



Knowledge and awareness of long-term and late treatment consequences amongst colorectal cancer survivors: A qualitative study



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ARTICLE INFO

Article history:

Received 14 May 2015

Accepted 23 August 2015

Keywords:

Late effects

Long term effects

Treatment consequences

Survivorship

Colorectal cancer

Cancer care

ABSTRACT

Purpose: To describe patient knowledge and awareness of long-term and late onset treatment consequences amongst colorectal cancer survivors.

Methods: Semi-structured qualitative interviews were conducted with 19 colorectal cancer survivors at least 12 months post-treatment. Interviews were audio-recorded, transcribed into NVivo 10 software and analysed using the framework method.

Results: Participants were aware of disease recurrence but not many other treatment consequences; change in bowel habit and impact on diet were common and had significant impact, yet many felt they had not received 'warning', considering it a gap in both information and support. Participants expressed preference to know about possible consequences early on and were willing to engage in education and support if offered. Information overload, timing of information provision and unequipped health care professionals were considered barriers to awareness.

Conclusion: Improvement in information provision, management of expectations and support around bowel function would facilitate patient self-empowerment and could improve holistic management of health and well-being after cancer.

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1. Introduction

Cancer survivorship, increasingly referred to in the UK as “living with and beyond cancer”, has been a recognised area of work since the 2007 Cancer Reform Strategy and has become a hugely important and a rapidly developing aspect of cancer care. 1 in 4 cancer survivors in the UK experience treatment consequences or late effects (Macmillan Cancer Support, 2013a); the functional, physical and psychological problems caused by cancer therapy, which can occur months or years after completion of treatment (Greenfield et al., 2009), 50% of colorectal survivors treated with radiotherapy report problems including frequency, urgency, flatulence and incontinence, often limiting quality of life. As many as

20–40% of those consider the impact of these treatment consequences as moderate to severe (Andreyev et al., 2010).

The realisation of the existence of treatment consequences over recent years has changed the way cancer patients are managed after treatment (DoH et al., 2010). Despite increasing awareness and acknowledgement of the adverse effect on long-term function and quality of life treatment effects can cause, they are still believed to be under-recognised and under-reported (Andreyev et al., 2010). The increasing prevalence of treatment consequences is inevitable with the rising cancer prevalence and survivor rate (DoH et al., 2010). Research suggests that coping with the increasing survivor population and effectively meeting their needs involves increasing focus on longer-term consequences (White et al., 2011) and offering holistic assessment of symptoms and needs throughout survivorship (DoH et al., 2010).

Treatment consequences that are specifically associated with colorectal cancer include change in bowel habit, abdominal adhesions and stoma following surgery (Knowles et al., 2013), peripheral neuropathy from chemotherapy agent oxaliplatin (Royal

Abbreviations: CNS, clinical nurse specialist; NCSI, National Cancer Survivorship Initiative; NICE, National Institute of Clinical Excellence; HCP, health care professional.

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Pharmaceutical Society, 2014) and radiotherapy induced gastrointestinal symptoms, malignancy, incontinence (Andreyev et al., 2010) and sexual dysfunction (White et al., 2011). Almost half of men and a quarter of women treated have difficulty maintaining sexual relations following radiotherapy (Beating Bowel Cancer, 2013; Macmillan Cancer Support, 2013b), and infertility is associated with both chemo and radiotherapy (Pacey and Eiser, 2014). These physical consequences of treatment are wide-ranging and require different management and levels of support (Nikoletti et al., 2008). Whilst improved surgical techniques, radiotherapy administration and shorter chemotherapy regimens have reduced likelihood of some problems and should decrease prevalence of treatment consequences in the future, services need to accommodate patients treated with the older, higher risk methods and the unavoidable consequences of newer treatments (DoH et al., 2010).

Previous research into sequelae of colorectal cancer treatment has acknowledged its physical implications on bowel function (Andreyev, 2007; Nikoletti et al., 2008) but the consequential impact on other aspects of life has been less thoroughly explored. A cancer diagnosis, treatment and physical effects of treatment can all lead to psychological dysfunction including anxiety and depression at any point in the cancer journey. Colorectal survivors have identified the cognitive and social consequences of adapting to a stoma or managing unpredictable bowel motions as the more significant challenges in survivorship (Schneider et al., 2007). Most of these challenges can be overcome but survivors need guidance and reassurance through the adaptation process (Macmillan Cancer Support, 2012) and given reports suggest that the emotional, cognitive and social implications can be the more challenging aspects of colorectal survivorship (Schneider et al., 2007), this is a critical area for exploration.

Although awareness amongst health care professionals (HCPs) has increased over recent decades (Faithfull and Samuel, unpublished) and research has explored needs in survivorship, to date very little is known about how much patients themselves know and understand about long term implications of treatment. Only one study was found (Ruud et al., 2012), where survivors of childhood acute lymphoblastic leukaemia in Norway were interviewed about their knowledge of treatment consequences. The study concluded that survivors had little understanding of long-term implications of treatment and that information provision should be improved (Ruud et al., 2012). Another study, primarily exploring patient views of cancer follow-up, found that 78% (n = 119) of patients had intended to discuss and learn more about treatment consequences during their follow up appointments, but only 36% (n = 55) had done so. The study concluded that this was most likely due to the medical agenda and time limitations often encountered in follow-up services (Absolom et al., 2009), highlighting some of the barriers to patient education around treatment consequences. 39% of patients who completed colorectal cancer treatment in 2009/10 reported that no health or social care professional had discussed the problems they may experience or needs they may have following treatment (Macmillan Cancer Support, 2013c). Currently there is no evidence to demonstrate whether this has improved since the publication of the 2011 NICE guidelines which state patients should be given specific information on bowel function detailing incontinence, diarrhoea, flatulence, bloating, difficulty emptying bowels, diet, and where to go should symptoms develop. Initial work exploring patient preferences concludes that in general survivors do want to be given information and learn about their disease and its consequences (Anderson et al., 2010; Papagrigoriadis and Heyman, 2003) and HCPs have reported interest in further education around treatment consequences to equip them to care for patients in survivorship (Baravelli et al.,

2009).

There is a little work exploring attitudes of patients who have recently completed treatment, but a study from 2012 showed that patients 5 years after diagnosis who identify themselves as cancer survivors (55%, n = 786) report better outcomes in acceptance, satisfaction and quality of life than those who had not developed this identity (Chambers et al., 2012). These patients may be more likely to engage in survivorship services, and it could be that patient education and knowledge of what to expect in survivorship is key to improving outcomes. If this is the case, then early development of the survivor identity and timely education in the cancer pathway could improve long-term outcomes even further. Work is needed to establish current levels of awareness and readiness for education regarding treatment implications, in order to inform service re-design and allow development of appropriate and accessible follow-up and survivorship services; hence this initial study into patient awareness of treatment consequences.

2. Research question

What knowledge and awareness of long-term and late treatment consequences do colorectal cancer survivors have when they are nearing discharge from oncology?

3. Methods

3.1. Design

This cross-sectional, qualitative study used semi-structured face-to-face interviews and sensitising concepts (Bowen, 2006) to gain an insight into awareness of treatment consequences and patient experiences in survivorship.

3.2. Sample

Patients attending the nurse-led colorectal surgical clinic in Sheffield from January–April 2014 were screened by Clinical Nurse Specialists (CNS) for eligibility. Any patient at least 12 months post treatment, over 18 years old, able to communicate in English and without a terminal diagnosis or dementia was identified as eligible. During appointments eligible patients were made aware of the study by the clinical nurse specialists. If the patient expressed interest, the clinical team introduced them to the researcher who gave them information about the study including the patient information sheet and all potential participants had an opportunity to ask questions. In view of the low risk of this pilot study; a single “visit” with no change of treatment and completion of simple interview and no invasive physical tests, patients were given a minimum of 15 min consideration time. Some then completed the consent process in clinic, but most were contacted by the researcher later in the week and those wishing to take part were consented at the beginning of their interview, arranged at a mutually convenient for participant and researcher. A convenience sample (Ritchie and Lewis, 2003) of 19 patients, 11 male and 8 female aged 37–84, having received different combinations of radiotherapy, chemotherapy and surgical treatments, (Fig. 1) were recruited.

3.3. Data collection

Audio-recorded interviews were carried out by the same researcher in participants' homes between February–April 2014. Interviews were based on a topic guide derived from literature review and included exploration of treatment impact, awareness

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