlight this complexity in the various different challenges that were identified. In order to properly identify and understand these complex barriers that physicians face, a mixed methods approach was instrumental in order to form a better, more comprehensive understanding of these challenges. Using a combination of research approaches also provided a complete and more comprehensive picture of the various hindrances in end of life care, as the qualitative responses were used to better understand the quantitative results. Each component should also be meaningfully integrated with each other in mixed methods research (Simons and Lathlean, 2010). The mixed methods research approach chosen for this study was a sequential explanatory mixed methods approach (Cameron, 2009). This type of mixed methods research is sequential, meaning that the quantitative data collection and analysis is followed by the qualitative data, which aims to explain or enhance the quantitative results (Doyle et al., 2009). This is important, as the qualitative data will be used to try to answer the questions that may arise from the quantitative results. This will improve the overall quality of the results of this study and will help in its contribution of meaningful results. The quantitative data will be used to firstly identify barriers and assess relationships between the challenges and physician and patient's characteristics, and the qualitative data will help to further understand the various challenges in end of life care.

9.0 Part II: Secondary data analysis on physician-perceived challenges in end of life care

9.1 Abstract:

Background: End of life is a critical time in a patient's medical journey. It is vital to determine the possible difficulties physicians may face in providing end of life care to understand and decrease these challenges.

Methods: A secondary data analysis was performed on the data of a pan-Canadian study with physicians on medical end of life practices to: (1) identify and understand physician-perceived challenges, and (2) assess the relationship between challenges and the physician and patient's sociodemographic characteristics.

Results: Results revealed that 26.9% of physicians reported at least one barrier in end of life care with their last patient who died in the last 12 months. The most frequently identified challenges involved conflicts (35.4%), cultural challenges (16.5%), language challenges (10.5%), and different religious beliefs (9.5%). Other challenges (49.1%) included lack of resources, complicated deaths, and physicians' comfort with end of life. Cultural challenges were associated with other workplaces (p=0.000) and the patient's age (p=0.001). Religious challenges were less reported by younger physicians (p=0.045). Family conflicts were associated with older physicians (p=0.005) and other workplaces (p=0.028). Other challenges, such as rural and resource challenges, were associated with female physicians (p=0.006), Quebec physicians (p=0.022), the patient's age (p=0.002), as well as hospital emergency department (p=0.007) and palliative care unit deaths (p=0.039). Thematic analysis of qualitative data found that differing opinions and unrealistic expectations (n=45) were often the cause of these obstacles.

Conclusion: Physicians face numerous difficulties in the provision of end of life care and these are influenced by various demographic factors. The results of this study can identify the current barriers that Canadian physicians face in providing end of life care.

9.2 Introduction:

End of life care is an integral component of a patient’s healthcare journey. Providing optimal end of life care for patients and their families is an important priority for every member involved in the care process. In particular, physicians play an important role in ensuring quality end of life care for patients. Challenges can occur at any part of the end of life process and can involve any of the members involved. Difficulties associated with communication and end of life care has been highlighted in the literature (Bloomer et al., 2013; Bloomer et al., 2015; Manias, 2015; Tan & Manca, 2013; Van Keer et al., 2015). Conflicts between members of the healthcare team can involve difficulties in arriving at a consensus, and can have devastating effects on end of life care (Bloomer et al., 2013, Van Keer et al., 2015; Brooks et al., 2017; Manias, 2015). As well, conflicts between the physician, the patient and their family can inhibit the essential discussions needed for quality interactions. Many studies have also reported that differing opinions based on cultural grounds impeded end of life discussions (Larochelle et al., 2009; Mpinga et al., 2006; Yapp, 2012). Likewise, language barriers can be a hindering factor to end of life communication between patients families, patients and physicians (Braun et al., 2010; Van Keer et al., 2015). With so many different and varying challenges to end of life care, it is imperative to identify and understand these difficulties from a physician’s point of view. There has been little published on the different obstructions that physicians face in the provision of end of life care. Most research focuses on one difficulty, such as cultural factors, however this does not permit the positioning of this challenge in a broader framework of comparison to other barriers. This study undertook quantitative and qualitative secondary analyses of data from a pan-Canadian study by Marcoux et al. (2016) on medical practices in end of life care to explore the different difficulties in end of life care, as reported by physicians. This study also seeks to understand the relationship between physician and patient's sociodemographic characteristics and the different barriers. This will help to provide insight on the various challenges in end of life care and may ultimately help improve the quality of care in this period of a patient's journey.

9.3 Methods:

The data used in this present study is based on the data obtained in a broader cross-sectional study on medical end of life practices with Canadian physicians by Marcoux et al. (2016). This study collected data across Canada from physicians in the form of a questionnaire (Appendix D).

9.3.1 Participants:

The population of the larger pan-Canadian study were physicians in active practice involved in the care of dying patients. They were recruited through stratified random sampling, based on medical specialties and regions through Scott's Directories (2018). Clinical experts created a list of 37 medical specialities and sorted them into 3 groups based on their likelihood of involvement in end of life care (high, low, nil), and physicians belonging to the high or low probability groups were included. Retired physicians and physicians in training were excluded from this study. The study population was also divided into five regions across Canada: Atlantic Canada (New Brunswick, Prince-Edward Island, Nova Scotia and Newfoundland and Labrador), Ontario, British Columbia, Quebec and the Northwest region (Alberta, Saskatchewan, Manitoba, Nunavut, Northwest Territories and Yukon) in order to obtain the highest diversity among the various areas of Canada. In total, the study population was comprised of 1 060 physicians.

9.3.2 Procedure:

Information was collected through a self-administered questionnaire. In order to maximize the response rate, the participants were given the option between two modes of completion; either by mail or online. An additional strategy used was the modified Dillman method (De Rada, 2016), which consisted of a five-step contacting procedure of a pre-notice letter, an introduction letter with information to consent and the questionnaire, a thank you card, a reminder letter with information to consent and another questionnaire, as well as a final reminder letter. The response rate of this study was 42%. Anonymity was ensured by removing any identification marks that could provide information associated with the respondents from the paper questionnaire, envelopes, and the online survey link. To further avoid indirect identification, certain categories related to some socio-demographic data, such as the medical specialty and the region of practice, were combined. Medical specialty of respondents was combined into two categories; family medicine (and general practice) and other specialities. Region of practice was organized into five categories, as stated above.

9.3.3 Instrument of Measure:

The questionnaire was developed and pre-tested in a pilot study (Marcoux et al., 2016). This questionnaire was based on validated instruments from European studies and was adapted through rigorous processes during the pilot study (Marcoux et al., 2016). The questions in the survey that pertained to this project focused on physicians' perceptions of the barriers associated with the decision-making process, such as cultural differences, language barriers, different religious beliefs, conflict between family members and the healthcare team, and other challenges. The physicians stated if they had encountered any challenges during the process of end of life care in considering their relationship with the last person who died under their care and/or their family members. Physicians were also able to provide qualitative information for each of these challenges.

Data related to characteristics of the patients' gender, age, place of death, and principal diagnosis were collected. Sociodemographic information of the physicians' gender, age, medical specialty, and region of practice were also collected.

9.3.4 Research ethics protocol

The national study received ethics approval from the University of Ottawa (ID Number: #H12-16-20). As this was a secondary data analysis on completely anonymous data, ethics approval was not required.

9.3.5 Statistical analysis

All data collected through the questionnaires was transferred to Statistical Package for the Social Sciences (SPSS), and quantitative analyses were carried out using SPSS version 24. The outcome variables of cultural issues, language barriers, religious differences, family and team issues, and other challenges were summarized by frequencies. Bivariate regression analysis was run to identify which demographic characteristic variables demonstrated a degree of association with each outcome variables of challenges. Physicians' age, sex, medical specialty and region of practice were each examined in relation to each challenge to observe the relationship. Patients' sex, age, primary diagnosis and place of death were also individually analyzed in relation to each of the different barriers. The variables that were significant at $p < 0.05$ were selected for multivariate regression analysis. A separate model was run for each outcome variable of challenges with the exception of languages barriers, for which there were no statistically significant results for the bivariate analysis. Results of the regression analyses were presented as odds ratios and 95% confidence intervals (CI). Statistical significance was set at $p < 0.05$ (two-sided) for the final regression analyses.

Qualitative data related to additional information provided by 252 physicians on the experienced challenges was also collected. This qualitative data was collected to further explain and contextualize the quantitative results, following a sequential explanatory, mixed methods design (Kroll & Neri, 2009). General inductive analysis was used to allow themes to inductively emerge from the data, using the approach from David R. Thomas (2006). Data was read through several times, and the data was condensed into a brief format in Excel. After reading the condensed data several times, categories were developed based on the processes that emerged from the text data (Thomas, 2006). Codes were developed to place the data into those inductively formed categories, and the data was placed into the appropriate categories. Thereafter, clear links were established between the research objectives and the findings (Thomas, 2006).

9.4 Results:

9.4.1 Sample characteristics

The study population was comprised of 1 060 physicians. The sample for this population was similar in terms of physicians' sex and age, with slightly more male participants (54%) and physicians that were 36 to 45 years old (28%). Most physicians in this sample worked in family medicine (69%) and in the community, such as in private clinics, home care or in community care centres (59%). Patients were male (51%), female (48%) or other (0.7%). The principal diagnosis of the patients was most often cancer (43%). Patients passed away most often in the regular unit at the hospital (27.5%). The mean age of patients was 74.6 ± 16.1. The sociodemographic characteristics of the physicians and patients in this study are shown in Table 3.

9.4.2 Quantitative results

The results of this secondary data analysis show that 26.9% of the physicians reported at least one challenge in the provision of end of life care with the last patient who died under their care in the previous 12 months. The most frequently identified difficulties involved conflicts with the patient’s family and healthcare team (35.4%), cultural challenges (16.5%), language barriers (10.5%), different religious beliefs (9.5%), and other challenges (49.1%).

The results of the regression analyses can be seen in Appendix C. The bivariate regression analysis found significant associations between physician and patient’s characteristics with the frequency and nature of the perceived difficulties. Cultural challenges were significantly associated with the physicians’ occupations. Physicians working in a community setting faced half as many cultural challenges compared to other physicians (OR=0.50, 95%CI=0.28-0.90). Physicians in other workplaces were also associated with cultural challenges (p=0.000). Patient’s place of death was also associated with the frequency of cultural barriers faced by physicians. Cultural challenges were encountered over three times as frequently when the patient deceased in an emergency department (OR=3.40, 95%CI=1.14-10.12). As well, patient’s age was associated to cultural challenges (p=0.001). Religious barriers were found to be associated with physicians aged 36 to 45 years (p=0.045). Family conflicts were associated with physicians aged over 65 years old (p=0.006). As well, physicians in other workplaces were more likely to report family conflicts (OR=2.19, 95%CI=1.03-4.64). Other obstacles were significantly associated with female physicians (p=0.008). Also, Quebec physicians were associated with other obstructions, in that physicians working in Quebec were more than twice as likely to encounter other challenges (OR=2.30, 95%CI=1.07-4.97). Patients’ age was also associated with other challenges (OR=0.99, 95%CI=0.98-1.00), as was patients in emergency departments (OR=0.32, 95%CI=0.12-0.85).

Emergency department deaths were less likely than all other deaths to have other difficulties reported by physicians. Language barriers were not found to be significantly associated with any sociodemographic characteristics.

The multivariate regression analysis found that cultural challenges were associated with physicians' other workplaces. Physicians who worked in other workplaces encountered over six times as many cultural challenges as other physicians (OR=6.02, 95%CI=2.38-15.27). Patient's age was significantly associated with cultural barriers. For every year increase in a patients' age, the odds of a cultural challenge occurring decreased (OR=0.97, 95%CI=0.96-0.99). Religion was associated with physicians aged 36 to 45 years. Younger physicians were less likely to experience religious barriers (OR=0.18, 95%CI=0.04-0.96). Conflicts between family members were significantly associated with physicians over the age of 65. Older physicians have a 5.88 lower odds of encountering family conflicts than physicians of other age groups (OR=0.17, 95%CI=0.05-0.58). Family conflicts were associated with physicians' other workplaces, and these other workplaces were more than twice as likely to encounter family conflicts (OR=2.36, 95%CI=1.09-5.08). Other obstacles were associated with female physicians. Female physicians were more likely to report other challenges than other genders (OR=1.68, 95%CI=1.16-2.44). Physicians residing in Quebec were also significantly associated with other barriers (OR=2.49, 95%CI=1.14-5.42), as well as the patient's age (OR=0.98, 95%CI=0.97-0.99). Patient's place of death was significantly associated with other challenges. Palliative care unit deaths were 50% less likely to experience other difficulties compared with other deaths (OR=0.50, 95%CI=0.26-0.97). Hospital emergency department deaths were even less likely to experience other challenges, with 4.55 lower odds of encountering other barriers compared to other deaths (OR=0.22, 95%CI=0.08-0.66).

9.4.3 Qualitative results:

The qualitative responses were comprised of open responses from 962 physicians, out of the 1 060 physicians who completed the questionnaire. Thematic analysis of qualitative data found five categories that emerged from the data; cultural challenges, language challenges, religious challenges, team and family conflicts and other challenges that emerged from the data. Differing opinions and unrealistic expectations (n=45) was the highest reported challenge from physicians.

Cultural challenges: Issues with Indigenous patients were identified in 7 responses. Three of these physicians identified barriers related to Indigenous cultures that caused unease in discussing death. Difficulties with the beliefs and the culture of Asian patients was also noted by six physicians.

Language challenges: Difficulties relating to language barriers often involved physicians not being able to communicate adequately with the patients and their families due to different languages (n=9). Five other physicians identified a difficulty in communication with complex medical terms. Four physicians also identified the need for interpreters.

Religious challenges: Six physicians noted limitations in end of life care related to differing religious views. Additionally, three respondents identified situations where the patient's religion prevented care options.

Team and family related conflicts: Conflicts arose in 8 situations where the patient wanted different treatment than their family, and conflict between family members occurred in 27 situations. Difficulties with the healthcare team were also present in 18 situations, such as impediments with oncology assistance. One of the most frequently mentioned challenges was a difficulty in acceptance and unrealistic care expectations, which was reported by 45 physicians. As well, a notable challenge that was reported by 16 physicians was withdrawn families and surrogate decision-makers and an absence of end of life preparation.

Other challenges: Other challenges primarily consisted of complicated and unusual situations, which were reported by 35 physicians. Many physicians mentioned a rapid deterioration in patients' health (n=10). Other issues involved physicians feeling uncomfortable with end of life care (n=6), and physicians who felt too close to their patient (n=7). As well, institutional factors, such as distance to patient and a lack of home care support, were reported by five physicians.

9.5 Discussion

The results of this mixed-methods study demonstrate that physicians perceived various challenges in end of life care. In fact, 26.9% of physicians reported a barrier in providing end of life care with the last patient who died in their care in the last 12 months. However, this number is lower than what other studies have reported, as they found that physicians' perception of conflicts ranged from 46%-99% (Abbott et al., 2001; Breen et al., 2001; Mpinga et al., 2006; Periyakoil et al., 2015; Schuster et al., 2014; Van Keer et al., 2015).

This study found that cultural challenges were identified by only 16.5% of physicians. These difficulties are significantly associated with working in other workplaces, such as cancer clinics and hospital combined with clinic work, and the patients' age. Other workplaces primarily consisted of other community locations, other hospital occupations, and physicians who worked simultaneously in several locations. As the responses in this category are broad, it is difficult to properly classify the results. As well, patients' age was also associated with cultural challenges. For every year increase in a patient's age, the odds of encountering a cultural challenge decreased. A study by Bluhme et al. (2017) found that oncologists identified patients' age as a key factor in their decisions, as they believed older adults were less likely to want treatment, and they were more highly motivated to treat younger patients. As patients from different cultures may be unable to effectively communicate their needs, physicians may assume to know their preferences. The qualitative results found that physicians identified issues with Indigenous and Asian patients, and with families to be the most difficult. Similarly, a Canadian case study on end of life decision-making in Aboriginal patients, by Kaufert (1999), found that explicit references to death and dying are often seen as disrespectful. These cultural conflicts may be due to different expectations of care practices, information exchange and the end of life decision making process between two different cultures (Van Keer et al., 2015).

Only 9.5% of physicians who participated in this study reported religious challenges. From the dataset, it became apparent that physicians aged 36 to 45 years were less likely to report religious challenges. This may be attributable to the fact that younger physicians who graduated more recently may therefore have a greater awareness of guidelines. As well, as more recent medical education has started placing more emphasis on end of life education, these physicians may have received more medical training on end of life issues and may be better positioned to avoid conflicts (Keating et al., 2010). In contrast, the qualitative results found that 9.5% of physicians reported religious barriers and more specifically, only three respondents identified situations where the patient’s religious beliefs prevented care options. Despite these low results, a study by Periyakoil et al. (2015) found that physicians report that religious and spiritual beliefs greatly influence end of life decisions.

Conflicts with the healthcare team and family were the most commonly reported barrier in this study, and these results are consistent with literature, as this difficulty is mentioned very frequently in end of life care situations. This study found that physicians over 65 years of age had a reduced likelihood of conflict than other age groups. This is similar to the results by Kabengele et al. (2006) who found that physicians, aged more than 40 years of age, experienced less conflict than physicians under 40 years old. Similarly, studies found that younger physicians may perceive conflicts more intensely than older physicians (Dzeng et al., 2015; Periyakoil et al., 2015). Physicians working in other workplaces were also significantly associated with healthcare team and family conflicts, however as this category encompasses various different responses, it is difficult to explain this relationship. The qualitative responses identified that one of the most frequently mentioned barriers was an acceptance difficulty and unrealistic care expectations. These expectations were previously identified in the literature, concerning the family's unrealistic expectations of treatment (Brooks et al., 2017; Colman et al., 2013; Granek et al., 2013; Tan & Manca, 2013). This resulted in an unwillingness to discuss end of life care (Colman et al., 2013; Tan & Manca, 2013).

Other challenges were reported by 49.1% of physicians, and these obstacles are associated with female physicians, physicians residing in Quebec, patients' age, palliative care units, and emergency departments. Physicians with patients who passed away in hospital emergency departments and palliative care units were less likely to report "other" challenges. The physicians with patients in the palliative care units may report fewer difficulties, as these physicians may be better prepared to face end of life issues. On the other hand, emergency department clinicians are trained for resuscitative and life-saving care, and may not consider end of life care in their scope of practice (Lamba et al., 2013; Smith et al., 2009; Stone et al., 2011). In contrast to the results found in this study, research by Smith et al. (2009) found that emergency department physicians have observed that patients with palliative care needs may be prioritized below other patients in emergency care. Patients' age is also associated to "other" challenges. For every year increase in a patient's age, the likelihood of experiencing "other" challenges decreased. A study by Granek et al. (2013) found that the younger the patient was, the more physicians may find it difficult to discuss end of life matters, as younger patients may have a hard time absorbing this information, and physicians may have a difficult time starting this conversation with younger patients. As well, female physicians were more likely to report challenges in the “other” category; nevertheless, there is no substantial amount of evidence involving gender and end of life issues. Several physicians reported in their qualitative responses that they felt uncomfortable providing end of life care, and certain stated that this was due to it being one of their first experiences providing this type of care. This might indicate a need for further specific training in end of life care. Furthermore, Quebec physicians were more likely to report “other” challenges than physicians in other provinces. The types of “other” challenges which may be linked to this result are due to complicated situations, resource issues, and rapid deterioration of patients’ health. Rural and remote areas of Quebec, such as Nunavik, may experience resource and distance issues. Many patients with advanced conditions are often flown to bigger cities (Hordyk, Macdonald, & Brassard, 2017), which may further complicate end of life care. The current literature does not focus on complicated situations, such as a rapid deterioration of health. Further research is necessary to determine how physicians deal with rapid end of life circumstances. However, information regarding advance directives (Bardach et al., 2015; Smith et al., 2009) and the timing of discussions (Balboni et al., 2014; Tan & Manca, 2013) is well noted in the literature.

This study has several limitations. First of all, since the response rate of the national study was 42%, the results may not be representative of Canadian physicians regarding a possible over- or underestimation of the frequency of reported barriers in end of life care. As well, this project was conducted with the use of secondary data; therefore, the data was not primarily collected to answer the research objectives. Further questions in the questionnaire on the challenges experienced could have aided in better understanding these difficulties. Consequently, these factors may affect the results by underreporting the amount of challenges experienced in end of life care. Culture and language are complex and interrelated concepts. In the questionnaire for this study, they were considered separate; however, this may have affected the reported frequencies of these challenges. Further research could consider language as a sub-theme to culture. Physicians were not asked to identify the culture they identify with in order to avoid indirect identification. However, this may have shifted responses for cultural challenges and may have skewed the results by an unknown, albeit small, degree. Not every response was supplemented with qualitative responses, and responses in the qualitative section showed that physicians may have checked the wrong response. For example, several physicians wrote a challenge related to culture in the other category. This may have skewed results, and it may be the reason for the category of other challenges having the highest reported barrier at 49.1%. The results of this study demonstrate a large variety of difficulties that physicians experience in providing end of life care. More research is needed to fully explore these challenges, and to focus on interventions and solutions to improve the quality and access to end of life care.

9.6 Conclusions:

Physicians face numerous impediments in the provision of end of life care, notably with conflicts with the patient's family and the healthcare team. This study found that 26.9% of Canadian physicians experienced a conflict with the last patient who passed away under their care in the past 12 months. Results demonstrated an association between cultural challenges and "other" workplaces, as well as with patients' age and cultural challenges. Religious challenges were associated with younger physicians, whereas conflicts with the healthcare team and family were associated with older physicians. Conflicts were also associated with "other" workplaces. As well, "other" obstacles were significantly associated with female physicians, physicians in Quebec, patients' age, as well as hospital emergency department and palliative care unit deaths. Canada is a vast country with many differences between provinces and territories; further research is needed to understand the challenges most experienced by physicians in different parts of the country. Despite the need for continued research, results of this study can inform stakeholders and policy-makers on the current barriers Canadian physicians face in providing end of life care, and may help in the identification of initiatives and interventions to improve end of life care quality and access.

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Table 3: Study sample sociodemographic characteristics

Characteristic	**Participants (n=1060)**	**Percentage of sample (%)**
Physicians' sex (n=1060)		
Male	570	53.77
Female	490	46.23
Physicians' age (1059)		
Under 35 years of age	140	13.22
36 to 45 years of age	295	27.86
46 to 55 years of age	250	23.61
56 to 65 years of age	253	23.89
Over 65 years of age	121	11.43
Medical specialty (n=1057)		
Family medicine	734	69.44
"Other" specialty	323	30.56
Physicians' workplace (n=1059)		
Community	626	59.11
Hospital	470	44.38
Nursing home	73	6.89
"Other" workplace	50	4.72
Regions of practice (n=1062)		
Atlantic Canada*	101	9.51
British Columbia	178	16.76
Northwest region**	209	19.68
Ontario	362	34.09
Quebec	212	19.96
Patients' sex (n=1061)		
Male	541	50.99
Female	513	48.35
Other	7	0.66
Patients' principal diagnosis (n=1062)		
Cancer	452	42.56

Cardiovascular disease	219	20.62
Chronic respiratory disease	92	8.66
Neurodegenerative disease	119	11.21
Renal disease	36	3.39
“Other”	144	13.56
Patients’ place of death (n=1060)		
At home	197	18.58
Hospital emergency department	83	7.83
Hospital palliative care unit	158	14.91
Hospital intensive care unit	91	8.58
Hospital regular unit	291	27.45
Nursing home or long-term care facility	132	12.45
Palliative care centre or hospice	83	7.83
“Other”	25	2.36

*Atlantic Canada is comprised of New Brunswick, Nova Scotia, Prince Edward Island, Newfoundland and Labrador.

**Northwest region is comprised of Alberta, Saskatchewan, Manitoba, Yukon, Northwest Territories and Nunavut.

Table 4: Frequency of the multiple response challenges in end of life care

Challenges (n=285)	**Responses**		**Percent of cases**
	Number	**Percent**	
Cultural	47	13.6%	16.5%
Language	30	8.7%	10.5%
Different Religious Beliefs	27	7.8%	9.5%
Family Conflicts	101	29.3%	35.4%
Other Challenges	140	40.6%	49.1%
Total	345	100%	121.1%

Dichotomy group tabulated at value 1

Table 5: Key examples of qualitative results

Challenge Experienced in EOL Care		Examples of Qualitative Responses
Cultural Challenges:		“First Nations and their beliefs”
		“Indigenous culture, uncomfortable discussing death”
		“Chinese are very opposed to dying in the home, due to fear of ghosts”
Language Barriers:		“Patient did not speak English. [We] communicated through family-interpreters.”
		“English [was] not the patient’s primary language, complex discussion”
		“Patient spoke a language I did not”
Religious Challenges:		“Patient [was] Jewish, I’m Christian”
		“Catholic religion of patient and family”
Family and Healthcare Team Conflicts:		“Some family members don't have a good grasp of patient's prognosis and symptom severity”
		“Family began force feeding as his health declined-staff caring for him worried about aspiration risk and that it went against his wish-he would push food away when with staff.”
		“Lack of support for patients with mental health disorders, conflict among team members and patient.”
		“Home care nursing refused to assist in the case on ethical grounds”
“Other” Challenges:	Organizational challenges	“lack of home care support; short staffing in palliative care team”
		“No local physician willing to provide MAID I had to drive 100km each way. Cost was not covered”
	Complicated situations	“lack of diagnostic clarity”
		“He had been previously well until about 1 month ago, so the sudden decline took us all by surprise”
	Physician Comfort Level	“First experience with MAID”
		“Daughter is my secretary”

10.0 Comparing results from the scoping review and the secondary data analysis

This thesis focused on physician-perceived challenges in end of life care. It is comprised of two articles: Part I consisting of a scoping review, and Part II involving a secondary data analysis. Many of the barriers found in the literature were similar to the results found in Part II of this thesis. However, the secondary data analysis also identified unique results that were not found in the scoping review. As such, further research is required to investigate these new findings. Similar results were found in the literature and in the secondary data analysis pertaining to the challenges of culture, religion, language and conflicts. "Other" challenges also contained similar elements to the institutional and organizational issues identified in the scoping review. Nevertheless, there were differences between the two articles. In this section, the similar results will be acknowledged and the differences in the two articles for each challenge will be identified.

The scoping review analyzed 40 articles and identified different obstacles in end of life care from the physicians' perspectives across various countries. These challenges were organized according to Bronfenbrenner's Ecological Systems Theory to better illustrate the different areas of end of life care that each challenge affects. First, the individual system comprised the physician's characteristics. The second layer is the microsystem, which included family issues, team conflicts, and team and family conflicts. Thereafter, the exosystem contained institutional and organizational factors, as well as training and educational factors. Finally, the macrosystem comprised ethical issues and cultural issues.

The secondary data analysis used data, collected during the pan-Canadian study by Marcoux et al. (2016), to identify the frequency of these challenges and to assess relationships between the barriers, and patient and physician's characteristics. The challenges were identified quantitatively and qualitatively through a cross-sectional questionnaire. The following categories of barriers were derived deductively: cultural challenges, language challenges, religious challenges, family conflicts, and other challenges. When analyzing the qualitative data, it became apparent that there were other challenges that could not be encompassed by the previously selected categories. As such, inductive categories were created to regroup these new difficulties. These "other" challenges included organizational and institutional factors, the patient's family and the healthcare team conflicts, and challenges related to complicated situations.

The scoping review revealed physicians' characteristics as a challenge. The scoping review found barriers, such as the physician's distress and internal conflict (Beck et al., 2008; Deep et al., 2008; El Sayed, Chan, Mcallister, et al., 2013; Granek et al., 2013), and the physician's personality (Larochelle et al., 2009; Yapp, 2012). This challenge was not considered prior to performing the scoping review and therefore, was not included in the broad quantitative categories in Phase II. However, several physicians in the qualitative responses of Phase II (n=13) reported feeling uncomfortable with the end of life process, and felt too close to the patients and the patients' families, which are characteristics found in the physicians' characteristics in the scoping review.

Another challenge identified in Phase I encompasses family conflicts, team conflicts, and family and team conflicts. Family conflicts mainly revolve around unrealistic expectations and the difficulty in reaching a consensus on end of life decisions. Team conflicts center mainly on a lack of communication and collaboration between team members. Finally, team and family conflicts focus on a lack of communication and differing opinions between health care providers and the patient's family. The secondary data analysis in Phase II also highlighted conflicts and issues with the family and team. This was the second highest reported quantitative challenge (35.4%) and was associated with older physicians and other workplaces. A difficulty in acceptance and unrealistic expectations was reported by 45 physicians in their qualitative responses. This qualitatively reported barrier identified not having end of life preparation as a challenge (n=16). A lack of timing for end of life discussions was also identified in organizational issues in the scoping review. However, the challenge of no prior end of life preparation was not clearly identified in any studies in Phase I. Physicians in several studies reported that although they knew they should commence end of life discussions earlier, in reality, these discussions often occur too late (Brooks et al., 2017; Nouvet et al., 2016; Bardach et al., 2015).

The next challenge identified in Phase I was institutional and organizational issues. These problems focused mainly on the lack of guidelines and protocols around end of life care, a lack of time, and a scarcity of resources. The results of the scoping review also demonstrated that these challenges were frequently mentioned, even though no study focused primarily on this barrier. The quantitative results in the secondary data analysis do not identify institutional and organizational factors, as this was not a challenge that was measured. However, physician's workplace, such as community, nursing home, hospital or "other", may play a part in institutional and organizational challenges. Physicians working in "other" workplaces, for example, were six times more likely to report cultural challenges. More research on the physician's workplace is needed to begin to understand this challenge, and how it relates to institutional and organizational issues. The qualitative results of the secondary data analysis in Phase II identified similar difficulties, although further research will be required to fully understand the impact of this type of challenge. Furthermore, the results in Phase II on institutional and organizational issues were mainly identified through the qualitative component. A scarcity of resources was reported by two studies in the scoping review (Hurst et al., 2007; Oberle & Hughes, 2001). The scoping review also found challenges related to a shortage of private spaces for end of life discussions (Balboni et al., 2014; Brooks et al., 2017; Dzeng et al., 2015; Lamba et al., 2013). The qualitative findings in the secondary data analysis focused on the distance taken to drive to patients and a lack of resources, such as beds and home care support. Notably, Quebec physicians were more likely to report "other" challenges, and this result may be linked to the rural and remote areas of northern Quebec, where institutional and organizational issues may be more abundant (Hordyk, Macdonald, & Brassard, 2017). In a country as large as Canada, it is important to ensure that rural and remote communities receive access to the same care and support as the urban areas of Canada.

In Phase I, training and educational factors were challenges identified in the scoping review. Many studies mentioned that training and further education for physicians would be vital to ensure quality end of life care (El Sayed et al., 2013; Nouvet et al., 2016; Periyakoil et al., 2015). This was perceived as necessary for physicians who demonstrated a poor understanding of end of life concepts or felt a lack of experience in communicating end of life news (El Sayed et al., 2013). This was not a barrier that was identified in Phase II of this project; however, in the qualitative results, certain physicians reported feeling uncomfortable discussing end of life care. Some of these physicians noted that they felt uncomfortable due to this being one of their first experiences with medical aid in dying or palliative care. It should be noted that medical training in recent years has improved significantly, however this is still a challenge that is reported by physicians in the scoping review, and with physicians not feeling comfortable with the end of life care process in the secondary data analysis. A physician who is dealing with one of their first cases of end of life, and who has not received proper education on it in medical school, may experience more challenges than a physician who has been fully prepared to deal with the complexities of end of life care.

Phase I of this thesis also identified cultural challenges, which included differing opinions on cultural grounds, differences in value systems and a lack of cross-cultural training. Some differences in value systems include a difference in cultural truth-telling, and large families who want to be included and to have a voice. The quantitative results of the secondary data analysis in Phase II also identified cultural challenges, which were identified in 16.5% of cases. Cultural challenges were found to be significantly associated with “other” workplaces and patients’ age. Qualitative results focused on obstacles in end of life care with Indigenous patients and families. In particular, qualitative challenges related to Indigenous communities’ beliefs and the unease with discussing death impeded end of life discussions. A similar challenge regarding cultural beliefs and values of Asian patients and families was also noted by six physicians. The scoping review identified that physicians admitted that they had a lack of cross-cultural training (Carrion, 2010; El Sayed et al., 2013), and this could be important for reducing differing value- and belief-based end of life situations. A focus on Indigenous beliefs and values should to be included in cross-cultural education, as this barrier was identified by physicians in the secondary data analysis. As well, culturally-appropriate research should be undertaken to better comprehend the impact of cultural differences in end of life care for all cultural groups in Canada. As Canada is receiving more immigrants every year (Statistics Canada, 2016), it is important to implement cultural initiatives to improve the quality of care. This is an important limitation to everyday healthcare, and this obstruction becomes exponential in end of life situations.

Subsequently, language challenges were identified in both articles of this study. Phase I identified challenges related to medical interpreters, as well as language and medical interpretation issues (Colón, 2012; Periyakoil et al., 2015). There were no significant quantitative results on language challenges, however, the qualitative results of the secondary data analysis also identified different first languages, difficulties related to comprehension of complex medical terms, and a need for more medical interpreters. Nine physicians reported a barrier with patients and families speaking an entirely different language than the healthcare team, and this indicates a serious issue.

This issue is linked to a lack of medical interpreters. In order to prevent challenges related to a lack of communication due to different languages, medical interpreters need to be trained and available. This would help reduce barriers related to the patients and their families understanding of complex medical terms when their primary language differs from that of the healthcare team.

Another difficulty that was identified in both studies was religious challenges. In Phase I, patient disagreement on religious grounds (Carter et al., 2006; Colón, 2012; Hurst et al., 2007) and physicians' reluctance to discuss religious beliefs were identified as the most common religious challenges (Balboni et al., 2014; Bateman & Clair, 2015; Braun et al., 2010). In Phase II, the quantitative data identified religious challenges in 9.5% of cases. Religious challenges were least likely to be reported by younger physicians, and this may be linked to younger adults are less likely to be religious (Kramer & Fahmy, 2018), and thus may not perceive religious challenges as such. These barriers were expanded in the qualitative results and revolved around differing religious views and situations where the patient's religion prevented or limited care options. These were similar results between Phase I and II that highlight the need for physicians to be understanding of patients' and their families' differing views and beliefs. Religion can represent an important component of end of life for many patients and should be offered in these discussions.

Over the course of conducting the scoping review in Phase I, ethical challenges were also identified. These obstacles were related to physicians not respecting patient autonomy and physicians' boundary issues related to decision-making (Beck et al., 2008; Bülow et al., 2012; Burkle et al., 2012). Nevertheless, this was not a common theme reported by physicians in the secondary data analysis. The qualitative data found that few physicians mentioned that they were not in agreement with the patient's decisions.

Conversely, the secondary data analysis also highlighted challenges that were not identified in the scoping review, which indicates the important contributions from this research to the existing knowledge base. Many of these unique results were identified in the “other” challenges category. An important qualitative barrier that was reported by 35 physicians consisted of complicated and unusual situations. These were situations that cannot be expected, but that represent the lived experience of physicians. Many of these complicated situations were linked with a rapid deterioration of the patient’s condition and to the emergency department. As complicated situations were often mentioned with rapid deterioration of a patient, complicated situations could occur more frequently in emergency rooms. The patient with the rapid deterioration may be sent to the emergency department. Challenges related to this may occur if there is no advance planning or communication for end of life care. “Other” challenges were also associated with the patients’ age, where younger patients have a difficult time absorbing difficult news (Granek et al., 2013). As well, the qualitative difficulty that some physicians felt too close to their patients and their patients’ families was a new challenge not identified in the scoping review. Physicians may feel uncomfortable delivering bad news to patients and patients’ families with whom they have a personal connection, and consequently, this challenge could be further explored in medical school by examining situations that may be difficult and ethically ambiguous. If physicians feel too close with the patient or the patient's family, they should be provided with additional support to help cope with the additional stress these cases may impose. Physicians also reported travelling long distances to provide medical care for rural patients. “Other” challenges, which contained rural and remote issues, were associated with physicians in Quebec. This specific barrier may be linked to the geographical size of Canada, and it may be a problem that is uniquely Canadian.

In summary, many of the difficulties found in the scoping review were reflected in the secondary data analysis, both in the quantitative and qualitative results. Many of the identified challenges were present in both studies, such as cultural challenges, languages challenges, religious challenges, healthcare team and family conflicts, as well as institutional and organizational issues. The scoping review also identified training and educational issues, physicians' personal factors and ethical challenges in the Bronfenbrenner model. The data in the secondary data analysis identified barriers related to care in rural and remote areas, physicians feeling too close to patients and patients' families, and complicated situations. The similar challenges should be further researched, and interventions to reduce the occurrence of these difficulties should be investigated. The different barriers that were identified in the secondary data analysis should be further researched in order to better understand the impact of these challenges in broader studies.

11.0 Final thesis conclusions

End of life care can be a challenging and emotional process. In order for this medical care to be of the highest quality possible, impediments and contexts that may affect end of life care need to be understood. Once these obstacles are properly understood, solutions to reduce these challenges can be developed and implemented. This thesis was based on physicians-perceived challenges in end of life care. Physicians are integral in not only providing access to end of life care, but also ensuring quality end of life care to patients. Therefore, their perspective on barriers that may prevent them from providing the highest quality of end of life care is an important step to better understand difficulties related to end of life care. First, a scoping review was completed to assess the scope of current literature on this topic. In this review, 40 studies were examined and different challenges were identified, which were organized using Bronfenbrenner's Ecological Systems Theory (Lerner, 2002). The challenges included physicians' characteristics, and conflicts among the healthcare team, families, and between the team, families and patients. Institutional and organizational factors, as well as training and educational factors were also identified as challenges. In addition, ethical issues and cultural challenges, such as religious issues, language barriers and value- and ethnicity-based issues, were found to be barriers to quality end of life care. Subsequently, a secondary data analysis was conducted on the data from a pan-Canadian study by Marcoux et al. (2016) to measure the frequency of physician-perceived challenges and to assess the relationship of these difficulties with patient and physician's socio-demographic characteristics. This study identified cultural challenges, religious challenges, language challenges, healthcare team and family conflicts, as well as other challenges. "Other" obstacles had the highest frequency of challenges at 49.1%. Cultural challenges were associated with "other" workplaces and patients' age. Religious challenges were significantly associated with physicians aged 36-45 years. Family conflicts were associated with physicians over 65 years old and "other" workplaces. Finally, the category of "other" challenges was associated with female physicians, physicians in Quebec, patient's age, hospital emergency department deaths, and palliative care unit deaths. Thematic analysis of the qualitative data discovered that physicians considered difficulties related to differing opinions and unrealistic expectations (n=45), as a frequent cause of conflicts. Patients having an unexpected or complicated death (n=35) was identified by physicians, as being a large obstacle grouped in the "other" category.

Difficulties that differed between the two studies included ethical challenges, which were identified in 10 studies in the scoping review. The scoping review also identified more clearly the physicians' personal factors and educational challenges. The qualitative data of the secondary data analysis revealed that physicians considered complicated and unusual situations and the closeness to their patients as a hindrance. Finally, the qualitative results also identified rural and remote issues.

The similarities and differences of these two studies demonstrate the importance of further research on end of life care, as it is important to properly identify and comprehend each challenge. Barriers that are well-identified in the literature, as well as throughout the secondary data analysis should be targeted to discover innovative solutions to reduce the preponderance of these difficulties. The different challenges identified in the secondary data analysis also need to be further studied in order to ascertain the effect of these challenges, especially in the Canadian context.

12.0 Significance and future directions

A Senate Report in 2005 on quality end of life care reported that despite a number of advancements in palliative and end of life care, significant disparities across Canada remain in access to end of life care, quality of care and out of pocket expenses to the patient (Sharon Carstairs, 2005). Results from this thesis help to provide background on the various challenges in end of life care in order to amplify the understanding of these issues surrounding the quality and access to end of life care in Canada. This information provides a useful base for future research on physician-perceived challenges in end of life care.

Further research could focus on the barriers that were identified in the secondary data analysis. Complicated and unusual situations need to be better understood, so that proper attention can be given to reduce these difficulties. These challenges may also be associated with the gender of physicians and the location of the patient's death. As this issue was often reported with a rapid deterioration, research on how often Canadian physicians initiate timely end of life discussions should be undertaken. Implementing advanced care planning with the patients and families could be beneficial in overcoming this challenge. In addition, although only a small number of physicians reported the distance to the patient as a challenge (n=3), this could be a larger obstacle for rural and remote communities. Quebec physicians were more than twice more likely to report these other challenges than physicians in other provinces. Research, focusing on the rural and remote areas of Canada, may better inform on the difficulties' physicians face, as this specific barrier could be particularly unique to these areas. Better home care support in rural and remote communities may help alleviate the physicians' burden in these areas. As well, research should focus on physician's perspectives of ethical principles challenges. This is an important challenge, as physicians may be exerting influence on patients and their families' decisions. It is important that physicians recognize and respect the importance of patient autonomy, and they must be vigilant to maintain boundaries to avoid transference (Yapp, 2012). Gathering the perspectives of Canadian physicians on patient autonomy may help inform on whether they understand this difficulty, and it may better help inform on how to better educate physicians on ethical issues in end of life care.

Further reviews could examine other perspectives of challenges in end of life care, such as the families of patients. As the results of the secondary data analysis indicated a significant amount of limitations in end of life care, this provides evidence that larger scale studies focused on challenges in end of life should be conducted. The physician's perspective on these difficulties is important to understand, as it provides an essential view of the encountered barriers by one of the key members engaged in the end of life process.

This thesis fills an important gap in knowledge for end of life care and identifies various challenges that physicians face in the provision of end of life care. The results of the scoping review, organized using Bronfenbrenner's Ecological Systems Theory, demonstrate the complexity and different layers of challenges in end of life care. This study may help to inform policy decisions on a small level. The national study takes place within the uniquely multicultural environment of Canada, where many difficulties related to this diverse setting were reported. Research outcomes of this thesis can have important implications for end of life care in Canada, and they demonstrate the importance in reducing these challenges affecting end of life care. As well, the results of this thesis demonstrate the need for further research on this subject. Barriers, that may prevent or limit the medical treatment and transmission of medical information, need to be countered in order to reduce the challenges that may arise in end of life care in the Canadian context.

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Appendix A: Search Strategy

Database: Medline (Ovid)

#	Search	Results
1	Doctor.tw., kw.	44784
2	Physicians/(exp)	80179
3	MD.tw, .kw	44784
4	1 or 2 or 3	139806
5	(social* or cultur* or religio* or (religion and medicine/) or language* or communication* or famil*) adj3 (issue* or barrier* or challeng* or conflict*).tw, .kw	1600
6	Ethics, Clinical or Ethics(exp)	3110
7	Terminal Care (exp) or Palliative Care (exp) or end of life.tw, .kw	17878
8	5 or 6	133117
9	8 and 4	4867
10	9 and 7	133

Embase Search

#	Search	Results
1	Doctor.tw., kw. Or MD.tw, .kw	62104
2	Exp Physicians	138565
4	1 or 2	306106

5	(social* or cultur* or religio* or (religion and medicine/) or language* or communication* or famil*) adj3 (issue* or barrier* or challeng* or conflict*).tw.	35523
6	Exp medical ethics	183189
7	Exp Terminal Care	58090
8	Exp Palliative therapy	89557
9	5 or 6	217171
10	4 and 9	14154
11	7 or 8	133743
12	10 and 11	1704

Web of Science

#	Search	Results
1	**TOPIC:** (doctor) *OR* **TOPIC:** (physician) Indexes=SCI-EXPANDED, SSCI, A&HCI, CPCI-S, CPCI-SSH, ESCI	355,620
2	**TOPIC:** (social*) *OR* **TOPIC:** (cultur*) *OR* **TOPIC:** (religio*) *OR* **TOPIC:** (language) *OR* **TOPIC:** (communication) *OR* **TOPIC:** (famil*) Indexes=SCI-EXPANDED, SSCI, A&HCI, CPCI-S, CPCI-SSH, ESCI	3,289,750
3	#2 AND #1	70,587

	Indexes=SCI-EXPANDED, SSCI, A&HCI, CPCI-S, CPCI-SSH, ESCI	
4	**TOPIC:** (issue*) *OR* **TOPIC:** (conflict*) *OR* **TOPIC:** (challenge*) *OR* **TOPIC:** (barrier*) Indexes=SCI-EXPANDED, SSCI, A&HCI, CPCI-S, CPCI-SSH, ESCI	2,075,346
5	#4 AND #3 Indexes=SCI-EXPANDED, SSCI, A&HCI, CPCI-S, CPCI-SSH, ESCI	18,250
6	**TOPIC:** (Ethics) *OR* **TOPIC:** (clinical ethics) Indexes=SCI-EXPANDED, SSCI, A&HCI, CPCI-S, CPCI-SSH, ESCI	74,735
7	#6 AND #5 Indexes=SCI-EXPANDED, SSCI, A&HCI, CPCI-S, CPCI-SSH, ESCI	973
8	**TOPIC:** (Palliative Care) *OR* **TOPIC:** (Terminal Care) *OR* **TOPIC:** (End of life) Indexes=SCI-EXPANDED, SSCI, A&HCI, CPCI-S, CPCI-SSH, ESCI	97,016
9	#8 AND #7 Indexes=SCI-EXPANDED, SSCI, A&HCI, CPCI-S, CPCI-SSH, ESCI	238

CINAHL

#	Search	Results
1	TX doctor OR TX physician OR TX MD	261,213
2	TX social* OR TX cultur* OR TX religio* OR TX language* OR communicati* OR famil*	530,513
3	TX issue* OR TX barrier* OR TX conflict* OR TX challenge*	350,010
4	TX clinical ethics OR TX ethics in healthcare OR TX ethic*	77,256
5	TX terminal care OR TX palliative care OR TX end of life*	54,395
6	(TX terminal care OR TX palliative care OR TX end of life*) AND (S2 AND S3)	4,652
7	((TX terminal care OR TX palliative care OR TX end of life*) AND (S2 AND S3)) AND (S1 AND S4 AND S5 AND S6)	479

Appendix B: Data Extraction Sheet Example

AUTHORS	STUDY POPULATION	METHODOLOGY	MAIN RESULTS	COMMENTS

Appendix C: Quantitative Results Tables

Table 6 : Cultural Challenges

Sociodemographic characteristic		**Unadjusted OR (95% CI)**	**Unadjusted p-value**	**Adjusted OR (95% CI)**	**Adjusted p-value**
Physician sex	Man	1.00			
	Woman	1.03 (0.57-1.84)	0.935		
Physician age	Under 35 years of age	1.00			
	36 to 45 years	0.95 (0.318-2.83)	0.923		
	46 to 55 years	2.10 (0.76-5.77)	0.153		
	56 to 65 years	1.00 (0.327-3.03)	0.994		
	Over 65 years	1.16 (0.33-4.12)	0.814		
Physician medical specialty	Family medicine	1.00			
	Other specialty	1.22 (0.66-2.28)	0.525		
Physician workplace community	No	1.00		1.00	
	Yes	0.50 (0.28-0.90)	0.020	0.85 (0.43-1.68)	0.633
Physician workplace hospital	No	1.00			
	Yes	1.58 (0.88-2.85)	0.125		
Physician workplace nursing home	No	1.00			
	Yes	1.65 (0.63-4.31)	0.305		
Physician “other” workplace	No	1.00		1.00	
	Yes	4.74 (2.08-10.77)	0.000	6.02 (2.38-15.27)	0.000
Regions of practice	Atlantic Canada	1.00			
	British Columbia	7.23 (0.92-56.44)	0.059		
	Northwest Canada	6.10 (0.78-47.51)	0.085		
	Ontario	5.23 (0.69-39.68)	0.109		

	Quebec	1.92 (0.21-17.43)	0.561		
Patient sex	Man	1.00			
	Woman	1.00 (0.53-1.74)	0.907		
	Other	3.60 (0.42-31.01)	0.245		
Patient age		0.98 (0.96-0.99)	0.001	0.97 (0.96-0.99)	0.001
Patient place of death	At home	1.00		1.00	
	In hospital (emergency department)	3.40 (1.14-10.12)	0.028	3.21 (0.98-10.48)	0.054
	In hospital (palliative care)	1.26 (0.40-3.97)	0.697	1.16 (0.36-3.75)	0.802
	In hospital (intensive care)	1.46 (0.40-5.32)	0.563	1.32 (0.34-5.13)	0.690
	In hospital (regular unit)	1.61 (0.61-4.26)	0.339	1.94 (0.69-5.43)	0.209
	In a nursing home or long-term care	1.52 (0.48-4.81)	0.480	2.15 (0.65-7.18)	0.212
	In a palliative care home	0.79(0.16-3.98)	0.771	0.69 (0.13-3.58)	0.659
	Other	1.33 (0.153-11.49)	0.798	0.86 (0.09-8.26)	0.855
Patient main diagnosis	Cancer	1.00			
	Cardiovascular disease	0.71 (0.31-1.61)	0.408		
	Chronic respiratory disease	0.63 (0.185-2.14)	0.458		
	Neurodegenerative disease	0.48 (0.14-1.64)	0.242		
	Renal disease	1.10 (0.25-4.85)	0.903		
	Other	1.33 (0.48-2.51)	0.826		

*significant at $p<0.05$; OR= Odds ratio; CI= Confidence interval

Table 7: Language challenges

Sociodemographic characteristic		Unadjusted OR (95% CI)	Unadjusted p-value	Adjusted OR (95% CI)	Adjusted p-value
Physician sex	Man	1.00			
	Woman	1.54 (0.74-3.20)	0.248		
Physician age	Under 35 years of age	1.00			
	36 to 45 years	0.56 (0.17-1.87)	0.346		
	46 to 55 years	1.01 (0.33-3.07)	0.988		
	56 to 65 years	0.77 (0.24-2.47)	0.658		
	Over 65 years	0.69 (0.16-2.93)	0.612		
Physician medical specialty	Family medicine	1.00			
	Other specialty	0.97 (0.44-2.15)	0.946		
Physician workplace community	No	1.00			
	Yes	0.79 (0.38-1.63)	0.515		
Physician workplace hospital	No	1.00			
	Yes	1.45 (0.70-2.10)	0.319		
Physician workplace nursing home	No	1.00			
	Yes	1.52 (0.45-5.14)	0.499		
Physician “other” workplace	No	1.00			
	Yes	2.32 (0.68-7.93)	0.179		
Regions of practice	Atlantic Canada	1.00			
	British Columbia	3.49 (0.41-29.39)	0.251		
	Northwest Canada	2.96 (0.35-24.88)	0.319		
	Ontario	4.02 (0.52-30.97)	0.181		
	Quebec	1.44 (0.15-13.97)	0.756		
Patient sex	Man	1.00			
	Woman	1.39 (0.67-2.90)	0.376		
	Other	0.00 (0.00-0.00)	0.999		
Patient age		1.01 (0.98-1.03)	0.559		

Patient place of death	At home	1.00	
	In hospital (emergency department)	1.06 (0.32-3.54)	0.927
	In hospital (palliative care)	0.27 (0.06-1.26)	0.095
	In hospital (intensive unit)	0.00 (0.00-0.00)	0.997
	In hospital (regular unit)	0.59 (0.22-1.56)	0.287
	In a nursing home or long-term care	0.65 (0.20-2.17)	0.486
	In a palliative care home	0.78 (0.21-2.97)	0.719
	Other	0.00 (0.00-0.00)	0.998
Patient main diagnosis	Cancer	1.00	
	Cardiovascular disease	0.68 (0.24-1.90)	0.462
	Chronic respiratory disease	0.00 (0.00-0.00)	0.997
	Neurodegenerative disease	1.01 (0.33-3.11)	0.982
	Renal disease	1.71 (0.38-7.81)	0.486
	Other	0.83 (0.27-2.55)	0.748

*significant at $p<0.05$; OR= Odds ratio; CI= Confidence interval

Table 8: Religious challenges

Sociodemographic characteristic		**Unadjusted OR (95% CI)**	**Unadjusted p-value**	**Adjusted OR (95% CI)**	**Adjusted p-value**
Physician sex	Man	1.00			
	Woman	0.68 (0.31-1.49)	0.335		
Physician age	Under 35 years of age	1.00		1.00	
	36 to 45 years	0.18 (0.04-0.96)	0.045	0.18 (0.04-0.96)	0.045
	46 to 55 years	0.66 (0.20-2.22)	0.505	0.66 (0.20-2.22)	0.505
	56 to 65 years	0.10 (0.33-3.03)	0.994	1.00 (0.33-3.03)	0.994
	Over 65 years	1.16 (0.33-4.12)	0.814	1.16 (0.33-4.12)	0.814
Physician medical specialty	Family medicine	1.00			
	Other specialty	0.51 (0.19-1.36)	0.177		
Physician workplace community	No	1.00			
	Yes	1.40 (0.62-3.13)	0.421		
Physician workplace hospital	No	1.00			
	Yes	0.86 (0.39-1.87)	0.700		
Physician workplace nursing home	No	1.00			
	Yes	1.72 (0.51-5.85)	0.386		
Physician “other” workplace	No	1.00			
	Yes	0.77 (0.10-5.80)	0.801		
Regions of practice	Atlantic Canada	1.00			
	British Columbia	3.49 (0.41-29.39)	0.251		
	Northwest Canada	2.96 (0.35-24.88)	0.319		
	Ontario	2.84 (0.36-22.46)	0.322		
	Quebec	1.92 (0.21-17.43)	0.561		
Patient sex	Man	1.00			
	Woman	2.03 (0.90-4.59)	0.090		
	Other	0.00 (0.00-0.00)	0.999		
Patient age		1.00 (0.98-1.02)	0.883		
Patient place of death	At home	1.00			
	In hospital (emergency department)	1.02 (0.26-4.04)	0.980		

	In hospital (palliative care)	0.53 (0.13-2.07)	0.357
	In hospital (intensive unit)	0.30 (0.04-2.49)	0.266
	In hospital (regular unit)	0.57 (0.19-1.73)	0.321
	In a nursing home or long-term care	0.63 (0.16-2.49)	0.511
	In a palliative care home	0.67 (0.14-3.30)	0.622
	Other	1.13 (0.13-9.59)	0.910
Patient main diagnosis	Cancer	1.00	
	Cardiovascular disease	0.38 (0.11-1.31)	0.126
	Chronic respiratory disease	0.00 (0.00-0.00)	0.997
	Neurodegenerative disease	0.47 (0.11-2.06)	0.313
	Renal disease	2.48 (0.69-8.94)	0.166
	Other	0.38 (0.09-1.70)	0.205

*significant at $p<0.05$; OR= Odds ratio; CI= Confidence interval

Table 9: Family Conflicts

Sociodemographic characteristic		Unadjusted OR (95% CI)	Unadjusted p-value	Adjusted OR (95% CI)	Adjusted p-value
Physician sex	Man	1.00			
	Woman	1.31 (0.88-1.99)	0.186		
Physician age	Under 35 years of age	1.00		1.00	
	36 to 45 years	0.71 (0.38-1.33)	0.288	0.74 (0.39-1.39)	0.345
	46 to 55 years	0.86 (0.45-1.61)	0.627	0.86 (0.46-1.62)	0.638
	56 to 65 years	0.71 (0.37-1.36)	0.302	0.72 (0.38-1.39)	0.330
	Over 65 years	0.17 (0.05-0.60)	0.006	0.17 (0.05-0.58)	0.005
Physician medical specialty	Family medicine	1.00			
	Other specialty	0.96 (0.61-1.50)	0.844		
Physician workplace community	No	1.00			
	Yes	1.01 (0.67-1.54)	0.950		
Physician workplace hospital	No	1.00			
	Yes	1.10(0.73-1.66)	0.647		
Physician workplace nursing home	No	1.00			
	Yes	0.84(0.36-1.99)	0.691		
Physician “other” workplace	No	1.00		1.00	
	Yes	2.19 (1.03-4.64)	0.041	2.36 (1.09-5.08)	0.028
Regions of practice	Atlantic Canada	1.00			
	British Columbia	1.08 (1.08-2.52)	0.860		
	Northwest Canada	0.91 (0.40-2.11)	0.817		
	Ontario	1.27 (0.59-2.71)	0.537		
	Quebec	0.95 (0.41-2.19)	0.901		
Patient sex	Man	1.00			
	Woman	0.95 (0.63-1.43)	0.808		
	Other	0.00 (0.00-0.00)	0.999		

Patient age		1.00 (0.99-1.01)	0.846
Patient place of death	At home	1.00	
	In hospital (emergency department)	0.66 (0.21-2.07)	0.479
	In hospital (palliative care)	1.79 (0.87-3.69)	0.116
	In hospital (intensive care)	2.18 (0.98-4.85)	0.056
	In hospital (regular unit)	1.39 (0.71-2.72)	0.333
	In a nursing home or long-term care	0.96 (0.40-2.28)	0.920
	In a palliative care home	2.00 (0.87-4.61)	0.105
	Other	1.14 (0.24-5.32)	0.871
Patient main diagnosis	Cancer	1.00	
	Cardiovascular disease	0.76 (0.43-1.36)	0.359
	Chronic respiratory disease	1.10 (0.53-2.28)	0.791
	Neurodegenerative disease	0.74 (0.35-1.56)	0.429
	Renal disease	0.26 (0.04-1.93)	0.187
	Other	1.38 (0.78-2.44)	0.276

*significant at $p<0.05$; OR= Odds ratio; CI= Confidence interval

Table 10: "Other" challenges

	Sociodemographic characteristic		Unadjusted OR (95% CI)	Unadjusted p-value	Adjusted OR (95% CI)	Adjusted p-value
"Other"	Physician sex	Man	1.00		1.00	
		Woman	1.63 (1.14-2.34)	0.008	1.68 (1.16-2.44)	0.006
	Physician age	Under 35 years of age	1.00			
		36 to 45 years	0.92 (0.52-1.62)	0.759		
		46 to 55 years	0.86 (0.48-1.56)	0.622		
		56 to 65 years	0.85 (0.47-1.54)	0.590		
		Over 65 years	0.58 (0.26-1.23)	0.150		
	Physician medical specialty	Family medicine	1.00			
		Other specialty	0.90 (0.61-1.33)	0.584		
	Physician workplace community	No	1.00			
		Yes	1.07 (0.74-1.53)	0.734		
	Physician workplace hospital	No	1.00			
		Yes	1.35 (0.93-1.94)	0.112		
	Physician workplace nursing home	No	1.00			
		Yes	0.80 (0.38-1.71)	0.571		
	Physician "other" workplace	No	1.00			
		Yes	1.48 (0.71-3.13)	0.299		
	Regions of practice	Atlantic Canada	1.00		1.00	
		British Columbia	1.99 (0.90-4.39)	0.089	2.07 (0.92-4.66)	0.078
		Northwest Canada	1.45 (0.65-3.23)	0.360	1.44 (0.64-3.23)	0.380
		Ontario	1.16 (0.54-2.50)	0.697	1.16 (0.53-2.53)	0.708
		Quebec	2.30 (1.07-4.97)	0.033	2.49 (1.14-5.42)	0.022

	Patient sex	Man	1.00			
		Woman	0.92 (0.64-1.31)	0.629		
		Other	1.05 (0.13-8.86)	0.963		
	Patient age		0.99 (0.98-1.00)	0.011	0.98 (0.97-0.99)	0.002
	Patient place of death	At home	1.00		1.00	
		In hospital (emergency department)	0.32 (0.12-0.85)	0.022	0.22 (0.08-0.66)	0.007
		In hospital (palliative care)	0.60 (0.32-1.12)	0.109	0.50 (0.26-0.97)	0.039
		In hospital (intensive unit)	0.68 (0.33-1.42)	0.309	0.66 (0.31-1.40)	0.279
		In hospital (regular unit)	0.86 (0.53-1.41)	0.555	0.85 (0.51-1.41)	0.521
		In a nursing home or long-term care	0.74 (0.39-1.38)	0.339	0.78 (0.40-1.52)	0.461
		In a palliative care home	0.68 (0.32-1.46)	0.321	0.55 (0.25-1.2)	0.135
		Other	0.95 (0.31-2.94)	0.924	0.85 (0.27-2.69)	0.780
	Patient main diagnosis	Cancer	1.00			
		Cardiovascular disease	0.67 (0.40-1.13)	0.130		
		Chronic respiratory disease	0.94 (0.49-1.83)	0.864		
		Neurodegenerative disease	0.91 (0.50-1.66)	0.752		
		Renal disease	1.80 (0.78-4.12)	0.166		
		Other	1.13 (0.67-1.92)	0.639		

*significant at p<0.05; OR= Odds ratio; CI= Confidence interval

Appendix D: Questionnaire from pan-Canadian study by Marcoux et al.

End-of-life Medical Practices in Canada

National project 2017

Let’s begin with some general background questions

1.You are: ☐ A man ☐ A woman ☐ Other *(Please specify)* ______________________________

2.Your age is:
☐ Under 35 years of age ☐ 36 to 45 years of age ☐ 46 to 55 years of age
☐ 56 to 65 years of age ☐ Over 65 years of age

3. Your medical specialty is: ☐ Family medicine (& general practice) ☐ Other specialty

4. You work mainly in:
☐ A hospital ☐ The community (private clinic, community centre, home care, etc.)
☐ A nursing home or a long-term care facility ☐ Other *(Please specify)* ______________

5. You practice medicine mainly in:
☐ Atlantic Canada (NB, PE, NS, NL) ☐ British Columbia ☐ Northwest region (AB, SK, MB, YT, NT, NU)
☐ Ontario ☐ Quebec

6. Please indicate the number of deaths, on average, for which you would be the treating or attending physician in the normal course of your duties. Answer <u>only one</u> of (a), (b) or (c). *(Please provide the most accurate estimate)*

(a)______ per week (b)______ per month (c)______ per year

7. Have you been the treating or attending physician in the case of a death in the last 12 months? ☐ Yes
☐ No → **go to # 28, p. 4**

Please refer to the MOST RECENT DEATH WITHIN THE LAST 12 MONTHS for which you were acting as the treating or attending physician. Please answer all of the following questions based on this particular death.

8.The deceased was: ☐ Male ☐ Female ☐ Other *(Please specify)* ______________________

9.The deceased was ________years old; (***if unsure***, *please estimate here*: around________years old)

10. This person died:
☐ At home ☐ In hospital (intensive care)
☐ In hospital (emergency department) ☐ In hospital (regular unit)
☐ In hospital (palliative care unit) ☐ Other
☐ In a nursing home or long-term care facility
☐ In a palliative care centre/hospice

11. According to you, what was the person's main diagnosis: *(only one answer)*
☐ Cancer ☐ Neurodegenerative disease (Alzheimer’s, Parkinson’s, etc.)
☐ Cardiovascular disease ☐ Renal disease
☐ Chronic respiratory disease ☐ Other *(Please specify)* ______________________

12. When was your first contact with this person?
☐ Before or at the time of death
☐ After death → **go to # 28, p.4**

12.1 How long had you known this person?
☐ More than 6 months ☐ Between 1 day and 1 week
☐ 1 to 6 months ☐ Less than 24 hours
☐ 1 to 4 weeks ☐ I did not know this person

13. Did this person, at any time, made an explicit request to:
☐ Prolong life ☐ Hasten death ☐ No request has been made ☐ I don’t know

14. At any time, was an explicit request made by another or several other persons to: *(multiple answers possible)*
☐ Prolong life
☐ Hasten death
☐ No request has been made
☐ I don’t know

14.1 By whom? *(multiple answers possible)*
☐ Partner, children or parent(s) ☐ Other relatives or friends
☐ Substitute decision-maker or proxy ☐ Nursing or other healthcare team members
☐ Someone else *(Please specify)* ______________________________

Let's now turn to matters relating specifically to different medical end-of-life practices that you may have undertaken.

15. Concerning this person, did you initially do everything possible to delay or prevent the occurrence of death?

☐ Yes →

☐ No

15.1 In your estimation, how much was the person's life extended?

☐ More than 6 months	☐ 1 to 4 weeks	☐ Less than 24 hours
☐ 1 to 6 months	☐ Between 1 day and 1 week	☐ Not at all

16. Concerning this person, did you withhold and/or withdraw any treatment(s) that may have delayed the occurrence of death?

☐ Yes, withhold →

☐ Yes, withdraw →

☐ Yes, withhold and withdraw

☐ No

↓

go to # 17

16.1 Which treatment(s) was (were) withheld or withdrawn ? *(multiple answers possible)*

	Withhold	Withdraw	Was done in last 24h	n/a
Artificial hydration (intravenous line, subcutaneous)	☐	☐	☐	☐
Artificial nutrition (parenteral nutrition, P.E.G. Tube)	☐	☐	☐	☐
Artificial ventilation (intubation or BPAP)	☐	☐	☐	☐
Cardiopulmonary resuscitation (CPR)	☐	☐	☐	☐
Other treatment with potential life-prolonging effect (Specify below)	☐	☐	☐	☐

Specify: ____

16.2 The decision to withhold and/or withdraw treatment(s) was made with the consent of the person, or his/her substitute decision-maker or proxy:

☐ Yes ☐ No → **16.2.1 The decision was made without consent because:**

____

____

16.3 Was the decision to withhold and/or withdraw treatment(s) made with the intention to hasten death?

☐ No

☐ Yes →

16.3.1 In your estimation, how much was the person's life shortened by this?

☐ More than 6 months	☐ Between 1 day and 1 week
☐ 1 to 6 months	☐ Less than 24 hours
☐ 1 to 4 weeks	☐ I don't know

17. In the last 24 hours of life, were drugs used for this person?

☐ Yes →

☐ No

↓

go to # 18

17.1 Which drugs were used? *(multiple answers possible)*

☐ Opioids

☐ Sedatives (benzodiazepines, etc.)

☐ Barbiturates

☐ Vasopressors (epinephrine, dopamine, etc.)

☐ Neuromuscular blocking agents (rocuronium, pancuronium)

☐ Intravenous potassium chloride

☐ Other (please specify) ____

17.2 The decision to use drugs was made with the consent of the person or his/her substitute decision-maker or proxy

☐ Yes ☐ No **17.2.1 The decision was made without consent because**

→

____

____

17.3 Were drugs used above what was needed for pain and symptom control? (e.g. rapid increase of opioids to an unconscious person without signs of pain)

☐ Yes ☐ No

17.4 Were drugs used with the intention to: *(multiple answers possible)*

☐ Alleviate the symptoms
☐ Extended the person's life
☐ Hastened the person's death →

17.4.1 In your estimation, how much was the person's life shortened by the use of drugs?

☐ More than 6 months ☐ Between 1 day and 1 week
☐ 1 to 6 months ☐ Less than 24 hours
☐ 1 to 4 weeks ☐ I don't know

17.4.2 In the last 24 hours of life, what was the evolution of the drugs dose?

☐ No change ☐ Gradual increase ☐ Strong increase

17.4.3 Who was the last person to administer the drugs (introduced them into the body)?

☐ Yourself ☐ Another healthcare professional
☐ The patient ☐ A relative
☐ Someone else *(please specify)* ____________________________

18. Did you discuss with the patient the various options related to end-of-life medical practices? *(multiple answers possible)*

☐ Yes, about the use of life-sustaining treatment(s) ☐ Yes, about withholding or withdrawing life-sustaining treatment(s) ☐ Yes, about giving drugs to alleviate pain and/or symptoms ☐ Yes, about the intentional use of lethal drugs ☐ No *(multiple answers possible* →

18.1 There was no discussion for the following reason(s):

☐ This person didn't have the capacity to discuss these options
☐ The decision(s) was (were) made according to the advance directives
☐ Other reason *(please specify)*______________________________

19. Did you discuss with anybody else about the various options related to end-of-life medical practices? *(multiple answers possible)*

☐ With partner, children or parent(s) ☐ With one or more medical colleagues ☐ Nobody else
☐ With the substitute decision-maker or proxy ☐ With the healthcare team ☐ Someone else *(please specify)* ______________________
☐ With other relatives or friends ☐ With the ethics committee

20. The discussion(s) was (were) initiated by: *(multiple answers possible)*

☐ N/A ☐ The partner, children or parent(s) ☐ Another physician
☐ Yourself ☐ The substitute decision-maker or proxy ☐ The healthcare team
☐ The patient ☐ Other relatives or friends ☐ Someone else *(please specify)*
____

21. According to you, over the last week before death, to what extent (0: none to 5: severe) were the following symptoms encountered by this person? *(mark each item in the column corresponding to your review)*

		0	1	2	3	4	5		Unknown	N/A
Pain	None	☐	☐	☐	☐	☐	☐	Severe	☐	☐
Drowsiness	None	☐	☐	☐	☐	☐	☐	Severe	☐	☐
Respiratory problems	None	☐	☐	☐	☐	☐	☐	Severe	☐	☐
Loss of consciousness	None	☐	☐	☐	☐	☐	☐	Severe	☐	☐
Confusion	None	☐	☐	☐	☐	☐	☐	Severe	☐	☐
Anxiety	None	☐	☐	☐	☐	☐	☐	Severe	☐	☐
Depression	None	☐	☐	☐	☐	☐	☐	Severe	☐	☐
Other. *Specify*______________	None	☐	☐	☐	☐	☐	☐	Severe		

22. According to you, which term is the most appropriate to describe the last medical act performed before the person's death? *(only one answer)*

☐ Prolongation of life ☐ Physician-assisted suicide
☐ Withholding or withdrawal of treatment(s) ☐ Euthanasia
☐ Alleviation of symptoms ☐ Medical assistance in dying
☐ Continuous palliative sedation
☐ Other *(Please specify)*____________________

→

22.1 Do the conditions under which this death occurred meet the criteria of the law in place in your province / territory?

☐ Yes
☐ No
☐ I don't know

For questions 23 to 25, please indicate on a scale of 1 to 7 the extent to which you agree or disagree with the following statements:

1. Strongly disagree	2. Moderately disagree	3. Somewhat disagree	4. Neutral or No opinion	5. Somewhat agree	6. Moderately agree	7. Strongly agree

23. In retrospect, you are satisfied with this person's end-of-life care.

1	*2*	*3*	*4*	*5*	*6*	*7*	*n/a*
Strongly disagree			*No opinion*			*Strongly agree*	

24. This death has been overwhelming for me.

1	*2*	*3*	*4*	*5*	*6*	*7*	*n/a*
Strongly disagree			*No opinion*			*Strongly agree*	

*Because*____

25. Medical practices at the end of life overwhelm me in general.

1	*2*	*3*	*4*	*5*	*6*	*7*	*n/a*
Strongly disagree			*No opinion*			*Strongly agree*	

*Because*____

26. Considering your relationship with this person or their family members, did you encounter any challenges during the process of end-of-life care such as: *(multiple answers possible)*

☐ Cultural differences *(Pleasespecify)*________________________________

☐ Language barrier *(Please specify)*________________________________

☐ Different religious beliefs *(Please specify)*____________________________

☐ Conflict between family members *(Please specify)*__________________________

☐ Other *(please specify)*____________________________________

☐ None

27. Is there any other information that you consider relevant and that you would like to share to help us better understand the situation?

____

____

____

____

In general...

28.Do you consider you have received enough training to deal with palliative care?

☐ Yes, formal training ☐ Yes, informal training ☐ No

29.Do you consider you have received enough training to deal with medical assistance in dying?

☐ Yes, formal training ☐ Yes, informal training ☐ No

30.Do your patients have access to palliative care services? *(multiple answers possible)*

☐ Yes, ambulatory care ☐ Yes, hospice care

☐ Yes, in-hospital care ☐ No

31.Are these services sufficient to meet the needs of your patients at the end of life? ☐ Yes ☐ No

☐ Partially ☐ I don't know

<u>Thank you for your participation in this important survey</u>.