END-OF-LIFE EXPERIENCES AND QUALITY OF DYING IN CANADA: AN ANALYSIS OF THE CANADIAN LONGITUDINAL STUDY ON AGING DECEDENT QUESTIONNAIRE

END-OF-LIFE EXPERIENCES AND QUALITY OF DYING IN CANADA: AN ANALYSIS OF THE CANADIAN LONGITUDINAL STUDY ON AGING DECEDENT QUESTIONNAIRE

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TITLE: End-of-Life Experiences and Quality of Dying in Canada: An Analysis of the Canadian Longitudinal Study on Aging Decedent Questionnaire

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Lay Abstract

The end-of-life experience is a deeply personal journey, yet many older adults in Canada encounter challenges in receiving care that aligns with their preferences. Some individuals wish to pass away at home, while others seek comfort in palliative care or hospice settings. Understanding the factors that contribute to a peaceful and dignified death can help improve end-of-life care across the country.

This thesis analyzed data from the Canadian Longitudinal Study on Aging (CLSA) to examine how various factors—such as and personal circumstances, location of death, and medical assistance in dying (MAiD)—shape experiencing peace with dying and overall quality of dying. Using information from next-of-kin interviews, the study assessed the end-of-life experiences of over 1,200 deceased individuals.

The findings indicate that while most older adults experience peace with dying, nearly one in five do not. Those who died in their preferred setting, had a substitute decision-maker, or had access to palliative care were more likely to experience a better quality of death. Additionally, individuals who considered or received MAiD were often reported to have a more peaceful end-of-life experience.

These insights highlight the importance of improved planning, communication, and access to high-quality palliative and hospice care. By addressing these gaps, healthcare systems can better support individuals and families, ensuring that more Canadians experience a dignified and peaceful death.

Abstract

Background: Understanding the factors that contributed to a peaceful and dignified death was essential for improving end-of-life (EoL) care in Canada. Despite ongoing efforts to enhance palliative and hospice services, variations persisted in the quality of death experiences based on location, medical decisions, and personal characteristics.

Objectives: This thesis examined the personal and end-of-life factors associated with peace with dying among older adults in Canada. It also explored how location of death and the consideration or receipt of medical assistance in dying (MAiD) influenced the perceived quality of death and dying.

Methods: A secondary analysis of data from the Canadian Longitudinal Study on Aging (CLSA) was conducted. The study included next-of-kin interviews of deceased CLSA participants who died between June 2016 and March 2022. Logistic regression was used to assess the association between demographic, clinical, and EoL characteristics and peace with dying. Additionally, the impact of location of death and MAiD on various quality-of-death indicators, including dying with dignity, dying without pain, and dying in one's preferred place, was examined.

Results: Among 3,672 deceased CLSA participants, 1,287 (35.0%) had completed next-of-kin interviews and were included in the analysis. While 66% were reported to have experienced peace with dying, 17% did not. Individuals who were widowed, had an appointed substitute decision-maker, or died of cancer were more likely to experience peace with dying. Those who died at home were more likely to pass away in their preferred location, while individuals in palliative care units or hospices experienced lower levels of pain. Of the decedents, 25.4% had considered MAiD, and 6.7% had received it. Those who considered or received MAiD were more likely to die in their preferred location and experience a positive death process as reported by their next of kin.

Conclusion: Nearly one in five older Canadians did not experience peace with dying, highlighting the need to improve EoL care services. While dying at home aligned with individual preferences, hospice and palliative care settings better addressed pain management. MAiD appeared to enhance the quality of dying for those who pursued it. These findings underscored the importance of advanced care planning and patient-centered EoL interventions to ensure dignified and peaceful deaths across care settings in Canada.

Acknowledgements

I would like to start by thanking my supervisor, Dr. Andrew Costa, for his exceptional guidance and expertise throughout my academic journey. Your unwavering support across all my research endeavors has been invaluable to the success of this thesis. I am deeply grateful for the many lessons you've imparted—ranging from academic insights to career advice and wisdom about life.

I am also incredibly grateful to my committee members, Dr. Aaron Jones, Dr. Lauren Griffith, and Dr. Peter Tanuseputro, for their thoughtful input, time, and dedication to this thesis. Dr. Aaron Jones, thank you for your constant support in data analytics and invaluable lessons about statistics. Dr. Lauren Griffith, thank you for your constructive feedback and positivity which have been instrumental in shaping the rigor of this research. Dr. Peter Tanuseputro, your insights on palliative care have been greatly appreciated, and I am thankful for your thoughtful advice throughout the process.

I would also like to extend my heartfelt thanks to the Health Research Methodology (HRM) program at McMaster University, all my colleagues in the Big Data & Geriatrics Models of Care Research Group, and friends for providing such a rich and supportive academic environment.

To my husband, Achyut Devkota, thank you for your unwavering love, patience, and belief in me. Thank you for staying up late to revise my code, listen to me practice my presentations, and teach me about colour schemes for data visualization methods. Your constant support has not only made this journey easier but also memorable.

I am also deeply thankful to my parents, Yuvraj and Saraswati Aryal, whose sacrifices and constant encouragement have been a source of strength throughout my life. You have always been my greatest supporters, and I dedicate this work to you both. Finally, to my siblings, Sagar and Nirmala Aryal, thank you for your support and encouragement. Your belief in me has been a constant source of motivation, and I am so grateful for everything you have done to help me reach this milestone.

‘

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List of Abbreviations

ADL	Activities of Daily Living
CD	Cardiovascular Disease
CGI	Client Generated Index
CI	Confidence Interval
CIHR	Canadian Institutes of Health Research
CLSA	Canadian Longitudinal Study on Aging
DOB	Date of Birth
DSD	Details Surrounding Death
ED	Emergency Department
Eastern	Eastern Provinces of Canada: New Brunswick, Newfoundland and Labrador, Nova Scotia, Prince Edward Island
EoL	End-of-Life
FBD	Function at 1 Month Before Death
GDI	Good-Death Scale
IADL	Instrumental Activities of Daily Living
LAP	Living Arrangements Prior to Death
LTC	Long-term Care Facility
MAiD	Medical Assistance in Dying
MCG	About the Main Caregiver
MQOL	McGill Quality of Life questionnaire
OR	Odds Ratio

PIC	Participant Information (previously collected)
PPD	Participant's Health Care Preferences and Decisions
PAD	Physician Assisted Death
PCU	Palliative Care Unit
QDD	Quality of Death and Dying
QODD	Quality of Dying and Death Questionnaire
QOD-LTC	Quality of Dying in Long-term Care
R	R Studio
RIDK	R = Respiratory diseases including emphysema, obstructive lung disease, asthma, chronic obstructive pulmonary disease; I = Influenza or pneumonia; D = Dementia; K = Kidney Diseases such as nephritis, nephrotic syndrome, or nephrosis
SD	Standard Difference
SDM	Substitute Decision Maker
STROBE	Strengthening the Reporting of Observational Studies in Epidemiology
VIF	Variation Inflation Factor
Western	Western Provinces of Canada: Alberta, Manitoba, Saskatchewan
WHOQOL-OLD	World Health Organization's Quality of Life (OLD) Assessment

Declaration of Academic Achievement

I, Komal Aryal, was responsible for the conceptualization, analysis, interpretation, writing, and revisions of all chapters comprising this thesis. The chapters include an introduction (Chapter 1), quality of death and dying analysis (Chapters 2), descriptive analysis on medical assistance in dying (Chapter 3), a regression analysis on location of death (Chapter 4), and a discussion (Chapter 5). I consulted with my PhD supervisor (Dr. Andrew Costa) and thesis committee members (Dr. Aaron Jones, Dr. Lauren E. Griffith, and Dr. Peter Tanuseputro) when methodological and contextual guidance was warranted.

Chapters 2, 3, and 4 utilized data obtained from the Canadian Longitudinal Study on Aging (CLSA), in accordance with CLSA guidelines for student investigators. Before submitting the included studies to academic journals, I collaborated with field leaders and methodological experts to review and contribute to the final drafts, including Dr. James Downar, Dr. Kieran Quinn, Dr. Deborah J. Cook, Dr. Paul C. Hebert, and Dr. Susan Kirkland.

CHAPTER ONE

Introduction

Aging and Dying in Canada

Over the past few decades, Canada has seen exponential growth in the proportion of older adults aged 65 and older. As of 2023, over 7.8 million, or 18.3% of the total Canadian population, were aged 65 or older, a figure projected to rise substantially by 2050.[1, 2] For this aging population, the reality of death becomes an imminent concern. As many Canadians will soon require end-of-life care due to chronic and progressive health conditions, older adults' experiences and perspectives during end-of-life are becoming critically important.[3] A better understanding of end-of-life care will enable older adults to take a proactive approach to managing their healthcare preferences.[4]

In Canada, between 60-70% of all deaths occur in hospitals with older adults dying in hospitals more commonly than younger adults.[5-7] Most older adults, however, report that they prefer home-based deaths making them disproportionally affected as their end-of-life experiences may not align with their preferences.[8-11] Further, older adults dying in hospitals may experience multiple complications and invasive interventions, that older adults may not be comfortable with.[12]

Over 90% of individuals die of chronic illnesses such as cancer, heart disease, organ failure, dementia, or frailty, making death due to these causes somewhat predictable or forthcoming, in Canada.[13] Older adults dying in hospitals are more likely to die of cancer, heart disease, and respiratory illnesses.[14] The healthcare system is currently facing increasing pressure to ensure optimal care policies and practice patterns are in place to meet individual end-of-life care needs.[15-18] Although policy initiatives to improve end-of-life care, such as the National Framework on Palliative Care, have been created, there remains significant variation in access and quality to optimal care across the country.[13, 19] Specifically, end-of-life care differs among the Canadian provinces, with some key differences between coverage for drugs or equipment and availability of team-based palliative care.[20]

Although end-of-life care across Canada may not be optimal, the landscape of end-of-life care is evolving in Canada, with a notable shift from hospital-based deaths to more community-oriented settings, such as home care and hospices.[5, 21] This transition in location of death results from understanding older adults preferences for dying in familiar and comfortable environments to meet their end-of-life preferences.[22] More older adults require optimal end-of-life care however, there is limited access to specialized end-of-life care such as palliative care or hospice services, that meets the needs of all older Canadians.[23, 24]

Challenges with Current End-of-Life Care

End-of-life care aims to provide holistic care for those near death to ensure a comfortable passing.[25, 26] The World Health Organization states that palliative care improves the quality of death and dying experiences for individuals with incurable illnesses.[27] Despite this, Canadian hospitals remain the primary end-of-life and palliative care facility.[18] A majority of older adults receive palliative care in these acute care environments.[28, 29] Similarly, over 54% of older adults state that they prefer non-invasive treatment during end-of-life but are transferred to the intensive care units or given life-prolonging treatments.[30] This discrepancy highlights a systemic issue where the healthcare infrastructure does not align with patient desires, leading to increased distress during end-of-life for patients and families.[31]

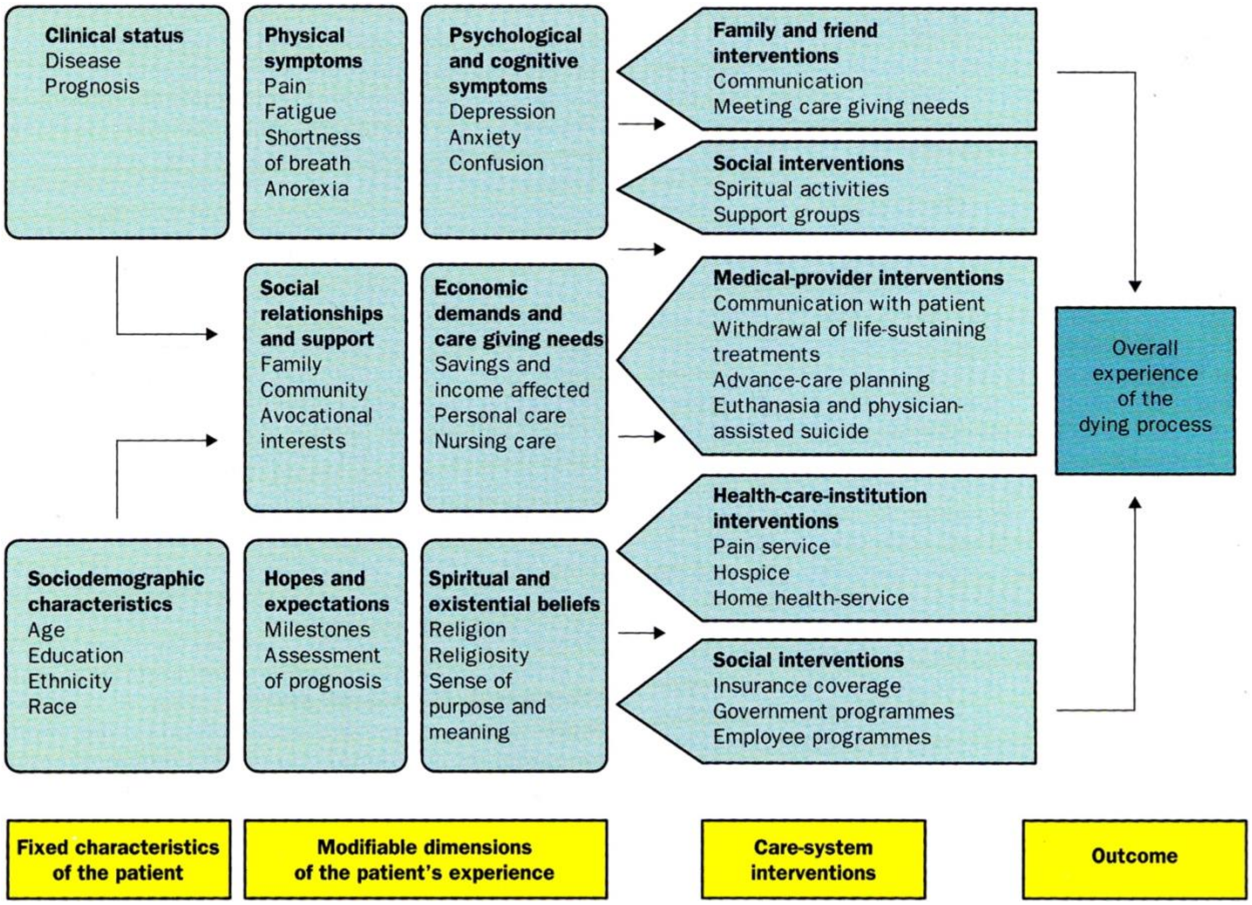
Older adults' personal and demographic characteristics also shape how end-of-life care is received in Canada. For example, many recent immigrants compared to long-standing residents are likely to die in acute care.[32] Additionally, younger, males, living in smaller or rural communities have poorer access to supportive end-of-life care.[33] In terms of health services, many clinicians may not have end-of-life conversations with older adults or not be trained on how to execute such conversations.[34]

A revaluation of healthcare systems is necessitated by the aging population worldwide to meet the increasing demand for palliative services. In many countries, including the United States and the United Kingdom, end-of-life care is often provided in hospital settings instead of through community-based services, like in Canada.[35, 36] Alongside, end-of-life care in hospital settings, fragmented end-of-life care is experienced by many patients, which does not adequately address physical, emotional, and spiritual needs.[37]

A Good Death

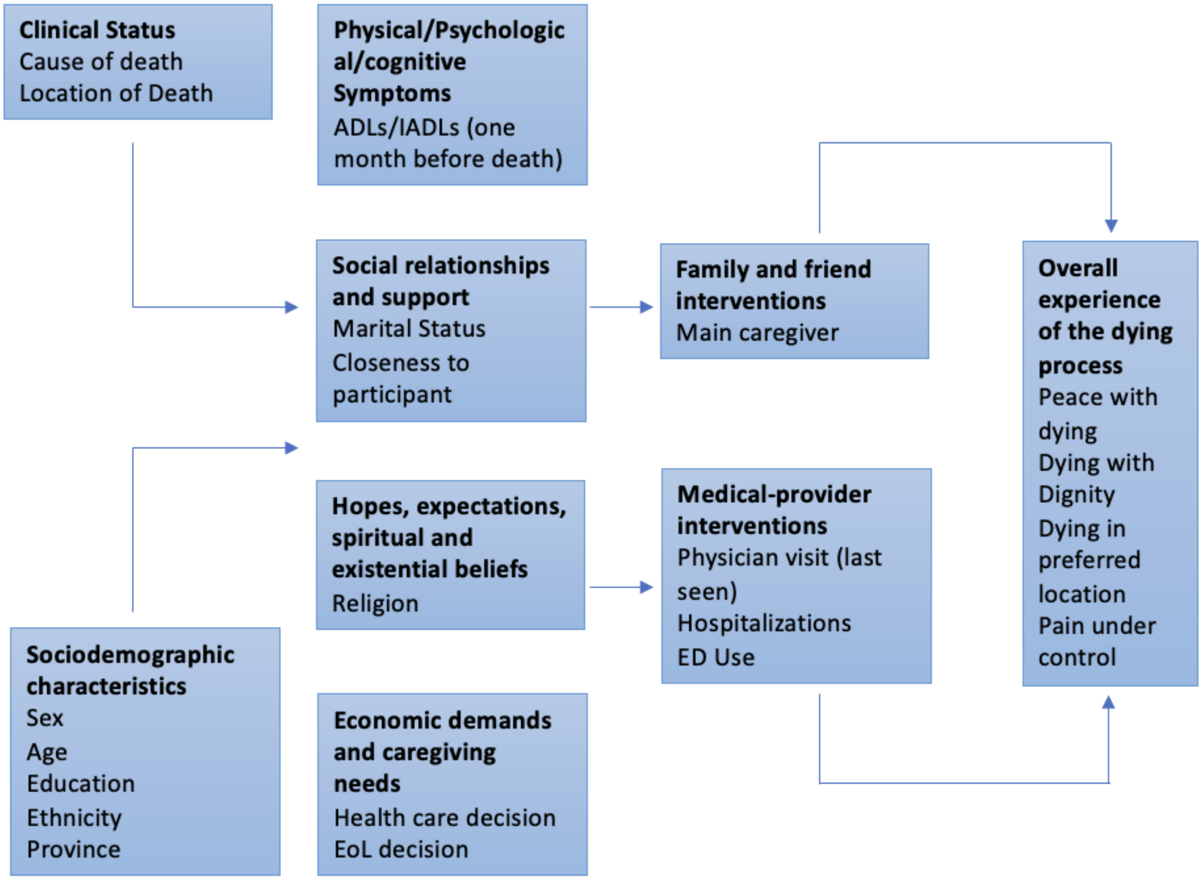
A good death, the outcome of a good quality of death and dying, and what constitutes a good death have been debated for many years.[38-44] Emanuel et Emanuel, published a framework on various personal and end-of-life characteristics that come together to understand the multidimensional experience of a good death (**Figure 1**).[45] This framework displays the dying process with four components 1) fixed characteristics, 2) modifiable characteristics, 3) potential interventions, and 4) the overall outcome.

Figure 1: Framework for a good death, Emanuel et Emanuel, 1998



This framework suggests the multifaceted characteristics combined with patient experience and a plethora of interventions that can be social or health system-related that are associated with the overall dying experience. For this thesis, we modified this framework to highlight the characteristics and interventions that are available in our dataset that can be categorized as the good death framework to understand the various end-of-life outcomes such as peace with dying, dying with dignity, dying in an individual's preferred place, and dying without pain (**Figure 2**). For older adults, caregivers, and policymakers, understanding factors that will allow older adults to experience a peaceful and high-quality end-of-life experience becomes critical.

Figure 2: Modified Framework Derived from the Good Death Framework (Emanuel 1998)



Understanding Quality of Death and Dying

The quality of death and dying has become increasingly recognized as a critical aspect of healthcare, focusing on alleviating suffering and restoring autonomy.[46, 47] Many aspects of end-of-life contribute to the quality of death and dying, such as, but not limited to, location of death, peace with dying, maintaining dignity, and end-of-life interventions.[48-50] Similarly, pain and symptom management are critical for older adults, and any uncontrolled symptoms, such as pain, are associated with a poorer quality of dying.[51, 52] Older adults often experience emotional distress, depression, and anxiety during end-of-life, and social support from family and caregivers plays a vital role in mitigating these issues, inevitably improving their quality of dying experience.[53] Older adults often welcome and sometimes prefer open conversations about end-of-life, as it allows for autonomy and decision-making.[54] Overall, the quality of death and dying for older adults is influenced by supportive care environments, pain management, psychological readiness, and effective communication. Ensuring that individuals' end-of-life needs are met, when possible, will allow for a better quality of death and dying experience and ensure older adults can die with dignity and peace.

A key component of a good quality of death is achieving a peaceful death. For older adults, peace with dying involves a complex interplay of personal preferences, family dynamics, cultural beliefs, and healthcare practices.[55] Peace with dying is often defined by the fulfillment of personal wishes and the alleviation of suffering.[50] Previous studies have found that older adults often prioritize a peaceful death characterized by effective pain and symptom management, reflecting a desire for quality over quantity of life.[56, 57] This understanding and preference for a peaceful death aligns with the broader understanding of a "good death."[58]

However, previous studies have found that, although autonomy over the dying experience and acceptance of death are likely to improve the quality of dying experience,[59] it does not always lead to individuals experiencing peace with dying.[50] Despite this, health services researchers and clinicians strive to investigate various methods aimed at improving end-of-life and peaceful experiences for older adults.[59, 60] Ensuring that older adults can die in a manner that aligns with their values and desires is essential for enhancing the quality of death.

Location of Death and Quality of Death and Dying

The setting in which a person dies—whether at home, in a hospice, or in a hospital—can profoundly impact the overall dying experience. Cultural norms and beliefs play a role in determining preferred locations of death, with some cultures prioritizing home deaths, while others may prefer institutional settings.[61] Many individuals indicate that home deaths tend to be the primary location that older adults prefer to die or where they experience a better overall positive quality of dying experience.[62-64] This preference is often associated with a perception of higher quality of end-of-life care, as home deaths provide a more personalized and dignified dying experience.[65] However, home deaths depend on strong support from family caregivers and palliative care services; without this, individuals' needs may go unmet, making it more difficult for older adults to experience a home death.[66] Hospice care, whether provided at home or in a dedicated facility, is widely recognized for ensuring the highest quality end-of-life experience, yet access to these services remains limited.[67] Despite these preferences and considerations, many older adults in Canada still die in hospitals, often due to unmet care needs or a lack of available home-based or palliative support.[68]

Hospital deaths are often associated with a lower quality of death.[69] Older adults in hospitals are more likely to undergo aggressive, life-prolonging treatments that may not align with their preferences.[67] While hospital deaths are often associated with higher-intensity medical interventions, they do not inherently equate to poor quality of death.[68] For example, the high rates of hospital deaths among older adults who die from falls suggest that many may have unmet end-of-life care needs, which could detract from their overall quality of death.[68] A better understanding of the interplay between experiences and support available to the individuals at the end-of-life and location of death is required in determining the quality of death and dying.

Medical Assistance in Dying and Quality of Death and Dying

Medical assistance in dying (MAiD) is an intervention at the end-of-life, defined as a procedure that allows individuals experiencing grievous and irremediable suffering to intentionally end their lives, either through self-administered means or through a healthcare provider's administration of lethal substances.[70] MAiD has been available since 2016 in Canada, but little is known about its influence on experiencing a "good death.[71-76] Reports from family members of MAiD recipients frequently express feelings of relief and validation regarding their loved one's choices, citing a sense of honor in supporting their decisions.[77, 78] In contrast, older adults who do not pursue MAiD may experience prolonged suffering, distress, and a lack of control over their dying process, potentially leading to a poor quality of dying experience.[77, 79]

MAiD was introduced as a way to provide relief to those experiencing intolerable suffering at the end of life, aiming to offer a dignified death in alignment with a patient's wishes, but there have been many disagreements and controversies about this topic.[80-83] Many oppose MAiD due to moral or religious grounds and concerns that vulnerable individuals, such as the elderly, might feel pressured to choose MAiD due to societal or familial expectations.[82, 84] Some argue that legalizing MAiD could undermine the trust between patients and healthcare providers, as patients may fear that their doctors might prioritize ending life over preserving it.[84]

MAiD represents a critical intersection of medical ethics, patient autonomy, and the quality of death. Understanding the extent to which it improves the quality of death is challenging.[71, 80, 85, 86] While it offers a pathway for individuals to exert control over their dying process, the implications for quality of death and dying are unknown.[87] Understanding the end-of-life experience of MAiD recipients could guide policies, improve MAiD practices, and provide healthcare professionals with the insights needed to support patients and families through their death and dying experience.[88, 89]

Measuring Quality of Death and Dying

Quality of death has been measured and assessed using various instruments and frameworks. Each framework or instrument aims to capture the multidimensional nature of the quality of death and dying process by focusing on factors such as symptom management, emotional well-being, and the fulfillment of personal preferences. A systematic review compared 18 tools and frameworks of measures related to quality of dying and death.[90] The validated measures include the Quality of Dying and Death Questionnaire (QODD), Good-Death Scale, Good Death Inventory (GDI), Quality of Dying in Long-term Care (QOD-LTC), the Client Generated Index (CGI) and McGill Quality of Life questionnaire (MQOL).[91-95] Out of these tools, the QODD is more comprehensive and more widely validated compared to the other tools.

Additional studies report ad hoc measures, which, while useful for specific studies, lack the rigor needed for broader application. Many of these instruments rely on single-item scales, while others assess multiple aspects, indicating variability in how quality is conceptualized and measured.[90] However, these instruments help researchers and clinicians better understand quality of death and dying for older adults and potentially how to improve end-of-life experiences.

Although not exclusively focusing on the quality of death, another commonly used tool is the WHOQOL-OLD instrument, an extension of the World Health Organization's Quality of Life assessment, specifically designed for older adults.[96] This tool, which includes six facets, of which one is Death and Dying, focuses on individuals' concerns, fears, and acceptance regarding the end of life.[97] Since this tool was developed through international collaboration, the module is designed to be applicable across diverse cultural contexts.[97-104] Although there is a thorough framework for assessing quality of end-of-life in older adults, the length of the tool and the distress that the questions may cause can affect the overall respondent experience.

The QODD is the primary tool to assess the end-of-life experience from the perspective of bereaved caregivers or healthcare professionals.[91] It comprises 31 items covering domains such as symptoms, personal care, preparation for death, moment of death, family involvement, treatment preferences, and whole-person concerns. Each item is rated on an 11-point scale (0–10), and the questionnaire is administered through a semi-structured proxy interview with retrospective recall. However, the questionnaire and its unidimensional domain structure do not fit all data types and may lack relevance to diverse cultural contexts. Despite this limitation, the QODD has shown strong internal consistency, with a Cronbach's alpha of 0.89 and is the most widely used validated tool, making it a reliable tool for capturing end-of-life experiences.[90, 91, 105-108]

Canada and Quality of Death and Dying

As Canada continues to adapt its healthcare policies and integrate palliative care principles to meet the needs of its aging population, it is imperative to consider the multifaceted aspects of dying and death.[109] This includes addressing the sociodemographic and EoL characteristics that influence older adults' experiences at the end of life, such as living arrangements, socioeconomic status, access to supportive care, quality indicators, location of death, and medical interventions.[110-114] Understanding these dynamics is crucial for developing effective strategies that ensure a dignified and high-quality end-of-life experience for older Canadians.

Data Sources

This thesis involved the analysis of secondary data. Using multiple analysis methods, the results from each of the studies informed research questions for subsequent studies. The secondary data source examined in chapters 2, 3, and 4, comprised of decedent interview data from the Canadian Longitudinal Study on Aging (CLSA). The CLSA is a prospective cohort study with a national, stratified sample of 51,338 community-dwelling adults aged 45–85 years at baseline who are followed every 3 years.[115, 116]

To summarize, the CLSA is comprised of the Tracking cohort, which includes participants randomly selected from all 10 Canadian provinces, and the Comprehensive cohort, which includes participants randomly selected from within a 25–50 km radius of one of 11 data collection sites located in British Columbia, Alberta, Manitoba, Ontario, Quebec, Nova Scotia, and Newfoundland. Both cohorts collect similar data, while the Comprehensive participants also undergo more detailed physical assessments. All participants included in the CLSA must have been able to speak English or French and provide informed consent at baseline. Individuals living in institutions, diagnosed with severe cognitive impairment, non-residents of the province they were living in, persons living on reserves or other Aboriginal settlements, and full-time members of the Canadian Armed Forces, at baseline, were excluded from the study. The majority of participant demographic and social characteristics at baseline are comparable to the 2011 Canadian census.[117]

Provincial data on the death certificate data from participants, while useful, contain limited information about the time and cause of death and are not sufficient to understand important issues about residential transitions (e.g., moving into long-term care or hospice) or health care utilization in the period prior to death. Therefore, between 2014 to 2017, the decedent interview was created and launched. The CLSA modules were extracted from previously validated questionnaires. The domains and questions were adapted from the decedent questionnaire used in the Canadian Study on Health and Aging, the English Longitudinal Study on Aging, and the Japanese Longitudinal Study on Aging.[118, 119] None of the longitudinal population-based studies included the domain of quality of dying and death, which was adapted from the Quality of Dying and Death Questionnaire.[91]

Data from these interviews were used to investigate the quality of death and dying and the characteristics were classified using the modified good death framework. Baseline and follow-up data contained sociodemographic characteristics and spiritual beliefs in both the tracking and comprehensive cohorts. The CLSA decedent questionnaire contains data about participants the clinical status, physical/psychological/cognitive symptoms, social relationships and support, economic demands and caregiving needs, family, friend, and medical provider interventions, and the overall experience of the dying process.

To collect data on death experiences, next of kin or primary contacts (most often identified by the Canadian Longitudinal Study on Aging participant at baseline) were contacted by mail once the Canadian Longitudinal Study on Aging received the confirmation of death from a family member, friend, or through provincial death records. Next of kin or primary contacts were then contacted via telephone two weeks after mailing to invite participation in a decedent interview. Decedent questionnaires (available online)[120] were completed for participants who died between January 2012 to March 2022 by telephone interview (French or English) with a trained Canadian Longitudinal Study on Aging decedent interviewer. Interviews were completed an average of 2 years after death (between 10 days to 6.3 years) depending on respondent availability and release of the participant’s deceased status. **Appendix A** has a copy of the decedent questionnaire used to gather decedent data on CLSA participants.

This secondary analysis was approved by the Hamilton Integrated Research Ethics Board (2023-16023-C).

Thesis Objectives

This thesis aims to understand the quality of death and dying experiences for older adults in Canada. The research objectives were threefold:

1. To describe the EoL characteristics associated with proxy reports of decedents’ experience of peace with dying.

2. To understand the quality of death, including dying with peace, dying with dignity, dying in one's preferred location, and dying without pain across different settings, including home, hospital, and hospice or palliative care units (PCU).
3. To investigate the sociodemographic and clinical factors associated with medical assistance in dying (MAiD) consideration and receipt and to assess the death and dying experience for these groups.

This thesis advances the epidemiological understanding of end-of-life experiences by addressing key aspects of perceived quality of death and dying for older Canadians. It contributes methodologically by describing how proxy reports of decedents' experiences can be used to understand the perceived quality of death and how the quality of death and dying can be measured. Further, it extends current knowledge on medical assistance in dying, a political concern, and assesses the quality of death pertaining to the consideration or receipt of MAiD. This work also informs healthcare professionals and policymakers who are working to improve end-of-life care, ensuring that it aligns with the values and preferences of older adults and their families.

This sandwich thesis consists of a secondary analysis of decedent interview data from the CLSA using statistical methods such as regression analysis to identify patterns in peaceful dying, quality of death at home, hospice, and hospital, and MAiD-related experiences. The observational studies follow the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) guidelines.[121]

Thesis Overview

Chapter 2 describes a secondary analysis where I investigated demographic and end-of-life characteristics associated with peace with dying. Chapter 2 contains the study titled "Peaceful Dying Among Canada's Elderly: An Analysis of the Canadian Longitudinal Study on Aging." Using decedent interview data from the CLSA, the analysis provides a comprehensive understanding of the sociodemographic and end-of-life characteristics that contribute to peace with dying. This study is published in PLOS One and establishes a broad conceptualization of what constitutes a good death.

Chapter 3 is a secondary analysis of the location of death titled "Home, Palliative Care Units or Hospice, and Hospital Deaths: An Analysis of the Canadian Longitudinal Study on Aging." This chapter explores how the location of death—home, hospital, or hospice/palliative care units— an important concern for end-of-life care, influences overall end-of-life experiences for older adults. The study examines the quality of death across these settings and investigates how factors such as personal, provincial, physical impairment, and the cause of death influence the location of death. This analysis highlights the potential trade-offs between the quality of care provided in each setting and the alignment of death location with individual preferences. This study is also under review for publication.

Chapter 4, titled "Considering and Receiving MAiD: An Analysis of the Canadian Longitudinal Study on Aging," links the concept of peace with dying and the location of death to the unique experiences of individuals who seek MAiD. It provides insight into the sociodemographic and end-of-life factors associated with both the consideration and receipt of

MAiD and assesses how these factors affect the reported death and dying experiences. This chapter contextualizes MAiD within the broader framework of end-of-life care in Canada, contributing to an understanding of how MAiD shapes the quality of death for those who choose this option. This study is also under review for publication.

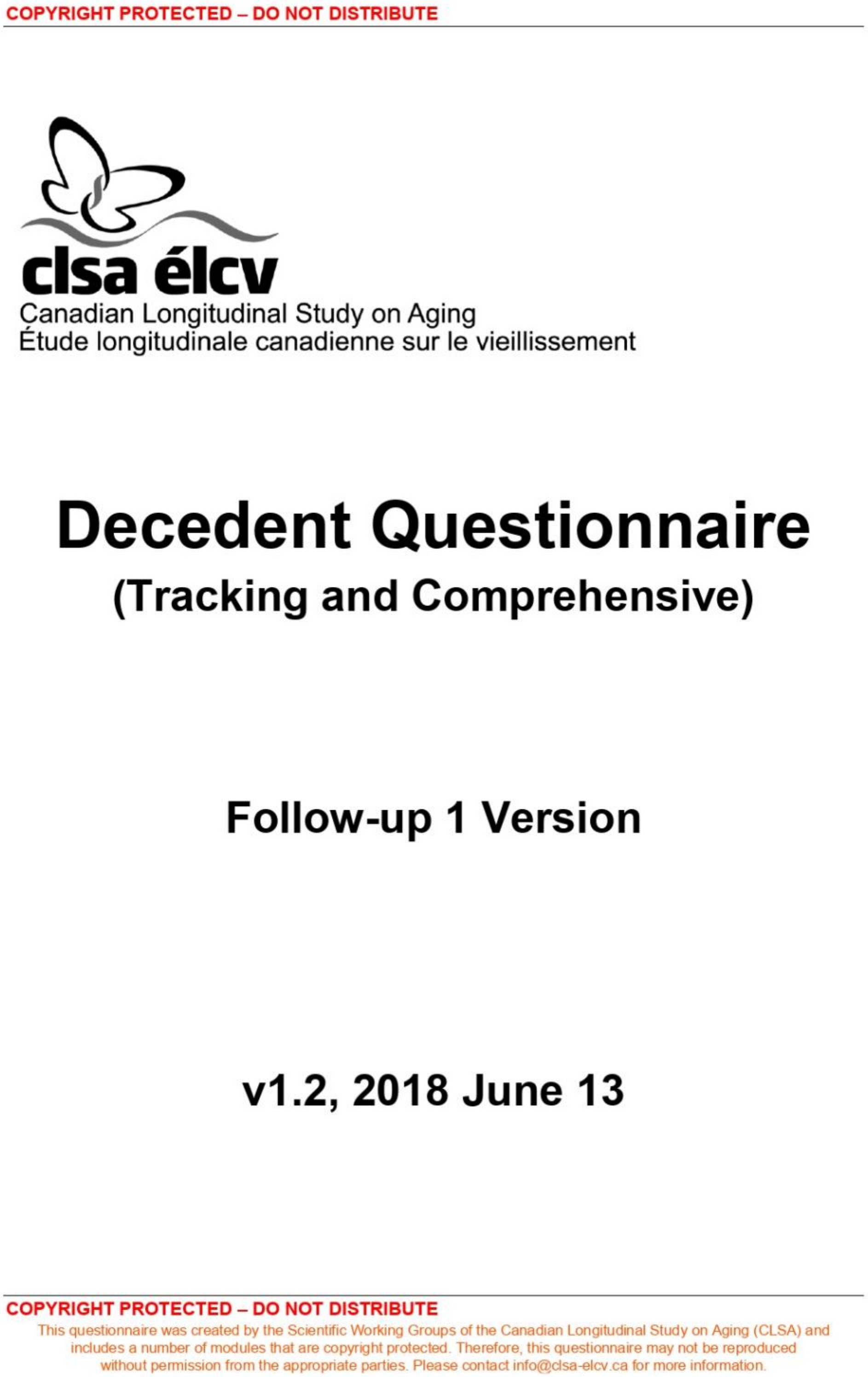
Chapter 5 synthesizes the findings from the preceding chapters and discusses their implications for both end-of-life care and public health policy in Canada. It highlights the methodological strengths and limitations of the analyses, compares the insights to existing literature, and outlines recommendations for improving end-of-life care practices, with a focus on enabling peaceful, dignified deaths in preferred locations, including for those considering MAiD. This chapter focuses on the importance of advanced care planning and tailored end-of-life interventions to address the complex needs of Canada's aging population.

Conclusion

Clinicians and researchers aim to improve the quality of death and dying experience for all older adults nearing the end-of-life. However, little is known about how different factors improve the overall quality of death and dying experiences for older adults. National-level end-of-life data has not been available previously to examine the quality of death and dying for older adults. This thesis uses novel data from the CLSA to understand various factors associated with perceived quality of death and end-of-life experiences. The chapters of this thesis examine unique aspects of end-of-life, including peace with dying, location of death, medical assistance in dying, and overall end-of-life experiences.

Appendices

Appendix A: Decedent Interview, Canadian Longitudinal Study on Aging

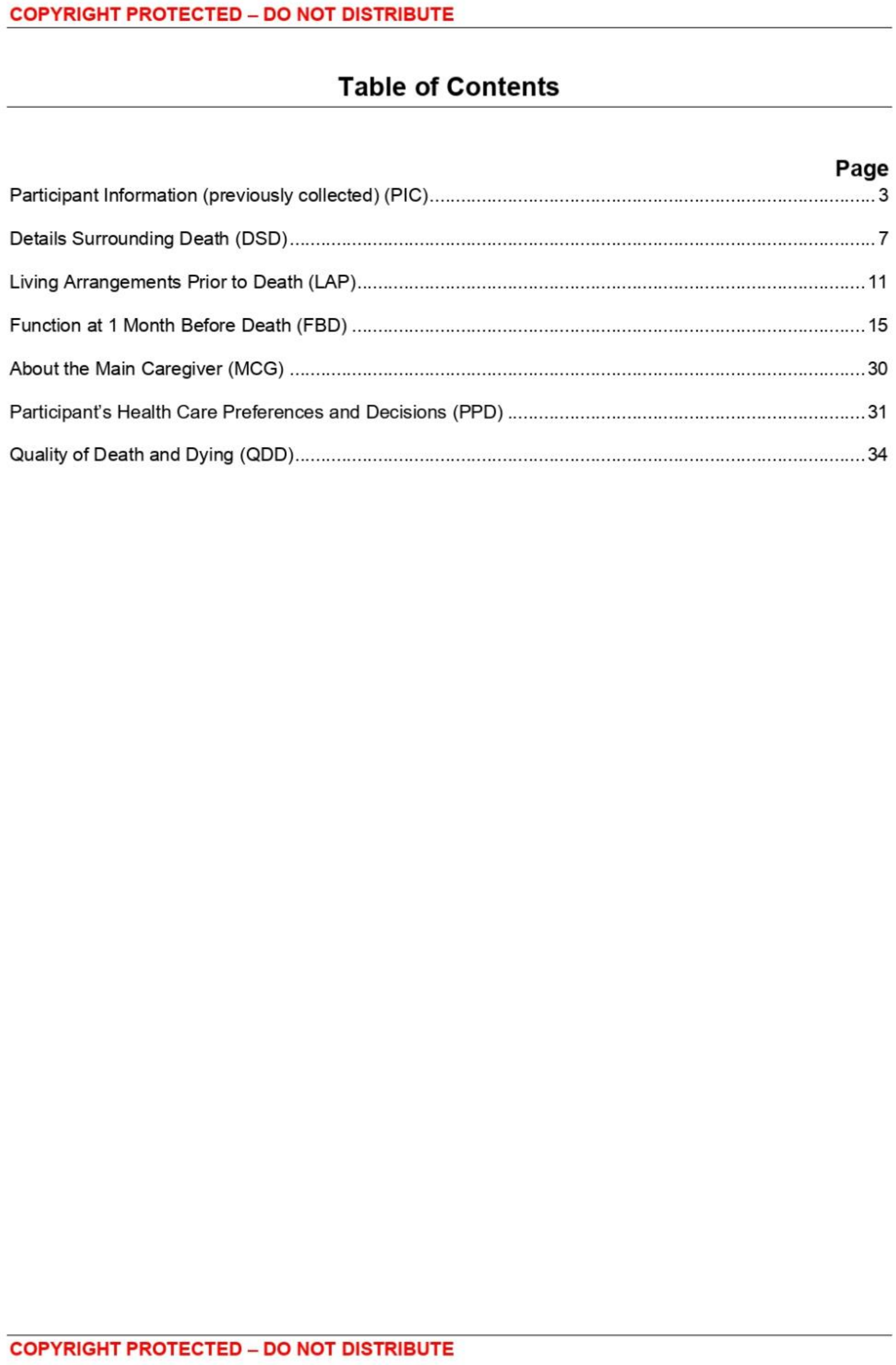


clsa élcv
Canadian Longitudinal Study on Aging
Étude longitudinale canadienne sur le vieillissement

Decedent Questionnaire
(Tracking and Comprehensive)

Follow-up 1 Version

v1.2, 2018 June 13



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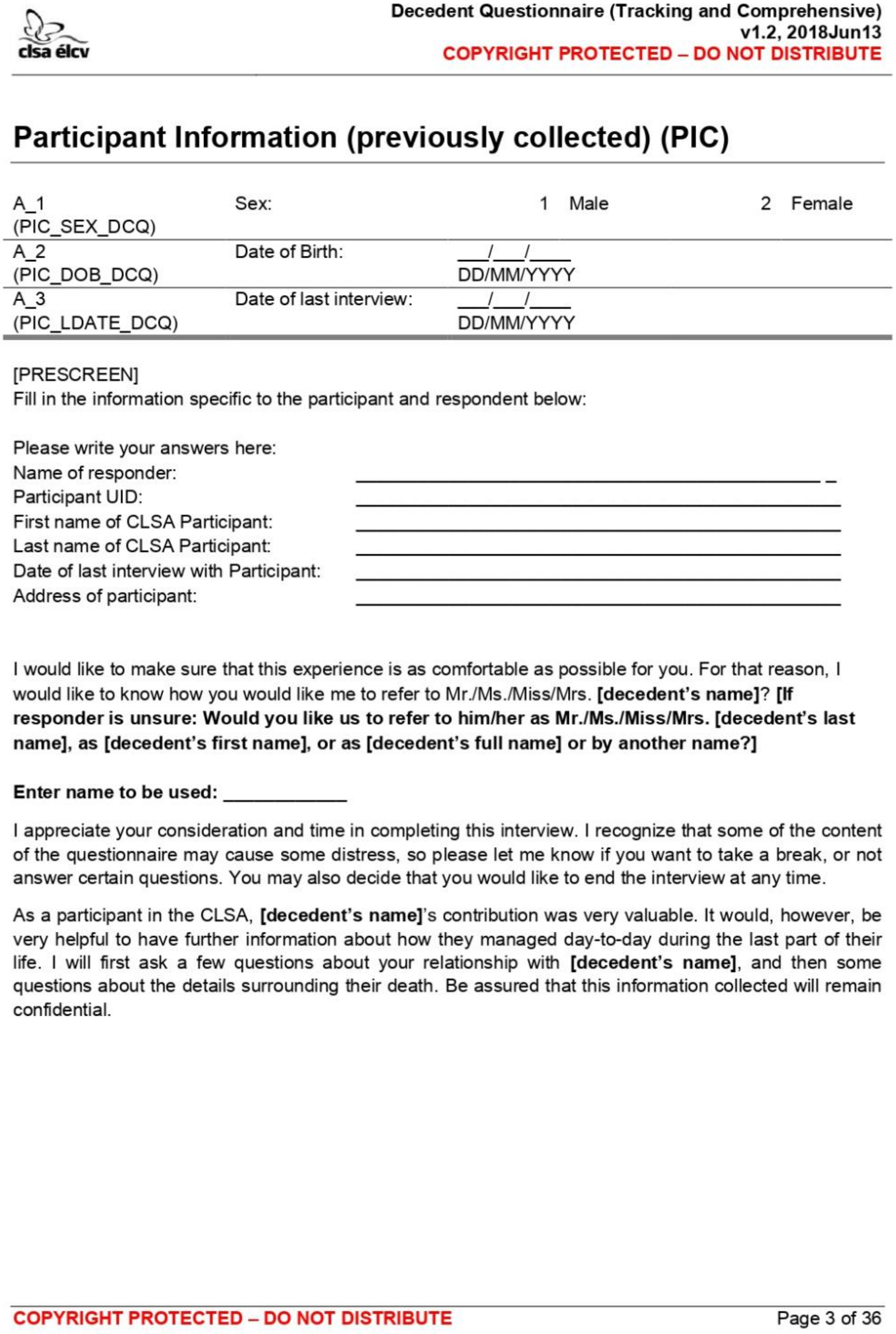


Participant Information (previously collected) (PIC)

A_1 (PIC_SEX_DCQ)	Sex:	1 Male	2 Female
A_2 (PIC_DOB_DCQ)	Date of Birth:	___/___/____ DD/MM/YYYY	
A_3 (PIC_LDATE_DCQ)	Date of last interview:	___/___/____ DD/MM/YYYY	

[PRESCREEN]
Fill in the information specific to the participant and respondent below:

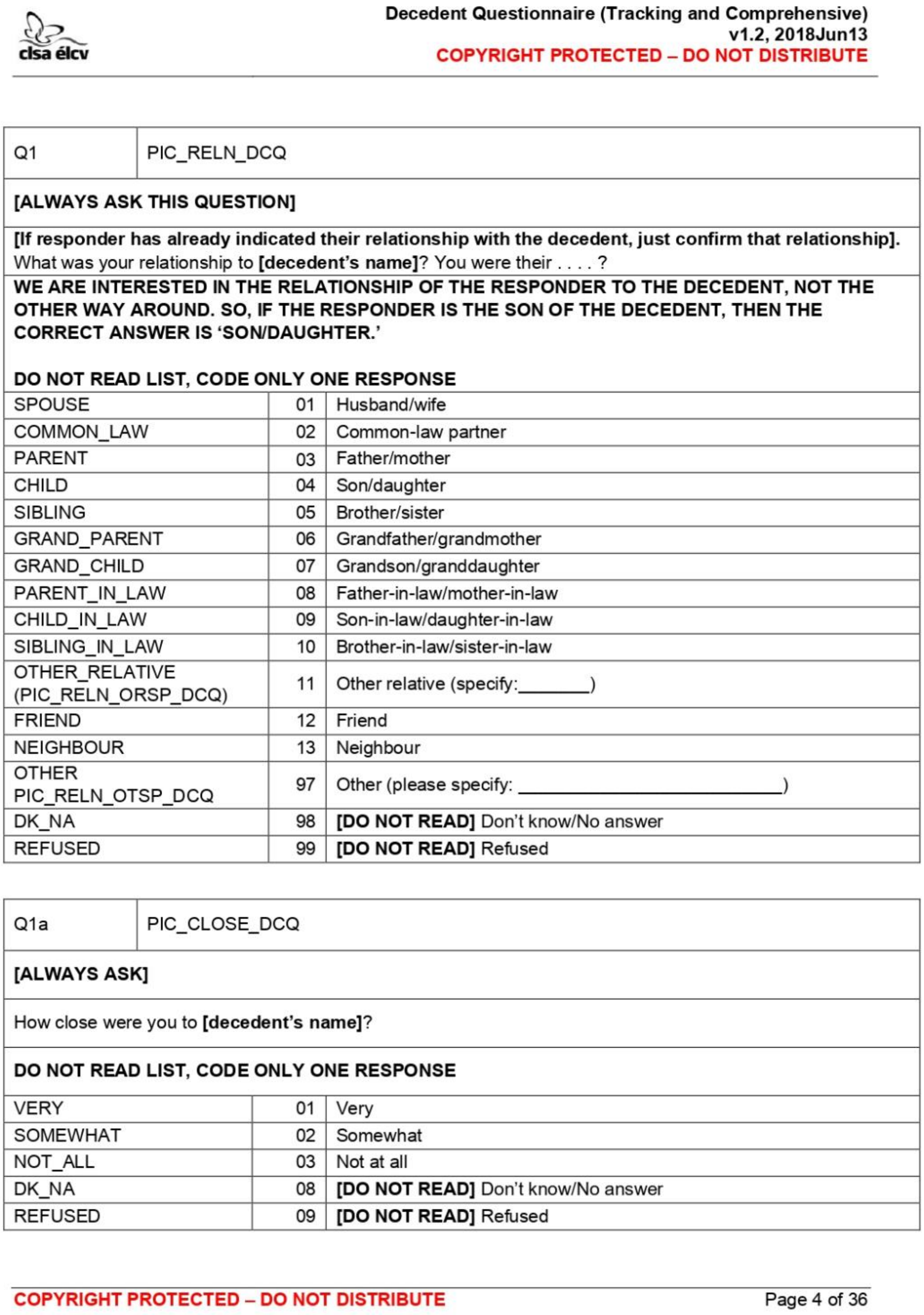
Please write your answers here:
Name of responder: ____ _
Participant UID: ____
First name of CLSA Participant: ____
Last name of CLSA Participant: ____
Date of last interview with Participant: ____
Address of participant: ____

I would like to make sure that this experience is as comfortable as possible for you. For that reason, I would like to know how you would like me to refer to Mr./Ms./Miss/Mrs. **[decedent's name]**? **[If responder is unsure: Would you like us to refer to him/her as Mr./Ms./Miss/Mrs. [decedent's last name], as [decedent's first name], or as [decedent's full name] or by another name?]**

Enter name to be used: ____________

I appreciate your consideration and time in completing this interview. I recognize that some of the content of the questionnaire may cause some distress, so please let me know if you want to take a break, or not answer certain questions. You may also decide that you would like to end the interview at any time.

As a participant in the CLSA, **[decedent's name]**'s contribution was very valuable. It would, however, be very helpful to have further information about how they managed day-to-day during the last part of their life. I will first ask a few questions about your relationship with **[decedent's name]**, and then some questions about the details surrounding their death. Be assured that this information collected will remain confidential.



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Q1	PIC_RELN_DCQ

[ALWAYS ASK THIS QUESTION]

[If responder has already indicated their relationship with the decedent, just confirm that relationship]. What was your relationship to **[decedent's name]**? You were their . . . . ?

WE ARE INTERESTED IN THE RELATIONSHIP OF THE RESPONDER TO THE DECEDENT, NOT THE OTHER WAY AROUND. SO, IF THE RESPONDER IS THE SON OF THE DECEDENT, THEN THE CORRECT ANSWER IS 'SON/DAUGHTER.'

DO NOT READ LIST, CODE ONLY ONE RESPONSE

SPOUSE	01	Husband/wife
COMMON_LAW	02	Common-law partner
PARENT	03	Father/mother
CHILD	04	Son/daughter
SIBLING	05	Brother/sister
GRAND_PARENT	06	Grandfather/grandmother
GRAND_CHILD	07	Grandson/granddaughter
PARENT_IN_LAW	08	Father-in-law/mother-in-law
CHILD_IN_LAW	09	Son-in-law/daughter-in-law
SIBLING_IN_LAW	10	Brother-in-law/sister-in-law
OTHER_RELATIVE (PIC_RELN_ORSP_DCQ)	11	Other relative (specify:________)
FRIEND	12	Friend
NEIGHBOUR	13	Neighbour
OTHER PIC_RELN_OTSP_DCQ	97	Other (please specify: ___________________________)
DK_NA	98	**[DO NOT READ]** Don't know/No answer
REFUSED	99	**[DO NOT READ]** Refused

Q1a	PIC_CLOSE_DCQ

[ALWAYS ASK]

How close were you to **[decedent's name]**?

DO NOT READ LIST, CODE ONLY ONE RESPONSE

VERY	01	Very
SOMEWHAT	02	Somewhat
NOT_ALL	03	Not at all
DK_NA	08	**[DO NOT READ]** Don't know/No answer
REFUSED	09	**[DO NOT READ]** Refused

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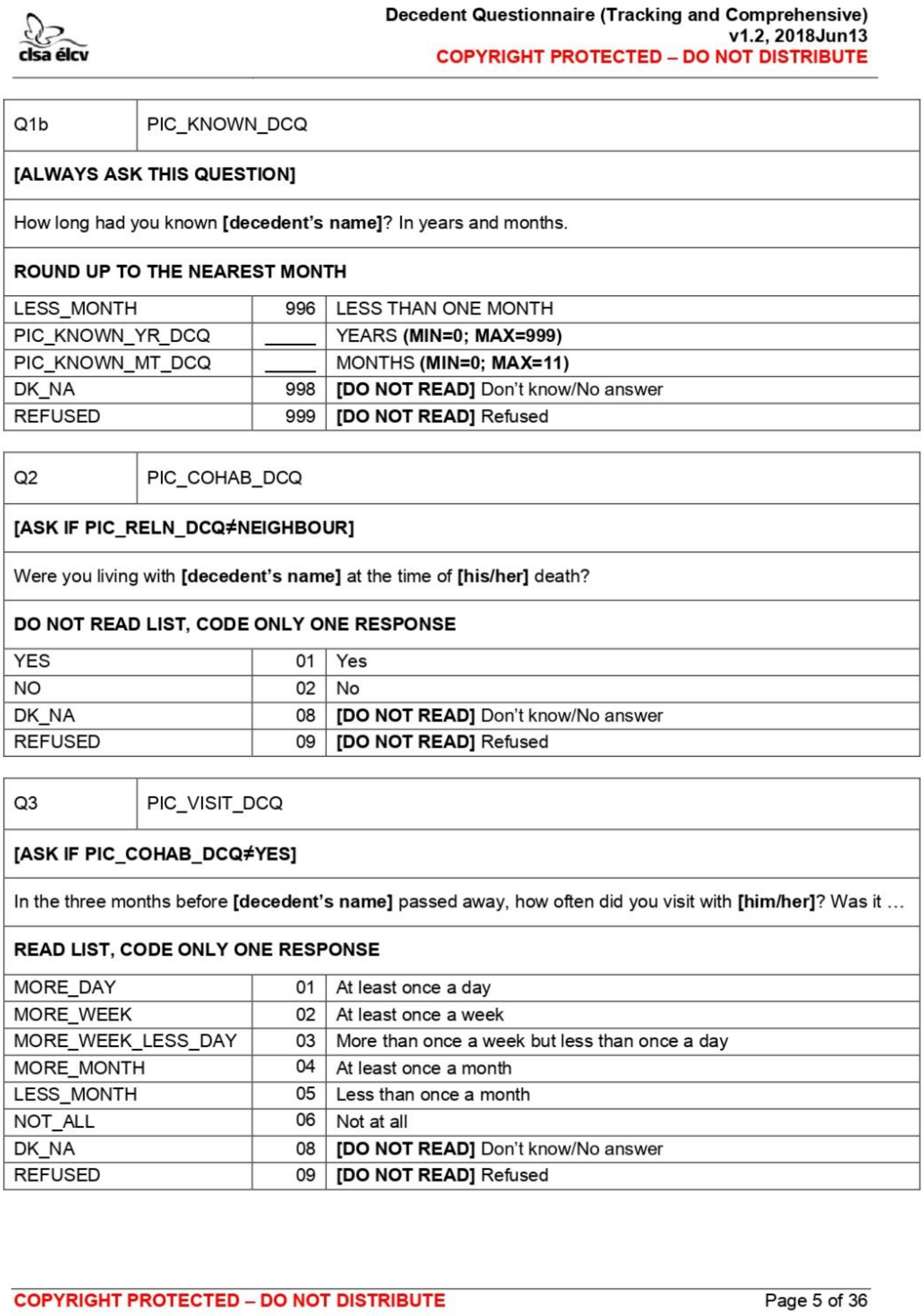
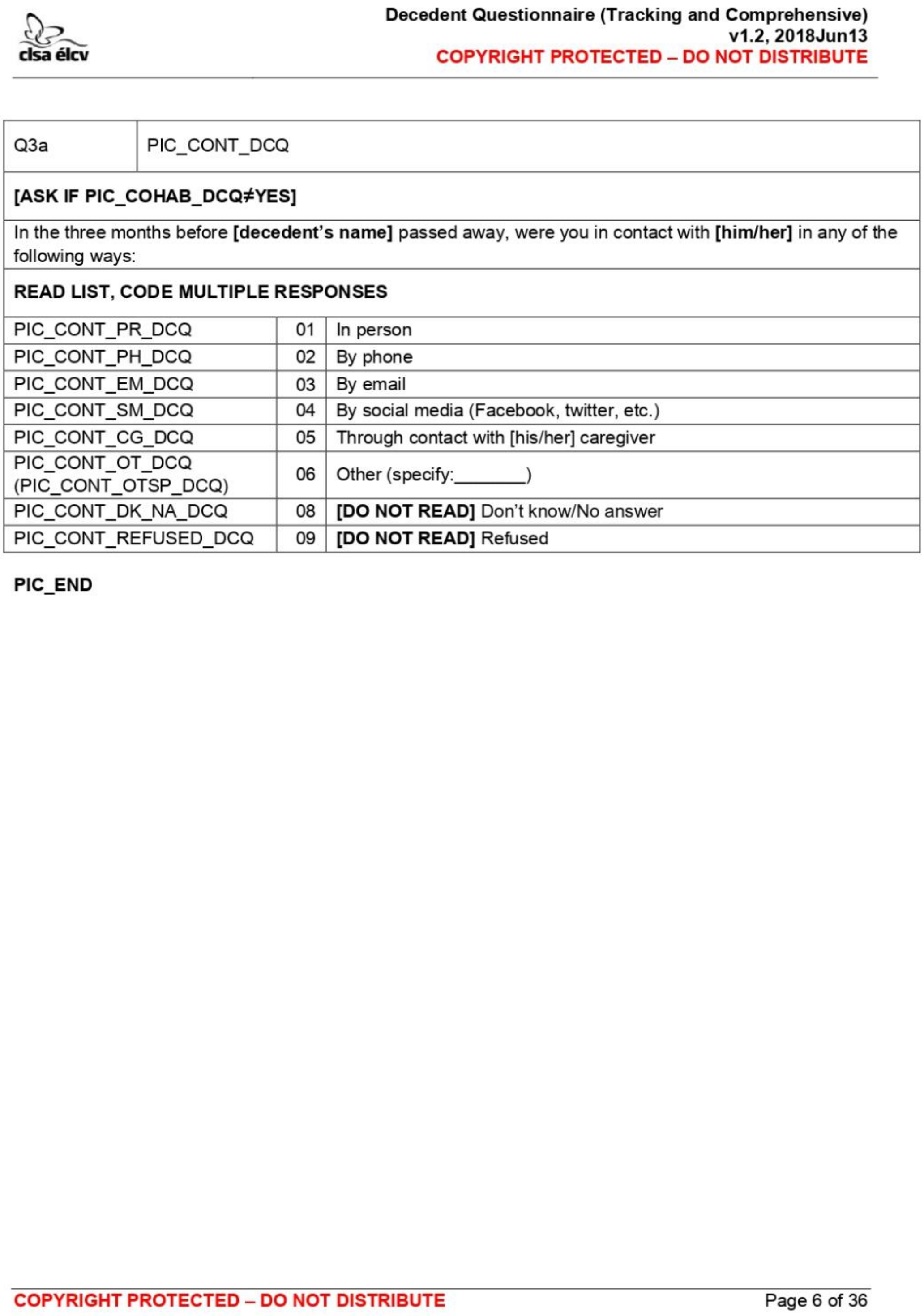


Q1b	PIC_KNOWN_DCQ	
[ALWAYS ASK THIS QUESTION]		
How long had you known **[decedent's name]**? In years and months.		
ROUND UP TO THE NEAREST MONTH		
LESS_MONTH	996	LESS THAN ONE MONTH
PIC_KNOWN_YR_DCQ	_____	YEARS **(MIN=0; MAX=999)**
PIC_KNOWN_MT_DCQ	_____	MONTHS **(MIN=0; MAX=11)**
DK_NA	998	**[DO NOT READ]** Don't know/No answer
REFUSED	999	**[DO NOT READ]** Refused

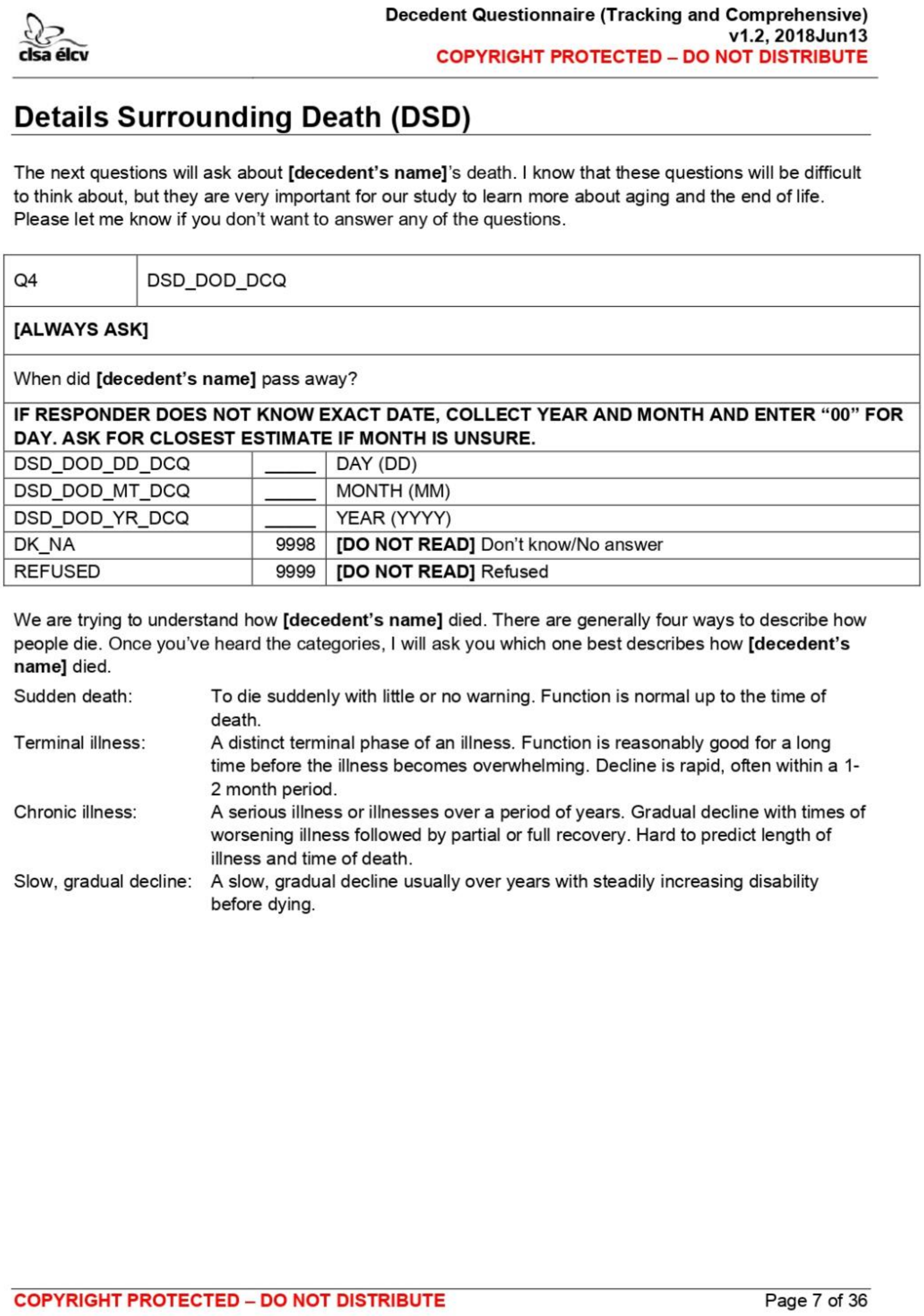
Q2	PIC_COHAB_DCQ	
[ASK IF PIC_RELN_DCQ≠NEIGHBOUR]		
Were you living with **[decedent's name]** at the time of **[his/her]** death?		
DO NOT READ LIST, CODE ONLY ONE RESPONSE		
YES	01	Yes
NO	02	No
DK_NA	08	**[DO NOT READ]** Don't know/No answer
REFUSED	09	**[DO NOT READ]** Refused

Q3	PIC_VISIT_DCQ	
[ASK IF PIC_COHAB_DCQ≠YES]		
In the three months before **[decedent's name]** passed away, how often did you visit with **[him/her]**? Was it …		
READ LIST, CODE ONLY ONE RESPONSE		
MORE_DAY	01	At least once a day
MORE_WEEK	02	At least once a week
MORE_WEEK_LESS_DAY	03	More than once a week but less than once a day
MORE_MONTH	04	At least once a month
LESS_MONTH	05	Less than once a month
NOT_ALL	06	Not at all
DK_NA	08	**[DO NOT READ]** Don't know/No answer
REFUSED	09	**[DO NOT READ]** Refused



Q3a	PIC_CONT_DCQ	
[ASK IF PIC_COHAB_DCQ≠YES]		
In the three months before **[decedent's name]** passed away, were you in contact with **[him/her]** in any of the following ways:		
READ LIST, CODE MULTIPLE RESPONSES		
PIC_CONT_PR_DCQ	01	In person
PIC_CONT_PH_DCQ	02	By phone
PIC_CONT_EM_DCQ	03	By email
PIC_CONT_SM_DCQ	04	By social media (Facebook, twitter, etc.)
PIC_CONT_CG_DCQ	05	Through contact with [his/her] caregiver
PIC_CONT_OT_DCQ (PIC_CONT_OTSP_DCQ)	06	Other (specify:________)
PIC_CONT_DK_NA_DCQ	08	**[DO NOT READ]** Don't know/No answer
PIC_CONT_REFUSED_DCQ	09	**[DO NOT READ]** Refused

PIC_END



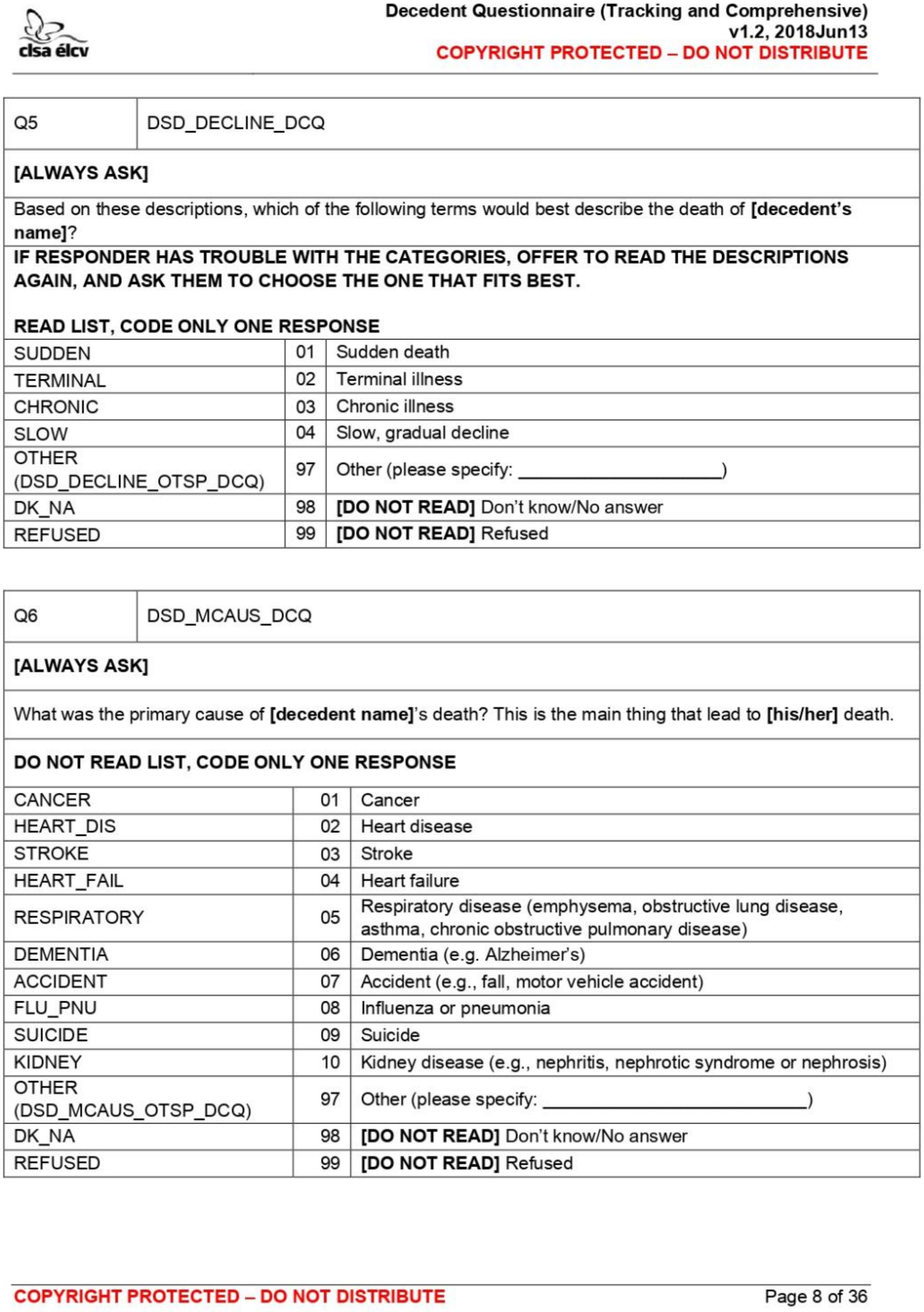
Details Surrounding Death (DSD)

The next questions will ask about **[decedent's name]**'s death. I know that these questions will be difficult to think about, but they are very important for our study to learn more about aging and the end of life. Please let me know if you don't want to answer any of the questions.

Q4	DSD_DOD_DCQ	
[ALWAYS ASK]		
When did **[decedent's name]** pass away?		
IF RESPONDER DOES NOT KNOW EXACT DATE, COLLECT YEAR AND MONTH AND ENTER "00" FOR DAY. ASK FOR CLOSEST ESTIMATE IF MONTH IS UNSURE.		
DSD_DOD_DD_DCQ	_____	DAY (DD)
DSD_DOD_MT_DCQ	_____	MONTH (MM)
DSD_DOD_YR_DCQ	_____	YEAR (YYYY)
DK_NA	9998	**[DO NOT READ]** Don't know/No answer
REFUSED	9999	**[DO NOT READ]** Refused

We are trying to understand how **[decedent's name]** died. There are generally four ways to describe how people die. Once you've heard the categories, I will ask you which one best describes how **[decedent's name]** died.

Sudden death:	To die suddenly with little or no warning. Function is normal up to the time of death.
Terminal illness:	A distinct terminal phase of an illness. Function is reasonably good for a long time before the illness becomes overwhelming. Decline is rapid, often within a 1-2 month period.
Chronic illness:	A serious illness or illnesses over a period of years. Gradual decline with times of worsening illness followed by partial or full recovery. Hard to predict length of illness and time of death.
Slow, gradual decline:	A slow, gradual decline usually over years with steadily increasing disability before dying.



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Q5	DSD_DECLINE_DCQ	
[ALWAYS ASK]		
Based on these descriptions, which of the following terms would best describe the death of **[decedent's name]**?		
IF RESPONDER HAS TROUBLE WITH THE CATEGORIES, OFFER TO READ THE DESCRIPTIONS AGAIN, AND ASK THEM TO CHOOSE THE ONE THAT FITS BEST. **READ LIST, CODE ONLY ONE RESPONSE**		
SUDDEN	01	Sudden death
TERMINAL	02	Terminal illness
CHRONIC	03	Chronic illness
SLOW	04	Slow, gradual decline
OTHER (DSD_DECLINE_OTSP_DCQ)	97	Other (please specify: ____________________)
DK_NA	98	**[DO NOT READ]** Don't know/No answer
REFUSED	99	**[DO NOT READ]** Refused

Q6	DSD_MCAUS_DCQ	
[ALWAYS ASK]		
What was the primary cause of **[decedent name]**'s death? This is the main thing that lead to **[his/her]** death.		
DO NOT READ LIST, CODE ONLY ONE RESPONSE		
CANCER	01	Cancer
HEART_DIS	02	Heart disease
STROKE	03	Stroke
HEART_FAIL	04	Heart failure
RESPIRATORY	05	Respiratory disease (emphysema, obstructive lung disease, asthma, chronic obstructive pulmonary disease)
DEMENTIA	06	Dementia (e.g. Alzheimer's)
ACCIDENT	07	Accident (e.g., fall, motor vehicle accident)
FLU_PNU	08	Influenza or pneumonia
SUICIDE	09	Suicide
KIDNEY	10	Kidney disease (e.g., nephritis, nephrotic syndrome or nephrosis)
OTHER (DSD_MCAUS_OTSP_DCQ)	97	Other (please specify: __________________________)
DK_NA	98	**[DO NOT READ]** Don't know/No answer
REFUSED	99	**[DO NOT READ]** Refused

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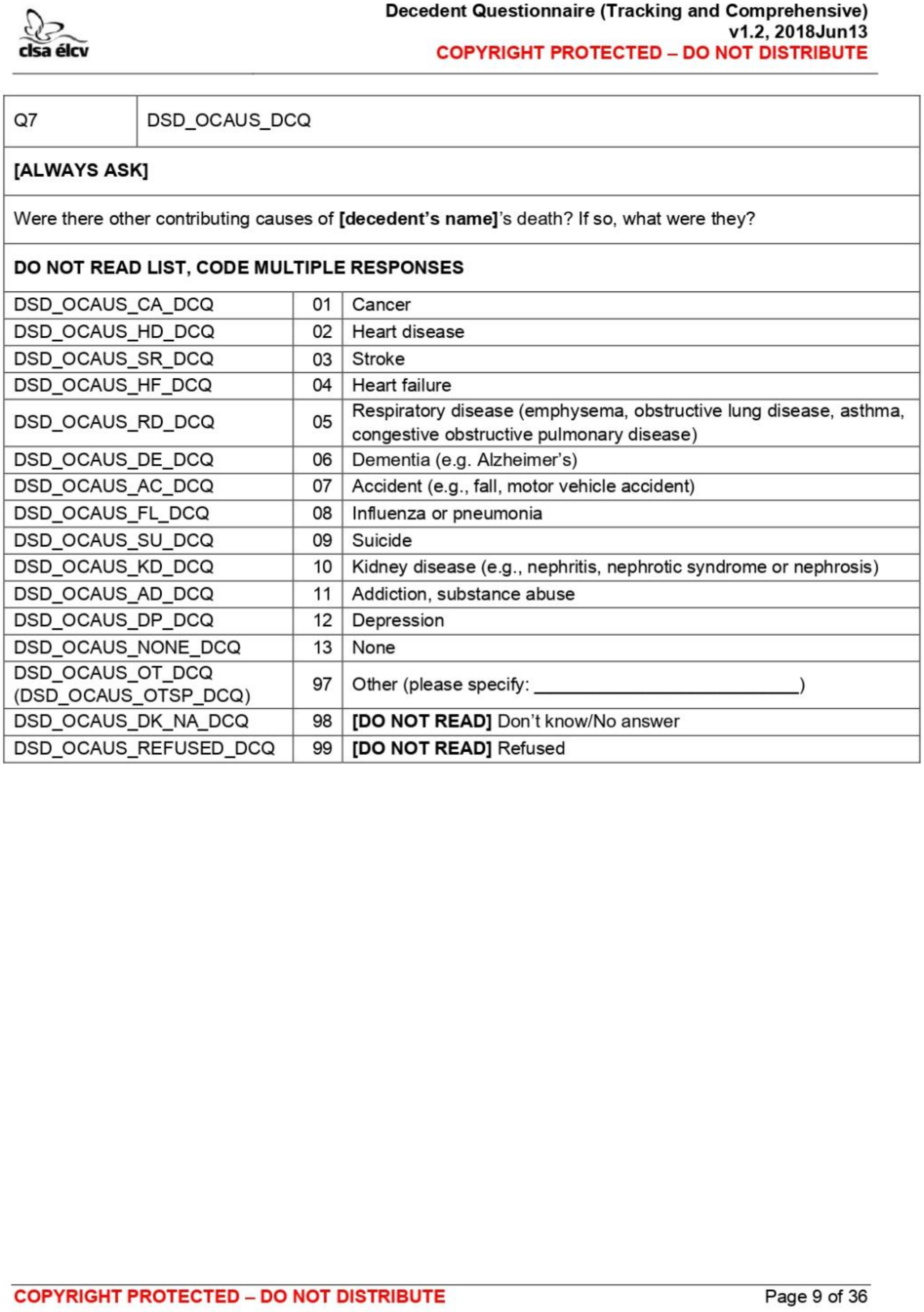
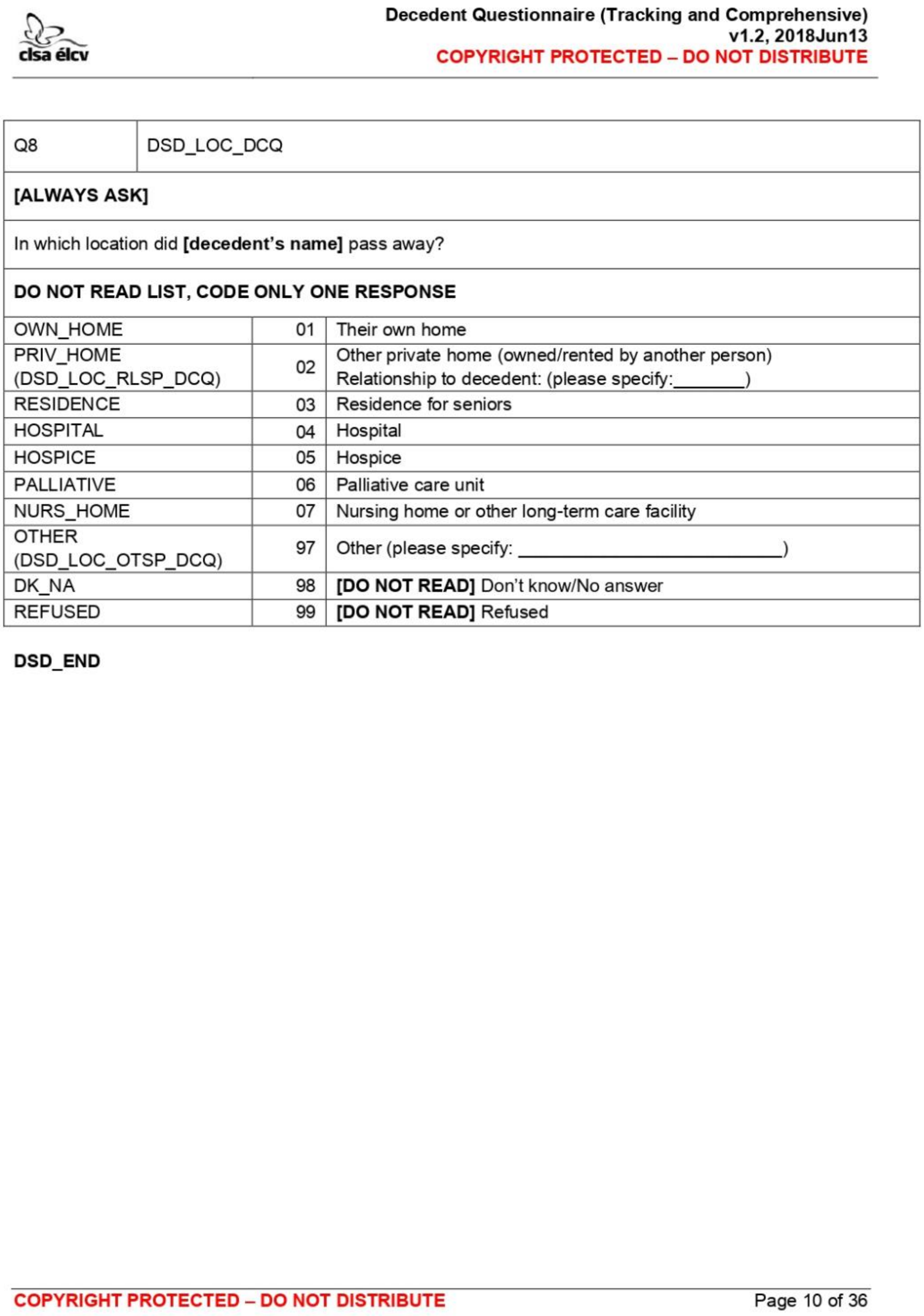
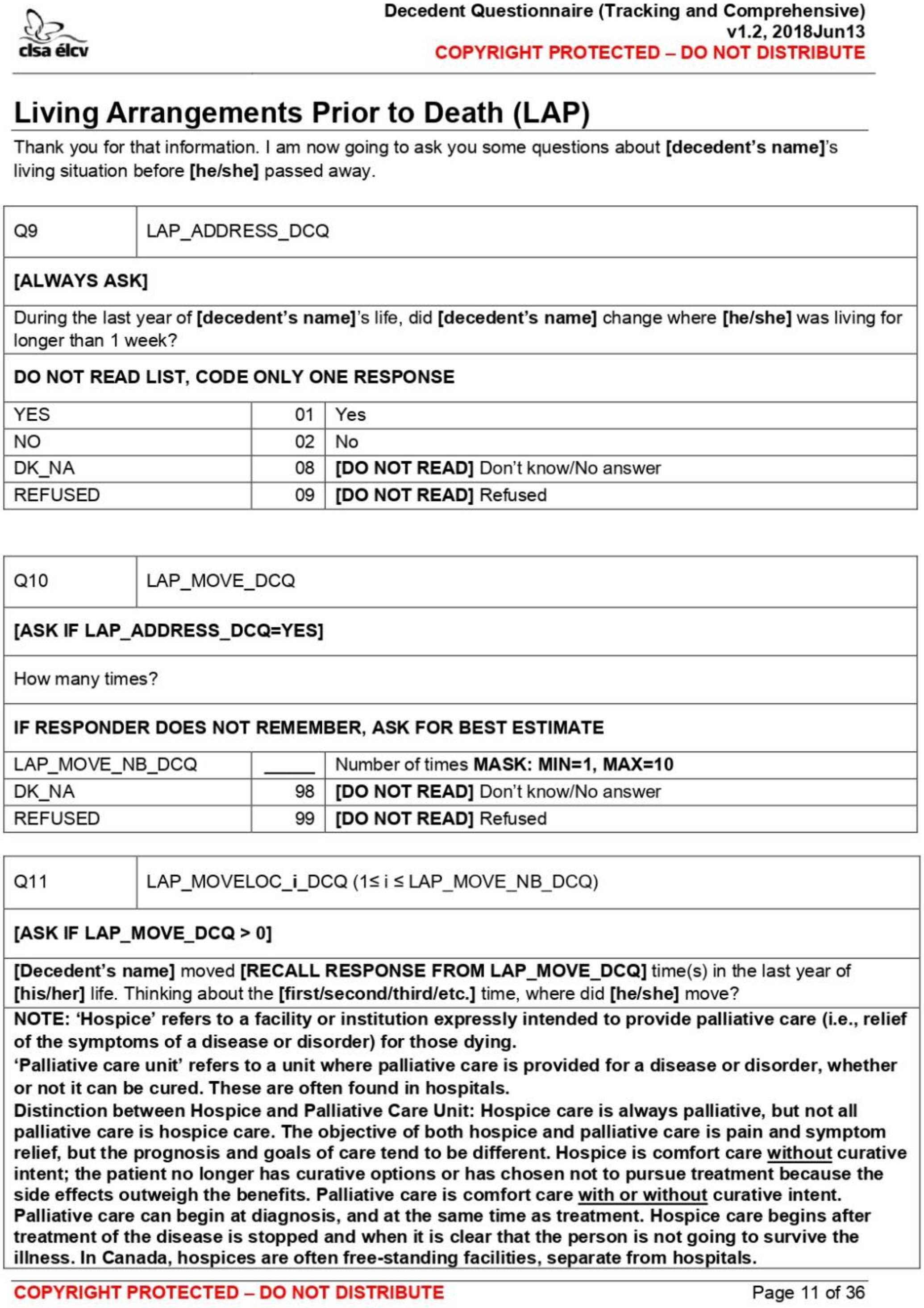


Q7	DSD_OCAUS_DCQ	
[ALWAYS ASK]		
Were there other contributing causes of **[decedent's name]**'s death? If so, what were they?		
DO NOT READ LIST, CODE MULTIPLE RESPONSES		
DSD_OCAUS_CA_DCQ	01	Cancer
DSD_OCAUS_HD_DCQ	02	Heart disease
DSD_OCAUS_SR_DCQ	03	Stroke
DSD_OCAUS_HF_DCQ	04	Heart failure
DSD_OCAUS_RD_DCQ	05	Respiratory disease (emphysema, obstructive lung disease, asthma, congestive obstructive pulmonary disease)
DSD_OCAUS_DE_DCQ	06	Dementia (e.g. Alzheimer's)
DSD_OCAUS_AC_DCQ	07	Accident (e.g., fall, motor vehicle accident)
DSD_OCAUS_FL_DCQ	08	Influenza or pneumonia
DSD_OCAUS_SU_DCQ	09	Suicide
DSD_OCAUS_KD_DCQ	10	Kidney disease (e.g., nephritis, nephrotic syndrome or nephrosis)
DSD_OCAUS_AD_DCQ	11	Addiction, substance abuse
DSD_OCAUS_DP_DCQ	12	Depression
DSD_OCAUS_NONE_DCQ	13	None
DSD_OCAUS_OT_DCQ (DSD_OCAUS_OTSP_DCQ)	97	Other (please specify: ___________________________)
DSD_OCAUS_DK_NA_DCQ	98	**[DO NOT READ]** Don't know/No answer
DSD_OCAUS_REFUSED_DCQ	99	**[DO NOT READ]** Refused



Q8	DSD_LOC_DCQ	
[ALWAYS ASK]		
In which location did **[decedent's name]** pass away?		
DO NOT READ LIST, CODE ONLY ONE RESPONSE		
OWN_HOME	01	Their own home
PRIV_HOME (DSD_LOC_RLSP_DCQ)	02	Other private home (owned/rented by another person) Relationship to decedent: (please specify:________)
RESIDENCE	03	Residence for seniors
HOSPITAL	04	Hospital
HOSPICE	05	Hospice
PALLIATIVE	06	Palliative care unit
NURS_HOME	07	Nursing home or other long-term care facility
OTHER (DSD_LOC_OTSP_DCQ)	97	Other (please specify: ____________________________)
DK_NA	98	**[DO NOT READ]** Don't know/No answer
REFUSED	99	**[DO NOT READ]** Refused

DSD_END



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Living Arrangements Prior to Death (LAP)

Thank you for that information. I am now going to ask you some questions about **[decedent's name]**'s living situation before **[he/she]** passed away.

Q9	LAP_ADDRESS_DCQ	
[ALWAYS ASK]		
During the last year of **[decedent's name]**'s life, did **[decedent's name]** change where **[he/she]** was living for longer than 1 week?		
DO NOT READ LIST, CODE ONLY ONE RESPONSE		
YES	01	Yes
NO	02	No
DK_NA	08	**[DO NOT READ]** Don't know/No answer
REFUSED	09	**[DO NOT READ]** Refused

Q10	LAP_MOVE_DCQ	
[ASK IF LAP_ADDRESS_DCQ=YES]		
How many times?		
IF RESPONDER DOES NOT REMEMBER, ASK FOR BEST ESTIMATE		
LAP_MOVE_NB_DCQ	_____	Number of times **MASK: MIN=1, MAX=10**
DK_NA	98	**[DO NOT READ]** Don't know/No answer
REFUSED	99	**[DO NOT READ]** Refused

Q11	LAP_MOVELOC_**i**_DCQ (1≤ i ≤ LAP_MOVE_NB_DCQ)
[ASK IF LAP_MOVE_DCQ > 0]	
[Decedent's name] moved **[RECALL RESPONSE FROM LAP_MOVE_DCQ]** time(s) in the last year of **[his/her]** life. Thinking about the **[first/second/third/etc.]** time, where did **[he/she]** move?	
NOTE: 'Hospice' refers to a facility or institution expressly intended to provide palliative care (i.e., relief of the symptoms of a disease or disorder) for those dying. **'Palliative care unit' refers to a unit where palliative care is provided for a disease or disorder, whether or not it can be cured. These are often found in hospitals.** **Distinction between Hospice and Palliative Care Unit: Hospice care is always palliative, but not all palliative care is hospice care. The objective of both hospice and palliative care is pain and symptom relief, but the prognosis and goals of care tend to be different. Hospice is comfort care without curative intent; the patient no longer has curative options or has chosen not to pursue treatment because the side effects outweigh the benefits. Palliative care is comfort care with or without curative intent. Palliative care can begin at diagnosis, and at the same time as treatment. Hospice care begins after treatment of the disease is stopped and when it is clear that the person is not going to survive the illness. In Canada, hospices are often free-standing facilities, separate from hospitals.**	

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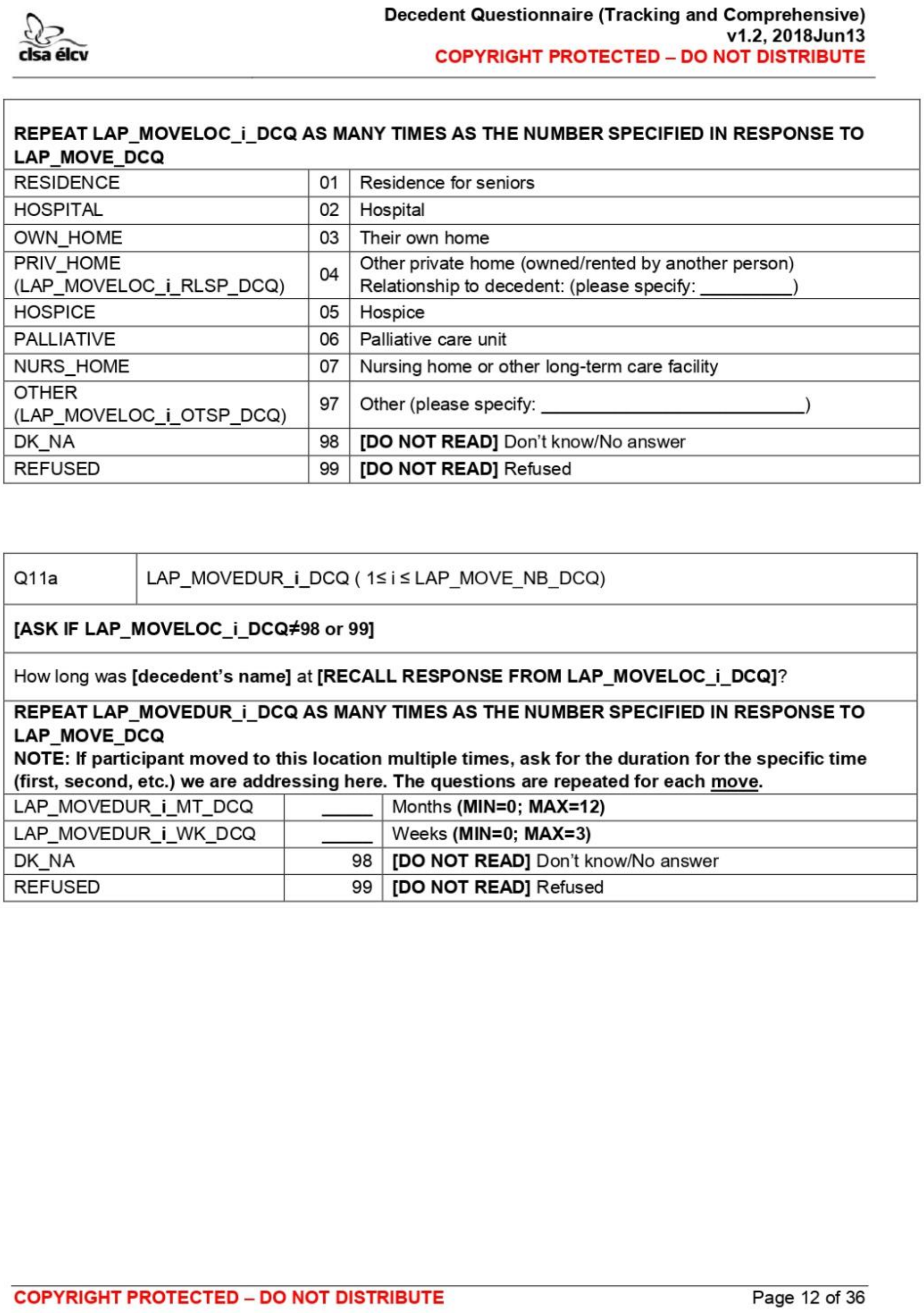

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REPEAT LAP_MOVELOC_i_DCQ AS MANY TIMES AS THE NUMBER SPECIFIED IN RESPONSE TO LAP_MOVE_DCQ		
RESIDENCE	01	Residence for seniors
HOSPITAL	02	Hospital
OWN_HOME	03	Their own home
PRIV_HOME (LAP_MOVELOC_**i**_RLSP_DCQ)	04	Other private home (owned/rented by another person) Relationship to decedent: (please specify: _________)
HOSPICE	05	Hospice
PALLIATIVE	06	Palliative care unit
NURS_HOME	07	Nursing home or other long-term care facility
OTHER (LAP_MOVELOC_**i**_OTSP_DCQ)	97	Other (please specify: _________________________)
DK_NA	98	**[DO NOT READ]** Don't know/No answer
REFUSED	99	**[DO NOT READ]** Refused

Q11a	LAP_MOVEDUR_**i**_DCQ (1≤ i ≤ LAP_MOVE_NB_DCQ)	
[ASK IF LAP_MOVELOC_i_DCQ≠98 or 99]		
How long was **[decedent's name]** at **[RECALL RESPONSE FROM LAP_MOVELOC_i_DCQ]**?		
REPEAT LAP_MOVEDUR_i_DCQ AS MANY TIMES AS THE NUMBER SPECIFIED IN RESPONSE TO LAP_MOVE_DCQ **NOTE: If participant moved to this location multiple times, ask for the duration for the specific time (first, second, etc.) we are addressing here. The questions are repeated for each move.**		
LAP_MOVEDUR_**i**_MT_DCQ	_____	Months **(MIN=0; MAX=12)**
LAP_MOVEDUR_**i**_WK_DCQ	_____	Weeks **(MIN=0; MAX=3)**
DK_NA	98	**[DO NOT READ]** Don't know/No answer
REFUSED	99	**[DO NOT READ]** Refused

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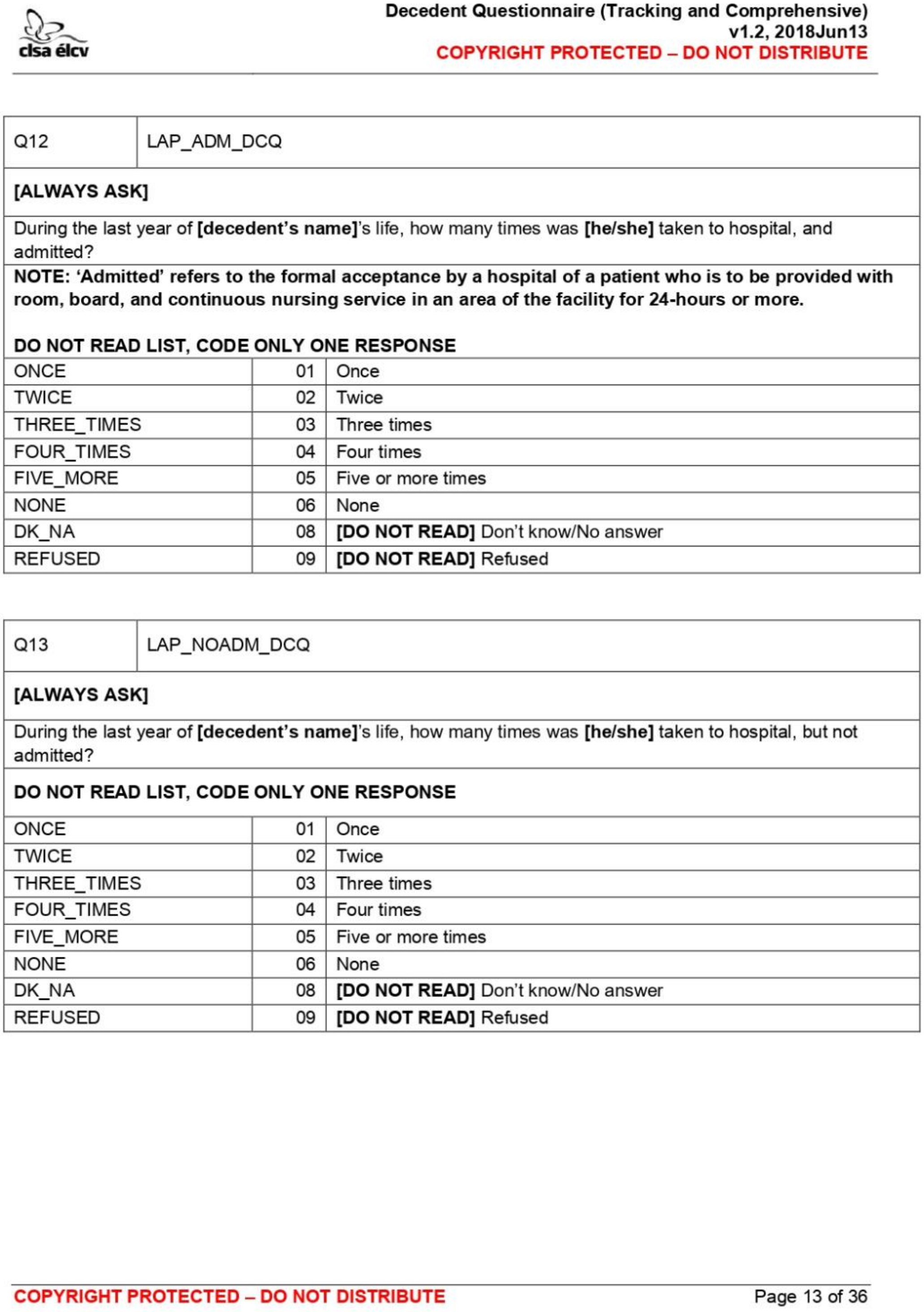

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Q12	LAP_ADM_DCQ	
[ALWAYS ASK]		
During the last year of **[decedent's name]**'s life, how many times was **[he/she]** taken to hospital, and admitted?		
NOTE: 'Admitted' refers to the formal acceptance by a hospital of a patient who is to be provided with room, board, and continuous nursing service in an area of the facility for 24-hours or more. **DO NOT READ LIST, CODE ONLY ONE RESPONSE**		
ONCE	01	Once
TWICE	02	Twice
THREE_TIMES	03	Three times
FOUR_TIMES	04	Four times
FIVE_MORE	05	Five or more times
NONE	06	None
DK_NA	08	**[DO NOT READ]** Don't know/No answer
REFUSED	09	**[DO NOT READ]** Refused

Q13	LAP_NOADM_DCQ	
[ALWAYS ASK]		
During the last year of **[decedent's name]**'s life, how many times was **[he/she]** taken to hospital, but not admitted?		
DO NOT READ LIST, CODE ONLY ONE RESPONSE		
ONCE	01	Once
TWICE	02	Twice
THREE_TIMES	03	Three times
FOUR_TIMES	04	Four times
FIVE_MORE	05	Five or more times
NONE	06	None
DK_NA	08	**[DO NOT READ]** Don't know/No answer
REFUSED	09	**[DO NOT READ]** Refused

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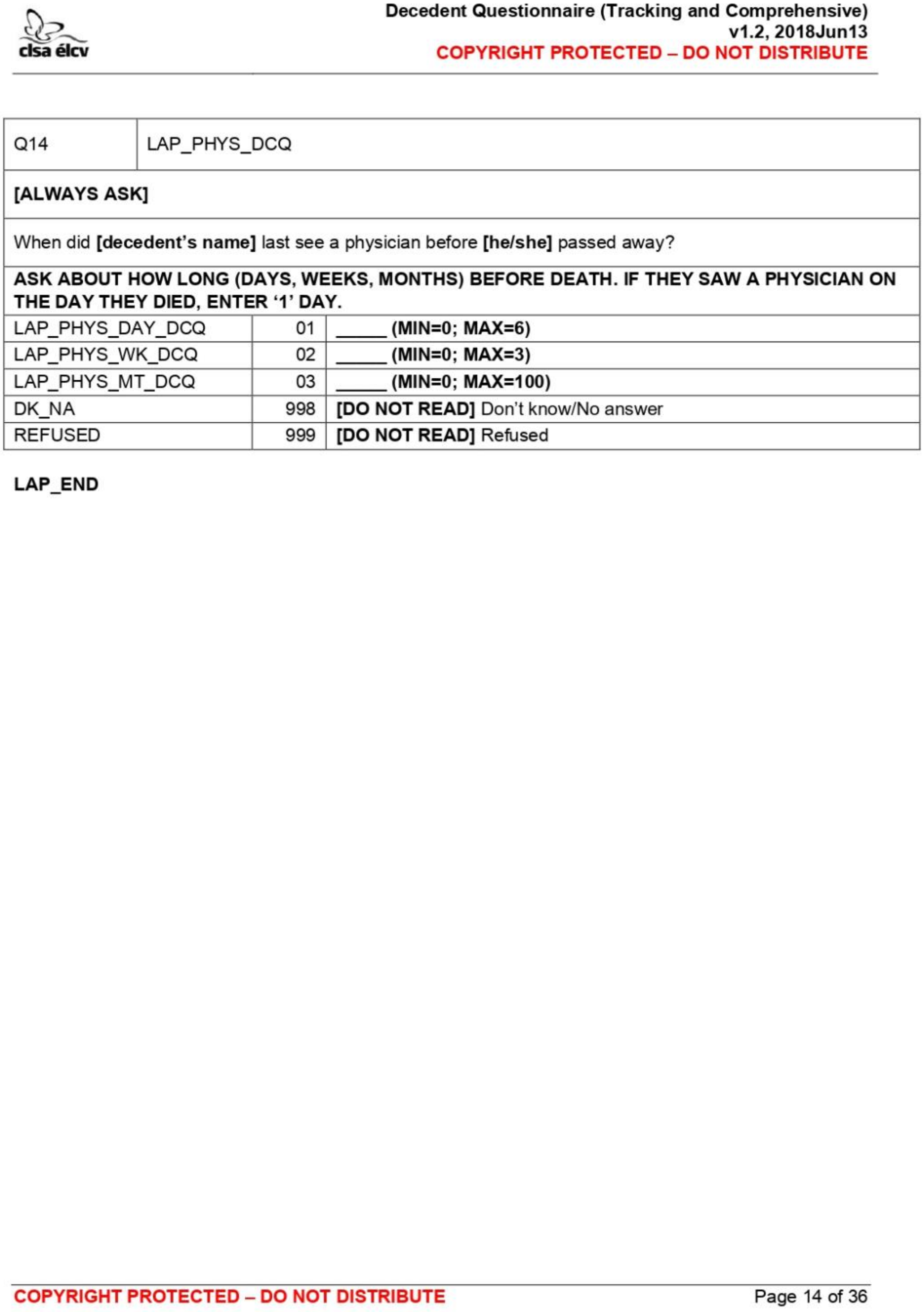

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Q14	LAP_PHYS_DCQ	
[ALWAYS ASK]		
When did **[decedent's name]** last see a physician before **[he/she]** passed away?		
ASK ABOUT HOW LONG (DAYS, WEEKS, MONTHS) BEFORE DEATH. IF THEY SAW A PHYSICIAN ON THE DAY THEY DIED, ENTER '1' DAY.		
LAP_PHYS_DAY_DCQ	01	**_____ (MIN=0; MAX=6)**
LAP_PHYS_WK_DCQ	02	**_____ (MIN=0; MAX=3)**
LAP_PHYS_MT_DCQ	03	**_____ (MIN=0; MAX=100)**
DK_NA	998	**[DO NOT READ]** Don't know/No answer
REFUSED	999	**[DO NOT READ]** Refused

LAP_END

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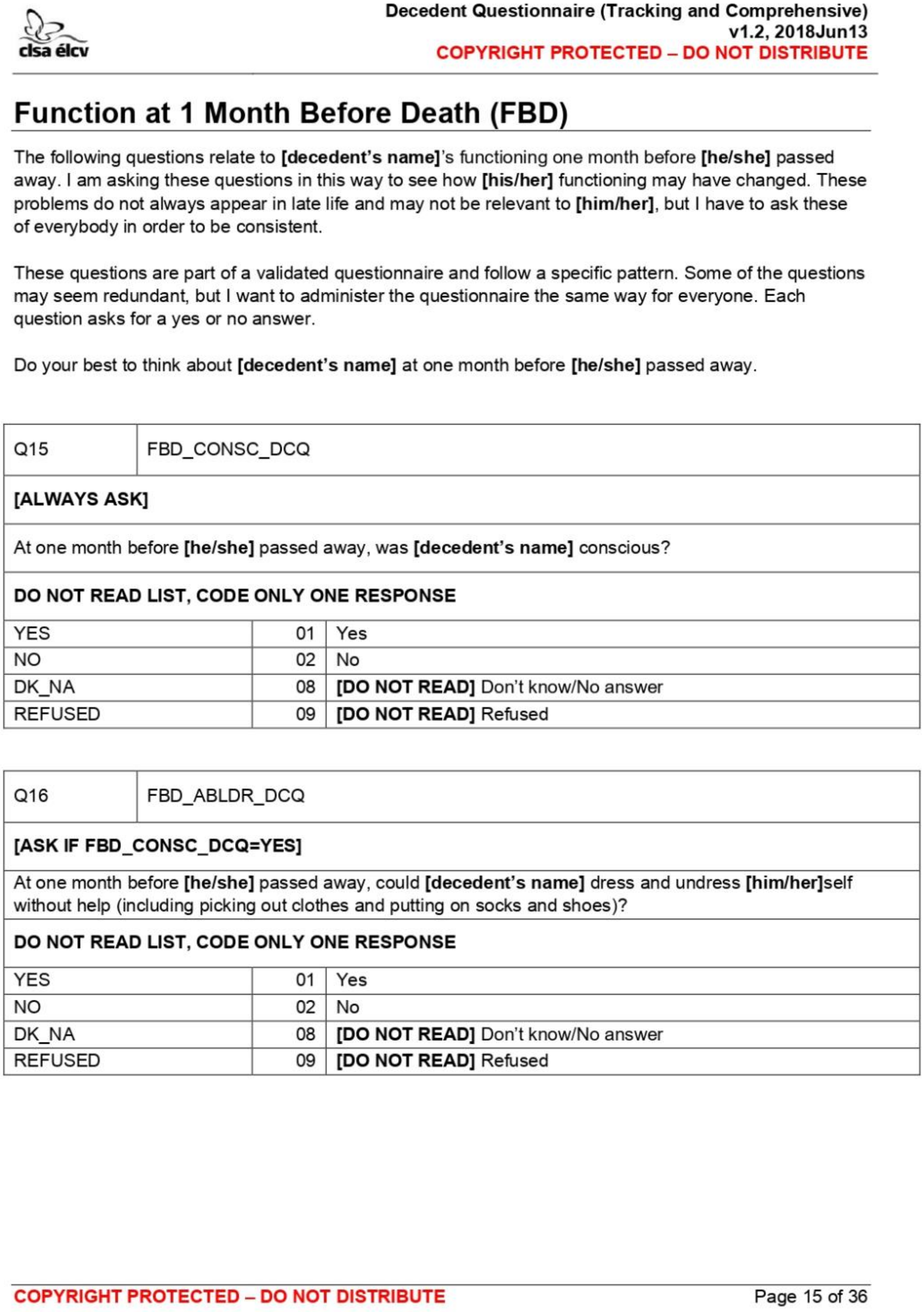

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Function at 1 Month Before Death (FBD)

The following questions relate to **[decedent's name]**'s functioning one month before **[he/she]** passed away. I am asking these questions in this way to see how **[his/her]** functioning may have changed. These problems do not always appear in late life and may not be relevant to **[him/her]**, but I have to ask these of everybody in order to be consistent.

These questions are part of a validated questionnaire and follow a specific pattern. Some of the questions may seem redundant, but I want to administer the questionnaire the same way for everyone. Each question asks for a yes or no answer.

Do your best to think about **[decedent's name]** at one month before **[he/she]** passed away.

Q15	FBD_CONSC_DCQ	
[ALWAYS ASK]		
At one month before **[he/she]** passed away, was **[decedent's name]** conscious?		
DO NOT READ LIST, CODE ONLY ONE RESPONSE		
YES	01	Yes
NO	02	No
DK_NA	08	**[DO NOT READ]** Don't know/No answer
REFUSED	09	**[DO NOT READ]** Refused

Q16	FBD_ABLDR_DCQ	
[ASK IF FBD_CONSC_DCQ=YES]		
At one month before **[he/she]** passed away, could **[decedent's name]** dress and undress **[him/her]**self without help (including picking out clothes and putting on socks and shoes)?		
DO NOT READ LIST, CODE ONLY ONE RESPONSE		
YES	01	Yes
NO	02	No
DK_NA	08	**[DO NOT READ]** Don't know/No answer
REFUSED	09	**[DO NOT READ]** Refused

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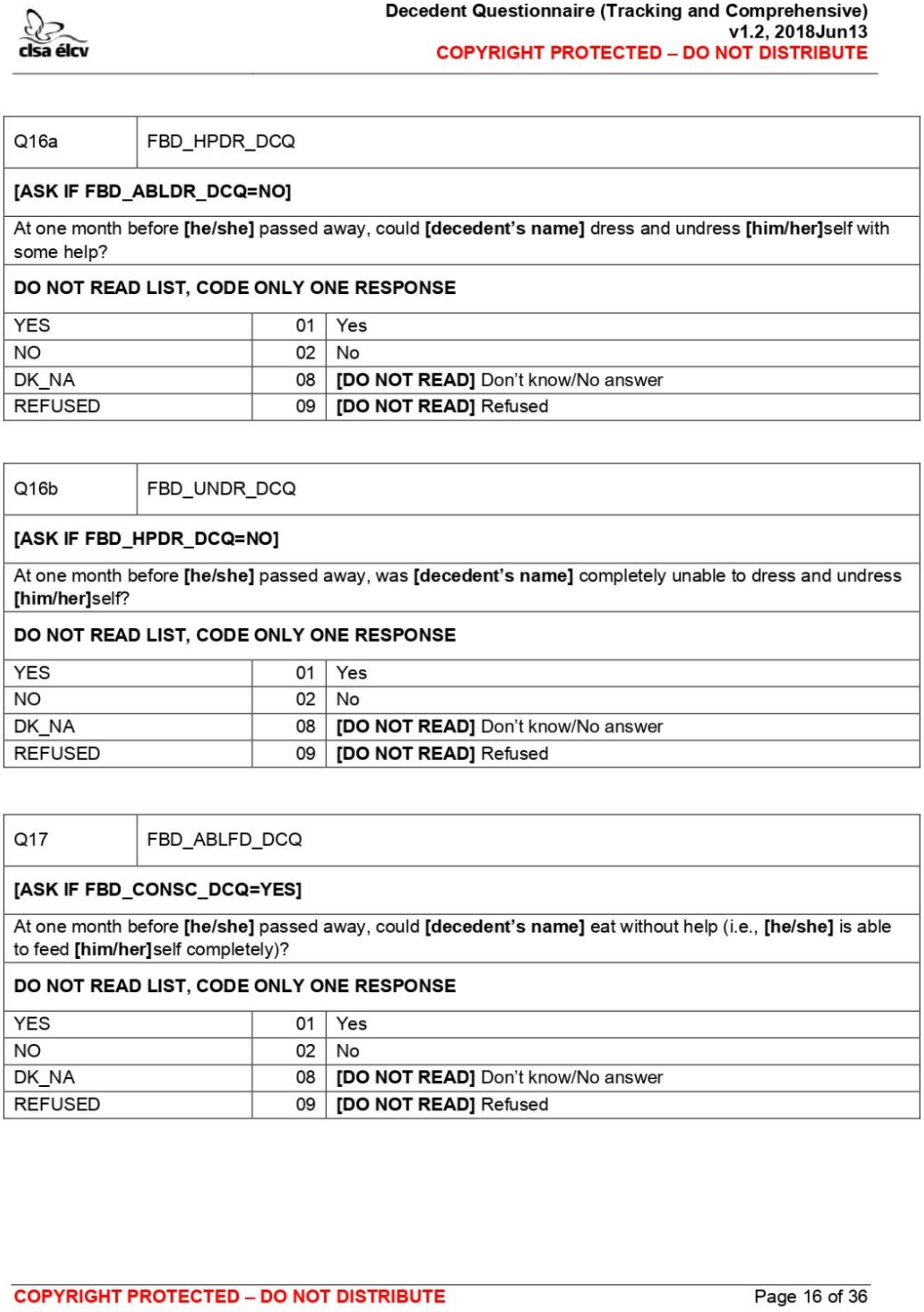
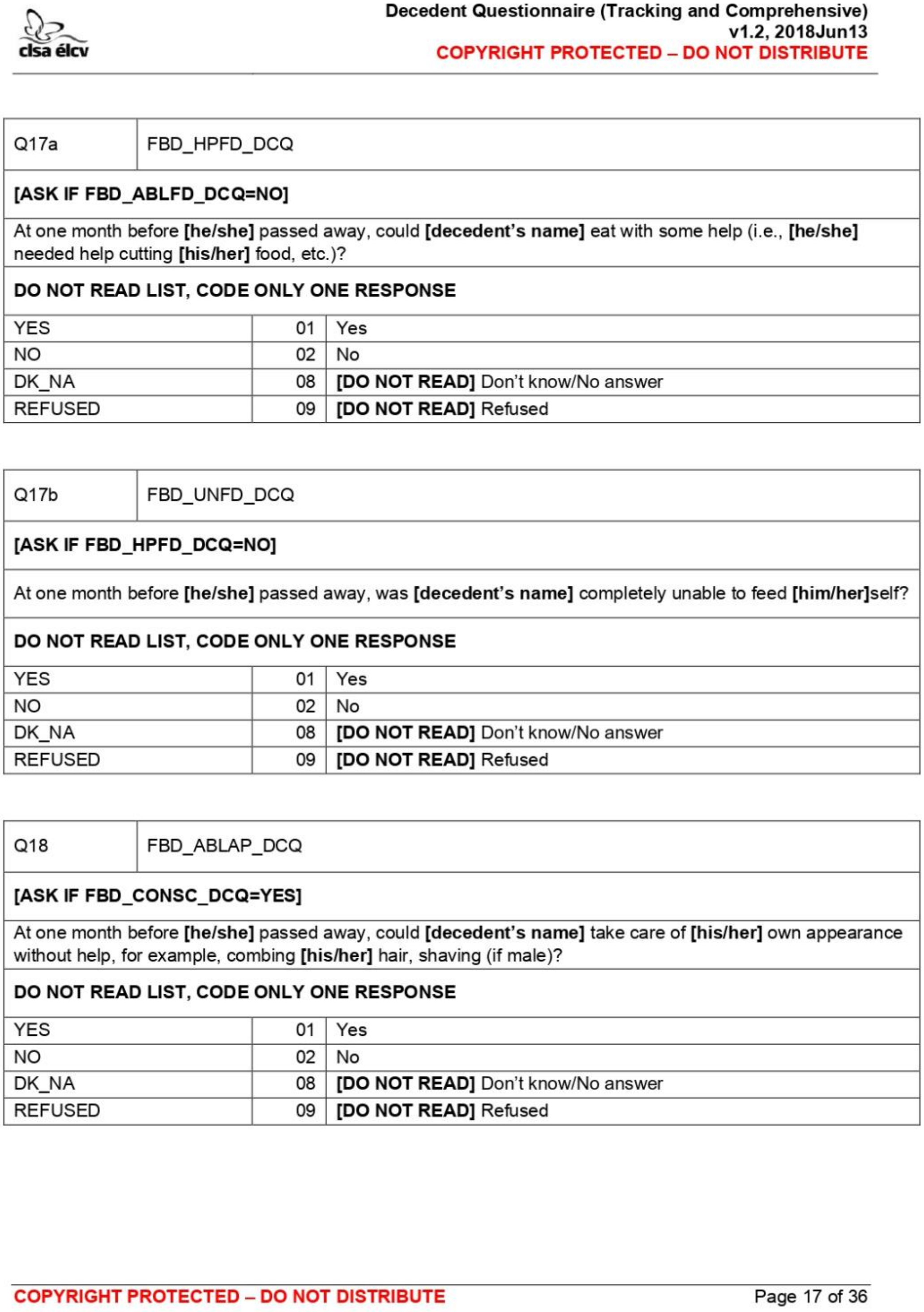


Q16a	FBD_HPDR_DCQ	
[ASK IF FBD_ABLDR_DCQ=NO]		
At one month before **[he/she]** passed away, could **[decedent's name]** dress and undress **[him/her]**self with some help?		
DO NOT READ LIST, CODE ONLY ONE RESPONSE		
YES	01	Yes
NO	02	No
DK_NA	08	**[DO NOT READ]** Don't know/No answer
REFUSED	09	**[DO NOT READ]** Refused

Q16b	FBD_UNDR_DCQ	
[ASK IF FBD_HPDR_DCQ=NO]		
At one month before **[he/she]** passed away, was **[decedent's name]** completely unable to dress and undress **[him/her]**self?		
DO NOT READ LIST, CODE ONLY ONE RESPONSE		
YES	01	Yes
NO	02	No
DK_NA	08	**[DO NOT READ]** Don't know/No answer
REFUSED	09	**[DO NOT READ]** Refused

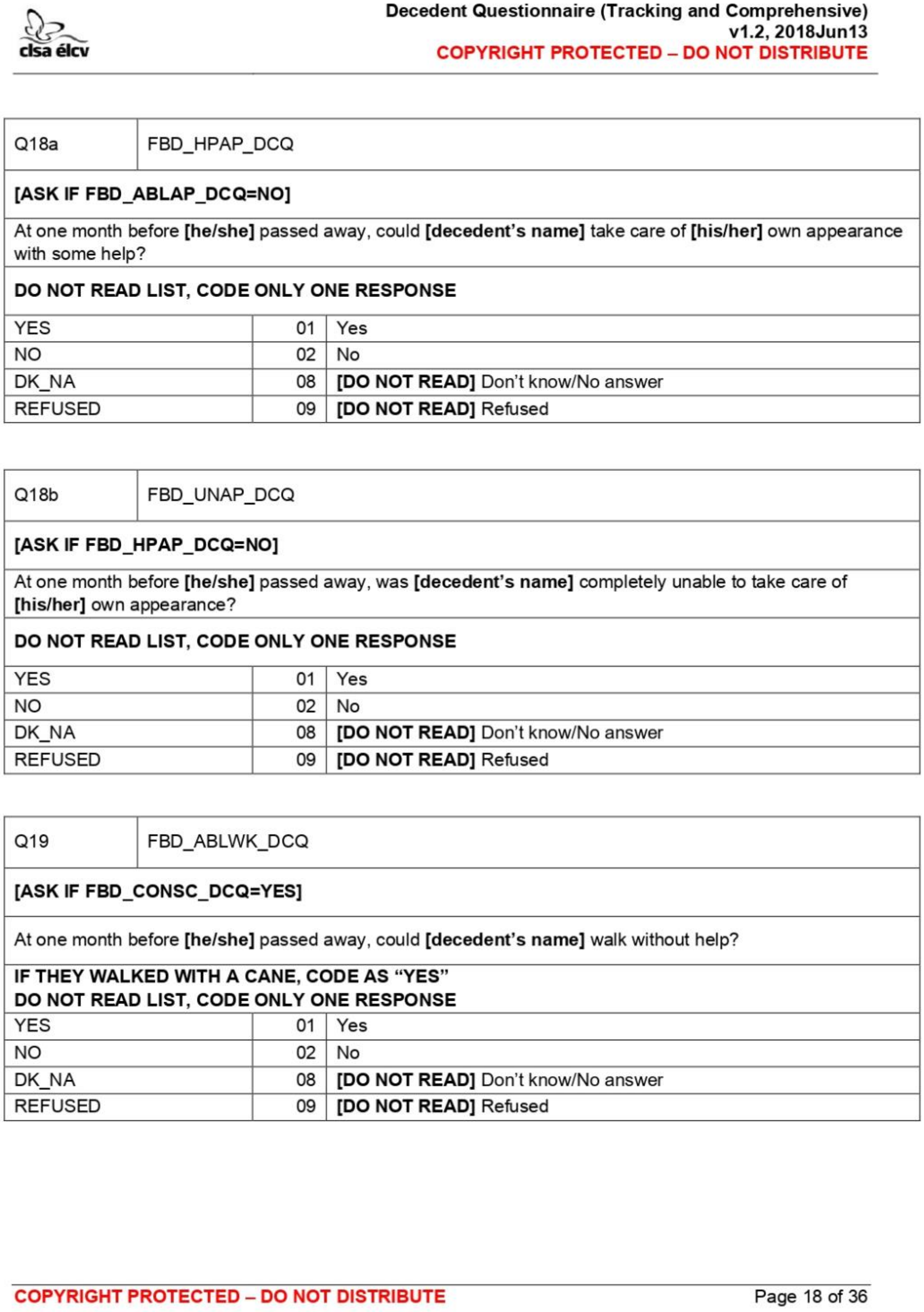
Q17	FBD_ABLFD_DCQ	
[ASK IF FBD_CONSC_DCQ=YES]		
At one month before **[he/she]** passed away, could **[decedent's name]** eat without help (i.e., **[he/she]** is able to feed **[him/her]**self completely)?		
DO NOT READ LIST, CODE ONLY ONE RESPONSE		
YES	01	Yes
NO	02	No
DK_NA	08	**[DO NOT READ]** Don't know/No answer
REFUSED	09	**[DO NOT READ]** Refused



Q17a	FBD_HPFD_DCQ	
[ASK IF FBD_ABLFD_DCQ=NO]		
At one month before **[he/she]** passed away, could **[decedent's name]** eat with some help (i.e., **[he/she]** needed help cutting **[his/her]** food, etc.)?		
DO NOT READ LIST, CODE ONLY ONE RESPONSE		
YES	01	Yes
NO	02	No
DK_NA	08	**[DO NOT READ]** Don't know/No answer
REFUSED	09	**[DO NOT READ]** Refused

Q17b	FBD_UNFD_DCQ	
[ASK IF FBD_HPFD_DCQ=NO]		
At one month before **[he/she]** passed away, was **[decedent's name]** completely unable to feed **[him/her]**self?		
DO NOT READ LIST, CODE ONLY ONE RESPONSE		
YES	01	Yes
NO	02	No
DK_NA	08	**[DO NOT READ]** Don't know/No answer
REFUSED	09	**[DO NOT READ]** Refused

Q18	FBD_ABLAP_DCQ	
[ASK IF FBD_CONSC_DCQ=YES]		
At one month before **[he/she]** passed away, could **[decedent's name]** take care of **[his/her]** own appearance without help, for example, combing **[his/her]** hair, shaving (if male)?		
DO NOT READ LIST, CODE ONLY ONE RESPONSE		
YES	01	Yes
NO	02	No
DK_NA	08	**[DO NOT READ]** Don't know/No answer
REFUSED	09	**[DO NOT READ]** Refused



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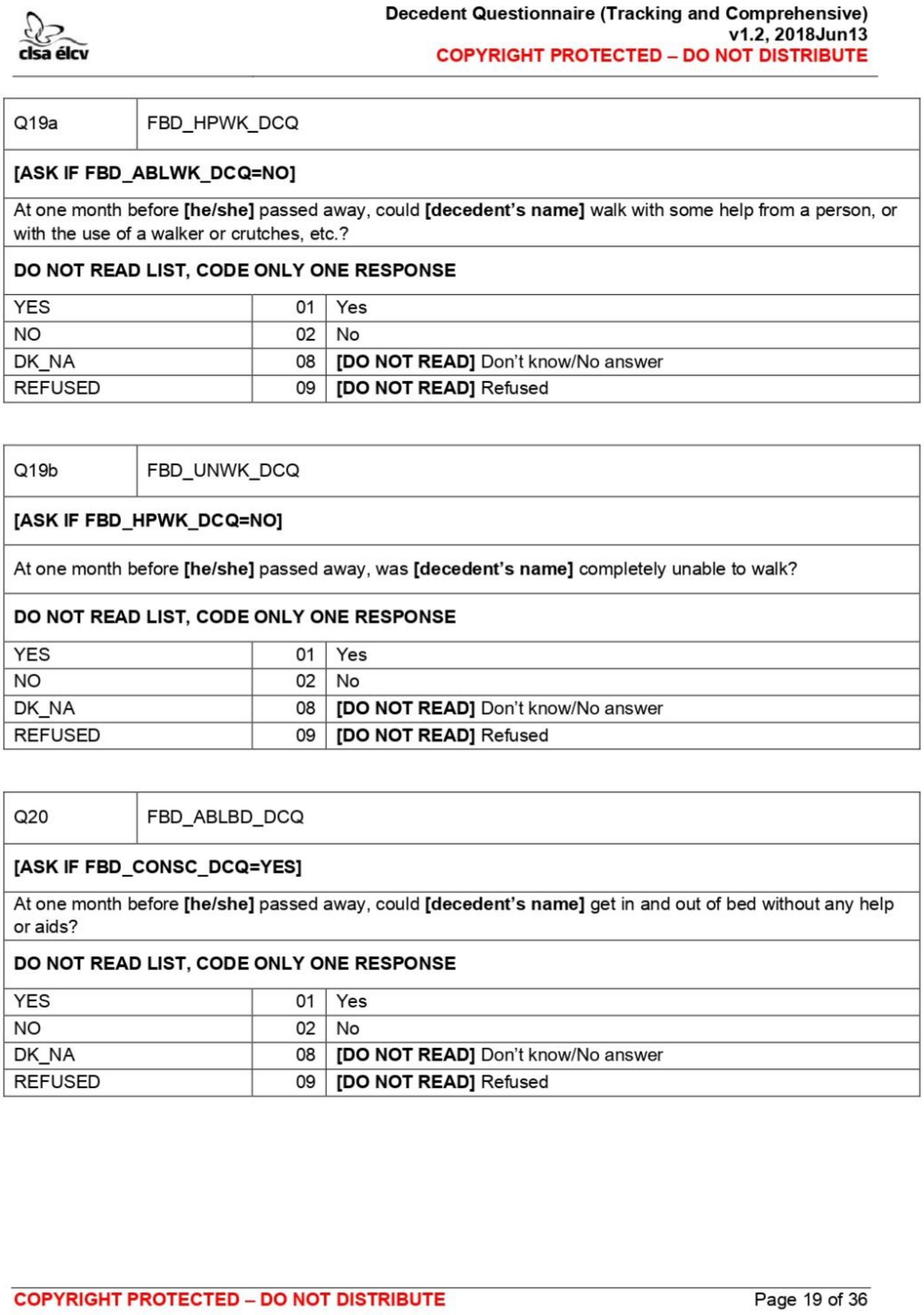
Q18a	FBD_HPAP_DCQ	
[ASK IF FBD_ABLAP_DCQ=NO]		
At one month before **[he/she]** passed away, could **[decedent's name]** take care of **[his/her]** own appearance with some help?		
DO NOT READ LIST, CODE ONLY ONE RESPONSE		
YES	01	Yes
NO	02	No
DK_NA	08	**[DO NOT READ]** Don't know/No answer
REFUSED	09	**[DO NOT READ]** Refused

Q18b	FBD_UNAP_DCQ	
[ASK IF FBD_HPAP_DCQ=NO]		
At one month before **[he/she]** passed away, was **[decedent's name]** completely unable to take care of **[his/her]** own appearance?		
DO NOT READ LIST, CODE ONLY ONE RESPONSE		
YES	01	Yes
NO	02	No
DK_NA	08	**[DO NOT READ]** Don't know/No answer
REFUSED	09	**[DO NOT READ]** Refused

Q19	FBD_ABLWK_DCQ	
[ASK IF FBD_CONSC_DCQ=YES]		
At one month before **[he/she]** passed away, could **[decedent's name]** walk without help?		
IF THEY WALKED WITH A CANE, CODE AS "YES" **DO NOT READ LIST, CODE ONLY ONE RESPONSE**		
YES	01	Yes
NO	02	No
DK_NA	08	**[DO NOT READ]** Don't know/No answer
REFUSED	09	**[DO NOT READ]** Refused



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Q19a	FBD_HPWK_DCQ	
[ASK IF FBD_ABLWK_DCQ=NO]		
At one month before **[he/she]** passed away, could **[decedent's name]** walk with some help from a person, or with the use of a walker or crutches, etc.?		
DO NOT READ LIST, CODE ONLY ONE RESPONSE		
YES	01	Yes
NO	02	No
DK_NA	08	**[DO NOT READ]** Don't know/No answer
REFUSED	09	**[DO NOT READ]** Refused

Q19b	FBD_UNWK_DCQ	
[ASK IF FBD_HPWK_DCQ=NO]		
At one month before **[he/she]** passed away, was **[decedent's name]** completely unable to walk?		
DO NOT READ LIST, CODE ONLY ONE RESPONSE		
YES	01	Yes
NO	02	No
DK_NA	08	**[DO NOT READ]** Don't know/No answer
REFUSED	09	**[DO NOT READ]** Refused

Q20	FBD_ABLBD_DCQ	
[ASK IF FBD_CONSC_DCQ=YES]		
At one month before **[he/she]** passed away, could **[decedent's name]** get in and out of bed without any help or aids?		
DO NOT READ LIST, CODE ONLY ONE RESPONSE		
YES	01	Yes
NO	02	No
DK_NA	08	**[DO NOT READ]** Don't know/No answer
REFUSED	09	**[DO NOT READ]** Refused

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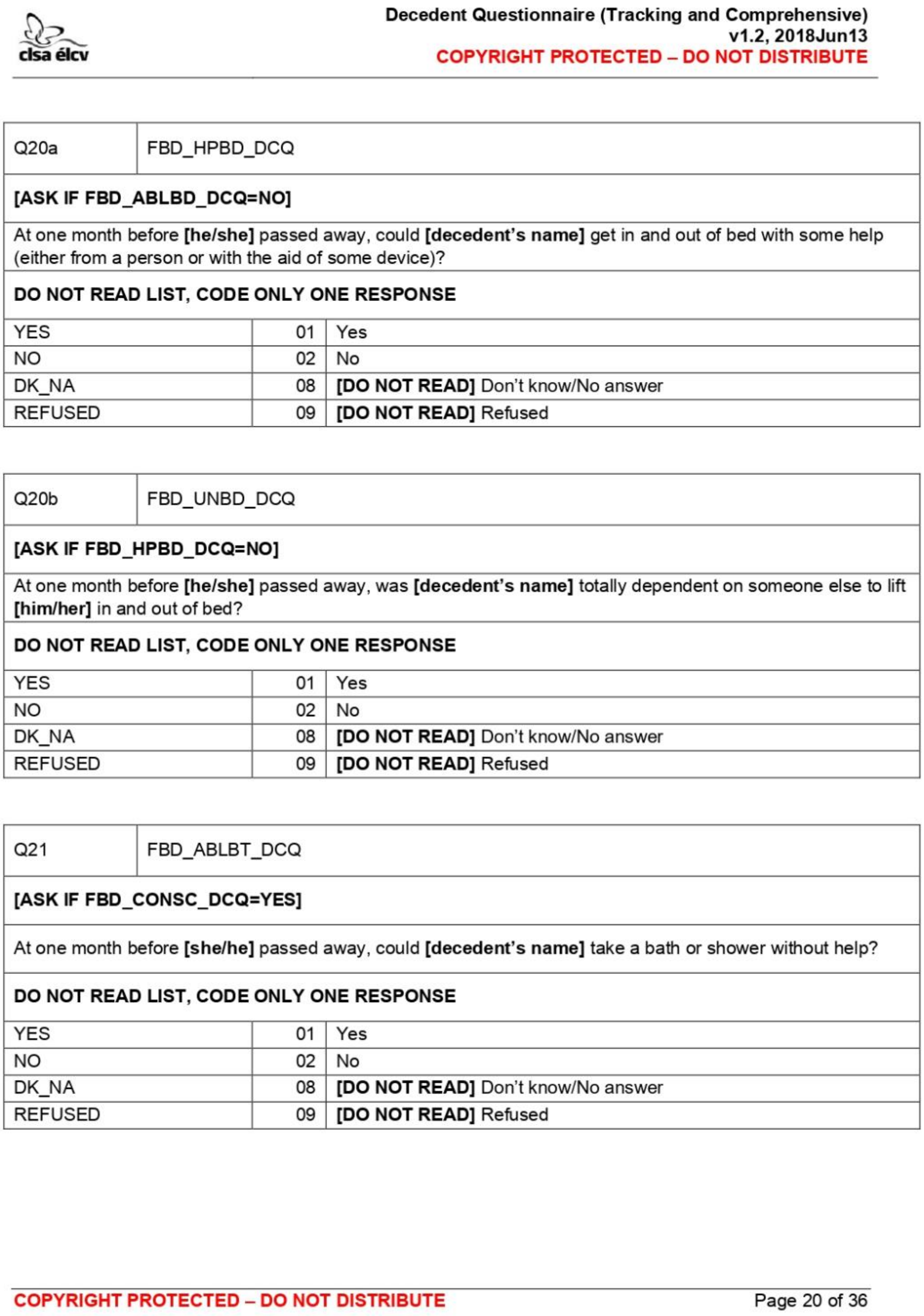
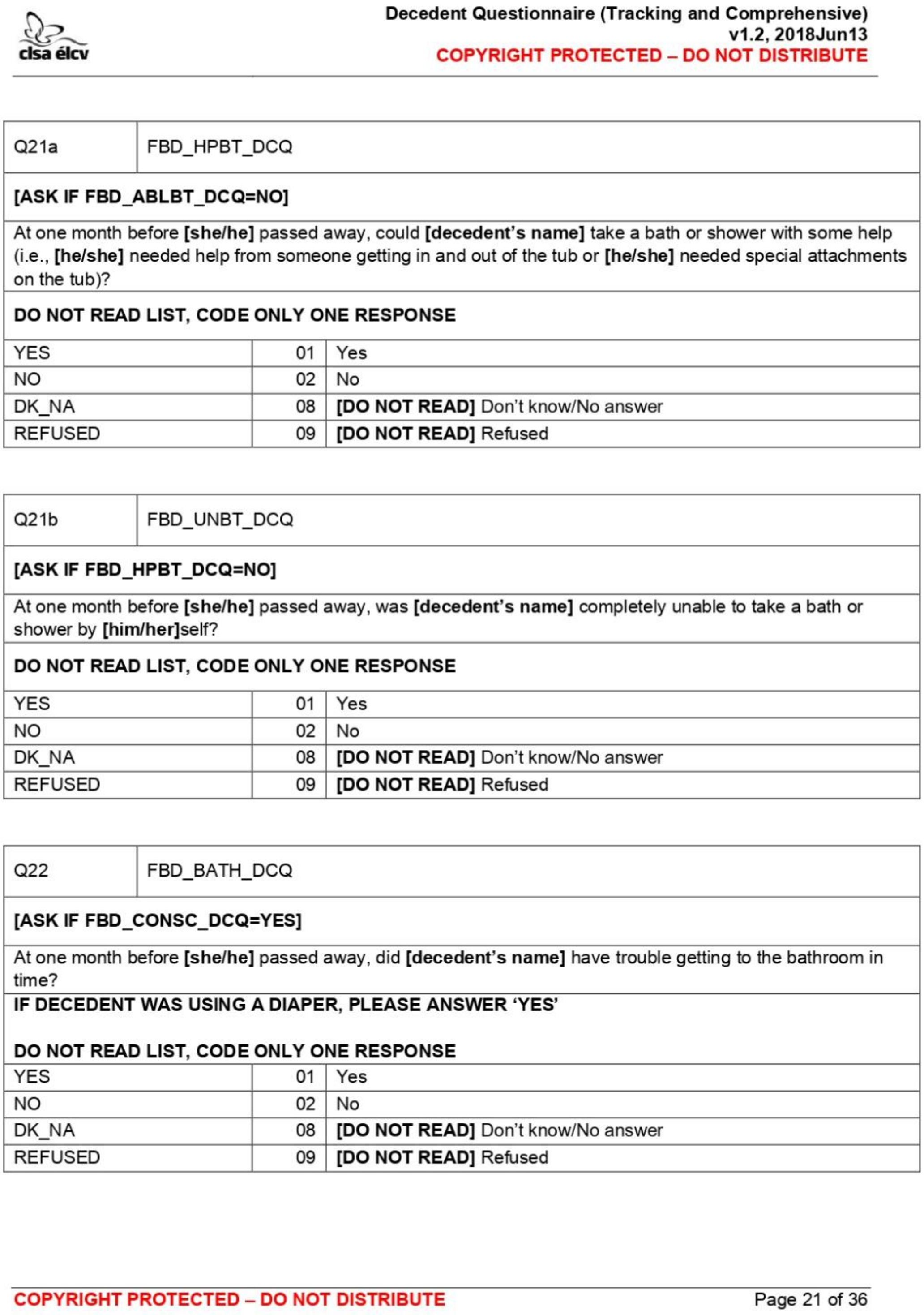


Q20a	FBD_HPBD_DCQ	
[ASK IF FBD_ABLBD_DCQ=NO]		
At one month before **[he/she]** passed away, could **[decedent's name]** get in and out of bed with some help (either from a person or with the aid of some device)?		
DO NOT READ LIST, CODE ONLY ONE RESPONSE		
YES	01	Yes
NO	02	No
DK_NA	08	**[DO NOT READ]** Don't know/No answer
REFUSED	09	**[DO NOT READ]** Refused

Q20b	FBD_UNBD_DCQ	
[ASK IF FBD_HPBD_DCQ=NO]		
At one month before **[he/she]** passed away, was **[decedent's name]** totally dependent on someone else to lift **[him/her]** in and out of bed?		
DO NOT READ LIST, CODE ONLY ONE RESPONSE		
YES	01	Yes
NO	02	No
DK_NA	08	**[DO NOT READ]** Don't know/No answer
REFUSED	09	**[DO NOT READ]** Refused

Q21	FBD_ABLBT_DCQ	
[ASK IF FBD_CONSC_DCQ=YES]		
At one month before **[she/he]** passed away, could **[decedent's name]** take a bath or shower without help?		
DO NOT READ LIST, CODE ONLY ONE RESPONSE		
YES	01	Yes
NO	02	No
DK_NA	08	**[DO NOT READ]** Don't know/No answer
REFUSED	09	**[DO NOT READ]** Refused



Q21a	FBD_HPBT_DCQ

[ASK IF FBD_ABLBT_DCQ=NO]

At one month before **[she/he]** passed away, could **[decedent's name]** take a bath or shower with some help (i.e., **[he/she]** needed help from someone getting in and out of the tub or **[he/she]** needed special attachments on the tub)?

DO NOT READ LIST, CODE ONLY ONE RESPONSE

YES	01	Yes
NO	02	No
DK_NA	08	**[DO NOT READ]** Don't know/No answer
REFUSED	09	**[DO NOT READ]** Refused

Q21b	FBD_UNBT_DCQ

[ASK IF FBD_HPBT_DCQ=NO]

At one month before **[she/he]** passed away, was **[decedent's name]** completely unable to take a bath or shower by **[him/her]**self?

DO NOT READ LIST, CODE ONLY ONE RESPONSE

YES	01	Yes
NO	02	No
DK_NA	08	**[DO NOT READ]** Don't know/No answer
REFUSED	09	**[DO NOT READ]** Refused

Q22	FBD_BATH_DCQ

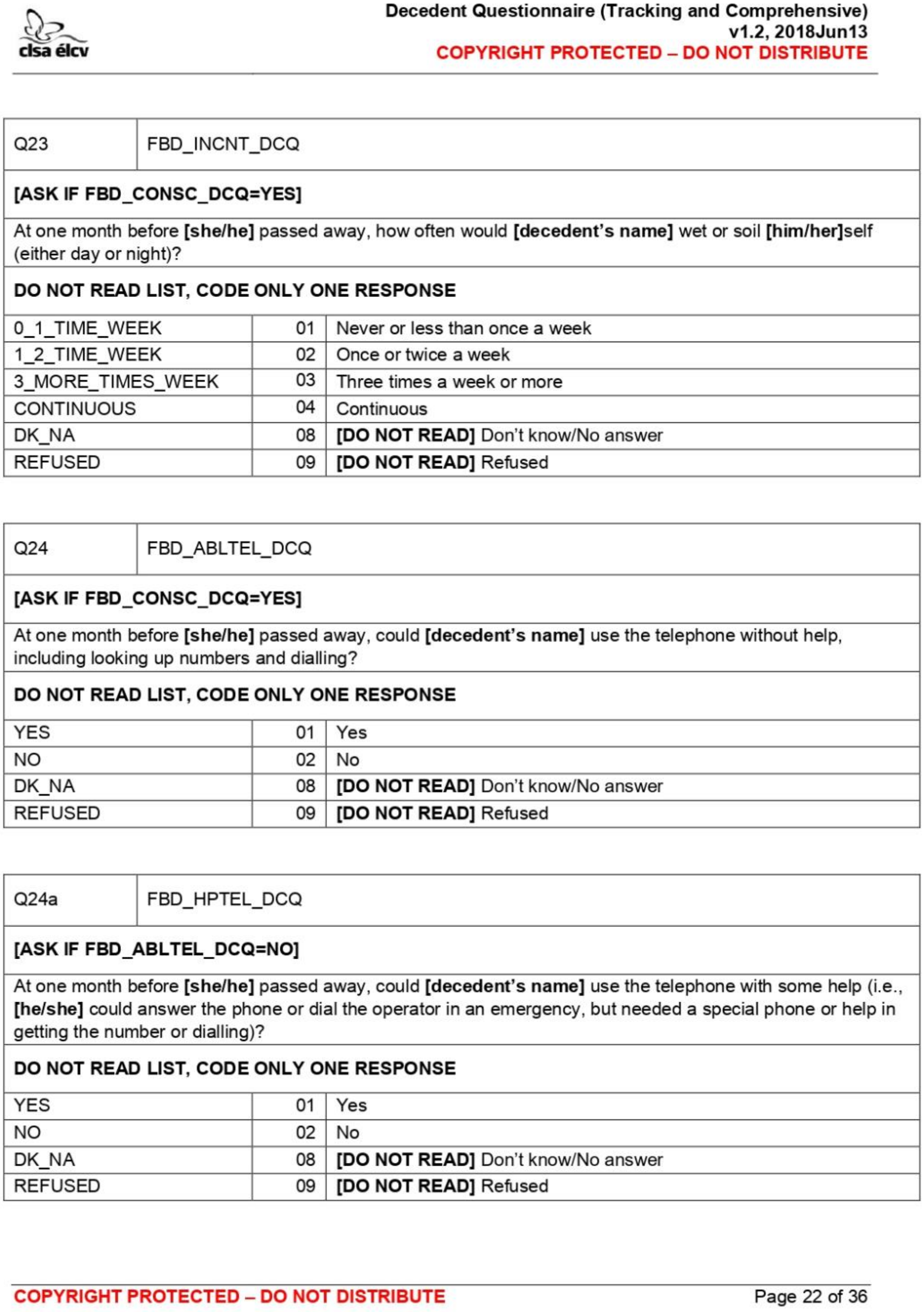
[ASK IF FBD_CONSC_DCQ=YES]

At one month before **[she/he]** passed away, did **[decedent's name]** have trouble getting to the bathroom in time?

IF DECEDENT WAS USING A DIAPER, PLEASE ANSWER 'YES'

DO NOT READ LIST, CODE ONLY ONE RESPONSE

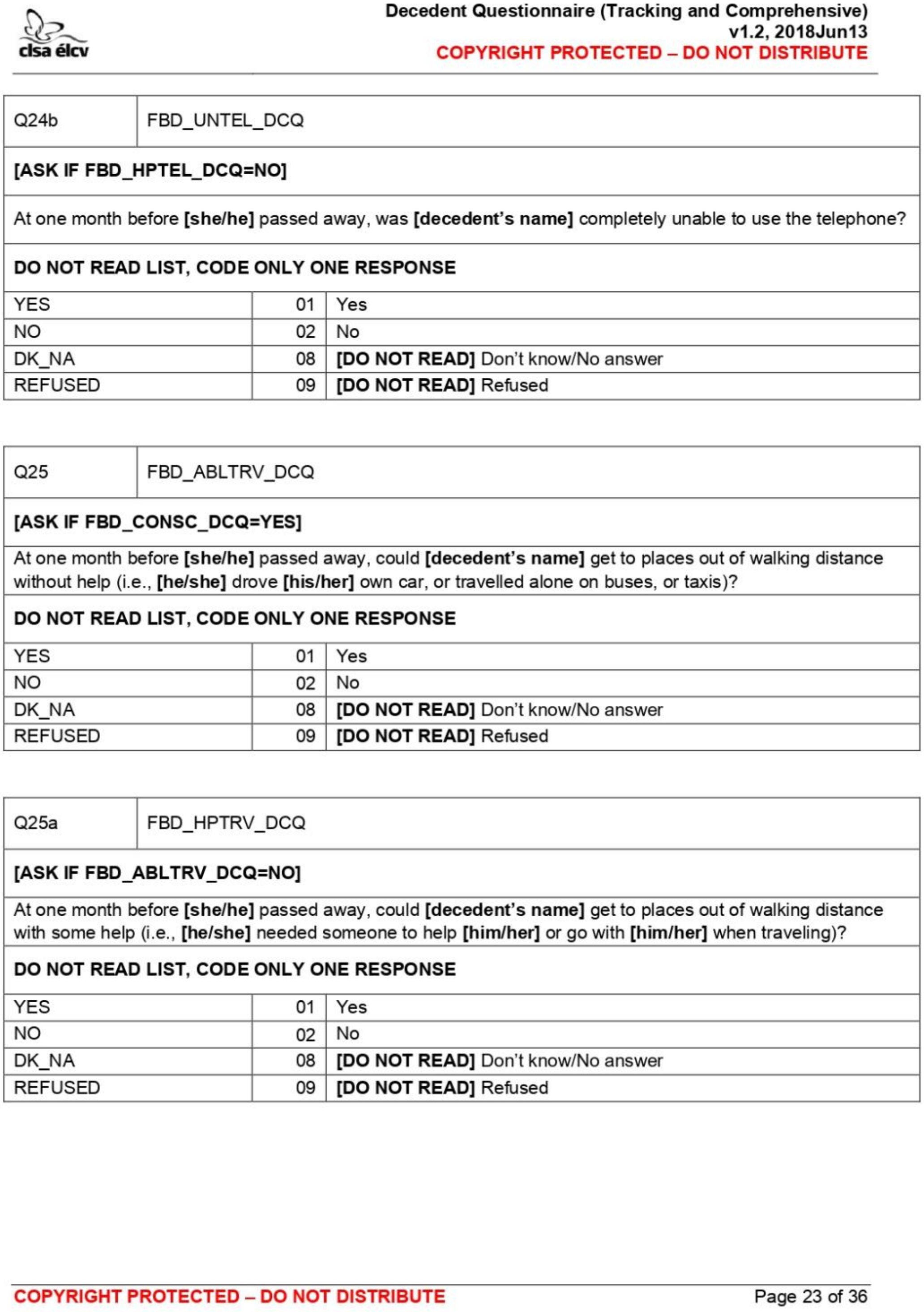
YES	01	Yes
NO	02	No
DK_NA	08	**[DO NOT READ]** Don't know/No answer
REFUSED	09	**[DO NOT READ]** Refused



Q23	FBD_INCNT_DCQ	
[ASK IF FBD_CONSC_DCQ=YES]		
At one month before **[she/he]** passed away, how often would **[decedent's name]** wet or soil **[him/her]**self (either day or night)?		
DO NOT READ LIST, CODE ONLY ONE RESPONSE		
0_1_TIME_WEEK	01	Never or less than once a week
1_2_TIME_WEEK	02	Once or twice a week
3_MORE_TIMES_WEEK	03	Three times a week or more
CONTINUOUS	04	Continuous
DK_NA	08	**[DO NOT READ]** Don't know/No answer
REFUSED	09	**[DO NOT READ]** Refused

Q24	FBD_ABLTEL_DCQ	
[ASK IF FBD_CONSC_DCQ=YES]		
At one month before **[she/he]** passed away, could **[decedent's name]** use the telephone without help, including looking up numbers and dialling?		
DO NOT READ LIST, CODE ONLY ONE RESPONSE		
YES	01	Yes
NO	02	No
DK_NA	08	**[DO NOT READ]** Don't know/No answer
REFUSED	09	**[DO NOT READ]** Refused

Q24a	FBD_HPTEL_DCQ	
[ASK IF FBD_ABLTEL_DCQ=NO]		
At one month before **[she/he]** passed away, could **[decedent's name]** use the telephone with some help (i.e., **[he/she]** could answer the phone or dial the operator in an emergency, but needed a special phone or help in getting the number or dialling)?		
DO NOT READ LIST, CODE ONLY ONE RESPONSE		
YES	01	Yes
NO	02	No
DK_NA	08	**[DO NOT READ]** Don't know/No answer
REFUSED	09	**[DO NOT READ]** Refused



Q24b	FBD_UNTEL_DCQ	
[ASK IF FBD_HPTEL_DCQ=NO]		
At one month before **[she/he]** passed away, was **[decedent's name]** completely unable to use the telephone?		
DO NOT READ LIST, CODE ONLY ONE RESPONSE		
YES	01	Yes
NO	02	No
DK_NA	08	**[DO NOT READ]** Don't know/No answer
REFUSED	09	**[DO NOT READ]** Refused

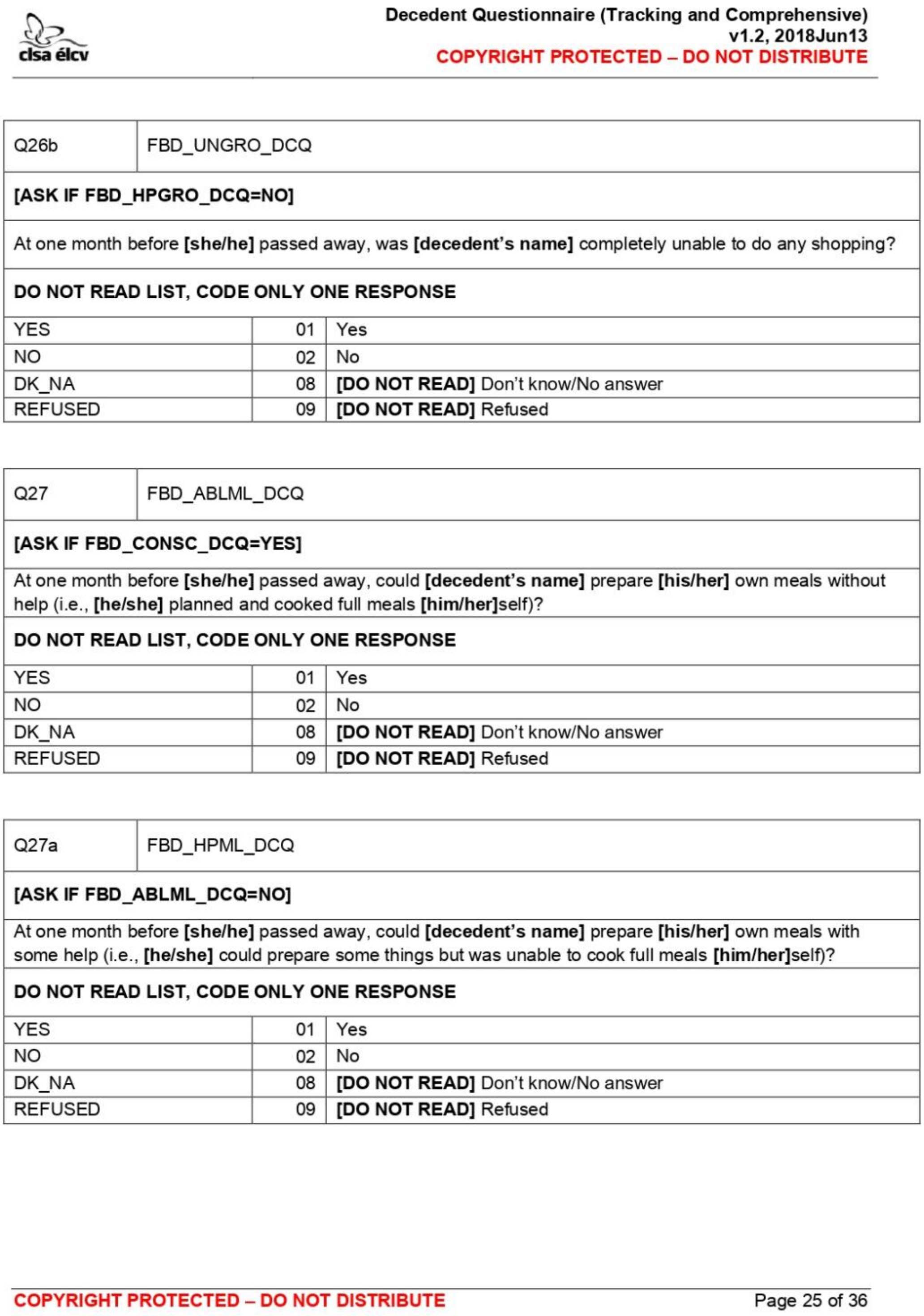
Q25	FBD_ABLTRV_DCQ	
[ASK IF FBD_CONSC_DCQ=YES]		
At one month before **[she/he]** passed away, could **[decedent's name]** get to places out of walking distance without help (i.e., **[he/she]** drove **[his/her]** own car, or travelled alone on buses, or taxis)?		
DO NOT READ LIST, CODE ONLY ONE RESPONSE		
YES	01	Yes
NO	02	No
DK_NA	08	**[DO NOT READ]** Don't know/No answer
REFUSED	09	**[DO NOT READ]** Refused

Q25a	FBD_HPTRV_DCQ	
[ASK IF FBD_ABLTRV_DCQ=NO]		
At one month before **[she/he]** passed away, could **[decedent's name]** get to places out of walking distance with some help (i.e., **[he/she]** needed someone to help **[him/her]** or go with **[him/her]** when traveling)?		
DO NOT READ LIST, CODE ONLY ONE RESPONSE		
YES	01	Yes
NO	02	No
DK_NA	08	**[DO NOT READ]** Don't know/No answer
REFUSED	09	**[DO NOT READ]** Refused

Q25b	FBD_UNTRV_DCQ	
[ASK IF FBD_HPTRV_DCQ=NO]		
At one month before **[she/he]** passed away, was **[decedent's name]** unable to travel unless emergency arrangements were made for a specialized vehicle, like an ambulance?		
DO NOT READ LIST, CODE ONLY ONE RESPONSE		
YES	01	Yes
NO	02	No
DK_NA	08	**[DO NOT READ]** Don't know/No answer
REFUSED	09	**[DO NOT READ]** Refused

Q26	FBD_ABLGRO_DCQ	
[ASK IF FBD_CONSC_DCQ=YES]		
At one month before **[she/he]** passed away, could **[decedent's name]** go shopping for groceries or clothes without help (taking care of all shopping needs **[him/her]**self)?		
DO NOT READ LIST, CODE ONLY ONE RESPONSE		
YES	01	Yes
NO	02	No
DK_NA	08	**[DO NOT READ]** Don't know/No answer
REFUSED	09	**[DO NOT READ]** Refused

Q26a	FBD_HPGRO_DCQ	
[ASK IF FBD_ABLGRO_DCQ=NO]		
At one month before **[she/he]** passed away, could **[decedent's name]** go shopping for groceries or clothes with some help (i.e., **[he/she]** needed someone to go with **[him/her]** on all shopping trips)?		
DO NOT READ LIST, CODE ONLY ONE RESPONSE		
YES	01	Yes
NO	02	No
DK_NA	08	**[DO NOT READ]** Don't know/No answer
REFUSED	09	**[DO NOT READ]** Refused



Q26b	FBD_UNGRO_DCQ	
[ASK IF FBD_HPGRO_DCQ=NO]		
At one month before **[she/he]** passed away, was **[decedent's name]** completely unable to do any shopping?		
DO NOT READ LIST, CODE ONLY ONE RESPONSE		
YES	01	Yes
NO	02	No
DK_NA	08	**[DO NOT READ]** Don't know/No answer
REFUSED	09	**[DO NOT READ]** Refused

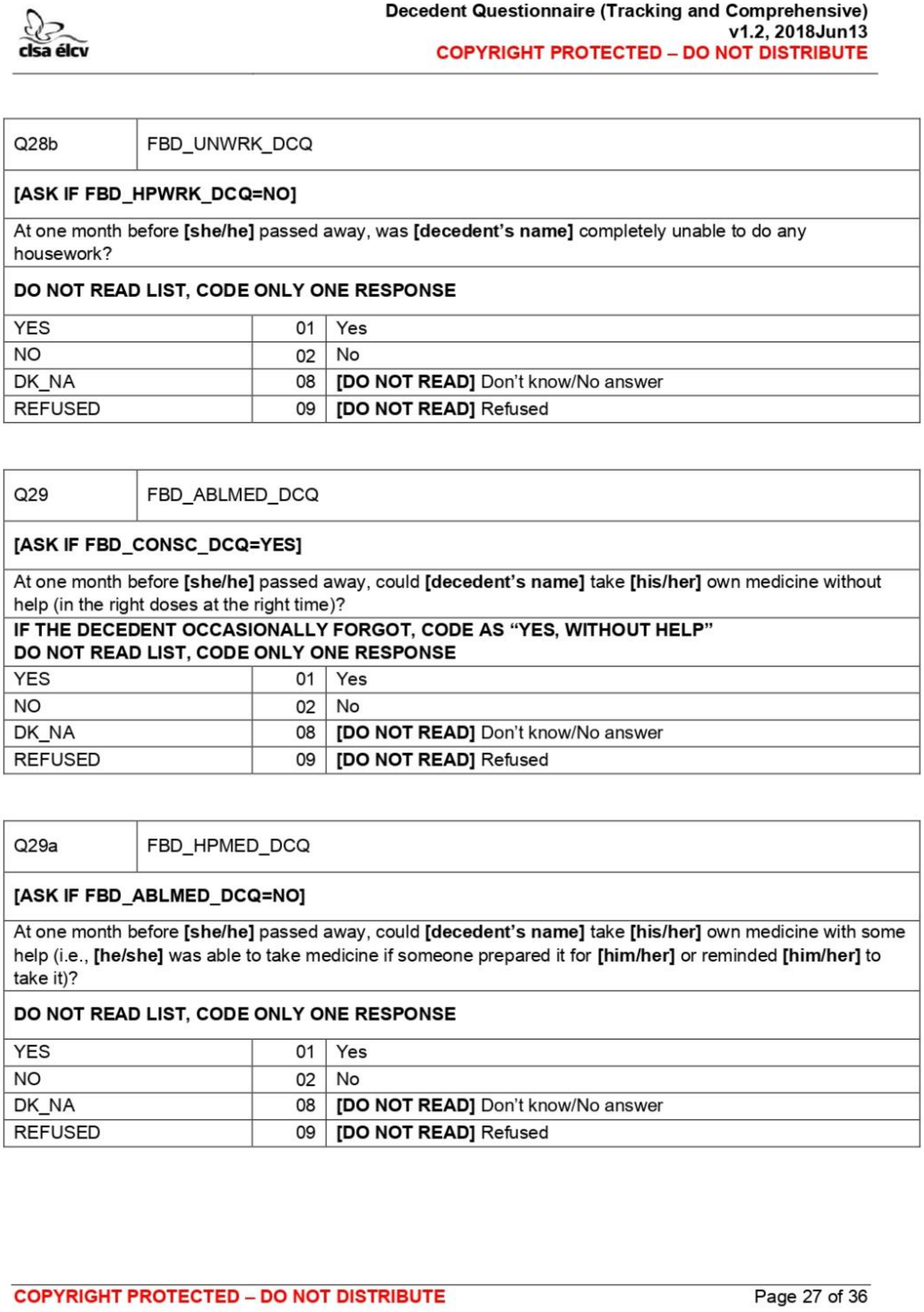
Q27	FBD_ABLML_DCQ	
[ASK IF FBD_CONSC_DCQ=YES]		
At one month before **[she/he]** passed away, could **[decedent's name]** prepare **[his/her]** own meals without help (i.e., **[he/she]** planned and cooked full meals **[him/her]**self)?		
DO NOT READ LIST, CODE ONLY ONE RESPONSE		
YES	01	Yes
NO	02	No
DK_NA	08	**[DO NOT READ]** Don't know/No answer
REFUSED	09	**[DO NOT READ]** Refused

Q27a	FBD_HPML_DCQ	
[ASK IF FBD_ABLML_DCQ=NO]		
At one month before **[she/he]** passed away, could **[decedent's name]** prepare **[his/her]** own meals with some help (i.e., **[he/she]** could prepare some things but was unable to cook full meals **[him/her]**self)?		
DO NOT READ LIST, CODE ONLY ONE RESPONSE		
YES	01	Yes
NO	02	No
DK_NA	08	**[DO NOT READ]** Don't know/No answer
REFUSED	09	**[DO NOT READ]** Refused

Q27b	FBD_UNML_DCQ	
[ASK IF FBD_HPML_DCQ=NO]		
At one month before **[she/he]** passed away, was **[decedent's name]** completely unable to prepare any meals?		
DO NOT READ LIST, CODE ONLY ONE RESPONSE		
YES	01	Yes
NO	02	No
DK_NA	08	**[DO NOT READ]** Don't know/No answer
REFUSED	09	**[DO NOT READ]** Refused

Q28	FBD_ABLWRK_DCQ	
[ASK IF FBD_CONSC_DCQ=YES]		
At one month before **[she/he]** passed away, could **[decedent's name]** do **[his/her]** housework without help (i.e., **[he/she]** could clean floors, etc.)?		
DO NOT READ LIST, CODE ONLY ONE RESPONSE		
YES	01	Yes
NO	02	No
DK_NA	08	**[DO NOT READ]** Don't know/No answer
REFUSE	09	**[DO NOT READ]** Refused

Q28a	FBD_HPWRK_DCQ	
[ASK IF FBD_ABLWRK_DCQ=NO]		
At one month before **[she/he]** passed away, could **[decedent's name]** do **[his/her]** housework with some help (i.e., **[he/she]** could do light housework but needed help with heavy work)?		
DO NOT READ LIST, CODE ONLY ONE RESPONSE		
YES	01	Yes
NO	02	No
DK_NA	08	**[DO NOT READ]** Don't know/No answer
REFUSED	09	**[DO NOT READ]** Refused



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Q28b	FBD_UNWRK_DCQ	
[ASK IF FBD_HPWRK_DCQ=NO]		
At one month before **[she/he]** passed away, was **[decedent's name]** completely unable to do any housework?		
DO NOT READ LIST, CODE ONLY ONE RESPONSE		
YES	01	Yes
NO	02	No
DK_NA	08	**[DO NOT READ]** Don't know/No answer
REFUSED	09	**[DO NOT READ]** Refused

Q29	FBD_ABLMED_DCQ	
[ASK IF FBD_CONSC_DCQ=YES]		
At one month before **[she/he]** passed away, could **[decedent's name]** take **[his/her]** own medicine without help (in the right doses at the right time)?		
IF THE DECEDENT OCCASIONALLY FORGOT, CODE AS "YES, WITHOUT HELP" **DO NOT READ LIST, CODE ONLY ONE RESPONSE**		
YES	01	Yes
NO	02	No
DK_NA	08	**[DO NOT READ]** Don't know/No answer
REFUSED	09	**[DO NOT READ]** Refused

Q29a	FBD_HPMED_DCQ	
[ASK IF FBD_ABLMED_DCQ=NO]		
At one month before **[she/he]** passed away, could **[decedent's name]** take **[his/her]** own medicine with some help (i.e., **[he/she]** was able to take medicine if someone prepared it for **[him/her]** or reminded **[him/her]** to take it)?		
DO NOT READ LIST, CODE ONLY ONE RESPONSE		
YES	01	Yes
NO	02	No
DK_NA	08	**[DO NOT READ]** Don't know/No answer
REFUSED	09	**[DO NOT READ]** Refused

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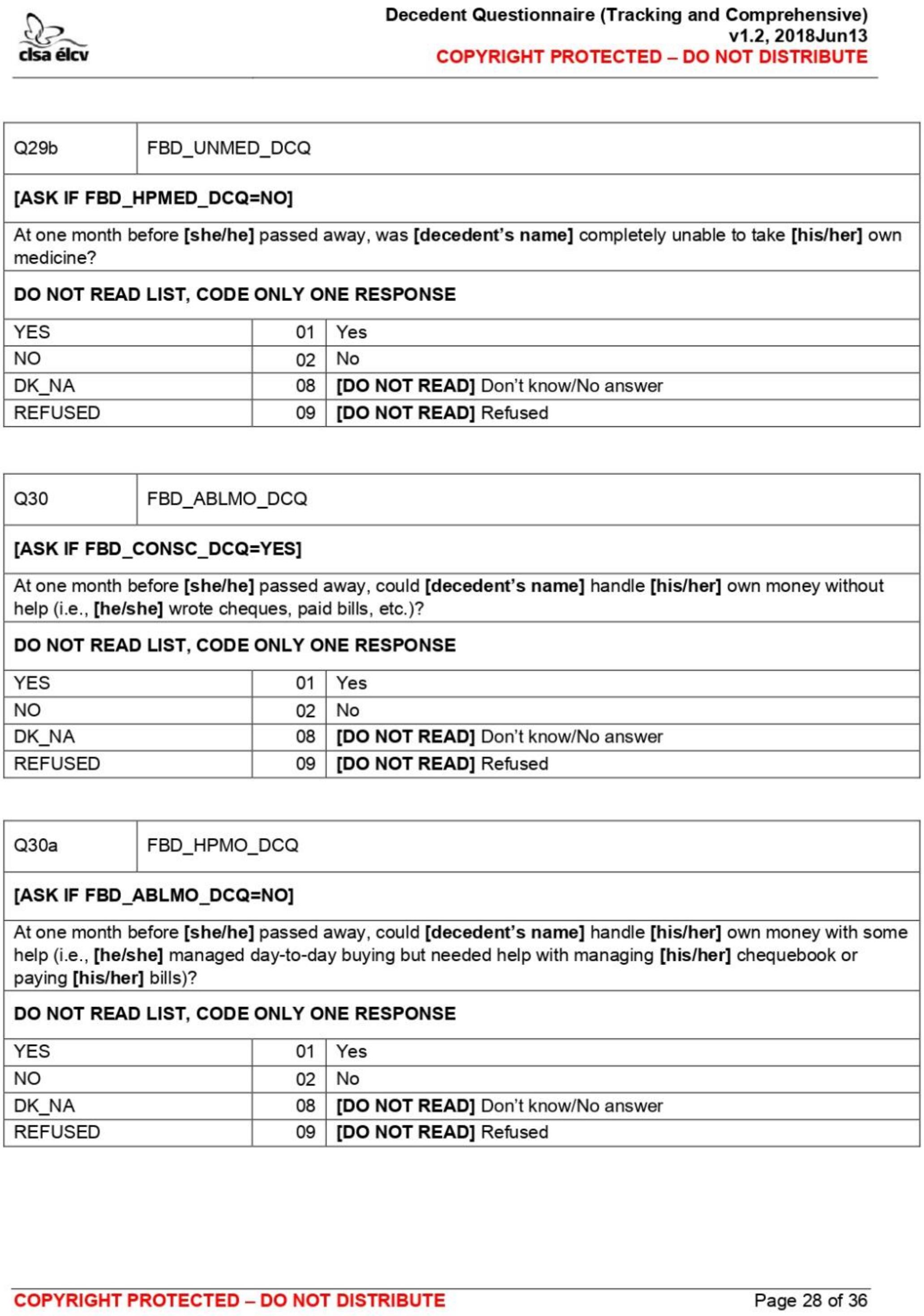
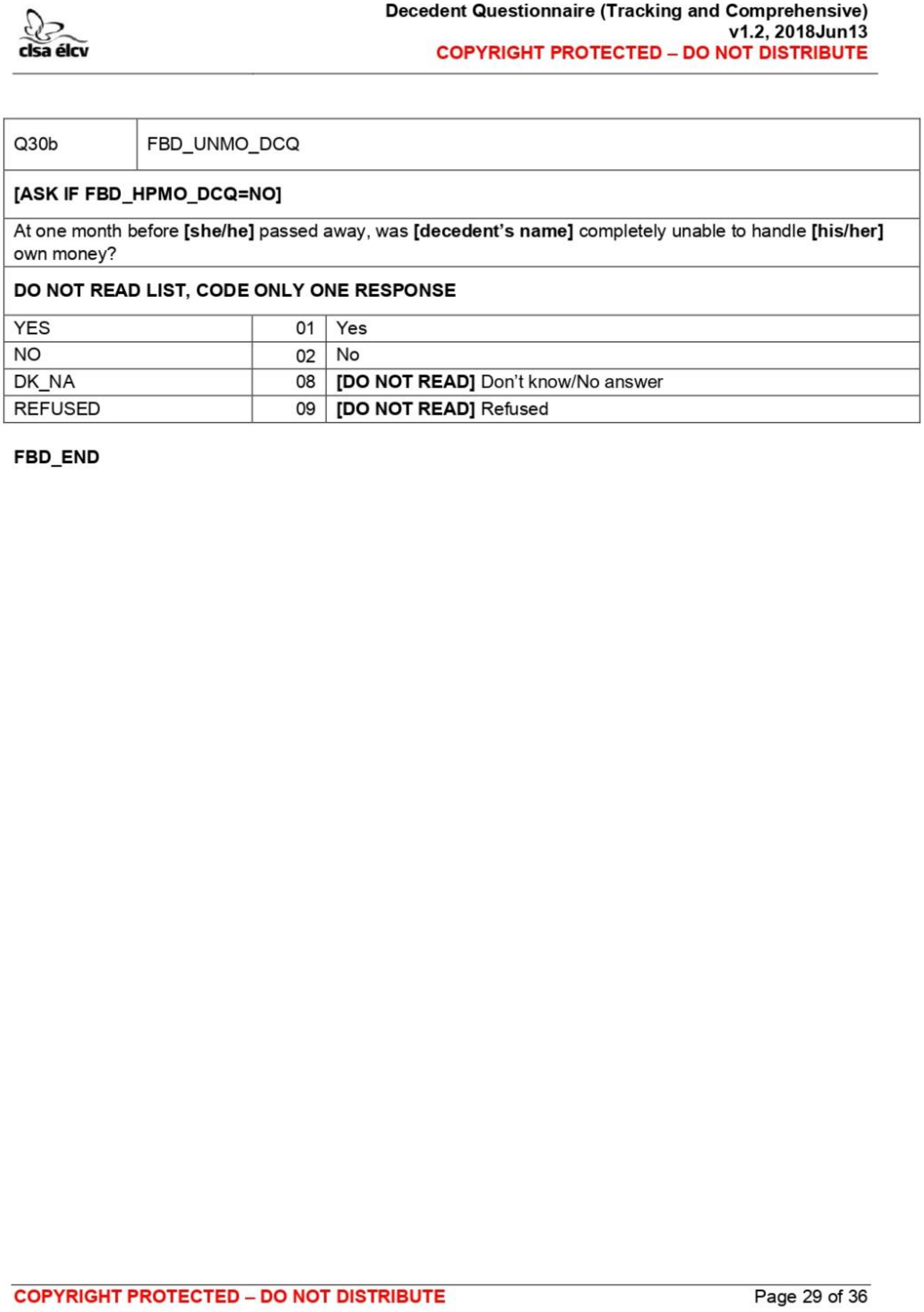


Q29b	FBD_UNMED_DCQ	
[ASK IF FBD_HPMED_DCQ=NO]		
At one month before **[she/he]** passed away, was **[decedent's name]** completely unable to take **[his/her]** own medicine?		
DO NOT READ LIST, CODE ONLY ONE RESPONSE		
YES	01	Yes
NO	02	No
DK_NA	08	**[DO NOT READ]** Don't know/No answer
REFUSED	09	**[DO NOT READ]** Refused

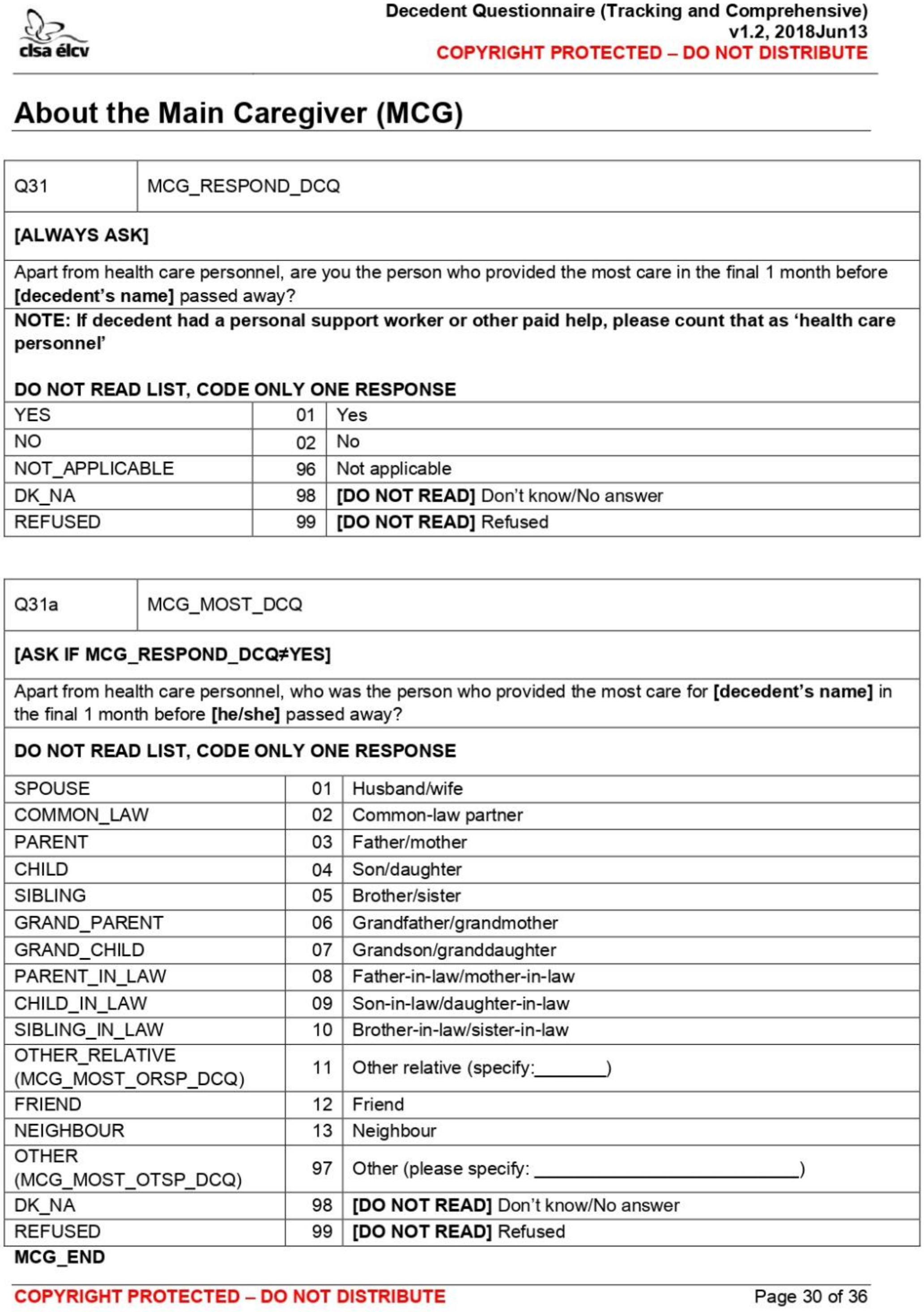
Q30	FBD_ABLMO_DCQ	
[ASK IF FBD_CONSC_DCQ=YES]		
At one month before **[she/he]** passed away, could **[decedent's name]** handle **[his/her]** own money without help (i.e., **[he/she]** wrote cheques, paid bills, etc.)?		
DO NOT READ LIST, CODE ONLY ONE RESPONSE		
YES	01	Yes
NO	02	No
DK_NA	08	**[DO NOT READ]** Don't know/No answer
REFUSED	09	**[DO NOT READ]** Refused

Q30a	FBD_HPMO_DCQ	
[ASK IF FBD_ABLMO_DCQ=NO]		
At one month before **[she/he]** passed away, could **[decedent's name]** handle **[his/her]** own money with some help (i.e., **[he/she]** managed day-to-day buying but needed help with managing **[his/her]** chequebook or paying **[his/her]** bills)?		
DO NOT READ LIST, CODE ONLY ONE RESPONSE		
YES	01	Yes
NO	02	No
DK_NA	08	**[DO NOT READ]** Don't know/No answer
REFUSED	09	**[DO NOT READ]** Refused



Q30b	FBD_UNMO_DCQ	
[ASK IF FBD_HPMO_DCQ=NO]		
At one month before **[she/he]** passed away, was **[decedent's name]** completely unable to handle **[his/her]** own money?		
DO NOT READ LIST, CODE ONLY ONE RESPONSE		
YES	01	Yes
NO	02	No
DK_NA	08	**[DO NOT READ]** Don't know/No answer
REFUSED	09	**[DO NOT READ]** Refused

FBD_END

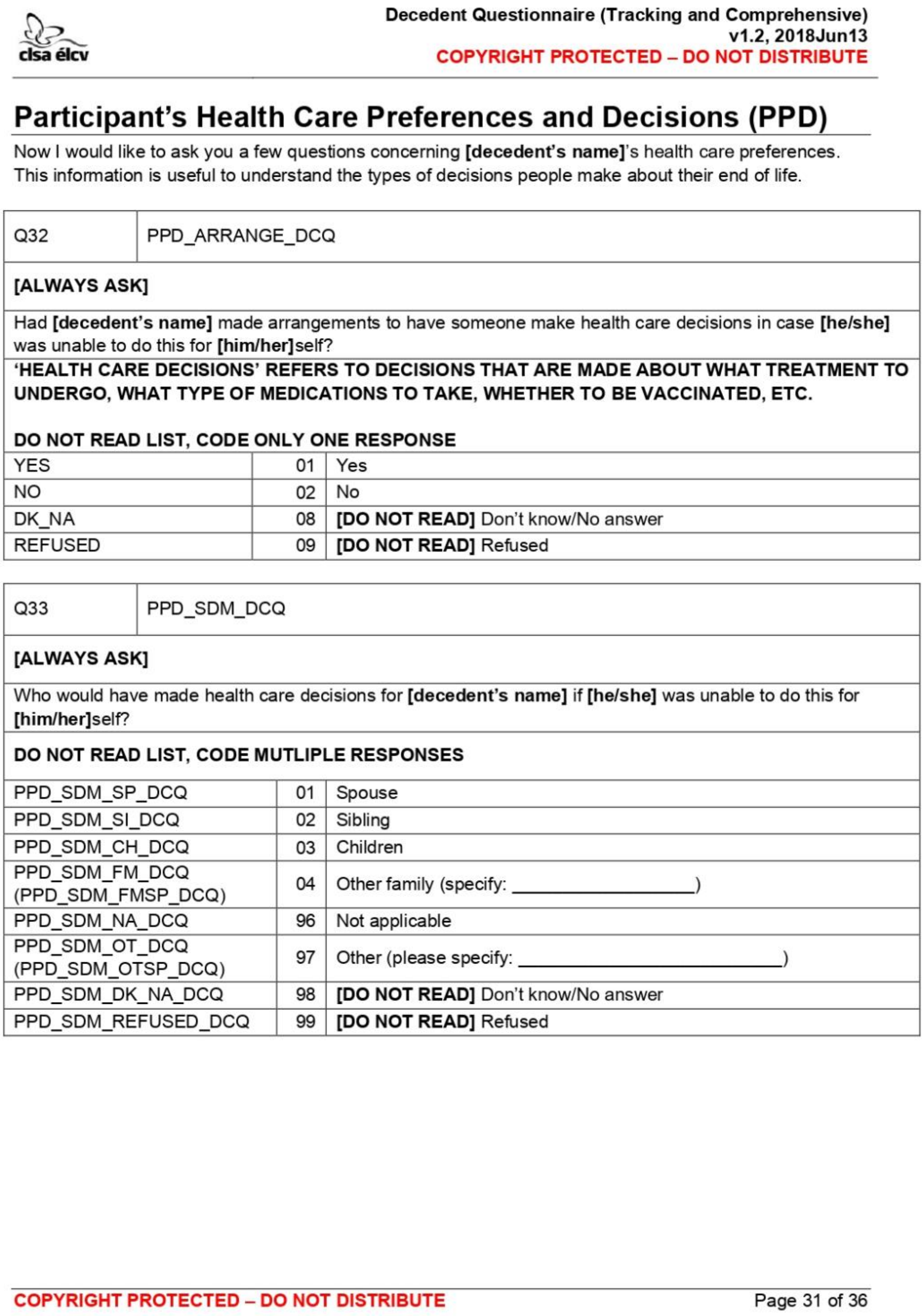


About the Main Caregiver (MCG)

Q31	MCG_RESPOND_DCQ	
[ALWAYS ASK]		
Apart from health care personnel, are you the person who provided the most care in the final 1 month before **[decedent's name]** passed away?		
NOTE: If decedent had a personal support worker or other paid help, please count that as 'health care personnel' **DO NOT READ LIST, CODE ONLY ONE RESPONSE**		
YES	01	Yes
NO	02	No
NOT_APPLICABLE	96	Not applicable
DK_NA	98	**[DO NOT READ]** Don't know/No answer
REFUSED	99	**[DO NOT READ]** Refused

Q31a	MCG_MOST_DCQ	
[ASK IF MCG_RESPOND_DCQ≠YES]		
Apart from health care personnel, who was the person who provided the most care for **[decedent's name]** in the final 1 month before **[he/she]** passed away?		
DO NOT READ LIST, CODE ONLY ONE RESPONSE		
SPOUSE	01	Husband/wife
COMMON_LAW	02	Common-law partner
PARENT	03	Father/mother
CHILD	04	Son/daughter
SIBLING	05	Brother/sister
GRAND_PARENT	06	Grandfather/grandmother
GRAND_CHILD	07	Grandson/granddaughter
PARENT_IN_LAW	08	Father-in-law/mother-in-law
CHILD_IN_LAW	09	Son-in-law/daughter-in-law
SIBLING_IN_LAW	10	Brother-in-law/sister-in-law
OTHER_RELATIVE (MCG_MOST_ORSP_DCQ)	11	Other relative (specify:_______)
FRIEND	12	Friend
NEIGHBOUR	13	Neighbour
OTHER (MCG_MOST_OTSP_DCQ)	97	Other (please specify: ________________________)
DK_NA	98	**[DO NOT READ]** Don't know/No answer
REFUSED	99	**[DO NOT READ]** Refused

MCG_END



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Participant's Health Care Preferences and Decisions (PPD)

Now I would like to ask you a few questions concerning **[decedent's name]**'s health care preferences. This information is useful to understand the types of decisions people make about their end of life.

Q32	PPD_ARRANGE_DCQ	
[ALWAYS ASK]		
Had **[decedent's name]** made arrangements to have someone make health care decisions in case **[he/she]** was unable to do this for **[him/her]**self?		
'HEALTH CARE DECISIONS' REFERS TO DECISIONS THAT ARE MADE ABOUT WHAT TREATMENT TO UNDERGO, WHAT TYPE OF MEDICATIONS TO TAKE, WHETHER TO BE VACCINATED, ETC. **DO NOT READ LIST, CODE ONLY ONE RESPONSE**		
YES	01	Yes
NO	02	No
DK_NA	08	**[DO NOT READ]** Don't know/No answer
REFUSED	09	**[DO NOT READ]** Refused

Q33	PPD_SDM_DCQ	
[ALWAYS ASK]		
Who would have made health care decisions for **[decedent's name]** if **[he/she]** was unable to do this for **[him/her]**self?		
DO NOT READ LIST, CODE MUTLIPLE RESPONSES		
PPD_SDM_SP_DCQ	01	Spouse
PPD_SDM_SI_DCQ	02	Sibling
PPD_SDM_CH_DCQ	03	Children
PPD_SDM_FM_DCQ (PPD_SDM_FMSP_DCQ)	04	Other family (specify: ___________________)
PPD_SDM_NA_DCQ	96	Not applicable
PPD_SDM_OT_DCQ (PPD_SDM_OTSP_DCQ)	97	Other (please specify: ___________________________)
PPD_SDM_DK_NA_DCQ	98	**[DO NOT READ]** Don't know/No answer
PPD_SDM_REFUSED_DCQ	99	**[DO NOT READ]** Refused

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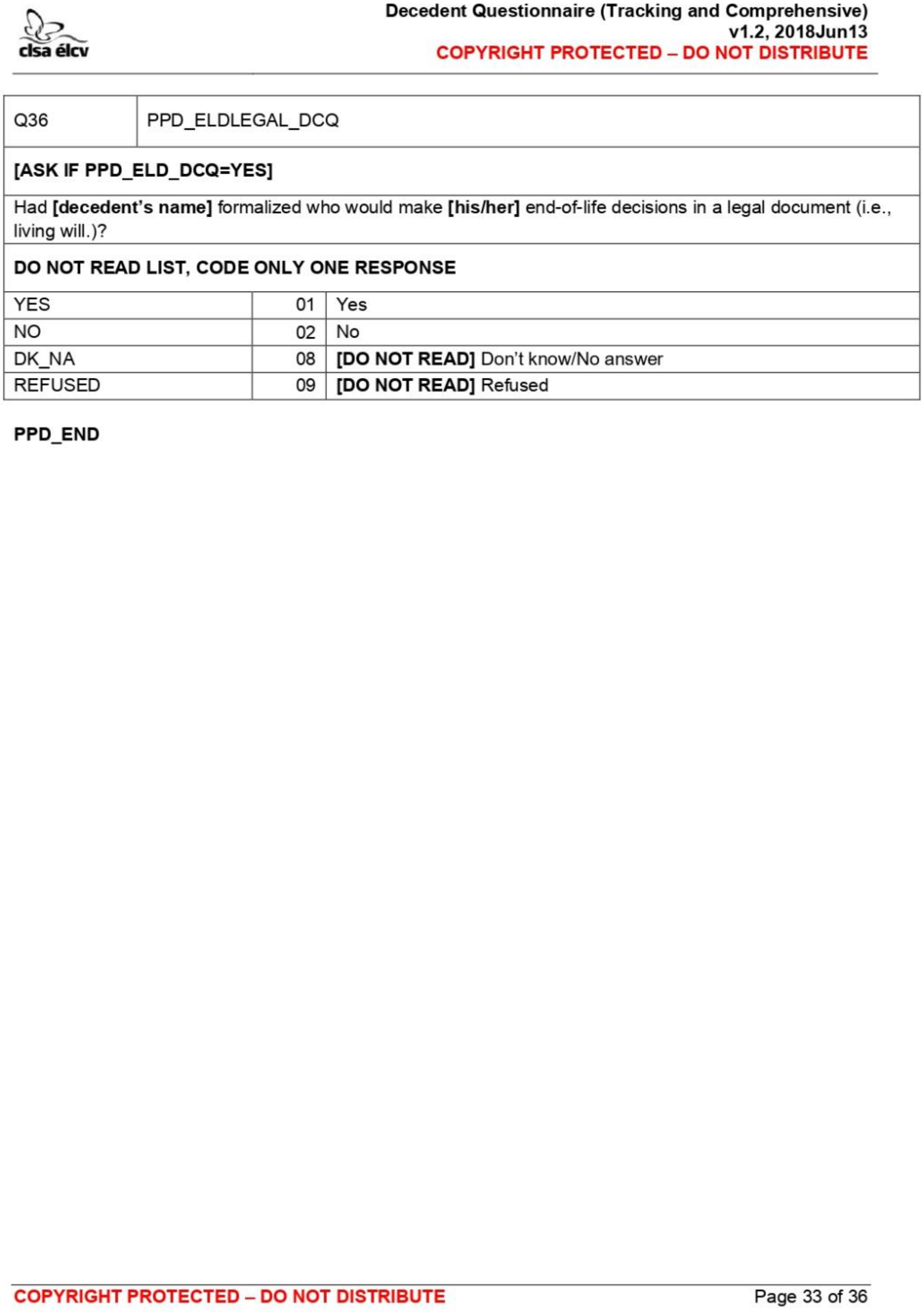
Q34	PPD_LEGAL_DCQ	
[ASK IF PPD_ARRANGE_DCQ=YES]		
Had **[decedent's name]** formalized **[his/her]** health care decisions in a legal document (i.e., power of attorney for personal care, etc.)?		
DO NOT READ LIST, CODE ONLY ONE RESPONSE		
YES	01	Yes
NO	02	No
DK_NA	08	**[DO NOT READ]** Don't know/No answer
REFUSED	09	**[DO NOT READ]** Refused

Q35	PPD_ELD_DCQ	
[ALWAYS ASK]		
Did **[decedent's name]** make arrangements for someone to make end-of-life decisions for **[him/her]**?		
'END-OF-LIFE' DECISIONS ARE CHOICES SUCH AS WHETHER TO BE RESUSCITATED, WHETHER TO STAY ON LIFE SUPPORT, ETC. **DO NOT READ LIST, CODE ONLY ONE RESPONSE**		
YES	01	Yes
NO	02	No
DK_NA	08	**[DO NOT READ]** Don't know/No answer
REFUSED	09	**[DO NOT READ]** Refused

Q35a	PPD_ELDSUB_DCQ	
[ALWAYS ASK]		
Who would have made end-of-life decisions for **[decedent's name]** if **[he/she]** was unable to do this for **[him/her]**self?		
DO NOT READ LIST, CODE MULTIPLE RESPONSES		
PPD_ELDSUB_SP_DCQ	01	Spouse
PPD_ELDSUB_SI_DCQ	02	Siblings
PPD_ELDSUB_CH_DCQ	03	Children
PPD_ELDSUB_FM_DCQ (PPD_ELDSUB_FMSP_DCQ)	04	Other family (specify:____________)
PPD_ELDSUB_NA_DCQ	96	Not applicable
PPD_ELDSUB_OT_DCQ (PPD_ELDSUB_OTSP_DCQ)	97	Other (please specify: __________________________)
PPD_ELDSUB_DK_NA_DCQ	98	**[DO NOT READ]** Don't know/No answer
PPD_ELDSUB_REFUSED_DCQ	99	**[DO NOT READ]** Refused



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Q36	PPD_ELDLEGAL_DCQ	
[ASK IF PPD_ELD_DCQ=YES]		
Had **[decedent's name]** formalized who would make **[his/her]** end-of-life decisions in a legal document (i.e., living will.)?		
DO NOT READ LIST, CODE ONLY ONE RESPONSE		
YES	01	Yes
NO	02	No
DK_NA	08	**[DO NOT READ]** Don't know/No answer
REFUSED	09	**[DO NOT READ]** Refused

PPD_END

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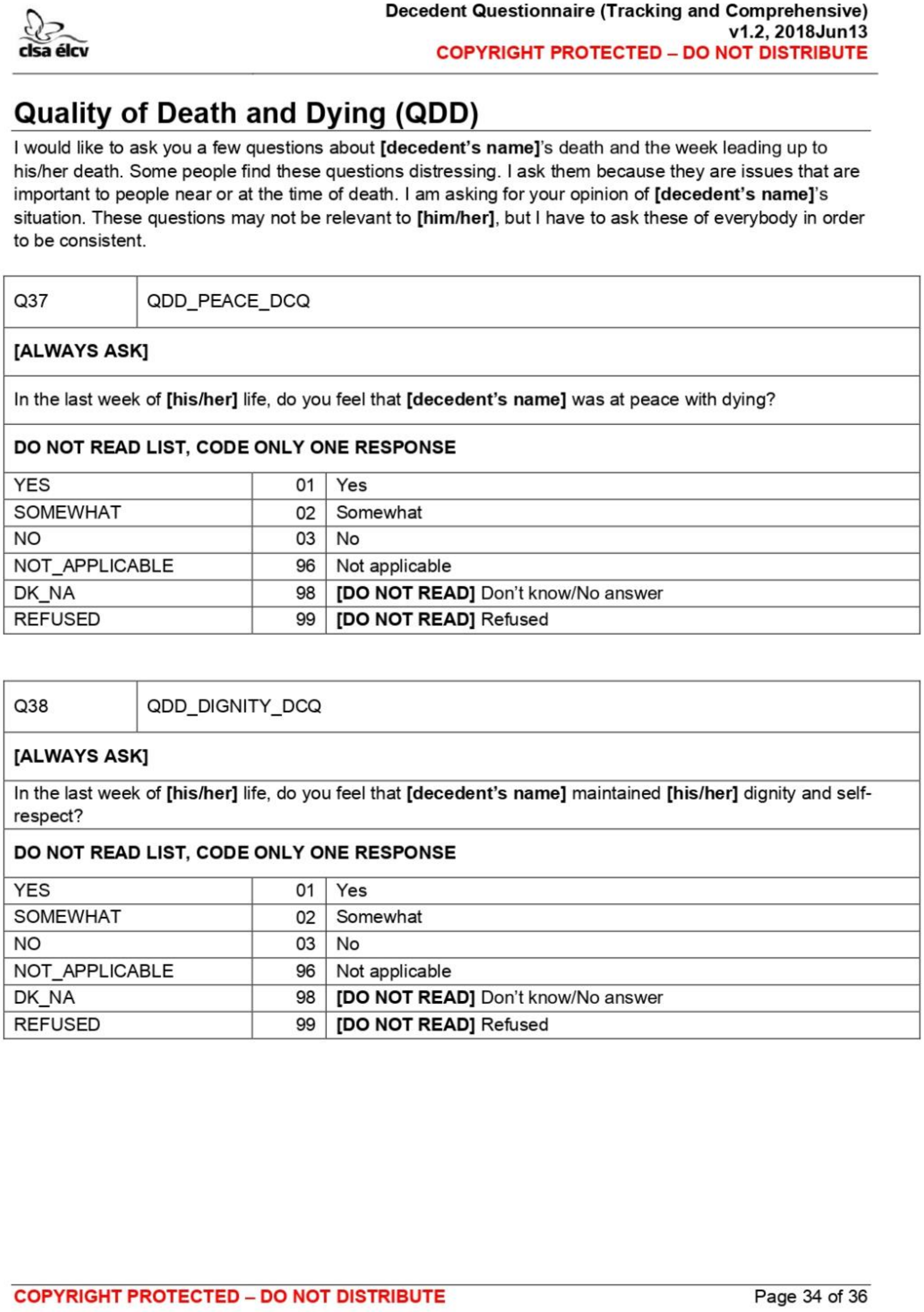

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Quality of Death and Dying (QDD)

I would like to ask you a few questions about **[decedent's name]**'s death and the week leading up to his/her death. Some people find these questions distressing. I ask them because they are issues that are important to people near or at the time of death. I am asking for your opinion of **[decedent's name]**'s situation. These questions may not be relevant to **[him/her]**, but I have to ask these of everybody in order to be consistent.

Q37	QDD_PEACE_DCQ	
[ALWAYS ASK]		
In the last week of **[his/her]** life, do you feel that **[decedent's name]** was at peace with dying?		
DO NOT READ LIST, CODE ONLY ONE RESPONSE		
YES	01	Yes
SOMEWHAT	02	Somewhat
NO	03	No
NOT_APPLICABLE	96	Not applicable
DK_NA	98	**[DO NOT READ]** Don't know/No answer
REFUSED	99	**[DO NOT READ]** Refused

Q38	QDD_DIGNITY_DCQ	
[ALWAYS ASK]		
In the last week of **[his/her]** life, do you feel that **[decedent's name]** maintained **[his/her]** dignity and self-respect?		
DO NOT READ LIST, CODE ONLY ONE RESPONSE		
YES	01	Yes
SOMEWHAT	02	Somewhat
NO	03	No
NOT_APPLICABLE	96	Not applicable
DK_NA	98	**[DO NOT READ]** Don't know/No answer
REFUSED	99	**[DO NOT READ]** Refused

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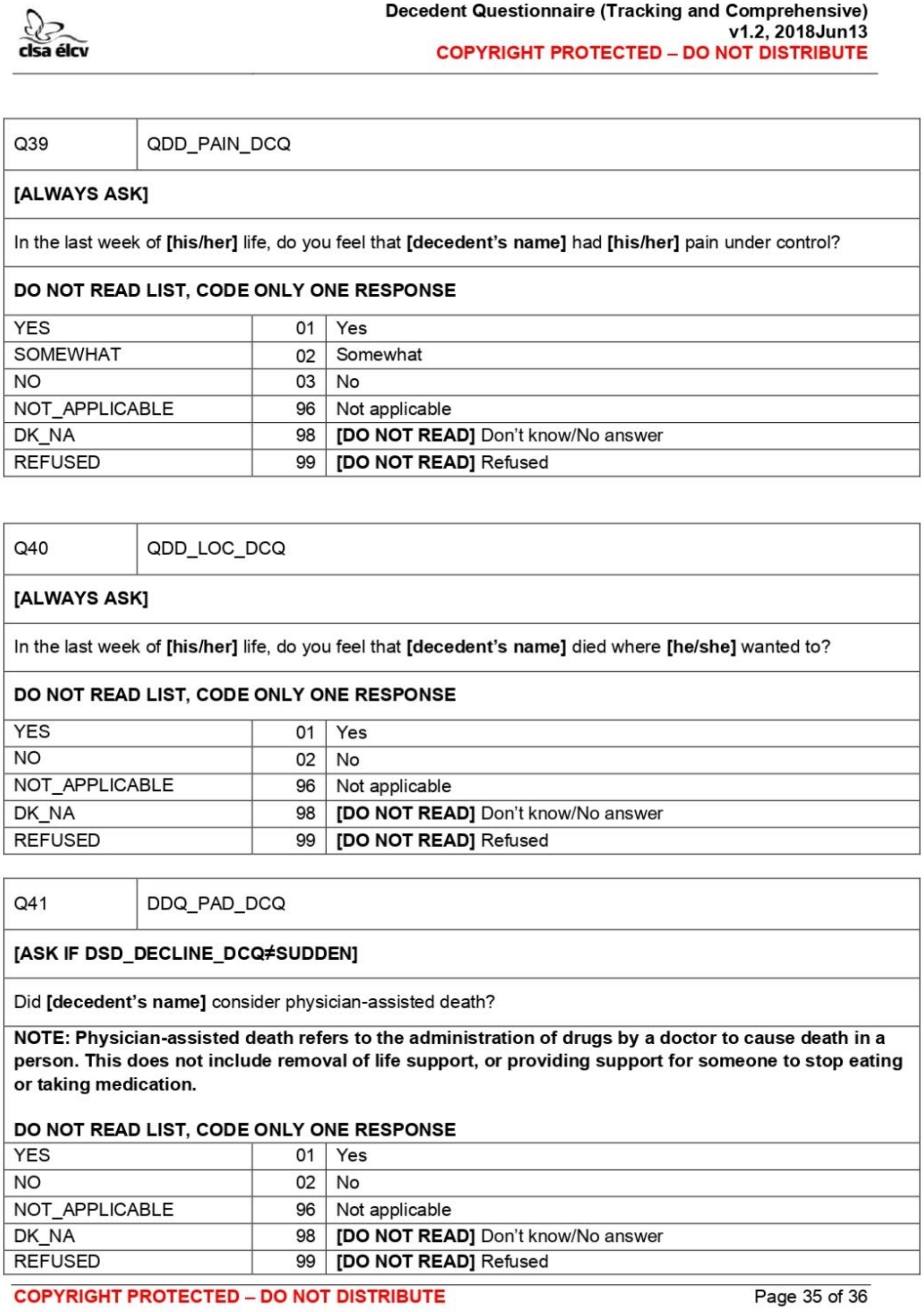
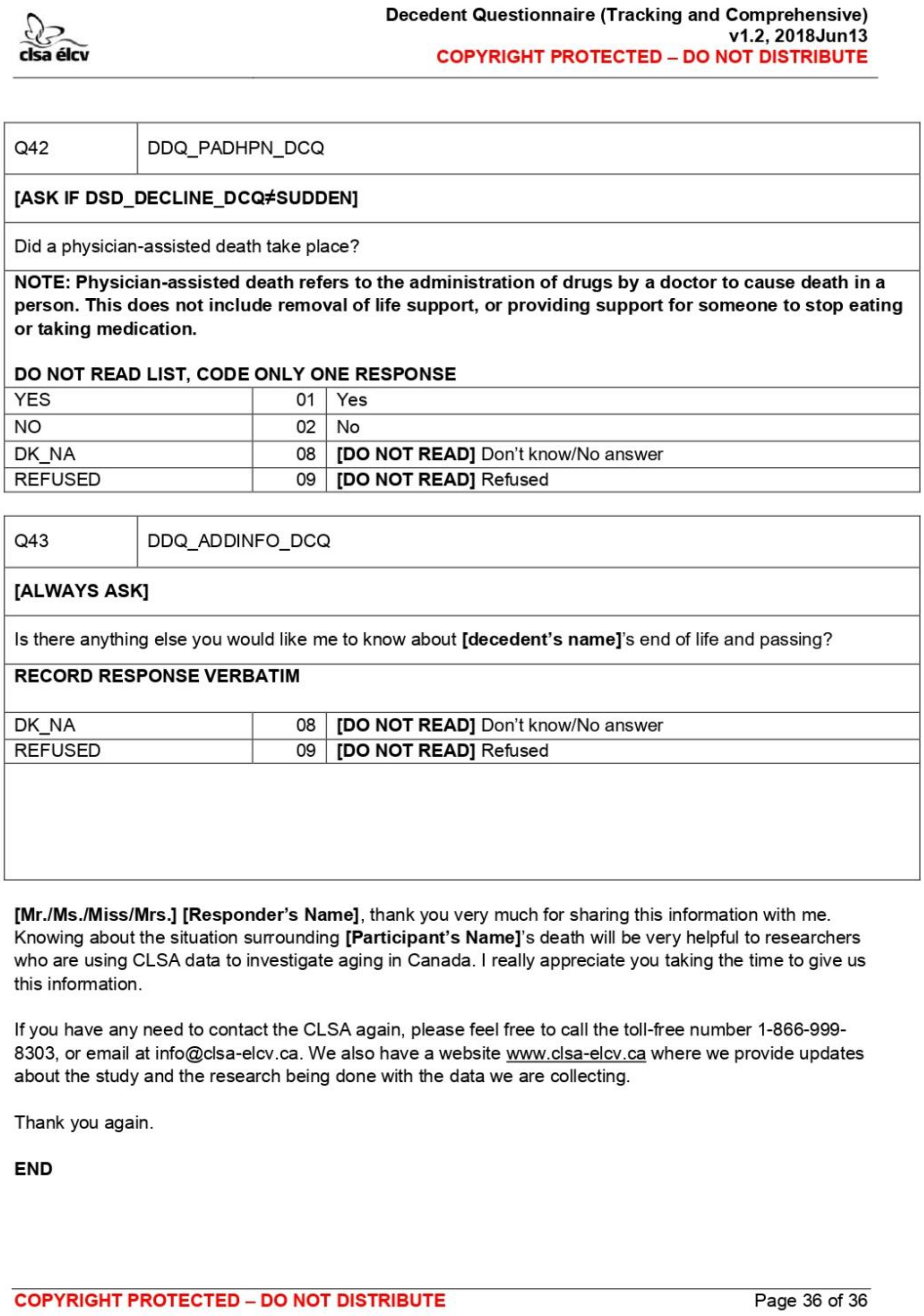


Q39	QDD_PAIN_DCQ	
[ALWAYS ASK]		
In the last week of **[his/her]** life, do you feel that **[decedent's name]** had **[his/her]** pain under control?		
DO NOT READ LIST, CODE ONLY ONE RESPONSE		
YES	01	Yes
SOMEWHAT	02	Somewhat
NO	03	No
NOT_APPLICABLE	96	Not applicable
DK_NA	98	**[DO NOT READ]** Don't know/No answer
REFUSED	99	**[DO NOT READ]** Refused

Q40	QDD_LOC_DCQ	
[ALWAYS ASK]		
In the last week of **[his/her]** life, do you feel that **[decedent's name]** died where **[he/she]** wanted to?		
DO NOT READ LIST, CODE ONLY ONE RESPONSE		
YES	01	Yes
NO	02	No
NOT_APPLICABLE	96	Not applicable
DK_NA	98	**[DO NOT READ]** Don't know/No answer
REFUSED	99	**[DO NOT READ]** Refused

Q41	DDQ_PAD_DCQ	
[ASK IF DSD_DECLINE_DCQ≠SUDDEN]		
Did **[decedent's name]** consider physician-assisted death?		
NOTE: Physician-assisted death refers to the administration of drugs by a doctor to cause death in a person. This does not include removal of life support, or providing support for someone to stop eating or taking medication. **DO NOT READ LIST, CODE ONLY ONE RESPONSE**		
YES	01	Yes
NO	02	No
NOT_APPLICABLE	96	Not applicable
DK_NA	98	**[DO NOT READ]** Don't know/No answer
REFUSED	99	**[DO NOT READ]** Refused



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Q42	DDQ_PADHPN_DCQ	
[ASK IF DSD_DECLINE_DCQ≠SUDDEN]		
Did a physician-assisted death take place?		
NOTE: Physician-assisted death refers to the administration of drugs by a doctor to cause death in a person. This does not include removal of life support, or providing support for someone to stop eating or taking medication. **DO NOT READ LIST, CODE ONLY ONE RESPONSE**		
YES	01	Yes
NO	02	No
DK_NA	08	**[DO NOT READ]** Don't know/No answer
REFUSED	09	**[DO NOT READ]** Refused

Q43	DDQ_ADDINFO_DCQ	
[ALWAYS ASK]		
Is there anything else you would like me to know about **[decedent's name]**'s end of life and passing?		
RECORD RESPONSE VERBATIM		
DK_NA	08	**[DO NOT READ]** Don't know/No answer
REFUSED	09	**[DO NOT READ]** Refused

[Mr./Ms./Miss/Mrs.] [Responder's Name], thank you very much for sharing this information with me. Knowing about the situation surrounding **[Participant's Name]**'s death will be very helpful to researchers who are using CLSA data to investigate aging in Canada. I really appreciate you taking the time to give us this information.

If you have any need to contact the CLSA again, please feel free to call the toll-free number 1-866-999-8303, or email at info@clsa-elcv.ca. We also have a website www.clsa-elcv.ca where we provide updates about the study and the research being done with the data we are collecting.

Thank you again.

END

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CHAPTER TWO

Peaceful Dying Among Canada's Elderly: An Analysis of the Canadian Longitudinal Study on Aging

Summary

The second chapter of this thesis describes personal and end-of-life characteristics associated with proxy reports of decedents' experience of peace with dying. This study outlines that approximately 20% of older adults do not experience peace with dying and our findings highlight the need for increased public attention and healthcare emphasis on improving the experience of dying. We found that experiencing peace with dying is multifaceted, shaped by a combination of personal characteristics, end-of-life planning, and access to end-of-life predictability of the illness trajectory. Understanding personal characteristics that are associated with peaceful dying experiences may enable the development of interventions that more effectively meet individual end-of-life care needs, ultimately promoting a dignified and comfortable end-of-life experiences for older adults.

This study provides key insights into understanding peace with dying and unique contributions to end-of-life research. First, this is the first study to use newly released data from the Canadian Longitudinal Study on Aging on end-of-life characteristics. Second, this is the first study to assess end-of-life characteristics reported by proxy of decedents' experience at a national level for older adults across all disease categories. Lastly, our findings suggest that the expansion of palliative care services and more intentional advanced planning may enhance the

experience of a peaceful death in Canada. These findings will inform national goal setting for dying and palliative care in Canada.

Citation

Aryal K, Jones A, Tanuseputro P, Griffith, LE, Hebert PC, Kirkland S, Cook DJ, Costa AP. (*Accepted*). Peaceful Dying Among Canada's Elderly: An Analysis of the Canadian Longitudinal Study on Aging. *PloS One.*

Introduction: Death is universal, yet relatively little is known about how Canadians experience their death. Using novel decedent interview data from the Canadian Longitudinal Study on Aging we describe the prevalence and characteristics of peace with dying among older Canadians.

Methods: We conducted a secondary analysis of decedent interview data from the Canadian Longitudinal Study on Aging. Proxies of deceased Canadian Longitudinal Study on Aging participants reported on participants' end-of-life experiences between January 2012 to March 2022. We examined end-of-life characteristics and their association with proxy reports of experiencing peace with dying. We conducted regression analysis to explore the association between demographic and end-of-life characteristics and experiencing peace with dying.

Results: Of 3,672 deceased participants, 1,287 (35.0%) had a completed decedent questionnaire and were included in the analysis. Respondents reported that two-thirds (66.0%) of the deceased experienced peace with dying and 17% did not experience peace with dying. The unadjusted odds of experiencing peace with dying were higher for those with an appointed power of attorney (OR 1.80; CI 1.39-2.33), those who died of cancer (OR 1.71; CI 1.27-2.30), those in hospice/receiving palliative care (OR 1.67; CI 1.19-2.37), individuals older than 75 years (OR 1.55; CI 1.04-2.30), or widowed (OR 1.53; CI 1.12-2.10). Widowhood (OR 1.51; CI 1.01-2.29), having an end-of-life SDM (OR 1.58; CI 1.14-2.17), and dying of cancer (OR 1.67; CI 1.19-2.23) increased the adjusted odds of dying with peace.

Conclusions: Close to 1 in 5 older Canadians may not experience peace with dying, which supports greater focus on improving the end-of-life care. Our findings suggest that advanced planning may enhance the experience of a peaceful death in Canada.

Introduction

Death holds profound significance as an inevitable event that marks the culmination of life's journey. Achieving a good quality of death is heavily influenced by the ability to experience peace with dying.[1, 2] The concept of dying peacefully can involve physical comfort, emotional acceptance, and spiritual well-being.[3, 4] From 2000 to 2013, the overall quality of death and dying experiences declined, highlighting the urgent need to understand and potentially improve the quality of the dying process.[5]

With Canada's population aged 85 and older projected to double by 2050, alongside a 25% increase in overall deaths, understanding the factors that influence peace with dying is crucial to improve the overall dying experience.[6, 7] Religious beliefs, healthcare professionals' attitudes, and end-of-life care practices directly shape a person’s experience of peace with dying.[8-10] Significant pain during end-of-life or receiving minimal support that does not align with personal preferences, has been linked not experiencing peace with dying .[11, 12] Despite the importance of dying with peace and dignity for individuals, caregivers, and healthcare providers,[13] few population-based data sources in Canada explore the relationship between end-of-life characteristics and peace with dying.[14-16] Identifying end-of-life characteristics associated with a peaceful death may allow older adults to experience a good quality of death and enable targeted improvements in care when these factors are not met.

Using newly released data from the Canadian Longitudinal Study on Aging we sought to describe the end-of-life characteristics associated with proxy reports of decedents’ experience of peace with dying. Based on previous findings, we hypothesized that personal and end-of-life characteristics, such as dying of cancer is correlated with experiencing peace with dying, while unexpected or unplanned deaths, such as those due to chronic illnesses or lack of an appointed decision-maker, decrease the likelihood of experiencing peace.

Methods:

Study Design and Data Source

We conducted a secondary analysis of decedent interview data from the Canadian Longitudinal Study on Aging (CLSA). The CLSA is a prospective cohort study platform with a national, stratified sample of 51,338 community-dwelling middle-aged and older adults, aged 45–85 years at baseline who are followed every 3 years. Previous reports have described the CLSA's design and methodology.[17-19] To summarize, the CLSA comprises of the Tracking cohort, which includes participants randomly selected from all 10 Canadian provinces, and the Comprehensive cohort, which includes participants randomly selected from within a 25–50 km radius of one of 11 data collection sites located in British Columbia, Alberta, Manitoba, Ontario, Quebec, Nova Scotia, and Newfoundland. Both cohorts collect similar data, while the Comprehensive cohort also undergoes a more detailed physical assessments. Participant demographic and social characteristics at baseline are comparable to the 2011 Canadian census.[17]

Decedent Questionnaire

Next of kin or primary contact (most often identified by the CLSA participant at baseline) were contacted by mail once the CLSA received the confirmation of death from a family member, friend, or through provincial death records. Next of kin or primary contacts were then contacted via telephone two weeks after mailing to invite participation in a decedent interview. Decedent questionnaires (available online)[20] were completed between September 2017 to

March 2022 by telephone interview (French or English) with a trained CLSA decedent interviewer. Interviews were completed 2 years after death on average (ranging between 10 days to 6.3 years), depending on respondent availability and release of the participant's deceased status.

Participants

CLSA participants who died between from January 6, 2012, to March 15, 2022, and for whom we had a completed decedent interview were included for analyses.

Peace with Dying

Respondents were asked whether they believed the deceased participant experienced peace with dying, defined as being at peace with the concept of dying during the last week of their life. There were six possible response options: 1) yes, they experienced peace with dying, 2) they were 'somewhat' at peace with dying, 3) they did not experience peace with dying, 4) this question is not applicable, 5) they don't know if the deceased participants experienced peace with dying, and 6) refused to answer the question. We used 1) yes, they experienced peace with dying, as the dependent variable in the analyses.

Statistical Analysis

We examined participant and end-of-life characteristics from the decedent questionnaire, including the location of death, cause of death, arrangements for health care decision-making, and arrangements for end-of-life care decision-making. Descriptive summaries were generated to characterize participant and end-of-life characteristics and compare between participants with a complete and incomplete decedent interview. We also compared the participant sociodemographic characteristics from both the CLSA and Statistics Canada for deceased Canadians.

We used a correlation matrix and computed the variance inflation factor (VIF) to examine multicollinearity among end-of-life and participant characteristics. We performed unadjusted logistic regression to estimate associations with peace with dying and multivariable logistic regression to determine adjusted associations. We reported the area under the receiver operating curve to assess model discrimination. We performed a subgroup analysis by sex, between those dying of cancer compared to those dying of other causes, and between time of death to time of decedent interview, to examine differences in the associations with dying with peace.

Ethics Approval

This secondary analysis was approved by the Hamilton Integrated Research Ethics Board (2023-16023-C).

Results:

There were 3,672 CLSA participants who died between 2012-2022, and 1,287 (35.0%) had a completed decedent questionnaire. CLSA decedents with a completed decedent questionnaire were on average 73.6 year of age at death, 62.7% were married or in a common-law relationship, 39.7% died of cancer, and 49.0% died in hospital. Deceased CLSA participants with a completed decedent interview were more likely to be male, older, married, and identify a religious affiliation compared to those without a decedent interview (**Table 1)**. CLSA deceased participants were older at death, more likely to be married or in a common-law relationship, less likely to have died of cancer, and less likely to have died in hospital compared to the general Canadian population who were 45 years or older[21] and died between 2012-2022 (**Appendix A**).

Approximately two-thirds (66.0%, n=855) of deceased participants experienced peace with dying, 7.0% (n=85) somewhat experienced peace with dying, and 1 in 5 participants (17.0%, n=213) did not experience peace with dying (**Figure 1**). Almost two-thirds (62.0%, n=798) of deceased participants were female, 66.7% (n=858) were 75 years old or older, 62.7% (n=807) were married, and 35.1% (n=452) had a bachelor's degree or higher. Regarding end-of-life characteristics, 39.7% (n=511) died of cancer, 49% (n=631) died in hospital, and 75.1% (n=967) and 81.5% (n=1,049) of participants had end-of-life substitute decision makers (SDM) and health care SDMs, respectively (**Table 2**). Based on the results of the correlation matrix and variance inflation factor, these characteristics were not significantly correlated **(Appendices B and C)**.

Our unadjusted analysis shows that being 75 years old or older (OR 1.55; CI 1.04-2.30), widowed (OR 1.53; CI 1.12-2.10), having Activities of Daily Living (ADL) or Instruments of Daily Living (IADL) impairment (e.g., moderate, OR 1.66; CI 1.13-2.48), having an appointed end-of-life SDM (OR 1.80; CI 1.39-2.33) or healthcare SDM (OR 1.63; CI 1.22-2.18), dying of cancer compared to heart disease (OR 1.71; CI 1.27-2.30) and dying in hospice (OR 1.67; CI 1.19-2.37), were associated with experiencing peace with dying **(Table 2)**. Adjusted odds showed that being widowed (OR 1.51; CI 1.01-2.29), having an end-of-life SDM (OR 1.58; CI 1.14-2.17), and dying of cancer (OR 1.67; CI 1.19-2.23) increased the odds of dying with peace. Model discrimination for the adjusted model was fair and similar for experiencing peace with dying model was (AUC=0.65).

Subgroup & Sensitivity Analysis

Stratified analyses showed similar end-of-life characteristics for females and males **(Appendix D)**. Stratified models for cancer and non-cancerous cause of death found that persons dying of cancer had greater odds of peace with dying with an healthcare and end-of-life SDM, or when they pass away at home. Conversely, persons not dying of cancer had greater odds of peace with dying when they had physical impairment and the presence of an appointed end-of-life SDM (**Appendix E**). Sensitivity analysis comparing the unadjusted odds between interviews completed within one year of passing compared to between one to 6.3 years after passing showed similar results (**Appendix F & G**). However, being male increased the odds of peace with dying when the interview was conducted within the first year after death and there was a lower likelihood of peace with dying after one year. Another sensitivity analysis examined the relationship of the respondent to the deceased participants (spouse, child or other) and its influence on the results and found no significant differences between the models (**Appendix H**).

Discussion:

In this Canadian study of older adults, we found that although most Canadians may experience peace with dying, close to 1 in 5 may not. This finding highlights the need for greater public attention and healthcare focus on improving the experience of dying. We documented that proxy reports of peace with dying are associated with a combination of personal characteristics, aspects of social connection, predictability of the illness trajectory, and end-of-life planning. Adjusted associations show that individuals who are widowed, diagnosed with cancer, and have an end-of-life SDM, were reported to have a higher likelihood of experiencing peace with dying. The interplay between cancer diagnosis, widowhood, and the presence of a decision maker highlights the complex interplay of personal circumstances, and preparedness or comfort with death, that can enhance the likelihood of experiencing peace with dying.[9, 22]

Previous studies have found that achieving peace with dying inevitably results in a "good death."[23] Individuals in this study diagnosed with cancer were more likely to experience peace with dying compared to those with other causes of death. A previous qualitative study found that individuals experience peace with dying when they have sufficient information about their disease and potential end-of-life care pathways.[9] Many persons diagnosed with cancer have established health and end-of-life care plans and better access to healthcare attention than others, which may contribute to their sense of peace with dying.

The matter of dying plays an important role in quality of death and dying, as those who experience death closely are more at peace with dying.[24] Widowed individuals, who are often caregivers or experience death very closely, may be more likely to experience peace with dying. Given the loss of a prominent social relationship and experiencing loss may have strengthened their ability to confront death. Although being surrounded by loved ones can alleviate feelings of loneliness and isolation, leading to a more comforting and peaceful end-of-life experience,[2] the dual role of being both a patient and a widow may foster a unique understanding arising from their grief or loss of a loved one that may result in increasing their likelihood of experiencing peace with dying. Widows often reflect on their lives and relationships in their final days, similar to cancer survivors who see their suffering as a catalyst for personal growth and transformation, which brings a sense of peace.[25]

Previous studies have reported fewer than 50% of participants having an appointed SDM.[26] We found over 75% of deceased CLSA participants with a decedent interview had a health and end-of-life SDM. We found that individuals with advance care directives or advance care planning documentations were more likely to experiencing peace with dying.[27] This suggests that establishing end-of-life plans may help alleviate emotional burden and fosters a sense of peace in individuals, leading to a more peaceful and improved quality of death.[28, 29] These findings support end-of-life planning initiatives such as, fulfilling individual's 'wishes' prior to dying, which brings forth a sense of peace with dying, inherently dignifying the dying process.[30] Our findings support the general presumption of advanced planning to support the quality of death.[8, 31]

Limitations

Though the CLSA decedent interviews were comprehensive, certain factors could not be considered, such as details of family support in the final months, whether and how psychosocial-spiritual needs were fulfilled, and the level of comfort with the medical team.[13, 32] We did not provide respondents with an explicit definition for a peaceful death and each response was subject to the respondents' recall of the death.

The majority of participants from the sample are white and only represent a third of the entire decedent population. The CLSA is comparable to the 2011 Canadian census: as such decedents in this study were relatively young and white hence our sample may not represent the dying experience of the 'oldest old' or of other ethnicities. Although ethnicity-based census data in 2011 is not available, in a study examining end-of-life care between 2004-2012 in Ontario, only 3.2% of total deaths were attributed to Chinese and South Asian ethnicities, but these groups had different end-of-life experiences.[33] Although our data could not capture these differences, this is the best available data we have on end-of-life experiences for a majority of older adults dying in Canada who have similar ethnic and religious backgrounds to our population. Therefore, as the largest study available to examine factors associated with peace with dying at national level, these findings are applicable to most end-of-life experiences in Canada.

Previous studies have identified that there is moderate agreement between family members on their assessment of peace with dying.[34] Therefore, this study is limited to one perspective and interviewing more than one respondent would have allowed for more perspectives of the dying experience. Similarly, caregivers may overestimate the degree of pain, and other symptoms, compared to the individual experiencing the symptoms.[35, 36] Receiving patient perspectives of the quality of death and dying may have provided a more accurate representation of the overall dying experience, which we did not have access to in this study.

Although limited, our study is susceptible to potential biases associated with the time elapsed after an individual's passing and the family members' reporting and or the completion of the decedent interview. It is conceivable that over time, the recollection of events may be influenced by various factors, potentially leading to a bias favoring positive end-of-life experiences.

Conclusions and Implications

Though most older Canadians may experience peace with dying, many may not. Experiencing peace with dying is multifaceted, influenced by a combination of personal characteristics, end-of-life planning, access to end-of-life care, and predictability of the illness trajectory. Awareness of factors that are associated with peaceful dying experiences may allow tailored interventions to better meet individual’s needs, facilitating dignified, comfortable end-of-life experiences for older adults.

Tables and Figures

Table 1*:* Comparison of Deceased Canadian Longitudinal Study on Aging Participants with Complete and Incomplete Decedent Questionnaires, 2012-2021

Category	Characteristic	Completed Decedent Interview	Did Not Complete the Decedent Interview
Total Deceased		**n=1,287**	**n=2,385**
Sex	Female	489 (38.0%)	974 (59.2%)
	Male	798 (62.0%)	1411 (40.8%)
Age	45-64	115 (8.9%)	562 (23.6%)
	65-74	313 (24.3%)	579 (24.3%)
	75+	858 (66.7%)	1,244 (52.1%)
Ethnicity	Non-White	24 (1.8%)	72 (3.0%)
	White	1,263 (98.2%)	2,313 (97.0%)
Religion	Not Religious	227 (17.6%)	720 (30.2%)
	Religious	1,060 (82.4%)	1,665 (69.8%)
Education	Less than High School	170 (13.2 %)	357 (15.0%)
	High School	158 (12.3%)	355 (14.9%)
	Other post-secondary education	507 (39.4%)	1,008 (42.3%)
	University degree or above	452 (35.1%)	665 (27.8%)
Marital Status	Single, Divorced or Separated	219 (17.0%)	535 (22.4%)
	Married	807 (62.7%)	1,275 (53.5%)
	Widowed	261 (20.3%)	575 (24.1%)

Figure 1: Peace with Dying Among Participants, The Canadian Longitudinal Study on Aging, 2012-2021

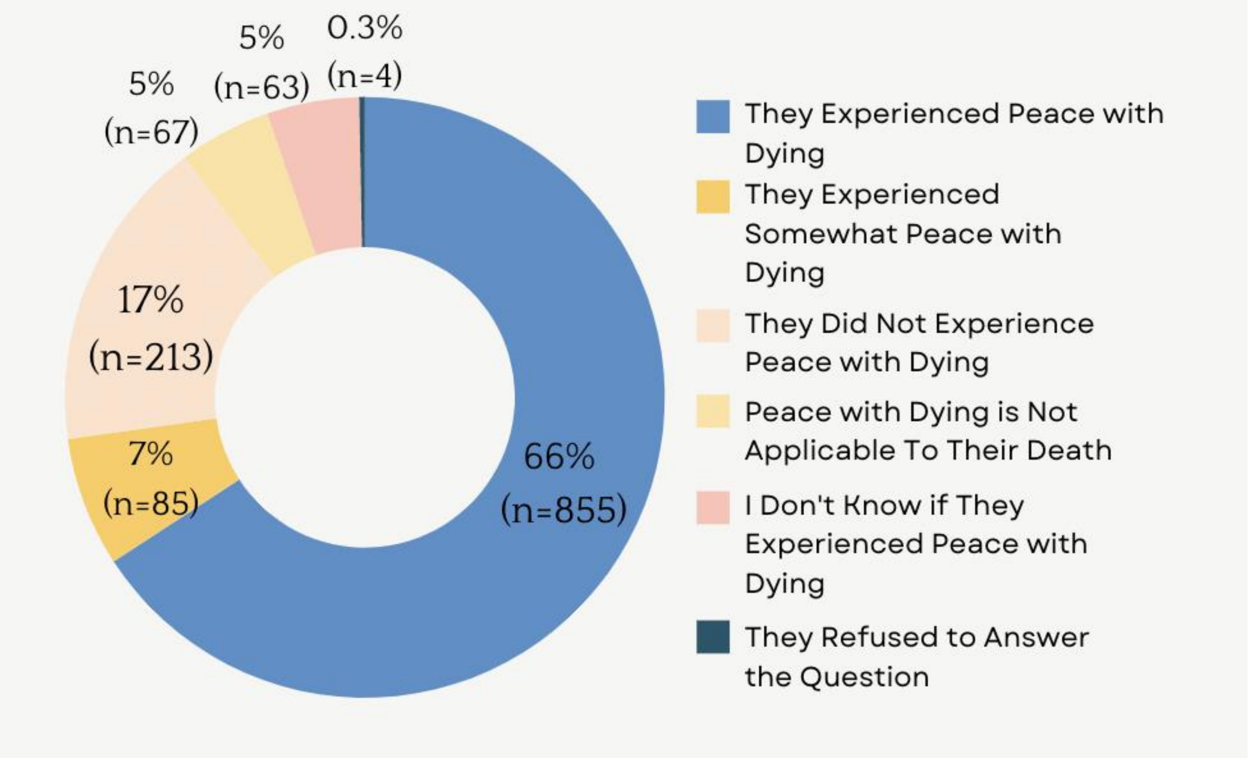


Table 2: Unadjusted and Adjusted Odds of Experiencing Peace with Dying, Canadian Longitudinal Study on Aging Decedents, 2017-2022

	Variable Category	**n(%)**	**Experienced Peace with Dying (n=855)**			
			Unadjusted OR	**95% CI**	**Adjusted OR**	**95% CI**
Sex	Female	798 (62.0%)	-		-	
	Male	489 (38.0%)	0.93	0.73- 1.18	1.06	0.80-1.39
Age	45-64	116 (9.0%)	-		-	
	65-74	313 (24.3%)	1.27	0.82-1.96	1.15	0.80-1.66
	75+	858 (66.7%)	1.55	1.04-2.30	1.30	0.91-1.87
Ethnicity	Non-White	24 (1.8%)	-		-	
	White	1,263 (98.2%)	1.42	0.61-3.21	1.28	0.53-3.00
Religion	Not Religious	227 (17.6%)	-		-	
	Religious	1060 (82.4%)	1.29	0.95-1.73	1.23	0.90-1.69
Education	Less than High School	170 (13.2 %)	-		-	
	High School	158 (12.3%)	0.98	0.61-1.57	1.02	0.63-1.66
	Other post-secondary education	507 (39.3%)	0.86	0.59-1.24	0.85	0.57-1.26
	University degree or above	452 (35.1%)	0.81	0.55-1.18	0.82	0.55-1.23
Marital Status	Married	807 (62.7%)	-		-	
	Single / Divorced / Separated	219 (17.0%)	0.73	0.54-1.00	0.79	0.52-1.20
	Widow	261 (20.3%)	1.53	1.12-2.10	1.51	1.01-2.29
ADL & IADL*	No/Mild Impairment	464 (36.5%)	-		-	
	Moderate impairment	167 (13.0%)	1.66	1.13-2.48	1.40	0.93-2.13
	Severe/Total Impairment	527 (40.9%)	1.32	1.01-1.71	1.06	0.79-1.43
Caregiver	Child	362 (28.1%)	-		-	
	Other	336 (26.1%)	1.13	0.77-1.67	1.18	0.83-1.68
	Spouse	589 (45.8%)	1.32	1.01-1.86	1.02	0.70-1.49
Health Decision-	Absent	238 (18.5%)	-		-	
	Present	1049 (81.5%)	1.63	1.22-2.18	1.01	0.76-1.56

Making SDM**						
End-of-Life Decision-Making SDM**	Absent	320 (24.9%)	-		-	
	Present	967 (75.1%)	1.80	1.39-2.33	1.58	1.14-2.17
Closeness	Not Close to Deceased	109 (8.5%)	-		-	
	Close to Deceased	1178 (91.5%)	1.38	0.92-2.05	1.22	0.79-1.87
Last physician visit	Did Not See Doctor Before Passing	715 (55.6%)	-		-	
	1-2 weeks	176 (13.7%)	1.08	0.76-1.55	1.07	0.73-1.57
	3-6 Weeks	136 (10.6%)	0.85	0.58-1.26	0.82	0.54-1.25
	7-51 Weeks	133 (10.3%)	0.64	0.44-0.94	0.64	0.42-0.96
	52+ Weeks	127 (9.9%)	0.77	0.52-1.14	0.83	0.54-1.29
Cause of death	Heart Disease	322 (25.0%)	-		-	
	Cancer	511 (39.7%)	1.71	1.27-2.30	1.67	1.19-2.23
	Other	305 (23.7%)	1.16	0.84-1.61	1.19	0.85-1.70
	RIDK**	149 (11.6%)	0.83	0.56-1.24	0.75	0.49-1.16
Location of Death	Hospital	631 (49.0%)	-		-	
	Home	292 (22.7%)	1.16	0.87-1.56	0.79	0.57-1.09
	Hospice/Palliative Care	222 (17.2%)	1.67	1.19-2.37	1.04	0.67-1.61
	Senior Home/LTC[1]/Other	142 (11.0%)	1.17	0.80-1.73	1.07	0.67-1.72

*ADL/IADL=Activities of Daily Living/ Instrumental Activities of Daily Living

**SDM=Substitute Decision Maker

***RIDK=R=Respiratory diseases including emphysema, obstructive lung disease, asthma, chronic obstructive pulmonary disease; I=Influenza or pneumonia; D=Dementia; K=Kidney Diseases such as nephritis, nephrotic syndrome, or nephrosis

[1] LTC=Long-term Care

Appendices

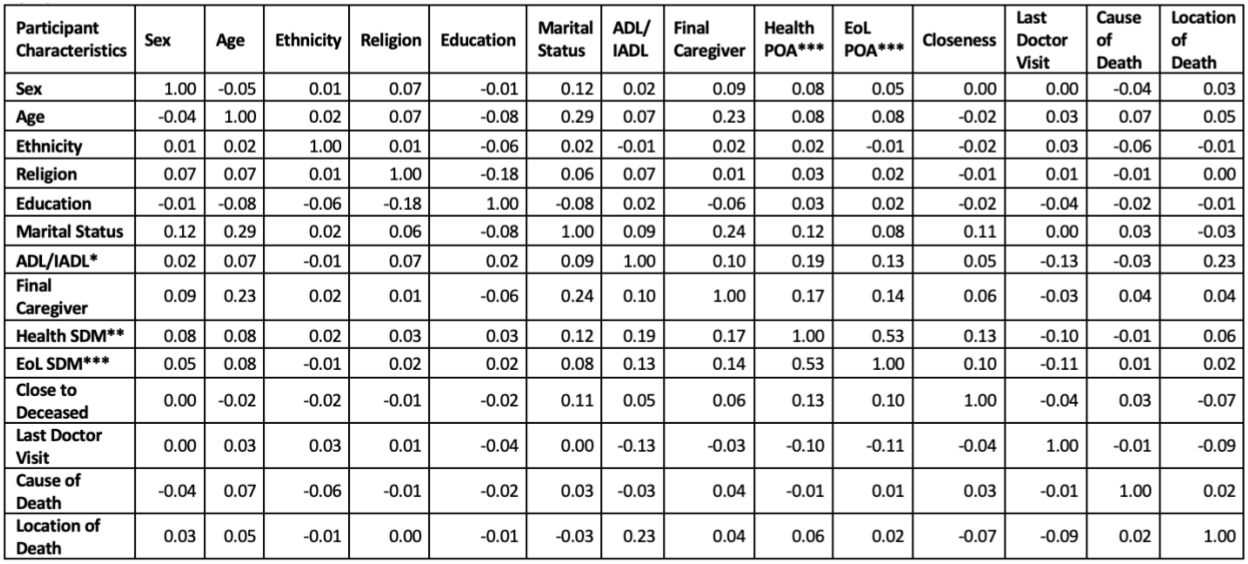
Appendix A: Characteristics of Deceased Canadian Longitudinal Study on Aging Participants with a Completed Decedent Interview (2012-2022) compared to Canadian Decedent Population (2012-2022)

Participant Characteristics	Variable	CLSA [n(%)]	Canada [n(%)]
Total Deceased		**1,287**	**2,936,807**
Sex	Male	798 (62.0)	1,481,701 (53.4)
	Female	489 (38.0)	1,291,489 (46.6)
Age at Death	45-64	116 (9.0)	470,365 (13.9)
	65-74	313 (24.3)	549,787 (18.7)
	75+	858 (66.7)	1,916,655 (67.4)
Marital Status	Single, never married or never lived with a partner	82 (6.4)	341,954 (12.1)
	Married/Living with a partner in a common-law relationship	807 (62.7)	1,150,610 (40.7)
	Widowed	261 (20.3)	1,045,606 (37.0)
	Divorced	115 (8.9)	135,015 (4.8)
	Separated	22 (1.7)	26,938 (1.0)
	Unknown	0 (0.0)	126,172 (4.4)
Location of death*	Hospital	631 (49.0)	1,831,105 (59.2)
	Non-Hospital	629 (48.9)	1,253,857 (40.5)
	Unknown	27 (2.1)	7,825 (0.3)
Cause of Death	Cancer	511 (39.7)	1,235,307 (42.1)
	Heart disease	33 (2.56)	644,241 (21.9)
	Respiratory disease**	51 (4.2)	110,572 (3.8)
	Dementia (e.g. Alzheimer's)	30 (2.5)	30,529 (1.0)
	Accident	32 (2.6)	103,978 (3.5)
	Influenza or pneumonia	43 (3.5)	60,762 (2.1)
	Suicide	8 (0.7)	21,292 (0.7)
	Kidney disease***	25 (2.1)	46,660 (1.6)
	Other	554 (43.0)	684,276 (23.3)

*Values reported for entire Canadian Population

**Respiratory diseases including emphysema, obstructive lung disease, asthma, chronic obstructive pulmonary disease
***Kidney Diseases such as nephritis, nephrotic syndrome, or nephrosis

Appendix B: Correlation Matrix for all Participant Characteristics and End-of-Life Characteristics, Canadian Longitudinal Study on Aging, 2012-2021



Participant Characteristics	Sex	Age	Ethnicity	Religion	Education	Marital Status	ADL/ IADL	Final Caregiver	Health POA***	EoL POA***	Closeness	Last Doctor Visit	Cause of Death	Location of Death
Sex	1.00	-0.05	0.01	0.07	-0.01	0.12	0.02	0.09	0.08	0.05	0.00	0.00	-0.04	0.03
Age	-0.04	1.00	0.02	0.07	-0.08	0.29	0.07	0.23	0.08	0.08	-0.02	0.03	0.07	0.05
Ethnicity	0.01	0.02	1.00	0.01	-0.06	0.02	-0.01	0.02	0.02	-0.01	-0.02	0.03	-0.06	-0.01
Religion	0.07	0.07	0.01	1.00	-0.18	0.06	0.07	0.01	0.03	0.02	-0.01	0.01	-0.01	0.00
Education	-0.01	-0.08	-0.06	-0.18	1.00	-0.08	0.02	-0.06	0.03	0.02	-0.02	-0.04	-0.02	-0.01
Marital Status	0.12	0.29	0.02	0.06	-0.08	1.00	0.09	0.24	0.12	0.08	0.11	0.00	0.03	-0.03
ADL/IADL*	0.02	0.07	-0.01	0.07	0.02	0.09	1.00	0.10	0.19	0.13	0.05	-0.13	-0.03	0.23
Final Caregiver	0.09	0.23	0.02	0.01	-0.06	0.24	0.10	1.00	0.17	0.14	0.06	-0.03	0.04	0.04
Health SDM**	0.08	0.08	0.02	0.03	0.03	0.12	0.19	0.17	1.00	0.53	0.13	-0.10	-0.01	0.06
EoL SDM***	0.05	0.08	-0.01	0.02	0.02	0.08	0.13	0.14	0.53	1.00	0.10	-0.11	0.01	0.02
Close to Deceased	0.00	-0.02	-0.02	-0.01	-0.02	0.11	0.05	0.06	0.13	0.10	1.00	-0.04	0.03	-0.07
Last Doctor Visit	0.00	0.03	0.03	0.01	-0.04	0.00	-0.13	-0.03	-0.10	-0.11	-0.04	1.00	-0.01	-0.09
Cause of Death	-0.04	0.07	-0.06	-0.01	-0.02	0.03	-0.03	0.04	-0.01	0.01	0.03	-0.01	1.00	0.02
Location of Death	0.03	0.05	-0.01	0.00	-0.01	-0.03	0.23	0.04	0.06	0.02	-0.07	-0.09	0.02	1.00

*ADL/IADL=Activities of Daily Living/ Instrumental Activities of Daily Living
**Health SDM=End-of-life Substitute Decision Maker
***EoL SDM=End-of-life Substitute Decision Maker

Appendix C: Variance Inflation Factor for all Participant Characteristics and End-of-Life Characteristics, Canadian Longitudinal Study on Aging, 2012-2021

Participant Characteristics	**VIF**	**Degrees of Freedom**
Sex	1.24	1
Age	1.28	2
Ethnicity	1.03	1
Religion	1.06	1
Education	1.13	3
Marital Status	2.36	2
ADL/IADL*	1.31	3
Final Caregiver	2.33	2
Healthcare Arrangements	1.49	1
End-of-Life Arrangements	1.42	1
Closeness	1.07	1
Last Doctor Visit	1.35	4
Cause of Death	1.41	3
Location of Death	1.59	3

*ADL/IADL=Activities of Daily Living/ Instrumental Activities of Daily Living

Appendix D: End-of-Life Characteristics for Males and Females With Completed Decedent Interviews, Canadian Longitudinal Study on Aging, 2012-2022

Variable Description	**Did Not Experience Peace with Dying**	**Did Not Experience Peace with Dying**
Primary cause of death	**Females n(%)**	**Males n(%)**
Cancer	154 (46.7)	220 (41.9)
Heart disease	70 (21.2)	128 (38.8)
RIDK*	25 (7.5)	60 (11.4)
Other	81 (24.5)	117 (22.3)
Location of Death		
Their own home	68 (20.6)	119 (22.7)
Other private home	7 (2.1)	1 (0.2)
Residence for seniors	9 (2.7)	3 (0.6)
Hospital	147 (44.5)	253 (48.2)
Hospice	25 (7.6)	35 (6.7)
Palliative care unit	41 (12.4)	64 (12.2)
Senior Home or LTC Facility**	28 (8.5)	40 (7.6)
Other (please specify)	5 (1.5)	10 (1.9)
Alternative Health Care Decision Maker		
Yes	288 (87.3)	431 (82.1)
No	42 (12.7)	94 (17.9)
Alternative End-of-Life Care Decision Maker		
Yes	272 (82.4)	403 (76.8)
No	58 (17.6)	122 (23.2)

*RIDK=R=Respiratory diseases including emphysema, obstructive lung disease, asthma, chronic obstructive pulmonary disease; I=Influenza or pneumonia; D=Dementia; K=Kidney Diseases such as nephritis, nephrotic syndrome, or nephrosis

**LTC=Long-term Care

Appendix E: Subgroup Analysis of Canadian Longitudinal Study on Aging Deceased Participants with a Completed Decedent Interview Based on Cause of Death, 2012-2022

Variable Category	Variable Characteristic	Cancer	Non-Caner
		Unadjusted OR(95%CI)	**Unadjusted OR(95%CI)**
Sex	Female	Reference	Reference
	Male	0.76 (0.49-1.12)	1.34 (0.94-1.9)
Age	45-64	Reference	Reference
	65-74	1.32 (0.77-2.24)	1.01 (0.61-1.66)
	75+	1.53 (0.91-2.53)	1.21 (0.75-1.94)
Ethnicity	Non-White	Reference	Reference
	White	2.77 (0.51-15.12)	1.17 (0.41-3.18)
Religion	No Religious Beliefs	Reference	Reference
	Holds Religious Beliefs	1.24 (0.76-1.99)	1.35 (0.9-2.02)
Education	Less than High School	Reference	Reference
	High School	1.60 (0.67-3.92)	0.8 (0.45-1.44)
	Other post-secondary education	1.00 (0.51-1.90)	0.81 (0.5-1.3)
	University degree or above	1.04 (0.53-1.99)	0.72 (0.44-1.17)
Marital	Married	Reference	Reference
	Single/Divorced	0.54 (0.33-0.89)	1.04 (0.62-1.75)
	Widowed	1.77 (0.98-3.42)	1.58 (0.96-2.61)
ADL & IADL*	No/Mild Impairment	Reference	Reference
	Moderate impairment	0.80 (0.43-1.51)	2.00 (1.16-3.55)
	Severe/Total Impairment	0.65 (0.40-1.06)	1.45 (1.00-2.11)
Caregiver	Child	Reference	Reference
	Other	0.85 (0.48-1.49)	1.16 (0.76-1.8)
	Spouse	0.98 (0.59-1.59)	0.97 (0.6-1.55)
Health Decision Making SDM**	Absent	Reference	Reference
	Present	**2.38 (1.47-3.82)**	0.72 (0.44-1.16)
EoL Decision Making SDM**	Absent	Reference	Reference
	Present	**2.02 (1.30-3.12)**	1.77 (1.16-2.71)
Closeness	Not Close to Deceased	Reference	Reference
	Close to Deceased	1.06 (0.51-2.08)	1.58 (0.91-2.72)
Last physician visit	Did Not See Doctor Before Passing	Reference	Reference
	1-2 weeks	1.63 (0.86-3.33)	1.02 (0.64-1.65)

	3-6 Weeks	0.74 (0.36-1.50)	1.05 (0.63-1.77)
	7-51 Weeks	1.00 (0.48-2.24)	0.64 (0.39-1.05)
	52+ Weeks	0.77 (0.38-1.65)	0.97 (0.58-1.64)
Location of Death	Hospital	Reference	Reference
	Home	**1.19 (1.04-4.02)**	1.06 (0.72-1.58)
	Hospice or Palliative Care	1.42 (0.91-2.23)	1.33 (0.68-2.69)
	Senior/LTC[1]/Other	0.89 (0.38-2.17)	1.31 (0.81-2.14)

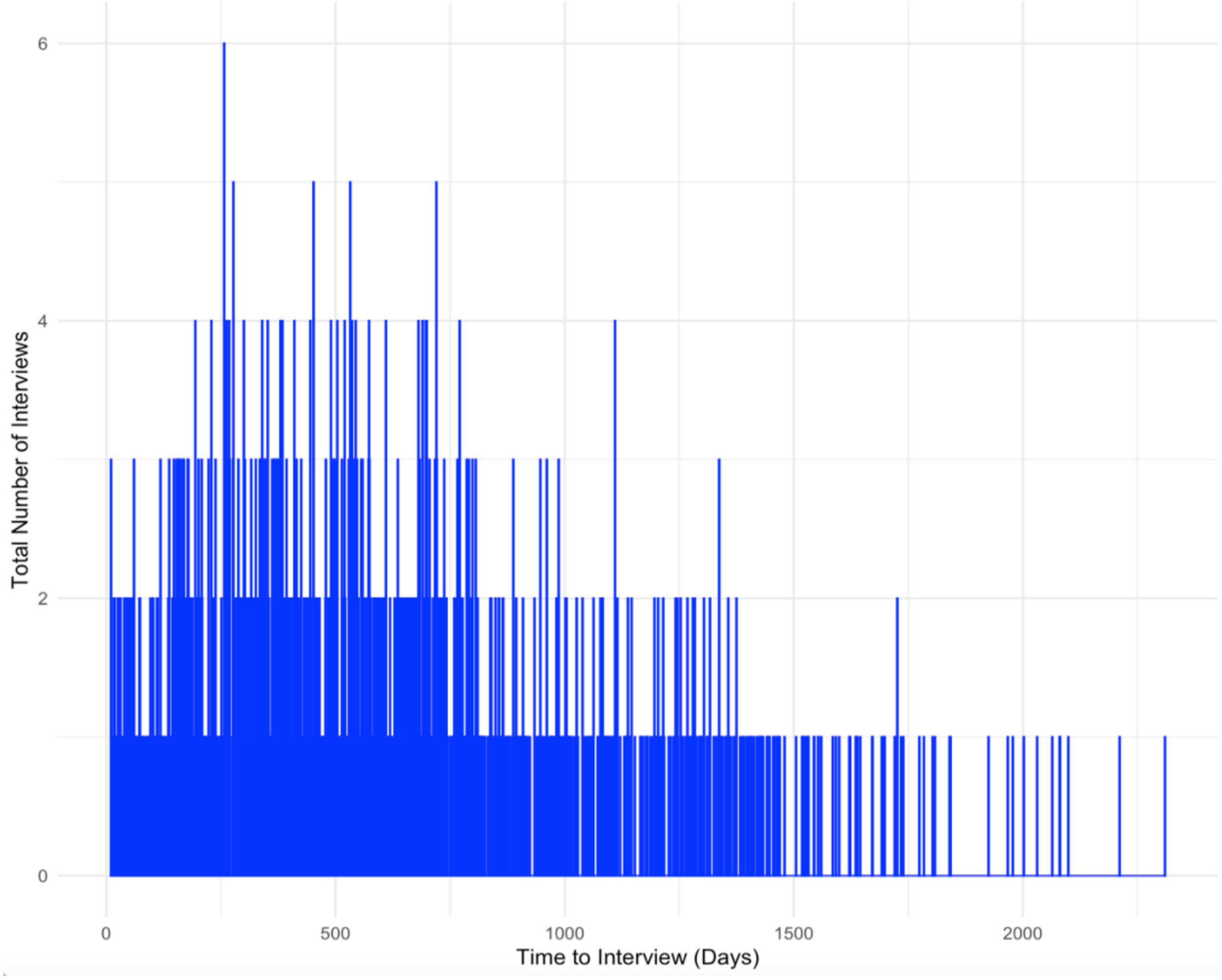
*ADL/IADL=Activities of Daily Living/ Instrumental Activities of Daily Living

** SDM=Substitute Decision Maker

***RIDK=R=Respiratory diseases including emphysema, obstructive lung disease, asthma, chronic obstructive pulmonary disease; I=Influenza or pneumonia; D=Dementia; K=Kidney Diseases such as nephritis, nephrotic syndrome, or nephrosis

[1] LTC=Long-term Care

Appendix F: Histogram of Time to Interview After Participant Death, Canadian Longitudinal Study on Aging, 2012-2022



Appendix G: Sensitivity Analysis of Peace with Dying for Participants with Completed Decedent Interview within One Year of Death Compared to More than One Year After Death, Canadian Longitudinal Study on Aging, 2012-2022

Variable Category	Variable Characteristic	Decedent Interview Completed within One Year of Death (n=395)	Decedent Interview Completed within More than One Year of Death (n=893)
		Unadjusted OR(95%CI)	**Unadjusted OR(95%CI)**
Sex	Female	Reference	Reference
	Male	1.63 (1.06-2.49)	0.72 (0.54-0.97)
Age	45-64	Reference	Reference
	65-74	1.21 (0.65-2.26)	1.13 (0.74-1.73)
	75+	1.49 (0.84-2.64)	1.31 (0.89-1.94)
Ethnicity	Non-White	Reference	Reference
	White	0.43 (0.05-3.91)	1.91 (0.77-4.74)
Religion	No Religious Beliefs	Reference	Reference
	Holds Religious Beliefs	1.92 (1.13-3.24)	1.07 (0.74-1.53)
Education	Less than High School	Reference	Reference
	High School	0.85 (0.36-2.00)	1.06 (0.60-1.86)
	Other post-secondary education	0.88 (0.44-1.75)	0.87 (0.56-1.37)
	University degree or above	1.00 (0.50-2.01)	0.75 (0.48-1.18)
Marital	Married	Reference	Reference
	Single/Divorced	0.62 (0.36-1.08)	0.78 (0.54-1.13)
	Widowed	1.12 (0.64-1.94)	1.73 (1.18-2.55)
ADL & IADL*	No/Mild Impairment	Reference	Reference
	Moderate impairment	1.70 (0.88- 3.30)	1.72 (1.06-2.79)
	Severe/Total Impairment	1.42 (0.91-2.21)	1.33 (0.97-1.83)
Caregiver	Child	Reference	Reference
	Other	1.00 (0.57-1.77)	0.84 (0.57-1.23)
	Spouse	1.14 (0.69-1.88)	0.82 (0.58-1.15)
Health Decision Making SDM**	Absent	Reference	Reference
	Present	1.69 (0.95-3.01)	1.65 (1.18-2.31)
	Absent	Reference	Reference

EoL Decision Making SDM**	Present	1.62 (0.98- 2.67)	1.91 (1.41-2.60)
Closeness	Not Close to Deceased	Reference	Reference
	Close to Deceased	1.73 (0.84-3.53)	1.27 (0.78-2.07)
Last physician visit	Did Not See Doctor Before Passing	Reference	Reference
	1-2 weeks	1.13 (0.62-2.03)	1.06 (0.67-1.67)
	3-6 Weeks	0.85 (0.44-1.63)	0.87 (0.54-1.40)
	7-51 Weeks	0.82 (0.41-1.63)	0.56 (0.36- 0.89)
	52+ Weeks	0.42 (0.19-0.94)	0.90 (0.57-1.42)
Cause of death	Heart Disease	Reference	Reference
	Cancer	1.03 (0.58-1.81)	1.22 (0.82-1.82)
	Other	1.48 (0.87-2.51)	1.80 (1.26-2.59)
	RIDK***	0.88 (0.44-1.77)	0.81 (0.50-1.31)
Location of Death	Hospital	Reference	Reference
	Home	1.15 (0.68-1.93)	1.17 (0.82-1.66)
	Hospice/Palliative Care	1.88 (0.98-3.61)	1.57 (1.05-2.35)
	Senior/LTC[1]/Other	1.19 (0.61- 2.33)	1.16 (0.72-1.86)

*ADL/IADL=Activities of Daily Living/ Instrumental Activities of Daily Living

** SDM=Substitute Decision Maker

***RIDK=R=Respiratory diseases including emphysema, obstructive lung disease, asthma, chronic obstructive pulmonary disease; I=Influenza or pneumonia; D=Dementia; K=Kidney Diseases such as nephritis, nephrotic syndrome, or nephrosis

[1] LTC=Long-term Care

Appendix H: Sensitivity Analysis of Peace with Dying for Participants with Different Decedent Respondents, Canadian Longitudinal Study on Aging, 2012-2022

Variable Category	Variable Characteristic	Spouse (n=542)	Child (n=434)	Other (n=311)
		Unadjusted OR(95%CI)	**Unadjusted OR(95%CI)**	**Unadjusted OR(95%CI)**
Sex	Female	Reference	Reference	Reference
	Male	0.86 (0.52-1.41)	1.25 (0.87-1.81)	1.25 (0.71-2.24)
Age	45-64	Reference	Reference	Reference
	65-74	1.42 (0.85-2.37)	0.94 (0.52-1.7)	0.93 (0.43-1.96)
	75+	1.18 (0.71-1.95)	1.36 (0.76-2.44)	1.53 (0.73-3.19)
Ethnicity	Non-White	Reference	Reference	Reference
	White	1.01 (0.23-3.99)	1.07 (0.3-3.53)	3.12 (0.45-26.18)
Religion	No Religious Beliefs	Reference	Reference	Reference
	Holds Religious Beliefs	1.12 (0.7-1.78)	1.28 (0.78-2.08)	1.84 (0.84-3.99)
Education	Less than High School	Reference	Reference	Reference
	High School	0.81 (0.36-1.83)	1.22 (0.64-2.34)	1.12 (0.35-3.61)
	Other post-secondary education	0.56 (0.28-1.06)	1.14 (0.68-1.9)	0.81 (0.33-1.89)
	University degree or above	0.61 (0.31-1.16)	0.97 (0.56-1.65)	1 (0.39-2.44)
Marital	Married	Reference	Reference	Reference
	Single/Divorced	1.06 (0.22-5.87)	0.63 (0.39-1.04)	0.88 (0.4-1.88)
	Widowed	1.19 (0.2-9.7)	1.38 (0.86-2.22)	1.45 (0.61-3.43)
ADL & IADL*	No/Mild Impairment	Reference	Reference	Reference
	Moderate impairment	1.32 (0.73-2.45)	1.25 (0.71-2.26)	0.57 (0.30-1.08)
	Severe/Total Impairment	1.46 (0.95-2.25)	0.79 (0.53-1.18)	0.91 (0.28-3.33)
Caregiver	Child	Reference	Reference	Reference
	Other	1.81 (0.33-9.0)	1.16 (0.77-1.76)	0.7 (0.25-1.79)
	Spouse	1.24 (0.2-6.99)	0.89 (0.5-1.59)	0.56 (0.14-2.07)
Health Decision Making SDM**	Absent	Reference	Reference	Reference
	Present	1.25 (0.72-2.14)	0.97 (0.56-1.65)	1.08 (0.51-2.29)

EoL Decision Making SDM**	Absent	Reference	Reference	Reference
	Present	1.35 (0.81-2.25)	2.03 (1.3-3.16)	1.51 (0.76-2.99)
Closeness	Not Close to Deceased	Reference	Reference	Reference
	Close to Deceased	2.35 (0.85-6.64)	1.05 (0.61-1.76)	0.75 (0.34-1.61)
Last physician visit	Did Not See Doctor Before Passing	Reference	Reference	Reference
	1-2 weeks	0.89 (0.5-1.64)	1.21 (0.71-2.1)	1.49 (0.62-3.93)
	3-6 Weeks	0.59 (0.31-1.12)	1.19 (0.65-2.24)	0.82 (0.33-2.14)
	7-51 Weeks	0.58 (0.31-1.09)	0.75 (0.41-1.38)	0.46 (0.18-1.15)
	52+ Weeks	0.81 (0.39-1.7)	0.99 (0.56-1.77)	0.35 (0.15-0.82)
Cause of death	Heart Disease	Reference	Reference	Reference
	Cancer	0.87 (0.50-1.50)	1.47 (0.91-2.4)	0.77 (0.35-1.63)
	Other	1.47 (0.86-2.49)	2.01 (1.26-3.24)	0.83 (0.32-2.16)
	RIDK***	0.58 (0.28-1.21)	0.81 (0.46-1.43)	1.02 (0.46-2.29)
Location of Death	Hospital	Reference	Reference	Reference
	Home	1.27 (0.78-2.09)	1.34 (0.83-2.18)	1.17 (0.56-2.51)
	Hospice/Pall	1.48 (0.84-2.67)	1.11 (0.65-1.9)	1.83 (0.81-4.29)
	Senior/LTC[1]/Other	1.18 (0.58-2.43)	1.56 (0.85-2.93)	1.74 (0.72-4.54)

*ADL/IADL=Activities of Daily Living/ Instrumental Activities of Daily Living

** SDM=Substitute Decision Maker

***RIDK=R=Respiratory diseases including emphysema, obstructive lung disease, asthma, chronic obstructive pulmonary disease; I=Influenza or pneumonia; D=Dementia; K=Kidney Diseases such as nephritis, nephrotic syndrome, or nephrosis

[1] LTC=Long-term Care

Appendix I: Unadjusted Odds of Experiencing Peace with Dying, Canadian Longitudinal Study on Aging Decedents, 2017-2022

	Variable Category	n(%)	Experienced Peace with Dying (n=855)		Did Not Experience Peace with Dying (n=213)	
			Unadjusted OR	95% CI	Unadjusted OR	95% CI
Sex	Female	798 (62.0%)	**Reference**			
	Male	489 (38.0%)	0.93	0.73- 1.18	0.91	0.67-1.23
Age	45-64	116 (9.0%)	**Reference**			
	65-74	313 (24.3%)	1.27	0.82-1.96	0.84	0.50-1.46
	75+	858 (66.7%)	1.55	1.04-2.30	0.69	0.43-1.14
Ethnicity	Non-White	24 (1.8%)	**Reference**			
	White	1,263 (98.2%)	1.42	0.61-3.21	0.47	0.20-1.23
Religion	Not Religious	227 (17.6%)	**Reference**			
	Religious	1060 (82.4%)	1.29	0.95-1.73	0.98	0.68-1.46
Education	Less than High School	170 (13.2 %)	**Reference**			
	High School	158 (12.3%)	0.98	0.61-1.57	1.04	0.57-1.90
	Other post-secondary education	507 (39.3%)	0.86	0.59-1.24	0.99	0.62-1.63
	University degree or above	452 (35.1%)	0.81	0.55-1.18	1.28	0.80-2.12
Marital Status	Married	807 (62.7%)	**Reference**			
	Single / Divorced / Separated	219 (17.0%)	0.73	0.54-0.99	1.79	1.24-2.55
	Widow	261 (20.3%)	1.53	1.12-2.10	0.82	0.54-1.22
ADL & IADL*	No/Mild Impairment	464 (36.5%)	**Reference**			
	Moderate impairment	167 (13.0%)	1.66	1.13-2.48	0.98	0.60-1.56
	Severe/Total Impairment	527 (40.9%)	1.32	1.01-1.71	0.91	0.65-1.27
Caregiver	Child	362 (28.1%)	**Reference**			
	Other	336 (26.1%)	1.13	0.77-1.67	0.88	0.60-1.30
	Spouse	589 (45.8%)	1.32	1.01-1.86	0.76	0.54-1.08
Health Decision-Making POA**	Absent	238 (18.5%)	**Reference**			
	Present	1049 (81.5%)	1.63	1.22-2.18	0.76	0.54-1.10

End-of-Life Decision-Making POA**	Absent	320 (24.9%)	**Reference**			
	Present	967 (75.1%)	1.80	1.39-2.33	0.62	0.45-0.86
Closeness	Not Close to Deceased	109 (8.5%)	**Reference**			
	Close to Deceased	1178 (91.5%)	1.38	0.92-2.05	0.57	0.36-0.92
Last physician visit	Did Not See Doctor Before Passing	715 (55.6%)	**Reference**			
	1-2 weeks	176 (13.7%)	1.08	0.76-1.55	0.91	0.57-1.41
	3-6 Weeks	136 (10.6%)	0.85	0.58-1.26	0.83	0.48-1.36
	7-51 Weeks	133 (10.3%)	**0.64**	**0.44-0.94**	1.06	0.64-1.69
	52+ Weeks	127 (9.9%)	0.77	0.52-1.14	0.79	0.45-1.32
Cause of death	Heart Disease	322 (25.0%)	**Reference**			
	Cancer	511 (39.7%)	1.71	1.27-2.30	0.83	0.56-1.22
	Other	305 (23.7%)	1.16	0.84-1.61	1.00	0.65-1.52
	RIDK**	149 (11.6%)	0.83	0.56-1.24	1.52	0.94-2.45
Location of Death	Hospital	631 (49.0%)	**Reference**			
	Home	292 (22.7%)	1.16	0.87-1.56	0.71	0.48-1.03
	Hospice/Palliative Care	222 (17.2%)	1.67	1.19-2.37	0.65	0.41-0.98
	Senior Home/LTC^1/Other	142 (11.0%)	1.17	0.80-1.73	0.56	0.32-0.94

*ADL/IADL=Activities of Daily Living/ Instrumental Activities of Daily Living

**POA=Power of Attorney

***RIDK=R=Respiratory diseases including emphysema, obstructive lung disease, asthma, chronic obstructive pulmonary disease; I=Influenza or pneumonia; D=Dementia; K=Kidney Diseases such as nephritis, nephrotic syndrome, or nephrosis

[1] LTC=Long-term Care

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CHAPTER 3

Home, Palliative Care Units or Hospice, and Hospital Deaths: An Analysis of the Canadian Longitudinal Study on Aging

Summary

This chapter assesses how different settings—home, hospital, and hospice or palliative care units (PCU)— are associated with the quality of death. Most Canadians are still dying in hospitals and reporting poor quality of deaths, despite their desire to die at home. Home deaths are often reported to have the highest quality of death experiences for older adults. Palliative care units and hospices, aim to create home-like environments for end-of-life, but the quality of death experiences in palliative care units or hospices, compared to home and hospitals, is unknown.

In this secondary analysis of deceased Canadian Longitudinal Study on Aging participants, we identified the quality of death (dying with dignity, dying without pain, dying with peace, and dying in ones preferred location) at the different locations. These findings show that there may be a compromise in location of death and quality of death based on whether one dies in hospice or home. Regional health and social policies may influence where older individuals die with palliative care being accessed or readily available in Quebec. These findings can inform policies that determine how to balance both end-of-life care settings and the overall comfort and dignity of patients.

Citation

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Abstract

Background: The location of death often plays a pivotal role in the quality of end-of-life experiences.

Aim: We aimed to assess how different settings—home, hospital, and hospice or palliative care units (PCU)— are associated with the quality of death.

Design: We conducted a secondary analysis of decedent interview data from the Canadian Longitudinal Study on Aging, between January 2012 to March 2022.

Setting/Participants: Proxies of deceased participants provided information on end-of-life experiences. We examined quality of death indicators across various locations and analyzed associations between end-of-life characteristics and the location of death.

Results: Among the 1,287 older adults with completed decedent questionnaires, 17.2% (n=222) of deceased participants died in hospice or PCU, 49% (n=631) died in hospital and 22.7% (n=292) died at home. Those who died at home died in their preferred place more frequently (89.4; standard difference (SD): 0.65), while individuals who died in PCU or hospice reported significantly lower levels of pain (81.5%; SD: 0.31). Dying in the Canadian province of Quebec (OR 3.77; CI 2.28-6.37), dying of cancer (OR 6.79; CI 4.10-11.9), and having total physical impairment (OR 2.08; CI 1.41-3.08) increased the odds of dying in PCU or hospice.

Conclusions: Dying in PCU or hospice may allow older adults to die peacefully and have their pain under control, though dying at home aligns more closely with individual preferences, suggesting a potential compromise between quality and location of death. Regional health and social policies may influence where older individuals die.

Background:

As adults approach the end-of-life, the location of their death plays a crucial role in end-of-life experiences and overall quality of death. Approximately 70% of Canadians express a desire to die at home yet only 15% achieve this outcome.[37, 38] The majority of Canadians still die in hospitals, which is associated with poorer symptom control and satisfaction.[37, 39] A home death is not always feasible or desired by patients and family members; but when it is, home-based palliative care services can help achieve this goal.[40] For people whose support needs exceed the capacity of the home-based palliative services, palliative care units and hospices can provide hospital-level monitoring and support while maintaining a focus on comfort.[41]

Previous studies show that dying at home enhances the overall quality of the dying experience, even with limited access to palliative care services.[37] Older adults dying in hospitals report higher levels of pain and dissatisfaction with their care compared to those who died at home or in palliative care settings.[42] The quality of dying for older adults in Canada varies significantly depending on the setting. Although death is an inevitable part of life, little is known about the quality of dying based on location of death.

The Canadian Longitudinal Study on Aging is a longitudinal population-based research platform that has been used to study a variety of health phenomena among Canadians as they age and approach end-of-life. For decedents, the Canadian Longitudinal Study on Aging includes next of kin reported measures of the quality of death and dying and location of death. We analyzed data from the Canadian Longitudinal Study on Aging to assess the quality of death, including dying with peace, dying with dignity, dying in ones preferred location, and dying without pain across different settings, including home, hospital, and hospice or palliative care units (PCU). Additionally, we identified the sociodemographic factors associated with dying in these locations.

Methods:

Study Design and Data Source

We conducted a secondary analysis of decedent interview data from the Canadian Longitudinal Study on Aging. The Canadian Longitudinal Study on Aging is a prospective cohort study with a national, stratified sample of 51,338 community-dwelling adults aged 45–85 years at baseline who are followed every 3 years. Previous reports have described its design and methodology.[18, 43] To summarize, the Canadian Longitudinal Study on Aging is comprised of the Tracking cohort, which includes participants randomly selected from all 10 Canadian provinces, and the Comprehensive cohort, which includes participants randomly selected from within a 25–50 km radius of one of 11 data collection sites located in British Columbia, Alberta, Manitoba, Ontario, Quebec, Nova Scotia, and Newfoundland. Both cohorts collect similar data, while the Comprehensive participants also undergoing more detailed physical assessments. The majority of participant demographic and social characteristics at baseline are comparable to the 2011 Canadian census.[17] We use the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) reporting guideline.[44]

Decedent Questionnaire

Next of kin or primary contact (most often identified by the Canadian Longitudinal Study on Aging participant at baseline) were contacted by mail once the Canadian Longitudinal Study on Aging received the confirmation of death from a family member, friend, or through provincial death records. Next of kin or primary contacts were then contacted via telephone two weeks after mailing to invite participation in a decedent interview. Decedent questionnaires (available online)[45] were completed for participants who died between January 2012 to March 2022 by telephone interview (French or English) with a trained Canadian Longitudinal Study on Aging decedent interviewer. Interviews were completed an average of 2 years after death (between 10 days to 6.3 years), depending on respondent availability and release of the participant's deceased status.

Participants

Canadian Longitudinal Study on Aging participants who died between January 6, 2012, to March 15, 2022, and for whom we had a completed decedent interview were included in the analyses.

Location of Death

Respondents were asked where the deceased participant passed away. There were nine possible response options with home, palliative care unit (located within a hospital) or hospice (located outside of a hospital), and hospital being assessed in this study. We excluded older adults who died in senior homes, long-term care facilities, other dwellings or institution, next of kin responses who did not know the location of death or refused to answer the question.

Quality of Death Characteristics

Respondents were asked whether they believed the deceased participant experienced peace with dying, died in their preferred place, died with dignity, and died without pain during the last week of their life. There were six possible response options: 1) yes, 2) somewhat, 3) no, 4) this question is not applicable, 5) they don't know, and 6) refused to answer the question. We used 1) yes, for the analysis of all four quality of death characteristics (**Appendix A**).

Statistical Analysis

We compared the participant sociodemographic characteristics between those who died in each setting, including sex, age, cause of death, activities of daily living (ADL) and instrumental activities of daily living (IADL) impairment in the last month of life, any physician visit weeks before dying, arrangements for health care decision-making, and arrangements for end-of-life care decision-making. We generated descriptive summaries and calculated standardised differences in quality of death and dying indicators across the settings; with a standardized difference of less than 0.1 indicating trivial differences, 0.2 indicating small differences, 0.5 indicating moderate differences, and 0.8 indicating large differences. We used Pearson's chi-square to test for differences in the quality of death and dying indicators across these groups.

We used a correlation matrix and computed the variance inflation factor to examine multicollinearity among end-of-life and participant characteristics. We performed adjusted logistic regression to estimate associations with location of death. We reported the area under the receiver operating curve to assess model discrimination. We performed a subgroup analysis by removing those dying from medical assistance in dying to examine differences in the associations with quality of death and dying.

Ethics Approval

This secondary analysis was approved by the Hamilton Integrated Research Ethics Board (2023-16023-C).

Results:

There were 3,672 Canadian Longitudinal Study on Aging participants who died between 2012-2022, and 1,287 (35.0%) had a completed decedent questionnaire. Canadian Longitudinal Study on Aging decedents with a completed decedent questionnaire were on average 73.6 year of age at death, 62.7% were married or in a common-law relationship, 39.7% died of cancer, and 49.0% died in hospital. Deceased Canadian Longitudinal Study on Aging participants with a completed decedent interview were more likely to be male, older, married, and identify a religious affiliation compared to those without a decedent interview (**Table 1 & Appendix B**).

Approximately, 17.2% (n=222) of deceased Canadian Longitudinal Study on Aging participants died in hospice or PCU, 49% (n=631) died in hospital and 22.7% (n=292) died at home (**Table 2**). Older adults dying at home were more likely to be from Ontario, die of cardiovascular diseases, and have little to no physical impairment. Those dying in PCU, or hospice were more likely to be from Quebec, die of cancer, be physically dependent for activities of daily living, and see a doctor in the last week of life. Older adults dying in hospital were older and more likely to have a recent hospitalization and a physician visit 1-2 weeks prior to death. There were 16 (1.2%) decedents who died in residences for seniors, 139 (10.8%) who died in nursing home, and 99 (7.7%) who died in other locations and were excluded from the cohort.

A large majority of individuals dying at home or in a PCU/hospice were at peace with dying, able to die in their preferred location, able to die with dignity and able to die without pain (**Table 3**). Those dying in PCU or hospice experienced more peace with dying compared to those dying in home or hospital (74.3% vs. 66.8% vs. 63.4%, respectively); the difference was small in both cases (SD: 0.16 and 0.24, respectively). Those dying at home reported dying in their preferred location more frequently than those dying in PCU/hospice or hospital (89.4% vs. 61.3 vs. 47.7%); the difference was moderate (SD: 0.65) and large (0.9), respectively. Those dying at home reported dying with dignity more frequently than those dying in hospice/PCU or hospital (90.4% vs. 82% vs. 84.3%, respectively; the difference was small in both cases (SD: 0.24 and 0.18, respectively). Individuals dying in PCU/hospice reported dying without pain more frequently than those dying at home or in hospital (81.5% vs. 67.5 and 64.8%, respectively); the differences were moderate in both cases (SD: 0.31 and 0.38, respectively).

Table 4 shows the adjusted logistic regression odds ratios (OR), and confidence intervals (CI) for demographic and end-of-life characteristics and their association with dying at home, in hospice or PCU, and dying in hospital. Dying in Quebec, British Colombia, or the Western provinces (OR 3.77; CI 2.28-6.37; OR 2.00; CI 1.10-3.64; OR 2.04; CI 1.17-3.62, respectively), dying of cancer (OR 6.79; CI 4.10-11.9), and having total physical impairment (OR 2.08; CI 1.41-3.08) increased odds of dying in PCU or hospice compared to hospital deaths. Being hospitalized one or more times (OR 3.15; CI 2.25-4.41), dying of RIDK (OR 1.96; CI 1.25-3.09) or other causes (OR 1.78; CI 1.25-2.54), and seeing a physician the same week of death (OR 3.12; CI 1.99-4.95), increased the odds of dying in hospital and decreased the odds of dying at home. In all these instances there is a lower odds of dying at home. The areas under the receiver operating curves, ranging from 0.58-0.81, are displayed in **Appendix C**.

Sensitivity Analysis

There were 60 (5.2%) MAiD deaths in the cohort with 13 (21.7%) occurring in PCU or hospice, 26 (43.3%) in hospital, and 21 (35.0%) at home. Due to insufficient sample size, a subgroup analysis of MAiD deaths could not be completed. We performed logistic regression analysis with and without MAiD deaths and there was no difference between the two analyses (**Appendix D**).

Discussion

In this secondary analysis of deceased Canadian Longitudinal Study on Aging participants, we found that approximately 50% of older adults die in hospital, 17% die in hospice or PCU, and 23% die at home. Older adults at the Canadian Longitudinal Study on Aging report a moderate quality of death and dying in all three locations with older adults dying in PCU or hospice experiencing more peace with dying compared to those dying in home or hospital. Older adults dying at home reported dying in their preferred location more frequently than those dying in PCU/hospice or hospital. Individuals dying at home reported dying with dignity more frequently than those dying in hospice/PCU or hospital, and those individuals dying in PCU/hospice reported dying without pain more frequently than those dying at home or in hospital. Quality of death was poorest for older adults who died in hospital. Older adults who died at home were more likely to die in their preferred place and die with dignity. However, older adults dying in hospice were more likely to experience peace with dying and dying without pain. Older adults dying from cancer or dying in Quebec were more likely to die in PCU or hospice than in hospital or home. Those dying at home were more likely to experience no physical impairment and were less likely to use health services compared to those dying in hospital or hospice or PCU.

This is, as far as we know, the first published study of quality of death indicators in a prospectively-defined cohort of individuals based on location of death. We found that while many individuals who die at home achieved a dignified death in their preferred location, those who die in palliative care units (PCUs) or hospices experienced greater peace and are more likely to die without pain. This suggests that there may be a compromise between dying in a familiar environment versus dying in PCU which is associated with more effective symptom control at the end-of-life. Older adults were more likely to die in their preferred place when at home, suggesting that home deaths may offer more autonomy or personal comfort for this group, but it may not be the best place of death for all older adults if adequate supports are not provided.[46, 47] The lower rates of pain-free death at home or in hospitals compared to hospices emphasize the importance of hospice care in managing physical discomfort at the end-of-life.[48, 49] These findings suggest that hospice or PCU care services provide effective overall quality of death experiences when people have greater dependency or if they are more focused on pain control.[39] End-of-life experiences are clearly complex, where location of death, available supports, and personal preferences all interact.

Older adults using health services prior to death such as acute care hospitalization or having a physician visit were more likely to die in hospital. These factors may indicate higher medical complexity and the need for acute care interventions, which reduces the feasibility of dying in a home setting (whether desired or not).[50] Our findings also indicate that individuals residing in Quebec, British Columbia, or the western provinces had higher odds of dying in palliative care units or hospices compared with Ontario. This suggests that these regions may offer greater access to, or utilization of, specialized end-of-life care facilities compared to Ontario,[51] or conversely, that Ontario has greater availability of home palliative care services, making a home death more likely. Previous studies have shown that palliative care and end-of-life policies and service availability may influence where people die.[52]

Limitations

Limitations of our study include the absence of data on certain factors not covered in the Canadian Longitudinal Study on Aging decedent interviews, such as types of end-of-life interventions used or caregiver burden to address overall quality of death and dying. For example, for patients who died at home or in hospital, we did not have data on the involvement of palliative care teams.

We also do not know whether regions with higher frequencies of death in PCU/hospice (e.g. Quebec) simply had a population with a preference for hospice, or if they had better hospice quality and availability than elsewhere, or whether they had poorer alternatives options (e.g. home palliative care services) compared to other provinces. The data on location of preference, dignity and symptom control suggest that preference was a factor, but these unaccounted variables would have allowed a more comprehensive understanding of quality of death based on location. As the first prospective, longitudinal assessment of quality and location of death, and with the Canadian Longitudinal Study on Aging still collecting data, our aim was to comprehend the initial findings.

Another limitation of our study is the lack of demographic diversity, as over 90% of our cohort belongs to a single ethnic group and we had only decedent interviews from 35.0% of the total decedent population. This homogeneity may have influenced the higher number of individuals reporting better quality of death experiences. Despite this, our data remains the most comprehensive available for comparing location and quality of death.

Our study is susceptible to potential biases associated with the time elapsed after an individual's passing and the family members' reporting and or the completion of the decedent interview. It is conceivable that over time, the recollection of events may be influenced by various factors, potentially leading to a bias favoring positive or negative end-of-life experiences based on grief symptoms.[53] While this might bias the responses, this is unlikely to bias the comparison between location and quality of death.

Conclusion

Our findings demonstrate that dying in palliative care units or hospices may provide more effective pain management, and a peaceful passing compared to hospital or home deaths. However, many individuals who die at home die with dignity and in their preferred place, highlighting the compromise between home deaths compared to hospice or PCU deaths. The regional differences, particularly in Quebec compared to Ontario, suggesting that certain regions may offer greater access to, or utilization of, specialized end-of-life care alternatives or greater availability of generalized palliative care in the community, compared to Ontario. These results highlight the need for higher quality end-of-life care across the country and a balanced approach to honoring patient preferences while ensuring comfort at the end-of-life.

Tables and Figures

Table 1: Characteristics of Deceased Canadian Longitudinal Study on Aging Participants with Complete Decedent Interview Compared to Participants with an Incomplete Decedent Interviews, 2012-2022

Variable Category	Variable Characteristic	Decedent Interviews Complete (n=1,287)	Decedent Interviews Incomplete (n=2,385)
Sex	Female	489 (38.0%)	974 (59.2%)
	Male	798 (62.0%)	1,411 (40.8%)
Age	45-64	428 (33.3%)	1,141 (47.9%)
	75+	858 (66.7%)	1277 (64.6%)
Residence	Ontario	274 (21.3%)	532 (22.3%)
	Quebec	302 (23.5%)	315 (13.2%)
	British Colombia	194 (15.1%)	361 (15.1%)
	Western*	234 (18.2%)	592 (24.8%)
	Atlantic**	283 (22.0%)	585 (24.5%)
Ethnicity	Non-White	24 (1.8%)	72 (3.0%)
	White	1,263 (98.2%)	2,313 (97.0%)
Religion	Roman Catholic	455 (34.4%)	397 (16.6%)
	United Church	157 (12.2%)	696 (29.2%)
	Anglican	136 (10.7%)	289 (12.1%)
	Other	312 (24.2%)	283 (11.9%)
	No Religion	227 (17.6%)	720 (30.2%)
Education	Less than High School	170 (13.2 %)	357 (15.0%)
	High School	158 (12.3%)	355 (14.9%)
	Other post-secondary education	507 (39.4%)	1,008 (42.3%)
	University degree or above	452 (35.1%)	665 (27.8%)
Marital Status	Single, Divorced or Separated	219 (17.0%)	535 (22.4%)
	Married	807 (62.7%)	1275 (53.5%)

Widowed	261 (20.3%)	575 (24.1%)

*** Western Provinces =** Alberta, Manitoba, Saskatchewan
****Atlantic Provinces =** New Brunswick, Newfoundland and Labrador, Nova Scotia, Prince Edward Island

Table 2: Characteristics of Deceased Canadian Longitudinal Study on Aging Participants who Died at Home or in a Hospice or Palliative Care Unit with Complete Decedent Interviews, 2016-2022

Variable Category	Variable Characteristic	Home Death n(%)	Hospice or Palliative Care Unit Death n(%)	Hospital Deaths n(%)
Overall		292 (22.7)	222 (17.2)	631 (49.0)
Age	< 65	56 (19.2)	49 (22.1)	87 (13.8)
	65+	236 (80.8)	173 (77.9)	544 (86.2)
Sex	Male	182 (62.3)	135 (60.8)	399 (63.2)
	Female	110 (37.7)	87 (39.2)	232 (36.8)
Province	Ontario	75 (25.7)	28 (12.6)	143 (22.7)
	Quebec	54 (18.5)	82 (36.9)	130 (20.6)
	British Columbia	52 (17.8)	31 (14.0)	86 (13.6)
	Western*	46 (15.8)	40 (18.0)	127 (20.1)
	Atlantic**	65 (22.3)	41 (18.5)	145 (23.0)
Education	Less than High School	30 (10.3)	27 (12.2)	97 (15.4)
	High School Graduate or Higher	262 (89.7)	195 (87.8)	534 (84.6)
Marital Status	Married	189 (64.7)	142 (64.0)	408 (64.7)
	Single, Divorced or Separated	43 (14.7)	41 (18.5)	100 (15.8)
	Widowed	60 (20.5)	29 (17.6)	123 (19.5)
Cause of Death	Cardiovascular Disease***	113 (38.7)	18 (8.1)	151 (23.9)
	Cancer	102 (34.9)	173 (77.9)	210 (33.3)
	RIDK+	13 (4.5)	7 (3.2)	93 (14.7)
	Other	64 (21.9)	24 (10.8)	177 (28.1)
ADL & IADL++	No or Little or Unknown Physical Impairment	170 (58.2)	70 (31.5)	319 (50.6)
	Moderate Physical Impairment	39 (13.4)	36 (16.2)	86 (13.6)
	Severe Physical Impairment	16 (5.5)	31 (14.0)	63 (10.0)
	Total Physical Impairment	67 (22.9)	85 (38.3)	163 (25.8)

ED Use	No Use	167 (57.2)	101 (45.5)	332 (52.6)
	One Time	44 (15.1)	18 (8.1)	81 (12.8)
	2 to 4 Times	45 (15.4)	55 (24.8)	125 (19.8)
	5 or more times	36 (12.3)	48 (21.6)	93 (14.7)
Hospitalization	No Use	153 (52.4)	38 (17.1)	110 (17.4)
	One time	64 (21.9)	68 (30.6)	229 (36.3)
	Two or More Times	75 (25.7)	116 (52.3)	292 46.3)
Last physician visit (weeks)	Did Not Visit	38 (13.0)	15 (6.8)	38 (6.0)
	Same Week	78 (26.7)	158 (71.2)	427 (67.7)
	1-2 weeks	57 (19.5)	21 (9.5)	69 (10.9)
	3-6 Weeks	59 (20.2)	13 (5.9)	46 (7.3)
	7+ Weeks	60 (20.5)	15 (6.8)	51 (8.1)

***Western Provinces =** Alberta, Manitoba, Saskatchewan

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*****Cardiovascular Disease** = Heart disease, Stroke, Heart Failure

[+]**RIDK**=R=Respiratory diseases including emphysema, obstructive lung disease, asthma, chronic obstructive pulmonary disease; I=Influenza or pneumonia; D=Dementia; K=Kidney Diseases such as nephritis, nephrotic syndrome, or nephrosis

[++]**ADL & IADL =** Activities of Daily Living and Instrumental Activities of Daily Living

Table 3: Standardized Difference Between Quality of Death Characteristics, Canadian Longitudinal Study on Aging Decedents, 2012-2022

Quality of Death and Dying	Home Death n(%)	PCU or Hospice Death n(%)	Hospital Death n(%)	Standard Differences (Home vs PCU/ Hospice) SD (p-value)	Standard Differences (Home vs Hospital) SD (p-value)	Standard Differences (PCU/ Hospice vs Hospital) SD (p-value)
Peace with Dying	195 (66.8)	165 (74.3)	400 (63.4)	0.16 (0.043)	0.07 (0.612)	0.24 (0.031)
Dying in their Preferred Place	261 (89.4)	136 (61.3)	301 (47.7)	0.65 (<0.001)	0.90 (<0.001)	0.27 (<0.001)
Dying with Dignity	264 (90.4)	182 (82.0)	532 (84.3)	0.24 (0.035)	0.18 (0.048)	0.06 (0.681)
Dying without Pain	197 (67.5)	181 (81.5)	409 (64.8)	0.32 (<0.001)	0.06 (0.675)	0.38 (<0.001)

Table 4: Adjusted Odds of Home Deaths Compared to Hospice/Palliative Care Unit, and Hospital Deaths, Canadian Longitudinal Study on Aging Decedents, 2012-2022

Variable Category	Variable Characteristic	Home Deaths (n=292)	Palliative Care Unit or Hospice Deaths (n=222)	Hospital Death (n=631)
		Odds Ratio (Confidence Interval)	Odds Ratio (Confidence Interval)	Odds Ratio (Confidence Interval)
Age	<65	-	-	-
	65+	0.84 (0.56-1.25)	0.76 (0.50-1.16)	1.37 (0.98-1.91)
Sex	Male	-	-	-
	Female	0.98 (0.70-1.37)	0.97 (0.70-1.36)	0.93 (0.73-1.20)
Province	Ontario	-	-	-
	Quebec	0.57 (0.36-0.89)	3.77 (2.28-6.37)	0.68 (0.47-0.98)
	British Columbia	0.91 (0.56-1.47)	2.00 (1.10-3.64)	0.67 (0.44-1.01)
	Western*	0.64 (0.40-1.02)	2.04 (1.17-3.62)	1.10 (0.75-1.63)
	Atlantic**	0.79 (0.51-1.23)	1.63 (0.94-2.85)	0.94 (0.65-1.36)
Cause of Death	Cardiovascular Disease***	-	-	-
	Cancer	0.84 (0.58-1.22)	6.79 (4.10-11.9)	0.55 (0.40-0.76)
	RIDK^{+}	0.26 (0.58-1.22)	0.56 (0.21-1.37)	1.96 (1.25-3.09)
	Other	0.54 (0.36-0.80)	1.21 (0.64-2.35)	1.78 (1.25-2.54)
ADL & IADL^{++}	No Impairment	-	-	-
	Mild or Moderate Impairment	1.07 (0.67-1.69)	1.62 (0.97-2.67)	0.69 (0.47-1.02)
	Severe Impairment	0.73 (0.38-1.32)	2.34 (1.35-4.02)	0.64 (0.40-1.01)
	Total Impairment	0.72 (0.50-1.04)	2.08 (1.41-3.08)	0.33 (0.24-0.45)
ED Use	No Use	-	-	-
	One Time	1.21 (0.77-1.89)	0.55 (0.30-0.97)	1.13 (0.77-1.66)
	2 to 4 Times	0.92 (0.60-1.39)	1.02 (0.67-1.53)	1.05 (0.76-1.46)
	5 or more times	1.09 (0.67-1.73)	0.84 (0.53-1.32)	1.09 (0.76-1.58)
Hospital Use in Last Year of Life	No Use	-	-	-
	One time	0.35 (0.24-0.51)	1.01 (0.62-1.63)	3.15 (2.25-4.41)
	Two or More Times	0.34 (0.24-0.50)	1.12 (0.72-1.77)	3.26 (2.35-4.55)

Last physician visit	No Visit	-	-	-
	Same week	0.34 (0.21-0.56)	1.67 (0.90-3.25)	3.12 (1.99-4.95)
	1-2 weeks	1.17 (0.68-2.02)	0.94 (0.43-2.09)	1.26 (0.74-2.15)
	3-6 Weeks	1.52 (0.87-2.67)	0.76 (0.31-1.80)	1.16 (0.66-2.03)
	7+ Weeks/Unknown	1.68 (0.97-2.9)	0.84 (0.37-1.95)	1.20 (0.69-2.08)

***Western Provinces =** Alberta, Manitoba, Saskatchewan

****Atlantic Provinces =** New Brunswick, Newfoundland and Labrador, Nova Scotia, Prince Edward Island

*****Cardiovascular Disease** = Heart disease, Stroke, Heart Failure

[+]**RIDK**=R=Respiratory diseases including emphysema, obstructive lung disease, asthma, chronic obstructive pulmonary disease; I=Influenza or pneumonia; D=Dementia; K=Kidney Diseases such as nephritis, nephrotic syndrome, or nephrosis

[++]**ADL & IADL =** Activities of Daily Living and Instrumental Activities of Daily Living

Appendices

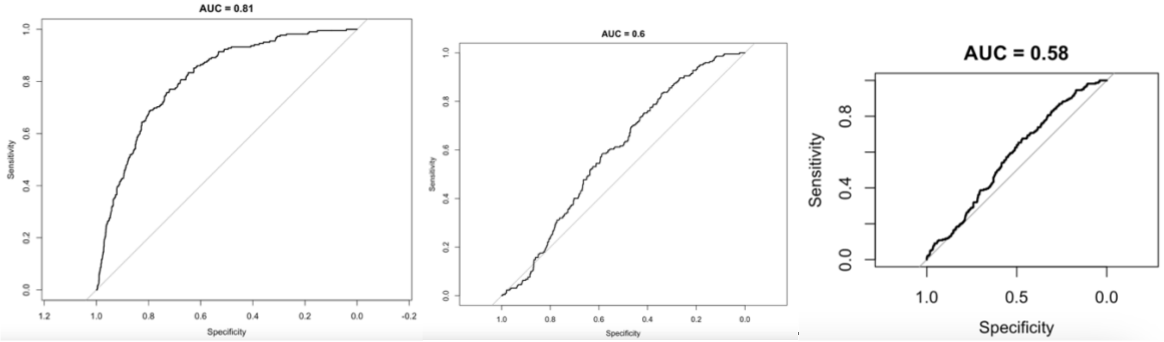
Appendix A: Quality of Death and Dying Indicators and Responses, Canadian Longitudinal Study on Aging, 2012-2022

Question	Response
In the last week of their life, do you feel that Person X was at peace with dying?	Yes Somewhat No Not Applicable Don't Know Refused
In the last week of their life, do you feel that Person X maintained their dignity and self-respect?	Yes Somewhat No Not Applicable Don't Know Refused
In the last week of their life, do you feel that Person X had their pain under control?	Yes Somewhat No Not Applicable Don't Know Refused
In the last week of their life, do you feel that Person X died where they wanted to?	Yes No Not Applicable Don't Know Refused

Appendix B: Location of Death, Canadian Longitudinal Study on Aging Decedents, 2012-2022

Location of Death	**Number of Participants n (%)**
Home	292 (22.7)
Hospice or Palliative Care Unit	222 (17.2)
Hospital	631 (49.0)
Residence for Seniors	16 (1.24)
Nursing Home or Long-Term Care Facility	99 (7.7)
Other	27 (2.1)

Appendix C: Area Under the Reciever Operating Curve for Home Deaths and Palliative Care or Hospice Deaths, Canadian Longitudinal Study on Aging Decedents, 2012-2022



a) Palliative or Hospice Deaths b) Home Deaths c) Hospital Deaths

Appendix D: Sensitivity Analysis of the Adjusted Odds of Home Deaths, Hospice/Palliative Care Deaths, and Hospital Deaths for Those Who Did Not Receive Medical Assistance in Dying, Canadian Longitudinal Study on Aging Decedents, 2012-2022

Variable Category	Variable Characteristic	Home (n=271)	Palliative (n=209)	Hospital (n=605)
Age	65+	0.75 (0.50-1.13)	0.76 (0.50-1.18)	1.43 (1.01-2.02)
Sex	Female	1.00 (0.73-1.37)	1.11 (0.79-1.57)	0.91 (0.70-1.18)
Province	Quebec (ref=ON)	0.54 (0.34-0.86)	3.54 (2.11-6.08)	0.68 (0.47-0.99)
	British Columbia	0.95 (0.58-1.56)	2.02 (1.10-3.72)	0.65 (0.43-1.00)
	Western*	0.63 (0.39-1.03)	1.99 (1.13-3.57)	1.09 (0.73-1.63)
	Atlantic**	0.81 (0.51-1.28)	1.62 (0.93-2.87)	0.91 (0.63-1.33)
Cause of Death	Cancer	0.79 (0.54-1.17)	7.27 (4.33-12.93)	0.56 (0.40-0.78)
	RIDK***	0.26 (0.12-0.50)	0.53 (0.19-1.33)	2.07 (1.30-3.31)
	Other	0.49 (0.32-0.75)	1.34 (0.70-2.63)	1.80 (1.26-2.59)
ADL & IADL⁺	Mild to Moderate Impairment	1.15 (0.71-1.85)	1.72 (1.00-2.90)	0.65 (0.43-0.97)
	Severe Physical Impairment	0.59 (0.28-1.15)	2.51 (1.42-4.39)	0.67 (0.41-1.08)
	Total Physical Impairment	0.72 (0.49-1.04)	2.20 (1.47-3.30)	0.32 (0.23-0.43)
ED Use	One Time	1.14 (0.71-1.81)	0.57 (0.31-1.01)	1.17 (0.79-1.73)
	2 to 4 Times	0.87 (0.56-1.34)	1.04 (0.68-1.59)	1.06 (0.75-1.49)
	5 or more times	1.14 (0.69-1.84)	0.80 (0.49-1.28)	1.11 (0.75-1.63)
Hospitalization (Last Year)	One time	0.34 (0.23-0.50)	0.99 (0.61-1.63)	3.26 (2.31-4.61)
	Two or More Times	0.35 (0.24-0.51)	1.08 (0.68-1.73)	3.37 (2.40-4.77)
Last Physician Visit	Same Week	0.31 (0.19-0.53)	1.80 (0.95-3.60)	3.24 (2.05-5.19)
	1-2 weeks	1.13 (0.64-1.98)	1.01 (0.45-2.30)	1.28 (0.75-2.22)
	3-6 Weeks	1.49 (0.85-2.64)	0.78 (0.32-1.88)	1.21 (0.69-2.14)
	7+ Weeks / Unknown	1.69 (0.97-2.97)	0.88 (0.38-2.08)	1.25 (0.72-2.19)

***Western Provinces =** Alberta, Manitoba, Saskatchewan

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***RIDK=R=Respiratory diseases including emphysema, obstructive lung disease, asthma, chronic obstructive pulmonary disease; I=Influenza or pneumonia; D=Dementia; K=Kidney Diseases such as nephritis, nephrotic syndrome, or nephrosis

⁺**ADL & IADL =** Activities of Daily Living and Instrumental Activities of Daily Living

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CHAPTER 4

The Characteristics and Experiences of Older Adults Considering and Receiving Medical Assistance in Dying: An Analysis of the Canadian Longitudinal Study on Aging

Summary

In this chapter we examined the sociodemographic and clinical characteristics of older adults who considered and received medical assistance in dying (MAiD), compared to those who neither considered nor received. Investigating the factors that influence the consideration and receipt of MAiD is crucial to improve the quality of care, address potential gaps, and understand patient' preferences. Data on the death experience of those who consider and receive MAiD is critical to understand whether they achieve a dignified and peaceful passing.

This research provides new insights into the sociodemographic and end-of-life characteristics associated with MAiD consideration and receipt. It provides new data on the proportion of persons who consider MAiD at the end of life. It also provides new data on the death experience of who considered and received MAiD, which has been a critical missing element in the debate of how MAiD is being experienced. The findings suggest that many older adults consider MAiD than those who ultimately receive it, and that those who considered or received MAiD had a reported better death experience, including peace with dying and dying in their preferred place.

Citation

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Abstract

Background: In 2016, Bill C-14 legalized Medical Assistance in Dying (MAiD) in Canada for individuals with a reasonably foreseeable natural death. We examined the characteristics and death experience of older adults who considered or received MAiD compared to those who did neither.

Methods: We conducted a secondary analysis of next-of-kin interviews from a national prospective cohort study, the Canadian Longitudinal Study on Aging, between June 6, 2016, and March 17, 2021, a period pertaining to Track 1 cases under Bill C-14. Descriptive and end-of-life characteristics, including quality of death and dying, were compared across groups: those who considered MAiD, received MAiD, or neither.

Results: Of 937 decedent participants, 25.8% considered MAiD and 6.8% received MAiD. Most were male, married, and died of cancer. Compared to those who did not consider or receive MAiD, those who considered MAiD were more likely to die in hospice or palliative care (OR 1.84; CI 1.19–2.84) and have a substitute decision-maker (OR 1.82; CI 1.19–2.86). Next of kin reported that MAiD considerers were more likely to die in their preferred location (64.7% vs. 56.2%, SD 0.72) and experience peace with dying (78.5% vs. 63.1%, SD 0.78). MAiD recipients were less likely to die in hospice (OR 0.41; CI 0.18-0.91) but it was reported that they had a better death and dying experience.

Interpretation: More older adults considered MAiD than received it. Individuals who considered or received MAiD were reported by their next of kin to have better death experiences compared to those who did neither.

Introduction:

As individuals approach the end of life, they may consider options to manage their final moments, including Medical Assistance in Dying (MAiD).[54-56] Legalized in Canada in 2016 under Bill C-14, the so called ‘Track 1’ MAiD allows competent adults with serious, incurable conditions, experiencing intolerable suffering, and advanced irreversible decline in functional capability to end their lives with medical assistance.[57] Acceptance of MAiD has grown across Canada since initial legalization, with surveys indicating strong support, particularly among those aged 55 and older.[58] Recent reports on socioeconomic differences between those receiving MAiD under ‘Track 2’ (for those whose death is not reasonably foreseeable) have fueled debates.[59]

The number of MAiD cases has increased steadily since legalization, with 13,241 deaths, 4.1% of all deaths in Canada, in 2022 resulting from MAiD.[56, 60] The primary reasons for requesting MAiD include loss of autonomy, inability to engage in meaningful activities, and unmanageable disease-related symptoms.[60-63] Not all individuals who express interest in MAiD ultimately receive it, due to factors such as procedural delays, personal or institutional objections, or loss of eligibility before the procedure.[64] National reports provide information on MAiD, including requests that do not ultimately result in a MAiD procedure.[60, 65] However, little is known about those who considered MAiD but never initiated a formal request, or the characteristics and quality of death for those who those who considered MAiD, as well as those who received MAiD, compared to other deaths.

The Canadian Longitudinal Study on Aging (CLSA), a nationally representative cohort recruited prior to MAiD legalization, offers a unique opportunity to examine MAiD consideration and receipt. We conducted a secondary analysis of CLSA to explore the characteristics and experience of decedents who considered or received MAiD compared to those who did neither, exclusively pertaining to MAiD deaths under Track 1.

Methods:

Study Design

We conducted a secondary analysis of decedent interview data from the CLSA. The CLSA recruited 51,338 adults aged 45-85 at baseline (2011-2015) collecting data via telephone interviews (Tracking cohort) and through in-home interviews and visits to designated data collection sites (Comprehensive cohort).[18] Previous reports can be referenced on the detailed design and methodologies of the CLSA cohort.[17, 18] We use the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) reporting guidelines.[44]

Data Sources

Participants completed a baseline questionnaire after enrolling into the study[17], and the first follow-up questionnaire was administered three years after baseline interviews and the second follow-up was administered three years after the first follow-up interview. Decedent questionnaires (available online)[20] were completed by proxies or next of kins of the participants who died from January 6, 2012, by telephone interview (French or English) with a trained CLSA decedent interviewer. We included all CLSA participants who died and who's next-of-kin participated in the decedent questionnaire between June 6, 2016 to March 17, 2021 – after 'Track 1' MAiD legalization (Bill C-14) and before Bill C-7 was enacted to expanded eligibility to individuals whose natural death is not reasonably foreseeable (so called 'Track 2').[66] We excluded participants with incomplete baseline assessments or decedent questionnaires.

Data Collection

Once the CLSA received the confirmation of death from a family member or friend of the deceased participant or through provincial death records, the next of kin or primary contact (identified by the CLSA participant at baseline) was contacted by mail. Interviews were completed within a range of 10 days to 6.3 years after death (average 2 years and median 14 months), depending on respondent availability and release of the participant's deceased status. The next of kin or primary contact were contacted via telephone two weeks after mailing to schedule a decedent interview, if interested. Either the next of kin or primary contact completed the decedent questionnaire via telephone, which averaged 30 minutes in duration. Respondents were asked whether the deceased participant considered or received MAiD (**Appendix A)** and we limited analyses to "yes" or "no" responses.

Analyses

We analyzed sociodemographic and end-of-life characteristics of all participants with a completed baseline interview and who had died. We compared deceased participants with and without a completed decedent interview. We examined end-of-life characteristics including the location of death, cause of death, arrangements for health care decision making, and arrangements for end-of-life care. We also assessed quality of death and dying from the decedent survey, including peace with dying, dying in their preferred place, dignity maintained prior to dying, and pain management.

We used unadjusted logistic regressions to estimate the associations between decedent characteristics for those who considered or received MAiD. A limited sample size, typical for such an outcome, precluded adjusted analyses. We calculated standardised differences in death and dying experience measures across three groups: those who did not consider MAID, considered but did not receive MAID, received MAID; interpreting that a standardized difference of less than 0.1 indicated trivial difference, 0.2 indicating small difference, 0.5 indicating moderate difference, and 0.8 indicating large difference. We used Pearson's chi-square to test for differences in the death and dying experience measures across these groups. We managed and analyzed all data using R-Studio 4.2.2.

Ethics and Reporting

Hamilton Integrated Research Ethics Board (2023-16023-C) reviewed and approved this study. Data are available from the CLSA (https://www.clsa-elcv.ca/data-access/).

Results:

There were 2,318 deceased CLSA participants and 937 (40.4%) had a completed decedent interview between 2016-2021 (**Table 1, Appendix B**). Males, people older than 75, married people we more prevent in among those that died. Deaths with a completed decedent interview were more likely to be older (mean age of 78.2 years at death); male (61.7%) and married (63.6%), approximately 17.5% had no religious affiliation; and 35.4% had education beyond a bachelor's degree. Differences between deaths with and without a completed decedent interview were small or trivial (Standardized Mean Differences 0.012-0.172).

Approximately a quarter (242, 25.8%) of deceased participants next-of-kin reported that that the participant considered MAiD and approximately a quarter (64 of 242, 26.4%) of those who considered MAiD ultimately received it (**Figure 1**) between June 6, 2016, to March 17, 2021.

Characteristics Associated with Considering MAiD

Dying of cancer (OR 4.07 ; CI 2.64-6.46) dying in hospice or palliative care units (OR 1.84; CI 1.19-2.84), experiencing increasing physical impairment (total; OR 1.73; CI 1.18-2.75), having identified a Substitute Decision Maker (SDM) (OR 1.82; CI 1.19-2.86), using the emergency department five or more times in the last year of life (OR 2.57; CI 1.72-3.83), being hospitalized two or more times in the last year of life (OR 1.49; CI 1.03-2.17) seeing a physician the same week before death (OR 1.74; CI 1.17-2.66) and having a bachelor's degree (OR 1.63; CI 1.01-2.69), were associated with increased odds of considering MAiD (**Table 2**). Being 75 years old or older (OR 0.52; CI 0.35-0.77), identifying with a religion (e.g. Roman Catholic: OR 0.53 ; COI 0.36-0.80) and dying in seniors housing or a nursing home (OR 0.52; CI 0.30-0.93), were associated with decreased odds of considering MAiD. Among those who considered MAiD, dying in hospice or a palliative care facility (OR 0.41; CI 0.18-0.91) was associated with a lower odds of receiving MAiD (**Table 3**). No other personal or end-of-life characteristics were associated with a higher or lower odds of receiving MAiD (among those who considered MAiD).

Although most deceased participants were reported to be at peace with dying, dying in their preferred place, maintaining their dignity, and dying without pain, these positive experiences were more prevalent among those who considered or received MAiD compared to those who did not (**Table 4**). Older adults considering MAiD were more likely to be reported as having experienced peace (78.5 vs 64.1; standard difference (SD): 0.78) and dying in their preferred place (64.7 vs 56.2; SD: 0.72) than those who did not consider MAiD. Individuals who received MAiD were more likely to be reported to have experienced peace (82.8 vs 78.5; standard difference (SD): 0.39), dying in their preferred place (75.0 vs 64.7; SD: 0.32), dignity

(89.0 vs 83.9; SD: 0.33), and dying without pain (71.9 vs 64.5; SD 0.37) more frequently than those who did not consider MAiD.

Discussion:

In this large prospective cohort of older adults, recruited before Medical Assistance in Dying (MAiD) had become legal, approximately a quarter of older adults considered MAiD as they approached death, and a quarter of those who considered it ultimately received it. While there were many differences in the sociodemographic and end-of-life characteristics of those who considered MAiD compared with those who did not, there were almost no differences between those who received MAiD and those who considered but did not receive MAiD. Sociodemographic and end-of-life factors may not influence receiving MAiD when someone has started considering it, or the effects of these factors may be small enough that a larger study would be needed to detect them. Potential reasons for considering but not receiving MAiD might include dynamic personal decisions, procedural delays, or the loss of capacity before MAiD can be administered.[61, 67] We could not determine whether individuals decided not to proceed with MAiD, or whether they preferred MAiD but were unable to receive it. Identifying the reasons why individuals who consider MAiD but do not ultimately receive it could identify improvement strategies for end-of-life care.

Our data provided unique information on how those who consider or receive MAiD experience death and dying. Although some MAiD requests may be driven by suffering amendable to high quality palliative care, those who considered MAID were more likely to have died in peace and in their preferred place than those who did not consider MAiD, and those who received MAiD had a better reported death experience across all measures reported by next-of-kins than those who considered but did not receive MAiD. Peace with dying and dying in their preferred place are core components to achieving a good death experience,[13] and these were the two factors most strongly associated with considering MAiD. We also found that those who considered MAiD had similar pain control as those who didn't consider MAiD, and that those who received MAiD had overall better pain control than those who didn't receive MAiD. Our finding are consistent with federal reports that show that pain control (or concern about pain control) is not a common factor driving MAiD requests.[60] We found that those who considered MAiD were more likely to have made end-of-life preparations, such as appointing a Substitute Decision Maker (SDM), than those who did not consider MAiD. This is consistent with the finding that MAiD recipients have very high involvement of palliative care services[68-70] where the consideration of MAiD may occur as a part of other end-of-life care planning. [71, 72] However, we cannot support any causal interpretations on whether advance care planning might prompt a consideration of MAiD, or whether individuals considering MAiD may also consider palliative care and advance care planning as they confront the multifaceted hurdles of advanced illness.[55] Having a SDM was associated with MAiD consideration, but was not associated with ultimately receiving MAiD. Previous studies also found that individuals receiving palliative care or advance care planning maintained autonomy over their dying process,[68] and advance care planning does not routinely affect the end-of-life care they receive.[70]

Individuals who died in hospice or palliative care units were more likely to consider MAiD but less likely to receive it (OR 1.73, CI 1.12-2.67 for considering, OR 0.42, CI 0.19-0.95 for receiving). Palliative care may be able to address suffering and reduce the desire for MAID, but also many Canadian hospice and palliative care policies explicitly prohibited the provision of

MAiD for at least part of the study period[69] and persons seeking MAiD may have been denied access to palliative facilities.[73, 74] Canadian data has shown very high rates of palliative care involvement among MAID recipients (~80%),[56, 60] making it unlikely that admission to a palliative care facility would have had a dramatic effect on the desire for MAiD.

Our study found potential disparities in MAiD consideration and receipt based on sociodemographic factors. For instance, individuals with higher education and those who were married were more likely to consider MAiD. Conversely, practicing a religion, was associated with a decreased likelihood of considering MAiD (OR 0.54, CI 0.36-0.80). These findings are consistent with what could be hypothesized from the public debate; preferences for MAiD are associated with cultural, educational, and religious factors.

Limitations:

Omitted variables not included in the CLSA decedent interviews, including reasons for considering MAiD and the decision to ultimately receive MAiD, would improve utility. Though referenced to the 2011 Canadian census, CLSA participants are generally wealthier and more likely to identify as White. We may overestimate the proportion considering MAiD relative to other groups during this period, and particularly for newer demographics. Without dedicated retrospective sampling of matched decedents next of kin, these are likely the best available data to understand Canadians who considered MAiD and perceptions of how death was experienced with limited, if any, selection biases between comparisons. Deficiencies in the generalizability of the CLSA sample also favour the known population of MAiD recipients, who also trend toward wealthier older adults of European ancestry[56, 60].

Next-of-kin reports are considered a valid and useful proxy for assessing end-of-life care and death experiences, given that direct feedback is clearly unavailable.[34, 75-79] However, our data may be susceptible to time elapsed after an individual's passing and the family members' reporting and or the completion of the decedent interview, yet it's not clear whether bias would favor positive or negative recollection based on grief symptoms.[53] Caregivers may overestimate the degree of pain, and other symptoms, compared to the individual experiencing the symptoms.[35, 36]Any bias is unlikely to affect the comparison between MAID and non-MAID deaths. Event rates limited the potential for time-dependent sensitivity analyses.

Conclusion:

Many more older adults consider MAiD than those who receive it. Individuals who considered or received MAiD are reported to have experienced a better death (peace with dying and dying in their preferred place) by their next of kin than those who did not. Improving access to comprehensive end-of-life care planning can help ensure that all individuals can experience a dignified and peaceful death.

Tables and Figures

Table 1: Characteristics of Deceased Canadian Longitudinal Study on Aging Participants, by Decedent Interview Completion, 2016-2021

Decedent Characteristic		With Decedent Interview (n=937)	Without Decedent Interview (n=1,381)	Standard Mean Difference
Sex	Female	359 (38.3)	565 (40.9)	0.036
	Male	578 (61.7)	816 (59.1)	
Age	45-64	152 (16.2)	319 (23.1)	0.172
	65-74	270 (28.8)	317 (23.0)	
	75+	515 (55.0)	745 (53.9)	
Country of Birth	Canada	774 (82.6)	1,131 (81.9)	0.012
	Other	163 (17.4)	250 (18.1)	
Province/ Region	Ontario	187 (20.0)	310 (22.4)	0.079
	Quebec	218 (23.3)	170 (12.3)	
	British Columbia	148 (15.8)	222 (16.1)	
	Western Region*	173 (18.5)	348 (25.2)	
	Atlantic Region**	211 (22.5)	331 (24.0)	
Ethnicity	White	919 (98.1)	1335 (96.7)	0.100
	Non-White	18 (1.9)	46 (3.3)	
Religion	Roman Catholic	338 (36.1)	384 (27.8)	0.018
	United Church	115 (12.3)	180 (13.0)	
	Anglican	94 (10.0)	155 (11.2)	
	Other	226 (24.1)	424 (30.7)	
	No Religion	164 (17.5)	238 (17.2)	
Education	Did Not Complete Secondary School	126 (13.4)	204 (14.8)	0.049

	Completed Secondary School	112 (12.0)	208 (15.1)	
	Some Post-Secondary or Diploma	367 (39.2)	567 (41.1)	
	Completed bachelor’s degree or Higher	332 (35.4)	402 (29.1)	
Marital Status	Single, Divorced or Separated	159 (17.0)	309 (22.4)	0.14
	Married	596 (63.6)	735 (53.2)	
	Widowed	182 (19.4)	337 (24.4)	
Private Life Insurance	Yes	599 (63.9)	779 (56.4)	0.064
	No / Unknown	338 (36.1)	602 (43.6)	

*** Western Region = Provinces include** Alberta, Manitoba, Saskatchewan
****Atlantic Region = Provinces include** New Brunswick, Newfoundland and Labrador, Nova Scotia, Prince Edward Island

Table 2: Unadjusted Odds of Considering Medical Assistance in Dying, Canadian Longitudinal Study on Aging Decedents, 2016-2021

		Considered Medical Assistance in Dying			
Decedent Characteristic		**Yes (n=242)**	**No (n=739)**	**Unadjusted OR (95%CI)**	**p-value**
Sex	Male	142 (58.7)	458 (62.0)	-	-
	Female	100 (41.3)	281 (38.0)	1.15 (0.85-1.54)	0.36
Age	45-64	53 (21.9)	108 (14.6)	-	-
	65-74	79 (32.6)	200 (27.1)	0.8 (0.53-1.22)	0.31
	75+	110 (45.5)	431 (58.3)	0.52 (0.35-0.77)	0.001
Born in Canada	No	43 (17.8)	129 (17.5)	-	-
	Yes	199 (82.2)	610 (82.5)	0.98 (0.67-1.44)	0.91
Province/ Region	Ontario	44 (18.2)	148 (20.0)	-	-
	Quebec	71 (29.3)	165 (22.3)	1.45 (0.94-2.25)	0.10
	British Columbia	47 (19.4)	108 (14.6)	1.46 (0.91-2.37)	0.12
	Western Region*	34 (14.0)	145 (19.6)	0.79 (0.47-1.30)	0.36
	Atlantic Region**	46 (19.0)	173 (23.4)	0.89 (0.56-1.43)	0.64
Ethnicity	Other	<10.0%	<10.0%	-	-
	White	>90.0%	>90.0%	0.85 (0.32-2.67)	0.76
Religion	No Religion	62 (25.6)	112 (15.2)	-	-
	Roman Catholic	81 (33.5)	274 (37.1)	0.53 (0.36-0.80)	0.002
	United Church	23 (9.5)	97 (13.1)	0.43 (0.24-0.73)	0.003
	Anglican	20 (8.3)	79 (10.7)	0.46 (0.25-0.81)	0.008
	Other	56 (23.1)	177 (24.0)	0.57 (0.37-0.88)	0.01
Education	Did Not Complete Secondary School	26 (10.7)	104 (14.1)	-	-
	Completed Secondary School	36 (14.9)	88 (11.9)	1.64 (0.92-2.94)	0.10
	Some Post-Secondary or Diploma	80 (33.1)	301 (40.7)	1.06 (0.65-1.77)	0.81
	Completed bachelor's degree or Higher	100 (41.3)	246 (33.3)	1.63 (1.01-2.69)	0.06
Marital Status	Single, Divorced, or Separated	45 (18.6)	122 (16.5)	-	-

	Married/Common-Law	150 (62.0)	466 (63.1)	0.87 (0.60-1.30)	0.49
	Widowed	47 (19.4)	151 (20.4)	0.84 (0.53-1.36)	0.48
Cause of Death	Heart Disease	28 (11.6)	192 (26.0)	-	-
	Cancer	149 (61.6)	251 (34.0)	4.07 (2.64-6.46)	<0.001
	RIDK***	28 (11.6)	92 (12.4)	2.09 (1.17-3.74)	0.012
	Other	37 (15.3)	204 (27.6)	1.23 (0.73- 2.13)	0.42
Location of Death	Own Home	56 (23.1)	159 (21.5)	-	-
	Hospital	100 (41.3)	372 (50.3)	0.76 (0.53-1.12)	0.16
	Hospice or Palliative Care Unit	66 (27.3)	102 (13.8)	1.84 (1.19-2.84)	0.06
	Senior Home, Nursing Home, or Other	20 (8.3)	106 (14.3)	0.52 (0.30-0.93)	0.03
Activities of Daily Living/ Instrumental Activities of Daily Living	No functional impairment	30 (12.4)	154 (20.8)	-	-
	Mild impairment	27 (11.2)	103 (13.9)	1.47 (0.81-2.54)	0.18
	Moderate impairment	38 (15.7)	90 (12.2)	2.26 (1.32-3.91)	<0.001
	Severe impairment	34 (14.0)	58 (7.8)	2.91 (1.62-5.15)	<0.001
	Total impairment	89 (36.8)	264 (35.7)	1.73 (1.18-2.75)	0.012
	Inconclusive	24 (9.9)	70 (9.5)	1.83 (1.02-3.45)	0.045
Final Caregiver	Son/Daughter	76 (31.4)	207 (28.0)	-	-
	Other	63 (26.0)	195 (26.4)	0.88 (0.60-1.29)	0.52
	Spouse	103 (42.6)	337 (45.6)	0.83 (0.59-1.18)	0.30
Substitute Decision Maker	No	28 (11.6)	142 (19.2)	-	-
	Yes	214 (88.4)	597 (80.8)	1.82 (1.19-2.86)	0.007
Living with Decedent at Time of Death	No	119 (49.2)	415 (56.2)	-	-
	Yes	123 (50.8)	324 (43.8)	1.32 (0.98-1.77)	0.06
Closeness between Decedent and Next of Kin	No	21 (8.7)	65 (8.8)	-	-
	Yes	221 (91.3)	674 (91.2)	1.01 (0.62-1.74)	0.96
ED Use in Last Year of Life	None	103 (42.6)	419 (56.7)	-	-
	One Time	36 (14.9)	83 (11.2)	1.76 (1.12-2.74)	0.01
	2 to 4 Times	48 (19.8)	150 (20.3)	1.30 (0.88-1.91)	0.19

	5 or more times	55 (22.7)	87 (11.8)	2.57 (1.72-3.83)	<0.001
Hospitalization in the Last Year of Life	None	51 (21.1)	204 (27.6)	-	-
	One time	76 (31.4)	226 (30.6)	1.35 (0.90-2.02)	0.186
	Two or More Times	115 (47.5)	309 (41.8)	**1.49 (1.03-2.17)**	**0.04**
Physician Visits (Weeks Before Death)	No Visits or Unknown	35 (14.5)	152 (20.6)	-	-
	Same Week	159 (65.7)	396 (53.6)	1.74 (1.17-2.66)	0.008
	1-2 Weeks	36 (14.9)	100 (13.5)	1.56 (0.92-2.66)	0.10
	3 or More Weeks	<10.0%	91 (12.3)	0.57 (0.27-1.13)	0.12
Has Life Insurance	No/ Unknown	99 (40.9)	283 (38.3)	-	-
	Yes	143 (59.1)	456 (61.7)	1.01 (0.74-1.37)	0.99

*** Western Region =** Provinces include Alberta, Manitoba, Saskatchewan
****Atlantic Region =** Provinces include New Brunswick, Newfoundland and Labrador, Nova Scotia, Prince Edward Island
*****RIDK** = Respiratory diseases including emphysema, obstructive lung disease, asthma, chronic obstructive pulmonary disease; I=Influenza or pneumonia; D=Dementia; K=Kidney Diseases such as nephritis, nephrotic syndrome, or nephrosis
$^{+}$**EoL**=End-of-Life

Table 3: Unadjusted Odds of Receiving Medical Assistance in Dying, Canadian Longitudinal Study on Aging, 2016-2021

Decedent Characteristic		**Received Medical Assistance in Dying**			
		Yes (n=64)	**No (n=178)**	**OR (95%CI)**	**p-value**
Sex	Male	44 (68.8)	98 (55.1)	-	-
	Female	20 (31.2)	80 (44.9)	0.57 (0.30-1.01)	0.06
Age	45-64	14 (21.9)	39 (21.9)	-	-
	65-74	26 (40.6)	53 (29.8)	1.37 (0.64-3.01)	0.43
	75+	24 (37.5)	86 (48.3)	0.78 (0.37-1.69)	0.52
Born in Canada	No	11 (17.2)	32 (18.0)	-	-
	Yes	53 (82.8)	146 (82.0)	1.06 (0.51-2.33)	0.89
Province/ Region	Ontario	11 (17.2)	33 (18.5)	-	-
	Quebec	25 (39.1)	46 (25.8)	1.63 (0.72-3.88)	0.25
	British Columbia	9 (14.1)	38 (21.3)	0.71 (0.26-1.92)	0.50
	Western Region*	8 (12.5)	26 (14.6)	0.92 (0.32-2.61)	0.88
	Atlantic Region**	11 (17.2)	35 (19.7)	0.94 (0.36-2.49)	0.90
Ethnicity	Non-White	<10.0%	<10.0%	-	-
	White	>90.0%	>90.0%	0.23 (0.03-1.43)	0.11
Religion	No Religion	19 (29.7)	43 (24.2)	-	-
	Roman Catholic	24 (37.5)	57 (32.0)	0.95 (0.46-1.97)	0.90
	United Church	<10.0%	19 (10.7)	0.48 (0.13-1.48)	0.23
	Anglican	<10.0%	15 (8.4)	0.75 (0.22-2.27)	0.63
	Other	12 (18.8)	44 (24.7)	0.62 (0.26-1.41)	0.26
Education	Did Not Complete Secondary School	<10.0%	22 (12.4)	-	-
	Completed Secondary School	11 (17.2)	25 (14.0)	2.42 (0.71-9.73)	0.18
	Some Post-Secondary or Diploma	25 (39.1)	55 (30.9)	2.50 (0.85-9.22)	0.12
	Completed bachelor’s degree or Higher	24 (37.5)	76 (42.7)	1.74 (0.59-6.37)	0.35
Marital Status	Married	43 (67.2)	107 (60.1)	-	-
	Single, Divorced, Separated	12 (18.8)	33 (18.5)	0.90 (0.41-1.88)	0.79

	Widowed	9 (14.1)	38 (21.3)	0.59 (0.25-1.28)	0.20
Cause of Death	Heart Disease	5 (7.6)	24 (13.5)	-	-
	Cancer	38 (59.4)	111 (62.4)	1.57 (0.60-4.94)	0.39
	RIDK***	8 (12.5)	20 (11.2)	1.84 (0.53-6.95)	0.35
	Other	13 (20.3)	23 (12.9)	2.49 (0.80-8.79)	0.13
Location of Death	Own Home	21 (32.8)	35 (19.7)	-	-
	Hospital	24 (37.5)	76 (42.7)	0.53 (0.26-1.07)	0.08
	Hospice or Palliative Care Unit	13 (20.3)	53 (29.8)	0.41 (0.18-0.91)	0.03
	Senior Home, Nursing Home, or Other	6 (9.4)	14 (7.9)	0.71 (0.22-2.08)	0.54
Activities of Daily Living/ Instrumental Activities of Daily Living	No functional impairment	8 (12.5)	22 (12.4)	-	-
	Mild impairment	<10.0%	24 (13.5)	0.34 (0.07-1.36)	0.15
	Moderate impairment	13 (20.3)	25 (14.0)	1.43 (0.51-4.22)	0.50
	Severe impairment	9 (14.1)	25 (14.0)	0.99 (0.32-3.06)	0.99
	Total impairment	22 (34.3)	67 (37.6)	0.90 (0.36-2.42)	0.83
	Inconclusive	9 (14.1)	15 (8.4)	1.65 (0.52-5.36)	0.40
Final Caregiver	Son/Daughter	16 (25.0)	60 (33.7)	-	-
	Spouse	32 (50.0)	71 (39.9)	1.28 (0.58-2.83)	0.56
	Other	16 (25.0)	47 (26.4)	1.69 (0.86-3.44)	0.14
Substitute Decision Maker	No	9 (14.1)	19 (10.7)	-	-
	Yes	55 (85.9)	159 (89.3)	0.73 (0.32-1.78)	0.47
Living with Decedent at Time of Death	No	29 (45.3)	90 (50.6)	-	-
	Yes	35 (54.7)	88 (49.4)	1.23 (0.70-2.20)	0.47
Closeness	No	8 (12.5)	13 (7.3)	-	-
	Yes	56 (87.5)	165 (92.7)	0.55 (0.22-1.46)	0.21
ED Use in Last Year of Life	None	29 (45.3)	74 (41.6)	-	-
	One Time	<10.0%	30 (16.9)	0.51 (0.18-1.28)	0.18
	2 to 4 Times	14 (21.9)	34 (19.1)	1.05 (0.48-2.22)	0.90
	5 or more times	15 (23.4)	40 (22.5)	0.96 (0.45-1.97)	0.91
Hospitalization in the Last Year of Life	None	12 (18.8)	39 (21.9)	-	-
	One time	20 (31.2)	56 (31.5)	1.16 (0.51-2.70)	0.72
	Two or More Times	32 (50.0)	83 (46.6)	1.25 (0.59-2.77)	0.56

Physician Visits (Weeks Before Death)	No Visits or Unknown	<10.0%	30 (16.9)	-	-
	Same Week	47 (73.4)	112 (62.9)	2.52 (0.99-7.74)	0.07
	1-2 Weeks	11 (17.2)	25 (14.0)	2.64 (0.84-9.33)	0.10
	3 or More Weeks	<10.0%	11 (6.2)	0.55 (0.03-3.91)	0.60
Has Life Insurance	No/Unknown	22 (36.1)	59 (36.2)	-	-
	Yes	39 (63.9)	104 (63.8)	1.01 (0.55-1.87)	0.99

*** Western Region = Provinces include** Alberta, Manitoba, Saskatchewan

****Atlantic Region = Provinces include** New Brunswick, Newfoundland and Labrador, Nova Scotia, Prince Edward Island

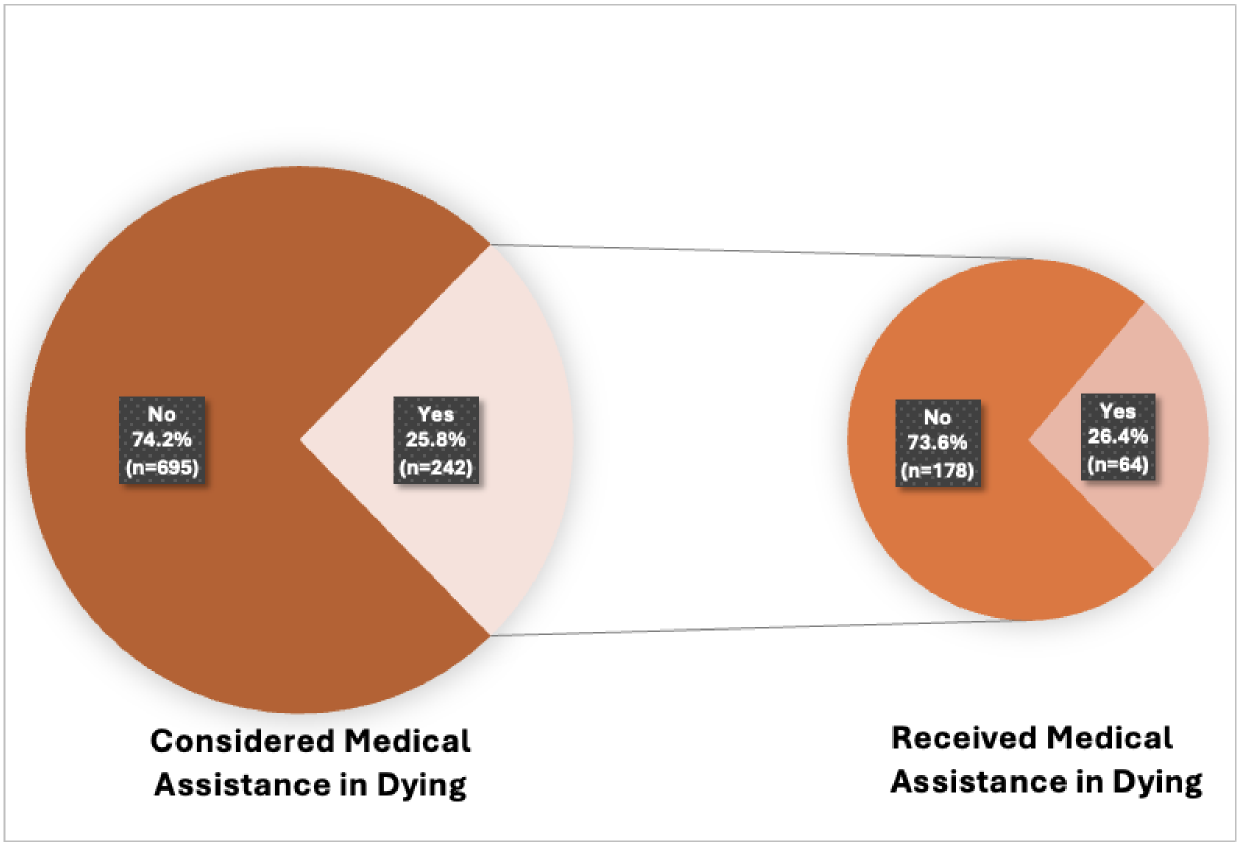
*****RIDK**=R=Respiratory diseases including emphysema, obstructive lung disease, asthma, chronic obstructive pulmonary disease; I=Influenza or pneumonia; D=Dementia; K=Kidney Diseases such as nephritis, nephrotic syndrome, or nephrosis

[+]**EoL**=End-of-Life

Table 4: Standardized Difference Between Quality of Death Characteristics, Canadian Longitudinal Study on Aging Decedents, 2016-2021

Quality of Death Characteristics	Received MAiD n(%)	Considered MAiD n(%)	Did Not Consider or Receive MAiD n(%)	Received vs Considered MAiD SD (p-value)	Considered vs Did Not Consider MAiD SD (p-value)
Peace with Dying	53 (82.8)	190 (78.5)	474 (64.1)	0.39 (<0.001)	0.78 (<0.001)
Dying in their Preferred Place	48 (75.0)	161 (64.7)	415 (56.2)	0.32 (<0.001)	0.72 (<0.001)
Dignity Maintained	57 (89.0)	203 (83.9)	615 (83.2)	0.33 (<0.001)	0.04 (0.751)
Died Without Pain	46 (71.9)	156 (64.5)	515 (69.7)	0.37 (<0.001)	0.02 (0.631)

Figure 1: Medical Assistance in Dying, Canadian Longitudinal Study on Aging, 2016-2021



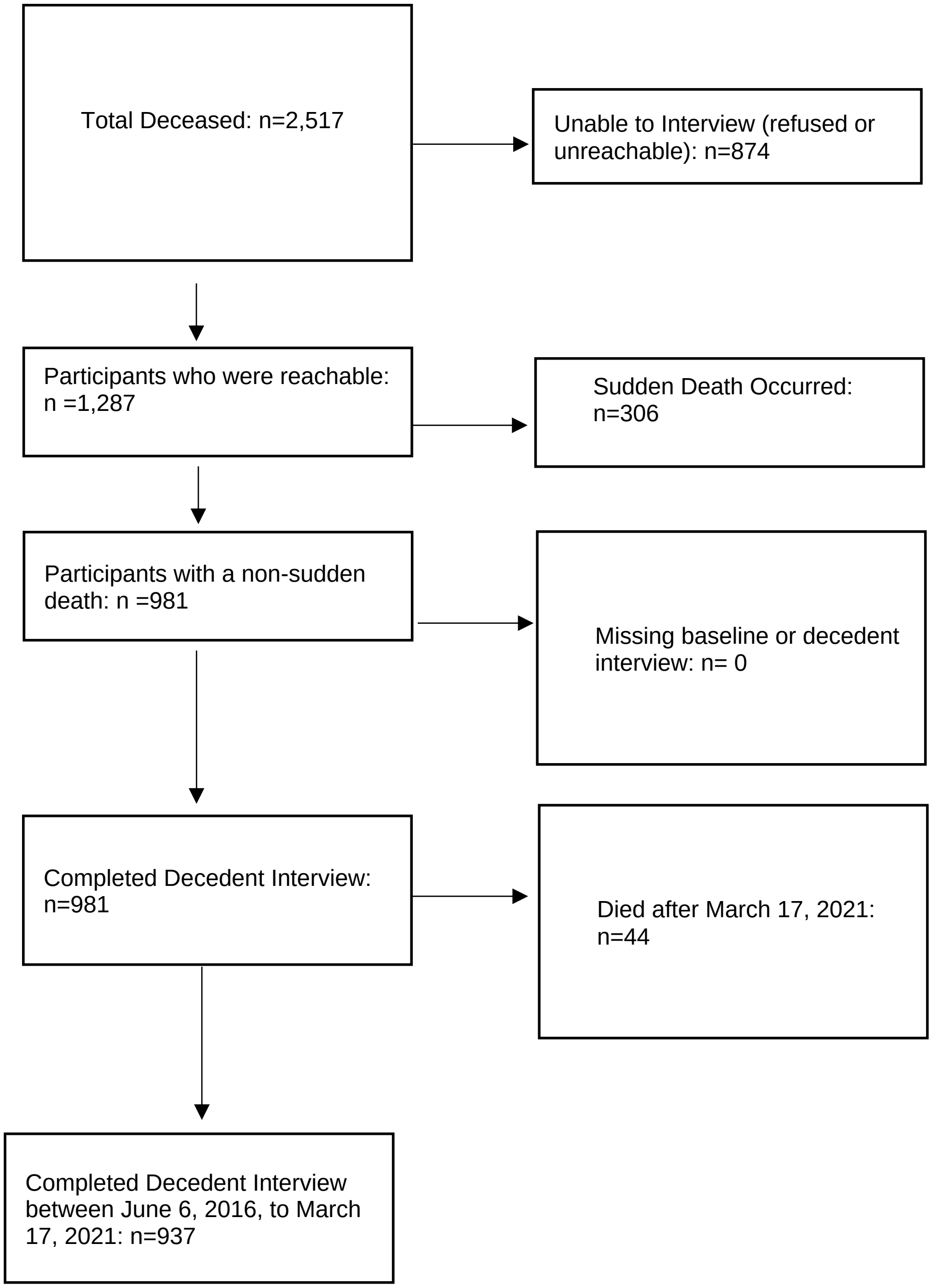
Appendices

Appendix A: Medical Assistance in Dying Questions and Responses

Question	Response
Did Person X consider physician-assisted death*?	Yes No Not Applicable Don't Know Refused
Did a physician-assisted death* take place?	Yes No Not Applicable Don't Know Refused

*Physician assisted death and medical assistance in dying were both accepted for these questions

Appendix B: Flow Diagram of Participant Inclusion and Exclusion from the Study, The Canadian Longitudinal Study on Aging, 2016-2021



Appendix C: Characteristics of Deceased Canadian Longitudinal Study on Aging Participants with a Completed Decedent Interview (2016-2021) compared to Canadian Decedent Population (2016-2021)

Participant Characteristics	**Variable**	**CLSA [n(%)]**	**Canada [n(%)]**	**Standard Mean Difference**
Total Deceased		**937**	**1,736,568**	
Sex	Male	578 (61.7)	835,971 (48.1)	0.22
	Female	359 (38.3)	812,538 (46.8)	
Age at Death	45-64	152 (16.2)	259,463 (14.9)	0.23
	65-74	270 (28.8)	314,403 (18.1)	
	75+	515 (55.0)	1,074,643 (61.9)	
Marital Status	Single, Divorced or Separated	159 (17.0)	364,697 (21.0)	0.30
	Married/Living with a partner in a common-law relationship	596 (63.6)	641,650 (36.9)	
	Widowed	182 (19.4)	580,610 (33.4)	
Location of death*	Hospital	450 (48.0)	1,006,929 (58.0)	0.33
	Non-Hospital	471 (50.3)	728,588 (42.0)	
	Unknown	16 (1.7)	1,051 (0.06)	
Cause of Death	Cancer	385 (41.1)	472,933 (27.2)	0.37
	Cardiovascular disease	209 (22.3)	428,201 (24.7)	
	RIDK**	116 (12.4)	255,884 (14.7)	
	Other	227 (24.2)	579,550 (33.4)	

*Values reported for entire Canadian Population

****RIDK** = Respiratory diseases including emphysema, obstructive lung disease, asthma, chronic obstructive pulmonary disease; I=Influenza or pneumonia; D=Dementia; K=Kidney Diseases such as nephritis, nephrotic syndrome, or nephrosis

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CHAPTER FIVE

Discussion

Summary of Main Findings

As the Canadian populations ages, improvements to quality of death and dying and overall end-of-life experiences is one of the Canadian health care systems primary goals.[1, 2] This thesis analyzes the first available national data on end-of-life experiences and quality of death indicators in a prospectively-defined cohort of older adults. To date, quality of death analyses in Canada have been limited to disease type and setting.[3-5] This thesis involved secondary data analysis aimed at better understanding location of death, peace with dying, and medical assistance in dying (MAiD) and its relationship to the overall dying experience. The findings are informative to researchers, policymakers, and medical care providers as more older adults seek end-of-life care.

The foundational principles of Emanuel and Emanuel's Good Death Framework guided this thesis by conceptualizing how personal characteristics and interventions impact the overall dying experience.[6] While the original framework provides a comprehensive model for evaluating a good death, adaptations were necessary, as many of its characteristics and interventions are not captured in the CLSA questionnaires. In Chapters 2, 3, and 4, we focused on domains that could be measured using responses from the decedent questionnaire, including participant sociodemographic and end-of-life characteristics that shape the overall dying experience. Using these available characteristics, we adapted and re-created a modified framework to guide our investigation into whether CLSA decedents experienced a good quality of death and dying. Our findings demonstrate that a good death experience is multifaceted with varying participant and end-of-life characteristics contributing to the unique quality aspects of the dying experience. Future research could explore the validity and applicability of this adapted framework in other populations or settings.

The study presented in Chapter 2 investigated factors associated with a peaceful death, one of the primary goals of end-of-life care. The study highlights how although most Canadians may experience peace with dying, close to 1 in 5 may not. Adjusted associations show that individuals who are widowed, diagnosed with cancer, and have an end-of-life SDM, were reported to have a higher likelihood of experiencing peace with dying. The interplay between cancer diagnosis, widowhood, and the presence of a decision maker highlights the complex interplay of personal circumstances, and preparedness or comfort with death, that can enhance the likelihood of experiencing peace with dying.[7, 8] We found that experiencing peace with dying is multifaceted, influenced by a combination of personal characteristics, end-of-life planning, access to end-of-life care, and predictability of the illness trajectory. Therefore, I decided to understand peace with dying, and additional quality indictors on subgroups of older adults to see if we could better understand the overall dying experience more granularly.

In Chapter 3, I investigated how different settings—home, hospital, and hospice or palliative care units (PCU)— are associated with the quality of death (dying with peace, dying with dignity, dying in ones preferred place, and dying without pain). This chapter aimed to understand the overall quality of death experience between older adults in the three different categories. I found that while many individuals who die at home achieved a dignified death in their preferred location, those who die in palliative care units (PCUs) or hospices experienced greater peace and are more likely to die without pain suggesting a compromise between dying in a familiar environment versus dying in PCU. Although dying at home is preferred by a majority of Canadians, it may not be the best place of death for all older adults if adequate supports are not provided.[9, 10] For example, the lower rates of pain-free death at home or in hospitals compared to hospices highlight the role hospice and PCUs play in managing physical discomfort at the end-of-life.[11, 12] My findings also indicate that individuals residing in Quebec, British Columbia, or the western provinces had higher odds of dying in palliative care units or hospices compared with Ontario suggesting regional differences in access to, or utilization of, specialized end-of-life care facilities or better home based palliative care in Ontario.[13, 14]

In Chapter 4, I wanted to investigate end-of-life interventions, specifically, MAiD, and quality of death and dying. I found that approximately a quarter of older adults considered MAiD as they approached death, and a quarter of those who considered it ultimately received it. Potential reasons for considering but not receiving MAiD might be dynamic personal decisions, procedural delays, or the loss of capacity before MAiD can be administered.[15, 16] I also found that, older adults who considered or received MAiD are reported to have had a better overall quality of death and dying experience than those who did not. My findings suggest that people are not driven to consider or request MAiD due to a poor care experience or gaps in care, or due to factors that are generally amenable to high quality palliative care.

Comparison of Findings with Relevant Literature

Each study in this thesis includes specific comparisons to relevant literature, detailed in its respective chapter. However, there are broader comparisons to the literature that warrant further discussion. Assessing quality of death and dying has been previously examined, but a national level examination of personal and end-of-life characteristics from older adults living across Canada has not been investigated previously.[17, 18]

Canadians prioritize a peaceful death; however, I found that approximately 20% of older adults in our study did not experience peace with dying. This is likely because many older adults exhibit complex symptoms hindering their ability to achieve peace and may not be prepared for end-of-life.[7, 8, 19] Although, some older adults did not experience peace with dying, we found that Canadians in our study experience peace with dying more commonly compared to those in Belgium.[20] This suggests potential cultural or contextual differences in end-of-life experiences that may warrant future investigation.

Previous studies have shown that dying at home is associated with higher satisfaction levels among patients and families.[21, 22] This thesis found that individuals die at home in their preferred place and die with dignity more often than those dying in palliative care units or hospices or hospitals, inevitably increasing satisfaction. Discrepancies between preferred and actual places of death are common, particularly in clinical scenarios where life-sustaining measures or disease progresses.[23, 24] Previous research shows that older adults report experiencing peace with dying and effective pain and symptom control when dying at home.[25-27] This reflects older adults' growing preference for spending their final moments in the comfort of their own homes.[27, 28] These findings contradict the findings of this thesis, as I found that older adults who die in palliative care settings experience greater peace and pain relief more often in those who die at home.

Our findings on MAiD offer new insights into the quality of death and dying for those considering or receiving MAiD. No previous study has examined informal considerations of

MAiD alongside quality of death, making this analysis a unique contribution to the field.[29-31] Further, these findings refute the existing hypothesis that individuals seek MAiD due to lack of access to health care resulting in premature death.[32] Our findings support the need for future investigation on quality of death and dying experiences for those who receive MAiD to a larger scale.

Implication of Thesis Findings

This thesis offers valuable insights for clinicians, researchers, and policymakers. I found that understanding quality of death and dying is multifaceted. Clinicians can use the findings of these studies to enhance training and practice in end-of-life care, focusing on personal characteristics, aspects of social connection, predictability of the illness trajectory, end-of-life planning, and knowledge of MAID policies and resources.

Having a cancer diagnosis, being a widow, and the presence of a decision maker increased the likelihood of peace with dying which highlights the complex interplay of personal circumstances and preparedness or comfort with death.[7, 8] Understanding these factors that lead to a peaceful death could encourage more open discussions among families about end-of-life wishes and planning, reducing the burden on families during decision-making. Additionally, previous research suggests that advance care planning (ACP) and designating a decision-maker enhance patient control, reduce end-of-life anxiety, and foster peace.[33] Our findings support this, indicating these practices ease complex decision-making during vulnerable times. These findings can inform policies that determine how to balance both end-of-life care settings and the overall comfort and dignity of patients.

When focusing on quality of death based on location, I found that there may be a compromise in location of death and quality of death based on whether one dies in hospice or home.[9, 10] These results may help clinicians tailor care protocols based on the setting (home, hospice, or hospital) to better support patients' end-of-life preferences, potentially improving quality of care in each environment. For instance, clinicians can focus on better pain management strategies for those who may experience a home death. Regional health and social policies may influence where older individuals die with palliative care being accessed or readily available in Quebec. In terms of policy, demonstrating the value of home and hospice settings for peaceful dying could advocate for increased funding and resources to support these options, potentially reducing hospital-based deaths.[14] These findings can inform policies that determine how to balance both end-of-life care settings and the overall comfort and dignity of patients such as, more access to hospice services for those dying at home.

When we investigated quality of death and dying for older adults who received MAiD, we found that a large portion of individuals are exploring MAiD as an option, yet many do not proceed to receive it. This research emphasizes the need for compassionate communication, symptom management, and knowledge of MAID policies. Individuals are not driven to consider or request MAiD due to a poor care experience or gaps in care, or due to factors that are generally amenable to high quality palliative care.[34-38] These findings could be used to develop or expand palliative care programs, ensuring that future healthcare providers understand the ethical, clinical, and emotional aspects of MAID and peaceful dying. Additionally, we observed that having a designated SDM was associated with MAiD consideration. This suggests that the presence of an SDM can facilitate discussions about sensitive end-of-life options such as, MAiD, ensuring that the individual's wishes are considered. These findings support ACP conversations and incorporating MAiD discussions between patients, families, and healthcare providers, ultimately enhancing the quality of the end-of-life experience.[39]

All three studies contribute valuable insights could inspire comparative studies examining how different regions and healthcare systems handle end-of-life care, leading to broader, more generalizable conclusions.

Strengths and Limitations

This thesis discusses the methodological strengths and limitations of each study in their respective chapters. However, several significant strengths and limitations are common across the studies. Each chapter contributes to understanding the landscape of end-of-life experiences in Canada and understanding different aspects of quality of death and dying. The use of the data from the CLSA enables the analysis of health, social, and biological data collected from a national cohort of older adults across Canada—enhancing the generalizability of findings and reducing selection biases associated with smaller, localized studies. As secondary data from CLSA was used, it allows for efficient research that builds on validated data collection methods, making findings more reliable and potentially more reproducible. Further, since decedent interviews were conducted by trained interviewers, there is no missing data in these fields. All three studies provide implications for end-of-life care policies, potentially informing resource allocation and healthcare strategies to support quality end-of-life experiences across different care settings and interventions.

In all three study there is an absence of data on certain factors not covered in the Canadian Longitudinal Study on Aging decedent interviews, such as types of end-of-life interventions used or caregiver burden to address overall quality of death and dying as a result of secondary data use.[40, 41] Since, CLSA interviews occur many months to years after death based on decedent interview launch date , death date, and date of next-of-kin contact, it is conceivable that over time, the recollection of events may be influenced by various factors, potentially leading to a bias favoring positive or negative end-of-life experiences based on grief symptoms.[42] While previous studies have highlighted the accuracy of one perspective, uncertainty exists regarding more sensitive topics like MAiD deaths, where conversations with the deceased may have been limited or absent.[43, 44] Similarly, this study is limited to one perspective and interviewing more than one respondent would have allowed for more perspectives of the dying experience as previous research shows there is moderate agreement between family members.[45] Further, caregivers may overestimate the degree of pain, and other symptoms, compared to the individual experiencing the symptoms.[46, 47] Though the CLSA sample is referenced to the 2011 Canadian census, participants are generally wealthier and more likely to identify as White. However, this is the best sample available to approximate the older adult end-of-life experiences.[29, 48]

Next Steps in Program of Research

This thesis sets up work to conduct follow-up studies using additional waves of CLSA or other population-based datasets to observe changes in end-of-life preferences, access to MAID, and quality of death over time, helping to track evolving trends in patient preferences and health policy impacts. These studies report quantitative findings, future studies can employ qualitative or mix-methods analyses, such as in-depth interviews or focus groups with patients, families, and healthcare providers, to capture nuanced perspectives on what constitutes peace with dying, challenges with considering MAiD, or experiences of dying in various locations and how it varies across individuals and settings. Finally, as more end-of-life data is collected at the CLSA, developing predictive models to identify patients who may benefit most from specific end-of-life services will allow for tailored approaches to end-of-life care planning.

Future studies can further investigate the individual experiences of older adults based on specific characteristics, such as among specific underserved populations (e.g., rural residents, Indigenous peoples, or lower-income individuals). This will allow researchers investigate disparities in access to preferred settings, quality of care, and peace with dying which can inform more equitable policy development. This research can be used to engage policy advocates by translating research findings into policy briefs, guidelines, and educational materials for healthcare providers and policymakers, aiming to improve end-of-life care practices and policies based on evidence.

Conclusion

This thesis investigated the experiences surrounding the end of life, with a particular focus on achieving peace in dying, considering or receiving MAiD, and how different settings—whether at home, in hospice, or in hospital—can impact the quality of dying. By conducting a secondary analysis of data from the CLSA, this work has contributed to the understanding of personal and end-of-life characteristics influencing a good quality of death in older adults in Canada.

The findings from chapter two show that peaceful death is multifaceted and strongly linked to the complex interplay of personal circumstances, and preparedness or comfort with death. Notably, the option of MAiD appears to influence death experiences with older adults who considered or received MAiD have better end-of-life experiences. Although, the poorest quality of deaths occurs in hospitals there may be a compromise in location of death and quality of death based on whether one dies in hospice or home.

The insights from this research have practical implications for clinicians, educators, and policymakers, suggesting a need promote high quality end-of-life care to Canadians. Future research could expand on these findings by examining diverse populations and conduct qualitative studies to understand patient satisfaction. By advancing our understanding of quality of death, this dissertation contributes a foundation for developing compassionate, patient-centered policies and practices in end-of-life care.

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