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Patients' experiences of living beyond colorectal cancer: A qualitative study

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ABSTRACT

Purpose of the research: This paper is a report of a study of the experiences of individuals with colorectal cancer in the period following their cancer treatment and the physical, psychological and social aspects associated with adjusting to everyday life.

Methods and sample: Qualitative interviews using a phenomenological approach were conducted with a purposive sample of 13 individuals who had completed active curative treatment for colorectal cancer.

Results: Study findings suggest that colorectal cancer survivors employ a broad range of techniques and approaches to manage adjustment to everyday life such as goal-setting, managing informal networks and adopting strategies for physical and emotional recovery. Personal interests were used to create a sense of meaning and through the cultivation of altruistic and utilitarian outlooks on life, positive emotional gains were obtained.

Conclusions: Colorectal cancer survivors employ personal strategies for managing life in the survivorship period following cancer treatment. The study findings demonstrate additional areas for exploration such as the effect of altruism on adjustment and the relationship to other groups of cancer survivors.

Introduction

Survivorship features on the UK national cancer agenda as a health policy priority (DH, 2000, 2005, 2008). The national cancer survivorship initiative was launched in England in September 2008 to address the needs of the 1.8 million people living with cancer in the long-term, 12% of who have a diagnosis of colorectal cancer (Devane, 2008; DH, 2010). Beyond the UK, cancer survivorship is receiving similar increased attention. In Europe the need for improved screening, needs assessment and rehabilitation services are recognised (Simonelli et al., 2008) and in the US investment in care services for cancer survivors is regarded as a priority (Shulman et al., 2009; Palesh et al., 2011), however, according to Fairley et al. (2009) there is scope for further investment in public health and education campaigns to improve the survivorship experiences of patients and their families. The investment in services is reflected in the very evident variations in worldwide cancer survival statistics. Five-year cancer survival varies considerably, for example in UK the figure is 40–50%, Sweden 60%, Australia 55–65% and Canada 82%. The US 5-year survival rate is 91% compared to an overall rate of 57% in Europe (Australian Institute of Health and Welfare, 2001; CTV.ca News Staff, 2008; International Agency for Research on Cancer (IARC), 2011).

There is a growing body of literature in the UK exploring the needs of patients who survive in the longer term and how services and research should be tailored to address these needs (Corner, 2008; Lofti-Jam et al., 2009). Survivorship forms an important part of the patient's cancer pathway, when patients and their families face specific challenges and adjustment is required to maintain and sustain living with and beyond cancer (NICE, 2004; DH, 2007). Colorectal cancer is the third most common cancer in the UK, with five year survival rates of between 50 and 53%. Again, patients in the UK do not fare as well as their European counterparts with rates of 55–65% in Finland and 65% in France (CRUK, 2004; Coleman et al., 2008; IARC, 2011). Nevertheless, there have been evident improvements in the UK colorectal cancer survival

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rates over the past decade due to improvements in detection and treatment (Karim Kos et al., 2008; Schurer and Kanavos, 2010).

Despite the exacting nature of colorectal cancer, its treatment and the long term side effects little is known about how survivors experience life following treatment. The completion of treatment is a significant landmark for patients, however the way in which individuals manage and adjust to daily life after this milestone can bring both positive and challenging issues (Phipps et al., 2008; Allen et al., 2009).

Background

Survivorship refers to living with a health condition in the long-term, usually following completion of treatment (Jefford et al., 2008). It signifies the period when individuals may experience uncertainty, isolation, fear of recurrence and loss of control, particularly when contact with healthcare professionals is reduced or lost (Doyle, 2008). Survivors of cancer can experience disruption to health, well-being and function as a result of symptoms and medication (Jenkins, 2006). Survivorship is subject to various definitions ranging from after diagnosis or treatment (Doyle, 2008) to five years without recurrence or living with long-term disease (Hodgkinson et al., 2007). It is often identified as encompassing elements of the disease and daily living activities for example, symptom management, relationships, work and social life (Jenkins, 2006; DoH, 2007).

The impact of cancer on everyday life is well recognised and peoples' need for information, supportive social networks and professional aftercare are known to be important in facilitating adjustment to living with a cancer diagnosis (McIllmurray et al., 2001; Corner et al., 2007). Recent research suggests that people have a high level of unmet need in the immediate post-treatment phase, particularly in relation to psychological and social support (Armes et al., 2009). A qualitative study by Hodgkinson et al. (2007) found high unmet need within relationships and social functioning of cancer survivors, however, their sample was drawn from a database of individuals who had previously expressed interest in survivorship research thereby increasing the likelihood of self selection bias and the identification of unrepresentative care needs. McIllmurray et al. (2001) found similar unmet needs particularly in relation to tumour and gender-specific information needs in a study using postal questionnaires with breast, colorectal, lung and lymphoma patients at different stages post diagnosis. The authors acknowledge that response bias was a limitation of their study and therefore results should be treated with caution. Despite this the evidence suggests a need to explore people's support requirements in the post-treatment period, an issue recognised by the National Cancer Survivorship Initiative (DH, 2010), which states that healthcare services should adequately prepare individuals for the long-term effects of living with cancer.

The symptom experience of patients with colorectal cancer can be distressing and often continue after treatment is complete. Physical effects range from fatigue and bowel disturbance, to erectile dysfunction, weight loss and altered body image (Houldin and Lewis, 2006; Bloom et al., 2007) and these symptoms often result in increased levels of psychological morbidity (Pezaro and Jefford, 2009). Donovan et al. (2010) concluded from their review of the literature that colorectal cancer survivors generally experience good health-related quality of life, although many continue with sexual dysfunction following treatment suggesting the need for improved interventions to address sexual health needs. Bloom et al. (2007) reviewed quality of life studies across seven cancer survivor groups including colorectal cancer. Increased levels of social support were associated with improved quality of life for colorectal survivors except in cases where co-morbidity and low income were present. Chronic health problems such as recurrent diarrhoea lowered quality of life scores, as did poor mental health and lower educational attainment. The presence of supportive environments, access to social networks and religious belief were associated with higher scores, the latter substantiated in a study by Clay et al. (2010). Rauch et al. (2004) found that pain and constipation was associated with reduced quality of life amongst rectal cancer survivors who were two years post diagnosis.

Various studies have explored factors impacting on quality of life amongst colorectal cancer survivors and their effect on health outcomes (Lynch et al., 2008; Steginga et al., 2009; McCaughan et al., 2012). Coping with uncertainty about the future and the presence of other health conditions were found by Steginga et al. (2009) to relate to increased distress and a reduction in functional adjustment. The return to prior levels of social functioning can be delayed for colorectal cancer survivors as a result of poor health, leading to loss of employment and consequently lower socioeconomic status (Sanchez et al., 2004; Earle et al., 2010). Individuals may also experience discrimination in the workplace (Jenkins, 2006). Other factors identified as hindering positive adjustment to colorectal cancer include the presence of a stoma, which significantly affects psychological and social adaptation (McMullen et al., 2008; Krouse et al., 2009; Lynch et al., 2010). In addition socio-demographic variables have been found to affect psychological adjustment to living with colorectal cancer in the long-term e.g. marital status, gender (Goldzweig et al., 2009) and household income (Lundy et al., 2009).

The survivorship literature suggests that colorectal cancer patients face a range of potentially distressing and life limiting consequences of the disease and its treatment that often continue throughout life. Therefore, follow-up care for colorectal cancer survivors, requires further attention (Earle and Neville, 2004). Monitoring for recurrence following treatment completion can heighten anxiety requiring additional psychosocial support in the survivorship period (Pezaro and Jefford, 2009; McCaughan et al., 2010). Several authors call for improved quality of post-treatment care for patients with colorectal cancer through individualised plans of care, co-ordinated follow up and health education (Snyder et al., 2007, 2008; Baravelli et al., 2009; Faul et al., 2010; Lynch et al., 2010; McCaughan et al., 2012).

Only a limited number of studies explore the needs of people with colorectal cancer in the five-year post-treatment period. Moreover, there have been very few in-depth qualitative studies.

Aims

The aim of the study was to explore in-depth, the lived experience of survivors of colorectal cancer. We adopted an operational definition of survivorship that incorporated the perspectives of Doyle (2008) and Hodgkinson et al. (2007) and thus included the time from completion of treatment to five years later. The objectives were to gain understanding of:

- how individuals experience the transition from patient to survivor
- the nature of the physical, social and psychological challenges faced by individuals during this period
- the factors that support and hinder individual adjustment

The qualitative methods used facilitated exploration of the experience, meaning, concerns and strategies used by individuals throughout the survivorship period and allowed for recommendations to be made for the delivery and provision of health service care.