Parents Living with Cancer: Bringing hope with compassion, honesty and creativity

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Objectives

- Overview of support available for children and parents at BCCA
- Themes that arise in parents group
- Ways to provide support for parents living with cancer
- Limitations of parents group
- Key takeaways
Incidence

- Incidence rate for all cancers for ages 20-39
  - Common Cancers in 20-39:
    - Breast
    - Thyroid
    - Colorectal
  - 1/3 of breast cancer patients have children <18 years old
  - US data at least 14% cancer patients live with children <18 years old
  - 1.58 million survivors ≈ 2.85 million children <18 years old live with a parent who has cancer
BC Cancer Agency
Patient and Family Counselling

• 1-1 counseling with parents
• Children's club and parents group
• BCCA website resources – Coping with Cancer
• Creation of www.cancerinmyfamily.ca and www.facts4teens.bccancer.bc.ca
• Links to other resources
Evolution

• Began in 1993
• Based on Kids Can Cope program in 1988 in St. Boniface Hospital in Winnipeg
• Started as 5-week program after school with kids only
• Art, music, educational components
• Inclusion of parents
Objectives of Children’s Group

1. Help kids understand cancer and its treatment
2. Supportive environment
3. Help kids explore and develop coping strategies
4. Opportunity for parents to share
5. Feedback to guide further program development
6. Fun!
Description of Children's Club

• Team: art therapist, counsellor, nurse, volunteer
• Session lay out
• Maximum 5-7 families
• Eligibility and assessment
Parents Group - Outline

• Setting the tone
• Group safety & confidentiality
• Introductions
• Sharing experiences
• Creative activity
• Connection with nurse
Role of Counselor

• Provide and hold a safe space
• Permission to express any emotion (and humour)
• Invite discussion and provide air time
Themes from Parents Group

Most common topics raised by parents:

• “Open and honest” vs. “Protection”
• Feelings about changes and role as parents
• Coping with uncertainty
• THE question: “Are you going to DIE?”
Themes from Parents Group

• Sharing of experiences
• Difficult emotions
• Search for meaning
• Enjoying the present
• Legacy
Key Takeaways

- Encourage open, honest and age-appropriate communication
- 3 C’s
- Tips for talking about death
- Model how to deal with adversity
- Don’t expect perfection
Key Takeaways

• Post-traumatic Growth (PTG)
• PTG vs. resilience
• Themes associated with PTG
• Factors contributing to PTG
Providing a Space for Hope

• What is HOPE?
• Hope vs. Wish
• Why hope?
Providing a Space for Hope

• Creative exercise
  – What are you learning from your children?
  – What have you seen in your children that made you feel hopeful?

BC Cancer Agency
CARE + RESEARCH
An agency of the Provincial Health Services Authority
Patient & Family Counselling
Evaluations: What are we learning

Limitations:

• Desire for more sessions

“Is it possible to have it bi-monthly year round? It would be very helpful for the kids to regularly meet other kids in the same situation.”
Evaluations: What are we learning

Limitations:

• Mixed diagnosis

“A separate group for terminal vs. not terminal patients would help.”
Evaluations: What are we learning

Strengths:

• Validation & Connection:

“It was helpful to know that Mike (parent) is doing things right with communicating so much to Rob (child). It was also great to meet other parents going through the same thing and realize that she is not alone in what she is experiencing.”
Evaluations: What are we learning

Strengths:

• Emotional Support

“It helped to validate the emotional cycle of the cancer experience. I have already gone through the anger and the sadness and I recognize it is a healthy process. I also know that I can stop the cycle and need to move forward instead of being angry. The group provided a forum to allow people to talk.”
Evaluations: What are we learning

**Strengths:**

- Informative

“Thoughtful content that enabled cancer survivors and caregivers a forum with their children”
“The greatest gift you can give your children is not protection from change, loss, pain or stress, but the confidence and tools to cope and grow with all that life has to offer them.”

~ Dr. Wendy Harpham, cancer survivor ~
Resources