

Patient’s Experience of Crohn’s Disease: A Conceptual Model Based on Qualitative Interviews

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Background

- Crohn’s disease (CD), an inflammatory bowel disease, can significantly impair patients’ health-related quality of life (HRQoL).^{1,2}
- For the effective management of CD, understanding the priorities of the patients is crucial.²

Objective

- The objective of this study was to develop a comprehensive conceptual model (CM) of the patient experience of CD by identifying the symptoms and impacts experienced by adults with CD in the United States (US).

Methods

- In this qualitative study, concept elicitation interviews were conducted among patients aged ≥18 years with a diagnosis of moderate-to-severe CD and clinicians experienced in treating CD in the US.
- IRB-approved semi-structured interviews were conducted online to explore CD symptoms and their impact on patients’ HRQoL.
- Interview transcripts were analyzed using Atlas.ti software (Version 9).

Results

Baseline characteristics

- Twelve patients with a mean age of 40.3 years (range: 22–54 years) were included.
- Six gastroenterologists, with an average practice duration of 23.5 years, participated in the study (Table 1).

Table 1: Demographic and clinical characteristics

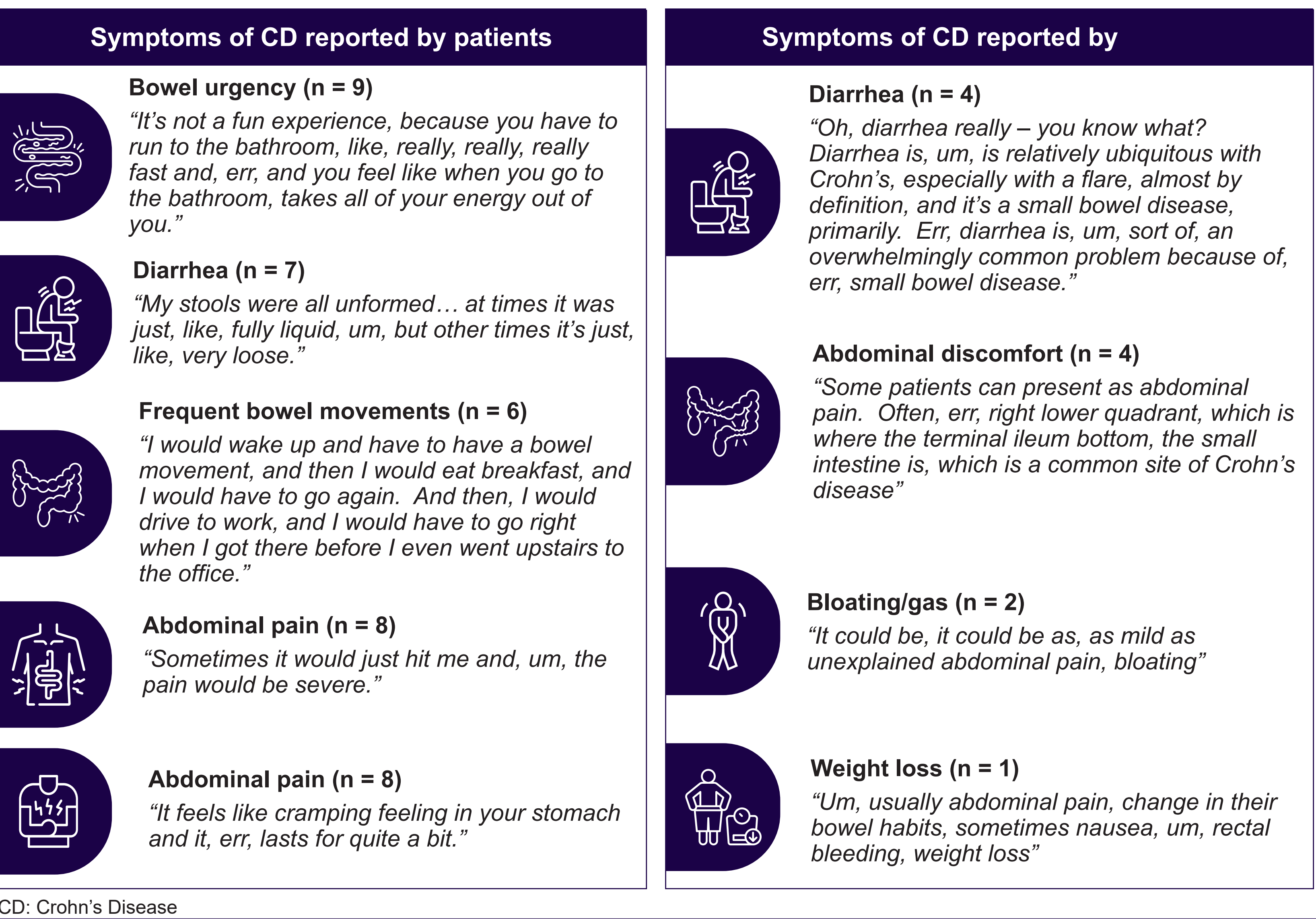
Patient characteristics	
Demographic characteristics	(N = 12)
Age, years, Mean (Median) [Range]	40.3 (45.0) [22–54]
Female, n (%)	8 (67)
Race, n (%)*	
White	10 (83)
Black or African-American	2 (17)
Asian	1 (8)
Ethnicity, n (%)	
Not Hispanic or Latino	9 (75)
Hispanic or Latino	3 (25)
Time since CD diagnosis, years	
Mean (Median) [Range]	10.3 (8.0) [2.5–28.8]
Number of current treatments, n	
1	11
2	1
Clinician characteristics	
Characteristics	(N = 6)
GI specialist, n	6
Years working as a physician, Mean (range)	23.5 (11–32)
Years treating and managing patients with CD, Mean (range)	23.2 (11–33)
Type of practice, n	
Private hospital	2
Specialist center	1
Clinic	2
Other (private practice)	1

*Not mutually exclusive; CD: Crohn’s disease; GI: gastrointestinal; N, total population; n, number of observations.

Most frequently reported symptoms by patients and clinicians

- The most frequent patient-reported gastrointestinal (GI) signs/symptoms were bowel urgency (n = 9/12), abdominal pain (n = 8/12), diarrhea (n = 7/12), frequent bowel movements (n = 6/12), and abdominal cramping (n = 6/12) (Figure 1).
- The most common patient-reported extraintestinal symptoms were fatigue (n = 11/12), anemia (n = 4/12), and weight loss (n = 4/12).
- Clinicians stated that diarrhea (n = 4) and abdominal pain/discomfort (n = 4) were the two core patient-reported symptoms.
- Change in bowel habits or diarrhea (n = 3), weight loss (n = 1), bloating (n = 1), and gas (n = 1) were the most typical or disease-defining clinician-reported symptoms of CD reported (Figure 1).
- Clinician-reported extraintestinal manifestations of CD were skin abnormalities (n = 2), eye diseases (n = 1), and rheumatological signs (n = 1).

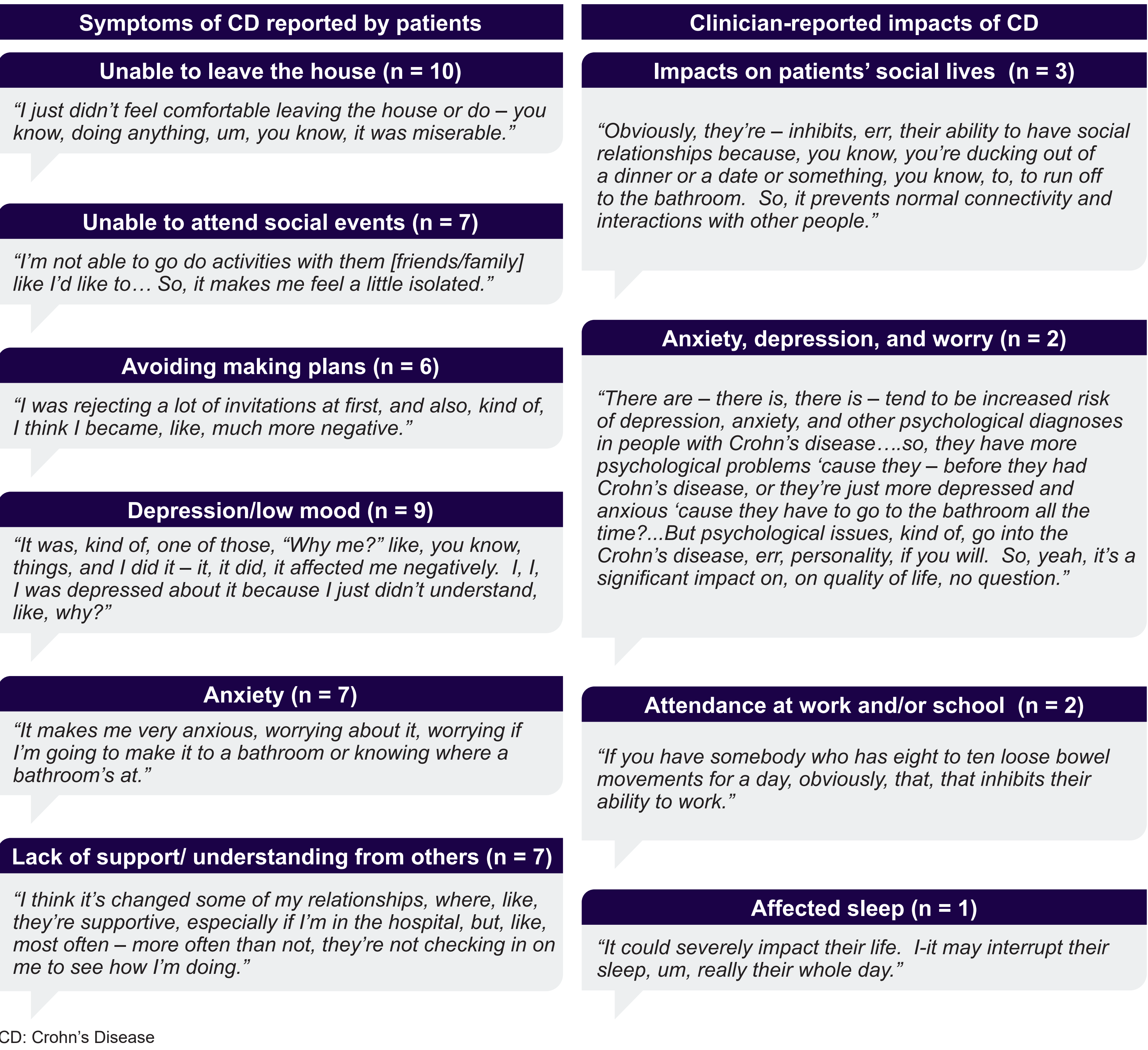
Figure 1: Patient and clinician description of symptoms of CD



Patient- and clinician-reported description of impacts of CD

- The most frequently reported impacts of CD by patients were as follows:
 - Being unable to leave the house (n = 10/12), and increased planning when going out (n = 9/12).
 - Depression/low mood (n = 9/12) or anxiety (n = 7/12).
 - Unable to attend social events (n = 7/12) or avoid making social plans (n = 6/12).
 - Feeling lack of support and understanding from others (n = 7/12) (Figure 2).
- The most common symptom-specific and general coping strategy among patients with CD were changing diet (n = 4/12) and overall attitude/mindset (n = 3/12), respectively.
- Clinicians stated that impacts on emotions, social activities, work and sleep were reported by their patients with CD (Figure 2).

Figure 2: Patient- and clinician-reported description of impacts of CD



Conceptual model

- A comprehensive CM was developed based on the qualitative interviews and a prior literature review (Figure 3).

Figure 3: Updated conceptual model of CD



Limitations

- Some participants had well controlled disease at the time of the interview, leading to reliance on recall for symptom reporting.
- Generalizability of the study results should be considered because the study included patients only from the US

Conclusions

- CD impacts most aspects of patients’ HRQoL.
- The CM provides insight into CD and outlines a wide spectrum of symptoms, effects, and coping mechanisms.
- The CM will serve as the foundation for more efficient patient-centered care strategies and options, as well as for the development of targeted future treatments.

References

- Knowles et al. *Inflamm Bowel Dis*. 2018; 24: 742–751.
- Mokrowiecka et al. *Adv Med Sci*. 2006; 51: 142–147.

Conflicts of interest

CC and SK are employees of Clarivate and were paid a fixed fee by Sanofi to undertake this research project, they may hold stock or stock options. KJ and LL are employees of Sanofi and may hold stock or stock options. EBH is a consultant for Sanofi.

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