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## Increasing Adult's Awareness of the Importance of End-Of-Life Care Discussions

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Increasing Adult's Awareness of the Importance of End-Of-Life Care Discussions

Taylor M. Gardner

A Capstone project for the Bachelor of Arts in Human Development and Family Studies

## Increasing Adult's Awareness of the Importance of End-Of-Life Care Discussions

### Introduction

For many American families, end-of-life care is often not discussed, until advanced illness or injury has fully disrupted everyday life. There are many benefits to discussing end-of-life care prior to any medical complications. Research has shown that individuals who plan their end-of-life processes with a hospice service provider and family members report a higher quality of death than individuals receiving common health care during their final six months of life. In order to make families and friends more comfortable with end-of-life discussions, I will conduct two one-hour educational sessions to students at California State University, Monterey Bay.

### Need Statement

Death does not discriminate based on race, age, socioeconomic status, gender, sexuality, or any other identity. However, we still find families and friends avoiding the topic of death or experiencing death anxiety. Negative views of death even penetrate professional healthcare settings. Conventional physicians can easily form a negative view of death, because their whole job is to keep their patients alive and healthy. In 2014, the American Heart Association conducted a research project with conventional physicians and found that about half of the sample size felt hesitant bringing up the topic of end-of-life care with their patients. About 1 in 10 health care providers explained that they felt uncomfortable with the topic, because they felt that it would diminish the hope that their patients had (American Heart Association, 2014). However, individuals diagnosed with terminal illnesses still need assistance finding resources and care options while they work on accepting death. If health care professionals are not

comfortable introducing the topic of end-of-life care, then it is left to family and friends to hold these discussions.

In order to educate individuals on the importance of end of life discussions, it is helpful to understand why families and friends avoid the topic of death. According to Keeley (2017), some of this avoidance stems from cultural norms, religious beliefs, fear, and a family's view of "death as a taboo topic." Keeley (2017) argues that communication, in general, requires practice in order to be used effectively, so conversations around death are not exempt from this. As well, some may struggle from death anxiety, which is a general fear of mortality. Death anxiety occurs most often in early adulthood, because death during this stage of development is less common (Cavanaugh & Blanchard-Fields, 2019). Individuals experiencing death anxiety are especially less likely to begin conversations about end-of-life planning, so it is important to educate adults while they're young on the processes of death and how to make it easier on everyone.

While losing a loved one is sad, there are movements to normalize the conversation around dying and how the last few months of life will be spent. Rather than aiming to prolong someone's life, hospice care focuses on making the remaining time alive worth living (Forman, Kitzes & Sheehan, 2003). Hospice care is offered to patients who will not benefit from curative treatments and have been given a 6-month life expectancy by at least one physician (American Cancer Society, 2016). Terminally ill cancer patients receiving hospice care reported a higher quality of death (QOD) than patients with the same diagnosis who were receiving conventional care (Wallston, Burger, Smith & Baugher, 1988). The measurement of QOD was based off several dimensions of life: amount of pain; physical and mental functional status; emotional quality of life; social involvement with the informal social support system; and overall quality of

life. Depending on the health situations, not all patients are involved in the decision to enroll in hospice care, and research studies indicate that patients and families need early education and intervention in order to properly discuss the patient's preferences (Hirschman, Corcoran, Straton & Kapo, 2010).

End-of-life decisions do not have to remain constant over time, but it is important to have the most up-to-date preferences documented prior to any medical complications. If families are not discussing death and end of life care, they may begin hospice care too late or not at all.

### Theory Application

The theory I am applying in my project, Increasing Adult Awareness of End-of-Life Care Discussions, is Jean Piaget's Theory of Cognitive Development. Two elements of his theory of Cognitive Development that apply to my approach are abstract thinking and deductive reasoning. According to Piaget's theory, all individuals enter the Formal Operational Stage during adolescence and remain in that stage through adulthood. During the Formal Operational Stage, adolescents develop the ability to think in abstract ways; this allows individuals to imagine hypothetical situations using previous knowledge or assumptions. The participants in my project, college students, may still be developing their formal operational thought skills. Although they are likely to be able to think abstractly and hypothetically, they may not be thinking so far into the future about end-of-life. The participants will rely on abstract thinking to imagine possible scenarios and analyze how the conversation could improve. In addition, adolescents also develop deductive reasoning during the Formal Operational Stage. Deductive reasoning allows adolescents and adults to prioritize future events and create opinions about experiences they have not had yet. The participants in my project, will rely on deductive

reasoning to determine respectful and appropriate dialogue during a future conversation. They will use deductive reasoning to decide which path is the most appropriate. During my project students will also learn about different types of care; participants will rely on deductive reasoning to decide which options may interest a family member.

#### Consideration of Diversity

This presentation will be conducted with college students at California State University, Monterey Bay. According to the university demographics, 42% of the student body is Latino, 29% is White, 8% is Asian American, 5% is African American, and both Native American and Pacific Islander are 1% of the student body (Institutional Assessment & Research, 2019). The participants for this project were from multiple majors, such as psychology, collaborative health and human services, and social and behavioral sciences. There were fifty-one participants in the project, and only ten of them were males. Students identifying as low income make up a third of undergraduates enrolled in the Spring 2019 semester, so it is important that this project provide resources for low income families. Hospice care provides financial flexibilities through a communal approach to comfort care and acceptance of Medicaid and MediCal.

Most of the resources for this presentation were provided in English, therefore participants will need to be proficient in English to engage in the activities, respond to the surveys, and understand the information presented to them. The resources from The Conversation Project can be found in multiple languages, including Spanish, if necessary. The structure of the educational sessions allows for mobility of the project, however I believe it is necessary to use a projector for the slideshow presentation.

### Learning Outcomes

In pursuance of increasing the awareness of the importance of end-of-life care discussions, I will provide two hour long educational sessions for students at California State University, Monterey Bay. This project will educate adults on what hospice care is and how to discuss the end-of-life decisions with family members.

By the end of the educational session, the participants will:

1. Describe appropriate conversation starters for end-of-life care discussions.
2. Distinguish the difference between hospice care and conventional care.
3. Identify common myths about hospice care.

### Method

First, I introduced myself to the students and explained why I was guest lecturing. I explained a little about what they would learn during the educational session. Then, I asked the participants to respond to a half-sheet survey (*See Appendix A*). This survey assessed the existing knowledge that the college students may have learned in lectures discussing lifespan processes. Then, I shared a video from The Conversation Project about practicing conversation starters for discussing end-of-life planning with someone (The Conversation Project, 2017). Then, I asked the participants to recommend examples of conversation starters and recorded the responses on the whiteboard.

In the second segment, I provided a fifteen-minute lecture on end-of-life care planning and care options with a slideshow (*See Appendix B*). During the lecture, I highlighted the main differences between conventional care and hospice care services. Then, I introduced common myths about hospice care, and I explained the truth behind each myth. During the presentation, I

provided examples from my own experience working with terminally ill patients through Heartland Hospice.

The last part of the informational session consisted of a role-play activity from The Conversation Project that provided an example scenario of an end-of-life care discussion between family members (*See Appendix C*). I separated the sessions into groups of four and gave them each a copy of the script. I provided the groups approximately twenty minutes to read through the script and discuss what they believe should have been done differently. During this time, I walked around the groups to provide assistance or clarification as needed. When the groups finished their discussions, I asked them to report back to me their opinions of what could have been done differently. I asked them how they felt each character contributed to the mess in the scenario. I, also, asked them if they could imagine this happening between some of their family members. After the discussions ended, I handed out the post-survey (*See Appendix D*) to assess the knowledge that the participants gained during the educational sessions.

### Results

Learning outcome one was that the participants would describe appropriate conversation starters for End-of-Life Care discussions. This learning outcome was measured by collecting free-response answers and recording them on a whiteboard. After both sessions, I analyzed the responses and sorted them into a table to better understand the results (*See Table 1*). I believe this learning outcome was not met, because only eleven out of the fifty-one participants suggested appropriate conversation starters for end-of-life discussions. All of the responses provided by the participants met the criteria discussed in the slideshow presentation (*See Slide 4 of Appendix B*).



However, not even half of the participants provided appropriate responses to the prompt, so I felt that this learning outcome was not met.

Learning outcome two was that participants would distinguish the difference between Hospice Care and Conventional Care. Learning outcome two was measured with a survey at the end of the educational session. Each participant was asked to define the purpose of conventional care and hospice care in their own words. Correct definitions for hospice care's purpose were: 24-hour care for individuals with six months to live, improving quality of life rather than quantity, and end-of-life care and support for the patient and their family. Accepted definitions for conventional care's purpose were: using medicine to heal a patient, aggressive treatment to prolong life, hospital care aimed to solve health problems with medicine or surgery. There survey responses that stated services of hospice care and conventional care, however, if the responses did not mention any of the definitions mentioned above, then they were considered incorrect. The focus of this learning outcome was to distinguish the main difference between two types of care, so the responses needed to reflect those differences. I believe this learning outcome was partially met, because there was a significant increase in correct definitions between the pre-survey and post-survey results (*See Table 2 & 3*). Before the presentation, only 19% of the participants were able to correctly define the purpose for both types of care. At the end of the educational sessions, 68% of the participants were able to correctly define the purpose of both types of care. These results show that learning outcome two was partially met, because over half of the participants were able to distinguish the difference between hospice care and conventional care.

Learning outcome three was that participants would identify common myths about Hospice Care. This learning outcome was also measured through the survey that was distributed at the end of the educational sessions. The myths were posed as true or false statements, and the participants should have identified them all to be false. The results from the pre-survey showed that most participants believed at least three of the statements to be myths (*See Table 4*). The results from the post-survey showed that all of the participants identified at least three myths. After the educational session, twenty out of the fifty-one participants identified all six statements as myths about hospice care. I believe this learning outcome was partially met, because there was a significant increase in myths identified in the post-survey compared to the pre-survey. The two most commonly misidentified myths were “Hospice is for the last days of life” and “Hospice is about dying.” During the presentation, I specified that hospice care is for the last six months of life, however I believe that participants felt that those two myths were different ways of saying the same thing. If these two myths were reworded, I feel that this last learning outcome would have higher results.

### Discussion

I believe that this project was not successful, because two of the three learning outcomes were partially met and one was not met. Although many of the participants discussed new strategies for discussing end-of-life care, not all of the necessary information was absorbed for future use. I felt that the participants engaged in abstract thinking and used deductive reasoning during the educational sessions, however, I do not feel like all of them are comfortable with discussing end-of life care. There are improvements to this project that could be made to receive higher results.

One improvement that could be made to this project would be to require the participants to remove all electronic devices prior to session beginning. Due to the location of this project, lecture students were allowed to use their laptops during the guest lecture. Therefore, participants were distracted by their own devices for the beginning of both informational sessions. Students were mostly distracted during the first activity and learning outcome, which I believe influenced the low results for this activity in both sessions. Another improvement for this project would be extending the sessions from 60 minutes to 90 minutes. During this extra time, the project facilitator would integrate more role-play practice for end-of-life care discussions. The participants showed the most critical thinking and deductive reasoning during the role-play activity and discussion. I believe that allowing the participants more time for guided discussions in small groups, rather than responding to open questions from the facilitator, would increase the amount learning during the project. One more improvement that I would like to suggest would be to provide information in a step-by-step format, for example the slide presentation could be formatted in a more chronological order of events for the participants to repeat later. The conversation starters activity could remain at the beginning, however then the facilitator could move on to advising participants what to do during and after having an end-of-life discussion. Although the information was provided, I feel that the order in which the information was formatted confused students and necessary information was mottled.

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# INCREASING ADULT AWARENESS END-OF-LIFE CARE

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Table 1

*Responses for Activity 1: What are some appropriate conversation starters for End-of-Life planning discussions?*

Compare planning method to other deceased relatives (both sessions)	Share personal preference and compare (both sessions)	I heard about private company that can assist decision-making discussed in both sessions)
“I read an article about hospice...”	“Can we talk about something important?”	“This lady came to my class today, and....”
“Would you prefer to be buried or cremated?”	Discuss music to play at funerals	

Table 2

*Conventional Care and Hospice Care Definition Results – Pre-Survey*

## Pre-Survey Definition Results

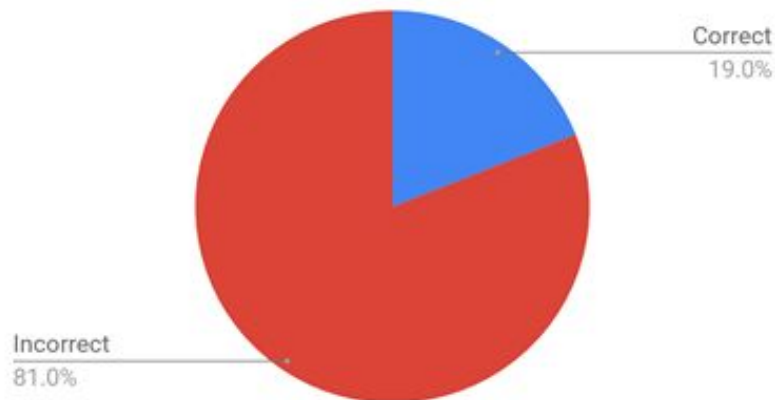


Table 3

Conventional Care and Hospice Care Definition Results – Post-survey

Post-Survey Definition Results

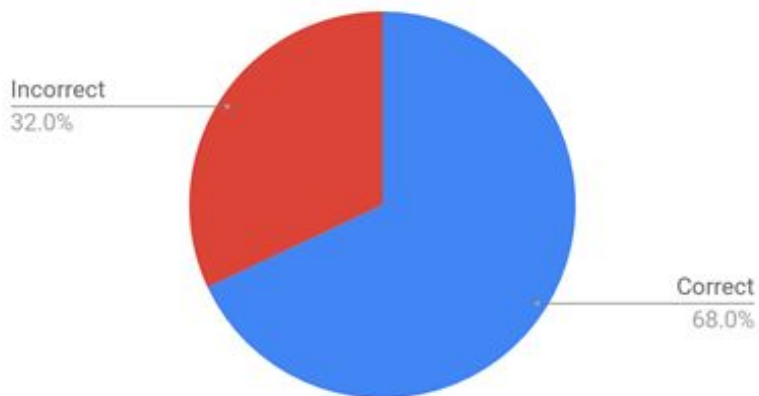
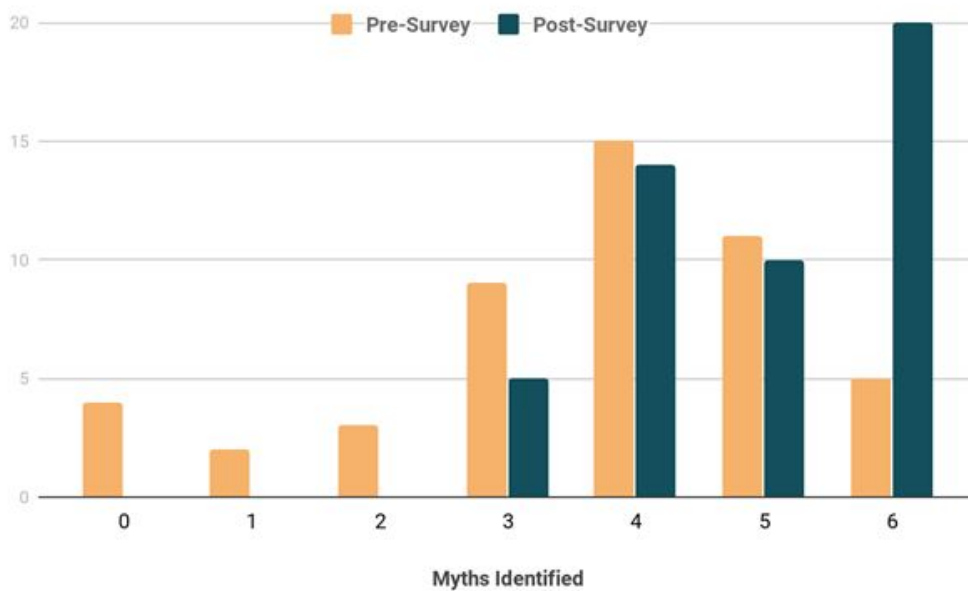


Table 4

Myths Correctly Identified in Surveys



*Appendix A*

*Pre-survey measuring existing knowledge of participants*

## End-Of-Life Planning

Have you ever discussed end-of-life planning with your family? \_\_\_\_\_

When is it a good time to discuss the end-of-life process?

---

What is the purpose of Conventional Care?

---

What is the purpose of Hospice Care?

---

True or False:

\_\_\_ Hospice is about dying.

\_\_\_ Hospice is only for the patient.

\_\_\_ Hospice is a place.

\_\_\_ Hospice is for the last days of life.

\_\_\_ Hospice is only for cancer patients.

\_\_\_ Hospice only provides daily care.

*Appendix B*

*Powerpoint on End-of-Life Planning*



Getting Comfortable with  
End-of-Life Discussions  
Taylor Gardner

### Why should we talk about dying?

Katherine Sleeman, Palliative Medicine Registrar at the Cicely Saunders Institute: "We prepare about the arrival of a new baby, we plan for it, we think about what we are going to buy and what we are going to call the new baby. It is part of our daily life, our conversation. Why do we not prepare for our death in the same way? I would like everyone to have a good death but we can't achieve that unless we as a society stop whispering and start talking about it."[1](#)

---

## End-of-life Planning Includes

1. The goals of care
  2. Where the care will take place
  3. Which treatments will be considered
  4. Creating an Advance Health Care Directive
  5. Writing a Will
  6. Planning a Funeral or Memorial Service
-



## It's a conversation...not a debate

- Appropriate Setting
- Ask Permission
- Know What to Expect
- Be a Good Listener

---

### Here are some ways you could break the ice:

"I need your help with something."

"Remember how someone in the family died—was it a 'good' death or a 'hard' death? How will yours be different?"

"I was thinking about what happened to , and it made me realize..."

"Even though I'm okay right now, I'm worried that , and I want to be prepared."

"I need to think about the future. Will you help me?"

"I just answered some questions about how I want the end of my life to be. I want you to see my answers. And I'm wondering what your answers would be."

## Questions to Ask

- If you were diagnosed with a life-limiting illness, what types of treatment would you prefer?
  - What would a good day look like?
  - How you named someone to make decisions on your behalf if you become unable to do so?
  - How would you like your choices honored at the end of life?
  - What can I do to best support you and your choices?
  - As You Reach the End of Your Life, Do You Want to Die at Home or Is Hospice Care, Including Palliative Care, an Option for You?
  - What are your fears about this topic?
  - What are the trade-offs you are and are not willing to make?
- 

## End-Of-Life Care Strategies

- Traditional/Conventional Care- cure patient of disease or heal intense injuries.
- Palliative Care- mitigate consequences of disease rather than mitigate the disease
- Hospice Care- reduce discomfort during the last 6 months.

## Conventional Care

A system in which medical doctors and other healthcare professionals (such as nurses, pharmacists, and therapists) treat symptoms and diseases using drugs, radiation, or surgery.

<https://www.cancer.gov/publications/dictionaries/cancer-terms>

## Hospice Care

A program that gives special care to people who are near the end of life and have stopped treatment to cure or control their disease. Hospice offers physical, emotional, social, and spiritual support for patients and their families. The main goal of hospice care is to control pain and other symptoms of illness so patients can be as comfortable and alert as possible.

---

## Conventional Care

- Aggressive/Curative Treatment
- Any time after diagnosis
- Life-Support Systems
- Big Medical Teams
- Hospital, Care Unit

## Hospice Care

- Comfort/Relief Treatment
  - Life Expectancy of 6 mos.
  - Medical and Emotional Support
  - Financial Flexibility
  - In-Home, Assisted Living, Nursing Homes
-

## Hospice Services

- Intermittent visits by team
  - Coordination of care between all involved
    - nurses, social workers, chaplains, hospice aides and volunteers
  - 24-hour phone availability for nursing consults to answer questions
  - Medications for symptom management related hospice diagnosis
  - Short-term respite care
  - Short term inpatient care for complicated symptom management
  - Office visits with your attending physician
  - Ambulance transport to and from respite or short-term inpatient care
- 

## Myths About Hospice

- *Hospice is only for cancer patients.*
    - Anyone with a disease causing a limited life expectancy of six months or less is eligible for hospice care. (Alzheimer's and other types of dementia, chronic obstructive pulmonary disease, congestive heart failure, stroke, and ALS)
  - *Hospice is only for the patient.*
    - The team also focuses on family, friends, and caregivers to offer emotional support.
  - *Hospice will only provide daily care.*
    - While hospice provides many services, including intermittent visits from, it does not provide services for daily personal care, medication, nor heavy transfers. Around the clock care needs are provided by family, friends, paid caregivers, and/or facility staff.
-

*Appendix C*

*Roleplay activity from The Conversation Project*

## The Conversation Project in Boulder County-Role Play

Characters:

- Narrator
- Nancy: mother and the terminally ill person
- Anita: daughter
- Bob: son

**Narrator:** The setting is a hospital in Albuquerque, New Mexico. Daughter Anita (age 48) has just arrived from Colorado after being summoned by her mother. The mother, Nancy (78) has told her daughter that she has been diagnosed with Stage 4 melanoma that has already spread to her brain. She asks Anita to come as soon as possible. Anita arrives 2 days later. Nancy had been having headaches for weeks and a seizure took her to the hospital 4 days ago.

**Anita:** Hello mom. Oh, I am so sorry to hear about what is happening with you. I am sorry that I couldn't come right away. I had some important work meetings. Tell me what the doctors are saying.

**Nancy:** They tell me that this is very serious and that I won't recover. One oncologist said that they can give me chemotherapy to "hold it at bay" for a while. The neurologist, however, didn't seem to think that chemo would be effective. I have seen friends go through chemotherapy and I just don't want to do it. I really want to go home. They made me wait until you got here because of the seizures. The social worker was in and mentioned hospice. That is what I want to do. Remember, that I have named you as my decision-maker.

**Anita:** You mentioned that on the phone. I didn't think you were serious. Bob is the oldest. Does he know about that? He was Dad's decision-maker and I thought he was yours, as well. When is he coming?

**Nancy:** I called him yesterday and he will be here in two days. I didn't talk to him about anything. You know that I was not happy with how he handled things with your father. Even though your dad said he did not want heroic measures, Bob insisted on that pacemaker, which only prolonged things. Fortunately, I don't think your father knew what was going on, but I sure did and I think he suffered, needlessly. I don't think I can trust him to do what I want.

**Anita:** I don't think he is going to be happy about this. Is he still the executor of your estate?

**Nancy:** Yes, I did leave him in charge of all of that. Anita, I really don't want to talk about this anymore. We can look at the paperwork after I get home.

**Narrator:** Nancy went home but that evening, she had more seizures and was becoming less lucid. Anita was able to find the advance directive paperwork, which was signed and notarized two weeks earlier. Anita found additional copies in the envelope. Had NANCY intended to send them to her children?

\

*The next day, Bob arrives.*

**Bob:** Hello Anita. How is mom doing?

**Anita:** Not well at all. The hospice nurse and social worker came by this morning. They are giving her morphine and a sedative for the pain and restlessness. She is lucid when awake but miserable.

**Bob:** I don't understand why she didn't want the chemotherapy. I spoke with the doctor yesterday and he seemed to think that it would help to shrink the tumor and buy her more time. I am going to talk to her and convince her to do that. I want to take her back to the doctor and see if he can talk some sense into her.

**Anita:** Bob, she doesn't want that. Furthermore, she has given me permission to make decisions for her when she cannot.

**Bob:** Hey...since when? I have a copy of the documents that she and Dad did 5 years ago, with that lawyer of theirs. I am her decision-maker.

**Anita:** Well, she changed her mind and appointed me. She saw what a hard time you had honoring Dad's wishes.

**Bob:** I cannot believe this! Let me see those papers! And I cannot believe you. Are you simply going to let her die without putting up a fight? How irresponsible can you be? Are you trying to get rid of her? Is it too much of an inconvenience for you to be here to take care of her? Is that what this is about? I need to go and talk to Mom.

**Anita:** Don't go in there and upset her. She has her mind made up. She talked it over with the oncologist. Of course, they wanted her to have treatments but she was very clear with both of her doctors.

**Bob:** Anita, you are going to regret this. How do I know if you are telling the truth about what she wanted? What kind of a daughter are you, anyway?

**Narrator:** Bob and Anita went into the back bedroom and found Nancy in a deep sleep. Bob tried to rouse her but she was very groggy and couldn't talk to him. He stormed out and went to stay at a hotel nearby. The next morning, Nancy was no clearer. She died 2 days later, with Anita and Bob at her side. She had made arrangements at the time of her husband's death to be cremated but she had left no other directions and Bob and Anita squabbled plenty as they put together a memorial service for her.

*Because Bob was the executor, he made decisions about Nancy's financial matters. To this day, they are barely speaking and Anita is certain that Bob did not fairly handle the distribution of her mother's meager estate.*

*DISCUSSION: What went wrong here? What might have helped this to go better? Could this happen in your family?*

*Appendix D*

*Post-Survey to measure Learning Outcomes 2 and 3*

## End-of-Life Planning

1. When is it a good time to discuss the end-of-life process?

---

2. What is the purpose of Conventional Care?

---

3. What is the purpose of Hospice Care?

---

4. True or False:

Hospice is about dying.

Hospice is only for the patient.

Hospice is a place.

Hospice is for the last days of life.

Hospice is only for cancer patients.

Hospice only provides daily care

*Appendix E*

*Capstone Slideshow*

## Increasing Adult Awareness of End-Of-Life Care Discussions



Taylor Gardner

## The Need

- ❖ End-of-life Care Discussions:
    - Increases quality of life for caregiver and individual
    - Reduces unnecessary spending
    - Allows individuals to voice concerns or final wishes
    - Improves bereavement process for families
  
  - ❖ Health care professionals recommend individuals discuss end-of-life plans before health conflicts arise.
  
  - ❖ Hospice Care
    - Reduced pain
    - Higher physical and mental functions
    - Increased emotional quality of life
    - Increased social involvement
- 

## Theory of Cognitive Development - Piaget

Formal Operational Stage:

- ❖ Adolescence through adulthood
  - ❖ Abstract thinking and metacognition
  - ❖ Deductive reasoning allows us to plan and organize our lives systematically.
- 
- ★ Participants are able to analyze hypothetical situations and create opinions without actual experience.
-



## Procedures

- ❖ Two 60 minute educational sessions
- ❖ CSU Monterey Bay in Seaside, CA
- ❖ 51 students interested in social work and community health professions
- ❖ Activities:
  - Pre-survey
  - Brainstorm end-of-life care conversation starters
  - Lecture overview of end-of-life care options
  - Discussion role play
  - Post-survey



## Learning Outcomes

### Participants will...

- 1) Describe appropriate conversation starters for end-of-life planning discussions.
- 2) Distinguish the difference between Hospice Care and Conventional Care.
- 3) Identify common myths about Hospice Care.

## Results

Compare planning method to other deceased relatives	Share personal preference and compare	I heard about private company that can assist decision-making
"I read an article about hospice..."	"Can we talk about something important?"	"This lady came to my class today, and...."
"Would you prefer to be buried or cremated?"	Discuss music to play at funerals	

Learning Outcome 1:  
Describe appropriate conversation starters for end-of-life planning discussions.

11 out of 51 participants provided appropriate conversation starters.

LO 1 was not met.

## Results

Learning Outcome 2: Distinguish the difference between hospice care and conventional care.

2. What is the purpose of Conventional Care?  
Hospital/Medicine care w/ licensed providers

3. What is the purpose of Hospice Care?  
Provide comfort for those diagnosed w/ little to live & friends & family support

4. True or False:

2. What is the purpose of Conventional Care?  
Conventional care is when you use regular medicine to heal & prevent.

3. What is the purpose of Hospice Care?  
To help people in their final months of living.

2. What is the purpose of Conventional Care?  
Conventional care helps to aid and control a disease through treatment/medicine (hospital setting).

3. What is the purpose of Hospice Care?  
The purpose of hospice is to make someone feel comfortable while there at the last 6-months of life.

4. True or False:

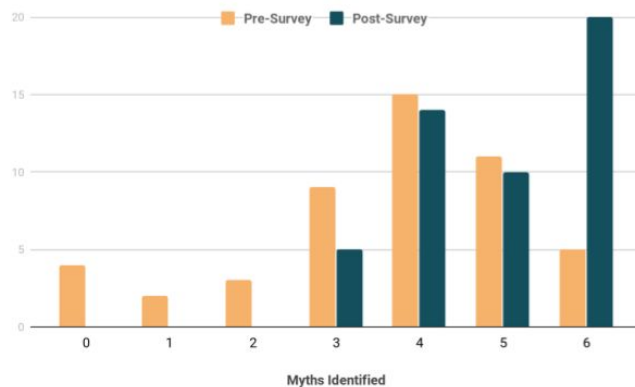
Pre-survey: 19% correctly defined both types of care  
Post-survey: 68% correctly defined both types of care  
LO 2 was partially met.

## Results

Learning Outcome 3: Identify common myths about hospice care

20/51 correctly identified all myths.

LO 3 was partially met.



## Discussion

- ❖ 2 in 3 Learning Outcomes were partially met
- ❖ Improvements:
  - Extend sessions to 90 minutes
  - Integrate more role-play practice
  - Provide step-by-step resources



**Thank you**

Questions



Increasing Adult Awareness of  
End-Of-Life Care Discussions

Taylor Gardner