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Patient experiences of nurse-led telephone follow-up following treatment for colorectal cancer



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A B S T R A C T

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Purpose: Colorectal cancer is the third most prevalent cancer worldwide, although mortality rates across most of Europe have decreased in recent years. Historically, patients are asked to return to hospital outpatient clinics following treatment to monitor for disease progression. However, new approaches are being called for that focus on meeting the information and support needs of patients. Telephone follow-up (TFU) by specialist nurses is an alternative approach; this study aimed to explore patient views of TFU. **Methods:** Qualitative interviews were conducted with 26 colorectal cancer patients who had received TFU. One interview was also conducted with the specialist nurse who had used a structured intervention to provide TFU. Data were analysed using content analysis.

Results: All patients found TFU to be a positive experience and all stated a preference for continuing with TFU. Three main themes emerged from the patient interviews; 1) accessible and convenient care, 2) personalised care, and 3) relationship with the specialist nurse. The themes from the specialist nurse interview were 1) knowing the patient, 2) the benefits of TFU and 3) the challenges of TFU.

Conclusions: TFU was well received by patients; it was perceived as highly convenient and had distinct advantages over hospital follow-up. Continuity of care was an important factor in building a trusting relationship between patient and nurse. Training in the use of the intervention is recommended and it may be useful for specialist nurses to initially meet eligible patients face to face to establish rapport before implementing TFU.

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Introduction

Colorectal cancer is the third most prevalent cancer worldwide (Parkin et al., 2005). However, mortality rates across most of Europe have decreased in recent years (Center et al., 2009). In the United Kingdom (UK), five year survival for those diagnosed at an early stage (Dukes A) is currently over 90%; those diagnosed at an early stage have a better prognosis than those who present at a later stage of disease (Cancer Research UK, 2014). However, despite most patients undergoing potentially curative surgery, 30–50% will develop recurrent disease and five year survival for advanced colorectal cancer is less than 5% (Young and Rea, 2001; Bohm et al., 1993). Incidence is strongly related to age; in the UK approximately 43% of bowel cancer cases were diagnosed in people aged 75 years

and over between 2009 and 2011 (Cancer Research UK, 2014). The mainstay of treatment is surgery, although radiotherapy and chemotherapy can be recommended depending on disease presentation and stage (NICE, 2011).

Following completion of treatment, colorectal cancer patients tend to return to hospital outpatient clinics for surveillance at regular but decreasing intervals for a period of three to five years, depending on national guidelines and local hospital policy. The reported purpose of follow-up after colorectal surgery is primarily to improve patient survival by early diagnosis of recurrence as well as resolving surgery related problems and providing psycho-social support (Li Destri et al., 2006). More intensive follow-up has been associated with improved five year survival (Jeffery et al., 2007; Tjandra and Chan, 2007). However, the most recent UK guidelines indicate that there is no consistent definition of what constitutes 'intensive' follow-up for colorectal cancer patients; no specific protocol for intensive follow up can therefore be recommended at present (NICE, 2011). Protocols for follow-up primarily focus on the most appropriate tests and investigations that will detect recurrent

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disease at an earlier stage and therefore improve survival (e.g. serum carcinoembryonic antigen tests CEA, CT scans, colonoscopy). However, few studies have focused on psycho-social aspects of colorectal cancer follow-up; providing patients with the information and support they need to live well beyond the cancer diagnosis.

It is estimated that there are now two million cancer survivors in the UK, predicted to rise by 3% a year (Maddams et al., 2009). Approximately 250,000 people living in the UK have received a diagnosis of colorectal cancer (NICE, 2011). The majority of colorectal cancer survivors are in phases of rehabilitation (the first year), early monitoring (up to 5 and 10 years from diagnosis), late monitoring (10 years +) and progressive illness (incurable disease but not end of life) (Maher and McConnell, 2011). Survivors of colorectal cancer are known to have specific information and support needs that are not met through traditional hospital follow-up (Nikoletti et al., 2008; Rozmovits et al., 2004; Sahay et al., 2000). The UK's National Cancer Survivorship Initiative (NCSI) calls for radical changes to the way follow-up/aftercare is provided following treatment, with a focus on providing patients with the information they need to live well beyond diagnosis, promoting supported self-management and evaluating alternative models of follow-up care (Department of Health, 2010). Given the ageing population in the UK (and across Europe), the favourable five year survival rates for those diagnosed with colorectal cancer at an early stage and the reported success of bowel cancer screening programmes in terms of early detection (Macafee et al., 2008), it seems likely that the traditional hospital outpatient approach to follow-up will become economically unsustainable.

Whilst traditional doctor-led models of care following treatment for cancer predominantly focus on the detection of recurrence, nurse-led models take a more holistic approach and have been shown to be acceptable with positive outcomes (Beaver et al., 2009; Knowles et al., 2007; Lewis et al., 2009; Moore et al., 2002; Wells et al., 2008). Knowles et al. (2007) successfully piloted a specialist nurse-led model of follow-up for 60 colorectal cancer patients who had undergone surgery with curative intent. The study demonstrated high levels of patient satisfaction, improvements in quality of life and global health as well as potential cost savings. Knowles et al. (2007) acknowledge that they were not able to conclude that improvements in health were directly attributable to the nurse-led model of follow-up but they did suggest that systematic symptom assessment and strict adherence to the follow-up protocol by the nurse specialists involved in the study may have led to the improvements reported.

Nurse-led telephone follow-up (TFU) has also been shown to be effective for colorectal cancer patients in a pilot randomised controlled trial (RCT) with those receiving TFU from a specialist nurse reporting higher levels of satisfaction with information and service than patients receiving traditional hospital follow-up (Beaver et al., 2012). Local protocols for tests and investigations aimed at detecting recurrent disease (e.g. CEA blood tests, CT scans) were unaltered and the telephone approach focused on addressing the psychological, supportive and information needs of patients in addition to detecting signs of recurrence. The telephone intervention consisted of a structured guide containing questions about changes in health, symptoms, information and support needs (histology, treatment and side effects, genetic risk, sexual attractiveness and function, self-care, impact on social life and family concerns). The Beaver et al. (2012) study provided preliminary evidence of effectiveness but to obtain more in-depth information on patients' experiences of TFU, as recommended in trials of complex interventions (Lewin et al., 2009), a qualitative study, involving semi-structured interviews with a sample of participants randomised to the telephone arm, was also conducted. This paper reports

on the qualitative study that explored colorectal cancer patients views on TFU to determine what aspects were perceived as beneficial. This information is important for health care providers planning to implement this approach in practice.

Aim

The primary aim was to explore patient experiences of TFU after treatment for colorectal cancer. A secondary aim was to explore the views of the Colorectal Nurse Practitioner (CNP) who administered the telephone intervention in the pilot RCT.

Methods

Design

A qualitative design using semi-structured interviews enabled participants to describe their experiences of TFU in depth and detail. This was intended to enrich the findings from the quantitative pilot trial that aimed to examine effectiveness of the telephone intervention. Although only one specialist nurse had delivered the telephone intervention in the pilot trial it seemed appropriate to also explore the views of the CNP on delivering the intervention and the CNP was therefore also interviewed in this qualitative study. Study participants were given the choice of a telephone or face-to-face interview. One researcher conducted all interviews which were digitally recorded, transcribed verbatim and analysed using content analysis. The study received ethical approval from the National Health Service Research Ethics Committee.

Sample

The pilot trial had recruited 65 patients; 32 were randomised to TFU. On completion of the trial, 26 patients who had received TFU were available for interview. All 26 were contacted by letter thanking them for their participation in the pilot study and asking if they would be prepared to talk about their experience of TFU with an experienced nurse researcher. Twenty one consented to be interviewed; 20 were interviewed by telephone and one face-to-face. Of the five patients who were not interviewed, three declined and two had been admitted to hospital with unrelated illnesses. All 21 patients who were interviewed had experienced telephone follow-up on at least one occasion; four participants had received two telephone appointments prior to being interviewed. The CNP who had provided TFU for the duration of the pilot study was provided with verbal and written information about the purpose of the interview and chose to be interviewed face to face. Written consent was obtained from all participants prior to interviews.

Data collection

Two interview guides were developed (patient and CNP) containing questions and probes relating to TFU. The semi structured format using open ended questions allowed the interviews to flow and provided the opportunity for the researcher to probe interesting and relevant issues as they arose. The patient interview guide asked patients to give their views on follow-up being carried out over the telephone instead of in hospital, how they felt about follow-up being conducted by a specialist nurse instead of a doctor, aspects of TFU that had been helpful or unhelpful, how they felt about the questions they were asked in the delivery of the intervention, whether they had experienced any problems with their appointments and their preferences for future follow-up. The CNP interview guide explored views on how TFU compared to hospital

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