



# Health determining concepts important to people with Crohn's disease and their coverage by patient-reported outcomes of health and wellbeing ☆, ☆ ☆

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## Abstract

**Background and aims:** Busy clinical settings often restrict the possibility to focus on concepts that determine health in a positive way, commonly assessed by using patient-reported outcomes (PROs). We aimed to explore which determinants of health (DHs) are important to people with Crohn's disease (CD), to understand possible gender differences and to analyze whether these DHs are covered by PROs used in CD.

**Methods:** Two systematic literature reviews were done to identify relevant DHs and clinically relevant PROs. We conducted a qualitative narrative biographical study and mapped the patients' experiences to concepts that determine health in a positive way. Experiences, DHs and

**Abbreviations:** DH, determinant of health; DHs, determinants of health; HP, health promotion.

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the items of the PROs were compared by the WHO International Classification of Functioning, Disability and Health (ICF) as a common framework.

**Results:** 15 people with CD with a median age of 46 years (IQR 34–60) and median disease duration of 15 years (IQR 8–30) participated. Self-efficacy, social support, job satisfaction and occupational balance were mentioned most frequently. While participation appeared to have greater meaning to men, appreciation and resilience seemed to be more important for women. Of 18 PROs the *Perceived Stress Questionnaire* (PSQ), the *Inflammatory Bowel Disease — Self-efficacy scale* (IBD-SES), the *Life Orientation Test — Revised* (LOT-R) and the *Patient Activation Measure 13* (PAM-13) cover most DHs.

**Conclusions:** This is the first study elaborating the coverage of patient's perspective by commonly used PROs in CD. The findings could support health professionals to focus on DHs in people with CD in clinical practice and research.

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## Summary box

### Significance of the study

#### What is already known about this subject?

- The positive effect of other determinants of health (DHs) on course of disease and health and wellbeing, such as of social support or coping strategies, is proven in people with Crohn's disease (CD).
- Patient reported outcomes (PROs) have been examined whether they cover patient's perspectives with other chronically autoimmune diseases.
- PROs have not been examined whether they cover patients' perspectives with CD based on qualitative data, nor if they cover DHs meaningful to people with CD, so far.

#### What are the new findings?

- Social support, self-efficacy, job satisfaction and occupational balance are meaningful DHs for people with CD.
- Social support is covered by five, self-efficacy by two PROs, reflecting in an optimistic way, is covered most often.
- Job satisfaction, occupational balance, secondary gain from illness, sense of coherence, vocational gratification, and work–life balance are not covered by any of the 18 identified PROs.
- The *Perceived Stress Questionnaire* (PSQ), the *Inflammatory Bowel Disease — Self Efficacy Scale* (IBD-SES), the *Life Orientation Test — Revised* (LOT-R) and the *Patient Activation Measure 13* (PAM-13) cover most DHs.

#### How might it impact on clinical practice in the foreseeable future?

- Other DHs beyond disease activity are important to people with CD. Appreciation, coping, social participation, reflecting in optimistic way, resilience, self-efficacy, and social support can be assessed in clinical practice.
- Self-efficacy could be assessed routinely with the IBD-SES or the PAM-13, social support is covered by IBD-SES, the LOT-R and by the PSQ.
- We recommend the use of the PSQ, the IBD-SES, the Lot-R and the PAM-13 in clinical routine to address HP in people with CD, to evaluate the need for HP interventions and their effect on the specific DHs.

## 1. Introduction

Crohn's disease (CD) is an inflammatory bowel disease (IBD) with a broad spectrum of clinical manifestations. CD may affect the entire gastrointestinal tract with discontinuous lesions involving all bowel layers. An irregular disease course with active and inactive periods is characteristic.<sup>1</sup> CD may profoundly change or influence the patient's life situation, quality of life, health and wellbeing.<sup>2</sup>

Several determinants of health (DHs), such as social support and optimism are recognized to have an impact on the course and outcome of chronic inflammatory diseases.<sup>3,4</sup> DHs include the social, economic and physical environment, as

well as the person's individual characteristics and behaviors, and can affect health either in a positive or in a negative way.<sup>5</sup>

There is a slight female predominance among patients with CD.<sup>1</sup> In CD, nervous, endocrine and immune functions, the course of the disease, experiences and the consequences in the management of CD show differences between women and men.<sup>6–8</sup>

Health outcome research seeks to understand the end results of health care in a particular disease, an individual, or a group of patients. A scientific basis for understanding and studying health including patients' perspectives is needed.<sup>9–11</sup> Patient reported outcomes (PROs) assess patients' perceptions within various dimensions of health, which still may deviate

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