

REVIEW PAPER**Speaking about Death and Dying to Parents' of Pediatric Patients who are Terminally Ill****Veronica Braganza, BScN****Student of Erasmus Mundus Master in Emergency and Critical Care Nursing, University of Oviedo, Asturias, Spain****Correspondence:** Veronica Braganza, 5C-21 Calle Gonzalez Besada, Oviedo 33007, Asturias, Spain. E-mail veronicabraganza@hotmail.com**Abstract****Introduction:** The phenomenon of speaking about death and dying is always a challenge, however to speak about it to parents of a terminally ill pediatric patient only makes the challenge greater.**Aim:** The aim of this article is to discuss what death and dying is, the importance of speaking about death and dying, the grief process and the barriers of speaking about death and dying for pediatric nurses. It will also aim to highlight the positive outcomes of breaking the bad news appropriately and how end of life care is encircled in holistically meeting the family's needs.**Method:** A comprehensive search was performed of recent literature related to death and dying in Pediatrics, breaking the bad news, barriers to speaking about death and dying, nurse's role in death and dying, and end of life care. Keyword searches were undertaken to summarize findings published in the past five year and those found in a few landmark studies.**Results:** The reviewed articles focus mainly on various definitions of death and dying, the concepts of a "good and bad" death, breaking the bad news and barriers associated with this process. It stresses the important role nurses play. Additionally, many studies focus on the importance of end-of-life care and Kubler Ross stages of grief. Furthermore, a lot of attention is given to the perceptions of nurses about their comfort with speaking about death and dying and the barriers they feel when discussing this topic and how nurses need to be supported as well through this difficult process.**Conclusion:** Nursing care in totality is caring for the patient and the family together. In order to achieve this uphill task it is recommended that nurses develop their skills of communication and comfort with this topic. But at an organizational level it is recommended that nurses be allowed to share the experiences and difficulties they face speaking about death and dying. Also specialized nurses should be part of the health care team to address palliative care in terminally ill children, to educate families and to help families through this difficult journey.**Key words:** pediatrics, nursing, nurses, death and dying, breaking bad news, grief model, end of life care.**Introduction**

No one expects a child to die, but they do. The death of a child is without a doubt something that is unthinkable. It totally counteracts the natural rhythm of life and death, and results in a feeling of grief and loss for the parents, relatives and all involved in the care of the child (Meyer, Ritholtz,

Burns and Truog, 2006). Many parents are unable to understand the reality associated with the death of a child; as in a single moment all their dreams and aspirations for their child seem futile. They are left sometimes with questions like "Why me", "Is there a God", "Can this really have happened?" The process of death and dying, in children may be sudden like that in a road traffic accident; or

prolonged like in the case of terminally ill cancer patients. However, in both cases it is a traumatic experience for the parent. What really matters though is how through the whole process of death and dying was the family supported, educated, and assisted. Sometimes, health care professionals think it is better to remain silent and allow the family to understand and walk through this process alone. At other times, they think maybe assurance is better, even if it is actually “false reassurance” and at other times they just ignore the whole death and dying phenomenon as they aren’t comfortable about it ourselves.

Once, a 5 year old was admitted in the Pediatric ward with respiratory distress. He had previously been diagnosed with a Mediasternal mass that was malignant. It was usual to see him come for the scheduled chemotherapy and other treatments; but to see him in this condition made everyone tensed. Many hours of intense treatment were initiated, and he improved minimally. However, after several tests it was seen that the tumour was enlarged and strategically placed; even a surgery was a major risk. His family was counseled about the prognosis, and that probably a curative approach would not help him anymore. The health care team, thought it best if the family chose the further course of treatment- curative versus palliative. The family was confused as to why before this, the physician had helped them with the decisions but now had left this integral decision up to them. Watching their child breathing, with evident difficulty blurred their thoughts. Everything seemed to be crumbling down, with no one there to pick the pieces. The mother sat trying to comfort her son but had tears running down her face. She turned to the nurses and asked “Is he going to die?” One of them told her not to talk like this as it was no use being negative. One said all was going to be good and to be strong and the next became busy in some medication preparations and avoided the question altogether. The mother just watched her child, and asked him for forgiveness for her inability to do anything

This scenario makes one think, about the whole process of speaking about death and dying to parents of terminally ill patients. Whether really a nurse can help with the family centered care

approach. What are the possible advantages of discussing the end of life and why nurses hesitate to do so? Lastly, are parents ‘really’ helped through the loss of their child if they are better informed and helped through the process?

To sort out these questions a literature search was performed. It was amazing how much literature exists on this topic, yet at the same time how each piece of work explained this phenomenon differently.

Death and Dying- the concept

Initially, it is important to understand death and dying. As Bryan (2007) states “death may not simply be seen as the cessation of life, but may be laden with complex and culturally constructed implications” (p.81). Thus, if we just look at death under a medical definition as the failure of a living being to biologically function; we will not be able to address the phenomenon of death and dying. We need to see death and the process of dying in context of the human being as part of the society he evolves from.

Nurses helping through the process

“Nurses are invested in the “good” of their patients, whether this good is found in supporting their young patients toward health or to ease dying” (Zielinski, 2011, p.18). However, the taboo associated with speaking about death and dying especially when it relates to children makes it difficult for pediatric nurses to tackle this topic.

It’s reasonable that when discussing something as sensitive as death and dying, there may be a fear of upsetting the other or just saying the wrong thing. But by building a therapeutic relationship we can become part of the person’s universe. Enabling us to, share the burden of suffering through empathy, caring and compassion (King & Jordan-Welch, 2003).

Additionally, Nielson (2007) highlights the significant role nurses play in the care of terminal ill patient. She shares that parents during this time may feel helpless. However, nurses are the one who can offer tools to the parents empowering them to address end-of-life issues and express their love to their dying child. This powerful contribution is only possible as the nurse is the one

who has assessed the patient and family needs, and knows what interventions must be done to support these needs.

The challenge for Pediatric Nurses

Well, if we truly believe that nurses can use their nurse-patient relationship to address something as difficult as the topic of death and dying. The question is why do nurses avoid this topic? As discussed by Dunn, Otten, and Stephens (2005) the reasons why nurses may not feel comfortable about discussing death and dying are associated with their attitude to the care of the dying patient. "Their attitude is the cumulative of their personal experiences (age, race, religion, attitude towards death), past experience (level of education and death training) and professional experiences (months of nursing experience and percentage of time spent in contact with terminally ill or dying patient)" (p.99).

It is portrayed that many nurses may be afraid to address the subject of death, as they aren't comfortable with this topic themselves. However, contrary to this; many nurses see death as a part of life and are focused to alleviate the pain and suffering associated with this. Dunn, et al. (2005) reported that "nurses usually found the barriers to communication as being family barriers that are lack of understanding regarding life support, not accepting a patient's poor prognosis, angry behaviors, and requesting more life-sustaining treatment against patients' wishes" (p.103). In a study done by Kaunonen, Tarkka, Hautamaki and Paunonen (2000) it highlights a very important concept that staff also grieve after the death of a child, some also find it difficult to forget the death and this impacts their feelings towards speaking about death. Others felt insecurity while supporting a grieving family. But all the nurses felt that education empowered them and enhanced their ability to support the family.

Additionally, a study was done by Cook, Lawrence, Grady, Liner, Hickey and Connor (2012) with nurses to understand their behaviour and coping strategies when caring for dying pediatric patients. The categories which emerged included: boundaries, memories, disconnecting, and labeling. Nurses felt that boundaries needed to

be "fluid" and change according to the particular patient and their family needs. However, a negative aspect was that this enabled them to get emotionally connected and made the acceptance of a death of a child hard to bear. Memories, was another theme that for some was positive for e.g. seeing a previous picture of the child made the patient seem more like a person, and helped nurses. Disconnecting and Labeling were two more aspects that nurses felt could help them emotionally detach themselves from this devastating task of nursing terminally ill pediatric patients.

Breaking the bad news- pros and cons

It is integral to remember that end-of-life [EOL] care entails breaking the bad news, there is no right way of doing this, neither any right time nor place. But it is an essential component that needs to be catered to. Thus, "the principles of breaking bad news to patients with a poor prognosis include: checking their existing awareness, eliciting their concerns before and after being given the news and checking their needs for information and responding appropriately" (Maguire, 2005, p. 29). The reason why these principles should be followed is that at many times health care professionals try to give information in a very casual "general information" way, but then a gap between the patient's needs and the knowledge disseminated exists. Parents of patients usually are preoccupied with their own concerns and will fail to assimilate what is being said. When they fail to comprehend what news is being shared this will result in them feeling that inadequate information was given to them; resulting in them having a negative appraisal of the situation and the news. Unwarranted stress, anxiety and depression escalate from this (Maguire, 2005).

Meyer, Ritholtz, Burns and Truog (2006) share that "parents identified 6 priorities for pediatric end of life care which are honest and complete information, ready access to staff, communication and care coordination, emotional expression and support by staff, preservation of the integrity of the parent child relationship and faith"(p.649). The rating of their priorities, clearly elicits the role that breaking the bad news plays. In the scenario above, the physicians broke the bad news that no curative

treatment would be beneficial and then just left the family to decide further their wishes. Burdening the family with the feeling of being abandoned at probably their most crucial time, additionally for them to make a decision of curative versus palliative was probably linked with many emotional bonds and the feeling of whether they are doing enough for their child or not.

End- of- life care & Grief stages: Family Centered Nursing Care

Kars, Grypdonck and van Delden (2011) identified “four EOL stages from the parents’ perceptions: becoming aware of the inevitable death, making the child’s life enjoyable, managing the change for the worse, and being with the dying child.” (p.E269). Nurses need to realize that the EOL care should encompass these stages, so that the parent child relationship can be preserved and the parent is enabled to see beyond the child’s physical deterioration. As addressing these needs would help parents to delay their grieving process, making memories of the time spent with their loved one. Additionally, parents could cope with their feeling of guilt as they would be consoled by the fact that they could be there to meet their child’s needs.

Kübler-Ross (1969) shares 5 stages of grief a person goes through namely Denial, Anger, Bargaining, Depression and Acceptance. However, each of these stages is very individualized, and the time each person spends in each stage is highly dependent on the support they receive during each stage. Parents are one of the vulnerable populations for this process as “all parents have hopes and dreams about their children's future. A child is a natural source of self-esteem for parents. When a child dies, the family's hopes and dreams die, too. The child's death insults the parents' ability to act as parents” (Laakso & Paunonen-Ilmonen, 2001, p.69) and so their grieving process needs to be focused on, and acknowledged when providing nursing care. Preparing parents for what to expect and discussing difficult themes and outcomes of care in advance can help them to live up to their

intentions in the more difficult later stages (Kars, et al, 2011, p. E270). Health care professionals should not enforce their own perceptions or give false reassurance; as parents are not guided by this but crippled. As in the scenario the nurse tried to comfort the mother but actually emotionally made her susceptible; as the realistic condition of the child was overshadowed by the nurse’s false consolation.

Nurses can make the whole grief experience different affecting a parent’s life after; they must remember that grief can have positives and negatives and should be treated carefully. “Positive aspects can be appreciation of one’s own life, strengthening of one’s own family ties and feeling grateful of events but negative aspects could hamper one’s life intensifying fears, increasing bitterness, and losing creativity and zest for living” (Laakso & Paunonen-Ilmonen, 2001, p.74).

Nurses can alleviate or at least decrease the negative aspects by nursing care that is family centered and holistic. This can be achieved by using the Framework Model of EOL care (Fig 1) shared by Nolan and Mock (2004). This model sees the patient and family in a broad spectrum seeing how external and internal factors influence a person’s and family’s integrity, internal and external threats to integrity and goals of care and outcomes of care. If nurses, see a patient and their family in this context; they can prioritize their care to meet the entire family’s needs. Making the whole terminally ill stage a journey that a family walks together with the health care professional, rather than a nightmare they fight against.

Therefore, the priority for nurses should be to provide “individualized instruction with proactive assessment of a family’s needs to help fulfill the family’s needs and maximize the adaptation” (Davidson, 2009, p.33). At all times in the caring process, nurses need to remember that any care which does not incorporate the family needs is care that has not been effective and successful in meeting the nursing care goals.

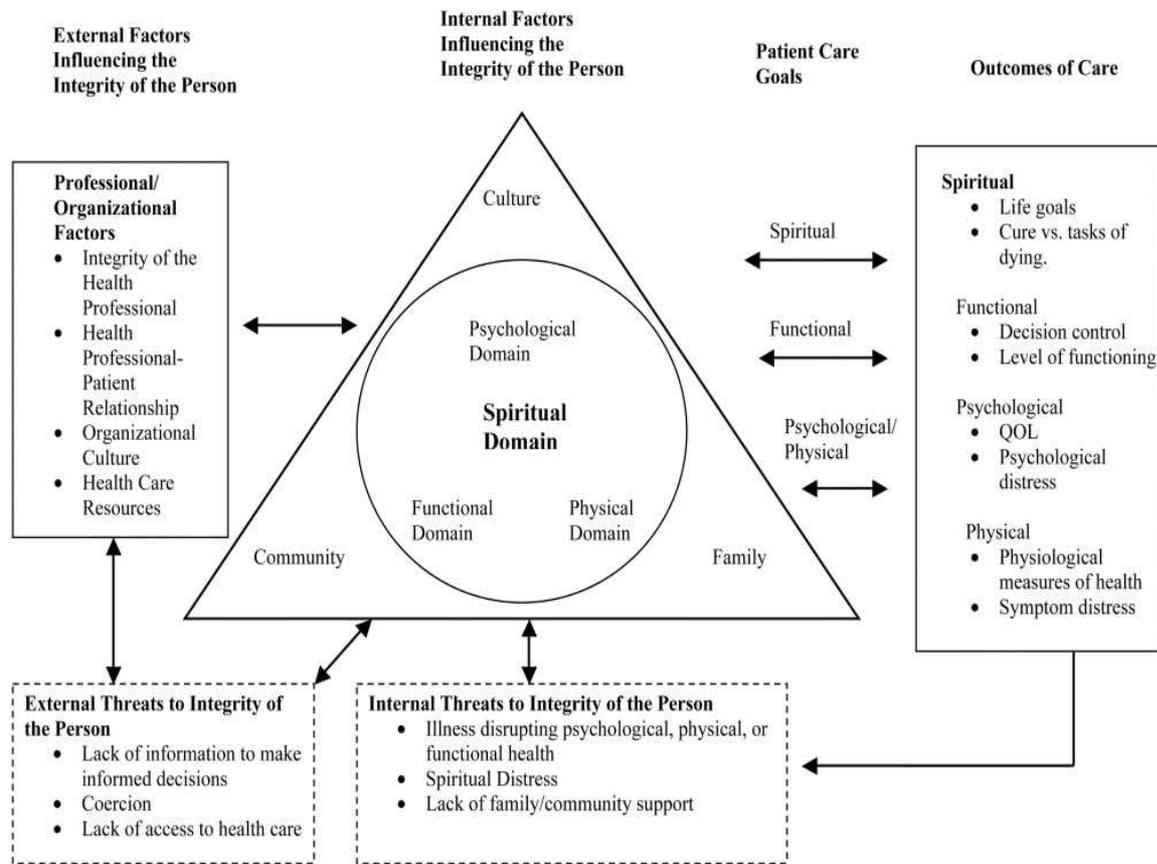


Fig 1: Framework model of EOL care (Nolan & Mark, 2004)

Conclusion

In conclusion, the whole death and dying process causes turmoil in a family. In this time of crisis it is nurses, who can help the family cope. At many times, nurses get involved in meeting the physical care needs of their patients and forget the psychological, spiritual and societal needs. The process of death can be made good, by alleviation of pain and suffering, provision of peace, comfort and a loving environment, and support to parents in decision making. The nursing role needs to enlighten a parent’s experience, helping them through this reality with minimal scars.

But this can only be possible, if they change their own attitude and approach to death and dying.

“There is a need to improve communication with patients and families about diagnosis and prognosis

to ensure that effective communication takes place and ‘blocking behaviour’ is avoided”(Costello, 2006,p.594). Nurses need to be non-judgmental not comparing any two families in their approach toward this type of crisis. Most importantly, health care teams must have a nurse solely dedicated to bereavement care, which can educate parents and equip them with the knowledge they need to make the frightening experience of death not so scary.

Nurses need to know that it’s alright to be affected by a child’s death as “the day we stop feeling is the day that we need to quit...if we don't get affected by a child's death, that's when you need to rethink your profession”(Cook, et al. ,2006, p.e15). Moreover, “the importance of supportive colleagues and resources available for nursing staff while caring for sick and dying children” (Cook, et al., 2006, p. e20) should be addressed in the health

care system. Additionally, pediatric nurses in the clinical and research area need to develop evidence-based, developmentally appropriate care of the dying child and their families. "Having a clear, consistent view of the concept of good death" (Welch, 2008, p.124).

Nurses must always remember to touch a person's life even if for a moment, but create a lasting impression. A family may not remember whether you gave their child the medication or were very skillful. But surely they will remember a nurse who supported them through probably the biggest tribulation of their life.

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