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RESEARCH

Exploring sexual health communication in early-onset colorectal cancer

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Abstract

Background Sexual dysfunction is a prevalent and distressing side effect of colorectal cancer treatment, especially in younger patients. Despite this, communication around sexual health is often neglected.

Aims This study aimed to investigate patterns of sexual health communication between patients with colorectal cancer under the age of 50 years (early-onset colorectal cancer, EOCRC) and healthcare providers, and identify perceived barriers from both perspectives.

Methods A retrospective cross-sectional study was conducted involving EOCRC survivors and healthcare providers (surgeons, trainees and nurse specialists) in Aotearoa New Zealand. Questionnaires assessed recall of sexual health discussions, communication preferences and barriers to raising sexual health concerns.

Results One hundred thirteen EOCRC patients and 64 healthcare professionals responded. Thirty per cent of patients recalled receiving adequate information about sexual health impacts during treatment, and 22% during follow-up. Women were significantly less likely than men to report receiving adequate information during treatment (14.3% vs 47.2%, $p = 0.002$). Most patients (78%) preferred that healthcare providers initiate discussions, yet only 22% and 13% of providers reported routinely doing so during treatment and follow-up, respectively. Key barriers included time constraints, concerns about offending patients and the presence of family members. Many patients indicated a preference for receiving information via multiple modalities, including verbal, written and online formats.

Conclusions Communication about sexual health in EOCRC is frequently inadequate, particularly for women. Healthcare providers should routinely initiate discussions about sexual health throughout CRC survivorship care. Practical low-cost strategies to improve communication could include better clinician education, provision of verbal and written information and allocation of time without family members present at the end of consultations.

Keywords Sexual health · Colorectal cancer · Early-onset colorectal cancer · Communication · Womens health · Erectile dysfunction

Background

The psychological impact of a diagnosis and subsequent management of colorectal cancer (CRC) can have a significant adverse effect on a patient's sexual health and subsequent quality of life (QOL). The incidence of early-onset colorectal cancer (EOCRC), diagnosed in patients under 50 years of age, has increased in recent decades [1]. Aotearoa New Zealand has the third highest incidence of EOCRC in the world, and in recent years has seen the fastest rates of increase of incidence [2]. CRC is the second most commonly diagnosed cancer and the second leading cause of cancer death nationally [3]. A systematic review examining the psychosocial

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impacts of EOCRC found concerns around sexual health to be a major issue for EOCRC patients [4]. Sexual health is defined by the World Health Organization as a state of physical, emotional, mental and social well-being in relation to sexuality, not merely the absence of disease, dysfunction or infirmity [5]. This broad definition extends beyond sexual dysfunction, a narrower term referring to impairment in one or more domains of sexual functioning (such as desire, arousal, lubrication or erectile function, orgasm and pain) and also encompasses the psychological and relational dimensions of sexuality, such as body image, intimacy and self-esteem, which are commonly affected by a cancer diagnosis. In the context of CRC, both sexual dysfunction and these broader dimensions of sexual health may be affected.

EOCRC survivors face sexual health concerns that differ from those of older CRC survivors. Although older CRC survivors have higher baseline rates of sexual dysfunction than younger adults, EOCRC survivors are more likely to be sexually active and are navigating fertility, relationship formation, body image and family life at the time of diagnosis, meaning treatment-related sexual dysfunction is likely to carry a disproportionate psychological and social impact [4, 6]. In a companion population-based case-control study by our group, 68% of EOCRC women reported clinically significant sexual dysfunction compared with 35% of age-matched controls, with significant impairment across the domains of desire, arousal, lubrication and orgasm; men did not have significantly higher rates of erectile dysfunction than controls but reported significantly lower sexual desire and orgasmic function [7]. These overall rates are broadly comparable to those reported across the wider CRC population [8], reinforcing that what distinguishes EOCRC is not necessarily a higher prevalence of dysfunction, but its occurrence at a life stage where sexuality, fertility and relationship formation carry particular importance, with survivors facing decades of life with unresolved dysfunction if it is not addressed. This makes discussions around sexual health of particular importance in this age group.

Sexual dysfunction after CRC treatment arises through several mechanisms. In women, pelvic surgery and radiotherapy can cause vaginal shortening, altered angulation, scarring, stenosis or dryness, resulting in reduced arousal, lubrication and dyspareunia, and can precipitate premature menopause and its associated hormonal changes [6, 8]. In men, damage to the pelvic autonomic nerves during rectal surgery can impair erectile and ejaculatory function, and radiotherapy and chemotherapy can further reduce desire and orgasmic function [6, 8]. The impact of a stoma on body image and subsequent sexual health is also well established [9]. Beyond these physical mechanisms, the psychological distress of a cancer diagnosis appears to be an important independent contributor to sexual dysfunction, which may explain why concerns are not confined to those CRC patients receiving pelvic treatment [7, 10]. Sexual minority patients may face distinct challenges in this area, and healthcare providers report greater difficulty discussing sexual health with lesbian, gay and bisexual patients than with heterosexual patients [11]. For example, gay and bisexual men who practise receptive anal intercourse may find rectal excision and stoma formation has a profound impact on their sexual relationships, while clinicians often offer only generic rather than orientation-specific counselling [12].

Despite this, discussions regarding the potential sexual side effects of CRC treatment are often neglected, with studies suggesting that approximately half of all patients receive no information about treatment-related sexual dysfunction, particularly women [13]. There are barriers to both patients and healthcare providers wishing to raise issues about sexual dysfunction with EOCRC patients that include embarrassment, time constraints, lack of awareness, inadequate training and/or the belief that these issues should not be raised in the setting of a new cancer diagnosis [14]. Given the negative impact that sexual dysfunction has on patients' QOL [4], gaining a better understanding of the patterns of communication around sexual health, as well as perceived barriers to this communication by both patients and healthcare providers, is essential. Moreover, if issues around sexual health are not addressed in these patients, then they cannot be managed.

This study examines the patterns of communication about the sexual health impacts of EOCRC treatment both during treatment and through follow-up, with the hypothesis that sexual health communication is likely to be often neglected in this patient group. The study then explores perceived barriers to this communication from the perspectives of both patients and healthcare providers.

Methods

Study design

This was a cross-sectional study of patients and healthcare providers examining experiences and perspectives relating to patterns of sexual function communication and perceived barriers to this process.

Study population

The primary study population comprised all patients diagnosed with colorectal adenocarcinoma aged 50 years or younger and living in the Canterbury region from 2010 to 2023. Patients were excluded if they had received any treatment within the 6 months preceding survey completion. This exclusion criterion was applied consistently across both this study and a concurrent study by our group examining sexual function outcomes (using the FSFI and IIEF) in the same population [7], for which the 6-month window

was required to minimise confounding from acute, transient treatment-related changes in sexual function, such as wound healing, post-operative nerve oedema, acute radiation-induced vaginal inflammation [15] or stoma-related body image adjustment [16], which then may improve or stabilise over coming months. Healthcare providers, including colorectal surgeons, surgical trainees and nurse specialists who manage CRC patients, were also included. Colorectal surgeons, surgical trainees and colorectal nurse specialists were selected as they have the greatest continuity of contact with CRC patients across diagnosis, treatment and surveillance follow-up within the Aotearoa New Zealand model of care, where the surgical team typically leads long-term survivorship follow-up. Medical and radiation oncologists, whose involvement is generally confined to a defined treatment window, and psychosocial providers such as psychologists and social workers, were not included in this initial study; this is acknowledged as a limitation, with their perspectives recommended for future research in this area (see Discussion).

This was a descriptive cross-sectional study, and no formal sample size calculation was performed. All eligible EOCRC patients identified within the study period were invited to participate.

Recruitment of study participants

Patients

A list of all patients diagnosed with CRC in Canterbury from 2010 to 2023 was obtained from the New Zealand Cancer Registry. Potential participants were sent a letter with an information sheet and a link to the online consent form and questionnaire. Non-responders were contacted by phone to request their participation.

Following patient consent, further detailed clinical and demographic information was obtained from Te Whatu Ota/Health New Zealand's electronic health records.

Healthcare providers

An email, followed by a reminder with a link to an online questionnaire, was sent to general surgeons who treat CRC in New Zealand secondary and tertiary hospitals, senior surgical trainees (including all general surgical trainees who were training in 2024), and colorectal clinical nurse specialists who regularly see CRC patients.

Data collection

Data was collected via electronic questionnaire. The questionnaire was constructed to establish the patterns of communication around the impact of CRC treatment on sexual health, both from the perspective of patients and healthcare providers. In addition, the authors designed a range of questions to investigate potential barriers to communication about this topic, based on a review of relevant literature [13, 14, 17–19]. Māori are the indigenous (tangata whenua) peoples of Aotearoa New Zealand and experience significant disparities in cancer outcomes, including CRC, relative to non-Māori [20]. Cultural considerations are therefore integral to health research conducted in this setting, and the patient questionnaire used in this study was reviewed by a Māori patient advocate to ensure its content and wording were appropriate and relevant to Māori participants. Exact versions of the questionnaires are available as a supplementary file. We had no missing data points.

Statistical analysis

The results for each question were tabulated, and selected questions were plotted in Excel. R was used for statistical analysis [21]. Two-sided Fisher tests were used to compare responses from different groups.

Ethical approval

Ethical approval for the study was obtained from the local District Health Board (DHB) (RO#23123), the Health and Disability Ethics Committee (HDEC) (ref:2023 EXP 13971) and the project was endorsed by the University of Otago, Christchurch, Māori Research Expertise Rōpū. Additionally, approval was received from the Ngai Tahu Research Committee. The study was conducted in accordance with the ethical principles of the Declaration of Helsinki.

Results

Study participants

Of a total of 277 eligible EOCRC survivors and 189 healthcare providers who were invited to participate, the final study population included 113 patients (56 female and 57 male) and 64 healthcare providers (41 surgeons, 12 senior trainees and 11 colorectal nurse specialists). This corresponds to response rates of 40.8% (113 of 277), 59.4% (41 of 69), 17.7% (12 of 68) and 21.1% (11 of 52), respectively. Of the included patients, 92% ($n=104$) were of European ethnicity, 4% ($n=5$) were Māori, 2% ($n=2$) were Middle Eastern/Latin American/African, 1% ($n=1$) were Pasifika and 1% ($n=1$) were Asian. The ethnicity of healthcare providers was not recorded (Table 1). The healthcare providers had a range of years of experience in their current role (0–2 years, 16%; 3–5 years, 31%; 6–9 years, 19%; 10–14 years, 14%;

Table 1 Basic characteristics of patients and healthcare providers

	Cases	Healthcare providers
Total	113	64
Sex		
Female	56 (49.6%)	25 (39.1%)
Male	57 (50.4%)	39 (60.9%)
Sexual orientation		
Heterosexual	109 (96.5%)	62 (96.9%)
Non-Heterosexual	1 (0.9%)	0 (0%)
Bisexual	3 (2.7%)	1 (1.6%)
Clinical characteristics[†]		
Tumour site		
Colon	57 (54.8%)	
Rectum	46 (44.2%)	
Stage of disease		
Stage 1	21 (20.4%)	
Stage 2	25 (24.3%)	
Stage 3	42 (40.8%)	
Stage 4	15 (14.6%)	
Received radiotherapy	33 (31.7%)	
Received adjuvant chemotherapy	48 (46.2%)	
Permanent stoma	14 (13.5%)	

[†]Clinical and demographic detail was linked via health records for 104 of the 113 patient respondents, linkage was not possible for 9 respondents, who are excluded from this table but retained in all communication analyses above

15 + years, 20%). Clinical details were available for 104 of the 113 patients (Table 1).

Using this same dataset, a companion study assessing sexual function outcomes (using the Female Sexual Function Index, FSFI [22] and the International Index of Erectile Function, IIEF [23]) and psychological symptoms (Depression measured using the Patient Health Questionnaire – 9, PHQ-9 [24], Anxiety measured using the Generalised Anxiety Disorder-7, GAD-7 [25] score) found that 67.9% of women and 44.7% of men had clinically significant sexual dysfunction, or erectile dysfunction compared with 34.9% and 29.4% of age-matched controls respectively, and that anxiety was significantly more common among male patients than controls (56.2% vs 25.4%, $p < 0.05$) [7]. Please see that study for more details.

Patterns of communication

Only 30.3% of patients surveyed recalled getting what they considered adequate information about the potential impact of their treatments on sexual health during the initial treatment phase, and this number fell to 21.6% during follow-up. Some patients did not recall receiving any information during treatment (41.3%) or during follow-up (50.5%). There were differences between the sexes, with women reporting receiving significantly less information than men. Only 14.3% of women reported receiving the amount of information they considered appropriate during treatment, compared to nearly half of men (47.2%, $p = 0.002$) (Fig. 1).

When healthcare providers were asked how often they raise issues of sexual health, only 22.2% and 12.5% of healthcare providers reported consistently giving information regarding the sexual health impacts of CRC during treatment and follow-up, respectively. Responses varied across different healthcare providers. While 56.1% of consultant surgeons raised issues of sexual health more than half (or always), this was in stark contrast to the senior trainees, where none reported routinely doing this ($p < 0.001$) (Table 2).

Interestingly, 50% of healthcare providers reported they were more likely to discuss issues of sexual health with men, with only one provider (1.6%) saying they would be more likely to raise the problems with women.

Patients were asked how this information was conveyed. Most (60.2%) reported receiving the information verbally; 23% received a written handout; and 11.5% were directed to online resources. The healthcare providers surveyed reported relying heavily on verbal discussion (90.6%), with few reporting using written handouts (7.8%) and online resources (9.4%).

When patients were asked which form of communication they preferred, 87.6% reported verbal discussion, but 64.5% also selected written handouts and 40.7% selected online resources, highlighting that most patients would like more than one method of conveying this information.

Although not specifically measured in the questionnaire, several healthcare providers noted in the free-text comments that they would routinely raise sexual health issues with patients with rectal cancer, but not with those with colon cancer.

Importance of discussions around sexual health

When patients were asked to rate how important they considered receiving information around the sexual health impacts of treatment at the time of diagnosis, roughly one quarter suggested it was 'very important' (26.5%), while only 15% of patients selected 'not at all'. Patients felt the issue was relatively more important during follow-up, with 60.8% reporting that this discussion was at least quite important. When the same questions were posed to healthcare providers, most considered these discussions to be important, with 64% and 65.7% rating them as at least 'quite important' during treatment and follow-up, respectively (Table 3).

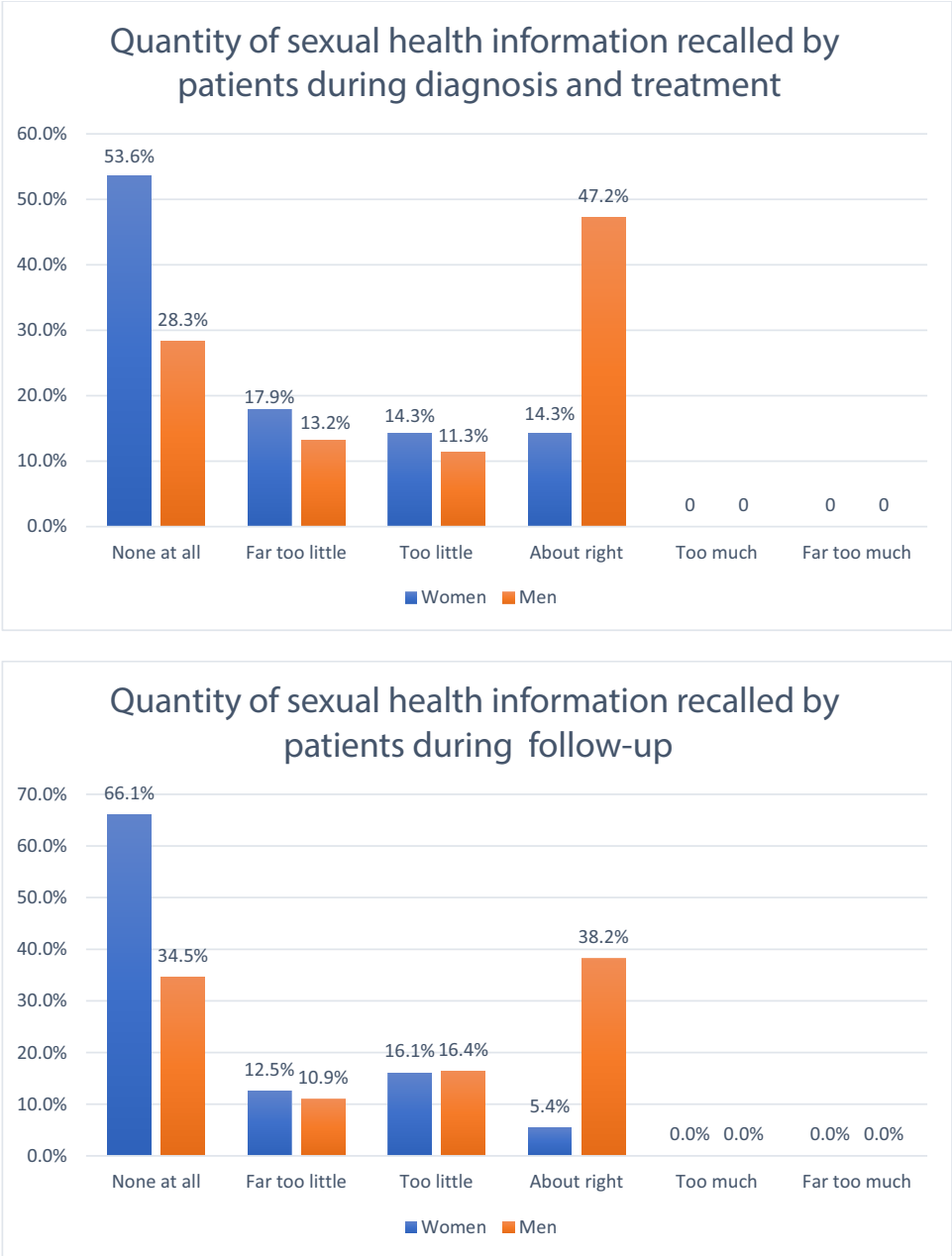


Fig. 1 The quantity of sexual health information recalled by patients during diagnosis and treatment

Barriers to communication around sexual health

Questions were asked of both patients and healthcare providers concerning possible barriers to effective communication around sexual functional issues during treatment or follow-up. The full results are shown in supplementary tables 1 and 2, with key findings summarised below.

One of the key findings from this study was the disconnect between patients and healthcare providers regarding who should initiate discussions about sexual health. While most patients (77.7%) preferred healthcare providers to raise these issues, the majority of providers (59.4%) reported that they did not routinely do so.

Although most patients felt comfortable raising sexual concerns (68.4%), this was significantly less common among women (47%) than men (71%, $p=0.045$). While some healthcare providers expressed concern about causing offence by enquiring about sexual health (18.8%), this appeared largely unfounded, as only 4.4% of patients reported that such discussions would be offensive. Nearly one in five patients (19.7%) reported greater difficulty discussing sexual health with a provider of a different gender, a finding that was more pronounced among women (35%). The presence of family members in the consultation room was a notable barrier for both patients (48.7%) and healthcare providers (71.9%), and time constraints were also commonly cited by providers as a barrier (34.4%).

Table 2 Patterns of communication by healthcare providers during treatment and follow-up

		Almost never or never *n* (%)	At times (less than half) *n* (%)	Sometimes (about half the time) *n* (%)	Most times (more than half the time) *n* (%)	Almost always or always *n* (%)	*P**
During the initial diagnosis and treatment period, how often do you raise the issue of the potential impact that CRC treatment will have on their sexual health?	Total	9 (14.3)	13 (20.6)	16 (25.4)	11 (17.5)	14 (22.2)	
	Surgeons	1 (2.4)	7 (17.1)	10 (24.4)	10 (24.4)	13 (31.7)	< 0.001
	Surgical Trainees	5 (41.7)	2 (16.7)	5 (41.7)	0 (0)	0 (0)	
	Nurse specialists	3 (30)	4 (40)	1 (10)	1 (10)	1 (10)	
During follow-up, how often do you ask about sexual health?	Total	10 (15.6)	22 (34.4)	11 (17.2)	13 (20.3)	8 (12.5)	
	Surgeons	4 (9.8)	12 (29.3)	9 (22)	12 (29.3)	4 (9.8)	0.078
	Surgical Trainees	4 (33.3)	5 (41.7)	2 (16.7)	0 (0)	1 (8.3)	
	Nurse specialists	2 (18.2)	5 (45.5)	0 (0)	1 (9.1)	3 (27.3)	

*Two-tailed Fisher test comparing responses between different healthcare providers

Table 3 Perceived importance of discussion around sexual health through diagnosis, treatment and follow-up

	Not at all *n* (%)	A little bit *n* (%)	Somewhat *n* (%)	Quite important *n* (%)	Very Important *n* (%)
Patients					
How important do you think it is for the doctors caring for you on your cancer journey to discuss issues surrounding sexual function with you at the initial diagnosis?	17 (15)	23 (20.4)	20 (17.7)	23 (20.4)	30 (26.5)
How important do you think it is for the doctors caring for you on your cancer journey to discuss issues surrounding sexual function with you during the treatment period?	8 (7.1)	18 (15.9)	23 (20.4)	32 (28.3)	32 (28.3)
How important do you think it is for the doctors caring for you on your cancer journey to discuss issues surrounding sexual function with you during follow-up visits?	3 (2.7)	19 (17)	22 (19.6)	34 (30.4)	34 (30.4)
Healthcare providers					
How important do you think it is during the initial diagnosis and treatment period to discuss issues surrounding sexual function?	0 (0)	7 (10.9)	16 (25)	18 (28.1)	23 (35.9)
How important do you think it is during the follow-up (or after treatment has finished) to discuss issues surrounding sexual function?	0 (0)	7 (10.9)	15 (23.4)	22 (34.4)	20 (31.3)

Discussion

This study has shown that the majority of EOCRC patients (particularly women) do not receive sufficient information regarding the potential impacts of CRC treatment on their sexual health. This is despite sexual health being identified as an important issue for EOCRC patients [4]. This study also noted a disconnect between patients and healthcare providers regarding who should initiate the discussion around sexuality and identified several barriers and preferences from both patients' and healthcare providers' perspectives, regarding communication around issues of sexual health during consultations. We are hopeful that by improving awareness of both the importance of sexual health discussions and the barriers that impede them, healthcare providers will feel better equipped to raise the issue with EOCRC patients.

The findings of this study are consistent with those of a growing body of research which reports that issues around sexual health are inadequately addressed throughout diagnosis, treatment and follow-up [6, 13, 17, 26–30]. One large systematic review examining communication about sexual concerns in cancer patients found that, on average, discussions occurred in 50% of cases [13], and were less than half as frequent when the patients were women. This disparity is reflected in the current study, where roughly double the proportion of women surveyed reported receiving no communication regarding sexual issues during treatment and/or follow-up when compared to the male patients, and in other studies [28, 31]. This is an area of particular concern given the finding that rates of sexual dysfunction are significantly higher in women diagnosed with EOCRC when compared to men [7], and highlights the importance of clinicians raising

sexual health with women. Furthermore, sexual dysfunction following cancer diagnosis and treatment is well documented in other cancer types, including breast and prostate cancer, where the impact extends beyond direct physiological effects (such as surgical scarring, mastectomy or erectile dysfunction after prostatectomy) to significant psychological and relational consequences, including altered body image, loss of identity and relationship strain [32]. These parallels reinforce that sexual health communication should be considered a core component of survivorship care across all cancer types.

Most patients in this study indicated they would rather the healthcare provider initiate the discussion around impacts on sexual health, rather than raising it themselves, consistent with multiple prior studies [27, 33, 34]. This is likely due to several reasons, including embarrassment [13, 18, 35], worry that their sexual dysfunction will not be viewed as a valid concern, that it is somehow 'inappropriate' to raise and/or not wanting to make the healthcare provider uncomfortable [14, 18]. Despite this, the majority of healthcare providers in this study reported not routinely raising these issues during treatment or follow-up, a finding echoed in other studies [36, 37]. This may be due to healthcare providers' worry that by raising issues of sexuality, they will offend or embarrass patients [19, 33, 38], as reported by many in this study (thankfully, however, the patient responses in this study appear to refute this). These findings align with a broader pattern reported across cancer types, in which sexual health concerns are rarely raised by health professionals unless the patient initiates the conversation. Similar reluctance among clinicians to broach the topic has been documented in breast, gynaecological and ovarian cancer populations [39–41].

Time constraints on healthcare providers were also recognised to be a factor contributing to poor communication, both in this study and in others [36], as were feelings of personal embarrassment or discomfort [38]. Other health care providers feel either inadequately trained or underprepared to have these discussions [37], or admit to having poor knowledge of potential treatment options should dysfunction be disclosed [42]. Collectively, these findings suggest that the onus should be on healthcare providers to routinely initiate conversations about possible impacts on sexual health, and that improved education for less experienced healthcare providers would enhance the frequency (and usefulness) of these discussions. This is consistent with recommendations from the American Society of Clinical Oncology (ASCO), which state explicitly in their guidelines for the management of sexual issues in cancer patients that the discussions should be initiated by the healthcare team [43]. Several simple tools can help healthcare providers better navigate discussions around sensitive topics such as sexual dysfunction. Such as the well-known PLISSIT model [44], which provides a stepwise approach to handling sensitive issues, avoids overwhelming the individual with excessive information, offers specific suggestions for treatment and encourages referral when necessary.

Having family present in the room was a barrier to the majority of healthcare providers and patients concerning raising issues of sexual health. One way to resolve this would be for healthcare providers to routinely allocate a proportion of the consultation to the patient (and/or partner) only, thereby enabling direct communication regarding more sensitive issues. This finding may carry particular significance for Māori patients, for whom attendance at hospital appointments with whānau (extended family) reflects an important cultural practice, and clinicians need be mindful of this when navigating this potential barrier.

While verbal communication was the most common way of providing information, patients preferred receiving additional information in written or online form. This finding is consistent with other qualitative studies, which find that written materials are helpful [29], and associated with improved patient recall of information [45]. Other studies report that having relevant leaflets and posters available facilitates discussions around sexuality and encourages patients to raise these issues [38]. An alternative tool may be the use of electronic questionnaires [46], where patients have the opportunity to disclose any problems prior to the clinic.

This study did not differentiate between patients with colon and rectal cancer. Still, several of the healthcare providers surveyed commented that they discuss sexual dysfunction with rectal cancer but not colon cancer patients. This reflects that treatment for rectal cancer, specifically radiation and pelvic surgery, is known to carry a greater risk of causing sexual dysfunction compared to colonic cancer [6, 8]. Whilst we acknowledge this, there is, however, growing evidence of the impacts of colon cancer treatment on sexual health [10]. Likely due to a major driver of sexual dysfunction being the psychological distress associated with a cancer diagnosis, and not just the physical side effects of treatment. Therefore, communication about sexual health should be a routine part of both rectal and colon cancer treatment and follow-up.

Treatment options for sexual dysfunction resulting from CRC treatment are variable, addressing both physical and psychological aspects and are determined by the underlying cause in each patient. Open communication about sexual health between healthcare providers and patients is crucial, and referral of patients and/or couples to counselling when issues are present is effective [47], and should be a routine part of CRC treatment and survivorship care. Basic medical interventions that healthcare providers for female sexual dysfunction can trial include oral hormonal replacement to address early menopause, as well as lubricants, topical oestrogens and pelvic floor physiotherapy for women

experiencing dyspareunia or vaginal dryness [48, 49]. Referral to a gynaecologist should be considered for any woman who is still having issues, or for those who have vaginal stenosis and who would benefit from the use of dilators. In women with radiation-induced vaginal stenosis, there is a window during which treatment must be instigated before changes can become permanent; therefore, it is critical that these issues must be identified early, when intervention is still effective. In men, the use of medications such as oral phosphodiesterase inhibitors, penile injections, or devices such as vacuum devices and erection rings can be explored for erectile dysfunction [49–51]. Men who do not respond to these can be referred to urologists for consideration of penile implant [52]. Addressing co-existing conditions like depression and anxiety is also vital, as these significantly impact sexual health; however, care must be taken as many medications that treat these conditions can cause sexual dysfunction [53, 54]; therefore, referral to a psychiatrist for assistance with medical management can be useful. In summary, a holistic and multidisciplinary approach that combines medical treatment, psychological support, and includes multiple different specialists can help to achieve the best outcomes for EOCRC survivors with sexual dysfunction.

Unfortunately, there are significant financial barriers to accessing some of these interventions in Aotearoa New Zealand. Poor access to help was a common theme in free-text comments from both patients and healthcare providers. For example, there is little counselling specifically for sexual dysfunction in Aotearoa New Zealand, and this is not publicly funded; therefore, for many, the cost is prohibitive. Likewise, surgical management for erectile dysfunction, such as penile implants, is not funded either, with these costing around $30,000 [55]; this is unfortunately out of reach for many patients.

Clinical implications

This study aims to increase both patient and health care provider awareness about the importance of sexual health communication during CRC survivorship, and highlights practical, low-cost changes that could be easily implemented in CRC survivorship care to improve communication about sexual health. Given that most patients prefer healthcare providers to initiate discussions regarding sexual dysfunction, clinicians should routinely raise these issues during both treatment and follow-up consultations, rather than waiting for patients to do so. This is particularly important for women, who in this study reported receiving significantly less information regarding sexual health. Communication around sexual health is important in both colon and rectal cancer patients, and is not limited solely to those undergoing pelvic surgery or radiotherapy.

Further changes include improved clinician education around sexual dysfunction, provision of written and online information alongside verbal discussion, and use of pre-appointment questionnaires to allow patients to identify concerns prior to clinic attendance, and flag these issues to the healthcare provider seeing them. Furthermore, routinely allocating time at the end of consultations without family members present may help patients discuss sensitive issues more comfortably.

As many forms of sexual dysfunction following CRC treatment are potentially manageable, improved communication may allow earlier identification of problems, facilitate referral to appropriate multidisciplinary services, and ultimately improve sexual function and overall quality of life for EOCRC survivors.

Strengths and limitations

The strengths of this study are that it is the first in Australasia to investigate current patterns of communication regarding sexual health and EOCRC, with only one similar study published in the international literature [28]. It is the first to investigate barriers to this communication in EOCRC patients. This is significant given evidence of the rising incidence of this disease among young people [1, 56]. However, there are several limitations. Firstly, our relatively small sample size prevented a more detailed analysis of factors associated with different communication patterns including possible associations between sociodemographic factors such as age and communication outcomes; larger studies would be needed to explore this. Secondly, patients asked to recall how much information they were given, often years earlier, likely posed a significant risk of recall bias. This study did not include answers from patients' partners, despite published studies indicating this can be beneficial [57]. The overall response rate among healthcare providers was low, which may introduce selection bias. This study also did not include medical and radiation oncologists, or psychosocial providers such as psychologists and social workers, whom would provide valuable perspectives and their involvement is recommended for future research in this area.

There were very few non-heterosexual patients or healthcare providers surveyed, which meant the results may not apply to sexual minority populations. This gains relevance as there is evidence that heterosexual healthcare providers find discussing issues of sexuality with homosexual and bisexual patients more challenging than with heterosexual patients [11]. Furthermore, this under-representation reflects a broader gap within the CRC literature. A recent qualitative study [12] in Colorectal Disease examining the experiences of LGB patients undergoing CRC surgery highlighted both the limited inclusion of sexual minority patients in research and the lack of tailored discussion around sexuality in clinical care. Together, these findings suggest that sexual minority populations remain underrepresented in CRC survivorship research.

Likewise, our cohort had very little ethnic diversity, with Māori comprising only a small proportion of respondents; the study findings may therefore not adequately reflect the experiences, preferences or barriers to sexual health communication faced by Māori patients. This is a significant limitation given the well-documented disparities in CRC outcomes experienced by Māori, including later-stage diagnosis and poorer survival [20]. Given that cultural factors, such as the role of whānau and Māori understandings of health and wellbeing, may shape communication preferences around sensitive topics such as sexual health in ways not captured by this study [58, 59]. To our knowledge, no published research has specifically examined sexual health communication preferences among Māori cancer patients, further underscoring this gap and highlighting a need for further research in this area in future.

Conclusion

Discussions between healthcare providers and EOCRC patients on issues around sexual health are often neglected, especially with women. Healthcare providers should routinely discuss the possible impact of cancer treatment on sexual health with patients, both throughout treatment and during follow-up. Information should be given verbally, and with written or online resources available for patients to refer to after the clinic appointment. Clinicians should consider sending some information to patients prior to being seen in the clinic, or asking patients to fill in a survey, so patients are prompted to raise issues of sexual dysfunction if relevant, and allocate time at the end of the consultation without family members present to help facilitate discussions of a sensitive nature.

Supplementary information The online version contains supplementary material available at https://doi.org/10.1007/s00520-026-11443-x.

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Author contributions Oliver Waddell conceived and designed the study, developed the questionnaires, collected and analysed the data, interpreted the findings, and drafted the manuscript. Jethro Palmer, Tamara Glyn, Andrew McCombie, Bryony Simcock, Rachel Purcell, Jacqueline Keenan, and Frank Frizelle contributed to study design, interpretation of the findings, and critical revision of the manuscript. Jethro Palmer and Raymond Phang contributed to data collection. Andrew McCombie contributed to data analysis. Jacqueline Keenan and Frank Frizelle supervised the project. All authors reviewed and approved the final manuscript.

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Data availability The datasets used and/or analysed during the current study are available from the corresponding author on reasonable request.

Declarations

Competing interests The authors declare no competing interests.

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