



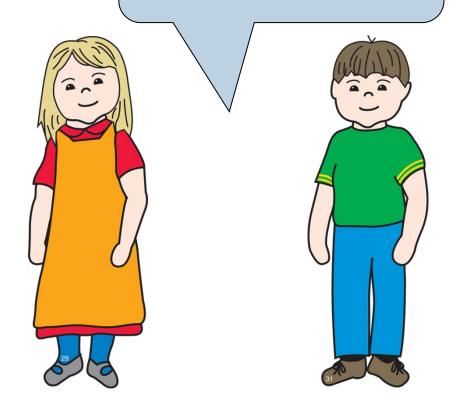
SIBLING SUPPORTERS' EXPERIENCES OF GIVING SUPPORT TO SIBLINGS WITH A CHILD WITH CANCER

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"Must we also have to get sick before someone care about us"?





Introduction

- Emotional bonds between brothers and sisters can be warm, sensitive, negative
- Siblings relationship has an impact on the emotional climate in the family
- Ties between siblings gets stronger when one of them get a life threading disease



Background

- Difficult to understand what's happening with the sick child
- Hard to understand why they think and react in the way they do
- Rights that promote their health and well-being under United Nations Convention on the Rights of the Child
- 2: prohibits all forms of discrimination or punishment
- 12: respects c/s perspective as well as rights to freely express thoughts & will
- 18: parents have the responsibility for the c/s and always consider what is best
- 19: describes that states must protect c/s against parents and other adults hitting them, being cruel or in another manner poorly caring
- 42: c/s and adults should be made aware of the rules in the UNCRC



Facts about sibling supporters in Sweden

- I990 siblings supporters became a part of Pediatric Oncology in Sweden
- 2013 all 6 children cancer center had a sibling supporters, and 2 at Ersta hospice, Stockholm (paid by BCF)
- 2 at Ronald McDonald house, Göteborg/Lund
- 2 fulltime positions at finns the playtherapi, Göteborg, DSBUS



Siblings supporter do

- After the sick child had their diagnosis
- During, after treatment, child s dying and after death
- After the family's wishes
- Listen to that sibling story and situation
- Help the healthy siblings to be involved with what is happening to the b/s
- Have activities along with siblings



Aim

 To explore sibling supporters' thoughts about the experiences they had in providing support for siblings

The research question

 What were the experiences of sibling supporters as they supported siblings of children with cancer?"

Method

Qualitative descriptive in design (Taylor & Bogdan, 1998)

Analysis

 Qualitative content analysis, to draw a systematic conclusion from the text and also to extract its message (Krippendorff, 2013)



Participants

- Preschool teacher, assistant nurse, pediatric nurse, communicator, writer
- All paid employees
- Educated by nurses, doctors, and counselor
- 9 women, 3 men
- 35 and 57 years (mean 46 years)
- Worked as a sibling supporter 1.5 and 15 years (mean 5 years)



Data collection

- August September 2014
- Qualitative interviews (Mishler, 1986; Nilsson, Gustafsson, & Nolbris, 2014; Patton, 2002)
- Via Skype included a semistructured interview (Nilsson, Gustafsson, & Nolbris, 2014)
- Main question What are your experiences to give support?
- Interviews lasted 23.31 71.04 minutes (mean 38.5 minutes)



Ethical Considerations

- Carried out in accordance with the ethical guidelines laid down in the Helsinki Declaration (World Medical Association, 2013)
- Carried out according to the recommendations of the regional ethics committee



Result 5 categories

- 1. Provide support to siblings for as long as needed
- From diagnose, during and after treat, during death and also after death

"A support for as long as needed" (Part 1)

"Contact after the end of treatment" (Part 3)



2. Facilitate opportunities for siblings to meet each other

- Importance of siblings meetings for a feeling of fellowship
- Set up situations and places

"Tried to go away with them, to meet and begin a friendship" (Part 2)

"Meet others who were in the same situation, so they could encounter each other" (Part11)



3. Promote age-appropriate activities for siblings

Siblings ranged from newborn up to 35 years of age (no age limit on)

"A very short and nearby outing was an ice cream café, which it only took 5 minutes by car"

(Part 6)

"Alone with the sibling supporter" (Part 9)

"Siblings might talk about difficult things" (Part 3)



4. Letting the siblings be encouraged by a positive environment

- Environment was important
- Activities that the siblings liked
- Needed to go outside the hospital

"The siblings needed to be associated with a positive thing" (Part 1)

"Going to museums" "Going to a cinema" "Fishing or biking" (Part 5) (Part 1) (Part 8)

Found it comfortable to return to the hospital

"Positive that kids love to come back to the hospital" (Part 8)



5. Encourage others to be supportive to siblings

 Parents and health care professionals discuss siblings situation and caring activities

"Colleagues also became aware of the siblings" (Part 11)

"Important that the sibling supporters worked with staff on the wards" (Part 2)



Conclusion

- Beneficial support to siblings who have a b/s with cancer
- Listened to the siblings' stories
- Met them where they were in their crisis
- Helpful part of the health care team



Article

Jenholt Nolbris M, Nilsson S. Sibling supporters experiences of giving support to siblings who have a brother or a sister with cancer.

Journal of Pediatric Oncology Nursing, 2017 Mar/Apr;34(2):83-89. doi: 10.1177/1043454216648920. Epub 2016 Jul 8.



Thank you!

