

Ethics in pediatric palliative oncology

For most children diagnosed with cancer initial treatment is given with a curative intent. If and when this treatment fails, there is often a second and third line of treatment to try. With the continuous emergence of new drugs and new indications for older ones it is easy to reach for yet another treatment when an earlier one fails. Even though we know from the statistics that approximately every fifth child diagnosed with cancer will die from his or her disease, we rarely know which child and when.

It should be noted that the ill child always exists in the context of a family and that close family members are affected by the care given. According to current research it appears that intensified treatment or lack of communication, e.g. not discussing a potential fatal outcome, makes it harder for parents and siblings to accept a potential death. So how to know when to stop trying for a cure?

The individual disease trajectory is uncertain and a fatal outcome is not always easy to foresee. The cancer of a few children will be incurable from start, whereas most children will initially be treated with hope of a cure. Progressive disease, treatment failure or relapse might lead to a shift in care when only a fatal outcome remains. Some children will have a long period of time after this shift in care until death, whereas others are recognized as being beyond cure late in the course of their illness, and die only days thereafter. In addition, some children die while still in potentially curative treatment, unexpectedly and from treatment complications.

When standard therapy no longer works and all that is left is treatment with low likelihood of cure, the parents – knowingly or unknowingly – face the dilemma of wishing their child to live as long as possible while simultaneously wanting to protect their child from unnecessary suffering. Treatment that does not result in prolonged life might in retrospect be seen as having caused the child unnecessary suffering (due to additional hospital visits and potential side-effects). In addition, continued treatment at the end of life can be estimated to provide the child as well as the parents and siblings with unrealistic expectations and a false sense of hope, that hinders them in planning for the last time together and using that time in a way they would have chosen had they known death was close.

Thus, keeping an open dialogue with the families regarding diagnosis, treatment and realistic expectations is vital. If and when the disease progresses and hope of cure diminishes palliative values gain in importance. The preferences for the individual family should be sought and care should be planned accordingly.