

# Dealing with Life's New Normal: The effects of IBD on parents and siblings

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# Objectives:

- \* To gain further understanding of the effect that IBD may have on family members of a child with IBD
- \* Present strategies to help family cope with and navigate potential effects of IBD

# Why a family perspective is important

- \* A chronically ill child affects the whole family
- \* Children learn to cope with IBD within a family, thus how the family copes with and manages the illness is a model for how the child learns to cope with IBD
- \* Research tells us that family functioning impacts the psychological outcome of the chronically ill child

# Common Concerns of Parents

- \* Children will be teased because of stunted growth, special diets, missing school
- \* IBD will affect fertility, conception and pregnancy
- \* Financial stress
- \* Fears that IBD will lead to cancer

# Balancing Act For Parents

- \* It's important to be vigilant re: the child's physical care and yet not be intrusive
- \* Advocate for special needs at school, while trying to ensure that their child is not singled out
- \* Give attention to the child with IBD and yet not neglect other family members (and yourself!)
- \* Constantly trying to find a balance between coping with IBD, and allowing their child to feel sense of normalcy

# Parent Quality of Life in the Context of Pediatric IBD

- \* Examined youth disease activity (DA) and youth Quality of Life (QoL) as predictors of parent QoL
- \* Higher youth QoL was associated with higher parent QoL in the mental health domain
- \* Greater DA was associated with lower parent QoL in the mental health and physical health domains
- \* When their children are experiencing disease exacerbations with their IBD, parents need extra support  
(Greenley & Cunningham, 2009)

# Positive Effects for Parents

- \* “I do think that managing this together has made us closer.”
  - \* -Dad of Ulcerative Colitis patient
- \* “There are times when it is really hard. But I have to say, I surprise myself with the things I am able to do now that I never thought I could.”
  - \* -Mom of Crohn’s patient

# Pediatric IBD and Siblings

Siblings often wonder:

- \* Will my sister or brother be okay?
- \* Am I going to get IBD?
- \* Did I do something to make my sibling sick?
- \* Will it help if I am extra good?



# Positive Effects for Siblings

- \* Studies have shown that there are positive effects of chronic illness on siblings. Some of these include increased empathy, patience, tolerance, passion for social justice and advocacy.
- \* Studies have also shown that siblings may be more resilient as adults
- \* Other positive effects: appreciation of life, cautiousness about health, and maturity

# Risk Factors for Siblings

- \* Siblings may face additional responsibility in the family and reduced physical and emotional availability of parents
- \* Siblings may experience intrusive and conflicting emotions, such as jealousy, shame and guilt
- \* Studies have also shown that siblings may be at increased risk for somatic complaints, excessive worry, and depression

# Risk Factors for Siblings

- \* Despite trends, each family and sibling will adjust differently
- \* Most influential factor in positive coping for siblings was the parents' ability to manage the needs of their well children in addition to their chronically ill child

# Important to Remember

- \* Some families report while their child's IBD has been difficult to manage, one unexpected benefit is that the need for increased communication has brought the family closer together

# Strategies-Within Community

- \* Establishing and connecting to community is important
- \* Utilizing extended family members and loved ones for support can decrease stress, increase feelings of connection, and deepen relationships
- \* Connecting with your IBD care team, CCFA events, Camp Oasis will increase feelings of normalcy, as well as increase resources and knowledge.

# Strategies-Within Family

- \* Ensure each individual family member has a network of supports
  - \* Positive adult influences for siblings
  - \* Positive outlets for adults
  - \* Availability of professional mental health/emotional support
- \* Make time for positive family time that does not involve issues related to the illness
  - \* Game night
  - \* Movie night
  - \* Weekly “Choose Your Own Adventure” night

# Strategies-Within Family

- \* Model positive coping
  - \* Establish positive coping skills for yourself
  - \* Encourage time for positive coping
  - \* Narrate skills for children
    - \* “I need a little ‘me’ time, I’m going on a walk.”
    - \* “Sometimes, it’s helpful for me to \_\_\_\_\_, so I’m going to do that. I’ll be back in an hour.”

# Strategies-Within Family

- \* Fully inform siblings about their brother or sister's illness
- \* Establish and maintain open communication with siblings to combat fears and anxiety due to a lack of knowledge
- \* Provide consistent education to siblings as questions, concerns and changes arise
- \* Spend quality alone time with siblings
- \* Encourage participation in group events with peers who have similar experiences



# A few more ideas!

- \* Remember to tend to your emotional needs to allow yourself to be present for others
- \* Try to keep in mind that most children with IBD do well: they lead productive lives, have families and follow occupations of their choice
- \* Work to understand the illness from your child's perspective as well as their siblings' perspective
- \* Communicate with other family members and support system
- \* Communicate with your IBD team, utilize resources

# Words of Wisdom From Your Flight Attendant:



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# Questions?

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