

Addressing Psychosocial Needs of Patients with Colorectal Conditions and their Families

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Goals

- Review psychosocial challenges associated with colorectal problems
- Share recent research
- Discuss effective strategies, including unique developmental needs

Survey of Adults with ARM



- Evaluated psychosocial functioning of adults with ARM
- 70 respondents from private online support group for adults with ARM; 18 – 75 years
- 73% female, 90% Caucasian
- 60% from the US, 11 other countries represented



Question 1

What percentage of patients in our study had a mental health concern?

1. 15%
2. 30%
3. 50%
4. 75%



“In high school and in my 20s. I suffered from depression, anxiety, anger issues, shame, embarrassment and planned my own suicide...The shame and embarrassment of living with the condition. I felt I would never get married or have children, that nobody would love me or find me attractive. I had many accidents over the years which caused me great mental anguish.”



Mental Health

- Over 50% endorsed history of mental health concern
- 65% had participated in therapy
- 50% had used medication to address a mental health concern



Question 2

What percentage of participants received accommodations while in school?

1. 10%
2. 33%
3. 50%
4. 80%



“Work is stressful and my management team isn’t helping me. I feel as if I have to walk on eggshells just to do anything and hide the fact that I have to use the restroom so much. My family tries to help as much as they can.”

School & Work



- School accommodations
- Work accommodations
- Employment status
- Need for increased education about school and workplace accommodations



“I honestly wish I didn’t have this problem. It’s embarrassing and hard to get close to people.”

Common Challenges



- Struggles to gain support
- High emotional distress
- Relationships with family members, peers, school environment, and larger community



“I was smelly and didn’t have many friends. Just 2 friends in grade school. Made me a loner and independent which I still have today. I still suffer with social anxiety.”

Bowel Management Survey



- Examined psychosocial functioning in BMW
 - Parental stress
 - Patient behavioral/emotional functioning
- 9yo on average, 61% male, 73% Caucasian
- Dx: ARM (49%), idiopathic constipation (21%), spinal condition (19%), HD (9%)



Question 3

What colorectal diagnosis had the highest rates of parental stress?

1. ARM
2. Idiopathic constipation
3. Spinal conditions
4. Hirschsprung disease



BMW Survey Results

- High levels of parenting stress
- Increased behavioral difficulty in patients with IC vs ARM
- Unique challenges associated with IC
- Patients with DD/ASD
- Need for psychosocial support during BMW

What helps patients succeed?



- Positive self-esteem
- Resilience
- Low levels of stress associated with treatment plan
- Easily identifiable motivators are key for treatment success

THE STORY OF  YOU



“My parents gave me the love and support I needed as a child and made me feel normal. My surgeon tried to give me a normal healthy life and I am grateful for these things.”

What helps caregivers succeed?



- Strong support system
- Self-care
- Caregiver collaboration





“Find other parents who have children with ARMs. Connect with others and help each other. Find other children with this condition and connect your child with them. Acknowledge openly that your child needed special accommodations.”

Question 4



How can I support my patients' psychosocial functioning?

1. Ask about their mental health
2. Consider their developmental level
3. Share psychosocial resources
4. All the above!



“I wish that those working in the healthcare field had told me there were many others like me. I wish they would have directed to any resources that were available. I wish they would have asked me about my mental health.”

How can I help my patients and their families?



- Be honest
- Consider development
- Be proactive
- Ask about how they are doing in multiple ways: physically, socially, emotionally





“I wish (I) opened up to a doctor and/or asked more questions about my condition when I was younger.”

“I wish children had a say in the medical treatment we experienced.”

Preparing for Medical Interventions



- Consider what/when to share info with a child
 - Very young children: simple and concrete information
 - School age: give basic information and likely results
 - Teens: give more details and allow more time to mentally prepare

Strategies for Children



- Talk about what to expect
- Use age-appropriate language
- Consider ways to involve the patient
- Encourage use of enjoyable activities to help with distraction

LOOK!
A Distraction!



Strategies for Adolescents



- Give opportunities for independence
- Help to maintain social relationships
- Focus on self-advocacy



Psychosocial Supports



- Psychosocial lecture during BMW
- Parent support groups
- Opportunities for individual meetings with social work or psychology
- Local and national support groups



Local and National Resources



- Facebook Groups
 - Colorectal Support Network
 - Doctors Pena Bischoff
 - Private Adult IA Group
- Summer Camps
 - Youth Rally
 - Serious Fun Network
- Other organizations
 - Pull-thru Network
 - One in 5000 Foundation



Colorectal Support Network >

Join Group



“A colorectal condition does not
mean you can't have a
wonderful life...
don't let it stop you from
following your dreams”



Questions?



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