# How well do we measure the impact of bowel dysfunction on health-related quality of life after rectal cancer surgery?

McGill Colon and Rectal Surgery

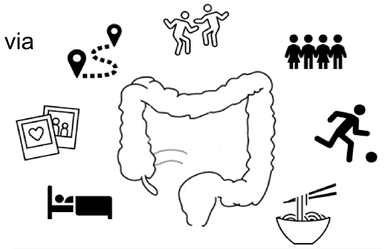
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## Introduction

- Rectal cancer surgery → Quality of Life (QOL) via Low Anterior Resection Syndrome (LARS)
- QOL is specific to each patient and current measures may not always be relevant
- Understanding relevant QOL areas → better patient-centered care



**Aim:**

- Determine the validity of generic QOL instruments in bowel dysfunction

## Methods

**Patient interviews (n = 54)**

Patient selection:
- Age ≥ 18 y.o.
- ≥ 1 year since rectal surgery
- No metastasis or local recurrence

Interviews
- Bowel function (LARS score)
- Patient-generated interview

→ **Recorded**
→ **Transcribed**

**Content analysis**

Analyzed:
- Interview transcripts
- **Common QOL surveys***
  - **SF36**
  - **EORTC-QLQ**
  - **EQ5D**
  - **FIQL**
  - **PGWBI**

→ **Content linked to WHO: International Classification of Functioning (ICF) codes**

**Assessment of content validity**

Assessed common QOL tools for:
- **Content density:** No. of important ICF concepts **/** Total items
- **Content diversity:** No. of different ICF categories **/** No. of ICF concepts
- **Ratio of relevant items** (items linked to an important ICF concept identified in interviews) **/** Total No. of items

**Example of ICF linkage**

**"I am worried if I will have an accident at work"**

- b152 Emotional functions
- b525 Defecation functions
- d850 Remunerative employment

*SF36: Short Form 36, EORTC: European Organization for Research and Treatment of Cancer Qualityof-Life Questionnaire-C30, EQ5D: EuroQol 5 Dimension, FIQL: Fecal Incontinence Quality of Life Scale, PGWBI: Psychological General Well Being Index

## Results

### 1. Important concepts: Impact of bowel dysfunction on QOL

**Body Functions**

- Sleep functions
- Energy & drive functions
- Emotional functions
- Mental functions, other
- Sensation of pain
- Defecation functions
- Sensations associated with the digestive system
- Urination functions
- Sexual functions

**Activities & Participation**

- Making decisions
- Carrying our daily routine
- Walking
- Moving around
- Moving around using equipment
- Driving
- Mobility, unspecified
- Washing oneself
- Eating
- Self-care, unspecified
- Intimate relationships
- Remunerative employment
- Recreation and leisure

**Note:** "Important concepts" were defined as those that occurred in more than the median frequency, ie ≥ 4 interviews

### 2. Content analysis of commonly used QOL instruments

| | SF36 | EORTC | EQ5D | FIQL | PGWBI |
|---|---|---|---|---|---|
| No. of items | 36 | 30 | 5 | 29 | 22 |
| No. of important concepts | 47 | 34 | 11 | 31 | 36 |
| No. of different ICF categories | 19 | 24 | 11 | 9 | 11 |
| **Content density** | **1.3** | **1.1** | **2.2** | **1.1** | **1.6** |
| **Content diversity** | **0.4** | **0.7** | **1.0** | **0.3** | **0.3** |

### 3. Concepts captured within common QOL instruments

| | SF36 | EORTC | EQ5D | FIQL | PGWBI |
|---|---|---|---|---|---|
| **No of important concepts** | 9 | 11 | 7 | 6 | 6 |
| **No. of relevant items** | 27 | 18 | 5 | 23 | 22 |
| **Ratio of relevant items:total items** | 0.75 | 0.6 | 1 | 0.8 | 1 |
| BODY FUNCTIONS | | | | | |
| Sleep functions | | X | | | X |
| Energy and drive functions | X | X | | X | X |
| **Emotional functions** | X | X | X | X | X |
| **Mental functions** | | | | | |
| Sensation of pain | X | X | X | | X |
| **Defecation functions** | | X | | X | |
| Sensations associated with the digestive system | | X | | | |
| Urination functions | | | | | |
| Sexual functions | | | | | |
| ACTIVITIES AND PARTICIPATION | | | | | |
| Making decisions | | | | | |
| Carrying out daily routine | X | X | X | | |
| Walking | X | X | X | | |
| Moving around | X | | | | |
| Moving around using equipment | | | | | |
| Driving | | | | | |
| Mobility, unspecified | | | | | |
| Washing oneself | X | X | X | | |
| Eating | | X | | X | |
| Self-care, unspecified | | | | | |
| Intimate relationships | | | | X | |
| Remunerative employment | X | X | X | | X |
| **Recreation and leisure** | X | | X | X | X |

**Note:** Bolded concepts were the top four most frequently occurring in interviews

## Conclusions

- The impact of bowel function on patients' lives involves important concepts not captured by common QOL surveys
- This could inform the development of improved decisional tools for patients with greater emphasis on patient-reported outcomes