

Evaluating unmet needs in patients undergoing surgery for colorectal cancer: A patient reported outcome measures (PROMS) study

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Abstract

Aim

Patient reported outcome measures (PROMs) are self-reported measures of patients' health status or health related quality of life at a single point in time. We aimed to evaluate the use of a colorectal PROM, and conducted a focus group to further explore this and other unmet needs in our patient population treated surgically for colorectal cancer.

Method

A multidisciplinary research group consisting of colorectal surgeons, nurse specialists, psychologists, sociologists and patient representatives devised a composite tool of new and existing outcome measures which was piloted in our local population (n=35). Participants were subsequently invited to attend a semi-structured focus group during which the PROM was reviewed and an unmet needs analysis performed. Thematic analysis of focus group transcripts was undertaken for emergent themes.

Results

Initial consensus was for a tool including the EQ-5D, FACT-C, the distress thermometer, a validated measure of stigma, an unmet needs analysis, and questions assessing the psychological impact of cancer. Median and IQR values suggested all metrics were discriminatory with the exception of FACT-C. All participants agreed the tool was acceptable, and reflected the current state of their health and emotions. Thematic analysis of focus group transcripts identified four major themes: Physical symptoms, emotional response, information provision and coping mechanisms.

Conclusion

Through expert consensus, local piloting and patient focus groups we have evaluated a novel PROM for colorectal cancer. Furthermore, through our direct engagement with patients we have identified several unmet needs which we are currently exploring within the clinical service.

What does this paper add to the literature?

Patients having surgery for colorectal cancer frequently have physical and psychological unmet needs. Units may utilise the tools and rich qualitative data from this study to explore ways in which they might enhance current pathways to help them better meet the holistic needs of their own patients.

Introduction

Over the past two decades colorectal surgery has benefited from major improvements in pre-operative selection and patient optimisation, surgical technique, minimally invasive approaches and the evolution of enhanced recovery after surgery.[1] The combination of these advances has ensured more patients are undergoing safe surgical treatment, however with this has come a greater understanding of the physical and psychological impact of this treatment.[2] Furthermore, awareness of psychosocial impacts of illness are crucial; a recent analysis demonstrates that psychological distress may be predictive of survival in some cancer groups.[3]

Patient reported outcome measures (PROMS) are an essential tool within the current NHS, being used to facilitate patient choice as well as quality assure and benchmark services.[4] PROMS measure a patient's health status or health related quality of life at a single point in time, and are collected through short self-completed questionnaires.[5] They also serve as useful patient-focussed endpoints for clinical studies.[6] There is growing interest in the surgical community in patient outcomes, particularly for cancer services. Indeed in their clinical guideline (CG131), NICE recommended the development of a set of PROMS for colorectal cancer.[7] Whilst the feasibility of incorporating PROMS assessments into routine colorectal practice has been shown, the optimum content has not yet been fully established.[8] Through a patient consultation exercise we aimed to conduct an unmet needs analysis to better understand the physical and psychological impact of surgery on our patients, and secondarily to evaluate the utility of a novel colorectal PROM.

Method

A multi-disciplinary team of surgeons, physicians, nurse specialists, psychologists, sociologists and patient representatives was formed. The research team devised a questionnaire comprising EQ5D-3L, the distress thermometer, a validated measure of stigma, FACT-C, the 34-item supportive care needs survey (SNCS-SF34) and a newer, brief scale assessing the Psychological Impact of Cancer.[9-14] Ethical approval was obtained from the North of Scotland Research Ethics Committee. The questionnaire, which also captured rudimentary patient details and an evaluation of its efficacy, was completed over a two month period by consecutive patients attending a dedicated surveillance clinic at the Countess of Chester Hospital NHS Foundation Trust.

Participants were subsequently invited to attend a focus group with three separate trained facilitators in order to further explore both the impact of surgical (and other) interventions on functional and psychological health as well as the suitability of the questionnaire to evaluate such parameters.[15] Written consent was obtained for the focus groups, and transcripts were analysed for emergent themes using the methodology described by Braun and Clarke.[16]

Data from the original questionnaires and thematic analysis of focus group transcripts were reviewed and analysed by the research team in order to formulate a tool for clinical use which identifies key problems relevant to this specific patient population. Data were also reviewed with the clinical team to identify areas of the clinical service to be targeted for improvement on the basis of this patient engagement exercise.

Results

The questionnaire was completed by 35 participants; 28 (80%) male with a median (IQR) age of 65.4 (58.6-73.1) years. Fourteen (40%) participants had right sided resections, 13 (37%) had rectal resections and eight (23%) left colonic resections. Ten (29%) participants had stomas fashioned during their primary procedure, however four (11%) had had a reversal at the time of enrolment into the study. Twenty-one (60%) participants underwent adjuvant chemotherapy, and four (11%) of the 13 patients with rectal cancer underwent neoadjuvant chemoradiotherapy. All patients were within 3 years of their diagnosis.

Questionnaire

EQ5D-3L data were available for 29 participants, and are shown in Table 1. The median (IQR) health state visual analogue scale score [0=worst imaginable; 100=best imaginable] was 80 (70-94). The Psychological Impact of Cancer scale was completed by 27 participants, with the number of individuals reporting features within each domain shown in Table 2. The median (IQR) distress level [0=no distress; 10=extreme distress] for 29 participants was 2 (0-4). Individual responses for the stigma score (n=29) can be seen in Table 3; the median (IQR) number of affirmative responses suggesting stigma in a questionnaire of six items was 2.0 (1.0 – 3.0). Data for FACT-C (maximum possible score 28 representing good quality of life) were available for 27 participants, with a median (IQR) score of 23 (19-25) and individual item scores [0=not at all; 4=very much] of: swelling/cramps (4), weight loss (4), bowel control (3), digestion (4), diarrhoea, (4), appetite (4) and appearance (2). Seven participants responded to the stoma subset questions, with a median score of two for embarrassment and zero for difficulty.

Twenty-six participants completed the 34-item Supportive Care Needs survey, with individual item scores reported in Table 4. The most frequently reported unmet needs were 'not being able to do things' (30.8%), 'uncertainty about the future' (30.8%) and 'concerns about the worries of those close to you' (30.8%). The number of participants reporting unmet needs in one or more aspect of the: physical domain was 10 (38.5%), psychological domain was 12

(46.2%), sexuality domain was 4 (15.4%), patient care domain was 2 (7.7%) and the health systems and information domain was 6 (23.1%).

To evaluate the questionnaire, participants rated acceptability of the questionnaire, as well as its ability to accurately reflect their health and their emotional wellbeing on a Likert score from 1 (not at all) to 5 (extremely well). Mean (SD) scores were 3.29 (+/-1.34), 3.79 (+/-1.18) and 3.71 (+/-1.20) respectively.

Focus Groups

The three focus groups were over-subscribed, and we witnessed a strong desire to participate in this process. Twenty-nine participants attended a session which lasted one hour, held in a seminar room on the hospital site. A number of key themes were identified during the discussions: Physical symptoms, emotional response, information provision, and coping mechanisms. These themes and their sub themes are depicted in Figure 1. Example quotes are used throughout, with further quotes provided in Supplementary Table 1.

Physical symptoms were the most dominant discussion points. These included the side effects of chemotherapy with numbness, itching and fatigue being reported. One participant reported that *“the chemo was worse than the operation.”* The effect of treatment on eating, both with regards to the need to modify the diet and a reduced lack of enjoyment was also discussed, with one participant saying *“you don’t want certain foods to eat because they can cripple you.”* These symptoms appeared to be more problematic than the post-operative problems with which we are more familiar, specifically the systemic symptoms of difficulty sleeping and anergia, local symptoms of bowel, urinary and sexual dysfunction, and difficulties encountered with the wound and stoma in the early post-operative phase. One participant recalled *“it took five days after I got home before I could be reasonably confident of going to bed without leaking.”*

The second most dominant theme was that of the emotional response to surgery. Understandably these were uniformly negative. Fear was the most dominant negative

emotional response discussed, justifying its inclusion as a sub theme within our analysis. This included fear of recurrence, progression, death, loss of function and the negative impact of one or all of those on their family and loved ones. One participant explained that *"I don't think you can avoid worrying about the cancer returning."* Other negative emotions described were the shock of the diagnosis, and requirement for treatment, depression, embarrassment and stigma, negative self-image and feelings of isolation. One participant summarised his feelings by saying, *"I look in the mirror before I go out and I think that's about as good as it gets."*

Whilst both of those themes could to a large extent have been predicted, an unexpected finding was the dominance of information provision within the focus group discussions. This included aspects of over-provision of information with some participants explaining that they found being given excessive facts and figures quite frightening. One participant explained that *"The blue [pre-operative information] book had too much information in there; it frightened me."* This was balanced by a number of participants feeling that the information they were given was unsatisfactory, specifically with regards to the side effects of chemotherapy and the logistical and practical arrangements of investigations, surgery and follow-up. One participant added that *"Maybe it [the pre-operative information booklet] should talk about some of the practicalities you might have to deal with."* The way information was accessed was also important to participants, as many sought information from electronic sources in addition to that supplied by the clinical team. Participants reported that staff availability appeared to be a barrier to effective information provision, with one saying that *"A lot of the issues were about access to communication"*. Many felt that they were reluctant to 'bother staff' with questions relating to their treatment.

Psychological coping mechanisms was a further major theme identified during the analysis. Denial was frequently described, with many attributing symptoms relating to their disease state or treatment as merely related to ageing. One participant explained, *"I'm in my seventies now, so all my problems are age related."* The role that family and friends play in supporting patients was clearly described, although this came with a concern of the impact to the individual of placing them in this caring role. One participant highlighted the importance of including these individuals in clinical encounters by explaining that *"The biggest thing going through my mind is that nobody had spoken to my wife."* Many participants describe that their best coping mechanisms were attending support groups and their determination to achieve a positive outlook on life, although how this was achieved was

not explained. One participant said, “*Everybody kept telling me how good I looked... you’ve got to think positive!*”

The original PROM tool was discussed in detail, and all participants agreed that whilst the tool was acceptable and reflected the current state of their health and emotions it was too long, with many participants describing it as “*Quite laborious to fill in,*” and suggested that it was “*Shortened to just a couple of pages.*” The final comments that were apparent from the transcripts were the therapeutic value of being invited to participate in such a forum. Participants were also grateful for the opportunity to raise concerns and feedback, as well as provide thanks and meet with other individuals who had received similar treatment.

Discussion and conclusions

Our study shows that patients treated with surgical resection for colorectal cancer have physical and psychological needs which are not met by our current treatment pathway. Through the two arms of our study we have identified several of these. The questionnaire was designed to address four key areas: patient's perception of their overall health state; the psychological impact of a colorectal cancer diagnosis; stigma surrounding colorectal cancer and identifying unmet needs. The focus groups generated high levels of patient participation, where discussion was encouraged and facilitated by a multidisciplinary team and covered a range of topics. Physical symptoms, particularly side effects of chemotherapy and stoma management, were the leading points for discussion, and these were often very patient-specific.

Many patients understandably reported experiencing emotional distress, such as worrying the cancer will return (48.1%) and feeling frightened (29.6%), therefore the assessment of holistic needs is extremely important in order to offer the necessary help and support. Only 34.5% of patients answered that they still felt attractive as a person, which is significant as self-image has been shown to have a positive effect on recovery.[17] Working towards normalising post-operative issues such as scars, stomas and change in bowel habit could be helpful, and would hopefully mean patients found these common problems less distressing.[18] Our data also revealed that the three most frequently reported unmet needs were not being able to do things (30.8%), uncertainty about the future (30.8%) and concerns about the worries of those close to you (30.8%).

A study published by NHS England in 2015 investigated quality of life in colorectal cancer survivors using similar PROMS tools.[19] Many of the same issues we identified were also highlighted in this national data set, for example lack of information on self-management and on treatment side-effects. The patients studied in the national series reported a higher incidence of bowel-related side effects such as loss of bowel control and frequency. This may be a genuine observation, or reflect a difference in patient preparation and expectation management during the pre-operative phase leading to reduced reporting. Another study assessing the use of PROMS in breast, colorectal and prostate cancer also identified fear of

cancer recurrence and fear of dying as the most significant findings, which again feature within our own thematic analysis. [20]

Another key message from the study is that the provision of clear and appropriate information about what to expect after an operation helps patients deal with these problems as they arise. There is clearly a fine line between overloading patients with excessive detail of risk, yet still conveying there are common difficulties that they could well encounter.[21] The importance of conveying material risk was highlighted in the Montgomery vs. NHS Lanarkshire trial.[22] This is something we appear to do well, with 88.5% of patients feeling adequately informed, and 92.3% felt they had been given sufficient information about managing their illness and side effects.

Obtaining individual patient feedback understandably produces a complex and diverse range of responses. Providing a safe place within a small group facilitated by clinicians and psychologists where patients can freely discuss problems is perceived very positively by patients.[23] This emphasises the need for a multidisciplinary approach and that psychological rehabilitation should play a significant role in the recovery pathway.[24] There may also be a role for further pre-operative discussions which would negate any confusion surrounding the standard issued leaflet and provide opportunity for patients to ask questions that may arise between their clinic appointment and attendance on the day of surgery. An additional benefit to this is to minimise the likelihood of patients resorting to potentially unreliable internet sources for information.[25] The benefits of involvement in research to the patient are well understood. By participating in this pilot study, patients enable us as clinicians to gain a better perspective and insight into the frequency and complexities of issues which arise once they've left hospital. If patients see changes implemented as a result of their participation, for example regular and more specific prehabilitation and focus groups, they may feel a sense of satisfaction in knowing future patients will receive better care.[26]

We were also able to evaluate the acceptability of our PROM questionnaire during the focus groups. Participants generally found the questionnaire too long and laborious to complete fully. This is particularly true of the unmet needs analysis. We observed considerable variability in all metrics with the exception of FACT-C. Each scoring system would need to be

considered for inclusion individually in the development of a future PROM tool depending upon its clinical utility. If the aim is to identify patients who require additional care, then items such as FACT-C which did not discriminate between patients are of less value. If the aim is to capture data to help develop and build a service, then clearly this information is highly desirable. Some of the newer psychometrics, such as the Psychological Impact of Cancer scale and stigma score, are undergoing additional validation using numerical (Likert-style) responses to provide added sensitivity, which may further increase their clinical and research utility.[13,14]

A key advantage of our study is that it incorporated patients who had a wide range of pathology and treatments, and thus findings are generalizable to other units treating patients across the spectrum of colorectal cancer. The sample size was relatively small, and it would be of interest to collect results from a larger group, potentially across multiple institutions. A larger sample size would also power more informative psychometric analysis of the PROM tool. Currently our study does not look into gender specific problems, and informal feedback from focus group facilitators suggested this important area was not adequately assessed.[27] What any PROM fails to afford is the ability to identify up front those who are likely to struggle, either physically or psychologically, with their cancer treatment. We are limited by the present methodology to identifying those who are having difficulties in the post-operative setting and would benefit from additional input, accepting the potential logistical challenges that this would pose. In our department, we are currently looking at ways of incorporating PROMS data collection into routine clinical practice, and preparing a bespoke pre- and rehabilitation programme. Data from this and other studies are key to tailoring programmes such as this towards the most prevalent issues facing patients.

Through expert consensus, local piloting and patient focus groups we have evaluated a novel PROM for colorectal cancer. Furthermore, through direct engagement with patients we have identified several unmet needs. Thematic analysis of focus group transcripts highlighted the most important issues to patients as physical symptoms and emotional response, with information provision and coping featuring highly. **Units may utilise the qualitative data** from this study to explore ways in which they might enhance current pathways to help them better meet the holistic needs of their patients.

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Figure Legend

Figure 1 – Thematic analysis of focus group transcripts highlighting the major themes of physical symptoms, emotional response, information provision and coping mechanisms, along with their sub themes and content.

Tables

EQ5D Domain	No Difficulty	Some Difficulty	Severe Difficulty
Mobility	24 (82.7%)	5 (17.2%)	0 (0.0%)
Self Care	25 (86.2%)	3 (10.3%)	1 (3.4%)
Usual Activities	21 (72.4%)	5 (17.2%)	3 (10.3%)
Pain	19 (65.5%)	8 (27.6%)	2 (6.9%)
Anxiety and Depression	21 (72.4%)	6 (20.7%)	2 (6.9%)

Table 1 – EQ5D-3L data for questionnaire participants (n=29). Participants recalling no, some and severe difficulty for each domain are shown.[9]

Domain		Participants Answering Affirmatively (%)
Cognitive Distress	I feel completely at a loss about what to do	1 (3.7%)
	I feel there is nothing I can do to help myself	0 (0.0%)
	I think it is the end of the world	0 (0.0%)
Cognitive Avoidance	Not thinking about it helps me cope	11 (40.7%)
	I make a positive effort not to think about my illness	17 (63.0%)
	I deliberately push all thoughts of cancer out of my mind	10 (37.0%)
Fighting Spirit	I see my illness as a challenge	16 (59.3%)
	I try to fight the illness	17 (63.0%)
	I am determined to beat this disease	20 (74.1%)
Emotional Distress	I worry about the cancer returning or getting worse	13 (48.1%)
	I am apprehensive	9 (33.3%)
	I am a little frightened	8 (29.6%)

Table 2 – Psychological impact of cancer data for questionnaire participants (n=27). The number of participants answering affirmatively (reversed where appropriate) are shown.[13]

Stigma Question	Participants Answering Affirmatively (%)
I feel having cancer has substantially affected my life	10 (34.5%)
I still feel an attractive person	10 (34.5%)
I am not to blame for my illness	16 (55.2%)
I feel differently about myself as my illness has progressed	9 (31.0%)
My illness is not contagious	13 (44.8%)
I try not to tell people about my illness	7 (24.1%)

Table 3 – Stigma score data for questionnaire participants (n=29). The number of participants answering affirmatively (reversed where appropriate) are shown.[14]

Domain	Item	Participants with Need Met (%)	Participants with Need Un-met (%)	Ranking
Physical	Pain	22 (84.6)	4 (15.4)	12 =
	Lack of energy/tiredness	19 (73.1)	7 (26.9)	4
	Feeling unwell a lot of the time	23 (88.5)	3 (11.5)	15 =
	Work around the home	21 (80.8)	5 (19.2)	6 =
	Not being able to do things	18 (69.2)	8 (30.8)	1 =
Psychological	Anxiety	21 (80.8)	5 (19.2)	6 =
	Feeling down or depressed	21 (80.8)	5 (19.2)	6 =
	Feelings of sadness	22 (84.6)	4 (15.4)	12 =
	Fears about the cancer spreading	21 (80.8)	5 (19.2)	6 =
	Worry that the results of treatment are beyond your control	21 (80.8)	5 (19.2)	6 =
	Uncertainty about the future	18 (69.2)	8 (30.8)	1 =
	Learning to feel in control of your situation	20 (76.9)	6 (23.1)	5
	Keeping a positive outlook	24 (92.3)	2 (7.7)	23 =
	Fears about death and dying	23 (88.5)	3 (11.5)	15 =
	Concerns about the worries of those close to you	18 (69.2)	8 (30.8)	1 =
	Sexuality	Changes in sexual feelings	23 (88.5)	3 (11.5)
Changes in your sexual relationships		23 (88.5)	3 (11.5)	15 =
Being given information about sexual relationships		23 (88.5)	3 (11.5)	15 =
Patient Care	More choice about which cancer specialists you see	26 (100.0)	0 (0.0)	33 =
	More choice about which hospital you attend	25 (96.2)	1 (3.8)	26 =
	Reassurance by medical staff that the way you feel is normal	25 (96.2)	1 (3.8)	26 =
	Hospital staff attending promptly to your physical needs	25 (96.2)	1 (3.8)	26 =
	Hospital staff acknowledging and showing sensitivity to your feelings and emotional needs	25 (96.2)	1 (3.8)	26 =
Health Systems and Information	Being given written information about the important aspects of your care	23 (88.5)	3 (11.5)	15 =
	Being given information about aspects of your managing your illness and side effects	24 (92.3)	2 (7.7)	23 =
	Being given explanations of those tests for which you would like explanations	25 (96.2)	1 (3.8)	26 =
	Being adequately informed	23 (88.5)	3 (11.5)	15 =

about the benefits and side-effects of treatments before you choose to have them			
Being informed about your test results as soon as feasible	21 (80.8)	5 (19.2)	6 =
Being informed about cancer which is under control of diminishing	26 (100.0)	0 (0.0)	33 =
Being informed about things you can do to help yourself get well	22 (84.6)	4 (15.4)	12 =
Having access to professional counselling if you or your family or friends need it	23 (88.5)	3 (11.5)	15 =
Being treated like a person not just another case	25 (96.2)	1 (3.8)	26 =
Being treated in a hospital or clinic that is as physically pleasant as possible	24 (92.3)	2 (7.7)	23 =
Having one member of hospital staff with whom you can talk to about all aspects of your condition, treatment and follow-up	25 (96.2)	1 (3.8)	26 =

Table 4 - 34-item supportive care needs survey (SNCS-SF34) responses for questionnaire participants (n=26). The number of participants with their needs met (score 1-2) and un-met (score 3-5) are shown. Items are ranked by the proportion of those with unmet needs in the studied population.[10]