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Increasing Awareness In End Of Life Care For Human Development And Family Studies Students

Nathan Ironside

HDEV 400A

California State University Of Monterey Bay

Capstone Proposal

Introduction

Much of the focus for Human Development and Family Studies "HDFS" students is on childhood and adolescence rather than late adulthood. If students are planning on working with families in the future, it is important that they understand the kinds of issues involving older adults. Since these students could be working with families with terminally ill elders, they need to know what the options are for the families and the terminally ill. Additionally, terminally ill elders need to understand their rights regarding the kind of care they are entitled to. If terminally ill elders understand the quality and type of care they are entitled to then this will help in recognizing malpractice and maltreatment towards the terminally ill elders. The two most common end of life options are hospice and palliative care. The proposal's focus was on hospice care issues and touched lightly on what palliative care is. It is important that the students working with families understand the rights of families and the terminally ill. For the project, I created a narrated PowerPoint presentation in order to teach HDFS students at CSUMB about Hospice care for older adults. The project was conducted at the CSUMB campus and aimed at HDFS students. The focal topics of the presentation are on hospice care and the rights of the families and the elderly in the program. I covered all areas about what kind of service terminally ill elders are entitled to, and what they can do if they encounter malpractice.

Needs Statement

In Erikson's lifespan theory, late adulthood begins at the age of 65 (Svetina, 2014). According to Erikson's theory, late adulthood is the integrity vs. despair stage (Svetina, 2014). Elderly adults have a unique set of developmental issues they potentially encounter in this stage of development. When confronting the inevitability of death individuals in the late adulthood stage tend to focus most of their attention on emotionally meaningful goals and activities. Individuals in the late adulthood stage have had many different experiences allowing them to be able to focus their attention on what they find meaningful in their life. According to Charles, S. T., & Carstensen (2010), this process is called the socioemotional selectivity theory. The socioemotional selectivity theory is the process of being very selective with the choices they make for the day, or who to spend their time with. The idea is to be able to maximize their remaining time with people or activities that will bring them the most for their emotional investment. At this stage, older adults can start to experience many physical and cognitive limitations which can cause a lot of frustration. The brain starts to lose its plasticity and memory is affected by the aging process. Their reaction time is slower and they continue to lose muscle strength, vision, hearing, and their immune system starts to weaken. With their loss of muscle, reaction time, vision and hearing mobility becomes a real issue for them causing frustration and added stress. In addition to their physical decline their information processing abilities also steadily decline with age (Kuther, 2019). For example, attention, memory, and processing speeds are affected by aging. Another challenge for older adults is coming to terms with the fact they will die at some point.

During this time of development elderly patients who are terminally ill experience, according to Kubler-Ross, either all five of the psychological stages of grief or just one of them.

These stages are not in any specific order, but they are experienced in some sort of fashion that the hospice team tries to help the patient and the family deal with (Kuther, 2019). According to Kubler Ross, the five stages of grief are denial, anger, bargaining, depression, and acceptance. The five stages of grief could be applied to the terminally ill emotions during this final stage of development. Kubler Ross has been considered a pioneer for this stage of grief for the terminally ill and has provided a blueprint for caregivers to help the terminally ill through these stages. Now, caregivers and family members can have a better understanding of what the terminally ill are experiencing through this difficult stage in their development.

At any time, the numerous needs of the elderly who are terminally ill can be overwhelming for the patient and their family. Hospice teams are equipped to handle these procedures for the patients and their families. A hospice care team is a special group of healthcare professionals who focus on patients with life-limiting illnesses and their families. Generally, the team includes a physician, nurse, hospice aide, social worker, volunteer, chaplain, and bereavement specialist. They also incorporate a religious aspect to their care if that is something that is desired for the patient and the family (Broom, 2012). There are seven pains that all terminally ill patients experience, physical pain, spiritual pain, intellectual pain, financial pain, bureaucratic pain, emotional pain, and interpersonal pain (Kuther, 2019). All of these pains or needs for the terminally ill is what the hospice team will address. In addition to these needs are also their basic needs to ensure their quality of life, which is another area hospice is to provide on a regular basis. Quality of life and pain management are of the utmost importance for hospice care so this type of care can be done at the patients' discretion.

Moreover, hospice care is for those who have been considered terminally ill and the illness is not responding to the treatments anymore. Also, the doctor expects the patient to die within the next six months (NIH, 2017). At this point, patients will no longer receive treatment for the illness, instead, the doctor and nurses will treat pain symptoms. If the patient does not die within the six month period another evaluation from the doctor is necessary to stay on the hospice program. Hospice care is not only for the patient but also for the family as well. Hospice will help the family through this difficult time and train them to help their loved one who is dying. In contrast, palliative care is strictly focused on their pain and dying concerns (NIH, 2017). With palliative care, the patient has as much control over their death as possible. Unlike hospice, palliative patients can continue to receive treatment for their terminal illness. The staff will issue pain medications as often as possible to keep the patient from being uncomfortable and with no pain. The issue with giving pain medications such as morphine is that they are known to accelerate death (Plonk & Arnold, 2005). Patients cleared for hospice care can be covered by Medicare, but palliative care is not guaranteed to be covered.

However, the issues that arrive from hospice care can be based on the misunderstanding of what hospice can and should do. Nevertheless, these misunderstandings are considered neglect which is a form of maltreatment. Since hospice will not treat the illness, many times nurses will ignore obvious signs of medical treatment needed to sustain life. There have been documented cases of the terminally ill person's family calling 911 because the staff at the hospice facility would not resuscitate or finds ways to keep the patient alive. The staff would mention that if it is not part of the detailed plan then they are not allowed to intervene. This can be frustrating for the family, but if the patient has signed a do not resuscitate document (DNR) then there is nothing

that can be done. The issue that comes up though is when they do not have a DNR and they still do not resuscitate then it is neglect. The hospice team is to prepare them for death, not to save them from it (Smith, 2011). In this specific case, the 91-year-old woman was later picked up by an ambulance and transported to a hospital where they found eleven maggots on a wound found on her big toe. She died of sepsis brought on by gangrene on her big toe. She died because of neglect from the hospice team and not from her illness which is what would have been acceptable according to hospice rights (Jayawardena & Liao, 2006). The morality behind hospice is to whether or not save someone from dying or continue to tend only to their pain symptoms.

HDFS students need to know of the complications that can arise to better aid the family. It is very important for HDFS students going into social work and counseling to understand the rights of the families and the terminally ill to help aid in this time of need. The need is there for their families to gain as much knowledge as possible to ensure that their loved one will have the best quality of life during this final stage of development. Social workers and counselors need to be equipped with knowledge about the rights of the families to better assist them during this difficult time.

Theory And Development

The intended audience for the narrated powerpoint project was geared toward late adolescence and early adulthood, specifically for HDFS CSUMB students. According to Piaget, twelve years of age and older are in a stage of development that he refers to as formal operational thought. (Kuther, 2019). It is during this stage of development early adults can begin to think in a scientific manner like generating predictions. This age group is capable of approaching problems with a systematic approach, rather than through trial and error like concrete operational thought

processes. Also, according to Erikson's stage theory, early adults have different psychosocial concerns than adults in late adulthood (Sventina, 2014). The narrated powerpoint project will help college students in early adulthood understand the concerns and challenges of adults in late adulthood. The capstone project was administered to HDFS CSUMB students where the common age for these students is 18 to 35 years of age. According to Piaget, these students are in formal operational thought and for this project, this is a necessity to understand the complicated grieving process adults in the late adulthood stage experience with end of life decisions.

The research that has been conducted on hospice care are from scholarly and peer-reviewed articles, making it pertinent that all participants are in the formal operational thought to understand the content that will be discussed with them. Understanding the concepts of death and dying and that dying is an inevitable final stage of human development is a complicated issue that does not have one answer. This would require the participants to be in formal operational thought to understand the concepts being discussed. The complicated concepts of understanding that there are many options to helping someone grieve would require the participants to be in the formal operational thought.

Consideration Of Diversity

Since this narrated powerpoint project is aimed at college students, there is a likelihood of some participants being of lower socioeconomic status. Most college students graduate with a considerable amount of debt and the demands on time college require its students makes having a job difficult while in college (Baker, 2018). It could range from low-income to lower-middle-

class, but the typical college student is within these ranges. Since most college students are considered to be low-income or lower-middle-class, having access to a computer or smartphone to access the emailed powerpoint project could be difficult for students. CSUMB offers free access to computers in the library as long as the students sign in with their Ilearn login information. Ilearn is for CSUMB students enabling them online access to their classes and to CSUMB online access. Having free access to a computer will allow CSUMB students to be able to participate in the project. Moreover, the narrated powerpoint project will be conducted through email to HDFS students at CSUMB. CSUMB has diverse demographics of students, but it does have a high amount of Latino students. The demographics of CSUMB are 42% Latino, 29% caucasian, 8% Asian American, 8% two or more ethnicity, 7% other or decline, 5% African American, 1% Native American, and 1% Pacific Islander. I will be presenting this powerpoint project in English, so the participants will have to be proficient in the English language.

Learning Outcomes

The focus of this narrated powerpoint presentation is to increase awareness in end of life care for HDFS students. The presentation covered knowledge of end of life care, end of life care options, rights of the patients and families, the terminally ill emotions during this final stage in development, and maltreatment. They were four outcomes that were assessed.

1. HDFS students will be able to identify two important facts about hospice care.
2. HDFS students will identify two differences between palliative care vs hospice care.
3. HDFS students will identify maltreatment from hospice staff.
4. HDFS students will identify two facts about the rights of the families and the terminally ill involving hospice care.

Method

Participants

The participants for this online project consisted of HDFS students from a CSUMB capstone class, located at Seaside, California. There were seven participants, but only five participants completed both assessment quizzes. The age group of the project participants ranged from 18 years old to 35 years old. The sociodemographics could not be determined but the CSUMB demographics for the university, which were previously mentioned, could apply towards the group of participants. The education level for the participants is senior standing at CSUMB.

Procedures and Materials

The presentation was an online workshop and the project was completed on November 23, 2019. The last participant for the project was completed on December 4, 2019. First, it is important to know that this online workshop had my voice integrated into each slide with the goal of educating the participants on end of life care. For the first slide, I introduced myself and the topic to be discussed. Next, I introduced what is end of life care, and the types of end of life care options for the elderly. Then, I showed a video explaining the difference between palliative care and hospice care. After that, I had the first assessment quiz. Participants were to highlight and copy the link onto their web browser and click on the search button. Following these instructions, the participants had to complete the assessment quiz. The first quiz was to assess the first two learning outcomes.

Subsequently, the following slide covers the five stages of grief theory as it applies to the terminally ill. Then the next slide touched on the rights of the terminally ill patients and their families. This slide also asked patients to highlight and copy the link, then paste the link into their web browser. The link is an official document of the rights of the patients and their families. Thereafter, the narrated project moves on to the subject of maltreatment. Finally, the next slide asks participants to highlight, copy, and paste the link into the web browser and complete the final assessment quiz. This assessment quiz was for assessing whether the participants mastered learning outcomes three and four.

The way the participants were assessed was through two separate quizzes which assessed whether or not the participants mastered the learning outcomes. The data was analyzed from the participants through google forms. Google form is a program that allows the user to create quizzes and help the user analyze the data. Each participant was to answer two questions correctly in order for the learning outcome to considered mastered. If the participant answered one question correctly then it was considered not mastered.

The materials used for this project were a laptop, research papers, headphones to integrate my voice into the slides, the computer program Microsoft PowerPoint, and the computer program google form. The laptop was the device used to conduct the project along with a pair of headphones to ensure clarity of voice integration. The computer program Microsoft PowerPoint was the program used to create the narrated presentation. Finally, the last material used was the computer program Google Form which was used to create the assessment quizzes and to analyze the data.

Results

The results were assessed through a program called google forms. In order for the learning outcome to be considered mastered the project participants had to give two correct answers for each question. Learning outcome 1 was that HDFS students will be able to identify two important facts about hospice care. This learning outcome was in between not met and partially met. The reason it is in between is that 42% of the participants answered the question assessing the first learning outcome correctly. Since it was answered with a low success rate, this learning outcome was considered to be in between not met and partially met. Some of the blame for the low success rate could be because of the answers being confusing. Also, the directions could have been confusing to understand. Some of the participants only gave one answer to the question which resulted in an automatic wrong answer. See table 1 for the question assessing the learning outcome along with the results for the question.

Learning outcome 2 was HDFS students will identify two differences between palliative care vs hospice care. This learning outcome was considered to be partially met but still considered to be a success. This learning outcome was considered to be a success because 71% of the project participants answered the question correctly. The video that was showed for this learning outcome could have aided in the high success rate. See table 2 for the question and results for the second learning outcome.

Learning outcome 3 was HDFS students will identify maltreatment from hospice staff. This learning outcome was partially met but also at a high rate of success. The success rate was 80% of the participants answered the question correctly. The number of participants dropped from 7 to 5 because either they did not understand the directions that two assessment quizzes were required or the link did not work for them. Overall this learning outcome was a success

because 4 out of 5 participants mastered the learning outcome. See table 3 for the question and results for the third learning outcome.

Learning outcome 4 was HDFS students will identify two facts about the rights of the families and the terminally ill involving hospice care. This learning outcome was partially met but at a low rate of success. The success rate was 40% of the participants answered the question correctly. The reason for the low rate of success could have been because the participants did not understand the directions to give two answers. See table 4 for the question and results for the fourth learning outcome.

Discussion

The online project focus was on increasing awareness in end of life care for HDFS students and I do believe this project was a success. The project was successful in increasing HDFS students knowledge on end of life care. Learning outcomes 2 and 3 had a high rate of success and learning outcomes 1 and 4 had a lower rate of success. Although learning outcomes 1 and 4 had a low rate of success I do believe the project was still a success because the low rate can be attributed to unclear directions and not having the ability to ask questions during the assessment. The answer they gave still showed they grasped the concept of the learning outcomes but they just did not give two answers to the question. For learning outcome 3 the high rate of success could have been because the participants already had education on elder abuse. The results coincide with Piaget's theory of cognitive development. The participants were able to understand the content and answer the questions successfully. Since the participants are in formal operational thought they were able to complete the online workshop successfully.

There were a few limitations to the project which include fine-tuning the project some

more. Some questions and answers were not as clear as it could be which is why some participants only give one answer for the questions instead of the required two. Also, 2 out of 7 participants only completed one of the required two assessments. The limitations of the narrated PowerPoint coincided with the results. The participants could not ask questions before or during the assessment or during the presentation. This would have cleared up any confusion about the material and what was required. For the future direction for this online project would be to change it from being an online workshop to a face to face presentation. This would clear the confusion that was experienced with the online project. The participants could ask questions if the material was unclear and they could ask questions during the assessment quizzes. Also, I could check the quizzes when they completed them to make sure they gave two answers to each question.

The online project was inclusive for HDFS students. If the participants have Microsoft PowerPoint they could click on the translate icon. This button will translate the content into subtitles on the bottom of the screen. This project could be used to educate the families looking to enroll a loved one into a hospice program. The online project would have to be altered so it is easier to understand. The project could also be applied to other colleges that offer Human Development as a degree to further their education in late adulthood specifically end of life care.

All in all the project was a success but I would have to change the format from online workshop to face to face workshop. This would make the data more comprehensible in seeing if the participants understand the content or not. Nevertheless, the participants learned from the content and they furthered their knowledge in end of life care.

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Table 1

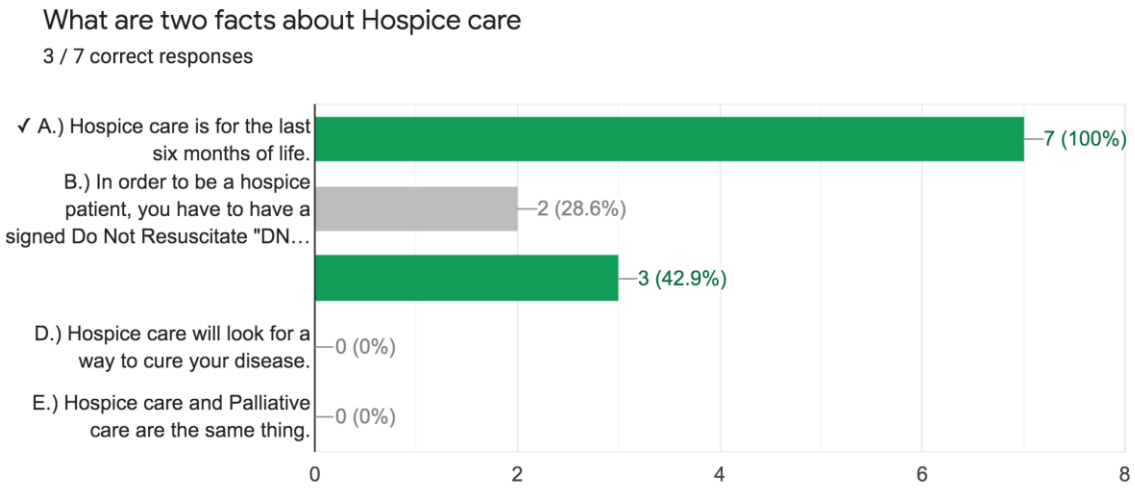


Table 2

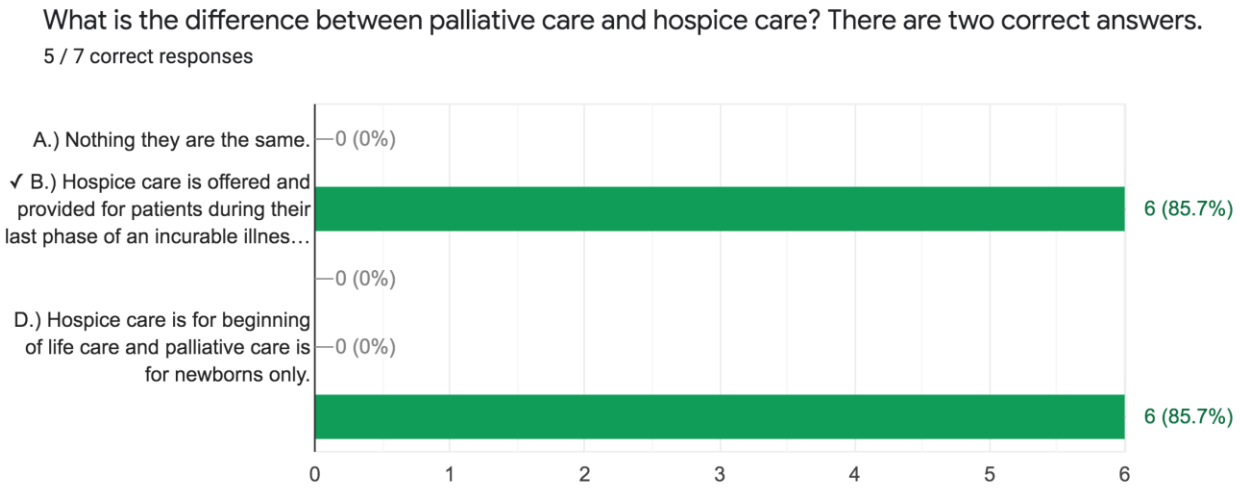


Table 3

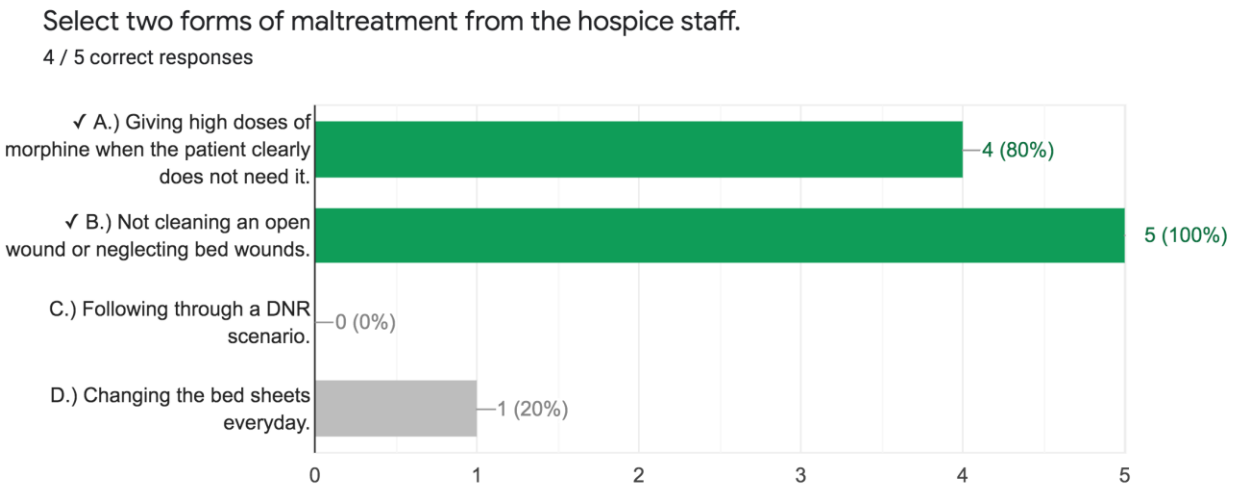
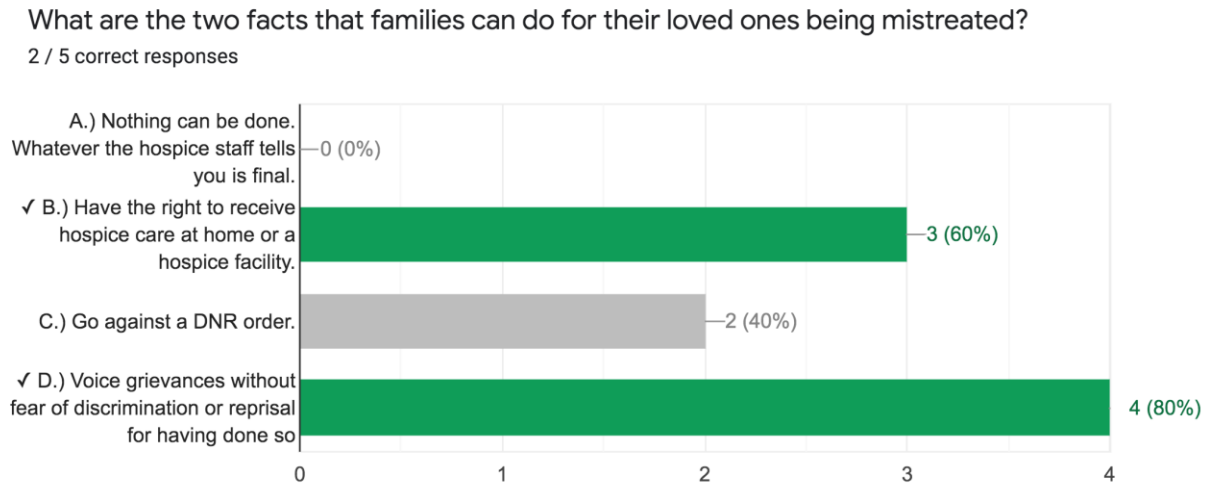
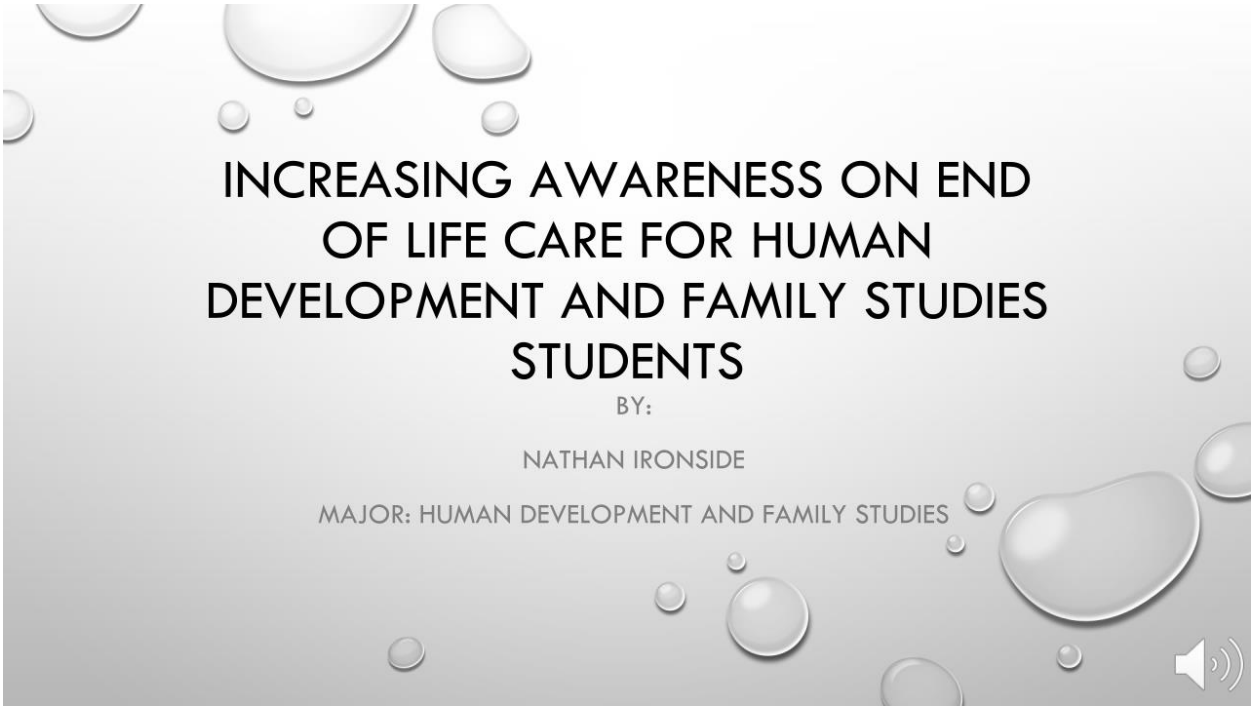


Table 4


What are the two facts that families can do for their loved ones being mistreated?
2 / 5 correct responses
A.) Nothing can be done. Whatever the hospice staff tells you is final.
0 (0%)
✓ B.) Have the right to receive hospice care at home or a hospice facility.
3 (60%)
C.) Go against a DNR order.
2 (40%)
✓ D.) Voice grievances without fear of discrimination or reprisal for having done so
4 (80%)
0
1
2
3
4

Appendix A.


INCREASING AWARENESS ON END OF LIFE CARE FOR HUMAN DEVELOPMENT AND FAMILY STUDIES STUDENTS
BY:
NATHAN IRONSIDE
MAJOR: HUMAN DEVELOPMENT AND FAMILY STUDIES

Putting the
Care
Back in End-of-Life
Healthcare
drscottmorris.org
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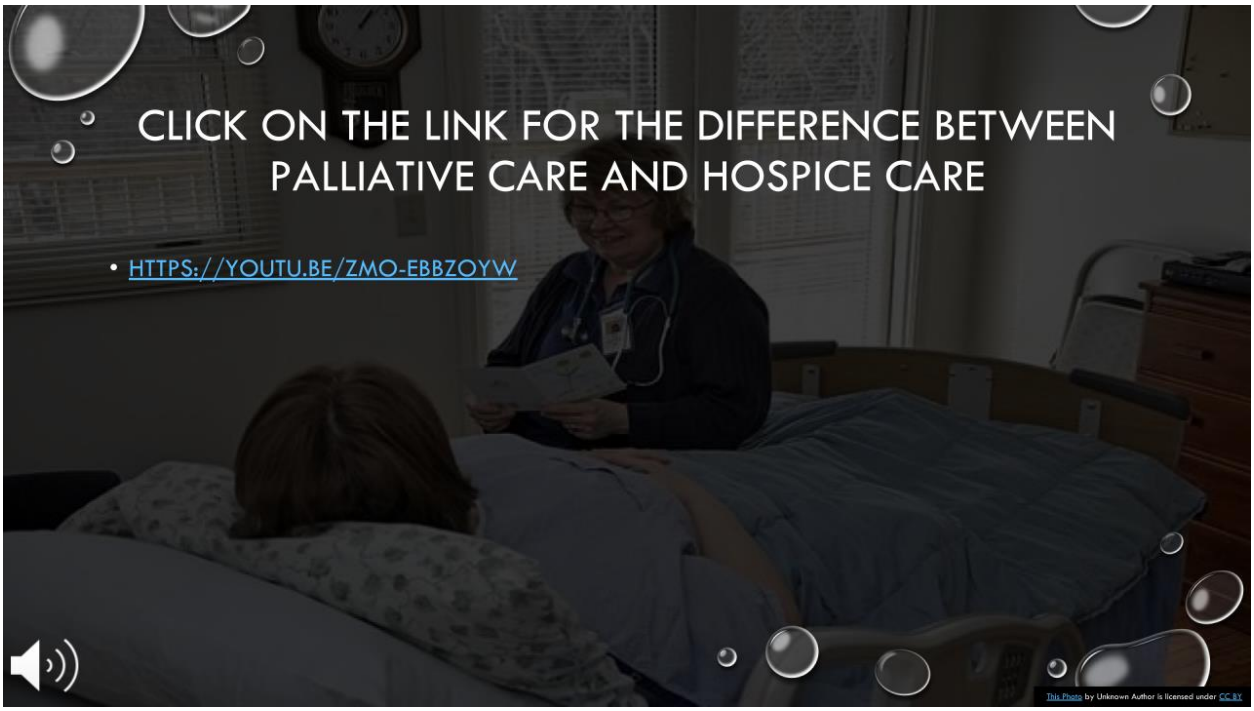
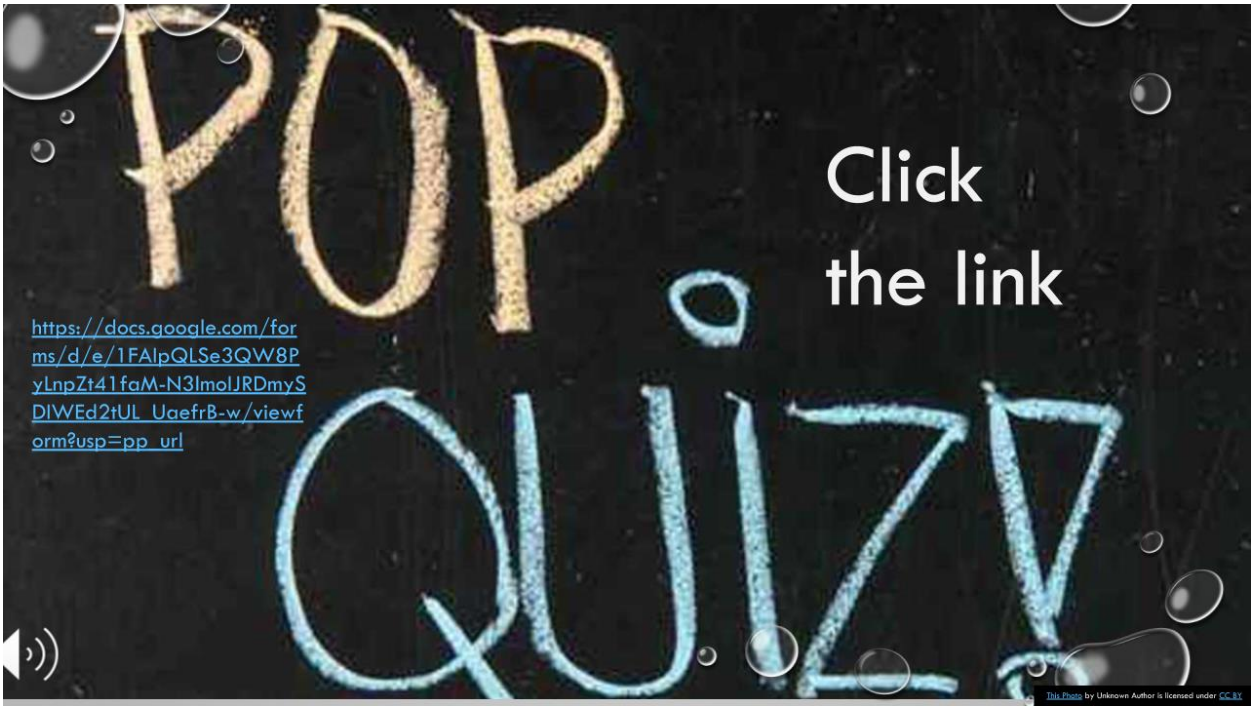
WHAT IS END OF LIFE CARE?
❑ Care for people who have stopped treatment for their terminal disease.
❑ Includes physical, emotional, social, and spiritual support for patients and their families.
❑ Control pain
❑ Hospice care, palliative care, and supportive care

TYPES OF END OF LIFE CARE
• HOSPICE CARE
• PALLIATIVE CARE


CLICK ON THE LINK FOR THE DIFFERENCE BETWEEN PALLIATIVE CARE AND HOSPICE CARE
• HTTPS://YOUTU.BE/ZMO-EBBZOYW
This Photo by Unknown Author is licensed under CC BY


POP QUIZ
Click the link
https://docs.google.com/forms/d/e/1FAIpQLSe3QW8PyLnpZt41faM-N3ImolJRDmySDIWEd2tUL_UaefrB-w/viewform?usp=pp_url
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DEALING WITH THE TERMINAL ILLNESS

- FIVE STAGES OF GRIEF
- ANGER
- DENIAL
- BARGAINING
- DEPRESSION
- ACCEPTANCE

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RIGHTS OF THE PATIENTS AND FAMILIES IN HOSPICE

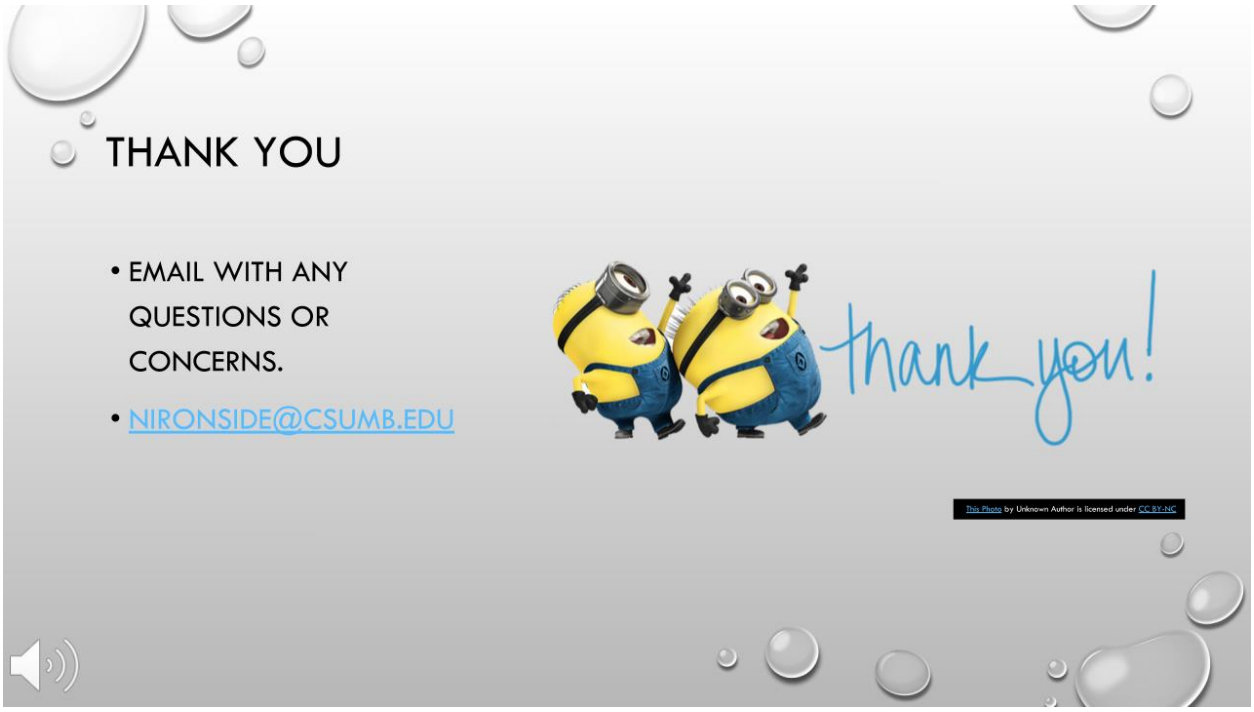
HTTP://WWW.NAHC.ORG/ASSETS/1/7/BILLOFRIGHTS.PDF

MALTREATMENT IN THE HOSPICE FACILITY

- SIGNS TO LOOK FOR
- WHAT YOU CAN DO IF YOU OR A LOVED IS BEING MALTREATED
- EXAMPLE OF MALTREATMENT

LET'S SEE HOW MUCH YOU HAVE LEARNED

https://docs.google.com/forms/d/e/1FAIpQLSeyP2wZt5-t9doEG16aR8LK2PWpRqch0O6aRBaKLuBLOV2m7g/viewform?usp=pp_url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thank you!
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