Child’s Perception on Death and Dying

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The ideas of death and dying are often perceived differently throughout the lifespan. As of late, in today’s society, the death of a child and a child’s experience with loss and death are concepts that are now considered as quite rare, with most children being sheltered from death, apart from the occasional exposure to television and video games (Matzo & Sherman, 2010). The death of a child is considered unnatural, and considered a threat to one’s understanding of the natural order; as such, learning to deal with the grief that comes with the loss of a child can be immensely challenging. Likewise, for a child that is experiencing grief, loss and death firsthand, and for the first time. Because very little is understood about a child’s perception and response to death and dying, as nurses it is our duty to first explore and examine children’s perceptions of death and dying to better understand and efficiently provide end-of-life care to a child.

In children, much like it is across the lifespan, the nurse caring for the dying client must establish rapport and a trusting relationship with the child. The only difference being that the nurse must also take into account the child’s parent/s and also establish a trusting relationship with them (Matzo & Sherman, 2010). Children are innately curious about everything, and naturally they will also be curious about their illness. Nevertheless, no matter how much one tries to explain and present, at an appropriate level that the child can grasp and comprehend, the information, each child will vary in how much information they can fully absorb. According to Matzo & Sherman (2010), children’s expression and verbalization of their potential death “can vary across the continuum and may be fluid over time.” Children at different levels and ages will also perceive death differently. Sometimes, they may acknowledge that they are very sick or “have a bad disease but will not mention death.” On a whole, children 7 or 8 years old or younger, being that they are not mature or old enough to fully grasp abstract concepts, may perceive death as temporary and reversible, thinking that it can happen only to others and not them. Moreover, they may also attribute it to being caused by “previous thoughts and actions.” On the other hand, the slightly more mature child that is over the age of 8 may comprehend the “central aspects of death” and may even verbally express the possibility of death from his/her illness. (Matzo & Sherman, 2010)

In addition, as noted on WebMD (2009), children under the age of 7 most typically view death as a separation, which may result in feelings of fear and being abandoned, whereas children between the ages of 7 and 12 view death as a threat to their personal safety. According to Hospice and Palliative Nurses Association (2012a), because children between the ages of 3-5 also perceive death as reversible, often they will need facts repeated; they may also believe that their thoughts or feelings are so powerful, enough so that they caused the illness or death. Meanwhile, children aged 6-9 years old may begin to perceive and understand death as a final concept, but will be curious about the physical details such as the cause of death (Hospice and Palliative Nurses Association, 2012b).

Death and loss are concepts that are difficult to grapple with on their own, most especially for children. But another concept that they must learn to contend with, particularly with severe or terminal illness, is that of grief. Grief is defined as “a universal human response that flows when security is shattered by loss” (Konecny, 2012). Usually an emotional response, grief according to Konecny (2012) is often evident in changes that occur in an individual’s “thoughts, behavior, social interaction, physical well-being and ability to go about everyday life.” Children often express grief in different ways, but the signs of grief among children most often initially appear through changes in their personality and/or behavior. Most notably among children under the age of 7, is the changes in sleeping patterns—as they may have trouble sleeping at night; and since they are not yet fully able to verbally express their feelings in ways in which adults understand, they may tend to act out their feelings, unleashing anxiety, anger and/or fear through temper tantrums, defying adults, and participating in role-play and pretend play (WebMD, 2009). Meanwhile, children between the ages of 2 and 5 may appear to develop changes and problems in eating, sleeping, and/or toileting (often reverting/regressing to pre-toilet-trained, bed-wetting); children between the ages of 7 and 12, on the other hand, may exhibit behaviors such as being unusually withdrawn, developing problems of concentration, especially as it relates to schoolwork, difficulty in following directions and in completing normal daily tasks (WebMD, 2009).

As previously mentioned, there are varying ways for children to express grief; usually however, children grief is manifested through somatic, psychological and behavioral changes. Some behavioral manifestations of grief among preschool children (ages 3-5) include increased activity, constipation, encopresis, enuresis, anger and temper tantrums, “out-of-control” behavior, nightmares and crying spells, while those manifested in school-age children (6-8 and 9-11) are as follows: resistance to attending school, loss of concentration, disinterest, lack of motivation, failure to complete assignments, and daydreaming in class—all of which contribute to a deterioration in school performance; crying spells, lying, and stealing (Pantell, Carey, et. al., 1992). In terms of somatic manifestations among the latter (school-aged children), nervousness, abdominal pain, headaches, listlessness, and fatigue are sometimes present (Pantell, Carey, et. al., 1992). Meanwhile, according to Worden (2001), younger children, such as those in the preschool age (3-5), tend to somaticize more than the older children since they have more limited verbal abilities. Among the somatic manifestations present among this stage are headaches and stomachaches (Worden, 2001). With regards to the psychological manifestations of grief, preschool children (3-5) often develop a fear of being alone and abandoned, often refusing to sleep alone or to leave the side of those that they love, often suffering from nightmares, while school-aged children tend to develop either bravery or fear of death, often becoming more withdrawn or staying close to someone they feel safe and protected with (WebMD, 2009). Hospice and Palliative Nurses Association (2012b), reiterate that school-aged children may also suffer from a loss of sense of security, as well as feelings of denial, as psychological manifestations of grief—which may perhaps explain their tendencies to be clingy or demanding.

There are numerous and various ways in which the nurse can assist children in expressing their grief. According to Matzo & Sherman (2010), grief and bereavement are important development stages, as such the nurse should “provide interventions that offer the opportunity for healing and growth,” follow-up with family (members), and encourage memorial rituals that would help to commemorate the deceased’s life and death. While these are appropriate measures that would enable children to express their grief, these are only applicable to the older children (ages 9-11), who have a better understanding of death and grief, and a better ability to verbally express their feelings. Some ways in which the nurse can help children around the ages of 3-5 and 6-8 to express their grief would be to engage them in play therapy (Brandell, 1998). Children around these ages love to play, and through an activity, which they are fond of and most comfortable with, they may be able to truly express how and what they feel. For instance, with play therapy dolls and/or puppets could be used to represent themselves or their family members, and how these figures would interact or won’t interact can be then be interpreted by the nurse, with a help of a therapist (Brandell, 1998). Art therapy is another outlet in which a nurse can help children to express themselves. Drawing allows children in these ages to conceptualize their thoughts; and since drawing comes naturally to them, and is considered as a “‘safe’ activity,” then children won’t feel intimidated or afraid of sharing their thoughts through this medium (Brandell, 1998).

Furthermore, taking steps to allow the child to play and have fun despite his/her loss, is another way a nurse can assist children to express their grief, particularly among the preschool ages (3-5 years); Providing them with certain books also enables the child to become more aware of his/her feelings, and may prompt him/her to talk about them, which will further help the healing process and appropriate expression of grief (Hospice and Palliative Nurses Association, 2012a). These same measures also apply to children in the school age (6-9 years); allowing the child to partake in rituals, or participate in a funeral or memorial service, if desired, are also ways that help them get a better idea of how real the situation is, aiding in the process of appropriately expressing their grief in healthier ways (Hospice and Palliative Nurses Association, 2012b).

Children much like adults, despite their limited ability to effectively express/verbalize feelings, still experience pain at the end of life (Matzo & Sherman, 2010). That said palliative-care is just as essential to dying children as it is to dying adults. Some essential aspects of palliative-care administered to dying children include pain management. According to Palliative Care for Children (2002), children receive less effective pain management as adults. In fact, children are less likely to receive any medication than adults, and children less than two years old are even lass likely to be treated for pain than are the older children (Palliative Care for Children, 2002). Pain management can be achieved through pharmacological treatment. It is essential that the nurse taking care of the dying child include parents and caregivers into the pain management plan, as “part of the therapeutic alliance” (Matzo & Sherman, 2010). Moreover, when assessing for pain prior to treatment, the nurse must observe for any behavioral changes, such as vocalizations, facial expressions, changes in usual patterns of sleep, etc., as well as rely on the child’s self-report of pain as this is actually a “valid indicator for estimate of pain location and intensity” (Matzo & Sherman, 2010). One other essential aspect of palliative-care administered to dying children is dyspnea management. According to Matzo & Sherman (2010), approximately 82% of parents with dying children report dyspnea at the end-of-life, which is second only to loss of appetite (100%). While dyspnea is not unusual during the end of life, because children have underdeveloped or immature respiratory function, deterioration may occur rapidly, particularly when a disease is present (Matzo & Sherman, 2010), which could further cause “a sense of anxiety bordering on panic” and the child may experience a feeling that can be likened to drowning (Palliative Care for Children, 2002). Breathing, a simple task that should come normally to healthy individuals is one of the first to be affected at the end-of-life; when an individual has difficulty breathing, particularly a child, this can cause not only discomfort, but also anxiety. The same can be said about pain; it can cause anxiety and moderate to severe discomfort. Thus, it goes without saying that providing care and comfort to children at the end of life would greatly ease the burden that they are already encumbered with. Alleviating, at the very least, the physiological stressors they are experiencing, is one essential aspect that should be considered.

Like any palliative care administered to dying clients, children also experience barriers in the care that they receive. Some of these barriers to palliative care include, but are not limited to insufficient knowledge of pain management and of palliative care, conflict among family members or between family members and staff members, cultural difference, staff shortages (Davies, Schring, et. al., 2008). Also, another barrier to palliative-care that children may experience is the lack of aggressive pain management. Because they are considered fragile, children are often thought of as not feeling pain as intensely as adults, and are thus thought of as not requiring aggressive palliative care like the adults do (Matzo & Sherman, 2010). Needless to say, this could not be more further from the truth as children’s pain are most likely as intense as adult’s pain, and should thus warrant an equally aggressive pain management treatment as the adults.

With regards to managing symptoms of a child at the end of life, pain management and palliation, achieved through pharmacological therapy, are key concepts to be considered. A nurse that is caring for the dying child must be well versed in managing pain in children, utilizing a “multidimensional approach with an awareness of issues specific to the pediatric population” (Matzo & Sherman, 2010). Moreover, a study conducted by Drake, Frost, et. al., (2002) that examined the symptom prevalence, characteristics, and distress of children at the end of life in the hospital, determined that “a more aggressive approach to symptom management” such as that of pharmacological therapy (e.g. use of benzodiazepines), helped improve symptom control and reduce symptom burden among children. Employing anticipatory guidance in one’s care of a child at the end of life is also another way of managing symptoms. This typically involves predicting “the course of illness and complications of therapies in order to anticipate demands the patient and family will face” (Konecny, 2012). In addition, anticipatory guidance also entails patient/family teaching—ensuring that both parties know what to expect, and guiding them to prepare for possible symptoms (Konecny, 2012).

According to Zerwekh (2006), in caring for an end-of-life client, it is imperative to remember that family members “want to speak a nurse who is genuinely listening and understanding to their unique situations, not a person who is only feigning to listen and care.” It is also important that support be given and lent to parents and siblings who are facing the death of a younger brother/sister. Naturally, parents of children at the end of life will have difficulty trying to make sense of what is being said or experienced (Matzo & Sherman, 2010). As a nurse, one can help parents untangle concrete issues—such as differentiating between decisions based on personal preference or those that entail grave implications—as well as in dealing philosophical issues that will entail determining what is best or right for their children and what is best or right for them, as parents (Matzo & Sherman, 2010). Also, ensuring that discussions with these parents, particularly those regarding end-of-life care, should be done so in a sensitive and caring manner is another suggestion (Matzo & Sherman, 2010). Meanwhile, siblings of dying clients also need someone to talk to, and someone to listen to what they are going through, so that they can voice out their stress, feelings and emotions, instead of projecting it into other aspects of their life, or letting it manifest in other areas, such as their behaviors. Children should also be referred to professional counseling, when necessary, and given access to grief and bereavement support groups (Hospice and Palliative Nurses Association). Referring to the Hospice and Palliative Nurses Association’s patient/family teaching sheets before speaking to the parents and siblings would be beneficial.

While trying to explain to a child, let alone talk to them, about facing their own death is undoubtedly an emotionally burdening experience, as a nurse taking care of a dying child, it is nevertheless imperative that one be as open and comfortable with broaching the subject with the child as possible. Equally important is exercising one’s authority as a nurse to encourage others to talk to dying children in the same manner. As a nurse, one can suggest that people talking to children who are facing their own death refer to the Hospice and Palliative Nurses Association’s guidelines for helping children prepare for death. The Hospice and Palliative Nurses Association (Hospice and Palliative Nurses Association, 2012b) suggests that the person talking to the child should be someone that they know and trust, and that the talk should be done in a private and quiet place. Furthermore, the Hospice and Palliative Nurses Association also suggest that the person doing the talk should address the child’s emotions, like telling them it is okay to be sad, to cry or be angry. Recognizing the fact that this may be a difficult and confusing time, and helping the child acknowledge this, as well as allowing him/her to see adults crying, grieving and expressing their emotions is also another approach that one should consider when talking to dying children. In addition, encouraging the child to ask questions is also important, as they may most likely be curious to hear about the facts regarding their illness or death (Hospice and Palliative Nurses Association). Again, keeping all these in mind, it is of the utmost importance that as a nurse, we suggest that talking to children who are facing their own death be approached in sensitive manner, and be done so in words and ways in which is appropriate for the child’s age.

Fortunately (or unfortunately, depending on how you look at it), I have not experienced firsthand caring for a dying child. While in some ways I am fortunate enough to never have had experienced the pain and suffering of grieving over the loss of a child I have provided care for, I am also at a disadvantage in that, I cannot learn from experiencing it firsthand. Moreover, with this disadvantage, despite what knowledge I’ve gained from class, I will never fully comprehend the depth of the suffering and grief the parent/s and child are undergoing as they are faced with a death experience. Nevertheless, with the information that I’ve gained from this course, I am equipped with the necessary knowledge to offer parents and children who are facing a death experience, the help they need. Beyond the direct care that a nurse can offer to parents and children who are facing a death experience, the emotional support that we as nurses can lend them, is of absolute paramount importance. Both the parents and children will undoubtedly be encumbered and preoccupied with the emotional roller coaster that the grieving process entails. As both the parents and children go through Kubler-Ross’ 5 stages of grief, they may find themselves seeking solace and finding comfort in various outlets and methods; and as nurses, it behooves us to guide and steer them in the right direction wherein they find the appropriate/healthy methods of overcoming their grief in ways that will be suitable for them. Physically and emotionally being there for the parent and children assures and provides them with the comforting notion that they do not carry the burden of grief alone. Being that emotional support is a given when it comes to dealing with parents and children who are facing a death experience, it also goes without saying that it is also imperative for the nurse to first understand his/her role in the end-of-life care—achieving emotional clarity and coming to terms with our own issues of death—so that s/he may be better prepared to face death, and be able to wholly invest himself/herself in catering to the needs of both parties (parents and children). Apart from the crucial emotional support that nurses can offer, there is also the referral to several resources (e.g. counselor, chaplain, etc.) and support groups that would enable both the parents and children to cope with their impending loss and grief. To reiterate, above all, offering parents and children, who are facing a death experience, the proverbial “shoulder to cry on” is arguably the best that the nurse can provide. Offering oneself speaks volumes of how much one truly cares for the client. When parents and children perceive death and dying as venturing out into the known, knowing that someone is at least there to commiserate with and empathize with brings a sense of peace and comfort to a death experience.

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