A classic case of non-diagnosis: erectile dysfunction following colorectal surgery

GEORGE DOWSWELL, TARIQ ISMAIL, SHEILA GREENFIELD, SUE CLIFFORD AND SUE WILSON

The prevalence of erectile dysfunction following colorectal cancer treatment is 75 per cent. Most men do not seek (and are not offered) help. Clinical care pre- and post-treatment could be improved in several simple ways to ensure that men are better informed, more engaged and experience more positive outcomes. More tailored and co-ordinated care is needed.

Colorectal cancer (CRC) is the third most common cancer in men in the UK and the second highest cause of death.¹ The prevalence of erectile dysfunction (ED) after CRC treatment is 75 per cent.² There are several reasons why ED is not being diagnosed and treated in this patient population.

WHY IS ED NOT DIAGNOSED IN PATIENTS WITH CRC?

In all healthcare systems, structural issues enable or inhibit patient care. Medical specialism enables clinicians to acquire and maintain specific knowledge and skills but can dissuade them from keeping abreast of developments in other fields. In the NHS, patients access specialist care through their GP, but oncologists and colorectal surgeons perceive only part of the patient's care as their responsibility. GPs generally feel unable to offer specialist advice on many medical matters. There are currently no national guidelines from NICE on treating ED following CRC and therefore no endorsement for prescribing free treatment to this patient group.

Traditionally men have been less likely than women to access healthcare. Older men may have concerns about the loss of sexual function but often do not seek help because our youth-dominated culture disbelieves in and disapproves of sexual activity in older people.
Both clinicians and patients are known to lack communication strategies to effectively address the sensitive issue of ED (Figure 1). In relation to sexual dysfunction in patients, we know that clinicians can be placed on a spectrum from denial to avoidance to expressing vulnerability to risk taking and, at best, negotiated communication. Similarly, cancer patients are generally found on a spectrum from those focused mainly on survival, to those increasingly trusting in the outcome, to those wanting to begin making choices, and those approaching the normalisation of their status as survivors. Beyond this stage, there are patients seeking negotiated communication to address outstanding health concerns, and this group includes CRC survivors who wish to address ED.

Hordern and Street identified a specific gap between clinicians and patients in relation to sexual dysfunction:

Patients want: information, emotional support and practical strategies... timed to suit their individual needs. Clinicians want a more 'homogenous' and rigid interpretation of patient sexuality and intimacy, based on assumptions they made about patients' age, gender, culture, partnership and disease status... in a problem- and disease-based manner, without checking these assumptions with the patients they were treating.

We know from the prostate cancer literature that ED can have a dramatic adverse effect on masculinity/self-image and a pervasive negative impact on quality of life. For this reason, prostate cancer patients are provided with adequate information before surgery and treated after it for ED. No similar process is found in CRC, in spite of similar rates of ED. As CRC diagnosis and treatment improve, five-year survival is also improving, so more men are likely to need appropriate care for ED.

Clinicians have generally taken a functional perspective on patient sexuality: ‘Does the machinery work?’ Wider psychosexual perspectives emphasise that patients vary in the extent to which sexuality is central or peripheral to their self-image and social circumstances. Exploration of the gap between the clinicians’ and patients’ perspective is hindered by many factors. Time constraints, embarrassment, lack of experience of discussing the issues and lack of expert knowledge are found in both parties. An additional obstacle is likely to be unconscious ageism of health professionals (and the wider media) related to the widespread belief that ‘people over 60 do not have sex’.

INTERVIEW STUDY
We conducted a semi-structured interview study involving 28 male patients (mean age 59, range 34–80) who had been treated for CRC in the West Midlands. We deliberately selected participants with a broad range of sociodemographic characteristics, experiences and perspectives (Box 1). We talked to them about their beliefs about the causes of ED, the impact it had on self-perception and relationships, their satisfaction with information and their experience of ED treatment. Data were analysed independently by three of the researchers using thematic analysis. Further details of methods and results can be found elsewhere.

Outcomes model
We drew a model to illustrate the good and poor outcomes in this patient group (Figure 2). This places the cancer narrative and ED in a broad context, the most important feature of which seemed to be associated with the patient, whether they had a partner, and how they perceived healthcare. Patient factors mediating response to cancer and ED include age, morbidity, self-image, work/life history, the importance of sex and prior history of ED. Having a partner, enjoying a good relationship and maintaining a sexual relationship all affected the impact of ED.

Participants in our study varied greatly in terms of their positive, neutral or negative perceptions of the health system, their GP and the specialist care they had received. This affected the likelihood and direction of their help seeking. Good outcomes included receiving effective treatment, not wanting any treatment or not needing any treatment. Poor outcomes were grouped into four categories: untreated ED, unmet information needs, dissatisfaction with care and relationship deterioration. All participants could be fitted into this simple model – they all came with a history and current context, they had all survived CRC (although some had a poor prognosis) and they all had at least one of the outcomes.

We elaborated on this simple model to illustrate characteristics associated with ED. As expected from our prevalence study, most of the sample had ED. Those without ED had no need of treatment (a good outcome, but unusual).

We subdivided those with ED into those seeking or not seeking help. Those not seeking help may have decided they did not want treatment for ED (they were not in a relationship or not in a sexual relationship). However, the majority of these patients were unhappy with the outcome. There were many complex reasons why those with ED do not seek help and therefore remain undiagnosed and untreated for ED. These included hoping that ED would resolve in time (hope), wanting other people to have care for more pressing needs (charity) and believing that clinicians would get around to sorting it out in due course (faith). We found that the most common reason was reticence. This may partly be cultural. Men also do not ask for help because they fear there may be risk...
associated with refusal – they do not want to jeopardise relations with clinicians in case they require future care for more life-threatening conditions. Some men simply had not ‘got round’ to asking for help. A small number thought that it was pointless or did not know who to ask.

Finally, we enhanced our model with the men who did seek help and their outcomes (see Figure 2). Ten sought treatment (of 24 with ED). Only one described the treatment as successful. One continued to seek a cure. The rest had persisted in seeking medical advice for variable lengths of time and eventually ceased to seek further help. All these men were dissatisfied. They reported phosphodiesterase-5 (PDE-5) inhibitors not working, being too expensive or unsatisfactory (unspontaneous).

Following CRC treatment, most men reported the serious distress ED had caused them. However, a minority were not greatly troubled. More than half suggested that they had not received adequate information before surgery. In the worst cases, they also described having been misled, insulted or cheated (Box 2).

It is likely that greater awareness and better training and support for clinicians could help to address this situation. Services could be reorganised to increase the likelihood of more consistent and co-ordinated care. Patients could be encouraged to seek the level of support they need from whichever primary or secondary care clinicians they are most comfortable approaching for help.

Limitations of the study
There are a number of possible sources of bias in our study. Our sample had similar characteristics to respondents in our larger prevalence survey, but we cannot claim that either are entirely representative of the population – response rates were good, but there are always some people who do not take part in studies. We could see that ED and sex were not widely discussed by many of the men who took part in our study, and it is possible that some men understated their experience. Ideally, a longitudinal qualitative study would capture men’s experiences over time. This would add further depth to our current knowledge.

BOX 2. Quotations from interview participants

- Misled: His nurse gave me the injection. I did ask the nurse will this interfere with any sexual activity and her reply to that was ‘oh you’ll be perfectly okay, we have tablets for that’
- Insulted: But he said ‘at your age I don’t think it will matter’ and he was nearly as old himself. (Laughs) I thought ‘that’s a bloody cheek’ – aged 72
- Insulted: She advised me I shouldn’t consider having children while under chemotherapy... she said ‘I don’t suppose this is a great concern to you at your age’ – aged 61 (with younger partner)
- Cheated: And that is part of the package which they really don’t tell you about. It’s like saying well you’re going on the package holiday, there’s the hotel, but they don’t tell you it’s half built at the back do they? And there’s no running water or whatever
Implications for clinical practice
Clinicians should consider three things carefully. First, making assumptions about likely, appropriate or adequate levels of sexual behaviour or interest will probably give offence to patients. They may not share your views on what someone of their age does or should consider the ‘right’ amount of sexual activity. We know that many older men may remain interested in sexual activity10 and retain optimism about the return of any sexual function lost as a result of cancer treatment.

Second, this study amplifies previous evidence that PDE-5 inhibitors are not a panacea. Many clinicians appear to believe, and to inform patients, that PDE-5 inhibitors work well for everyone. The research evidence has never suggested this, but media coverage has perhaps overstated and oversimplified the effects of these drugs.

Third, it was very clear from our research that most men simply do not ask for information or help with ED (and clinicians do not routinely provide this help – for a number of reasons). However, there is an onus on clinicians to raise the subject of ED with patients, because untreated ED has serious negative consequences on the majority of men following CRC treatment. It also has a detrimental effect on relationships between patients and clinicians.

Consideration needs to be given to the provision of more tailored and co-ordinated ED care. We know from earlier work that there is a great advantage to patients when clinicians become more aware of the information needs of individuals. Tailoring information to cancer patients’ own agendas has a beneficial effect on psychological adaptation to illness and treatment.11

It is possible that colorectal clinical nurse specialists may be the most appropriate people to provide information, co-ordinate treatment and monitor progress. However, any such service development would need to be carefully planned and fully evaluated before it could be recommended.

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REFERENCES

KEY POINTS
- Our prevalence study established that more than 75 per cent of male colorectal cancer (CRC) patients will develop erectile dysfunction (ED) during and after treatment
- In order to describe the experiences and unmet needs of men who develop ED after CRC treatment, we arranged interviews with a sample of men who took part in our survey
- Despite the high prevalence of ED, we found that information and treatment for ED are not generally offered to male CRC patients
- Our research implies that many clinicians are inadvertently neglecting, potentially misleading and frequently giving offence to CRC patients
- This patient group is very diverse, so there is no universal solution. More co-ordination of care and consistent strategies to address unmet needs are required.