Colorectal cancer survivors’ perceptions of dietary advice: a literature review.

Abstract

Background: There are increasing numbers of colorectal cancer (CRC) survivors in the UK. Healthy dietary changes have been shown to improve survivors’ prognoses. However, research indicates that CRC survivors are dissatisfied with the dietary advice they receive.

Aims: To review CRC survivors' perceptions of dietary advice.

Methods: A literature review and thematic analysis of six qualitative research papers and two mixed method research papers.

Findings: Five major themes emerged from the data analysis: the perceived inadequacy of dietary advice; motivating factors; barriers to dietary changes; information sources; and the impact of symptoms.

Conclusion: Individualised dietary advice and nurse-facilitated peer sessions could support person-centred, holistic care for survivors. However, nurses may need additional training from dietitians and experienced nurse specialists to enable them to deliver this.

Key Words

colorectal cancer survivor; dietary advice; motivating factors; information sources; impact of symptoms; nurse-led peer support

Key Points

- CRC survivors express frustration at the lack of adequate dietary advice and would prefer individualised guidance
- CRC survivors identify empowerment, peer support, maximising health and individualised guidance as motivating factors in making dietary changes
• Nurse-facilitated, peer support sessions could better support the dietary information needs of CRC survivors

Introduction

Colorectal cancer (CRC) is the fourth most common cancer in the UK, with approximately 41,000 new diagnoses annually (National Institute for Health and Care Excellence (NICE) 2020). There are increasing numbers of CRC survivors in the UK; the current estimate of 240,000 survivors is expected to increase to 630,000 by 2040 (Maddams et al 2012). In comparison to the general population, CRC survivors have higher rates of comorbidities, such as hypertension, arthritis and depression, which can affect their quality of life (Cummings et al 2018). Healthier diets may improve CRC survivors’ prognoses (van Zutphen et al 2017). The importance of promoting healthy lifestyle changes after cancer treatment has been highlighted by the Department of Health (DH) (2013). However, dietary guidance provided to cancer survivors has been deemed unsatisfactory by respondents to a study (National Institute in Health Research (NIHR) 2015). Inadequate information from healthcare professionals may lead survivors to search other sources, such as the internet and social media (Dau et al 2020) which may not have a reliable evidence base (Gentile et al 2018). Several cancer charity websites provide comprehensive healthy lifestyle information but cannot offer individualised support (Saltaouras et al 2018).

Aim

A literature review was undertaken in order to understand CRC survivors’ perceptions of dietary advice and to identify recommendations for nursing practice. In this review, a ‘CRC survivor’ is defined as someone who has completed their treatment and is in a period of recovery or rehabilitation but may still be under active surveillance.
Method

This literature review thematically analyses the findings of existing primary research on the perceptions of the dietary advice received by CRC survivors. The Population, Exposure and Outcomes (PEO) framework (Khan et al 2003) was used to identify the population: CRC survivors; the exposure: the provision of dietary advice by healthcare professionals and the outcome: survivors’ perceptions. Key words and their synonyms used to identify material included: colorectal cancer*, survivors, diet*, nurs* and advice*. Boolean operators, truncation and phrase searching were used to increase the breadth of identifiable items.

Searches were conducted using CINAHL Complete, MEDLINE Complete, Web of Science and PsychInfo databases. The PRISMA flowchart (Moher et al 2009) at Figure 1 depicts the process of finalising the primary research used in this literature review. The initial database search yielded 253 potential papers, with a further 36 identified from three other sources: SCOPUS, hand searching and grey literature. These papers were screened, following the limiters documented in Figure 1. Inclusion criteria were: peer reviewed, English language, full text, qualitative papers, published since 2010. Mixed-methods design studies that had a substantial qualitative element, revealing survivors’ perspectives through open-ended questions, were also included. Only papers from the UK, Australia or European countries were included, as these were judged to have comparable populations and healthcare services. The exclusion criteria were: quantitative research; papers published before 2010; and papers focused on patients receiving active treatment or palliative care.

After screening, 19 research papers remained and were assessed for eligibility. Research was excluded if it focused exclusively on other types of cancers; on lifestyle changes without substantial data relating specifically to dietary issues; or tested survivors’ responses to a specific healthy eating campaign, because it was felt that these might evaluate only the
campaign features, rather than more broadly reviewing survivors’ perceptions of all dietary advice received.

Figure 1: PRISMA Flow Diagram
A total of six qualitative and two mixed-methods primary research papers made up the final sample. These were assessed, using the Critical Appraisal Skills Programme (2018) qualitative checklist and the Mixed Methods Appraisal Tool (Hong et al 2018), to support the transparency, reliability and validity of the research process. Data from the papers were
thematically analysed and are presented in Figure 2 (embedded link). The themes were tested with peers and an academic supervisor.

Findings

Five major themes emerged from the data analysis. These were: dissatisfaction with dietary advice; motivations for making changes to diet; barriers to making dietary change; formats and sources of dietary information; and the impact of symptoms caused by treatment and diet.

Dissatisfaction with dietary advice

Seven of the eight studies identified the inadequacy of dietary advice as a dominant theme. Matsell et al’s (2020) mixed-methods study, involving 70 CRC survivors and 5 carers, revealed that 69.3% of participants (n = 52) had not received the dietary advice they needed. Participants in Beeken et al’s (2016) semi-structured interviews, of which one was a survivor of CRC, reported having either basic or no information. Burden et al’s (2016) interpretive phenomenological study of 25 CRC survivors, reported that no-one was given nutritional advice on how to increase protein and energy within their daily diet, although two participants directly requested this information: “I asked about it but nobody ever [replied]…” (Female, 64, colon cancer). This caused anxiety, as eating well at regular meal times and gaining weight were interpreted by participants as key indicators of overall rehabilitation and a return to normality.

Similarly, participants in Anderson et al’s (2013) qualitative study, involving 40 CRC survivors, referred to “broad, useless advice” which left them feeling confused and anxious. In Brown et al’s (2016) interviews of 19 CRC survivors, participants reported struggling with generalised guidance: “Everybody talks about your diet...yet...you don't actually know what they mean by that.” (Participant 18). This finding was repeated in Hardcastle et al’s (2017) qualitative study, involving 24 participants. Survivors without a colostomy reported wanting, but not receiving,
specific calorie intake recommendations and help to understand food labels, classification of food types and portion sizes. Participants in this study with a stoma (n = 6) felt better supported and reported receiving booklets to identify which foods to avoid.

Dietary advice was also seen as counterintuitive, inconsistent or unachievable. Corbett et al’s (2018) semi-structured interviews, involving 8 CRC survivors, revealed concerns that recommended dietary changes would negatively impact on wellbeing: “...If I try a new eating plan, it’s going to throw my body out” (Colon, male, 7 years post-treatment). Some participants reasoned that they had made seemingly unhealthy choices for years without adverse effects: “I've survived 78 years on what I've been doing...So my lifestyle hasn't been that bad.” (Colon, male, 2 years post-treatment). In Anderson et al’s (2013) study, participants questioned the value of reinstating a healthy diet, when they felt it had offered them no protection from cancer in the past. Inconsistent advice from healthcare professionals was reported by Hardcastle et al’s (2017) participants; one CRC survivor commented on “Very, conflicting information” (Mary, aged 65). Other participants simply rejected the dietary guidance they received as unrealistic: “Who the hell is going to eat five vegetables?” (Barbara, aged 76).

The findings across these seven studies identify participants’ different perspectives of the way in which dietary information fell short of what was required or expected by CRC survivors.

Motivating factors for making dietary changes

Seven studies identified motivating factors, of which there were four main categories: empowerment, peer support, maximising general health and individualised advice. The most frequently occurring theme was empowerment, mentioned by seven studies. Participants used terminology such as wanting to take control, not wanting to be seen as a victim and retaining autonomy and agency. In Hoedjes et al’s (2017) mixed-methods study, 17.5% of 1198 CRC survivors (n = 210) reported the need for additional support to initiate dietary
Participants (n = 16) in the focus groups discussed wanting to make informed and autonomous choices; one respondent commented: “It has to be without obligation. I want to be able to...say yes or no”. Indeed, feeling pressured into making changes or blamed for the consequences of poor dietary choice were cited as major barriers to change in Corbett et al (2018).

Having the support of other survivors in individual, online or group settings was highlighted as a motivating factor in four studies (Anderson et al 2013, Burden et al 2016, Hardcastle et al 2017, Hoedjes et al 2017). However, for participants in Corbett et al’s (2018) research, the lack of realistic peer role models in health promotion literature was demotivating, as they felt that campaigns celebrating extraordinary individual survivor achievement failed to acknowledge the impact of diagnosis and treatment on many people.

Maintaining or maximising health was also identified as a motivating factor for dietary change. Respondents referred to “stacking the odds” (Anderson et al 2013); trying to be “even healthier” (Burden et al 2016) and preventing cancer recurrence (Beeken et al 2016, Corbett et al 2018). Finally, participants in four studies cited individualised support from a dietitian or nurse as a potent motivator, discussing a holistic survivorship package (Anderson et al 2013), lifestyle audit (Anderson et al 2013, Hoedjes et al 2017), targeting the individual (Matsell et al 2020) and individual contact to support personal accountability for change (Hardcastle et al 2017).

Barriers to dietary changes
Barriers to making dietary changes included concern about the effect of making changes on their overall wellbeing (Corbett et al 2018); worrying about flatus and diarrhoea (Anderson et al 2013, Matsell et al 2020); lack of self-efficacy (Hardcastle et al 2017, Hoedjes et al 2017, Corbett et al 2018) and limited knowledge or support (Brown et al 2016, Corbett et al 2018). In
addition, Corbett et al’s (2018) study identified non-cancer related barriers, which included mistrust of experts and concerns about the perceived additional costs of healthy food. These participants raised doubts about the reliability of research evidence, preferring instead to trust information from familiar media outlets such as television programmes, websites and newspapers.

Seven studies reported motivating factors and six identified barriers to change. A number of these seem to fall along common axes and addressing these could inform improvements to current practice: by supporting empowerment to tackle survivors’ lack of self-efficacy; resolving lack of knowledge by providing individualised guidance; acknowledging concerns about side effects by supporting discussions with expert peers.

Sources and Formats of Dietary Information

Sources of information was a theme in four of the studies. Participants in three studies expressed a desire for individualised guidance and support from healthcare professionals, specifically dietitians (Matsell et al 2020, Hoedjes et al 2017, Brown et al 2016). Of the 75 participants in Matsell et al’s study, 23 reported that they had received advice from their healthcare team, 56.5% from a nurse, 34.8% from a dietitian and 26.1% from a specialist oncology dietitian. Of these 23 participants, the majority received the advice in written format (73.9%), with only 47.8% receiving face-to-face advice or advice via a telephone call. CRC survivors in Hoedjes et al’s (2017) study expressed a preference for face-to-face group support and described exclusively digital-based support as impersonal.

Anderson et al’s (2013) participants favoured basic, printed information, to enable time for reading and processing. This preference was repeated by Matsell et al’s (2020) participants, 73.3% of whom reported seeking out additional written guidance, as well as advice from cancer charity websites (49.3%), online medical advice (29.3%) and recipe books (28%).
These respondents also reported using social media, including Facebook and patient blogs, reasoning that “you can see what works for other people with the same diagnosis”.

The importance of support groups was seen in three studies (Brown et al 2016; Hoedjes et al 2017; Matsell et al 2020). Support group attendees reported to Brown et al (2016) that they were more aware of dietary advice being an unmet need, because this had been discussed widely in the support forums. A participant in Matsell et al’s (2020) study commented: “without…the support group, I would not have had the help I needed”.

Impact of Symptoms Caused by Dietary Change on Survivors’ Lived Experience

The impact of bowel function and weight fluctuations caused by dietary changes on survivors’ lived experience was discussed in five of the papers. Survivors revealed fears that altered eating patterns would potentially increase diarrhoea, flatus and stoma activity, causing embarrassment and curtailing activities. One CRC survivor in Matsell et al’s (2020) study stated: “I have anxiety whilst travelling due to bowel issues”. In Hardcastle et al (2017) a participant reported that debilitating bowel habit changes meant that on occasion he felt “tethered to the toilet”. A participant in Brown et al’s study (2016) described the restrictions to his life altered bowel habits had caused: “it stopped us, we used to go and stay with people”. Some participants in this study felt too embarrassed to discuss symptoms with healthcare staff; one respondent stated: “I’m not going to admit I can’t hold a fart and all this sort of stuff”. A survivor reported pain and fear of pain associated with eating to Anderson et al (2013): “[eating was] a very scary process…it was very painful to eat anything at all”.

Changes in weight were associated with anxiety for participants in Burden et al's (2016) study, who saw weight loss as evidence of increased vulnerability. These participants attributed weight gain to fatigue, stoma output management and decreased mobility. The symptoms associated with treatment and dietary change had an impact on both the physical and psychosocial wellbeing of these respondents.
Within all 8 studies, authors noted that convenience sampling or participant bias could potentially undermine the generalisability of the results. Further limitations noted were: potential researcher bias (Beeken et al 2016), reliance on participants’ recall (Burden et al 2016), under-representation of some CRC sub-groups (Hoedjes et al 2017) and using multiple interviewers (Corbett et al 2018).

**Discussion and implications for practice**

The findings of this literature review indicate that the majority of research participants did not believe they received adequate dietary information to support healthy lifestyle changes. This is in line with the findings of other reviews (NICE 2020, Rutherford et al 2020) and a UK-wide survey (NIHR 2015) which highlighted that individualised nutritional advice was a critical unmet need of CRC survivors.

The provision of person-centred care is a key healthcare policy aim (DH 2005, DH 2010). Person-centred care should include assessing unmet needs (Sodergren et al 2019). The themes identified in this literature review relate to humanising nursing practice and understanding these could enhance oncology service users’ experience. Empowerment, peer support and individualised guidance, raised by research participants as key motivators to enable change, can be considered within the dimensions of Todres et al’s (2009) humanising values framework. Empowerment can be considered within the agency/passivity dimension, which describes humanised care as supporting individual choices and accountability. Expanding individual choice over treatment options and sharing control of care with patients is a core concept of the NHS Long Term Plan (DH 2019). Making lifestyle changes can support survivors’ sense of agency over their recovery and future health (Miles et al 2010) and the provision of evidenced nutritional information has an important role in this. The themes raised in this review identify preferred sources and formats for this advice.
Peer support can be seen in relation to the togetherness/isolation dimension, which recognises that social isolation is damaging to health. Providing opportunities to discuss lived experience with fellow survivors has been shown to support individuals to anticipate and better respond to the side effects of treatment (Kanters et al 2018) and improve adherence to health behaviour change (Moore et al 2019). Facilitating local peer support sessions could enable nurses to identify knowledge gaps and provide further guidance.

Individualised nutritional guidance can be seen within the uniqueness/homogenisation dimension. Humanised care avoids generalisation, identifying instead the unique needs of a person. Incorporating choice and recognising differences between individuals’ preferences and values is recognised as a service provision aim by the NHS (DH 2019). Understanding underlying motivating factors for making dietary changes will enable nurses and the interdisciplinary team to target their messages and support individuals more effectively. This approach is in line with the Making Every Contact Count (MECC) initiative (Public Health England 2016), which promotes person-centred interactions, to support healthy, sustainable changes.

However, Moore et al (2017) identify factors at the level of the practitioner that prevent individualised care including: habitual practice; scepticism of alternative approaches; stereotypical attitudes and time constraints. In addition, Lloyd et al (2018) discuss organisational barriers, such as: staffing constraints; levels of staff experience; staff workload; physical resourcing issues and environmental constraints. Healthcare professionals are likely to need additional support in order to work in partnership with patients (DH 2019) and change the way in which survivors are supported to improve lifestyle (DH 2013).
Most CRC survivors do not see a dietitian (Sullivan et al 2020); indeed, many prefer to receive information from a specialist nurse rather than a dietitian (Wright et al 2017). Enabling nurses to address the specific dietary information needs of CRC survivors is necessary to contribute to the delivery of high quality, person-centred oncology care. However, healthcare professionals involved in oncology care may feel ill-prepared to provide dietary advice (Koutoukidis et al 2018, Murphy et al 2020) and nurses’ knowledge of diet and lifestyle guidance for survivors may be limited (Rodman and Murphy 2011). Supporting nurses’ understanding of diet and oncology survivorship is therefore required. Nurses have an important role in advocating for their patients (Davoodvand et al 2016); for CRC survivors, this should extend to ensuring their dietary needs are discussed at MDT meetings and identifying who might benefit from input from a specialist dietitian.

To ensure currency and consistency of dietary messaging, van Veen et al (2019) recommend establishing a single point of contact for all advice to health professionals, such as a named dietitian. One way of improving nurses’ understanding of the evidence base would be Continuous Professional Development (CPD) events, led by a specialist oncology dietitian and clinical nurse specialist. Dissemination of new learning could be further supported with a resource pack, that would enable nurses to lead CRC survivors’ health promotion clinics. This could include: suggested session formats; visual aids for portion control and healthy meals; and a template symptom diary, to track changes and identify tolerated foods.

**Recommendations**

The themes raised in this literature review suggest that a mixture of individualised support and peer sessions would be a potential way of better supporting CRC survivors. Nurse-led clinics could therefore include an initial assessment of the individual dietary needs and preferences of the person, as an adjuvant to the Macmillan Cancer Support (2013) Holistic Needs Assessment. At this initial session, discussing symptoms and recognising that each survivors’ dietary rehabilitation will progress differently, could help tackle the perception of dissatisfactory
advice. This could then be followed by nurse-facilitated peer support sessions, to ensure that knowledge gaps raised by participants can be addressed from a clear evidence base, from knowledge gained during the dietitian-led CPD sessions attended by the nurse.

This literature review has a significant limitation; its reliance on predominantly qualitative primary research, with small participant numbers in each study, means the results may not be representative of the wider CRC survivor population. Notwithstanding this and the limitations highlighted by the authors in individual studies, the thematic analysis of these eight pieces of primary research, involving the commentary of 203 CRC survivors, overwhelmingly reveals unmet dietary information needs and clear trends in the motivating and demotivating factors reported by participants.

Conclusion
Increasing numbers of people are surviving after treatment for colorectal cancer. Lifestyle interventions, including a healthy diet, are positively associated with survival rates. However, the findings of this literature review indicate that CRC survivors feel dissatisfied with the dietary information they receive. Addressing this unmet need could support the delivery of holistic oncology care. CRC survivors identify motivating and demotivating factors to making dietary changes. Understanding these will enable nurses to better support individuals to make sustainable changes. CPD events to develop nurses’ knowledge of the specific dietary needs of CRC survivors will better prepare them to provide this individualised guidance and facilitate peer support sessions, using a clear evidence base.

References


