Health Disparities in Timely Goals of Care Discussions and Hospitalizations Due to Infections in Nursing Home Residents

Jung A Kang

Submitted in partial fulfillment of the
requirements for the degree of
Doctor of Philosophy
under the Executive Committee
of the Graduate School of Arts and Sciences

COLUMBIA UNIVERSITY

2024

Abstract

Health Disparities in Timely Goals of Care Discussions and Hospitalizations Due to Infections in Nursing Home Residents

Jung A Kang

This dissertation investigates the effectiveness of and disparities in timely goals of care (TGOC) discussions in nursing homes (NHs), as well as hospitalizations due to infections. Chapter One provided an overview of the dissertation, including its aims and conceptual frameworks. Chapter Two is a systematic review of the current evidence concerning the timing of goals of care discussions in NHs and their impact on end-of-life outcomes. Chapter Three examines the differences in TGOC discussions in NHs for Black. Chapter Four analyzes the association between TGOC discussions and hospitalizations due to infections. Finally, Chapter Five synthesizes all findings. Key findings demonstrate that while effective TGOC discussions are associated with reduced hospitalizations due to infections in NH residents, significant racial and ethnic disparities exist, particularly among NHs with higher proportions of Black residents and those located in socioeconomically disadvantaged areas. These findings highlight the need for improved TGOC practices and targeted interventions to address systemic barriers and ensure equitable end-of-life care.

Table of Contents

List of Tables

List of Figures

Acknowledgments

This dissertation would not have been possible without the essential support and guidance provided by many. Foremost among my inspirations for choosing Columbia Nursing was Dr. Patricia W. Stone, whose contributions to nursing science profoundly impacted me even before I entered the program. I am deeply grateful to and respect Dr. Stone, an incredible mentor whose guidance has been invaluable. Since I began my research in 2020, Dr. Stone has been my greatest role model and the person I aspire to emulate in all respects.

My sincere appreciation also extends to my dissertation committee: Drs. Andrew Dick, Lara Dhingra, Veronica Barcelona, Gregory Alexander. I am particularly thankful to Dr. Andrew Dick, whose confidence in me surpassed even my own and whose expertise significantly expanded the scope of this work. Additionally, I appreciate Dr. Laurent Glance, who has always generously added a critical and professional perspective to all my studies.

I am grateful for the support and collaboration of my colleagues at the Center for Health Policy, including Dr. Ashley Chastain, Dr. Gayani Perera, Dr. Denise Quigley, Bridget Morse-Karzen, Lily Zhao, Tenzin Trinley, and Khadra Dualeh.

A heartfelt thanks goes to the Columbia Nursing faculty, from whom I have learned immensely: Drs. Arlene Smaldone, Maureen George, Elizabeth Corwin, Elaine Larson, Kasey Jackman, Jean-Marie Bruzzese, Jianfang Liu, Adriana Arcia, Sue Bakken, and Lusine Poghosyan. Special thanks to Dr. Jingjing Shang, who not only gave me the opportunity to join her research team but also provided support and mentorship.

I am also thankful for the encouragement and support of my peers and colleagues, especially the Special 2020 cohort: Sarah Leonard, Brittany Taylor, Eleanor Turi, Mollie

Hobensack, Amy McMenamin, Yashika Sharma, and Kylie Dougherty, along with Drs. Leah Estrada, Aluem Tark, and Jiyoun Song, who have been pillars of support.

Appreciation is also due to the grant management office, particularly Alex Mangone and Kristine Kulage, and the staff of the Columbia Nursing PhD program, Judith Kelson, Ruben Flores, and Ashley Fonville.

To my family—my parents Mia Kwon and Dongwoo Kang, my sister Sohee Kang, and Soyoo—thank you for your support and love. Mom, you have always been my lifetime role model and mentor, with an intrinsic motivation to improve systems at the policy level through scientific work that helps large populations, which has always inspired me.

Finally, I acknowledge the financial support of the National Institute for Nursing Research (T32 NR014205, F31 NR020566), which funded my doctoral studies.

Dedication

This dissertation is dedicated to all the patients I have encountered in my nursing journey, at their most fragile moments and nearing their end-of-life, across various healthcare settings and communities. I hope that the small insights gained from this work will make the final stages of life, which everyone ultimately faces, a time that is comfortable, painless, and filled with ample moments spent with loved ones.

Chapter 1: Introduction

Chapter one presents a comprehensive outline of the dissertation, which examined end-of-life care and infection management in nursing homes (NHs) with a focus on health disparities. Particularly, this dissertation investigated the suboptimal timely goals of care discussions (TGOC) in NHs resulting hospitalizations due to infection during the end-of-life period. This first chapter identifies the existing gaps in knowledge concerning health disparities in NH end-of-life care services, provides an overview of the conceptual framework guiding the study, outlines the specific aims of the dissertation, and highlights the contributions to future knowledge in the fields of health disparities, end-of-life care, and infection management in NHs.

1.1 Nursing Homes

Facility-based long-term care services encompass a range of options such as those that provide board and care homes, assisted living facilities, NHs, and continuing care retirement communities (The National Institute on Aging, 2017). The focus of this dissertation is NHs, which are also referred to as skilled nursing facilities. NHs offer an extensive range of healthcare and personal assistance services. Their emphasis on healthcare is typically greater compared to most assisted living facilities and commonly include nursing care, round-the-clock supervision, daily meals, and support with daily activities. Additionally, rehabilitation services like physical, occupational, and speech therapy are provided (The National Institute on Aging, 2017). According to the Centers for Disease Control and Prevention (CDC) (Centers for Disease Control and Prevention, 2021b), in 2018, there were approximately 15,600 NHs in the US, providing care for over 1.3 million residents who occupied around 1.7 million beds. A significant majority (83.5 %) of NH residents are 65 years and older. Furthermore, over one-third (38.6 %) of residents are aged 85 and older (Harris-Kojetin et al., 2019). In the US and globally, the population is rapidly aging. Approximately half of individuals who are currently age 65 will require some form of paid long-term care services during their lifetime. By the year 2030, one in every four Americans will be 65 or older. The demographic group with the highest rate of growth are individuals 85 and older. It is projected that this group will increase from 6.5 million in 2035 to 11.8 million in 2060 (National Academies of Sciences & Medicine, 2022; Vespa et al., 2020).

Approximately 14.9 percent of individuals residing in NHs require assistance with at least five activities of daily living (ADLs) (Centers for Medicare & Medicaid Services, 2015). The majority of these individuals have multiple serious chronic conditions such as arthritis, hypertension, diabetes, heart disease, or osteoporosis and also may experience cognitive impairments or behavioral health conditions. Long-term residents often present with multiple serious chronic conditions, including one or more geriatric syndromes, which are prevalent health conditions among older adults (National Academies of Sciences & Medicine, 2022; Sherman & Touhy, 2017). These syndromes, including pressure ulcers, incontinence, falls, functional decline, and delirium, share four common risk factors: older age, baseline cognitive impairment, baseline functional impairment, and impaired mobility (Inouye et al., 2007). Management requires routine assessment by nursing professionals to identify changes in medical status or disease severity that may lead to hospitalization or death. To meet the diverse needs of residents, some NHs have expanded their services to include specialized care, such as dementia care and most NHs have contract with hospice agencies for end-of-life care (Dhingra et al., 2019; National Academies of Sciences & Medicine, 2022; Sherman & Touhy, 2017).

NHs play a crucial role in providing care until the end-of-life, with a majority (80.7 %) of NHs providing access to hospice services (Harris-Kojetin et al., 2019). Prior to the COVID-19 pandemic, from 1999 to 2019, an average of 21 percent of all deaths and 27 percent of deaths among individuals aged 65 years or older in the US took place in NHs (Centers for Diesase Control and Prevention, 2020a). Additionally, more than one-third of older Americans experience a stay in a NH within the last 90 days of their life (Teno et al., 2018).

With advanced age and chronic serious illness, NH residents were especially vulnerable to the COVID-19 pandemic resulting in one-third of all COVID-19 deaths in the US (Centers for Disease Control and Prevention, 2021a; Kaiser Family Foundation, 2021). Furthermore, disparities among NH residents during the pandemic were exacerbated with the disproportionate impact of COVID-19 on racially and ethnically minoritized populations (Travers et al., 2021). However, limited understanding of disparities among racially and ethnically minoritized populations in NHs poses challenges in promoting health equity (National Academies of Sciences & Medicine, 2022).

1.2 Infection Management in Nursing Homes

In 2016, infection control (45.4%) was the top deficiency cited among CMS certified NHs (Harrington et al., 2018; National Academies of Sciences & Medicine, 2022). This is problematic because NH residents are particularly susceptible to infections due to compromised physiologic barriers (e.g., skin breakdown and use of devices such as indwelling urinary catheters), immune-suppression, malnutrition, dehydration, comorbidities, and functional impairments (e.g., incontinence and/or immobility) (Fu et al., 2020; Harris-Kojetin et al., 2019; Montoya et al., 2016; Smith et al., 2008). Prior to the COVID-19 pandemic, there were up to 2.7 million infections annually in NHs and more than 380,000 residents died of infections each year (Herzig et al., 2017; Montoya & Mody, 2011). The risks for infectious diseases in NH residents have been further illuminated by the COVID-19 pandemic with NH residents representing 1.2%

of the population and one third of all COVID-19 deaths in the US (Centers for Disease Control and Prevention, 2021a; Kaiser Family Foundation, 2021). NH residents who are nearing the end-of-life are at high risk of infections making NHs critical care settings for infection management during this period.

1.3 Hospitalizations Due to Infection at the End-of-Life in Nursing Homes

Prior to the COVID-19 pandemic, about 50% of NH residents were transferred to acute care hospitals due to suspected infections, and up to 55% of these hospitalizations were identified as potentially avoidable (Lemoyne et al., 2019). Furthermore, 60% of NHs report that they would transfer terminally ill residents with suspected infections to the hospital rather than providing comfort care (Mitchell et al., 2014; A. Tark, L. V. Estrada, et al., 2020). NH residents who are hospitalized for infection have worse outcomes compared to those who remained in NHs (Gracner et al., 2021; Griffith et al., 2020; Lemoyne et al., 2019). The former group has increased cognitive impairments and functional decline compared to the latter group (Gracner et al., 2021; Griffith et al., 2020). This may be because many NH residents who get seriously ill from infections do not tolerate aggressive care such as unnecessary intravenous antimicrobials and mechanical ventilation when hospitalized. Furthermore, NH residents transferred to the hospital may die there, which may not be congruent with resident's and family's end-of-life wishes (Gilissen et al., 2020). In fact, up to 90% NH residents and families chose symptom management as the primary goals of care, which is not consistent with being hospitalized for infection management (Cohen et al., 2019; Ernecoff et al., 2018; Mitchell et al., 2009). Poor infection management at the end-of-life is associated with poor resident outcomes, including hospitalization (Harrison et al., 2021), which may not be consistent with the resident and family preferences (Cohen et al., 2019; Ernecoff et al., 2018; Mitchell et al., 2009).

1.4 Palliative and End-of-Life Care in Nursing Homes

Palliative care is a model of care that occurs alongside usual treatments and is individualized according to the patient's and family's unique sources of distress and illness burden, and personal values and preferences. It is a clinical approach focused on enhancing quality of life by managing the illness burden experienced by patients with serious chronic illness, and their families, from the time of diagnosis forward (*Oxford Textbook of Palliative Medicine*, 2021). Hospice is a service delivery approach that provides specialist palliative care services and impacts potentially avoidable hospitalizations. Comprehensive NH-based care at the end-of-life can be provided by hospice, a government-supported health care system that offers treatments and services consistent with specialist palliative care for advanced illness at no cost to the resident and family (*Oxford Textbook of Palliative Medicine*, 2021).

Palliative care has core principles, practice norms, standards, and professional competencies, and the services that provide palliative care vary by populations served, specific treatments, level of specialization, and other characteristics. "Hospice" is the name applied to varying types of palliative care programs around the world. Hospice is now a large government-supported and highly regulated health care system providing specialist palliative care for eligible patients living at home or in NHs (*Oxford Textbook of Palliative Medicine*, 2021).

With an aging population and high prevalence of functional and/or cognitive impairments, many older adults with serious illness reside in NHs in their final stage of life (Juthani-Mehta & Quagliarello, 2010). Since the COVID-19 pandemic began, there has been a significant rise, five times greater, in the number of completed advance directives and advance care planning compared to the period before March 2020 (Auriemma et al., 2020). Indeed, over 1.3 million residents live in the 15,600 NHs across the nation and about 90% are aged 65 and older (Centers for Disease Control and Prevention, 2021b; Harris-Kojetin et al., 2019). Among all long-term care residents, 65% die within 12 months of admission emphasizing the role of NHs as important end-of-life care settings (Kelly et al., 2010).

1.5 Timely Goals of Care Discussions

TGOC discussions allow clinicians to share prognostic information, elicit decision-making preferences, and promote family involvement at the end-of-life (Bernacki & Block, 2014; Crighton et al., 2008; Jenerette & Mayer, 2016; Ketcher et al., 2020; Tinetti et al., 2016; Tinetti et al., 2019). Early discussions about preferences increase goal-congruent care, better quality of life, reduced use of aggressive care near death, increased use of palliative care, and reduced healthcare costs (Bernacki & Block, 2014; Hanson et al., 2017; Yao et al., 2015). In particular, discussions about infection management at the end-of-life may reduce unnecessary antimicrobial use and decrease hospitalizations due to infection as well as improve quality of life and quality of death for the resident. Therefore, discussions about preferences for care should be established early and occur periodically in the care trajectory (Boyd et al., 2019; Mitchell et al., 2014; Tark et al., 2021; Yao et al., 2015).

Despite this importance, researchers have found that discussions with NH residents about infection treatment decisions were often delayed until the time of medical crisis, which can lead to increased care burden such as hospitalizations at the end-of-life (A. Tark, J. Song, et al., 2020). Researchers have found that when residents and families are faced with urgent decision making in “crisis” situations, they are often emotionally distressed and not afforded sufficient time to engage in discussions to explore values and preferences (Jain & Bernacki, 2020; Aluem Tark et al., 2020). Therefore, it is recommended that discussions about preferences for care should occur earlier in the care trajectory and be revisited periodically to discuss medical prognosis and risks and benefits of treatment options throughout the NH resident's illness course (Glajchen et al., 2022; Jain & Bernacki, 2020). Despite the importance of TGOC discussions, we do not know how variations in TGOC discussions are related to hospitalizations due to infection at the end-of-life in NHs.

1.6 Health Disparities in End-of-Life Care in Nursing Homes

Health disparities are defined as systematic variations in the distribution of health resources and health status among different groups of people (World Health Organization, 2018). Black and Hispanic residents often receive poor quality of care in NHs compared to White and Non-Hispanic residents (Estrada et al., 2021). Black and Hispanic residents are more likely to be hospitalized at the end-of-life and less likely to receive palliative care compared to White and Non-Hispanic residents (Cai et al., 2016; Ellington et al., 2016; Estrada et al., 2021; Frahm et al., 2012; Gozalo et al., 2011; Zheng et al., 2011). The reasons for these disparities may involve complex social determinants of health (SDOH), which are defined as social factors and physical conditions of the environment in which people are born, live, learn, play, work, and age (Centers for Disease Control and Prevention (CDC). ; Lewis & Riegel, 2010; O'Conor et al., 2019; Scott et al., 2020; U.S. Department of Health and Human Services.). Structural inequities contribute to unequal experiences and can lead to disparities in health outcomes (National Academies of Sciences & Medicine, 2017). For example, NHs with a high proportion of Black and Hispanic residents are often large for-profit NHs that have a greater number of Medicaid residents and limited resources including poor staffing (Li et al., 2020; Smith et al., 2007). Facility (e.g., staffing) and community (e.g., rurality) characteristics plays a key role in access to quality NH care and infection-related outcomes (Gorges & Konetzka, 2020, 2021; Mor et al., 2005; Travers et al., 2021; Zheng et al., 2011). NHs with a higher proportion of Black residents and those located in rural settings had higher COVID-19 cases and deaths compared to NHs with lower proportion of Black residents in urban settings (Mackey et al., 2021; Travers et al., 2021). Therefore, it is crucial to evaluate and address SDOH in order to achieve health equity (National Center for Chronic Disease Prevention and Health Promotion, 2021). However, there is limited knowledge about whether TGOC discussions vary by race and ethnicity, and other SDOH at the resident-, facility-, and community-level. Also, the differences in the relationship of TGOC discussions and hospitalizations due to infection are not known.

1.7 Gaps in Existing Literature

Several studies have examined the impact of discussions about care preferences at the end-of-life on resident outcomes (Anna Clarissa Araw et al., 2014; Emiloju et al., 2020; Lamberg et al., 2005; Lima & Miller, 2017; Lindner et al., 2007; Martin et al., 2016; Susan C. Miller et al., 2017; Mitchell et al., 2017; Nicholas et al., 2014; Odejide et al., 2020; Starr et al., 2019). However, few studies have determined whether variations in TGOC discussions impact the end-of-life care outcomes, and most extant studies focus on acute care settings and cancer populations (Emiloju et al., 2020; Odejide et al., 2020; Starr et al., 2019). Furthermore, no known studies have examined differences in the receipt of TGOC discussions and resulting hospitalizations due to infections in NH settings by race and ethnicity, and other resident, facility, and community characteristics. Thus, this dissertation will address these gaps by identifying the existing disparities in TGOC discussions and the association with end-of-life outcomes (e.g., hospitalizations due to infections) in NHs.

1.8 Conceptual Framework Guiding Dissertation Research

An integrated conceptual framework using the Donabedian Model (Donabedian, 1966) and Minority Access to End-of-Life Care Model (Laguna et al., 2012) guided the dissertation's approach (Figure 1.1). The Donabedian Model examines health care quality along three dimensions including structures, processes, and outcomes (Donabedian, 1966). The Minority Access to End-of-Life Care Model was developed to better explain health disparities in end-of-life care; this model identifies the interactions between patient-level, system-level, and societal-level barriers that result in health disparities (Laguna et al., 2012). The selection of this conceptual framework was through systematic search and review, and this work has been published (See Appendix A). Together, these frameworks are useful to address disparities in minority access to timely end-of-life care and the relationship with infection-related outcomes in NHs.

There are three main concepts in the integrated conceptual framework: SDOH, Processes, and Outcomes. SDOH encompass resident, facility, and community characteristics, including factors such as socioeconomic status, education, and neighborhood context. It is important to note that race and ethnicity, while included in the analysis, are not SDOH themselves but reflect the impact of structural racism and discrimination on health. Therefore, in this framework, race and ethnicity are considered in the context of social and political determinants rather than biological factors. Race and ethnicity, which are the main predictors, are separated from the other resident characteristics in the figure. Processes include TGOC discussions and the outcomes include hospitalizations due to infection. Together, this integrated framework guided this dissertation.

1.9 Specific Aims

Aim 1: Assess the current scientific evidence on TGOC discussions in NHs and the impact on residents' end-of-life care outcomes. This aim was completed by a systematic literature review.

Aim 2: Identify differences in TGOC in NHs by resident, facility, and community characteristics. This is a national NH-level quantitative analysis.

Aim 3: Determine the association between TGOC discussions and hospitalizations due to infections and examine differences by resident, facility, and community characteristics. This is a nationwide individual resident-level quantitative analysis.

1.10 Theoretical Linkages Among Proposed Manuscripts

In chapter two, the systematic literature review synthesized the current evidence concerning TGOC discussions in NHs, factors related to TGOC discussions, and the association with end-of-life outcomes. In chapter three, a nationwide quantitative analysis, TGOC discussions (Processes) will be described, and differences will be examined by race, ethnicity, and other resident characteristics at the facility-level (Aim 2). In chapter four, a nationwide quantitative analysis, associations between hospitalizations due to infections (Outcomes) and TGOC discussions (Processes) will be examined at the resident-level (Aim 3). In all aims, the influence of SDOH (resident, facility, and community characteristics) will be examined.

1.11 Institutional Review Board Approval

This dissertation reports empirical research involving the analysis of extant data from US NH residents. The data sources included secondary data from the Study of Infection Management and Palliative Care at End-of-Life (SIMP-EL; R01 NR013687) and Medicare claims data. All data utilized in this study are strictly confidential, de-identified, and accessible only to the research team approved by the Institutional Review Board. Approval for this dissertation research was obtained from the Columbia University Institutional Review Board (IRB-AAAU3141). Additionally, a dissertation data reuse agreement (RSCH-2023-59448) was secured from the Centers for Medicare and Medicaid Services to ensure compliance with data use regulations and protocols. No identifiable information at the resident, provider, or facility-level is included in any publications or presentations resulting from this research. The confidentiality and privacy of all individuals involved in the data collection process are rigorously maintained.

1.12 Contributions to Future Knowledge

This dissertation will provide information for NH leaders, clinicians, and health policy makers on the extent to which timing variations of goals of care discussions impact on the infection-related health outcomes in NHs and health disparities within these issues. NHs are critical care settings for infection management at the end-of-life. However, suboptimal end-of-life care processes increase care burden, particularly hospitalization due to infection in NH residents. Furthermore, Black and Hispanic populations in NHs have been suffering from exacerbated health disparities in end-of-life care and infection-related outcomes due to the pandemic. However, there are a limited number of publications addressing this issue. Aligned with the National Institute of Nursing Research focus of promoting health equity with a special emphasis on reducing systemic and structural inequities, this study will provide evidence to identify differences in TGOC discussions, and potential disparities that result from these differences. This dissertation provides a foundation to develop knowledge informing evidence-based policy recommendations to reduce health disparities in end-of-life and palliative care practices and infection-related outcomes. Given the contributions to future knowledge, this dissertation research is funded by The National Institute of Nursing Research Ruth L. Kirschstein Predoctoral Research Award (F31 NR020566).

Figure 1.1

An integrated conceptual framework using the Donabedian Model and Minority Access to End-of-Life Care

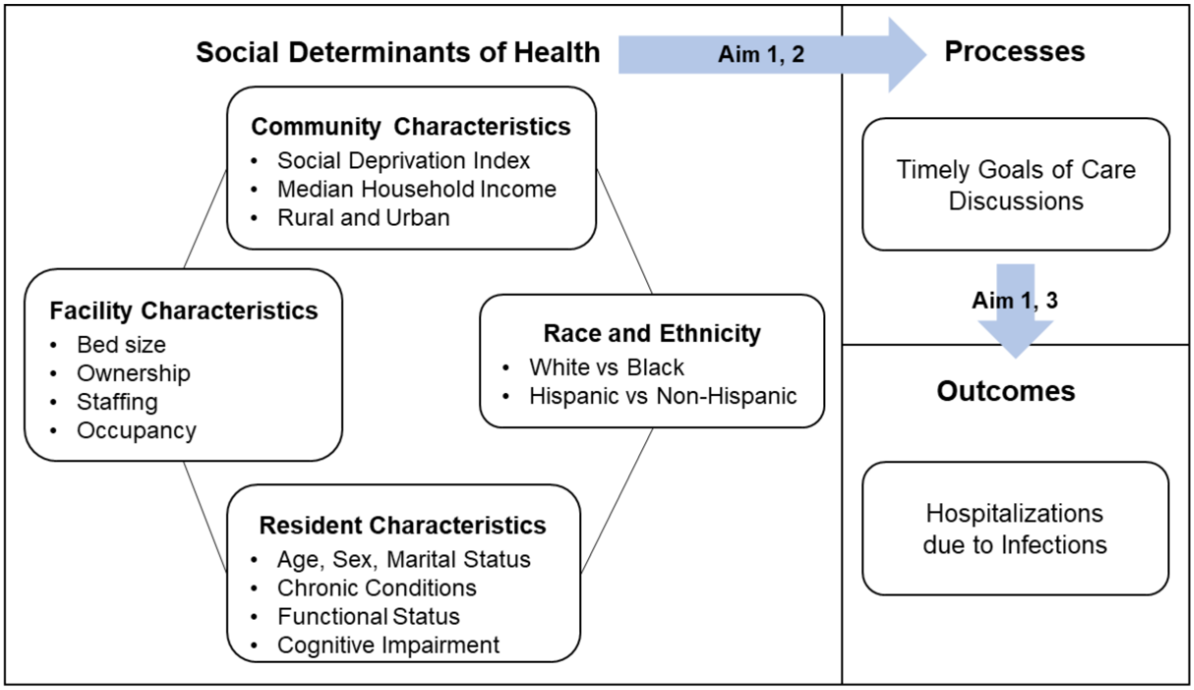


Figure 1. An Integrated Conceptual Model using the Donabedian Model and Minority Access to End-of-Life Care

Chapter 2: Timing of Goals of Care Discussions in Nursing Homes: A Systematic Review

Note. The manuscript in Chapter 2 has been published in the Journal of the American Medical Directors Association. Citation for the final published version is as follows:

Kang, J. A., Tark, A., Estrada, L.V., Dhingra, L. & Stone, P. W. (2023). Timing of Goals of Care Discussion in Nursing Homes: A Systematic Review. *Journal of the American Medical Directors Association, 24*(12), 1820–1830. https://doi.org/10.1016/j.jamda.2023.09.024

Related appendices:

Appendix B: Preferred Reporting Items for Systematic Review and Meta-Analyses*

Appendix C: Prospero registration for Chapter 2 Systematic Review*

Appendix D: Search Strategy for Chapter 2 Systematic Review

Appendix E: Modified Newcastle-Ottawa Scale for Chapter 2 Systematic Review

*Appendix not in published manuscript

2.1 Abstract

Objectives

Discussions between health professionals and nursing home (NH) residents or their families about the current or future goals of health care may be associated with better outcomes at the end-of-life (EOL), such as avoidance of unwanted interventions or death in hospital. The timing of these discussions varies, and it is possible that their influence on EOL outcomes depends on their timing. This study synthesized current evidence concerning the timing of goals of care (GOC) discussions in NHs and its impact on EOL outcomes.

Design

Systematic review.

Setting and Participants

Adult populations in NH settings.

Methods

This systematic review followed the Preferred Reporting Items for Systematic Reviews and Meta Analyses guidelines. We searched PubMed, Embase, and Cumulative Index of Nursing and Allied Health from January 2000 to September 2022. We included studies that examined timing of GOC discussions in NHs, were peer-reviewed, and published in English. Quality of the studies was assessed using the Newcastle-Ottawa Scale.

Results

Screening of 1,930 abstracts yielded 149 papers that were evaluated for eligibility. Of the 18 articles, representing 16 distinct studies, that met review criteria, 12 evaluated the timing of advance directives. There was variation in the timing of GOC discussions and compared to discussions that occurred within a month of death, earlier discussions (e.g., at the time of facility

admission) were associated with lower rates of hospitalization at the EOL and lower health care costs.

Conclusions and Implications

The timing of GOC discussions in NHs varies and evidence suggests that late discussions are associated with poorer EOL outcomes. The benefits of goal-concordant care may be enhanced by earlier and more frequent discussions. Future studies should examine the optimal timing for GOC discussions in the NH population.

2.2 Introduction

In the United States (US), more than 15,600 nursing homes (NHs) provide long-term care to more than 1.3 million elderly adults. About 40% of NH residents have advanced illnesses, and prior to the pandemic, more than 27% of all deaths in those 65 years or older occurred in NHs, making high-quality end-of-life (EOL) care critical for this population (Cronin & Evans, 2022; Das Gupta et al., 2021; Veronese et al., 2021). During the COVID-19 pandemic, the importance of good EOL care in NHs increased (Auriemma et al., 2020) and it is likely that some broad-based changes have occurred, exemplified by a five-fold increase in the rate of advance directive (AD) completion since the start of the pandemic (Auriemma et al., 2020). However, the outcomes associated with EOL care in NHs continue to be viewed as suboptimal (Towsley et al., 2015). For instance, up to 70% of NH residents experience potentially avoidable hospitalizations during the last 30 days of life (K. Allers et al., 2019).

A goals of care (GOC) discussion involving a person with chronic illness, or a surrogate if the person lacks decisional capacity, clarifies care preferences and may include advance care planning (ACP) (Bernacki & Block, 2014). ACP can provide clearly documented ADs, such as a living will, designation of a power of attorney for health decisions, or a physician's order defining the types of interventions preferred for EOL care. In countries where ACP and ADs may not be widely accepted, due to cultural or legal factors, GOC discussions can still take place within customary practice (Horn, 2014; Veshi & Neitzke, 2015). These discussions, as formalized in ADs, should respect patient and family values, aiding healthcare professionals in treatment decisions. Establishing ADs through GOC discussions can lead to improved EOL outcomes, (Bernacki & Block, 2014) including avoidance of unwanted therapies and alignment with palliative care (Gonella, Basso, et al., 2019; Smith-Howell et al., 2016). This review adopts a 'universal perspective' on documenting care preferences, primarily informed by ACP discussions. AD legality varies, and consent may be necessary for treatments (Horn, 2014; Veshi & Neitzke, 2015). Therefore, our focus is on documenting GOC preferences through ACP discussions, which can subsequently inform consent conversations and decision-making. This approach enhances the broad applicability of our findings, despite varying legal and cultural contexts affecting ADs.

The extent to which GOC discussions positively affect EOL outcomes may be influenced by the timing of the discussions. This timing varies widely. Some NH residents, or their surrogates, discuss care preferences at the time of NH admission, whereas others have no GOC discussions until dying is imminent (M. C. van Soest-Poortvliet et al., 2015). It is possible that earlier GOC discussions associate with better EOL outcomes by encouraging goal-concordant care. Earlier discussions may allow sufficient time to understand the resident's condition, prognosis, and treatment options, and facilitate effective ACP (Gonella, Campagna, et al., 2019). These considerations have led some experts to recommend that GOC discussions occur early and be revisited regularly (Gonella, Basso, et al., 2019; Sullivan et al., 2022).

The optimal timing of GOC discussions in NHs has received limited empirical attention (Glajchen et al., 2022). A systematic review was undertaken to 1) summarize current information on the timing of GOC discussions in NHs and 2) clarify the association between this timing and EOL care outcomes among NH residents.

2.3 Methods

This systematic review was conducted in accordance with the Preferred Reporting Items for Systematic reviews and Meta Analyses (PRISMA) guidelines (Page et al., 2021) (See Appendix B). A priori protocol was registered in PROSPERO (See Appendix C; CRD42021246498).

Data Sources and Search Strategy

Studies were identified using three electronic databases (i.e., PubMed, Embase, and Cumulative Index of Nursing and Allied Health). The search strategy was developed in collaboration with the Columbia University School of Nursing Informationist. The search terms included keywords related to: 1) NHs, 2) GOC discussions, 3) EOL care, and 4) timing. The full search strategy is available in Appendix D.

Eligibility Criteria

This review included peer-reviewed observational studies that were published from January 2000 to September 2022. The inclusion criteria were: 1) study populations of NH residents $\geq$ age 60 or NH personnel; 2) NH setting (defined as a long-term care facility); and 3) measured time frame of GOC discussions. We excluded studies that were: 1) written in non-English languages, 2) qualitative studies, 3) clinical trials, or 4) non-peer reviewed.

Study Selection

At least two authors (JK, AT, LVE) screened titles and abstracts independently the using Covidence software program.(Veritas Health Innovation) The full text of screened articles was reviewed by at least two authors independently (JK, AT, LVE). Any conflicts were resolved by discussions through meetings to reach consensus (JK, AT, LVE, PS, LD).

Data Extraction and Synthesis

Items for data extraction were documented prior to the review process in PROSPERO. All authors participated in discussions to develop the data extraction tool. Extracted data included study design, objectives, characteristics of study populations, setting, GOC discussion measures, GOC discussions timing measures, outcomes measured, and study limitations. We synthesized data narratively by identifying common themes found across the studies. The large heterogeneity in study methodologies (timing measures, types of GOC discussions, and outcome measures) rendered quantitative analysis of the data impractical.

Quality Appraisal

Cohort study quality was assessed using the non-modified Newcastle-Ottawa Scale (NOS) (Wells et al., 2014). Cross-sectional study quality was assessed with the modified NOS Scale, which has been used in multiple previous systematic reviews (Mackey et al., 2021; Moskalewicz & Oremus, 2020; Yuan et al., 2019). The NOS scale was then categorized as “poor”, “fair”, or “good” quality using the Agency for Healthcare Research and Quality (AHRQ) threshold (Mackey et al., 2021; Moskalewicz & Oremus, 2020; Yuan et al., 2019). The modified NOS scale and AHRQ rating system are in Appendix E.

2.4 Results

Study Selection

A total of 2,492 articles were identified. After removing 562 duplicates, we screened 1,930 titles and abstracts. There were 1,781 articles that did not meet the inclusion criteria and were excluded. We reviewed 149 full text articles, and 18 articles from 16 studies were included in the final review. The most common reasons for exclusion were: the timing of the GOC discussion was not measured (*n* = 68), the full text was unavailable for review (*n* = 23), and an observational design was not utilized (*n* = 20), see Figure 2.1.

Quality of Studies

Of the 16 included studies, 12 (14 articles in total) were cohort (Andreasen et al., 2019; A. C. Araw et al., 2014; Bouwstra et al., 2015; Brink, 2014; Hold et al., 2019; Konttila et al., 2020; Lamberg et al., 2005; McAuley et al., 2006; Susan C. Miller et al., 2017; Paque et al., 2019; ten Koppel et al., 2019; Tsai et al., 2017; Mirjam C van Soest-Poortvliet et al., 2015; van Soest-Poortvliet et al., 2014) and four were cross-sectional (Hickman et al., 2018; Johnson & Bott, 2016; Aluem Tark et al., 2020; Wenger et al., 2013). Among the cohort studies, 11 articles were rated as good quality (Andreasen et al., 2019; Bouwstra et al., 2015; Brink, 2014; Konttila et al., 2020; Lamberg et al., 2005; Susan C. Miller et al., 2017; Paque et al., 2019; ten Koppel et al., 2019), and 3 as poor quality (A. C. Araw et al., 2014; Hold et al., 2019; McAuley et al., 2006). The 4 cross-sectional studies were all rated as poor quality. All studies rated as poor quality had a lack of comparability (i.e., did not control for confounding factors in the study design or analysis). However, we included all studies in this review since our purpose was to describe the current descriptive status of the timing of GOC discussions. Detailed quality ratings for each study are in Table 2.1.

Study Characteristics

Of the 16 included studies, two articles (11.1%) were reported before 2010 (Lamberg et al., 2005; McAuley et al., 2006), six (33.3%) were reported between 2010 and 2015 (Anna Clarissa Araw et al., 2014; Bouwstra et al., 2015; Brink, 2014; van Soest-Poortvliet et al., 2014; M. C. van Soest-Poortvliet et al., 2015; Wenger et al., 2013), and 10 (55.6%) were reported after 2016. About half of the studies were conducted in the US (*n* = 9; 56%) (A. C. Araw et al., 2014; Hickman et al., 2018; Hold et al., 2019; Johnson & Bott, 2016; Lamberg et al., 2005; McAuley et al., 2006; Susan C. Miller et al., 2017; Aluem Tark et al., 2020; Wenger et al., 2013), 5 (31%) in European countries (Andreasen et al., 2019; Bouwstra et al., 2015; Konttila et al., 2020; Paque et al., 2019; ten Koppel et al., 2019; Mirjam C van Soest-Poortvliet et al., 2015; van Soest-Poortvliet et al., 2014), and 2 (13%) in Taiwan (Tsai et al., 2017) and Canada (Brink, 2014), respectively (Table 2.2). Of the 9 US studies, most used regional data (e.g., state-level data; *n* = 7; 77.8%) (A. C. Araw et al., 2014; Hickman et al., 2018; Hold et al., 2019; Johnson & Bott, 2016; Lamberg et al., 2005; Susan C. Miller et al., 2017; Wenger et al., 2013), and 2 (22.2%) used national data (McAuley et al., 2006; Aluem Tark et al., 2020). Of the 5 European studies, 2 (40%) were from the Netherlands (Bouwstra et al., 2015; Mirjam C van Soest-Poortvliet et al., 2015; van Soest-Poortvliet et al., 2014), one each in Belgium (Paque et al., 2019) and in Finland (Konttila et al., 2020) and one presented data from multiple European countries (reported in two articles) (Andreasen et al., 2019; ten Koppel et al., 2019).

Most articles (*n* = 14; 77.8%) sampled NH residents (Andreasen et al., 2019; A. C. Araw et al., 2014; Bouwstra et al., 2015; Brink, 2014; Hold et al., 2019; Konttila et al., 2020; Lamberg et al., 2005; McAuley et al., 2006; Susan C. Miller et al., 2017; Paque et al., 2019; ten Koppel et al., 2019; Tsai et al., 2017; Mirjam C van Soest-Poortvliet et al., 2015; van Soest-Poortvliet et al., 2014), 4 (22.2%) sampled NH personnel (e.g., staff) (Hickman et al., 2018; Johnson & Bott, 2016; Aluem Tark et al., 2020; Wenger et al., 2013). Of the 14 articles of residents, the sample size ranged from 149 (Hold et al., 2019) to 112,746 (Brink, 2014). One study that did not report sample size analyzed national data and likely had a very large sample (McAuley et al., 2006). Some studies that included NH residents described the sample by mean age (A. C. Araw et al., 2014; Bouwstra et al., 2015; Brink, 2014; Konttila et al., 2020; Paque et al., 2019; Tsai et al., 2017; Mirjam C van Soest-Poortvliet et al., 2015; van Soest-Poortvliet et al., 2014) (range 70 (Tsai et al., 2017) to 86 (Konttila et al., 2020) years) and sex (proportion of females range 49 (Tsai et al., 2017) to 85% (Hold et al., 2019)). Seven articles included deceased residents (Andreasen et al., 2019; Konttila et al., 2020; Lamberg et al., 2005; Susan C. Miller et al., 2017; ten Koppel et al., 2019; Mirjam C van Soest-Poortvliet et al., 2015; van Soest-Poortvliet et al., 2014), and 5 included residents diagnosed with dementia (Konttila et al., 2020; Lamberg et al., 2005; Susan C. Miller et al., 2017; Mirjam C van Soest-Poortvliet et al., 2015; van Soest-Poortvliet et al., 2014). One study included residents in a rural NH setting (Hold et al., 2019).

Of the 4 articles sampling NH personnel, sample sizes ranged from 238 (Wenger et al., 2013) to 2,191 (Johnson & Bott, 2016). These articles surveyed staff responsible for ACP discussions (Hickman et al., 2018) such as those providing direct care (Johnson & Bott, 2016), nurse directors (Aluem Tark et al., 2020), or administrators (Wenger et al., 2013).

Timing of Goals of Care Discussions

Table 2.3 summarizes the results. Among the 18 included reports, GOC discussions were measured in terms of 1) ACP discussion or AD completion (*n* = 12; 66.7%) (Andreasen et al., 2019; Brink, 2014; Lamberg et al., 2005; McAuley et al., 2006; Tsai et al., 2017); 2) communication about care preferences (*n* = 4; 22.2%) (Johnson & Bott, 2016; Susan C. Miller et al., 2017; Aluem Tark et al., 2020; van Soest-Poortvliet et al., 2014); or 3) provision of palliative care or comfort care (*n* = 2; 11.1%) (ten Koppel et al., 2019; Mirjam C van Soest-Poortvliet et al., 2015). Methods included surveys (*n* = 8; 44.5%) (Andreasen et al., 2019; Hickman et al., 2018; Johnson & Bott, 2016; Aluem Tark et al., 2020; ten Koppel et al., 2019; Mirjam C van Soest-Poortvliet et al., 2015; van Soest-Poortvliet et al., 2014; Wenger et al., 2013), medical record review (*n* = 7; 38.9%) (A. C. Araw et al., 2014; Bouwstra et al., 2015; Hold et al., 2019; Lamberg et al., 2005; Susan C. Miller et al., 2017; Paque et al., 2019; Tsai et al., 2017), or review of items in the Minimum Data Set (*n* = 3; 16.7%) (Brink, 2014; Konttila et al., 2020; McAuley et al., 2006). The time interval between NH admission and a GOC discussion was measured in days (*n* = 8; 57.1%) (A. C. Araw et al., 2014; Bouwstra et al., 2015; Hold et al., 2019; Lamberg et al., 2005; Susan C. Miller et al., 2017; ten Koppel et al., 2019; Tsai et al., 2017; Wenger et al., 2013), weeks (*n* = 2; 14.3%) (Mirjam C van Soest-Poortvliet et al., 2015; van Soest-Poortvliet et al., 2014), months (*n* = 2; 14.3%) (Brink, 2014; McAuley et al., 2006), and years (*n* = 2; 14.3%) (Konttila et al., 2020; Paque et al., 2019), or in terms of specified events (e.g., on admission/during care plan meetings/following an event/when the condition changes; *n* = 3; 16.7%) (Hickman et al., 2018; Johnson & Bott, 2016; Aluem Tark et al., 2020); and residents' capacity to state their wishes at the time of admission (*n* = 1; 5.6%) (Andreasen et al., 2019).

ACP discussion or AD completion

The timing of AD completion was examined in 5 studies (Andreasen et al., 2019; Brink, 2014; Lamberg et al., 2005; McAuley et al., 2006; Tsai et al., 2017). Two studies measured any type of ADs (Andreasen et al., 2019; McAuley et al., 2006). A European study found that residents who could express their preferences at NH admission were likely to complete ADs on admission (Andreasen et al., 2019). A study of US NHs observed that the prevalence of AD completion at admission, and 12 months later, was 45.3% and 59.5%, respectively, in 2000; and 44.5% and 62.7%, respectively, in 2004, and that family members were more likely to make EOL decisions at the 12-month follow-up (McAuley et al., 2006).

Two studies measured do-not-resuscitate (DNR) orders (Brink, 2014; Tsai et al., 2017). A Canadian study found that DNR orders at NH admission were more common when residents were older, had family members, and had limited prognosis (six months or less) and that DNR orders at a three-month follow-up assessment were more common among residents admitted from home and those who were older and had more severe physical and cognitive impairment (Brink, 2014). A study from Taiwan observed that the mean time between admission and completion of a DNR order was 840.65 days (SD=1168.89, range 0–4,848 days, median=159); and, DNR completion was more common after hospitalization (Tsai et al., 2017).

A study of US NHs found that about 84% of NH residents had a do not hospitalize (DNH) order at the time of death, about 40% had a DNH order during the last 30 days of life, and about 34% had it 180 days before death (Lamberg et al., 2005). Having a DNH order was associated with older age, having a surrogate decision maker other than the resident's adult child, and having eating problems.

Five studies measured the timing of Medical Orders for Life-Sustaining Treatment (MOLST) completion (A. C. Araw et al., 2014; Bouwstra et al., 2015; Hickman et al., 2018; Hold et al., 2019; Wenger et al., 2013). The median time from NH admission to MOLST completion ranged from 1 day (Bouwstra et al., 2015) (Netherlands) to 48 days (A. C. Araw et al., 2014) (US). Most NH residents had the MOLST completed on admission (Hickman et al., 2018) or within 7 to 10 days thereafter (Bouwstra et al., 2015; Hold et al., 2019). In one US study, the median time from NH admission to MOLST completion varied by race (white: 21 days vs. other: 229 days) (A. C. Araw et al., 2014). A study from Indiana observed that about 14% of NH staff reported that the MOLST discussion occurred after a decline or change in functional status (Hickman et al., 2018), and about half of the residents in a California study completed the MOLST after NH admission (Wenger et al., 2013). In a rural NH, about 12% of residents completed the MOLST 100 or more days after admission (Hold et al., 2019).

The rate of ACP discussions was examined in two studies (Konttila et al., 2020; Paque et al., 2019). In Belgium, about 22% of NH residents had ACP initiated at admission, 21% after one year, and 19% after two years; 38% had no ACP discussions (Paque et al., 2019). ACP was initiated for about 23% of residents without dementia and only 16% of those with dementia (p=0.003) (Paque et al., 2019). A Finnish study observed that the prevalence of ACP completion doubled between 2004-2009 and 2010-2013, and the timing of ACP completion was significantly earlier in 2010-2013 compared to 2004-2009 (Konttila et al., 2020).

Communications About Care Preferences

In 4 studies, researchers measured the timing of communications about care preferences with NH residents and families (Johnson & Bott, 2016; Susan C. Miller et al., 2017; Aluem Tark et al., 2020; van Soest-Poortvliet et al., 2014). One Dutch study reported that about 65% of families had discussions about their personal care preferences with their care providers, and about 86% had these conversations within 8 weeks after admission (van Soest-Poortvliet et al., 2014). In one US study, NH staff indicated that communications about death and dying should occur when residents are at the EOL (75%) and when families express a desire for these discussions (75%) (Johnson & Bott, 2016). In another US study, NH staff reported that communication about care preferences for infection management were more likely after a clinical change in the resident's health condition, such as fever or an event like aspiration (Aluem Tark et al., 2020).

Provision of Palliative Care or Comfort Care

A US study evaluating the timing of palliative care consultations reported that earlier consultations (31-180 days before death) were associated with younger age, less cognitive impairment, and worsening cognition or a decrease in activities of daily living (Susan C. Miller et al., 2017). Late consultations (1-30 days before death) were associated with older age, being female, and short-term NH stays (<90 days) (Susan C. Miller et al., 2017). A study of six European countries noted that the median time to initiate palliative care was two weeks before death (ten Koppel et al., 2019) and that earlier referrals were associated with GOC discussions (geometric mean ratio 1.36; 95% CI 1.08, 1.70) (ten Koppel et al., 2019). One Netherlands study observed that about 61% of residents had comfort care as their main goal, about 89% of these residents had this goal established at EOL, and about 18% of those who died did not have any goals established (Mirjam C van Soest-Poortvliet et al., 2015).

Outcomes Related to Timing of Goals of Care Discussions

Six studies investigated outcomes related to GOC discussions (A. C. Araw et al., 2014; Konttila et al., 2020; Susan C. Miller et al., 2017; Tsai et al., 2017; Mirjam C van Soest-Poortvliet et al., 2015; van Soest-Poortvliet et al., 2014). One US study observed that about 87% of residents with a MOLST had their EOL wishes honored; goal concordance was not assessed for those without a MOLST (A. C. Araw et al., 2014). The timing of MOLST completion was not associated with differences in EOL outcomes in a Finnish study (Konttila et al., 2020). A Taiwanese study showed that differences in mortality between residents with and without DNR orders (unadjusted hazard ratio 2.03; 95% CI 1.10, 3.98) became nonsignificant when adjusted for age (Tsai et al., 2017). In a US study of residents with dementia, earlier palliative care consultations were associated with a 13.2% lower rate of hospitalization in the last week of life, and 18.4% fewer burdensome transitions before death (e.g., hospital/hospice admission 3 days before death) (Susan C. Miller et al., 2017); these differences were not found in the group with later palliative care consultations (1-30 days before death). The latter study also observed lower health care expenses in the last 7 days of life, but not the last month of life, in the group with earlier palliative care consultations (Susan C. Miller et al., 2017).

A Dutch study noted that 86.3% of initial ACP discussions in NHs occurred within 8 weeks of NH admission and that 69.8% of families perceived that this timing was appropriate; 8.0% reported that the timing was "too early" and 4.7% described it as "too late" (van Soest-Poortvliet et al., 2014). Families and residents were more likely to establish a comfort care goal when they were satisfied with the ACP discussions (van Soest-Poortvliet et al., 2014). Also, when a comfort care goal was established shortly after the admission, families of residents were more satisfied with EOL care (adjusted b: 4.5; 95% CI: 2.8, 6.3) (Mirjam C van Soest-Poortvliet et al., 2015). However, quality of dying was not associated with the comfort care goal and its timing (Mirjam C van Soest-Poortvliet et al., 2015).

2.5 Discussion

A review of 12 cohort studies (Andreasen et al., 2019; A. C. Araw et al., 2014; Bouwstra et al., 2015; Brink, 2014; Hold et al., 2019; Konttila et al., 2020; Lamberg et al., 2005; McAuley et al., 2006; Susan C. Miller et al., 2017; Paque et al., 2019; ten Koppel et al., 2019; Tsai et al., 2017; Mirjam C van Soest-Poortvliet et al., 2015; van Soest-Poortvliet et al., 2014) and 4 cross-sectional studies (Hickman et al., 2018; Johnson & Bott, 2016; Aluem Tark et al., 2020; Wenger et al., 2013), meeting the current synthesis criteria, confirms varied timing of GOC discussions among NH residents. Typically, earlier discussions and those linked with AD completion are more prevalent among residents with decisional capacity or those in decline (Andreasen et al., 2019). In the US, most NH residents acquire DNH orders prior to death, but some receive them within the last 30 days of life (Lamberg et al., 2005). In Taiwan, DNR orders were usually completed over a span of more than 2 years, often after hospitalizations (Tsai et al., 2017). Belgium NHs tended to delay ACP discussions, particularly for residents with dementia, and these discussions usually occurred after disease severity worsened or life-threatening events (Johnson & Bott, 2016; Aluem Tark et al., 2020). The implementation of palliative care and comfort care often was delayed (ten Koppel et al., 2019; Mirjam C van Soest-Poortvliet et al., 2015), but when GOC discussions occurred, care was initiated earlier (ten Koppel et al., 2019). These findings underscore significant variability in the timing of GOC discussions in NH populations.

Up to 90% of NH residents and families chose comfort as the primary GOC, which may not be consistent with hospitalization at the EOL (K. Allers et al., 2019). Hospitalization may result in rapid cognitive and functional decline (Gracner et al., 2021; Griffith et al., 2020) and risks the hospital death that the resident seeks to avoid (Ernecoff et al., 2018). Although the relationship between the timing of GOC discussions and EOL care outcomes has yet to be adequately characterized, one US study found that earlier discussions are associated with lower hospitalization rates and EOL care costs (Susan C. Miller et al., 2017). This aligns with a greater preference to avoid hospitalizations when residents have better cognitive function. Recent research also associated DNR and DNH orders with lower hospitalization rates (Adekpedjou et al., 2022). Nonetheless, nonadherence to DNH orders is common, highlighting implementation challenges (Adekpedjou et al., 2022). DNH orders can pose issues when a resident's GOC focuses on pain relief, and an acute problem arises (e.g., bone fracture). Clinicians must carefully consider individual circumstances and preferences when handling DNH orders. Further studies are needed to elucidate the relationships between GOC discussion timing/frequency and various EOL outcomes, with the ultimate aim of achieving goal-concordant care, associated with higher satisfaction in EOL care (Mirjam C van Soest-Poortvliet et al., 2015; van Soest-Poortvliet et al., 2014).

Most of the reviewed studies measured the timing of events (e.g., ADs) and did not document the use of structured or standardized communication tools. GOC discussion tools may be useful but are seldom employed (Gonella, Basso, et al., 2019). Studies are needed to examine the timing of GOC discussions in NHs using validated, standardized GOC discussion tools (i.e., that include prompts and triggers for initiating a discussion) and determine whether tools can result in earlier discussions.

Future research should assess various factors influencing GOC discussions, including clinician-related concerns like the time commitment, training, and clinical competence, which may be deemed burdensome by NH staff (Bernacki & Block, 2014; Glajchen et al., 2022). Additionally, issues pertaining to residents and caregivers, such as their comprehension of illnesses, health literacy, access to legal support, and the alignment of surrogate decision-making with residents' preferences, warrant investigation (Bailoor et al., 2018). To enhance the timeliness of GOC discussions, some studies recommend systemic adjustments, like providing financial incentives for providers, implementing collaborative care models, addressing staffing challenges, and standardizing regulations across states (Bailoor et al., 2018; Glajchen et al., 2022).

Variations in GOC timing were evident among countries, potentially influenced by national policies and practices. For instance, Finland exhibited increasing ACP completion rates and earlier completion between 2004-2009 and 2010-2013, contrasting the US where rates declined and completions were delayed from 2000 to 2004 (Konttila et al., 2020; McAuley et al., 2006). Finnish law mandates GOC discussions and goal-concordant care in NHs, potentially explaining this disparity (Konttila et al., 2020). Similarly, the Netherlands, with NH physicians specializing in elderly care, demonstrated earlier MOLST completions than the US (Houttekier et al., 2010; Koopmans et al., 2010). In 2016, the US Centers for Medicare and Medicaid Services (CMS) introduced compensation for ACP discussions, resulting in a notable rise in outpatient ACP billing from 2016 to 2019, although it remained under 7.5% across patient subgroups (Palmer et al., 2021). A recent US review emphasized the importance of public education on ACP, suggesting messages that dispel misconceptions, increase awareness, and normalize EOL care (Fromme et al., 2023). Further research should investigate cross-national differences in GOC discussions concerning policy, clinician education, resident/family attitudes, cultural influences, and more.

This review highlights the limited data available to assess the nature, timing, and impact of GOC discussions in NHs on EOL outcomes. Further robust observational studies are required to empirically establish the benefits of early GOC discussions. Palliative care specialists recommend initiating these discussions shortly after NH admission, with repetitions following major events like hospitalization or significant changes in residents' health, and ADs updated accordingly. While these approaches are considered best practices based on expert opinion, there's a need for research to confirm whether systematic efforts to define and document care preferences and implement goal concordant care are enhanced by timely GOC discussions conducted before residents experience physical and cognitive decline.

To promote equity in NH care, work is needed to understand the specific factors that drive racial and ethnic disparities in the timing of MOLST completions in US NHs (A. C. Araw et al., 2014). This finding is consistent with many prior studies of practices and outcomes associated with NH care of advanced illness, and underscores the continuing need for research that characterizes the contributing factors that must be addressed to establish effective and equitable care.

Limitations

Most studies evaluated in our review measured the timing of GOC through events, such as AD completion. These events are proxies for serious illness discussions and the lack of specific information about the discussions themselves is a limitation of the work. Additionally, surveys that utilize self-report data may introduce bias. Also, studies evaluated were conducted across varied countries which differ in EOL care policies, reimbursement structures, and staffing for NH residents and clinician training.

2.6 Conclusions and Implications

It is widely accepted that GOC discussions are important for the provision of high quality EOL care in NHs. Although palliative care specialists endorse the value of a systematic approach to engage patients and families in relatively early discussions, with the expectation that timely discussions increase the likelihood of goal concordant care and better EOL outcomes, the timing of GOC discussions is largely delayed and varied across NHs. Studies are needed to provide additional evidence about the impact of GOC discussions, including their characteristics, triggers, timing, and impact on patient and family satisfaction levels. Our group and others have developed communication tools to facilitate these discussions with ambulatory populations (Dhingra et al., 2021) and more effective strategies for implementing GOC discussions in NH settings are needed. Policymakers and educators should develop approaches to promote earlier and effective GOC discussions for NH residents with varying backgrounds, morbidities, and informational needs.

Figure 2.1

PRISMA 2020 Flow Diagram

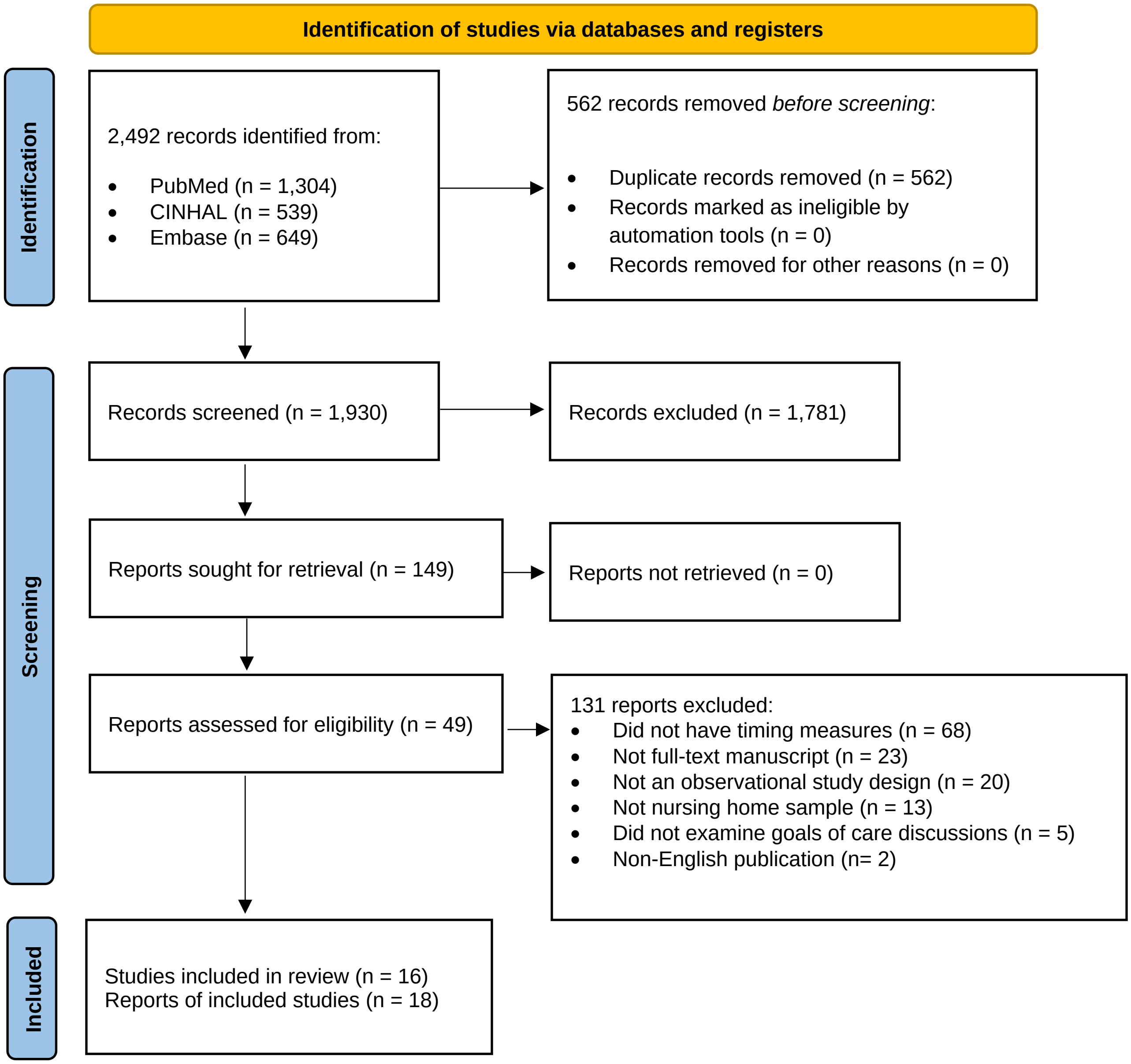


Table 2.1

NOS with AHRQ Thresholds

Study	Selection				Comparability	Outcomes			NOS Total	AHRQ Rating
Cohort Studies										
	Representative-ness of exposed cohort	*Selection of non-exposed cohort*	*Ascertainment of exposure*	*Outcome not present at start of the study*	*Outcome groups comparable, confounding controlled*	*Assessment of outcomes*	*Length of follow-up*	*Adequacy of follow-up*	Max=9	
Andreasen et al. 2019	*	*	*	*	**	*	*	*	9	Good
tenKoppel et al. 2019	*	*	*	*	**	-	*	*	8	Good
Araw et al. 2014	*	*	*	*	-	*	*	*	7	Poor
Bouwstra et al. 2015	*	*	*	*	*	*	*	*	8	Good
Brink 2014	*	*	*	*	**	*	*	*	9	Good
Hold et al. 2019	*	*	*	*	-	*	*	*	7	Poor
Konttila et al. 2020	*	*	*	*	**	*	*	*	9	Good
Lamberg et al. 2005	*	*	*	*	**	*	*	*	9	Good
McAuley et al. 2006	*	*	*	*	-	*	*	*	7	Poor
Miller et al. 2017	*	*	*	*	**	*	*	*	9	Good
Paque et al. 2019	-	*	*	*	**	*	*	*	9	Good
Tsai et al. 2017	*	*	*	*	**	*	*	*	9	Good

VanSoest-Poortvliet et al. 2014	*	*	*	*	**	-	*	*	8	Good
VanSoest-Poortvliet et al. 2015	*	*	*	*	**	-	*	*	8	Good
					Cross-Sectional Studies*					
Study	Selection				Comparability	Outcomes			NOS Total	AHRQ Rating
	Representativeness of the sample	*Sample size*	*Ascertainment of exposure*	*Missing data*	*Outcome groups comparable, confounding controlled*	*Assessment of outcome*	*Statistical test*	*Non-respondents*	Max=9	
Hickman et al. 2018	*	*	*	*	-	*	*	*	7	Poor
Johnson & Bott 2016	*	*	*	*	-	*	*	*	7	Poor
Tark et al. 2020	*	*	*	*	-	*	*	-	6	Poor
Wenger et al. 2013	*	*	*	*	-	*	*	*	7	Poor

Note. AHRQ, Agency for Healthcare Research and Quality; NOS, Newcastle-Ottawa Scale;

*NOS rating for cross-sectional studies were modified based on the previous studies.

Table 2.2

Study Characteristics of Included Studies

Author, Year	Study Design	Country	Sample and Setting	GOC Discussions Measure (Data Sources)	Timing Measure (Data Sources)	End-of-life care outcome
Andreasen et al. 2019	Cohort	Six European countries (Belgium, Finland, the Netherlands, Italy, Poland and United Kingdom)	1,384 deceased residents in 302 LTCFs Deceased residents were predominantly in older age and female. About 69% residents had decision-making capacity at the time of admission.	ADs (European Union-funded PACE database through survey)	The resident's capacity of expressing his or her wishes at the time of admission (Assessed by the staff members)	NA
tenKoppel et al. 2019			1,298 deceased residents in 300 LTCFs Age > 85 = 55.7% Female = 65.7%	Palliative care initiation (survey)	Number of days before death (survey)	NA
Araw et al. 2014	Cohort	United States	182 residents in 2 LTCFs Mean age = 83.4(10) Female = 68.7% White = 91%	Medical Orders for Life-Sustaining Treatment (MOLST; chart review)	Days from admission to MOLST signing (chart review)	The interdisciplinary team's compliance with documented wishes
Bouwstra et al. 2015	Cohort	Netherlands	7,375 residents in 14 NHs Mean age = 78.6(10.9) Female = 64.7%	Physician Treatment Orders (PTO; digital medical records)	Days from admission to PTO completion (digital medical records)	NA
Brink 2014	Cohort	Canada	112,746 NH residents Mean age = 84.5	DNR orders (Resident Assessment Instrument; Canadian MDS)	On admission; three-month follow-up (Resident Assessment Instrument; Canadian MDS)	NA

			Female = 70%			
Hickman et al. 2018	Cross sectional	United States	486 staff responsible for ACP in 535 NHs	Physician Orders for Scope of Treatment (POST; survey)	- At time of admission - With decline or change in status only - Care plan conference only - Multiple points - When physician decides it is time - Resident or family request - When resident becomes long-stay resident (survey)	NA
Hold et al. 2019	Cohort	United States	149 residents in a rural NH Age range = 56-101 Female = 85.1% White = 88.1%	Resident preference for life-sustaining treatment (RPLST; chart review)	Number of days before signing RPLST (chart review)	NA
Johnson & Bott 2016	Cross sectional	United States	2,191 direct care staff in 85 NHs Mean bed size = 89 (39-254) Rural = 63% For-profit = 63%	Communication about Death and Dying, obtaining a DNR Order, and obtaining a Hospice Referral (survey)	- On admission - At the next care-plan meeting - When he/she is at end of life - After her physician does - When the resident's family member wants to (survey)	NA
Konttila et al. 2020	Cohort	Finland	403 residents with advanced dementia aged 65 years or older, who died in 18 NHs Group 1 Mean age = 86.3(7.0) Female = 77.4% Group 2 Mean age = 85.1(6.9) Female = 74.3%	ACP in the form of PTOs (Finland MDS)	Years before the death (Finland MDS)	Symptoms, treatments, possible burdensome interventions and inconsistencies with the PTOs in the last week of life

Lamberg et al. 2005	Cohort	United States	240 residents with advanced dementia who died between Jan 1, 2001 and Dec 31, 2003 Median age = 92 Female = 75.8% White = 99.2%	DNH orders (medical records)	Days before death (medical records)	NA
McAuley et al. 2006	Cohort	US	Residents in NHs from MDS (2000 to 2004)	ADs (MDS)	At admission vs. 12 months post-admission (MDS)	NA
Miller et al. 2017	Cohort	United States	203 residents with dementia in 31 NHs who died between 2006 and 2010 Earlier consultations (n = 91) Age 85-89 = 23.1% Male = 33.0% Nonwhite = 7.7% Later consultations Age 85-89 = 17.0% Male = 42.9% Nonwhite = 6.3%	Palliative care consultations including GOC discussions (medical records)	Later vs. earlier (1-30 days and 31-180 days before death, respectively; medical records).	Burdensome transitions before death. Expenditure at the end-of-life
Paque et al. 2019	Cohort	Belgium	741 residents in 67 NHs Mean age = 83.94 (range 65-105) Female = 65.7%	ACP (chart review)	At admission; 1 year; 2 year after admission (chart review)	NA
Tark et al. 2020	Cross sectional	United States	Nurse directors from 892 NHs	Communication about infection management preferences at the end-of-life (survey)	- On admission - During care plan meetings - Following an event - When condition changes (survey)	NA
Tsai et al. 2017	Cohort	Taiwan	563 residents in 6 NHs Mean age = 70.02(15.71)	DNR (chart review)	- Days between NH admission and DNR signing (chart review)	Mortality

			Female = 48.67%			
VanSoest-Poortvliet et al. 2014	Cohort	Netherlands	326 residents with dementia who died in 28 NHs Mean age = 83.7(6.9) Female = 70.9%	ACP discussions (survey)	- 8 weeks after admission - Family was asked how they felt about the timing (too early; at just the right time; too late; discussions are undesirable) (survey)	Establishment of a comfort care goal
VanSoest-Poortvliet et al. 2015			148 residents with dementia who died in 28 NHs Mean age = 84.9 (6.2) Female = 66.2%	Establishing a comfort care goal (survey)	- 8 weeks after admission - Shortly after admission vs. no care goal (survey)	Family satisfaction with end-of-life care; quality of dying
Wenger et al. 2013	Cross section al	California, US	283 NHs in California 143 community coalition areas 140 non-community coalition areas	Physician Orders for Life Sustaining Treatment (POLST; survey)	At admission vs. 30 days after admission (survey)	NA

Note. ACP, Advance Care Planning; AD, Advance Directive; DNH, Do Not Hospitalize; DNR, Do Not Resuscitate; GOC, Goals of Care; LTCF, Long Term Care Facility; MDS, Minimum Data Set; NA, Not Applicable; NH, Nursing Home; PACE: Parliamentary Assembly of the Council of Europe

Table 2.3

Summary of Results

Author, Year	Objective	Results	Limitations
Andreasen et al. 2019	To examine the prevalence of AD and its association with sociodemographic among deceased LTCF residents in six European countries.	About one-third of the deceased residents had written ADs (range 0-77%). In the multivariate multilevel analyses, capability of expressing care preferences at the time of admission was the independent predictor for written AD (aOR 3.26, 95% CI 2.26 to 4.71). In addition, residents in LTCFs where physician was available on site were less likely have written AD compared to those in LTCFs where physician is not available (aOR 2.86, 95% CI 1.59 to 5.23).	- Representativeness of the sample - Having written AD does not mean that there has been a conversation
Araw et al. 2014	To study the intervals between NH admission to Medical Orders for Life-Sustaining Treatment (MOLST) completion, and between MOLST completion to death. Also, to determine the team's compliance with documented wishes.	Median time from NH admission to MOLST signing was 48 days (95% CI: 12–119 days). Median time from admission to MOLST signing for White residents was 21 days (95% CI: 10–98 days); for Others (Black, Hispanic, and Asian residents) was 229 days (95% CI: 32–616 days). Almost one third of White residents signed the MOLST by the first day of admission 30.3% (95% CI: 23.9–37.9%); for Others (Black, Hispanic, and Asian residents), this percentage was lower, at 11.8% (95% CI: 3.1–39.4%). Among those who signed a MOLST, about 87% had their wishes met.	- Utilization of a convenience sample
Bouwstra et al. 2015	To determine the time duration between NH admission and Physician Treatment Orders (PTO) completion.	Median time between NH admission and PTO form completion was 1 day. Most NH residents had PTOs within first week after admission.	- No information on the number of PTOs based on ACP discussions
Brink 2014	To examine the prevalence of DNR orders among LTCF residents in Ontario, Canada.	On admission, when residents had family members, designated as end-of-life cases (six months or less), older age, and health were related to having DNR orders (OR 1.645; OR 2.995; OR 1.044; OR 1.079 respectively, $p < 0.05$). At the three-month follow up, residents from home were less likely to have DNR orders (OR 0.844, $p < 0.05$).	- The medical records might not have represented the true number of DNR orders

		At the three-month follow up, residents were older, and whose Activities of Daily Living (ADL) and levels of cognition were deteriorating were more likely to have DNR orders (OR 1.041; OR 1.025; OR 1.145; respectively, $p < 0.05$).		
Hickman et al. 2018	To assess the use of Physician Orders for Scope of Treatment (POST) form and associated practices in NHs	NH staffs responded that POST from typically introduced to residents and families at time of admission (68.4%), with decline or change in status only (14.7%), care plan conference only (3.9%), multiple points (2.8%), when physician decides it is time (2.4%), resident or family request (1.4%), and when resident becomes long-stay resident (1.0%).	-	Social desirability bias due to facility level survey
Hold et al. 2019	To describe use of ACP at a large, rural LTCF	About 76.7% of residents completed the resident preference for life-sustaining treatment (RPLST) within 10 days of admission, and 11% completed within 100 days; 6% between 101-349 days; and 6% over 1 year after admission.	-	Included only one NH in a rural county
Johnson & Bott 2016	To determine when communication about death and dying, DNR, and hospice referral should occur	NH staffs responded that communication about death and dying should occur on admission (39.2%), at the next care-plan meeting (53.7%), when he/she is at end of life (75.0%), after her physician does (60.9%), and when the resident's family member wants to (74.9%). For communication about obtaining a DNR order, on admission (79.3%) and after the doctor orders hospice or comfort care (79.1%) were the most prevalent responses. For communication about obtaining a hospice referral, when the physician orders it (84.4%) was the most prevalent response.	-	Social desirability bias due to facility level survey
Konttila et al. 2020	To describe changes in ACPs, and related end-of-life care outcomes among NH residents who died between 2004-2009 and 2010-2013 in Finland	The number of PTOs regarding forgoing antibiotics or parenteral antibiotics, forgoing artificial nutrition or hydration or forgoing hospitalization doubled between 2004–2009 and 2010–2013 (38.1% vs. 64.9%, $p < 0.001$; 40.0% vs. 81.7%, $p < 0.001$; 28.1% vs. 69.5%, $p < 0.001$, respectively). ACPs (PTOs) were done significantly earlier before death in 2010–2013 compared to in 2004–2009 (DNR: 3.7 years vs. 2.8 years; DNH: 0.9 years vs. 1.6 years). There were no significant differences in end-of-life care outcomes (symptoms, burdensome interventions experienced by residents at the end-of-life) between the two groups.	-	Included only one Finnish city

Lamberg et al. 2005	To describe the prevalence, factors associated with and timing of DNH orders among residents with dementia in Boston, US.	At the time of death, 83.8% of residents had a DNH order. About 40% of DNH orders were written during the last 30 days of life; 34.4% were done 180 days before death. Having a DNH order before death was related to surrogate decision maker was not the resident's child (aOR 4.39, 95% CI 1.52 to 12.66), eating problems (aOR 4.17, 95% CI 1.52 to 11.47), aged 92 and older (aOR 2.78, 95% CI 1.29 to 5.96), and long-term (2 years and longer; aOR 2.34, 95% CI 1.11 to 4.93).	- Included only a single LTCF - Population is almost all White Jewish limits generalizability
McAuley et al. 2006	To examine the prevalence of ADs at admission and 12 months after admission from 2000 to 2004 in US.	Residents who have any AD at admission decreased in 2000 (45.3%) compared to 2004 (44.5%) ($p < 0.0001$). Residents who have any AD at 12 months follow up increased in 2000 (59.5%) compared to 2004 (62.7%) ($p < 0.0001$). Residents who remained in facilities over 12 months were more likely to have their decisions made by family members and to have any ADs.	- NA
Miller et al. 2017	To examine the value of palliative care consultations for NH residents with dementia	Residents with earlier palliative care consultations (31-180 days before death) were younger, less cognitively impaired but worsening of cognitive/activities of daily living change. Residents with later consultations (1-30 days before death) were older, women, and short NH stays (< 90 days). With earlier consultations, hospitalization rates in last 7 days (mean rate difference -13.2%; 95% CI: -21.8%, -4.7%), 30 days of life (mean rate difference -18.4%; 95% CI: -28.5%, -8.4%); ER visits in last 30 days of life (mean rate difference -11.9%; 95% CI: 20.7%, -3.1%); burdensome transitions (mean rate difference -20.2%; 95% CI: -28.5%, -12.0%) were lower compared to no consultations. Later consultations group had no differences compared to no consultations. Residents with earlier palliative care consultations had lower total Medicare Part A expenditures in the last 7 days of life compared with controls, \$2938 (95% CI \$2768, \$3108) vs. \$3399 (95% CI \$3203, \$3595); expenditures in the last 30 days of life were not significantly different. For residents with later consultations, the expenditures did not differ from those in controls.	- Palliative care consultations may vary across NHs

Paque et al. 2019	To describe the timing of ACP initiation after NH admission and how it is related with dementia and physical health in Belgium	ACP was initiated at admission for 22% of the residents, and for 21% postponed to year 1, for 19% to year 2. About 38% ACP was never initiated. ACP initiation was associated with dementia but not physical health. ACP was initiated at admission for 16% of residents with dementia, but for 23% of those without dementia. After 1 and 2-year follow up, ACP was initiated for 38% and 64% for residents with dementia, but for 34% and 53% for those without dementia. Thus, ACP initiation was postponed when residents had dementia (*p* =0.003).	- Loss of study sample due to death - The content and quality of ACP were not measured
Tark et al. 2020	To describe the current status of palliative care and infection management at the end-of-life in NHs	On average, for those who are terminally ill, residents' or families' preferences for infection management were more likely to be elicited following a change in condition such as developing a fever (μ = 84.93, SE = 0.82) or an event such as aspiration (μ = 82.29, SE = 0.88), and less likely during care plan meetings (μ = 75.83, SE = 0.98), or upon admission (μ = 72.56, SE = 1.11). Just over half (55%–60%) of NHs almost always elicited these preferences during a change in condition versus eliciting preferences upon admission or care plan meetings (about 45% of all NHs).	- Social desirability bias due to facility level survey - Low response rate
tenKoppel et al. 2019	To describe ACP factors related to the timing of palliative care initiation in LTCFs	The median time of initiating palliative care was within 2 weeks and ranged from 0 to 410 days before death. Palliative care was initiated significantly earlier when staff had GOC discussions with residents compared to whom had not had GOC discussions (geometric mean ratio 1.36, 95% CI 1.08 to 1.70).	- Lack of a definition of palliative care in the questionnaire
Tsai et al. 2017	To examine the timing between NH admission and AD signing, factors associated with having AD, and association between AD signing and mortality in Taiwan.	About 28.8% had DNR completed at admission. The mean time between admission and DNR signing was 840.65 days (2.30 years; SD = 1168.89, range 0–4848 days, median = 159). Among those who signed DNR, the mean time for first transfer to hospital was 742.4 days after admission (SD = 1.75). Residents with DNR had greater risk of death compared to those without DNR but it was not significant when adjusted for age (unadjusted hazard ratio 2.03; 95% CI 1.10 to 3.98; *p* = 0.02).	- Chart review may have influenced the reliability of the data

VanSoest-Poortvliet et al. 2014	To examine care goals in NH residents with dementia and factors associated with a comfort care goal	About 65% of the families responded that they had ACP discussions with a professional, and 86.3% reported the first discussion had been within 8 weeks after admission. Of the families who had ACP discussions, 69.8% felt the timing was just right; 8% felt the timing was too early; 4.7% felt it was too late. When the families were satisfied with physician communication, residents were more likely to have a comfort care goal.	- Family members' subjective opinions about the timing of ACP discussions
VanSoest-Poortvliet et al. 2015	To examine end-of-life care outcomes associated with having a comfort care goal	Shortly after admission, 60.8% of residents had the main care goal as comfort. About 89% of residents had a comfort care goal at death. About 17.6% had not had care goals. Families of residents were more satisfied with end-of-life care when a comfort care goal was established shortly after admission (adjusted b: 4.5 95% CI: 2.8, 6.3; $p < 0.05$). Quality of dying was not associated with the comfort care goal.	- Small sample size and suboptimal power
Wenger et al. 2013	To study Physician Orders for Life Sustaining Treatment (POLST) implementation in California NHs	About 15% of the newly admitted residents over the last 30 days had a completed POLST form. About 54% of residents had a POLST after admission.	- One state in the US - Low response rate - Social desirability bias due to facility level survey

Note. ACP, Advance Care Planning; AD, Advance Directive; CI, Confidence Interval; DNH, Do Not Hospitalize; DNR, Do Not Resuscitate; ER, Emergency Room; LTCF, Long Term Care Facility; NH, Nursing Home; OR, Odds Ratio; SE, Standard Error

Chapter 3: Differences in Timely Goals of Care Discussions in Nursing Homes for Black Residents

Manuscript has been submitted to: Journal of Palliative Medicine

3.1 Abstract

Background

In the United States, Black nursing home (NH) residents have poorer end-of-life (EOL) care outcomes than White residents. EOL outcomes could be improved by timely goals of care (TGOC) discussions between health providers and residents or caregivers about present or future health care goals. However, there is limited knowledge about how the TGOC discussions varies by race in NHs.

Objectives

Examine the association between the proportion of Black residents within NHs and TGOC discussion outcomes.

Design

A national analysis of palliative care survey data from NHs merged with the Minimum Dataset 3.0 and administrative data.

Setting/Subjects

892 NHs representing a weighted sample of 14,981 facilities.

Measurements

We calculated the proportion of Black residents within NHs as the exposure variable (≤ 2%, 2.1-15%, >15%), and an TGOC index score summarizing the timing and frequency of goals

of care discussions from the palliative care survey (ranging from 0-18). Multivariable analyses were conducted to evaluate the NH-level association between the TGOC index score and the proportion of Black residents in each NH.

Results

In the multivariable analyses, the West NHs with 2.1-15% (-0.97 score; 95%CI -1.86, -0.07; p<.05) and 15% or more Black residents (-3.86 score; 95%CI -6.62, -1.10; p<.01) showed lower TGOC index scores compared to NHs with 2% or fewer Black residents. In the Northeast, NHs with 2.1-15% Black residents had 1.29 lower TGOC index scores compared to NHs with 2% or fewer Black residents (95%CI -2.51, -0.07; p<.05).

Conclusions

In US NHs, the TGOC discussions varies by the proportion of Black residents. Interventions targeting to address regional disparities and NHs serving higher proportions of Black residents may promote more equitable EOL care.

3.2 Introduction

Nursing home (NH) settings play an integral role in end-of-life (EOL) care for residents with serious illness (National Academies of Sciences & Medicine, 2022). In the United States (US), over 1.3 million residents reside in approximately 15,600 NHs, with approximately 90% who are 65 and older (Centers for Disease Control and Prevention, 2021b; Harris-Kojetin et al., 2019). Nearly two-thirds of long-term care residents die within 12 months of admission, highlighting the importance of NHs as crucial EOL care settings (Kelly et al., 2010). Timely goals of care (TGOC) discussions are considered a best practice for ensuring present or future health care that aligns with NH resident values and preferences. These discussions provide a process for clinicians to share prognostic information, engage residents in shared decision-making about treatments, and foster family involvement, all of which are important for ensuring goal-concordant EOL care (Bernacki & Block, 2014; Crighton et al., 2008; Jenerette & Mayer, 2016; Ketcher et al., 2020; Tinetti et al., 2016; Tinetti et al., 2019). Specialists in palliative care recommend that clinicians engage NH residents and their caregivers in goals of care discussions early (e.g., following admission) and following changes in disease severity to ensure medical decisions honor personal preferences and values at the EOL (Boyd et al., 2019; Mitchell et al., 2014; Tark et al., 2021; Yao et al., 2015).

Prior studies have found that goals of care discussions in NHs are often delayed until residents experience life-threatening events, potentially leading to unwanted disease-modifying therapies or unnecessary hospitalizations near the EOL (A. Tark, L. V. Estrada, et al., 2020). Although these studies show that Black residents are more likely to receive poorer quality EOL care than White residents (Estrada et al., 2021), there is limited information on whether the timing of goals of care discussions varies by race. To address this gap in knowledge, we examined whether the timing and frequency of goals of care discussions in US NHs differed by the proportion of Black residents in each NH. We hypothesized that TGOC discussions in NHs with higher proportions of Black residents would be reduced compared to those NHs with a lower proportion of Black residents.

3.3 Methods

Approval for the study was granted by the Columbia University Irving Medical Center Institutional Review Board (IRB-AAAU3141).

Data Sources

This analysis involved secondary from the Study of Infection Management and Palliative Care at End-of-Life (SIMP-EL; R01 NR013687) (Stone et al., 2019) We used 2018 SIMP-EL facility-level survey data that included an TGOC index completed by NHs across the country (Stone et al., 2019). Adapted from the Palliative Care Survey (Thompson et al., 2011), items assess how often NHs engage residents/families in goals of care discussions related to infection management across four contextual domains: 1) on NH admission; 2) during care plan meetings; 3) when a resident's condition changes, and 4) following a medical event. Each item is scored on a 4-point Likert-type scale, ranging from 'Never' to 'Always'.

Data files from the 2018 Long-Term Care Minimum Data Set version 3.0 (MDS 3.0), provided by the Centers for Medicare and Medicaid Services (CMS), were merged with a public use file from the same year, the Provider of Service (POS). The MDS is a standardized, comprehensive dataset containing assessments of health status for all NH residents in Medicare or Medicaid certified facilities (i.e., more than 95% of all NHs in the country) (Centers for Diesase Control and Prevention, 2006). It includes information on resident-level sociodemographic characteristics, such as race and ethnicity and is well validated in terms of race group identification (Eicheldinger & Bonito, 2008) and item reliability (Saliba & Buchanan, 2012). The POS database is compiled quarterly by CMS and contains administrative, facility-level data, including bed count, ownership status, chain affiliation, geographic region, and provider identification number.

Study Sample

The study sample included all 892 NHs that participated in the parent survey on palliative care service delivery (49% response rate). Eligible NHs in the parent study were randomly selected from the Certification and Survey Provider Enhanced Reports (CASPER) data and stratified by state, and urban and rural status. NHs were excluded from the study if they were specialty, primarily rehabilitation, or hospital-affiliated facilities, or had a census of < 30 residents or > 900 residents per year (the latter ensured a nationally representative sample). To ensure the data's applicability to a broader context, survey population weights were employed to make the sample representative of about 15,000 NHs (Stone et al., 2019).

Description of Variables

The survey provided the primary outcome variable, the TGOC index score. We calculated the index score based on standard scoring methods for the Palliative Care Survey (Figure 1). Responses are summed across all items to compute a facility-level score ranging from '0' (minimum) to '18' (maximum) points, with higher scores indicating earlier and more frequent goals of care discussions. The index has face validity and was internally consistency (Cronbach's alpha = 0.82). The exposure variable was the proportion of Black residents, categorized as ≤ 2%, 2.1-15%, and > 15%. We used a 15% threshold based on the national average proportion of NH Black residents (Harris-Kojetin et al., 2019). We controlled for facility-level characteristics (i.e., bed count, ownership status, chain affiliation, and provider type) and community-level characteristics, including the location (urban/rural and region) of the NH.

Data Analysis

Data from the 2018 MDS 3.0, POS, and survey were combined, and we identified NH residents 65 years and older in our sample using the MDS 3.0. Analyses were performed in Stata version 17.0 (Stata Corp) (Benjamini et al., 2001; Sankoh AJ, 1997; *Stata Statistical Software: Release 15* 2017). All final models were stratified by region. The threshold for statistical significance was a two-sided $p < .05$.

Before conducting the statistical analyses, the data were examined for outliers and missing variables. We then calculated weighted descriptive statistics using Pearson and Wald chi-square tests as appropriate. In our analytical approach, we employed Huber–White robust standard errors, clustered at the state-level, to accommodate for the possible correlation of errors within observations from the same NH.

First, unadjusted patterns of TGOC by concentrations of Black residents were examined. We then estimated a multivariable linear regression model at the NH-level. Let

$$Y_j = \beta_0 + \beta_1 R_j + \beta_4 FC_j + \beta_5 CC_j + \varepsilon_j,$$

where Y_j = TGOC discussions index score (based on the frequency and timing of the goals of care discussions) for NH_j, R_j is the NH concentration of Black residents (≤ 2%, 2.1-15%, > 15%), FC_j is a vector of facility characteristics, CC_j is a vector of community characteristics, and ε_j is the error term.

3.4 Results

Sample Characteristics

Of the 892 NHs, after cleaning and merging data sets, our final analytic sample consisted of 867 NH representing 15,981 NHs, representing a weighted sample of 14,981 NHs. Some observations were dropped due to unmatched data points between datasets. Table 1 presents the weighted descriptive characteristics of the NHs. Approximately half of the NHs in the sample had 2% or fewer Black residents. The majority of NHs in the sample had both Medicare and Medicaid beneficiaries, had fewer than 100 beds, were for-profit, were chain affiliated and were in urban areas. NHs located in the South region had the highest proportion of facilities with Black residents, accounting for 55.9% of NHs with more than 15% Black residents. The mean TGOC index score, ranging from 0 to 18, was 13.4 (SD = 5.0). Regionally, NHs in the West had the highest mean TGOC index score (14.6, SD = 3.8), while those in the Midwest had the lowest mean TGOC index score (12.6, SD = 5.4).

In the unadjusted analyses across all regions, NHs with more than 15% Black residents experienced a non-significant decrease in TGOC index scores by 0.61 points compared to those with 2% or fewer Black residents. NHs with 2.1-15% Black residents generally showed no significant differences in TGOC discussions compared to the reference group across most regions, except for the West where NHs with 2.1-15% Black residents experienced a reduction in TGOC index scores by 0.86 points (95% CI [-1.61, 0.11], $p < .05$).

In the adjusted analyses, the overall trends mirrored those observed in the unadjusted analyses, with the model that included all regions showing non-significant results. Specifically, NHs with more than 15% Black residents showed a decrease in TGOC index scores by 0.91 points compared to NHs with 2% or fewer Black residents, but this difference did not reach statistical significance (95% CI [-2.39, 0.56]). However, in the West, NHs with more than 15% Black residents experienced a significant reduction in TGOC index scores by 3.86 points (95% CI [-6.62, -1.10], $p < 0.01$) compared to NHs with 2% or fewer Black residents. For NHs with 2.1-15% Black residents, the results were largely non-significant across all regions, with the exception of a decrease in the Northeast and West by 1.29 points (95% CI [-2.51, -0.07], $p < 0.05$) and 0.97 points (95% CI [-1.86, -0.07], $p < 0.05$) compared to the reference group, respectively.

3.5 Discussion

In this national analysis of NHs across the US, we calculated an index score that measured the timing and frequency of goals of care discussions and found that in some regions, NHs with higher proportions of Black residents had significantly lower TGOC index scores compared to NHs with lower proportions of Black residents. These trends were consistent across most regions of the US. These findings are potentially important because they suggest that Black individuals are less likely to be engaged in timely and personalized discussions about their preferences for healthcare towards the EOL than White individuals. This disparity persisted even after controlling for facility- and community-level characteristics, underscoring the systemic nature of these inequities.

The lower TGOC index scores observed in NHs with higher percentages of Black residents may reflect broader systemic issues, including institutional racism and implicit biases in healthcare delivery, or other potentially important facility-level differences, such as the proportion of seriously ill NH residents, limited NH staffing levels or resources, and regional poverty level. Our findings align with previous research indicating that Black patients are less likely to engage in advance care planning conversations and are more likely to receive lower quality EOL care compared to their White counterparts (Estrada et al., 2021). For instance, one study conducted in two New York City NHs highlighted a difference in the time from admission to completion of the medical orders for life-sustaining treatment (MOLST)—21 days for White residents versus 229 days for residents of other racial and ethnic groups, including Black and Hispanic residents (A. C. Araw et al., 2014).

The significant regional variations observed in our analysis further highlight the complexity of these disparities, suggesting that local cultural, socioeconomic, and healthcare system factors also play a crucial role. Our results not only affirm the critical role of race in influencing the TGOC discussions, but mirror prior data indicating that NHs with greater numbers of Black residents tend to experience higher rates of COVID-19 cases and fatalities (Travers et al., 2021). This disparity is further exacerbated by regional differences, thereby deepening racial inequities. The regional disparities suggest that the challenges faced by Black residents in NHs may be modified by local factors (Travers et al., 2021).

Our findings mirror prior reports of disparate EOL care within NHs, findings which cannot be attributed to a single factor and may highlight the need for multilevel strategies. After adjusting for facility- and community-level characteristics in our models, differences in TGOC discussions persisted. Studies have documented that patient/family, system, and clinician factors may serve as barriers and facilitators to effective TGOC discussions and completion of advance directives. For example, limited clinician education and training in having TGOC discussions is common and patients and families often report these conversations are delayed or limited. Early and regular goals of care discussions may help prevent unwanted disease-modifying therapies or unnecessary interventions towards the EOL, such as avoidable hospitalizations, thereby improving quality of life and care costs (S. C. Miller et al., 2017).

Studies have identified the need for targeted interventions aimed at improving the frequency and timeliness of goals of care discussions in NHs serving higher proportions of Black residents. Such interventions could include training programs for healthcare providers on cultural competency and implicit bias, as well as policies to promote more inclusive and equitable advance care planning processes. More broadly, the disparities observed underscore the importance of engaging with underserved communities to understand and address the barriers to advance care planning faced by Black residents and their families. Efforts to enhance communication and trust between healthcare providers and residents/families are critical in ensuring that care aligns with the preferences and values of all individuals, regardless of racial, ethnic or cultural background.

Limitations

The limitations of our study include the use of secondary facility-level data and the potential for unmeasured confounding factors that could influence TGOC discussions, such as the proportion of residents with advanced illness, limited prognosis, or poor social support. The cross-sectional design limits our ability to infer causality and the study's survey data were self-reported by NH administration, which could introduce bias. Our assessment was limited to structural factors related to TGOC discussions and actual information from residents' medical records on advance care planning and advance directives was not available. Future research should focus on EOL-related decisions and outcomes using a health equity lens to examine individual preferences and cultural influences consistent with residents' values and goals. Notwithstanding these limitations, our study contributes valuable and novel evidence to the ongoing efforts to understand and address disparities in palliative and EOL care in NHs.

3.6 Conclusion

In this national study of NHs, we found disparities in the timing and frequency of goals of care discussions. Addressing these disparities may require a multifaceted approach, encompassing both systemic changes in healthcare delivery and targeted interventions at the facility-level. Future research should focus on developing and evaluating strategies to improve TGOC discussions in diverse care settings, ultimately ensuring that all individuals receive high-quality, culturally competent, and goal-concordant care at the EOL.

Figure 3.1

TGOC Index and Weighted Score

TGOC Index				
Scoring	Never	Sometimes	Often	Always
How often does your facility elicit residents'/families' preferences for infection management (such as antibiotic use) for terminally ill residents in the following situations:				
1) On admission	0	4	5	6
2) During care plan meetings	0	3	4	5
3) When a resident's condition changes, such as developing a fever	0	2	3	4
4) Following an event such as an aspiration	0	1	2	3

Note:
Abbreviation: TGOC, timely goals of care;

Table 3.1

Nursing home characteristics (unweighted N = 867, weighted N = 14,981)

	Concentration of Black residents				
	All NHs	≤ 2%	2.1-15%	> 15%	p
Weighted (%)*					
All NHs	100	50.5	35.9	13.6	<0.001
Northeast	18.0	18.6	16.4	19.9	
Midwest	35.1	47.5	23.8	18.8	
South	33.6	17.6	47.7	55.9	
West	13.3	16.3	12.1	5.4	<0.001
Timely Goals of Care Index					
Weighted mean (SD)					
All NHs	13.4 (5.0)	13.5 (4.9)	13.4 (5.2)	12.9 (5.1)	0.57
Northeast	14.2 (4.5)	14.9 (4.0)	14.0 (4.5)	12.4 (5.7)	0.07
Midwest	12.6 (5.4)	12.5 (5.3)	12.6 (5.7)	13.4 (4.8)	0.69
South	13.3 (5.2)	13.4 (4.9)	13.4 (5.5)	12.9 (5.1)	0.84
West	14.6 (3.8)	15.0 (3.8)	14.2 (3.9)	13.2 (4.9)	0.41
NH characteristics (%)*					
Bed size					
0-100	50.7	65.5	37.0	32.2	
101-200	44.0	32.7	56.1	54.2	
>200	5.3	1.8	6.9	13.6	<0.001
Ownership					
For-profit	70.2	60.5	76.9	88.5	
Not-for-profit	23.5	31.8	17.1	9.7	
Government	6.3	7.7	6.0	1.8	<0.001
Provider type					
Medicare only	3.0	3.6	2.1	2.8	
Medicaid only	1.9	3.6	0	0.4	
Medicare & Medicaid	95.1	92.8	97.9	96.8	0.009
Urban/rural location					
Urban	71.0	57.4	86.1	81.9	
Rural	29.0	62.6	13.9	18.1	<0.001

* Values are column percents

Abbreviation: NHs, nursing homes; SD, standard deviation; CI, confidence interval;

Table 3.2

Unadjusted bivariate models estimating the timely goals of care discussions

Variables/Coefficient (95% CI)	Region				
	All	Northeast	Midwest	South	West
Concentration of Black residents					
≤ 2%	Ref	Ref	Ref	Ref	Ref
2.1-15%	-0.11 (-0.80, 0.57)	-0.87 (-2.04, 0.29)	0.15 (-1.81, 2.12)	-0.07 (-1.81, 1.67)	-0.86* (-1.61, 0.11)
> 15%	-0.61 (-1.90, 0.68)	-2.52 (-5.31, 0.27)	0.91 (-1.20, 3.02)	-0.54 (-2.96, 1.87)	-1.77 (-4.78, 1.25)

Note: Abbreviation: Ref, reference; CI, confidence interval;
* $p < .05$;

Table 3.3

Multivariable linear regression models estimating the timely goals of care discussions

Variables/Coefficient (95% CI)	Region				
	All	Northeast	Midwest	South	West
Concentration of Black residents					
≤ 2%	Ref	Ref	Ref	Ref	Ref
2.1-15%	-0.44 (-1.32, 0.44)	-1.29* (-2.51, -0.07)	-0.02 (-1.69, 1.66)	-0.30 (-2.61, 2.02)	-0.97* (-1.86, -0.07)
> 15%	-0.91 (-2.39, 0.56)	-2.79 (-6.45, 0.87)	1.06 (-1.57, 3.70)	-1.03 (-3.76, 1.71)	-3.86** (-6.62, -1.10)
Nursing home characteristics					
Bed size					
<100	Ref	Ref	Ref	Ref	Ref
101-200	0.41 (-0.27, 1.10)	0.31 (-0.95, 1.56)	0.73 (-0.78, 2.23)	-0.30 (-1.52, 0.91)	0.65 (-0.37, 1.68)
>200	0.01 (-1.71, 1.73)	0.44 (-2.21, 3.10)	-0.95 (-6.16, 4.26)	-1.26 (-7.96, 5.43)	1.32* (0.03, 2.60)
Ownership					
For-profit	Ref	Ref	Ref	Ref	Ref
Not-for-profit	-0.21 (-1.30, 0.87)	0.05 (-1.31, 1.21)	0.93 (-0.42, 2.28)	-1.73 (-4.22, 0.76)	0.01 (-1.29, 1.31)
Government	0.91 (-0.72, 2.55)	3.96*** (2.77, 5.16)	2.01* (0.29, 3.73)	-2.75 (-6.49, 1.00)	1.95 (-0.25, 4.15)
Chain					
No	Ref	Ref	Ref	Ref	Ref
Yes	0.47	0.65	-0.08	1.01	1.03
	(-0.15, 1.09)	(-0.36, 1.66)	(-1.08, 0.91)	(-0.51, 2.52)	(-0.31, 2.37)
Provider type					
Medicare only	Ref	Ref	Ref	Ref	Ref
Medicaid only	-0.58 (-3.68, 2.52)	-	2.99 (-1.12, 7.11)	-2.29 (-7.36, 2.78)	-6.81*** (-9.64, -3.98)
Medicare & Medicaid	-0.77 (-2.88, 1.35)	3.81 (-0.19, 7.80)	0.07 (-4.41, 4.55)	-2.17 (-5.36, 1.03)	-4.12*** (-6.03, -2.22)
Urban/rural location					
Urban	Ref	Ref	Ref	Ref	Ref
Rural	-0.30 (-1.01, 0.41)	0.01 (-3.36. 3.39)	-0.68 (-1.70, 0.34)	-0.22 (-1.88, 1.44)	-0.05 (-2.15, 2.04)
Region					
Northeast	Ref	-	-	-	-
Midwest	-1.73** (-2.85, -0.61)	-	-	-	-
South	-0.94 (-1.90, 0.03)	-	-	-	-

West	0.28 (-0.74, 1.29)	-	-	-	-

Note: Models were adjusted. Standard errors were clustered at the state-level.
Abbreviation: Ref, reference; CI, confidence interval;
* $p < .05$; ** $p < .01$; *** $p < .001$.

Chapter 4: Association of Timely Goals of Care Discussions with Hospitalizations Due to Infections in Nursing Homes

Manuscript to be submitted to: Journal of the American Geriatrics Society

4.1 Abstract

Background

Infections among nursing home (NH) residents are common and potentially lead to poor end-of-life outcomes, including unnecessary, unwanted treatments and hospitalizations. Understanding resident and family views, especially preferences for hospitalization may improve goal-concordant care and end-of-life outcomes. This study aims to determine the association between timely goals of care (TGOC) discussions and hospitalizations due to infections in NH residents.

Methods

The TGOC index (range 0-18) came from a 2018 national cross-sectional survey of NHs. Resident characteristics came from the 2018 Minimum Data Set 3.0. Hospitalizations due to infections were identified in MedPAR. Facility and community characteristics came from publicly available data. Multivariable logistic regression models were used to examined the association between TGOC discussions and hospitalizations due to infections, adjusting for race and ethnicity, as well as other resident, facility, and community characteristics.

Results

A total of 867 NHs with 988,502 resident observations were identified. Average resident age was 82.2 years old (SD=8.8) and most were White (84.6%), female (63.9%), and widowed (46.1%). Higher TGOC index scores were associated with lower rates of hospitalization due to

infections (6-10: AOR = 0.80, 95% CI: 0.66-0.97, $p<.05$; >15: AOR = 0.84, 95% CI: 0.71-0.99, $p<.05$). Predictors of increased hospitalization included Black race (AOR = 1.25, 95% CI: 1.16-1.33, $p<.001$), lower socioeconomic community status (AOR = 1.38, 95% CI: 1.19-1.60, $p<.001$), lower functional status (AOR = 1.38, 95% CI: 1.20-1.60, $p<.001$), and severe cognitive impairment. NH chain and nonprofit ownership were associated with lower odds of hospitalization.

Conclusions

TGOC discussions in NHs are associated with reduced hospitalization rates due to infections, emphasizing the importance of these discussions in end-of-life care management. Efforts to address the complexities of end-of-life care in NHs through systematic TGOC protocols could improve the quality of life for NH residents and reduce unnecessary care at the end-of-life.

4.2 Introduction

Nursing home (NH) residents who are approaching the end-of-life experience a high risk of infections (Herzig et al., 2017; Montoya & Mody, 2011), making NHs critical care settings for infection management during this period. As function declines at the end-of-life, immune response may become compromised, leaving residents more susceptible to infections (Fu et al., 2020; Harris-Kojetin et al., 2019; Montoya et al., 2016; Smith et al., 2008). These infections can significantly impact the quality of life for residents and may lead to hospitalizations, which can be inappropriate, burdensome and distressing for both residents and their families (Mitchell et al., 2014; A. Tark, L. V. Estrada, et al., 2020).

Timely goals of care (TGOC) discussions play a crucial role in ensuring that residents' goals and preferences for care are appropriately addressed. These discussions involve conversations between health care providers and residents and their families to establish and document the goals of care, including infection management, towards the end-of-life (Bernacki & Block, 2014; Crighton et al., 2008; Jenerette & Mayer, 2016; Ketcher et al., 2020; Tinetti et al., 2016; Tinetti et al., 2019).

Social Determinants of Health (SDOH) include the social and environmental factors that contribute to health care access, experiences, and outcomes. SDOH characterize the communities in which people reside, work, and age, and include socioeconomic status, educational level, neighborhood and physical environment, employment, and social support networks, as well as health care access and quality (Centers for Disease Control and Prevention (CDC). ; Lewis & Riegel, 2010; O'Conor et al., 2019; Scott et al., 2020; U.S. Department of Health and Human Services.). Various SDOH can lead to inequitable health outcomes and affect quality of care processes, including TGOC, potentially exacerbating the risk of unwanted or unnecessary hospitalizations due to infections at the end-of-life (Gorges & Konetzka, 2020, 2021; Mor et al., 2005; Travers et al., 2021; Zheng et al., 2011). Structural racism is widely documented in the health care system and in NHs, and racially and ethnically minoritized residents have health disparities and poorer end-of-life care outcomes, including more hospitalizations and aggressive treatments.

Recognizing the importance of effectively managing infections in NHs at the end-of-life, and acknowledging the salient impact of SDOH and race and ethnicity, this study aims to: determine the association between TGOC discussions and hospitalizations due to infections in NH residents and clarifying the impact of resident, facility, and community characteristics, with a specific focus on the effect of race and ethnicity. Our hypotheses are that 1) residents living in NHs with higher levels of TGOC discussions have fewer hospitalizations due to infections compared to NH residents living in NHs with lower levels of TGOC discussions; and 2) hospitalizations due to infections differ by resident's race and ethnicity, as well as other resident, facility, and community characteristics.

4.3 Methods

This study was a retrospective cross-sectional, secondary analysis of data acquired from a national palliative care study in US NHs. The Columbia University Irving Medical Center Institutional Review Board approved the study (IRB-AAAU3141).

Data Sources

A national survey of NHs and five national datasets were linked including: the Study of Infection Management and Palliative Care at End-of-Life (SIMP-EL; R01 NR013687) survey, the 2018 Minimum Data Set 3.0 (MDS), the Provider of Service (POS) file, the American Survey (ACS), 2018 Medicare Provider and Analysis Review (MedPAR), and NH payroll data. For the SIMP-EL survey, NHs were randomly selected from the Certification and Survey Provider Enhanced Reports (CASPER) data, stratified by state, and urban or rural status (Stone et al., 2019). To maintain a sample that was nationally representative, exclusions from the parent study included specialty NHs, those primarily providing sub-acute rehabilitation, hospital-affiliated facilities, and any with an annual census below 30 or above 900 residents. In 2018, 892 NHs completed and returned surveys of the parent study, yielding a response rate of 49%. Population weights were applied, rendering the sample representative of the national NH population, which encompasses over 15,000 NHs (Stone et al., 2019). The MDS 3.0 data contains comprehensive information on resident-level characteristics from all NHs certified by the Centers for Medicare and Medicaid Services, which represents more than 95% of all NHs in the country (Centers for Diesase Control and Prevention, 2006). The MDS includes various variables at the resident-level, such as demographics, functional status (e.g., Activities of Daily Living [ADL]), cognitive impairment level (e.g., Cognitive Function Scale [CFS]), and race and ethnicity. The POS database contains facility-level characteristics such as bed size, ownership, provider type, and urban-rural regions. In addition, payroll data provides facility-level staffing information. The ACS data includes the Social Deprivation Index (SDI) aggregated at the Zip Code Tabulation Area level. The MedPAR data are inpatient and the NH final action stay records include procedures, diagnosis (International Classification of Diseases [ICD] 10 codes), diagnostic related groups, and length of stay.

Conceptual Framework and Variables

Our integrated conceptual framework (Figure 1), combined the Donabedian Model's (Donabedian, 1966) focus on healthcare quality dimensions (structures, processes, and outcomes) with the Minority Access to End-of-Life Care model's (Laguna et al., 2012), and served as the foundation for this study's approach and variable selection. Central to our analysis is the examination of SDOH, which includes a wide range of factors including resident-, facility-, and community-level characteristics. Among these, race and ethnicity are identified as key covariates due to their significant role in shaping health outcomes and access to care, particularly at the end-of-life (Kang & Barcelona, 2023).

The dependent variable in this study was an indicator [yes/no] for hospitalizations due to infections in the last 90 days of life (Cai et al., 2016; Hanson et al., 2017). Infections were identified based on ICD 10 codes in the MedPAR data. Hospitalizations were classified as due to infection if the infection was indicated as the MedPAR admitting diagnosis code or as the primary diagnosis (1st of 25 diagnosis codes) and was present on admission. The list of infection-related ICD codes and coding for hospitalizations due to infection has been developed by the research team and used in multiple papers (Gracner et al., 2021; Harrison et al., 2021).

The main independent variable was the facility-level TGOC index from the survey. Adapted from the Palliative Care Survey (Thompson et al., 2011), the TGOC discussions were scored as an index, from four items where the responses across all 4 items were summed to calculate a facility-level index ranging from 0 (minimum) to 18 (maximum) points (see Figure 2). Higher scores indicate more frequent and earlier engagement in TGOC discussions. The index has face validity and was internally consistent (Cronbach's alpha = 0.82).

Resident characteristics from MDS included race and ethnicity, age, sex as a biological variable, and marital status. Additionally, we controlled residents' functional status (e.g., ADL), and level of cognitive impairment (e.g., CFS). CFS ranges from 1 (intact) to 4 (severe impairment). ADL scores, which quantify functional independence and range from 0 (complete independence) to 16 (total dependence), were categorized into quartiles.

Facility characteristics included bed size, ownership, provider, chain status, staffing, and occupancy. Facility characteristics from the POS data included bed size (<50, 50-100, >100), ownership (for-profit, nonprofit, or government-owned), provider type (Medicare, Medicaid, or both), and chain status (part of a chain or independent). To accurately assess the impact of nursing staff availability, we created measures of staffing hours per resident, and occupancy rates derived from publicly available payroll data. The measures included staffing (measured by registered nurses [RNs], director of nurses [DONs], and licensed practical nurses [LPNs] hours per resident day and categorized by quartiles). A measure of occupancy rates was also included (a percentage of occupied beds categorized by quartiles).

Community characteristics from ACS included the SDI (grouped by quartiles). The SDI incorporates key socioeconomic indicators: income level, employment status, education level, housing conditions, family structure, vehicle availability, and language barriers. These indicators collectively provide a nuanced understanding of the social and economic factors influencing the effectiveness of TGOC discussions and their role in mitigating hospitalization rates (Butler et al., 2013; Liaw et al., 2018; Phillips et al., 2016). The SDI ranges from 0-100 with higher values indicating greater social deprivation. It is a well-validated metric of socioeconomic status that predicts health care access and need (The Robert Graham Center, n.d.). Both variables were included in the models to quantify the socioeconomic variation in health outcomes. Location (rural and urban) of the NH county was derived from POS.

Study Sample

The study sample included residents with a NH stay longer than 100 days (long-term), and older adults (> 64 years of age) in NHs who participated in the 2018 survey (Centers for Diesase Control and Prevention, 2020b).

Data Analysis

After linking the data, descriptive statistics were examined to determine the distribution and frequencies of the variables. Given the critical importance of race and ethnicity as predictor of societal status within our conceptual model and their established influence on health disparities, we conducted analyses that adjusted only for these variables (Model 1). This approach allows us to isolate the effect of race and ethnicity on infection-related hospitalizations in NHs, thereby providing a nuanced understanding of how the fundamental aspects of race and ethnicity interact with the care processes (i.e., TGOC index) and the outcome (i.e., hospitalizations due to infections). By first focusing only on race and ethnicity, we aimed to understand the unique contribution to differences in TGOC and its subsequent impact on infection-related hospitalization. Then multivariable models controlling for other SDOH were estimated. Because the other SDOH variables are the result of the accumulation of historical factors such as systemic racism, multivariable models were carefully specified and interpreted in the context of these considerations (Jacoby et al., 2018). We used Stata version 17 to perform all analyses. Two-tailed test with alpha = 0.05 was used.

To examine the hypotheses, multivariable logistic regression models at the resident-level were estimated with standard errors clustered at the NH level to account for correlations within NHs (Model 2).

Let Y_{ij} = indicator [yes/no] that the i^{th} resident in the j^{th} NH who was hospitalized due to infections in last 90 days of life. Probability of Y_{ij} is Pr $\left(Y_{ij} = 1\ p_{ij}\right)$:

$$logit\left(p_{ij}\right) = \beta_0 + \beta_1 TGOC_j + \beta_2 RE_{ij} + \beta_3 RC_{ij} + \beta_4 FC_j + \beta_5 CC_j$$

where β and α parameters are coefficients. This model includes vectors describing TGOC discussions ($TGOC$) (calculated in index score) provided to resident i in NH j, and race and ethnicity (RE), of each resident. Other resident characteristics (RC), and facility (FC), and community (CC) characteristics are covariates. Hypotheses were examined, conditional on RE, RC, FC, and CC by testing the null hypothesis that $\beta_1 = 0$.

4.4 Results

A total of 892 NHs completed the survey (49% response rate). After merging it with other datasets, we included 867 NHs with a total of 988,502 observations. NHs (n = 25) were excluded from the analysis due to discrepancies in matching data points across different datasets. The mean TGOC index across the sample was 13.6 (SD = 5.1), with the distribution showing that 49.4% of observations fell into the highest category of TGOC index scores (15-18) (Table

1). In Table 1, all of the variables varied across the levels of the TGOC index. The majority of residents were White (84.6%), female (63.9%), widowed (46.1%) with an average age of 82.2 years (SD = 8.8). Furthermore, about 45.9 % of the residents were categorized as having severe cognitive impairment (i.e., CFS score = 4). In terms of functional ability, residents exhibited a moderate level of dependence, with ADL scores averaging at 6.4 (SD = 4.7). The majority of the NHs in the study had a bed size ranging between 100 and 200 (53.3%), had for-profit ownership status (62.4%), were part of a chain (54.3%), situated in urban areas (79.4%), and accepted both Medicare and Medicaid (97.4%). Additionally, the SDI for the communities in which these NHs were located had an average score of 49.5 (SD = 27.3), reflecting a mid-range level of social deprivation relative to the possible range of the index.

In the Model 1, the adjusted odds ratios (AORs) for hospitalization due to infections showed a non-significant association with TGOC index (Table 2). Additionally, race and ethnicity were significant predictors of hospitalization due to infections. Compared to White residents, Black residents had a higher likelihood of hospitalization (AOR = 1.25, 95% CI: 1.16, 1.33, $p < .001$). Similarly, Asian residents, Native Hawaiian or Pacific Islander and Hispanic residents had increased odds of hospitalization with AORs of 1.16 (95% CI: 1.02, 1.31, $p < .05$), 1.41 (95% CI: 1.07, 1.83, $p < .05$), and 1.19 (95% CI: 1.08, 1.31, $p < .01$), respectively.

In the fully adjusted Model 2, residents in the 6-10 TGOC Index category had lower odds of hospitalization due to infection (AOR = 0.80, 95% CI: 0.66, 0.97, $p < .05$) compared to the reference group (0-5). Similarly, those in the >15 category also showed reduced odds (AOR = 0.84, 95% CI: 0.71, 0.99, $p < .05$). In the adjusted model, disparities in hospitalization among racial and ethnic groups were no longer significant.

Residents older than 75 and 85 years had lower odds of hospitalization (AOR = 0.81, 95% CI: 0.75, 0.87, $p < .001$; AOR = 0.65, 95% CI: 0.59, 0.71, $p < .001$, respectively) compared to those aged 65-75. Female residents had lower odds of hospitalization than males (AOR = 0.63, 95% CI: 0.59, 0.67, $p < .001$). Residents with mild, moderate, and severe impairment on the CFS and varying levels of ADL dependence also had significant differences in hospitalization, underscoring the influence of health status on hospitalization risks.

For the facility and community characteristics, residents in not-for-profit ownership and government owned NHs had lower odds of hospitalization compared to residents in for-profit and independent facilities (AOR = 0.80, 95% CI: 0.71, 0.90, $p < .001$; AOR = 0.66, 95% CI: 0.51, 0.85, $p < .01$, respectively). Residents in chain affiliated NHs also had lower odds of hospitalization (AOR = 0.82, 95% CI: 0.74, 0.91, $p < .001$). Further, residents in rural facilities exhibited slightly lower odds than their urban counterparts (AOR = 0.86, 95% CI: 0.76, 0.97, $p < .05$). Finally, residents from communities with the lowest socioeconomic status (SES) had higher odds of hospitalization (AOR = 1.38, 95% CI: 1.19, 1.60, $p < .001$), highlighting the impact of social determinants on health outcomes.

4.5 Discussion

This study examined the association between TGOC discussions and hospitalizations due to infections among NH residents, incorporating the effects of resident, facility, and community characteristics. Consistent with our hypotheses, we found that higher levels of TGOC discussions were significantly associated with reduced odds of hospitalization due to infections, particularly in the highest TGOC index categories (6-10 and >15). These results underscore the importance of TGOC discussions in effectively managing end-of-life care, especially in reducing the burden of hospitalizations due to infections.

TGOC Discussions and Hospitalization

Our study builds on existing literature emphasizing the critical role of TGOC discussions in NH settings. The significant reduction in infection-related hospitalizations with higher TGOC index scores suggests that when NHs engage in frequent and early TGOC discussions, they are better positioned to align care with residents' preferences, potentially leading to more appropriate infection management strategies that avoid unnecessary hospitalizations (Harrison et al., 2021). This finding aligns with prior research highlighting the benefits of advanced care planning and TGOC discussions in enhancing quality of life and reducing aggressive treatments at the end-of-life (Bernacki & Block, 2014; Crighton et al., 2008; Jenerette & Mayer, 2016; Ketcher et al., 2020; Tinetti et al., 2016; Tinetti et al., 2019).

Influence of Race and Ethnicity

The observation that racially and ethnically minoritized groups show higher rates of hospitalization due to infection when models are adjusted only for race and ethnicity, but this association becomes insignificant in fully adjusted models, can be attributed to several factors. These factors typically involve the inclusion of variables that account for a broader range of influences on health outcomes. Fully adjusted models often include variables related to SES, such as income, education, and employment status, or community-level factors like the SDI. Racially and ethnically minoritized groups often disproportionately experience lower SES (Williams et al., 2016), which is associated with higher infection risks and hospitalization rates. Including SES in the model may account for some of the disparities initially attributed to race or ethnicity alone.

While race and ethnicity are important determinants of health disparities, their impact on specific outcomes like hospitalization due to infection is interwoven with a multitude of other factors. Fully adjusted models that account for these factors can provide a more nuanced understanding of health disparities, often revealing that the disparities attributed to race and ethnicity are also deeply connected to broader social, economic, and healthcare-related determinants (Williams et al., 2016).

Influence of Resident, Facility, and Community Characteristics

Our study found how different resident characteristics, including sex, age, marital status, and cognitive and functional status, influence hospitalization risks. NH residents aged 75 and older, particularly those aged 85 and above, had lower odds of hospitalization due to infections compared to those aged 65-75. Consistent with the previous systematic review (Katharina Allers et al., 2019), these findings suggest a protective effect of advanced age against hospitalization for infections. Older residents may have more established and well-communicated care plans, including advanced directives and TGOC discussions, which align their care preferences with less aggressive interventions. These discussions often emphasize comfort and quality of life over aggressive treatment measures that can lead to hospitalization. As a result, these residents might receive more consistent and goal-concordant care within the NH, reducing the need for hospital transfers (Katharina Allers et al., 2019). Specifically, our study highlighted the significant impact of residents' cognitive and functional statuses on hospitalization due to infections. Individuals with intact cognitive function and higher dependency in ADLs faced increased risks of hospitalization. The influence of CFS and ADL scores on hospitalization risks emphasizes the need for TGOC discussions tailored to the specific needs of residents with varying levels of cognitive and functional impairment. TGOC discussions that proactively address the care preferences and potential infection management strategies for residents with significant functional dependencies could play a pivotal role in mitigating the risk of hospitalizations. Such discussions may facilitate the implementation of personalized care plans that better align with the residents' health status and preferences, potentially reducing the need for hospital-based interventions.

Facility characteristics, such as ownership type and chain affiliation, were associated with differences in hospitalization odds. Not-for-profit ownership and chain affiliation were linked to lower odds of hospitalization, possibly reflecting differences in resource allocation, staffing patterns, and organizational priorities that influence the quality of care and infection management practices. Furthermore, the observation that rural NHs had slightly lower odds of hospitalization compared to urban ones suggests that geographical and community contexts play a role in care practices and outcomes, possibly due to differences in healthcare access, population health needs, and local healthcare recourses (Cyr et al., 2019; Tsui et al., 2020).

Community characteristics, particularly SES as measured by the SDI, were found to influence hospitalization odds. Residents from lower SES communities had higher odds of hospitalization, underscoring the impact of SDOH on NH residents' outcomes. This finding is consistent with the growing body of research recognizing the importance of addressing social and environmental factors in improving health outcomes and reducing disparities (Thornton et al., 2016).

Our study highlights the indispensable role of TGOC discussions in mitigating infection-related hospitalizations in NHs. It also brings to light the multifaceted influences of race, ethnicity, resident, facility, and community characteristics on these outcomes. Addressing these complex determinants may require culturally sensitive, comprehensive strategies that go beyond individual-level interventions to encompass broader system-level changes.

Limitation

While this study provides valuable insights, there are limitations. The use of secondary data and the cross-sectional design restrict our ability to infer causality. Additionally, the TGOC index, while a novel measure of care planning engagement, may not capture all perspectives of TGOC discussions and their implementation across different NHs. Moreover, the study does not include direct measures of racism at any levels—individual, institutional, or structural. This omission represents a significant limitation when seeking to understand the reasons behind racial disparities in TGOC discussions. Without these measures, it is challenging to fully grasp the impact of systemic racism on the observed disparities. Future research should aim to include direct measures of racism and other relevant social determinants to better understand the underlying causes of these disparities. Additionally, studies should focus on developing and evaluating strategies to improve TGOC discussions and their outcomes across diverse care settings. Qualitative research could further illuminate the mechanisms through which TGOC discussions impact care practices and decisions.

4.6 Conclusion

Our findings affirm the pivotal role of TGOC discussions in reducing hospitalizations due to infections among NH residents, highlighting the need for systematic integration of these discussions into NH care practices. By acknowledging the influence of resident demographics, facility characteristics, and community contexts, healthcare providers and policymakers can better address the complexities of end-of-life care in NH settings. Efforts to promote equitable and effective TGOC discussions could significantly improve the quality of life for NH residents and reduce the burden of unnecessary hospitalizations, particularly for those at the end-of-life.

Figure 4.1

An Integrated Conceptual Model using the Donabedian Model and Minority Access to End-of-Life Care

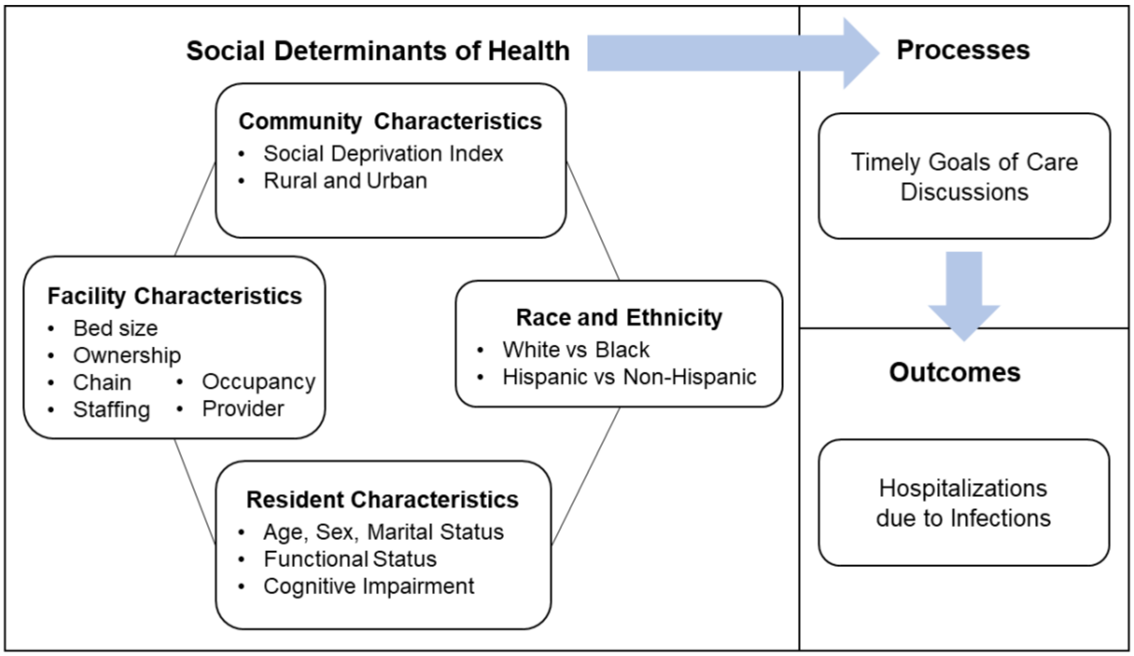


Figure 4.2

TGOC Index and Weighted Score

TGOC Index				
Scoring	Never	Sometimes	Often	Always
How often does your facility elicit residents'/families' preferences for infection management (such as antibiotic use) for terminally ill residents in the following situations:				
1) On admission	0	4	5	6
2) During care plan meetings	0	3	4	5
3) When a resident's condition changes, such as developing a fever	0	2	3	4
4) Following an event such as an aspiration	0	1	2	3

Abbreviation: TGOC, timely goals of care;

Table 4.1

Resident, nursing homes, and community characteristics in sample. (867 NHs, 988,502 observations)

	TGOC Index					
Variables	All	0-5	6-10	11-15	15-18	p
TGOC Index (0-18) Mean (SD)	13.6 (5.1)					
N (%)	988,502 (100)	96,929 (9.8)	136,137 (13.8)	266,711 (27.0)	488,725 (49.4)	*p* < .001
Resident-level Characteristics						
Race and Ethnicity n (%)*						
White	836,152 (84.6)	79,254 (81.8)	115,433 (84.8)	221,830 (83.2)	419,635 (85.9)	
Black	83,608 (8.5)	11,470 (11.8)	11,784 (8.7)	22,681 (8.5)	37,673 (8.5)	
Asian	22,565 (2.3)	1,358 (1.4)	3,323 (2.4)	5,914 (2.2)	11,970 (2.5)	
American Indian Alaska Native	6,700 (0.7)	191 (0.2)	973 (0.7)	2,085 (0.8)	3,451 (0.7)	
Native Hawaiian Pacific Islander	4,012 (0.4)	516 (0.5)	734 (0.5)	1,100 (0.4)	1,662 (0.3)	
Hispanic	35,465 (3.6)	4,140 (4.3)	3,890 (2.9)	13,101 (4.9)	14,334 (2.9)	*p* < .001
Age mean (SD)	82.2 (8.8)	81.7 (8.7)	82.2 (8.8)	81.9 (8.7)	82.4 (8.8)	*p* < .001
Female n (%)*	631,946 (63.9)	59,290 (61.2)	88,727 (65.2)	170,116 (63.8)	313,813 (64.2)	*p* < .001
Marital Status n (%)*						
Never married	114,910 (13.1)	12,248 (10.6)	14,169 (11.9)	30,933 (12.0)	57,560 (11.9)	
Married	278,289 (28.8)	26,635 (28.4)	37,736 (28.3)	77,698 (29.8)	136,220 (28.5)	
Widowed	445,323 (46.1)	41,886 (44.6)	63,597 (47.8)	117,694 (45.2)	222,146 (46.4)	
Separated	8,998 (0.9)	876 (0.9)	1,328 (1.0)	2,751 (1.1)	4,043 (0.8)	
Divorced	118,766 (12.3)	12,210 (13.0)	16,319 (12.3)	31,327 (12.0)	58,910 (12.3)	*p* < .001
CFS n (%)*						
Intact	69,055 (8.8)	6,749 (8.8)	8,542 (7.9)	18,360 (8.8)	35,404 (9.2)	
Mild impairment	184,425 (23.6)	17,070 (22.3)	27,527 (25.4)	48,975 (23.4)	90,853 (23.5)	

Moderate impairment	168,585 (21.6)	17,037 (22.3)	23,315 (21.6)	45,783 (21.8)	82,450 (21.3)	
Severe impairment	358,715 (45.9)	35,584 (46.6)	48,818 (45.1)	96,471 (46.0)	177,842 (46.0)	$p < .001$
ADL score (0-16) mean (SD)	6.4 (4.7)	6.1 (4.7)	6.3 (4.8)	6.4 (4.7)	6.5 (4.7)	$p < .001$
Facility-level Characteristics						
Bed size n (%)*						
<100	309,599 (31.3)	32,021 (33.0)	56,383 (41.4)	76,956 (28.9)	144,239 (29.5)	
100-200	526,403 (53.3)	53,139 (54.8)	67,372 (49.5)	146,181 (54.8)	259,711 (53.1)	
>200	152,500 (15.4)	11,769 (12.1)	12,382 (9.1)	43,574 (16.3)	84,775 (17.4)	$p < .001$
Ownership n (%)*						
For-profit	616,356 (62.4)	57,688 (59.5)	90,409 (66.4)	172,236 (64.6)	296,023 (60.6)	
Not-for-profit	29,259 (30.2)	39,502 (29.0)	77,734 (29.2)	164,022 (33.6)	310,517 (31.4)	
Government	61,629 (6.2)	9,982 (10.3)	6,226 (4.6)	16,741 (6.3)	28,680 (5.9)	$p < .001$
Chain affiliated n (%)*	537,055 (54.3)	48,478 (50.0)	77,132 (56.7)	146,790 (55.0)	264,655 (54.2)	$p < .001$
Located in Rural n (%)*	203,888 (20.6)	25,376 (26.2)	36,944 (27.1)	52,979 (19.9)	88,589 (18.1)	$p < .001$
Provider n (%)*						
Medicare only	21,430 (2.2)	2,491 (2.6)	4,604 (3.4)	3,757 (1.4)	10,578 (2.2)	
Medicaid only	4,715 (0.5)	317 (0.3)	1,667 (1.2)	374 (0.1)	2,357 (0.5)	
Medicare and Medicaid	962,357 (97.4)	94,121 (97.1)	129,866 (95.4)	262,580 (98.5)	475,790 (97.4)	$p < .001$
Community-level Characteristics						
SDI Score (1-100) mean (SD)	49.5 (27.3)	52.5 (25.6)	49.6 (25.9)	47.2 (28.5)	50.1 (27.3)	$p < .001$

Note: *column percentage
P values were calculated using Pearson Chi-Square or ANOVA, as appropriate.
Abbreviation: ADL, activities of daily living; CFS, cognitive function scale; SD, standard deviation; SDI, Social Deprivation Index; SES, socioeconomic status; TGOC, timely goals of care;

Table 4.2

AOR for hospitalization due to infection in nursing home residents

	Model 1			Model 2		
Variables	AOR	RSE	95% CI	AOR	RSE	95% CI
TGOC Index (0-18)						
0-5	ref			ref		
6-10	0.88	0.06	0.77, 1.00	0.80*	0.08	0.66, 0.97
11-15	0.96	0.06	0.85, 1.08	0.87	0.08	0.73, 1.05
>15	0.94	0.06	0.83, 1.05	0.84*	0.07	0.71, 0.99
Resident-level Characteristics						
Race and Ethnicity						
White	ref			ref		
Black	1.25***	0.04	1.16, 1.33	1.06	0.05	0.96, 1.17
Asian	1.16*	0.07	1.02, 1.31	1.02	0.10	0.84, 1.23
American Indian Alaska Native	1.13	0.14	0.89, 1.34	1.09	0.35	0.58, 2.03
Native Hawaiian Pacific Islander	1.41*	0.20	1.07, 1.83	1.10	0.25	0.70, 1.70
Hispanic	1.19**	0.06	1.08, 1.31	0.97	0.09	0.80, 1.16
Age						
65-75				ref		
>75				0.81***	0.03	0.75, 0.87
>85				0.65***	0.03	0.59, 0.71
Sex						
Male				ref		
Female				0.63***	0.02	0.59, 0.67
Marital Status						
Never married				ref		
Married				1.06	0.05	0.97, 1.16
Widowed				0.97	0.05	0.88, 1.07
Separated				1.23	0.16	0.96, 1.58
Divorced				1.01	0.06	0.91, 1.13
CFS						
Intact				ref		
Mild impairment				0.06***	0.00	0.06, 0.07
Moderate impairment				0.15***	0.01	0.13, 0.17
Severe impairment				0.04***	0.00	0.04, 0.05
ADL						
Independent				ref		
Mild dependence				2.04***	0.12	1.81, 2.29
Moderate dependence				3.56***	0.22	3.15, 4.02
Dependent				1.38***	0.10	1.20, 1.60
Facility-level Characteristics						

Bed size			
<100	ref		
100-200	1.06	0.07	0.93, 1.21
>200	1.10	0.14	0.86, 1.40
Ownership			
For-profit	ref		
Not-for-profit	0.80***	0.05	0.71, 0.90
Government	0.66**	0.09	0.51, 0.85
Chain			
No	ref		
Yes	0.82***	0.04	0.74, 0.91
Urban Rural			
Urban	ref		
Rural	0.86*	0.05	0.76, 0.97
Provider			
Medicare only	ref		
Medicaid only	0.47	0.22	0.18, 1.17
Medicare and Medicaid	0.94	0.15	0.69, 1.29
Community-level Characteristics			
SDI Score (1-100)			
Higher SES	ref		
Moderate-high SES	1.08	0.08	0.93, 1.25
Moderate SES	1.14	0.09	0.98, 1.32
Lower SES	1.38***	0.10	1.19, 1.60

Note: $*p < .05$; $**p < .01$; $***p < .001$
Fully adjusted models included facility-level characteristics: hours per resident for registered nurses, directors of nursing, and licensed practical nurses, and resident occupancy.
Abbreviation: ADL, activities of daily living; AOR, adjusted odds ratio; CI, confidence interval; CFS, cognitive function scale; ref, reference; RSE, robust standard errors; SDI, Social Deprivation Index; SES, socioeconomic status; TGOC, timely goals of care;

Chapter 5: Synthesis

This chapter provides a comprehensive synthesis of the findings presented in this dissertation. It summarizes the results of each study and proceeds to explore the potential implications for research, practice, and policy. Finally, the chapter concludes with an examination of the strengths and limitations inherent in this body of work.

5.1 Discussion

Chapter 2 systematically reviewed the previously published literature that examined how TGOC discussions impacts end-of-life care outcomes in NHs. The review revealed that earlier TGOC discussions—ideally at the time of NH admission or shortly thereafter—are associated with improved end-of-life outcomes. These outcomes include reduced hospitalizations and lower healthcare costs, underscoring the benefit of integrating advanced care planning early into the provision of care across the continuum. This chapter also identified a critical gap in information across extant studies regarding the optimal timing for initiating these discussions to maximize their effectiveness.

Chapter 3 focused on disparities in the timing and frequency of goals of care discussions among Black residents in NHs compared to their White counterparts. Utilizing a national palliative care survey focused on infection management at the end-of-life merged with a publicly available dataset, the findings highlighted that NHs with a higher proportion of Black residents had lower TGOC index scores. This suggests that systemic barriers may prevent timely and frequent discussions, which are crucial for goal-concordant care at the end-of-life. Given the evidence of disparities highlighted in this chapter, I concluded that there is a clear need to explore in the next chapter whether TGOC discussions can impact the actual end-of-life care outcomes for residents, and how these outcomes may vary based on different SDOH.

Chapter 4 investigated the association between TGOC discussions and hospitalizations due to infections among NH residents. Analyzing data from the national survey used in chapter 3 linked with data on resident, facility, and community characteristics and healthcare outcomes, the study found that higher TGOC index scores were correlated with a lower rate of hospitalizations due to infections. This chapter significantly contributes to understanding how timely discussions can directly impact residents' health outcomes, potentially reducing the strain on healthcare systems and improving the quality of life for NH residents. See Table 5.1 for a summary of the individual dissertation study findings.

Varied Types of Goals of Care Discussions

In the landscape of end-of-life care within NHs, goals of care discussions take various forms, each tailored to meet specific aspects of resident needs and preferences. The systematic review conducted in Chapter 2 highlighted the prevalent forms of these discussions, primarily centered around obtaining advance directives and engaging in advance care planning. A goals of care discussion involving a person with chronic illness, or a surrogate if the person lacks decisional capacity, clarifies care preferences and may include advance care planning. Advance care planning can provide clearly documented advance directives, such as a living will, designation of a power of attorney for health decisions, or a physician's order defining the types of interventions preferred for EOL care. Goals of care discussions, as codified in advance directives, should honor the values and preferences of the patient and family, and guide health care professionals in treatment decisions when illness is advanced and dying is likely to occur soon (Bischoff et al., 2013). This variety in goals of care discussions underscores the complexity of addressing the individualized needs of residents within a structured care framework. The differing state or county-level policies further complicate the implementation of goals of care discussions, making it challenging to maintain consistency and transferability across healthcare settings (Bailoor et al., 2018). These policy variations often require adaptations in approach and documentation, complicating the continuity of care when residents transition between care providers or settings (Bailoor et al., 2018).

Challenges in Measuring TGOC Discussions

The measurement of TGOC discussions in NHs presents several challenges, as highlighted by the diverse methodologies found in the literature. While the most common measure involves checking whether goals of care discussions occur at admission, many studies also track the timing of these discussions in days, months, or years following admission. This approach, however, often overlooks the frequency of goals of care discussions, which was seldomly assessed systematically across studies.

Despite the focus on initial discussions, the ongoing frequency of goals of care discussions is critical, as it addresses the dynamic nature of residents' preferences and values throughout their care trajectory in NHs. As we found in Chapter 4, residents with different cognitive impairments and functional statuses had different end-of-life outcomes, such as hospitalizations due to infections, emphasizing that values and preferences can shift due to changes in health status. Therefore, it is essential to revisit goals of care regularly to ensure they remain aligned with the residents' current needs and preferences.

Unfortunately, the variability in how TGOC discussions are implemented—often influenced by specific facility practices and the individual needs of residents—adds another layer of complexity. This variability can result in significant differences in the quality and effectiveness of care planning and decision-making processes across different settings. My findings suggest a need for standardized approaches not only to initiate but also to regularly update advance directives and advance care planning. Such standardization would help ensure that care remains aligned with the evolving wishes of residents, thereby enhancing the relevance and applicability of care plans over time.

Disparities in TGOC Discussion

Chapter 3 of the dissertation exposed significant disparities in the timing and frequency of goals of care discussions, with a focus on Black residents in NHs. These disparities highlight systemic barriers that these residents face in accessing equitable end-of-life care. The lower TGOC index scores in facilities with a higher proportion of Black residents suggest a systemic issue where racially and ethnically minoritized residents receive less frequent and timely care discussions, impacting their end-of-life care quality and outcomes. This points to a critical need for targeted interventions to address these inequities and ensure that all residents receive culturally competent and respectful care.

SDOH and Hospitalizations Due to Infections

The Social Determinants of Health (SDOH) significantly influence hospitalizations due to infections among NH residents, as detailed in Chapter 4. Factors such as socioeconomic status, community characteristics, and racial disparities not only affect the quality of end-of-life care but also the likelihood of hospitalizations due to infections. These determinants frame a broader context within which TGOC discussions take place, affecting their timing, frequency, and effectiveness. Addressing these social determinants through targeted policies and practices is crucial for improving health outcomes and reducing unnecessary hospitalizations.

5.2 Clinical Practice Implications

The study findings may have implications for clinical practice in NHs. Healthcare professionals can leverage the results to prioritize and facilitate TGOC discussions with residents and their families, particularly in situations where infection management decisions are crucial. By engaging in frequent and early TGOC discussions, NHs can better align care with residents' preferences, potentially leading to more appropriate infection management strategies that avoid unnecessary hospitalizations. Below are some potential strategies for NHs and healthcare providers.

Systemic Protocols for TGOC Discussions

To improve end-of-life care quality, NHs should implement systematic protocols for initiating TGOC discussions at admission and revisiting them periodically. As highlighted in Chapter 2's systematic review as well as our analyses, the TGOC index and most studies define the earliest timing of goals of care discussions as having TGOC at admission. Therefore, it is advisable to establish a facility-level protocol that initiates these discussions as soon as residents arrive at NHs. Considering that many NH residents experience cognitive impairments and some degree of functional decline (Centers for Medicare & Medicaid Services, 2015; Mukamel et al., 2023), it is crucial to set these goals early, in collaboration with residents and their families, before there is a significant loss of decision-making capacity. Such protocols not only streamline the process but also ensure consistency in how care goals are communicated and updated, making them more tailored and responsive to the evolving needs of residents, as disease severity worsens, or health declines. This approach helps safeguard the dignity and preferences of residents throughout their stay in the NH.

Structured TGOC Discussions

Given the varied forms and the essential nature of TGOC discussions, there is a pressing need for structured TGOC communication tools. Structured approaches can provide clinicians with the training and tools necessary to conduct thorough and consistent discussions across different settings (Ma et al., 2020). A growing body of study supports the use of evidence-based structured goals of care discussion tools, which include recommendations on optimal times to initiate these conversations, often triggered by specific indicators such as physical or cognitive decline, or a new diagnosis (Baxter et al., 2022; Baxter et al., 2024; Dhingra et al., 2021). By standardizing the form and content of TGOC discussions, facilities can improve the quality of end-of-life care, ensuring that it aligns more closely with the preferences and needs of residents (Gonella, Basso, et al., 2019). Such structured approaches are crucial for enhancing the effectiveness of TGOC discussions and ensuring that they lead to meaningful outcomes for residents. This method not only helps in maintaining a consistent quality of discussions but also supports healthcare providers in making timely and appropriate decisions that reflect the changing health statuses of residents (Pusa et al., 2024).

Addressing Disparities

The disparities identified in the timely initiation of GOC discussions among Black residents highlight the need for targeted interventions. These should include training on implicit bias and cultural competency for healthcare providers to ensure these discussions are both meaningful and inclusive (Lagrotteria et al., 2021). Regular reviews and revisions of policies and procedures are essential to ensure inclusivity and equity in NHs. Engaging with stakeholders, particularly from underrepresented communities, and fostering interdisciplinary teams can enrich the care planning process and make it more person-centered.

5.3 Public Policy Implications

Our systematic review highlighted significant variations in the TGOC discussions across different countries, influenced by varying national policies and practices. This variability underscores the impact that legislative frameworks and national health policies can have on end-of-life care practices within NHs. For instance, in Finland, legislation mandates goals of care discussions and goal-concordant care, which has led to increasing advance care planning completion rates and earlier discussions between 2004 and 2013 (Konttila et al., 2020; McAuley et al., 2006). This contrasts sharply with the United States, where despite the introduction of compensation for advance care planning discussions by the Centers for Medicare and Medicaid Services (CMS) in 2016, the completion rates have been relatively low and the timing of discussions has seen delays (Palmer et al., 2021). Similarly, the Netherlands, with its specialized NH physicians for older adults, achieves earlier goals of care completions compared to the United States (Houttekier et al., 2010; Koopmans et al., 2010). These examples illustrate how different policy environments can directly influence the effectiveness and timeliness of end-of-life care discussions.

In addition, our findings underscore significant racial disparities and SDOH differences in the timing and effectiveness of goals of care discussions across NHs. These disparities highlight the urgent need for policy interventions that specifically target these inequities to ensure that all residents, regardless of race or socioeconomic status, receive equitable and culturally competent end-of-life care. To address these disparities, policymakers must consider strategies that directly target the underlying causes of inequities in TGOC discussions.

To address racial disparities and SDOH in end-of-life care, mandatory cultural competency and sensitivity training for healthcare providers should be implemented, supported by resources that enhance engagement with diverse populations. Provider training and education in serious illness discussions is key, and many models and communication approaches to guide these discussions have been published (AriadneLabs, n.d.; VitalTalk, n. d.). Regulatory frameworks need strengthening to ensure NHs comply with end-of-life care standards and actively reduce disparities, potentially enforced through regular audits and public reporting of outcomes by race and SDOH. Community engagement programs should be enhanced to better incorporate insights from organizations representing underserved populations, aiding in the customization of TGOC discussions. Financial incentives and specific funding should support NHs in underserved or diverse areas that demonstrate significant improvements in care disparities. Additionally, promoting research and improving data collection practices on racial and SDOH impacts on end-of-life care will further aid in assessing and refining policy effectiveness. These measures aim to foster equitable and effective end-of-life care practices across healthcare settings.

By implementing the above policy recommendations, it is possible to create a more equitable healthcare environment within NHs. This will ensure that every resident has the opportunity to engage in meaningful and respectful TGOC discussions that reflect their personal values and cultural backgrounds.

5.4 Future Research

Setting Optimal Timing and Frequency for TGOC Discussions

Despite the recognized importance of TGOC discussions, there is still no consensus on the optimal timing and frequency for these discussions to occur. Findings across the literature suggest that many residents and families feel that the discussions are not only insufficient but also often delayed, failing to meet the immediate needs of the residents (Fosse et al., 2014; Teno et al., 2012). This gap in knowledge and practice underscores the need for further research to define and implement guidelines that can standardize the timing and frequency of these crucial discussions, ensuring that they are both timely and effective.

Resident-Centered End-of-Life Care

Culturally sensitive end-of-life care is a crucial factor that should be integrated into all research efforts. Although our study could not capture culture-related factors due to limitations in the available datasets, future studies should explore the unique, individual and cultural preferences for end-of-life conversations, potentially through qualitative research methods. This approach would deepen understanding of how cultural nuances influence TGOC discussions and impact care practices and decision-making in NHs. Research is also needed to evaluate the effectiveness of initiatives designed to enhance TGOC discussions and reduce hospitalizations due to infections, thereby improving overall care outcomes.

Future researchers should prioritize addressing the gaps identified in this dissertation by exploring the varying impacts of TGOC discussions across different NH settings and among diverse resident demographics. This would help to generalize findings and assist in crafting interventions tailored to specific needs. Employing longitudinal or experimental designs to test culturally competent interventions could provide insights into the long-term effects of structured TGOC discussions on patient and family satisfaction, quality of life, and healthcare utilization, clarifying causal relationships and inform the refinement of the next generation of intervention strategies.

Additionally, future researchers should assess various factors influencing goals of care discussions, including clinician-related concerns such as the time commitment, training, and clinical competence, which may be deemed burdensome by NH staff. Issues pertaining to residents and caregivers, such as their comprehension of illnesses, health literacy, access to legal support, and the alignment of surrogate decision-making with residents’ preferences, also warrant investigation.

5.5 Strength and Limitations

The dissertation study benefited from its large sample size and comprehensive analysis of resident, facility, and community characteristics. The use of a national dataset and a robust methodological framework provides a comprehensive view of the issues at hand, allowing for a significant contribution to the fields of geriatric and palliative care research.

While this study offers important insights, limitations include reliance on self-reported facility-level data, which may bring the social desirability bias and lack of specificity at the individual resident-level. Limitations also include the use of secondary data and the cross-sectional design, which restrict the ability to infer causality.

5.6 Conclusion

This dissertation contributes to a deeper understanding of how TGOC discussions can significantly reduce hospitalizations due to infections and improve the quality of end-of-life care in NHs. It highlights the need for systematic, early, and culturally sensitive communication about end-of-life care preferences and emphasizes the role of policy and practice in addressing health disparities. By integrating these discussions into routine care, NHs can ensure that end-of-life care is both effective and respectful of residents' dignity and preferences.

Table 5.1

Summary of individual dissertation study findings

Aim	Chapter	Objective	Methods	Results Summary
1	2	To synthesize current evidence on the timing of goals of care discussions in NHs and its impact on end-of-life outcomes.	Systematic Review	- 18 articles from 16 studies identified - Timing of goals of care discussions largely varied across the studies. - Most studies (n = 12) measured order completions (e.g., Advance Care Planning). - When NH residents had earlier goals of care discussions end-of-life care - outcomes (e.g., rate of hospitalization care discussions. - Future studies are needed to examine the optimal timing for the goals of care discussions and related end-of-life outcomes.
2	3	To examine the association between the proportion of Black residents within NHs and TGOC discussion outcomes.	Cross-sectional, multivariable linear regression model with state clustering	- Mean TGOC Index Scores: • Overall mean: 13.5 (SD = 5.1) • Highest in West: 14.7 (SD = 4.0) • Lowest in Midwest: 12.6 (SD = 5.6) - NHs in the West and Northeast with a higher proportion of Black residents had significantly lower TGOC Index scores compared to those with fewer Black residents.
3	4	To examine the association between TGOC discussions and hospitalizations due to infections in NH residents.	Cross-sectional, multivariable logistic regression model with facility clustering	- Higher TGOC index scores were associated with lower rates of hospitalization due to infections - Predictors of increased hospitalization included Black race, lower socioeconomic community status, lower functional status, and severe cognitive impairment. - NH chain and nonprofit ownership were associated with reduced hospitalization.

Note. Abbreviation: TGOC, timely goals of care; NH, nursing home

References

Adekpedjou, R., Heckman, G. A., Hébert, P. C., Costa, A. P., & Hirdes, J. (2022, 2022/01/03). Outcomes of advance care directives after admission to a long-term care home: DNR the DNH? *BMC Geriatrics*, *22*(1), 22. https://doi.org/10.1186/s12877-021-02699-5

Allers, K., Hoffmann, F., & Schnakenberg, R. (2019). Hospitalizations of nursing home residents at the end of life: A systematic review. *Palliative Medicine*, *33*(10), 1282-1298. https://doi.org/10.1177/0269216319866648

Allers, K., Hoffmann, F., & Schnakenberg, R. (2019, Dec). Hospitalizations of nursing home residents at the end of life: A systematic review. *Palliat Med*, *33*(10), 1282-1298. https://doi.org/10.1177/0269216319866648

Andreasen, P., Finne-Soveri, U. H., Deliens, L., Van den Block, L., Payne, S., Gambassi, G., Onwuteaka-Philipsen, B. D., Smets, T., Lilja, E., Kijowska, V., & Szczerbińska, K. (2019, May 21). Advance directives in European long-term care facilities: a cross-sectional survey. *BMJ Support Palliat Care*. https://doi.org/10.1136/bmjspcare-2018-001743

Araw, A. C., Araw, A. M., Pekmezaris, R., Nouryan, C. N., Sison, C., Tommasulo, B., & Wolf-Klein, G. P. (2014, Apr). Medical orders for life-sustaining treatment: is it time yet? *Palliat Support Care*, *12*(2), 101-105. https://doi.org/10.1017/s1478951512001010

Araw, A. C., Araw, A. M., Pekmezaris, R., Nouryan, C. N., Sison, C., Tommasulo, B., & Wolf-Klein, G. P. (2014). Medical orders for life-sustaining treatment: Is it time yet? *Palliative and Supportive Care*, *12*(2), 101-105. https://doi.org/10.1017/S1478951512001010

AriadneLabs. (n.d.). *Ariadne Labs*. https://www.ariadnelabs.org/

Auriemma, C. L., Halpern, S. D., Asch, J. M., Van Der Tuyn, M., & Asch, D. A. (2020). Completion of Advance Directives and Documented Care Preferences During the Coronavirus Disease 2019 (COVID-19) Pandemic. *JAMA Network Open, 3*(7), e2015762-e2015762. https://doi.org/10.1001/jamanetworkopen.2020.15762

Bailoor, K., Kamil, L. H., Goldman, E., Napiewocki, L. M., Winiarski, D., Vercler, C. J., & Shuman, A. G. (2018, Jun). The Voice Is As Mighty As the Pen: Integrating Conversations into Advance Care Planning. *J Bioeth Inq, 15*(2), 185-191. https://doi.org/10.1007/s11673-018-9848-7

Baxter, R., Fromme, E. K., & Sandgren, A. (2022, Mar 31). Patient Identification for Serious Illness Conversations: A Scoping Review. *Int J Environ Res Public Health, 19*(7). https://doi.org/10.3390/ijerph19074162

Baxter, R., Pusa, S., Andersson, S., Fromme, E. K., Paladino, J., & Sandgren, A. (2024, Feb 13). Core elements of serious illness conversations: an integrative systematic review. *BMJ Support Palliat Care*. https://doi.org/10.1136/spcare-2023-004163

Benjamini, Y., Drai, D., Elmer, G., Kafkafi, N., & Golani, I. (2001, Nov 1). Controlling the false discovery rate in behavior genetics research. *Behav Brain Res, 125*(1-2), 279-284. https://doi.org/10.1016/s0166-4328(01)00297-2

Bernacki, R. E., & Block, S. D. (2014, Dec). Communication about serious illness care goals: a review and synthesis of best practices. *JAMA Intern Med, 174*(12), 1994-2003. https://doi.org/10.1001/jamainternmed.2014.5271

Bischoff, K. E., Sudore, R., Miao, Y., Boscardin, W. J., & Smith, A. K. (2013, Feb). Advance care planning and the quality of end-of-life care in older adults. *J Am Geriatr Soc, 61*(2), 209-214. https://doi.org/10.1111/jgs.12105

Bouwstra, H., Smalbrugge, M., & Hertogh, C. M. (2015, 2015/08/01/). Physician Treatment Orders in Dutch Nursing Homes. *Journal of the American Medical Directors Association, 16*(8), 715.e711-715.e715. https://doi.org/https://doi.org/10.1016/j.jamda.2015.05.018

Boyd, C., Smith, C. D., Masoudi, F. A., Blaum, C. S., Dodson, J. A., Green, A. R., Kelley, A., Matlock, D., Ouellet, J., Rich, M. W., Schoenborn, N. L., & Tinetti, M. E. (2019). Decision Making for Older Adults With Multiple Chronic Conditions: Executive Summary for the American Geriatrics Society Guiding Principles on the Care of Older Adults With Multimorbidity. *67*(4), 665-673. https://doi.org/https://doi.org/10.1111/jgs.15809

Brink, P. (2014). Examining Do-Not-Resuscitate Orders Among Newly Admitted Residents of Long-term Care Facilities. *Palliat Care, 8*, 1-6. https://doi.org/10.4137/pcrt.S13042

Butler, D. C., Petterson, S., Phillips, R. L., & Bazemore, A. W. (2013, Apr). Measures of social deprivation that predict health care access and need within a rational area of primary care service delivery. *Health Serv Res, 48*(2 Pt 1), 539-559. https://doi.org/10.1111/j.1475-6773.2012.01449.x

Cai, S., Miller, S. C., & Mukamel, D. B. (2016, Sep). Racial Differences in Hospitalizations of Dying Medicare-Medicaid Dually Eligible Nursing Home Residents. *J Am Geriatr Soc, 64*(9), 1798-1805. https://doi.org/10.1111/jgs.14284

Centers for Diesase Control and Prevention. (2006). *U.S. Nursing Homes Profiled in A New Report*. https://www.cdc.gov/nchs/pressroom/00facts/nurshome.htm

Centers for Diesase Control and Prevention. (2020a). *About Underlying Cause of Death, 1999-2020*.

https://wonder.cdc.gov/controller/datarequest/D76;jsessionid=DAF37CC1A927ECD997AE74CA476A

Centers for Diesase Control and Prevention. (2020b). *MDS 3.0 Frequency Report*. https://www.cms.gov/Research-Statistics-Data-and-Systems/Computer-Data-and-Systems/Minimum-Data-Set-3-0-Public-Reports/Minimum-Data-Set-3-0-Frequency-Report

Centers for Disease Control and Prevention. (2021a). *Interim Infection Prevention and Control Recommendations to Prevent SARS-CoV-2 Spread in Nursing Homes*. https://www.cdc.gov/coronavirus/2019-ncov/hcp/long-term-care.html

Centers for Disease Control and Prevention. (2021b). *Nursing Home Care*. https://www.cdc.gov/nchs/fastats/nursing-home-care.htm

Centers for Disease Control and Prevention (CDC). (August 13, 2020). *Social Determinants of Health: Know What Affects Health*. Retrieved November 13, 2020 from https://www.cdc.gov/socialdeterminants/index.htm

Centers for Medicare & Medicaid Services. (2015). *Nursing home data compendium*. Centers for Medicare & Medicaid Services.

Cohen, S. M., Volandes, A. E., Shaffer, M. L., Hanson, L. C., Habtemariam, D., & Mitchell, S. L. (2019, Jan). Concordance Between Proxy Level of Care Preference and Advance Directives Among Nursing Home Residents With Advanced Dementia: A Cluster Randomized Clinical Trial. *J Pain Symptom Manage, 57*(1), 37-46.e31. https://doi.org/10.1016/j.jpainsymman.2018.09.018

Crighton, M. H., Coyne, B. M., Tate, J., Swigart, V., & Happ, M. B. (2008, Nov-Dec). Transitioning to end-of-life care in the intensive care unit: a case of unifying divergent desires. *Cancer Nurs, 31*(6), 478-484. https://doi.org/10.1097/01.NCC.0000339257.14066.d5

Cronin, C. J., & Evans, W. N. (2022, Mar). Nursing home quality, COVID-19 deaths, and excess mortality. *J Health Econ, 82*, 102592. https://doi.org/10.1016/j.jhealeco.2022.102592

Cyr, M. E., Etchin, A. G., Guthrie, B. J., & Benneyan, J. C. (2019, Dec 18). Access to specialty healthcare in urban versus rural US populations: a systematic literature review. *BMC Health Serv Res, 19*(1), 974. https://doi.org/10.1186/s12913-019-4815-5

Das Gupta, D., Kelekar, U., Turner, S. C., Sule, A. A., & Jerman, T. G. (2021). Interpreting COVID-19 deaths among nursing home residents in the US: The changing role of facility quality over time. *PLoS One, 16*(9), e0256767. https://doi.org/10.1371/journal.pone.0256767

Dhingra, L., Lam, K., Cheung, W., Hynes, G., Fleming-Damon, C., Hicks, S., Huang, P., Chen, J., Chang, V., & Portenoy, R. (2021, Sep). Development and Pilot Test of a Culturally Relevant Toolkit to Enhance Advance Care Planning With Chinese American Patients. *J Pain Symptom Manage, 62*(3), e186-e191. https://doi.org/10.1016/j.jpainsymman.2021.02.031

Dhingra, L., Lipson, K., Dieckmann, N. F., Chen, J., Bookbinder, M., & Portenoy, R. (2019, Dec). Institutional Special Needs Plans and Hospice Enrollment in Nursing Homes: A National Analysis. *J Am Geriatr Soc, 67*(12), 2537-2544. https://doi.org/10.1111/jgs.16103

Donabedian, A. (1966, Jul). Evaluating the quality of medical care. *Milbank Mem Fund Q, 44*(3), Suppl:166-206.

Eicheldinger, C., & Bonito, A. (2008, Spring). More accurate racial and ethnic codes for Medicare administrative data. *Health Care Financ Rev, 29*(3), 27-42.

Ellington, L., Clayton, M. F., Reblin, M., Cloyes, K., Beck, A. C., Harrold, J. K., Harris, P., & Casarett, D. (2016, May). Interdisciplinary Team Care and Hospice Team Provider Visit Patterns during the Last Week of Life. *J Palliat Med, 19*(5), 482-487. https://doi.org/10.1089/jpm.2015.0198

Emiloju, O. E., Djibo, D. A. M., & Ford, J. G. (2020, Jun). Association Between the Timing of Goals-of-Care Discussion and Hospitalization Outcomes in Patients With Metastatic Cancer. *Am J Hosp Palliat Care, 37*(6), 433-438. https://doi.org/10.1177/1049909119882891

Ernecoff, N. C., Zimmerman, S., Mitchell, S. L., Song, M. K., Lin, F. C., Wessell, K. L., & Hanson, L. C. (2018, Oct). Concordance between Goals of Care and Treatment Decisions for Persons with Dementia. *J Palliat Med, 21*(10), 1442-1447. https://doi.org/10.1089/jpm.2018.0103

Estrada, L. V., Agarwal, M., & Stone, P. W. (2021, Feb). Racial/Ethnic Disparities in Nursing Home End-of-Life Care: A Systematic Review. *J Am Med Dir Assoc, 22*(2), 279-290.e271. https://doi.org/10.1016/j.jamda.2020.12.005

Fosse, A., Schaufel, M. A., Ruths, S., & Malterud, K. (2014, 2014/10/01/). End-of-life expectations and experiences among nursing home patients and their relatives—A synthesis of qualitative studies. *Patient Educ Couns, 97*(1), 3-9. https://doi.org/https://doi.org/10.1016/j.pec.2014.05.025

Frahm, K. A., Brown, L. M., & Hyer, K. (2012, Nov). Racial disparities in end-of-life planning and services for deceased nursing home residents. *J Am Med Dir Assoc, 13*(9), 819.e817-811. https://doi.org/10.1016/j.jamda.2012.07.021

Fromme, E. K., Montgomery, C., & Hickman, S. (2023, Aug). Advance Care Planning in the United States: A 2023 review. *Z Evid Fortbild Qual Gesundhwes, 180*, 59-63. https://doi.org/10.1016/j.zefq.2023.05.006

Fu, C. J., Mantell, E., Stone, P. W., & Agarwal, M. (2020, Jan). Characteristics of nursing homes with comprehensive antibiotic stewardship programs: Results of a national survey. *Am J Infect Control, 48*(1), 13-18. https://doi.org/10.1016/j.ajic.2019.07.015

Gilissen, J., Pivodic, L., Unroe, K. T., & Van den Block, L. (2020, Aug). International COVID-19 Palliative Care Guidance for Nursing Homes Leaves Key Themes Unaddressed. *J Pain Symptom Manage, 60*(2), e56-e69. https://doi.org/10.1016/j.jpainsymman.2020.04.151

Glajchen, M., Goehring, A., Johns, H., & Portenoy, R. K. (2022, May). Family Meetings in Palliative Care: Benefits and Barriers. *Curr Treat Options Oncol, 23*(5), 658-667. https://doi.org/10.1007/s11864-022-00957-1

Gonella, S., Basso, I., Dimonte, V., Martin, B., Berchialla, P., Campagna, S., & Di Giulio, P. (2019, Mar). Association Between End-of-Life Conversations in Nursing Homes and End-of-Life Care Outcomes: A Systematic Review and Meta-analysis. *J Am Med Dir Assoc, 20*(3), 249-261. https://doi.org/10.1016/j.jamda.2018.10.001

Gonella, S., Campagna, S., Basso, I., De Marinis, M. G., & Di Giulio, P. (2019, Dec). Mechanisms by which end-of-life communication influences palliative-oriented care in nursing homes: A scoping review. *Patient Educ Couns, 102*(12), 2134-2144. https://doi.org/10.1016/j.pec.2019.06.018

Gorges, R. J., & Konetzka, R. T. (2020, Nov). Staffing Levels and COVID-19 Cases and Outbreaks in U.S. Nursing Homes. *J Am Geriatr Soc, 68*(11), 2462-2466. https://doi.org/10.1111/jgs.16787

Gorges, R. J., & Konetzka, R. T. (2021, Feb 1). Factors Associated With Racial Differences in Deaths Among Nursing Home Residents With COVID-19 Infection in the US. *JAMA Netw Open, 4*(2), e2037431. https://doi.org/10.1001/jamanetworkopen.2020.37431

Gozalo, P., Teno, J. M., Mitchell, S. L., Skinner, J., Bynum, J., Tyler, D., & Mor, V. (2011, Sep 29). End-of-life transitions among nursing home residents with cognitive issues. *N Engl J Med, 365*(13), 1212-1221. https://doi.org/10.1056/NEJMsa1100347

Gracner, T., Agarwal, M., Murali, K. P., Stone, P. W., Larson, E. L., Furuya, E. Y., Harrison, J. M., & Dick, A. W. (2021, Apr 1). Association of Infection-Related Hospitalization With Cognitive Impairment Among Nursing Home Residents. *JAMA Netw Open, 4*(4), e217528. https://doi.org/10.1001/jamanetworkopen.2021.7528

Griffith, M. F., Levy, C. R., Parikh, T. J., Stevens-Lapsley, J. E., Eber, L. B., Palat, S. T., Gozalo, P. L., & Teno, J. M. (2020, Dec). Nursing Home Residents Face Severe Functional Limitation or Death After Hospitalization for Pneumonia. *J Am Med Dir Assoc, 21*(12), 1879-1884. https://doi.org/10.1016/j.jamda.2020.09.010

Hanson, L. C., Zimmerman, S., Song, M. K., Lin, F. C., Rosemond, C., Carey, T. S., & Mitchell, S. L. (2017, Jan 1). Effect of the Goals of Care Intervention for Advanced Dementia: A Randomized Clinical Trial. *JAMA Intern Med, 177*(1), 24-31. https://doi.org/10.1001/jamainternmed.2016.7031

Harrington, C., Carrillo, H., Garfield, R., & Squires, R. (2018). *Nursing Facilities, Staffing, Residents and Facility Deficiencies, 2009 Through 2016*. https://www.kff.org/report-section/nursing-facilities-staffing-residents-and-facility-deficiencies-2009-through-2016-introduction/

Harris-Kojetin, L., Sengupta, M., Lendon, J., Rome, V., Valverde, R., & Caffrey, C. (2019, Feb). Long-Term Care Providers and services users in the United States, 2015-2016. *Vital Health Stat 3*(43).

Harrison, J. M., Agarwal, M., Stone, P. W., Gracner, T., Sorbero, M., & Dick, A. W. (2021, Sep). Does Integration of Palliative Care and Infection Management Reduce Hospital Transfers among Nursing Home Residents? *J Palliat Med, 24*(9), 1334-1341. https://doi.org/10.1089/jpm.2020.0577

Herzig, C. T. A., Dick, A. W., Sorbero, M., Pogorzelska-Maziarz, M., Cohen, C. C., Larson, E. L., & Stone, P. W. (2017, Jul 1). Infection Trends in US Nursing Homes, 2006-2013. *J Am Med Dir Assoc, 18*(7), 635.e639-635.e620. https://doi.org/10.1016/j.jamda.2017.04.003

Hickman, S. E., Sudore, R. L., Sachs, G. A., Torke, A. M., Myers, A. L., Tang, Q., Bakoyannis, G., & Hammes, B. J. (2018). Use of the Physician Orders for Scope of Treatment Program in Indiana Nursing Homes. *66*(6), 1096-1100. https://doi.org/https://doi.org/10.1111/jgs.15338

Hold, J., Payne, C., Lesandrini, J., & Glover, A. C. (2019). Successful Advance Care Planning in a Rural Nursing Home. *36*(5), 357-361. https://doi.org/10.1177/1049909118812162

Horn, R. J. (2014, Mar). Advance directives in english and French law: different concepts, different values, different societies. *Health Care Anal, 22*(1), 59-72. https://doi.org/10.1007/s10728-012-0210-7

Houttekier, D., Cohen, J., Bilsen, J., Addington-Hall, J., Onwuteaka-Philipsen, B. D., & Deliens, L. (2010). Place of Death of Older Persons with Dementia. A Study in Five European Countries. *Journal of the American Geriatrics Society, 58*(4), 751-756. https://doi.org/https://doi.org/10.1111/j.1532-5415.2010.02771.x

Inouye, S. K., Studenski, S., Tinetti, M. E., & Kuchel, G. A. (2007, May). Geriatric syndromes: clinical, research, and policy implications of a core geriatric concept. *J Am Geriatr Soc, 55*(5), 780-791. https://doi.org/10.1111/j.1532-5415.2007.01156.x

Jacoby, S. F., Dong, B., Beard, J. H., Wiebe, D. J., & Morrison, C. N. (2018, Feb). The enduring impact of historical and structural racism on urban violence in Philadelphia. *Soc Sci Med, 199*, 87-95. https://doi.org/10.1016/j.socscimed.2017.05.038

Jain, N., & Bernacki, R. E. (2020, May). Goals of Care Conversations in Serious Illness: A Practical Guide. *Med Clin North Am, 104*(3), 375-389. https://doi.org/10.1016/j.mcna.2019.12.001

Jenerette, C. M., & Mayer, D. K. (2016, May). Patient-Provider Communication: the Rise of Patient Engagement. *Semin Oncol Nurs, 32*(2), 134-143. https://doi.org/10.1016/j.soncn.2016.02.007

Johnson, S., & Bott, M. J. (2016). Communication With Residents and Families in Nursing Homes at the End of Life. *18*(2), 124-130. https://doi.org/10.1097/njh.0000000000000222

Juthani-Mehta, M., & Quagliarello, V. J. (2010). Infectious diseases in the nursing home setting: challenges and opportunities for clinical investigation. *Clinical infectious diseases : an official publication of the Infectious Diseases Society of America, 51*(8), 931-936. https://doi.org/10.1086/656411

Kaiser Family Foundation. (2021). *State COVID-19 Data and Policy Actions*. https://www.kff.org/coronavirus-covid-19/issue-brief/state-covid-19-data-and-policy-actions/#long-term-care-cases-deaths

Kang, J. A., & Barcelona, V. (2023, 2023/05/01). A comparison of conceptual frameworks to examine health inequities in End-of-Life care. *Journal of Advanced Nursing, 79*(5), 2025-2041. https://doi.org/https://doi.org/10.1111/jan.15393

Kelly, A., Conell-Price, J., Covinsky, K., Cenzer, I. S., Chang, A., Boscardin, W. J., & Smith, A. K. (2010). Length of Stay for Older Adults Residing in Nursing Homes at the End of Life. *58*(9), 1701-1706. https://doi.org/https://doi.org/10.1111/j.1532-5415.2010.03005.x

Ketcher, D., Ellington, L., Baucom, B. R. W., Clayton, M. F., & Reblin, M. (2020, May). "In Eight Minutes We Talked More About Our Goals, Relationship, Than We Have in Years": A Pilot of Patient-Caregiver Discussions in a Neuro-Oncology Clinic. *J Fam Nurs, 26*(2), 126-137. https://doi.org/10.1177/1074840720913963

Konttila, T., Finne-Soveri, U. H., Leskinen, R., Niemelä, K., & Antikainen, R. (2020, 2020/01/01/). Progress in advance care planning among nursing home residents dying with advanced dementia—Does it make any difference in end-of-life care? *Archives of Gerontology and Geriatrics, 86*, 103955. https://doi.org/https://doi.org/10.1016/j.archger.2019.103955

Koopmans, R. T. C. M., Lavrijsen, J. C. M., Hoek, J. F., Went, P. B. M., & Schols, J. M. G. A. (2010). DUTCH ELDERLY CARE PHYSICIAN: A NEW GENERATION OF NURSING HOME PHYSICIAN SPECIALISTS. *Journal of the American Geriatrics Society, 58*(9), 1807-1809. https://doi.org/https://doi.org/10.1111/j.1532-5415.2010.03043.x

Lagrotteria, A., Swinton, M., Simon, J., King, S., Boryski, G., Ma, I. W. Y., Dunne, F., Singh, J., Bernacki, R. E., & You, J. J. (2021, Aug 2). Clinicians' Perspectives After Implementation of the Serious Illness Care Program: A Qualitative Study. *JAMA Netw Open, 4*(8), e2121517. https://doi.org/10.1001/jamanetworkopen.2021.21517

Laguna, J., Enguídanos, S., Siciliano, M., & Coulourides-Kogan, A. (2012). Racial/ethnic minority access to end-of-life care: a conceptual framework. *Home Health Care Serv Q, 31*(1), 60-83. https://doi.org/10.1080/01621424.2011.641922

Lamberg, J. L., Person, C. J., Kiely, D. K., & Mitchell, S. L. (2005). Decisions to Hospitalize Nursing Home Residents Dying with Advanced Dementia. *53*(8), 1396-1401. https://doi.org/https://doi.org/10.1111/j.1532-5415.2005.53426.x

Lemoyne, S. E., Herbots, H. H., De Blick, D., Remmen, R., Monsieurs, K. G., & Van Bogaert, P. (2019, Jan 21). Appropriateness of transferring nursing home residents to emergency departments: a systematic review. *BMC Geriatr, 19*(1), 17. https://doi.org/10.1186/s12877-019-1028-z

Lewis, L. M., & Riegel, B. J. (2010, Jan-Feb). Determinants of perceived health in older adults with hypertension. *Heart Lung, 39*(1), 41-49. https://doi.org/10.1016/j.hrtlng.2009.06.010

Li, Y., Cen, X., Cai, X., & Temkin-Greener, H. (2020, Nov). Racial and Ethnic Disparities in COVID-19 Infections and Deaths Across U.S. Nursing Homes. *J Am Geriatr Soc, 68*(11), 2454-2461. https://doi.org/10.1111/jgs.16847

Liaw, W., Krist, A. H., Tong, S. T., Sabo, R., Hochheimer, C., Rankin, J., Grolling, D., Grandmont, J., & Bazemore, A. W. (2018, May-Jun). Living in "Cold Spot" Communities Is Associated with Poor Health and Health Quality. *J Am Board Fam Med, 31*(3), 342-350. https://doi.org/10.3122/jabfm.2018.03.170421

Lima, J. C., & Miller, S. C. (2017, 2018/02/01). Palliative Care Consults in U.S. Nursing Homes: Not Just for the Dying. *Journal of Palliative Medicine, 21*(2), 188-193. https://doi.org/10.1089/jpm.2017.0099

Lindner, S. A., Ben Davoren, J., Vollmer, A., Williams, B., & Seth Landefeld, C. (2007). An Electronic Medical Record Intervention Increased Nursing Home Advance Directive Orders and Documentation. *55*(7), 1001-1006. https://doi.org/https://doi.org/10.1111/j.1532-5415.2007.01214.x

Ma, C., Riehm, L. E., Bernacki, R., Paladino, J., & You, J. J. (2020, Apr-Jun). Quality of clinicians' conversations with patients and families before and after implementation of the Serious Illness Care Program in a hospital setting: a retrospective chart review study. *CMAJ Open, 8*(2), E448-e454. https://doi.org/10.9778/cmajo.20190193

Mackey, K., Ayers, C. K., Kondo, K. K., Saha, S., Advani, S. M., Young, S., Spencer, H., Rusek, M., Anderson, J., Veazie, S., Smith, M., & Kansagara, D. (2021, Mar). Racial and Ethnic Disparities in COVID-19-Related Infections, Hospitalizations, and Deaths : A Systematic Review. *Ann Intern Med, 174*(3), 362-373. https://doi.org/10.7326/m20-6306

Martin, R. S., Hayes, B., Gregorevic, K., & Lim, W. K. (2016, Apr 1). The Effects of Advance Care Planning Interventions on Nursing Home Residents: A Systematic Review. *J Am Med Dir Assoc, 17*(4), 284-293. https://doi.org/10.1016/j.jamda.2015.12.017

McAuley, W. J., Buchanan, R. J., Travis, S. S., Wang, S., & Kim, M. (2006). Recent Trends in Advance Directives at Nursing Home Admission and One Year After Admission. *The Gerontologist, 46*(3), 377-381. https://doi.org/10.1093/geront/46.3.377 %J The Gerontologist

Miller, S. C., Lima, J. C., Intrator, O., Martin, E., Bull, J., & Hanson, L. C. (2017, Jul). Specialty Palliative Care Consultations for Nursing Home Residents With Dementia. *J Pain Symptom Manage, 54*(1), 9-16.e15. https://doi.org/10.1016/j.jpainsymman.2017.03.005

Miller, S. C., Lima, J. C., Intrator, O., Martin, E., Bull, J., & Hanson, L. C. (2017, 2017/07/01/). Specialty Palliative Care Consultations for Nursing Home Residents With Dementia. *Journal of Pain and Symptom Management, 54*(1), 9-16.e15. https://doi.org/https://doi.org/10.1016/j.jpainsymman.2017.03.005

Mitchell, S. L., Palmer, J. A., Volandes, A. E., Hanson, L. C., Habtemariam, D., & Shaffer, M. L. (2017, 2017/09/01/). Level of Care Preferences Among Nursing Home Residents With Advanced Dementia. *Journal of Pain and Symptom Management, 54*(3), 340-345. https://doi.org/https://doi.org/10.1016/j.jpainsymman.2017.04.020

Mitchell, S. L., Shaffer, M. L., Loeb, M. B., Givens, J. L., Habtemariam, D., Kiely, D. K., & D'Agata, E. (2014, Oct). Infection management and multidrug-resistant organisms in nursing home residents with advanced dementia. *JAMA Intern Med, 174*(10), 1660-1667. https://doi.org/10.1001/jamainternmed.2014.3918

Mitchell, S. L., Teno, J. M., Kiely, D. K., Shaffer, M. L., Jones, R. N., Prigerson, H. G., Volicer, L., Givens, J. L., & Hamel, M. B. (2009, Oct 15). The clinical course of advanced dementia. *N Engl J Med, 361*(16), 1529-1538. https://doi.org/10.1056/NEJMoa0902234

Montoya, A., Cassone, M., & Mody, L. (2016, Aug). Infections in Nursing Homes: Epidemiology and Prevention Programs. *Clin Geriatr Med, 32*(3), 585-607. https://doi.org/10.1016/j.cger.2016.02.004

Montoya, A., & Mody, L. (2011, Dec). Common infections in nursing homes: a review of current issues and challenges. *Aging health, 7*(6), 889-899. https://doi.org/10.2217/ahe.11.80

Mor, V., Papandonatos, G., & Miller, S. C. (2005, Feb). End-of-life hospitalization for African American and non-Latino white nursing home residents: variation by race and a facility's racial composition. *J Palliat Med, 8*(1), 58-68. https://doi.org/10.1089/jpm.2005.8.58

Moskalewicz, A., & Oremus, M. (2020, Apr). No clear choice between Newcastle-Ottawa Scale and Appraisal Tool for Cross-Sectional Studies to assess methodological quality in cross-sectional studies of health-related quality of life and breast cancer. *J Clin Epidemiol, 120*, 94-103. https://doi.org/10.1016/j.jclinepi.2019.12.013

Mukamel, D. B., Saliba, D., Ladd, H., & Konetzka, R. T. (2023, 2023/06/01). Dementia Care Is Widespread In US Nursing Homes; Facilities With The Most Dementia Patients May Offer Better Care. *Health Affairs, 42*(6), 795-803. https://doi.org/10.1377/hlthaff.2022.01263

National Academies of Sciences, E., & Medicine. (2017). *Communities in Action: Pathways to Health Equity*. The National Academies Press. https://doi.org/doi:10.17226/24624

National Academies of Sciences, E., & Medicine. (2022). *The National Imperative to Improve Nursing Home Quality: Honoring Our Commitment to Residents, Families, and Staff*. The National Academies Press. https://doi.org/doi:10.17226/26526

National Center for Chronic Disease Prevention and Health Promotion. (2021). *Social Determinants of Health*. https://www.cdc.gov/chronicdisease/programs-impact/sdoh.htm#ftn4

Nicholas, L. H., Bynum, J. P. W., Iwashyna, T. J., Weir, D. R., & Langa, K. M. (2014, 2014/04/01). Advance Directives And Nursing Home Stays Associated With Less Aggressive End-Of-Life Care For Patients With Severe Dementia. *Health Affairs, 33*(4), 667-674. https://doi.org/10.1377/hlthaff.2013.1258

O'Conor, R., Benavente, J. Y., Kwasny, M. J., Eldeirawi, K., Hasnain-Wynia, R., Federman, A. D., Hebert-Beirne, J., & Wolf, M. S. (2019, Sep 17). Daily Routine: Associations With Health Status and Urgent Health Care Utilization Among Older Adults. *Gerontologist, 59*(5), 947-955. https://doi.org/10.1093/geront/gny117

Odejide, O. O., Uno, H., Murillo, A., Tulsky, J. A., & Abel, G. A. (2020, Feb 1). Goals of care discussions for patients with blood cancers: Association of person, place, and time with end-of-life care utilization. *Cancer, 126*(3), 515-522. https://doi.org/10.1002/cncr.32549

Oxford Textbook of Palliative Medicine. (2021). Oxford University Press. https://doi.org/10.1093/med/9780198821328.001.0001

Page, M. J., McKenzie, J. E., Bossuyt, P. M., Boutron, I., Hoffmann, T. C., Mulrow, C. D., Shamseer, L., Tetzlaff, J. M., Akl, E. A., Brennan, S. E., Chou, R., Glanville, J., Grimshaw, J. M., Hróbjartsson, A., Lalu, M. M., Li, T., Loder, E. W., Mayo-Wilson, E., McDonald, S., McGuinness, L. A., Stewart, L. A., Thomas, J., Tricco, A. C., Welch, V.

A., Whiting, P., & Moher, D. (2021). The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. *372*, n71. https://doi.org/10.1136/bmj.n71 %J BMJ

Palmer, M. K., Jacobson, M., & Enguidanos, S. (2021, 2021/04/01). Advance Care Planning For Medicare Beneficiaries Increased Substantially, But Prevalence Remained Low. *Health Affairs*, *40*(4), 613-621. https://doi.org/10.1377/hlthaff.2020.01895

Paque, K., Ivanova, I., Elseviers, M., Stichele, R. V., Dilles, T., Pardon, K., Deliens, L., & Christiaens, T. (2019). Initiation of advance care planning in newly admitted nursing home residents in Flanders, Belgium: A prospective cohort study. *19*(2), 141-146. https://doi.org/https://doi.org/10.1111/ggi.13576

Phillips, R. L., Liaw, W., Crampton, P., Exeter, D. J., Bazemore, A., Vickery, K. D., Petterson, S., & Carrozza, M. (2016, Nov 1). How Other Countries Use Deprivation Indices-And Why The United States Desperately Needs One. *Health Aff (Millwood)*, *35*(11), 1991-1998. https://doi.org/10.1377/hlthaff.2016.0709

Pusa, S., Baxter, R., Andersson, S., Fromme, E. K., Paladino, J., & Sandgren, A. (2024, Apr 1). Core Competencies for Serious Illness Conversations: An Integrative Systematic Review. *J Palliat Care*, 8258597241245022. https://doi.org/10.1177/08258597241245022

Saliba, D., & Buchanan, J. (2012, Sep). Making the investment count: revision of the Minimum Data Set for nursing homes, MDS 3.0. *J Am Med Dir Assoc*, *13*(7), 602-610. https://doi.org/10.1016/j.jamda.2012.06.002

Sankoh AJ, H. M., Dubey SD. (1997). Some comments on frequently used multiple endpoint adjustment methods in clinical trials. *Stat Med*, *16*(22), 2529-2542.

Scott, J., Dardas, L., Sloane, R., Wigington, T., Noonan, D., & Simmons, L. A. (2020, Feb). Understanding Social Determinants of Cardiometabolic Disease Risk in Rural Women. *J Community Health*, *45*(1), 1-9. https://doi.org/10.1007/s10900-019-00710-0

Sherman, R. O., & Touhy, T. (2017). An Exploratory Descriptive Study to Evaluate Florida Nurse Leader Challenges and Opportunities in Nursing Homes Settings. *SAGE Open Nursing*, *3*, 2377960817718754. https://doi.org/10.1177/2377960817718754

Smith, D. B., Feng, Z., Fennell, M. L., Zinn, J. S., & Mor, V. (2007, Sep-Oct). Separate and unequal: racial segregation and disparities in quality across U.S. nursing homes. *Health Aff (Millwood), 26*(5), 1448-1458. https://doi.org/10.1377/hlthaff.26.5.1448

Smith, P. W., Bennett, G., Bradley, S., Drinka, P., Lautenbach, E., Marx, J., Mody, L., Nicolle, L., Stevenson, K., Society for Healthcare Epidemiology of, A., Association for Professionals in Infection, C., & Epidemiology. (2008). SHEA/APIC Guideline: Infection prevention and control in the long-term care facility. *American journal of infection control, 36*(7), 504-535. https://doi.org/10.1016/j.ajic.2008.06.001

Smith-Howell, E. R., Hickman, S. E., Meghani, S. H., Perkins, S. M., & Rawl, S. M. (2016, Feb). End-of-Life Decision Making and Communication of Bereaved Family Members of African Americans with Serious Illness. *J Palliat Med, 19*(2), 174-182. https://doi.org/10.1089/jpm.2015.0314

Starr, L. T., Ulrich, C. M., Corey, K. L., & Meghani, S. H. (2019, Oct). Associations Among End-of-Life Discussions, Health-Care Utilization, and Costs in Persons With Advanced Cancer: A Systematic Review. *Am J Hosp Palliat Care, 36*(10), 913-926. https://doi.org/10.1177/1049909119848148

Stata Statistical Software: Release 15 In. (2017). StataCorp LLC.

Stone, P. W., Agarwal, M., Ye, F., Sorbero, M., Miller, S. C., & Dick, A. W. (2019, Sep). Integration of Palliative Care and Infection Management at the End of Life in U.S. Nursing Homes. *J Pain Symptom Manage, 58*(3), 408-416.e401. https://doi.org/10.1016/j.jpainsymman.2019.06.001

Sullivan, D. R., Iyer, A. S., Enguidanos, S., Cox, C. E., Farquhar, M., Janssen, D. J. A., Lindell, K. O., Mularski, R. A., Smallwood, N., Turnbull, A. E., Wilkinson, A. M., Courtright, K. R., Maddocks, M., McPherson, M. L., Thornton, J. D., Campbell, M. L., Fasolino, T. K., Fogelman, P. M., Gershon, L., Gershon, T., Hartog, C., Luther, J., Meier, D. E., Nelson, J. E., Rabinowitz, E., Rushton, C. H., Sloan, D. H., Kross, E. K., & Reinke, L. F. (2022, Sep 15). Palliative Care Early in the Care Continuum among Patients with Serious Respiratory Illness: An Official ATS/AAHPM/HPNA/SWHPN Policy Statement. *Am J Respir Crit Care Med, 206*(6), e44-e69. https://doi.org/10.1164/rccm.202207-1262ST

Tark, A., Agarwal, M., Dick, A. W., Song, J., & Stone, P. W. (2021, Jul). Impact of the Physician Orders for Life-Sustaining Treatment (POLST) Program Maturity Status on the Nursing Home Resident's Place of Death. *Am J Hosp Palliat Care, 38*(7), 812-822. https://doi.org/10.1177/1049909120956650

Tark, A., Estrada, L. V., Tresgallo, M. E., Quigley, D. D., Stone, P. W., & Agarwal, M. (2020, May). Palliative care and infection management at end of life in nursing homes: A descriptive survey. *Palliat Med, 34*(5), 580-588. https://doi.org/10.1177/0269216320902672

Tark, A., Estrada, L. V., Tresgallo, M. E., Quigley, D. D., Stone, P. W., & Agarwal, M. (2020). Palliative care and infection management at end of life in nursing homes: A descriptive survey. *34*(5), 580-588. https://doi.org/10.1177/0269216320902672

Tark, A., Song, J., Parajuli, J., Chae, S., & Stone, P. W. (2020, Nov 28). Are We Getting What We Really Want? A Systematic Review of Concordance Between Physician Orders for Life-Sustaining Treatment (POLST) Documentation and Subsequent Care Delivered at End-of-Life. *Am J Hosp Palliat Care*, 1049909120976319. https://doi.org/10.1177/1049909120976319

ten Koppel, M., Onwuteaka-Philipsen, B. D., Van den Block, L., Deliens, L., Gambassi, G., Heymans, M. W., Kylänen, M., Oosterveld-Vlug, M. G., Pasman, H. R. W., Payne, S., Smets, T., Szczerbińska, K., Twisk, J. W., & van der Steen, J. T. (2019). Palliative care provision in long-term care facilities differs across Europe: Results of a cross-sectional study in six European countries (PACE). *33*(9), 1176-1188. https://doi.org/10.1177/0269216319861229

Teno, J. M., Casarett, D., Spence, C., & Connor, S. (2012, 2012/04/01/). It Is "Too Late" or Is It? Bereaved Family Member Perceptions of Hospice Referral When Their Family Member Was on Hospice for Seven Days or Less. *Journal of Pain and Symptom Management, 43*(4), 732-738. https://doi.org/https://doi.org/10.1016/j.jpainsymman.2011.05.012

Teno, J. M., Gozalo, P., Trivedi, A. N., Bunker, J., Lima, J., Ogarek, J., & Mor, V. (2018, Jul 17). Site of Death, Place of Care, and Health Care Transitions Among US Medicare Beneficiaries, 2000-2015. *Jama, 320*(3), 264-271. https://doi.org/10.1001/jama.2018.8981

The National Institute on Aging. (2017). *Residential Facilities, Assisted Living, and Nursing Homes*. https://www.nia.nih.gov/health/residential-facilities-assisted-living-and-nursing-homes

The Robert Graham Center. (n.d.). *Social Deprivation Index (SDI)*. https://www.graham-center.org/rgc/maps-data-tools/sdi/social-deprivation-index.html

Thompson, S., Bott, M., Boyle, D., Gajewski, B., & Tilden, V. P. (2011, Jan). A measure of palliative care in nursing homes. *J Pain Symptom Manage, 41*(1), 57-67. https://doi.org/10.1016/j.jpainsymman.2010.03.016

Thornton, R. L., Glover, C. M., Cené, C. W., Glik, D. C., Henderson, J. A., & Williams, D. R. (2016, Aug 1). Evaluating Strategies For Reducing Health Disparities By Addressing The Social Determinants Of Health. *Health Aff (Millwood), 35*(8), 1416-1423. https://doi.org/10.1377/hlthaff.2015.1357

Tinetti, M. E., Esterson, J., Ferris, R., Posner, P., & Blaum, C. S. (2016, May). Patient Priority-Directed Decision Making and Care for Older Adults with Multiple Chronic Conditions. *Clin Geriatr Med, 32*(2), 261-275. https://doi.org/10.1016/j.cger.2016.01.012

Tinetti, M. E., Naik, A. D., Dindo, L., Costello, D. M., Esterson, J., Geda, M., Rosen, J., Hernandez-Bigos, K., Smith, C. D., Ouellet, G. M., Kang, G., Lee, Y., & Blaum, C. (2019). Association of Patient Priorities–Aligned Decision-Making With Patient Outcomes and Ambulatory Health Care Burden Among Older Adults With Multiple Chronic Conditions: A Nonrandomized Clinical Trial. *JAMA Internal Medicine, 179*(12), 1688-1697. https://doi.org/10.1001/jamainternmed.2019.4235 %J JAMA Internal Medicine

Towsley, G. L., Hirschman, K. B., & Madden, C. (2015, May). Conversations about End of Life: Perspectives of Nursing Home Residents, Family, and Staff. *J Palliat Med, 18*(5), 421-428. https://doi.org/10.1089/jpm.2014.0316

Travers, J. L., Agarwal, M., Estrada, L. V., Dick, A. W., Gracner, T., Wu, B., & Stone, P. W. (2021, Apr). Assessment of Coronavirus Disease 2019 Infection and Mortality Rates Among Nursing Homes With Different Proportions of Black Residents. *J Am Med Dir Assoc*, *22*(4), 893-898.e892. https://doi.org/10.1016/j.jamda.2021.02.014

Tsai, H.-H., Tsai, Y.-F., & Liu, C.-Y. (2017, 2017/03/01/). Advance directives and mortality rates among nursing home residents in Taiwan: A retrospective, longitudinal study. *International Journal of Nursing Studies*, *68*, 9-15. https://doi.org/https://doi.org/10.1016/j.ijnurstu.2016.12.006

Tsui, J., Hirsch, J. A., Bayer, F. J., Quinn, J. W., Cahill, J., Siscovick, D., & Lovasi, G. S. (2020). Patterns in Geographic Access to Health Care Facilities Across Neighborhoods in the United States Based on Data From the National Establishment Time-Series Between 2000 and 2014. *JAMA Network Open*, *3*(5), e205105-e205105. https://doi.org/10.1001/jamanetworkopen.2020.5105

U.S. Department of Health and Human Services. *Health People 2030: Social Determinants of Health*. Retrieved November 12, 2020 from https://health.gov/healthypeople/objectives-and-data/social-determinants-health

van Soest-Poortvliet, M. C., van der Steen, J. T., de Vet, H. C., Hertogh, C. M., Deliens, L., & Onwuteaka-Philipsen, B. D. (2015). Comfort goal of care and end-of-life outcomes in dementia: A prospective study. *29*(6), 538-546. https://doi.org/10.1177/0269216315570409

van Soest-Poortvliet, M. C., van der Steen, J. T., de Vet, H. C. W., Hertogh, C. M. P. M., Onwuteaka-Philipsen, B. D., & Deliens, L. H. J. (2014, 2014/12/01). Factors Related to Establishing a Comfort Care Goal in Nursing Home Patients with Dementia: A Cohort

Study among Family and Professional Caregivers. *Journal of Palliative Medicine, 17*(12), 1317-1327. https://doi.org/10.1089/jpm.2014.0205

van Soest-Poortvliet, M. C., van der Steen, J. T., Gutschow, G., Deliens, L., Onwuteaka-Philipsen, B. D., de Vet, H. C., & Hertogh, C. M. (2015, Nov 1). Advance Care Planning in Nursing Home Patients With Dementia: A Qualitative Interview Study Among Family and Professional Caregivers. *J Am Med Dir Assoc, 16*(11), 979-989. https://doi.org/10.1016/j.jamda.2015.06.015

Veritas Health Innovation. *Covidence systematic review software*. www.covidence.org

Veronese, N., Koyanagi, A., Stangherlin, V., Mantoan, P., Chiavalin, M., Tudor, F., Pozzobon, G., Tessarin, M., & Pilotto, A. (2021, Jun). Mortality attributable to COVID-19 in nursing home residents: a retrospective study. *Aging Clin Exp Res, 33*(6), 1745-1751. https://doi.org/10.1007/s40520-021-01855-6

Veshi, D., & Neitzke, G. (2015, 31 Jul. 2015). Advance Directives in Some Western European Countries: A Legal and Ethical Comparison between Spain, France, England, and Germany. *European Journal of Health Law, 22*(4), 321-345. https://doi.org/https://doi.org/10.1163/15718093-12341368

Vespa, J., Medina, L., & Amstrong, D. M. (2020). *Demographic turning points for the United States: Population projections for 2020 to 2060*. https://www.census.gov/content/dam/Census/library/publications/2020/demo/p25-1144.pdf

VitalTalk. (n. d.). *VitalTalk*. https://www.vitaltalk.org/

Wells, G. A., Wells, G., Shea, B., Shea, B., O'Connell, D., Peterson, J., Welch, Losos, M., Tugwell, P., Ga, S. W., Zello, G. A., & Petersen, J. A. (2014). The Newcastle-Ottawa Scale (NOS) for Assessing the Quality of Nonrandomised Studies in Meta-Analyses.

Wenger, N. S., Citko, J., O'Malley, K., Diamant, A., Lorenz, K., Gonzalez, V., & Tarn, D. M. (2013, 2013/01/01). Implementation of Physician Orders for Life Sustaining Treatment in Nursing Homes in California: Evaluation of a Novel Statewide Dissemination Mechanism. *Journal of General Internal Medicine, 28*(1), 51-57. https://doi.org/10.1007/s11606-012-2178-2

Williams, D. R., Priest, N., & Anderson, N. B. (2016, Apr). Understanding associations among race, socioeconomic status, and health: Patterns and prospects. *Health Psychol, 35*(4), 407-411. https://doi.org/10.1037/hea0000242

World Health Organization. (2018). *Health inequities and their causes*. https://www.who.int/news-room/facts-in-pictures/detail/health-inequities-and-their-causes

Yao, Y., Stifter, J., Ezenwa, M. O., Lodhi, M., Khokhar, A., Ansari, R., Keenan, G. M., & Wilkie, D. J. (2015, Oct). Infomarkers for transition to goals consistent with palliative care in dying patients. *Palliat Support Care, 13*(5), 1427-1434. https://doi.org/10.1017/s1478951515000103

Yuan, T., Fitzpatrick, T., Ko, N. Y., Cai, Y., Chen, Y., Zhao, J., Li, L., Xu, J., Gu, J., Li, J., Hao, C., Yang, Z., Cai, W., Cheng, C. Y., Luo, Z., Zhang, K., Wu, G., Meng, X., Grulich, A. E., Hao, Y., & Zou, H. (2019, Apr). Circumcision to prevent HIV and other sexually transmitted infections in men who have sex with men: a systematic review and meta-analysis of global data. *Lancet Glob Health*, *7*(4), e436-e447. https://doi.org/10.1016/s2214-109x(18)30567-9

Zheng, N. T., Mukamel, D. B., Caprio, T., Cai, S., & Temkin-Greener, H. (2011, Nov). Racial disparities in in-hospital death and hospice use among nursing home residents at the end of life. *Med Care*, *49*(11), 992-998. https://doi.org/10.1097/MLR.0b013e318236384e

Appendix A: A Comparison of Conceptual Frameworks to Examine Health Inequities in End-of-Life Care

The following supplemental appendix is a systematic review that identified potential conceptual frameworks applicable to the study of inequities in end-of-life care and related health outcomes.

Note. The contents of this appendix A have been published in the Journal of Advanced Nursing. Citation for the final published version is as follows:

Kang, J. A., & Barcelona, V. (2022). A comparison of conceptual frameworks to examine health inequities in End-of-Life care. *Journal of Advanced Nursing*, *00*, 1–17. https://doi.org/10.1111/jan.15393

Abstract

Aims: To discuss existing conceptual frameworks that can be applied to the examination of health inequities in end-of-life care and related health outcomes. We used the Fawcett and Desanto-Madeya evaluation technique modified by the National Institute on Minority Health and Health Disparities Research Framework to include individual, interpersonal, community, and societal levels of influence.

Design: Discussion paper.

Data sources: We performed a systematic review of PubMed, CINAHL, and Embase for conceptual frameworks of health inequities in end-of-life care and health outcomes published as of February 2022.

Implications for nursing: There is a strong need for research that can address multiple factors influencing end-of-life care inequities and health outcomes. In order to mitigate the complex nature of social determinants of health and structural inequities, researchers, clinicians, educators and administrators should have solid conceptualizations of these multi-level factors. Based on sound and comprehensive frameworks, nurses with interdisciplinary partnerships can promote health equity with a broader health care scope through addressing social determinants of health.

Conclusion: We identified and reviewed three frameworks. We concluded all three frameworks have the potential for use in the examination of health inequities in end-of-life care and health outcomes. However, the Conceptual Framework of Minority Access to End-of-Life Care was more applicable to diverse studies and settings when adapted to include fundamental characteristics such as sex and gender.

Impact: Despite the substantial rise in end-of-life care delivery, health inequities persist in end-of-life care access and utilization. Though some studies have been conducted to promote health

equity by addressing social determinants of health, progress is hampered by their complex and multi-faceted nature. Through a concrete conceptual framework, researchers can comprehensively examine multi-level factors influencing health inequities in end-of-life care.

No patient or public contribution: This discussion paper focused on reviewing existing evidence.

Introduction

The National Institute of Nursing Research (2021) recently announced their new 2022-2026 Strategic Plan, which prioritizes the advancement of health equity with a particular emphasis on eliminating systemic and structural inequities. *Health inequities* are systematic differences in the distribution of health resources or in health status between different population groups (World Health Organization, 2018). Health inequities often stem from *structural inequities* which refers to the personal, interpersonal, institutional, and systemic disadvantages in policies, practices, and culture (National Academies of Sciences Engineering and Medicine, 2017). Structural inequities lead to inequitable experiences of social determinants of health and ultimately shape unfair differences in health outcomes (National Academies of Sciences Engineering and Medicine, 2017). Thus, it is critical to assess and address social determinants of health to achieve health equity (National Center for Chronic Disease Prevention and Health Promotion, 2021).

Health inequities in end-of-life care are emerging globally. Since the onset of the COVID-19 pandemic, there has been a five-fold increase in the completion of Advanced Directives and Advanced Care Planning compared to before March 2020 (Auriemma et al., 2020). It is important to clearly distinguish between services often provided at the end-of-life. Palliative care is defined as patient and family-centered care that promotes quality of life with focuses on the pain, symptoms, and stress of serious illness (National Hospice and Palliative Care Organization, 2019). Unlike end-of-life care which is for people with a life expectancy of 6 months or less, palliative care can be provided regardless of life expectancy (National Hospice and Palliative Care Organization, 2019). Despite the substantial rise in end-of-life care delivery, health inequities persist in end-of-life care access and utilization (Ornstein et al., 2020). Multiple studies have revealed that Black individuals are significantly less likely to use end-of-life care and more likely to have multiple emergency department visits and hospitalizations, and undergo aggressive treatments in acute care settings during their end-of-life compared to White individuals (Estrada et al., 2021; Ornstein et al., 2020). Moreover, Black individuals who receive aggressive care in acute care settings at the end-of-life have higher health care spending and lower quality of life (Byhoff et al., 2016; Estrada et al., 2021). In addition to racialized populations receiving poorer end-of-life care, other social determinants of health also contribute to inequities. Individuals with limited access to health care due to geographic location, and those with lower socioeconomic status are also known to receive inequitable end-of-life care (Hutchinson et al., 2021; Noh et al., 2021).

Though some studies have been conducted on health inequities in end-of-life care and how to promote health equity by addressing social determinants of health (Bazargan & Bazargan-Hejazi, 2021; Brown et al., 2018; Hutchinson et al., 2021; Noh et al., 2021), progress is hampered by complex and multi-faceted nature of both end-of-life care and social determinants of health (Alvidrez et al., 2019). End-of-life care requires holistic and individualized approaches in response to physical, psychological, social, and spiritual needs through a multidisciplinary team (Finucane et al., 2021; Nelson et al., 2021). Therefore, end-of-life care processes and outcomes could be better understood by carefully evaluating clinician and patients, family perspectives as well as structures of the health care system by conducting well-designed studies (Finucane et al., 2021). Understanding and addressing the complex interactions of determinants of health also requires structural strategies (Alvidrez et al., 2019). To understand those important linkages, it is critical to include factors across individual, interpersonal, community, and societal levels in these studies (Alvidrez et al., 2019).

Background

Conceptual frameworks are logically-developed arguments that justify the need of the research study (Varpio et al., 2020). Through the development of conceptual frameworks, researchers can identify gaps in the current knowledge and outline the methodological underpinnings of the research project (Varpio et al., 2020). The development and use of concrete conceptual frameworks are essential to guide the study of health inequities in end-of-life care (Nelson et al., 2021). Conceptual frameworks guide study design and provide strategic structure to examine complex social structures (Fawcett & Desanto-Madeya, 2013; Varpio et al., 2020). To support and guide research that addresses health disparities and promotes health equity among minoritized populations, the National Institute on Minority Health and Health Disparities (NIMHD) developed a research framework that reflects a conceptualization of a wide array of determinants of health (Alvidrez et al., 2019). Built upon the National Institute on Aging (NIA) health disparities research framework, the NIMHD framework further extends the NIA framework by classifying determinants of health in accordance with levels of the socioecological model (Alvidrez et al., 2019). The resulting NIMHD framework spans different domains and levels of influence that facilitate a comprehensive analysis of the health of minoritized individuals and health equity research. This framework has been used in many studies, however few studies have used this or other conceptual frameworks to examine health inequities in end-of-life care (Nelson et al., 2021).

Thus, the purpose of this paper was to: 1) identify potential conceptual frameworks that may be applicable to the study of inequities in end-of-life care and related health outcomes through a systematic search; 2) analyze and evaluate these conceptual frameworks to assess their comprehensiveness, logical congruence, and applicability; and 3) compare the conceptual frameworks using the Fawcett and Desanto-Madeya (2013) analysis and evaluation technique to identify those that can be applied to the study of multi-level factors influencing health inequities in end-of-life care and related health outcomes.

Data Sources

Search Strategy

In February 2022, we performed a systematic review of PubMed, Cumulative Index to Nursing and Allied Health Literature (CINAHL), and Embase for conceptual frameworks of health inequities in end-of-life care. The search included terms related to conceptual framework (e.g., 'conceptual model'), health inequity (e.g., 'health disparity'), social determinants of health (e.g., 'structural determinants of health'), and end-of-life care (e.g., 'palliative care'). A complete list of search terms is available in supporting information. Two researchers (JK, VB) independently screened titles and abstracts for potentially applicable conceptual frameworks through the Covidence program, a systematic review software, and then reviewed full articles to determine if they met inclusion criteria. Any conflicts were resolved through discussions. Conceptual frameworks were selected based on: 1) peer-reviewed publications; 2) description of development of the conceptual framework; 3) a focus on health inequities or social determinants of health in end-of-life care; and 4) inclusion of a figure displaying the conceptual framework. We excluded conceptual frameworks that solely focused on one level of influence (i.e., conceptual frameworks assessing individual-level wishes and values at the end-of-life) as we were interested in frameworks that would inform the study of multi-level health inequities. We also excluded frameworks that did not explicitly mention end-of-life care outcomes. Searches were also restricted to publications in English. Due to the small number of eligible studies, we did not restrict by publication date.

Analysis and Evaluation Technique

The two researchers extracted data following the previous study by Cohen and Shang (2015) that compared and evaluated conceptual frameworks by using the Fawcett and Desanto-Madeya (2013) analysis and evaluation technique for nursing models and theories. This technique provides a comprehensive approach to analyze and evaluate conceptual frameworks allowing researchers to ensure that the selected conceptual frameworks are logically aligned with study design and objective (Fawcett & Desanto-Madeya, 2013). It includes analysis questions regarding origins, focus, and contents of the conceptual framework; as well as evaluation questions such as explication of origins, comprehensiveness of contents, logical congruence, legitimacy, and contributions of the conceptual framework. The original Fawcett and Desanto-Madeya (2013) technique includes specific questions regarding content of nursing model, which includes four concepts of the meta-paradigm – human beings, environment, health, and nursing. However, we modified those questions in the original technique based on the NIMHD research framework in order to address a broad range of health issues that disproportionately impact minoritized populations (Alvidrez et al., 2019). In particular, four levels of influence – individual, interpersonal, community, and societal levels were included to reflect the multi-level factors that influence health inequities in end-of-life care (Alvidrez et al., 2019). The NIMHD research framework also includes fundamental characteristics such as sex, gender, disability, and geographic location and these characteristics were embedded into the evaluation technique (Alvidrez et al., 2019). In Table 1, we present the modified Fawcett and Desanto-Madeya (2013) analysis and evaluation technique used in this paper. We denoted the modified questions in bold in Table 1.

Discussion

We present a summary of the studies reviewed in a PRISMA flow diagram (Figure 1). Our literature search yielded 679 publications, 48 of which were duplicates. We screened titles and abstracts of the remaining 631 articles to ensure they met inclusion criteria. After screening, 25 articles remained for full text review, which resulted in the inclusion of three publications. Of the 22 excluded studies during the full text review stage, the primary reason for exclusion was not having a health equity or social determinants of health concept in the framework (n = 15). Thus, the systematic review resulted in the inclusion of three frameworks for the present comparison: A Conceptual Framework of Minority Access to End-of-Life Care (Laguna et al., 2012); A Conceptual Framework for the Role of Healthcare Service Factors in Place of Death (Gao et al., 2018); and An Adapted Conceptual Model Integrating Palliative Care in Serious Illness and Multiple Chronic Condition (Murali et al., 2020).

Next, we will compare each of the three conceptual frameworks (Gao et al., 2018; Laguna et al., 2012; Murali et al., 2020), summarized in Table 2 by key attributes.

A Conceptual Framework of Minority Access to End-of-Life Care

Description

Laguna et al. (2012) proposed the Conceptual Framework of Minority Access to End-of-Life Care to offer a more comprehensive understanding of the factors associated with end-of-life care disparities in minoritized populations. Specifically, the authors (Laguna et al., 2012) aimed to understand factors contributing to the underuse of end-of-life care among racial and ethnic minority groups that ultimately impacted care intensity and patient outcomes at the end-of-life.

There are four constructs in this framework which include: 1) *barriers*; 2) *health care mediators*; 3) *care at end-of-life*; and 4) *outcomes*. Laguna et al. (2012) described a dynamic interaction between *barriers* and *health care mediators* through a bidirectional relationship. This interaction influences *care at end-of-life* and ultimately impacts patient *outcomes* at the end-of-life. For example, the cultural backgrounds of both patients and providers influence their end-of-life communication and finally shape patient end-of-life care outcomes. The visualization of this conceptual framework is presented in Figure 2.

Analysis

Origins. Laguna et al. (2012) described that despite a significant growth of end-of-life care in the U.S., many studies reported the underuse of end-of-life care by racial and ethnic minority populations. However, there had been no studies that comprehensively incorporated the full scope of factors related to end-of-life care disparities among minoritized racial and ethnic groups (Laguna et al., 2012). Motivated by this gap, the Conceptual Framework of Minority Access to End-of-Life Care was developed based on two previous conceptual models and multiple studies that investigated factors related to end-of-life care disparities (Laguna et al., 2012). The Institute of Medicine (1993) proposed a Model for Monitoring Access to Health Care to explain factors related to the health care disparities. Later in 2002, Cooper et al. (2002) expanded this model by adding mediators to reduce health disparities and developed a Model of Equitable Health Care. Building on these two models, Laguna et al. (2012) developed the current framework to exclusively address disparities and promote equitable end-of-life care.

Both deductive and inductive reasoning were used to formulate this framework. Deduction occurs when specific conclusions were drawn from general principles or theories (Alligood, 2014). Laguna et al. (2012) deduced the framework on end-of-life care disparities based on concepts from both the Institute of Medicine (1993) and Cooper et al. (2002). On the other hand, induction occurs when generalizations were drawn from multiple specific observations (Alligood, 2014). After shaping the concepts from the previous models, Laguna et al. (2012) added new barriers and mediators to the proposed framework by searching empirical studies that investigated factors associated with end-of-life disparities among racial and ethnic minority groups. Also, Laguna et al. (2012) calls for further studies to examine the relationship between those factors in order to revise and adapt the current framework.

Fawcett (1993) categorized a parsimonious set of three worldviews – reaction, reciprocal interaction, and simultaneous action – which reflect philosophical claims about the nature of humans and the human-environment relationship. These worldviews are often used to guide nursing scientific knowledge development. The reaction worldview refers to the way humans react to environments in a linear manner. Reciprocal denotes how human beings interact with their environments. Finally, simultaneous action describes the continuous and unpredictable interchange between humans and their environment. The Laguna et al. (2012) framework reflects the reciprocal interactions worldview between human beings and environments rather than the reaction worldview (Fawcett, 1993). In this framework, minoritized patients with personal-level barriers dynamically interact with external environments. Laguna et al. (2012) described a bidirectional interaction between barriers and mediators rather than a linear and casual relationship between patients and external factors.

Focus. The unique focus of this framework is on individual-level barriers related to health disparities in end-of-life care access for minoritized people. Laguna et al. (2012) defined minoritized people as those who belong to racial and ethnic minority groups without specifying any race or ethnicity. However, studies that guided the development of the proposed framework investigated end-of-life care disparities among Black, Hispanic, Asian and Pacific Islander, and

Native American individuals compared to White individuals. Also, this framework well-incorporated the end-of-life care outcomes through the literature reviews.

Contents. End-of-life care was defined and described with the two most prevalent end-of-life care models, hospice and palliative care, using the National Hospice and Palliative Care Organization (2010) definition – care focuses on comfort in lieu of aggressive interventions including patient-centered pain and symptom management, care planning, psychosocial and spiritual support. The proposed framework (Laguna et al., 2012) does not include fundamental characteristics such as sex, gender, and disability of patients, thus requiring an adaptation of the framework to align with the NIMHD framework. All four NIMHD levels of influence are included in this framework, and aligned with levels of influence. Relationships between the levels of influence are described by the author as they have interactions between personal, system and societal-level barriers with healthcare-level mediators. However, Laguna et al. (2012) asserts that more studies are needed to examine these interactions. The goal of this framework is to increase awareness of multi-level barriers of end-of-life care access to target interventions to reduce end-of-life disparities (Laguna et al., 2012).

Evaluation

The origins of the framework were explicitly described, including personal-level barriers, such as race and ethnicity, as well as explanations of all four levels of influence and their relational positions. The authors also provide recommendations for clinicians when employing this framework. For instance, the framework presents targeted interventions by delineating provider-level mediators. Also, Laguna et al. (2012) guide researchers to further examine the explanatory nature of the interaction between barriers and mediators by providing some sample topics. Lastly, Laguna et al. (2012) suggest that educators and administrators identify innovative strategies to educate both patients and healthcare providers in end-of-life care in order to enhance patient-provider communication that can lead to more equitable end-of-life care.

We found that this framework is logically congruent as it was developed with both deductive and inductive reasoning and is aligned with the reciprocal interaction worldview. The framework has not yet generated any theories however, one study adapted this model to develop a new conceptual framework (Gao et al., 2018).

Laguna et al. (2012) did not conduct an evaluation of the framework however, the framework was developed based on existing studies and their empirical findings which make this framework sound and credible. With its comprehensive levels of influence impacting end-of-life care disparities, we deduce that this framework is a useful guide for examining end-of-life care inequities in diverse settings. Indeed, six studies cited this framework (Choi et al., 2015; Delgado-Guay et al., 2018; Fang et al., 2016; Gao et al., 2018; Sharma et al., 2015; Wang et al., 2017). One study adapted the Laguna et al. (2012) framework to develop a conceptual framework examining factors related to place of death (Gao et al., 2018). This framework was also included in this analysis paper and was explicitly examined. The Laguna et al. (2012) framework contributed to the service components related to the end-of-life care outcomes or service access such as service type, workforce, and commissioning in the newly developed framework. As noted above, Laguna et al. (2012) did not include sex, gender, and disability in the framework which are fundamental characteristics described by the NIMHD framework. Thus, Gao et al. (2018) identified individual socio-demographic and disease-related characteristics (patient factors) from another conceptual framework in order to include comprehensive fundamental characteristics.

Four studies used the Laguna et al. (2012) framework to interpret and discuss their study findings relevant to health disparities in end-of-life care (Choi et al., 2015; Delgado-Guay et al., 2018; Sharma et al., 2015; Wang et al., 2017). Three studies (Delgado-Guay et al., 2018; Sharma et al., 2015; Wang et al., 2017) examined patients with advanced cancer and one study (Choi et al., 2015) included patients with subarachnoid hemorrhage. All four studies were conducted in hospitals and included both inpatient and outpatient settings. Among the four studies, two studies (Choi et al., 2015; Sharma et al., 2015) focused on racial and ethnic disparities and the remaining two studies (Delgado-Guay et al., 2018; Wang et al., 2017) examined multi-factors related to end-of-life care disparities. All four studies cited this framework to discuss about factors related to end-of-life care utilization (i.e., decision making process, hospice referral, and removing barriers to hospice usage).

One scoping review included this framework to identify barriers and enablers of culturally- and spiritually-sensitive end-of-life care (Fang et al., 2016). The authors viewed the Laguna et al. (2012) framework as a guide for culturally-sensitive end-of-life care by providing strategies for shared decision-making between patients and providers. This review highlighted the mitigating barriers at the patient, system and societal-levels that are particularly relevant for end-of-life care.

Based on the studies that cited the Laguna et al. (2012) framework, we conclude that it has the potential to be used in the development of new theories or frameworks when adapted to include more comprehensive fundamental characteristics of minoritized populations such as sex, gender, and disability. Multiple studies have used this framework to discuss a broad range of factors related to end-of-life disparities, yet there is a need for studies that utilize this framework to examine populations in long-term care settings with more diverse populations (e.g., noncancer patients). For example, Fang et al. (2016) provided evidence that researchers have used this framework to guide improved end-of-life care and reduce multi-level barriers. However, as noted above, this framework lacks sex, gender, and disability characteristics which are listed as fundamental characteristics in the NIMHD framework. Therefore, for improved applicability, it requires adaptations to include those additional individual factors.

The overall contribution of this framework is that it attempted to identify the full scope of factors influencing health disparities in end-of-life care. Also, it has been highly influential since the framework has been cited and used in subsequent studies to address social determinants of health in end-of-life care.

A Conceptual Framework for the Role of Healthcare Service Factors in Place of Death

Description

Next, we examined the Conceptual Framework for the Role of Healthcare Service Factors in Place of Death by Gao et al. (2018). Gao et al. (2018) aimed to use this framework to identify healthcare service factors which can improve end-of-life care. It is based on seven constructs: 1) *end-of-life care policies*; 2) *service commissioning*; 3) *healthcare service characteristics*; 4) *other environmental factors*; 5); *patient factors*; 6) *service utilization*; and 7) *place of death*. *Healthcare services characteristics* depend on the *end-of-life care policies* and their execution through healthcare *service commissioning*. Healthcare services then influence the *service utilization* and finally *place of death*. Environmental and patient factors also influence the service utilization and place of death, however Gao et al. (2018) describes that they are not the focus of this framework. Finally, *service utilization* and *place of death* produce reciprocal feedback to inform *end-of-life care policies* and *service commissioning* (Gao et al., 2018). The visualization of this conceptual framework is presented in Figure 3.

Analysis

Origins. The motivation for the development of this framework was a lack of empirical studies that examined the impact of healthcare services on place of death – an evolving quality indicator of end-of-life care outcome – because of the dearth of conceptual frameworks (Gao et al., 2018). Gao et al. (2018), thus, conducted a literature review on frameworks describing determinants of place of death. Initially, Gao et al. (2018) identified only one framework meeting these criteria, and as such, the authors integrated six other frameworks relevant to other end-of-life care outcomes and access/utilization. The study listed the seven frameworks and their contributing components.

Unlike Laguna's model, where previous frameworks were applied and new components were introduced to develop their framework, Gao et al. (2018) used components of each framework to formulate the new proposed framework. From this, it is considered that knowledge development was based on retroductive reasoning (also called abductive reasoning) where the science makes a conceptual leap from preknowledge to arrive at an educated guess or theory about a phenomenon (Reed, 1995). It is often used in fields that have few available theories so that the phenomenon of interest requires further research (Alligood, 2014). Considering that the framework has a dynamic feedback loop rather than a one-off process (Gao et al., 2018), we can infer that the reciprocal interaction worldview is reflected (Fawcett, 1993).

Focus. This study (Gao et al., 2018) focused place of death as their end-of-life outcome, and specifically on healthcare service provision at the population-level.

Contents. Gao et al. (2018) do not define end-of-life care but rather characterized by service type (e.g., palliative vs. hospice) or location (e.g., home vs. hospital based palliative care). In addition, this framework does not include direct concepts related to health inequities, and instead covers a wide array of determinants which can be addressed to reduce structural inequities in end-of-life outcomes. Although health disparity populations were not defined or described, Gao et al. (2018) emphasized several unique groups. For example, Gao et al. (2018) described populations in rural areas, individuals with limited social/community/family support and individuals with higher needs of end-of-life care such as frail older adults with multiple chronic conditions as factors related to inequitable end-of-life care use and place of death. The framework includes all four levels of influence consistent with the NIMHD framework. The health care service characteristics construct is especially pertinent to end-of-life care as it includes a wide array of community and societal levels of influence reflecting quality of care and availability of health services. Other fundamental characteristics including sex and gender, disability, and geographic region well-align with socio-demographics of patient and location of the service. The framework has a dynamic relationship between the levels of influence. The ultimate goal of this framework is to guide a population-based study that examines healthcare services and place of death (Gao et al., 2018).

Evaluation

Gao et al. (2018) describe the origins of the framework in detail, and all frameworks are acknowledged and cited. Because it was developed to guide population-based analyses and policies relevant to the place of death, the framework lacks recommendations for the clinician and educator. However, researchers are given sufficient direction about what questions to ask (e.g., population level end-of-life care policy analysis) and what research designs (e.g., multi-level analysis) to use for future research. Furthermore, Gao et al. (2018) emphasize the administrator’s role for developing systems for service data collection.

Although Gao et al. (2018) encountered a limited number of previous theories and models, the proposed framework is logically congruent and multiple frameworks are well-integrated. Given its recent publication, the framework has only been cited by three articles (Chukwusa et al., 2019; Iacobuzio-Donahue et al., 2019; MacNeil Vroomen et al., 2020) in PubMed. It is assumed that Gao et al. (2018) later used this framework to guide an examination of urban and rural differences in end-of-life care and place of death (Chukwusa et al., 2019). Chukwusa et al. (2019) emphasized place of death as an important outcome measure of end-of-life care referring this framework. Another study used this framework for the interpretation of their study findings related to hospice care and factors related to the location of death in older adults with and without dementia (MacNeil Vroomen et al., 2020). MacNeil Vroomen et al. (2020) noted a scarcity of studies that examined place of death as an end-of-life care outcome, and cited this framework to compare international studies that examined place of death. Lastly, Iacobuzio-Donahue et al. (2019) included this framework in their review paper discussing the use of research autopsies in cancer research, place of death, and environmental conditions for the obtained tissues. From these three studies, we noticed that the utilization of this framework was limited to studies with an outcome measure of place of death. Also, though one study described geographical locations related to end-of-life care disparities (Chukwusa et al., 2019), other studies did not define any disparity groups. Therefore, future studies are needed to investigate the utilization of the framework in health disparity research. To do this, the Gao et al. (2018) framework requires a clear definition of health disparity group or concepts related to health inequity.

Although this framework has limitations related to disparity groups in end-of-life care, it is comprehensive and encompasses all four levels of influence and fundamental characteristics of

NIMHD framework. Gao et al. (2018) emphasized its contributions to science, including being the first study to focus on healthcare service factors (determinants of health) related to the place of death. However, the framework's focus on population-level analysis of policies can limit its application to practice and individual-level usage. Also, its focus on place of death may limit its applicability to research examining other end-of-life care outcomes.

An Adapted Conceptual Model Integrating Palliative Care in Serious Illness and Multiple Chronic Conditions

Description

Murali et al. (2020) developed this conceptual framework to address the clinical complexity of multiple chronic conditions using palliative care in seriously ill adults based on four main constructs: 1) *factors affecting needs*; 2) *factors affecting services received*; 3) *service-related variables*; and 4) *outcomes*. Murali et al. (2020) described that complex care needs of the seriously ill adult with multiple chronic conditions can generate an unmet need-services gap. Therefore, to provide optimal care for this complex population, the author (Murali et al., 2020) focused on the integration of palliative care within the care of adults with multiple chronic conditions and serious illness. The visualization of this conceptual framework is presented in Figure 4.

Analysis

Origins. Murali et al. (2020) described that seriously ill adults with multiple chronic conditions are likely to receive fragmented care because of their inherent complexity. To mitigate this complexity, Murali et al. (2020) affirmed that research focus on the integration of palliative care in patients with serious illnesses and multiple chronic conditions are imperative. However, comprehensive conceptual frameworks to guide such research were lacking in the literature, leading to the development of the Adapted Conceptual Model Integrating Palliative Care in Serious Illness and Multiple Chronic Conditions. First, Murali et al. (2020) adapted A Conceptual Model of the Role of Complexity in the Care of Patients With Multiple Chronic Conditions (Grembowski et al., 2014) to address complexity of multiple chronic conditions in seriously ill adults. This original framework was developed by the Agency for Healthcare Research and Quality Multiple Chronic Condition Research Network (Grembowski et al., 2014), which defines complexity as the gap between patient needs and services. In addition, Murali et al. (2020) conducted a literature review to complete the adaptation of the framework by integrating palliative care in the conceptualization of serious illness and multiple chronic conditions.

This study applied retroductive reasoning to develop knowledge as the author (Murali et al., 2020) not only used empirical studies but also used expert literature to adapt the previous framework. However, the author (Murali et al., 2020) calls for future studies to test the proposed framework encouraging inductive reasoning of knowledge development. Considering that the complex health systems in the framework are interconnected in nonlinear and dynamic manner, we can conclude that the framework reflects the reciprocal interaction worldview (Fawcett, 1993).

Focus. The unique focus of this study (Murali et al., 2020) is on the integration of palliative care as a means of addressing care complexity in seriously ill adults with multiple chronic conditions. They addressed the misalignment between ‘needs’ and ‘services’, which are affected by multiple contextual factors such as social determinants of health (Grembowski et al., 2014; Murali et al., 2020).

Contents. This framework was developed to be used in palliative care rather than end-of-life care. However, this framework aligns well, given that end-of-life care is an essential domain in palliative care for adults with serious illness (Ferrell et al., 2018). Indeed, the framework (Murali et al., 2020) incorporated multiple end-of-life care outcomes (e.g., site of death, goal concordant care, advance care planning). The authors (Murali et al., 2020) described palliative care as primary, secondary, and tertiary palliative care by service setting (e.g., non-specialist vs. palliative care specialist) and type (e. g., symptom management vs. palliative sedation). Though the framework was not originally developed to assess health inequities, social determinants of health and health disparities are included as core concepts. The author described the health disparity population as the population influenced by ineffective social policies or unjust economic structures (Murali et al., 2020). The framework includes all four levels of influence according to the NIMHD framework. Each construct was affected by contextual factors incorporating multiple-level of influences that address care complexity. Fundamental characteristics including sex and gender, disability, and geographic region were included in the sociodemographic and clinical characteristics. The framework has nonlinear and dynamic relationships between all levels of influence (Murali et al., 2020). The ultimate goal of this framework is to guide research studies that investigate how to integrate palliative care in the care of seriously ill adults with multiple chronic conditions (Murali et al., 2020).

Evaluation

Murali et al. (2020) described the origins of the framework in detail by describing the previous model and including a flow diagram of the literature review. The framework encompasses all four levels of influence and fundamental characteristics in accordance with the NIMHD framework. The relational positions were delineated in the figure, however the author noted that the relationships between concepts and factors would have to be tested in future research. Researchers are given comprehensive directions about what questions to ask (i.e., how to integrate palliative care in seriously ill individual with multiple chronic conditions) and what methodology (e.g., prospective, observational studies) to use. On the other hand, Murali et al. (2020) acknowledged some of the shortfalls of the adapted framework when using in clinical practice (i.e., does not account for the key interdisciplinary workforce) and application of the framework for education and administration were not presented. However, the authors do note that these will be developed through the research evidence generated by the framework.

Murali et al. (2020) conclude the article with the recommendation to develop knowledge using the inductive approach. Although this framework needs to be tested empirically, it was developed based on a comprehensive literature review of 58 articles, making the framework sound and credible. Since its development in 2020, this framework was cited by one study (Murali et al., 2021a) in PubMed. Murali et al. (2021a) used this framework to guide a study that conducted latent class analysis of symptom burden in seriously ill adults at the end-of-life. In addition, Murali et al. (2021b) conducted another latent class analysis to characterize multiple chronic conditions in seriously ill adults at the end-of-life. From these two studies, we can conclude that the framework is applicable for use in end-of-life populations. However, no clinical studies have utilized this framework to examine or address social determinants of health related to end-of-life care. Therefore, more studies are needed to examine the frameworks' usefulness in health inequity studies.

The main purpose of this framework was not to examine health inequities in end-of-life care, however it includes comprehensive contextual factors related to health inequities in end-of-life care. Murali et al. (2020) described that this is the first study that incorporates palliative care into the care of seriously ill adults with multiple chronic conditions. Some limitations include lack of empirical testing and lack of applicability to clinicians, educators, and administrators are noted.

Comparison and Selection of Conceptual Frameworks

In Table 3, we present the overall evaluation of this conceptual framework using the Fawcett and Desanto-Madeya (2013) evaluation technique. Through the use of this technique, which was modified to include the levels of influence in the NIMHD framework, the three conceptual frameworks developed by Laguna et al. (2012), Gao et al. (2018), and Murali et al. (2020) were evaluated. Although all three frameworks were recognized to have potential to examine health inequities in end-of-life care and related health outcomes, they each had distinct purposes and related features. First, the frameworks had differences in their focus and goal. The Conceptual Framework of Minority Access to End-of-Life Care (Laguna et al., 2012) is unique in its focus on health disparity populations which are defined as minoritized racial and ethnic groups and barriers and mediators related to end-of-life care access and outcomes are described. On the other hand, the Conceptual Framework for the Role of Healthcare Service Factors in Place of Death (Gao et al., 2018) emphasizes population-based factors such as end-of-life care policies and healthcare service factors uniquely related to the place of death. The Adapted Conceptual Model Integrating Palliative Care in Serious Illness and Multiple Chronic Conditions (Murali et al., 2020) illuminates the clinical complexity of seriously ill adults with multiple chronic conditions and how the integration of palliative care addresses this challenge.

As seen in the focus and goal, only Laguna et al. (2012) originally developed their framework to examine health inequities in end-of-life care and explicitly defined the health disparity population. Both Gao et al. (2018) and Murali et al. (2020) described the health disparity population, but Gao et al. (2018) did not include concepts relevant to health inequity or health disparity in the framework. On the other hand, Murali et al. (2020) included health disparity and social determinants of health as core concepts in the framework.

Another difference is in end-of-life care outcome measure of the three frameworks. All three frameworks included a construct related to the end-of-life care utilization which can affect end-of-life care outcomes. In the Conceptual Framework for the Role of Healthcare Service Factors in Place of Death (Gao et al., 2018), this utilization uniquely influences the place of death. However, in the Conceptual Framework of Minority Access to End-of-Life Care (Laguna et al., 2012) and the Adapted Conceptual Model Integrating Palliative Care in Serious Illness and Multiple Chronic Conditions (Murali et al., 2020), this utilization leads to more comprehensive end-of-life care outcomes including not only the place of death (i.e., care consistent with the patient's goals and values, site of death) but also the patient satisfaction and quality of life which are considered as critical outcome measures when examining health inequities in end-of-life care (Estrada et al., 2021).

Unlike Laguna et al. (2012) or Murali et al. (2020), Gao et al. (2018) particularly described that the individual, interpersonal, and community level factors are not their focus so that those factors should be always controlled when analyzing the healthcare services factors based on their framework. Due to this limitation, the Conceptual Framework for the Role of Healthcare Service Factors in Place of Death (Gao et al., 2018) provides limited guidance for the clinician and educator. Furthermore, controlling the individual, interpersonal, and community level factors should be carefully considered when analyzing health inequities since those are highly associated with social determinants of health and structural health inequities (National Academies of Sciences Engineering and Medicine, 2017). Therefore, researchers should not just control for those factors but specify and interpret studies carefully in the context of the structural inequities because social determinants of health at personal, interpersonal, and community levels can be resulted from the accumulation of historical factors such as systemic racism (Jacoby et al., 2018).

Considering the above differences, we conclude that the Conceptual Framework of Minority Access to End-of-Life Care (Laguna et al., 2012) and the Adapted Conceptual Model Integrating Palliative Care in Serious Illness and Multiple Chronic Conditions (Murali et al., 2020) are more applicable to diverse studies examining end-of-life inequities and measuring various end-of-life care outcomes compared to the Conceptual Framework for the Role of Healthcare Service Factors in Place of Death (Gao et al., 2018). However, both frameworks have several limitations. First, the Conceptual Framework of Minority Access to End-of-Life Care has limitations in its comprehensiveness. Although the three frameworks include the NIMHD framework's four levels of influence including individual, interpersonal, community, and societal levels of influence, the Conceptual Framework of Minority Access to End-of-Life Care (Laguna et al., 2012) lacks the fundamental characteristics denoted by the NIMHD framework, such as sex, gender, and disability which are the critical factors associated with end-of-life care inequities (Adam et al., 2020; Javier, 2021). However, Laguna et al. (2012) encouraged researchers to find additional factors that impede the end-of-life care access to strengthen the proposed framework. Therefore, researchers may need to adapt the current framework to include those important characteristics. Second, the Adapted Conceptual Model Integrating Palliative Care in Serious Illness and Multiple Chronic Conditions (Murali et al., 2020) has much more focus on research and not been tested for clinical practice limiting its use for clinicians, educators, and administrators. Also, due to its recent publication, not many studies have cited nor applied this framework to examine health inequities in end-of-life care.

Based on the above comparisons, we conclude that the framework by Laguna et al. (2012) has shown its legitimacy and contributions to health equity in end-of-life care resulting in the best-fit for the purpose of examining health inequities in end-of-life care and related health outcomes. As Laguna et al. (2012) stated, future studies are encouraged to include additional fundamental factors in the framework in order to augment analysis and improve applicability to health inequities research. Current evidence shows sex and gender are important fundamental factors for end-of-life care delivery (Javier, 2021; Kemery, 2021). Sexual and gender minority populations have been disproportionately impacted by less than optimal access to end-of-life care (Javier, 2021). Factors associated with these inequities range from the individual-level factors such as physical and mental health disparities to societal-level including non-protective regulatory policies (Javier, 2021). In order to examine this structural stigma experienced by these vulnerable populations, a concrete conceptualization of structural factors should be integrated to future frameworks. The Minority Stress Model (Meyer, 2003) is widely used for studies examining multi-level minority stress, including stigma, prejudice, and discrimination. Researchers should adequately incorporate aspects of both of these models to more fully understand the structural factors related to health inequities in end-of-life care among sex and gender minority populations. In addition, more studies are needed to identify strategies to address unique determinants of health in this population.

Disability is another factor that merits further consideration and inclusion in future research. A recent a systematic review examined factors related to palliative care access in adults with intellectual disability (Adam et al., 2020). Adam et al. included several studies examining multi-level factors influencing end-of-life care inequities, demonstrating the urgent need for future research to include disability in end-of-life care frameworks. Also, the majority of studies in the Adam et al. (2020) review included health care professionals as study participants to examine end-of-life care needs in disability populations (Adam et al., 2020). Therefore, future research should include people with disabilities and their families for an in-depth exploration of their end-of-life care needs (Adam et al., 2020; Hunt et al., 2020). In sum, the Laguna et al. (2012) framework can be adapted and expanded to include fundamental characteristics such as sex, gender, and disability through understanding the unique needs of those vulnerable populations.

Implications for Nursing

In this discussion paper, we identified, analyzed, evaluated, and compared conceptual frameworks applicable to examine health inequities in end-of-life care and related health outcomes. Overall, we found a limited number of studies available to fit our purpose. There is a strong need for research evidence that attempts to address multiple factors influencing end-of-life care inequities and health outcomes. In addition, to mitigate the complex nature of social determinants of health and structural inequities, researchers, clinicians, educators and administrators should have solid conceptualizations of these multi-level factors. Based on sound and comprehensive conceptual frameworks, future nurses with interdisciplinary partnerships can promote health equity with a broader scope of health care through addressing social determinants of health (McKinley Yoder & Pesch, 2020; Porter et al., 2020). Eventually, policies at individual, interpersonal, community, and society level (e.g., the coverage of end-of-life care for Medicare or Medicaid beneficiaries) should mitigate persistent health inequities in end-of-life care access in vulnerable populations (Zuckerman et al., 2016).

Limitations

We note some limitations in this paper. First, there were a limited number of studies describing conceptual frameworks that focused on health inequities in end-of-life care and related health outcomes. Second, the Fawcett and Desanto-Madeya (2013) analysis and evaluation technique for nursing models and theories was not developed to compare and contrast conceptual frameworks. However, the technique allowed the researchers to comprehensively analyze and evaluate the three frameworks and eventually, compare and contrast them. Another limitation includes the lack of publications that used the included frameworks when evaluating the 'generation of theory', and 'contributions to the discipline/science' sections in the Fawcett and Desanto-Madeya (2013) criteria. Since the included studies were published recently, the conceptual frameworks have not been applied yet, and further work using and refining these models should be done. Also, given that not all studies cite or indicate frameworks they used for their research, it is plausible that we missed studies that used these frameworks.

In addition, our evaluation of frameworks did not include another important factor, namely strength-based perspectives. Strengths-based nursing is a philosophy of nursing and a value-driven approach guides clinicians, educators, researchers, and key stakeholders (Gottlieb & Gottlieb, 2017). This perspective focuses on inner and outer strengths of patients and families thereby promoting empowerment, self-efficacy, and hope (Gottlieb, 2014). None of the frameworks included this theoretical approach in their descriptions, and for Laguna et al. (2012) in particular, the application of strengths-based perspectives would improve its applicability to health inequities research. Incorporating this holistic approach would complement medical care by strengthening the patient and family's innate capacities for health and healing (Gottlieb, 2014).

Conclusion

Conceptual frameworks allow researchers to comprehensively outline study processes considering the research question and study design. Frameworks are especially relevant in the examination of health inequities in end-of-life care due to its complex and multi-faceted nature. Through the modified Fawcett and Desanto-Madeya (2013) evaluation technique with the NIMHD framework, three conceptual frameworks were analyzed and evaluated. The Conceptual Framework of Minority Access to End-of-Life Care was identified to have the best fit when examining health inequities in end-of-life care and related health outcomes. Future studies examining multi-level factors related to health inequities in end-of-life care should consider use of this framework to frame and guide their research.

References

Adam, E., Sleeman, K. E., Brearley, S., Hunt, K., & Tuffrey-Wijne, I. (2020). The palliative care needs of adults with intellectual disabilities and their access to palliative care services: A systematic review. *Palliat Med*, *34*(8), 1006-1018. https://doi.org/10.1177/0269216320932774

Alligood, M. R. (2014). *Nursing theorists and their work*.

Alvidrez, J., Castille, D., Laude-Sharp, M., Rosario, A., & Tabor, D. (2019). The National Institute on Minority Health and Health Disparities Research Framework. *Am J Public Health*, *109*(S1), S16-s20. https://doi.org/10.2105/ajph.2018.304883

Auriemma, C. L., Halpern, S. D., Asch, J. M., Van Der Tuyn, M., & Asch, D. A. (2020). Completion of Advance Directives and Documented Care Preferences During the Coronavirus Disease 2019 (COVID-19) Pandemic. *JAMA Network Open*, *3*(7), e2015762-e2015762. https://doi.org/10.1001/jamanetworkopen.2020.15762

Bazargan, M., & Bazargan-Hejazi, S. (2021). Disparities in Palliative and Hospice Care and Completion of Advance Care Planning and Directives Among Non-Hispanic Blacks: A Scoping Review of Recent Literature. *Am J Hosp Palliat Care*, *38*(6), 688-718. https://doi.org/10.1177/1049909120966585

Brown, C. E., Engelberg, R. A., Sharma, R., Downey, L., Fausto, J. A., Sibley, J., . . . Curtis, J. R. (2018). Race/Ethnicity, Socioeconomic Status, and Healthcare Intensity at the End of Life. *J Palliat Med*, *21*(9), 1308-1316. https://doi.org/10.1089/jpm.2018.0011

Byhoff, E., Harris, J. A., Langa, K. M., & Iwashyna, T. J. (2016). Racial and Ethnic Differences in End-of-Life Medicare Expenditures. *Journal of the American Geriatrics Society*, *64*(9), 1789-1797. https://doi.org/https://doi.org/10.1111/jgs.14263

Choi, H. A., Fernandez, A., Jeon, S. B., Schmidt, J. M., Connolly, E. S., Mayer, S. A., . . . Lee, K. (2015). Ethnic disparities in end-of-life care after subarachnoid hemorrhage. *Neurocrit Care*, *22*(3), 423-428. https://doi.org/10.1007/s12028-014-0073-x

Chukwusa, E., Verne, J., Polato, G., Taylor, R., I, J. H., & Gao, W. (2019). Urban and rural differences in geographical accessibility to inpatient palliative and end-of-life (PEoLC) facilities and place of death: a national population-based study in England, UK. *Int J Health Geogr*, *18*(1), 8. https://doi.org/10.1186/s12942-019-0172-1

Cohen, C. C., & Shang, J. (2015). Evaluation of conceptual frameworks applicable to the study of isolation precautions effectiveness. *J Adv Nurs*, *71*(10), 2279-2292. https://doi.org/10.1111/jan.12718

Cooper, L. A., Hill, M. N., & Powe, N. R. (2002). Designing and evaluating interventions to eliminate racial and ethnic disparities in health care. *J Gen Intern Med*, *17*(6), 477-486. https://doi.org/10.1046/j.1525-1497.2002.10633.x

Delgado-Guay, M. O., Ferrer, J., Ochoa, J., Cantu, H., Williams, J. L., Park, M., & Bruera, E. (2018). Characteristics and Outcomes of Advanced Cancer Patients Who Received Palliative Care at a Public Hospital Compared with Those at a Comprehensive Cancer Center. *J Palliat Med*, *21*(5), 678-685. https://doi.org/10.1089/jpm.2017.0236

Estrada, L. V., Agarwal, M., & Stone, P. W. (2021). Racial/Ethnic Disparities in Nursing Home End-of-Life Care: A Systematic Review. *J Am Med Dir Assoc*, *22*(2), 279-290.e271. https://doi.org/10.1016/j.jamda.2020.12.005

Fang, M. L., Sixsmith, J., Sinclair, S., & Horst, G. (2016). A knowledge synthesis of culturally- and spiritually-sensitive end-of-life care: findings from a scoping review. *BMC Geriatr*, *16*, 107. https://doi.org/10.1186/s12877-016-0282-6

Fawcett, J. (1993). From a plethora of paradigms to parsimony in worldviews. *Nurs Sci Q*, *6*(2), 56-58. https://doi.org/10.1177/089431849300600202

Fawcett, J., & Desanto-Madeya, S. (2013). *Contemporary nursing knowledge: Analysis and evaluation of nursing models and theories* (3rd ed.). F. A. Davis Company.

Ferrell, B. R., Twaddle, M. L., Melnick, A., & Meier, D. E. (2018). National Consensus Project Clinical Practice Guidelines for Quality Palliative Care Guidelines, 4th Edition. *J Palliat Med*, *21*(12), 1684-1689. https://doi.org/10.1089/jpm.2018.0431

Finucane, A. M., Swenson, C., MacArtney, J. I., Perry, R., Lamberton, H., Hetherington, L., . . . Carduff, E. (2021). What makes palliative care needs "complex"? A multisite sequential explanatory mixed methods study of patients referred for specialist palliative care. *BMC Palliative Care*, *20*(1), 18. https://doi.org/10.1186/s12904-020-00700-3

Gao, W., Huque, S., Morgan, M., & Higginson, I. J. (2018). A Population-Based Conceptual Framework for Evaluating the Role of Healthcare Services in Place of Death. *Healthcare (Basel)*, *6*(3). https://doi.org/10.3390/healthcare6030107

Gottlieb, L. N. (2014). CE: Strengths-Based Nursing. *AJN The American Journal of Nursing*, *114*(8), 24-32. https://doi.org/10.1097/01.NAJ.0000453039.70629.e2

Gottlieb, L. N., & Gottlieb, B. (2017). Strengths-Based Nursing: A Process for Implementing a Philosophy Into Practice. *J Fam Nurs*, *23*(3), 319-340. https://doi.org/10.1177/1074840717717731

Grembowski, D., Schaefer, J., Johnson, K. E., Fischer, H., Moore, S. L., Tai-Seale, M., . . . LeRoy, L. (2014). A conceptual model of the role of complexity in the care of patients with multiple chronic conditions. *Med Care*, *52 Suppl 3*, S7-s14. https://doi.org/10.1097/mlr.0000000000000045

Hunt, K., Bernal, J., Worth, R., Shearn, J., Jarvis, P., Jones, E., . . . Todd, S. (2020). End-of-life care in intellectual disability: a retrospective cross-sectional study. *BMJ Support Palliat Care*, *10*(4), 469-477. https://doi.org/10.1136/bmjspcare-2019-001985

Hutchinson, R. N., Han, P. K. J., Lucas, F. L., Black, A., Sawyer, D., & Fairfield, K. (2021). Rural disparities in end-of-life care for patients with heart failure: Are they due to geography or socioeconomic disparity? *J Rural Health*. https://doi.org/10.1111/jrh.12597

Iacobuzio-Donahue, C. A., Michael, C., Baez, P., Kappagantula, R., Hooper, J. E., & Hollman, T. J. (2019). Cancer biology as revealed by the research autopsy. *Nat Rev Cancer*, *19*(12), 686-697. https://doi.org/10.1038/s41568-019-0199-4

Institute of Medicine. (1993). A model for monitoring access. In M. Millman (Ed.), *Access to health care in America*. National Academies Press. https://doi.org/10.17226/2009

Jacoby, S. F., Dong, B., Beard, J. H., Wiebe, D. J., & Morrison, C. N. (2018). The enduring impact of historical and structural racism on urban violence in Philadelphia. *Soc Sci Med*, *199*, 87-95. https://doi.org/10.1016/j.socscimed.2017.05.038

Javier, N. M. (2021). Palliative care needs, concerns, and affirmative strategies for the LGBTQ population. *Palliat Care Soc Pract*, *15*, 26323524211039234. https://doi.org/10.1177/26323524211039234

Kemery, S. A. (2021). Family perceptions of quality of end of life in LGBTQ+ individuals: a comparative study. *Palliat Care Soc Pract*, *15*, 2632352421997153. https://doi.org/10.1177/2632352421997153

Laguna, J., Enguídanos, S., Siciliano, M., & Coulourides-Kogan, A. (2012). Racial/ethnic minority access to end-of-life care: a conceptual framework. *Home Health Care Serv Q*, *31*(1), 60-83. https://doi.org/10.1080/01621424.2011.641922

MacNeil Vroomen, J. L., Kjellstadli, C., Allore, H. G., van der Steen, J. T., & Husebo, B. (2020). Reform influences location of death: Interrupted time-series analysis on older adults and persons with dementia. *PLoS One*, *15*(11), e0241132. https://doi.org/10.1371/journal.pone.0241132

McKinley Yoder, C., & Pesch, M. S. (2020). An Academic-Fire Department Partnership to Address Social Determinants of Health. *J Nurs Educ*, *59*(1), 34-37. https://doi.org/10.3928/01484834-20191223-08

Meyer, I. H. (2003). Prejudice, social stress, and mental health in lesbian, gay, and bisexual populations: conceptual issues and research evidence. *Psychol Bull*, *129*(5), 674-697. https://doi.org/10.1037/0033-2909.129.5.674

Murali, K. P., Merriman, J. D., Yu, G., Vorderstrasse, A., Kelley, A., & Brody, A. A. (2020). An Adapted Conceptual Model Integrating Palliative Care in Serious Illness and Multiple Chronic Conditions. *Am J Hosp Palliat Care*, *37*(12), 1086-1095. https://doi.org/10.1177/1049909120928353

Murali, K. P., Yu, G., Merriman, J. D., Vorderstrasse, A., Kelley, A. S., & Brody, A. A. (2021a). Latent Class Analysis of Symptom Burden Among Seriously Ill Adults at the End of Life. *Nurs Res*, *70*(6), 443-454. https://doi.org/10.1097/nnr.0000000000000549

Murali, K. P., Yu, G., Merriman, J. D., Vorderstrasse, A., Kelley, A. S., & Brody, A. A. (2021b). Multiple Chronic Conditions among Seriously Ill Adults Receiving Palliative Care. *West J Nurs Res*, 1939459211041174. https://doi.org/10.1177/01939459211041174

National Academies of Sciences Engineering and Medicine. (2017). *Communities in action: Pathways to health equity*. The National Academies Press. https://doi.org/doi:10.17226/24624

National Center for Chronic Disease Prevention and Health Promotion. (2021). *Social Determinants of Health*. https://www.cdc.gov/chronicdisease/programs-impact/sdoh.htm#ftn4

National Hospice and Palliative Care Organization. (2010). *NHPCO facts and figures: Hospice care in America*. http://www.nhpco.org/files/public/Statistics_Research/Hospice_Facts_Figures_Oct-2010.pdf

National Hospice and Palliative Care Organization. (2019). *Palliative Care VS Hospice*. https://www.nhpco.org/wp-content/uploads/2019/04/PalliativeCare_VS_Hospice.pdf

National Institute of Nursing Research. (2021). *Mission & strategic plan*. https://www.ninr.nih.gov/aboutninr/ninr-mission-and-strategic-plan

Nelson, K. E., Wright, R., Fisher, M., Koirala, B., Roberts, B., Sloan, D. H., . . . Davidson, P. M. (2021). A Call to Action to Address Disparities in Palliative Care Access: A Conceptual Framework for Individualizing Care Needs. *J Palliat Med*, *24*(2), 177-180. https://doi.org/10.1089/jpm.2020.0435

Noh, H., Lee, H. Y., Lee, L. H., & Luo, Y. (2021). Awareness of Hospice Care Among Rural African-Americans: Findings From Social Determinants of Health Framework. *Am J Hosp Palliat Care*, 10499091211057847. https://doi.org/10.1177/10499091211057847

Ornstein, K. A., Roth, D. L., Huang, J., Levitan, E. B., Rhodes, J. D., Fabius, C. D., . . . Sheehan, O. C. (2020). Evaluation of Racial Disparities in Hospice Use and End-of-Life Treatment Intensity in the REGARDS Cohort. *JAMA Netw Open*, *3*(8), e2014639. https://doi.org/10.1001/jamanetworkopen.2020.14639

Page, M. J., McKenzie, J. E., Bossuyt, P. M., Boutron, I., Hoffmann, T. C., Mulrow, C. D., . . . Moher, D. (2021). The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. *Bmj*, *372*, n71. https://doi.org/10.1136/bmj.n71

Porter, K., Jackson, G., Clark, R., Waller, M., & Stanfill, A. G. (2020). Applying Social Determinants of Health to Nursing Education Using a Concept-Based Approach. *J Nurs Educ*, *59*(5), 293-296. https://doi.org/10.3928/01484834-20200422-12

Reed, P. G. (1995). A treatise on nursing knowledge development for the 21st century: beyond postmodernism. *ANS Adv Nurs Sci*, *17*(3), 70-84. https://doi.org/10.1097/00012272-199503000-00008

Sharma, R. K., Cameron, K. A., Chmiel, J. S., Von Roenn, J. H., Szmuilowicz, E., Prigerson, H. G., & Penedo, F. J. (2015). Racial/Ethnic Differences in Inpatient Palliative Care Consultation for Patients With Advanced Cancer. *J Clin Oncol*, *33*(32), 3802-3808. https://doi.org/10.1200/jco.2015.61.6458

Varpio, L., Paradis, E., Uijtdehaage, S., & Young, M. (2020). The Distinctions Between Theory, Theoretical Framework, and Conceptual Framework. *Acad Med*, *95*(7), 989-994. https://doi.org/10.1097/acm.0000000000003075

Wang, X., Knight, L. S., Evans, A., Wang, J., & Smith, T. J. (2017). Variations Among Physicians in Hospice Referrals of Patients With Advanced Cancer. *J Oncol Pract*, *13*(5), e496-e504. https://doi.org/10.1200/jop.2016.018093

World Health Organization. (2018). *Health inequities and their causes*. https://www.who.int/news-room/facts-in-pictures/detail/health-inequities-and-their-causes

Zuckerman, R. B., Stearns, S. C., & Sheingold, S. H. (2016). Hospice Use, Hospitalization, and Medicare Spending at the End of Life. *J Gerontol B Psychol Sci Soc Sci*, *71*(3), 569-580. https://doi.org/10.1093/geronb/gbv109

Table 1

Modified Fawcett and DeSanto-Madeya (2013) Analysis and Evaluation Technique

Questions for Analysis
Step 1. Origins of the conceptual framework?
What is the historical evolution of the conceptual framework?
What motivated development of the conceptual framework?
What strategies for knowledge development were used to formulate the conceptual framework?
What scholars influence the conceptual framework authors' thinking?
What world view is reflected in this conceptual framework?
Step 2. Unique focus of the conceptual framework
What is the unique focus of the conceptual framework?
Step 3. Content of the conceptual framework within the National Institute on Minority Health and Health Disparities Research Framework
How is end-of-life care defined and described?
How are health disparity populations defined and described?
Does the conceptual framework include fundamental characteristics: sex and gender, disability, and geographic region?
How is *individual-level of influence* defined and described?
How is *interpersonal-level of influence* defined and described?
How is *community-level of influence* defined and described?
How is *societal-level of influence* defined and described?
What statements are made about the relations among the levels of influence?
What is the goal of this conceptual framework?
Questions for Evaluation
Step 1. Explication of origins • Are the origins on which the conceptual framework is based explicit?

- Are the scholars who influenced the thinking of the conceptual framework author acknowledged, and are bibliographical citations given?

Step 2. Comprehensiveness of contents within the National Institute on Minority Health and Health Disparities Research Framework

- **Does the conceptual framework provide adequate descriptions of all four levels of influence?**
- **Do the relational propositions of the conceptual framework completely link for National Institute on Minority Health and Health Disparities Research Framework concepts?**
- Is the clinician given sufficient direction to execute a course of action that achieves the goal specified in a variety of practice situations?
- Is the researcher given sufficient direction about what questions to ask and what methodology to use?
- Does the educator have sufficient guidelines to construct a curriculum?
- **Does the administrator have sufficient guidelines to organize and deliver equitable end-of-life care services?**

Step 3. Logical congruence

- Does the conceptual framework reflect more than one world view?
- Do the components of the conceptual framework consistently reflect a logical translation or reformulation of diverse perspectives? Is the conceptual framework logically congruent?

Step 4. Generation of theory

- What theories have been generated from the conceptual framework?

Step 5. Legitimacy of the conceptual framework

- **Is the conceptual framework a useful guide for examining health inequities in end-of-life care?**
- Does evaluation of the use of the conceptual framework reveal that the content of the conceptual framework is sound and believable?
- Are education and special skill training required before applying to conceptual framework in practice?
- Is it feasible to implement practice protocols derived from the conceptual framework?
- **To what extent is the conceptual framework actually used to guide equitable end-of-life care practice, research, education, and administration?**
- Does the conceptual framework lead to activities that meet the expectations of the public and health-care professionals of various cultures and in diverse geographic regions?
- Does application of the conceptual framework, when linked with relevant theories and appropriate empirical indicators, make important differences in the health conditions of the public?

Step 6. Contributions to the discipline/science of health equity in end-of-life care

- **What is the overall contribution of the conceptual framework to advancement of health equity in end-of-life care?**

Note. This evaluation technique is modified from Fawcett, J., & Desanto-Madeya, S. (2013). *Contemporary nursing knowledge: Analysis and evaluation of nursing models and theories* (3rd ed.). F. A. Davis Company. Contents and comprehensiveness of nursing model questions in the original criteria (e.g., four concepts of the meta-paradigm) were modified to include four levels of influence in accordance with Alvidrez, J., Castille, D., Laude-Sharp, M., Rosario, A., & Tabor, D. (2019, Jan). *The National Institute on Minority Health and Health Disparities Research Framework.* https://doi.org/10.2105/ajph.2018.304883 Bold questions denote modifications to the NIMHD research framework.

Table 2

Comparison of Key Attributes in the selected Conceptual Framework

Framework	Authors	Description	Constructs
A Conceptual Framework of Minority Access to End-of-Life Care	Laguna et al. (2012)	Proposed a conceptual framework to understand minority access to end-of-life care results from an interaction between personal, system, and societal-level barriers with health care mediators.	• Barriers • Health Care Mediators • Care at End-of-Life • Outcomes
A Conceptual Framework of for the Role of Healthcare Service Factors in Place of Death	Gao et al. (2018)	Targeted to propose a conceptual framework to understand the role for healthcare services in place of death through a literature review of previous models.	• End-of-Life Care Policies • Service Commissioning • Healthcare Service Characteristics • Other Environmental Factors • Patient Factors • Service Utilization • Place of Death
An Adapted Conceptual Model Integrating Palliative Care in Serious Illness and Multiple Chronic Condition	Murali et al. (2020)	Adapted from a conceptual model of the role of clinical complexity in the care of patients with multiple chronic conditions (Grembowski et al., 2014), this framework integrates palliative care with serious illness and multiple chronic conditions.	• Factors Affecting Needs • Factors Affecting Services Received • Service-Related Variables • Outcomes

Table 3

Evaluation of Conceptual Frameworks by Modified Fawcett and DeSanto-Madeya (2013)

Evaluation Technique

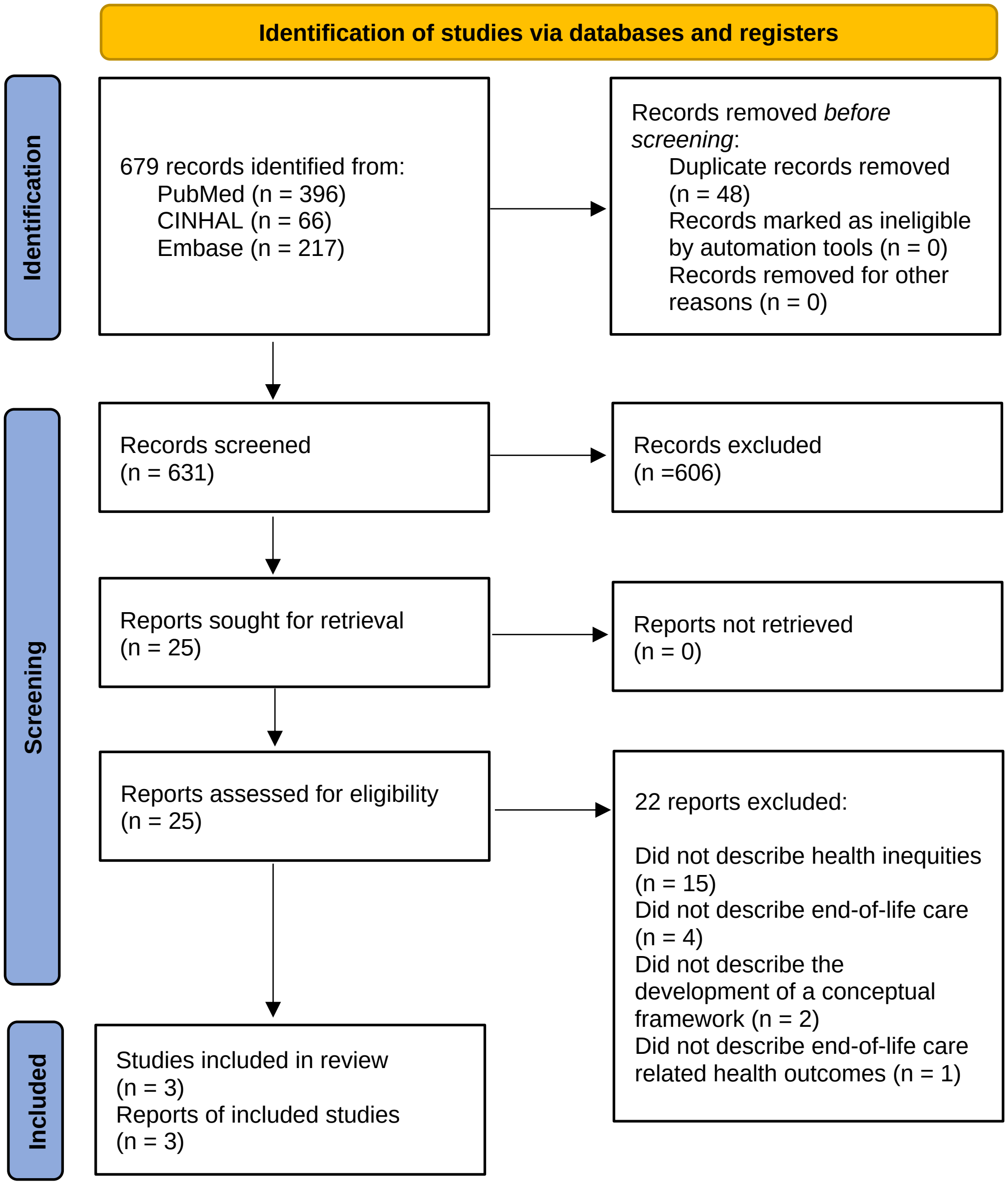
Evaluation Criteria	Laguna et al. (2012)	Gao et al. (2018)	Murali et al. (2020)
Explication of Origins	**Yes.** Motivated by the need for a comprehensive conceptual framework that examine factors related to health disparities in end-of-life care. Two previous frameworks (Cooper et al., 2002; Institute of Medicine, 1993) and literatures are acknowledged and cited.	**Yes.** To guide population-based research examining the role of healthcare services in place of death. Seven conceptual frameworks are acknowledged and cited.	**Yes.** To develop a comprehensive conceptual framework that guides studies integrate palliative care in seriously ill adults with multiple chronic conditions. One previous framework (Grembowski et al., 2014) and literatures are acknowledged and cited.
Comprehensiveness of Content	**High.** All four levels of influence and relational propositions addressed, though not all fundamental characteristics are included. Clinician, researcher, educator, and administrator have sufficient direction and guidance.	**Moderate to High.** All four levels of influence, fundamental characteristics and relational propositions addressed. Researchers and administrators have sufficient direction and guidance, but clinician and educator contents are limited due to its focus on policy and population-based analysis.	**Moderate to High.** All four levels of influence, fundamental characteristics and relational propositions addressed. Researchers have sufficient direction and guidance, but clinician, educator, and administrator contents are limited due to its focus on research.
Logical Congruence	**Yes.** Consistent with the reciprocal worldview (Fawcett, 1993), following both inductive and deductive reasoning (Alligood, 2014).	**Yes.** Consistent with the reciprocal worldview (Fawcett, 1993), following retroductive reasoning (Alligood, 2014).	**Yes.** Consistent with the reciprocal worldview (Fawcett, 1993), following retroductive reasoning (Alligood, 2014).
Generation of Theory	**Yes.** One publication (Gao et al., 2018) used this framework to generate a new conceptual framework.	**Unknown.** One publication (Chukwusa et al., 2019) with the same author (Gao et al., 2018) used this framework as background of the study.	**Yes.** One publication (Murali et al., 2021a) and one study under review (Murali et al., 2021b) used this framework to generate research questions.
Legitimacy	**Yes.** The framework has been used to guide the interpretation of study findings related to health disparities in end-of-life care (Choi et al., 2015; Delgado-Guay et al., 2018; Sharma et al., 2015; Wang et al., 2017)	**Yes.** One study used this framework in the background (Chukwusa et al., 2019), and many study used it for the interpretation of the study findings (Iacobuzio-Donahue et al.,	**Moderate.** The framework has been used for the development of two research aims. However, given the recent publication, only one study (Murali et al., 2021a) cited this framework.

		and included in the review paper identifying barriers and enablers of end-of-life care (Fang et al., 2016).	2019; MacNeil Vroomen et al., 2020).	
	Social Utility	**High.** No education or skills are required prior to use of this framework. Practice protocols can be driven by the framework by targeting the intervention(s) listed in the mediators construct.	**Moderate.** No education or skills are required prior to use of this framework. However, limitations exist when implementing protocols based on this framework due to its focus on population and policy-based purposes.	**Moderate.** No education or skills are required prior to use of this framework. Because the framework was developed to guide research, usage in clinical settings need further testing of the framework.
	Social Congruence	**Moderate.** Used for diverse patient populations and facilities in diverse geographical locations. However, this framework lacks individual's sex and gender, and disability characteristics which are fundamental characteristics in the NIMHD framework. Therefore, adaptation is required for more diverse application and usefulness.	**Unknown.** Because of its recent development, few studies have cited this framework. However, this framework includes all fundamental characteristics included in the NIMHD framework representing diverse populations.	**Unknown.** Because of its recent development, one study has cited this framework in seriously ill adults at the end-of-life. However, this framework comprehensively examines social determinants of health and person-specific factors representing diverse populations.
	Social Significance	**High.** The framework is well-aligned with the four levels of influence based on the NIMHD research framework that could broadly impact the population-level public health. Also, this framework covers various end-of-life care outcomes.	**High.** The framework is well-aligned with the NIMHD research framework. It covers comprehensive factors associated with place of death which is an important outcome measure for end-of-life care. Therefore, it can significantly impact the public health.	**High.** The framework is well-aligned with the NIMHD research framework. This framework includes concepts such as population health and health policy, which can significantly impact the public health.
Contributions to Health Equity in End-of-Life Care		**High.** One of the initiative frameworks examined multi-level influences of the health disparities in end-of-life care. Contributed to the development of a conceptual framework.	**Moderate to High.** It is the first framework that focus on the healthcare services factors related to the place of death. However, the original purpose was not to examine health inequities thus, the framework lacks the explicit definition of health disparity populations.	**Moderate to High.** Although the original purpose of the framework was not for health equity in end-of-life care, comprehensive contextual factors including social-determinants of health were described in the framework. Further research needed to test the framework and its applicability.

Note. Logical congruence is based on Fawcett (1993) categorization of worldview: 1) reaction, 2) reciprocal interaction, and 3) simultaneous action, and Reed (1995) and Alligood (2014) categorization of knowledge development: 1) deductive reasoning, 2) inductive reasoning, and 3) retroductive reasoning. NIMHD: The National Institute on Minority Health and Health Disparities

Figure 1

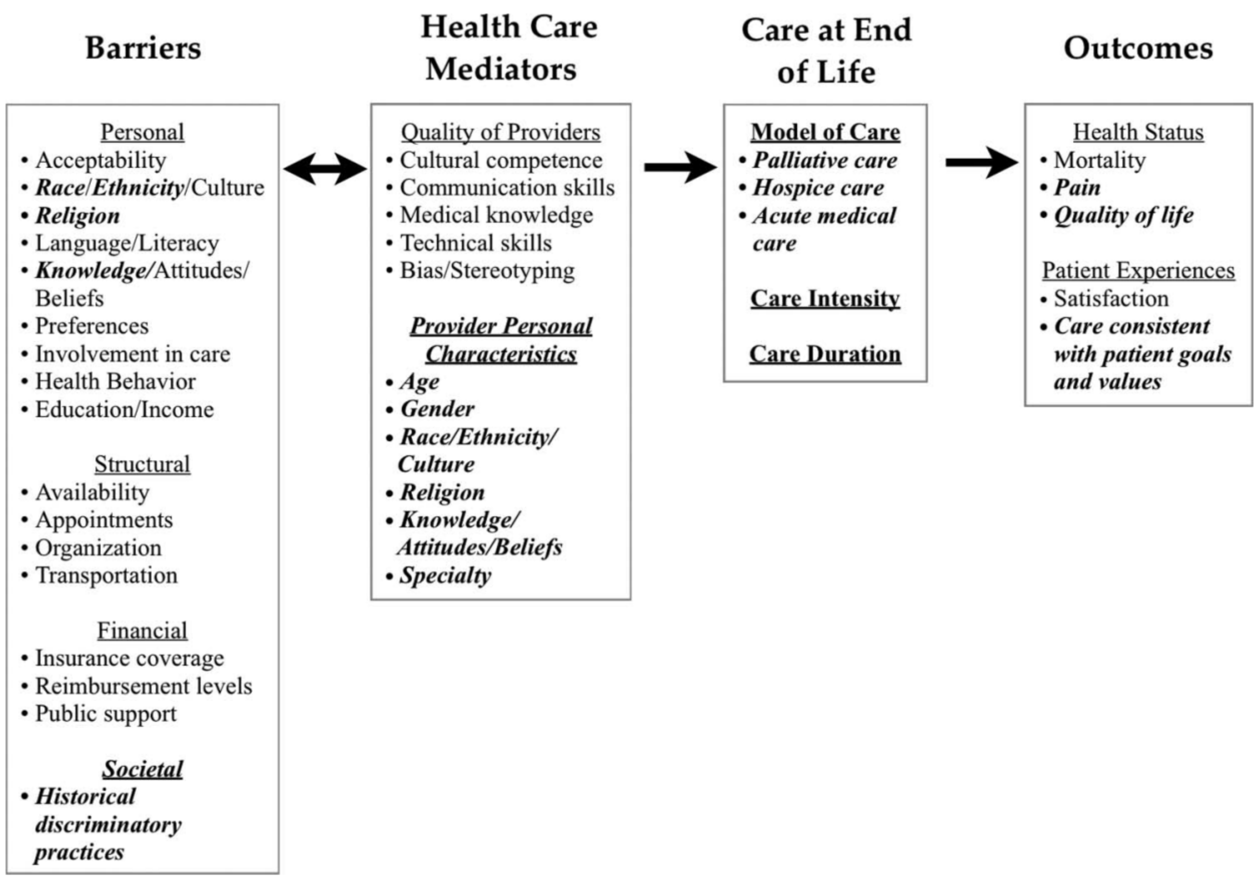
PRISMA 2020 Flow Diagram



Note. Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: An updated guideline for reporting systematic reviews. BMJ 2021;372:n71. doi: 10.1136/bmj.n71

Figure 2

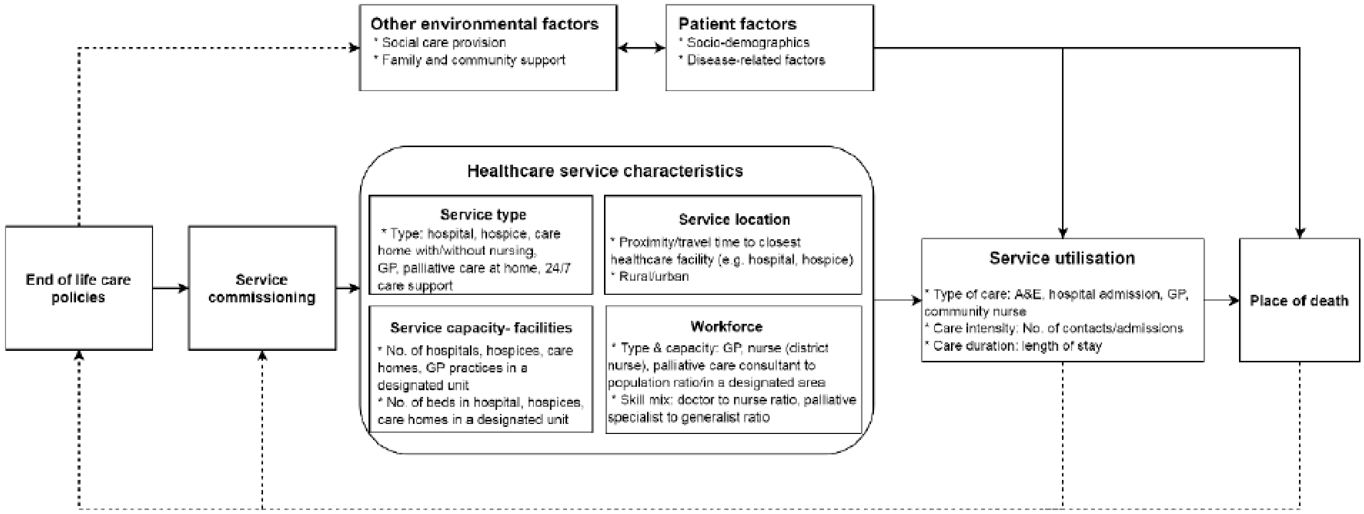
A Conceptual Framework of Minority Access to End-of-Life Care



Note. This model shows access to end-of-life care with patient, system, and societal-level barriers and health care-level mediators. From "Racial/Ethnic Minority Access to End-of-Life Care: A Conceptual Framework," by J. Laguna, S. Enguidanos, M. Siciliano, & A. Coulourides-Kogan, 2012, *Home Health Care Services Quarterly*, *31*(1), p. 66. (https://doi.org/10.1080/01621424.2011.641922).

Figure 3

A Conceptual Framework for the Role of Healthcare Service Factors in Place of Death



Note. This model presents the impact of healthcare services on the place of death. From "A Population-Based Conceptual Framework for Evaluating the Role of Healthcare Services in Place of Death," by W. Gao, S. Huque, M. Morgan, & I. J. Higginson, 2018, *Healthcare*, *6*(3), p. 3. (https://doi.org/10.3390/healthcare6030107).

Supporting Information Appendix

PubMed

"Health Disparity, Minority and Vulnerable Populations"[Mesh] OR "Health Inequities"[Mesh] OR "Healthcare Disparities"[Mesh] OR “health disparity” OR “health disparities” OR “healthcare disparity” OR “healthcare disparities” OR “health care disparity” OR “health care disparities” OR “disparities in health” OR “health inequity” OR “health inequities” OR “health care inequality” OR “Health Care Inequalities” OR “healthcare inequality” OR “healthcare inequalities” OR "Health Equity"[Mesh] OR "Health Services Accessibility"[Mesh]

"Social Determinants of Health"[Mesh] OR “social determinants of health” OR “Health Social Determinant” OR “health social determinants” OR “structural determinants of health” OR “health structural determinants” OR “social environment” OR “socioeconomics” OR “socioeconomic factors” OR “social factors” OR “environmental factors” OR “social conditions” OR “SES” OR “socioeconomic status” OR “social disparity” OR “social disparities”

"hospices"[MeSH] OR "hospice care"[MeSH] OR "palliative care"[MeSH] OR "palliative medicine"[MeSH] OR "hospice and palliative care nursing"[MeSH] OR "terminal care"[MeSH] OR "palliative" OR "end of life care" OR "comfort care" OR "hospice care" OR "EoL" OR "End-of-Life"

"models, theoretical"[MeSH] OR "models, nursing"[MeSH] OR "conceptual framework" OR “conceptual frameworks” OR "theoretical model" OR “theoretical models” OR “conceptual model” OR "conceptual models"

(HI OR SDOH) AND EoL AND CF

CINAHL

((MH "Health Disparity, Minority and Vulnerable Populations") OR (MH "Health Inequities") OR (MH "Healthcare Disparities") OR (MH "Health Equity") OR (MH “Health Services Accessibility")) OR TI “health disparity” OR AB “health disparity” OR TI “health disparities” OR AB “health disparities” OR TI “healthcare disparity” OR AB “healthcare disparity” OR TI “healthcare disparities” OR AB “healthcare disparities” OR TI “health care disparity” OR AB “health care disparity” OR TI “health care disparities” OR AB “health care disparities” OR TI “disparities in health” OR AB “disparities in health” OR TI “health inequity” OR AB “health inequity” OR TI “health inequities” OR AB “health inequities” OR TI “health care inequality” OR AB “health care inequality” OR TI “Health Care Inequalities” OR AB “Health Care Inequalities” OR TI “healthcare inequality” OR AB “healthcare inequality” OR TI “healthcare inequalities” OR AB “healthcare inequalities”

(MH "Social Determinants of Health") OR TI “social determinants of health” OR AB “social determinants of health” OR TI “Health Social Determinant” OR AB “Health Social Determinant” OR TI “health social determinants” OR AB “health social determinants” OR TI “structural determinants of health” OR AB “structural determinants of health” OR TI “health structural determinants” OR AB “health structural determinants” OR TI “social environment” OR AB “social environment” OR TI “socioeconomics” OR AB “socioeconomics” OR TI “socioeconomic factors” OR AB “socioeconomic factors” OR TI “social factors” OR AB “social factors” OR TI “environmental factors” OR AB “environmental factors” OR TI “social conditions” OR AB “social conditions” OR TI “SES” OR AB “SES” OR TI “socioeconomic status” OR AB “socioeconomic status” OR TI “social disparity” OR AB “social disparity” OR TI “social disparities” OR AB “social disparities”

((MH "hospices") OR (MH "Hospice Care") OR (MH "Palliative care") OR (MH "palliative medicine") OR (MH " hospice and palliative care nursing ") OR (MH "Terminal Care")) OR TI "palliative" OR AB "palliative" OR TI "end of life care" OR AB "end of life care" OR TI "comfort care" OR AB "comfort care" OR TI "hospice care" OR AB "hospice care" OR TI "end-of-life" OR AB "end-of-life"

((MH "Nursing Theory") OR (MH "Nursing Practice, Theory-Based") OR (MH "Models, Theoretical") OR (MH "Nursing Models, Theoretical")) OR (TI "conceptual framework" OR AB "conceptual framework" OR TI "conceptual frameworks" OR AB "conceptual frameworks" OR TI "conceptual model" OR AB "conceptual model" OR TI "conceptual models" OR AB "conceptual models" OR TI "theoretical model" OR AB "theoretical model" OR TI "theoretical models" OR AB "theoretical models")

(HI OR SDOH) AND EoL AND CF

Embase

'health disparity'/exp OR 'health disparities' OR 'health disparity' OR 'health inequality' OR 'health inequities' OR 'health inequity' OR 'health status disparities' OR 'health status disparity' OR 'health status inequality' OR 'health status inequity' OR 'health care disparity'/exp OR 'health care disparities' OR 'health care disparity' OR 'healthcare disparities' OR 'healthcare disparity' OR 'health care inequality'/exp OR 'health care access'/exp OR 'access to health care' OR 'health care access' OR 'health services accessibility' OR 'healthcare access'

'social determinants of health'/exp OR 'social determinant' OR 'social determinants' OR 'social determinants of health' OR 'social determining factor' OR 'social factors determining health' OR 'social health determinant' OR 'social environment'/exp OR 'environment, social' OR 'interpersonal climate' OR 'social climate' OR 'social context' OR 'social environment' OR 'socioeconomics'/exp OR 'economic value of life' OR 'health care, indigent' OR 'indigent health care' OR 'medical indigency' OR 'social economic aspect' OR 'social economics' OR 'social-economic factor' OR 'socio-economic aspect' OR 'socio-economic factor' OR 'socio-economics' OR 'socioeconomic aspect' OR 'socioeconomic factor' OR 'socioeconomic factors' OR 'socioeconomics' OR 'value of life' OR 'social status'/exp OR 'social achievement' OR 'social condition' OR 'social conditions' OR 'social economic status' OR 'social employment' OR 'social function' OR 'social importance' OR 'social rank' OR 'social standing' OR 'social state' OR 'social status' OR 'socio-economic status' OR 'socioeconomic status' OR 'status, social'

'terminal care'/exp OR 'eol care' OR 'end-of-life care' OR 'terminal care' OR 'palliative therapy'/exp OR 'palliation' OR 'palliative care' OR 'palliative consultation' OR 'palliative medicine' OR 'palliative radiotherapy' OR 'palliative surgery' OR 'palliative therapy' OR 'palliative treatment' OR 'symptomatic treatment' OR 'palliative nursing'/exp OR 'hospice and palliative care nursing' OR 'palliative care nursing' OR 'palliative nursing' OR 'hospice care'/exp OR 'hospice care'

'conceptual framework'/exp OR 'conceptual framework' OR 'theoretical framework' OR 'conceptual model'/exp OR 'conceptual model'

(HI OR SDOH) AND EoL AND CF

Appendix B: Preferred Reporting Items for Systematic Review and Meta-Analyses for Chapter 2 Systematic Review

Section and Topic	Item #	Checklist item	Location where item is reported
TITLE			
Title	1	Identify the report as a systematic review.	Title page
ABSTRACT			
Abstract	2	See the PRISMA 2020 for Abstracts checklist.	Abstract line 1-26
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of existing knowledge.	Introduction Line 47-58
Objectives	4	Provide an explicit statement of the objective(s) or question(s) the review addresses.	Introduction Line 58-60
METHODS			
Eligibility criteria	5	Specify the inclusion and exclusion criteria for the review and how studies were grouped for the syntheses.	Eligibility criteria line 71-76
Information sources	6	Specify all databases, registers, websites, organisations, reference lists and other sources searched or consulted to identify studies. Specify the date when each source was last searched or consulted.	Data Sources and Search Strategy Line 65-70 Line 72-73
Search strategy	7	Present the full search strategies for all databases, registers and websites, including any filters and limits used.	Data Sources and Search Strategy Line 65-70 Appendix 1
Selection process	8	Specify the methods used to decide whether a study met the inclusion criteria of the review, including how many reviewers screened each record and each report retrieved, whether they worked independently, and if applicable, details of automation tools used in the process.	Study Selection Line 77-81
Data collection process	9	Specify the methods used to collect data from reports, including how many reviewers collected data from each report, whether they worked independently, any processes for obtaining or confirming data from study investigators, and if applicable, details of automation tools used in the process.	Data Extraction and Synthesis Line 82-88
Data items	10a	List and define all outcomes for which data were sought. Specify whether all results that were compatible with each outcome domain in each study were sought (e.g. for all measures, time points, analyses), and if not, the methods used to decide which results to collect.	Data Extraction and Synthesis Line 82-88 Table 2

Section and Topic	Item #	Checklist item	Location where item is reported
	10b	List and define all other variables for which data were sought (e.g. participant and intervention characteristics, funding sources). Describe any assumptions made about any missing or unclear information.	Data Extraction and Synthesis Line 82-88 Table 2
Study risk of bias assessment	11	Specify the methods used to assess risk of bias in the included studies, including details of the tool(s) used, how many reviewers assessed each study and whether they worked independently, and if applicable, details of automation tools used in the process.	Quality Appraisal Line 89-94 Appendix 2 Table 1
Effect measures	12	Specify for each outcome the effect measure(s) (e.g. risk ratio, mean difference) used in the synthesis or presentation of results.	Table 3
Synthesis methods	13a	Describe the processes used to decide which studies were eligible for each synthesis (e.g. tabulating the study intervention characteristics and comparing against the planned groups for each synthesis (item #5)).	line 82-88 synthesized data narratively by identifying common themes found across the studies
	13b	Describe any methods required to prepare the data for presentation or synthesis, such as handling of missing summary statistics, or data conversions.	n/a synthesized data narratively by identifying common themes found across the studies
	13c	Describe any methods used to tabulate or visually display results of individual studies and syntheses.	line 82-88
	13d	Describe any methods used to synthesize results and provide a rationale for the choice(s). If meta-analysis was performed, describe the model(s), method(s) to identify the presence and extent of statistical heterogeneity, and software package(s) used.	line 82-88
	13e	Describe any methods used to explore possible causes of heterogeneity among study results (e.g. subgroup analysis, meta-regression).	n/a synthesized data narratively by identifying common themes found across the studies
	13f	Describe any sensitivity analyses conducted to assess robustness of the synthesized results.	n/a synthesized data narratively by identifying common themes found across the studies
Reporting bias assessment	14	Describe any methods used to assess risk of bias due to missing results in a synthesis (arising from reporting biases).	Table 1
Certainty assessment	15	Describe any methods used to assess certainty (or confidence) in the body of evidence for an outcome.	n/a synthesized data narratively by identifying common themes found across the studies

Section and Topic	Item #	Checklist item	Location where item is reported
RESULTS			
Study selection	16a	Describe the results of the search and selection process, from the number of records identified in the search to the number of studies included in the review, ideally using a flow diagram.	Study Selection Line 96-102 Figure 1
	16b	Cite studies that might appear to meet the inclusion criteria, but which were excluded, and explain why they were excluded.	Study Selection Line 96-102 Figure 1
Study characteristics	17	Cite each included study and present its characteristics.	Study Characteristics Line 111-127 Table 2
Risk of bias in studies	18	Present assessments of risk of bias for each included study.	Table 1
Results of individual studies	19	For all outcomes, present, for each study: (a) summary statistics for each group (where appropriate) and (b) an effect estimate and its precision (e.g. confidence/credible interval), ideally using structured tables or plots.	Table 3
Results of syntheses	20a	For each synthesis, briefly summarise the characteristics and risk of bias among contributing studies.	line 128-213
	20b	Present results of all statistical syntheses conducted. If meta-analysis was done, present for each the summary estimate and its precision (e.g. confidence/credible interval) and measures of statistical heterogeneity. If comparing groups, describe the direction of the effect.	Quality of Studies Line 103-110
	20c	Present results of all investigations of possible causes of heterogeneity among study results.	line 238-243
	20d	Present results of all sensitivity analyses conducted to assess the robustness of the synthesized results.	n/a synthesized data narratively by identifying common themes found across the studies
Reporting biases	21	Present assessments of risk of bias due to missing results (arising from reporting biases) for each synthesis assessed.	n/a synthesized data narratively by identifying common themes found across the studies
Certainty of evidence	22	Present assessments of certainty (or confidence) in the body of evidence for each outcome assessed.	n/a synthesized data narratively by identifying common themes found across the studies
DISCUSSION			
Discussion	23a	Provide a general interpretation of the results in the context of other evidence.	line 214-274

Section and Topic	Item #	Checklist item	Location where item is reported
	23b	Discuss any limitations of the evidence included in the review.	line 275-281
	23c	Discuss any limitations of the review processes used.	line 275-281
	23d	Discuss implications of the results for practice, policy, and future research.	line 282-293
OTHER INFORMATION			
Registration and protocol	24a	Provide registration information for the review, including register name and registration number, or state that the review was not registered.	line 62-64
	24b	Indicate where the review protocol can be accessed, or state that a protocol was not prepared.	line 62-64
	24c	Describe and explain any amendments to information provided at registration or in the protocol.	n/a no change
Support	25	Describe sources of financial or non-financial support for the review, and the role of the funders or sponsors in the review.	title page acknowledgement
Competing interests	26	Declare any competing interests of review authors.	line 294-295
Availability of data, code and other materials	27	Report which of the following are publicly available and where they can be found: template data collection forms; data extracted from included studies; data used for all analyses; analytic code; any other materials used in the review.	n/a all included in the tables and appendices

Appendix C: Prospero Registration for Chapter 2 Systematic Review

PROSPERO
International prospective register of systematic reviews

NHS
National Institute for Health Research

UNIVERSITY of York
Centre for Reviews and Dissemination

Systematic review

1. * Review title.

Give the title of the review in English

Timing of Goals of Care Discussions in Nursing Homes: A Systematic Review

2. Original language title.

For reviews in languages other than English, give the title in the original language. This will be displayed with the English language title.

3. * Anticipated or actual start date.

Give the date the systematic review started or is expected to start.

30/04/2021

4. * Anticipated completion date.

Give the date by which the review is expected to be completed.

31/08/2021

5. * Stage of review at time of this submission.

Tick the boxes to show which review tasks have been started and which have been completed. Update this field each time any amendments are made to a published record.

Reviews that have started data extraction (at the time of initial submission) are not eligible for inclusion in PROSPERO. If there is later evidence that incorrect status and/or completion date has been supplied, the published PROSPERO record will be marked as retracted.

This field uses answers to initial screening questions. It cannot be edited until after registration.

The review has not yet started: No

Review stage	Started	Completed
Preliminary searches	Yes	Yes
Piloting of the study selection process	Yes	Yes
Formal screening of search results against eligibility criteria	No	No
Data extraction	No	No
Risk of bias (quality) assessment	No	No
Data analysis	No	No

Provide any other relevant information about the stage of the review here.

6. * Named contact.

The named contact is the guarantor for the accuracy of the information in the register record. This may be any member of the review team.

Jung A Kang

Email salutation (e.g. "Dr Smith" or "Joanne") for correspondence:

Chloe

7. * Named contact email.

Give the electronic email address of the named contact.

jk4469@cumc.columbia.edu

8. Named contact address

Give the full institutional/organisational postal address for the named contact.

560 W. 168th Street, New York, NY 10032

9. Named contact phone number.

Give the telephone number for the named contact, including international dialling code.

10. * Organisational affiliation of the review.

Full title of the organisational affiliations for this review and website address if available. This field may be completed as 'None' if the review is not affiliated to any organisation.

Columbia University

Organisation web address:

http://nursing.columbia.edu

11. * Review team members and their organisational affiliations.

Give the personal details and the organisational affiliations of each member of the review team. Affiliation refers to groups or organisations to which review team members belong. **NOTE: email and country now MUST be entered for each person, unless you are amending a published record.**

Mrs Jung A Kang. Columbia University
Ms Leah Estrada. Columbia University
Dr Patricia Stone. Columbia University
Dr Aluem Tark. Columbia University

12. * Funding sources/sponsors.

Details of the individuals, organizations, groups, companies or other legal entities who have funded or sponsored the review.

National Institute of Nursing Research

Grant number(s)

State the funder, grant or award number and the date of award

R01NR019587 (July 1, 2012)

T32NR014205 (July 1, 2020)

13. * Conflicts of interest.

List actual or perceived conflicts of interest (financial or academic).

None

14. Collaborators.

Give the name and affiliation of any individuals or organisations who are working on the review but who are not listed as review team members. **NOTE: email and country must be completed for each person, unless you are amending a published record.**

John Usseglio. Columbia University

15. * Review question.

State the review question(s) clearly and precisely. It may be appropriate to break very broad questions down into a series of related more specific questions. Questions may be framed or refined using PI(E)COS or similar where relevant.

This systematic review will compare variations in timing of Goals of Care discussions and impact on end of life care in nursing homes.

16. * Searches.

State the sources that will be searched (e.g. Medline). Give the search dates, and any restrictions (e.g. language or publication date). Do NOT enter the full search strategy (it may be provided as a link or attachment below.)

Sources that will be searched include MEDLINE (PubMed), Embase and the Cumulative Index to Nursing and Allied Health Literature (CINAHL), English language studies published from January 1, 2000 to March 31, 2021. Grey literature was not included.

17. URL to search strategy.

Upload a file with your search strategy, or an example of a search strategy for a specific database, (including the keywords) in pdf or word format. In doing so you are consenting to the file being made publicly accessible. Or provide a URL or link to the strategy. Do NOT provide links to your search **results**.

https://www.crd.york.ac.uk/PROSPEROFILES/246498_STRATEGY_20210401.pdf

Alternatively, upload your search strategy to CRD in pdf format. Please note that by doing so you are consenting to the file being made publicly accessible.

Do not make this file publicly available until the review is complete

18. * Condition or domain being studied.

Give a short description of the disease, condition or healthcare domain being studied in your systematic review.

Establishments of Goals of Care (GOC) discussion often occur late in the course of an illness. Studies have shown that about 40% of patients with an advance illness lost decision-making capacity before an GOC discussion could take place, and about 34% of patients transferred to hospice care in their last week of life. Earlier GOC discussion, however, leads early utilization of hospice and palliative care, improved bereavement outcomes, and increased rates of care congruent with patient preferences. Especially, GOC discussion is critical in nursing home settings where the most of residents are older adults near their end of life. However, a review of the literature on this has not been conducted. Given the high importance of early GOC discussion, further reviews of the literature regarding how timings of GOC discussion impact end of life care in nursing homes are needed.

19. * Participants/population.

Specify the participants or populations being studied in the review. The preferred format includes details of both inclusion and exclusion criteria.

This review will include nursing home residents aged 60 years or older.

20. * Intervention(s), exposure(s).

Give full and clear descriptions or definitions of the interventions or the exposures to be reviewed. The preferred format includes details of both inclusion and exclusion criteria.

The interventions for this systematic review are goals of care discussions including Advance Care Planning and Advance Directives that are designed to document treatment wishes and elicit goals of care discussion at end of life.

21. * Comparator(s)/control.

Where relevant, give details of the alternatives against which the intervention/exposure will be compared (e.g. another intervention or a non-exposed control group). The preferred format includes details of both inclusion and exclusion criteria.

The comparators for this systemic review are different timings of goals of care discussions.

22. * Types of study to be included.

Give details of the study designs (e.g. RCT) that are eligible for inclusion in the review. The preferred format includes both inclusion and exclusion criteria. If there are no restrictions on the types of study, this should be stated.

This systematic review will include observational study designs including cross-sectional, cohort and case-control studies. Experimental designs, qualitative design, case reports and grey literature will be excluded.

23. Context.

Give summary details of the setting or other relevant characteristics, which help define the inclusion or exclusion criteria.

The study setting will be nursing homes.

24. * Main outcome(s).

Give the pre-specified main (most important) outcomes of the review, including details of how the outcome is defined and measured and when these measurement are made, if these are part of the review inclusion criteria.

The main outcomes will be timing of Goals of Care discussions in nursing homes.

Measures of effect

Please specify the effect measure(s) for you main outcome(s) e.g. relative risks, odds ratios, risk difference, and/or 'number needed to treat.

Not applicable

25. * Additional outcome(s).

List the pre-specified additional outcomes of the review, with a similar level of detail to that required for main outcomes. Where there are no additional outcomes please state 'None' or 'Not applicable' as appropriate to the review

The additional outcomes will be end of life care in nursing homes such as date of death, concordance of care, hospice/palliative care use and hospitalization at end of life.

Measures of effect

Please specify the effect measure(s) for you additional outcome(s) e.g. relative risks, odds ratios, risk difference, and/or 'number needed to treat.

Not applicable

26. * Data extraction (selection and coding).

Describe how studies will be selected for inclusion. State what data will be extracted or obtained. State how this will be done and recorded.

This systematic review will follow the Preferred Reporting Items for Systematic Reviews and Meta-Analyses Protocols (PRISMA) guidelines. Studies will be selected by using Covidence. Duplicates will be removed and two authors will independently review titles and abstracts for eligibility criteria. If authors have uncertain abstracts, full texts will be reviewed by two authors independently. Any disagreements will be discussed until consensus is reached. Reasons for exclusion at full text review will be recorded and reported. Data will be extracted by one author co-signing by a second author. The data extracted will include study years, purpose, study design, sample characteristics, types of goals of care discussions, timing of goals of care discussions, end of life care outcomes, data analysis and study limitations.

27. * Risk of bias (quality) assessment.

State which characteristics of the studies will be assessed and/or any formal risk of bias/quality assessment tools that will be used.

Risk of bias will be assessed using the Newcastle-Ottawa Scale by two independent reviewers.

28. * Strategy for data synthesis.

Describe the methods you plan to use to synthesise data. This **must not be generic text** but should be **specific to your review** and describe how the proposed approach will be applied to your data. If meta-analysis is planned, describe the models to be used, methods to explore statistical heterogeneity, and software package to be used.

The study inclusion process will be presented in a PRISMA flow diagram. Data extracted will be summarized in a table. Synthesis of results and interpretation will be narratively described. We will examine how different timings of Goals of Care discussions impact end of life care in nursing homes. Further implication and recommendation will be described in narrative form.

29. * Analysis of subgroups or subsets.

State any planned investigation of 'subgroups'. Be clear and specific about which type of study or participant will be included in each group or covariate investigated. State the planned analytic approach.

Not applicable

30. * Type and method of review.

Select the type of review, review method and health area from the lists below.

Type of review

Cost effectiveness
No

Diagnostic
No

Epidemiologic
No

Individual patient data (IPD) meta-analysis
No

Intervention
No

Living systematic review
No

Meta-analysis
No

Methodology
No

Narrative synthesis
No

Network meta-analysis
No

Pre-clinical
No

Prevention
No

Prognostic
No

Prospective meta-analysis (PMA)
No

Review of reviews
No

Service delivery
No

Synthesis of qualitative studies
No

Systematic review
Yes

Other
No

Health area of the review

Alcohol/substance misuse/abuse
No

Blood and immune system
No

Cancer
No

Cardiovascular
No

Care of the elderly
Yes

Child health
No

Complementary therapies
No

COVID-19
No

Crime and justice
No

Dental
No

Digestive system
No

Ear, nose and throat
No

Education
No

Endocrine and metabolic disorders
No

Eye disorders
No

General interest
No

Genetics

No

Health inequalities/health equity
No

Infections and infestations
No

International development
No

Mental health and behavioural conditions
No

Musculoskeletal
No

Neurological
No

Nursing
No

Obstetrics and gynaecology
No

Oral health
No

Palliative care
Yes

Perioperative care
No

Physiotherapy
No

Pregnancy and childbirth
No

Public health (including social determinants of health)
No

Rehabilitation
No

Respiratory disorders
No

Service delivery
No

Skin disorders
No

Social care
No

Surgery
No

Tropical Medicine
No

Urological
No

Wounds, injuries and accidents
No

Violence and abuse
No

31. Language.

Select each language individually to add it to the list below, use the bin icon to remove any added in error.
English

There is not an English language summary

32. * Country.

Select the country in which the review is being carried out. For multi-national collaborations select all the countries involved.

United States of America

33. Other registration details.

Name any other organisation where the systematic review title or protocol is registered (e.g. Campbell, or The Joanna Briggs Institute) together with any unique identification number assigned by them. If extracted data will be stored and made available through a repository such as the Systematic Review Data Repository (SRDR), details and a link should be included here. If none, leave blank.

34. Reference and/or URL for published protocol.

If the protocol for this review is published provide details (authors, title and journal details, preferably in Vancouver format)

Add web link to the published protocol.

Or, upload your published protocol here in pdf format. Note that the upload will be publicly accessible.

No I do not make this file publicly available until the review is complete

Please note that the information required in the PROSPERO registration form must be completed in full even if access to a protocol is given.

35. Dissemination plans.

Do you intend to publish the review on completion?

Yes

Give brief details of plans for communicating review findings.?

The review will be submitted to a peer-reviewed journal for publication.

36. Keywords.

Give words or phrases that best describe the review. Separate keywords with a semicolon or new line. Keywords help PROSPERO users find your review (keywords do not appear in the public record but are included in searches). Be as specific and precise as possible. Avoid acronyms and abbreviations unless these are in wide use.

systematic review, end of life care, goals of care, nursing homes

37. Details of any existing review of the same topic by the same authors.

If you are registering an update of an existing review give details of the earlier versions and include a full bibliographic reference, if available.

38. * Current review status.

Update review status when the review is completed and when it is published.New registrations must be ongoing so this field is not editable for initial submission.
Please provide anticipated publication date

Review_Ongoing

39. Any additional information.

Provide any other information relevant to the registration of this review.

40. Details of final report/publication(s) or preprints if available.

Leave empty until publication details are available OR you have a link to a preprint (NOTE: this field is not editable for initial submission). List authors, title and journal details preferably in Vancouver format.

Give the link to the published review or preprint.

Appendix D: Search Strategy for Chapter 2 Systematic Review

PubMed Search

("Nursing Homes"[MeSH Terms] OR nursing home*[tw] OR intermediate care facilit*[tw] OR skilled nursing facilit*[tw] OR extended care facilit*[tw] OR "long term care"[MeSH Terms] OR "long term care"[tw] OR "Residential Facilities"[MeSH Terms] OR residential facilit*[tw] OR "assisted living"[tw] OR group home*[tw] OR "homes for the aged"[tw] OR "home for the aged"[tw] OR old age home*[tw] OR care home*[tw])

AND

(("Patient Care Planning"[MeSH Terms] OR "Advance Care Planning"[Mesh] OR "Living Wills"[Mesh] OR "goals of care"[tw] OR care goal*[tw] OR treatment goal*[tw] OR care plan*[tw] OR treatment plan*[tw] OR advance medical plan*[tw] OR advance healthcare plan*[tw] OR advance discussion*[tw] OR end of life discussion*[tw] OR end of life conversation*[tw] OR end of life communication*[tw] OR "discussing end of life"[tw] OR "Advance Directives"[MeSH Terms] OR advance directive*[tw] OR "medical power of attorney"[tw] OR living will*[tw] OR "health care power of attorney"[tw] OR psychiatric will*[tw] OR ulysses contract*[tw] OR healthcare prox*[tw] OR health care prox*[tw] OR "POLST"[tw] OR “MOLST”[tw] “Physician Orders for Life-Sustaining Treatment”[tw] OR “portable medical order”[tw] OR “Medical Orders for Life-Sustaining Treatment”[tw] OR "Resuscitation Orders"[MeSH Terms] OR resuscitation order*[tw] OR “do not resuscitate”[tw] OR resuscitation decision*[tw] OR resuscitation polic*[tw] OR "Withholding Resuscitation"[tw] OR “do not hospitalize”[tw] OR DNH[tw] OR DNR[tw] OR serious illness discussion*[tw])

OR

("Terminal Care"[MeSH Terms] OR "Terminal Care"[tw] OR "end of life care"[tw] OR "hospice care"[tw] OR hospice program*[tw] OR "Palliative Care"[MeSH Terms] OR "Palliative Care"[tw] OR palliative treatment*[tw] OR "palliative supportive care"[tw] OR palliative surger*[tw]))

AND

(earl*[tw] OR immediat*[tw] OR "timely"[tw] OR "timing"[tw] OR "timings"[tw] OR time*[tw] OR initiat*[tw] OR establish*[tw] OR “on admission”[tw])

Embase Search

'nursing home'/exp OR 'residential home'/exp OR ‘nursing home*’:ti,ab,kw OR ‘residential home*’:ti,ab,kw OR ‘skilled nursing facilit*’:ti,ab,kw OR ‘long term care facilit*’:ti,ab,kw OR ‘intermediate care facilit*’:ti,ab,kw OR ‘extended care facilit*’:ti,ab,kw OR ‘residential facilit*’:ti,ab,kw OR ‘assisted living’:ti,ab,kw OR ‘group home*’:ti,ab,kw OR ‘homes for the aged’:ti,ab,kw OR ‘old age home*’:ti,ab,kw OR ‘care home*’:ti,ab,kw

AND

'advance care planning'/exp OR 'living will'/exp OR 'physician orders for life sustaining treatment'/exp OR ‘advance care planning’:ti,ab,kw OR ‘living will*’:ti,ab,kw OR ‘patient care planning’:ti,ab,kw OR ‘advance directive*’:ti,ab,kw OR ‘resuscitation order*’:ti,ab,kw OR ‘goals of care’:ti,ab,kw OR ‘care goal*':ti,ab,kw OR 'treatment goal*':ti,ab,kw OR 'care plan*':ti,ab,kw OR 'treatment plan*':ti,ab,kw OR 'advance medical plan*':ti,ab,kw OR 'advance healthcare plan*':ti,ab,kw OR 'advance discussion*':ti,ab,kw OR 'end of life discussion*':ti,ab,kw OR 'end of life conversation*':ti,ab,kw OR 'end of life communication*':ti,ab,kw OR 'discussing end of life':ti,ab,kw OR 'medical power of attorney':ti,ab,kw OR 'health care power of attorney':ti,ab,kw OR 'psychiatric will*':ti,ab,kw OR 'ulysses contract*':ti,ab,kw OR 'healthcare prox*':ti,ab,kw OR 'health care prox*':ti,ab,kw OR 'POLST':ti,ab,kw OR 'MOLST':ti,ab,kw OR 'physician orders for life sustaining treatment':ti,ab,kw OR 'portable medical order':ti,ab,kw OR 'medical orders for life-sustaining treatment':ti,ab,kw OR 'do not resuscitate':ti,ab,kw OR 'resuscitation decision*':ti,ab,kw OR 'resuscitation polic*':ti,ab,kw OR 'withholding resuscitation':ti,ab,kw OR 'do not hospitalize':ti,ab,kw OR 'DNH':ti,ab,kw OR 'DNR':ti,ab,kw

AND

'terminal care'/exp OR 'palliative therapy'/exp OR 'hospice care'/exp OR 'palliative nursing'/exp OR 'palliative care':ti,ab,kw OR 'hospice care':ti,ab,kw OR 'end of life care':ti,ab,kw OR 'end-of-life care':ti,ab,kw OR 'terminal care':ti,ab,kw OR 'hospice program*':ti,ab,kw OR 'palliative treatment*':ti,ab,kw OR 'palliative supportive care':ti,ab,kw OR 'palliative surger*'

AND

'earl*':ti,ab,kw OR 'immediat*':ti,ab,kw OR 'timely':ti,ab,kw OR 'timing':ti,ab,kw OR 'timings':ti,ab,kw OR 'time*':ti,ab,kw OR 'initiat*':ti,ab,kw OR 'establish*':ti,ab,kw OR 'on admission'

Cumulated Index to Nursing and Allied Health Literature Search

((MH "Nursing Homes+") OR (MH "Residential Facilities+") OR (MH "Skilled Nursing Facilities") OR (MH "Long Term Care"+) OR (TI nursing home* OR AB nursing home* OR TI intermediate care facilit* OR AB intermediate care facilit* OR TI skilled nursing facilit* OR AB skilled nursing facilit* OR TI extended care facilit* OR AB extended care facilit* OR TI long term care OR AB long term care TI residential facilit* OR AB residential facilit* OR TI assisted living OR AB assisted living OR TI group home* OR AB group home* OR TI homes for the aged OR AB homes for the aged OR TI old age home* OR AB old age home* OR TI care home* OR AB care home*)

AND

((MH "Patient Care Planning+") OR (MH "Advance Care Planning+") OR (MH "Living Wills+") OR (MH "Advance Directives+") OR (MH "Resuscitation Orders+") OR (TI goals of care OR AB goals of care OR TI care goal* OR AB care goal* OR TI treatment goal* OR AB treatment goal* OR TI care plan* OR AB care plan* OR TI treatment plan* OR AB treatment plan* OR TI advance medical plan* OR AB advance medical plan* OR TI advance healthcare plan* OR AB advance healthcare plan* OR TI advance discussion* OR AB advance discussion* OR TI end of life discussion* OR AB end of life discussion* OR TI end of life conversation* OR AB end of life conversation* OR TI end of life communication* OR AB end of life communication* OR TI discussing end of life OR AB discussing end of life OR TI advance directive* OR AB advance directive* OR TI medical power of attorney OR AB medical power of attorney OR TI living will* OR AB living will* OR TI health care power of attorney OR AB health care power of attorney OR TI psychiatric will* OR AB psychiatric will* OR TI ulysses contract* OR AB ulysses contract* OR TI healthcare prox* OR AB healthcare prox* OR TI health care prox* OR AB health care prox* OR TI POLST OR AB POLST OR TI MOLST OR AB MOLST OR TI

Physician Orders for Life-Sustaining Treatment OR AB Physician Orders for Life-Sustaining Treatment OR TI portable medical order OR AB portable medical order OR TI Medical Orders for Life-Sustaining Treatment OR AB Medical Orders for Life-Sustaining Treatment OR TI resuscitation order* OR AB resuscitation order* OR TI do not resuscitate OR AB do not resuscitate OR TI resuscitation decision* OR AB resuscitation decision* OR TI resuscitation polic* OR AB resuscitation polic* OR TI Withholding Resuscitation OR AB Withholding Resuscitation OR TI do not hospitalize OR AB do not hospitalize OR TI DNH OR AB DNH OR TI DNR OR AB DNR))

AND

((MH “Terminal Care+") OR (MH "Palliative Care+") OR (TI Terminal Care OR AB Terminal Care OR TI end of life care OR AB end of life care OR TI hospice care OR AB hospice care OR TI hospice program* OR AB hospice program* OR TI Palliative Care OR AB Palliative Care OR TI palliative treatment* OR AB palliative treatment* OR TI palliative supportive care OR AB palliative supportive care OR TI palliative surger* OR AB palliative surger*))

AND

(TI earl* OR AB earl* OR TI immediat* OR AB immediat* OR TI timely OR AB timely OR TI timing OR AB timing OR TI timings OR AB timings OR TI time* OR AB time* OR TI initiat* OR AB initiat* OR TI establish* OR AB establish* OR TI on admission OR AB on admission)

Appendix E: Modified Newcastle-Ottawa Scale for Chapter 2 Systematic Review

Adapted Newcastle-Ottawa Scale for Cross-Sectional Studies

Selection: (Maximum of 5 stars)

1. **Representativeness of the sample:**

a) Truly representative of the average in the target population. **(all subjects or random sampling)** *

b) Somewhat representative of the average in the target population. **(non-random sampling**) *

c) Selected group of users.

d) No description of the sampling strategy.

2. **Sample size:**

a) Justified and satisfactory.*

b) Not justified.

3. **Ascertainment of exposure:**

a) Validated measurement tool.*

b) Non-validated measurement tool, but the tool is available or described.*

c) No description of the measurement tool.

4. **Non-respondents:**

a) Comparability between respondents and non-respondents characteristics is established, and the response rate is satisfactory.*

b) The response rate is unsatisfactory, or the comparability between respondents and non-respondents is unsatisfactory.

c) No description of the response rate or the characteristics of the responders and the non-responders.

5. **Complete data:**

d) Yes < 20% missing data.*

e) No > 20% missing data

f) No description of the missing data

Comparability: **(Maximum of 2 stars)**

1. **The subjects in different outcome groups are comparable, based on the study design or analysis. Confounding factors are controlled:**

a) The study controls for the most important factor (age).*

b) The study controls for at least one additional factor on the following list.*

Outcome: (Maximum of 2 stars)

1. **Assessment of outcome:**

a) Independent blind assessment.*

b) Record linkage.*

c) Self-report.*

d) No description.

2. **Statistical test:**

a) The statistical test used to analyze the data is clearly described and appropriate, and the measurement of the association is presented, including confidence intervals or probability level (p-value).*

b) The statistical test is not appropriate, not described, or incomplete.

*Extracted/adapted from: Ho PJ, Gernaat SA, Hartman M, Verkooijen HM. Health-related quality of life in Asian patients with breast cancer: a systematic review. BMJ open. 2018 Apr 1;8(4):e020512.

Adapted thresholds for converting the Newcastle-Ottawa scales to AHRQ standards (good, fair, and poor):

Good quality: 4 or 5 stars in selection domain AND 1 or 2 stars in comparability domain AND 1 or 2 stars in outcome/exposure domain (total 6-9)
Fair quality: 3 stars in selection domain AND 1 or 2 stars in comparability domain AND 1 or 2 stars in outcome/exposure domain (total 5-7)
Poor quality: 2 star or less in selection domain OR 0 stars in comparability domain OR 0 stars in outcome/exposure domain

Appendix F: The Association of Nursing Home Infection Preventionists' Training and Credentialing with Resident COVID 19 Deaths

The following supplemental appendix is an original research paper that examined whether COVID-19 resident deaths were associated with differences in the training and credentialing of the nursing home person in charge of the infection prevention and control program.

Note. The contents of this additional appendix B have been published in the Journal of the American Geriatrics Society. Citation for the final published version is as follows:

> Kang, J. A., Stone, P. W., Glance, L. G., & Dick, A. W. (2024). The association of nursing home infection preventionists' training and credentialing with resident COVID 19 deaths. *Journal of the American Geriatrics Society*, 10.1111/jgs.18760. Advance online publication. https://doi.org/10.1111/jgs.18760

Abstract

Background: Nursing home (NH) residents' vulnerability to COVID-19 underscores the importance of infection preventionists (IPs) within NHs. Our study aimed to determine whether training and credentialing of NH IPs were associated with resident COVID-19 deaths.

Methods: This retrospective observational study utilized data from the Centers for Disease Control and Prevention’s National Healthcare Safety Network NH COVID-19 Module and USAFacts, from May 2020 to February 2021, linked to a 2018 national NH survey. We categorized IP personnel training and credentialing into four groups: 1) LPN without training; 2) RN/advanced clinician without training; 3) LPN with training; and 4) RN/advanced clinician with training. Multivariable linear regression models of facility-level weekly deaths per 1,000 residents as a function of facility characteristics, and county-level COVID-19 burden (i.e., weekly cases or deaths per 10,000 population) were estimated.

Results: Our study included 857 NHs (weighted n=14,840) across 489 counties and 50 states. Most NHs had over 100 beds, were for profit, part of chain organizations, and located in urban areas. Approximately 53% of NH IPs had infection control training and 82% were RNs/ advanced clinicians. Compared to NHs employing IPs who were LPNs without training, NHs employing IPs who were RNs/advanced clinicians without training had lower weekly COVID-19 death rates (-1.04 deaths per 1,000 residents; 95%CI -1.90, -0.18), and NHs employing IPs who were LPNs with training had lower COVID-19 death rates (-1.09 deaths per 1,000 residents; 95%CI -2.07, -0.11) in adjusted models.

Conclusions: NHs with LPN IPs without training in infection control had higher death rates than NHs with LPN IPs with training in infection control, or NHs with RN/advanced clinicians in the IP role, regardless of IP training. IP training of RN/advanced clinician IPs was not associated

with death rates. These findings suggest that efforts to standardize and improve IP training may be warranted.

Introduction

About 90% of nursing home (NH) residents are age 65 and older, with over 50% of residents being long-term (Centers for Disease Control and Prevention, 2020; Harris-Kojetin et al., 2019). NH residents are vulnerable to infectious diseases due to their advanced age, comorbidities, and compromised immune systems as well as communal living (Stone et al., 2018). It is estimated that approximately 2.7 million infections occur annually in NHs, resulting in over 380,000 NH resident deaths each year due to infections (Herzig et al., 2017). The impact of infectious diseases on NH residents has been magnified by the COVID-19 pandemic (Centers for Disease Control and Prevention, 2021; Kaiser Family Foundation, 2021). Despite NH residents making up only 1.2% of the U.S. population, they accounted for one-third of all COVID-19 deaths (Kaiser Family Foundation, 2021).

Prior to the pandemic, the Centers for Medicare and Medicaid Services (CMS) Final Rule in 2016 required all CMS-certified NHs to designate at least one infection preventionist (IP) in charge of an infection prevention and control program ("Medicare and Medicaid Programs; Reform of Requirements for Long-Term Care Facilities. Final rule," 2016). An IP is a healthcare professional dedicated to ensuring that both medical staff and patients adhere to the highest standards of practice for infection control. Most IPs are clinicians, but they may also be epidemiologists and other public health professionals (Association for Professionals in Infection Control and Epidemiology, n.d.). According to the 2016 Final Rule, the IP was also required to participate in the NH’s quality assessment and performance improvement committee ("Medicare and Medicaid Programs; Reform of Requirements for Long-Term Care Facilities. Final rule," 2016). However, the implementation of the 2016 Final Rule was not mandated until November 2019, and this federal regulation still lacks specific policies regarding details of IP training and credentialing. Notably, there were marginal changes from 2014 to 2018 in NH IP staffing characteristics, with only 7% of NHs having an IP trained in infection control in 2018 (up from 3% in 2014) (Stone et al., 2020).

Throughout the pandemic, the Centers for Disease Control and Prevention (CDC) guidance to prevent the spread of COVID-19 in NHs evolved (Centers for Disease Control and Prevention, 2021). One of the core infection prevention and control practices includes having one or more IPs with training in infection control to provide on-site management of the infection prevention and control program. Specifically, the CDC recommended having at least 1 full-time IP for NHs with ≥ 100 residents or NHs that provide on-site ventilator or hemodialysis services (Centers for Disease Control and Prevention, 2021). In addition, the National Academies of Sciences, Engineering, and Medicine (NASEM) recently issued "The National Imperative to Improve Nursing Home Quality 2022", which recommends that NH have an IP who is a registered nurse (RN), advanced practice RN, or a physician (National Academies of Sciences & Medicine, 2022). Starting with California in January 2021, several states have passed legislation or have regulations to ensure adequate staffing standards for IPs in NHs including Connecticut, New Jersey, and Illinois.

The role of the IP in NHs is relatively new. It is common for the person in charge of the infection prevention and control program in NHs to have multiple roles and responsibilities (Stone et al., 2015). Furthermore, persons in charge of the infection control program in NHs are less likely to receive formal training in infection control compared to IPs in acute-care settings (Stone et al., 2015). Indeed, in a national survey it was found that most individuals in charge of the NH infection control program had minimal training in infection control and lacked a formal IP role (Pogorzelska-Maziarz & Kalp, 2017).

The impact of IP training and credentialing policies on the COVID-19 burden in NHs remains unknown. Therefore, to understand how to prevent and mitigate future outbreaks, this study aimed to determine whether COVID-19 resident deaths were associated with differences in the training and credentialing of the person in charge of the infection prevention and control program. We hypothesized that, after adjusting for NH resident and facility characteristics, as well as county-level COVID-19 severity, NHs with infection control-trained and RN or advanced clinician IPs will have lower rates of COVID-19 resident deaths compared to NHs with non-trained and licensed practical nurse (LPN) in charge of the infection prevention and control program.

Methods

Data

Since 05/2020, the CMS mandated that all NHs report COVID-19 metrics every week, including resident mortality, to the CDC's National Healthcare Safety Network (NHSN) Long-Term Care Facility COVID-19 Module. Using a retrospective observational study design, we examined the CDC's COVID-19 NH resident mortality data from 05/25/2020, to 02/21/2021 (Centers for Diesase Control and Prevention, 2020b).

This publicly available dataset was merged with data from a 2018 national survey of NHs (R01 NR013687 PI: Stone) (Stone et al., 2019). We used the 2018 survey as it was the most recent data available prior to the pandemic, and it included a comprehensive description of the training and credentialing of the professional in charge of the infection prevention and control program. The survey was a cross-sectional facility-level survey of a stratified, random sample of U.S. NHs (N = 892; a 49% response rate). The random sampling process involved stratification based on the regions of Quality Innovation Network-Quality Improvement Organizations, ensuring a balanced representation of NHs across all 14 regions. The survey was completed by the Director of Nursing at each facility, encompassing questions about infection prevention and control programs, including IP training and credentialing. Additional details on the survey have been published elsewhere (Stone et al., 2019).

The survey data were merged with the 2018 Minimum Data Set (Centers for Medicaid and Medicare Services, 2021) and 2020 Provider of Services data (Centers for Medicaid and Medicare Services, 2021) to identify facility and resident characteristics. Lastly, we linked USAFacts data to identify county-level COVID-19 cases and deaths (USA Facts, 2020). This study was approved by the Columbia University and RAND Institutional Review Boards.

Measures

Our primary outcome was the NH weekly rate of resident COVID-19 deaths per 1,000 residents. This variable was defined as the number of residents with suspected or laboratory positive COVID-19 who died in the facility or another location as reported by the NH (Centers for Diesase Control and Prevention, 2020b).

The primary exposure variables were the pre-pandemic training and credentialing of the professional in charge of the infection prevention and control program from the survey data. The survey question inquired about any personnel who were in charge of the infection prevention and control program in NHs, encompassing their characteristics such as training and credentialing. For simplicity, irrespective of training and credentialing, we define this professional as an IP and training was defined as (1) certification in infection control; (2) state or local training by a professional society; or (3) other training. If a NH reported that their IP had no specific infection control training or responded with "don't know", we treated that NH as having an untrained IP. The measure of IP credentialing was based on the professional degree, grouped as "RN or advanced clinician" and "LPN." The category of "RN or advanced clinician" included individuals with the credentials of RN, nurse practitioner (NP), or other advanced clinical roles (e.g., physician, master-level nurse educator, clinical nurse specialist). We then created a four-category measure (henceforth referred to as ***IP training and credentialing***): 1) LPN without training; 2) RN or advanced clinician without training; 3) LPN with training; and 4) RN or advanced clinician with training.

We controlled for facility-level characteristics, including bed size (categorized as 1-99 and 100+ beds); ownership (for-profit, not-for-profit, and government); change of ownership (since 2019); part of a multi-facility organization; and urban/rural. We also controlled for facility-level aggregates of resident characteristics, such as age (categorized by the proportion of residents aged 64 and below, 65-84 years old, and 85 years and older), sex (proportion of female residents), and race (proportion of non-Hispanic White residents). In addition, we controlled for the county-level burden of COVID-19 cases (and alternatively deaths) from USAFacts data, operationalized as a 5-week moving average (current week and the prior 4 weeks) of county-level COVID-19 cases (alternatively deaths) per 10,000 people in the county.

Analyses

We assessed the association between NH IP-training and credentialing and resident COVID-19 deaths between 05/25/2020 and 02/21/2021. The unit of observation was the NH-week, and to ensure the accuracy of our analysis, we excluded the first period of the NHSN data. This decision stemmed from the CDC's reporting of accumulated deaths occurring anytime between 01/01/2020 and 05/24/2020. Notably, it is acknowledged that about 40% of COVID-19 deaths that occurred before 05/24/2020 were not reported in the NHSN NH COVID-19 data (Shen et al., 2021). Consequently, we excluded this period from our analyses to avoid drawing misleading conclusions about the factors influencing NH outbreaks (Shen et al., 2021). The CDC reporting for subsequent periods was on a weekly basis. By extending our analysis up to February 2021, we captured not only early response to the pandemic but also the peak periods of COVID-19 transmission, particularly around December 2020. This broader time frame enabled us to examine how IP training and credentialing were associated with COVID-19 outcomes during different phases of the pandemic.

Probability weights were used to account for the stratified sampling design of the NH survey, making the data nationally representative. Weighted descriptive statistics were stratified by the four IP training and credentialing categories and calculated using the Pearson chi-square test and adjusted Wald test when appropriate. We then estimated multivariable linear regression given by

$$Y_{jct} = \beta_0 + COVID_{ct} * (\beta_1 + \beta_2 IP_{jc} + \beta_3 NH_{jc}) + \mu_t + \varepsilon_{jct},$$

where Y_{jct} is COVID deaths / 1,000 residents in NH *j* and county *c* during week *t; $COVID_{jt}$* is a 5-week moving average of COVID-19 burden for county *c*, including week *t* and the 4 weeks prior to *t*; IP_{jc} is a vector of the NH IP-training and credentialing measures with untrained-LPN as the referent; NH_{jc} is a vector of NH characteristics and aggregate resident characteristics, which do not vary with *t*; μ_t are weekly calendar-time fixed effects, and ε_{jct} is an error term. Although we assumed NH COVID-19 death rates were a function of levels of county COVID-19 intensity (β_1), we also assumed the relationships with other covariates would be proportional to the COVID-19 risk. Thus, we interacted all remaining covariates with county-level COVID-19 burden. In the absence of the interaction, each covariate would have the same effect size regardless of the COVID-19 risk. In sensitivity analyses, we used county COVID-19 deaths rather than cases, excluding a NH's deaths from the measure of county deaths to avoid endogeneity. We normalized each of the county-level COVID burden measures by its standard deviation so that a 1-unit change represented a change of 1 standard deviation in the weekly county COVID-19 cases or deaths. We calculated empirical Huber-White standard errors, clustered at the NH level, to account for the potentially correlated errors across all observations of a NH. Coefficient estimates of indicator variables therefore represent the effect size given a one standard deviation change in COVID-19 risk, as measured by the 5-week moving average of county COVID-19 cases (alternatively deaths). Finally, we generated adjusted predictions from the models and created figures to help visualize and interpret substantive effect sizes of the model estimates. We considered p <.05 as statistically significant. All statistical analyses were performed using STATA 17.0 (StataCorp).

Results

Descriptive statistics

Table 1 shows descriptive statistics of the NHs stratified by IP training and credentialing. A total of 857 NHs (weighted n = 14,840; N of NH-weeks = 33,414) located in 489 counties and 50 states were identified and included in this study. The majority of NHs had over 100 beds (53.5%), were for profit (69.3%), part of a chain organization (57.3%), and located in urban areas (71.4%). NH residents were mostly female (60.5%), between 65 and 84 years old (48.9%), and White (80.0%). Just over half of the (53.2%) of NHs IP had training in infection control. Most of the NH IPs were RNs or advanced clinicians (82.2%). Among the IPs who were RNs or advanced clinicians, 44% had training in infection control.

IP training and credentialing

Table 2 shows the results from the multivariable linear regression models. Overall, IP training and credentialing measures were associated with weekly resident COVID-19 death rates.

When compared to NHs with untrained LPNs serving as IPs, NHs with each of the other categories of IP training and credentialing had similar reductions in COVID-19 deaths, as described below. Furthermore, the size of the gap in NH deaths between untrained LPNs serving as IPs and other IPs widened as the county COVID burden increased (Figures 1 and 2).

NHs Employing IPs who were RNs or Advanced Clinicians with No Training: For each increase of 1 standard deviation of COVID-19 burden, NHs employing RNs or advanced clinicians with no training as IPs had fewer COVID-19 deaths (-1.04 per 1,000 residents; 95% CI: -1.90 to -0.18) than NHs with LPNs without training. The estimate was similar (-1.05 deaths per 1,000 residents; 95% CI: -1.97 to -0.13) when controlling for county COVID-19 deaths rather than cases.

NHs Employing IPs who were LPNs with Training: For each increase of 1 standard deviation of COVID-19 burden, NHs that employed trained LPNs had fewer deaths (-1.09 per 1,000 residents; 95% CI: -2.07 to -0.11) than those employing LPNs without training. Although similar in magnitude, this reduction was not significant when adjusting for county-level deaths (-0.92 deaths per 1,000 residents; 95% CI: -1.94 to 0.10).

NHs Employing IPs who were RNs or Advanced Clinicians with Training: For each increase of 1 standard deviation of COVID-19 intensity, NHs employing IPs who were RNs or advanced clinicians with training had similar reductions in deaths as LPNs with training (-0.87 deaths per 1,000 residents; 95% CI: -1.75 to 0.01), although this reduction was not significantly different from the referent group. However, when adjusting for county-level deaths rather than cases, the reduction was significant (-0.97 deaths per 1,000 residents; 95% CI: -1.88 to -0.05).

Discussion

To our knowledge, our study is the first study to examine the relationship between IP training and credentialing and COVID-19 deaths in NHs. Overall, NHs that employed an LPN as an IP without training had higher rates of COVID-19 deaths than other NHs and this gap increased when COVID-19 burden in the community was higher. This finding likely resulted from the ability of a more highly trained or credentialed IP to better oversee the infection prevention and control program in NHs including educating staff and residents ("Medicare and Medicaid Programs; Reform of Requirements for Long-Term Care Facilities. Final rule," 2016). Furthermore, it is likely that these IPs would have been more able to rapidly implement evidence-based infection prevention and control policies than untrained LPNs.

Consistent with our findings, prior studies have demonstrated a positive association between IP training in infection control and enhanced infection-related outcomes, as well as the implementation of more comprehensive infection prevention and control programs within NHs (Fu et al., 2020; Herzig et al., 2016; Stone et al., 2018). Notably, national-level studies have revealed that NHs with infection control-trained IPs have more comprehensive antibiotic stewardship programs compared to those lacking specific training (Fu et al., 2020; Stone et al., 2018). Additionally, the likelihood of receiving an infection control deficiency citation was higher in NHs with non-trained IPs, coupled with reduced resources for ongoing infection control education (Herzig et al., 2016).

During the pandemic, a qualitative study involving 73 NH IPs underscored the persistent challenge of inadequate COVID-related training programs faced by IPs (Rebmann et al., 2021). Furthermore, an environmental scan identified training and knowledge in infection control as one of the areas to improve NH infection prevention and control during COVID-19 pandemic

(Rubano et al., 2022). Despite these findings regarding the role of IP training in infection control, there is wide variation in IP training standards across NHs (Fu et al., 2020). About 46% of NHs in the national survey reported that their IP had no specific infection control training, and most of them were not certified or trained in infection control (Fu et al., 2020). Our findings highlight the importance of infection control training when infection prevention and control programs are overseen by LPNs. This is an area that should be a focus for enhancement NH infection prevention and control programs.

Although increasing RN staffing in NHs has been a persistent recommendation to improve the quality of care in NHs, there has been a lack of evidence reflecting optimal NH IP training and credentialing standards (National Academies of Sciences & Medicine, 2022; Stone et al., 2020). Our finding that a NH IP with RN or advanced clinician staffing, whether trained or not, is associated with fewer COVID-19 deaths than a NH staffed with an untrained LPN is in line with the NASEM recommendation that a NH IP be a RN or advanced clinician (National Academies of Sciences & Medicine, 2022). Nevertheless, it is important to note that many successful IPs come from other fields such as microbiology or epidemiology (Pogorzelska-Maziarz et al., 2023).

Adding to the complexity, federal regulations currently lack specific guidelines or recommendations for training or certification standards for IPs. Fortunately, there are now specialized infection prevention and control training programs uniquely designed for IPs in long-term care settings (Association for Professionals in Infection Control and Epidemiology, n. d.; Centers for Diesase Control and Prevention, 2020a). In addition, the Certification Board of Infection Control and Epidemiology now offers a certification for long-term care infection prevention, attesting to competence in infection prevention and control practices within such settings (Certification Board of Infection Control and Epidemiology, n. d.). These advancements, which were not available when the survey was conducted, hold promise for addressing the existing gaps in NH and bolstering infection prevention efforts in these long-term care facilities.

Limitations

This study has several limitations that should be acknowledged. We noted the concern about underreporting of COVID-19 deaths to NSHN, estimated to be as many as 40%, during the early stage of the pandemic (through 05/24/2020), prompted us to exclude this period from our analysis. IP training and credentialing may have been particularly important during this early stage of the pandemic. Conversely, the chaos of the early periods of the pandemic may have overwhelmed any IP training and credentialing effects, and IP training and credentialing may have become more important as lessons emerged from the early-stage experiences. Another limitation of our data is that the survey took place two years prior to the onset of the pandemic, and this temporal gap is an important consideration when interpreting our findings in the context of the pandemic's impact on IP practices. Additionally, we lacked measures about the IP training and credentialing policies that occurred during the pandemic. We know that IP training in NHs underwent significant changes in response to the evolving pandemic situation. As a result, our use of fixed pre-pandemic measures may underestimate the importance of IP training and credentialing particularly during later stages of the pandemic. Although we made efforts to capture relevant workforce data through the survey, the lack of distinction between RNs and advanced practice RNs, and potential confounding influence of NH staffing levels such as dedicated time of the IP are also limitations of our study. We chose to use county-level COVID-19 cases as a proxy for COVID-19 risk in NHs. We recognize that county case rates could be significantly influenced by testing availability during the pandemic period (McGarry et al., 2023). Testing accessibility and frequency might have introduced variability in the reported case numbers, potentially affecting our results. As a sensitivity analysis, we substituted county-level COVID-19 deaths for cases. Recognizing that NH COVID-19 deaths made up a large fraction of all COVID-19 deaths, particularly early in the pandemic, we adjusted the county-data to mitigate concerns regarding endogeneity. We found the results were robust, and although not always significant, the substantive effect sizes were similar across models. Despite these limitations, our study underscores the crucial role of IP policies in NHs by revealing meaningful associations between pre-pandemic levels of IP training and credentialing and COVID-19 deaths.

Conclusions

Nursing homes with an LPN untrained in infection control in the role of infection preventionist had higher death rates than NHs with an IP who was either an LPN trained in infection control or an RN/advanced clinician. Infection control training was only associated with better outcomes when the infection preventionist was an LPN and not when the infection preventionist was an RN or advanced clinician. Given the wide variability in infection control training, and the lack of evidence that this training is associated with better outcomes in NHs with RN or advanced clinicians in the IP role, efforts to standardize and improve IP training may be warranted.

References

Association for Professionals in Infection Control and Epidemiology. (n. d.). *Long-Term Care Infection Preventionist Essentials*. https://apic.org/course/ltc-ip-essentials/

Association for Professionals in Infection Control and Epidemiology. (n.d.). *Who are infection preventionists?* https://apic.org/monthly_alerts/who-are-infection-preventionists/

Centers for Diesase Control and Prevention. (2020a). *Infection Prevention Training*. https://www.cdc.gov/longtermcare/training.html

Centers for Diesase Control and Prevention. (2020b). *LTCF COVID-19 Module*. https://www.cdc.gov/nhsn/ltc/covid19/index.html

Centers for Disease Control and Prevention. (2020). *Infection Control for Nursing Homes*. https://www.cdc.gov/coronavirus/2019-ncov/hcp/long-term-care.html

Centers for Disease Control and Prevention. (2021). *Interim Infection Prevention and Control Recommendations to Prevent SARS-CoV-2 Spread in Nursing Homes*. https://www.cdc.gov/coronavirus/2019-ncov/hcp/long-term-care.html

Centers for Medicaid and Medicare Services. (2021). *Minimum Data Set (MDS) 3.0 for Nursing Homes and Swing Bed Providers*. https://www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/NursingHomeQualityInits/NHQIMDS30

Certification Board of Infection Control and Epidemiology. (n. d.). *About the Long-Term Care Certification in Infection Prevention (LTC-CIP)*. https://www.cbic.org/CBIC/Long-term-care-certification.htm

Fu, C. J., Mantell, E., Stone, P. W., & Agarwal, M. (2020, Jan). Characteristics of nursing homes with comprehensive antibiotic stewardship programs: Results of a national survey. *Am J Infect Control*, *48*(1), 13-18. https://doi.org/10.1016/j.ajic.2019.07.015

Harris-Kojetin, L., Sengupta, M., Lendon, J., Rome, V., Valverde, R., & Caffrey, C. (2019, Feb). Long-Term Care Providers and services users in the United States, 2015-2016. *Vital Health Stat 3*(43).

Herzig, C. T., Stone, P. W., Castle, N., Pogorzelska-Maziarz, M., Larson, E. L., & Dick, A. W. (2016, Jan). Infection Prevention and Control Programs in US Nursing Homes: Results of a National Survey. *J Am Med Dir Assoc*, *17*(1), 85-88. https://doi.org/10.1016/j.jamda.2015.10.017

Herzig, C. T. A., Dick, A. W., Sorbero, M., Pogorzelska-Maziarz, M., Cohen, C. C., Larson, E. L., & Stone, P. W. (2017, Jul 1). Infection Trends in US Nursing Homes, 2006-2013. *J Am Med Dir Assoc*, *18*(7), 635.e639-635.e620. https://doi.org/10.1016/j.jamda.2017.04.003

Kaiser Family Foundation. (2021). *State COVID-19 Data and Policy Actions*. https://www.kff.org/coronavirus-covid-19/issue-brief/state-covid-19-data-and-policy-actions/#long-term-care-cases-deaths

McGarry, B. E., Gandhi, A. D., & Barnett, M. L. (2023, Mar 23). Covid-19 Surveillance Testing and Resident Outcomes in Nursing Homes. *N Engl J Med*, *388*(12), 1101-1110. https://doi.org/10.1056/NEJMoa2210063

Medicare and Medicaid Programs; Reform of Requirements for Long-Term Care Facilities. Final rule. (2016, Oct 4). *Fed Regist*, *81*(192), 68688-68872.

National Academies of Sciences, E., & Medicine. (2022). *The National Imperative to Improve Nursing Home Quality: Honoring Our Commitment to Residents, Families, and Staff*. The National Academies Press. https://doi.org/doi:10.17226/26526

Pogorzelska-Maziarz, M., & Kalp, E. L. (2017, Jun 1). Infection prevention outside of the acute care setting: Results from the MegaSurvey of infection preventionists. *Am J Infect Control*, *45*(6), 597-602. https://doi.org/10.1016/j.ajic.2017.03.020

Pogorzelska-Maziarz, M., Monsees, E., & Hessels, A. (2023, Mar). APIC Megasurvey 2020: Methodology and overview of results. *Am J Infect Control*, *51*(3), 241-247. https://doi.org/10.1016/j.ajic.2022.12.002

Rebmann, T., Alvino, R. T., Mazzara, R. L., & Sandcork, J. (2021, Sep). Infection preventionists' experiences during the first nine months of the COVID-19 pandemic: Findings from focus groups conducted with Association of Professionals in Infection Control & Epidemiology (APIC) members. *Am J Infect Control*, *49*(9), 1093-1098. https://doi.org/10.1016/j.ajic.2021.07.003

Rubano, M. D., Kieffer, E. F., & Larson, E. L. (2022, Jan-Feb). Infection prevention and control in nursing homes during COVID-19: An environmental scan. *Geriatr Nurs*, *43*, 51-57. https://doi.org/10.1016/j.gerinurse.2021.10.023

Shen, K., Loomer, L., Abrams, H., Grabowski, D. C., & Gandhi, A. (2021, Sep 1). Estimates of COVID-19 Cases and Deaths Among Nursing Home Residents Not Reported in Federal Data. *JAMA Netw Open*, *4*(9), e2122885. https://doi.org/10.1001/jamanetworkopen.2021.22885

Stone, P. W., Agarwal, M., & Pogorzelska-Maziarz, M. (2020, Mar). Infection preventionist staffing in nursing homes. *Am J Infect Control*, *48*(3), 330-332. https://doi.org/10.1016/j.ajic.2019.12.010

Stone, P. W., Agarwal, M., Ye, F., Sorbero, M., Miller, S. C., & Dick, A. W. (2019, Sep). Integration of Palliative Care and Infection Management at the End of Life in U.S.

Nursing Homes. *J Pain Symptom Manage, 58*(3), 408-416.e401. https://doi.org/10.1016/j.jpainsymman.2019.06.001

Stone, P. W., Herzig, C. T., Pogorzelska-Maziarz, M., Carter, E., Bjarnadottir, R. I., Semeraro, P. K., Cohen, C. C., Travers, J., & Schweon, S. (2015, Jul-Aug). Understanding infection prevention and control in nursing homes: A qualitative study. *Geriatr Nurs, 36*(4), 267-272. https://doi.org/10.1016/j.gerinurse.2015.02.023

Stone, P. W., Herzig, C. T. A., Agarwal, M., Pogorzelska-Maziarz, M., & Dick, A. W. (2018, Jan-Dec). Nursing Home Infection Control Program Characteristics, CMS Citations, and Implementation of Antibiotic Stewardship Policies: A National Study. *Inquiry, 55*, 46958018778636. https://doi.org/10.1177/0046958018778636

USA Facts. (2020). *US Coronavirus Cases & Deaths by State*. https://usafacts.org/visualizations/coronavirus-covid-19-spread-map/

Table 1. *Nursing home and resident characteristics in sample*

	IP Training and Credentialing					
	Total NHs	LPN with No Training	RN or Advanced Clinician with No Training	LPN with Training	RN or Advanced Clinician with Training	p
Number of NHs	857	62	316	76	403	
Weighted %	100	8.5	38.3	9.3	43.9	
Types of training (%)*						
Certified in infection control	7.4	.	.	12.2	14.4	
State, local, or professional society	34.6	.	.	71.0	63.7	
Other	11.2	.	.	16.8	21.9	
None	46.8	100	100	.	.	<0.001
Types of credential (%)*						
LPN	17.7	100	.	100	.	
RN	80.7	.	98.5	.	97.8	
NP	0.8	.	1.0	.	1.0	
Other	0.8	.	0.5	.	1.2	<0.001
NH characteristics (%)*						
Bed size						
0-99	46.5	40.6	46.4	56.3	45.7	
100 +	53.5	59.4	53.6	43.7	54.3	<0.001
Ownership						
For-profit	69.3	69.5	72.8	78.3	64.3	
Not-for-profit	23.9	17.1	21.2	15.4	29.4	
Government	6.8	13.4	6.0	6.3	6.3	<0.001
Change of ownership						
No	95.0	91.9	93.3	97.6	96.5	
Yes	5.0	8.1	6.7	2.4	3.5	<0.001
Chain organization						
No	42.7	39.1	38.7	38.2	47.9	
Yes	57.3	60.9	61.3	61.8	52.1	<0.001
Urban rural location						
Urban	71.4	73.0	68.2	74.9	71.4	
Rural	28.6	27.0	31.8	25.1	28.6	<0.001
NH resident characteristics						
Percent female	60.5	58.3	59.9	59.9	61.4	
95% CI	(60.3, 60.6)	(57.9, 58.8)	(59.8, 60.1)	(59.5, 60.3)	(61.2, 61.6)	<0.001
Percent age 65 – 84	48.9	48.4	49.8	50.7	47.9	
95% CI	(48.8, 49.0)	(48.0, 48.8)	(49.6, 49.9)	(50.4, 50.9)	(47.7, 48.0)	<0.001
Percent age 85 and older	35.3	29.8	33.8	34.2	37.8	
95% CI	(35.1, 35.4)	(29.2, 30.4)	(33.6, 34.1)	(33.7, 34.7)	(37.5, 38.1)	<0.001
Percent White	80.0	73.3	81.5	77.0	80.8	
95% CI	(79.8, 80.3)	(72.2, 74.4)	(81.1, 81.9)	(76.2, 77.8)	(80.3, 81.2)	<0.001
N = 33,414 NH-weeks						
Mean weekly COVID-19 deaths/1,000 residents	2.9	3.6	2.9	2.8	2.8	
95% CI	(2.7, 3.0)	(2.9, 4.2)	(2.6, 3.2)	(2.3, 3.4)	(2.5, 3.0)	0.1
Mean weekly COVID-19 cases/1,000 residents	13.8	15.2	14.5	15.8	12.4	
95% CI	(13.1, 14.4)	(12.7, 17.6)	(13.4, 15.7)	(13.2, 18.5)	(11.5, 13.3)	0.003

* Values are column percents
Abbreviation: NHs, nursing homes; IP, infection preventionist; LPN, licensed practical nurse; RN, registered nurse; NP, nurse practitioner; CI, confidence interval;

Table 2. *Multivariable linear regression model estimating weekly COVID-19 deaths per 1,000 residents*

Variables/Coefficient (95% CI)	Weekly COVID-19 deaths per 1,000 residents Adjusting for county-level cases	 Adjusting for county-level deaths
IP training and credentialing		
LPN with no training	Ref	Ref
RN or advanced clinician with no training	-1.04*	-1.05*
	(-1.90, -0.18)	(-1.97, -0.13)
LPN with training	-1.09*	-0.92
	(-2.07, -0.11)	(-1.94, 0.10)
RN or advanced clinician with training	-0.87	-0.97*
	(-1.75, 0.01)	(-1.88, -0.05)
Nursing home characteristics		
Bed size		
0-99	Ref	Ref
100 +	-0.01	-0.35
	(-0.55, 0.52)	(-0.85, 0.16)
Ownership		
For-profit	Ref	Ref
Not-for-profit	-0.35	-0.13
	(-1.04, 0.33)	(-0.75, 0.48)
Government	-0.25	0.16
	(-1.13, 0.63)	(-0.48, 1.00)
Chang of ownership		
No	Ref	Ref
Yes	0.90	-0.11
	(-0.51, 2.30)	(-0.78, 0.56)
Chain organization		
No	Ref	Ref
Yes	0.05	0.03
	(-0.50, 0.60)	(-0.47, 0.53)
Urban rural location		
Urban	Ref	Ref
Rural	0.29	-0.27
	(-0.32, 0.89)	(-0.84, 0.31)

Note: Models were adjusted for weekly calendar time fixed effects, 5-week moving average of county-level COVID-19 intensity (normalized cases or deaths per capita), and interactions between the county-level COVID-19 measure and facility characteristics (age, sex, race). Standard errors were clustered at the facility-level. Measures of county-level COVID-19 intensity were transformed to have a standard deviation of 1.
Abbreviation: IP, infection preventionist; Ref, reference; LPN, licensed practical nurse; RN, registered nurse;
* $p < 0.05$

Figure 1

Predicted NH Deaths per 1000 Residents by Decile of County Cases

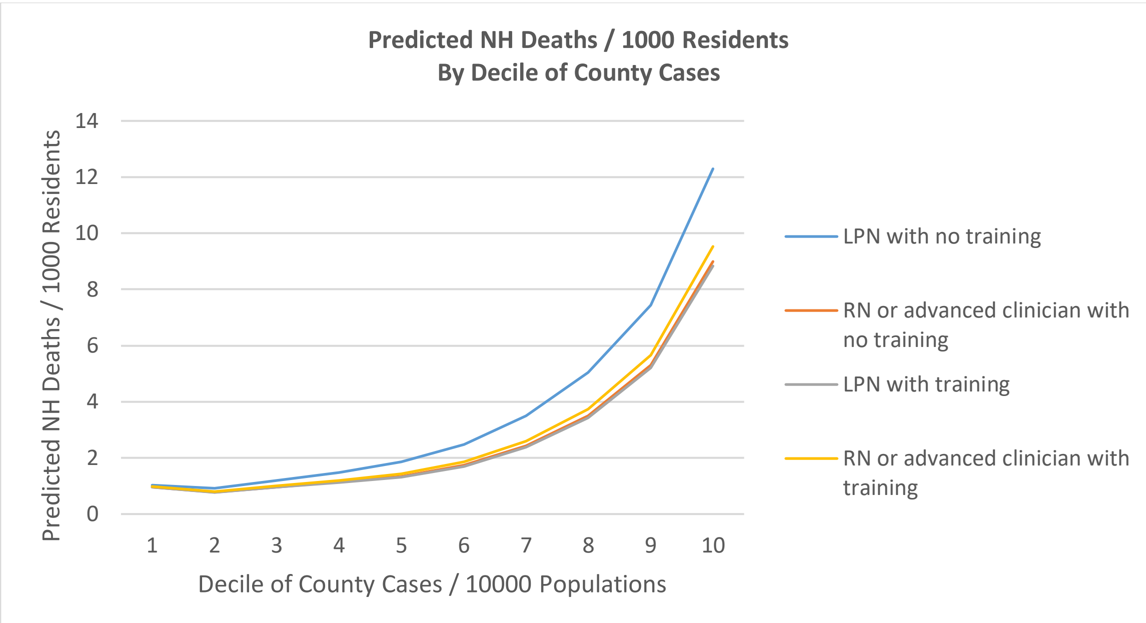


Figure 2

Predicted NH Deaths per 1000 Residents by Decile of County Deaths