

Experiences of colorectal cancer survivors in returning to primary coordinated healthcare following treatment

Claudia Rutherford^{A,B,*}, Bora Kim^{A,C}, Kate White^{A,B,D}, Cheri Ostroff^{E,F}, Louise Acret^{A,B}, Marguerite Tracy^G, Janani Mahadeva^H and Simon M. Willcock^H

For full list of author affiliations and declarations see end of paper

*Correspondence to:

Claudia Rutherford
Faculty Medicine and Health, Sydney Nursing School, Cancer Care Research Unit (CCRU), University of Sydney, Level 6 North, Chris O'Brien Lifehouse C39Z, Sydney, NSW 2006, Australia
Email: claudia.rutherford@sydney.edu.au

Received: 13 September 2022

Accepted: 6 February 2023

Published: 6 March 2023

Cite this:

Rutherford C et al. (2023)
Australian Journal of Primary Health, 29(5), 463–470.
doi:[10.1071/PY22201](https://doi.org/10.1071/PY22201)

© 2023 The Author(s) (or their employer(s)). Published by CSIRO Publishing on behalf of La Trobe University.
This is an open access article distributed under the Creative Commons Attribution-NonCommercial-NoDerivatives 4.0 International License (CC BY-NC-ND).

OPEN ACCESS

ABSTRACT

Background. Advances in screening and treatments for colorectal cancer (CRC) have improved survival rates, leading to a large population of CRC survivors. Treatment for CRC can cause long-term side-effects and functioning impairments. General practitioners (GPs) have a role in meeting survivorship care needs of this group of survivors. We explored CRC survivors' experiences of managing the consequences of treatment in the community and their perspective on the GP's role in post-treatment care. **Methods.** This was a qualitative study using an interpretive descriptive approach. Adult participants no longer actively receiving treatment for CRC were asked about: side-effects post-treatment; experiences of GP-coordinated care; perceived care gaps; and perceived GP role in post-treatment care. Thematic analysis was used for data analysis. **Results.** A total of 19 interviews were conducted. Participants experienced side-effects that significantly impacted their lives; many they felt ill-prepared for. Disappointment and frustration was expressed with the healthcare system when expectations about preparation for post-treatment effects were not met. The GP was considered vital in survivorship care. Participants' unmet needs led to self-management, self-directed information seeking and sourcing referral options, leaving them feeling like their own care coordinator. Disparities in post-treatment care between metropolitan and rural participants were observed. **Conclusion.** There is a need for improved discharge preparation and information for GPs, and earlier recognition of concerns following CRC treatment to ensure timely management and access to services in the community, supported by system-level initiatives and appropriate interventions.

Keywords: colorectal cancer, consumer participation, continuity of patient care, health transition, patient experiences, primary care, primary health care, qualitative study, survivorship care.

Background

The number of people living with and beyond cancer treatment is increasing, and is predicted to reach 1.9 million in Australia by 2040 ([Cancer Council Victoria 2018](#)). People living beyond colorectal cancer (CRC) treatment form the largest group of cancer survivors. Advances in effective screening, surveillance and treatments have improved survival rates and duration ([Luo et al. 2022](#)), leading to a large and growing population of CRC survivors living in the community, with ~20 000 new cases diagnosed in Australia each year ([Australian Institute of Health and Welfare 2012](#)). Approximately 70% of patients treated for CRC survive to 5-years ([National Cancer Control Indicators 2020](#)). Early-stage (I-III) CRC is curable, and those treated for early-stage disease have a 70–99% 5-year relative survival rate ([Siegel et al. 2017](#); [National Cancer Control Indicators 2019](#)).

Standard treatment for CRC includes surgery, chemotherapy or radiotherapy alone or in combination, depending on the stage at diagnosis, pre-existing comorbidities and patient preference ([Cancer Council Victoria and Department of Health Victoria 2021](#)). Reviews highlight 20–30% of survivors experience late and long-term consequences of treatment

(Foster *et al.* 2009; Rutherford *et al.* 2020; Ju *et al.* 2021). These include physical, psychosocial and sexual functioning impairments, altered bowel function (e.g. frequency, irregularity, incontinence), fatigue, disrupted sleep, skin irritations, urinary problems, impact on relationships, informal and formal supportive healthcare needs, and financial and occupational challenges up to 5 years post-cancer treatment. Bowel dysfunction is experienced by as many as 79% of survivors 2 years post-treatment; 65% continue to have mobility problems, 40% report pain and discomfort 3 years post-treatment (Ju *et al.* 2021), and 15% report depression 5 years after surgery (Calman *et al.* 2021). Some require permanent or temporary stomas, which come with their own challenges (Rutherford *et al.* 2020).

Concerningly, many consequences of treatment go unmanaged, and ~60–90% of CRC survivors report at least one long-term unmet need (Vu *et al.* 2019; Rutherford *et al.* 2020). Current models of post-treatment care fail to adequately address these chronic/late-occurring treatment effects (Wiltink *et al.* 2020). Follow up, with a focus on surveillance, has traditionally been provided by specialist oncology services. However, specialist services may not be equipped or funded to meet the ongoing survivorship care needs of the increasing numbers of CRC survivors, nor are they best placed to solely manage long-term treatment effects, secondary prevention, health promotion, self-management promotion, management of comorbid illnesses and care coordination. General practitioners (GPs) routinely take responsibility for these roles and, therefore, have an important role in the survivorship care of cancer survivors (Jefford *et al.* 2020). Primary care is increasingly promoted as a way to meet the increasing demand for care, stabilise healthcare costs and provide care close to home, and there is emerging evidence for GP- and nurse-coordinated care to support the transition (Rubin *et al.* 2015).

Many cancer survivors transitioning between hospital and general practice are vulnerable to discontinuity; inconsistency and variation in care, surveillance testing and follow up; and experience a sense of isolation and loss (Ireland *et al.* 2017). Given these issues, GPs have an important role in the assessment and management of a range of survivorship issues to improve patient outcomes. This study aimed to explore CRC survivors experience of post-treatment care in the community and their perspectives on the role of their GP in coordinating supportive care.

Methods

We undertook a qualitative study using an interpretive descriptive approach to allow in-depth exploration of key areas of interest during interviews (Braun and Clarke 2006; Hunt 2009).

Participants

Participants aged ≥ 18 years, who had completed treatment following a CRC stage 1–3 diagnosis and spoke English, were eligible. Participants representing a broad range of demographic and clinical characteristics were sought; accrual was reviewed to ensure representation across characteristics (Table 1).

Recruitment

The study was advertised through our investigators' collegial networks, consumer organisations and social media (see acknowledgements) between 10 March 2021 and 31 August 2021. This was done through either an invitation email or an open advertisement on a notice board, membership newsletter or social media page with appropriate approvals. These contained a participant information sheet with information about what would be involved in taking part in the study and how to contact the study researcher. We also used a snowball recruitment strategy, where upon interview completion, each participant was invited to forward the study information to their peers.

Participants interested in taking part contacted the researcher directly by email or telephone. The researcher provided a detailed explanation and answered any questions. If the participant agreed to take part, a date and time for the interview was arranged. Participants were emailed an e-consent form and asked to complete it prior to their interview. If e-consent forms were not returned, verbal consent was obtained and recorded prior to interview commencement. Ethics approval was obtained prior to study commencement.

Data collection

Semi-structured interviews were undertaken following a topic guide (Box 1) developed by our investigator team including three GPs, two nurses and two CRC survivors. Interviews were conducted via telephone or zoom by one researcher

Table 1. Matrix for targeting patient recruitment.

	Treatment type			Stoma		Location of cancer		
	Surgery	Radiotherapy	Chemotherapy	Yes	No	Colon	Anus	Rectum
Male ^A	X	X	X	X	X	X	X	X
Female ^A	X	X	X	X	X	X	X	X

^ARecruited across a broad range of age groups.

(BK) and audio recorded. The researcher took notes and fed back comments made to participants during the interview to ensure their intended meaning was understood and captured. Interviews were iterative, whereby each interview informed the next, and subsequent interviews explored new issues raised and identified any gaps in information, until saturation, with no new issues emerging.

Data analysis

Thematic analysis was performed to identify similarities and differences in individuals' experiences while considering participants' unique life circumstances, such as life stage (e.g. young adult, retiree) and geography (e.g. city, regional; Braun and Clarke 2006). This enabled understanding of care gaps unique to certain demographic groups. Audio recordings were not transcribed, but interpreted by directly listening and scribing findings, guided by six steps outlined by Halcomb and Davidson (2006). First, audio recordings of interviews were listened to repeatedly (BK), during which the researcher (BK) scribed patient words, including exemplar phrases from the interviews (i.e. typically one or two sentences of transcribed participants' narrative of their experience), the context for their experience (e.g. 'becoming own care-coordinator') and any non-verbal cues, such as disappointment and frustration, expressed through voice tones and pauses. Off-topic conversation and filled pauses (i.e. 'um', 'err') were omitted from transcription. This process enabled capturing the researchers' thoughts and interpretation during the process of listening to audiorecordings. Key codes were then identified across interviews. Codes representing similar phenomena were grouped into themes. All themes were reviewed, taking into consideration differences and similarities in findings across participants. A second researcher listened to the audio recordings, and verified the first researcher's scribed codes and provisional themes. Both researchers reviewed the themes to ensure the thematic framework captured the depth and range of data collected across interviews. Discrepancies were discussed, and revisions to the themes agreed on.

Ethics approval

Ethics approval was obtained from the University of Sydney Human Research Ethics Committee, Project No: 2020/851, prior to study commencement. All participants provided informed written or verbal recorded consent to take part in the study.

Results

Interview sample

We interviewed 19 CRC survivors (Table 2) from six Australian states, including metropolitan, regional and rural locations, who spoke English as their first language. The results are summarised below by 10 themes. Quotations are used throughout to illustrate key findings using participant words.

Consequences of treatment

Most participants experienced mild-to-severe post-treatment effects. These included: physical symptoms, such as 'peripheral neuropathy', 'lymphoedema', 'bowel changes', faecal 'incontinence, constipation and diarrhoea'; problems with sexual function, intimacy and closeness; problems with cognition (e.g. poor memory, 'difficulty finding my words'); fatigue; weight gain; and psychological effects, such as fear of cancer recurrence, anxiety or distress, and altered body image. These effects significantly impacted their lives, and contributed to relationship problems, 'difficulty returning to work' and 'financial problems'. Bowel control problems were particularly disruptive. Participants felt 'unable to leave the house' to socialise or 'had to plan activities around toilet access'. Others had difficulty fulfilling usual and care roles, and 'eating a normal diet'. Only a minority of participants experienced few effects and were able to return to their pre-treatment lives.

Patient expectations of their GP

Participants acknowledged that 'GPs are generalists' and, therefore, it was 'unreasonable to expect them to know

Box 1. Interview guide

Interviews sought survivors' opinions about how to effectively transition follow-up care to primary care and potential changes needed to current practice to improve outcomes for survivors of CRC.

Topics explored included:

1. Side-effects or concerns experienced post-treatment;
2. Experiences transitioning care from acute to GP-coordinated care and the care received in the community post-treatment;
3. Care gaps in terms of monitoring and managing acute to long-term side-effects or concerns in the community;
4. Perceptions about GPs' role in post-treatment follow-up care and ways in which care could be improved.

Table 2. Participant characteristics.

Patient ID	Sex	Geographic location	Year diagnosed	Age at diagnosis (years)	Cancer location	Cancer stage	Treatment received
PM001	M	Rural	2007	50–59	Colon	3	Surgery/CT
PM002	M	Metropolitan	2016	20–29	Colon	2	Surgery/CT
PM003	M	Regional	2005	60–69	Rectum	2	Surgery/CT
PF005	F	Regional	2020	50–59	Colon	3	Surgery/CT
PF006	F	Metropolitan	2018	30–39	Colon	3	Surgery/CT
PF007	F	Metropolitan	2018	30–39	Colon	3	Surgery/CT
PM008	M	Metropolitan	2015	40–49	Colon	3	Surgery/CT
PF009	F	Regional	2017	50–59	Colon	3	Surgery
PF010	F	Rural	2020	50–59	Rectum	2	Surgery
PF011	F	Regional	2011	50–59	Colon	2	Surgery
PF012	F	Metropolitan	2019	20–29	Colon	3	Surgery/CT
PF013	F	Metropolitan	2018	30–39	Colon	3B	Surgery/CT
PM014	M	Metropolitan	2019	50–59	Rectum	2–3	Surgery
PF015	F	Metropolitan	2017	30–39	Colon	2	Surgery/CT
PF016	F	Metropolitan	2019	50–59	Colon	3B	Surgery/CT
PF017	F	Metropolitan	2019	>70	Colon	UN	Surgery
PF018	F	Rural	2020	40–49	Rectum	3	Surgery/CT/RT
PF019	F	Rural	2019	60–69	Colon	2	Surgery/CT
PF020	M	Rural	2020	60–69	Colon	3NI	Surgery/CT

CT, chemotherapy; RT, radiotherapy; UN, unknown.

about all cancer issues'. One male participant aged in his 40s from a metropolitan location felt that 'patients need to be proactive', as 'GPs aren't mind readers'. However, others were disappointed by their GPs' 'lack of insight into local services', and inability to adequately support them with necessary referrals and access to services. Most participants felt that GPs were vital in post-treatment supportive care and viewed as a key person that could influence all aspects of a patient's care experience post-treatment. However, 'the current health system needs improving, so that GPs themselves were better supported' to enable adequate referral and provision of information to their cancer patients. When expectations around post-treatment care were met (e.g. perceived adequate management of treatment side-effects, acknowledgement of possible supportive care needs), participants were satisfied with their experiences with their GP and 'valued the support' received. However, when expectations were not met, participants felt 'unsatisfied', 'disappointed' and 'like I was missing out on vital care'.

Patient experience of GP care

Participants who were positive about their GP experiences described their GP as 'sympathetic' and 'provided emotional support': 'My GP was accessible by email', '...squeezed me

in for appointments', '...prioritised me when I was sick' and '...phoned to check up on me'. They were someone who they trusted and had established good rapport. For participants with a longstanding relationship with their GP, usually those from metropolitan areas, they were a 'good consistent part of my whole journey', and particularly important as specialist visits decreased over time. One female participant aged in her 20s from a metropolitan location described her GP as being 'actively involved in my care...I had 4–6 weekly visits as part of a return-to-work plan'.

Access and referral to services post-treatment

Access and referral to health care providers after completing cancer treatment was varied. Participants whose GPs placed them on a Chronic Disease Management Plan received access to allied health providers. However, unless the providers had experience in post-CRC treatment effects, or cancer more broadly, 'they were not particularly helpful'. For example, several participants felt '...my GP did not always know who the best health care provider was to refer me to...so I had to research other providers or try different things [to alleviate problems] that often failed or caused me additional problems'. Some participants felt that 'CRC patients lacked the

same resources that other cancer patients received', namely, breast cancer.

Patient and GP communication

Participants reported that during visits, their GP focused on specific issues that patients presented with and generally '...did not ask about my cancer treatment or the impact it had on my life'. One participant thought '...time was a barrier for discussion about my general wellbeing after cancer'. Some participants felt 'comfortable raising any issue with [their] GP', whereas others felt '...awkward discussing things like sexual intimacy' and negative emotions despite having a good patient-GP relationship. Others felt '...[their] GP did not understand cancer-related issues...I would have preferred a GP who had more knowledge and interest in symptoms post-surgery'. One female participant aged in her 50s from a regional location felt '...uncomfortable making an appointment with [her] GP to just have a chat about [her] emotional concerns', while another female participant in her thirties from a metropolitan location '...preferred to talk to someone that [she] did not have an existing health care relationship with, such as a counsellor'. For others, 'having an existing relationship with [their] GP made it easier for [them] to bring up difficult issues' (female, 20s, metropolitan). Young CRC participants had specific needs that were not discussed around relationships, working after surgery, fertility and chemical-induced menopause.

Self-management and information seeking

Typically, participants initially sought help with managing post-treatment effects from their GP, surgeon or oncologist. However, ongoing unresolved side-effects resulted in lengthy '...periods of trial and error', particularly '...finding a diet that helped alleviate diarrhoea' and seeking '...information and support online to help manage [their] side-effects'. For example, one male participant aged in his 50s from a metropolitan location found: 'online that using a daily enema enabled [him] to go out without being concerned about incontinence'. Participants became knowledgeable about their illness through information from the Internet, YouTube videos and social media, but felt '...this information should come from [their] health care team': 'Facebook sites have been a godsend and that shouldn't be the case' (male, 50s, metropolitan). Bowel cancer organisation websites were a common starting point for information and access to counsellors, and 'bowel cancer nurses were excellent and the service valuable' (female, 50s, regional).

Participants accessed peer support through social media platforms and CRC organisation websites, but reported mixed experiences. Some found it valuable for self-management strategies, and information on available services and allied

healthcare providers: '...being able to connect to [other women] has been great. That's how I found out about different services that are available, different things that might apply to us...having that community is fabulous' (female, 50s, metropolitan) and 'Other sufferers of the same cancer really know what you are going through in a way that other people do not' (female, 50s, regional).

'Own' care coordinator

Several participants reported having no choice but to be their own care coordinator. Some wanted to be more involved in their care and felt '...it was important to take ownership of [their care]', whereas others '...had no one else who was able to do it'. One participant read clinical practice guidelines and realised that the gold standard for survivorship care was not translated into practice. This realisation prompted her to put together an allied health care support team. However, the problem with overseeing your own care is that '...when you are quite ill, the other people need to make the effort...you can't advocate and reach out yourself' (female, 50s, regional).

Disparities in care for rural patients

Participants from the Australian Capital Territory, regional and rural areas expressed more problems with GP care than those from metropolitan areas. Perceived GP shortages, difficulties getting prompt appointments and GP mobility contributed to dissatisfaction with the care received. For example, '...despite living in a town that was well serviced by GPs, many were transient and not necessarily committed to the town' (female, 50s, rural). Others experienced problems with access to providers and services locally due to limited options available. Several spoke about having to 'find [their] own information and referrals'. Rural GPs were perceived as having inadequate knowledge of cancer treatment effects, survivorship care and who to refer their patients to. Consequently, rural patients had to '...think about things or hear about things and push to be referred to them' (female, 50s, regional). Patients who did not have a regular GP felt '...[they] had to advocate for myself and educate my GP about side-effects post-surgery' (female, 50s, rural). Participants '...didn't get direction from the GP or the surgeon', and felt like they were 'floundering', 'out in the cold' and 'didn't know where to from here'.

Need for improved discharge preparation

Most participants felt ill-prepared for the short- and long-term consequences of treatment they experienced, the impact these had on their life, and how slow and painful recovery was going to be. Participants described: 'feeling alone after treatment'; 'not having a care plan', 'guidance' or '...adequate information or preparation for what was to

come'; feeling 'shocked by their symptoms'; and '... dismayed by the lack of support [they] received' after completing primary treatment. Better preparation at discharge, such as dedicated time to discuss and provide information on what to expect post-treatment, suggested self-management strategies, who to contact and for what issues, what issues they should be concerned about, and available allied health services, was needed.

Single point of contact

Several participants felt expert nurses should have a greater role in the ongoing support of CRC patients. Participants suggested a bowel cancer nurse would have been valuable to their care; for example, to clarify which issues needed to be seen by a GP versus a cancer specialist or to communicate directly with their GP: 'Having a specialist care nurse, like breast cancer does, who works between the hospital and GP would be nice' (female, 30s, metropolitan). One female participant aged in her 40s from a rural location described having a cancer nurse coordinator attend appointments with her oncologist, follow up on issues, check up on her general welfare, explain medications, and connect her with psycho-oncology and palliative care services extremely helpful: 'she is accessible and able to connect with the right services or people... she played such an important role, a bigger role than my GP'.

Discussion

There is ongoing debate about survivorship care coordination. Despite release of the 2006 Institute of Medicine report on cancer survivorship, urging 'primary care providers, oncologists and other care providers to work together... to agree on how to communicate with each other, and to work out streamlined transitions in care' (Hewitt *et al.* 2006), the post-treatment care for CRC survivors remains suboptimal. Our study explored CRC survivors experiences of post-treatment care and found several inadequacies; mainly around inadequate information provision at discharge from primary cancer treatment to both patients and GPs, poorly recognised and managed consequences of treatment in the community, and lack of availability of or mechanisms to access supports and allied health professionals experienced in managing CRC treatment effects. Improved sharing of information between cancer specialists and GPs, engagement with general practice, standardised methods to detect ongoing consequences of treatment, and referral pathways to manage them may help support general practices in providing survivorship care.

Consistent with others (Rutherford *et al.* 2020; Ju *et al.* 2021), we found that many CRC survivors experience a range of post-treatment effects that they feel ill-prepared for, but that are often long-term problems that negatively

impact quality of life. These are inadequately screened for or managed in the community. Despite some treatment effects being common and somewhat predictable, there lacks a framework or means for routinely assessing for these.

Survivors of CRC are often given little information routinely at discharge from primary treatment, and consequently self-seek information from the Internet and other sources to help relieve their treatment effects. Consistent with others (Durcinoska *et al.* 2017), when completing primary treatment, survivors would benefit from tailored information, written supportive care plans and improved access to allied health care providers experienced in managing CRC treatment effects.

Participants acknowledged GPs were generalists and, therefore, not expected to meet all their supportive care needs. This required a range of expertise. They did, however, expect their GP to enquire about concerns after cancer treatment, and facilitate access to secondary care through appropriate referrals. Of note, all our participants had contact with a GP post-treatment, and this was highly valued by some. Consistent with others (Nugteren *et al.* 2017), participants generally welcomed transition of long-term post-cancer care back to general practice, but felt that GPs needed improved engagement, support and information from tertiary cancer services to better care for their patients.

As found previously (Arndt *et al.* 2004), younger patients and those living in rural areas experience particular challenges. Younger people have specific information needs about relationships and fertility, and support needs to enable caring for children. Patients living in rural areas do not always have access to a regular GP, the same services or health care providers that are available to those in metropolitan areas.

Our sample was English speaking and unusually young (68% aged <50 years) and, therefore, may not represent the general CRC population, those with poorer health literacy or for whom English is their second language. Future research could explore how a variety of sociocultural demographic variables impact patients' views about the role of the GP in survivorship care. Although CRC diagnosis among those aged <50 years is increasing, in Australia, ~11% are aged <50 years (Bowel Cancer Australia 2020). Therefore, the findings from this study are particularly relevant for those diagnosed at a younger age. Tumour type and stage was self-reported, and the majority of participants experienced treatment-effects that affected their ability to return to their pre-treatment lives. Other studies indicate a higher percentage of early-stage CRC patients do well after treatment (Valeikaite-Tauginiene *et al.* 2022), suggesting some selection bias; those with ongoing problems may have been more likely to take part in our study. It does, however, highlight ongoing problems and unmet needs in the healthcare system to be addressed.

Recommendations

Outside of normal follow up with cancer specialists, there is variation and inconsistency in supportive care, with bowel problems and intimacy issues often not addressed, despite being highly prevalent and problematic (Rutherford *et al.* 2020; Ju *et al.* 2021). Routine assessment of these beyond the acute treatment period would enable identification of patients with unmet needs where appropriate supportive care through referral/clinical pathways could be beneficial.

Patients highlighted the need for better communication between cancer specialists and GPs, integration of all members of the treating team including GPs, and coordination of care after primary cancer treatment. One way this could be accomplished is through standardised processes for communicating follow-up care and potential allied health needs. However, system-level issues (e.g. inadequate Medicare-supported allied health sessions per year), unfunded GP non-clinical work and patient out-of-pocket expenses for non-Medicare funded support are barriers to adequate supportive care.

Additionally, improved mechanisms for information sharing with both patients and GPs about potential short- and long-term effects of treatment is needed to better prepare patients for likely effects and what to do if effects occur. For example, nurses on wards completing patient discharge could routinely prepare an individualised follow-up summary, outlining potential long-term/late-effects of treatment and care of these informed by all members of the treating multidisciplinary team, supportive care needs assessment, and referrals to allied health services actioned as required. This is consistent with current recommendations in the optimal care pathways for people with colorectal cancer (Cancer Council Victoria and Department of Health Victoria 2021). Patients should also be instructed to make a long appointment with their GP to share the follow-up summary and enable development of appropriate care plans. The follow-up summary would be a key resource for the patient and their health care providers, and used to improve communication and care coordination. In turn, this would reduce the need for GPs having to directly contact cancer specialists for information about their patients; an activity that has resource and financial implications, as these activities are not currently government funded.

Currently, some patients feel like their own care coordinator. Those who want to coordinate their care could be better equipped to do so by being provided with the 'right' information and resources as part of their discharge information. Others who perhaps are feeling unwell, are elderly or have other limiting factors would need additional support with managing the consequences of treatment and getting referrals to the right health care professional. Many CRC survivors are satisfied when their GP becomes responsible for coordinating follow-up care, and many found providing sympathy, emotional support, and potentially

going above and beyond a meaningful part of their therapeutic relationship. It is unfortunate that these activities receive inadequate government funding. Future research should explore whether this model is optimal and who should pay for coordination of care. However, if not the GP, there is need for another central person responsible for recognition of post-treatment concerns, and referral and access to relevant supports and services to manage these in the community. Specialists and services are often outside of cancer, so the mechanism by which they can be accessed needs improving.

Finally, to reduce inadequacies and disparities in follow-up survivorship care, there is the need for a team-based patient-centred health service model that aligns with CRC survivors' specific needs and management of post-treatment effects. Such a patient-centred model of survivorship care requires effective resourcing of all parts of the care team, including both generalist and specialist services. Chronic underfunding of primary care is likely a barrier to optimising care processes in the community. Contemporary models of team-based care could help to align inconsistent and parallel post-treatment care with better recognition of the roles of each team member.

Given the various ongoing needs of CRC survivors, with long-term CRC survivorship care already expanding beyond specialty cancer settings into general practice, it requires better access to interdisciplinary support for patients, and improved methods for detecting and managing post-treatment effects to minimise the impact on quality of life. For this to happen, we need better engagement between acute care/specialty cancer services and primary care, tailored information provision to patients, and improved sharing of information between cancer specialists with both GPs and patients. Current models of follow-up care inadequately address the complex needs arising after CRC treatment. Further, system issues preventing high-quality care for patients, such as inadequate funding for GP supportive care, need to be urgently addressed.

Supplementary material

Supplementary material is available [online](#).

References

- Arndt V, Merx H, Stegmaier C, Ziegler H, Brenner H (2004) Quality of life in patients with colorectal cancer 1 year after diagnosis compared with the general population: a population-based study. *Journal of Clinical Oncology* 22, 4829–4836. doi:10.1200/JCO.2004.02.018
- Australian Institute of Health and Welfare (2012) Cancer incidence projections: Australia, 2011 to 2020. Australian Institute of Health and Welfare, Canberra.
- Bowel Cancer Australia (2020) Young-onset bowel cancer. Available at <https://www.bowelcanceraustralia.org/young-onset>
- Braun V, Clarke V (2006) Using thematic analysis in psychology. *Qualitative Research in Psychology* 3, 77–101. doi:10.1191/1478088706qp0630a

- Calman L, Turner J, Fenlon D, Permyakova NV, Wheelwright S, Patel M, Din A, Winter J, Richardson A, Smith PWF, Foster C, motCSA Committee (2021) Prevalence and determinants of depression up to 5 years after colorectal cancer surgery: results from the ColoRECTal Wellbeing (CREW) study. *Colorectal Disease* **23**, 3234–3250. doi:10.1111/codi.15949
- Cancer Council Victoria (2018) Australians living with and beyond cancer in 2040. Available at <https://www.cancervic.org.au/research/registry-statistics/statistics-data/cancer-prevalence-in-2040.html> [Accessed 28 May 2020]
- Cancer Council Victoria and Department of Health Victoria (2021) 'Optimal care pathway for people with colorectal cancer.' (Cancer Council Victoria)
- Durcinoska I, Young JM, Solomon MJ (2017) Patterns and predictors of colorectal cancer care coordination: a population-based survey of Australian patients. *Cancer* **123**, 319–326. doi:10.1002/cncr.30326
- Foster C, Wright D, Hill H, Hopkinson J, Roffe L (2009) Psychosocial implications of living 5 years or more following a cancer diagnosis: a systematic review of the research evidence. *European Journal of Cancer Care* **18**, 223–247. doi:10.1111/j.1365-2354.2008.01001.x
- Halcomb EJ, Davidson PM (2006) Is verbatim transcription of interview data always necessary? *Applied Nursing Research* **19**, 38–42. doi:10.1016/j.apnr.2005.06.001
- Hewitt M, Greenfield S, Stovall E (Eds) (2006) 'From cancer patient to cancer survivor: lost in transition.' (National Academies Press: Washington)
- Hunt MR (2009) Strengths and challenges in the use of interpretive description: reflections arising from a study of the moral experience of health professionals in humanitarian work. *Qualitative Health Research* **19**, 1284–1292. doi:10.1177/1049732309344612
- Ireland MJ, March S, Crawford-Williams F, Cassimatis M, Aitken JF, Hyde MK, Chambers SK, Sun J, Dunn J (2017) A systematic review of geographical differences in management and outcomes for colorectal cancer in Australia. *BMC Cancer* **17**, 95. doi:10.1186/s12885-017-3067-1
- Jefford M, Koczwara B, Emery J, Thornton-Benko E, Vardy JL (2020) The important role of general practice in the care of cancer survivors. *Australian Journal for General Practitioners* **49**, 289–292. doi:10.31128/AJGP-10-19-5133
- Ju A, White K, Wiltink L, Faiz N, Koh C, Candelaria D, Rutherford C (2021) Prevalence of long-term patient-reported consequences of treatment for colorectal cancer: a systematic review. *Iranian Journal of Colorectal Research* **9**, 125–143.
- Luo Q, Lew J-B, Steinberg J, Worthington J, Yu XQ, Caruana M, Soerjomataram I, Bray F, Lawrance S, Arcorace M, O'Connell DL, Canfell K, Feletto E (2022) Trends in colon and rectal cancer mortality in Australia from 1972 to 2015 and associated projections to 2040. *Scientific Reports* **12**, 3994. doi:10.1038/s41598-022-07797-x
- National Cancer Control Indicators (2019) Relative survival by stage at diagnosis (colorectal cancer). Available at <https://ncci.cancer.gov.au/outcomes/relative-survival-rate/relative-survival-stage-diagnosis-colorectal-cancer> [Accessed 17 May 2022]
- National Cancer Control Indicators (2020) 5-year relative survival. Available at <https://ncci.canceraustralia.gov.au/outcomes/relative-survival-rate/5-year-relative-survival>
- Nugteren IC, Duineveld LAM, Wieldraaijer T, van Weert HCPM, Verdonck-de Leeuw IM, van Uden-Kraan CF, Wind J (2017) Need for general practitioner involvement and eHealth in colon cancer survivorship care: patients' perspectives. *Family Practice* **34**, 473–478. doi:10.1093/fampra/cmw139
- Rubin G, Berendsen A, Crawford SM, Dommett R, Earle C, Emery J, Fahey T, Grassi L, Grunfeld E, Gupta S, Hamilton W, Hiom S, Hunter D, Lyratzopoulos G, Macleod U, Mason R, Mitchell G, Neal RD, Peake M, Roland M, Seifert B, Sisler J, Sussman J, Taplin S, Vedsted P, Voruganti T, Walter F, Wardle J, Watson E, Weller D, Wender R, Whelan J, Whitlock J, Wilkinson C, de Wit N, Zimmermann C (2015) The expanding role of primary care in cancer control. *The Lancet Oncology* **16**, 1231–1272. doi:10.1016/S1470-2045(15)00205-3
- Rutherford C, Muller F, Faiz N, King MT, White K (2020) Patient-reported outcomes and experiences from the perspective of colorectal cancer survivors: meta-synthesis of qualitative studies. *Journal of Patient-Reported Outcomes* **4**, 27. doi:10.1186/s41687-020-00195-9
- Siegel RL, Miller KD, Fedewa SA, Ahnen DJ, Meester RGS, Barzi A, Jemal A (2017) Colorectal cancer statistics, 2017. *CA: A Cancer Journal for Clinicians* **67**, 177–193. doi:10.3322/caac.21395
- Valeikaite-Tauginiene G, Kraujelyte A, Poskus E, Jotautas V, Saladzinskas Z, Tamelis A, Lizdenis P, Dulskas A, Samalavicius NE, Strupas K, Poškus T (2022) Predictors of quality of life six years after curative colorectal cancer surgery: results of the prospective multicenter study. *Medicina* **58**, 482. doi:10.3390/medicina58040482
- Vu JV-T, Matusko N, Hendren S, Regenbogen SE, Hardiman KM (2019) Patient-reported unmet needs in colorectal cancer survivors after treatment for curative intent. *Diseases of the Colon & Rectum* **62**, 815–822. doi:10.1097/DCR.0000000000001326
- Wiltink LM, White K, King MT, Rutherford C (2020) Systematic review of clinical practice guidelines for colorectal and anal cancer: the extent of recommendations for managing long-term symptoms and functional impairments. *Supportive Care in Cancer* **28**, 2523–2532. doi:10.1007/s00520-020-05301-7

Data availability. The data that support this study cannot be publicly shared due to ethical or privacy reasons and may be shared upon reasonable request to the corresponding author if appropriate.

Conflicts of interest. The authors declare no conflicts of interest.

Declaration of funding. The researchers gratefully acknowledge the HCF Research Foundation and RACGP Foundation for their support of this project. These foundations have provided a grant that funds the whole project (HCF2020-25).

Acknowledgements. The researchers gratefully acknowledge the Primary Care Collaborative Cancer Clinical Trials Group (PC4) for their support of this project. We thank Cancer Voices Australia, our consumer networks and patient support groups, and all the peak Australian cancer and primary care organisations who disseminated information about our study via their members, facilitating recruitment.

Author affiliations

^ACancer Care Research Unit, Faculty of Medicine and Health, The University of Sydney, Sydney, NSW, Australia.

^BThe Daffodil Centre, The University of Sydney, a joint venture with Cancer Council NSW, Sydney, NSW, Australia.

^CNursing & Midwifery and Health Sciences, Faculty of Medicine, Notre Dame University, Sydney, NSW, Australia.

^DSydney Local Health District, Sydney, NSW, Australia.

^EConsumer Representative, Adelaide, SA, Australia.

^FUniversity of South Australia, Centre for Workplace Excellence, Adelaide, SA, Australia.

^GSydney School of Public Health, University of Sydney, Sydney, NSW, Australia.

^HMQ Health General Practice, Macquarie University, Sydney, NSW, Australia.