



Telephone follow-up after treatment for endometrial cancer: A qualitative study of patients' and clinical nurse specialists' experiences in the ENDCAT trial

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ABSTRACT

Purpose: Endometrial cancer is the sixth most common female cancer worldwide. There is little evidence that routine hospital surveillance increases survival or decreases morbidity following treatment. Gynaecology Oncology clinical nurse specialists (CNSs) are ideally placed to provide the care, information and support to enable women with a gynaecological cancer to self-manage and live well. A multi-centre randomised controlled trial (RCT) compared hospital follow-up (HFU) with telephone follow-up (TFU) by CNSs. The structured telephone intervention focused on information provision to meet patients psychosocial and information needs. This study aimed to explore the views of women who had received TFU and the CNS's who had delivered the service. **Method:** A qualitative study to complement the RCT using semi-structured interviews was conducted. Twenty-five patients were randomly selected from participants in the TFU arm stratified by study site. Seven CNSs were interviewed.

Results: Patient and CNS regarded TFU positively; Three themes emerged from the patient interviews; Convenient Care, Discrete Personalised Care, Confidence and Reassurance. Themes arising from the CNS interviews were Patient Centred Care, Holistic Care and, Confidence and Skills. Patients found that TFU with CNS's was convenient and enabled discussion of issues and information provision at time-points relevant to them. The CNS's found the structured format of TFU enabled them to utilise their skills and knowledge to identify and meet patients holistic needs.

Conclusions: Alternative models of care such as TFU provided by CNSs provides the care, information and support to enable women treated for endometrial cancer to self-manage and live well.

1. Background

Endometrial cancer is the sixth most common female cancer worldwide (WCRF, 2016) and the most common gynaecological cancer in developed countries (Cancer Research UK, 2015). Most endometrial cancers are diagnosed at an early stage with a five-year survival rate of over 91% (World Cancer Research Fund International, 2016). Following treatment for endometrial cancer, patients traditionally receive follow-up appointments in hospital outpatient clinics at regular but decreasing intervals for 3–5 years, reportedly to detect recurrence of disease at an early stage and thus increase survival (Jeppesen et al., 2017; Kew et al., 2005). However, most recurrences of endometrial cancer are symptomatic (Jeppesen et al., 2017) and there is no current evidence that routine surveillance of patients with endometrial cancer increases survival or morbidity (Baekelandt and Castiglione, 2009; Kew

et al., 2005; Lajer et al., 2010; Tjalma et al., 2004). There is also increasing evidence that cancer survivors have long term physical, psychological and social needs which are not addressed through traditional hospital based follow-up (Pennery and Mallet, 2000; Lajer et al., 2010; Beaver et al., 2009; Williamson et al., 2015).

In the United Kingdom (UK), the Living With and Beyond Cancer programme has advocated alternative approaches to hospital based follow-up (DoH, 2013). Trials comparing hospital and nurse-led telephone follow-up (TFU) with patients who had completed treatment for breast and colorectal cancer demonstrated that TFU was an effective way to meet patients psycho-social and information needs without physical or psychological detriment (Beaver et al., 2009, 2012). However, this approach had not been evaluated for endometrial cancer patients. A multi-centre randomised non-inferiority trial compared traditional hospital follow-up (HFU) with telephone follow-up (TFU)

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provided by gynaecology oncology clinical nurse specialists (CNS) with patients at low risk of recurrence (the ENDCAT trial). Patients having TFU were not distressed or less satisfied by forgoing face-to-face consultations and physical examinations and, there were no differences in quality of life or time to detection of recurrence between HFU and TFU (Beaver et al., 2016). The TFU appointments followed a different format to hospital appointments as the structured telephone intervention focused on information provision asking patients about physical, social, psychological, treatment and information needs. Patients were asked questions about the signs and symptoms of recurrent disease (vaginal bleeding, discharge, abdominal pain), information needs relating to cancer diagnosis, treatments, side effects, genetic risk, sexual attractiveness, sexual function, caring for themselves and how they and their family were coping. A closing question asked if there was anything else they wanted to discuss. The questions were repeated at each telephone appointment, as it is known that patients information needs continue after completion of treatment and that priorities change over time (Beaver et al., 1999; Mistry et al., 2010; Tariman et al., 2014). To maintain the integrity of the intervention the CNSs received training on delivering the intervention and telephone consultations were recorded. To complement the trial, a qualitative study involving semi-structured interviews with a sample of participants randomised to the telephone arm and CNS's who provided TFU was conducted to obtain in-depth information on their experiences (Lewin et al., 2009).

Regaining and maintaining confidence, and physical and psychological well-being following treatment for cancer, requires a supportive infrastructure to enable self-management in much the same way as patients with other chronic conditions (Foster and Fenlon, 2011). Traditional doctor-led models of care following treatment for cancer predominantly focus on the detection of recurrence, whereas nurse-led models take a more holistic approach and have been shown to be acceptable to patients with positive outcomes (Beaver et al. 2009, 2015, Knowles et al., 2007, Lewis et al., 2009, Wells et al., 2008). Although alternative models of follow-up to meet patients' psycho-social needs have been reported as effective, they have not replaced traditional HFU. Reasons include lack of longitudinal data, lack of trials, clinician and patient expectation and, in the UK, funding being secured for face-to-face hospital follow-up (Davies and Batehup, 2011; Frew et al., 2010; Jefford et al., 2013). The Living With and Beyond Cancer programme is underpinned by the recognition that traditional models of follow-up are unsustainable but, more importantly, that patients need to be provided with information and support to self-manage (DoH, 2013). The model of care suggested is called a recovery package which is multi-faceted and includes care planning informed by risk stratification and a holistic needs assessment (HNA), treatment summaries for patients and General Practitioners (GPs), a cancer care review in primary care, and education and information to support self-management. It has been reported that women treated for gynaecological cancer have problems surrounding impaired quality of life, physical, social and sexual functioning but that health care professionals (HCP) rarely discuss these difficulties with patients (Stead et al., 2003; Reis et al., 2010). The role of the CNS in the UK is to coordinate care, provide technical and psychosocial information, and emotional support (DoH, 2007, Macmillan, 2011). Women treated for gynaecological cancer want to participate in their care and not leave responsibility to HCPs; for this to occur they need information that is personalised and meaningful to their everyday lives (Ekwall et al., 2003; Sekse et al., 2012). Gynaecology Oncology CNSs are ideally placed to provide the care, information and support to enable women with a gynaecological cancer to self-manage and live their lives well (Maughan and Clarke, 2001, Sekse et al., 2012). The telephone intervention delivered as part of the ENDCAT trial was designed to meet patient information and support needs. This study reports on the views and experiences of patients who received TFU and the CNSs who provided the TFU.

2. Aim

To explore patient and CNS experiences of telephone follow-up after treatment for endometrial cancer.

3. Methods

3.1. Design

A qualitative design was justified as this study aimed to explore the views and experiences of patients and nurses through semi-structured interviews to enhance the quantitative findings from the ENDCAT trial, which recruited 259 patients across five study sites in the North West of England.

3.2. Sample

Twenty-five patients were randomly selected from the 129 participants in the TFU arm, stratified by study site (5 per site). Only one declined to participate as she did not want to talk about something she felt was no longer a part of her life; another participant was randomly selected from the same study site and consented to interview. Eight nurse specialists delivered the intervention. One had retired by the end of the study and was unavailable for interview; seven were interviewed.

3.3. Access and recruitment

Ethical approval was obtained from the NHS Research Ethics Service in the UK, Research and Development departments at the five study sites and the University of Central Lancashire.

Potential participants were sent a participant information sheet (patient or CNS version), consent form, prepaid self-addressed envelope for return of consent forms, and contact details of a researcher if they wished to discuss the study further. On receipt of signed consent a date and time for interview was arranged.

3.4. Interviews

Two interview guides were developed (patient and CNS). Questions and probes were designed to ascertain how participants felt about receiving or providing follow-up appointments over the telephone rather than face-to-face at a hospital. Interviews explored the perceived advantages or disadvantages of TFU. Patients and CNS's were asked how they felt about being asked, or asking, the same questions at each appointment. Participants were asked if any of the questions made them feel uncomfortable or embarrassed. All participants were asked if they had encountered any problems with receiving or providing TFU. Patients were asked whether or not they wanted to continue with TFU or return to HFU and CNSs were asked if they would like to continue to provide TFU. All patient participants chose to be interviewed in their own homes. CNS interviews were carried out at work. Interviews were conducted by two nurse researchers.

With participant consent all interviews were digitally recorded.

3.5. Analysis

Data were analysed using content analysis. Interviews were transcribed verbatim and all identifying features were removed. Two researchers independently coded the data, all codes identified were applied to the whole data set (Morse and Field, 1998; Saldana, 2009) and collapsed after discussion and review to ensure trustworthiness and reliability (Shenton, 2004). Analytical memos were recorded as ideas and themes emerged and discussed with the research team. Data summaries were sent to some participants (patients and CNS's) to ensure researcher interpretation accurately reflected their views.

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