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Colorectal and anal cancer patients experiences during pelvic radiotherapy: a service evaluation

Joseph David Bowen[1], Bridget Porritt[1] and Linda Appleton[2]

[1]University of Liverpool, Brownlow Hill, Liverpool, UK and [2]The Clatterbridge Cancer Centre, Liverpool, UK

Original Article

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Corresponding author:
Bridget Porritt; Email: bporritt@liverpool.ac.uk

Abstract

Introduction: Pelvic radiotherapy can be an important management option for people diagnosed with colorectal or anal cancer, who often experience a wide range of adverse effects that can be detrimental to Quality-of-Life (QoL) due to the radiotherapy. Clinical nurse specialists (CNS) are valuable multi-disciplinary members who provide a range of practical and holistic support to these patients, via on-treatment review appointments. A lack of evidence exists relating to colorectal and anal cancer patients' perceptions of on-treatment CNS review appointments.
Methods: A service evaluation of the nurse-led on-treatment appointments using a questionnaire was undertaken. Yes/No, Likert Scale and free-text questions were asked, allowing for quantitative and qualitative data collection. Ethical approval was obtained. Standard quantitative data analysis and thematic analysis (TA) methods were used.
Results: Twelve [12] colorectal and anal cancer patients participated. The data showed that patients had positive experiences with their appointments, but had fears regarding the unknown and the future.
Conclusion: Patients were satisfied with the on-treatment review service, and the results suggest that the service is efficient and effective. Future research should evaluate this type of colorectal CNS service across a larger colorectal and anal cancer patient population.

Introduction

Introduction and background

Colorectal cancer (CRC) is the 4th most common cancer diagnosis in England. Each year, around 44,000 cases are diagnosed[1] with the highest incidence rates in males and people aged 85 to 89.[2] Whilst CRC incidence rates have remained steady over the last 5 years, and cancers are being diagnosed at an earlier stage due to the bowel cancer screening programme and public health initiatives.[3] There are concerns that incidence is rising in young adults and more CRC patients are living with the consequences of their cancer and treatment for longer due in part to improvements in screening and CRC treatment.[4]

Patients with CRC require a collaborative multi-disciplinary approach to treatment, as treatment often involves surgery, chemotherapy and radiotherapy.[5] CRC patients often require intensive support and care due to having multi-modality treatments compared to other pelvic radiotherapy patients, which impacts quality of life both during and after treatment.[6,7] Therefore, CRC supportive care is essential in ensuring that these patients receive the optimum care throughout their cancer care journey.[5] The management approach is an individualised process that involves many oncology multi-disciplinary team (MDT) members including but not limited to surgeons, oncologists, therapeutic radiographers and clinical nurse specialists (CNSs); all are key to ensuring that CRC patients receive evidence-based inclusive care which meets their needs.[8]

An integral member of the CRC MDT is the colorectal CNS, who is crucial in providing effective care to CRC patients throughout treatment and follow-up, offering valuable supportive and holistic care alongside the management of treatment-related side effects.[9,10] The symptoms and tolerance to treatment experienced by some CRC patients during and following treatment can be distressing and wide-ranging. Common side effects of this pelvic radiotherapy include fatigue, pain and gastrointestinal and genitourinary problems.[11,12] Continued evaluation of the CRC patient experience is key to ensuring that current and future models of support meet the evolving needs of the diverse CRC population. A recent review highlighted that CNS support is associated with improved survival.[13]

Alongside managing physical side effects, holistic support management is an important role of all healthcare professionals (HCPs) involved in the patient's cancer pathway.[9,14] CNSs are in ideal positions to provide this support due to regular on-treatment appointments with patients. Research, evaluating the impact of CNS appointments on Quality-of-Life (QoL) in CRC patients, would enable an effective review of the colorectal CNS on-treatment appointment service.

Due to the COVID-19 pandemic, many healthcare appointments were moved to a digital environment, including colorectal CNS on-treatment appointment services.[15] A large proportion of telemedicine literature endorses the use of telemedicine with randomised controlled trials and systematic reviews concluding that telemedicine has high levels of patient satisfaction and engagement.[16,17] However, when completing The National Cancer Patient Survey, 81.6% of patients completed the survey on paper, suggesting that there is an apprehension towards using information communication technology (ICT) in the cancer patient population.[18] Research identifying patient satisfaction with ICT will help establish patients' apprehension towards using ICT in a consultation environment.

Study justification

CRC patients are often seen weekly by CNSs whilst undergoing radiotherapy treatment. There is a lack of evidence on CRC patient preferences for engaging with the CNS while receiving radiotherapy, that is, whether face-to-face, telephone or online. Limited evidence specifically relates to these patients' views of their QoL discussions with their CNS.

This study aims to evaluate CRC patients' views of on-treatment appointments during radiotherapy with their CNS. A survey was used to assess patients' preferred appointment format and satisfaction with QoL discussions. Results from this survey will be used to guide the format and content of CNS appointment discussions within the CRC patient population.

Methods

This study aimed to evaluate CRC and AC Radiotherapy patients' satisfaction with their on-treatment review appointment format and QoL discussion with their CNS. The study lead worked with a statistician from the Trust at which the study was conducted to consider which statistical tools should be used to analyse the dataset. The questionnaire was developed by the study using principles of design informed by current frameworks and best practices.[19,20]

Ethical Approval was granted on the 6th July 2023 by an audit committee via a Quality Improvement Proposal Form (QUIP) **(Appendix A)**. A Confidentiality statement was attained on 11th August 2023 **(Appendix B)**. This stated the confidential requirements of the project, regarding the collection and intended use of the data.

Sample

The purposive convenience sample of 12 people diagnosed with CRC wasrecruited, who were receiving pelvic radiotherapy and on-treatment CNS appointments at one National Health Service Foundation Trust (NHSFT) (Figure 1). The sample size was determined by the number of CRC patients attending on-treatment CNS appointments and the timescales of the study.

Participants were recruited via their CNS during appointments. The survey took place from 21st November 2023 to 13th March 2024.

Data collection

The survey was made available through the Trust survey tool, with participants using a QR code to access it and complete it anonymously. No identifiable information was collected from participants. Patients without access to a mobile device or who preferred to complete a paper survey were provided with a paper copy. The questionnaire was self-completed by the patient independently, with no requirement for recorded responses. Each patient completed the survey once.

- Colorectal cancer patients,
- Participants receiving radical radiotherapy as part of their Colorectal cancer treatment,
- Participants receiving on-treatment appointment(s) with a Clinical Nurse Specialist,
- Participants have the ability and understanding to give informed consent, as defined by the Mental Capacity Act 2005,
- Participants can receive and answer questions verbally and/or in writing in English,
- Participants are **not** in a vulnerable group such as palliative, a prisoner, have mental health problems or detained under the Mental Health Act 1983,
- Participants who are **not** deemed fit enough by the Clinical Nurse Specialist to undertake the study, in line with legal and/or practice legislation/guidelines are ineligible,
- Participants are over the Age of 18,
- Participants are/have received radiotherapy treatment/Clinical Nurse Specialist appointment at one National Health Service Foundation Trust.

Figure 1. Recruitment eligibility criteria.[21,22]

The survey collected data via a questionnaire with closed-answer questions, Likert Scale questions and free-text questions, to enable the attainment of quantitative and qualitative data.

The questionnaire was completed following a colorectal CNS review appointment. Patients were invited to take part by the CNS, who provided details about the nature of the study and the opportunity for any questions to be answered. If the patient was willing to complete the survey, consent was implied by the return of the completed survey.

Participants were at various stages of their radiotherapy treatment when they completed the questionnaire, as per the eligibility criteria. All the survey results were collected and transcribed quantitatively by the NHSFT and quantitative data analysis was performed. No statistical tests were performed due to the homogeneity and limited number of responses.

Data analysis

The researcher conducted Thematic Analysis (TA) to analyse the qualitative data that arose in the free-text comments. Four themes arose in the data when conducting TA: a positive patient experience, holistic support, the fear of the unknown and sexual health concerns.[23] TA is a popular analytical method of choice for exercising phenomenology, and in this research, it effectively enabled the patient's reasoning and meanings to be understood and analysed.[24]

Results

This survey enabled patients to reflect on the experience of their on-treatment appointments with CNSs via a questionnaire by answering twenty-three questions divided into Yes/No closed-answer questions, Likert Scale and free text questions. Twelve [n = 12] patients with either rectal cancer (RC) [n = 7] or AC [n = 4] participated in the survey (Table 1). One [n = 1] participant stated to have bowel cancer (Table 1). Participants wrote their answers into a free-text box, therefore variations of 'Rectal Cancer' and 'Anal Cancer' arose such as 'Rectal' [n = 2] and 'Anal' [n = 2]. These answers were accepted into the data analysis. The

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Table 1. Cancer diagnosis

Cancer Diagnosis	Number (n = 12)	Percentage (%)
Rectal cancer	7	58
Anal cancer	4	33
Others	1	8

Table 2. Number of radiotherapy treatments patients received

Participant	Treatment number
Participant 1	28
Participant 2	9
Participant 3	16
Participant 4	28
Participant 5	25
Participant 6	20
Participant 7	25
Participant 8	25
Participant 9	20
Participant 10	22
Participant 11	12
Participant 12	14
Mean = 20.3 *Median = 21.0* *Mode = 20.0* *Range = 9.0–28.0*	

Table 3. Method of survey completion

Method of Survey Completion	Number (n = 12)	Percentage (%)
On paper	9	75
Electronic	3	25

participants were at various stages of their radiotherapy treatment for CRC or AC, ranging from 9 to 28 fractions [mean = 20.3] (Table 2). They completed the survey either on paper [n = 9] or electronically [n = 3] (Table 3).

All the participants had received a weekly follow-up appointment and were satisfied that they were able to discuss all the issues that mattered to them. The Likert Scale answers ranged from 'Extremely satisfied' to 'Neither satisfied nor dissatisfied' with no negative answers such as 'Not satisfied'. This suggests that the patients had a positive experience of their appointments with the CNS. There were no significant differences in the responses from the patients who completed the survey on paper compared to electronically.

Key finding—positive patient experience

Regarding a positive experience, patients commented on the friendly and caring nature of the CNSs.

'I felt heard and well supported' (P9, Q11)

Participants also commented on their satisfaction with discussions around physical health concerns and emotional health concerns.

'I was given cream for my burning skin' (P7, Q9)

'[CNS] always enquired about my self-wellbeing'. (P4, Q11)

Participants were also satisfied with the length of their appointment time, commenting on their flexibility and sufficient length.

'Appointments are very flexible'. (P12, Q22)

'I was given as much time as I needed'. (P7, Q7)

Key finding—holistic support provided

Participants also reported well-being and care that goes beyond physical and practical interventions as important to them, and they valued the time they had with their CNS.

'Helped talk when felt a bit down'. (P5, Q11)

'I look forward to my appointments with the nurse'. (P6, Q9)

Key finding—fear of the unknown

Despite the positive patient experiences, 50% of patients expressed worries/concerns about future healthcare pathways or the fear of cancer recurrence (FCR).

'I will always worry about upcoming scan results' (P1, Q21)

'The fear of the unknown'. (P12, Q21)

Key finding—sexual health needs

Participants reported receiving education and information on sexual health issues, suggesting positive levels of patient satisfaction.

'We talked about the dilator and how to use it . . . ' (P1, Q13)

'Good information'. (P3, Q20)

Discussion

This study aimed to evaluate CRC Radiotherapy patients' satisfaction with their on-treatment appointments through a questionnaire. Limited evidence exists evaluating these patients' views of on-treatment appointments, especially around format and QoL discussions. This is surprising as CRC prevalence in the UK is high[1] and the QoL assessment tool PROMs (Patient Reported Outcome Measures) are used extensively within cancer care.[6] This survey enabled the identification of any current or possible future challenges in sustaining this colorectal CNS-led on-treatment and follow-up service. Analysis is based on a very small survey population, and further large-scale data collection is needed to strengthen findings and inform future service delivery.

Participants consistently reflected on their positive experience of the appointments, often attributing them to the useful practical solutions they were offered to manage physical and sexual health concerns, the friendly and positive relationship they had with their CNS and the sufficient time for appointments. The positive experience of the participants reflects the overall patient experience in the National Health Service (NHS), as the National Cancer Patient Survey reported that 89.6% of participants felt they had a positive experience of their cancer care.[18] Positive patient experiences create an empowered patient population that becomes more actively involved in healthcare and health promotion, leading to better care outcomes.[18,25,26] Furthermore, patient satisfaction is

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an important aspect of effective and safe healthcare delivery, including radiotherapy.[27,28]

The need to provide effective and holistic care is essential in delivering an effective cancer care service.[28,29] The findings suggest that CNSs are key support mechanisms for patients and are valuable MDT members.[8,10] Due to CNSs having regular appointments with patients, they are in an ideal position to provide this holistic support.

Despite patients having positive experiences, worries and or concerns surrounding future healthcare pathways and FCR were expressed. FCR is one of the leading causes of reduced QoL in cancer patients during the post-treatment phase.[30] There are various management strategies for FCR including cognitive behaviour therapy (CBT). The SWORD trial found that a blended CBT approach was effective in managing FCR and HCP, specifically, CNSs could utilise it.[30,31]

Despite high levels of patient satisfaction around practical management solutions for sexual health concerns, discussions around the psychological and social effects of sexual health concerns and dysfunction were absent. In the literature, patient-HCP sexual health discussions in the cancer population are often minimal, with Morgan reporting that discussions around sexual functioning in female patient cohorts are inadequate and that education and training of HCPs are essential in increasing these discussions and providing the best support to patients.[32]

The findings of this service evaluation assure that the colorectal CNS service at the NHSFT is effective, efficient and has high levels of patient satisfaction. This service evaluation had several important limitations. Limitations were that this was a single-centre study recruiting a small sample size. The only negative response portrayed was the fear of the unknown. Due to the layout of the questionnaire, respondents were limited in the amount of contextual information they were able to provide. If respondents were able to transcribe or be interviewed, it would likely enable respondents to discuss or explain their answers further, increasing the clarification of their answers. No demographic or patient data regarding previous treatment, stage and grade of disease were attained. This data could have enabled analysis and comparisons of demographic groups and may have enabled the CNSs to provide more targeted support. Baseline QoL data were not attained. Baseline QoL information would have been useful for comparison of QoL effects.

Conclusion

This study aimed to evaluate CRC patients' experience of their on-treatment CNS appointments regarding appointment format, length and QoL discussions. The findings show that patients have positive experiences with their CNS and are satisfied with the appointment format and length. The results identify that the CNSs provide effective, practical and holistic care and have a pivotal role in patient care. The focus of the discussions in the appointments should remain around physical health concerns; however, enhanced discussions around sexual health would be beneficial. Furthermore, the layout and format of the appointments should remain the same due to the high levels of patient satisfaction around these issues.

Recommendations for future practice

This service evaluation provides some assurance that colorectal CNS approach to CRC patient support during radiotherapy is effective, efficient and has high levels of patient satisfaction. A longitudinal, large cohort study of this work would be beneficial, as it would allow data to be compared at different stages of radiotherapy and would enable comparison. There is a known gap in the literature regarding discussions around sexual health concerns. Further research evaluating sexual health discussions in the CRC cancer population would be beneficial. In addition, research into the enablers and barriers of sexual health discussions in the oncology workforce would be beneficial.

Supplementary material. The supplementary material for this article can be found at https://doi.org/10.1017/S1460396925100150.

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Competing interests. The author(s) declare none.

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