

Cancer-stricken children want the truth

September 21 2015, by Elin Bäckström

Children with cancer want honest but hopeful information. But giving appropriate information is difficult and improvements are needed for the sake of the child, the siblings and the parents. In a dissertation from Uppsala University, Li Jalmsell stresses the need for a family perspective and involvement at the end of the child's life.

Both [information](#) and [family involvement](#) in care can improve the child's wellbeing at the end of life. But it is also good for the families. In her interviews with children with cancer, Jalmsell found that children want information about what is going to happen, bad news included. As long as it is presented in a hopeful way.

Li Jalmsell also analysed the results of a nationwide survey of families who have lost a child to cancer. She is able to show that parents who talked to their children about death found it meaningful and they often had those conversations on the child's own initiative. The children often used simple things like fairy tales as starting points for questions and talks about what was going to happen. Li Jalmsell believes that there are some things that paediatric oncology wards could do to help families talk:

'Stocking the shelves with a few books and films that depict death is one example. Making them available for those who want to talk but not pushing the theme on those who are not ready to talk about death' , says Li Jalmsell.

Li Jalmsell found a correlation between how parents experienced the

suffering of their dying child and their own psychological well-being. How parents felt was also related to whether their child had died despite intense and difficult treatments like [bone marrow transplants](#). Siblings wished they had more information at the end of their brother's or sister's life. They felt they weren't prepared for the loss. She also found a higher prevalence of anxiety in [siblings](#) that hadn't talked to anyone about what to expect when their brother or sister was dying.

'When you are caring for children who are ill – perhaps even dying – it is important to extend your focus to include the whole family. Siblings and [parents](#) are also affected. Not only by the fact that a [child](#) is about to die, but also by the well-being and 'ill-being' of their son or daughter, brother or sister' says Li Jalmsell.

Li Jalmsell also looked at [medical records](#) of children who have died from cancer. Even though most children in that study were considered beyond cure when they died, their medical records show that the end was already near when the doctor's recognized this fact. This leaves precious little time to discuss how to spend the last days.

"I think we need more focus on palliative values in the care for these children. I hope for better communication, symptom relief and family involvement in paediatric oncology in the future. That would help both the [children](#) and their families", says Li Jalmsell.

More information: Read the [thesis](#), "Towards Good Palliation for Children with Cancer: Recognizing the Family and the Value of Communication"

Provided by Uppsala University

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