Beyond treatment: establishing priorities in colorectal cancer supportive care and approaches to addressing them

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Introduction

Colorectal cancer (CRC) is a common cancer with improving survival rates. Post-treatment effects are common; however, little is known about longer-term effects of treatment for this growing population of cancer survivors, or what their supportive care needs and priorities are.

We undertook a program of research to identify unmet needs of CRC survivors and pathways for addressing them. A comprehensive survivorship patient reported outcome (PRO) assessment model was subsequently developed to guide assessment of PROs in clinical practice.

Aims

Our research program aimed to identify:

- Patient-reported outcomes (PROs) and experiences (PREs) during treatment, recovery, and long-term survivorship
- Patient needs and priorities for supportive care interventions
- Suitable interventions and pathways for addressing needs for delivery into clinical practice

Methods

The program of research included:

- A series of systematic reviews
- An international survey of clinicians with experience treating CRC patients post treatment
- Interviews with survivors and clinicians with experience treating CRC patients

Triangulation of findings identified key unmet needs, interventions and pathways for addressing them, and informed development of the PRO model.

Results Overall key findings

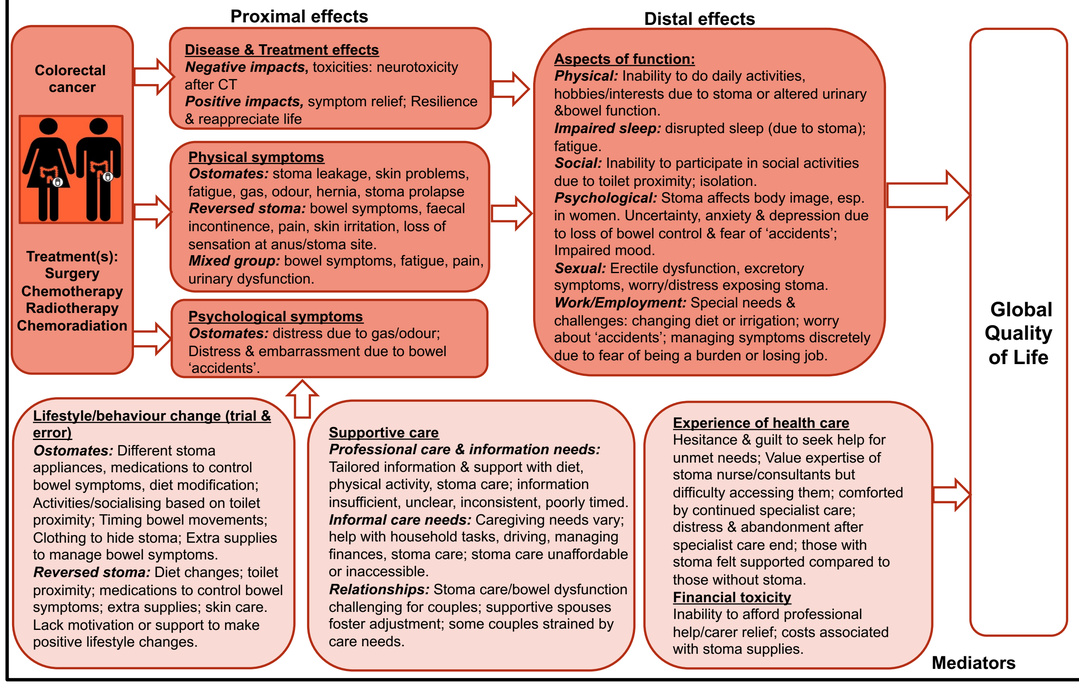
- CRC survivors experience post-treatment side-effects: bowel and sexual/intimacy concerns, commonly continue >1y post-treatment.
- Limited information about treatment-effects provided to patients results in CRC survivors being unprepared for managing side-effects.
- No coordinated systematic approach for assessment and management of these concerns, leaving CRC survivors unaware of who to ask and where to get help. Side-effects of treatment are therefore often poorly managed and largely unaddressed.
- Poor access to supportive care and allied health contributes to patients self-managing their side-effects rather than seeking help.
- Major barrier to general practitioners' ability to provide optimal supportive care is insufficient information transfer from cancer services.

- CRC survivors experience ongoing symptoms, sexual concerns and information/access unmet needs
- Behavioral adjustments ("Trial and error")
- Reluctance to seek professional support

→ Need routine PRO screening to detect unmet needs & provide timely support

PRO assessment model

Includes **6 PRO** (symptoms, impaired sleep, physical, social, psychological, sexual function), **6 mediating factors** (comorbidity, disease stage, age, lifestyle & health behaviours, financial toxicity, work), **3 PRE** (supportive care needs, healthcare experiences, financial toxicity).



PROs

- Symptoms are most sensitive to treatment and healthcare interventions.
- Persistent and unpredictable symptoms impact on physical, social, psychological, and social functioning, consequently impacting on QOL.

Mediating factors

- Lifestyle and behavior changes that reduce or exacerbate symptoms.
- Preventative and protective strategies allow participation in social and work activities, and sexual relationships.
- Age, disease stage, and comorbidities affect symptom burden and degree of functioning impairment.

PREs

- Most help from loved ones, potentially straining relationships due to changed roles, and altered sexual/intimate relationships.
- Hesitance and guilt to seek help for unmet needs.
- Value expertise of stoma nurse/consultants but difficulty accessing them.
- Unmet information needs: diet, physical activity, stoma care.
- Information insufficient, unclear, inconsistent, poorly timed.

Conclusions

CRC survivors face health challenges post-treatment but there are significant care gaps in addressing them despite evidence-based supports and guidelines available. Our model guides comprehensive assessment of PROs in CRC clinical practice and future clinical trials.

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