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ORIGINAL ARTICLE

A survey of adults with anorectal malformations: perspectives on educational, vocational, and psychosocial experiences

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Abstract

Purpose Despite medical advances, individuals with anorectal malformations (ARM) experience significant medical and psychosocial challenges due to their complex conditions. This study aimed to obtain the perspectives of adults with ARM throughout their lifetime regarding their medical, school/vocational, and psychosocial functioning.

Methods A 40-item survey was administered electronically to members of an international ARM Facebook group (56% response rate; $n = 125$). Survey items included demographics, medical diagnosis/treatment, school/workplace accommodations, mental health diagnosis/treatment, and life perspectives.

Results Majority of respondents were female (73%), aged 25–34 years (31%), Caucasian (92%), US residents (60%), and attended public school (86%). 53% of respondents are currently employed. 32% of respondents received school-based accommodations and 24% at work. 58% of respondents had a mental health diagnosis, with depression (82%) and anxiety (81%) being the most common.

Conclusions Results suggest that adults with ARM experience ongoing difficulties related to schooling, employment, and mental health, in addition to medical complications. It is becoming increasingly clear that improving patients' physical well-being is not enough; psychosocial concerns must also be addressed directly. Thus, it is important for clinicians to be aware of and partner with psychosocial providers to support these challenges associated with ARM, to maximize patients' overall health and well-being.

Keywords Anorectal malformations (ARM) · Adult patients · Fecal incontinence · Psychosocial functioning · Mental health · International survey

Introduction

Anorectal malformations (ARM) occur in approximately 3.09 of 10,000 births [1]. While surgical interventions have improved significantly in the last 30 years with the adoption of the posterior sagittal anorectoplasty (PSARP) [2], there is a high level of variability in the presence of fecal continence depending on the type of ARM, medical comorbidities, and success of the surgical repair [3]. Many patients require lifelong medical interventions including rectal enemas, use of daily laxatives, or other surgical interventions to maintain fecal continence. Specialized bowel management programs are becoming more popular as pediatric surgeons recognize the need for close follow-up with their patients [4].

It is well established that fecal incontinence has negative implications for overall quality of life [5], which includes educational, vocational, and broader psychosocial functioning. From an educational and vocational standpoint, there is limited information about how ARM directly impacts functioning. Mantoo and colleagues found that adult patients with ARM had higher rates of enrollment in higher education compared to the general population; however, they also preferred to participate in "low to mid level office jobs" despite having high educational qualifications that could

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lead to more advanced positions [6]. Respondents reportedly preferred to have sedentary jobs, that were less physically and mentally demanding compared to other positions. The authors, however, did not evaluate whether patients received any supports or accommodations within their educational or employment setting, which can have a positive impact on school and work performance.

With regards to psychosocial functioning, studies have noted that adults with ARM were statistically more likely than healthy controls to indicate that their bowel functioning negatively impacted their well-being, social life, and social mobility [7]. Similarly, Grano et al. noted that adults with ARM had lower quality of life within emotional functioning, body image, and physical symptoms in comparison to children with ARM (as rated by their parents) [8]. Few studies have documented rates of depression or anxiety in adults with ARMS. However, Grano and colleagues examined the relationship between fecal incontinence and depression in adults with ARM [9]. They found gender differences with regards to predictors of depression, whereby men who had higher rates of worries and concerns about social and sexual relationships were more likely to present with depression, whereas women who had higher rates of negative feelings about fecal incontinence were more likely to experience depression. Additional information about the frequency of mental health disorders within adults with ARM as well as their experience of therapy and psychotropic medication is needed.

The aim of the present study is to obtain the perspectives of adults with ARM throughout their lifetime in multiple domains, including their medical, school/vocational, and psychosocial functioning, using an online survey.

Methods

Survey and study participants

A 40-item survey was developed by the study authors to gather respondents' perspectives on demographics, medical diagnosis and treatment, school and workplace accommodations, mental health diagnosis and treatment, and other life challenges. Personal identifiers were not collected during the survey to preserve anonymity of respondents.

The survey was administered online using SurveyMonkey™ platform. An electronic link to the survey was distributed via a private social media support group called the "Adults Living with Imperforate Anus". An account administrator oversees the site and vets each new member for inclusion to the group. All members of this group are required to be 18 years old and above, and has been diagnosed with ARM. To date, there are approximately 125 active members globally. The authors contacted the account administrator prior to the study to obtain permission to recruit participants from the group. Once permission was granted, survey link was circulated to the members, and it remained active for 4 weeks (January–February 2019). Reminders soliciting participation were sent out regularly by the account administrator, although it was made clear that participation was completely voluntary.

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 (18–2744).

Data analyses

Quantitative data were analyzed using descriptive statistics (SAS version 9.4). Data were further stratified by country of residence or gender, and results showing differences in trends are reported below.

Results

Demographic profile of respondents

Seventy respondents participated in the survey contributing to a response rate of approximately 56%. Demographic information of the respondents is summarized in Table 1. In summary, the majority of respondents were female (73%), between the age range of 25–34 years (31%), identified as white/Caucasian (91%), and not of Hispanic/Latino ethic background (91%). Most respondents (60%) currently reside in the United States (US), although 11 other countries were represented (Table 1). Respondents indicated completion of different levels of education, with the top three levels being high school (27%), college (47%), and advanced degree (17%). They have also denoted various relationship status with 44% being currently married, 31% being single and never married, and the remaining 25% in other types of relationships (Table 1). Further, 63% of respondents indicated that they do not have children, while 27% mentioned they have biological children.

Medical diagnosis and bowel management

More than half of respondents (59%) learned about their medical condition before 2 years of age, and 57% had one to five surgeries for their condition. Diagnoses for anorectal malformation ranged from recto-perineal fistula, recto-vestibular fistula, recto-bladder neck fistula, cloaca, imperforate anus without fistula, or recto-vaginal fistula, among others. Interestingly, a small percentage of respondents (15%) indicated they did not know what type of anorectal malformation they have. In terms of bowel management strategies being

Table 1 Demographic profile of survey respondents, including medical diagnosis and bowel management ($n = 70$)

Characteristics	*n* (%)
Gender	
Female	51 (73)
Male	18 (26)
Transgender	1 (1)
Age (in years)	
18–24	8 (11)
25–34	22 (31)
35–44	16 (23)
45–54	11 (16)
55–64	10 (14)
65–74	1 (1)
75 or older	2 (3)
Race	
White or Caucasian	64 (91)
Black or African American	1 (1)
Asian	2 (3)
Other (respondents specified the following: mixed race, Latin American)	3 (4)
Ethnicity	
Hispanic or Latino	3 (4)
Not Hispanic or Latino	63 (91)
Prefer not to answer	3 (4)
Country of residence	
United States	42 (60)
Other country (respondents specified the following: Canada, Australia, Brazil, Ireland, France, Chile, United Kingdom, Hungary, Germany, Scotland, and Philippines)	28 (40)
Highest level of education completed	
Elementary/middle school	1 (1)
High school	19 (27)
College	33 (47)
Advanced degree	12 (17)
Prefer not to answer	1 (1)
Other	4 (6)
Current relationship status	
Married	31 (44)
Widowed	2 (3)
Separated/divorce	7 (10)
In a domestic partnership or civil union	5 (7)
Single, but cohabiting with a significant other	3 (4)
Single, never married	22 (31)
Parenting status (select all that apply)	
Have biological children	19 (27)
Have adopted children	6 (9)
Partner has children	6 (9)
Do not have children	44 (63)
Other (respondent specified as "through IVF technology")	1 (1)
Age when first learned about medical condition	
Younger than 2 years of age	40 (59)
3–5 years old	16 (24)
6–10 years old	8 (12)
11–17 years old	2 (3)
Older than 18 years	2 (3)

Table 1 (continued)

Characteristics	*n* (%)
Type of ARM (select all that apply)	
Recto-perineal fistula	1 (1)
Rector-vestibular fistula	6 (9)
Recto-urethral bulbar fistula	0 (0)
Recto-urethral prostatic fistula	0 (0)
Recto-bladder neck fistula	1 (1)
Cloaca	13 (19)
Imperforate anus without fistula	32 (46)
Do not know the type	10 (15)
Other (examples of responses include: recto-vaginal fistula, imperforate anus with fistula)	19 (28)
Number of colorectal/urogenital surgeries experienced	
None	2 (3)
1–5	39 (57)
6–10	11 (16)
11–15	7 (10)
More than 16	10 (15)
Type of bowel treatment being currently used (select all that apply)	
Enema	16 (23)
Laxative	18 (26)
None	22 (32)
Other (examples of responses include: Imodium, Peristeen system, diet, colostomy)	29 (42)

used in daily living, respondents identified using either one of these approaches or as a combination: laxative (26%), enema (23%), and other approaches (e.g., anti-diarrheal medication, colostomy, fiber supplements, and managing diet). However, 32% of respondents indicated that they did not use any bowel management approaches. More details about these outcomes are detailed in Table 1.

Living experiences related to attending school

A large proportion of respondents indicated that they had attended public school (87%), while others attended private school (32%), being home-schooled (6%), and/or online schooling (3%). Among these respondents, only 32% indicated that they received support from their schools to accommodate their medical condition. The most common support provided was unlimited access to the bathroom (91%), access to clean clothing (59%), and visits to the nurse's office whenever needed (50%). On the other hand, among the 68% of respondents who indicated they did not receive any support from their respective schools, 45% mentioned that such support was not available or that they were unclear of availability (45%). Overall, all these trends did not differ when data were stratified by gender.

It is interesting to note that when the data were stratified by country of residence (i.e., the US vs. other countries), trends related to receiving support from their respective schools were the same, whereby the percentage of those who received support was significantly smaller than those who did not receive any. However, a larger proportion of respondents in US noted that they were not aware of the availability of school supports (62%), in comparison to those who reported that the school did not provide any support (31%). On the other hand, a higher percentage of respondents from other countries mentioned that the school did not provide support (62%), rather than they were being unclear about availability of support (24%). Table 2 summarizes the above outcomes in more detail.

Living experiences related to the workplace setting

Half of total respondents (54%) indicated that they are currently employed, with 78% of them holding full-time employment. Among those who mentioned that they are currently not employed, 81% indicated that they had previously worked full time, part time (53%), and/or never held any employment (3%). 43% of respondents indicated that their current employment/unemployment status was related to their medical condition, while 51% did not. Only 24% of respondents denoted that they received support from their workplace for their medical condition. The top three forms of support included unlimited access to the bathroom (69%), taking rest period whenever needed (38%), and being given additional sick days (31%). Other accommodations that were mentioned included having supportive managers, and being allowed to work from home. Among 76% of respondents

Table 2 Respondents' school and vocational experiences ($n=69$)

Characteristics	*n* (%)
Type of school attended (select all the apply)	
Public school	60 (87)
Private school	22 (32)
Online schooling	2 (3)
Home schooling	4 (6)
Other	0 (0)
"Did you receive any school-based accommodations for your condition?"	
Yes	22 (32)
No	47 (68)
Accommodations received at school (select all that apply)	
Unlimited access to the bathroom	20 (91)
Unlimited access to the school nurse	11 (50)
Access to extra clothing	13 (59)
Access to water	6 (27)
Other (examples of responses include: extra time to get to class, missed classwork sent to home)	7 (32)
"Were accommodations available at your school?"	
Yes	5 (11)
No	21 (45)
I do not know	21 (45)
"Are you currently employed?"	
Yes	37 (54)
No	32 (46)
"Have you ever been employed?" (select all that apply)	
Yes, full time	26 (81)
Yes, part time	17 (53)
Never been employed	1 (3)
"Do you feel that your current employment or unemployment is related to your colorectal condition?"	
Yes	29 (43)
No	34 (51)
I do not know	4 (6)
"Have you ever received accommodations within a work setting?"	
Yes	16 (24)
No	51 (76)
Accommodations received at the workplace (select all that apply)	
Unlimited access to the bathroom	11 (69)
Availability of water or food	3 (19)
Breaks as needed	6 (38)
Additional sick days	5 (31)
Private office or space	0 (0)
Physically accessible space	2 (13)
Other (examples of responses include: ability to work from home or return home as needed, flexible hours)	8 (50)
"Were accommodations available at your workplace?"	
Yes	8 (16)
No	22 (43)
I do not know	21 (41)

who did not receive any support at their workplace, 43% noted that such support was not available and 41% indicated they did not know whether any support was available. Collectively, the trends listed above were preserved when data were stratified by gender.

When data were stratified by country of residence, there were a larger proportion of respondents in the US who

identified as employed than unemployed (61% and 39%, respectively). This trend is reversed in respondents from other countries (43% employed and 57% unemployed). Similarly to trends observed for respondents' knowledge about the availability of school-based support, there were a larger proportion of respondents in the US who were unclear about the availability of support (48%) than those who indicated that support was not available (29%). This trend is also reversed in respondents from other countries, whereby 30% did not know if support was available at their workplace and 65% indicated support was not available. The above results are further outlined in Table 2.

Mental health concerns

More than half of respondents (58%) had received a mental health diagnosis, with the top three most common diagnoses being depression (87%), anxiety (85%), and post-traumatic stress disorder (PTSD; 46%). 52% of respondents had taken medication to address their mental health concerns. Considering these diagnoses, it was unsurprising that antidepressants were most commonly prescribed (89%), followed by anti-anxiety medications (66%). Other psychotropic medications mentioned included mood stabilizer (14%), stimulant (3%), as well as anti-psychotics (17%). Overall, the proportion of female respondents who received medications was higher than male (55% to 41%). Further, 67% of respondents indicated they had participated in counseling or therapy, with talk therapy and cognitive behavioral therapy (CBT) being the most common approach (82% and 51%, respectively). On a 5-Likert scale ranging from "1 = not useful at all" to "5 = very useful", respondents indicated usefulness of counseling or therapy at 3.6 and medication at 3.1 (as weighted average).

When data analysis was stratified by country of residence, the only trend that differed was related to prescription of medications. In the US, 59% of respondents received medications and 41% did not. However, the trend was reversed for respondents from other countries, whereby there were a higher proportion of those who did not receive medication than those who did (57% and 43%, respectively). Females residing in the US were also more likely to be treated with medications than those living in other countries (37% and 18%, respectively). Table 3 summarizes survey results as related to mental health functioning.

Discussion

This survey gathered a broad range of information from adults living with ARM regarding their lifetime experiences coping with their condition. Respondents were primarily from the US, followed by Australia and the United Kingdom, but there were respondents from Europe, North and South America, and Asia as well. Despite their country of residence, their experiences generally mirror each other with regards to their medical backgrounds, schooling and employment, and psychosocial concerns, which are discussed in detail below.

In terms of medical diagnosis, nearly half the number of respondents (46%) indicated that they had been diagnosed with imperforate anus without fistula, which is quite notable, given that this is a rare type of ARM, typically only seen in roughly 5% of all cases globally [10]. Similarly, 8% of the female respondents indicated that they had rectovaginal fistulas, which are incredibly rare in incidence (1% of females) [11]. In addition, 15% of respondents indicated that they were unaware of their diagnosis. Taken together, these observations indicate that adults with ARM may not necessarily be well informed about their medical condition. Given the dearth of medical providers familiar with ARM, it is critical that patients are accurately informed about their medical conditions so that they can advocate appropriately for themselves. In addition, patients are encouraged to obtain copies of their operative reports, which can provide future providers with important surgical history. It would also be helpful for patients to have a "health passport" or some type of documentation that outlines their medical diagnoses, surgeries, and other relevant health information. A recent study conducted by Heifetz and Lunsky showed that having such documentation was helpful to facilitate effective communication for adult patients with intellectual disabilities in the emergency department [12]. Health passports have also been recommended for use with young adults with chronic heart disease to ease their transition from pediatric to adult care [13].

While the majority of respondents attended public school for at least part of their formal education, less than one-third of them reported that they had received school-based accommodations. In the US, there are two laws that provide supports for people with disabilities: the American with Disabilities Act [14] and the Individuals with Disability Education Act [15]. Under the ADA and IDEA, students who have a physical or mental condition that negatively impacts one or more major life activity who attend public schools are eligible for accommodations [14, 15]. Students with ARM would typically meet this criteria since the condition impacts their fecal continence, and consequently may impair their daily living activities. Similarly, within Australia and the United Kingdom, "reasonable accommodations" are available for students with disabilities [16, 17]. Thus, it is surprising that rates of school-based accommodations are relatively low. One factor that could contribute to this lack of formal educational support is the respondent's country of residence. It is possible that countries other than the US, Australia, and the United Kingdom do not provide similar level of supports

Table 3 Respondents' mental health functioning ($n=67$)

Characteristics	*n* (%)
"Have you ever received a mental health diagnosis?"	
Yes	38 (58)
No	28 (42)
Current or previous diagnosis (select all that apply)	
Depression	34 (87)
Anxiety	33 (85)
Post-traumatic stress disorder (PTSD)	18 (46)
Adjustment disorder	1 (3)
Attention-deficit hyperactivity disorder (ADHD)	2 (5)
Obsessive compulsive disorder (OCD)	4 (10)
Other (examples of responses include: body dysmorphia, psychotic episodes without hallucinations, borderline personality disorder, bipolar disorder)	11 (28)
"Have you ever taken medication to address a mental health concern?"	
Yes	35 (52)
No	32 (48)
Type(s) of psychiatric medication taken (select all that apply)	
Anti-depressant	31 (89)
Anti-anxiety	23 (66)
Mood stabilizer	5 (14)
Stimulant	1 (3)
Other (respondents specified the following: anti-psychotic, tranquilizer)	6 (17)
"Have you ever participated in counseling/therapy?"	
Yes	45 (67)
No	22 (33)
Type(s) of counseling/therapy received (select all that apply)	
Cognitive-behavioral therapy (CBT)	23 (51)
Psychodynamic	6 (13)
Talk therapy	37 (82)
I do not know	4 (9)
Other (examples of responses include: group therapy, eye movement desensitization and reprocessing (EMDR) therapy, dialectical behavior therapy (DBT), hypnotherapy)	9 (20)

for students with chronic illnesses. In addition, it is possible that these supports were not available at the time of the respondents' schooling, given the age range of respondents.

Other differences that were observed regarding survey respondents' educational experience were related to availability of school-based accommodations. Within the US, nearly two-thirds of respondents noted that they were unaware of whether accommodations were available and one-third noted that these accommodations were not available. On the other hand, this trend was reversed for respondents not residing in the US. While it is challenging to explain the true reason for these differences, it could be surmised that respondents outside of the US may have had more experiences in which they were explicitly told that they could not receive support or accommodations for their medical concerns due to unavailability of these supports or lack of formal policy that advocates for their condition.

The majority of respondents have engaged in part-time or full-time work at some point in their careers, however, less than one-quarter of them received support within their workplace for their medical condition. While formal supports may vary by country, the United Nations' Convention on the Rights of Persons with Disabilities (CRPD) was adopted in 2006, which includes recommendations that "state parties shall…ensure that reasonable accommodation is provided to persons with disabilities in the workplace" (Article 27) [18]. Persons with disabilities include those who have "long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others" (Article 1) [18], thus adults with ARM would be eligible for these supports. Consistent with educational accommodations, it is surprising that more adults have not received accommodations within their workplace. In addition, it is notable that half of the respondents felt that their current employment status was not impacted by their ARM, given other studies have shown that a high percentage (64%) of adults with

ARM indicated that their career choice was influenced by ARM [6].

Another consideration that could impact students and employees receiving accommodations for their medical condition is related to medical disclosure (i.e., the amount of information that an individual feels comfortable disclosing within their academic or work setting). In most schools or work environments, accommodations are typically provided only with formal documentation from a medical professional that explicitly outlines the medical condition and recommended supports. Individuals may be concerned about the level of stigma associated with their medical condition (e.g., fecal incontinence), which may negatively influence their willingness to disclose personal information. In a qualitative study of adolescents in Canada having various disabilities, Lindsay et al. [19] found that there were several discouraging factors to share medical information with others including "a fear of stigma and discrimination, lack of employer's knowledge of disabilities and accommodations, negative past experiences of disclosing and not disclosing on your own terms". While the study did not clarify whether participants had difficulties with fecal incontinence, the themes discussed are relevant for adults with ARM. More so, this indicates an area that should be studied further in individuals with ARM since studies on the impact of disclosure within school and vocational settings for this population are limited thus far.

Adults with ARM were also asked in the survey about their mental health experiences. Overall, survey respondents reported high levels of depression and anxiety (52% and 50%, respectively). These rates are significantly higher than the global rates, which was reportedly 4.4% with depression and 3.6% with anxiety in 2015 [20]. In addition, endorsement of post-traumatic stress disorder (PTSD) was also relatively common, as nearly half of respondents noted that they had been diagnosed with PTSD currently or in the past. While the survey did not ask respondents to define incidences that led to PTSD symptoms, it is reasonable to consider that adults with ARM may have higher rates of medical trauma than the general public given the necessity of invasive medical procedures and cares, as studies have found that patients are at elevated risk for future trauma symptoms following surgery [21]. In addition, these numbers may be an underestimate given that the phrase "mental health diagnosis" was used in the survey to frame the question. It is possible that respondents could have experienced mental health concerns (e.g., depression, anxiety, PTSD) without being formally diagnosed. Although most respondents that endorsed mental health concerns mentioned that they had participated in therapy/counseling and/or taken medication, it is interesting to note that there were not any gender differences in counseling/therapy, but these were present in use of psychotropic medication. Similarly, differences by country were found for medication use, but not for engagement in therapy/counseling. It is possible that this reflects a greater stigma for psychotropic medication outside of the US or decreased availability of effective provisions of psychiatric medication outside of the US.

Collectively, while school-based and vocational supports may differ by country, there is clearly a need for additional education for patients and their families about the educational and vocational supports that are available to them. The creation of a universal guideline for school-based and vocational supports for patients with ARM is certainly warranted and would ideally be adapted to the local and national educational and employment laws within individual countries. These survey results also clearly demonstrate that adults with ARM have higher rates of depression, anxiety, and trauma than the public. Thus, it is critically important for mental health screening to be part of standard practice during bowel management programs as well as within regular clinic visits. In addition, the inclusion of psychologists and social workers with expertise in treating patients with chronic illness, ideally ARM, are necessary. Finally, it is vital that patients are able to identify and work with mental health clinicians within their communities, who have knowledge of how to support patients with co-morbid psychiatric and medical concerns. Formal mental health guidelines for patients with ARM are also warranted.

This study presented several limitations, which should be considered. First, the results of the survey were based on voluntary participation via an online support group of adults with ARM and may not be representative of larger adult population with ARM. It is also possible that adults who participate in an online support group are having more difficulty with their management of ARM, which leads them to seek out this support group, than adults who have bowel control and good quality of life (i.e., selection bias). In addition, since the majority of respondents were from the US, this may further limit generalizability of the observations.

Conclusion

Key findings of this study suggest that adults with ARM experience ongoing difficulties in multiple domains including knowledge of their medical condition, schooling and employment, as well as mental health. It is becoming increasingly clear that improving patients' physical well-being is not enough and psychosocial concerns must also be directly addressed. Thus, it is important for medical and surgical providers to be aware of these additional challenges associated with ARM, and collaborate with psychosocial providers to maximize patients' overall health and well-being through the provision of education and support to

promote resilience with pediatric patients with ARM and their families.

All the procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee (Colorado Multiple Institutional Review Board, 18–2744) and with the 1964 Helsinki Declaration and its later amendments or comparable ethical standards.

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