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Doing Death Better: Practical Ways for Healthcare Professionals to Care for the Dying Patient and Their Families

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Practical Ways for Healthcare Professionals to Care for the Dying Patient and Their Families

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Abstract

Healthcare professionals care for patients with unique personal, cultural, religious, and medical needs, but these needs are not always met in a way that ensures the patient and their families are being treated as unique individuals. This paper first provides an overview of the physiological aspects of dying and how to educate patients and their families regarding expectations in end-of-life. The impacts of the death of a child and a parent were explored, and areas in need of more resources for these individuals were identified. The beliefs and practices of Hindu, Native American, and Islamic cultures were discussed, and lessons from these cultures that healthcare professionals can apply to patients cross-culturally were stated. This paper then examines different aspects of post-mortem considerations such as family member perceptions and presence during resuscitative measures, as well as the role of nurses during end-of-life care, and the effects this can have on the profession. The results of multiple studies were discussed throughout the paper, including the implications of these results and ways to improve the experience of death and dying for both the patient and their loved ones.

Keywords: death, dying, end-of-life, death of a child, death of a parent, culture, post-mortem

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Chapter 1: Introduction

"Time of death: 2359." These are usually the first words uttered by a healthcare professional immediately after the death of a patient, but what about the moments leading up to this time? What was the last thing the patient heard? If the patient could speak from beyond the grave, would they attest to experiencing a "good death," or were their needs and desires left unmet? Would their family members consider the death of their loved one to be the best it could have been under the circumstances, or would they feel as though their own needs and the needs of their loved ones were dismissed? These are just a few of the questions healthcare professionals should consider when thinking about how they are caring for their patients during the time of death and dying.

How can healthcare professionals "do death better?" This question seems a bit absurd to some, but when the dying experience becomes a routine instead of an opportunity to serve vulnerable patients and their families, values and goals within the healthcare community must be reconsidered. Death and dying tend to be topics many Americans are uncomfortable facing or discussing. When one is exposed to death at an early age, whether this be the death of a family member or attending the funerals of friends or family, the gravity and potential discomfort of this inevitable event may be lessened. As a healthcare professional, experiencing death can be a more common occurrence than for the average person; however, the frequency of encountering death does not always mean that these individuals approach their patients and their families in the best way. According to a study conducted by Curtis et al. (2002) using the Quality of Death and Dying (QODD) questionnaire, the individuals involved reported a higher QODD score when members of their loved one's care team listened to them and their concerns and when the team thoroughly explained the condition of their family member.

Healthcare professionals need to understand the definition of death and many common causes of death to educate their patients based on evidence-based knowledge and practices. There are many changes likely to occur in the patient as they near death such as increased anxiety, change in respirations, and decreased oral intake. Explaining to the patient and their family what might happen in the weeks and days leading to death might prevent unnecessary fear and anxiety relating to the process. Learning how to properly communicate with the patient and their family is an important way to build rapport and trust among the healthcare team and the patients they are serving. Proper communication allows healthcare professionals to show patients and their families that their individual needs are recognized and valued.

Understanding the implications of an expected death versus an unexpected death can also be helpful to the healthcare professional. Each of these deaths presents different needs from the perspective of the family members and loved ones. The death of a child and the death of a parent are other circumstances which should warrant special consideration from healthcare professionals. The health of parents significantly declines and surviving children are predisposed to many psychological conditions, and both situations require more resources to assist these individuals.

An area with major potential for neglect among healthcare professionals is cultural and religious needs. As Americans, it is easy to become comfortable and accustomed to the needs of the majority. However, there are large populations in the United States whose individual needs are neglected due to a lack of education regarding medical practices and the wishes of other cultures and religions. There are specific needs for those belonging to different cultures, but there are lessons that can be learned from the way these cultures approach death and dying which can be applied to patients cross-culturally.

Reflecting on the experiences of family members who experienced the death of a loved one in an acute care setting is important in finding ways to better serve these patients moving forward. Adhering to the preferences of the patient and thoroughly communicating with the family are just a few of the ways the death experience can be improved overall. The role of the nurse during the process of death and dying and the impact this has on them is another critical point to examine. Burnout rates increase when members of the healthcare team are not being taken care of properly, and this affects their ability to provide quality care to their patients.

The purpose of this thesis is to draw attention to the importance of approaching death and dying from a realistic perspective. Practical ways to care for dying patients, their loved ones, and the healthcare professionals taking care of them will be discussed. This thesis will focus primarily on healthcare professionals to advance knowledge on dealing with death, as discussion of this topic is often avoided. An overview of the process of death, as well as cultural practices and lessons to learn will be discussed. The effects of an expected versus unexpected death in the context of a child and an adult and how to best care for the ones impacted by these deaths will be considered. Finally, this thesis will discuss measures to promote respect for the deceased and their family, as well as the importance of supporting healthcare professionals as they support others.

Chapter 2: Overview of Death and Dying

2.1 Defining Death

According to Price (1978), the legal definition of the term "death" is attributed to the Blacks Law Dictionary. This work describes death as "the cessation of life; the ceasing to exist defined by physicians as a total stoppage of the circulation of the blood, and a cessation of the animal and vital functions consequent thereon, such as respiration, pulsation, etc" (p. 49). Understanding the physiological process of death is a crucial step in the process for healthcare professionals as they learn to best serve their clients as they are approaching the end of life. Many clients and their support persons have questions regarding their health and the things which may happen to their bodies while receiving medical care. Proper understanding of the process of death and declaring death can allow members of the healthcare team to provide evidence-based knowledge to their clients to aid them in a potentially frightening experience.

2.2 Types of Death

2.2.1 Brain Death

While the criteria for brain death have been argued over many decades, the definition which has been accepted and endorsed by the American Academy of Neurology in 2019 states brain death is the "irreversible cessation of all brain functions, including those of the brain stem" (Milliken & Uveges, 2020, p. 33). Brain death often results from accidental injuries which are a common cause of death. There are three steps required to declare brain death. The first is when the physician ensures whatever caused the condition cannot be reversed and will ultimately lead to death. The second step is removing any medications, such as sedation, which could interfere with determining the neurological status of the client. The physician would then perform a series

of exams to evaluate the status of the brain. The third step may not always be mandatory. If it is, laboratory confirmation tests can be completed (Kondziella, 2020).

2.2.2 Sudden Cardiac Death

Sudden cardiac death, and cardiovascular disease, is when a heart condition causes an individual to die unexpectedly. It is one of the leading causes of death in western countries, and it accounts for many deaths attributed to a cardiac cause. Coronary Artery Disease specifically, is a primary condition causing sudden cardiac death. Because this is such a major portion of many causes of death, healthcare providers need to understand things that puts someone at risk for sudden cardiac death to promote the health of their clients. Some risk factors for sudden cardiac death include age, history of cardiac events, ventricular tachycardia, and syncope (Kumar, 2021).

2.2.3 Cancer

Cancer, another leading cause of death, is also important to look at when understanding the process of death and dying. Cancer can have a unique impact on everyone it affects, and when death occurs, its etiology can stem from a variety of things. In some cases, cancer starts in one area but then spreads to a healthy portion of the body. These cells can proliferate at such a fast rate causing them to account for nutrients the body needs to sustain life. Cancer can also affect specific organs and systems which can lead to death. For example, when cancer affects the lungs, it can invade too much of the tissue resulting in the remaining healthy portion not being able to meet the oxygen demands of the body. When the digestive system is impacted, the client can become severely malnourished. Cancer in the bone marrow can cause many complications which can eventually lead to death. These complications include a low red blood cell, white blood cell, and platelet count. These diminished components can cause a decrease in oxygen

circulating throughout the body, a decreased ability to fight infections, and a decreased ability to clot when bleeding (National Cancer Institute, 2021). Educated healthcare professionals can recognize the signs of these complications and explain to their clients what is happening in their bodies during end-of-life care.

2.3 Signs of Impending Death

When a person is approaching the end of life, perhaps due to progressing illness or age, there are often signs leading members of the healthcare team to prepare. Withdrawal is one sign. The client might not be as engaged in activities they used to love, and they might be quieter toward their family and friends. Sleep can also be impacted when death is imminent. A practical way healthcare team members or family members can support the client as they approach the end of life is to offer to stay with them. Those providing medical care to the client should explain to the family how even if the person is unconscious, they can still talk to them and offer their support as the person may still be able to hear them (National Cancer Institute, 2021).

Another way to potentially improve the dying client's care is to provide them with their favorite foods or beverages while never forcing them to eat or drink. Because the body is preparing for death, food requirements and desire may decrease. The patient may also be too weak to feed themselves, so the person providing care should offer to assist with feeding if the patient desires (National Cancer Institute, 2021).

According to the National Cancer Institute (2021), the dying process may lead to bowel and bladder incontinence, altered breathing patterns, and skin changes. There are many interventions which can be performed to make a positive impact on the client's perception of their experience as well as the family's. Changing bed linens often and using absorbent underpads which can be removed will help the patient and their surroundings remain clean and

fresh. Breathing pattern changes related to death can be concerning for those who have never experienced them. Educating family and friends about what they might hear or see the client experiencing can help reduce anxiety and fear as they provide support for the client. The National Cancer Institute also recommends positioning the person on their side to facilitate easier breathing. Covering the client with a blanket can provide extra warmth as their skin might become cool or blue due to circulation slowing. Allowing family members or support persons to be involved in some of these interventions can provide them with a sense of peace knowing they provided some comfort to their loved one during their last days.

Chochinov (2006) discusses different psychiatric changes or challenges that might arise as death nears. It is stated that fifteen to twenty-eight percent of terminally ill patients develop an anxiety disorder to some degree. Anxiety can present alone or in addition to depression. Patients which have an existing anxiety condition are at risk for developing more severe symptoms. Twenty-five percent of terminally ill cancer patients were reported to experience severe symptoms of depression. Patients approaching death might experience "an overwhelming sense of hopelessness, existential or spiritual angst, loss of sense of dignity or a waning of one's will to live and a growing desire for death" (p.87). While the physical comfort and needs of the dying patient are of great importance, healthcare professionals should not neglect their psychological needs as well.

2.4 Communication Regarding Death

Another point to be considered when serving patients and their families in the time surrounding death is knowing what to say or what not to say to provide comfort. Healthcare professionals should never force someone to talk, but it is important to ask open-ended questions to promote a healthy discussion of their feelings and attitudes during this time. Questions such as

“Are you okay?” or “Do you want to talk?” are examples of closed-ended questions warranting a one or two-word response. These questions do not facilitate an open dialogue between the member of the healthcare team and the patient or family member. However, questions or statements such as “How does this make you feel?” or “You seem upset. Let’s talk about what worries you.” provide a way for the providers to allow those they are serving to openly communicate their feelings and needs.

Van der Merwe (2020) discussed the importance of avoiding certain phrases tending to be overused in difficult situations. He identifies statements such as “everything happens for a reason, it is probably God’s will, you are strong, or you will get through this” (p. 1) as some which should be excluded from communication with patients or families. Healthcare professionals sometimes do not know the religion or beliefs of their patients; therefore, some statements could be perceived as offensive or overall unhelpful, even though intentions are often pure.

This leads to another important area in need of open communication. To avoid saying or doing something which could offend the patient or their family, the healthcare team should not hesitate to ask the patient about their religious or cultural preferences. If the patient discloses what religion or culture he or she belongs to, a healthcare team member should ask what accommodations can be made to allow the incorporation of their cultural needs into their care. By having an intentional conversation about this early on, the team will have time to make arrangements and troubleshoot potential problems when accommodating their needs such as visitation needs, ritual performances, and simple wishes or desires when it comes to implementing certain medical interventions or in the handling of the body after the patient has passed away.

A practical way to communicate with the patient approaching death is simply asking questions to get to know the patient as a person. Asking the person about their family or the things they love to do can be a way for the patient to reflect upon their life and acknowledge the people who have meant the most to them. If this is upsetting to the client, the healthcare professional can ask the client what things are important to them during their time in the hospital. Doing this allows the healthcare team to convey to the patient the importance of their needs and desires while promoting autonomy and dignity for the patient. Assuring the patient their wishes are heard and will be adhered to can provide comfort as they enter a time when they may feel a loss of control.

2.5 Improving the Experience for the Dying Patients and Their Families

Because of the feelings the process of death can bring toward the patient and family, it is important to determine what needs are present which would allow all individuals to have a better experience. To some family members participation is very valuable, while to others it can make the experience harder. Healthcare professionals can help the patient and family understand the benefits of active participation from the family in the client's care when the client is comfortable with it. This could include helping brush the patient's hair, repositioning the patient if it is safe, providing mouth care, and other basic tasks to ensure the comfort of the dying patient.

Another simple way healthcare professionals can improve the experience of the patient and their family is to spend a few extra minutes in the room to allow for questions, concerns, or support. Patients are often grateful when their nurse or doctor puts themselves at eye level and takes the time to thoroughly explain what is happening in their body as well as what their options are moving forward. Promoting a therapeutic relationship between professionals and their

patients is critical in ensuring each patient or family member feels supported instead of just another patient.

In a qualitative meta-synthesis by Meeker et al. (2018) different aspects relating to making the transition from care focusing on the improvement of the individual to care focusing on the comfort of the person were examined. The first point emphasized is providing information to the family to help them fully understand the condition of their loved one. Providing this information allowed family members to understand why the outlook for their family member was poor. Some barriers to delivering this information included the hesitancy of physicians and the poor acceptance of the news by patients. While it can be difficult for some to deliver information about a poor prognosis, it is vital the patient and their family fully understand their condition so they can make well-informed decisions about their care.

Another factor identified by Meeker et al. (2018) is emotional support. It was stated how support could be provided by "providing presence, bearing witness to the patient and family experience and listening" (p. 2065). One way healthcare professionals can support their patients is by allowing time to process difficult news and make decisions. For some, accepting they are approaching death can be a very difficult and long process. By allowing the patient and family time to come to terms with their situation, healthcare professionals are conveying their support. Validating the experiences and emotions of both the family and the patient is another way to build trust and offer support.

Viewing the patient as a unique individual is another way to ease the transition as a patient approaches death. Members of the healthcare team have many patients to care for throughout the day. However, stopping to learn more about who the patient is and getting to know them aside from their condition can be an important way to make a difficult and vulnerable

experience more bearable (Meeker et al., 2018). Another way to promote individuality is to work with the patient and family to establish patient-centered goals and expectations. Identifying what is important to them and working to meet those needs is a way to convey to the patient they are respected and valued as an individual and more than just a patient.

Lastly, providing control allows patients to have a better experience with their care overall. For many, the feeling of having a lack of control can produce anxiety. Meeker et al. (2018) explain how when given options about their care, patients reported feeling a sense of control which improved their anxiety while in the hospital. It is important to remember while healthcare professionals have experience making difficult decisions, their patients often do not. The healthcare team can explain the risks and benefits of each option, but it is important to explain how the decision is ultimately in the hands of the patient or their family when the patient is unable to make decisions.

Chapter 3: Expected Versus Unexpected Death

When a death occurs, it is either expected or unexpected to the family and friends of the deceased. If it is unexpected, this means death took place earlier than was anticipated for the individual. This could mean death happened as a result of something acute, for example, a car accident, which was a surprise to family, friends, or even members of the healthcare team. An unexpected death could also mean death was ultimately expected, but it happened earlier than anticipated (Hui, 2015).

An expected death occurs when healthcare providers can examine the diagnosis of an individual and create a tentative timeline of when they can expect to make a decline toward death. Expected deaths often occur with a diagnosis such as cancer. Certain physical changes are happening as death nears. Hui (2015) states the patient's heart rate often increases, blood pressure decreases, and oxygen saturation decreases. He also references a study which examined other changes occurring leading to death. The two earliest signs were a decrease in performance and a change in mental status. There were also later signs resulting from neurocognitive, neuromuscular, and cardiovascular decline.

Because it is not always possible to predict when someone will pass away, there are many implications resulting from an unexpected death. The emotional and psychological effects on the surviving loved ones can be profound. There are often personal matters left unfinished, and the loved ones may not know the wishes of the deceased. However, an expected death can help the family and friends of the patient feel more prepared. When there is a projected timeline, the patient and their family can get certain affairs in order if needed. The days and weeks leading to the death of a patient are also a time for the family to establish what the patient wishes in terms of medical care, funeral wishes, and what should be done with their belongings.

Chapter 4: Death of a Child

When a child passes away, there are profound and lasting impacts on the parents, siblings, and other family or friends. While every death can be devastating no matter what age the person is, the death of a child seems to carry an even heavier weight. It is expected for children to outlive their parents and grow into adulthood. When this does not happen, it is often a struggle for the surviving loved ones to be able to redefine what their life looks like without the child. This is an experience to which many healthcare professionals cannot relate personally. While members of the healthcare team can be sympathetic and show compassion toward grieving loved ones, it is important to attain a better understanding of what these individuals will have to cope with so there can be a more personal delivery of care to them. A better understanding of these effects will also allow healthcare professionals to know what resources are available to these families so they can be educated while in the hospital and before they go home.

Because of medical and technological advances in first-world countries, the incidence of death among children or neonates is rather low compared to developing countries. Due to the lower incidence, many individuals including other family members do not know how to handle the situation when it occurs. The loss of a child can lead to the isolation of the parents as they struggle to navigate through their grief with little support from their community (October et al., 2018).

4.1 Physical Impacts

October et al. (2018) present different ways parents are affected when they lose a child. The first finding these authors gathered from their literature review was an increased mortality rate among parents who lost a child, specifically mothers. One implication of this finding should

be to reinforce to the parents the importance of maintaining physical and mental health and possibly even setting up an appointment with their healthcare provider for some time in the following weeks. For some, the grieving process can lead to neglecting one's own needs which is why it is important to ensure grieving parents understand both the importance of their health as well as the importance of having a support system to call upon. By setting up an appointment with their primary care provider for them, they will not have to devote the time or energy to do this for themselves.

As previously stated, there are physical implications when it comes to losing a child. The overall physical health of grieving parents declines during the grieving process. Because of this decline in health, parents must take work days to care for themselves. They also experience a lack of sleep which can lead to more physical and mental health issues. Losing a child puts parents at risk for developing certain health conditions and disease processes such as myocardial infarction, cancer, and multiple sclerosis. These parents also experience health problems affecting their immune, neuroendocrine, and cardiovascular systems (October et al., 2018). When someone is experiencing a physical illness, it can make it difficult to care for themselves aside from that illness. When the grieving process adds to their illness, their physical health can often lose priority which can cause a worsening of these conditions and therefore put their own lives at risk. It is important to understand and respect grieving parents when they can receive education. When they can receive education, it is critical to make sure they understand how important it is to eat a healthy diet, exercise regularly, and follow up with their healthcare providers regularly to ensure proper health promotion.

4.2 Mental Health Impacts

Understandably, many mental health complications can result from losing a child. Many of these parents even deal with suicidal ideations and increased suicide risks. Disorders such as anxiety, depression, and post-traumatic stress are prevalent among this population. Complicated grief can prolong the feelings and responses that come with losing a child, and it causes a chronic stress response in the bereaved person. To be diagnosed with complicated grief, the death triggering the grief experience must have happened six months or more in the past. About one-fifth of all grieving individuals will suffer from complicated grief. However, about 60 percent of parents who have lost a child will experience complicated grief that lasts well past six months after the death of their child (October et al., 2018).

Parents who have support from friends or loved ones are often surrounded in the time immediately following the death of their child. However, many of these parents are not being checked on routinely in the months and years following the death of their child. Because of the risk of developing mental health issues and complicated grief, there should be a plan in place to follow up with parents months and even years after they leave the setting where their child passed away. One way this could be done is to contact a psychologist to set up an appointment to speak with the parents at regular intervals to equip these individuals with healthy ways to process their grief and even provide other therapy options or medications for mental health disorders they may develop. Mental health care provided to these parents should be individualized to their specific needs and desires during their time of grief. If medication is something that these families are opposed to, then it should not be forced upon them. Instead, other resources can be provided to them such as support groups, family therapy, or individual therapy.

4.3 Social Impacts

The death of a child can affect the social life of the family as they navigate the loss and how it impacts their life moving forward. In a study conducted by Fernandez-Sola et al. (2020), a qualitative approach was used to examine the social impacts among thirteen mothers and eight fathers who had experienced perinatal death. In the study, interviews were carried out by researchers who were midwives. There were seven sub-themes discovered from this study, and two main themes were found. The main themes were the effects on the family dynamic and the effects of the social environment of the parents.

The first subtheme that was found was the struggle of grieving fathers to balance their emotions with their role as a protector and providers in the family. Many men reported that they felt as though they had to remain strong to support the mother of their baby, but this in turn complicated their emotional expression of grief. These men also reported that support and care in the acute care setting were geared toward the mother and their needs instead of providing care for the father also (Fernandez-Sola et al., 2020). As previously stated, complicated grief is often experienced by grieving parents. While it is more common among mothers, fathers can be at an increased risk for experiencing complicated grief when their feelings and emotions are not recognized and validated. It is important to ensure that these fathers are given the resources they need to properly cope with their emotions. Healthcare professionals can validate the need of these men to support the mother of the baby while also enforcing the need to address their own needs and feelings before they lead to a more severe mental health problem.

Much of the focus of support for grieving individuals related to child loss is geared toward the parents. However, if there are other children involved, their needs must be addressed as well. They are forced to process their grief and emotions while also experiencing the grief of

their parents, and this often leads to the neglect of the mental health of these children. It has been discussed how parents tend to neglect their health when they lose a child, and they can also neglect the health of their other children, often unintentionally. Many children develop anxiety as a result of the death of their sibling (Fernandez-Sola et al., 2020). To provide care to the siblings of a deceased child, a certified child psychologist can be consulted to help the child cope with their emotions. These professionals use many different methods which are better suited for children as they discuss their feelings and emotions such as art or puppet therapy. A social worker can also be utilized in the hospital setting if a sibling is being neglected. These individuals can help find resources for the child and their family as they proceed.

Another theme discovered by Fernandez-Sola et al. (2020) is an increased fear of future pregnancies. It was found that these mothers utilized emergency services significantly more during pregnancies following the loss of a child. Many even took measures to prevent another pregnancy due to the fear of going through the loss of a child again. To serve these anxious parents, healthcare professionals should happily answer any new questions they may have regarding their pregnancy or comply with any extra testing the family desires. Peace of mind is valuable for these families who have lost a child.

Marital impacts were also discussed in the study. In some cases, the relationship among the parents of the deceased child was strengthened. Some parents choose to see the experience as a time to grow their relationship as they face the challenge together. It was found that couples experienced an increase in arguments during the months after losing their child. Each parent experienced grief in their own way which sometimes led to disagreements in the marriage. The sexual aspect of the relationship was also impacted by the grief process. Sexual intimacy either significantly decreased or ended altogether for some couples (Fernandez-Sola et al., 2020).

Healthcare professionals can prepare these parents to expect challenges in their relationship as they process their grief. Healthcare professionals can refer them to a counselor that specializes in both individual and couples therapy so parents can use this as a resource to cope individually and also learn how their partner needs to be supported.

The extended family is also impacted by the death of a child. Grandparents of the deceased child experience grief from losing their grandchild, but they also experience the emotions of watching their child go through the process of losing a child (Fernandez-Sola et al., 2020). If the parents desire it, the extended family should be allowed to be present at the hospital to support the parents as they experience the sickness and loss of their child.

The careers of grieving parents are negatively affected during this time. Some individuals have already experienced unemployment before the death of their child if they have had to provide care for their sick child. Some parents also become unemployed after the death of their child due to mental health concerns and the overall inability to come to work because of their grief. According to October et al. (2018), fifteen weeks is the average amount of time that parents have had to take off work without pay. However, some reported viewing work as a time to escape the overwhelming emotions and grief they were experiencing (Fernandez-Sola et al., 2020).

4.4 Improvements to be Made

The importance of healthcare professionals understanding the parents, siblings, and extended family cannot be stated enough. It is critical to understand the specific needs of the grieving loved ones. Understanding allows professionals to provide the resources that are needed for these families to mitigate preventable outcomes from losing a child such as complicated grief, physical disorders, and marital problems.

Healthcare professionals or social workers can communicate with extended family members or family friends to suggest implementing a meal train system to ensure the family is eating healthy food to aid in physical health. Members of the team should also determine if the family has a psychologist or counselor in place to visit, or if they need a referral to one. Promoting and destigmatizing mental health to these parents can encourage them to pursue help in this area before they reach a state of suicidal ideations or thoughts. Parents need to be educated on how often they should follow up with their primary care providers and psychologists to ensure proper health promotion in the months and even years following the death of their child.

Support groups can be created to allow space for grieving parents, children, and extended family members to express their emotions and feelings to others who have gone through a similar experience. Because mothers and fathers who have lost a child often feel isolated, healthcare professionals should make sure these parents are aware that these support groups exist. Members of the healthcare team can ask the family what their specific needs are emotionally, physically, or financially before they leave the hospital to make sure they are connected to the resources they need as they enter the following weeks and months.

Research has shown that fathers are not provided with adequate resources and support as they cope with the loss of a child. These fathers may feel like they have to suppress their emotions to support and continue to provide for their family. If there are financial concerns of the family which are causing fathers to feel like they cannot take time from work to care for their mental health, social workers should be involved to assist the family in finding resources to alleviate some of these concerns. Open-ended questions should be asked of the father to facilitate conversation regarding his grieving process. There is even a need for support groups specifically

for fathers who have lost a child so these men can speak with other men who know firsthand what it is like to lose a child from a father's perspective. Healthcare professionals need to express to the fathers specifically before they leave the hospital, the benefits of not dismissing their grief experience. These professionals can acknowledge the position that the fathers are in to provide for their family while also making sure they know how to properly care for themselves to prevent developing complicated grief or other mental health disorders.

Another area in need of improvement is increased support for the siblings of the deceased child. Children are not equipped to handle such intense emotions and grief as some adults are. Parents are often consumed in their grief and emotions which leads to the neglect of their remaining children. While this is not necessarily intentional, it can be difficult for parents to manage their needs along with the needs of others. Hospitals should always have a psychologist and a child psychologist available to assist in processing what the family is going through. Different methods of therapy should be used to cater to children to help them learn effective coping strategies.

Marriage counseling should be encouraged for couples who experience child loss. The grieving process can cause a decrease in patience as well as increased emotions overall. Parents are engaging in their journey of healing, so it is difficult to cater to the needs of their partners. If the couple becomes pregnant again, the increased fear associated with this can also cause marital stress. Parents should be encouraged to voice these fears to their healthcare professionals, and these professionals need to remain sensitive to these needs and emotions that may be present in future pregnancies.

Because of the potential need to miss hours of work after the loss of a child, employers need to implement a bereavement policy so employees do not experience the added stress of

trying to come to work in the time immediately following a death. There are also resources such as The TEARS Foundation that provide financial assistance for funeral costs to families who have experienced child loss (The TEARS Foundation, 2019).

Chapter 5: Death of a Parent

When a child experiences the death of a loved one, specifically a parent, there can be major behavioral and mental health problems that present. According to Spuij et al. (2013), five to ten percent of children who experience a loss develop severe psychological problems such as depression, posttraumatic stress disorder, and prolonged grief disorder. These children also suffer from neuroendocrine dysregulation (Hagan et al., 2011). These children and their health must be addressed properly and in a timely way. If children do not receive the proper care they need, their risk of developing these psychological disorders increases significantly.

5.1 Grief-Help Study

Spuij et al. (2013) presented a study that would use a randomized control trial to examine the impacts of both Grief-Help therapy and supportive counseling. Participants in the study would be children or adolescents, eight through eighteen years old, who had experienced loss and had sought treatment for their mental health concerns. The children would be randomly placed into two separate treatment groups, and follow-up appointments would be carried out immediately after treatment and at three, six, and twelve months.

In Grief-Help therapy, the child is asked to share things they would want to tell the person who has died. The child is then introduced to four tasks they will be completing in the following weeks and months after loss such as returning to normal activities or accepting the loss of the person. There are different techniques used to help these children develop problem-solving skills and confront the reality of the death of the loved one. At the end of the treatment, the skills that have been taught to the child are reviewed, and they are equipped with information about how to handle their grief when it may present in a way that is too overwhelming (Spuij et al., 2013).

On the other hand, supportive counseling is based upon the premise that prolonged grief can be alleviated by having a dialogue about what grief has caused in different aspects of their lives. Participants in this form of therapy are asked to speak openly about all thoughts, feelings, and emotions they have related to the death of the loved one. Children may present with many different thoughts and feelings, and supportive counseling gives them a way to properly express themselves while learning to cope with their grief. There are three steps to this method. The first is geared toward finding out what areas in the child's life have become more difficult. In the second step, the participant and the therapist discuss what was discovered in the first step to determine how the child wants to go about expressing their emotions. This could be through talking, playing, or some other way. In the final step, the child and therapist discuss the upcoming end of their sessions (Spuij et al., 2013).

While the study discussed had only been presented, it shows the importance of examining and further developing counseling services that are specifically tailored to children and their specific needs. There is not enough research on the effectiveness of different grief services that are geared toward children (Spuij et al., 2013). Because of the prevalence of prolonged grief in children who have experienced loss, there is a great need to determine how to better serve these children.

5.2 Cortisol Levels in Bereaved Children

Another aspect of parent loss that has been studied in children is cortisol levels. The death of a parent has been found to disrupt neuroendocrine function resulting in higher levels of cortisol. Hagan et al. (2011) conducted a study which utilized children and adolescents who had lost a parent between four and thirty months prior and who were not receiving mental health treatment. Items measured in the study included positive parenting, recent negative events, and

current mental health issues. Higher cortisol levels were found in those who did not experience as much positive parenting and those who had been through more stressful and negative events. Therefore, a lack of positive parenting predisposes a child to higher cortisol levels and more dysregulation of their neuroendocrine system after the death of a parent. It also highlights the importance of addressing these negative life events that occur in the lives of children early on before they can develop into more complex mental health issues later in life.

5.3 Improvements to be Made

When a child loses a parent, they are often losing a major source of love, comfort, and safety in their life. It can be incredibly difficult for a child or even an adolescent to deal with such a significant adverse life event and learn to live without that parent. Even if there is a complicated relationship between the child and the parent, the loss is still significant and should be treated as such by healthcare professionals. These professionals should take time to understand how the loss of a parent impacts a child and what it puts a child at risk for. There is a great need to reexamine the way healthcare professionals are meeting the needs of grieving children in the acute care setting when their parent is sick and approaching death.

For some children, it may help them to process the situation if they can be involved. For example, a nurse or nurse aide can allow the child to bring a drink or a pillow to their parent. However, for some children, helping might be too overwhelming emotionally. No matter the needs or desires of the child, healthcare professionals should encourage the child to ask questions and they should be answered truthfully in a way that is appropriate for the age of the specific child. Children may also be afraid to touch their mother or father while they are in an acute care setting. There are often many lines, devices, and pieces of equipment which can be scary to the child. Healthcare professionals should explain to the child how they can safely be close to and

touch their parent so the needs of the child are being met appropriately. Getting on the level of the children can be a more effective way to communicate with them in a personal, non-threatening way.

Healthcare professionals can also ask the other parent or caregiver what the needs of the child are. This provides a way for the other support persons to communicate openly about the needs of the child and possibly their own needs as well. The child might benefit from distraction. If this is the case, coloring books, puzzles, or children's books could be provided for the family to utilize during their stay. This is another implication for healthcare systems. Hospitals could make children's boxes according to different age groups to have on hand for times when a child is spending a significant amount of time in the hospital with their parent. These boxes could have age-appropriate toys or fun educational material so the parents or other caregivers are not having to worry about having to provide these things on their own. These materials would allow the child to be present with their dying parent while also providing an element of consistency while in an unfamiliar place.

Another factor to consider when caring for children as they face the death of a parent is their safety and needs once they leave the hospital setting. They are often going home with the surviving parent who is experiencing their intense grief process. It has been previously discussed the physical and emotional toll grief can take on an adult. The child's caregiver might become too depressed or they might experience posttraumatic stress disorder in a way that prevents them from properly caring for the grieving child. Due to these concerns, healthcare professionals should assess the needs of the family before they leave. A social worker can also be called in to help facilitate this discussion. It should be conveyed to the family that there is absolutely no

judgment, but it is the job of the healthcare team to ensure the safety of the child and other loved ones before they return home after such a tragic event.

Chapter 6: Examining Different Cultures

Cultural competency and sensitivity are important aspects of patient-centered care. Each culture holds different values and beliefs regarding healthcare and decisions when death is approaching. Healthcare professionals need to educate themselves about the practices of other cultures so they can be sensitive to the needs of their patients. It is also important for healthcare professionals to approach other cultures with respect and dignity without forming a bias against them. There are many lessons to be learned from the ways other cultures approach death which can be applied cross-culturally as healthcare professionals serve their patients.

6.1 Hindu

The religion of Hinduism can be described as multiple religions combined. When Persia invaded India, they called the Indus River "Sindhu." Therefore, they referred to the people living there as Hindustani, meaning they were followers of the Hindu religion. This illustrates how long the Hindu religion has been established as it is one of the oldest religions still in existence (Rowland, et al., 2021). According to Gupta (2011), "nonviolence, truthfulness, friendship, compassion, fortitude, self-control, purity, and generosity" (p. 246) are some of the major values the Hindu religion is built upon.

Americans often joke about the concept of karma, but it is a very serious topic to those who belong to this religion and should be regarded as such. They believe what they have done in their current lives as well as past ones impact their future in both a positive and negative way. When one exhibits moral behavior, also referred to as Dharma, they are considered to be Hindu (Gupta, 2011). The Hindu religion believes there are rites and rituals associated with each stage

of life. There are specific death rites believed to have a direct impact on the recently deceased soul's journey to its next destination. These rites begin with the dying person. They repeat meditative sounds as this helps them to focus their minds. Another ritual related to burial is shaving the deceased's hair before burial (Rowland, et al., 2021). The importance of understanding these rites and rituals as a healthcare provider should be emphasized. Members of the healthcare team can spend time asking the individual what accommodations can be made to make these rituals easier to take part in.

Another important aspect to be aware of in the Hindu religion is the value of purity. Bodily fluids are considered to be one of the most impure substances to this group of people. Because of this, females are seen as more impure than males due to menstruation. A baby even becomes impure during the process of childbirth. However, because birth is often a favorable event, the impurity of the child is often forgotten, especially if the baby is a male. The preference for males in the Hindu religion is related to several factors. One is the role of the oldest son in his father's death. When the father dies, the oldest son is responsible for igniting the pyre at the funeral. He is also responsible for carrying out rituals each year which are said to be in favor of his father's next life. In addition to his responsibilities surrounding his father's death, the oldest son is also at the head of the family and is in charge of providing for the women in his family. The implication for healthcare professionals is allowing and encouraging this male representative to be present with a female patient belonging to the Hindu religion if she wishes. Another implication healthcare professionals should consider is how these individuals might not accept a male provider (Coward & Sidhu, 2000). Because the female assumes a lower role in the Hindu religion, the only male potentially allowed to participate in her care is the head of the family. If this is the case, care should be handed to a female provider if it is safe.

In a qualitative study carried out by Rashmi Gupta (2011), three focus groups were formed which included senior, middle-aged, and young adults. These individuals had either immigrated to the United States from India in later life, been in the United States most of their lives, or were born in the United States. To participate in the study, these individuals had to have attended a funeral within the past five years. The goal of the study was to examine Hindu beliefs and rituals regarding death. The participants were asked questions about their experiences with death, rituals they take part in, and other questions to gain a better understanding of how death and dying are viewed by Hindus of all ages.

There were many aspects of death examined in Gupta's study. One point which was agreed upon by all focus groups was how there is a clear difference between the body and soul of a person, and the body has no use after death. Another finding from the study was that for a Hindu person to experience a "good death," there were three criteria which must be met. These criteria are having relatives prepared for the death, the absence of physical or mental trauma to the deceased individual, and those who needed to say goodbye had the opportunity to do so. While the Western culture may not use the term "good death," these criteria are things which can also be important to those who are not of the Hindu religion. Therefore, healthcare professionals can be sensitive to these needs (Gupta, 2010).

Concerning practices and rituals surrounding death, there were many discussed throughout Gupta's (2010) study. Before death occurs, the Hindu religion believes it is important the person should be thinking and speaking about God as their thoughts and words when they pass away directly affect their soul in the afterlife. To facilitate this, the family will often pray with the dying person, and when death is near, they will place Ganges holy water into their mouth. While traditional Hindu custom is to not use measures to prolong life, some Hindus in the

United States have opted to use devices such as respirators while under medical care. Participants in the study also reported when death has occurred, a basil leaf, ghee, and gold piece are placed into the deceased person's mouth. While Hindus' bodies can be cremated, buried, or placed in the Ganges River, the preferred method of dealing with the body after death is cremation within twenty-four hours.

Because of the importance of Hindu death rituals and practices surrounding death, healthcare professionals should implement things to assist these individuals in facilitating a "good death." Each Hindu family might view death differently and have different wishes. These should be honored. If a woman is having her menstrual cycle while being cared for, members of the healthcare team might inquire about the best way to handle her bodily fluids to maintain dignity and respect as this process is often viewed as making a woman impure. Ensuring the family is properly educated on what to expect regarding their loved one's death might help facilitate a better experience for them. Allowing any family members, friends, or spiritual leaders to say goodbye to the patient will help in creating a favorable experience surrounding death.

6.2 Native American

Native Americans were the first people native to America. While not all of them are federally recognized, there are over 500 tribes in North America. Some Native Americans live on tribal land while others live in more generally populated areas. Many still prefer to speak their native language as opposed to English (Cacciatore, 2009). There are many health-related issues impacting Native Americans greatly. Deaths caused by accidental injuries are significantly high within this population. According to Broome and Broome (2007), they are "2.3 times as likely as Caucasian adults to be diagnosed with diabetes" (p. 162). Blood pressure and obesity are more common in these individuals as well as certain cancers such as stomach and liver cancers.

Native Americans view death as a part of life. Many children in this culture are exposed to death at an early age as they would attend rituals performed when someone passed away. They believe there is a higher being such as God who is in control of everything living. While many cultures and religions view humans as superior to other creatures, Native Americans view humans and other living things equally. Spirituality is a major theme in this group. Because of this, rituals and ceremonies serve as a method of communication with the Creator or God. Native Americans do not view death as the end of life but rather as a transition time. Speaking about death and dying can be perceived as disrespectful by these individuals as they strive to let life consume their thoughts (Colclough, 2017).

For Native Americans, health, medicine, and healing is directly related to spirituality. These individuals often still use traditional healers. This is mostly due to their culture. About one-fourth of Native American families are considered to be living in poverty with the average income per family being about $33,627 (Broome & Broome, 2007). Healthcare professionals should be aware of this potential financial issue when caring for these patients. Social workers or case managers may need to be consulted to help find resources for them to help once they leave the hospital or healthcare setting.

Because Native Americans believe all living things are connected through the Creator, their perception of the care they are receiving can be greatly based on how they view the spirituality of their provider. They also believe if someone is diagnosed with a physical problem they in turn have a powerful mind and strong spirit within them to counteract their ailment. However, if a Native American has a genetic condition, they believe it is caused by behavior which does not align with their beliefs or by a spirit. Certain treatments for illnesses through modern methods might get in the way of lessons which are to be learned (Broome & Broome,

2007). If this population declines certain interventions, their wishes should be respected. Education can still be provided on other options if needed, but healthcare providers need to be educated on why they might decline services.

According to Broome and Broome (2007), there are many ceremonies and rituals performed to promote healing. Prayers, chants, and herbal remedies are things potentially involved in these ceremonies. Smudging is another method sometimes used. This is when special herbs are incinerated and the smoke is used to negate negative spirits. Massage and acupuncture are utilized often. Knowing this should encourage members of the healthcare team to inquire about what they can do to help these patients and their family members perform those ceremonies and rituals. This might include allowing more family members in the room than is normally allowed to let these rituals be carried out. While smoke is dangerous in a healthcare facility, there might be other options to perform rituals involving smoke. Other oils, sprays, or substances might be suitable as a substitute.

Anderson and Woticky (2018) describe the last moments of life as an opportunity for Native American individuals to experience healing of their spirit, and it has only been in recent times these ceremonies are being allowed. Policies and procedures in healthcare settings need to be updated to accommodate different cultures and practices. These things can be the difference between a good or bad experience while an individual is approaching the end of life.

6.3 Islamic

According to the Islamic religion, each person is granted a certain amount of time for their life when they are born. When this time is up, the angel of death removes the person's soul from their body. Muslim believe life and death align with the will of God, and these individuals are very supportive of each other during the time of bereavement. This religion discourages a

long and drawn-out public display of their grief experiences as this is said to inhibit the mourners as they return to normal life. Returning to life after a tragic event is seen as religious by these individuals (Yasien-Esmael & Rubin, 2005).

Crying and highly emotional reactions to death are frowned upon greatly in the Islamic religion. When mourners cry or wail, it is believed the one who died will reap the consequences of these actions. The consequences do not come from God, but from the person who has passed away. When an Islamic person dies, their death is often announced in the main town or surrounding areas. Many women "shout, wail, tear out their hair and tear their clothes" (Yasien-Esmael & Rubin, 2005, p. 498) when they hear about the passing of their friend or loved one. However, there is also a group who tries to limit this behavior as it is indicative of the lack of acceptance of God's will. The men tend to be much more quiet and reserved in their grieving process, and they might also have to be the ones to quiet the women or even hold them back when their emotional responses become too much (2005). To some, an emotional display might be startling if not prepared. Knowing the customs of this culture is important for healthcare professionals so they will know what to expect when someone of this religion passes away.

Jahangir and Hamid (2022) discussed a qualitative study they conducted in which the aim was to compile information about Islamic death and mourning practices. Participants who were of the Kashmiri culture were interviewed to gather data. One custom observed during the study was the preparation of food for the grieving family. It is important to Islamic people for other members of the family or even friends to take over the responsibility of preparing food for some time after a death has occurred. For the people in Kashmir, community support is prevalent when death is near. Many like to come together to comfort the dying and their family. Healthcare professionals can accommodate these needs by providing an area for many family members to

gather if their loved one is in a healthcare facility. They might also allow food to be brought in if this is something the family requests immediately following death while still in the healthcare facility.

The study also revealed certain practices which are done to the body of the deceased by the people of the Kashmir area and the Islamic religion. Before the person dies, they are placed lying flat, pointing toward Qiblah, the direction of Mecca and the direction Muslims turn toward for their prayers, and their extremities are straightened out. They then place water or honey into their mouth and the person is asked to state the shahadah. The shahadah says “there is no God but Allah and Muhammad is his servant and Messenger” (Jahangir & Hamid, 2022, p. 735). The individuals surrounding the dying person then offer up supplications to aid the dying person's pain or suffering. It was also noted the eyes and mouth of the person should be closed immediately when death occurs. Relatives or friends of the deceased read verses from the Qur’an as the body is being washed after death (2022). If hospital policy includes the body being washed or wiped down, the family should be consulted to determine if they wish to be present to carry out any readings during this time.

For some members of the Islamic religion, adhering to traditional beliefs and practices is of utmost importance. However, some have adapted these practices as time has progressed. When caring for someone of the Islamic religion, it should be noted what practices the person or their family wishes to conduct so arrangements can be made prior if needed.

6.4 American

In modern America, there have been significant advances in technology and medical treatments as well as improvements made to existing technology. So much of healthcare treatment is aimed toward fixing the problem and ensuring the patient does not die. In critical

care areas, there are many different pieces of equipment used to sustain life. New medications and treatments for a variety of illnesses are being tested every day. The average lifespan has also increased. According to Meeker et al. (2018), 50% of patients with Medicare visited the emergency room in the month leading up to their death, and one-third of Medicare patients stayed in an intensive care unit. It is common in America to desire to prolong life as long as possible.

Many Americans belong to the Christian religion. Christians believe when one has accepted Christ as their Lord and Savior, they will have eternal life. Therefore, when the physical body dies, the soul of the Christian is eternal. Some Christians view suffering as a part of life, but they do not necessarily turn away measures to reduce suffering as other cultures and religions do. This is why it is still important to present all interventions to the patient and confirm they align with their wishes.

For many Americans and Christians, there are often people from their churches or their communities who want to visit when they are in the hospital or other healthcare setting. They often bring food or other gifts to the person and their family. If they are religious, members of their church might visit and offer to pray with the patient and their loved ones. If the patient wants visitors, arrangements should be made to give them privacy with them. The patient or their family might also request for the hospital chaplain to visit with them. Patients should be made aware of what spiritual support is available to them. If they are not spiritual, then members of the healthcare team should determine if the family or the patient would like to speak with a counselor.

Chapter 7: Lessons to Learn from Other Cultures

Learning how other cultures respond to and deal with death can be an enlightening experience for those in the healthcare profession. Death can become a common occurrence for the healthcare professional, which often leads to desensitization. We learn to cope with loss from a healthcare perspective, but do we lose perspective of how those impacted by the death are coping? It may an individual's first time experiencing the death of a loved one or friend, but healthcare professionals treat it like it is another day at work. Examining the way other cultures approach death and dying can not only provide insight on how to better serve these patients and their families, but it can also teach us about how to better handle death when we encounter it in a healthcare facility.

7.1 Hindu

From the Hindu religion, healthcare professionals can be reminded to treat the dying or deceased person of all cultures with gentleness and respect. Hindus believe physical or mental trauma can cause a poor experience with death. By treating each person's body with care and speaking to them respectfully even when they may be sedated or in a state of declared brain death, healthcare professionals are working toward maintaining the humanity and dignity of each patient.

The Hindu religion also teaches the importance in taking the extra step when keeping our patients clean. This group of people views bodily fluids as impure. While this is not the view of many other religions or cultures, it still has its implications. Ensuring patient linens are not soiled at regular intervals can help families as they see their loved ones in an already vulnerable state. Death can cause the expulsion of different substances, but simply wiping them away and keeping

the body clean is a simple but important step in promoting the comfort of the family as they mourn the loss of their loved one.

7.2 Native American

The perspectives and beliefs of Native American culture can encourage healthcare professionals to be cautious when speaking about death and dying. Many Native Americans can be offended if death or dying is discussed. Even though this does not apply to many other cultures or beliefs, this can serve as a reminder to be aware of what is being said about death and to whom it is being said. As healthcare professionals, talking about death and dying has potentially become an easy thing to do. Part of the job of a nurse, doctor, etc is to educate patients and their families about their condition and what to expect. However, many patients view death as a very difficult subject to talk about, and many choose to avoid the topic altogether.

Another lesson which can be learned from the Native American culture is the importance of being sensitive to the healthcare preferences of patients and the reasons why these preferences exist. Many Native Americans will decline certain interventions as they feel it interferes with the lesson they should be learning. Individuals belonging to other cultures and religions might decline certain services for personal, religious, or cultural reasons. Some patients may be concerned about cost when declining a service. It is the responsibility of healthcare professionals to educate all patients about the benefits and risks of each intervention while also respecting their wishes. Resources such as clinical trials, coupons, free samples, and social work services should be offered to the client if there are financial concerns.

7.3 Islamic

One lesson from the Islamic religion which can be applied to all patients and their families is the act of being sensitive to emotional responses to death. Some patients and families are very stoic while others are outwardly emotional. It can be easy to pass judgment on someone's reaction when it does not seem to be emotional enough or maybe when it seems too emotional. Everyone processes difficult events differently, and healthcare professionals should be accommodating to each emotional need. This could be as simple as providing a private area for families to be able to openly express emotions where other patients or visitors would not be able to see or hear.

The Islamic religion also teaches the importance of accepting help and support. When a loved one passes away, it is expected that other members of the family and community will surround them to offer support and prepare food for some time so the family can focus on grieving. Healthcare providers also have to go through the grieving process when a patient dies. Whether they have taken care of a patient for years or one day, there is a connection which can be formed. Many professionals feel as though they have to repress their feelings due to the needs of their other patients or coworkers. It might be hard for them to allow themselves to properly process the emotions which come along with losing patients and dealing with death often. Like those belonging to the Islamic religion, healthcare providers should seek the support of those around them and accept the help and resources provided to them to prevent emotional burnout.

Chapter 8: Reflecting on the Death Experience

Reflecting on the experiences of family members during the loss of a loved one is important in improving the quality of the experience for future patients and families. In a study conducted by Curtis et al. (2002), the Quality of Death and Dying instrument was used to examine the perceptions of care during the death and dying process of the loved ones of individuals in Missoula, Montana. The Quality of Death and Dying instrument uses an interview system to rate different experiences on a scale from zero to ten.

In the study, one area examined and ranked by participants was how well the patient's medical preferences were followed. About twenty-two percent of answers, or a little over one-fifth, indicated that either none of their preferences were adhered to or only some of their preferences were adhered to. While this is not the majority, this is still a significant portion. A higher score on the Quality of Death and Dying tool was reported for participants whose loved ones' preferences were followed during their time of death (Curtis et al., 2002). If something that a patient wishes poses a significant risk to their health, healthcare professionals should take time to explain the risks associated with that intervention before choosing to move forward. However, the patient or their appointed decision maker should be the one to have the final say. This is why the importance of establishing an advanced directive should be explained to the patient and their family. This ensures that the healthcare team will not operate outside of the wishes of the patient when they may get to a point where they can no longer express their desires.

This study also revealed around sixty-five percent of participants were not asked about their religious needs or concerns relating to their health (Curtis et al., 2002). This means over half of the patients who passed away being considered in this study were not provided with completely individualized care while in the death and dying process, and this is unacceptable.

The importance of determining cultural or religious values has been attested to. Certain cultures value less invasive methods, implementing rituals, or avoiding certain topics of discussion. When the healthcare team is not aware of these wishes and desires, they are at risk of doing or saying something that could make the patient or the family uncomfortable which would be detrimental to the trust that is needed between patients and their providers.

Around fifty-six percent of participants in the study reported they did not receive information regarding what would happen to their loved one right before they passed away. They were not told what the patient might look like, sound like, or experience in the moments before death. For many, death is a scary experience for both the one about to experience it and the family and friends watching their loved one's health deteriorate (Curtis et al., 2002). Changes such as Cheyne-Stokes respirations or mottling of the skin can be startling to witness. If their loved one had never experienced problems with incontinence, this might cause concern for the family. By educating the family and the patient on what to expect as death approaches, they might feel more autonomy and control instead of being blindsided by these significant changes. One of the primary roles of the healthcare team is to educate, and this is one of many times in which education has proven to be incredibly beneficial in improving the perception of end-of-life care for both the patient and their loved ones.

8.1 Effects of Family Presence During Cardiopulmonary Resuscitation

The effects of family presence during cardiopulmonary resuscitation (CPR) were examined by de Stefano et al. (2016). The study used a qualitative design to determine how family members perceived their experience when present during the administration of CPR on their loved ones. Thirty individuals whose loved ones had not survived after CPR at their homes were included in the population for this study. Four main themes were identified as a result of the

study. The first was the family member's choice to be present or not to be present during CPR. There were many reasons given by the participants as to why they made the choice they did such as support for the patient, seeing the resuscitation process take place, avoiding difficult images, or being there to support other loved ones present.

The second theme identified in the study was aspects of communication between the healthcare providers and the witnessing family members. The importance of being aware of what the medical team was doing to their loved ones and why they were doing it was important to many. Those who were dissatisfied with the lack of communication from the healthcare professionals described the healthcare team as "robots" performing a task (Stefano et al., 2016). This attests to the lack of empathy and humanity which can sometimes happen as healthcare professionals are carrying out routine tasks without communicating with loved ones.

The third theme identified was how witnessing CPR take place impacted the family's acceptance of the death of their loved one. For some, even the initial presence of the healthcare team was enough to bring the reality of the situation into perspective. For others, actually witnessing the intensity of CPR aided in their acceptance of the condition of their loved one, and they were more apt to accept that nothing else could be done to resuscitate them without prolonging the traumatic experience (Stefano et al., 2016).

The last major theme presented by the researchers in this study was how the family members were impacted by choosing to either witness or not witness CPR being performed. Some participants reported they felt comforted knowing that their loved one did not suffer while the healthcare team was implementing interventions. However, some loved ones continued to be flooded with images of the experience in a way that negatively impacted them in the future. It was difficult for some to witness the intensity and reality of CPR. When participants were asked

to not witness CPR, some reported the difficulty of simply hearing what was happening. They felt as though only hearing and not participating in some way made them feel as though they were not granted an opportunity to make peace with the loss of their loved one and say goodbye to them in their final moments (Stefano et al., 2016).

While the results of this study suggest being present for CPR on a loved one can be helpful and aid in the family's acceptance of reality, it can also be too much for some to handle emotionally both in the present time and in the future. Therefore, healthcare professionals should always present both options to family members who may be present in both the acute care setting and out in the field where medical emergencies may occur. A member of the healthcare team who is not actively participating in resuscitative measures should always take the time to step aside and explain to the family members what is happening to their loved one, why they are implementing certain interventions, and the potential benefits to witnessing the resuscitation of their loved one. If the family member has questions, healthcare professionals should take the time to answer these. When the person has decided to either be present or leave the room for CPR, this decision should be respected by all.

Chapter 9: Role of the Nurse in Death and Dying

When death and dying are near, every member of the healthcare team has a very important and specific role. However, nurses are often the ones who spend the most consecutive time with the patients and their families. Because of this, a nurse can drastically improve the experience of the patient and their family. There are many qualities a nurse should possess which add to their impact on the lives of their patients and their family members. Nurses embody empathy, compassion, patience, and trustworthiness which promote a healthy relationship with the patient.

9.1 Communication

The first thing a nurse can do during the death and dying experience is to promote communication among the patient, their family, and the healthcare team. Patients and their families may be more comfortable speaking with the nurse rather than a healthcare provider simply due to the amount of time they spend with the nurse. Open-ended questions are a valuable resource for the nurse. This allows the nurse to prompt the patient or their family to express themselves constructively. The nurse should also provide evidence-based education and clarifying information. Patients can become overwhelmed with information as they are told about their diagnosis, prognosis, and options moving forward. They might not know what questions to ask at the moment, but as they process the news, questions will often arise. Nurses can provide objective information so their patients are fully informed when making decisions about their care moving forward.

9.2 Advocating

Another important thing the nurse is responsible for is advocating for his or her patient. There are often common orders or medications used for certain diagnoses or in end-of-life care.

However, some patients may prefer to use a nonpharmacological approach when dealing with their illnesses or symptoms. These preferences may be due to their cultural, religious, or personal convictions. Nurses should ensure their patients know they have a choice and the ultimate decision in their care to provide autonomy to the patient. Nurses should also advocate for their patients when they see something wrong. If a patient is quickly deteriorating or showing signs of pain, they should quickly obtain orders for medications to ensure the patient is remaining as comfortable as possible during this time. They also determine what else the patient might want to make them comfortable such as aromatherapy, music, dimming the lights, and other nonpharmacological interventions.

9.3 Nursing Interventions

Another role of the nurse is simply to implement medical interventions such as giving medications, changing dressings, inserting catheters, starting IVs, and other nursing skills. They are also responsible for the self-care needs of the patient such as mouth care, baths, and toileting. The nurse can implement these interventions with compassion by educating the patient and family on what they are doing or what medication they are giving and providing the opportunity for the patient to be involved in their care. The nurse should also perform these tasks with gentleness while ensuring privacy. Even though the patient might be sedated or unresponsive, the nurse needs to maintain their dignity until their last breath and even after. While the nurse might be accustomed to death and dying, their patients are often not. The nurse should not neglect to treat each patient with respect and dignity while providing the best, well-rounded care to them and their family members.

9.4 Post-Mortem Care

The nurse is also responsible for post-mortem care. Nurses should be educated on what to do or what not to do with the deceased person's body based on certain criteria such as when the body will be taken for an autopsy. If this is the case, the body should remain as is with no washing, removal of lines, or closing of their eyes (Schreiber, 2020). If the body is not going to be autopsied and the nurse will be performing full post-mortem care, they should know what their hospital policy is regarding this procedure. If the patient belongs to a culture that embodies certain values or wishes regarding post-mortem care, the nurse should determine what these wishes are before death occurs if possible, and he or she should work to accommodate these needs. One of the most important roles of the nurse while performing post-mortem care is to treat the body with gentleness and dignity, even if there are no loved ones present watching. It can become a routine procedure for the nurse to perform, but this should not change the way the nurse handles the body.

Chapter 10: The Effect of Death on Nurses

For most nurses who commonly deal with death, there is an established relationship with the person who has passed away. Nurses spend twelve hours shifts with their patients which provides ample opportunity for the nurse-patient relationship to develop. The nurse is usually the one that is by the patient's side when they are admitted to an acute care setting, and they are the ones who are present when the patient takes their last breath. Because nurses often embody such an empathetic spirit, seeing their patients die can be an emotional experience for them (de Swardt & Fouche, 2017).

In a study conducted by de Swardt & Fouche (2017), ways to gain a deeper understanding of nurses' attitudes toward post-mortem care in an intensive care unit were examined. The care for the dead body was a major emerging theme. Participating nurses stated how having two nurses performing post-mortem care made the experience more manageable. Many nurses valued taking the time to ensure that the body looked comfortable after death by placing the body in a normal position. The nurses also reported how placing the body in a neutral position allowed the family to view their loved one in a more familiar state in a very unfamiliar experience.

Nurses also valued handling the body with gentleness and respect during post-mortem care. Even though these nurses take on the task of post-mortem care respectfully, it was common for many of them to struggle to touch the body after it had cooled off following death. Religious and cultural considerations were mentioned by the participants as a part of their post-mortem considerations; however, they stated there was a lack of education regarding rituals and interventions that should be provided for other cultures. Some nurses even practice their own

spiritual convictions by praying for the patient and their family either alone or with the family depending on the needs of the family (de Swardt & Fouche, 2017).

The second emerging theme was the detachment of these nurses while providing post-mortem care. The nurse had invested so much of themselves into the care of the patient which made performing post-mortem care very difficult emotionally. They forced themselves to disassociate in some ways when caring for the dead body to care for their own emotional needs. While they sometimes had to detach themselves from the present task, they also used the time to say their goodbyes and come to terms with the loss of their patient while caring for their body for the last time (de Swardt & Fouche, 2017). If nurses are not equipped with healthy coping strategies and continue to suppress their emotions to adequately complete their job, they are at risk for developing emotional or mental health disturbances and even burnout.

Fear of death was a theme that was common among the participating nurses which some might not expect. Many nurses were fearful of their death and the implications of that for their families (de Swardt & Fouche, 2017). Experiencing the death of others sometimes forces nurses to examine their own views and preferences when it comes to dying a "good death." It is important for healthcare professionals to not avoid the topic of death when it comes to themselves or their family members so they can be prepared and determine their wishes before the time comes.

This study emphasizes the different emotional, physical, and spiritual impacts nurses must face when dealing with death and dying. Maneuvering the body can be a significant task for one person to accomplish physically. If a nurse is not aware of proper body mechanics, they are at risk for injury when performing post-mortem care. It can also be useful for hospitals and other healthcare facilities to implement a debriefing session after each death that occurs. This would

allow members of the healthcare team to discuss their feelings and unresolved emotions related to the loss of the patient, and improvements that could be made, as well as things the team succeeded at.

10.1 Combating Burnout

To combat burnout that is common among those in the nursing profession, Bateman et al. (2020) proposed a randomized controlled trial to evaluate the effectiveness of sessions geared toward allowing intensive care unit physicians and non-physicians to debrief their thoughts and feelings related to experiencing death. These sessions are similar to "Death Cafes" which discuss topics like death and grief. The participants would be divided into two groups with one group participating in the debriefing sessions and the other group not. Burnout rates would be measured using the Maslach Burnout Inventory score, and depression and anxiety levels would be measured as well. These items would be assessed before the study and at one, three, and six months after.

This study would be an important step in learning more about how to better care for the needs of healthcare professionals. Bateman et al. (2020) state, "burnout not only impacts the ability to enjoy work but also may lead to depression, posttraumatic stress disorder, substance abuse disorder, and suicidality" (p. 2). Healthcare professionals go to great lengths to meet the needs of their patients and the families of their patients. They attend to the physical, spiritual, psychological, and emotional needs of strangers, but how can they be expected to do this when their own needs are not being met? Burnout among nurses is not a new problem, but it has been brought to light with the COVID-19 Pandemic. Healthcare providers were seeing patients die multiple times a day, but they had no time to properly deal with the personal repercussions of this. It is imperative for healthcare facilities to greatly value the mental well-being of their

employees. They should ensure these healthcare professionals are given adequate resources to prevent mental health issues and burnout. When members of the administration value their employees and their health, they will be more likely to retain healthcare professionals who can provide quality care for their patients.

Chapter 11: Conclusion and Discussion

The role of healthcare professionals encompasses many aspects, especially when it comes to caring for patients and their families during the death and dying process. There are many physical, psychological, and emotional needs of both the patient and their loved ones. Members of the healthcare team should never lose sight of the impact of even the smallest details when caring for these patients. It is easy to remember how to implement certain interventions or care for these patients, but it is just as important to remember the "why" behind these interventions. Meeting the needs of these individuals during what could be the most vulnerable time of their lives can be a truly rewarding experience if done correctly.

A critical step in improving the experience for both the patient and their loved ones is being intentional with them. When patients feel valued and seen as unique individuals, they might be more receptive and trusting of those providing care to them. Communication education needs to be reinforced for healthcare professionals regularly to ensure patients are being provided with an opportunity to express their specific desires as they relate to their end-of-life care.

As previously stated, there are similar and different aspects to an expected and unexpected death. Healthcare professionals should understand the importance of facilitating communication with the patients and their families about their desires before the need arises and that information has not been provided. The importance of increasing resources for grieving

children should not be ignored, and more research needs to take place to determine more ways to serve these children. This is a vulnerable population that cannot be neglected. Increased health screenings for grieving parents is another important implication of this research as parents of a deceased child are at an increased risk for many preventable health complications.

In regards to being sensitive to other cultures and their specific needs, more education needs to be provided for healthcare professionals. By providing more education, there will be more culturally competent professionals providing higher quality care to their patients. Learning more about other cultures and how they approach death provides healthcare professionals with lessons they can apply to all patients such as ensuring the cleanliness of the patient, treating the body gently even after death has occurred, and speaking cautiously about death.

The impacts of facing death and dying frequently have been seen among all healthcare professionals, especially nurses with burnout and shortages. These findings alone should highlight the importance of caring for the people whose job is to care for others. The mental health and well-being of healthcare professionals should be prioritized, and there is a need for more resources for them to ensure they can care for patients with the highest quality care.

Overall, there is a need for healthcare providers to consistently provide self-check-ins to determine if they remember why they do what they do. Each professional should ask themselves if the humanity in death has been lost and determine what their role is in promoting a “good death” experience for every patient and their family. Every member of the healthcare team has an opportunity to provide exceptional, personalized care to each patient and their family as they navigate the death and dying experience.

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