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

Ashley Jarrett, MSW, LSWAIC April 2nd, 2016

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."

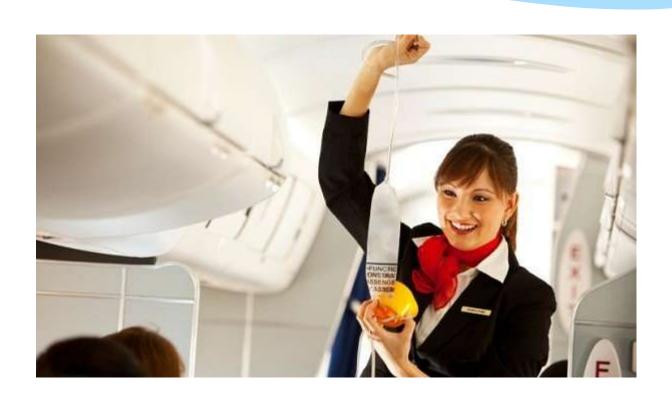
Strategies-Within Family

- * 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?

* Contact:

- * Ashley Jarrett, MSW, LSWAIC
 - * 206.987.6440
 - * ashley.jarrett@seattlechildrens.org