Caring for Children at the End-of Life: A Family Centered Death and Dying Experience

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The terminal diagnosis for a pediatric client can be disheartening to all of those involved. When a child dies it has profound effect on the perceived meaning of the cycle of life. As a registered nurse (RN) one must investigate and assess how children’s awareness of death, grief and coping affects them. Having insight on this allows the RN to provide appropriate assistance through the death experience. Throughout this paper we will seek to examine the multiple questions that arise. First we will look into how do children perceive death? Secondly we will examine how do children manifest grief? Thirdly how could a RN assist a child to manifest their grief? Another question that stems from this theme is how can children’s symptoms could be managed near the EOL? Another area that we must consider is parents and siblings since they are also affected by the imminent death of a member of their family. The RN should prepare beforehand to have a conversation with the family important to address the general area of their concerns and what issues must be addressed? How can a RN prepare themselves to address the dying school-aged child to face their own imminent death? How will the RN see to answer the child general concerns and issue regarding their impending death?

Children’s perceptions of death differ due to the different developmental stages that they are in. Erik Erickson has categorized each stages in one’s development from birth through death. In this paper we will be examining the perception of children from infants to adolecents regarding death. The infant stage ranges from birth to 18 months. In this stage children are less cognizant of the significance of death, especially those under 6 months of age. The major developmental task of this stage is building a sense of trust with caregivers, therefore the even if the child is separated for a temporary period of time can have a profound effect. The toddler stage goes from 18 months to three years old. This stage is characterized by egocentric behavior, also they vaguely separate reality from fantasy thus making it impossible for them to fully comprehend absence of life. According to Hockenberry & Wilson “instead of understanding death this age-group is affected more by any change in lifestyle” (2009, p.598).

Preschoolers range from age four to six, death is seen as temporary to a child in this developmental stage. Children in this stage believe that “their thoughts are sufficient to cause death. Death is seen as temporary and gradual; life and death can change places with one another” (2009, p. 598). The children in this stage believe that one’s thoughts can be responsible of causing death, which can make a child prone to blaming themselves for the death. Preschoolers are unable to understand the permanence of death that it’s irreversible and that it happens inevitably.

The school age child ages range from 6-10 years old. According to Himebauch et al. “children understand that death is final and irreversible but do not believe that it is universal or could happen to them. Death is often personalized and/or personified” (2009, p. 1). Though the children in this stage operate at a higher cognitive level they still associate their behavior as being responsible to causing death. Another thing that is characteristic of children this age is personify death as an evil force, like a monster, the devil or the bogeyman.

The next stage is adolecents these children ages range from 11-19. These children “have a mature understanding of death. They are still influenced by remnants of magical thinking and are subject to guilt and shame” (Hockenberry & Wilson, 2009, p. 599). Adolecents are able to have an adult understanding of death. They are capable of thinking abstractly and are more curious about what death involves. We have examined how these children perceived death but in order to fully understand the effects that death has, it’s important to look at how they manifest grief. Everyone grief is manifested differently, and children are not different in this matter.

Children in the age group of 3-5 have a sense of loss. One will “anticipate regression, clinging. Aggressive behavior common. Worries about who will care for them” (Matzo & Sherman, 2015, table 10.4). The child in this stage might regress to behavior that might seem out of the ordinary or abnormal their parents like biting others. The child might joke, giggle, and engage in attention seeking behavior indicating the need to distance from current situation. The outward expression of grief might not be so pronounced due to their few defense mechanisms. Losing a significant person is such a devastating, painful experience that the child might distance themselves from the loss by engaging in the above mentioned behavior.

Children from age 6-8 are able to comprehend death they more mature than their younger peers. These children “are likely to exhibit fear through verbal uncooperativeness rather than actual physical aggression. Their fear of the unknown is greater than their fear of the known” (Hockenberry & Wilson, 2009, table 18-3). These children are in the “industry vs. inferiority” stage they need to be actively involved and to be informed. Death can be seen as a punishment for their behavior, making them feel responsible. The child might have difficulty concentrating on duties. The child might also deny or hide feelings, lessening their vulnerability.

The child that’s 9-11 has achieved more mental maturity. The emotional reaction of these children is stronger than their younger peers. They are aware that death is a permanent loss of a loved one. According to Matzo & Sherman “may regress, revert to fantasy. May somaticize, intellectualize, morbid preoccupation” (2015, p. 221). These children might express their grief as a headache, or stomach ache. The might socially isolate themselves in order to digest the implications of the death.

These differences in how children manifest grief are vital for a RN to understand. Many children are unable to express in appropriate matter. Each of these patients require assistance in expressing their grief even though those that are able to communicate might not know how to express themselves. As a RN we are a vital force in aiding these children in expressing their grief in a positive manner.

One of the most vulnerable populations are the children from age 3-5. These children must be reminded that their loved one is not returning. As RN I have to give accurate information, and one must answer their questions. As Matzo & Sherman states “involve in ‘farewell’ ceremonies. Encourage questions and expression of feelings” (2015, p. 221). These kids can take advantage from being part of a stable home environment it reduces anxiety and provides reassurance. As RN I would assist my patient in this age group to putting their emotions into feelings. These children need reassurance of having a caregiver that will provide care.

The child that’s in the age group of 6-8 require that the registered nurse provide more information. Allowing them to freely express their emotions and providing opportunities to doing so. They need to feel as useful so if they desire to participate in the funeral arrangements and ceremony it can be very helpful. As previously discussed these kids believe that evil forces are behind death. They need factual information this reduces their guilt. These children benefit from having a structure in their household, keeping a schedule of activities and need a resilient parent to aid their coping (Matzo & Sherman, 2015). Children can also reflect their anger towards the deceased, or family members for not taking the necessary steps to save them.

The age group that would cause more concern to the RN is the 9-11 year olds. As a RN I would need to provide precise information. The preteen developmental needs require to be informed. I would allow my preteen patient to express their emotions freely both verbal and non-verbally. Encourage them to find a trusted advisor to guide them. I would need to help them find a concrete way to remember their loved one. I remember losing a very close uncle from chronic kidney disease at this age and how being able to say goodbye helped me cope. I was able to rely on my parents for information on why did he died? I was given factual information which led me to feel at peace that his suffering was over. His passing away was one of the driving forces that led me to nursing.

Dying children have very specific needs to be meet during the EOL. They experience symptoms that are similar to those experienced by adults. Pharmacological interventions must be also tailored to them, the pediatric doses are not the same as those given to adults. Below I’ll examine physical symptoms, evidence based interventions and pharmacological interventions to manage the symptoms.

The first symptom is pain: The following three nursing interventions are recommended:

1. Use the Wong-Baker FACES Scales for the young child (4 years of age and older). Another tool that can be used is the Faces Pain Scale to determine the level of pain present (Ackley & Ladwig, 2011).
2. Include parents in the plan of care. Remembering that parents know what’s best for their child and what works (Matzo & Sherman, 2015, p. 459).
3. Help children and adolescents learn and use techniques such as relaxation and cognitive-behavioral techniques to handle pain (Ackley & Ladwig, 2011, p. 616).

The following are two pharmacological interventions that can aid in pain relief:

1. Morphine, 0.01-0.06 milligrams/kilograms/hour IV, opioid pain relief. Adverse effects: dizziness, weakness, sedation, paradoxical excitation, nausea, flushing, sweating, respiratory depression, decreased cough reflex, constipation, hypotension. Nursing implications give in the smallest effective dose, encourage respiratory exercises, careful use to avoid respiratory depression, monitor input and output (I&O) and bowel patterns (Skidmore-Roth, 2014, p. 839).
2. Methadone (Dolophine) 0.005-0.2 mg/kg IV bolus every 2 hours. Adverse effects: dizziness, weakness, sedation, paradoxical excitation, nausea, flushing, sweating, respiratory depression, decreased cough reflex, constipation, hypotension. Nursing implications: observe for dependence, respiratory depression, encourage high-bulk foods (Skidmore-Roth, 2014, p. 790).

The second symptom is dyspnea: the following three nursing interventions are recommended:

1. Assess the client’s level of anxiety and physical reactions to anxiety (e.g., tachycardia, tachypnea, nonverbal expression of anxiety) (Ackley & Ladwig, 2011, p. 140).
2. Provide backrubs/massage for the patient it aids in decreasing anxiety (Ackley & Ladwig, 2011, p. 141).
3. Observe for adverse changes if anti-anxiety drugs are taken (Ackley & Ladwig, 2011, p. 141).

The following are two pharmacological interventions that can aid in dyspnea relief:

1. Lorazepam (Ativan) 0.025-0.05 mg/kg/dose, orally, antianxiety agent. Adverse effects: dizziness, drowsiness, lethargy, respiratory depression, apnea, cardiac arrest, constipation. Nursing implications assessment of continued needed, continued assessment of degree of anxiety and prior mental status (Skidmore-Roth, 2014, p. 755).
2. Diazepam (Valium) 0.08-0.12 mg/kg every 8-12 hours, orally, antianxiety agent. Adverse effects: dizziness, drowsiness, lethargy, respiratory depression, apnea, cardiac arrest, constipation. Nursing implications assessment of continued needed, continued assessment of degree of anxiety and prior mental status (Skidmore-Roth, 2014, p. 399).

The third symptom is nausea: the following three nursing interventions are recommended:

1. Assessment of signs and symptoms to discover the root of the nausea (Matzo & Sherman, 2015, p. 563).
2. Use of antiemetics in order to relieve symptoms (Matzo & Sherman, 2015, p. 563).
3. Relaxation through the progressive contraction and relaxation (Matzo & Sherman, 2015, p. 56).

The following are two pharmacological interventions that can aid in dyspnea relief:

1. Ondansetron, Zofran, 0.15 mg/kg IV, antiemetic. Adverse effects: bronchospasm. Nursing implications QT prolongation (Skidmore-Roth, 2014, p. 909).
2. Promethazine, Phenergan, 0.25-0.5 mg/kg q4-6hr prn, PO/IV/IM/RECT, antiemetic. Adverse effects: neuroleptic malignant syndrome, thrombocytopenia, agranulocytosis, hemolytic anemia, apnea in neonates, infants, and young children. Nursing implications monitor I&O ratio, respiratory status, cardiac status, neuroleptic malignant syndrome (Skidmore-Roth, 2014, p. 1004).

The fourth symptom is delirium: the following three nursing interventions are recommended:

1. Limiting sensory stimuli such as watching television (Matzo & Sherman, 2015, p. 533).
2. Make surrounding familiar with objects from such a pictures and toys (Matzo & Sherman, 2015, p. 533).
3. Soothing touch and voice aid in promoting a calm athmosphere (Matzo & Sherman, 2015, p. 533).

The following are two pharmacological interventions that can aid in delirium:

1. Haloperidol, Haldol, 0.01-0.03 mg/kg up to 6mg/mg/day every 8hr, by mouth, neuroleptic. Adverse effects: seizures, neuroleptic malignant syndrome, cardiac arrest, tachycardia, sudden death, ileus, hepatitis, laryngospasm, respiratory depression. Nursing consideration monitor for neuroleptic malignant syndrome, QT prolongation (Skidmore-Roth, 2014, p. 618).
2. Olanzapine, Zyprexa, 1.25mg-2.5 mg per day, by mouth, antipsychotic. Adverse effects: seizures, neuroleptic malignant syndrome, heart failure, hepatitis, neutropenia. Nursing implications monitor mental status, monitor for neuroleptic malignant syndrome (Skidmore-Roth, 2014, p. 902).

The fifth symptom is constipation: the following three nursing interventions are recommended:

1. Assess for the cause of constipation (Ackley & Ladwig, 2011).
2. Adequately hydrate client, encourage frequent repositioning (Ackley & Ladwig, 2011).
3. Use a diet with higher fiber concentration (Ackley & Ladwig, 2011).

The following are two pharmacological interventions that can aid constipation:

1. Magnesium hydroxide, MOM, 5-15 ml/day, by mouth. Adverse effects: flaccid paralysis, circulatory collapse. Nursing considerations cramping, rectal bleeding, nausea, vomiting, if so this product should be discontinued (Skidmore-Roth, 2014, p. 766).
2. Bisacodyl, Dulcolax, 5-10 mg rectally, laxative. Adverse effects: tetany. Nursing consideration monitor I&O ratio, cramping, nausea, vomiting (Skidmore-Roth, 2014, p. 196).

Communicating with the parents and siblings of a dying child might be one of the most difficult things one can do as RN. The family will be soon losing a loved member and many questions arise during this period. Parents have to make hard decisions regarding their child’s care. One area of concern for parents is not being able to care for their child at home when they are near death. Siblings worry that they might be at fault for the death of their brother/sister. As a registered nurse I could first help parents express their emotions and carefully listen. Many parents go through a great deal of anger, sadness, isolation and stress. I would ask them how I could assist them? In this difficult process. A second area is discussing where would they prefer that their child die? Many parents are unsure if they would like to have their baby die at a hospital (Mullen, Reynolds, & Larson, 2015). Discussing palliative care at home could be a viable option. Last but not least the siblings can also be a vital part of the end of life process. Allowing them to participate to a reasonable degree in caring for their sibling can decrease anxiety. Siblings can assist parents bringing them the supplies to provide care for their dying brother/sister. But the conversation that would be most emotional for me is talking to my dying patient about their imminent death. Before I took this course that was one of the things I had always hoped that I would never encounter. Preparing beforehand and tailoring the information to their developmental age is a basic first step.

Speaking to a dying child that’s 8-10 years old is a challenging task. As previously discussed in this paper these children have a better understanding of death. Encouraging the child to express their emotions is very important. Finding out what the child is aware of is also vital in order to tailor the conversation to their needs. I would ask my patient what you would like to know. This ensures that the information I deliver is what they want to know. These children need to be aware that expressing their feelings is important and provide them an effective outlet. I would be empathetic with my dying pediatric patient by spending time with them and listening to their concerns. Letting them know that I know this must be hard for them, that I’m here to help them. I would allow them to keep control over their body and retain their independence in order to fulfill their autonomy and reduce feelings of inferiority. The child at this age fears the unknown so letting them know what will happen to them eases that preoccupation. I would also involve this child their own post death services. This allows control and personalization of their funeral service. Allowing them to say their goodbyes is also empowering and enables them to be in control.

In conclusion throughout our careers we will find ourselves in that position caring for a child that will die. I find that through the research for this assignment and the course I’m better prepared to do it. Knowing that every child has different needs is imperative to deliver the care they deserve. Building a trusting relationship with our patient and their family they’re a unit that needs to be cared for. Though knowing all of this doesn’t make it any easier on the RN, but it ensure that we are able to provide the holistic care they deserved. Sitting with them and using our presence is reassuring, it shows that we too mourn the loss of a young child.

The nursing recommendations that this paper encourages is the need for more education regarding palliative services for all nurses. Many are unaware of the resources that are available to assist us registered nurses to help the families going to this emotional time. We need to be present with the family, being there shows that we care as nurses. We must not be afraid to cry, we are humans our emotions show that we understand how difficult the situation is. We also need to take time to reflect how we deal with grief. Finding healthy ways to express our grief, we must not afraid to get help when we need it.

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