

Psychosocial Aspects of Familial Polyposis

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Challenges Associated with Living with FAP

- Frequent screening for cancer
- Decisions about surgery
- Adjustment to surgery [ileorectal anastamosis (IRA) vs. ileal pouch anal anastamosis (IPAA)]
- Thinking about having children and passing down the risk of FAP
- Worries about developing cancer
- Coping with other relatives affected with FAP and their experiences
- Other healthcare providers lack of experience with FAP (e.g., family doctors)

What is the Impact of FAP?

- Many people need to make adjustments to using the washroom, especially at work and for social activities
 - There is an adjustment period after surgery, after which this becomes more manageable
- Most report their employers have been supportive
- Participants in research report that friendships and education not affected, typically
- Around 20% of people have reported worry about potential need to have additional surgery, possibility of developing cancer, or other family members being diagnosed with cancer
- People who want professional support typically want to discuss these type of worries, in addition to coping with illness in other family members, family planning, worry about cancer screening

FAP and Relationships

- People have reported being concerned to tell new partners about FAP and difficulties with first sexual encounters. A minority do report some sexual side effects after surgery.
- Within families, people have mentioned a variety of reactions to being diagnosed with FAP: bringing the family closer together, parents feeling guilty for passing FAP on to the child, lack of communication.
 - Seems to be dependent on the existing dynamic within the family
 - Most people prefer open communication about FAP
 - Parents and other family members are a major source of support

Quality of Life in Younger Children After Surgery

- Overall quality of life is comparable to the general population for physical health and mental health
- Tend to have more incontinence, and more embarrassment due to incontinence
- However, very few report restrictions at school and only a minority have restrictions in sport activities
- Self-esteem and body image also within normal ranges
- Some do report worrying about developing cancer after colectomy; tends to also be worse in children under the age of 18
- Kids also worry about the health of their FAP-affected parent
- In general, younger age is associated with more difficulties in adapting to life after surgery; support is needed for adolescents

Talking to Kids about FAP

- Younger children need simpler explanations.
- A single conversation is likely to not be enough. Consider having brief conversations to keep the lines of communication open.
- Remind them they did not do anything to cause FAP.
- It's ok for your child to have many different feelings. Validate them.
- Offer a realistic but hopeful assessment of the situation, and focus on the steps to treat FAP.
- Explain that although their treatment could have difficult side effects, it's to keep them healthy.
- Be honest when answering questions. It's ok to say "I don't know."
- Older kids may want to be involved in making decisions about their treatment.
- Remember you are your child's most important source of information and support!
- Consider meeting with a counsellor, who can help you appropriately address your child's unique needs and stage of development when talking about FAP.