

# Optimal care in Crohn's Disease and Ulcerative Colitis:

# HOW ALIGNED ARE HEALTHCARE PROVIDERS WITH PATIENTS' NEEDS AND EXPECTATIONS?


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## 1 Purpose

Identify the educational needs and practice gaps of Canadian healthcare providers (HCP) who care for patients with Crohn's Disease (CD) and Ulcerative Colitis (UC), with a focus on discrepancies between patients' needs/expectations and the care offered by HCP

## 2 Methods

IRB-approved multi-level needs assessment:

PHASE	METHOD
<b>1 Background Information</b>	<ul style="list-style-type: none"> <li>IRB approval – ethics review, received December 2011</li> <li>Background information collected through faculty input, review of selected literature, and two (2) discussion groups with CD/UC patients (n=15) in Quebec &amp; Ontario</li> </ul>
<b>2 Quantitative Surveys</b>	<ul style="list-style-type: none"> <li>Design / development of quantitative data collection instruments</li> <li>Recruitment through e-mail invitations / patient advocacy group (Crohn's &amp; Colitis Foundation of Canada)</li> <li>Two quantitative online surveys deployed between June &amp; August 2012                             <ul style="list-style-type: none"> <li>One among patients and caregivers, and one among HCP</li> <li>HCP participants screened out if caseload UC&amp;CD &lt;10%</li> </ul> </li> </ul>
<b>3 Analysis &amp; Interpretation</b>	<ul style="list-style-type: none"> <li>Collaborative analysis and interpretation of findings:                             <ul style="list-style-type: none"> <li>Statistical analysis (means, frequencies, and mean group differences using ANOVA)</li> <li>Source triangulation (combining perspectives of different professions, and patients/caregivers to increase trustworthiness of findings)</li> <li>Identifications of discrepancies between patients' needs/expectations and the care offered by HCP</li> </ul> </li> </ul>

## 3 Sample

Sub-sample	n
Gastroenterologists	93
Nurses / Nurse Practitioners	44
Others	11
<b>Healthcare Provider (HCP) Total</b>	<b>148</b>
Patients/Caregivers	76
<b>Total sample</b>	<b>224</b>

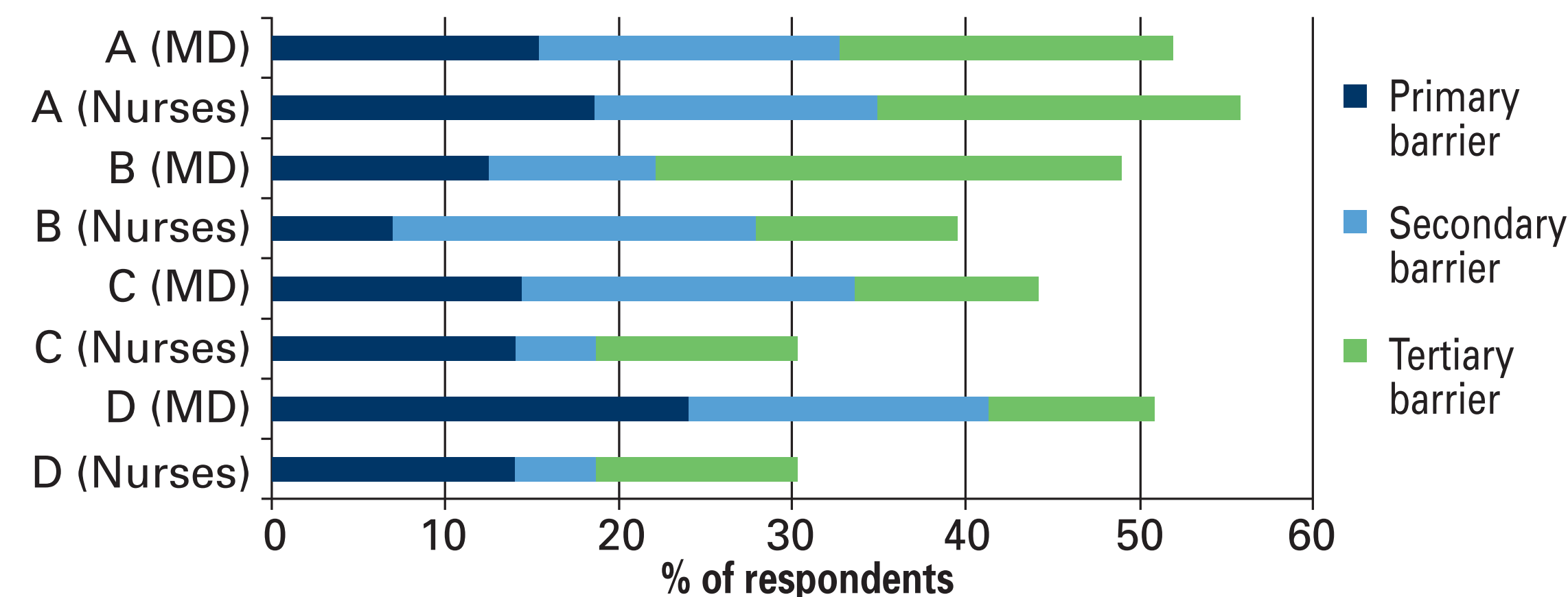
- 30% of Nurses had CNA certification in gastroenterology
- Others included 6 Internists and 5 GI Surgeons
- Patients/Caregivers survey was completed by 72 patients and 4 caregivers for patients with CD or UC; 44 had CD and 32 had UC

## 4 Results

Gaps and barriers were identified across the continuum of care. Two specific discrepancies between the patients' needs and HCP's expertise were identified.

### 1- Addressing the emotional component of the disease

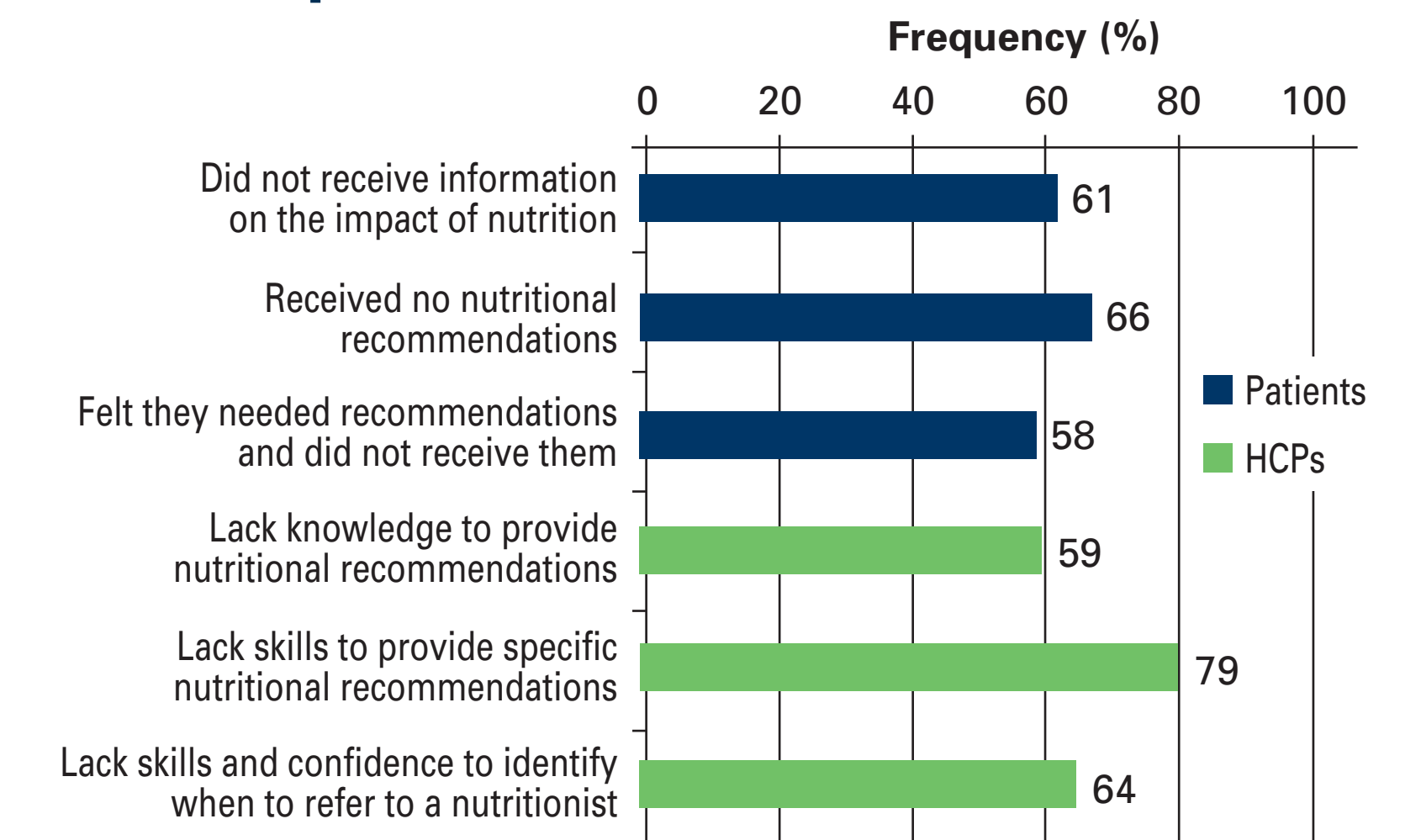
- 51% of patients reported that the healthcare team poorly discussed the emotional impact of their diagnosis with them, even though 61% of patients perceived this as important
- Up to 74% of HCP respondents reported a lack of skills in different aspects of emotional support



- A Patients' misinformation about their disease by non-medical sources
- B Patients' unrealistic expectations and disproportionate fears
- C Patients' lack of adherence to treatment plan
- D Patients' misunderstandings or confusion related to their disease or treatment plan

"An emotional aspect will always accompany this disease. Doctors should be aware to watch for signs of depression or quality of life issues" — Patient

### 2- Nutritional aspects of IBD care



"I find my GI very nice, he always says to call him and come in if I am feeling sick and that's just great, but there is zero nutritional information. If I ask he just says that there are no trigger foods, that it's just a myth." — Patient

- In two recent studies, information on nutritional recommendations was regarded by the patient population as one of the most important<sup>1</sup>, and as the least adequately addressed<sup>2</sup>

### Other findings

- Management of flare-ups**
  - 65% of patients report they did not receive sufficient information on how to manage flare-ups
  - 68% of Nurses lack knowledge on managing patients' concerns from flare-ups
- Patient resources and credible information**
  - 87% of patients reported they did not receive information on their disease at different life stages in the first 5 years after diagnosis
  - 57% of Nurses reported a lack of knowledge of reliable, credible sources of information

## 5 Conclusions

- The results from this study question whether patients' expectations and needs are fully known and understood
- The barrier in emotional support reflects gaps in HCP skill sets, including some specific aspects of communication
  - Gap has been observed across many therapeutic areas<sup>3,4,5</sup>
- The gap in nutritional information is at least partially explained by a lack of clear evidence and guidance on the role of nutrition in UC/CD
  - Regardless, patient-centric practice requires that HCP understand and address expectations of IBD patients, even if only to explain lack of evidence
- Educational initiatives aiming to improve patient-centric practice and communication, particularly the aspects mentioned above, could lead to improved communication, enhanced compliance and optimized health outcomes

## 6 REFERENCES

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**ACKNOWLEDGEMENTS:** This needs assessment was conducted by AXDEV Group and was financially supported with educational research funds from AbbVie Corporation.