

# Death, Dying, and End-of-Life Care in the US and the Netherlands: A Scoping Review

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## ABSTRACT

**Introduction:** The aim of End of Life (EOL)-care in any setting is to improve the quality of life of patients and families through medical or non-medical interventions. The study aims at identifying gaps in the literature produced on the topic and informs areas for future research in the field.

**Objective:** To identify articles that discuss death and dying, with 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. Using the inclusion and exclusion criteria, the selected studies were analysed and categorized by themes, and then summarized based on positive, negative and ambiguous views on death discussions at all four (4) levels of discussion.

**Results:** From a total of one hundred and fifty-nine studies, twenty-five studies passed the selection criteria. Twenty-one were for the U. S., and four were for the Netherlands. The selected studies were analysed and categorized by themes.

**Conclusion:** The review pointed to a dearth of material that measured the outcome of discussions on the subject of death and dying with the elderly. Future studies could consider discussions on death and dying from the perspective of patients' anxiety and distress, instead of concerns over financial support, religious and ethnic issues, ethical and legal parameters, and extra medical training.

**Keywords:** death, dying, end-of-life care, the US, the Netherlands

## INTRODUCTION

Although preservation of life is medicine's central goal, ultimately however, death is an unavoidable outcome. In the last decade, there have been a tremendous increase in nursing homes, assisted living homes, long-term care centers, along with a very significant increase in older people living alone in their own homes in both developed and developing countries (Chandler, Williams, Maconachie, Collett, & Dodgeon, 2004). It is estimated that 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 by 2030 (Health-and-Human-Services, 2007).

Although death and dying has been a taboo topic for many cultures, it is gradually becoming a legitimate issue for scientific and social discussions in recent years. In the Netherlands and the US, 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. (Van der Heide et al., 2007; Anderson, Williams, Bost, & Barnard, 2008)). Moreover, health systems, in the US and the Netherlands have begun to provide and finance hospice care, nursing homes, and long-term care services for the elderly.

That said, there is still a significant difference between the two countries. 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 end-of-life care often inflames religious sentiment that holds the sanctity of life paramount. The need for "good death" conversations has never been greater. Governments and healthcare 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.

The objective of this review is to identify and map research on death and dying at all four levels of discussion in the US and

the Netherlands, that is: 1) Discussions with Health Care Professionals (HCP); 2) Discussions with family and friends; 3) Discussions with HCP, family, friends and self; 4) Reflections by self. The identification of the studies would clarify the current state of the EOL-care in nursing homes, assisted homes, private homes and hospitals. Summarizing the current literature would aid in future studies that would measure the outcome of these discussions on death and encourage research in the area by HCP and policy makers in future planning and development of Hospice/Palliative care, Advanced Care Planning (ACP), Advanced Directive (AD) and End-of-Life (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.

## METHODS

### Search Methodology

This scoping review of the literature was conducted by applying the methodological framework set out by Levac et al. and Arksey and O'Malley (Arksey & O'Malley, 2005; Levac et al., 2010). The steps include (1) identifying research questions, (2) identifying all relevant studies, (3) selecting significant studies, (4) charting the relevant data, and then (5) summarizing and reporting the results. A core team (SR, and AK) met regularly to ensure consistency throughout the process. Ethics approval was not required for the study. Authors were assisted by the UIO Library services with the review protocol.

### Data Sources and Search Strategy

The search was performed in Medline via PubMed. The databases were initially searched from January 01, 2013 - March 31, 2018, using predefined search terms. Two health sciences librarians at the University of Oslo Medical Library provided professional support for the study. PubMed was searched because it's the most accessed database.

The research question was, "Could discussions on death and dying, with the elderly ease anxiety and depression?" In order to capture the studies that would contribute to a thorough review, the final search terms included were [(death AND dying) OR (advanced care planning AND end of life care)] AND (US) OR USA OR Netherlands OR palliative care OR terminal care OR hospice OR dying OR nursing homes OR advanced care directives). Furthermore, the words "Advanced Care Planning" were used because a search with these terms extracted many more studies than without it.

### Study Selection

For the purposes of this search, the following inclusion criteria were used (a) English language; (b) older adults, age > = 70; (c) settings: nursing homes, assisted living, private homes, hospice care, palliative care, hospital and community care; (d) original publication; (e) utilization of a communication mechanism between the HCP, family and friends, and the patient, where death and dying and end of life care plans were discussed; (f) studies on the US and the Netherlands.

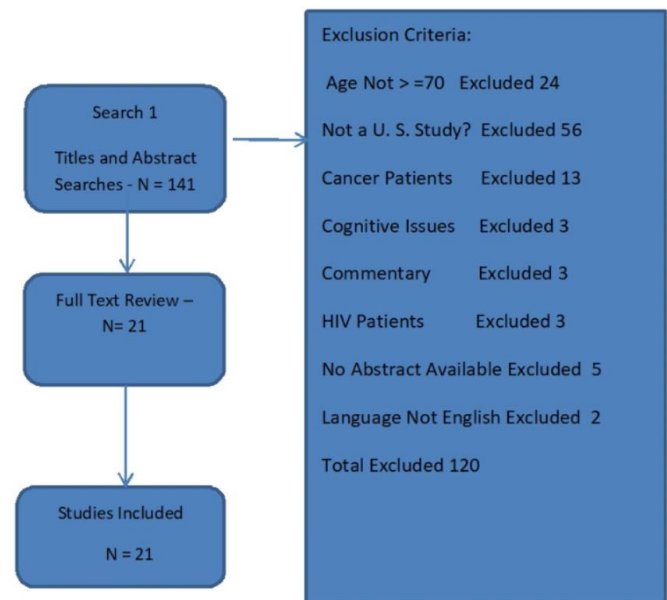


Figure 1. Flow chart of the US Studies

The following exclusion criteria were used (a) younger patients; (b) cancer patients; (c) HIV patients; (d) dementia patients; (e) stroke patients; (f) other cognitive impairments; (g) studies that focused only on staff training; (h) studies that focused only on Physician Assisted Suicides (PAS); (i) studies that covered multiple regions. Reasons for excluding dementia patients; stroke patients and cognitively impaired patients is that discussion on death and dying would have simply not been possible, hence searching for these studies would be pointless. Similarly, discussions on death and dying with younger patients, HIV patients, and cancer patients were excluded because such patients are generally not old, they are seeking more treatment and discussions might hinder their recovery process. Focus of this study were the elderly who are alone, depressed, anxious of the consequences of death, and just wasting away in nursing homes and other facilities.

### Data Extraction

The authors abstracted the data from the selected articles using a data abstraction form developed for the objective of this review. The data abstracted included year of publication, last name of the first author, institution/affiliation and country of first author, last name of the corresponding author, institution/affiliation and country of the corresponding author, name of the journal, type of publication, study design, and year of study. Additionally, the authors abstracted the following variables: patient age and setting, measured outcomes, family and friends' engagement with the patient, hospital care staff and their interaction with the patient, discussions on death and dying by the patient, family and friends and by the health care staff. Informal discussions over dinner and formal discussions with the clergy were also included. Our systematic search of the electronic databases yielded 159 (the U.S. = 141; the Netherlands =18) potential articles. After deletion of duplicates, 25 articles (the U.S. = 21; the Netherlands =4) remained for the analysis (see Figures 1 and 2).

**Table 1.** Comparison of the US and the Netherlands-End of Life

US	Netherlands	Comparison
End of life discussions are much needed but after years of debate, only seven states have approved Physician Assisted Suicide (PAS)	End of Life discussions ended. PAS is legal. 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 %. After 2030	Areas of increase as a % age of the total medical spending budget, by 2035.
US is the most expensive medical system in the world.	Netherlands is shown an exemplary medical system in Europe.	There is a positive relationship between cost of elderly care and quality of care especially in EOL-care.

**Figure 2.** Flow chart of the Netherlands Studies

## RESULTS

### The U.S.

In searching whether or not, deliberations on death and dying added to the quality of elderly care, eased anxiety and depressions, the review generated four main themes.

Out of 21 studies that met the selection criteria, eight described health care practitioner’s perspective on death and dying, that is theme 1 (see **Figure 1**). Three studies involved family and friends, that is, theme 2. Six studies described consultation with a combination of relatives, HCP and self that is theme 3. Only four studies focused on self- reflection and directives for end of life care (see **Table 2**).

The settings in which the studies took place ranged from nursing homes, assisted living, private homes, end of life 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.

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

**Theme 2 - Family and Friends:** A total of three studies were identified. One study was a research paper with philosophical overtones. The research did not comment on the patients’ wellbeing as an outcome of contemplation. One was a mixed method study of multi-specialty Doctors, caring for ethnically different patients. One was a mixed method study quantifying the results of public comments made on regulations.

**Theme 3 - A combination of Family and Friends, HCP and Self:** Six studies were identified. One study was a systematic review of older adults, age range: 72 -88 years. Three studies were face-to-face interviews with physicians, nurses, social workers, supervisors, chaplains and HCP teams. One was a cross-sectional study, which used a survey method. One study was in-depth in-person interviews with hospice patients.

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

### The Netherlands

Out of the four studies that met the selection criteria, two (2) were literature reviews (see **Figure 2**). One 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).

**Table 2a.** Chronological Overview of the Selected Studies – Theme 1 HCP

Author & Date of Publication	Title	Settings for Theme 1: HCP	Type of Study	Outcome
(Young, Redfield, Strand, and 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 Improving End-of-Life Care	Palliative Care. Hospitals, ICUs, assisted living, nursing homes and sometimes 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 the end, not much easier, especially for those people whose lives end in hospitals, ICUs, and nursing homes. (A= Ambiguous)
(Periyakoil Vjeyanthi 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, and 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, and Mukamel, 2013)	Site of Death among Nursing Home Residents in the United States: Changing Patterns, 2003–2007	Nursing Home residents throughout 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 also to stem the growth of Medicare spending (A = Ambiguous)

**Table 2b.** Chronological Overview of the Selected Studies – Theme 2 Family and Friends

Author & Date of Publication	Title	Settings for Theme 2: Family and Friends	Type of Study	Outcome
(Prince-Paul and 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= Ambiguous)
(Bhavsar, Constand, Harker, and 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= Ambiguous)
(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= Negative)

**Theme 1 - HCP:** Two studies were identified that were qualitative and exploratory studies with interviews with physicians.

**Theme 2 - Family and Friends:** There was no study found.

**Theme 3 - A combination of Family and Friends, HCP and Self:** One study was identified which was a longitudinal aging study that employed after death interviews with proxies.

**Theme 4 - Self-reflection:** One study was identified which was a literature review of professional studies.

**Table 2c.** Chronological Overview of the Selected Studies-Theme 3 Family & Friends HCP & Self

Author & Date of Publication	Title	Settings for Theme 3: Family Friends - HCP & Self	Type 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= Ambiguous)
(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= Ambiguous)
(Waldrop, Clemency, Lindstrom, and 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 emergent themes.	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 = Positive)
(Kwon, Kolomer, and 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 = Positive)
(Kwak, Ko, and 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= Negative)
(Waldrop and 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 = Positive)

**Table 2d.** Chronological Overview of the Selected Studies – Theme 4 Self Reflection

Author & Date of Publication	Title	Settings for Theme 4: Self Reflection	Type of Study	Outcome
(Dennis and 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 = Positive)
(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= Ambiguous)
(Black and 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 = Positive)
(Gellie, Mills, Levinson, Stephenson, and 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 = Positive)

## DISCUSSION

The goal of this scoping review was to find studies that measured the well-being of the patients as an outcome of discussions on death and dying. The findings make it abundantly clear that a measurement matrix is much needed in reporting results of death discussions with the elderly in EOL-care.

One important reason for comparing the Netherlands against the U. S. was to assess whether cultural comfort or discomfort constitute a significant factor in easing the path towards open discussions of death and dying with the elderly. The U. S. presents a culture where death and dying are stigmatized to the point where it is taboo, for example, in the study done by Kwak, Ko, & Krame et al. the 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.

On the other hand, Netherlands, where PAS is legal, (Klinkenberg, Willems, Onwuteaka-Philipsen, Deeg, & van der Wal, 2004), the study found that encouraging the elderly to express their preferences to their loved ones and physicians was rather important and suggested that the healthcare providers could help in increasing the patients' awareness of the importance of a timely discussion.

Cultural and historical factors did indeed constitute the main difference between the U.S and Netherlands. 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. Thus cultural and social differences appear to be pivotal in embracing death with ease vs. death with fear and anxiety.

From the studies selected for the U.S., 95% 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. There were five percent (Dennis & Washington, 2018) (Van Scoy et al., 2016) that measured the emotional well-being of the patients and the families, and encouraged discussions on death and dying.

In the Netherlands, where ethical and legal issues are not barriers to discussions, almost 100% of the studies encouraged discussions on death and dying early in life, although they did not report on well-being or general lack of anxiety, because of such discussions.

For both U.S and the Netherlands, medical spending for the aging population > 65 is rising around 10% and will be > 20%, hence there is much similarity in allocation of the medical expenditure (Smits, van den Beld, Aartsen, & Schroot, 2014)

Of the two studies that encouraged discussions on death and dying (Van Scoy, 2016 ) 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.

The second study was (Dennis & Washington, 2018). In 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 elders, (Dennis & Washington, 2018) concluded that 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).

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. 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 (Maryjo Prince-Paul & Evelina DiFranco, 2017).

Given that in the U.S, there were only two studies that measured the emotional well-being of the patients and the families, it suggests of a culture that is fearful of embracing death discussions as a natural outcome of life. 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 on the elderly in EOL care. Therefore, the findings of this study did not support the initial hypothesis that discussions on death and dying could improve the well-being of the elderly, and reduce anxiety and depression.

## LIMITATIONS

First, the review included studies only in the English language and thus important studies in other languages may have been missed. Second, a systematic review of the available literature on the subjects was not conducted, so there is no information available on the quality of the studies selected. Third, the search was only conducted in PubMed which means that studies that were registered on other databases were not included. Fourth, the results of the study are limited to the key search terms used in the research.

## 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 Advance Care Planning 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).

A significantly large number of studies 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, there were only four (4) studies, and out of those four (4), one reported on patients' weariness with life and thus their choice of Physician Assisted Suicide. 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. On the other hand, if discussions on death and dying were easily accepted and anticipated with much joy and deep reflection, as they are in the culture of tribal elders on a Native American Reservation, we could begin to measure and identify emotional well-being parameters.

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 are significant challenges 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.

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