Understanding the End-of-Life Care Needs of The Aged, Terminally Ill and the Disabled Living in Long-Term Care Facilities

Texas ADONA Conference

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"If we cannot face death with equanimity, how can we be of assistance to our patients?"

(Dr. Elisabeth Kubler-Ross 1969)

End-of-Life &
Quality of Life
Preparation & Education

Given death is an inevitable for every living human being, it is the goal of the Tarrant County College Long-Term Care Administration Department to prepare our students for leadership related to all clinical, administrative and regulatory matters. The death and dying process is emphasized throughout our student's didactics and clinical courses.

Death, dying, grief and loss are taught in the following courses:

1. **Introduction of LTCA**: Hospice services – a continuum of LTC; Role Play – death and dying topics as an Administrator
2. **Resident Care Management**: Physiology, psychosocial & spiritual care offerings and understanding pain management
3. **Organizational Management**: Staffing and volunteers who will care for the dying and his/her family
4. **LTC Legal** – Ethical matters at life's end; Alleviation of suffering
5. **LTC Finance** – Costs and financing of Hospice care
6. **LTCA 2660 & 2661** – Administrator in Training (AIT Clinical Courses); students will engage with family/resident and hospice care conferences.

Problem Statement:

- Residents living with serious often illness lack one-one spiritual care and/or psychosocial support services.
- One-one psychosocial & spiritual care is often offered to terminally ill residents via contracted hospice chaplains, however, due to advancing disease processes, engagement of care may be too late.
- Care should be offered sooner –following admission, and/or immediately following a new diagnosis and one with a serious illness and/or a major healthcare crisis.
- **Introducing services sooner via Palliative Care offerings will help to increase one's overall mental health and quality of life are important.**

Mental Health is a Public Health Dynamic

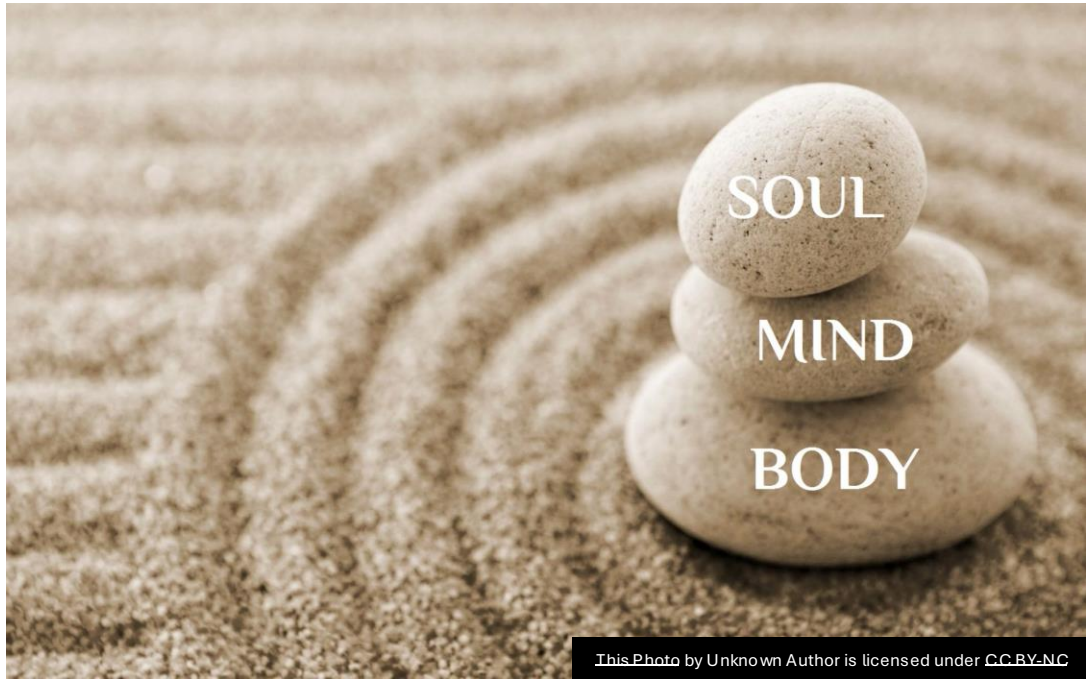
HEALTH: “A state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity” (CDC, 2022).

Because mental health is a significant component of one’s overall health, it must be treated as intentionality and urgency as one’s physical health.

As residents age, they become more prone to the risks of pursuing mental health imbalance, increasing stressors, decreased functional ability, isolation, loneliness and chronic health problems.

Focus: HOLISTIC CARE:

Body, Mind and Spirit/Soul



The Significance of Depression

The aging process is both physiological and psychological. Depression is the most common functional mental illness observed in older adults.

Common diagnosis among older persons includes

a. Anxiety

b. Severe cognitive impairment

c. Mood disorders:

d. Depression

e. Bipolar disorder

f. Mental health disorders are also implicated in cases of suicide.

CDC

Principles of a Good Death

As the final season of life approaches, every resident deserves to die with dignity and to receive care and support to aid in a "good death", and one with dignity. During the dying process, staff should treat the entire family as "one" unit.

1. To know that death is coming and to understand what can be expected.
2. To be able to retain reasonable control of what happens.
3. To be afforded dignity and privacy.
4. To have adequate control over pain relief and other symptoms.
5. To have choice about where death occurs (even within the facility).
6. To have access to desired spiritual and emotional support.
7. To have access to palliative or hospice care in any location (home, hospital or long-term care facility)
8. To have a say about who is present and who shares the end
9. To be able to administer advance directives that ensure wishes are respected
10. To have time to say GOODBYE.
11. To be able to leave when it is time to go and not have life prolonged pointlessly.

(Smith, Richard, "A Good Death" British Medical Journal 320; (January 15, 2000).

Palliative Care Services

Palliative Care: A multidisciplinary approach, seeking to eliminate or minimize a person's human suffering experiences

Suffering takes on many forms and is not just physical

a. EMOTIONS - anger, anxiety, sadness, loneliness

b. SPIRITUAL BURDENS; including a life-limiting, or terminal illnesses: guilt, abandonment, fear

Like hospice, Palliative Care emphasizes the burdens of the illness are experienced and carried by both the patient and the family.

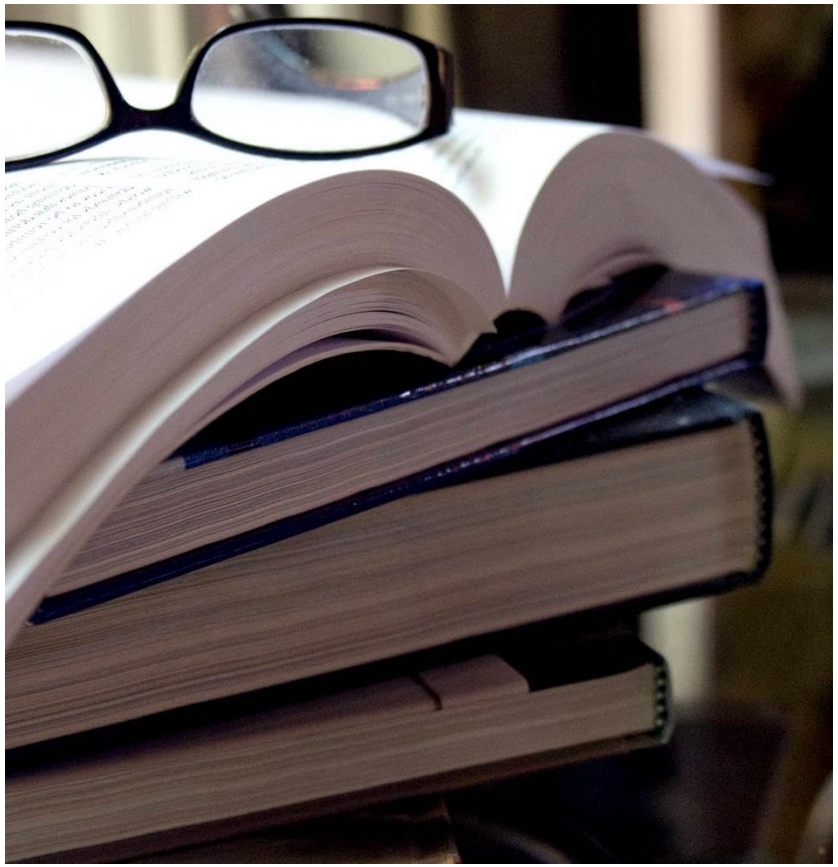
(National Consensus Project for Quality Palliative Care, 2004).

Long Term Care Regulations: End of Life Care Health and Human Services Commission (HHSC)

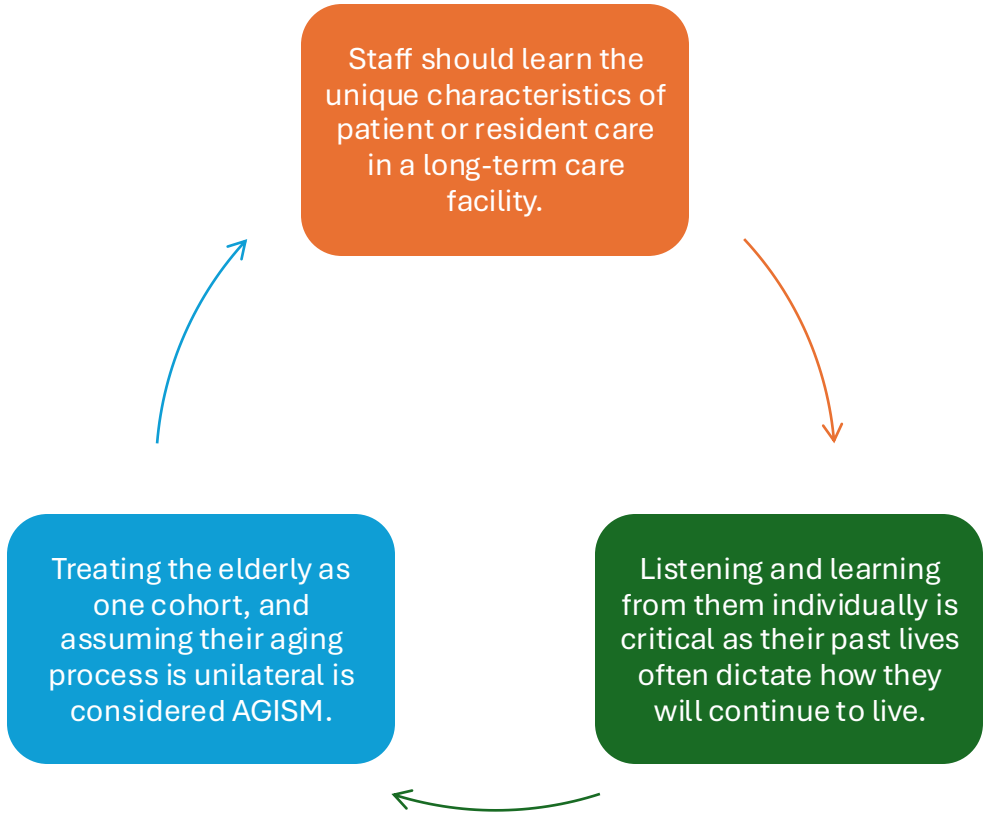
The resident has a right to a dignified existence , self-determination, and communication with and access to persons and services inside and outside the facility.

19.402: EXERCISE OF RIGHTS: Residents should be aware of one's rights, and this should be routinely emphasized. Resident's rights pertaining to participation in spiritual and religious activities are as follows:

The facility must allow the resident the right to observe his religious beliefs. The facility must respect the religious beliefs of the resident in accordance with 42 United States Code; 1396f. The facility must be instrumental in assisting the resident and/or his/her family to achieve their religious needs in a variety of ways.



Distinctive Features of Resident & Patient Care in a Long-Term Care Facility



End of Life Preparation:

19.419: ADVANCE DIRECTIVES: A facility must communicate in writing the advanced care planning process. Within 14 days after admission, the process must be communicated and documented regarding the resident's preferences for all matters related to death and dying.

19.701: QUALITY OF LIFE: The facility must promote care for residents in a manner and in an environment that promotes and maintains or enhances each resident's dignity and respects in full recognition of the resident's individuality.

(Health and Human Services Commission 2023)

Advance Directives

a. Provide written policies regarding the implementation of advance directives via educational materials;

b. Resident's rights; to make his/her own decisions regarding care

c. Changes updated – quarterly, annually and upon a change of condition –positive changes or significant deterioration

d. Facility must document the oral discussion and the provision of the written information in the resident's clinical record.

e. Document whether or not the resident has executed an advance directive or not

f. ALLOW THE RESIDENT TIME TO MAKE DECISIONS, AND NOT MAKING THEM FEEL RUSHED IN THE PROCESS.

Treating and Respecting our Elders with Biblical References

- Regarding serving, treating and respecting our Elders, the Synoptic Gospels – the Book of Acts especially themes of resilience, spiritual growth, and resilience.
- Practices and attitudes toward treatment of the elderly are highlighted with significance; how they can thrive as they age.
- Spiritual growth and transformation are key themes, especially as challenges and losses associated with aging can lead to greater reliance on God, and a greater understanding of grace.
- *"To emphasize his concern for vulnerable adults, Jesus demonstrated sympathy for the plight of widows in his parables and teachings" (Harris 1987).*
- *Honoring our parents is held with high honor as a critical behavior whereby responsibilities to care for them should be fulfilled.*

Harris 1987

Treating and Respecting our Elders with Biblical References

The Haustafeln: “household codes”, provides instruction about children caring for their aging and feeble parents, especially as one’s health begins to fail.

Understanding the biblical themes of caring for the aged is important as it demonstrates the necessity for social structures to be developed that will help strengthen a given community for this caring process (Harris 1987).

Resident Assessments

The Code of Federal Regulations (CFR) as outlined by the Centers for Medicare and Medicaid Services requires long-term care facilities to conduct comprehensive assessments of each resident's needs, strengths, goals, life history, preferences, and functional capacity.

Assessments are to be accessed and completed through the Minimum Data Set (MDS) system that was first developed in 1990. Completion within 14 days of admission, a new change of condition, quarterly and annually.

Psychosocial Functioning: This includes the resident's preferences, social interactions and participation in activities.

Health Status: Includes diagnoses, medications, symptoms, and other health-related information.

The MDS system is a form with a detailed list of questions and with guidelines for providing care to a resident along with examples of care interventions as problems arise.

Assessments

Helpful tools that can be utilized:

- Spiritual Care Assessments
- Spiritual History Assessments
- Bereavement Risk Assessment Tool: BRAT;
- Suicide Risk Assessment: Should be done in private

Spiritual Care Assessment & Questions for Care Planning:
Joint Commission for Health Care Facilities

1. Who or what provides the patient with strength and hope?
2. How does the use or claiming of faith help the patient cope with illness?
3. Does the patient use prayer in his/her life?
4. What drives the patient to keep going day after day?
5. What type of spiritual/religious support does the patient desire?
6. What does suffering mean to the patient?
7. What Is there a role of the church/synagogue in the patient's life?
8. What helps the patient cope, and manage his/her healthcare experience?
9. How has this illness affected the patient and his/her family?
10. Does the patient have access to clergy, ministers, chaplains, pastor or a rabbi?

(Joint Commission 2022)

Suicide Risk Assessment

Suicidal ideation is common among the elderly, and upon admission, or throughout one's stay, it is recommended that nursing staff or the social worker should speak privately to the resident. A sample verbal statement could include:

"*At our facility, we are committed to patient/resident safety. Many things, including medical problems, can cause emotional distress, sometimes leading people to have thoughts of suicide, therefore we are asking all residents & patients a few questions related to this topic".*

If a screening is positive, the following should be spoken: "It is important that you have spoken up about your emotions. We will speak with the team to continue monitoring you, and we will also reach out to a specialist to speak with you in person" (National Institute of Mental Health 2020).

Questions:

1. In the past few weeks, have you been thinking about killing yourself? (If yes, ask how often: Once or twice/day, several times/day, a couple of times a week, etc.)
2. When was the last time you had these thoughts?
3. Are you having thoughts of killing yourself right now? (If yes, the patient requires an urgent/STAT Mental Health Evaluation and should not be left alone. A positive response indicates imminent risk.

Suicide Safety Assessment

- If a resident articulates a detailed plan, this is very concerning.
- If a resident has had thoughts, but no detailed plan, continued monitoring should take place.
- Ask about the method and access to means;

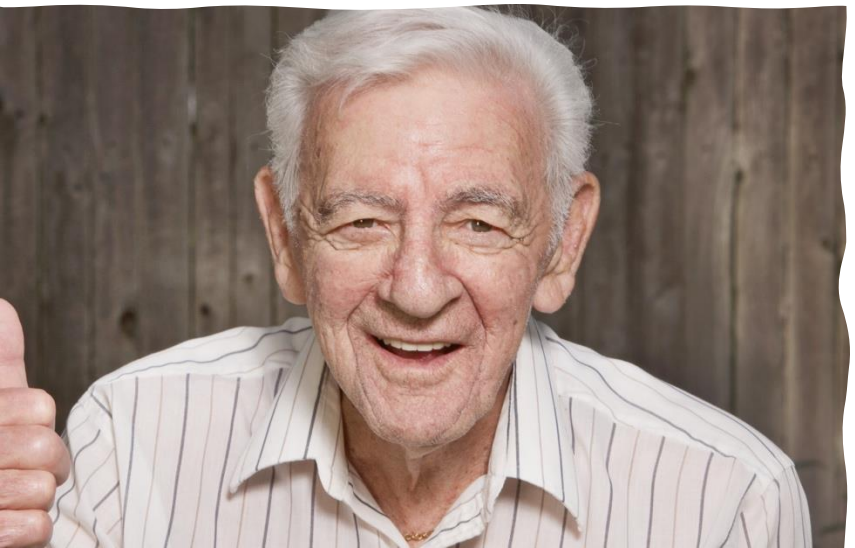
“If you were going to kill yourself, how would you do it?”

If a plan is feasible; taking pills, having access to pills, etc.; this is of greater concern, and staff should make every effort to remove or secure items; pills, ropes, guns, etc. (National Institute of Mental Health, 2020).

Bereavement Risk Assessment Tool (BRAT)

- The BRAT was developed by Victoria Hospice Society to help “communicate personal, interpersonal and situational factors that may place a caregiver or family member at greater risk for a significantly negative bereavement experience” (Victoria Hospice Society, n.d.)
- Organized into 11 domains and 40 items.

1. Kinships/relationships
2. Mental health and coping
3. Spirituality and Religion
4. Concurrent Stressors
5. Previous Bereavements
6. Supportive measures received that provide a positive bereavement outcome
7. Circumstances involving the patient, care or the death



Definition of “Good” Quality of Life” and Emotional Well-Being

The definition of health has shifted away from “the absence of disease” toward a “state of physical, mental, and social well-being (World Health Organization, 1946).

- Greater emphasis is placed on quality of life as a major component of health

Multi-dimensional, broad concept including subjective evaluations of one’s physical health, psychological state, independence, social relationships, personal beliefs, as well as one’s living and/or working environment.

Good Quality of Life: Assessed differently by each person, it includes the domains that contribute to an overall feeling of well-being. This may include:

- ✓ Social health
- ✓ Physical well being
- ✓ Environment
- ✓ Spiritual and emotional well being

Death Anxiety Questions

Assessing a resident's death anxiety is important should be assessed at regular intervals. Questions staff should ask or contemplate regarding death over time may include questions regarding a pending dying process and should be taken seriously when answers are recorded.

1. Will my death involve a long, difficult, painful, or undignified death?
2. Will it release me from hardships and suffering?
3. What will happen to me after my death?
4. Am I anxious about the unknown?
5. Am I fearful of judgment or punishment after death?
6. Am I anticipating a heavenly reward, and/or passage to a better life?
7. Am I looking forward to reuniting with loved ones who precede me in death?

Wellman 2023)

Living with the Awareness of Death

The concept, "**Nearing Death Awareness**" invites caregivers and family members to have greater insight about the dying process.

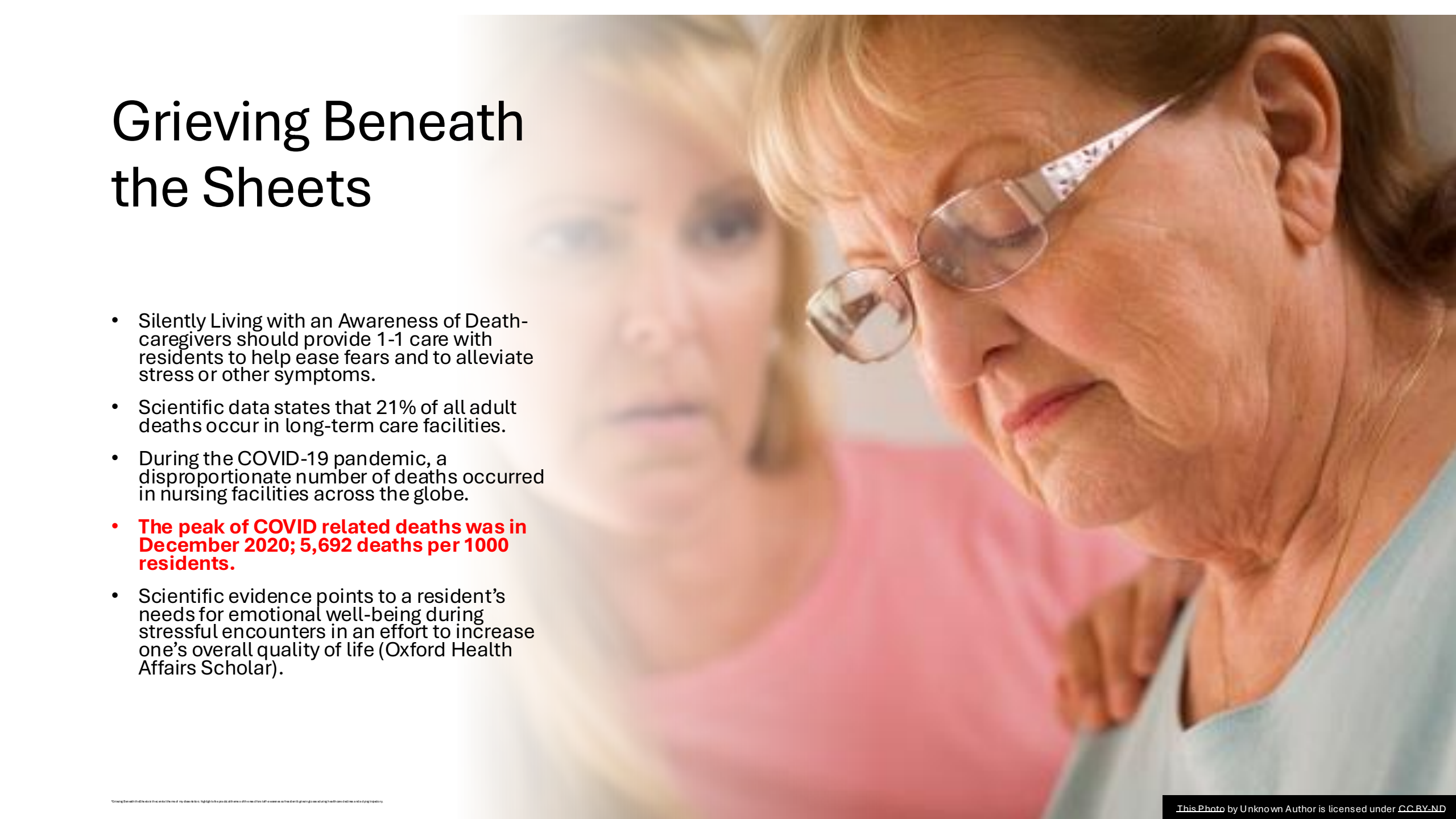
Death anxiety is a conscious or unconscious psychological state resulting from a defense mechanism that can be triggered when people feel threatened by death; a feeling of unsafety, anxiety or fear related to death or near death

It is more common for older adults and mechanisms should be in place to help patients process a pending death.

"The goal in any health care setting is to help relieve the burden associated with death anxiety as this will play an important role in the quality of life and mental health/emotional well-being of residents (Zhang 2019).

Grieving Beneath the Sheets

- Silently Living with an Awareness of Death- caregivers should provide 1-1 care with residents to help ease fears and to alleviate stress or other symptoms.
- Scientific data states that 21% of all adult deaths occur in long-term care facilities.
- During the COVID-19 pandemic, a disproportionate number of deaths occurred in nursing facilities across the globe.
- **The peak of COVID related deaths was in December 2020; 5,692 deaths per 1000 residents.**
- Scientific evidence points to a resident's needs for emotional well-being during stressful encounters in an effort to increase one's overall quality of life (Oxford Health Affairs Scholar).



*Grieving Beneath the Sheets is the central theme of my dissertation; highlights the practical themes of the need for staff-awareness of resident's grieving processes during healthcare declines and dying trajectory.

Reason for Integrating Spirituality

- Residents over the age of 65 are the most religious of any age group in the US, in part because the grew up at a time when religion was a sharp influential force in culture and society – more than it is today;
- Religion and spirituality gives meaning to later life and provides hope for the future;
- Because religion and spirituality encourage us to move toward our hope and future and by giving us meaning and purpose it will help influence medical decision making, especially those living with a terminal illness
- Religious and spiritual involvement helps to move residents and patients toward to an increase in emotional well-being and better mental health status, as well as social support and more positive health behaviors

What is Spirituality

- Spirituality is whatever the resident decides it is as there is so many broad definitions.
- Spirituality may often include one’s religious needs but not always necessarily
- It may often involve existential needs related to purpose and meaning
- The resident’s spiritual history is **really important** in determining what the residents' needs are, and to help identify the language and the needs that are necessary like there are many definitions of rituals and icons based on one’s cultural beliefs

Spiritual Needs

Spiritual needs and care involves time, emotional space and physical space. Health and Human Services highlights in the RESIDENT'S RIGHTS (regulations) that the facility must provide personal space for privacy and intimate conversations.

Thanatologists recommend dying persons to consider a wide variety of tasks and efforts that include spiritual workings to improve one's overall emotional well-being.

SPIRITUAL WORK
forgiveness, self-exploration, search for balance

SPIRITUAL DESPAIR:
alienation, loss of self, dissonance, etc.

SPIRITUAL WELL-BEING:
connections, self-actualization, consonance

Cultural and religious beliefs influence personal ones in ways we may not recognize, and that may complicate our coping or increase our suffering.

(Meager and Balk 2013)

Supporting residents through religious ad spiritual exercises and rituals, along with 1-1 processing are associated with an increase in better health outcomes and overall emotional well-being.

Religious Coping Styles and Depressive Symptoms in the Elderly

Scientific studies of religious coping styles provides ways of engaging residents to find support in their religion and based on previous practices and rituals.

Some scholars emphasize the relationship between positive (and negative) religious coping styles in geriatric patients; and namely the developmental process of integrity and despair is important.

It is important for residents living with chronic illness, disability, or problems to practice religious/spiritual rituals as health declines occur.

Religious Rituals

- This may include beliefs about God
- Attending religious services
- Praying
- Meditation
- Religious reading of meditational devotionals
- Sacrificial ceremonies like the eucharist (Holy Communion)
- Confession
- Baptism

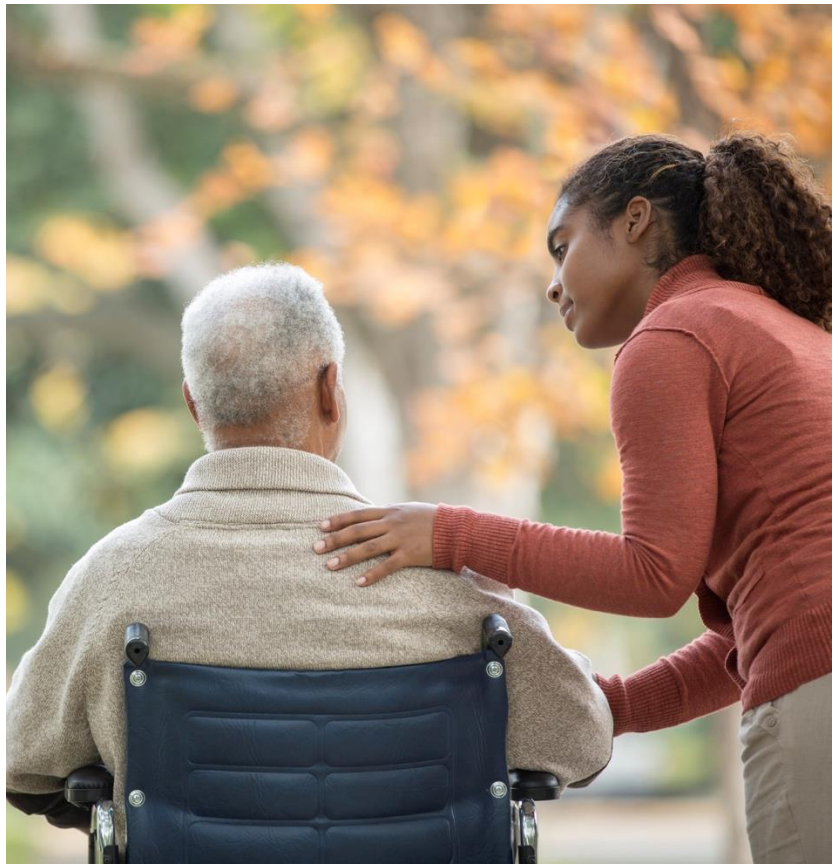
Victor Frankl: Meaning-Making

Concept that helps center one's capacity of a person to feel the worth of his individual life; (Meager and Balk 2013)

- ❖ Focusing on relationships that matter and are significant;
- ❖ To better understand a loss, hardship or of physical capacity or function
- ❖ To shape and respond to the meaning of loss, suffering and/or the response of physical function, pain or the death of someone close.

A growing body of research indicates that a sense of meaning in life is associated with improved psychological well-being, satisfaction with life, and overall quality of life.

Victor Frankl, an Australian neurologist, psychologist, philosopher, Holocaust survivor and founder of LOGOTHERAPY (psychotherapy). Frankl's work revealed the need for persons to search for life's meaning as this is a central human movtivational force. (Frankl 2006)



Spiritual Care Offerings

Texas facilities offer a variety of spiritual services to their residents. An example is listed below. Some local congregations volunteer their time for this purpose.

a. Catholic volunteers will visit Catholic residents, and on weekends, providing the Eucharist

b. Blessings upon request blessings

c. Anointing of the sick

d. Praise and Worship teams – singing medleys & hymns

e. Sermons

f. Bible Study

During the COVID-19 pandemic, some Dallas County facilities experienced multiple deaths of volunteer clergy, and facilities are unable to provide service opportunities as they did in the past.

The need to recruit new volunteers & with new methods is important.

Life Review Process: A Psychotherapy and Spiritual Care Technique Used for Aging and/or Terminally Ill Patients

- ✓ To assist with reflection over their lives & to find ways to feel better about one's life story.
- ✓ Helps to resolve conflict, regrets, anger, and other negative emotions
- ✓ To find a sense of purpose and to acknowledge gratitude
- ✓ Categories:

1. Childhood & school days
2. Youth to career/vocation
3. Adulthood I: vocational life, partnerships, until first child-birth
4. Adulthood II: children from birth until moving out of the family home
5. Adulthood III: from age 50 to retirement
6. Retirement years to present

Traumatic Events and Losses are asked as open-ended questions.

Services Impacting End of Life Care

PALLIATIVE CARE SERVICES (Not offered in LTC)	HOSPICE CARE (Offered in LTC)
Goal of Care: Relives suffering for patients with life-limiting or terminal illness	Goal of Care: Relieves suffering; maximizes quality of care throughout patient's life
May continue aggressive Life Saving Therapies (LST)	Patients must acknowledge terminal illness and be willing to eliminate heroic measures of prolonging life
May be a bridge to hospice	May revoke services at any time
Routine charges for service and activity help manage care	Patient is recertified every six months if life is prolonged
When managed properly, helps to minimize unnecessary trips to hospital ER and other stressful and unnecessary events	Works with all diagnoses through a team of Interdisciplinary Team members

Staff Education and Training

- Most staff working in LTC facilities may lack skill and knowledge related to mental health and spiritual care needs of a resident.
- While primary emphasis is on maintenance of their activities of daily living (ADL), one's emotional and spiritual needs are equally as important.
- Given this paucity in skills, and training, this results in poorly coordinated health and social services and an avoidance of assessment and treatments of mental illness (Meeks and Burton, 2004).

Staff Education and Training:

Develop our LOSS HISTORY;

a. List the first 2-3 losses in one's life

b. Who died? (Or what was lost?)

c. How was the news received?

d. How did the person/family, and/or community memorialize the deceased? (Was there a funeral or a Memorial Service?)

e. What observations did the person make about the experience of death and dying; family/culture/spiritual?

f. Talking openly about these experiences will be helpful to caregivers, allowing each to relate to others experiencing death/dying.

Staff Education and Training

There’s also a need for attention for LTC employees to have broader mental health education and training as they continue to support their needs.

Partnering with our Psychological and Psychiatric support networks will help increase skill and knowledge levels of our staff.

Learning mechanisms:

- Role Play
- Provide Case Studies

Widening the Circle of Care

Residents who may experience death anxiety need support from trained clergy and/or mental health practitioners to sort through his/her emotions.

Connect with Seminary Internship Coordinators (Perkins School of Theology/SMU and Brite Divinity/TCU have training programs.)

Connect with schools of Psychology and/or Psychiatry for the same

Request volunteerism from therapists or seasoned volunteers from the Area Agency on Aging

Psychosocial Support Offerings

Psychiatric and Psychology Support Services:

a. PhDs that visit residents for psychology visits

b. SW coordinates with them on frequency of need and report changes in mood/mental health status

c. Some visits in person; most are offsite, and resident will travel to another location.

Widening the Circle of Care

Area Agency on Aging (AAA) & Community Council of Greater Dallas: National networks administered by the Federal Administration on Aging and funded under the Older Americans Act.

- ✓ Grants are provided to ensure the needs of our seniors are met through a wide variety of services.

Churches and local denominational headquarters:

- ✓ Request support from local pastors or ministers who are willing to volunteer time; organizing weekly worship services, Bible studies or other cultural religious traditions and rituals.

Other Resources:

- ✓ **AARP**
- ✓ **Alzheimer's Association**
- ✓ **American Cancer Foundation**

Final Salute

"*Dying is a special situation in living; it cannot properly or fully be understood without taking account of the entirety of a person's life or fully be understood without taking account of the entirety of a person's life, both individually and within the social systems in which that person* is *living*" (Meager and Balk 2013)

Citations

- Centers for Disease Control: The State of Mental Health and Aging on America. 2008
- Quality of Life and Well-Being for Residents in Long-Term Care Communities: Perspectives on Policies and Practices. Johs-Artisensi, Jennifer, and Hansen, Kevin 2022
- Harris, J. Gordon 1987. Biblical Perspectives on Aging: God and the Elderly
- Mileski, Michael, McClay, Rebecca. Nursing Home Administration.
- Singh, Douglas. Effective Management of Long
  Term Care Facilities.
- Health and Human Services Commission. Regulations for Long Term Care Administration.
- The Long Road Ahead: Important Spiritual and Psychosocial Support Needs for the Aged, the Disabled and the Terminally Ill for Residents Residing in Long Term Care Residential Facilities

Thank You!

I appreciate your time and attention today and am grateful for all the ways you are attending to the emotional and spiritual care needs of our residents and patients.

Please feel free to reach out any time with questions:

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