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Original Research Article

Pediatric Irritable Bowel Syndrome: Perspectives on Pain and Adolescent Social Functioning

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Abstract

Objective. The goal of the study was to describe the experiences of adolescents with irritable bowel syndrome (IBS) from the perspective of adolescents, their parents, and health care providers who treat adolescents who have IBS.

Design. The study consisted of semistructured interviews.

Setting. Participants were recruited from multidisciplinary pain clinics.

Subjects. Thirty-six people participated in the study: 12 adolescents, 12 parents, and 12 health care providers.

Results. Two main themes associated with the impact of IBS on adolescents' social functioning emerged from the qualitative interview data: 1) disconnection from peers and 2) strain on family relationships, with subthemes reflecting the perspectives of adolescents, parents, and health care providers.

Conclusions. Participants in our study described that adolescents with IBS encounter significant peer- and family-related social stress. Helpful interventions may be those that focus on social support from other adolescents with similar conditions, as well as family-based therapeutic interventions.

Key Words. Pain; Complementary Therapies; Irritable Bowel Syndrome; Adolescents

Introduction

Irritable bowel syndrome (IBS) is a common condition that affects 23% of adolescents in North America [1] and has profound effects on adolescents' quality of life [2,3]. A complex, chronic, functional disorder, IBS is characterized by abdominal pain or discomfort and altered bowel habits; other symptoms may include nausea, vomiting, and bloating [4].

IBS takes a significant toll on all areas of functioning [3], but during adolescence challenges to social functioning can be particularly distressing. By early adolescence, teens spend more time with peers than with siblings or parents [5], and being accepted by peers becomes increasingly important to adolescents' social development [6]. IBS-related symptoms cause embarrassment, shame, and isolation, with fear of pain, bloating, and/or diarrhea negatively impacting adolescents' social lives with friends, severely limiting willingness to attend school and social outings [7]. Unfortunately, adolescents with chronic pain, including those with IBS, report poor

social functioning, fewer friends, and more peer victimization and isolation compared with children without chronic pain [8,9]. For example, compared with peers, children with frequent abdominal pain reported being subjected to more overt and relational victimization than healthy peers, with victimization contributing to the link between pain and school-related functioning [11]. Compared with healthy children, adolescents with IBS also report significantly higher functional and academic impairment, including more missed school days, days sick in bed/too ill to play, and days needing someone to care for them, factors that may collectively further impair social functioning [3].

Family functioning is also significantly impacted by pediatric pain [3]. An important developmental outcome of adolescence is becoming independent from parents. However, achieving balance between parental involvement and autonomy is a challenging albeit critical issue for adolescents with chronic pain [12]. For example, Lewandowski and Palermo (2009) found that lower levels of adolescent autonomy and higher levels of family conflict and poorer family functioning were associated with higher levels of depression among adolescents with chronic pain [13]. In addition, many parents of children and adolescents with chronic pain experience anxiety and depressive symptoms and parental role stress [14,15].

Given the complex challenges experienced by adolescents with IBS and their families, qualitative assessment methods may help increase understanding of these families' lived experiences. To our knowledge, no such qualitative studies have been conducted with an IBS-specific adolescent sample. Qualitative data can help to inform patient-centered interventions that aim to increase functioning, coping, and quality of life in adolescents with IBS. To this end, we interviewed adolescents, their parents, and providers who treat adolescents who have IBS.

Method

Design

This study consisted of semistructured interviews. Our overall qualitative approach was deductive, informed by social cognitive theory [16], which emphasizes the importance of self-efficacy for managing health conditions. As such, both the interview guides and codebooks were structured based on the theory. This approach was chosen in contrast to an inductive approach, which aims to inductively generate bottom-up theory to describe and explain a phenomenon. The interviews were conducted as a part of a larger study focusing on the development and testing of a mobile app-based psychosocial intervention.

Participants

Adolescents who were 13–17 years old and had a parent-reported, physician-based diagnosis of IBS were

eligible to participate. Inclusion criteria for parents were having an adolescent who was enrolled in the study and being fluent in English. The inclusion criterion for health care providers was having at least five years' experience treating adolescents who have IBS. To learn from a range of participants, we purposefully sampled adolescents to represent both genders and a range of ages. Health care providers were purposefully recruited to represent the range of treatment approaches offered to adolescent patients at the recruitment site clinics, (e.g., pediatric gastroenterology, clinical psychology). Research psychologists specializing in pediatric pain were also interviewed because of their expertise.

Recruitment

Adolescents and their parents were recruited from two outpatient chronic pain clinics. Author Lonnie K. Zeltzer is Director of both programs. During the clinic appointment, a research team member presented the family with a flyer and a brief description of the study; interested potential participants gave permission for a research team member (not LKZ) to call them later to do an eligibility screening over the phone. Interview times were scheduled for participants who met inclusion criteria and represented both younger (<15) and older teens and both genders (at least two males). Adolescent and parent participants provided written assent and consent prior to beginning study procedures. Author LKZ emailed study invitations to providers, and interested providers were contacted by research personnel. Providers gave oral consent over the phone prior to beginning study procedures.

Procedure

Two female research team members with qualitative research experience conducted the interviews. Both of the interviewers were familiar with the study population due to their professional roles; however, no interviewer and interviewee had a prior relationship. Patient and parent interviews were conducted in person (at the research study's hospital-based offices) or by phone, and health care provider interviews were conducted by phone. All interviews lasted between 30 and 60 minutes. Interviewees were offered \$25 (adolescents), \$50 (parents), or \$150 (providers) as compensation for participating in the larger study. The research team continued to collect interview data until 12 adolescents, 12 parents, and 12 providers had been interviewed. This coincided with when the team reached consensus regarding thematic saturation. All interviews were audiorecorded, transcribed verbatim, and de-identified for analysis. Interviews were conducted from July 2015 to January 2016.

Development of Interview Guides

We developed three semistructured interview guides to allow for in-depth exploration of challenges experienced by adolescents with IBS: one was created for adolescents,

one for parents, and one for health care providers. The purpose of the interviews was to explore adolescents' self-efficacy for managing IBS and its effect on social functioning. Thus, the (all three) interview guides were informed by the social cognitive approach [16], which maintains that an individual's confidence in his/her ability to manage and cope with pain (i.e., self-efficacy) is associated with engaging in adaptive health behaviors (e.g., spending time with friends despite pain). Specific questions and probes were informed by the Functioning Despite Pain Scale [17] and the Pain Coping Questionnaire [18] to help elicit insights surrounding a range of potential functioning issues (e.g., making it through a day of school and being with friends) and coping strategies (e.g., distraction, seeking social support). The main topics in the interview guides were Impact of IBS and Coping with IBS. Examples of questions are "What do you do to help you relax when you experience stress or you're having a hard time?" and "Who do you turn to for help when you are in pain?" (adolescent interview guide); "Could you start by telling me a bit about what life is like for your family?" and "How difficult or easy is it to communicate with your child about IBS symptoms?" (parent interview guide); and "When it comes to adolescents' social lives, what are the areas where you see them struggling?" and "Who do adolescents seem to seek out for support?" (provider interview guide). We also asked about use of technology as the interviews informed a larger study centering on the development and testing of a mobile app-based intervention. First drafts of the semistructured interview guides were created by author Elizabeth Donovan and were revised with significant input from the research team. Throughout data collection, the research team met to discuss the interview responses, and additional questions or probes were added to the interview guides based on team consensus. After four parent interviews, questions and probes were added to ensure we were collecting adequate information about potential parent coping styles to inform the psychosocial intervention. To facilitate comparison of multiple perspectives on the same topics, the parent and provider interview guides mirrored the patient interview guide, except that parents and providers were asked to share their beliefs about adolescents' functioning. Interview guides are available on request.

Data Analysis

We used deductive coding, informed by the preexisting research that informed the larger interview guide [16–18]. As such, author ED created an initial coding structure based on the interview guide. Coding of interview transcripts was completed in duplicate by three research team members trained in qualitative analysis; discrepancies were resolved with discussion. We chose this approach because attending to the effect of the researcher's frame of understanding on their interpretation of the data presents an opportunity to strengthen the study. Incorporating multiple researcher perspectives at this stage—taking into consideration different ways of approaching the same subject—can result in

an increased understanding of complex phenomena [19]. Coded interview transcripts were entered into NVivo software (version 10). Two members of the team independently reviewed data associated with each code and met weekly to discuss emerging themes each had independently identified, ending the discussion when three to five themes were agreed upon. Themes were entered into an Excel sheet, noting supporting quotes and exceptions to the themes. The study was approved by the University California, Los Angeles, Institutional Review Board.

Results

Characteristics of Participants

In total, 36 participants were interviewed. Fifteen potential parent-child dyads were screened for eligibility (telephone screens were conducted with the parent). All screened dyads were eligible at the time of screening. Twelve dyads participated; the remaining three dyads did not participate for the following reasons: One adolescent turned 18 before they were able to participate, making them no longer eligible. Two families did not respond to phone calls after the initial screening. Adolescents (N = 12) ranged in age from 13 to 16 years (mean = 14.9 years, SD = 1.2 years, 83% female). All adolescents reported a diagnosis of IBS. The average time since diagnosis was 34.7 months, ranging from eight months to 96 months (eight years). All 12 parent participants were mothers. Of the 12 providers, 75% (N = 9) were female. Provider specialties included pediatric gastroenterology (N = 3), research in pediatric pain (N = 2), clinical psychology (N = 2), functional nutrition (N = 1), and complementary and alternative medicine (hypnotherapy, lyengar yoga, acupuncture, and physical/aqua therapy, N = 4).

We identified two main themes associated with the impact of IBS on adolescents' social functioning, with sub-themes reflecting the perspectives of adolescents, parents, and health care providers (Table 1). The two main themes were 1) disconnection from peers and 2) strain on family relationships.

Main Theme 1: Disconnection from Peers

Adolescents, parents, and providers all described the challenge that adolescents face as they learn to manage a chronic health condition. All three groups emphasized the difficulty of managing IBS during adolescence, when fitting in with peers is so central to adolescent development.

Adolescents

Adolescents overwhelmingly described struggling to fit in with their peers and finding it difficult to communicate about their health needs. Health-related absences from

Table 1 Summary of themes and subthemes

Theme	Subtheme
Disconnection from peers	
Adolescents	Trying to fit in Adolescents with similar health conditions understand
Parents	Pain of seeing a child left behind Helplessness
Providers	Communication challenges Cycle of isolation
Strain on family relationships	
Adolescents	Comfort of Mom Relying on family for practical assistance
Parents	All-consuming Mom role Family assumes responsibility for managing pain Uncertainty associated with IBS puts pressure on family relationships
Providers	Separation challenges for the adolescent with IBS Importance of treating the whole family

IBS = irritable bowel syndrome.

school added to this stress. Adolescents also described deriving great comfort from talking with other adolescents with similar health conditions.

Subtheme 1: Trying to Fit in. Many adolescents described daily encounters that left them feeling alone. For example, one adolescent described feeling awkward about being unable to fully participate in normal social activities:

Sometimes it does, yeah. A lot of times, my friends, they eat a lot of ice cream or whatever, and I'm like, "No I can't have ice cream," so I just sit there and they'll just eat the ice cream and I just won't eat it and then they'll all feel bad and I'm like, "No, just eat it," because I know I can't eat it, and then I'll feel bad that they all feel bad because I just can't eat it. (PA-03)

Another adolescent expressed that she sometimes felt that she was being judged by other adolescents but felt unable to communicate about her experience:

It was really hard, because there would be some days where I just couldn't even make it through the day at school. Then I'd end up feeling better by the end of the day, so I'd go to soccer practice or something. Then, if I'd see a friend there who goes

to school with me, they'd be like, "Hey. Why weren't you at school today and you're here now?" It was really hard to explain to other people. That was probably the biggest difficulty. (PA-10)

Managing symptoms associated with IBS caused many of the adolescents in our study to be absent from school. From the adolescents' perspective, the most significant consequence of missing school was missing out on social engagement with friends, as described by one adolescent:

Well, my teachers were really accepting. They took it easy on me for that amount of time. The actual academics wasn't very.... That wasn't a problem. Missing so much school really left me out of a lot of things that were going on at that time. The absence from social situations left me behind in a lot of cases. (PA-10)

Some adolescents described that social and peer-related challenges simply added to their already stressful social lives:

I think that I was already...I'm a natural kind of anxious person, and so having obviously friend drama and social stuff be added to that was just another stress for me to have to make the symptoms worse. (PA-08)

Subtheme 2: Adolescents with Similar Health Conditions Understand. Perhaps because of the stress associated with these challenging daily encounters, many adolescents described a special bond with other adolescents experiencing similar health conditions. One adolescent described her excitement at finding support:

My mom found some web support group stuff. I've made some great friends that have a lot more stuff than I do. They are online. We started emailing first. After we emailed for several months, we finally met in person. We actually have a lot more common that we thought or know, so she actually has a plethora of medical issues, but she's probably one of the closest people I've ever met. (PA-04)

Parents

Parents described being acutely aware of the challenges their children faced while trying to fit in with peers. For many, this was a painful experience, leaving some parents feeling helpless.

Subtheme 1: Pain of Seeing a Child Left Behind. One parent described the disappointment of seeing her child unable to accept an invitation to join a highly selective arts program:

Especially for a kid where it's such a social environment with kids who are performing, and then she

sees this one now got this audition and now she's in a musical group, and this one's doing plays, and this one's doing...and she sees all her friends living this life and living their dreams, and she's basically in her house almost all the time unless we're going to doctors. I try to do things with her, but there is no part of her life that is not touched by this, that's not affected by this, and it's unfortunate. (PA-02)

Other parents described the difficulty of seeing their child's friends drift away. This was particularly true for parents of adolescents who were homeschooled due to disability, as described by one mother:

She still had a couple of friends, and they would invite her for a sleepover and to the movies, and I'd have to bring her wheelchair and show the parent how to fold it and take it. We were super grateful, but of course after a couple of times of doing that... We were grateful that she was going, so after a couple of times of doing that they are not interested anymore because now they are in middle school and they are with a friend in a wheelchair and it's too much work and she can't play volleyball. Over the course of the past five years, she has lost all her friends. She doesn't have a friend network. (PA-05).

Subtheme 2: Helplessness. Many parents described feeling helpless as they saw the impact of their child's IBS symptoms on their social life. One parent described her fears for the future:

I just fear that because she's so unreliable because of [her IBS symptoms], not now, but eventually people are going to... I'm at a point where I'm like, "I'm so sick of it myself." I'm always in fear that at some point her friends are just going to be like, "I'm not going to ask her because who knows if she'll come or not?" Because, like, she had a birthday party I had to cancel in the eleventh hour the other day because she was sick. (PA-07)

Providers

Consistent with the experiences of adolescents and parents, most providers described a cycle of isolation that they had become accustomed to hearing about from their patients.

Subtheme 1: Communicating Challenges. A theme among providers was adolescents' difficulty communicating in general, and in particular about health problems. One provider described her impressions:

They feel like outsiders. They don't want to talk about their problems with their friends, because their friends, if you can't see it, a lot of the teenagers, adolescents don't want to hear about it.

They're not into it. They're dismissive of it. That's definitely a problem. (P-05)

Subtheme 2: Cycle of Isolation. Almost all the providers described a cycle of isolation that they believed centered on adolescents' embarrassment of their symptoms, which led them to withdraw from peers, which in turn caused them to miss out on social events and feel further socially isolated. One provider described how bathroom noises and smells are a cause of acute embarrassment for adolescents in the school setting:

They have to hurry up, and they're worried that they're going to miss class. An awful lot of the restrooms in the public schools have some lack of privacy, and that could be because the way they put the doors on, they've got this little space, and you can see through the space. Then some of them don't even have doors. Kids have vandalized them, or the door has broken. Then another issue is the door doesn't have a latch, so they're anxious because somebody could come in on them. They may also be anxious about using a public restroom at all, because of sounds or noise or smell. Even if they had the time, they don't want to be in a public arena, because what might somebody hear or say or smell. (P-02)

Another provider described that, over time, adolescents begin to withdraw:

I hear that they're not interacting with their friends the way they used to, or they've lost a lot of friends because they're not able to attend to their social commitments. They've dropped out of ballet, debates, football, or whatever, and so they're not running in the same crowds. They've missed a lot of school or they're home schooled, and they fill the sick role. When they do that, they tend to get marginalized, so they don't have the same interactions that they used to with their peers. (P-03)

Main Theme 2: Strain on Family Relationships

The common thread among adolescent, parent, and provider descriptions of family life was that IBS affects the whole family. All three groups described both the ways that family members support the adolescent with IBS and the strain that managing IBS puts on relationships within the family.

Adolescents

Subtheme 1: Comfort of Mom. In contrast to the challenges adolescents described experiencing with their peers, overwhelmingly, adolescents expressed the importance of the support and comfort they received specifically from their mothers. One adolescent described the ease with which she could communicate with her mother about her health:

She understands how I communicate about my pain. She knows how to decrypt the code basically, and it's really easy to talk to her. She makes it so easy. I feel like having great listeners is something that's important when you have pain, somebody who just will listen to you because sometimes you don't want somebody to say, "It's just going to be great. It's going to get better," because that can be a little irritating. If somebody just listens to you, and is like, "Is there anything I can do to help? Is there something I can get for you? Do you want to just watch a movie?" They're not telling you how you're going to fix it; they're just supporting you. That's better. For me, she does that really, really well. (PA-02)

Another adolescent described how her mother helped her to regulate her emotions:

She'll remind me, "You had this before. You just kind of have to push through it," or she'll help me not be angry. Usually when I'm in pain, I get kind of angry, so I'll kind of lash out at her. So she usually deals with it pretty well. She won't yell back at me, which kind of helps me calm down. (PA-05)

As an exception to this theme, a few adolescents described difficulty communicating about symptoms of IBS with their parents, fearing an overreaction. For example, one adolescent described communicating with his parents about his pain:

Sometimes if I'm just watching TV or whatever, I won't mention it. But if it's [related to] school or something, I'll casually try to mention it and try to relax for a little bit before they have a panic attack... It used to bother me seeing how it stressed out my mom, but I got over it. I just got over it eventually. Yeah, and it's a little bit like, "Seriously you're the one stressed out? You're not even doing all the homework or anything," so it's like, "Settle, settle, I got this." (PA-06)

Subtheme 2: Relying on Family for Practical Assistance. Many adolescents described how the family responds when the adolescent is not feeling well:

If I'm in really bad pain, my dad won't have me do any other chores or whatever, and tell me just relax, have my siblings do it. And my siblings understand too, and they'll help me, if I'm sick or something like that, they'll help me with making me food or something like that, or get me blankets if I'm really cold or something like that. It really helps. They're all pretty helpful. (PA-03)

And,

Well, they'll get me things. If I'm like, "Can you grab the heating pad from the closet?" Or, "Can you go ask mom to get the pill?" My younger sister has usually been in the same schools as me. She's

in middle school, and I'm in middle school, so she can grab my schoolwork for me. (PA-05)

Parents

Subtheme 1: All-Consuming Mom Role. Like the adolescents in the study, most mothers described a close parent-child relationship. Mothers also detailed the pressure resulting from the intense bond. One mother described the stress associated with the exclusive nature of the relationship:

It's like, okay, we're trying to get her to go to sleep but she can't go to sleep. So I stay up with her until maybe 1 or 2; it's, she goes, "This is our late night. Mom and I stay up, and we watch TV and it's our time together." We have certain shows that she'll watch and then she'll delete them so nobody else can watch them because it is only our show. And they go, "What happened to that one, it comes on and then it's gone and we can't watch it." She goes, "Too bad. It's our show and you can't see it." (PA-03)

Another mother described the intensity of the relationship:

No. I'm her comfort for sure. She would have me sitting on her lap. She wants me as close to her as possible. I can't do anything except stare at her. No noise, no nothing. She just needs the calmness. Even if my other daughter walks in, she needs her out of the room. She just needs me to look at her and focus on her and concentrate on her, which frustrates me. Because if I'm sitting there with her, let me at least distract myself, like, let me return emails or phone calls or whatever. No, I have to be really with her while she's suffering and in the pain, so that's hard on me. (PA-07)

Subtheme 2: Family Assumes Responsibility for Managing Pain. While mothers may be a primary source of comfort, many parents also described how the whole family had come together to share the responsibility of managing the adolescent's IBS.

She's not realizing what is causing her stomach to cramp. We're like, "Okay, drink the water, calm down and sit." The whole family has learned how to do this and just see the stages and just, "okay," to the point that we don't even see it that much anymore because we've learned how to deal with this so well. (PA-03)

Subtheme 3: Uncertainty Associated with IBS Puts Pressure on Family Relationships. An additional main theme that emerged from the interviews with parents was the significant stress that uncertainty associated with IBS puts on family relationships. Parents overwhelmingly described how it was impossible to plan, and that work, travel, and social events were often disrupted or canceled because of the unpredictable nature

of IBS symptoms. One mother described the stress caused by family travel plans being disrupted.

For the family, it's hard because we have planned numerous activities. We had whole trips, we were in Utah with the skis at the resort; everybody is ready to ski, and she had an attack that lasted the whole time we were there. We had already rented the skis and bought the clothes and everything, and then the very next day she was sick. We were just in Hawaii and same thing. She had it for about four or five days when we were snorkeling and going on a boat trip. Usually what we do is someone stays home with her, either me or my husband, so we can take the other kids. It breaks up the family, so that's sad that the whole family didn't go on the boat together, or didn't go skiing together. (PA-05)

Another mother described that these kinds of disruptions can be particularly hard on siblings.

It's hard for her obviously, but it is hard for us as a family, especially her younger sister, because she doesn't have the chronic pain, so we've had to learn to sometimes do things separately. My husband will maybe do something with my younger daughter if [child's name]'s not feeling good or I might take her somewhere, because in the beginning it was, "Well your sister doesn't feel good, so we're not doing that." (PA-11)

Providers

Providers, too, described the pressure that managing symptoms of IBS puts on family relationships and the importance of treating the child within the context of the family and offering strategies for the whole family.

Subtheme 1: Separation Challenges for the Adolescent with IBS. Adding another perspective to the mother-daughter relationship, many providers also described observing an intense bond between a parent and child. One provider described the challenge for adolescents to become independent:

I see them struggling with individuation. Often the parents are overprotective. The kids are often being treated as younger than they are. Often the parents don't have a good sense of what are age-appropriate activities. Often it's coming from the kid too, but sometimes the kids are still sleeping in the parents' room. They're like 11 and they still sleep in the parents' room. (P-09)

Subtheme 2: Importance of Treating the Whole Family. Finally, providers described the importance of viewing the adolescent as part of a family managing IBS, noting the family conflict that often resulted from managing the needs of the adolescent with IBS. One provider described the difficulty for siblings of adolescents with IBS:

They're the one that's keeping the imposition on the family not being able to go out for ice cream or something like that. So, the other kids may be holding that against them in some way. Also they may have symptoms that get them more attention from their parents and siblings may not like that, so there's a whole lot that comes from it. (P-06)

Another provider described parental conflict over treatment approach.

It changes the family dynamic to a big extent in terms of conflict between the child and the parent, or between the two parents about parenting style. Whether to keep the kid home or not, or whatever, so it sets up a lot of conflict within the family. (P-03)

Finally, one provider summarized the impact on the family as a unit:

I think that it's really hard to be the designated problem, and that life is extremely stressful, and that even if parents are trying to do the best they can, they've got their kids like they're like hamsters in a cage, or they're so on the treadmill, and lives are so busy and so stressful. Then the parents' anxiety, constantly asking how they're feeling, all of those kinds of things make it difficult. I know that they're idling high; there's just a base level of anxiety and tension and whatever. Base level is starting so high up that they don't have ways of unwinding, relaxing, enjoying together. (P-01)

Discussion

The aim of the study was to add to the current pediatric chronic pain literature and further explore the specific impact of IBS on social functioning through qualitative interviews with adolescents with IBS, their parents, and the providers who treat this population. Overall, the participants in our study described that adolescents with IBS encounter significant peer- and family-related social stress.

Adolescents, parents, and health care providers all described the challenges that adolescents face as they try to manage their symptoms in the context of adolescent social development. As others have reported, chronic and recurrent pain can significantly affect adolescents' willingness to participate in activities with peers [7,8]. Data from the qualitative interviews in the current study revealed factors that contributed to a cycle of isolation in adolescents with IBS. Specifically, the adolescents in our study described beliefs that peers could not understand their experience and difficulty communicating their needs and explaining what they were going through, factors that collectively likely contribute to social isolation. These findings align with themes in a previous qualitative study that described a tendency for adolescents with chronic pain to distance themselves from

their peers to avoid explaining their condition or symptoms to others [20]. From the providers' perspective, much of the isolation stemmed from embarrassment surrounding using the bathrooms in schools. Parents and providers both described a cycle whereby shame and embarrassment over symptoms led adolescents to withdraw, miss out on more social activities, and become further isolated.

Collectively, these findings suggest that both individual and environmental intervention targets may be indicated for adolescents with IBS, as well as the need for parent education, e.g., strategies that focus on fostering the child's resilience and coping strategies in spite of pain. Adolescents may benefit from learning how to explain their condition to peers and communicate their needs. Adolescents in the current study described feeling particularly close to others who had a similar condition, and given their reported concerns about relating to healthy peers, IBS peer-to-peer social support or peer mentoring groups may be particularly helpful for this population. Indeed, research in other pediatric chronic pain and chronic illness populations indicates that peer mentoring interventions are associated with beneficial outcomes [21–24]. Utilization of telehealth and technology-based platforms may also be warranted when developing interventions for these adolescents, as these modalities may help reduce patient burden and increase treatment accessibility [20,25]. The current findings also indicate that addressing environmental challenges may help minimize negative social experiences. For example, providers could refer patients to the social work or psychology service to coordinate appropriate school accommodations (e.g., restroom passes during class, access to private restrooms) and connect patients with support services.

IBS was described by all three groups as a problem that affected the entire family, putting a strain on individual relationships. In particular, participants in our study described an intense emotional bond between mother and child. Mothers in our study described the hopelessness and frustration felt as a result of seeing their children miss out on opportunities. Parenting practices characterized by overprotectiveness and worry have been reported in other studies, including among mothers and adolescents living with juvenile arthritis [26]. It is understandable that watching a child struggle with pain and other symptoms of IBS and seeing a child fall behind their peers could result in parents engaging in more solicitous behaviors, but this may serve to discourage adolescents' independence and developmentally appropriate adaptive behaviors. A growing body of research suggests that engagement in maladaptive behaviors, including increased dependence on parents and limited engagement in developmentally appropriate social activities, can exacerbate symptoms and lead to poor functioning [27–29]. Mothers also described stress surrounding managing their children's pain and navigating disease uncertainty. Taken together, our results suggest that families with a child with IBS may benefit from

therapeutic interventions that involve the entire family and minimize a focus on the "sick role" of the young IBS patient. Further, given the parental stress endorsed in the current study as well as other work examining parental distress in pediatric chronic pain [29], interventions targeting parental distress and stress management (e.g., relaxation, mindfulness) may be beneficial and potentially improve parents' ability to manage and respond to their child's pain.

While our findings suggest a number of areas of future research, limitations exist. Specifically, similar to other qualitative studies, our analysis represents the beliefs of a small subset of the population under study and thus cannot be generalized to a larger group or adolescents with other chronic conditions. All adolescent participants were recruited from an outpatient tertiary chronic pain clinic, so their symptoms were severe enough to warrant a referral to a specialty clinic; however, disease severity data were not collected. In addition, although we collected data from adolescents, parents, and providers, our sample did not include fathers or other caregivers. As others have reported [30], the findings also indicate that siblings may experience negative consequences as a result of pooling the family's resources to take care of the adolescent with IBS, and further research is warranted to understand the functioning of siblings.

In conclusion, current findings highlight the significant impact of IBS on social functioning in adolescents and their families. Collective responses from adolescents, parents, and providers indicated an unfortunate cycle of isolation, which is perpetuated by multiple individual, family, environmental, and disease-related factors. Given the importance of social functioning and the impact of social stress during adolescence, assessing social stressors and providing appropriate referrals for support may be warranted in this population. Interventions may include social support groups with similar peers, social communication skills education, and family-based support or psychotherapy.

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