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Surviving cancer treatment: An investigation of the experience of fear about, and monitoring for, recurrence in patients following treatment for colorectal cancer

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ABSTRACT

Background: It is known that many individuals worry about their cancer recurring after colorectal cancer treatment but the significance and specific manifestations of this problem require exploration.
Purpose: This paper reports upon the research findings of a qualitative study to explain how fears of recurrence can affect individuals recovering from curative colorectal cancer surgery.
Methods: A longitudinal, grounded theory study was conducted. Sixteen participants who had received curative treatment for colorectal cancer were interviewed on up to four occasions during the 12 months following their surgery, 62 interviews were conducted in total.
Results: Many participants expressed anxiety about if and when their cancer might return, despite the knowledge that they had had successful treatment for early-stage colorectal cancer. This fear led some to adopt new behaviours in a desire to achieve a more dependable and controllable body. Heightened monitoring and management of the body characterised a state of 'guarding' – a concept developed from the data. By contrast, other participants did not perceive the risk of cancer recurrence to be as personally threatening or were able to assume strategies to manage any such concerns and find a sense of resolution to their recovery.
Conclusion: The nature of an individual's response to fears of recurrence and consequent impact on their recovery warrants greater clinical consideration. Providing opportunities to openly discuss the possibility of cancer recurrence, assessing individual fears and offering suggestions on possible coping strategies to lessen the associated distress, are essential supportive activities enabling transition to life beyond cancer.

Introduction

Colorectal cancer is the third commonest cancer with an estimated one million people diagnosed worldwide each year (Cancer Research UK, 2010). There has been a steady increase in survival rates for this cancer and, now, over half those diagnosed will survive at least five years (Cancer Research UK, 2010). Survival is dependent on a complete surgical excision (Abcarian, 1992), increasingly complemented by chemo- and or radio- therapy delivered pre and/or post-surgery.

If the cancer returns beyond six months after completing an initial cancer therapy (NCI, 2010), this is termed as recurrence. Recurrent colorectal cancer is detected during the first two years after treatment in 90% of cases (Secco et al., 2000). Over a third of those who do develop metastatic colorectal cancer either locally or in the liver can still potentially be cured (Moriya, 2006; Nordlinger et al., 2009). Furthermore the increasing range of treatment options available means individuals re-presenting with recurrent disease can survive for a median of five years (Hoerske et al., 2010).

Despite these treatment advances, fear of recurrent disease continues to be a significant aspect of the experience of surviving colorectal cancer (Denlinger and Barsevick, 2009). The literature indicates that fear of recurrence:

- causes considerable anxiety (Deimling et al., 2005; Salsman et al., 2009)
- may be most acute in the first few months after completing treatment (Ramsey et al., 2002)
- and may continue for a number of years (Mullens et al., 2004; Schag et al., 1994)

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Sapp et al. (2003) found approximately a third of their sample continued to feel anxious about recurrence several years after diagnosis, a frequency which correlates closely with Deimling et al.'s (2005) data. However, variation in study findings does exist about the extent to which fear of cancer recurrence is experienced by colorectal cancer patients: with Krouse et al. (2009) suggesting it is of only a minimal concern (7% of their sample, $n = 491$) to Baker et al. (2005) suggesting it to be main problem for over half (58%, $n = 65$) of those treated for colorectal cancer. Evidence from non-colorectal cancer studies provides a strong correlation between fear of recurrence and levels of psychological distress (e.g. Simard et al., 2010) and is viewed as a potential indicator of cancer survivors' overall adjustment (Ronson and Body, 2002).

It is clear that the period after completion of active treatment brings its own set of unique, and in some cases, still poorly understood challenges (Hewitt et al., 2005; Jansen et al., 2010). Whilst there are likely to be similarities in the psychosocial problems experienced across cancer types, different features are associated with each cancer (Baker et al., 2005). Particular issues for individuals treated for colorectal cancer include: stoma management (Liu et al., 2010), reduction in energy (Forsberg and Cedermark, 1996) bowel symptoms (DeCosse and Cennerazzo, 1997; Pachler and Wille-Jøorgensen, 2005), body image problems (Schag et al., 1994) and financial concerns (Baker et al., 2005; Lundy et al., 2009). Fear of recurrence then becomes another difficulty which they must cope with as they continue to survive.

Fortunately many of these concerns diminish in intensity over time (Ramsey et al., 2000) although it is suggested that this cannot be explained by the recovery process alone. It is known that employment of deliberate processing and coping strategies can reduce post-traumatic stress disorder symptomology, anxiety and depression (Salsman et al., 2009; Lynch et al., 2008). Also, many colorectal cancer survivors report positive psychological outcomes and improvements in quality of life after treatment (Arndt et al., 2006; Rauch et al., 2004), although it is not currently possible to predict who will fare better than others.

A current lack of in-depth understanding of the nature and consequences of being diagnosed and treated for colorectal cancer provided the rationale for a qualitative, longitudinal study examining recovery. One of the aims of the study was to examine the difficulties experienced during different phases of recovery with time from surgery. The overall theory emerging from this study was reported elsewhere (Taylor et al., 2010). It was discovered that whilst physical recovery from curative colorectal cancer surgery is characterised by a relatively steady progression of health back to optimal functioning and fitness, psychosocial recovery is less straightforward. This paper reports findings focussing on the later features of this recovery process as individuals make the transition from acute recovery into survivorship. Its specific contribution is to explain the significance of a colorectal cancer survivor's fears of cancer recurrence and introduce a new concept termed guarding.

Methods

A prospective, longitudinal study was undertaken to discover how individuals adapted over time, and recovered from, being surgically treated for bowel cancer. Grounded theory underpinned the methodological approach to the study because its pursuit of theoretical understanding over description offers greater potential for generalisability than other qualitative methodologies (Glaser and Strauss, 1967). This approach enables the discovery of meaningful insights from the field on enquiry as well as any perceived difficulties in understanding and action (see also Glaser, 2001).

Sixteen participants diagnosed with colorectal cancer and surgically treated with curative intent, were recruited from three hospitals in the South of England by the local colorectal cancer nurse specialists. Sampling was initially achieved by use of purposive sampling until clear categories emerged enabling theoretical sampling to direct later stages of data collection. Those requiring chemotherapy or radiotherapy in addition to surgery, recovering from permanent stoma formation and/or diagnosed with advanced or incurable disease were not approached. Ethical approval was gained from the relevant local research ethics committees and informed consent gained in accordance with good clinical research practice guidelines (WHO, 2002).

Data were primarily collected by semi-structured interviews, chosen for their interactive and generative potential (Mason, 2002). Data collection points were determined at the outset of the study to provide some consistency across cases; with specific time periods selected according to known recovery points. Each participant was interviewed up to four times following their surgery: at six weeks then at three, six and twelve months.

All interviews were tape-recorded and accurately transcribed. Analysis commenced as soon as data were collected supported by the computer software package. NUD*IST N-Vivo. Data were analysed using the constant comparative analysis method which in conjunction with written memos and diagrams, enhanced theoretical development of the data. As data analysis progressed, further structure was added to the data collection process. Box 1 presents core questions which all participants were asked during the final interviews at one year. In addition, individuals were asked a few individual questions which arose from the analysis of their previous interview date. These were derived by returning to the open coding within each interview. By comparing chronological components of participant data it was possible to develop and modify the emerging concepts (Creswell, 1998). This iterative process of simultaneously collecting and analysing data helped complete understandings of the recovery experience.

Box 1. Interview guide for all final interviews conducted.

1) Looking back, can you summarise what this year has been like for you?
2) What a) promoted and b) hindered your recovery?
3) What impact did your recovery have on you and are there any lasting effects?
4) What were the key features of the whole experience and what still stands out?

Analysis also involved the researcher writing memos which helped move some parts of the data on to the next stages of coding by promoting the level of abstraction. Following discovery and saturation of the core category – embodied control - relevant literature was theoretically sampled, directed by theoretical questions arising from analysis. This deductive process led to further comparative analysis between all study data, enabling verification and correction of the emerging categories.

Theoretical coding led to the emergence of the concept of guarding, which helped to explain associations in the data regarding individual beliefs about survival and fears of the cancer returning, which changed their relationship with their body (See Fig. 1). Connections with two other categories: 'Regaining body' and 'Risk management' also became established. This data was later compared with relevant literature identified by theoretical sampling. Analysis continued until the categories fitted into stages