

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



The longer a patient
has incontinence,
the greater the chance of
developing behavioral and
emotional problems.

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



“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.”



Question 1

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

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



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



“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.”



Question 2

What percentage of participants felt that their employment status was related to their medical condition?

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

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

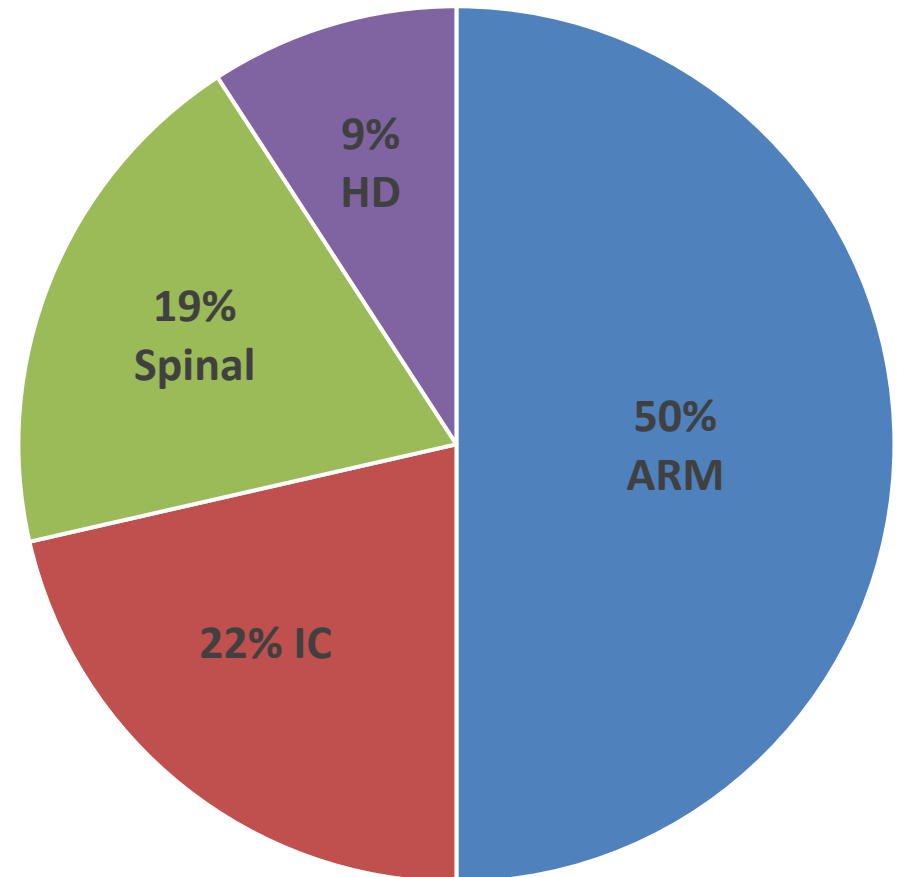


“I was smelly and didn’t have many friends. Just 2 friends in grade school. Made me a loner and independent which I still have today. I still suffer with social anxiety.”

Bowel Management Survey



- Examined psychosocial functioning in BMW
 - Parental stress
 - Patient behavioral and emotional functioning
- 9yo on average
- 61% male, 73% Caucasian





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 overall
 - Particularly for IC group
- Patient behavioral/emotional functioning
 - Idiopathic constipation
 - Developmental delays & autism
- Unique challenges associated with IC
- 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 providers support their 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 providers help their patients and 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.”

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
- Support groups
- Opportunities for individual meetings with social work or psychology
- Local and national resources



Local and National Resources



Social Media

- Facebook
 - Doctors Pena Bischoff
 - Colorectal Support Network
 - Private Adult IA Group
- YouTube
 - Dr. De la Torre's channel

Summer Camps

- Youth Rally
- Serious Fun Network

Other organizations

- Pull-thru Network
- One in 5000 Foundation





“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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