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# 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

- 1990 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”*  
(Part 5)

*“Going to a cinema”*  
(Part 1)

*“Fishing or biking”*  
(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!

