Children with dying parents should get more support

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Health authorities are not good enough at understanding and supporting children with terminally ill parents. New research offers insight and some solutions.

Life changes dramatically when someone you know is diagnosed with a terminal illness. If you’re a child when this happens, the difference between life before and after this difficult news is even greater.

The parent that was once a strong dad or a tough mum suddenly becomes a patient. The home turns into a waiting room. The roles in the family change and more duties start to emerge. Friends’ talk about makeup and boyfriends lose all meaning. The pain is constantly present, but it has no outlet.

These are some of the conclusions of a new PhD thesis by Danish palliative care nurse Dorte Buchwald, who has a background in educational psychology.

She argues that to prevent permanent problems with trust and relations for children of dying parents, health authorities should up their efforts to understand and help these children while they are in the midst of their crisis.

“When you have responsibility for a sick person, the whole family becomes your area of responsibility. As adult professionals, whether we’re care workers or for instance teachers, we share a duty to care for these children,” says Buchwald.

Video diary and interviews

Palliative care is the area within the healthcare system that deals with people who suffer from terminal illness. Palliative care nurses like Buchwald work in hospitals, but they also visit patients in their homes.

“We go out to families where the mother or the father are very sick, and that creates situations that are hard to tackle. I thought there was a need to find out more about how we can provide the children with the best possible help in these situations,” she says.

The thesis deals with children aged 11-17 and is a case study of seven children in families where the father or mother is dying and is expected to live for no longer than six months.

First, the children were interviewed by Buchwald, and then they were handed a video camera, which they used to film themselves every day for a month.

The children kept a video diary of their thoughts, experiences and concerns in relation to their parents’ illness. They were then interviewed once again.
Six themes describe the children’s lives

In her thesis, Buchwald groups the content of the video diaries and the interviews into six themes that recur in the children’s responses.

**Death’s waiting room:** “All the children focus a lot on the fear of loss, regardless of whether or not they knew about the parent’s prognosis. They are not naive, so we shouldn’t try to fool them into anything. The children felt to a strong degree that their home had turned into waiting rooms, where they were waiting for death,” says the researcher.

**Masquerades:** ”Just like adults traditionally protect children, the children also protect their surroundings in situations where there is a very ill parent. They don’t want to cause more worries. I asked one of the boys in the survey how others would describe him. He said: ‘Like a happy boy, because I use joy as a cover-up’. Children can cry in bed, and then when they go out to their parents or into the classroom, they smile and say they’re fine.”

**Living in a world that others cannot relate to:** ”Normal teens are interested in makeup, girlfriends and boyfriends and parties. These children, on the other hand, focus more on whether the house has been cleaned, whether mum has taken her pills or whether dinner has been made. They enter a world that other kids don’t understand. That could leave them very lonely.”

**The difficult emotions:** ”The children are naturally sad and angry. The surroundings understand and accept ‘sad’, whereas anger is a more anti-social feeling. One of the older boys told me that he has become more aggressive when he goes out on the town, sometimes resulting in fights. Others turn their emotions inward, which can result in physical symptoms such as headaches and stomach aches. But none of the children directed their anger at their parents.”

**Finding meaning in the meaningless:** Just like grown-ups, children try to find bright patches. The children say ‘I used to quarrel with my mum, but after she became sick, our relationship has improved dramatically.’ They find comfort in seeing positive aspects of the disease.”

**From care recipient to caregiver:** “These kids go from being teenagers who think the universe revolves around them to suddenly shifting their focus onto their sick parent. They assume more duties and want to help caring for their parent. But here it’s important to discuss when the children should help with the caretaking. It’s good that they feel they’re making a difference, but they should probably not be present when bandages on large, weeping wounds are being changed.”

**Current efforts not good enough**

Buchwald sees it as crucial that an effort is made to help these children retain their capacity for good relationships – that they don’t experience the loss in a way that makes them shun personal relationships because of their fear of loss.

"I don’t think we’re good enough at helping these kids. I started five years ago, and a lot of improvements have been made. But I don’t think there is sufficient focus on this problem and we’re not doing a good enough job.”

**How the children can be helped**

The thesis offers some specific recommendations to healthcare workers who deal with children of dying parents:
• Contact to the families should be established as early as possible
• The children should be welcomed and shown around the ward when the mother or father is hospitalised
• The ward should be furnished in a child-friendly way
• The children should be assigned a contact person
• Family consultations should be established
• There should be a description of the children’s lives and interests – with whom do they feel at ease?
• The children should be informed about the disease in a way that makes sense to them
• Nursing staff should possess up-to-date knowledge about family counselling, bereavement support groups, support in schools, etc.
• There should be offers of contact to the school and possible visits to the child’s class

The recommendations are currently being implemented at Buchwald’s workplace, Vendsyssel Hospital in Denmark, where ‘Project Børnevenlig’ (‘Project Child-friendly’) is in the start-up phase.

“We are doing a three-day course for the nursing staff, focusing on psychology and communication, where the nurses get the chance to put their skills into practice,” she says.

“We’re also working to furnish some rooms with flat screen, sofa, carpets and other household goods that give the children a sense of being in a place where there’s something for them to do.”

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Read the Danish version of this article at videnskab.dk [8]

Fact box

Palliative care also involves supporting the family during the course of the disease and subsequently in connection with the grieving process.

The objective of palliative care is to create as much quality of life as possible for patients and relatives.

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