

The Effect on Family with a Child with a Terminal Cancer Diagnosis and Recommendations for Nursing Practice to Support Families

By Lucy Godwin

A parent's worst fear is to lose a child before their time. It is exceedingly more difficult to watch the process occur, being unable to prevent the inevitable death of their child. The child is facing their own internal battles with the acceptance of death, while siblings' may become lonely and isolated, and feel their sibling is being unrightfully taken. This is a situation that family units face globally when a child's cancer diagnosis becomes terminal. As nurses, we are able to support and assist families on this journey through implications in practice.

Effect on Diagnosed Child

- Loss in their sense of self due to both physical appearance, and ability to be themselves with the symptoms they experience (McGrath & Phillips, 2008).
- Fear of death and feel vulnerable knowing that they are unable to fight the inevitable (Marijke et al, 2011)



Photo by: Mytchall Bransgrove (November 5th 2015). *More brain surgery for Grace Hooke, 8, following complications.* The Timaru Herald, Timaru, NZ

Effect on Parents

- Parents become aware of the inevitable death and manage changes as they arise. Parental role adapts, including making end of life decisions (Marijke et al, 2011).
- Psychological effects including; depression, compassion fatigue, grief, and fear of death (Fletcher, 2010).
- Parents provide 24/7 care and support for the terminal child. This results in lack of time invested into marital and family life causing social pressures, and lack of income due to inability to work, and extra costs of healthcare and travel put financial strain on families.

“Their usual parenting role of accompanying the child in unknown and threatening situation failed, meaning the bond between parent and child was broken by death.”
(Page 267, Marijke et al, 2011).

Effect on Siblings

- Lack of support and unmet needs due to parental stress and decreasing parent-child communication (Malone & Price, 2012).
- Question if parents love the sick child more as they are getting all parental attention, and consequently feel survivor's guilt (Woodgate, 2006).
- Adopt negative coping mechanisms such as; attention seeking, fight, difficulty sleeping, and become solitary and isolated (Malone & Price, 2012)

Recommendations for Nursing Practice

- Work in partnership with the family, not taking negativity offensively- blaming can be a parental coping mechanism (Thompson, 2002).
- Recommend a child psychologist, and utilize the full MDT team and resources available for support and comfort care (McGrath, and Phillips 2008).
- Promote sibling camps as a productive way of coping and support (Packman et al, 2004).
- Provide an environment that encourages parental support, and the “being there” for the child (Marijke et al, 2011).

References

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- Thompson, G. (2002). Taking the Measures of a Father's Grief. *Nursing*, 32(3). 46-47
- Woodgate, R. (2006). Siblings' experiences with childhood cancer: a different way of being in the family. *Cancer Nursing*, 27(1), 17-24.

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PECOT category	Information relating to question	Explanation
Population	Families with young children	I focussed my research on families with children to base my research in the paediatric field
Exposure (intervention)	Exposure to one of the children to terminal cancer	Exposure of the child, and ultimately the family to terminal cancer
Comparison / Control	Comparing effect on members of the family	I was interested in family functioning when a child is diagnosed with terminal cancer, and compare how each member of the family is effected
Outcome	Family dealing with the diagnosis	Being human, we know that dealing with this situation is incredibly hard. I hope to find out outcomes to increase support and coping for the child, their parents and their siblings
Time	Length of time of terminal diagnosis to death	The time frame looked at is from time of terminal diagnosis, through to post death coping of the family left behind

For this assignment, I decided to do a poster instead of a submission because I'm not attempting to change any policy, instead the purpose of my research is to educate health care professionals about the effect of terminal cancer diagnosis of a child on a family, and make some recommendations of how support these families through our practice. A poster is an eye-catching way to portray this information, and present the information in a way assist health care professionals support these families. A poster is a visual aid, which means that it is more likely to be read than words on a paper, meaning that I am more likely to get my research across to people on a poster, rather than in a submission. Also, my topic is touching so I felt that the use of poster was much more appropriate as I was able to use a picture, which is more powerful than any words I could have used.

A study by Ohaja, Dunlea & Muldoon in 2013 found that as well as posters being an effective way to present information for education, posters were enjoyable for students to produce- therefore making them beneficial for the students education, and educating others. For these reasons, I decided on a poster instead of a submission.

Reference:

Ohaja, Dunlea & Muldoon (2013). *Group marking and peer assessment during a group poster presentation: The experiences and views of midwifery students*. Nurse Education in Practice, 13, 466-70.