

Bereaved siblings' advice to health care professionals working with children with cancer and their families



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Background

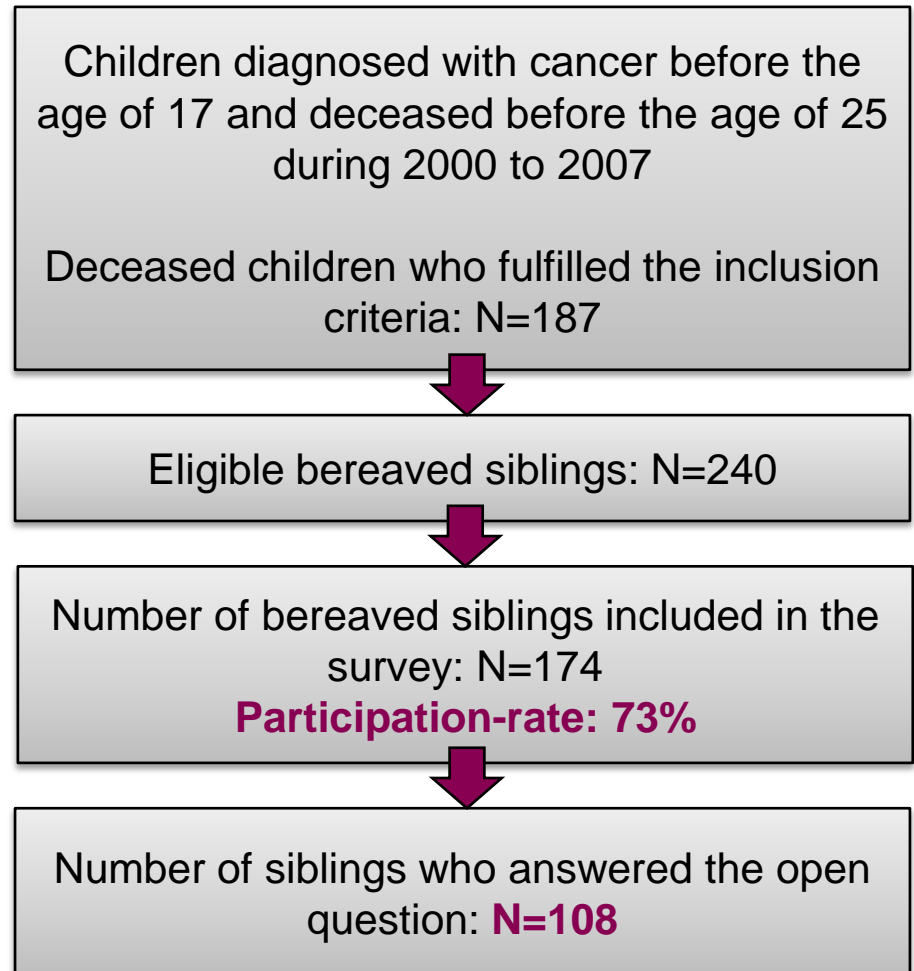
- Siblings experience several distressing problems:
 - Absent parents
 - Post-traumatic stress symptoms, negative emotional reactions
 - Lower self-esteem, more difficulties falling asleep and lower levels of maturity
 - Unresolved grief
- Aim: To explore siblings' advice to health care professionals working with children with cancer and their families



Material and Methods

- Nationwide survey in Sweden, 2009
 - *“What advice would you give to HCPs working with children with cancer and their siblings?”*

A supplementary focus group discussion, 2014



Demographic characteristics

	All siblings (N=174)	All siblings whose answers were included in the analysis (N=108)
Sex		
<i>Male</i>	42%	36%
<i>Female</i>	58%	64%
Age		
19-23	51%	48%
24-28	34%	35%
29-33	15%	17%
Levels of education		
<i>Elementary school</i>	2%	2%
<i>Senior high school</i>	60%	52%
<i>University</i>	38%	46%

$p < 0.01$

- Focus group
- All women
- Age: 19-23

Data analysis: content analysis



Examples of categories:

**Siblings' wish for
own support**



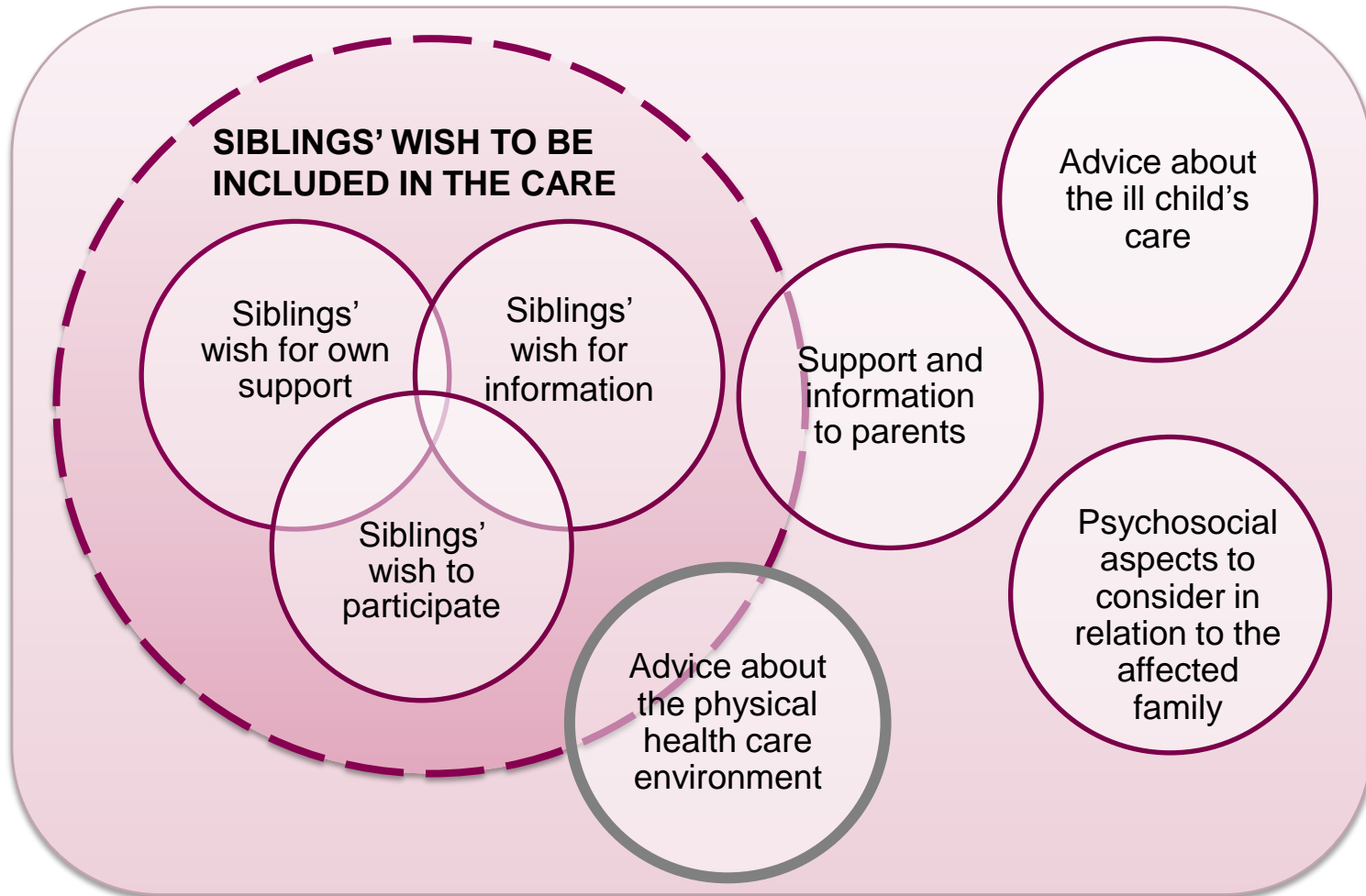
**Siblings' wish for
information**

Krippendorff, C. Introduction to Content Analysis. 2004. Sage Publications.

Hsieh, H. F. & Shannon, S. E. Three approaches to qualitative content analysis. Qualitative Health Research. 2005, 15 (9): 1277-88.

Results

A total of 245 pieces of advice



Sibling's wish for own support

SUB-CATEGORIES	EXAMPLES OF ADVICE
The wish to seen and get attention	<i>"Don't forget the siblings", "Pay more attention to the siblings"</i>
The wish to talk to a professional, e.g. a psychologist	<i>"Offer contact with counselor/psychologist at different time points", "Need for counseling both after the death and later on"</i>
The wish to participate in support groups and other activities for siblings	<i>"Meet others who have lost a sibling", "Suggest activities at the children's ward"</i>
Other advices	<i>"Stop by with a game, a sticker, tea etc. for siblings", "Help with homework".</i>



“It’s hard for a parent to find energy, time, willingness and opportunity to sit down and help with homework and so on. Or now the class is going on a class field trip and everything has be gotten ready and things need to be done (...) It would be good to get support from someone else.”

Siblings had a wish for support in daily life, e.g. homework, school activities, hobbies.

Siblings' wish for information

- Disease
 - Treatment
 - Prognosis
 - Available support
-
- The same info as the parents
 - With and without parents
-
- On a suitable level
 - In a playful way

"A what? A counselor? What's that? Is it some kind of sports car or something... you don't quite get it."

"They came in with a book for me, with a bunch of happy cartoons (...) They had drawn in a bunch of smileys and things and they sort of like leafed through it for me and told me exactly how cells worked."

Diagnosis - - - - -> After bereavement



"I felt like I didn't want to ask her (the mother) because I sensed that no, she shouldn't have to explain when she's sad enough already. She shouldn't have to explain it because I think the doctors should do that."

- *"Talk to me directly"*
- Parents sometimes excluded information
- They used their parents' facial expressions to interpret information
- Hard to ask the parents - brought up negative emotions

Sibling's wish to participate

- Practical participation

"It's actually possible to be involved in a fun way. I did that once with a nurse, and then I could help her punch the buttons, like. I thought that was pretty fun; like I was giving my brother his medicine."



- The siblings felt **important, good and needed** when they participated in the care.

Support and information to parents

"Inform parents about how much distress siblings experience, even though it's nobody's fault, so parents can be more aware of that."

"Give support to parents"

"Give the parents help in how to involve the siblings more"

Advice about the ill child's care

- *"Let the sick child be as normal as possible"*
- Ask how they want to be cared for
- Communication about death:
"Those who have fallen ill don't want to hear constantly that they are going to die"



Psychosocial aspect to consider in relation to the family

SUB-CATEGORIES	EXAMPLES OF ADVICE
Mediate positivity, hope and happiness — realism and honesty	<i>"Be honest", "Be positive and cheerful", "Be encouraging, strengthen hopes, but don't give false hopes"</i>
Be empathic and responsive	<i>"Be sympathetic", "Put yourself into their situation", "Show empathy"</i>
"Be natural, be yourself"	<i>"Be yourself", "Do things in a natural way", "Be normal – dare to laugh, for example"</i>
Other advices	<i>"Be patient", "Treat everyone warmly", "Don't butt in, but be nearby", "That staff members are patient and don't just do the same things as they've always done"</i>

Advice about the physical health care environment

- The white-yellow color on the walls influenced the well-being negatively
- Suggestions about how to improve the environment



"It doesn't have to be some fancy work of art, just let the kids paint a bit. Slap a colorful handprint onto the wall and draw whatever they like."

Summary



- More psychosocial support to siblings
- Better medical information
- Support to parents = support to siblings
- Practical participation in the care
- Better psychosocial care for the family
- Improved physical health care environment

- Most of what siblings suggested to be improved is also the kind of assistance that is recommended in guidelines for the past 15 years: **Why does it not work?**

Medical and Pediatric Oncology 33:395–398 (1999)

Guidelines for Assistance to Siblings of Children With Cancer: Report of the SIOF Working Committee on Psychosocial Issues in Pediatric Oncology

John J. Spinetta, PhD,¹ Momcilo Jankovic, MD,² Tim Eden, MD,³
Daniel Green, MD,⁴ Antonio Gentil Martins, MD,⁵ Christine Wandzura,⁶
Jordan Wilbur, MD,⁷ and Giuseppe Masera, MD^{2*}

This is the seventh official document of the SIOF Working Committee on Psychosocial Issues in Pediatric Oncology, instituted in 1991. This document develops an additional topic discussed and approved by the SIOF Committee, "Assistance to siblings of children with cancer." It is addressed to the pediatric oncology community and outlines general principles for

helping siblings throughout the process: at diagnosis, during treatment, at relapse, during bone marrow transplantation, after completion of therapy, during palliative care and the terminal phase. *Pediatr. Oncol.* 33:395–398, 1999. © 1999 Wiley-Liss, Inc.

Key words: siblings; childhood cancer; psychosocial support

Medical and Pediatric Oncology 32:44–48 (1999)

Guidelines for Assistance to Terminally Ill Children With Cancer: A Report of the SIOF Working Committee on Psychosocial Issues in Pediatric Oncology

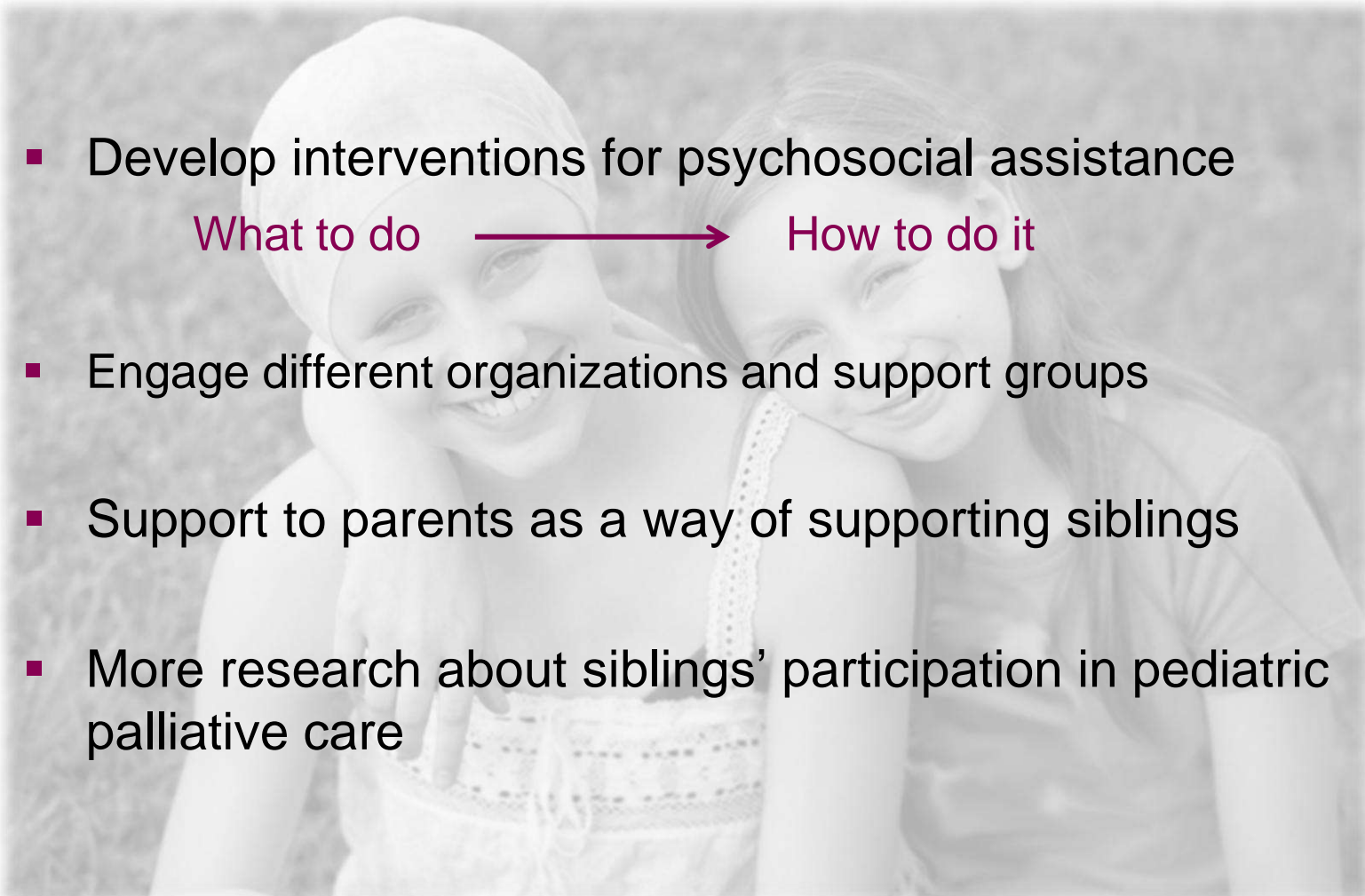
Giuseppe Masera, MD,^{1*} John J. Spinetta, PhD,² Momcilo Jankovic, MD,¹
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This, the sixth official document of the SIOF Working Committee on psychosocial issues in pediatric oncology, develops another important and especially difficult topic: assistance for terminally ill children with cancer. This is provided for the pediatric oncology community as a useful set of guidelines. It should be always possible for a declining child to die without unnecessary physical pain, fear, or anxiety. It is

essential that he or she receive adequate medical, spiritual, and psychological support, and that the child at no point feels abandoned. Palliative care, in the terminal phase of cancer, should be tailored to the different needs and desires of the child and the family, with the goal of providing the best possible quality of life for the days that remain. *Med. Pediatr. Oncol.* 32: 44–48, 1999. © 1999 Wiley-Liss, Inc.

Key words: palliative care; death and dying; childhood cancer; psychosocial issues

Implications and further studies

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- A grayscale background image showing two young children, a girl and a boy, smiling and leaning their heads against each other. The girl is on the left, wearing a headscarf, and the boy is on the right.
- Develop interventions for psychosocial assistance
What to do → How to do it
 - Engage different organizations and support groups
 - Support to parents as a way of supporting siblings
 - More research about siblings' participation in pediatric palliative care

Thank you for your attention!



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