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#### Information- and Health-care Seeking Behaviors in Patients With Irritable Bowel Syndrome

\*Andrea Shin, <sup>†</sup>Sarah Ballou, <sup>^</sup>Michael Camilleri, <sup>#</sup>Huiping Xu, <sup>†</sup>Anthony Lembo \*Division of Gastroenterology and Hepatology, Department of Medicine, Indiana University School of Medicine, Indianapolis, Indiana, <sup>†</sup>Division of Gastroenterology, Department of Medicine, Beth Israel Deaconess Medical Center, Boston, Massachusetts, <sup>^</sup>Clinical Enteric Neuroscience Translational and Epidemiological Research (C.E.N.T.E.R.), Division of Gastroenterology and Hepatology, Mayo Clinic, Rochester, Minnesota, <sup>#</sup>Department of Biostatistics, Indiana University Richard M. Fairbanks School of Public Health and School of Medicine, Indianapolis, Indiana,

Short Title: Healthcare seeking behavior and IBS

Word Count: 745

**Conflict(s) of Interest:** AL serves as a consultant for Ironwood Pharmaceuticals, Takeda, and Shire IM Health. AS, SB, MC, and XU declare no personal or financial conflicts.

**Disclosures:** The authors have no other relevant personal or financial disclosures.

**Funding:** Commissioned by the American Gastroenterological Association and conducted with the financial support of Ironwood Pharmaceuticals, Inc. and Allergan plc.

**Abbreviations:** IBS=irritable bowel syndrome, D=diarrhea, C=constipation, OR=odds ratio **Author contributions:** AS: conduct of the study, writing and critical revision of the manuscript; SB: data analysis, writing and critical revision of the manuscript; MC: study concept and design, conduct of study and critical revision of the manuscript; HX: statistical analysis, writing and critical revision of the manuscript; AL: conduct of the study and critical revision of the manuscript.

### **Corresponding author:**

Andrea S. Shin, M.D., M.Sc.

This is the author's manuscript of the article published in final edited form as:

Shin, A., Ballou, S., Michael Camilleri, Xu, H., & Lembo, A. (2019). Information- and Health-care Seeking Behaviors in Patients With Irritable Bowel Syndrome. Clinical Gastroenterology and Hepatology. https://doi.org/10.1016/j.cgh.2019.09.020

Indiana University School of Medicine

702 Rotary Circle, Suite 225

Indianapolis, IN 46202

Email: ashin@iu.edu

Tel: (317) 274-3505

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2

### **INTRODUCTION**

IBS is common and clinically heterogeneous gastrointestinal disorder that can be divided into four subtypes: IBS with constipation (IBS-C), IBS with diarrhea (IBS-D), IBS with mixed bowel habits, and unclassified IBS. IBS decreases quality of life<sup>1</sup> and imposes a substantial economic burden on the healthcare system.<sup>2</sup> In order to develop efficient approaches to address the individual needs of IBS patients while minimizing healthcare resource overutilization, it is important to identify the factors that drive patients to seek care, clarify the burden associated with distinct IBS subtypes, and to be aware of the resources from which IBS patients seek health-related information. We aimed to compare healthcare and information seeking between individuals with IBS-C and IBS-D.

# **METHODS**

#### The study cohort

Adults ages 18-100 years were recruited from a national sample to participate in an online consumer survey study between September 14, 2015 and October 21, 2015 to assess healthcare and information seeking. Details of the study design are described elsewhere.<sup>3</sup>

# Statistical analysis

Associations of healthcare and information seeking with IBS subtype were examined using multivariate logistic regression, negative binomial regression, and the proportional odds model where appropriate adjusting for relevant covariates (age, sex, race/ethnicity, marital status, education level, employment status, and IBS diagnosed by a doctor).

### RESULTS

**Healthcare seeking in IBS-C and IBS-D:** Among 3,254 participants, 82% (N=2674) reported speaking to at least one healthcare professional about their symptoms. Women with IBS-D were associated with a decreased odds ratio (OR, 95% C.I.) of seeking care from an

obstetrician/gynecologist or a pharmacist than women with IBS-C. Among those who saw at least one healthcare professional (N=2674), there were no significant differences in the number of healthcare professionals ever spoken to. However, IBS-D was associated with a decreased number (8% less) of healthcare professionals spoken to in the past twelve months compared to IBS-C. Comparisons of reasons for which participants waited to seek care revealed that IBS-C participants (16.3%) reported that other health conditions took priority more frequently than IBS-D participants (8.0%). Results are summarized in the Table.

**Resources and information seeking in IBS-C and IBS-D:** Only 15% of respondents had not discussed their gastrointestinal symptoms with anyone. IBS-D participants more frequently discussed their symptoms with others than IBS-C participants. Among those (N=2757) who had spoken to someone other than a doctor, 59% (N=1625) reported receiving advice for their symptoms and 90% (N=1465) of those receiving advice reported following it. Univariate analyses revealed significant differences in the proportion of individuals with IBS-C vs. IBS-D who received (63.1% IBS-C, 56.8% IBS-D, p<0.001) and followed advice (91.6% IBS-C, 88.6% IBS-D, p=0.048). Overall, 67.7% reported seeking information on IBS from their doctor, 64.5% from online sources, and 45.5% from Google or other search engines. IBS-C participants more frequently utilized social media networks, television, pharmaceutical or healthcare companies, and product websites than IBS-D participants (Table)

# DISCUSSION

In this large nationwide survey study, we found that IBS-C participants were more likely to discuss symptoms with an obstetrician/gynecologist than IBS-D participants. This association may be due to previously described relationships between chronic pelvic pain,<sup>4</sup> dyssynergic defecation,<sup>5</sup> or pelvic floor related symptoms<sup>6</sup> and constipation. IBS-C participants were less

likely to discuss symptoms with other individuals within their social networks than those with IBS-D, suggesting that IBS-C may often be a private and isolating experience. IBS-C participants also reported speaking to a higher number of healthcare professionals in the past 12 months and more frequently reported that other health conditions took priority. Although the reasons for these observations are unclear, it is possible that IBS-C patients may exhibit a higher frequency of care-seeking within defined time periods as previously reported by others<sup>7</sup> and that symptoms of constipation could be a surrogate for poorer health as suggested in another population-based study<sup>8</sup>

Study limitations include the possibility of recall and responder bias and the inability to confirm diagnoses by review of the medical records or by physician assessments. This study was conducted within the U.S. and participants were recruited from all 50 states in order to ensure individuals from all regions had an equal chance of being invited to participate. However, the study sample was not nationally representative and results may not be generalizable to other regions of the world.

In summary, study findings suggest that patient attitudes towards healthcare and knowledge gathering differ by IBS subtype. Further studies are required to verify these potential associations as recognizing these differences will be important in addressing the unique needs of IBS patients and reducing the associated burden of illness. Table: Summary of Effects of Irritable Bowel Syndrome (IBS) Subtype on Healthcare and

Information Seeking Behaviors Based on Multivariate Analyses

	*IBS-D vs. IBS-C (95% CI)	p-value
Types of healthcare professionals consulted		
A primary care physician	1.02 (0.85, 1.22)	0.82
A gastroenterologist	0.88 (0.75, 1.04)	0.13
Obstetrician/Gynecologist (women only)	0.71 (0.59, 0.86)	<0.001
Nurse/Nurse practitioner	0.97 (0.83, 1.13)	0.66
Physician's assistant	0.99 (0.84, 1.17)	0.9
Pharmacist	0.81 (0.67, 1.00)	0.045
Proctologist/colorectal Surgeon	1.01 (0.79, 1.30)	0.92
Other	0.89 (0.62, 1.27)	0.51
Number of healthcare professionals (HCP) ever spoken to	1.07 (0.99, 1.15)	0.1
Number of HCP spoken to in the past 12 months	0.92 (0.86, 0.98)	0.009
Duration of symptoms before seeing a doctor	0.91 (0.80, 1.05)	0.2
Reason why patient waited to talk to provider		
Symptoms weren't important enough	1.04 (0.81, 1.32)	0.78
Symptoms were severe enough	1.16 (0.98, 1.38)	0.093
Other health conditions that take priority	0.45 (0.35, 0.57)	<0.001
Felt I should deal with it on my own	0.90 (0.68, 1.20)	0.48
Didn't think there was anything they could do	1.15 (0.93, 1.43)	0.2
Too embarrassed	0.93 (0.72, 1.20)	0.59
Have learned to deal with it on my own	1.25 (0.94, 1.66)	0.13
Other	1.51 (1.12, 2.04)	0.007
Individuals with whom participants discussed symptoms		
Spouse/partner	1.06 (0.88, 1.28)	0.55
Significant other/person you are dating	1.22 (0.98, 1.53)	0.077
Kids	1.40 (1.15, 1.71)	<0.001
Boss	1.70 (1.17, 2.48)	0.006
Parents/In-laws	1.46 (1.23, 1.73)	<0.001
Coworkers	1.33 (1.04, 1.71)	0.023
Friends	1.24 (1.07, 1.44)	0.005
Therapist	0.91 (0.68, 1.23)	0.56
Other	1.15 (0.85, 1.54)	0.37
No one	0.77 (0.62, 0.95)	0.013

# Table 2 (continued)

Sources from which participants seek information		
WebMD/MayoClinic/Wikipedia/other online sources	1.08 (0.93, 1.25)	0.31
Google/other search engines	0.94 (0.81, 1.08)	0.38
Facebook/Twitter/other social networks	0.50 (0.36, 0.69)	<0.001
TV	0.64 (0.50, 0.82)	<0.001
Pharmaceutical/Healthcare company	0.64 (0.50, 0.83)	<0.001
Specific product web site	0.60 (0.46, 0.79)	<0.001
Articles in newspapers/magazines	1.09 (0.89, 1.33)	0.42
Friends	0.88 (0.74, 1.05)	0.16
Family	0.90 (0.77, 1.06)	0.21
Your doctor	1.04 (0.88, 1.24)	0.64
Advocacy group	1.62 (0.96, 2.74)	0.07
Medical specialty society	1.19 (0.79, 1.80)	0.4
Other	1.03 (0.70, 1.52)	0.88

\*Effect measures are ratio of means for number of healthcare professionals among patients who

have ever seen or spoken to at least one healthcare professionals and odds ratios for all other

outcomes. Associations between variables of interest and IBS subtypes examined using

multivariate logistic regression, negative binomial regression, and the proportional odds model

where appropriate adjusting for age, sex, race/ethnicity, marital status, education level,

employment status, and IBS diagnosed by a doctor.

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