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Things I need you to know: a qualitative analysis of advice-giving statements in early-onset colorectal cancer patients’ personal accounts published online

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ABSTRACT

Objective People with early-onset colorectal cancer (EOCRC), defined as colorectal cancer (CRC) before the age of 50, now constitute a significant patient population. In empirical and grey literature EOCRC patients report unsatisfactory experiences of care, especially in relation to protracted intervals from first help-seeking to diagnosis. This study is the first to investigate EOCRC patients’ perspectives on ways to improve experiences of care. The objective is to provide foundational knowledge for the development of EOCRC-specific patient-reported experience measures (PREMs).

Design The study was designed as qualitative Internet Mediated Research, involving a thematic analysis of unsolicited narratives recounting personal experiences of EOCRC care. We examined advice-giving statements in 120 online texts written by EOCRC patients and survivors.

Setting The Internet is the broad research setting. The host websites of three prominent charitable CRC support organisations were selected as specific research sites: Bowel Cancer Australia, Bowel Cancer UK and Bowel Cancer New Zealand.

Results We found that 90% of texts comprised statements of advice to new patients about the importance of self-advocacy in achieving quality care. Four key contexts for self-advocacy were identified: (1) accessing relevant diagnostic services; (2) driving diagnostic investigations when symptoms are not resolved; (3) involvement in treatment decision-making and (4) proactiveness about preferred outcomes. Over 30% of advice-giving texts also directed statements of advice to healthcare providers, indicating that their youthfulness had been a barrier to timely diagnosis.

Conclusion Healthcare barriers to, and facilitators of, patient self-advocacy may be indicators of quality EORC care. There is a need for greater awareness of the impact of age bias on the responsiveness of clinicians and healthcare services in EOCRC care. Our findings support the development of EOCRC-specific PREMs that can guide age-appropriate policy and practice for this newly identified patient population.

INTRODUCTION

Colorectal cancer (CRC) is most common in people over the age of 50 however the global incidence of the disease in younger people has been rising since the 1980s. People with early-onset colorectal cancer (EOCRC) now constitute a significant patient population with epidemiologically, and potentially biologically, distinct characteristics from late onset CRC patients. EOCRC accounts for 6% of all CRC cases in the UK, 10.7% of CRC cases in Australia and 11.5% of CRC cases in New Zealand (NZ). As a result of the rising incidence of the disease in younger people and static or decreasing CRC incidence in older patients, in higher income countries especially, people with EOCRC are becoming a larger proportion of all CRC cases; by one US estimate, for example, early-onset patients will make up 11% of colon cancers and 23% of all rectal cancers by 2030.

Causes of the rising incidence of CRC in younger people are not yet well established.
Poor diet, decreased physical activity, obesity and overuse of antibiotics, especially in early years of life, are implicated. Further, rising incidence may be part of a trend; early-onset cancers are increasing in prevalence globally. EOCRC patients differ from older people with CRC in their diagnostic trajectories; time to diagnosis can be 60% longer for younger patients with a greater number of missed diagnostic opportunities, and younger people are more likely to be diagnosed in later stages of the disease.

Late stage diagnosis increases the likelihood of aggressive treatment with physical, psychosocial and quality of life outcomes that are uniquely challenging for this under-50 patient population. Few studies have investigated how this newly identified patient population views their healthcare trajectory from help-seeking for symptoms through to treatment outcome and as yet no patient-reported experience measures (PREMs) have been developed specifically targeting EOCRC. We have little empirical data to guide patient-centred best practice in EOCRC care.

CRC support organisations provide online platforms through their websites for CRC patients and survivors to publish accounts of their experiences in the public domain. These platforms present a substantial source of patient-reported, qualitative data on EOCRC care. The unsolicited nature of these data offers researchers a unique opportunity to understand what EOCRC patients want to say about their experiences and to examine the advice these patients offer others. Patient advice is of particular relevance to patient populations that are newly identified; new patients may prioritise the online advice of other patients, especially those whose disease is most personally relevant.

In this paper, we report our investigation of EOCRC patients’ online accounts of diagnosis and treatment. Our study asks: What experiences and perceptions of health services are reflected in the online advice offered by EOCRC patients? The translational aim of this study is to deliver evidentiary support for the development of EOCRC-specific PREMs that can guide healthcare practitioners and policymakers towards best patient-centred EOCRC practice.

**MATERIALS AND METHODS**

This study is reported in accordance with Standards for Reporting Qualitative Research (SRQR items S5-S15) (online supplemental appendix 1).

**Approach and research paradigm**

As yet there is no clear guidance on an appropriate research methodology for online research investigating unsolicited narratives. We devised a method we termed Personal Recollections Organised as Data (PROD). The PROD approach is theoretically constructivist, seeking out the knowledge that materialises as patients recount and reflect on their experiences of healthcare in unsolicited research contexts, such as online environments. The PROD approach is also grounded in pragmatism and framed by complexity science, seeking real world knowledge of healthcare dynamics that can translate to tools for improvement in healthcare quality. Further detail on the analytic methods involved in the PROD approach is available in the protocol for this study.

**Researcher characteristics and reflexivity**

The team was unified in exploring options for data collection, analysis and reporting that would adequately capture and reflect the guidance offered by EOCRC patients in their online narratives. Many of these personal accounts are deeply moving and all represent a challenging time in the life of the patients. In addition to adhering to formal guidelines for the protection of identity the team regularly discussed the authenticity of context in our use of excerpts from the texts and the validity of themes drawn from narrative descriptions.

**Context**

This study is designed as Internet Mediated Research (IMR). The Internet is the broad research setting and the host websites of three key charitable support organisations were selected as specific research settings: Bowel Cancer Australia, Bowel Cancer UK and Bowel Cancer New Zealand. US-based sites were not included because of substantial differences between the US and other care systems; we predicted a heterogeneity of findings that would be a barrier to the translational aims of the research. With permission from the selected organisations and institutional ethics approval we accessed the public domain sections of these websites in which bowel cancer survivors ‘post’ accounts of their experiences, under banners such as ‘real life stories’ or ‘your stories’.

**Population**

The selection of texts was based on the age of the author at date of diagnosis; written accounts were included if an author was aged under 50 at the time of CRC diagnosis. One organisation had stratified the personal accounts on its website that relate to <50 years CRC in contrast to ≥50 years CRC; the personal accounts published on the other two websites had not been curated according to age, so the texts were screened to identify the ages of the authors. Accounts were excluded from the study if they solely comprised feedback on a medical institution or clinician.

**Data collection and analysis**

All online texts that met the inclusion criteria were downloaded into the NVivo qualitative data analysis software for analysis.
software programme (QSR International Pty Ltd. V.12, 2018), deidentified and assigned a unique participant study number. These accounts were then analysed for advice-giving features, which we defined as actionable recommendations for readers. Advice-giving features were differentiated from recounting of, and reflections on, personal experiences by the use of second-person grammar in addition to key words such as ‘advice’ or ‘advise’, ‘recommend’, ‘suggest’ and ‘counsel’. Only advice-giving content that focused on health service use was included; this was contrasted with advice-giving text that related to illness mindsets and behaviours.

In line with the PROD method for analysis of unsolicited online narratives, we analysed the advice-giving texts quantitatively to determine the demographic profile of the authors of the texts. We then conducted a thematic analysis to address and explore the research question. The thematic analysis followed the precepts established by Braun and Clarke, originally in their seminal paper in 2006 and described by them more recently in the literature with Terry et al. The analysis was inductive and critically realist in its focus on meanings that were semantically explicit in the data. KL led the thematic analysis with review and consensus from coauthors.

Ethics approval
The selected CRC support organisations consented to the analysis and/or the use of quotes and excerpts from the personal accounts published on their websites and to the dissemination of findings. Information/data related to the study is stored on password-protected computers and archived on electronic databases on a secure server. In accordance with the Australian National Health and Medical Research Council guidelines for management of data and information in research, the records of this study will be retained for a minimum of 5 years post-study completion or last relevant publication.

Techniques to enhance trustworthiness
To ensure rigour in our investigation, we routinely discussed the criteria for trustworthiness proposed by Lincoln and Guba and further explored by Morrow, involving credibility, dependability, confirmability and transferability. Iterative results were reviewed by a subgroup of study authors and all authors to the study confirmed the results. As noted, the development of themes and the use of excerpts to exemplify themes was a point of regular discussion among study authors; authenticity to the meaning intended by patients was confirmed by re-reading the texts. Results were reviewed in relation to extant literature, supporting credibility of consistency between the themes identified as emergent in the data and external evidence.

Patient and public involvement
No patients and/or public were involved in the design, conduct, reporting or dissemination plans of the research. No patients and/or public were asked to review the findings of the study or to review manuscripts that report the findings. The CRC support organisations that approved data collection from the public domain spaces of their websites were not involved in the design, conduct, reporting or dissemination plans of the research.

Figure 1 Key healthcare advice themes in early-onset colorectal cancer (CRC) patients’ online narratives.
**RESULTS**

An overview of the results is presented in figure 1.

**Demographics**

Age and gender demographics of the authors of the accounts were identified either directly through information specified by the writers about themselves or by text analysis of the accounts to identify embedded information. From the three websites, a total of 273 personal accounts were included. Some two-thirds identified as female (n=200, 73.3%) and approximately half were aged 30–39 years (n=131, 48%). Almost half (n=156, 49.8%) were from the UK website, 42.5% (n=116) were from the Australian website and 7.7% (n=21) were from the NZ website.

Of the 273 patient online narratives that met the age and content selection criteria, 44% (n=120) were identified as offering advice about EOCRC-related health services. Of these, 80% identified as females and over half were aged 30–39 years (53%). Just over a third (n=37) were from the UK website, 58% (n=70) were from the Australian website and 11% (n=13) were from the NZ website.

**Key themes**

Advice-giving discourse across all texts focused on the importance of self-advocacy in managing an EOCRC care trajectory (n=108, 90%). Self-advocacy in cancer care has been defined as ‘the ability of an individual with cancer to overcome challenges in getting their preferences, needs, and values met’ [44] (see table 1 for key themes and illustrative excerpts). Over a third of the advice-giving texts (n=43, 36%) also recommended greater awareness among healthcare providers of the potential for age bias in EOCRC diagnosis (see table 2 for key themes and illustrative excerpts).

**Self-advocacy advice themes**

...it is crucial if you have any symptoms at all that you are concerned with, request to have a further investigation and DO NOT let anyone tell you, you are too young to get bowel cancer!

Guidance on self-advocacy in managing an EOCRC healthcare trajectory dominated the advice-giving texts. We identified two broad concerns: self-advocacy during diagnosis; and self-advocacy during treatment and recovery (see Table 1). Advice text related to diagnosis highlighted accessing relevant health services and taking the lead in medical investigations if symptoms persist. Advice text related to treatment and recovery focused on playing an active role in treatment planning and management, and proactivity in maximising personalised outcomes.

**Age bias advice themes**

No 26-year-old should have to go through what I went through—we need to change the conversation and smash the belief that this is an older person’s disease.

The study also identified advice narratives directed to the medical community regarding age discrimination in the diagnosis of EOCRC. These focused on four key issues: changing the mindset of practitioners towards age-based criteria for CRC investigation; raising awareness of the diagnostic importance of family history of CRC and genetically inherited syndromes; drawing provider attention to broad symptoms that may indicate CRC in younger people and the potential for misdiagnosis; and understanding the importance of person-centred care and listening to patients in EOCRC diagnosis. Table 2 summarises these results with illustrative excerpts.

**Singular data points**

Six per cent of advice-giving texts (n=7) comprised diverse practical matters, recommending: an infuser port (n=2); choosing one proprietary colonoscopy-preparation treatment over another (n=1); obtaining private health insurance (n=1) and preparedness for long appointment waiting times (n=1). There was also a recommendation for funding of immunotherapy treatment breaks (n=1) and a suggestion that health professionals provide newly diagnosed patients with a list of contacts for cancer support services and early referral to a dietician (n=1). Given the small proportion and heterogeneous nature of experiential advice on these matters, we have not investigated these data for themes.

**DISCUSSION**

Our principal finding is that the EOCRC patients in our study view self-advocacy as an essential resource for ensuring that their clinical and supportive care needs are met by health services. This finding is drawn from self-reported data capturing the experiences and observations that patients prioritise as personally meaningful [24,45]; it presents a new perspective on EOCRC patient experience and opens a level of inquiry into how these patients negotiate, adapt to and get best use of the health services and systems available to them.

Self-advocacy is of particular significance for EOCRC patients who face diagnostic challenges. EOCRC diagnostic trajectories commonly involve multiple medical consultations at all levels of care and feature a variety of tests other than colonoscopy over periods from 3 months to 5 years and sometime more [15,46]. Increasingly disturbing symptoms that significantly impact quality of life [13] and eventual late stage diagnosis [35,48] can have potentially devastating consequences for this patient population—people who are early to mid-career, just starting or raising families and consolidating their finances [46,47]. Self-advocacy may be viewed as the key to maximising the chance of an early diagnosis.

Given the narrative nature of our data, patients recounted the sequence of events from first help-seeking for symptoms to clinical outcome and recovery. Self-advocacy was reported as a vital resource across the entire trajectory of care. Guidance on the
take-up of psycho-emotional support services through treatment and recovery was a prominent aspect of self-advocacy advice; patients spoke of wishing they had used support services or finding support services important to their health status as well as quality of life. The relevance of this patient-to-patient guidance is reflected in a survey of 885 EOCRC patients which found that some 75% had concerns regarding their mental health, and over 60% acknowledged having received support for depression.47

<table>
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<tr>
<th>Phase</th>
<th>Key self-advocacy themes</th>
<th>Self-advocacy subthemes</th>
<th>Illustrative excerpts</th>
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<tr>
<td>Diagnosis</td>
<td>Obtain access to relevant healthcare</td>
<td>Push past screening guidelines</td>
<td>‘The earlier the diagnosis the better the outcome. Do not allow the free bowel screening age to stop you …’</td>
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<td></td>
<td></td>
<td>Shape GP decision-making</td>
<td>‘My advice to other young people is to please not ignore symptoms, no matter how embarrassing, and even more important, please don’t allow your doctor/s to be complacent about your symptoms’.</td>
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<td></td>
<td>Seek second opinions</td>
<td>‘… if you are not comfortable with your GP’s diagnosis get a second, third or fourth opinion! You are the only one who really knows your body. If I had taken the word of my GP I would not be here today!’</td>
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<tr>
<td>Drive investigations</td>
<td>Investigate early</td>
<td>‘My advice is to persist and if something feels wrong, please investigate. It often goes unnoticed in younger people until it has advanced in stage, when it is not as easily or as successfully treated’.</td>
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<td></td>
<td>Petition for tests</td>
<td>‘Don’t be the person worse off, get tests, don’t put it off, seek answers and push, push until you have your answers or resolution, don’t wait, it is your health, it’s your life’.</td>
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<td></td>
<td>Request colonoscopy</td>
<td>‘It was this ownership of my own health, requesting the colonoscopy, going through with the colonoscopy no matter how intrusive it seemed, that has saved my life’.</td>
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<td>Treatment and recovery</td>
<td>Play an active role in treatment</td>
<td>Gather personalised information</td>
<td>‘My advice to other women would be to arm yourself with as much information as possible, ask every question that comes to mind even if you think it is stupid’.</td>
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<td>Seek satisfactory interpersonal care</td>
<td>‘I encourage everyone to find a specialist that they feel comfortable with — you need to be able to discuss confronting subjects with this person. So if possible, try and choose a team you feel comfortable with as it is hard enough dealing with cancer’.</td>
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<td></td>
<td></td>
<td>Steer treatment decisions</td>
<td>‘Make sure you have a really good specialist surgeon …. Make sure ALL options are used’.</td>
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<td></td>
<td>Be proactive about outcomes</td>
<td>Navigate fertility issues</td>
<td>‘For young women going through radiation, ask about the damage the radiation can do internally, especially if you want kids in the future …. The damage to my uterus and surrounds was too much from the radiation to carry a child’.</td>
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<td></td>
<td>Use psycho-social support services</td>
<td>‘You are going to need all your energy, strength and focus during the treatment. Don’t waste energy on other areas. If you don’t know how to do this, see a professional/psychologist. I was provided with one during my treatment and it was very beneficial. I still talk to her to this day’.</td>
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| | | Lead post-treatment follow-up | ‘I wish I had known, however, that I have to have a loud voice, especially post-surgery. Several issues were identified post-discharge’.

GP, general practitioner.
Further, this patient population may deal with different, and potentially more severe, emotional and psychological challenges than are faced by older CRC patients, especially in relation to self-image and sexual functioning. In our study, access to psycho-social or other support services was not noted as an issue; rather the focus of concern was self-advocacy in the take-up of such services. Patients felt guilty about spending time away from family or felt that family and friends were providing all the emotional support needed. Some expressed a perception of being a fraud in the wider cancer patient community if their treatment did not result in a dramatic hair loss or a stoma. Key issues for policy and practice may relate to identifying and recruiting patients to supportive care; young patients may not perceive the need or ‘right’ to access supportive care, particularly if there are no outward aesthetic changes.

In our second set of findings, EOCRC patients directed advice to the medical community and the general public to be aware of age bias in CRC diagnosis. The implications of this advocacy are complex. Previous work by this research team and others has identified a number of cultural or linguistic challenges, could be an intrinsic feature of patient-centred care.58 59 Self-advocacy has been recognised as a patient-centred resource that can be formally and informally supported to enhance the quality and safety of care.44 The current focus of patient-centred care programmes, however, emphasises the interpersonal skills of providers and the development of tools for shared decision-making.39 60 Self-advocacy is under-explored in interventions to improve patient-centred care46 61 and has not been investigated at all in relation to EOCRC patients. It may be a key topic for inclusion in EOCRC-specific PREMs. Relevant questions may be developed to measure health service facilitators of, and barriers to, the enactment of self-advocacy. The value of these self-identified self-advocacy skills could be validated at population level by cross-checking against time from symptoms to first diagnosis. If validated as effective, patients with lower levels of self-advocacy skills, or who face barriers in enacting self-advocacy such as physical, psychosocial, cultural or linguistic challenges, could be prioritised for patient advocacy support services.

**Limitations**

The strengths of this study in collecting self-determined patient experience data from unsolicited online narratives

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<tr>
<th>Theme</th>
<th>Illustrative excerpts</th>
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<tr>
<td>Shift conventional understanding of colorectal cancer</td>
<td>‘I have been open in sharing my story in the hopes that it helps someone else to recognise the symptoms and to get help. I also share it in the hope that medical professionals will change their mindset and accept that bowel cancer CAN HAPPEN to young people and that you are Never Too Young’.</td>
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<td>Raise awareness of family history and inherited syndromes</td>
<td>‘I would strongly encourage all young people to find out about their family bowel cancer history including a history of bowel polyps. You are #Never2Young for bowel cancer and you should not avoid seeking care when things are not right. We also need to change the mindset of healthcare professionals to realise that bowel cancer DOES affect young people’.</td>
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<tr>
<td>Raise awareness of misdiagnosis in EOCRC</td>
<td>‘Many young people end up with advanced bowel cancer. They get misdiagnosed as having dietary intolerances, or worse, their GP believes they are too young to have bowel cancer. My message is that bowel cancer can happen to young, fit people’.</td>
</tr>
<tr>
<td>Importance of person-centred care</td>
<td>‘I feel lucky that my current GP is tenacious and listens! There are many men and women who weren’t so lucky and it’s for them that we, as a community, need to do whatever we can to shift the focus off of cancer discriminating against age. Never too young!!’</td>
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EOCRC, early-onset colorectal cancer.

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Table 2 Illustrative excerpts representing themes related to age bias in EOCRC patients’ online narratives

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are mobilised alongside the limitations of a research population whose recollections of events cannot be validated. We had to assume the veracity of the perspectives and opinions presented in the narratives based on the legitimacy of the source websites. Our quantitative demographic analysis of our data made it evident that the perspectives of females are over-represented in our study, in relation to the incidence by gender of EOCRC. Generally, men and women contract EOCRC at similar rates, however, 80% of the advice-giving narratives we analysed were written by women. This limitation reflects the literature indicating higher female participation in online health platforms. Additionally, despite the presence of Indigenous and immigrant populations in the countries of interest, we note a lack of advice-giving data relevant to culturally and linguistically diverse (CALD) EOCRC populations. Linguistic and socio-cultural barriers may preclude CALD populations from sharing healthcare experiences on social media platforms. These limitations impact the transferability of the findings to wider EOCRC populations.

Conclusions

Barriers to and facilitators of patient self-advocacy may be important indicators of quality EOCRC care. Further research on this aspect of EOCRC patient experience may support the development of self-advocacy questions as a component of EOCRC-specific PREMs. Given our findings, self-advocacy as a crucial resource in timely EOCRC diagnosis may be an effective message to embed in public health campaigns targeting consumer-oriented, younger patient populations. On a wider level of cancer care, especially for young people, our finding points to self-advocacy as a mechanism to support patient-centred care.

A growing body of grey and peer-reviewed literature supports EOCRC patients’ concerns with age bias, however, clinical guidelines do not as yet distinguish EOCRC from CRC in older populations and it can be challenging for medical practitioners to identify and screen for EOCRC in average-risk individuals. Researchers, policy makers and healthcare professionals may benefit from engagement with EOCRC patient online communities and consumer advocates to comprehend youthfulness as a barrier to timely diagnosis.

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published on the public domain spaces of their websites. The team appreciates the time taken by authors of the texts to convey their hard-earned advice.

Contributors KL devised the study and is responsible for the overall content. KL and DF-P undertook the detailed design of the study, in consultation with GA, SSO, BNGE and YT. KL and DF-P prepared the study materials. KL undertook the analysis in consultation with DF-P, SSO and GA. KL wrote the first draft of the manuscript. KL, DF-P, GA, SSO, BNGE, YT, WL and JB contributed to and approved the final manuscript.

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Competing interests None declared.

Patient and public involvement Patients and/or the public were not involved in the design, or conduct, or reporting, or dissemination plans of this research.

Patient consent for publication Not applicable.

Ethics approval This study involves human participants and was approved by Macquarie University Human Research Ethics Committee approved the study (MO HREC Reference ID S20200245811575/7) and the study has been conducted in accordance with the Australian National Statement on Ethical Conduct in Human Research (2007–updated 2018) and poses no risk of privacy infringement to authors of the texts. The study also adheres to the principles for IMR established by the British Psychological Society. Participants gave informed consent to participate in the study before taking part.

Provenance and peer review Not commissioned; externally peer reviewed.

Data availability statement Data are available upon reasonable request.

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