Long-term outcomes of adult patients following surgery for congenital colorectal conditions: analysis of psychosocial functioning

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Abstract

Purpose This study aimed to obtain information about the psychosocial functioning of adults with various congenital colorectal conditions (e.g., anorectal malformation, Hirschsprung disease).

Methods A research registry of adult patients with colorectal conditions was developed. Items included demographics, medical diagnosis/treatment, and measures of anxiety and depression. Descriptive and inferential statistical approaches were applied to summarize data and determine significant differences in the average scores for depression and anxiety between various groupings of diagnoses, gender, race, and the use of psychotropic medication.

Results Study measures were completed by 131 adults. Depression and anxiety scores were significantly higher for women than men and those self-identified as non-binary (p = 0.012, < 0.001, respectively). No significant differences in depression and anxiety scores were found due to colorectal diagnosis (p > 0.05). Participants who identified as Asian had significantly higher depression scores than participants of other races (p = 0.002); but no significant difference was noted for anxiety scores (p = 0.065).

Conclusions Results suggest that depression and anxiety scores were significantly influenced by gender and race. However, colorectal diagnosis was not a predictor of depression or anxiety. It is important for colorectal providers to be aware of the psychosocial implications of congenital colorectal conditions and consider how to provide adequate support to address patients’ psychosocial needs.

Keywords Anorectal malformation · Hirschsprung disease · Psychosocial functioning · Depression · Anxiety

Introduction

Congenital colorectal conditions include anorectal malformation (ARM), Hirschsprung disease (HD), and related conditions and affect approximately 1 in 5000 births [1]. While these conditions are typically not life-limiting, they require significant medical intervention across the lifespan, including surgery and bowel management regimens to achieve fecal continence. These treatments may include the use of daily rectal enemas, oral laxatives, or other interventions, which can be time-consuming and distressing.

Adults with chronic medical conditions may be at higher risk for psychosocial difficulties, including depression and anxiety, than their healthy peers due to the challenge of coping with a chronic medical condition in addition to other life demands [2]. Patients with congenital colorectal conditions may be at even higher risk for these psychosocial difficulties, given the stigma associated with having a colorectal condition and the impact on fecal continence. For example,
a study of youth and young adults with HD found nearly double the rates of depression in those with HD in comparison to healthy matched controls in a broad national study [3]. In a recent study of adults with ARM, more than half of the participants reported having a mental health diagnosis (e.g., depression, anxiety, post-traumatic stress disorder) [4]. However, few studies of adults with colorectal conditions have included validated self-report measures of depression and anxiety. Thus, it would be helpful to formally assess the rates of depression and anxiety in adults.

The aim of this study was to gather information about the psychosocial functioning of adults with various congenital colorectal conditions (e.g., anorectal malformation, Hirschsprung disease) using validated measures of anxiety and depression.

Methods

A research registry of adult patients with colorectal conditions willing to be contacted about research was developed by a national colorectal center at a large midwestern medical school and associated hospital. An existing database of pediatric patients with congenital colorectal conditions that were surgically corrected as a child (ARM, HD) was examined to identify those who were now in adulthood. Adult patients were then contacted by the research team to confirm their identity and determine their interest in being a member of the adult colorectal registry. Exclusionary criteria included participants who did not speak English, had a developmental delay, or a disability which would significantly impact their ability to complete the surveys on their own. In addition, citizens of the European Economic Area were excluded from this study.

Surveys collected information pertaining to basic demographic, health, and contact information for these adult patients. Registry members were then asked to complete surveys on the following topics: General Health, Depression, and Anxiety. The depression and anxiety measures were taken from the National Institute of Health’s Patient-Reported Outcomes Measurement Information System (PROMIS) Emotional Distress measures, and included the Depression short form and the Anxiety short form [5].

All parts of this study received the approval of the Colorado Multiple Institutional Review Board (COMIRB), which provides regulatory oversight for human subject research at the study site (Protocol 21-3153, and 21-3154).

Descriptive and inferential statistical approaches (e.g., count, percent frequency, mean ± standard deviation, t test, ANOVA) were applied to summarize data and determine significant differences in the average t scores for depression and anxiety between various groupings of relevant predictors (e.g., colorectal diagnoses, gender, race, use of psychotropic medication; SAS Studio, SAS Inc., Cary, NJ). Non-parametric approaches were applied when data did not show normal distribution. Significance level was set at $p < 0.05$.

Results

Demographic and clinical profile of study participants

A total of 131 adult patients completed the surveys, contributing to a response rate of approximately 63%. Briefly, most respondents were male (50.4%), White/Caucasian (90.2%), and identified as not of Hispanic/Latino ethnic background (91.5%). The average age of respondents was 32.3 ± 10.0 years (median of 30 years old). In terms of clinical profile, 84.0% of respondents were diagnosed with ARM, followed by HD (12.2%), while the remaining 3.9% indicated other type of colorectal malformation. Further, a majority of these study participants did not have any history of kidney transplant (96.9%), have not completed antegrade procedure (73.3%), do not have a colostomy or ileostomy (94.7%), or other type of surgery related to their colorectal conditions (50.4%). Respondents also indicated having received medication prescriptions (63.4%; any type of medications). When prompted further, there was approximately an even split on the number of respondents noted to have been prescribed with psychotropic medication (27.5%), received medication prescription but not psychotropic medication (35.9%), or have not been prescribed any medication at all (36.6%). Psychotropic medications prescribed to survey respondents were mostly for treating depression and anxiety, which include norepinephrine and dopamine reuptake inhibitors (NDRI), selective serotonin reuptake inhibitors (SSRI), anxiolytic medications, and benzodiazepine. Table 1 outlines the demographic and clinical profile of the respondents in more detail.

Depression trends of study participants

PROMIS t scores for depression indicated that most participants had none to slight level of depression (61.8%), followed by moderate and mild levels (16.8% and 16.0%, respectively; Table 1). Approximately 5.3% indicated severe depression (Table 1). Overall, the mean t score for depression for study participants was 51.8 ± 10.2, with minimum and maximum scores at 37.1–77.9 (Table 1). Inferential statistical analyses indicated that female participants had significantly higher t score values for depression than male counterparts ($p = 0.012$; Table 2). Notably, respondents identified as Asian/Pacific Islander had significantly higher depression scores than White/Caucasian counterparts ($p = 0.002$; Table 2). Other predictors...
| Variables                                      | All participants (n = 131) |
|------------------------------------------------|-----------------------------|
| Age of participants (mean ± SD; in years)     | 32.3 ± 10.0                 |
| Gender (n, %)                                  |                             |
| Male                                           | 66 (50.4)                   |
| Female                                         | 63 (48.1)                   |
| Non-binary                                     | 2 (1.5)                     |
| Race (n, %)                                    |                             |
| Caucasian/White                                | 118 (90.2)                  |
| African American/Black                         | 4 (3.0)                     |
| Asian/Pacific Islander                         | 5 (3.8)                     |
| Other                                          | 4 (3.0)                     |
| Ethnicity (n, %)                               |                             |
| Hispanic/Latino                                | 9 (6.9)                     |
| Non-Hispanic/Non-Latino                       | 118 (90.1)                  |
| Not specified                                  | 4 (3.1)                     |
| Colorectal diagnosis (n, %)                    |                             |
| Anorectal malformation (ARM)                   | 110 (84.0)                  |
| Hirschsprung disease (HD)                      | 16 (12.2)                   |
| Other                                          | 5 (3.9)                     |
| History of kidney transplant (n, %)            |                             |
| Yes                                            | 4 (3.1)                     |
| No                                             | 127 (96.9)                  |
| History of antegrade procedure (n, %)          |                             |
| Yes                                            | 35 (26.7)                   |
| No                                             | 96 (73.3)                   |
| History of colostomy/ileostomy (n, %)          |                             |
| Yes                                            | 7 (5.3)                     |
| No                                             | 124 (94.7)                  |
| History of other surgery (n, %)                |                             |
| Yes                                            | 65 (49.6)                   |
| No                                             | 66 (50.4)                   |
| Prescribed with medication (n, %)              |                             |
| Yes                                            | 83 (63.4)                   |
| No                                             | 48 (36.6)                   |
| Prescribed with psychotropic medication (n, %) |                             |
| Not prescribed with any medication             | 48 (36.6)                   |
| Received prescription including psychotropic medication | 36 (27.5)                   |
| Received prescription but not psychotropic medication | 47 (35.9)                   |
| Participants’ $T$ score for depression (mean ± SD; min–max scores) | 51.8 ± 10.2; 37.1–77.9 |
| $T$ score interpretation for depression (n, %) |                             |
| None to slight                                 | 81 (61.8)                   |
| Mild                                           | 21 (16.0)                   |
| Moderate                                       | 22 (16.8)                   |
| Severe                                         | 7 (5.3)                     |
| Participants’ $T$ score for anxiety (mean ± SD; min – max scores) | 55.3 ± 10.9; 36.3–82.7 |
| $T$ score interpretation for anxiety (n, %)    |                             |
| None to slight                                 | 62 (47.3)                   |
| Mild                                           | 22 (16.8)                   |
| Moderate                                       | 35 (26.7)                   |
| Severe                                         | 12 (9.2)                    |
Table 2 Differences in values of T score for depression as stratified by respective groupings

| Variables                          | T score values (mean ± SD) | p values |
|-----------------------------------|----------------------------|----------|
| Gender                            |                            |          |
| Male                              | 49.2 ± 9.2a                | 0.012*   |
| Female                            | 54.5 ± 10.7b               |          |
| Non-binary                        | 49.8 ± 5.1a,b              |          |
| Race                              |                            |          |
| Caucasian/White                   | 50.7 ± 9.8a                | 0.002*   |
| African American/Black            | 59.2 ± 13.1a,b             |          |
| Asian/Pacific Islander            | 66.4 ± 6.6b                |          |
| Other                             | 57.8 ± 4.7a,b              |          |
| Ethnicity                         |                            |          |
| Hispanic/Latino                   | 56.8 ± 10.4                | 0.120    |
| Non-Hispanic/Non-Latino           | 51.4 ± 10.1                |          |
| Colorectal diagnosis              |                            |          |
| Anorectal malformation (ARM)      | 51.6 ± 10.0                | 0.493    |
| Hirschsprung disease (HD)         | 50.7 ± 11.7                |          |
| Other                             | 57.8 ± 10.8                |          |
| Colorectal diagnosis (Male)       |                            |          |
| Hirschsprung disease (HD)         | 49.3 ± 11.4                | 0.923    |
| Perineal fistula                  | 48.6 ± 8.5                 |          |
| Bladderneck fistula               | 49.5 ± 10.9                |          |
| Bulbar fistula                    | 49.2 ± 8.8                 |          |
| Prostatic fistula                 | 47.6 ± 10.6                |          |
| No fistula                        | 49.8 ± 11.1                |          |
| Exstrophy (cloacal)               | 48.2 ± 0.0                 |          |
| Unknown                           | 53.8 ± 5.1                 |          |
| Colorectal diagnosis (Female)     |                            |          |
| Hirschsprung disease (HD)         | 55.1 ± 13.3                | 0.505    |
| Cloaca                            | 54.8 ± 10.7                |          |
| Vestibular fistula                | 55.6 ± 10.4                |          |
| Recto-perineal fistula            | 41.7 ± 6.4                 |          |
| Recto-vaginal fistula             | 56.2 ± 0.0                 |          |
| No fistula                        | 37.1 ± 0.0                 |          |
| Exstrophy (cloacal)               | 60.7 ± 1.3                 |          |
| Unknown/other                     | 55.3 ± 11.4                |          |
| History of kidney transplant      |                            |          |
| Yes                               | 52.2 ± 14.9                | 1.000    |
| No                                | 51.7 ± 10.1                |          |
| History of antegrade procedure    |                            |          |
| Yes                               | 52.9 ± 10.2                | 0.328    |
| No                                | 51.4 ± 10.2                |          |
| History of colostomy/ileostomy    |                            |          |
| Yes                               | 55.9 ± 10.0                | 0.227    |
| No                                | 51.5 ± 10.2                |          |
| History of other surgery          |                            |          |
| Yes                               | 52.2 ± 10.3                | 0.519    |
| No                                | 51.3 ± 10.2                |          |
| Prescribed with medication        |                            |          |
| Yes                               | 52.2 ± 9.8                 | 0.391    |
| No                                | 51.0 ± 10.9                |          |
such as ethnicity, types of colorectal diagnoses, history of kidney transplant, history of antegrade procedure, history of colostomy/ileostomy, and history of other types of surgery related to colorectal condition, did not show any significant differences in scores among the groupings (all \( p > 0.05 \); Table 2). Similarly, there was no significant differences in \( t \) scores for depression when data were stratified by medication prescriptions, including whether participants were prescribed with psychotropic medications (all \( p > 0.05 \); Table 2). Although mean \( t \) scores for depression varied by colorectal diagnoses in male and female participants, these differences were not found to be significantly different among each diagnosis by gender group (all \( p > 0.05 \); Table 2).

### Anxiet trends of study participants

The mean PROMIS \( t \) scores for anxiety was 55.3 ± 10.9, with minimum and maximum scores at 36.3–82.7 (Table 1). The mean \( t \) scores for anxiety indicated a similar trend to \( t \) scores for depression. The majority of participants indicated none to slight level of anxiety, followed by moderate, mild, and severe levels (47.3, 26.7, 16.8, and 9.2%, respectively; Table 1). In addition to experiencing depression as outlined above, female participants also indicated significantly higher levels of anxiety than male participants \( (p < 0.001) \); Table 3). However, in contrast to the state of depression, there was no significant difference observed in anxiety \( t \) scores among various races of the participants \( (p = 0.065) \); Table 3). Anxiety \( t \) scores were also not significantly different among various ethnicity, colorectal diagnoses (including when grouped by gender), history of kidney transplant, history of antegrade procedure, and history of colostomy/ileostomy and other colorectal surgery \( (p > 0.05) \); Table 3). On average, anxiety \( t \) scores for participants who were prescribed with medication were higher than those who were not (56.7 ± 10.9 vs. 52.8 ± 10.6), however, the difference was not distinctly significant \( (p = 0.05) \). Participants who were prescribed psychotropic medication indicated significantly higher levels of anxiety than those who were not prescribed any medication, or those prescribed medication but not including psychotropic medication \( (p = 0.001) \).

### Discussion

This study examined prevalence of depression and anxiety in adult patients with congenital colorectal conditions. We assessed for the impact of colorectal condition, gender, race, and use of psychotropic medication on participants’ psychosocial functioning.

In summary, the prevalence of depression and anxiety were higher in this study than the general population. In particular, anxiety scores were elevated in comparison to the general population used to standardize the measure \( (50.0 ± 10.0) \) [5]. This likely demonstrates an increased risk for anxiety in adults with colorectal conditions [6]. These findings are consistent with other studies of PROMIS measures in adults with chronic medical conditions [7]. For example, in a study of adults with inflammatory bowel disease (IBD), a chronic gastrointestinal condition characterized by diarrhea, abdominal pain, and fatigue, patients with IBD had elevated mean scores of depression and anxiety in comparison to the general population [8]. This finding has been replicated with other measures of anxiety and depression as well [9, 10]. Thus, adults with colorectal or similar gastrointestinal conditions are at increased risk for anxiety and depression, in comparison to peers without a chronic medical condition.

We also examined the impact of the specific colorectal condition (e.g., type of anorectal malformation) on depression and anxiety scores. While we did not find any significant differences, this may be reflective of our small sample size rather than a lack of difference in psychosocial functioning. Previous studies have postulated that patients with severe types of colorectal conditions (e.g., cloaca; total colonic aganglionosis) have more difficulty with bowel and bladder continence than milder types, which corresponds to more difficulty in overall psychosocial functioning [11]. Additional studies that include large sample sizes are needed to gather additional information on this topic.

Participants who identified as women had higher scores of both depression and anxiety, in comparison
Table 3  Differences in values of T score for anxiety as stratified by respective groupings

| Variables                        | T score values (mean ± SD) | p values |
|----------------------------------|----------------------------|---------|
| Gender                           |                            |         |
| Male                             | 51.5 ± 9.9<sup>a</sup>     | <0.001<sup>*</sup> |
| Female                           | 59.6 ± 10.4<sup>b</sup>    |         |
| Non-binary                       | 43.8 ± 10.6<sup>a,b</sup>  |         |
| Race                             |                            |         |
| Caucasian/White                  | 54.6 ± 10.8                | 0.065   |
| African American/Black           | 57.8 ± 14.5                |         |
| Asian/Pacific Islander           | 65.4 ± 3.1                 |         |
| Other                            | 61.0 ± 11.2                |         |
| Ethnicity                        |                            |         |
| Hispanic/Latino                  | 59.7 ± 11.2                | 0.266   |
| Non-Hispanic/Non-Latino          | 54.9 ± 10.9                |         |
| Colorectal diagnosis             |                            |         |
| Anorectal malformation (ARM)     | 55.5 ± 10.9                | 0.382   |
| Hirschsprung disease (HD)        | 52.2 ± 11.5                |         |
| Other                            | 58.9 ± 10.2                |         |
| Colorectal diagnosis (Male)      |                            |         |
| Hirschsprung disease (HD)        | 48.5 ± 9.8                 | 0.583   |
| Perineal fistula                 | 53.9 ± 11.0                |         |
| Bladderneck fistula              | 53.8 ± 4.6                 |         |
| Bulbar fistula                   | 49.8 ± 9.4                 |         |
| Prostatic fistula                | 50.7 ± 10.9                |         |
| No fistula                       | 51.7 ± 13.3                |         |
| Exstrophy (cloacal)              | 48.4 ± 0.0                 |         |
| Unknown                          | 56.3 ± 7.7                 |         |
| Colorectal diagnosis (Female)    |                            |         |
| Hirschsprung disease (HD)        | 63.3 ± 9.2                 | 0.236   |
| Cloaca                           | 59.0 ± 11.1                |         |
| Vestibular fistula               | 60.1 ± 8.8                 |         |
| Recto-perineal fistula           | 48.0 ± 4.7                 |         |
| Recto-vaginal fistula            | 68.9 ± 0.0                 |         |
| No fistula                       | 36.3 ± 0.0                 |         |
| Exstrophy (cloacal)              | 66.4 ± 5.4                 |         |
| Unknown/other                    | 62.7 ± 7.1                 |         |
| History of kidney transplant     |                            |         |
| Yes                              | 57.5 ± 22.0                | 0.899   |
| No                               | 55.2 ± 10.5                |         |
| History of antegrade procedure   |                            |         |
| Yes                              | 58.2 ± 10.7                | 0.090   |
| No                               | 54.2 ± 10.8                |         |
| History of colostomy/ileostomy   |                            |         |
| Yes                              | 58.1 ± 11.7                | 0.367   |
| No                               | 55.1 ± 10.9                |         |
| History of other surgery         |                            |         |
| Yes                              | 55.7 ± 11.2                | 0.625   |
| No                               | 54.8 ± 10.7                |         |
| Prescribed with medication       |                            |         |
| Yes                              | 56.7 ± 10.9                | 0.050   |
| No                               | 52.8 ± 10.6                |         |
to participants who identified as male or non-binary. This finding is consistent with previous global studies of depression and anxiety, which found that women historically present with higher rates of these mental health diagnoses than men [12]. Some colorectal studies have supported this gender difference in depression rates (e.g., higher rates of depression in women with study of adults with ARM) [13], while others have not (equal proportion of depression among men and women in study of adults with HD) [3]. It would be helpful to further examine the impact of gender (including gender diverse individuals) on depression and anxiety prevalence within the colorectal community.

In regard to race, participants who identified as Asian/Pacific Islander were more likely to present with elevated levels of depression than Caucasian/White participants. This finding is inconsistent with most epidemiological studies of depression in the United States, which found that White/Caucasian adults have higher levels of depression than Asian/Pacific Islander adults [14]. In addition, there have not been any other studies of depression in adults with colorectal conditions that examined racial differences. However, cultural factors may impact the differences found within this study. It is well-documented that there is a high level of stigma associated with colorectal conditions, given the high prevalence of fecal incontinence [15]. This may be particularly salient for adults who identify as Asian/Pacific Islander as certain Asian cultures may associate colorectal conditions with being “cursed” [16]. Thus, having a colorectal condition may lead to significant distress and depression. Additional research is needed on the impact of race and ethnicity on mental health functioning in adults with colorectal conditions.

Finally, this study found that participants who were prescribed psychotropic medication had higher rates of anxiety, but not depression, compared to those who did not take medication or only non-psychotropic medication. While it is not surprising that anxiety rates were higher, the lack of difference in depression rates is unexpected. It is possible that the majority of patients in this study who take psychotropic medication experience mild depressive symptoms, which are well-controlled by psychotropic medication (e.g., anti-depressants). This may also be explained by the severity of anxiety and depression scores overall in the study, as the mean values of anxiety scores were quite a bit higher than the depression scores.

### Conclusion/clinical implication

This study examined the proportion of self-reported depression and anxiety in adults with colorectal conditions. Given the findings in this study, it appears that adults with colorectal conditions may be at an elevated risk for depression and anxiety in comparison to healthy peers. Thus, it is vitally important to include psychosocial providers (e.g., psychologists, social workers) in multidisciplinary colorectal clinics, to ensure that adult patients receive the appropriate assessment and treatment of any presenting psychosocial concerns.

#### Author contributions

LJ-G, MA, and JK designed the study, which was based on a patient database created by JK, AP, LT, and AB. LJ-G and MA wrote the main manuscript text, and MA prepared the figures. All authors reviewed the manuscript.

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None.

#### Declarations

**Conflict of interest** All authors declare that they have no conflict of interest.

**Human and animal rights** This prospective study was approved by the Colorado Multiple Institutional Review Board (COMIRB; Protocol 21–3153 and 21–3154). All co-investigators underwent appropriate compliance and ethics training prior to the study onset. All data were stored on a password protected server and data access was limited to only co-investigators to ensure data security.

#### References

1. Levitt MA, Pena A (2007) Anorectal malformations. Orphanet J Rare Dis 2:33. https://doi.org/10.1186/1750-1172-2-33
2. U.S. Department of Health and Human Services, National Institute of Mental Health (NIMH) (2021) Chronic illness and mental health: recognizing and treating depression

3. Amin L, Skoglund C, Wester T, Granstrom AL (2019) Swedish national population-based study shows an increased risk of depression among patients with Hirschsprung disease. Acta Paediatr 108(10):1867–1870. https://doi.org/10.1111/apa.14801

4. Judd-Glossy L, Arielfdjohan M, Curry S, Ketzer J, Pena A, Bischoff A (2019) A survey of adults with anorectal malformations: perspectives on educational, vocational, and psychosocial experiences. Pediatr Surg Int 35(9):953–961. https://doi.org/10.1007/s00383-019-04508-y

5. Cella D, Riley W, Stone A, Rothrock N, Reeve B, Amtmann D, Bode R, Buysse D, Choi S, Cook K, De Vellis R, DeWalt D, Fries JF, Gershon R, Hahn EA, Lai JS, Pilkonis P, Revicki D, Rose M, Weinfurt K, Hays R (2010) The patient-reported outcomes measurement information system (PROMIS) developed and tested its first wave of adult self-reported health outcome item banks: 2005–2008. J Clin Epidemiol 63(11):1179–1194. https://doi.org/10.1016/j.jclinepi.2010.04.011

6. Schalet BD, Pilkonis PA, Yu L, Dodds N, Johnston KL, Yount S, Riley W, Cella D (2016) Clinical validity of PROMIS depression, anxiety, and anger across diverse clinical samples. J Clin Epidemiol 73:119–127. https://doi.org/10.1016/j.jclinepi.2015.08.036

7. Rothrock NE, Hays RD, Spritzer K, Yount SE, Riley W, Cella D (2010) Relative to the general US population, chronic diseases are associated with poorer health-related quality of life as measured by the patient-reported outcomes measurement information system (PROMIS). J Clin Epidemiol 63(11):1195–1204. https://doi.org/10.1016/j.jclinepi.2010.04.012

8. Kappelman MD, Long MD, Martin C, DeWalt DA, Kinneer PM, Chen W, Lewis JD, Sandler RS (2014) Evaluation of the patient-reported outcomes measurement information system in a large cohort of patients with inflammatory bowel diseases. Clin Gastroenterol Hepatol 12(8):1315–1323.e2. https://doi.org/10.1016/j.cgh.2013.10.019

9. Hoel AT, Toft L, Bjornland K, Gjone H, Teig CJ, Oresland T, Stenstrom P, Andersen MH (2021) Reaching adulthood with Hirschsprung’s disease: patient experiences and recommendations for transitional care. J Pediatr Surg 56(2):257–262. https://doi.org/10.1016/j.jpedsurg.2020.05.015

10. Neuendorf R, Harding A, Stello N, Hanes D, Wahbeh H (2016) Depression and anxiety in patients with inflammatory bowel disease: a systematic review. J Psychosom Res 87:70–80. https://doi.org/10.1016/j.jpsychires.2016.06.001

11. Drissi F, Meurette G, Baayen C, Wyart V, Cretolle C, Guinot A, Podevin G, Lehr PA (2019) Long-term outcome of Hirschsprung disease: impact on quality of life and social condition at adult age. Dis Colon Rectum 62(6):727–732. https://doi.org/10.1097/DCR.0000000000001363

12. WHO (2022) Mental health and COVID-19: early evidence of the pandemic’s impact

13. Grano C, Bucci S, Aminoff D, Lucidi F, Violani C (2014) Feelings of depression in people with ARM: the role of critical incidents and perceived difficulties in close and sexual relationships. Pediatr Surg Int 30(8):823–828. https://doi.org/10.1007/s00383-014-3532-8

14. Hasin DS, Sarvet AL, Meyers JL, Saha TD, Ruan WJ, Stohl M, Grant BF (2018) Epidemiology of adult DSM-5 major depressive disorder and its specifiers in the United States. JAMA Psychiat 75(4):336–346. https://doi.org/10.1001/jamapsychiatry.2017.4602

15. Ryan G, Vyrosteck S, Aminoff D, Booth K, Driesbach S, Fisher M, Gerberick J, Haanen M, Mullins C, Parker L, Schwarzner N (2020) Importance of education and the role of the patient and family in the care of anorectal malformations. Semin Pediatr Surg 29(6):150990. https://doi.org/10.1016/j.sempedsurg.2020.150990

16. Zhang JE, Wong FK, You LM, Zheng MC, Li Q, Zhang BY, Huang MR, Ye XM, Liang MJ, Liu JL (2013) Effects of enterostomal nurse telephone follow-up on postoperative adjustment of discharged colostomy patients. Cancer Nurs 36(6):419–428. https://doi.org/10.1097/NCC.0b013e318266c8eb