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Alyssa Nesbitt

Wayne State University School of Medicine, gc7793@wayne.edu

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# Talking to children about their terminal disease and ultimate death

ALYSSA NESBITT, Wayne State University School of Medicine, [gc7793@wayne.edu](mailto:gc7793@wayne.edu)

**ABSTRACT** A critical appraisal and clinical application of Kreicbergs U, Valdimarsdóttir U, Onelöv E, Henter J, Steineck G. Talking about death with children who have severe malignant disease. *New Eng J Med.* 2004;351(12):1175-1186. doi: [10.1056/nejmoa040366](https://doi.org/10.1056/nejmoa040366).

**Keywords:** terminal disease, children, death

## Clinical Context

A 13-year-old male presents to the pediatric genetics clinic due to 6 months duration of visual hallucinations and myoclonic seizures. He has no cognitive delays, is social, and even participates in sports after school. Before the onset of these symptoms he would have been described as a normal child. However, he has already watched two brothers die in his short lifetime. He saw them develop similar symptoms, until the point they eventually became nonexistent in their own body. He does not know why his brothers died, why he is being brought into the clinic, nor what he is being tested for. Unknown to him, his family has a known history of consanguinity and both parents are carriers of a mutation in the EMP2A gene for Lafora disease. It is a rare autosomal recessive neurodegenerative condition usually diagnosed in late childhood and characterized by progressive seizures, ataxia, and mental deterioration until eventual death typically within 10 years of the initial onset of symptoms. In contrast the parents are aware. They know why both their sons died, they know their two oldest children are not affected, and they now are worried their youngest son may be dying too. His deceased brothers never knew their disease or fate because the parents believed it would cause them further pain and suffering. Even though our patient was found to be homozygous for the mutation, they will not tell him about the familial disease, that he will deteriorate just as his brothers did, or that he will die within a few years. Does he have the capacity to understand and handle this information? To our knowledge, no one assessed his awareness of his condition. Our team questioned if we should encourage the parents to disclose the diagnosis and prognosis to the patient.

## Clinical Question

Should parents be encouraged to allow their child to know they have a terminal disease?

## Research Article

Kreicbergs U, Valdimarsdóttir U, Onelöv E, Henter J, Steineck G. Talking about death with children who have severe malignant disease. *New Eng J Med.* 2004;351(12):1175-1186. doi: [10.1056/nejmoa040366](https://doi.org/10.1056/nejmoa040366)

ALYSSA NESBITT is a 3<sup>rd</sup> year medical student at Wayne State University School of Medicine.

## Related Literature

PubMed database was used to search for articles that contained the keywords “children” OR “minor” OR “adolescent” AND “terminal” OR “death” OR “dying” AND “nondisclosure” OR “telling” OR “disclosure” yielding 469 results which titles and abstracts were reviewed for relevance to the clinical question. Of the relevant publications, the majority were review articles, without primary research, that summarized old research and ethical perspectives. They were analyzed for relevant citations. It is important to note that based on the ethical nature of the question we will not determine a definite answer from primary research. This will remain a complex ethical debate that changes based on an individual’s unique situation. Instead, our goal is to find evidence to guide what we should encourage the parents to do in the best interest of their child.

The clinical question is complicated by the child’s autonomy, a physician’s duty, and parental authority. Deciding when to talk to a child about their death as a physician is dependent on finding a balance between the commitment to properly treat a child patient while respecting the parent’s ultimate right to decide. While a parent’s desire to protect is understandable it does not trump the physician’s duty to their patient and a patient’s age, developmental status, experience with death, and impact of the disease on their health should all be considered when disclosing diagnoses.<sup>2</sup> The leading argument against informing a child of their terminal illness is to avoid further harm. This mindset leads to the formation of mutual pretense in which all parties are fully aware of the terminal prognosis but act as if they are not. A publication by Dunlop argues that most children are aware of the fact they are dying.<sup>3</sup> While the aim is to protect, mutual pretense can instead inhibit open communication, increase fear and isolation, and decrease the ability of the both parties to properly support the child. The search yielded a paper by Clafin and Barbarin who performed a longitudinal study of families with children with cancer. They determined that older children, greater than 9 years of age, were more likely to be told of their diagnosis but young children who were not informed reported just as much disruption and distress from their illness as older children who were.<sup>4</sup> This study was not selected as it was retrospective, based on 43 volunteers, and all the children were still alive and were not faced with imminent death.

Another argument is that a child does not have the capacity to recognize what death means. Aldrige et al. discusses how this is a common misconception that young children do not understand the irreversibility of death and instead it is largely dependent on experience, so that many young children can understand if they have experienced bereavement and/or terminal illness.<sup>5</sup> Berger reviewed therapeutic nondisclosure and determined it is ethical acceptable only when disclosure would result in distress that effects decision making capacity, distress that is incapacitating, and when it would violate a patient’s personal/cultural/social values.<sup>6</sup> This emphasizes that while disclosure of terminal illness can be understood by children and often does not result in increased harm, it is not always the correct choice.

Many articles were helpful in approaching the clinical question but did not provide original research to back up their claims. Of the articles that were research trials they almost entirely focused on cancer and children who were not deceased. Having a life altering illness without certain death is a fundamental disparity with our clinical context. There were no studies that we found that specifically studied noncancer terminal disease. Additionally, there is minimal research from the child’s perspective.<sup>3</sup>

The article chosen for this critical appraisal was a cross-sectional survey study of 449 parents of deceased children in Sweden with informed consent, established face validity, and anonymity mirroring blinding. It is a level 4 level of evidence based on the Oxford Centre for Evidence-Based Medicine. Kreicbergs et al. interviewed parents that lost a child to cancer questioning if they talked to their child about death and if they wished they would have. Since this study focused on families with deceased children it was most relevant in answering the clinical question and was chosen for critical appraisal.

## Critical Appraisal

Participants were parents, defined as the guardian at time of diagnosis, of deceased children identified from the Swedish Cause of Death Registry from 1992 to 1997. 368 children diagnosed with cancer before the age of 17 and who died before the age of 25 were recognized and 561 parents of these children met criteria. An introductory letter explaining the objective and inviting parents to participate was individually sent to mothers and fathers of the identified deceased children. They were then telephoned for informed consent, questionnaires were mailed, and return instructions specified mailing back two separate envelopes one containing anonymous questionnaires and one for reply cards letting the study know they completed the form. A total of 449 questionnaires were returned.

The questionnaire included “Did you talk about death with your child at any time?” with response categories yes and no. If the parent answered no, the follow-up question was “Do you wish that you had?”. If the response was yes they were asked “do you wish you had not?”. They were also asked “when do you think your child realized he or she was going to die?” and parents were screened for distress using the Spielberger’s State Trait Anxiety Inventory. Of the returned questionnaires, 429 provided information about if they talked to their child about death with 34% responding yes and 66% responding no. While 27% of those that did not talk about death regretted it, none of the parents who did talk regretted it. Those who regretted not talking to their child about death were more likely to be parents of older children and looking back believed their child was aware they were dying. These parents had a higher level of anxiety 4-9 years after their child’s death.

Since there was a delay between when their child died and completion of the questionnaire it is possible parents forgot what happened or transformed memories into something more comforting. Designing an anonymous study helped compensate for possible fear, shame, or embarrassment from how parents handled talking to their child but does not eliminate potential response bias. Without knowing the children’s perspective, we cannot know if there was a higher percentage of children who were aware of their coming death and how it would affect parents if this was contrary to their belief. The possibility of selection bias cannot be ruled out. Parents who were open to completing the survey may also have been more open in discussing death with their child. There may be inadequate representation of parents who were uncomfortable filling out the survey, especially the 11% of participants who initially agreed to participate but did not return the forms, whether it be because of how they handled the discussion of death, their regrets, or some other factor. Since both parents of deceased children received surveys individually, they may be likely to respond in a similar way, increasing the frequency of their response. However it cannot be ruled out that parents may differ in responses especially regarding regret. Additionally, the study was conducted only in Sweden which could affect the generalizability to other cultures that may have different perspectives on talking about death, what death entails (afterlife), or the rights of children.

Another limitation of this study is that it evaluated parents of deceased children only caused by cancer. A group that was instead inclusive of parents of all terminally ill children would provide more complete information. Neurodegeneration dramatically alters physical and mental ability which could affect a child’s perspective and their understanding of a terminal illness. The children in the study ranged in age from 0-16 years. It is unknown how the responses related to the age of the child. Age of the children would certainly affect the decision to disclose and parental perception of the child’s awareness. Additionally, by only interviewing parents our view of the child is unavoidably biased. While it would be difficult to interview dying children about if they know they are dying, it would allow us a better insight into their understanding, desires, and point of view.

## Clinical Application

Many things can cause inevitable death in minors, yet many of these children may never be told their fate. Instead caregivers are faced with the burden of knowing their child is dying and having to decide whether they should know. Kreicbergs et al., along with this critical appraisal, agree that with established experience and age, parents should tell their child of their forthcoming death or might regret not doing so later. While our patient is similar enough to the study population to make it relevant, he is unique in that he already watched two brothers die in the same way he will. His direct experience with the same disease in his brothers, experience of death, older age, and unaffected mental capacity make it likely that he knows he is dying and that he can understand and handle his fate. Nondisclosure from his parents might cause isolation and anger rather than protecting him from further harm. This isolation compromises the physician-patient and family relationship so that the patient may feel that he must face his death alone. This all increases the chance the parents will regret not talking to him about his disease and death.

Alternatively, denial may be the only psychological defense available to the family. To take that away could also cause harm.

Within this situation it is in the best interest of the patient for the team to encourage the parents to be open to an opportunity for disclosure of the disease and prognosis. Also, doctors should care for the parents facing this tragedy. Perhaps with support, they can expand their parenting skills to allow a compassionate way forward.

Notably, this evidence should not be used to universally encourage parents to inform their children that they are dying. It is critically important to avoid any sense of judgment of the parents' decision. Instead it should be utilized in conjunction with a patient's unique characteristics, such as age and experience with death, to help inform parents what may offer the least harm to their child.

Learning points:

1. Terminal diseases often strain family relationships
2. Experience with death is an important element of understanding its irreversibility
3. Parents with an older child are more likely to feel regret about not talking to their child about their death

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