


## Essay/Personal Reflection

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Pediatric hospice care (PHC) is an ultimately complicated medical service that involves a diverse range of specialized interventions at multiple levels. Practice in this area requires a holistic approach that addresses medical, social, cultural, and financial challenges within the atmosphere of a dying child. Compared to other fields of medicine, the discipline of hospice care for children purposefully embraces the whole family, besides the patient. This is one of the reasons that professionals consider it as a philosophy, rather than a medical procedure or intervention (García-Baquero Merino 2018). However, the major focus of medical literature in this field is on patient and the health care team (Koorn et al. 2020). The next center of attention in a considerable number of studies is headed toward the parents (Boyden et al. 2021). Despite the fact that PHC is a relatively new chapter in the history of modern medicine, the number of scientific and academic publications on this topic is considerably high. In this vast and constantly augmenting pool of information, one specific area has been significantly neglected (Winger et al. 2020). This missing piece of the puzzle belongs to the siblings of the dying children.

## Challenges of the siblings

Unfortunately, adequate data for the demography of this population are not available. However, a logical presumption leads us to classify them at child- or pre-adulthood age groups. With this assumption, a number of life- and soul-threatening challenges can be counted for them that require certain measures for prevention or diminution.

- A. Young siblings of a child with terminal illness live in a long-lasting environment of stress, sorrow, and despair. It has been proven that this traumatic period of family life adversely affects the psychosocial well-being of somatically healthy children in the household (Rosenberg et al. 2015).
- B. Financial burden of hospice care due to devotion of the whole family resources toward only one member deprives the siblings from many of the routine amenities of their counterparts in the society (Fletcher et al. 2018). In this way, several aspects of life of a sibling including education, leisure activities, or even nutrition can be affected.
- C. Lack of adequate attention to other children is a very common familial pathology, while almost all the energy and spiritual concentration of the parents is spent on the child with the end-of-life status (Howard Sharp et al. 2018). Again, this inevitable malpractice in parenting may cause serious damages to psychologic, social, and bodily health of the rest of offspring (Chin et al. 2018).
- D. Decision-making is one of the most complicated areas of PHC. It has been demonstrated that involvement of the patient and the whole family for the initiation, continuation, and direction of hospice care is mandatory to preserve the holistic health of all the bereaving ones. In this case, parents are commonly considered as the legal and practical decision makers for the last days of their loved one (Giovanola 2005; Warnick 2015). Hence, involvement of siblings at lower ages is being ignored in this life changing transition, which can bear a huge amount of regret, distress, and disappointment in their future (Gaab et al. 2014).
- E. After losing a child, there are several well-established psychosocial support resources for the parents and adults. Due to current immaturity of PHC as a newly developed field of practice in health care, establishment of parallel resources for the children who have lost a sibling is lagging behind (Fullerton et al. 2017; Lane and Mason 2014). Although several organizations and public or academic entities have been developed for this specific purpose in recent years, during this process of maturation of the infrastructures, a great number of children will be irreversibly affected by the grave consequences of the loss.

### How to tackle these challenges?

Based on the above-mentioned information, it can be stated that education is the number one solution for amelioration of this family-oriented ailment in PHC. After educating the practitioners, the knowledge should be transferred to parents of the dying child, in order to make them more vigilant and proactive, regarding the rest of the children. Emphasis on the evolving physical, social, and mental needs of the other children during and after this harsh and soul-crushing transition will act as an alarm for the guardians to spend a more balanced amount of time, passion, energy, and monetary resources on the others, as well. In addition, considering the protective measures against the overwhelming mental stress for other children in the household can be life saving for the siblings. In this way, active help seeking from the professionals with experience in the field of pediatric psychology or psychiatry will be highly valuable. The third safeguarding factor might be the most sophisticated one. Recognition of the role and capability of the siblings of the dying child in determination of the specification of hospice care implementation is a state-of-the-art approach that can be achieved through collaboration of the medical team, social supports, and legal representatives. In this decision-making complex, truth telling and honesty among the care givers and care takers are mandatory. Guardians should meticulously measure the acceptance and tolerance level of the involved children and enlighten them about the gravity of the situation to the most possible level (Kreicbergs et al. 2022). Sharing the ideas and brainstorming about the initiation of hospice care, the place for implantation, discontinuation of excessive treatments, and horizons of the decision will adequately involve all the siblings in this familial hazard management (Gaab et al. 2014). Therefore, the level of sorrow and regret will be dampened after the occasion. Finally, some regulatory and strategic modifications are required to decrease the adverse effects of the end-of-life situation on the siblings. Besides the establishment of resources for supporting the patients and parents in PHC, similar but age-adjusted measures should be generated with the target audience of the low age siblings (Olivier D'Avignon et al. 2017; Olivier-D'Avignon et al. 2017). In this venue, financial reinforcements, social activities, educational plans, and psychological supports have to be considered for utilization in a timely manner. Youth bereavement camps, which have been recently popularized, are telling samples of productive measures regarding the preservation of psychosomatic health and well-being of children who have lost a sibling.

At the end, it cannot be overemphasized that hospice care for pediatric group of patients is an intermingled complex with numerous core elements and a diverse range of variegating dependant attachments. Every single scenario requires a unique, goal-directed, and wise approach. In this constellation of distracting variables, negligence about the siblings is undeniably probable. Therefore, preparation of guidelines and check lists that include this specific issue plus presence of knowledgeable coordinators among the PHC teams is a necessity to address the challenges of the siblings.

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