

## **IBD through the Ages**

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"Growing up is not easy. Growing up with a chronic condition is inherently more difficult."

Judith A. Vessey, PhD, RN, C, DPNP - Primary Care of the Child with a Chronic Condition

### **How many children get IBD?**

- Estimated that 1,000,000 Americans have IBD & that 20% of those are children
- Most common to develop IBD between the ages of 15-35 years
- In children under 10 years, colitis is more common than Crohn's disease

### **Medical Therapy at different ages**

- Therapy similar
- Goals might be different depending on age
- Drug preparations might be different
- Principles of therapy do not change

### **Goals of therapy**

- Control of symptoms with the least possible medications and side effects
- Return the child to usual activities
- Control overall disease activity so as to promote growth - Even when symptoms are quiet, growth may not be adequate

### **Goals of therapy - Pitfalls**

- Maintain patience while medications take their effect - Some medications take up to 2 weeks or longer to have an effect
- Medications may have side effects. The more significant the medication, the more significant the side effects
- Reluctance to use medications if not necessary. Need to consider that therapies might keep the illness from worsening
- Children do not like taking medications

### **What makes children different?**

Children are different from adults and have unique management needs including the consideration of:

Growth

Development

Nutrition

Medications

Family dynamics

## School/Peer Relationships

### **IBD in the very young child**

13% of the children followed at Mount Sinai are 5 years or younger

#### Making a diagnosis

- Time between symptom onset and diagnosis may be longer because IBD is not typical in this age group
- Young children are less likely or unable to verbalize complaints

#### Medication - Challenges in the very young child

- Have to be suspensions (liquid), which prevents the use of some delayed release medications (i.e. Asacol®)
- Not palatable
- Effects of long term medication use

#### Growth and Development

- Effects of chronic illness can cause delays in developmental milestones, including toilet training
- Regression
- Separation anxiety, both for child and parent (i.e. child care choices, returning to work, preschool decisions)

#### Psycho-social needs of very young children with IBD

- The majority of chronically ill children experience normal social & intellectual development
- The majority of psychological studies of chronically ill children focus on the school age child & adolescents, but increasing numbers of children are diagnosed at a younger age
- When a child has an illness, the quality of parental care has a major impact on early development
- Parental response to chronic illness is of prime importance
- Parents of young children play a key role in compliance
- Parental perceptions of IBD will shape the treatment of the child; need for education, talk to others, seek role models

### **IBD in School Aged Children**

50% of the children followed at Mount Sinai are aged 6-12 years

#### Medications - Challenges in the school aged child

- How does the dosing schedule fit in with their activities?
- Giving medications during the school day
- Timing of medications that need to be taken more than twice a day

### Psycho-social needs of school age children with IBD

- It is essential for a child this age to feel involved with school & peers
- They need time to engage in activities outside the home and form friendships
- May experience increased school absences or school avoidance
- May be less involved in age related activities
- Strategies may be needed to involve children in sports, play dates, sleepovers, camp, etc.
- Understanding of illness is limited by cognitive skills
  - May assume it is punishment for being bad
  - Angry at parents or doctors for not making them feel better
- School age children will be exposed to regular childhood illnesses; challenge to differentiate symptoms of IBD from other colds and viruses

### **IBD in Adolescents**

37% of the children followed at Mount Sinai are adolescents and young adults

#### Medications

- Compliance issues
- Taking responsibility for their own illness
- Allowing teenagers to participate in decision making with parents & health care provider regarding treatment options

Medication Compliance - Why is taking medication a problem for adolescents?

- A reminder that they have a chronic illness
- They forget, especially with more than twice a day dosing
- Some medications taste bad
- Interactions with alcohol
- Once in remission, they feel good and don't see the need for medications
- During flares "it doesn't work anyway attitude"
- Adolescents are risk takers and test limits
- Control issues
- Undesirable side effects, especially with steroids (acne/weight gain/hirsute)

#### Psycho-social needs of Adolescents with IBD

- Adolescence is a challenging time of testing limits, arguing with parents and spending time away from home. ALL THIS IS NORMAL.
- Many adolescents feel pulled in opposite directions: increased dependence due to illness & increased need for autonomy

Adolescents need:

- Independence from family
- membership in a peer group
- Sexual identity & sexual roles
- To consider future plans/studies/careers

Parents can:

- Encourage safe activities, encourage supportive peer group (familiar with disease the disease if the teen is comfortable with this)
- Discuss and prepare for increased independence
- Work with school to foster comfort & normal activities/routines
- Identify and support child's strengths
- Give responsibilities, choices & maintain expectations
- Encourage education regarding IBD & promote independence in disease management

REMEMBER, THE MAJORITY OF CHRONICALLY ILL CHILDREN EXPERIENCE NORMAL SOCIAL AND INTELLECTUAL DEVELOPMENT!