
Poster

A Patient-Centered Approach to Developing a Mobile-Based Self-Management Intervention, Featuring a Virtual Coach, for Adolescents With Irritable Bowel Syndrome

Elizabeth Donovan¹, PhD; Tara Cousineau¹, PhD; Jennie CI Tsao², PhD; Lonnie K Zeltzer², MD; Subhadra Evans³, PhD

¹BodiMojo, Inc, Boston, MA, United States

²David Geffen School of Medicine, University of California, Los Angeles, Los Angeles, CA, United States

³Pediatric Pain Program, David Geffen School of Medicine, University of California, Los Angeles, Los Angeles, CA, United States

Corresponding Author:

Elizabeth Donovan, PhD
BodiMojo, Inc
30 Newbury Street, 3rd Floor
Boston, MA, 02116
United States
Phone: 1 617 333 0441
Fax: 1 617 333 0441
Email: liz@bodimojo.com

Abstract

Background: Irritable bowel syndrome (IBS) is a complex, chronic, functional disorder that has no cure and is characterized by abdominal pain/discomfort and altered bowel habits; other symptoms may include nausea, vomiting, and bloating; and it can also result in social isolation and shame. While in-person self-management skills training for IBS has been shown to be effective in adults and older adolescents, this training is inaccessible for most. Mobile technology may be a feasible way to deliver an intervention to adolescents designed to promote self-management and positive coping skills.

Objective: To conduct in-depth interviews with key stakeholders to inform the development of a mobile-based intervention, featuring an empathetic virtual coach, designed to promote self-management skills and positive coping skills in adolescents with IBS.

Methods: A total of 12 adolescents with IBS and 12 parents recruited from the UCLA Pediatric Pain Program (PPP) and Whole Child LA, and 12 multi-disciplinary health care providers, including gastroenterologists, nutritionists, and mental health providers, participated in 60-minute in-depth interviews. Interview guides were designed to elicit information about functioning challenges and coping strategies and to gather feedback about preliminary features for a mobile-based intervention and preferences for new features. Participants were shown images of three proposed main features and a video animation of a virtual coach. Thematic analysis informed coding and analysis of interview data.

Results: Results of the in-depth interviews revealed 6 main themes around adolescents' functioning, coping, and preferences for a mobile-based intervention. Data from the interviews were incorporated into a demonstration version of the mobile app using emotional modeling algorithms for a virtual coach.

Conclusions: A patient-centered approach is a useful way to inform development of a mobile-based intervention for adolescents struggling to manage IBS. A next phase of the research includes a pilot study with 24 adolescents using the application and acceptance testing with caregivers and providers.

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KEYWORDS

virtual coach; mobile application; irritable bowel syndrome; adolescence; emotional modeling; mHealth

This poster was presented at the Connected Health Symposium 2016, October 20-21, Boston, MA, United States. The poster is displayed as an image in [Figure 1](#) and as a PDF in [Multimedia Appendix 1](#).

Figure 1. Poster.

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Elizabeth Donovan, Ph.D., Bodimojo, Inc; Tara Cousineau, Ph.D., Bodimojo, Inc; Jennie C. I. Tsao, Ph.D., David Geffen School of Medicine at UCLA; Lonnie K. Zeltzer, MD, David Geffen School of Medicine at UCLA; Subhadra Evans, Ph.D., UCLA Pediatric Pain Program, Department of Pediatrics, David Geffen School of Medicine at UCLA

BACKGROUND. Irritable Bowel Syndrome (IBS) is a complex, chronic, functional disorder that has no cure and is characterized by abdominal pain/discomfort and altered bowel habits; other symptoms may include nausea, vomiting, and bloating (Ersyd, Posserd, Abrahamson, Simrén, 2007). While in-person self-management skills training for IBS has been shown to be effective in adults and older adolescents (Dom, 2010), this training is inaccessible for most. Mobile technology may be a feasible way to deliver an intervention to adolescents designed to promote self-management and positive coping skills.

OBJECTIVE. To conduct in-depth interviews with key stakeholders to inform the development of a mobile-based intervention, featuring an empathetic virtual coach, designed to promote self-management skills and positive coping skills in adolescents with IBS.

METHOD. Participants included 12 adolescents with IBS and 12 parents of adolescents with IBS recruited from UCLA Pediatric Pain Program (PPP) and Whole Child LA, as well as 12 multi-disciplinary health care providers, including gastroenterologists, nutritionists, and mental health providers. Adolescents, parents and providers participated in 60-minute in-depth interviews. Interview guides were designed to (1) elicit information about functioning challenges and coping strategies, (2) gather feedback about preliminary features for a mobile-based intervention and (3) understand preferences for new features. Participants were shown images of three proposed main features, and a video animation of a virtual coach. Coding and analysis of interview data was informed by guidelines for the management of IBS (Chiou & Nurko, 2010) and by assessments of functioning (Bursch, Tsao, Meldrum & Zeltzer, 1998) and coping (Reid, Gilbert & McGrath, 1998) with pain.

RESULTS.

Response to proposed features

1. Design of app appealed most to younger teens
2. Appreciated positive tone
3. Desire for individually tailored suggestions

Themes from semi-structured interviews

Results of the in-depth interviews revealed six main themes around adolescents' functioning, coping, and preferences for a mobile-based intervention. Data from the interviews were incorporated into a demonstration version of the mobile app.

Teens:

- (1) **Teens have limited coping skills, particularly for managing pain while at school or with friends.** "I did homeschooling almost all of eighth grade. I went for a month, and then I realized I couldn't handle it because, at that time, I was going to performing arts high school, so that was extra, extra work, ... and I just couldn't handle it, so I left." And "so I was kind of a doormat ... people weren't mean to me, but when I would feel left out, or when I wasn't feeling great, like I didn't really do anything about it."
- (2) **Teens lack the skills to communicate about IBS, believing that most people cannot understand their situation.** "Sometimes it's hard to explain to some of my friends, is they would think because ... there wasn't a real thing, because there's nothing that is usually diagnosed, that it's not a thing."

Parents:

- (1) **Uncertainty** "It's just that it's the uncertainty of when she's going to get sick, so living on the edge. You never know whenever we're going to have to drop everything to go get her or drop everything I'm doing to sit in the room with her while she's sick, or the bathroom with her. It's just distracting to our lives."
- (2) **Overwhelming stress** "It's emotional. It's very depressing, and I guess you're just worried, maybe. Maybe I worry too much about the distant future. My husband does that even more so. I had to find a way to calm him down while I'm trying to calm myself down."

Health care Providers:

- (1) **Teens with IBS often experience persistent anxiety.** "A lot of these kids are very anxious, anxious to begin with. You've got kids who are anxious, who are not keeping up to their own standards, really struggling. Again, then, there are [those] working on relaxation, setting realistic goals for themselves, working with tutors if they need to."
- (2) **Importance of helping teens to cope.** "My primary goal is to get them back to functioning in their normal activities to the greatest extent possible and feeling confident about their ability to cope with the symptoms. They're the ones, for them to feel comfortable coping with it, in other words not to rely on the parent to handle it."

Integration of themes into demonstration program

1. Mood cloud – recently tracked moods populate a cloud.
2. Wellness tip – daily health tips
3. Gratitude diary – free-text responding to "what went well today?"
4. Hospital-based Facebook page – social support for pediatric pain patients
5. Coping skills module- tailored coping advice based on evidence-based categories (Bursch et al., 1998) of functioning challenges

CONCLUSION. A patient-centered approach is a valuable way to inform the development of a mobile-based intervention for adolescents struggling to manage IBS. A next phase of the research includes a pilot study with 24 adolescents using the application and acceptance testing with caregivers and providers. An independent project is focused on the development of an intervention for parents of teens with chronic pain.

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Emotional Intelligence on the Go

- Empathetic Dialog Tool
- Meditations
- Mood Cloud
- Coping Skills
- Social Support
- Daily Messages
- Gratitude Journal

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Multimedia Appendix 1

Poster.

[PDF File (Adobe PDF File), 2MB-Multimedia Appendix 1]

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