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**Crohns Disease Analysis Kit (CDAK)**

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The full complete version of the CDAK includes –
- Crohns Disease Overview information
- Crohn's Disease Activity Index (CDAI)
- CDAI Scoring/ Administration instructions
- CDAI clinical validity
- Living with Crohns handout
- Crohn's health assessment strategies
- Crohn Disease Specific Measures Analysis
- Educational Training Video on Crons Disease (30min)
- Inflammatory Bowel Disease Questionnaire (IBDQ-SV) Short version.
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Crohn’s Disease

Introduction
Crohn's disease is one of the 2 most common inflammatory bowel diseases or IBD. The other one is ulcerative colitis. Crohn's disease and ulcerative colitis both cause inflammation in the intestines and have very similar symptoms and diagnostic approaches. Together, these 2 diseases affect about 1 million Americans at any one time.

Crohn's disease and ulcerative colitis are two different forms of IBD. There are some important differences between them. Crohn's disease can affect any part of the gastrointestinal system from the mouth to the anus, whereas ulcerative colitis only affects the colon. In Crohn's disease the inflammation involves the full thickness of the bowels, whereas in ulcerative colitis only the inside layer of the bowels is usually affected. Both predispose to cancer but ulcerative colitis to a greater extent.

This reference summary will help you understand Crohn's Disease and how it can be treated.

Anatomy
Swallowed food goes through the “esophagus” which is the feeding tube.

Next, food passes through the stomach, where it is partially digested. Digested food goes from the stomach to the small intestines, where most nutrients are further digested and absorbed into the body.

Fibers and digested food finally reach the colon. In the colon, the rest of the nutrients get absorbed and stools are formed.

This is the end of the SAMPLE Crohns Disease Overview info. Please return to page 1 to purchase the complete version.
The Crohn’s Disease Activity Index, its derivatives and the Inflammatory Bowel Disease Questionnaire: A review of instruments to assess Crohn’s disease

Eric M Yoshida MD FRCP C

EM Yoshida. The Crohn’s Disease Activity Index, its derivatives and the Inflammatory Bowel Disease Questionnaire: A review of instruments to assess Crohn’s disease. Can J Gastroenterol 1999;13(1):65-73. The Crohn’s Disease Activity Index (CDAI) has been used to measure Crohn’s activity for over a quarter of a century. The development of the CDAI is reviewed and its reliability and validity are examined. Instruments used to assess Crohn’s disease that were developed subsequent to the CDAI, including the Harvey-Bradshaw Index, the Cape Town Index and a three-variable version of the CDAI (modified for survey research), are similarly reviewed. The most recent instrument to assess Crohn’s disease, the Inflammatory Bowel Disease Questionnaire, which assesses patients in the domains of bowel, systemic, emotional and social function, is also discussed.

Key Words: Cape Town Index, Crohn’s Disease Activity Index, Harvey-Bradshaw Index, Inflammatory Bowel Disease Questionnaire, Reliability, Validity, Van Hees Index

The two main diseases that comprise inflammatory bowel disease (IBD) are ulcerative colitis (UC) and Crohn’s disease (CD). Both conditions are chronic illnesses associated with significant patient morbidity and have natural histories characterized by exacerbations of disease activity and episodes of quiescence. The etiology of both conditions is unknown (‘idiopathic’), although it is widely accepted that the pathogenesis of both conditions is on the basis of immunodysregulation (1). As a consequence of the similarities in inflammatory mucosal damage, medications that typically

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Crohn's disease activity index (CDAI)

Patient reported stool pattern

☐ Average number of liquid or soft stools per day over seven days (14 points per stool)
☐ Using diphenoxylate or loperamide for diarrhea (30 points)

Average abdominal pain rating over seven days

☐ None (0 points)
☐ Mild pain (35 points)
☐ Moderate pain (70 points)
☐ Severe pain (105 points)

General well being each day over seven days

☐ Well (0 points)
☐ Slightly below average (49 points)
☐ Poor (98 points)
☐ Very poor (147 points)

This is the end of the SAMPLE CDAI questionnaire. Please return to page 1 to purchase the complete version.
CDAI Interpretation

Patients requiring steroids to remain asymptomatic are not considered to be in remission but are referred to as being "steroid dependent."

Absolute deviation of hematocrit is simply the difference in hematocrit from standard. A male patient with a hematocrit of 40% has an absolute deviation of 7.

Percent deviation from standard weight is \( (1 - \frac{\text{weight}}{\text{standard weight}}) \times 100 \), thus positive percent deviation represents weight loss, adding points to the CDAI.

This is the end of the SAMPLE CDAI scoring instructions. Please return to page 1 to purchase the complete version.

References


Mapping from Disease-Specific Measures to Utility: An Analysis of the Relationships between the Inflammatory Bowel Disease Questionnaire and Crohn’s Disease Activity Index in Crohn’s Disease and Measures of Utility

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ABSTRACT

Objectives: To examine the relationship between the Inflammatory Bowel Disease Questionnaire (IBDQ), Crohn’s Disease Activity Index (CDAI) and measures of utility (EQ-5D and the SF-6D indexes), and to estimate algorithms to map the two utility values from IBDQ and CDAI scores.

Methods: A large data set from clinical trials in Crohn’s disease provided contemporaneous patient responses to all four questionnaires. Paired observations from multiple timepoints were analyzed. We calculated mean utility scores by IBDQ and CDAI score deciles; Spearman correlation coefficients for paired observations between IBDQ and EQ-5D (n = 3320) and IBDQ and SF-6D (n = 3230), and explored regression models using maximum likelihood estimation. The IBDQ/SF-6D model was validated against paired observations from an independent data set.

Results: The IBDQ decile analysis demonstrated a consistent positive relationship with both utility indexes. Correlations between the IBDQ and both the EQ-5D and SF-6D were statistically significant (P < 0.0001), with correlation coefficients of 0.76 and 0.85, respectively. A simple linear model between EQ-5D and IBDQ explained 45% of the variance. The residuals plot for the IBDQ/SF-6D model suggested some nonlinearity and a nonlinear model explained 69% of the variance. In the validation analysis, no statistically significant difference was observed between the mean observed SF-6D and the SF-6D scores estimated using the IBDQ/SF-6D regression model.

Conclusions: Given the strength, consistency, and predictable characteristics of the relationships, the algorithms appear to provide valuable and valid methods to estimate utilities from IBDQ scores (but not CDAI) in trials of Crohn’s disease patients that have collected IBDQ scores but not utilities.

Keywords: CDAI, Crohn’s disease, EQ-5D, IBDQ, SF-6D, utility.

Background

The increasing use of cost-utility analysis, particularly by reimbursement agencies and national advisory bodies such as the National Institute for Health and Clinical Excellence (NICE) in the UK, imposes requirements for additional data from trials. Ideally, all trials would now include a general measure from which a utility value could be directly attributed, such as the EQ-5D [1], SF-6D [2], or Health Utilities Index (HUI) [3]. In the absence of data from such instruments it may be possible to map their values indirectly from a generic health-related quality of life (HRQoL) or a disease-specific instrument included in the trial. A number of such “algorithms” to map utilities from generic HRQoL instruments have been published [4,5], as have some from disease-specific measures, such as breathlessness and angina severity in cardiac patients [6]. This article presents such an exercise for mapping from instruments applicable to Crohn’s disease, to both EQ-5D and SF-6D and to compare the values obtained.

Crohn’s disease is a chronic gastrointestinal disorder characterized by relapsing and remitting inflammation of the gastrointestinal tract. Patients experience substantial impairment in HRQoL as a consequence of abdominal pain, diarrhea and fatigue. In Crohn’s patients, disease activity is normally measured using the Crohn’s Disease Activity Index (CDAI) [7], and the Inflammatory Bowel Disease Questionnaire (IBDQ), a 32-item disease-specific measure, is commonly used to measure HRQoL in Crohn’s disease [8]. The
An Analysis of Disease-Specific Measures for Crohns Disease.

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Sample Crohns disease handout.
The UK IBDQ—A British version of the inflammatory bowel disease questionnaire: development and validation

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Abstract

Measurement of health-related quality of life (HRQL) is becoming more important in studies of patients with inflammatory bowel disease. The McMaster IBDQ is the most widely used HRQL instrument for these patients. However, its use with patients in the United Kingdom has not been validated. This study develops and validates a UK version of the McMaster IBDQ (UK IBDQ). The UK IBDQ was tested with two samples of patients for its reliability, validity, reproducibility, and responsiveness. The first sample consisted of 180 patients participating in a randomized clinical trial. The second was recruited from members of the National Association for Colitis and Crohn’s Disease. Reliability of the subscales and the summary score of the UK IBDQ is demonstrated by Cronbach's alpha and item-total correlations. Their validity is demonstrated by their correlations with SF-36 subscales and an empirical index of disease activity. Good intraclass correlations and responsiveness ratios show their reproducibility and responsiveness. The findings support the reliability, validity, reproducibility, and responsiveness of the UK IBDQ and its acceptability to patients in UK. © 2000 Elsevier Science Inc. All rights reserved.

Keywords: Inflammatory bowel disease; Quality of life; Outcome assessment

1. Introduction

The inflammatory bowel diseases (ulcerative colitis and Crohn’s disease) are chronic relapsing inflammatory disorders of the gut, which can cause negative impact on patients’ quality of life[1–16]. There is a clear trend towards more frequent use of patients’ health-related quality of life as an outcome indicator in health research in the past 10 years [17]. Some disease-specific quality of life measures have been developed in North America [18–23], of which the McMaster Inflammatory Bowel Disease Questionnaire (IBDQ) [18–20] is the most widely used. The McMaster IBDQ has been validated for use both in interviews and as a self-administered questionnaire [24]. It has also been tested for cross-cultural validity with a Dutch population [25], condensed into a short-form version [26], and provided with an alternative approach to scaling [25,27]. The need to modify and Anglicize the McMaster IBDQ was identified when the study team was planning a randomized trial comparing two methods of outpatient follow-up for patients with inflammatory bowel disease (OPFUS) [28]. The questionnaire was circulated to the OPFUS project board, which consisted of two consultant gastroenterologists, one senior registrar, one general practitioner, two researchers, one information scientist, and one project manager. The consensus was that the wordings of some questions were ambiguous and the response options were too complex.

Following the philosophy proposed by Guyatt [29], we Anglicized the McMaster IBDQ, modified the wording of the questions, simplified the response options, and systematically validated the adapted instrument (the UK IBDQ). This validation included comparison with the short-form 36-item health survey (SF-36), a general HRQL index well validated in both the US [30–32] and the UK [33,34].

2. Data collection

The study was based on two samples of patients. The first comprised 180 patients who were participating in OPFUS. A questionnaire including the UK IBDQ and the Anglicized version of the SF-36 was given to these patients for self-completion on recruitment.

The second sample was recruited from 100 randomly selected addresses on the membership list of the West Wales branch of the National Association for Colitis and Crohn’s
**Inflammatory Bowel Disease Questionnaire**

**Scoring & Administration instructions**

**Overview**

The inflammatory bowel diseases (ulcerative colitis and Crohn’s disease) are chronic relapsing inflammatory disorders of the gut, which can cause negative impact on patients’ quality of life. There is a clear trend towards more frequent use of patients’ health-related quality of life as an outcome indicator in health research in the past 10 years.

The sensitivity of the IBDQ to promptly reflect the changes in a patient’s condition is a crucial parameter for the assessment of short-term response to therapeutic interventions.

**Scoring:**

The IBDQ is a self-administered, 32-item questionnaire concerning 4 domains of quality of life:

This is the end of the SAMPLE IBDQ scoring. Please return to page 1 to purchase the complete version.

**Domain Specific:**

See below table for IBDQ questions categorised into their specific domains:

Print the following table out to use as your domain specific analysis.

Add up scores for each domain and place in Totals Scores column.

<table>
<thead>
<tr>
<th>Domains</th>
<th>Question Numbers</th>
<th>Max scores</th>
<th>Total Scores</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bowel Function</td>
<td>1, 5, 9, 13, 17, 22, 24, 26, 29</td>
<td>0 - 36</td>
<td></td>
</tr>
<tr>
<td>Social functioning</td>
<td>4, 8, 12, 16, 28,</td>
<td>0 - 20</td>
<td></td>
</tr>
</tbody>
</table>

*Higher scores indicate a ‘worse quality of life’.*
The Inflammatory Bowel Disease Questionnaire

DATE:_________ NAME: ____________________________________________ DOB_________________

The following questions ask about your bowel problem and how it affected your life over the last two weeks. Please tick one answer for each of the questions. If you are unsure about how to answer any question, just give the best answer you can. Do not spend too much time answering, as your first thoughts are likely to be the most accurate.

1. On how many days over the last two weeks have you had loose or runny bowel movements?
   a) none
   b) on one or two days only
   c) on three to seven days
   d) on eight to fourteen days (ie more than every other day)

2. On how many days over the last two weeks have you felt tired?
   a) none
   b) on one or two days only
   c) on three to seven days
   d) on eight to fourteen days (ie more than every other day)

4. In the last two weeks, has your bowel condition prevented you from carrying out your work or other normal activities?
   a) No, not at all
   b) Yes, for one or two days
   c) Yes, for three to seven days
   d) Yes, for eight to fourteen days (ie more than every other day)

5. On how many days over the last two weeks have you opened your bowels more than three times a day?
   a) none
   b) on one or two days only
   c) on three to seven days
   d) on eight to fourteen days (ie more than every other day)

This is the end of the SAMPLE IBDQ questionnaire. Please return to page 1 to purchase the complete version.