Siblings Do Matter
Supporting and Empowering
Siblings of Medically Fragile
Children

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Disclosure Statement

We have no actual or potential conflict of interest in relation to this presentation

*consent was obtained for all photos used*

St. Mary’s Hospital for Children

- Founded in 1870: oldest pediatric hospital in the metropolitan area
- Oldest pediatric palliative care program in the nation
- 125 bed facility with a mixed population of long term and short term rehab patients age infancy-21
- 50% of our population receive palliative care services
- St. Mary’s System: Medical Day Care, Feeding Program, preschool, home care
Objectives

- You will be able to identify the impact on children of having a chronically ill sibling
- You will be able to identify 4 therapeutic group interventions which are essential components of the St. Mary’s Sibling Group
- You will be able to identify 2 challenges and solutions in running a sibling support group

Patient and Family Centered Care

- Patient and family centered care in pediatrics
- In developing our sibling group, it was important to include the same principles as the PFCC model
- Belief that the family is the child’s primary source of strength and support

SIBSPLACE

- Affiliated with South Nassau Community Hospital and located in Hewlett, NY, where their program runs daily
- Focus on the challenges the well sibling faces living with an ill loved one
• What is a Medically Fragile Child?
  - Complex Medical Condition
  - Professional 24 hour supervision

• What is Pediatric Palliative Care at St. Mary’s?
  - Providing comfort care
  - Improving quality of life
  - Support of interdisciplinary team
  - Based on need

Research


• Siblings of children with chronic illnesses are 2 to 3 times more likely than their peers to experience psychological adjustment problems (Cadman, Boyle, & Offord, 1988; Sahler et al., 1994)

• Sibling challenges within their family (Bluebond-Langner, 1996)
  - Extra caregiver burden
  - Differential treatment
  - Imbalance of family resources

• Sibling Challenges outside of their family (Bluebond-Langner, 1996)
  - Limited access to information
  - Negative peer reactions
  - Disruptions in social activities

Research (cont’d)

Psychosocial Difficulties

• Unaddressed needs
• Lack of resources
• Psychological/emotional
• School
Sib’s Group

- Meet twice a month (Weekday and Weekend)
- Age range: 5y to 17y
- Group is free
- Parents must stay on site
- At least 2 facilitators running the group
- Therapeutic Goals

Therapeutic Interventions

Four Therapeutic Interventions:

- Writing/Journaling
- Verbal
- Art
- Music

Music

“There would be no music and no need for it if it were possible to communicate verbally that which is easily communicated musically” (E. Thayer Gaston, 1958)
Case Example #1

- 9 siblings ages ranging from 5y to 21y
- 17 year old female, History of seizures, Hypoxic Ischemic Encephalopathy, vent dependent
- Facilitated open discussion within the family

Sample Session #1

- Journal Time: What feelings do you feel on the inside about your sibling?
- Verbal Activity: Feelings Jenga
- Art Activity: All Feelings are Okay!
- Music: Drumming & Singing

"Feelings"
To the tune of: "Twinkle Twinkle"

I have feelings, so do you.
Let’s all sing about a few.
We get happy, we get sad.
We get scared, we get mad.
I am proud of being me
That’s a feeling, too, you see.
I have feelings, so do you.
We just sang about a few.
Case Example # 2

- 11 year old group participant
- The resident is an 8 year old female with a diagnosis of Trisomy 21, tracheostomy, Chronic Lung Disease
- Peer Support
Sample Session # 2

- Journal Time: What do you do when it rains?
- Verbal Activity: Rain Drops
- Art Activity: Pre-cut umbrellas and rain drops
- Music: “Count on me”

“Count on Me”

You can count on me
like one two three and I’ll be there
And I know when I need it
I can count on you
like four three two and you’ll be there
‘Cuz that’s what friends are supposed to do
Oh yea
Case Example # 3

- 2 older brothers ages 14 and 17 years old
- Resident is a 3 year old female with a trauma related history of narcotic abstinence syndrome and anoxic brain injury due to co-sleeping
- The brothers felt extremely hesitant prior to coming to group
- “Oh you guys are not so bad”

Challenges

- Attendance- returning attendees
- Scheduling- school holidays, religious holidays, nights
- Age gap
- Parents

Solutions

- Offering group on the weekends
- Keeping in mind school holidays and all religious holidays
- Evening times during the school year
Benefits of Sibs Group

- Siblings can identify their emotions
- Normalize St. Mary’s for the siblings
- Siblings come and visit more frequently
- Siblings learn effective coping skills
- Strengthen the family system
- Peer Support

What helps when running group

- Preparation
- Having multiple facilitators
- Being flexible and adaptive

Conclusion

- The overall care and treatment of a patient includes the interdisciplinary team as well as family members, which includes siblings.
- Providing support to the sibling enables them to utilize the tools they learn to be a support for their brother/sister who is at St. Mary’s.
SIBLINGS DO MATTER

Sometimes we need someone to simply be there, not to fix anything, or to do anything in particular, but just to let us know that we feel cared for and supported.

References


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