

The Long-Term and Late Effects of the Diagnosis and Treatment of Colorectal Cancer

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Background

Colorectal cancer is the 3rd most common cancer in the UK. Through early detection and improved treatments more people than ever are surviving this disease. Surgery, chemotherapy and radiotherapy are the cornerstones of management, but these invasive treatments can cause a number of long-term and late effects. Using qualitative methods this study aimed to; explore peoples experiences with long-term and late effects of colorectal cancer, how these effects impacted on their lives and how participants managed them.

Method

Semi-structured qualitative interviews were conducted with 15 participants who had completed curative treatment. Interviews were transcribed and analysed using the Framework approach to identify themes and categorise text data.

Results

Many long-term and late effects of colorectal cancer were explored including bowel dysfunction, sexual dysfunction, pain, metastatic disease and cognitive dysfunction. These effects caused distress for many and were linked to depression and social limitation. Previously unidentified long-term effects included decreased libido and joint pain which respondents attributed to chemotherapy. Anxiety and depression were found predominantly to be late effects. Management of long-term and late effects was varied with healthcare services often ineffective.

Conclusion

Insight gained into long-term and late effects and their treatment, indicated that many participants suffered because of their after-effects and had unmet health needs. It adds a qualitative insight into an area where quantitative research has already been conducted. Improvements in cancer follow-up could offer opportunities to effectively identify, manage and monitor these effects. Further interventional studies are required to develop effective care pathways to achieve optimal care.

Key words

Colorectal cancer, long-term effects, late effects, after effects, Survivorship

Study Title: The long-term and late effects of the diagnosis and treatment of colorectal cancer

Colorectal cancer is the fourth most commonly diagnosed Cancer in the United Kingdom (third in the world). With an incidence of over 41,000 it makes up 11% of all Cancer diagnosed each year¹. The mainstay of curative management remains surgical resection, chemotherapy and/or radiotherapy². These treatments can have long-term and late effects on a patient that can impact almost any aspect of their lives. Through improved screening and treatments, the 10-year survival for Colorectal Cancer has more than doubled with over 50% of patients alive 10 years after diagnosis¹. Consequently, there is now an ever-increasing number of people who have survived and are living with the aftereffects of the disease and its treatment. Many now consider Cancer as a chronic illness however this doesn't universally fit as it tends to be an acute pathology that is curatively treated followed by a sequela of aftereffects³.

These Aftereffects are usually divided into long-term and late effects.

- Long-term effects have been defined as those that develop during active treatment or immediately after the completion of treatment and persist longer than six months after the completion of treatment⁴.
- Late effects are defined as those effects that are not present or identified during or after treatment but may develop months or years later due to the effects of the disease or treatment on organ systems or psychological processes⁵.

It has been well documented that patients have many long-term and late effects due to colorectal cancer. These effects are greatly affected by cancer site, operative technique and the use of chemotherapy and/or radiotherapy. Fatigue, altered bowel habit, sexual dysfunction⁶ are some of the physical effects and there is also a significant mental impact with regards to Anxiety and Depression⁵. These papers suggest that there is a need to identify and better understand the physical and psychological consequences of this disease and its treatment.

There is also evidence that patients are unaware of these after effects and this can impact on their management⁷.

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Hence, using qualitative methods, this study aimed to identify long-term and late effects of colorectal cancer and explore in-depth participants experiences with them, how these aftereffects impacted on their lives, and how participants chose to manage these effects.

METHODS

Participants were recruited consecutively from oncology and general surgery clinics at Aberdeen Royal Infirmary from January 2013 to March 2013. Patients were eligible if they had a diagnosis of colorectal cancer Dukes A, B or C, had completed curative treatment at least 6 months previously and were over 18 years old. Patients were excluded if they were unable to give informed consent or unable to understand English.

With informed consent, one of the Authors interviewed patients in their own homes. They underwent semi-structured interviews based on a topic guide. This covered their journey from their initial management onwards, to illicit any effects from their treatment. The topic guide then prompted patients to discuss these symptoms further and how they managed them. Finally a checklist that was created following a literature review was used to explore any symptoms not realised while going through the topic guide. The digitally recorded interviews were then transcribed verbatim.

Data was analysed using the framework approach. Data collected was sorted, organised and classified using the software package NVivo 9. The data was organised to key themes and analysed for emergent categories, patterns, connections and comparisons by the Author and two other researchers independently reviewed the data during analysis.

We aimed to recruit patients until data saturation was achieved and we felt we had a fully and comprehensive account of patients after affects.

RESULTS

Participant characteristics

Our varied sample of 15 participants consists of a range of ages, diagnoses and treatment modalities Tab1. No new themes were developed from the last three interviews so at this time we were satisfied that data saturation had been achieved.

Three overarching themes were developed with respect to the aims of the project. They were 'long-term effects', 'late affects' and 'management'. These formed the basis for organising emerging themes and preconceived themes.

Long-term effects

Bowel dysfunction

Bowel dysfunction was the most frequently identified long-term effect of colorectal cancer described by 13 participants.

For those who had a stoma almost all described in detail their distaste for the stoma. The most common reason for disliking

Table 1

Age at Interview	Number of people
40-50	1
51-60	3
61-70	8
80+	3
Dukes Classification	
A	3
B	4
C	8
Operation	
Right Hemicolectomy	5
Transverse colectomy	1
Left Hemicolectomy	2
Anterior resection	7 (5 ileostomy)
Adjuvant Treatment	
Chemoradiotherapy	3
Chemotherapy alone	9
Radiotherapy alone	0

the stoma was the bag leaking and the anxiety around this.

"I was scared to go out with it encase it burst or something you know. I had gone to (location) with a friend, and I had gone to (location) and it had burst... I was really terrified." (Participant 1)

A negative effect the stoma had on participants' body image was also identified.

"...but you (consultant) can wear normal clothes, normal skirt how come I can't (said to a consultant)? So as I said its one of those things that you get irritated by..." (Participant 15)

As well as the social limitations that the stoma brought.

"...it did stop me, it was a sort of exercise class in the water which I used to quite enjoy, I had to stop that..." (Participant 1)

Faecal incontinence

Several subjects described faecal incontinence as a long-term effect of colorectal cancer and associated their condition with surgery.

"I was frequently incontinent, sometimes when I was walking home from town when everything was bad."

"It is very difficult to have a good social life you know we had a really good social, and we love walking and we did socialise... at times unbearable." (Participant 5)

This highlighted a link between incontinence and decreased social functioning, as the fear of an incident inhibited them from enjoying activities.

Faecal frequency

All participants who reported faecal frequency associated it with surgery. For the majority this was manageable, however, for one participant faecal frequency had a debilitating affect.

"My frequency of bowel movement now was 10–20 times a day, I kept a journal. One particular 24-hour period it was 30 times but I was, it was always incomplete and hugely painful never passed and I had to twist my body, rock and all kinds of things to try and pass stools, not successfully." (Participant 5)

Faecal urgency

The severity of faecal urgency varied between participant but if severe it resulted in the participant becoming house bound and depressed.

*"I felt that every time I stood up I had the sensation that I needed to go to the toilet."
"...I said this is really getting me down because I'm house bound..." (Participant 15)*

Pain

Participants were asked about their experiences with pain and two clear sub-themes appeared. Pain originating from the abdominal region and pain felt elsewhere in the body. In all, two thirds of participants identified pain as a long-term effect.

*"I mean I have had pain, abdominal pain"
(participant10)*

For some the pain was severe and debilitating, being described as like putting "a sword up your rectum", forcing some to retire from their job and lead to "suicidal thoughts".

Two participants reported pain in other parts of the body, especially in or around joints. Chemotherapy was identified as the cause in all participants. One participant clearly linked her chemotherapy treatment as the cause for recurrent flares of her rheumatoid arthritis. Another described pain at joints where he had previous injuries.

"...but also I've noticed old injuries are sore. Like I snapped this thumb, I smashed it up in a motorcycle accident and its really painful here (pointing to his metacarpophalangeal joint). My knee, which I smashed in the same motorcycle accident, is painful as well..." (Participant 3)

Sexual dysfunction

Several participants were concerned by a reduction sexual function. Some associated sexual effects with chemotherapy and others with surgery.

*"Ooh yes, ooh yes your libido disappears"
(Participant 15)*

Yeah less sex drive than I used to have, definitely that's for sure and less sensitivity (of the penis). (Participant 2)

Chemotherapy caused decreased sex drive and increased penile sensitivity while participants with a stoma revealed

apprehension towards sex due to fear of the bag bursting and body image issues.

"(During sex) I had to be careful not to put weight on my stomach when I had the stoma bag, I was very conscious in case it burst" (Participant 15)

LATE EFFECTS**Depression**

Many participants described times of "feeling down", in a "black area" or getting "very down". Some attributed it to other aftereffects such as bowel dysfunction or the presence of a stoma as a cause.

"and I was getting very down because I couldn't leave the house" (Participant 15)

This participant also emphasised that limitations in social interaction and activities of daily living as contributing factors for depression.

Complications resulting from surgery had a negative impact on a participant's mood. One participant had a liver resection resulting in the removal of her gallbladder and worsening Gastroesophageal Reflux.

"My bile, I'm always very acidic anyway but it became so bad it was actually interrupting my sleep and making me very depressed." (Participant 4)

For another it was the return of their long-term and late effects that resulted in her becoming severely depressed.

"I did become clinically depressed and had to actually be admitted privately... I felt I was going downhill again physically and I'd come so far you know." (Participant 4)

Anxiety

Although no participants stated they suffered from anxiety disorder many did reveal periods of anxiety. These periods were strongly correlated to follow-up clinic appointments, follow-up scans and receiving results of the scans. At all these moments it was the fear of recurrence or the fear that something was 'not right' that caused anxiety.

"I got my scan and then a letter came in on the Thursday to go for one the following week and I just panicked, just totally panicked so ended up going to my GP in you know floods of tears..." (Participant 11)

Management

The range of long-term and late effects, coupled with the breadth of severities, has resulted in aftereffects being managed in various ways.

Self Management

Numerous participants simply "lived with" their condition. This attitude of "acceptance" was particularly pertinent regarding bowel dysfunction.

"I have had problems with the bowels... you start to accept what you're left with and you start to appreciate that you can't be perfect again, you know, you'll never be just perfect again." (Participant 10)



Lifestyle changes

Several participants altered their lifestyle by eating more healthily, increasing the amount of exercise they undertook or by using self-help book. Some made dietary changes either to combat bowel dysfunction while others altered their diet to include more fruit and vegetables to improve their health.

“(In response to constipation management) yes but I eat figs, figs are the answer honest to goodness... far better than Fybogel or any of these moggy things.” (Participant 14)

Participants used vitamin D and E to help manage depression and peripheral neuropathy to good effect.

“This lady had put herself onto vitamin E which she felt helped with the tingling so I thought right I’ll give it a go as well and emm I’ve been taking it ever since just one tablet a day.” (Participant 11)

However there is always a risk associated with self-management as patients can develop potentially harmful habits and beliefs.

“I have one book that proposes you don’t get chemotherapy, eat your way to fitness...” (Participant 3)

General Practitioner

A third of participants consulted their GP to manage the aftereffects such as painful joints, abdominal pain, numbness, chilblains, constipation, anxiety and Insomnia

“My GP was excellent she gave me various pain killers and muscle relaxants... GP came into my house and he gave me a laxative and an Enema.” (Participant 4)

Some patients were reluctant to attend their GP as they believed they were unwilling or unable to manage the long-term and late effects.

“I’ve never been asked by my GP or by the consultant about any mental issues” (Participant 3)

Some had difficulty communicating to their GP how they were feeling, and that this impacted on the care she received.

“I couldn’t seem to get, my GP to understand how I felt, I just couldn’t seem to get that across” (Participant 5)

Consultants

Consultants treated many aftereffects of colorectal cancer and consequently didn’t feel the need to go to the GP; however, when they went for routine follow-up appointments, they took the opportunity to reveal their aftereffects. Subsequently oncologists and general surgeons are accredited for managing many participants’ aftereffects such as constipation and diarrhoea.

“(In response to a question asking who recommended Movicol) No it was recommended by the hospital actually... I think it was the Oncologist so it was, I’m sure yes.” (Participant 1)

Discussion

Current Literature has Identified that many patients suffer from Gastrointestinal side effects following treatment⁸, Pain⁹ and sexual dysfunction as has been highlighted in this study. Anxiety and Depression also affect many cancer survivors⁵. These late and long-term affects of colorectal cancer were not only numerous, affecting different parts of the body but also had far reaching consequences on patients mental health and social mobility. Due to qualitative⁶ nature of the data we also began to see how surgery lead to more gastrointestinal issues whereas as chemotherapy lead to more problems with pain and sexual dysfunction. It was also clear that these physical aftereffects had a significant impact on the patients mental health with many reporting that they felt depressed and/or anxious following treatment.

The nature of the aftereffects suggest that primary care could have an important role in addressing many of these. Adams et al¹⁰. looked into views of cancer care reviews in primary care. They again showed there was unmet needs due to cancer aftereffects and suggested that some participants did not want to bother the GP with aftereffects (this was also identified in our study).

The NICE guideline on colorectal cancer² also emphasizes the importance of long-term and late effects of colorectal cancer. They encourage specific information on aftereffects to be provided to patients. Yet, in our study many participants were given little or no information on potential aftereffects. Subsequently they were unaware of some, and some turned to unreliable sources that gave potentially harmful advice such as “don’t have chemotherapy, eat your way to fitness”.

This growing body of evidence has led to a report by the The National Cancer Survivorship Initiative (NCSI)¹¹ looking at the management of cancer survivors. They stated “that failure to manage the consequences of treatment can have a significant impact on patients and on the National Health Service (NHS), so it makes sense to design and commission pathways and services that minimise the consequences of cancer treatment and address unmet needs among patients”.

In light of our study and this report we propose that;

- All colorectal survivors should be monitored during and after treatment for long-term and late effects for as long as necessary.
- Long-term and late effects our study revealed such as bowel dysfunction, sexual dysfunction, pain and psychological issues are all conditions that are primarily managed in primary care and GPs would have a wealth of experience in dealing with many of them.
- Information should be provided on what to expect after treatment, what is considered normal and when patients should seek further medical advice. Clear and effective communication of information can improve wellbeing and quality of life.

Recently there has been increasing evidence for the use of patient reporting outcomes measures (PROM) and eHealth apps to support cancer patients' care during treatment¹² as well as online Holistic needs assessments^{13,14}. They can help identify aftereffects and allow Doctors to provide effective and long-term follow up of patients.

Advances in colorectal cancer treatment more and more people are now surviving this disease. This has created a new cohort of patients with healthcare needs that this study has endeavoured to shed light on. The experiences of these patients ranged from a simple annoyance, to severely debilitating and even life threatening.

This study has also highlighted that many survivors had unmet health needs as a consequence of these aftereffects. The results indicated a need for improved management and healthcare structures to be implemented, to effectively identify, manage, and support colorectal cancer survivors who are left with the long-term and late effects of their disease.

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