

Discussions on Death and Dying:
*Ascoping review of the studies on end of life care of
the elderly comparing U.S to Netherlands*



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Abstract

Context: Discussing death and dying with the elderly in nursing homes, assisted living, hospitals, private homes, hospice centres, and community centres is an important aspect of End of Life (EOL)-care. Very few Health Care Professionals (HCP), engage in these conversations, have limited training and/or are comfortable with the process. Friends and family too, are reluctant to participate and when they do, it is too late.

Objective: To assess whether discussions on death and dying could ease depression and anxiety, and promote general well-being for the elderly ≥ 70 , living at home, or in nursing homes, in assisted living, or community centres, in hospice or palliative care, in hospitals or emergency care.

Methods: A scoping review of studies in the U. S. and in the Netherlands.

Results: From a total of one hundred and fifty nine (59) studies, twenty-five (25) studies passed the selection criteria. Twenty-one (21) were for the U. S., and four (4) were for the Netherlands. The selected studies were analysed and categorized by themes, and then summarized based on the outcome of a positive view on death discussions, negative view on death discussions or an ambiguous view on death discussions.

Conclusion: A scoping review of the selected studies points to a dearth of material on the subject of death and dying with the elderly. There were only two studies that measured the emotional well-being of the patients and the families. The rest pointed to fear, discomfort, anxiety, and lack of financial support for the HCP in EOL care, lack of training and a need for ethical legal discourse. In the Netherlands, where ethical and legal issues are not barriers to discussions, only four (4) studies were identified and out of those four (4), one reported on patients' weariness with life and thus they chose Physician Assisted Suicide (PAS). The rest encouraged discussions on death and dying early in life, but did not report on well-being or general lack of anxiety, as an outcome of discussions on death and dying or lack thereof.

Keywords: End-of-life care, Advance Care Planning, death, dying, elderly.

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List of Abbreviations

Abbreviations	Explanation
ACD	Advanced Care Directive
ACP	Advanced Care Planning
AD	Advanced Directives
DNR	Do Not Resuscitate
EOL	End of Life
F & F	Family and Friends
HCP	Health Care Professional
PAD	Physician Assisted Death
PAS	Physician Assisted Suicide

Introduction

For most of human history, medicine could do little to prevent or cure illness or extend life, and living to an old age required considerable good fortune. Because many deaths occurred at home, people were likely to care for dying relatives and, thus, to have a fairly personal and direct experience with death and dying (Field MJ, 1997). Modern medicine has not only cured illness and extended life but also changed our perception of death.

The problem then is that people live far longer because of medicine, and the aging population is accustomed to thinking that death can be indefinitely postponed. Hence, death in our (global) culture is an act of fundamental resistance. We pretend it is far away because it sounds so gloomy to talk about it, and appears like a ghastly accident (Watts, 1978).

Therefore, over the last decade, and around the world (both developed and developing countries) there has been a tremendous increase in nursing homes, assisted living homes, long term care centres, along with a very significant increase in older people living alone in their own homes (Chandler, Williams, Maconachie, Collett, & Dodgeon, 2004).

For the first time in the history of humanity, people over the age of 65 will soon outnumber children under the age of five. By 2030, the number of people aged 65 and older is projected to reach one billion (or one in eight of the global population), rising even more sharply (by 140%) in developing countries (Health-and-Human-Services, 2007). While Europe's population has been among the fastest to age, US is catching up. According to the Pew Research Center, 13% of the population is now over the age of 65, up from 4% in 1900. By 2050, about one-in-five Americans will be over the age of 65, with about 5% reaching 85 and older (Health-and-Human-Services, 2007). The need for discussing death and dying, in an age of ever-proliferating nursing homes, high-tech apps, diets, nutrition and exercise, etc., has never been greater.

A large body of research points to cultural and historical influences that shape our attitudes towards death and some recent research also affirms that death is an individual journey, shaped by our personal biographies. In most cultures, discussions on death and dying have negative associations and thus negative consequences for the dying, the HCP, and the

bereaved. That taboo is slowly beginning to lift in the U. S., where the hospice and palliative care is supported by the public health system, also known as the Medicare in the U. S. (Anderson, Williams, Bost, & Barnard, 2008).

In the Netherlands, however, there have been open discussions and debates on the impact of chronic diseases on death and much attention on patient-centred care at the end of life. This has generated interest in the role of medicine on the mode, timing and method of death and dying (Van der Heide et al., 2007). Such openness and discussions are slowly changing (Dutch) society's attitudes and visibility of death.

In the healthcare community in the Netherlands, and especially, in ACP, in EOL-care, in hospice and palliative care, there have been discussions on death and dying and on what is good death. Studies also suggest that "efforts to bring EOL care into accord with patients' wishes through use of ADs and DNRs have had limited success, in part because meaningful options are often offered too late," and preferences are rarely documented in the patient's medical record (Van der Heide et al., 2007).

For the elderly in nursing homes, or at home, there is frustration, in that they have lived their lives in an abstraction, a rational inference from experience, which exists only for the brain. The verbal and abstract thinking of the brain gives the false impression of being able to cut loose from all the finite limitations, however, when the body is worn out and the brain is tired, the whole organism welcomes death (Watts, 1978).

The principal value in reflecting and assimilating the concept of death is to provide a set of lenses through which we can view the phenomena of death and dying as a natural process of life, and make intelligent, fearless decisions about our health and well-being.

The goal of this scoping review is to identify and chart current research that involves open discussions on death and dying at all four levels of discussion, that is, 1) Discussions with HCP 2) Discussions with F & F 3) Discussions with HCP, F & F and self-4) Reflections by self. Additionally, the purpose is to observe whether these discussions reduce depression and anxiety and are generally beneficial to all parties. This review should add to our understanding of death discussions as they happen in the U. S. and in the Netherlands. It should also identify gaps in the current literature and encourage research in the area by

health care professionals and policy makers in future planning and development of Hospice/Palliative care, ACP, AD and EOL-care. This is an area of considerable public health significance and measurements of its impact on the patients, their families, and the overall healthcare system, is of immense importance.

Reasons for US vs. Netherlands Studies

In the Netherlands, the conclusive death and dying debates have created a culture of acceptance, whereas, in the US, there exists a culture where death and dying are stigmatized to the point where it is taboo. The discussion of EOL-care often inflames religious sentiment that holds the sanctity of life paramount. The need for “good death” conversations has never been greater. Governments and providers are in a race against time to assimilate their end-of-life care infrastructure, they may still not be able to meet the even faster pace at which their citizens are reaching an age or condition where they need those services.

Table 1: U. S. Vs. Netherlands

US	Netherlands	Comparison
EOL discussions are much needed but after years of debate, only seven states have approved PAS.	EOL discussions ended. PAS is legal. This makes the experience of the PAD-discussions easy; often result in strong relationship between Doctor-patient.	Impact of PAD discussions on death and dying.
Recent healthcare reform debates in the US—with references in some quarters to a “euthanasia bill”—have forced the issue of end-of-life care into the background.	The subject is neither taboo nor presents extreme cultural discomfort as in the US.	Impact of cultural and sociological factors on discussion of death and dying in Hospice and Palliative care.
Medical spending for the aging population > 65 is rising around 10% and will be >20%.	Medical spending for the aging population > 65 is rising around 10% and will be approximately 26%.	Areas of increase as a %age of the total medical spending budget, by 2035. Source: (Smits, van den Beld, Aartsen, & Schroots, 2014)

US is the most costly medical system in the world.	Netherlands is an exemplary medical system in Europe.	Is there a positive relationship between cost of elderly care and quality of care especially in EOL-care?
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Methods

Search Methodology

This scoping review applies Arksey and O'Malley's (Arksey & O'Malley, 2005) paper on the conduct of scoping reviews, and provides a methodological framework to carry out this type of review. This framework suggests five stages, which are Identification of the research question, identification of studies relevant to the research question; selection of studies to include in the review; charting of information and data within the included studies; and collating, summarizing and reporting results of the review. An optional sixth stage involves consultation with stakeholders to ensure comprehensive inclusion of all relevant material.

Throughout this process, I followed a five-stage methodological framework, eliminating the optional sixth stage. The scoping process requires analytical reinterpretation of the literature in a field where there is a dearth of randomized control trials and represents a way to examine the extent, range and nature of research activity. It identifies gaps in the literature and then makes recommendations for future studies. Levac et al., 2010 identified that adopting a scoping review implies that one can incorporate a range of study designs, empirical studies, literature reviews, exploratory studies, randomized control trials, as well as complex interventions (Levac et al., 2010).

Data sources

A review of the evidence on discussions of death and dying on the elderly ≥ 70 in nursing homes, hospitals, assisted living or private homes, is invaluable in considering recommendations and priorities for future research. In this review of the evidence concerning death discussions with the elderly, data-base searches were guided by the following:

Research question:

- Could discussions on death and dying with the elderly (≥ 70) in Western countries, reduce anxiety surrounding death, and enable a smoother transition towards EOL-care. In particular;
 1. Discussions with F & F
 2. Discussions with HCPs
 3. Joint discussion with HCP, F & F and the patient
 4. Reflection on death and dying by the patient
- What are the harms and benefits in the various discussions and any self-reflection between these groups?

On the basis of the above research questions, the following keywords were selected: For the U.S: death and dying; advanced care planning and end of life care (2013 - 2018). For the Netherlands: death and dying; advanced care planning and end of life care (No limit on years). Keyword searches were performed on PubMed/Medline, once without any country affiliation and the second time with Netherlands as a restrictive parameter. Additionally, individual electronic searches were conducted from the reference lists of important and significant studies. As an example of individual searches, the study "Dying in America: Improving quality and honoring individual preferences near the end of life" (Institute of Medicine (US) Committee on Care at the End of Life; Field MJ, 2014) led to other significant studies. These studies were: 1) Pew Research Center, 2013 – End of Life Medical Treatment 2) Reinhardt et al., 2012 - Home alone: Family caregivers providing complex chronic care.

These studies were individually examined for relevance to this scoping review and for significant data on discussions on death and dying in the U. S.

Table 2. Search Strategy.

Search Details	PubMed Citations	Total Selected
Search #1: “Death and Dying Advanced Care Planning End of Life Care”	144	21
Search #2: “Death and Dying Advanced Care Planning End of Life Care Netherlands”	18	4

Inclusion Criteria

I screened the titles and abstracts of all articles retrieved through the initial database search, and obtained the full texts of all studies that could potentially meet the inclusion criteria. I examined the full text of the articles, in an effort to determine whether the studies met criteria for inclusion in the review. I also checked the reference sections of all included studies for relevant papers.

The first search for years (2013–2018) resulted in n = 144 studies without restricting the country of origin. The next screening of titles and abstracts, using the screening criteria resulted in a count of n = 21 studies. Please see Figure (1).

The second search was for studies in the Netherlands. This search resulted in n=18 studies. The next screening of titles and abstracts, using the screening criteria resulted in a count of n=4 studies. Please see Figure (2).

Screening Criteria

- Regions: US and Netherlands
- Language: English
- Population: Elderly - with age range ≥ 70
- A range of study designs, empirical studies, literature reviews, exploratory studies, randomized control trials, as well as complex interventions.
- Reported on decision-making related to EOL-care, ACP, discussions with family and loved ones, in a nursing home, at home, hospice center, homeless and/or a hospital
- Not related to Cancer treatments, Dementia, Stroke or HIV or other cognitive impairment
- Not Op-ed style or commentary on other studies
- Years (2013 – 2018) For the U. S, and no restriction on dates for the Netherlands

My focus was on papers that explicitly discussed the terms 'death and dying', 'end-of-life care or decision-making', 'advanced care planning', 'nursing homes', 'hospice', 'palliative care', and 'advanced care directives'.

The inclusion criteria for the studies were:

- 1) Older adults, age ≥ 70
- 2) Language; English
- 3) Setting: Nursing homes, assisted living, private homes, hospice care, palliative care, hospital and community care
- 4) Reported original data, for example: RCTs, interviews, and not editorials or comments to articles and studies
- 5) Utilized a communication mechanism between the HCP, F & F, and the patient, where death and dying and EOL - care plans were discussed
- 6) Regions: USA and the Netherlands
- 7) Years (2013 – 2018) For the U. S, and no restriction on dates for the Netherlands

The exclusion criteria were:

- 1) Younger patients
- 2) Cancer patients
- 3) HIV patients
- 4) Dementia patients
- 5) Stroke Patients
- 6) Other cognitive impairments
- 7) Studies that focused only on staff training
- 8) Studies that focused only on Physician Assisted Suicides (PAD)
- 9) Studies that covered multiple regions, for example, US, UK, Australia

Data Extraction.

Studies were selected by title and abstract. Thereafter, the full text was examined and studies that did not satisfy the inclusion criteria were discarded. I did not assess the selected studies for quality as quality review is not part of this study. Characteristics of the studies reviewed were: patient age and setting, measured outcomes, F & Fs' engagement with the patient, HCP and their interaction with the patient, discussions on death and dying by the patient, F & F and by the HCP. Informal discussions over dinner and formal discussions with the clergy were also included. Flow charts of the selected studies are Figure 1 and Figure 2.

Figure. 1 (US - Selected Studies)

Related to discussions of death and dying for the elderly ≥ 70 .

Studies were first selected by abstract and title, resulting in 141 studies. Thereafter the full text was examined for inclusion and eligibility, which resulted in a count of 21 studies.

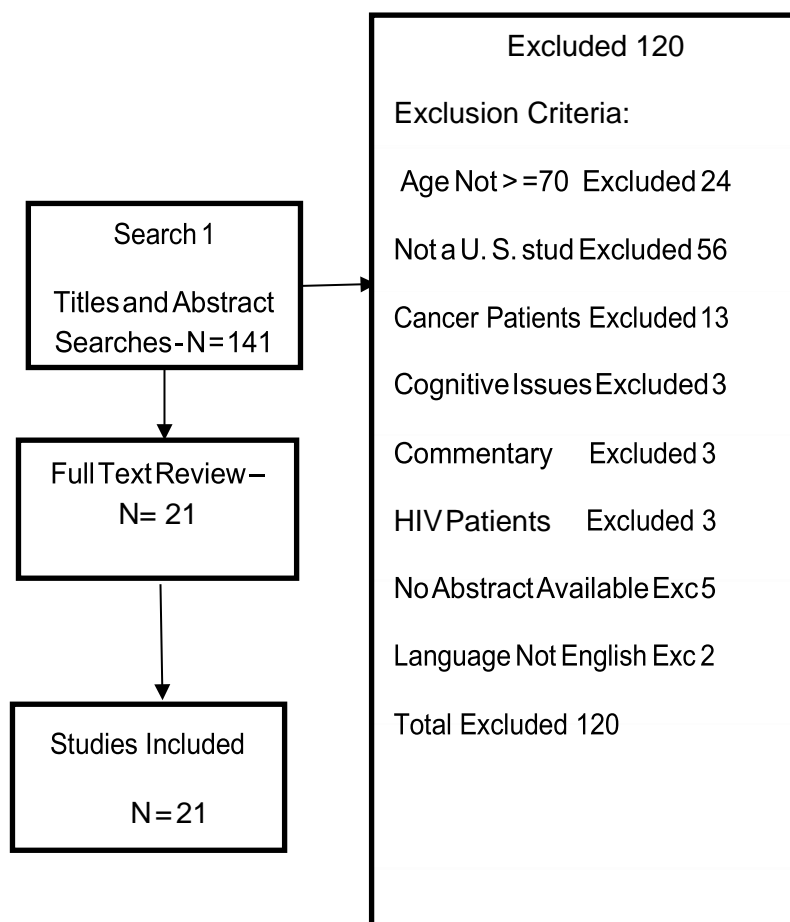


Figure. 2 (Netherlands - Selected Studies)

Related to discussions of death and dying for the elderly ≥ 70

Studies were first selected by abstract and title, resulting in 18 studies. Thereafter, full text was examined for inclusion and eligibility, which resulted in a count of 4 studies.

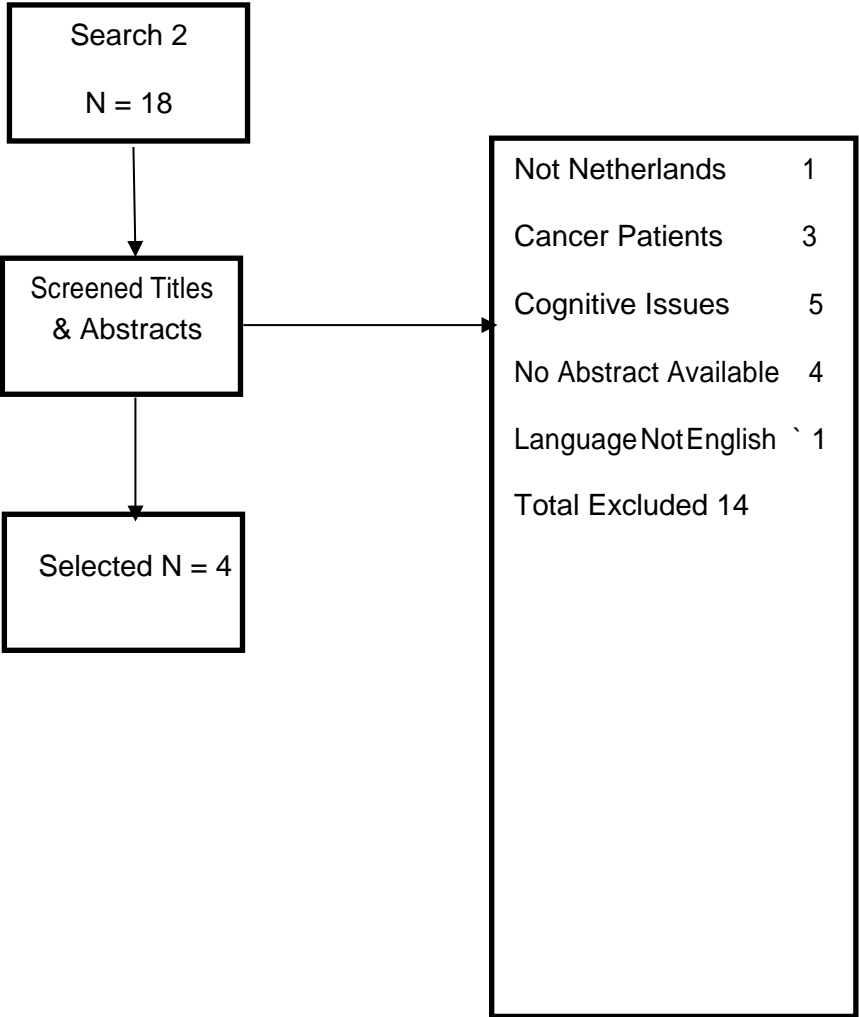


Table 3: PICOS - Criteria for Eligibility

Population	Intervention	Comparison	Outcome	Settings
Elderly- Age: > = 70	Reflection and discussions on death by the patient, ACP, AD, APC, Hospice, EOL-care instructions and private conversations.	One's own preferences, discussions, instructions, and reflections on EOL, AD, and ACP or just over the dinner talk.	What is death, how it happens, is it something to fear, mourn, or be anxious of, or accept as part of life.	Private homes, nursing homes, hospitals, hospice centres, assisted living community care centres.
Friends and Family (F & F)	Family Members' discussions reflections and advice on death- ACP, AD, APC, Hospice, EOL-care instructions.	By F & F	Impact of death on F & F. The bereavement process.	Private homes, nursing homes, hospitals, hospice centres, assisted living community care centres
Health Care Professionals (HCP)	Discussions on death by Doctors, Nurses, Social workers - ACP, AD, APC, Hospice, EOL-care instructions.	By Health Care Professionals (HCP)	Cost and emotional stress of EOL care.	Private homes, nursing homes, hospitals, hospice centres, assisted living community care centres
Combined discussions: F & F, HCP and self.	Discussions on death by Doctors, Nurses, Social workers - ACP, AD, APC, Hospice, EOL-care instructions	By F & F, HCP and self.	Cost and emotional stress of EOL care and the bereavement process.	Private homes, nursing homes, hospitals, hospice centres, assisted living community care centres

Characteristics of the U. S. Reviewed Studies

Out of 21 studies that met the selection criteria, eight (8) described health care practitioner's perspective on death and dying, that is theme 1. Three (3) studies involved F & F, that is, theme 2. Six (6) studies described consultation with a combination of relatives, HCP and self that is theme 3. Only four (4) studies focused on self-reflection and directives for end of life care. Within each theme, the studies reflected a positive, a negative or an ambiguous outcome.

The settings in which the studies took place ranged from nursing homes, assisted living, private homes, EOL-care, homeless in emergency rooms, hospitals, surveys, inpatient palliative care, medical student training and one took place on a reservation of a Native American Tribe, and one was a discussion over dinner in a private home setting. (Please see the charts for U. S Themes 1, 2, 3 and 4).

Study methods also varied:

For U.S. Theme 1 - HCP: Eight (8) studies were identified. One (1) was an observational cohort study with face-to-face interviews. One (1) study was for Medical Student Training. Two (2) studies were literature reviews. One (1) study was a card game that involved action-reflection learning method with students, supervisors and pastors. One (1) study was a cross-sectional online survey. One (1) was a retrospective longitudinal study that used a chronic condition database, and was also supported by the centers for Medicare and Medicaid.

For U.S. Theme 2 - Family and Friends: A total of three (3) studies were identified. One (1) study was a research paper with philosophical overtones, for example, the author concluded: "We all die. Yet, to many of us, the details of dying and death are a mystery. It is an abstraction we would rather not think about. Contemplating our own death and doing the necessary preparatory work is a rarity in modern America." The research did not comment on the patients' wellbeing because of the said contemplation. One (1) was a mixed method study of multi-specialty Doctors, caring for ethnically different patients. One (1) was a mixed method study quantifying the results of public comments made on regulations.gov.

For U.S. Theme 3 - A combination of F & F, HCP and Self: Six (6) studies were identified. One (1) study was a systematic review of older adults, age range: 72 -88 years. Three (3)

studies were face-to-face interviews with physicians, nurses, social workers, supervisors, chaplains and HCP teams. One (1) was a cross-sectional study, which used a survey method. One (1) study was in-depth in-person interviews with hospice patients.

For U.S. Theme 4 - Self-reflection: Four (4) studies were identified. One (1) study was face-to-face interviews with tribal elders on a Native American Reservation. One (1) was a mixed method study with literature-reviews, meetings, site visits, online testimony, debates and discussion. Two (2) studies were reflective exploratory literature-reviews.

Characteristics of the Netherlands Reviewed Studies

Out of the four (4) studies that met the selection criteria, two (2) were literature reviews. One (1) was a survey method for delegates, attending an international conference on EOL care practices. One (1) was a longitudinal aging study, which employed after death interviews with proxies.

The settings in which the studies took place ranged from interviews in hospitals, surveys sent to an international conference of health care practitioners and academic settings for literature-reviews. (Please see the charts for the Netherlands - Themes 1, 2, 3 and 4).

For Netherlands Theme 1 - HCP: Three (3) studies were identified. Two (2) were qualitative and exploratory studies with interviews with physicians.

For Netherlands Theme 2 - F & F: There was no study found.

For Netherlands Theme 3 - A combination of F & F, HCP and Self: One (1) study was identified which was a longitudinal aging study that employed after death interviews with proxies.

For Netherlands Theme 4 - Self-reflection: One (1) study was identified which was a literature review of professional studies.

United States - Themes

Theme 1 HCP				
Author & Date of Publication	Title	Settings for Theme 1: HCP	Kind Of Study	Outcome
(Young, Redfield, Strand, & Dunlay, 2017)	End of Life discussions in patients with heart failure	Patients hospitalized with heart failure conditions	Observational cohort study that included the administration of face-to-face questionnaires	Did not recall discussing EOL with their physicians (N= Negative)
(Schulz et al., 2017)	Beyond Simple Planning: Existential Dimensions of Conversations With Patients at Risk of Dying From Heart Failure	Medical Student Training and Clerkship	Student Training	Research points to cultural and historical influences that shape our attitudes towards death. More engagement (P = Positive)
(Hubbell, 2017)	Advance care planning with individuals experiencing homelessness	Public health practice Public Hospitals	Literature review & recommendations for public health practice	Homeless remain unidentified and fearful of death. Study suggested that Public health practitioners should facilitate advance care planning for the homeless. (N= Negative)
(Van Scoy et al., 2016)	Exploring the Topics Discussed During a Conversation Card Game About Death and Dying: A Content Analysis	Inpatient care. Hospitals, nursing homes, assisted living.	“Action–reflection” learning method in which students and their certified supervisors reflect upon the student’s pastoral encounters. A card game: My Gift of Grace.	<i>My Gift of Grace</i> can stimulate topics of discussion that are important to the ACP process. It appeared to be an effective means for conveying and organizing deep emotions. (P = Positive)
(Peres, 2016)	A Time and Place: The Role of Social Workers in	Palliative Care. Hospitals, ICUs, assisted living, nursing homes	Literature review of IOM’s 2014 Report on EOL care.	The subject of dying may be less taboo now, but the process is, in

	Improving End-of-Life Care	and sometimes homes.		the end, not much easier, especially for those people whose lives end in hospitals, ICUs, and nursing homes. (A= Ambiguous)
(Periyakoil Vyjeyanthi S., 2016)	Multi-Ethnic Attitudes Toward Physician-Assisted Death in California and Hawaii	Hospitals, nursing homes.	A cross-sectional online survey of 1095 participants (a 75.8% survey completion rate) from California and 819 from Hawaii (a 78.4% survey completion rate).	In the ethnically diverse states of California and Hawaii, faith/religion/spirituality and age are major influencers of attitudes toward PAD and not ethnicity and gender. (A=Ambiguous)
(Periyakoil, Neri, & Kraemer, 2015)	No Easy Talk: : Doctors Reported Barriers to Conducting Effective End-of-Life Conversations with Diverse Patients	Doctors caring for patients in two large academic medical centres at the end of the training.	A Mixed Methods Study	Doctors Reported Barriers to Conducting Effective End-of-Life Conversations with Diverse Patients. (N= Negative)
(Temkin-Greener, Zheng, Xing, & Mukamel, 2013)	Site of Death among Nursing Home Residents in the United States: Changing Patterns, 2003–2007	Nursing Home residents through out the US.	This was a retrospective, longitudinal study using nation-wide administrative data from the Chronic Condition Data Warehouse (CCW), established and supported by the Centres for Medicare and Medicaid	A more effective provision of on-site medical services to this very vulnerable population of nursing home residents is likely to improve the quality of care and life and perhaps alsoto stem the growth of Medicare spending (A = Ambiguous)

Theme 2 F & F				
Author & Date of Publication	Title	Settings for Theme 2: F & F	Kind Of Study	Outcome
(Prince-Paul & DiFranco, 2017)	Upstreaming and Normalizing Advance Care Planning Conversations—A Public Health Approach	Recommended many settings: Churches, synagogues, temples, and other places of worship (and their leaders) Book Clubs Senior Centres	Maryjo Prince-Paul conceived of and designed the article, collected data, and wrote the paper.	“We all die. And yet, to many of us, the details of dying and death are a mystery. It is an abstraction we would rather not think about. Contemplating our own death and doing the necessary preparatory work is a rarity in modern America.” (A)
(Bhavsar, Constand, Harker, & Taylor, 2017)	Death of outrage over talking about dying	Public comments made on regulations.gov were reviewed for relevance to ACP policy and their perceived position on ACP (ie, positive, negative and neutral). Descriptive statistics were used to quantify the results.	Mixed method study: Descriptive statistics were used to quantify the results.	If discussions between physicians, patients and their family were reimbursed by Medicare, then there is a potential for a large impact on the quality of life of persons near death. (A)
(Periyakoil et al., 2015)	No Easy Talk: A Mixed Methods Study of Doctor Reported Barriers to Conducting Effective End-of-Life Conversations with Diverse Patients	Large academic medical centres at the end of the life training; data were collected from 2010 to 2012	Mixed-methods study of multi-specialty doctors caring for diverse, seriously ill patients in two large academic medical centres at the end of the training;	Doctors report struggles with conducting effective EOL conversations with all patients and especially with those whose ethnicity is different from their own. (N)

Theme 3 F & F, HCP and Self				
Author & Date of Publication	Title	Settings for Theme 3: F&F -HCP&Self	Kind Of Study	Outcome
(Weathers et al., 2016)	Advance care planning: A systematic review of randomised controlled trials conducted with older adults	A systematic review of randomised controlled trials conducted with older adults	A systematic Review of older adults – age range: 72-88 years.	ACP interventions in nursing homes and long-term care settings can reduce unnecessary, and sometimes traumatic, hospitalizations of frail older adults. Only a minority get the opportunity to discuss EOL care. (A)
(Frances et al., 2016)	Exploring Health Care Providers' Views About Initiating End-of-Life Care Communication	Conducted at 2 medical centres in Los Angeles, California, and is a part of a larger study on participants' experiences with barriers that limit EOL care Communications	Face to face interviews with Physicians, nurses, social workers, and chaplains with at least some clinical experience working with seriously ill patients.	Numerous factors impede effective and timely end-of-life (EOL) care communication, and suggested a joint effort by HCP, Chaplains and social workers to communicate with patients and families about EOL care. (A)
(Waldrop, Clemency, Lindstrom, & Cordes, 2015)	We Are Strangers Walking Into Their Life-Changing Event: How Prehospital Providers Manage Emergency Calls at the End of Life care.	Emergency Care in Hospitals – after 911 calls	In-depth and in-person interviews with 43 prehospital providers. Qualitative data analysis involved systematic and axial coding to identify and describe	Prehospital providers must use skills in managing crises and conflict. Providers identified the need for additional training and preparation for dealing with the intensity of family reactions to a loved one's death. (P)

			emergent themes.	
(Kwon, Kolomer, & Alper, 2014)	The Attitudes of Social Work Students Toward End-of-Life Care Planning	Structured surveys completed by 102 social work students (N = 102) at a school of social work in the southeast.	A cross sectional research study	Suggested a need for recognition of personal preferences in end-of-life care, higher levels of comfort when discussing death, while maintaining the ethical principle of the client's right to self-determination in end-of-life planning. (P)
(Kwak, Ko, & Kramer, 2014)	Facilitating advance care planning with ethnically diverse groups of frail, low-income elders in the USA: perspectives of care managers on challenges and recommendations	Interviews with Supervisors and care managers of health care management teams	Part of a larger descriptive, case study. Data was analyzed with qualitative thematic analysis method.	Participants identified four main challenges: 1) Death and dying are taboo discussions 2) The dying process is beyond human control 3) Family and others hold decision-making responsibility 4) Planning for death and dying is a foreign concept. (N)
(Waldrop & Meeker, 2014)	Final decisions: How hospice enrollment prompts meaningful choices about life closure	Post hospice enrolment.	An exploratory, descriptive, cross-sectional design was employed using qualitative methods. In-depth in-person interviews with hospice patients (n = 35).	Patients, with support of family members, may be able to create a satisfying and meaningful final phase of life. Benefits accrue to both patient and family during the dying phase, and continue for family members. (P)

Theme 4 Self Reflection				
Author & Date of Publication	Title	Settings for Theme 4: Self Reflection	Kind Of Study	Outcome
(Dennis & Washington, 2018)	Just Let Me Go: End-of-Life Planning Among Ojibwe Elders	Great Lake Reservations: About 20 tribal elders living on a reservation participated in semi-structured, face-to-face interviews	Face-to-Face interviews to explore the tension between Western approaches to end-of-life care, including its emphasis on ACP, and the expectations and wishes of one community of AI elders	Many were readily able to describe their wishes for a peaceful death and had already developed funeral and burial or cremation plans. Many Indigenous people view death as a natural part of life (Hampton et al., 2010). This view is at odds with more mainstream U.S. perspectives. (P)
(Pizzo, 2016)	Thoughts about Dying in America: Enhancing the impact of one's life journey and legacy by also planning for the end of life	Comprehensive report that addressed the state of health care in the United States for individuals facing a serious illness or medical condition that would likely result in death	Extensive literature reviews, six meetings (including three public meetings), site visits, commissioned papers, and a review of online testimony together with a lot of debate and discussion by the committee members	Highlighted the importance of changing the policy and payment system issues that impede the delivery of high-quality EOL- care where broad and deep public discourse about <i>Dying in America</i> take place.(A)
(Black & Csikai, 2015)	Dying in the Age of Choice	A Reflective Exploratory Study	Literature Review	Study recommended reflective considerations about one's core values and

				beliefs as well as the legal, ethical, and medical knowledge about dying options. (P)
(Gellie, Mills, Levinson, Stephenson, & Flynn, 2015)	Death: A foe to be conquered? Questioning the paradigm	A Reflective Exploratory Study	Literature Review	Death is a given in life, and yet death is often thought of today as the 'loss of the battle' against illness, as if annihilated by death, instead of embracing it and recognizing the time for true rest. (P)

Netherlands - Themes

Theme 1 HCP				
Author & Date of Publication	Title	Settings for Theme 1: HCP	Kind Of Study	Outcome
(Voorhees, Rietjens, van der Heide, & Drickamer, 2014)	Discussing Physician-Assisted Dying: Physicians' Experiences in the United States and the Netherlands.	Interviews with Physicians in three different and distinct regions: 1) US. North East - (PAS) (not legal) 2) US. State of Oregon (PAS) (legal) and 3) Netherlands (PAS) (legal)	Qualitative & Exploratory Study.	It appeared that legality made it easier to discuss EOL- care. In both Oregon and the Netherlands, the Physicians and the patients felt that they had some rewarding discussions surrounding end of life care. (P)
(Latour, Fulbrook, & Albarran, 2009)	EfCCNa survey: European intensive care nurses' attitudes and beliefs towards end-of-life care	Delegates (n=419) attending an international critical care nursing conference were invited to complete a self-administered questionnaire about their involvement with EOL care practices	A survey method	Most nurses felt that the discussion about EOL-care occurred too late. The ultimate aim should always be to provide the best quality of care during the EOL phase, which results in the dignified and pain-free death of the patient. The impact of these discussions was not studied. (A)

Theme 2 F & F				
Author & Date of Publication	Title	Settings for Theme 2: F & F	Kind Of Study	Outcome
No Studyfound				

Theme 3 F & F HCP and Self				
Author & Date of Publication	Title	Settings for Theme 3: Discussions with HCP, F & F and self-reflection.	Kind Of Study	Outcome
(Klinkenberg, Willems, Onwuteaka-Philipsen, Deeg, & vander Wal, 2004)	Preferences in end-of-life care of older persons: after-death interviews with proxy respondents	This population-based study employed after-death interviews with proxies describes older persons' preferences regarding medical care at the end of life. Location: Netherlands.	Longitudinal Aging Study Amsterdam.	The study found that encouraging the elderly to express their preferences to their loved ones and physicians was rather important. The study suggested that healthcare providers can help to increase the patients' awareness of the importance of a timely discussion. (P)
Theme 4 Self Reflection				
Author & Date of Publication	Title	Settings for Theme 4: Self-Reflection	Kind Of Study	Outcome
(Davis, Genel, Howe, Iii, & et al., 1996)	Good Care of the Dying Patient	A third in a series of reports on PAS – delivered to the American Medical Association.	A literature review of professional studies	One in five subjects whose death resulted from voluntary PAS listed a weariness with life as one of the reasons for choosing death. The study did

				not report on discussions with friends, family or HCP. When a patient chooses PAS, it indicates some level of reflection. (P)
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In Figure 3, studies are broken down by themes with assigned categories of P, N and A. P = Positive attitude towards discussing death and dying, N = Negative attitude towards discussing death and dying and A = Ambiguous attitude.

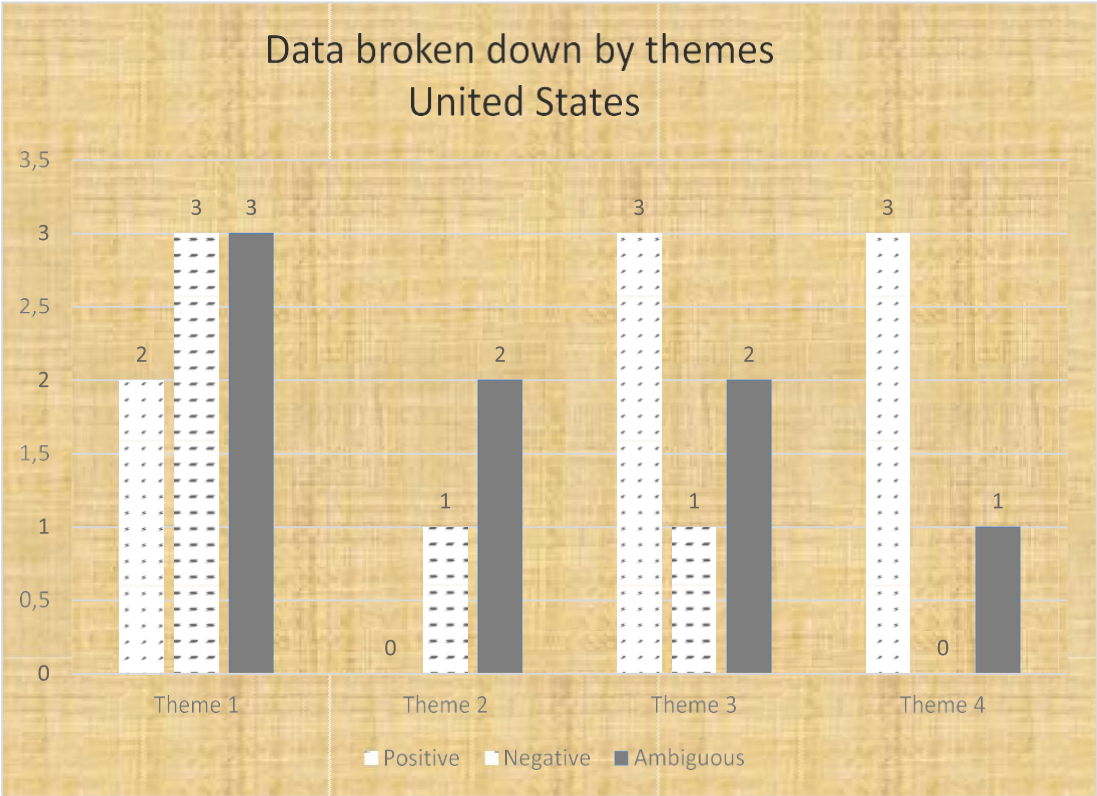
Theme 1: Analysis of Discussions with HCP - P = 2, N = 3, A = 3.

Theme 2: Analysis of Discussions with Family and Friends – P = 0, N = 1, A = 2.

Theme 3: Analysis of Discussions with all – families, friends & health care staff
P = 3, N = 1, A = 2.

Theme 4: Analysis of Self Reflection – P = 3, N = 0, A = 1.

Figure 3: Shows Data for United States by Themes



In Figure 4 studies broken down by themes with assigned categories of P, N and A. P = Positive attitude towards discussing death and dying, N = Negative attitude towards discussing death and dying and A = Ambiguous attitude.

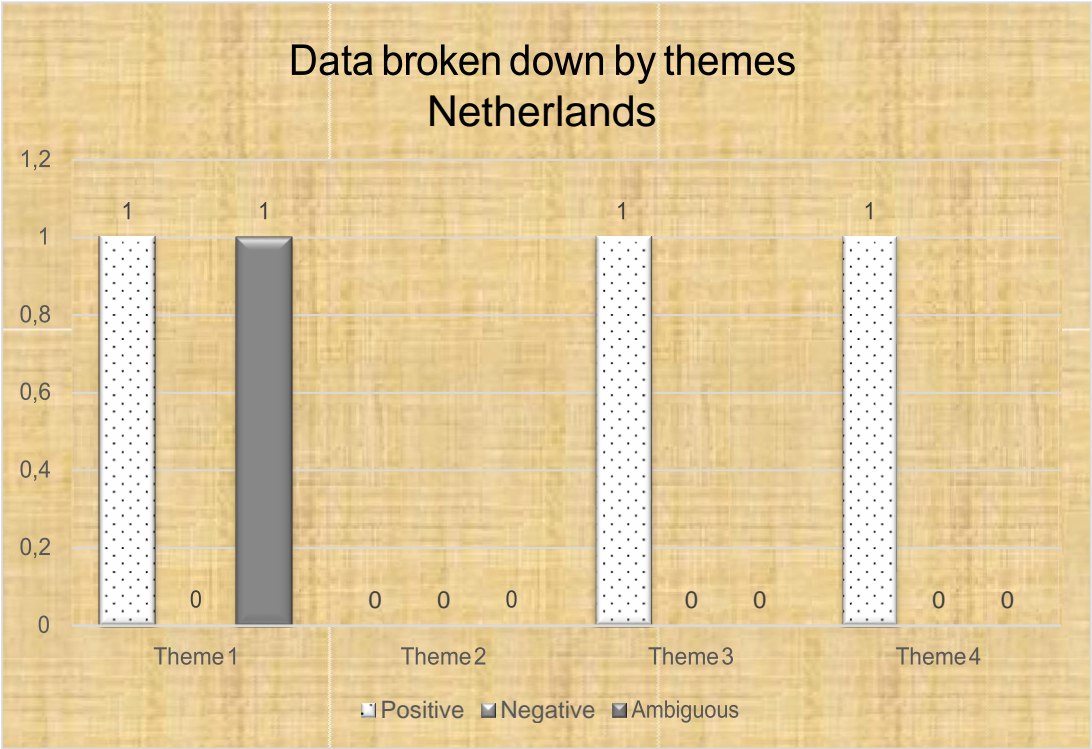
Theme 1: Analysis of Discussions with HCP - P = 1, N = 0, A = 1.

Theme 2: Analysis of Discussions with Family and Friends – No study found.

Theme 3: Analysis of Discussions with all – families, friends & health care staff
P = 1, N = 0, A = 0.

Theme 4: Analysis of Self Reflection – P = 1, N = 0, A = 0.

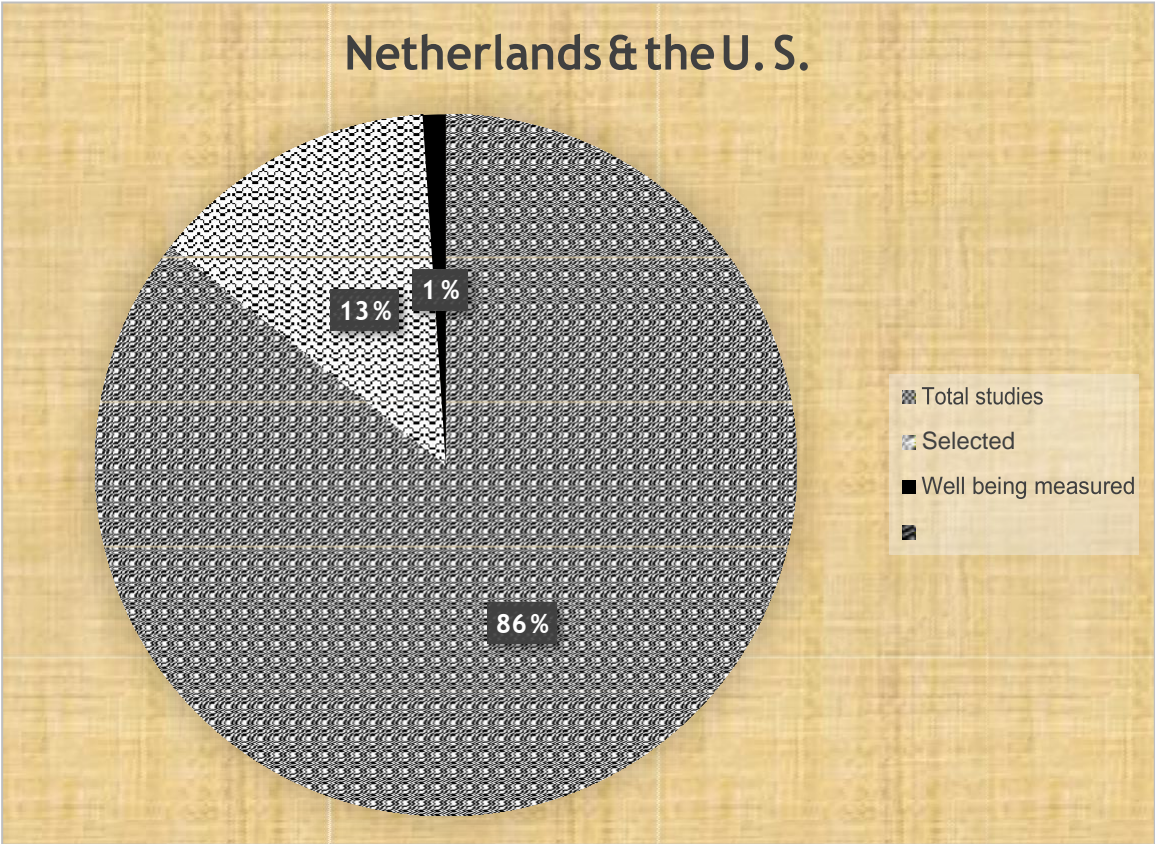
Figure 4: Shows Data for Netherlands by Themes



In Figure 5 studies broken down by their measurement of emotional and physical well-being of the elderly.

Total Reviewed 162; Total Selected 25; Total studies that measured emotional and physical well-being as an outcome of discussing death and dying = 2.

Figure 5: Shows Data for Netherlands & the U.S.



Analysis of Studies Related to the U. S

Theme 1: Analysis of Discussions with HCP

In studies of EOL-care where Doctors needed to discuss death and dying with the patients, research found: 'Although guidelines call on clinicians to conduct regular conversations about advance care planning and end-of-life (EOL) preferences with patients with heart failure (HF), research suggests that physicians often avoid these discussions.' Majority of the patients hospitalized with heart failure conditions did not recall discussing EOL with their physicians (Young et al., 2017).

The research study of Schulz et al., noted that despite communication guides to improve decision making with patients reaching the end of their lives, the conversations remained challenging. Of particular concern were the existential dimensions to these conversations, which included evasive manoeuvres, powerful emotions and the phenomena of death without dying (Schulz et al., 2017).

Another study concluded that the homeless have increased morbidity and mortality risks, yet lack opportunities to communicate EOL preferences. The concerns of the homeless included fears of dying alone, dying unnoticed, or remaining unidentified after death. The homeless had a range of views of health care providers, some trusted them, while others perceived them as overcontrolling. The study suggested that Public health practitioners should facilitate ACP for people who are homeless by providing opportunities for education and discussion on care options and advance directives (Hubbell, 2017).

A mixed methods study (Periyakoil et al., 2015) was undertaken to empirically identify barriers faced by doctors (if any) in conducting effective EOL conversations with diverse patients and to determine if the doctors' age, gender, ethnicity and medical sub-specialty influenced the barriers. The study found that most patients wish to discuss EOL issues, but the doctors are reluctant to conduct end-of-life conversations.

A study funded in part by the Social Science Research Institute at Penn State University, the Milton S. Hershey Penn State College of Medicine, explored the impact of a card game for

discussions on death and dying. The authors concluded that their study provided encouraging evidence that the conversation game *My Gift of Grace* can stimulate topics of discussion that are important to the ACP process, and it can do so without a facilitator. The card game facilitated ACP discussions with clinicians whose time constraints often preclude the storytelling many patients use to illustrate their wishes for end-of-life care. It appeared to be an effective means for conveying and organizing deep emotions, constructing one's identity, and even serving as a therapeutic experience for addressing bereavement issues (Van Scoy et al., 2016). The study suggested, "When communication is suboptimal, patients and families experience increased anxiety, depression, and dissatisfaction with care."

A study that examined the recommendations of the IOM's 2014 report, also promoted the idea of discussions on end of life care with social workers. The study cited that the subject of dying may be less taboo than it was 20 years ago, but the process is, in the end, not much easier, especially for those people whose lives end in hospitals, ICUs, and nursing homes (Peres, 2016).

A mixed method study of multi-specialty doctors caring for diverse, seriously ill patients reported barriers in conducting EOL care discussion. Out of 996 Doctors, only one (1%) reported no-barriers. Struggles were greater with those whose ethnicity was different from their own. The study cited research (Zhang et al., 2009) that patients who have EOL conversations with their physicians are less likely to experience physical distress (Periyakoil et al., 2015; Periyakoil Vyjeyanthi S., 2016).

Another retrospective, longitudinal study using nation-wide administrative data from the Chronic Condition Data Warehouse (CCW), established and supported by the Centers for Medicare and Medicaid Services (CMS) examined EOL-care for the elderly in nursing homes across the US. The objectives of this study were to: 1) investigate the longitudinal trends and geographic variations in place of death among decedent nursing home residents across the US; and 2) examine the association between hospice use, presence of advance directives and the probability of nursing home residents dying in hospitals. The study found that for the most part US-based studies on the site of death, and specifically on EOL hospital transfers of nursing home residents, have been largely absent. Despite the intensive

longitudinal study on dying elderly patients, contemplation on death or discussions with the participants remained a remote subject. The authors concluded that there was a need to rethink how best to provide care to EOL nursing home residents. The study emphasized medical care, for example: “A more effective provision of on-site medical services to this very vulnerable population of nursing home residents is likely to improve the quality of care and life and perhaps also to stem the growth of Medicare spending.” (Temkin-Greener et al., 2013)

Theme 2: Analysis of Discussions with F & F

The study done by Prince-Paul and DiFranco 2017 was a comprehensive study on society’s attitudes towards death and dying, and the authors noted that sixty (60) percent of people say making sure their family is not burdened by tough decisions is extremely important, yet 56% of them have not held a conversation about death and dying. In most issues involving end-of-life care, the suffering could be avoided, or at least mitigated, by some education on dying and death and informed conversations about it.

Regarding family’s wishes and patient’s wishes regarding death and dying, the study added, “We all die. And yet, to many of us, the details of dying and death are a mystery. It is an abstraction we would rather not think about. Contemplating our own death and doing the necessary preparatory work is a rarity in modern America.”

Vyjeyanthi Periyakoil 2015 and her team spent years conducting interviews and focus groups in multiple languages with people in the community and talking to numerous patients and their families about the challenges of having and preparing for discussions about the last phase of life. Their research has shown that most Americans find it extremely difficult to discuss this important topic with both their family members and friends, as well as their health care providers. Citing other studies, the authors noted, “a sense of meaning and purpose in life, supported by spirituality is related to lower death anxiety, death avoidance, and depression, and an overall sense of greater subjective well-being.” The researchers did not measure the impact of such discussions on their subjects.

Another study on ACP stated that if discussions between physicians, patients and their family were reimbursed by Medicare, then there is a potential for a large impact on the quality of life of persons near death, which can greatly impact public health and the comfort in dealing with our ultimate demise (Bhavsar et al., 2017).

The study done on end-of-life care by Institute of Medicine, Committee on Care at the End of Life, 2014, cited other studies, for example: Studies identified improvements in symptoms of depression, distress, quality of life and satisfaction with care and communication. Family members reported emotional and spiritual growth and were more satisfied with care feeling that the needs of their relatives were addressed appropriately (Eychmüller, 2016).

Theme 3: Analysis of Discussions with F & F, HCP and Self

A Randomized Controlled Trial (RCT) of 3646 older adults, age range (72–88) demonstrated the feasibility of conducting RCT trials, and concluded that overall, ACP may have benefits for the patients, family, the staff, and the health work force. Furthermore, it cited other studies that suggest ACP interventions in nursing homes and long-term care settings can reduce unnecessary, and sometimes traumatic, hospitalizations of frail older adults. It concluded that the majority of older adults would like an opportunity to discuss their EOL care, only a minority get that opportunity (Weathers et al., 2016).

A study found that numerous factors impede effective and timely end-of-life (EOL) care communication, and suggested a joint effort by HCP, Chaplains and social workers to communicate with patients and families, defined by ethnicity and cultural affiliations, about EOL care (Nedjat-Haiem Frances R., 2016).

A cross sectional research study conducted a survey of 102 social workers in an effort to measure their comfort level in discussing death and dying issues with individuals in end of life care. The study emphasized that identifying the social workers' beliefs, perceptions and attitudes towards death is an important first step in providing sensitive end of life care. The study did not measure the impact of discussions around death and dying on the elderly (Kwon et al., 2014).

In an exploratory, and cross sectional study with in-depth interviews to explore and describe prehospital providers' assessment and management of end-of-life emergency calls, the authors stated, "Pre-hospital providers are confronted with many difficulties during end-of-life emergency calls. They have to assess the patient's situation, handle family stress, and manage the emotionality of a call. Prehospital providers must use skills in managing crises and conflict that are often outside the parameters of their jobs and the providers identified the need for additional training and preparation for dealing with the intensity of family reactions to a loved one's death." (Waldrop et al., 2015)

A research study with seven in-depth interviews and two focus groups was conducted. The participants were supervisors and care managers of health care management teams. This project was part of a larger descriptive, case study. Data was analyzed with qualitative thematic analysis method. Participants identified four main challenges: 1) Death and dying are taboo discussions 2) The dying process is beyond human control 3) Family and others hold decision-making responsibility 4) Planning for death and dying is a foreign concept (Kwak et al., 2014).

An exploratory, descriptive, cross sectional study examined the impact of transitioning from cure based treatment to care based treatment, especially hospice and palliative care. In both the hospice and palliative care, there is open recognition that the dying phase is a process and a distinct stage of the human life cycle, which is comparable to infancy, childhood, adolescence, adulthood, and late life (Waldrop & Meeker, 2014). The positive note in the study was that the recognition of the dying process "involved opportunities for reciprocal growth and the opportunity to finish a relationship through the consideration of important and meaningful decisions and the completion of salient tasks" (Witt-Sherman, 1998). Furthermore, discussions of life completion may improve important health outcomes for people with advanced serious illnesses and ease caregivers in bereavement (Dumont et al., 2008).

Theme 4: Analysis of Self Reflection

Of the 21 studies (in the U. S.) and four (4) in the Netherlands that were examined, only one described in detail the transformative nature of discussing end of life care with everyone older than age 18 years, encouraging them to have an advance care planning conversation and complete a health care directive. Known as Honoring Choices Minnesota (HCM), the world's largest nongovernmental, voluntary community-centered initiative, HCM is changing the culture around speaking of death and dying, one conversation at a time. "Consumers are not the only ones urged to begin this family conversation. Physicians, nurses, social workers, chaplains, and other health care providers are now being carefully trained to initiate this conversation and to complete their own directives." (Greene, 2013).

The uniqueness of this Minnesota-based initiative lies in its adaptation of an ACP model known as the Gundersen Health System's physician-led, not-for-profit health care system. Among other things, the Minnesota-based initiative has a collective website, www.honoringchoices.org, which houses more than 700-videotaped conversations on end-of-life care decision making. The outcome of these efforts has been the development of an innovative virtual community of individuals from diverse backgrounds and histories who share common ground through poignant experiences about EOL-care and decision-making.

In a study of 20 tribal elders living on a Great Lakes reservation, the elders participated in semi-structured, face-to-face interviews. The interviews were analysed using an inductive thematic analysis approach. Not only were they open to discussing the end of life care, but described their wishes for a peaceful death and had already developed funeral and burial or cremation plans (Dennis & Washington, 2018). This study pointed to other studies on tribal elders, for example: Among the Ojibwe tribe of American Indians (AI), life and death are traditionally viewed as different points on a continuum of spiritual existence (Palmer & Palmer, 2006). As death approaches, access to the spiritual world increases, and perceptions or reports of contact between dying individuals and their deceased ancestors are not uncommon, often bringing about a sense of peace within the dying person (Palmer & Palmer, 2006).

The Institute of Medicine (IOM) 2017 study concluded that an important component of quality care is that patients and clinicians engage in end of life care discussions early in life and in the same manner as they go through life for a driver's license, get married or other such stages (Pizzo, 2016). It is unclear whether the study encouraged open discussions on death and dying with physicians and care providers, and even with society as a whole, essentially, there was no attempt to encourage self-reflection.

Dying in an age of choice (Black & Csikai, 2015): A reflective study examined the setbacks experienced by the elderly in end-of-life care. This study recommended reflective considerations about one's core values and beliefs as well as the legal, ethical, and medical knowledge about dying options. Despite the improvements in ACP and AD, the dying still face limited attention to their pain and suffering (Institute of Medicine (US) Committee on Care at the End of Life; Field MJ, 2014).

Another serious and reflective study on death and society's fear of death is, "Death: a foe to be conquered? Questioning the paradigm." There are few certainties in life, and death is one of them, write the authors, and yet death is often thought of today as the 'loss of the battle' against illness, as if annihilated by death, instead of embracing it and recognizing the time for true rest. In earlier societies, death was the natural, meaningful, end to life. The 'war against disease' has entrenched itself in medical philosophy (Gellie et al., 2015). Excluding accidents, we now experience death as a battle lost to disease and old age.

Analysis of Studies Related to the Netherlands

Theme 1: Analysis of Discussions with HCP

A qualitative study: "Discussing Physician-Assisted Dying: Physicians' Experiences in the United States and the Netherlands" conducted interviews with Physicians in three different and distinct regions, which were: 1) US. North East PAS (not legal) 2) US. State of Oregon PAS (legal) and 3) Netherlands PAS (legal). It appeared that legality made it easier to discuss EOL-care.

In the Northeast where PAS was not legal, Physicians said they were afraid to discuss death and PAS because of the prohibition and would not place their license and freedom on the line, however, the study also found that if the Physician expressed openness towards discussing death, the patients were comfortable with the subject as well. In both Oregon and the Netherlands, the Physicians and the patients felt that they had some rewarding discussions surrounding end of life care. (Voorhees et al., 2014)

Another European study (Latour et al., 2009) identified the beliefs and attitudes of European critical care nurses towards EOL care. Of the 419 questionnaires distributed, a total of 164 (39.1%) were returned completed. Of the 160 respondents who stated their country of practice, the majority were from the Netherlands ($n=43$, 26.9%), Italy ($n=32$, 20.0%), Norway ($n=17$, 10.6%), Sweden ($n=11$, 6.9%) and UK ($n=10$, 6.3%).

The European EOL recommendations presented by (Carlet et al., 2004) provide a clear vision that the health care team should build a close relationship with the patient and family to gain a deeper understanding of the patient's and family's beliefs, rituals and spiritual needs. Most nurses felt that the discussion about EOL care occurred too late, and this may be one of the reasons that nurses felt the need to initiate discussions with physicians. The ultimate aim should always be to provide the best quality of care during the EOL phase, which results in the dignified and pain-free death of the patient and addresses the well-being of the whole family (Latour et al., 2009). The impact of these discussions was not studied.

Theme 2: Analysis of Discussions with Family and Friends

No study found.

Theme 3: Discussions with all - families, friends and the health care staff

A European study (Klinkenberg et al., 2004) researched the preferences of the deceased older adults, with regard to their view on death and dying. In this study, the majority of the deceased had not left an AD and neither expressed preferences for EOL-care. Formulation of ADs may help professionals who work with older people to understand these preferences better, especially in the case of non-cancer patients and those with low perceived self-efficacy.

The Klinkenberg study found that encouraging the elderly to express their preferences to their loved ones and physicians was rather important. The study suggested that the HCP could help to increase the patients' awareness of the importance of a timely discussion. This study added that in the absence of ADs on the majority of dying older persons, the role of the family is also important in this respect. Although relatives do not always know what patients would have decided for themselves if possible, it is assumed that relatives and physicians act in the best interest of the patient. In general, this implies adequate pain and symptom management, and avoiding inappropriate prolongation of dying.

Theme 4: Analysis of Self Reflection

A multi-nation study (Davis et al., 1996) "Good Care of the Dying Patient", reported on the status of those seeking death through PAS. According to this study, one in five subjects whose death resulted from voluntary PAS listed a weariness with life as one of the reasons for choosing death. The study did not report on discussions with friends, family or HCP, but when a patient chooses PAS, it indicates some level of reflection.

Outcome - Summary

My review generated four main themes, with a focus on deliberations on death and dying. In searching whether these deliberations added to the quality of care, eased anxiety and depression, I looked for studies that reported on the outcome of the discussions on death and dying with the patients, with their families, with the HCP and self-reflection. I further subdivided the four themes into “P”, “N” and “A”. P = Positive reflection on death and dying, for example, “with a knowing that death is inevitable and a time for true rest.” (Gellie et al., 2015). N = Negative attitudes towards death, fear, anxiety, and/or a focus on medical interventions, cure at any costs, infinite extension of life, and expansion of the payment system to cover more treatments where possible. A = Ambiguous, that is, there was not enough evidence to support a positive or negative outcome, for example, “Most nurses felt that the discussion about EOL care occurred too late. The ultimate aim should always be to provide the best quality of care during the EOL phase” (Latour et al., 2009).

Of the twenty one (21) selected studies (in the U.S.) most were exploratory, retrospective or were analysis of patients’ records, review of ACP, assessment of EOL-care instructions, and review of ADs. Several studies included face-to-face interviews between the patient and the HCP, between the patient, patient’s family and friends, between the HCP and F&F. Depending on the spiritual and religious leaning of the patients, there were discussions with the clergy, or a revered person within one’s faith. One study where the elderly had a very creative and pleasant anticipation of death was a study of the tribal elders, living on a reservation. (Dennis & Washington, 2018). Another fearless, pleasant and creative death discussion was one that involved discussions of death and dying over dinner (Van Scoy et al., 2016).

Schulz et al. 2017, pointed to the historical and cultural perspectives that shape our attitudes and emotions to the subject of death and dying.

The settings of the various studies varied, meaning the studies and discussions took place in nursing homes, private homes, hospitals, hospice centres, emergency wards, medical training forums, a Native American reservation and community care centres or assisted living. Challenges in discussing death while the patient was still healthy appeared to be a paramount theme and a great setback for the patient and those responsible for the patient.

Social, cultural and religious perspectives played a significant role. Fear of dying, leaving the loved ones behind, being an un-necessary burden for those caring for the patient, along with certain taboos on broaching the subject, caused great anxiety and unease among the elderly.

In general, majority of the studies recommended more effective medical care, more training for the medical staff, more funding for EOL-care services through Medicare or private practitioners, as a method for easing distressful symptoms for those in nursing homes or for the elderly in general. ((Bhavsar et al., 2017) (Kwon et al., 2014) (Frances et al., 2016) (Pizzo, 2016) (Waldrop et al., 2015) (Weathers et al., 2016)).

Of the four (4) selected studies (in the Netherlands), two (2) were qualitative and exploratory studies, with face-to-face interviews with the Physicians, and HCP. One (1) was a survey of delegates attending a conference on EOL-care. One (1) was a longitudinal study which employed after-death interviews with proxies, and one was a lit-review of professional studies. Of the five (5) studies, four (4) demonstrated immense promise from discussions surrounding death and dying, for example, "In both Oregon and the Netherlands, the Physicians and the patients felt that they had some rewarding discussions surrounding end of life care." (Voorhees et al., 2014). Only one study pointed to the ambiguity in EOL-care discussions, in the sense that the study pointed to the lateness of the EOL-care discussions.

Discussion

The goal of this study was to gain an understanding on whether or not discussions on death and dying would ease depression and anxiety among the elderly (age > 70) who live in nursing homes, are in assisted living, or in hospice, or in hospitals, or at home with limited mobility. Moreover, to analyse whether or not, these discussions are beneficial or harmful to all the parties, that is, to the elderly, the bereaved and the health care staff. From the studies selected for the U.S., I found only two studies (Dennis & Washington, 2018) (Van Scoy et al., 2016) that measured the emotional well-being of the patients and the families. The rest pointed to fear, discomfort, anxiety, and lack of financial support for the HCP in EOL care, lack of training and a need for ethical legal discourse. In the Netherlands, where ethical and legal issues are not barriers to discussions, I found the studies encouraged discussions on death and dying early in life, but did not report on well-being or general lack of anxiety, because of such discussions.

One important reason for comparing the Netherlands against the U. S. was to assess whether cultural comfort or discomfort constitutes a significant factor in easing the path to open discussions of death and dying with the elderly. U. S. presents a culture where death and dying are stigmatized to the point where it is taboo, whereas in the Netherlands, debates on legalizing PAS became legal almost a decade ago. This point was discussed by (Schulz et al., 2017).

Schulz et al. 2017 pointed to the historical and cultural perspectives that shape a particular society's attitudes and emotions to the subject of death and dying. This appears to be a pivotal difference in embracing death with ease and without fear and anxiety. Cultural and social differences also are the core factors defining EOL care, and shaping the emotional perspectives of the dying, the families and the HCP. Culture cannot be exported from another place and cultural perspectives take a long time to change and do not occur overnight but we can begin now.

Van Scoy et al's 2017 study pointed to the positive impact on participants' well-being during a card game that involved discussions on death and dying. Thus, this card game's favourable effect is in agreement with the research question of my scoping review, which is, " Could discussions on death and dying with the elderly (>= 70) in Western countries, reduce

anxiety surrounding death, and enable a smoother transition towards end of life (EOL) care.” The limited overall evidence of a favourable psychological effect from discussions of death and dying, could be because of a lack of identifying emotional well-being with EOL discussions. Future studies would benefit from observing psychological impact on patients and families, when HCP and families enter into these discussions, at appropriate times. Studies should report on the benefits and harms of these discussions.

Ethnicity played a significant role in two studies (Periyakoil et al., 2015) (Periyakoil Vyjeyanthi S., 2016). Overall, the results indicate that the culture of a place has a lot to do with the way we embrace death, for example the Economist Intelligence Report stated: “In the US, appropriate end-of-life care is often trumped by the “cure at all cost” attitude of doctors, along with the strong religious views many families hold on the sanctity of life. “We’re the epicentre for the technologies that allow us to keep people alive for 60 additional days with no improvement in outcome but with substantial increase in costs,” says Paul Keckley, Executive Director of the Deloitte Centre for Health Solutions, the health services research arm of Deloitte, an international consulting and accounting firm. “And the more fundamentalist, evangelical or conservative, the less likely people are to challenge a physician’s opinion or to want anything done that’s not recommended by the doctor.”

In the study done by (Prince-Paul & DiFranco, 2017) the authors concluded that on a societal level, we simply don’t talk about this universal experience called dying and death; in fact, we ignore it until we have to face it. As a public health concern, if we can upstream the advance care planning discussion into usual health promotion activities, perhaps, as a society, we can begin to normalize and reshape how we make decisions about the last chapters of our lives. The study pointed to a sociological environment that is reluctant to engage in discussions about dying and death, and how the dying would prefer to be cared for at the end of their lives.

In most issues involving EOL- care, the suffering could be avoided, or at least mitigated, by some education on dying and death and informed conversations about it. Ultimately, this will involve a fundamental change in society in which dying, death, and bereavement will be thought about, seen, and accepted as a natural part of life’s cycle (Prince-Paul & DiFranco, 2017).

A New Zealand study concluded, “a growing body of literature affirms the need for an early iterative ACP process to begin when people are young and healthy. “ This also implies that discussions on death and dying should begin early in life to make an impact upon one’s quality of life. The study added that a significant gap appears to exist in the literature regarding the utility of death conversations outside the end-of-life context (Llewellyn et al., 2017). Could ‘death conversations’ early in life be an effective tool by which doctor and patient can co-construct a more healthful way of life, and realistic relationship with death?

Additionally, the above study demonstrated the utility of death conversations as an effective tool to engage patients in a meaningful exploration of their psycho-socio-spiritual and cultural context. Within the context of ACP, a better understanding of health care expectations, anxieties, and cross-cultural difficulties, while outside the context of immediate life threatening illness, discussions on death for people of all ages, may provide insights that enhance quality of life and peace of mind against the more generalized inevitability of mortality.

Conclusion

Death as a natural consequence of life has become much less visible than it was in the past due to our longer life expectancies and lack of infectious disease. The continued thrust for treatment, wedded with a failure to recognise the dying process, can rob individuals of a peaceful, dignified death. Presently, progress in ACP and palliative care is limited by the existing paradigm of death as a 'foe to be conquered'. It is time for a shift in this paradigm (Gellie et al., 2015).

From the studies selected for the U.S., I found only two studies (Dennis & Washington, 2018) and (Van Scoy et al., 2016) that measured the emotional well-being of the patients and the families. Of the two (2) studies, one suggested a cultural change through social activities and engagements, for example, a card game. The other was a study of tribal elders who were already members of a culture that embraced discussions of death and dying with comfort and ease. Not only discussions on death and dying are acceptable in this culture, but also that such discussions are anticipated with much joy and deep reflection. Therefore, my research question, "Could discussions on death and dying with the elderly (≥ 70) in Western countries, reduce anxiety surrounding death, and enable a smoother transition towards end of life (EOL) care" remains unanswered.

The rest pointed to fear, discomfort, anxiety, and lack of financial support for the HCP in EOL care, lack of training and a need for ethical legal discourse. In the Netherlands, where ethical and legal issues are not barriers to discussions, I found only four (4) studies, and out of those four (4), one reported on patients' weariness with life and thus they chose PAS. The rest encouraged discussions on death and dying early in life, but did not report on well-being or general lack of anxiety, because of such discussions.

In a few studies, social, cultural and religious perspectives played a significant role. Fear of dying, leaving the loved ones behind, being an un-necessary burden for those caring for the patient, along with certain taboos on broaching the subject, caused great anxiety and unease among the elderly. Yet these studies recommended more effective medical care, more training for the medical staff, more funding for EOL care services through Medicare or

private practitioners, as a method for easing distressful symptoms for those in nursing homes or for the elderly in general ((Bhavsar et al., 2017) (Kwon et al., 2014) (Frances et al., 2016) (Pizzo, 2016) (Waldrop et al., 2015) (Weathers et al., 2016)).

Of the two studies that encouraged discussions on death and dying (Van Scoy, 2016) Van Scoy et al.'s was an innovative approach to encouraging the conversations using card games. The researchers engaged participants in a conversation card game, *My Gift of Grace*, that used a questionnaire to measure the readiness of the participants in engaging in ACP, and EOL issues, and quality versus quantity of life with loved ones. "The researchers concluded that a game format may be an effective strategy for motivating individuals to engage in important advance care planning." (Van Scoy et al., 2016). The study demonstrated that the card game was a positive, well-received experience for participants.

In light of the very few studies that obtained data directly from patients, or patients' reflections on death and dying, through diaries, and journals, my research question remains unanswered. Very little is known about dying patients' thoughts and preferences, and there is no effort to measure the impact of these discussions on reducing anxiety and depression.

Much more research is needed, in both the U.S., and the Netherlands to ensure that the preferences of the elderly, in all settings, are taken into account, and then measured for their impact on emotional and physical well-being. Additionally, there is a challenge in reshaping the thinking of all participants in looking at death as a natural outcome of life, not a foe that is to be avoided indefinitely.

Future studies could consider measuring outcomes of discussions on death and dying from the perspective of patients' anxiety and distress, rather just financial support, and extra medical training. Since important studies pointed to cultural and religious taboos as reasons for not discussing death and dying, it would benefit all parties, that is, the patient, the families, the HCP, to incorporate culturally appropriate care for the elderly, while demonstrating the importance of culture and spiritual leanings of those in elderly care. This study illustrates the importance of early death discussions, of promoting a culture that views death as another aspect of life, not a foe to contend with but a friend to embrace.

Limitations

There are several limitations of this review. A focus on death and dying, particularly of the elderly ≥ 70 could have eliminated important studies, thus introducing the possibility of a publication bias. The review also excluded studies that involved patients with cancer, dementia, HIV, stroke, and with that exclusion, could have eliminated meaningful discussions on death and dying, thus creating a subjective bias.

The review included studies only in the English language and there were obviously studies in the Dutch language on Netherlands that were excluded. Additionally, confining the selection of studies for the U. S. to years 2013 - 2018, and searching only PubMed/Medline databases reduced the findings to a small number of studies, thus diminishing the generalizability of this review.

Finally, this is a qualitative review, employing participants' opinions, perceptions, statements, expressions, and feelings in highly emotional settings, and as such, the study carries a risk of subjective bias. The very subject of the study, that is death and dying, can colour and distort perceptions, and skewed perceptions then influence the overall outcome of the study.

Disclosure

There is no potential conflict of interest with respect to the research, authorship, and/or publication of this thesis.

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