

COMMUNICATING WITH THE DYING CHILD: AN INVITATION TO LISTENING. A REPORT OF THE SIOP WORKING COMMITTEE ON PSYCHOSOCIAL ISSUES IN PEDIATRIC ONCOLOGY

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ABSTRACT

This is the twelfth official document of the SIOP Working Committee on Psychosocial Issues in Pediatric Oncology since its creation in 1991. This twelfth document describes the use of direct statements from the children themselves, solicited from parents and physicians, on how children of various ages approached their final days. The parents and professionals who submitted the verbatim case examples were asked to present the children's statements at the seminar as a stimulus for discussion. The children were seeking reassurances from their parents as they faced their own death, talking about a journey to a faraway place where they were going to go after they died and where they would eventually be joined by their parents. The themes are presented, not as exclusive and complete nor as scientifically valid, but solely as a stimulus for SIOP members to pursue in their respective centers and in their own cultural milieus this active "listening" approach in learning from the children themselves the type of concerns they have and the kind of support they are looking for as they enter the terminal phase of their illness.

INTRODUCTION

The previous eleven documents of the SIOP Working Committee on Psychosocial Issues in Pediatric Oncology, developed at the annual SIOP meetings were prescriptive in nature, offered as guidelines to be implemented internationally in the treatment of children with cancer (*). This twelfth document in the series was developed, not as a guideline, but as a procedure, an approach to supporting the children after treatment has been judged to be no longer effective and the difficult decision is made to move from the curative to the palliative and terminal phases of care.

What kind of support is the dying child looking for? Research over the years has shown that the great majority of children who enter palliation come to an understanding, from what they see and

feel going on around them, that something very serious is happening to them; even the youngest children know at some level that they are dying (1-6). Children with cancer often reach an understanding of what death means for them at an earlier age than their peers and earlier than their level of development would suggest. The dying children -- even the younger children whose understanding is still not fully developed -- express their knowledge and emotions about death in various ways, both verbal and non-verbal (7-8).

The objective for this annual meeting of the SIOP Working Committee was to discuss a method for tapping into the children's level of awareness of their impending death, in order to offer them the support they are looking for and ultimately to encourage pediatric oncology professionals throughout the SIOP membership to explore the question in their own cultural milieu.

METHOD

For the 2004 annual SIOP meeting, verbatim case examples were solicited from parents and physicians on how children of various ages approached their final days: what the children said, how the adults in their lives responded, and whether the adult was truly "listening" to the child. This initial attempt was not envisioned as a scientific study but as a stimulus for discussion at the seminar. Sixteen samples were submitted. The physicians and parents who submitted the children's statements were asked to present them at the seminar. The presentations stimulated a very active discussion among the over-100 persons in attendance. What follows is a synopsis of the submitted case examples.

SYNOPSIS

There are several consistent themes that the children expressed in their dying conversations, themes that were raised and discussed at the seminar. They are not raised here as conclusions to a scientific study, which this was not. These themes are a summary of the discussions at the seminar and are presented as working hypotheses for others to pursue in their own "listening" to the statements of the dying child.

(1) The most common way that the children 10-years-and-under expressed their awareness of their impending death was to talk about a faraway place to which they were going to go after they died. Within their own family's belief system, these children were viewing their death as a journey, not an end. They were looking for reassurance from their parents that they would not be alone while dying, that they would not be alone when they arrived in their faraway place, and that one day their parents would join them:

-A 4-year-old (f1) talks about her fantasies of what heaven will be like and what she will do when she gets there. She wants to wear her fairy dress to go there with bells on her toes. She does not appear at all distressed or upset or scared throughout the discussion. She wants her doll to come with her and be an angel too.

-An 8-year-old (e1) says "death is like falling asleep, in a nice dream and staying there." He will bring his books and his music and a photo of his grandfather with him so he can recognize him again when he gets there.

-A 9-year-old (f2) says that it is time to start her journey to heaven, a long and steep climb, but when she gets there it will be worth it. Although "it is sad to climb the stairs alone," she will wait at the top of the stairs to welcome each family member as they arrive.

-A 10-year-old (a) will go to meet his grandfather in heaven. He will not be alone because his grandfather is already there waiting for him.

(2) A second theme expressed in the children's conversations is that they did not want to live on in pain. If they had to die, they wanted to die peacefully and without any more hurt:

-A 7-year-old (b1) talks about no more treatments.

-A 9-year-old (c1) just wants to be "a nine-year-old kid without cancer. It stinks trying to live with all this sickness."

-A 10-year-old (g) is angry at the tumor.

-The older children express the same theme: they want the pain to stop.

(3) A third theme mirrored the child-centered view of the children's own role in the family structure and their concerns about whether their parents could go on without them:

-A 10-year-old (a) asks whether his parents can possibly find the strength to go on without them, without the child's presence and support to sustain the parents.

-Another 10-year-old (e2) can no longer be the best child in the class and is not ready to die because she does not want to disappoint her parents.

-A 12-year-old (d2) asks: "Mum, you won't go to pieces when I die, will you?" The girl asks for reassurance that, even though it will be difficult, the parents will be able to move on and cope with their lives without the child.

(4) The children in their adolescent years, with a more adult-like understanding of the permanence of death (9), reflected both anger about their impending death and reluctant acceptance of it:

-A 13-year-old (b2) is "scared" but feels that "it is important to accept and embrace the moment of death."

-A 14-year-old (h) is depressed and angry, saying a loud "NO!" to those trying to comfort him.

-A 16-year-old (c2) knows what is going to happen but just does not want to talk about it: "I am not in denial or anything. I just hate talking about it. I'd rather talk about what I would like to be doing now."

CONCLUSION

Participants at the seminar expressed the view that, in "listening" to the child, it is critical to respect the readiness of the child as well as his/her willingness to talk about this experience at a developmental level that is comfortable for the child. The participants discussed their own initial desire as adults to shelter the already suffering children, wanting to protect them from awareness of impending death. But, over time, as they came to realize that children were already aware that something very serious was happening to them, both the parents and the professionals in the group recognized the children's need to be reassured about their concerns over what would be happening to them.

Addressing these issues not only helps the child, but also helps the parent, even long after the child has died. A recent study of parents, 6-to-9 years after the death of their child, found that both the parents who had had conversations with their child about death and those who talked about the child's need and concerns without talking directly about the death were able to look back with a sense of having done all that they could in supporting their child through his or her last days. But a large minority of the parents, about one-third, looked back with regret that they had not communicated more fully with their dying child about the child's impending death and had given false reassurances rather than being attentive to the child's expressed concerns (10).

In the limited number of examples reviewed in the seminar, the children viewed death from their own young perspective, sharing their philosophy of what was happening to them. Above all else, the children were just asking to be heard, to be listened to, to be reassured as they expressed their concerns.

The hope is that these examples will stimulate parents, physicians, nurses, and the other health care professionals and volunteers working with the children with cancer to truly "listen" to the children and develop within their own centers a culturally appropriate understanding of what the children are saying about their impending death. By truly listening to what the dying children are telling us, we can learn from them the things that they want to be reassured about.

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