

Perspectives, Experiences, and Concerns Among Patients With Short Bowel Syndrome (SBS) and Their Caregivers: Insights From Social Media Platforms

Carine Khalil¹; Taylor Dupuy¹; Sam Eberlein¹; Shirley Paski²; Bram P. Raphael³; Corey Arnold⁴; Brennan M.R. Spiegel¹

1. Cedars-Sinai Center for Outcomes Research and Education (CS-CORE), Cedars-Sinai Medical Center, Los Angeles, CA; 2. Karsh Division of Gastroenterology and Hepatology, Cedars-Sinai Medical Center, Los Angeles, CA; 3. Takeda Pharmaceuticals, Inc., Lexington, MA, USA; 4. Medical Imaging Informatics, Department of Radiology, UCLA, Los Angeles, CA

BACKGROUND AND AIMS

- Short bowel syndrome (SBS) is a rare chronic and severe disease resulting from physical loss and functional deficiency of portions of intestine, primarily due to surgical resection.
- Patients with SBS frequently need parenteral nutrition, which strongly impairs patients' quality of life and impacts their physical, social, and psychological wellbeing.
- We analyzed social media posts to examine the perspectives, experiences, and concerns among patients with SBS and their caregivers. Given the low prevalence of SBS and the associated burden, social media offer individuals a virtually borderless environment where patients can communicate freely without feeling embarrassed or ashamed.

METHODS

- We extracted 20,221 publicly available posts from seven SBS-related forums (e.g. Careplace, Reddit) between 1/1/10-1/11/21. After applying keyword filters (e.g. short bowel, short gut, SBS) and manual review, we identified 316 relevant posts.
- An open coding technique was used to qualitatively analyze the posts. Posts were read multiple times and codes were generated inductively, sorted, and grouped into themes and subthemes.
- An empathy map was developed to visualize the different themes and subthemes.

RESULTS

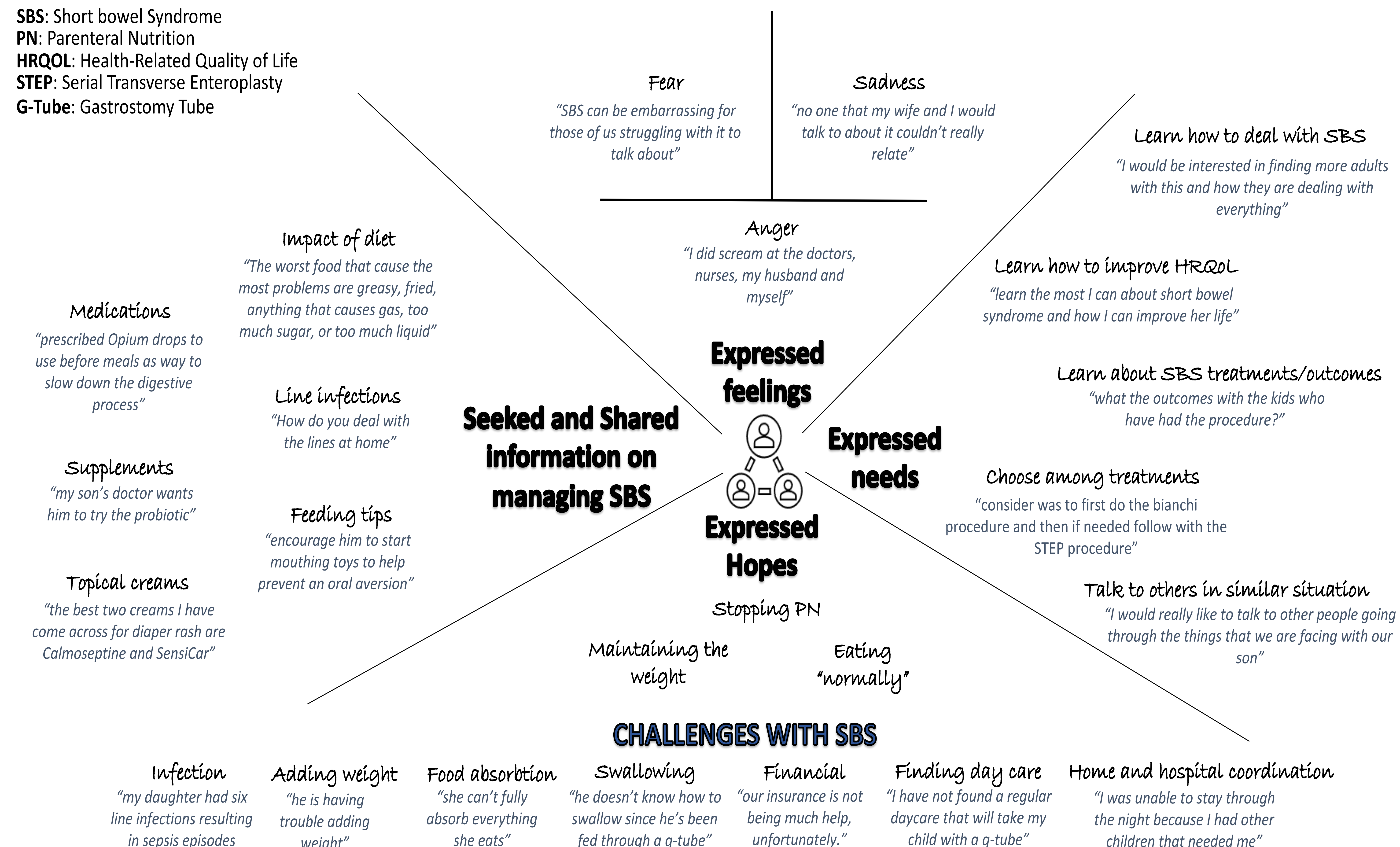
ACRONYM DESCRIPTION

SBS: Short bowel Syndrome
 PN: Parenteral Nutrition
 HRQOL: Health-Related Quality of Life
 STEP: Serial Transverse Enteroplasty
 G-Tube: Gastrostomy Tube

SOURCES OF SOCIAL MEDIA POSTS

Caregivers	Patients	Unclear
70.6%	14.9%	14.6%

RESULTS - EMPATHY MAP



DISCUSSIONS

- Our analysis supports previous evidence on the marked burden SBS has on physical, social, and mental health for both patients and caregivers.
- Caregivers and patients use targeted-disease forums to seek and share information that might help them deal with the condition such as alleviate physical symptoms, managing PN, and strengthen their mental health.

LIMITATIONS

- However, this study has two main limitations. First, the data was extracted from a limited number of US-based, English language forums. Second, by using social media platforms as a sole data source, we cannot confirm the diagnosis of individuals with SBS.

FUNDING

- This study was supported by Takeda Pharmaceuticals, USA, Inc.