Title:

A systematic review of the follow-up priorities of colorectal cancer survivors

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Abstract

Background: Colorectal cancer (CRC) is the third most common cancer worldwide. Survival has improved over recent years and CRC survivors are a growing group of patients living with and beyond a diagnosis of cancer. This study aims to explore the follow-up priorities of CRC survivors and to determine if all those affected by CRC have been given a voice through current literature. **Method:** A systematic integrative literature review was performed across three databases— CINAHL, Medline and PsycINFO—from 2014 to 2024. This yielded 12 papers for inclusion. Thematic analysis was undertaken with themes from each paper identified and coded. Common themes grouped and renamed. **Results:** Six themes emerged: understanding and managing long-term effects of treatment; the importance of good information; delivery of follow-up care; ease of access to care and investigations; fear of recurrence; and the changing impact of cancer treatment. Ethnic minority groups and non-native language speakers appeared underrepresented in the included studies; only 50% of included studies made ethnicity data available. It was not possible to determine whether other groups had been included, such as members of the LGBTQ+ community, those with learning disabilities or those with mental health conditions. **Conclusions:** Survivors of CRC require access to information and support to manage the effects of treatment in the short, medium and long term to optimise quality of life post treatment. The approach to this should be shaped to the preference and need of the individual. Colorectal cancer Clinical Nurse Specialists need to tailor practice and use their expertise to meet the needs of CRC survivors during follow-up care processes. More evidence is needed on the follow-up priorities of CRC survivors from underrepresented groups to ensure that the voice of all groups is heard and their needs addressed.

Key words

Colorectal Cancer follow-up.
Nurse patient relationship.
Underrepresented groups.
Personalised Care.
Managing Effects of Treatment.

Key points

During follow up Colorectal Cancer Patients require:
Good Information about follow up care and managing the short- and long-term effects of treatment.
Choice about how follow up care is delivered.
Support to manage fear of recurrence.
More research is needed to explore the views of underrepresented groups.

CPD reflective questions

Consider the role of the Clinical Nurse Specialist in the follow up care of colorectal cancer patients.

Consider how nursing research could ensure that the voice of all those affected by colorectal cancer is heard through academic literature.

Consider in what circumstances would the personalised care pathway of remote follow up supported by Holistic Needs Assessments and Health and Wellbeing Events not be accessible for colorectal follow up patients.

How might your current service meet the needs of those affected by Colorectal Cancer during follow-up?

Author contribution

Claire Coughlan undertook the systematic review as part of a Professional Doctorate in Nursing. All other authors are part of the supervisory team and provided guidance on methodology and discussion of themes. The paper was written in full by Claire Coughlan with comments and revisions guided by the wider team of authors.

Main copy

Colorectal cancer (CRC) is the third most common cancer worldwide; survival has improved over recent years (Qaderi et al, 2020). Survival rates for CRC patients vary depending on its' stage of severity, with stage 1, 2 and 3 rate being 95%, 90& and 70%, respectively (Qaderi et al, 2020). High survival rates have made CRC survivors a large, growing cohort of patients living with and beyond cancer (Haas et al, 2023). In 2013, the government in the UK set out its survivorship agenda in: *Living with and beyond cancer: taking action to improve outcomes* (NHS England, 2013). This outlined a range of initiatives aimed at supporting cancer survivors away from the traditional hospital outpatients setting and into the community. It recommended the implementation of conference-style health and wellbeing events, cancer care reviews by GPs and holistic needs assessments carried out by specialist nurses. While the document focused on personalised care for cancer survivors, cost savings were also an anticipated outcome, with savings coming from a reduction of appointments in secondary care.

Implementation of the survivorship agenda has begun in many NHS Trusts. This has followed principles of 'best practice' based on evidence (Pearson et al, 2009). There has been a substantial amount of research into what CRC survivors want from follow-up care, which has included effective and digestible information to manage the effects of cancer treatment ((Beaver et al, 2010; Richards et al, 2011). There is evidence that the survivorship agenda yielded positive outcomes (Beaver et al, 2010; Richards et al, 2011; Taylor and Odey, 2011; Siddika et al, 2015; Qaderi et al, 2020). However, many of the findings are limited by exclusion of patients who:

- Could not speak the native language
- Have low health literacy
- Were from minority ethnic groups
- Were from the LGBTQ+ community
- Were from socially disadvantaged groups
- Have a learning disability (Beaver et al, 2010; Qaderi et al, 2020; National Institute for Health Care Research (NIHR), 2021).

This has been acknowledged by the NIHR, who published a diversity data report in 2021 highlighting that much current care provision is based on evidence not fully representative of the society served (NIHR, 2021). NIHR went on to develop a strategy to address this deficit (NIHR 2021).

If the preferences of survivors of CRC are not heard, acknowledged and acted upon, survivors may experience unnecessary negative impacts to their quality of life in health, economic and social terms (NIHR, 2021). To explore what is known about follow-up care priorities of survivors of CRC, and to inform the sampling strategy for further research, a review of the literature has been undertaken using the research question: What are the follow-up care priorities of survivors of CRC?

Aims

This research study had two central aims:

- To determine the follow-up preferences of CRC survivors.
- To determine if the preferences of all survivors of CRC are described in the literature, or if some groups are either underrepresented or have been excluded.

Methods

An integrative review, where studies are reviewed and re-interpreted to explore common themes (Whittemore and Knafl, 2005; Aveyard et al, 2016), was selected as the methodological framework. The integrative review included primary research papers with different methodological approaches, including qualitative, quantitative and mixed methods. A total of 12 papers were identified for inclusion in the study.

Search strategy

The search strategy was developed by the research team (Table 1). Three databases were selected to run the searches including CINAHL, Medline, PsycINFO. These were selected for their focus on physical and psychological health. As the focus of the review was on current approaches to follow-up care, the timeframe set for the search was from the beginning of March 2014 to the beginning of March 2024.

[Table 1: at back]

Eligibility criteria

Studies were considered for inclusion or exclusion based on the criteria shown in Table 2.

[Table 2: at back]

A total of 2091 articles were found through the search. The articles were screened first by title, then by abstract in accordance with the inclusion and exclusion criteria. A total of 34 articles were screened in full, with 12 studies being retained for inclusion in the review (Figure 1).

[Figure 1: at back]

Quality assessment

Studies were assessed using the Joanna Briggs Institute (JBI) Critical appraisal checklists. Three checklists were used; the JBI Critical Appraisal Checklist for Analytical Cross Sectional Studies (JBI, 2020b), the JBI Critical Appraisal Checklist for Cohort Studies (2020a) and the JBI Critical Appraisal Checklist for Qualitative Research (2020c). A combination of appropriate checklists were used for mixed-method studies. In all cases, the studies selected for inclusion were deemed to be appropriate in their methodological approach.

Results

Data extraction and synthesis of findings

The 12 papers included were read in full to identify themes relating to the experiences of colorectal cancer survivors. They were also analysed to see if demographic data was included and, if so, if this included ethnicity and if the study had been made accessible to non-native language speakers. The findings are summarised below in Table 3.

Themes and results described in each paper were coded. Prevalence of themes was then denoted to identify commonality of themes that were identified in multiple papers. The common themes were grouped and renamed.

Data comparison and characteristics of selected studies

The approach to the literature review meant that studies from all methodological disciplines could be included. Five of the studies were qualitative using focus groups and interviews (Williamson et al, 2015; Mead et al, 2020; Yoon et al, 2020; Vos et al, 2022; Fernandes et al, 2023). Six were quantitative and used questionnaires and statistical analysis (Murchie et al, 2016; Wieldraaijer et al, 2017; Wright et al, 2017; Wildraaijer et al, 2019; Sodergren et al, 2019; Drury et al, 2020). The remaining study adopted a mixed-methods approach, and used data from the cross-sectional part of the energy for Life after CRC (EnCoRe) study; interviews were also carried out using subjects from the study population of the cross-sectional study (Breedveld-Peters et al, 2020). This study examined connected results of both the cross-sectional study and the interviews for a better understanding of the participation restrictions on health and functioning problems experienced by CRC survivors (Breedveld-Peters et al, 2020). The numbers of respondents in the quantitative or mixed-methods studies that purely focused on CRC survivors ranged from 179 to 526. The number of participants in the qualitative studies ranged from 21 to 32.

All the papers included some demographic data. Biological gender and age were available for all papers. However, data on the ethnicity of respondents were not presented in six of the studies (Williamson et al, 2015; Murchi et al, 2016; Wieldraaijer et al, 2017; Wildraaijer et al, 2019; Breedveld-Peters et al, 2020; Vos et al, 2022). Sodergren et al, (2019) was the only study that stated that non-native language speakers were given the opportunity to participate, although it was not clear if any had done so. Fernandes et al (2023) stated that despite attempts at inclusion, there were no participants from an ethnic minority background included in their study. None of the studies reported on inclusion of those with existing mental health conditions (except for depression, which was listed in studies explicitly listing co-morbidities), learning disabilities or if members of the LGBTQ+ community were represented. While some studies included socio-demographic data; for example, employment or insurance status, only Sodergren et al (2015) drew a conclusion from this, stating that no significant associations were found between co-morbidities and any other socio-demographic, clinical or treatment factors that limited daily activities.

Themes

Six themes were identified across the 12 papers. The themes in each article were initially identified and recorded on an Excel spreadsheet with theme titles (or codes) being allocated to each new theme. Then, they were further broken down into subgroups. The subgroups were clustered and renamed, which resulted in the identification of six themes. In addition, the demographic, ethnicity, sociodemographic information included in each study was extracted to establish the groups that were represented in each study.

Theme 1: understanding and managing long-term effects of treatment

Studies highlight the value that CRC survivors place on understanding post-treatment effects (Murchie et al, 2016; Mead et al, 2020; Yoon et al, 2020). Survivors expressed a clear need for health professionals to acknowledge the effects of treatment and the management of these effects. Mead et al (2020) focused on 13 core principles, one of which demonstrates the adjustment required by cancer survivors to live with the consequences of their cancer treatment. Many of the focus group discussions explored the importance of healthcare professionals recognising and emphasising the extent of consequences of treatment. Similarly, Yoon et al (2020), who studied Asian CRC survivors, identified a recurring theme focusing on what they describe as the 'distressing long-term effects' of cancer treatment. They highlighted common physical side effects of altered bowel habits, peripheral neuropathy and fatigue. For some, these effects prohibited or limited daily activities. For others, there was a fluctuation of long-term effects that had a psychological impact.

In some studies, there was an expressed need for counselling, with this being important to patients managing the effects of their treatment (Murchie et al, 2016; Yoon et al, 2020; Drury et al, 2020). Murchie (2016) identified that CRC survivors have a greater need for support in managing late effects when compared to survivors of other cancers. Breedveld-Peters et al's (2020) study explored the impact of restrictions on everyday life caused by long-term effects of treatment for CRC. Fatigue, peripheral neuropathy and unpredictable bowel function were found to negatively affect participants' satisfaction, resulting in their inability to function on a day-to-day basis. Passing flatus, haemorrhoidal bleeding and fatigue were highlighted as issues negatively impacting their daily lives (Sodergren et al, 2019; Breedveld-Peters et al, 2020; Vos et al, 2022). Further evidence of the long-term effects of treatment was discussed by Breedveld-Peters (2020), where despite some interviewed participants (10 CRC survivors) having had treatment for CRC almost 7 years previously, they reported that the consequences of treatment still impacted their daily lives.

Vos et al (2022) used supportive care domains to categorise patients' needs identified in recorded outpatient consultations. The domains used were divided into health system information, cancer-related physical and daily living, non-cancer-related physical and daily living, psychological, and sexuality. While concerns were spread over the domains, most related to the domain of 'physical and daily living', both related and unrelated to cancer and the impact of this on daily life. Interestingly, they observed that there were few concerns expressed about sexual function or intimacy, and few healthcare professionals prompted a discussion on the topic. Other studies had reported concerns about sexual or intimate relationships after treatment (Sodergren et al, 2019). Many studies (Wright et al, 2017; Sodergren et al, 2019; Wildraaijer et al, 2019; Breedveld-Peters et al, 2020; Drury et al, 2020; Mead et al, 2020; Yoon et al, 2020; Vos et al, 2022) discussed that managing the effects of treatment, and understanding that there would be a need for this, was a key priority for participants.

Theme 2: the importance of good Information

The need for clear, relevant accessible information was consistent throughout the reviewed literature. Wright et al (2017) looked specifically at preferences for the provision of dietary information and examined the cost of care delivery, needs and preferences. They identified subgroups within the total CRC survivorship population and found that those identified as most 'at risk' from poor adherence to healthy behaviours were most likely to benefit from lifestyle and dietary advice and information being delivered in the way that they identified as preferential. In Drury et al's (2020) study, 80% of respondents stated they had access to a named healthcare professional to approach for information; despite this, two thirds of respondents reported one or more unmet information need.

While some patients reported feeling well informed about their treatment and follow-up programme, they also reported feeling ill-informed about what to expect in the future. This feature highlighted the importance of effective, continuous information (Wieldraaijer et al, 2019). This supports the findings of Mead et al (2020), who found that CRC survivors expressed that healthcare professionals had a lack of understanding of the long-term effects of treatment and the resulting care needs, and they found it difficult to access information on the subject. Wieldraaijer et al (2019) also found that over a 5-year follow-up period, patients consistently expressed that they required more information on future expectations, nutrition and exercise, as well as hereditary cancer. Furthermore, patients felt best informed in their first 6 months of follow-up care. The impact of good information aiding the ability of patients to manage at each stage of their treatment and follow-up pathway was evident in some study results (Murchie et al, 2016; Wright et al, 2017; Sodergren et al, 2019; Drury et al, 2020).

Drury et al (2020) specifically examined the association between healthcare experiences and quality of life. The study was conducted in Ireland where, similarly to the UK, care plans and treatment summaries that provide information listing potential effects of treatment were undertaken in some areas. Drury et al (2020) found that treatment summaries may not positively affect communication and information needs. While one third of the 304 participants in their study had an end of treatment summary, over two thirds of respondents had at least one unmet information need. They speculate that at worst, end of treatment summaries may be detrimental and associated with greater symptom burden. Similarly to Drury et al's (2020) findings, the ColoREctal Well Being (CREW) study, a large multicentre study carried out in the UK by Sodergren et al (2019) examined the association between unmet needs and health related quality of life. They found that unmet needs persisted over time and, similarly to Wieldraaijer et al (2019), having more unmet needs was detrimental to quality of life.

Theme 3: delivery of follow-up care

This literature review highlights the importance of approach to delivery in follow-up care (Mead et al, 2020; Yoon et al, 2020). Mead et al (2020) reported that 185 respondents valued supportive and responsive providers of follow-up care. However, they reported that some participants expressed frustration that they could not access this. There was also high value placed on seamless care, with many participants finding this was unavailable. Yoon et al (2020) found that many of the 30 long-term CRC survivors interviewed for their study of support needs of Asian survivors were anxious about when their face-to-face appointments and follow-up checks would stop. They expressed that at times, the quality of follow-up appointments left them feeling that they were navigating health care with 'limited direction'

(Yoon et al, 2020). While there was value placed on peer support, some participants highlighted the lack of ethnic diversity in peer support they accessed.

Drury et al (2020) found that of the 304 CRC survivor participants surveyed, 95% of those receiving hospital-based follow-up care in surgical and oncology clinics were satisfied with the support received, compared to 76% satisfied with support in primary care and 61% in community settings. They also found that access to a named nurse in secondary care was directly related to emotional wellbeing. A lack of confidence in the cancer-related knowledge of primary care professionals was expressed. Williamson et al (2015) looked specifically at experiences of nurse-led telephone follow-up care following treatment for CRC. While consent to participate may indicate a preference for telephone follow-up care, all participants found it to be a positive experience. Similarly to the findings of other studies (Drury et al, 2020; Yoon et al, 2020; Vos et al, 2022), personalised follow-up care was seen as very important.

The value of the nurse patient relationship was also seen as key to a positive experience, with patients commenting that because of their relationship with the specialist nurse they found it possible to discuss even the most intimate problems (Williamson et al, 2015; Drury et al, 2020). Williamson et al (2015) explored telephone follow-up care and reported that participants found it to be useful. This supports the finding of Wright et al (2017), who showed that in general, older patients preferred a telephone approach, while younger CRC survivors preferred face-to-face contact with a specialist bowel cancer nurse. However, there are limitations to the generalisability of the study findings, as it focused on the preferences of CRC survivors on different aspects of dietary interventions, rather than on more general follow-up care.

Murchie et al (2016) focused specifically on the preference of cancer survivors for the model of follow-up care. This was a mixed tumour site study, with results that were separated by tumour group. A total of 165 CRC survivors were surveyed about their preference for follow-up care. Conversely to Williamson et al (2015) study, the majority preferred face-to-face contact, with telephone and video follow-up care being seen as less preferable. Follow-up care from a specialist nurse was seen as acceptable, with the greatest importance being placed on continuity of care. However, Fernandes et al's (2023) study reported that some participants were happy with telephone follow-up care because of the associated convenience, although one participant was concerned that they were called when in a public space and felt they could not comfortably divulge private information. Another respondent felt that a telephone follow-up was not an adequate replacement for face-to-face contact. Fernandes et al (2023) identified that video consultations may be an effective alternative.

Theme 4: ease of access to care and investigations

Following treatment for CRC, survivors highlighted the importance of having accessible services (Mead et al, 2020; Vos et al, 2022). Focus group participants felt they needed easier access to expert clinical services to help with monitoring and evaluation of new and recurring problems. They highlighted the need for better coordination of care, better access to care and investigations (Mead et al, 2020).

The importance of access to clinical services and of communication about how to gain access to investigations was also found to be both important and lacking in some studies (Sodergren et al, 2019; Vos et al, 2022). Vos et al's (2022) study was in part, observational and they observed instances of what they described as ‘missed cues’ as patients tried to articulate concerns about a lack of access to health care professionals. Similarly, Sodergren et al (2019) explored unmet needs in relation to quality of life and found that there was a strong correlation between unmet health system needs (regarding access to care and information) and poorer global health related quality of life and health status. Participants in Fernandes et al (2023) expressed that the primary focus of their follow-up consultations was on the cancer being cleared, not on the effects of their treatment, which acted as a barrier to them discussing concerns. Insufficient time allocated to appointments also acted as a barrier to care (Fernandes et al, 2023).

Theme 5: fear of recurrence

Fear of recurrence was a common theme across the cancer literature. The ColoREctal Wellbeing (CREW) study conducted by Sodergren et al (2019) found that fear of recurrence was a concern for 9.5% and 11% of the 526 CRC patients included in the study, at 15 and 24 months, respectively. In addition to this, a significant number experienced anxiety, stating that concerns around results and future treatments being beyond their control, and uncertainty about the future, were major contributing factors. Vos et al (2022) identified similar findings, with 14% of surveyed patients in their study expressing a long-term fear of recurrence. Interestingly, Yoon et al (2020) drew a correlation between minor symptoms causing a fear of recurrence. Wieldraaijer et al (2017) found that nearly 40% of patients in their study showed concern about what they described as their future health. Many studies highlighted that this ‘fear of recurrence’ needed to be addressed by health care professionals (Wieldraaijer et al, 2017; Yoon et al, 2020; Vos et al, 2022; Fernandes, 2024); one focus group participant in Mead et al (2020) highlighted that this need was ‘constantly with them’. Participants also called for continued access to psychological support as a means of helping to cope with the emotional impact of cancer and fear of recurrence. Similarly, two of the10 participants surveyed in Breedveld-Peters et al (2020) stated that they had difficulties in coping with fear of recurrence. Wright et al (2017) provided evidence that those who consider themselves most ‘at risk’ in the follow-up phase of their care expressed a preference for face-to-face care to help them manage these worries.

Theme 6: the changing impact of cancer treatment

Almost all studies reviewed identified the ever-changing landscape of survivorship and the impact that this has on the lives of survivors (Murchie et al, 2016; Wieldraaijer et al, 2017; Sodergren et al, 2019; Wildraaijer et al, 2019; Breedveld-Peters et al, 2020; Drury et al, 2020; Mead et al, 2020; Yoon et al, 2020; Vos et al, 2022). Fernandes et al (2023) found that participants in their study enjoyed support from their clinical team immediately after diagnosis and treatment. However, when it came to seeking support for ongoing needs, for example social support, occupational therapy or emotional support, they were left lacking.

Mead et al (2020) identified the detrimental impact that practical long-term life issues, like the financial impact of cancer treatment, can have. They also explored the need to monitor what they term ‘the new normal’, which they say differs from survivor to survivor. Drury et al (2020) concur, reporting that unemployed survivors have higher long-term emotional needs. Physical factors were also found to change over time, adversely impacting quality of life. Reversal and presence of a stoma was commonly found to be related to poorer functional and wellbeing outcomes over time (Wildraaijer et al, 2017; Drury et al, 2020). Breedveld-Peters et al (2020) also found other physical factors—including limited participation in normal activities over time, the presence of fatigue and peripheral neuropathy—were particularly limiting. Sodergren et al (2019) is perhaps the most enlightening study about patterns of needs over time, as they evaluated patients' supportive care needs at 15 months post-treatment, and then again at 24 months. While they found a small proportion of patients with no moderate or severe unmet needs at the end of treatment (15%), all of these went on to report one or more moderate or severe unmet needs at 24 months. They also found that in the longer term, patients expressed worries about their own physical and psychological health, and the impact of their illness on their family and friends.

Discussion

This literature review aimed to understand the needs and priorities of survivors of CRC, and evaluate whether those receiving follow-up care after curative treatment for CRC were represented in literature. The six themes found in the 12 studies provided evidence of the experiences and priorities of survivors of CRC. Priorities were identified as:

- A need to understand and manage the long-term effects of treatment, such as bowel function, peripheral neuropathy and fatigue (Wildraaijer et al, 2019; Drury et al, 2020; Mead et al, 2020; Yoon et al, 2020; Vos et al, 2022)
- Needs and access to information (Wright et al, 2017; Wildraaijer et al, 2017; Sodergren et al, 2019; Wildraaijer et al, 2019; Drury et al, 2020; Mead et al, 2020; Fernandes et al, 2023)
- How follow-up care is delivered and how easy it is to access (Williamson et al, 2015; Wright et al, 2017; Wildraaijer et al, 2019; Drury et al, 2020; Mead et al, 2020; Yoon et al, 2020)
- Addressing unmet needs, particularly support for fear of recurrence (Wieldraaijer et al, 2017; Wright et al, 2017; Sodergren et al, 2019; Breedvelt-Peters et al, 2020; Mead et al, 2020; Yoon 2020; Vos et al, 2022; Fernandes et al, 2023)
- Care to reflect the changing nature of cancer treatment over time (Wildraaijer et al, 2017; Sodergren et al, 2019; Drury et al, 2020; Mead et al, 2020).

These themes make it clear that survivors of CRC require long-term access to knowledgeable healthcare professionals to enable them to manage the consequences of cancer and its treatment. These findings are mirrored by previous systematic reviews. Galica et al (2022) conducted a systematic review into CRC survivors' preferred models of follow-up care, and highlighted the importance of both communication and coordination of care. While a variety of approaches to follow-up care are acceptable, the literature suggests a personal approach is needed to ensure patients are supported in managing the effects of diagnosis and treatment (Rutherford et al, 2020; Haas et al, 2023).

- Whether current approaches meet the follow-up needs of patients from all groups is difficult to discern. Yoon et al (2020) concluded that culturally tailored cancer survivorship care plans are needed for Asian CRC survivor,s, particularly with regard to dietary advice that they found lacked information tailored to the values and beliefs of Asian CRC survivors. If this is the case, it is not unreasonable to suggest that this should also be the case in Western countries treating patients from multicultural backgrounds. No evidence was found in the literature in the review that patient-initiated follow-up care is accessible or acceptable to non-native language speakers.

- The studies included in this review came from a wide range of countries. All the studies that made ethnicity data available had what appeared to be underrepresentation from ethnic minority groups, when compared with their respective nation's population data (US Census 2020; Central Statistics Office of Ireland, 2021; Office of National Statistics, 2021; Statista, 2022). NIHR (2021) published a diversity data report in that highlighted that a significant proportion of health care provision is based on evidence that is not fully representative of the society served. The findings of this review are in common with this report. It may be that there should be a targeted arm of recruitment for all studies to ensure inclusivity for all groups highlighted by the NIHR (2021). This may go part way to ensuring policymakers consider the needs of diverse groups prior to recommending amendments to clinical service delivery. This is key to the equitable provision of healthcare.

The literature also suggests that CRC survivors experience the effects of treatment to varying degrees and at differing times. Studies list long-term effects such as fatigue, peripheral neuropathy and the psychological effects of treatment are impacting health and wellbeing (Breedveld-Peters et al, 2020; Drury et al, 2020; Mead et al, 2020; Yoon et al, 2020; Vos et al, 2022; Fernandes et al, 2023).

This may be influenced by wider unmet needs. Yoon et al (2020) reported that when participants were followed up in a hospital outpatient clinic where the focus was on detection of recurrence, psychological distress did not alter with the passage of time. This contrasts with Wieldraaijer et al (2017), where follow-up care addressed holistic needs and psychological wellbeing improved over time. Other studies highlighted that CRC survivors require support with dietary advice after treatment to reduce the negative impacts of bowl function (Murchie et al, 2016; Wright et al, 2017; Wildraaijer et al, 2019).

Vos et al (2022) observed that there were few concerns expressed about sexual function or intimacy, and few healthcare professionals prompted a discussion on the topic. This may be a larger unexpressed concern, with participants not having been given adequate opportunity or felt comfortable to address concerns around intimacy. Sexual function of both male and female patients can be negatively impacted by surgery, radiotherapy and chemotherapy, all of which are treatments for CRC (Haas et al, 2023). However, Vos et al (2022) included survivors of colon cancer, rather than rectal cancer, and as a result the effect on sexual function in the absence of pelvic radiotherapy may have been less impactful. There is wider evidence that cancer survivors' needs around intimacy and sexuality not being met (Hordern et al, 2008), and that intimacy-focused interventions can offer benefits (Reese and Haythornwait, 2016). Healthcare professionals must ensure that CRC survivors can address and seek help for concerns around intimacy. Assessment and, if necessary, onward referral and intervention should be a part of everyday practice.

CRC survivors express the importance of clear, consistent, readily available information (Murchie et al, 2016; Sodergren et al, 2019; Wildraaijer et al, 2019; Drury et al, 2020; Mead et al, 2020; Yoon et al, 2020; Vol et al, 2022). Timing of information was highlighted as essential, with some pointing out that they felt most well informed during and immediately after treatment (Wieldraaijer et al, 2019). Most reported that they need information to be provided throughout their 5-year follow-up period (Murchie et al, 2016; Sodergren et al, 2019; Vos et al, 2022). When considering the theme of understanding and managing long-term effects of treatment, alongside the priority of information needs, it may be necessary to increase the amount of information given during follow-up care.

Fernandes et al (2023) found evidence that there was a lack of additional support provided to patients who had been treated for CRC, which impacted their daily living, psychological, social and physical quality of life. As the study was carried out against a background of health policies that required the implementation of supportive care, its findings are likely attributable to the intensity of contact between the clinical nurse specialists (CNSs) and the wider clinical team, lessening as time from diagnosis passes. Colorectal CNSs are traditionally placed at the start of the pathway, aiding patients to navigate their way through diagnosis and treatment. CNSs need to ensure that patients have access to support and information to address health needs during the survivorship period of care. How and when survivors have access to healthcare providers is vital. Given the findings of this literature review, healthcare professionals must challenge themselves to provide accessible information, both written and verbal, and ensure that information acknowledges cultural, social and economic differences, as well as wider health inequalities.

Mead et al (2020), Drury et al (2020) and Murchie et al (2016) all reported that many survivors of CRC wanted to be seen in a follow-up appointment by a cancer specialist clinician or CNS. However, this contradicts the objective of the NHS Long Term Plan (NHS England, 2019), which aims shift the focus to remote or patient-initiated follow-up (PIFU). PIFU involves contact with a cancer specialist after treatment is provided, where the patient is able to express an unmet need. While some studies demonstrated acceptability of telephone follow-up support (Williamson et al, 2015; Wright et al, 2017), there is thus far little evidence as to whether self-triggered follow-up support in the CRC setting is seen as acceptable.

Evaluation of PIFU can be found in the wider literature. A recent systematic review found eight studies exploring the impact of PIFU on overall survival, progression-free survival, patient satisfaction, psychological morbidity, quality of life and economic costs compared to hospital follow-up (HFU), for any type of cancer. The review found that only one study listed survival as a primary outcome. Regarding quality of life, they found little evidence of a difference in impact between PIFU and other approaches to follow-up care, though one study reported an increased fear of recurrence with PIFU. Overall, the review concluded that randomised controlled trials are required to determine the full impact of PIFU (Newton et al, 2022). Galica et al (2022) also reviewed models of follow-up care for CRC survivors and found insufficient evidence to recommend a follow-up model for all survivors. Further evaluation of the acceptability and benefits of PIFU is required and needs to extend to the underrepresented groups highlighted through this literature review.

Personalised care for cancer survivors often consists of an end-of-treatment summary, which details the short- and long-term effects of treatment, and access to information giving events. This can range from health and wellbeing events, to holistic needs assessments and cancer care reviews (Richards et al 2011). However, much of personalised care is self-directed, with cancer survivors being required to contact a healthcare professional about their own self-identified needs (Richards et al, 2011). Mead et al (2020) suggest that participants want to feel empowered to manage the consequences of their treatment themselves, and that an easy to access and navigate system of healthcare is important. End of treatment summaries and PIFU, a requirement of personalised care, may be able to provide the information needed to allow patients, and potentially their primary care physician, to identify needs created by cancer treatment and request the appropriate help. However, as Drury et al (2020) found that many of the 304 CRC survivors in their study reported unmet information needs, end of treatment summaries may in some cases be detrimental and associated with greater symptom burden. This is concerning, as end of treatment summaries are a key part of personalised care and can a significant amount of specialist nursing time to deliver. The NHS transformation team states that the time taken to complete end of treatment summaries will vary depending on individual patient need (NHS England, 2016). End of treatment summaries require, along with the wider PIFU programme, further evaluation, inclusive of the views of underrepresented groups to ensure the valuable time spent in their delivery is of true benefit to patients.

Williamson et al (2015) and Sodergren et al (2019) both highlighted the importance of continuity and of the nurse-patient relationship. Specialist nurses whose patients, as a part of personalised follow-up do not regular outpatient appointments will need to ensure that they have an established nurse-patient relationship with survivors of CRC, if patients are to feel confident to raise intimate care needs. Charities, such as Bowel Cancer UK and Macmillan, who often have self-advocacy tools accessible and available to patients, may have a role to play here. In their concept analysis of the nurse-patient relationship, Allande-Cusso et al (2022) described how the nurse-patient relationship takes time to develop. This was echoed in Williamson (2015), which focused on patient and specialist nurses' views on telephone follow-up care; many nurses acknowledged that consultations were more difficult if they had not met their patients in person in the past.

CNSs work at an advanced level to support those affected by cancer in achieving positive outcomes (Health Education England, 2022). Mitchell (2010) describes the level of 'entrepreneurial activity' that expert nurses must practice ensure the needs of patients are met. This skill should also be practiced by cancer CNSs, to ensure that services are developed in line with local and national agendas for the benefit of all patients.

Strengths and limitations

A systematic search was carried out for this review using the PRISMA guidelines. The search was not exhaustive, as it was limited to three databases. Grey literature was not explored. The search was also limited to English language publications only. The study is unique in that it examined the priorities of CRC survivors and which patients had been represented in literature, allowing for a greater analysis of the identified priorities.

Conclusions

This article improves the knowledge base surrounding the priorities of CRC survivors. The needs of CRC survivors alter over time and for some, worsen, demonstrating the need for ease of access to care and information for years after their treatment has finished. As the numbers of CRC survivors increase, the role of third-sector charity providers in provision of information and support in managing the effects of cancer treatment will be key. They must work with health professionals to ensure that they are informed about how to signpost to resources available to CRC survivors. For policymakers and healthcare professionals, the challenge is to ensure that patients have access to the information and support they need to manage the effects of treatment in the short, medium and long term to aid survivors to optimise quality of life post treatment. The approach to this should be tailored to individuals' preferences and needs. CRC CNSs must tailor practice to utilise their expertise to meet the needs of CRC survivors during follow-up care. More evidence is needed on the priorities for follow-up care of CRC survivors from underrepresented groups to ensure the needs of all are effectively addressed.

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Tables & figures

Table 1: Search strategy

Keywords	‘Bowel cancer’ OR ‘colorectal cancer’ OR ‘rectal cancer’ OR ‘colon cancer’
AND	
Keywords	‘Follow up’ OR ‘follow-up’ OR ‘surviv*’
AND	
Keywords	‘Preferences’ OR ‘needs’ or ‘want’ OR ‘understanding’

Table 2: Inclusion and exclusion criteria

Inclusion criteria ● Studies focusing on the follow-up needs of patients that have had curative treatment for colorectal cancer ● Studies focusing on follow-up needs of multiple tumor groups providing the results are presented clearly separating the views of colorectal cancer patients ● Qualitative studies ● Mixed-method studies ● Quantitative studies ● Studies undertaken in the last 10 years, from March 2014 to March 2024. ● Written in the English language
Exclusion criteria

- Studies that include most patients with metastatic disease
- Studies that focus on cancer follow-up investigation protocols
- Literature reviews
- Studies in languages other than English

Table 3

Study	Aims	Methods	Sample	Findings
Mead et al. 2020. Identifying patient priorities for quality survivorship: conceptualising a patient-centred approach to survivorship care. USA.	To explore cancer survivors’ experiences and priorities for survivorship to develop a patient centred approach.	Qualitative. Focus groups. Thematic analysis.	170 cancer survivors. 23% bowel cancer survivors. 59% female, predominantly White. 15% African, 3 % Latino, 7% other. Insurance status included, all but 1 CRC patient insured. Inclusion of non-native language speakers, not recorded	Importance of understanding the chronic nature of effects on cancer survivorship. Importance of positive experiences of support, peer networks, information and mental health. Supportive and responsive providers seen as vital along with seamless support without barriers to access but not always available.
Yoon et al, 2020. Living with long term consequences: Experience of follow-up care and support needs among Asian long-term CRC survivors. Singapore.	Exploration of follow-up care experiences and supportive care needs in long-term survivors within multi-ethnic Asian communities.	Qualitative. Purposive sampling. Semi structured interviews. Grounded theory.	28 CRC survivors. Majority Chinese (90%), tried to recruit Malays and Indians but underrepresented. Education level recorded. Inclusion of non-native language speakers not recorded.	Dealing with adaptation: impact on money, changes to diet and lack of information. Navigating healthcare with limited direction, sense of abandonment at discharge from follow up. Living with potentially distressing long-term consequences. NB: the cohort had consultant led follow up and the principal aim was to detect recurrence.
Wildraaijer et al, 2019. Information needs and information seeking behaviour of patients during follow-up of CRC in the Netherlands. Netherlands.	To explore the need for information and information seeking behaviour in CRC survivors.	Quantitative. Questionnaires. Prospective cohort study. Results presented over time: at 3 months, 6-12 months and later than 12 months after surgery.	222 CRC survivors. Average age 67. 54% male. Sociodemographic data included. Co-morbidities included. Inclusion of non-native language speakers, not recorded.	Survivorship: more information needed on nutrition, what to expect, improving symptoms and return to work and normal life. Seeking information: online and from health professionals. Younger patients searched for more information about follow-up and effects.
Drury et al, 2020. Identifying associations between quality of life outcomes and healthcare related variables among CRC survivors. Ireland.	To explore associations between CRC survivors health care experiences and quality of life.	Quantitative. Questionnaires. Cross sectional study.	304 CRC survivors. Predominantly White Irish. 50% of participants had insurance. Employment status and urban/rural status recorded. Non-native language speakers, excluded.	Unmet information needs. 65% had social difficulties associated with poor physical well-being. Poorer emotional well being in unemployed participants and females.
Williamson 2015. Patient experiences of nurse led telephone follow-up following treatment for CRC. UK.	To explore the views of CRC survivors on telephone follow up.	Qualitative. Observational study.	21 CRC survivors. Gender and age included but no ethnicity data. Employment status recorded. Inclusion of non-native language speakers not recorded.	Convenience of access provided by telephone follow-up was positive. Personalised care. The value of this achieved by telephone follow-up. Importance of the nurse patient relationship.
Vos et al, 2022. Addressing colon cancer patients needs during follow-up consultations at the outpatient clinic. A multicentre observational study. Netherlands.	To describe colon cancer patients needs during follow-up and how health care providers respond to these during hospital consultations.	Qualitative study. Observational.	30 CRC survivors. 15 men 15 women. Mean age 68.3. No ethnicity data. Educational attainment recorded. Inclusion of non-native language speakers, not recorded.	Planning of tests and results, patients not feeling properly informed. Missed cues from health professionals. Unmet physical and daily living needs during survivorship. Fear of recurrence.
Breedveld-Peters et al, 2020. The impact of participation restrictions on everyday life on CRC survivors in the EnCoRe study. A mixed method study UK.	To explore the nature and impact of CRC treatment on everyday life on long-term survivors.	Mixed method study. Semi-structured interviews and questionnaires.	10 interviews. 151 questionnaires. 62.3% male. Mean age 69.8. Smoking status recorded: 135 participants current non-smokers. Socio-demographic data recorded. Inclusion of non-native speakers, not recorded.	Fatigue limiting participation. Treatment induced bowel complaints impacting participation in everyday life. 1 in 5 survivors reported dissatisfaction with participation in daily life. Identified need for follow-up visits.
Sodergren et al, 2015. Supportive care needs of patients following treatment for CRC: risk factors for	To explore the unmet needs of patients treated for CRC at the end of treatment and	Quantitative: Cohort Study. Questionnaires: surveys completed at 3-, 6-, 15- and	526 CRC survivors. The majority of participants were of White ethnic origin. 60% were male. Mean age 68.	Sexuality – unmet needs. Patient care and support – unmet needs.

unmet needs and the association between unmet needs and health-related quality of life- results for the ColoREctal Wellbeing (CREW) study. UK.	whether unmet needs improve over time.	24-months post operatively (surgery +/-chemotherapy).	Sociodemographic data and Co-morbidities recorded and reported on. Inclusion on non-native language speakers, not recorded.	Health system and information – unmet needs. 43% of survivors found to have unmet needs at 15-months post operatively.
Wieldraaijer et al, 2017. Follow up of colon cancer patients: causes of distress an need for supportive care: Results from the ICARE Cohort Study. Netherlands.	To study investigated distress in patients after curative surgery for colon cancer and corresponding need for supportive care.	Quantitative. Questionnaires. Cohort Study. Patients divided into 4 groups depending on treatment and time: surgery only less than 6 months post treatment. Patients having adjuvant chemotherapy, patients who had completed adjuvant chemotherapy less than 3 months before and those that had finished surgery and chemotherapy more than 6 months before.	227 colon cancer survivors. 155 male, 129 female. Mean age 68. Sociodemographic data included. Co-morbidities included. Inclusion of non-native language speakers not recorded.	Minimal help requested for psychological support. Greater degrees o distress associated with stomas, adjuvant chemotherapy and recent treatment. Symptoms decreased over time, though psycho-social concerns remain the same.
Wright et al, 2017. What are CRC survivors preferences for dietary advice: A best worst discrete choice experiment. UK.	To quantify the preferences of dietary interventions for CRC survivors.	Quantitative. Questionnaires.	179 questionnaires. Mean age 68.9. 51% male, 49% female. 36% had no formal education. Ethnicity was clearly recorded: 94% White British, 2.2 % Irish, 0.5% Pakistani and 2.2% Socio-demographic data included: income, education status, smoking status. Other. Non-native language speakers were included.	Preference for information to be given by a specialist nurse. Preference for face-to-face information. Older patients found telephone follow-up more acceptable. Those with poorer adherence to healthy behaviours were most likely to benefit from healthy lifestyle and dietary advice and preferred this face-to face.
Murchie et al, 2016. Determining cancer survivors' preferences to inform new models of follow-up care. UK: North Scotland.	To compare British cancer survivors, follow up preferences and compare the preferences of to assess survivors from different cancers.	Quantitative. Questionnaires.	Multiple tumour groups included. 777 survivors in total: 165 (24.7%) CRC survivors. 58.4% female. Inclusion on non-native language speakers, not recorded.	CRC patients preferred continuity of follow-up; CNS follow-up was acceptable. CRC survivors wanted diet and lifestyle advice.
Fernandes et al, 2023. Understanding CRC patient follow-up: a qualitative interview study. UK.	To understand the follow-up experience of CRC patient in the UK and identify the terminology they prefer following diagnosis and treatment.	Qualitative study: two 1 to 1 semi structured interviews.	17 participants. 53% male. Median age 62. No participants for ethnic minority backgrounds though attempts at recruitment were made.	Factors that created barriers to discussing symptoms: not feeling post treatment symptoms were relevant to clinicians. Methods that facilitated better consultations, face-to-face or video. Key issues; the psycho-social burden of living with and beyond a CRC diagnosis, access to support for personal care needs and nutritional care needs.

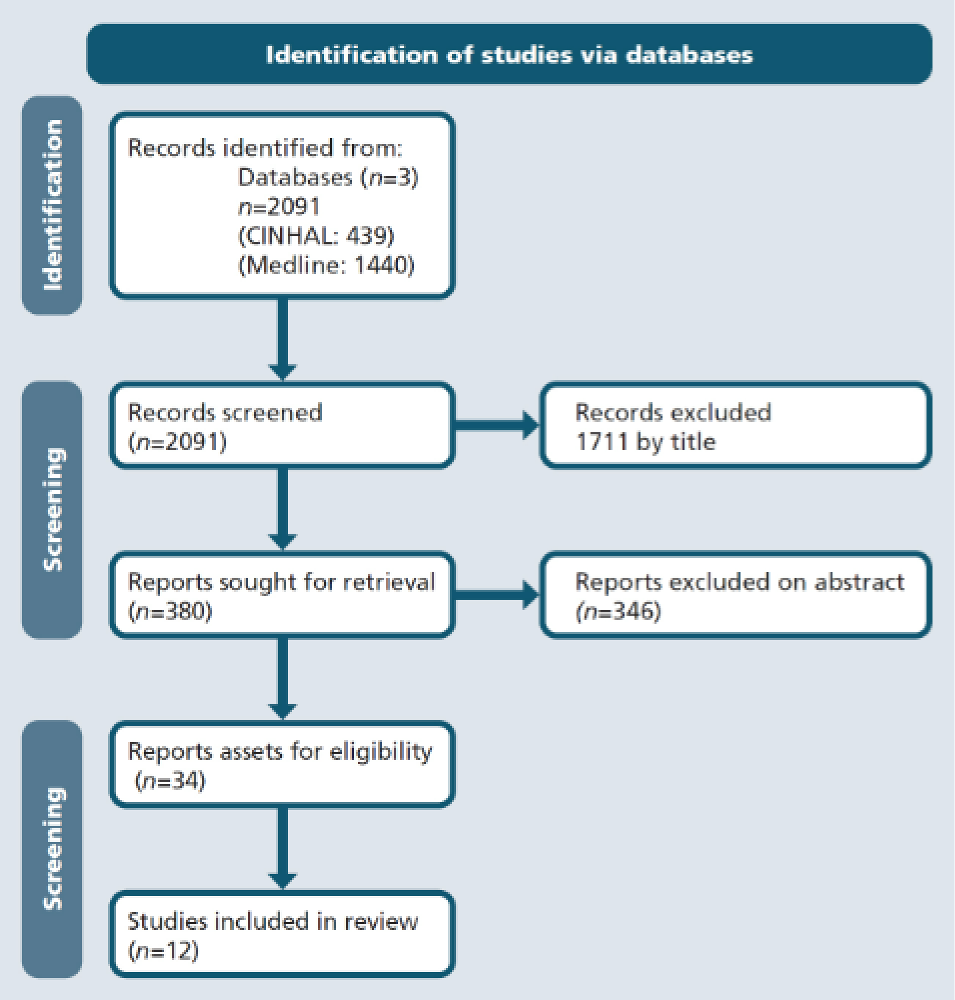

Figure 1. Prisma flow diagram