

# “Please Don’t Tell My Child She’s Dying!”

## An exploration of ethical, legal and clinical issues regarding truth telling

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### THE CASE

The patient is an 12 year girl diagnosed with acute lymphoblastic leukemia 15 months earlier.

She had an excellent initial response to her chemotherapy and tolerated treatment without unusual side effects.

Fifteen months into therapy she comes to clinic with a story of intermittent chest pain and feeling fatigued. A test of her bone marrow shows relapsed disease.

She is admitted for re-induction therapy. She receives 3 cycles of intensive therapy but her disease does not respond and she has multiple serious complications of therapy.

The oncologist meets with her parents to discuss her grave prognosis and care options.

Her parents understand her dismal prognosis. They state emphatically “She can’t know that she is going to die”

What will be your response?

### THE LAW

- Existing case law does not define how the principle of the parents’ right to make decisions for their child should be balanced against the right of a capable patient to be fully informed about his/her medical condition.

- The right of a parent to parent is limited by the *Child and Family Services Act* in situations where a child is found to be in need of protection.

- The *Health Care Consent Act* defines a person as being capable where he/she is able to understand the information relevant to making a decision about treatment, and able to reasonably foresee the consequences of a decision or lack thereof. A capable individual is entitled to receive the information relevant to providing informed consent.

- Determinations of capacity can become particularly difficult where parents seek to withhold relevant medical information from a child patient.

### THE ETHICS

**What is an ethical dilemma?** An ethical dilemma exists when ethical principles and sound ethical reasoning support two different and incompatible courses of action.

**What is THIS ethical dilemma?** Some adults (often patients’ parents) wish to withhold potentially distressing information from children, believing it is in the children’s best interests to do so. Some adults (often their health care providers) believe disclosing this sort of information to children is often in the children’s best interests.

#### Ethically Grounded Reasons Supporting Respecting Parents’ Wishes

- One should respect the moral authority and role of parents.
- Sometimes an unspoken agreement exists between parent and child not to speak of distressing things. “Mutual pretense” is a coping mechanism for some patients and families (beneficence).
- Parents may indeed know their child best, and what is in their child’s best interests.
- To do so is consistent with our values of “Respecting Diversity” and providing “Family-Centered Care”.

#### Ethically Grounded Reasons Supporting Disclosure to the Child Despite Parents’ Wishes

- It is necessary for maintenance of trust between caregiver and patient.
- It is respectful of patients as persons.
- It may help reduce anxiety (non-maleficence) and improve coping (beneficence).
- It supports a child’s ability to participate in decision making.
- It may be seen as a legal and professional duty.
- It is good role-modeling, i.e. honesty in adults may foster honesty in children.

### CLINICAL CONSIDERATIONS

Children from whom information about a serious illness or impending death is withheld are sometimes more anxious and fearful than those who have the opportunity to discuss their feelings. Clinicians should be mindful of this when decisions are made around:

- Discontinuing ongoing cancer directed therapy
- Changes in aggressiveness of supportive care
- Plans to go home
- Enrollment on phase 1 trials (requiring child’s assent)
- No CPR decisions

### SOME CONCLUSIONS<sup>3</sup>

Presumption against lying: children may ask professional caregivers direct questions. Once these questions have been clarified, they should be answered honestly and fairly, sensitively and in a way that can be properly understood.

Planned disclosure to the child may avoid harms experienced when information is withheld or when disclosure occurs inadvertently.

Parents motivated by love and concern, who know their child well, whose family ethos has always been to protect the child, and where the child does not give indications to the contrary, might be correct that this is best for their child, and that this is what the child would prefer.

Professional Caregivers may experience moral distress when their ethical values conflict with those of others.

### WHAT DO WE KNOW FROM RESEARCH

#### STUDY OF BEREAVED PARENTS<sup>1</sup>

Study of all parents who had lost a child to cancer in Sweden, 1992-1997, by survey, asked whether they had spoken with their child about death.

	Regretted talking	Regretted not talking	Did not regret not talking
Parents who talked	0/147 (0%)	-	-
Parents who did not talk	-	69/258 (27%)	189/258 (73%)

Most significant “risk factor” for having talked about death was a sense that the child was aware of his or her imminent death.

Most significant “risk factor” for regretting having not talked with the child about death was a sense that the child was aware of his or her imminent death.

#### STUDY OF CHILDRENS’ AND PARENTS’ DECISION MAKING<sup>2</sup>

PATIENTS	At diagnosis	Phase 1/2	Palliative chemo
Patient	4%	49%	44%
Parents	7%	20%	23%
Doctor	89%	31%	33%

PARENTS	At diagnosis	Phase 1/2	Palliative chemo
Patient	2%	17%	15%
Parents	29%	80%	74%
Doctor	69%	5%	10%

Survey of pediatric patients and their parents reported that children wanted to be a decision maker when considering enrollment on early phase research studies and palliative therapy .

### REFERENCES

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