Online Patient Education for Inflammatory Bowel Disease– Are Patients Being Misinformed?

Sophie Trujillo DO[2]; Sherif Saleh MD[1], Erin Walsh DO[1], Aakash Desai MD[1], Nisheet Waghray MD[1]
[1]Case Western Reserve University/MetroHealth Medical Center, [2]University of California-Irvine

SCHOOL OF MEDICINE
CASE WESTERN RESERVE UNIVERSITY

UC Irvine Health

Introduction

- Studies have shown that approximately 50% of patients with inflammatory bowel disease (IBD) use the internet to gather IBD-specific information.
- The aim of our study was to evaluate the accuracy, comprehensiveness, and readability of online patient education resources for IBD.

Methods and Materials

- A cross-sectional analysis of online patient educational resources for IBD using Google in June 2022.
- We divided the US into four major regions and performed online searches based on socioeconomic status and population size (figure 1):
  1) Two wealthiest and poorest cities
  2) Two largest and smallest cities in each region
  Purpose was to determine if variation existed in the availability of online resources.
- The top 10 Google websites, blogs and videos from each of the 16 cities were included and independently reviewed.
- An independently generated list of criteria with 30 items related to IBD that we believe should be included in patient information materials was used to screen the accuracy and comprehensiveness of patient resources and were recorded (Table 1).
- The readability of each website and blog was assessed using the Flesch-Kincaid readability test.

Table 1. Percentage of each IBD criteria met by each category of websites, blogs and YouTube videos. Average reading level for each criteria is listed below.

Criteria (n=30)		Website		Blogs (n=10)	Videos (n=10)
		Academic (n=3)	Other (n=7)		
Background	Defines IBD	100%	100%	70%	80%
	Differentiates between UC and CD	100%	86%	50%	60%
	Risk factors associated with IBD	67%	57%	70%	80%
Clinical Manifestation	Diarrhea	100%	100%	90%	80%
	Abdominal pain	100%	100%	90%	80%
	Weight loss	100%	100%	90%	70%
	Gastrointestinal bleeding	100%	100%	70%	60%
	Fatigue	100%	71%	70%	50%
Complications	Colon cancer	33%	100%	70%	40%
	Joint involvement	67%	100%	60%	70%
	Eye involvement	67%	100%	40%	50%
	Skin manifestations	67%	100%	60%	50%
	Coagulopathy	33%	43%	30%	20%
	Malnutrition	33%	71%	70%	0%
	Fistulas in CD	67%	86%	70%	40%
	Bowel perforation, obstruction, or stricture	67%	71%	50%	50%
Diagnosis	Lab tests	100%	86%	60%	60%
	Stool studies	100%	86%	50%	50%
	Endoscopy	100%	100%	60%	40%
	Imaging: CT, MRI	100%	100%	60%	50%
Management	Anti-inflammatory medication	100%	100%	80%	40%
	Immunosuppressive medication	100%	100%	100%	60%
	Antibiotics	100%	86%	70%	40%
	Surgery	100%	100%	80%	50%
Miscellaneous	Should be followed by a gastroenterologist	33%	57%	30%	40%
	Encourage health maintenance and vaccinations	0%	0%	20%	30%
	Routine colonoscopy screening	0%	71%	40%	40%
	Nutrition recommendations	67%	57%	80%	40%
	Lifestyle modifications: stress relief, physical activity	67%	86%	70%	50%
	Association with mental health: depression, anxiety	67%	57%	70%	50%
Average reading level		8th grade	8th grade	8th grade	NA

Figure 1. Map of United States where websites were searched.

Census Regions and Divisions of the United States

Key
- Small cities
- Large cities
- Wealthy cities
- Poor cities

Results

- No difference in accessibility to websites, blogs or videos between the 16 cities.
- No website, blog or video met 100% of the criteria. Average percentage of total IBD criteria mentioned was 72% for academic websites, 83% for other websites, 65% for blogs, and 49% for videos.
- 75% of the websites and blogs exceeded the recommended reading level of 6th grade for patient education materials by the National Institute of Health.

Conclusions

- The websites, blogs and videos are consistent and accessible regardless of search location.
- These resources varied dramatically in their comprehensiveness. It is important for clinicians to be familiar with these patient resources.
- Clinicians should provide vetted online and paper patient education materials to ensure accessibility and comprehensiveness.