



## Understanding the impact of the treatment pathway upon the health-related quality of life of women with newly diagnosed endometrial cancer – A qualitative study



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### A B S T R A C T

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**Purpose:** (1) To determine the impact of treatment and recovery on the health-related quality of life (HRQoL) of endometrial cancer (EC) patients. (2) To explore how treatment types and delivery affect HRQoL and invite suggestions for improvement.

**Methods:** Qualitative study. In-depth, semi-structured interviews at 3, 6, 9 or 12 months post-treatment were carried out with 22 women with stage IA to IVB EC who had undergone treatment at a tertiary referral centre for gynaecological cancers in Sheffield, UK. 21 were treated surgically and 4 received adjuvant treatment. Data were analysed using an inductive thematic approach.

**Results:** Four dominant themes emerged regarding the treatment pathway: pre-treatment concerns, experience during treatment, post-treatment and survivorship issues. Expectations and understandings of EC and its treatment were often inaccurate. Proper explanations eased anxiety but were uncommon. Laparoscopic surgery was welcomed where offered but did not necessarily influence coping ability. Instead, women evaluated treatment impacts against their expectations. Treatments affected women's physical abilities, self-perception and relationships resulting in re-evaluation of lifestyle.

**Conclusions:** The impact of treatment upon HRQoL for women with EC differs from other gynaecological cancers. Better information provision would enhance coping ability. Coping methods and expectations appear to influence HRQoL more than treatment modality.

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### Introduction

Endometrial cancer (EC) is the fourth commonest cancer in UK women (CRUK, 2008) and incidence is increasing with rising longevity, obesity and uptake of hormone replacement therapy (HRT) (Kaaks et al., 2002; Sabbatini et al., 2002). Around 80% of ECs present at an early stage with less aggressive histology, consequently in these cases the five year survival rate is over 80% (Holland and Kitchener, 2007). Health-related quality of life (HRQoL) issues focus on patients' concerns and priorities and influence treatment acceptability and cost-benefit analysis (Rapley,

2003). HRQoL is an important outcome for these patients who may live with the impact of a cancer diagnosis, associated lifestyle changes and treatment sequelae for many years.

In recent years several studies have assessed how treatment affects HRQoL using numerical tools i.e. validated questionnaires. Immediately pre-surgery EC patients' HRQoL scores are lower than normal population equivalents (Zullo et al., 2005; Vaz et al., 2007). Scores improve steadily over at least the first six months post-surgery; the increase is faster and possibly greater in patients who receive laparoscopic surgery, and is more marked in younger patients (von Gruenigen et al., 2005; Zullo et al., 2005; Kornblith et al., 2006; Kornblith et al., 2009; Janda et al., 2010).

Adjuvant radiotherapy reduces HRQoL scores compared to surgery alone (Zhu et al., 2005; van de Poll-Franse et al., 2007). Scores drop during the first weeks of radiotherapy, then increase,

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becoming stable and equivalent to non-irradiated patients although lower than normal population controls by 6 months (Klee and Machin, 2001; Ahlberg et al., 2005; Kamer et al., 2007; Le et al., 2009; Nout et al., 2009). Sequelae of radiotherapy including bowel and bladder dysfunction, hot flushes and fatigue with their associated impacts on HRQoL may persist for many years (Huguenin et al., 1999; Klee and Machin, 2001; von Gruenigen et al., 2005; Nout et al., 2009).

Whilst quantitative assessment of HRQoL allows comparison of treatments for policy planning and illustrates trends in recovery, numerical methods cannot discern which specific issues are most problematic or how different aspects of HRQoL are valued. Qualitative research is increasingly used to understand the meanings patients attribute to their experiences and explore unquantifiable impacts of treatment. This can explain discrepancies between patients' subjective assessment of their HRQoL and objective health indicators (Britten, 1995; O'Cathain et al., 2007).

The authors found nine existing qualitative studies on the impact of treatment for gynaecological cancer on HRQoL, eight interview studies (Lamb and Sheldon, 1994; Butler et al., 1998; Bradley et al., 1999; Velji and Fitch, 2001; Ekwall et al., 2003; Juraskova et al., 2003; Wray et al., 2007; Reis et al., 2010) and one qualitative questionnaire study (Steginga and Dunn, 1997). The number of EC patients included ranged from 4–19 in the interview studies and 25 in the qualitative questionnaire study. Only one study used a population of exclusively EC patients (Lamb and Sheldon, 1994); otherwise EC and other gynaecological cancer patients were grouped together masking the demographic and disease related factors specific to EC patients. Furthermore, the majority of articles published to date have been written from a nursing rather than a medical perspective i.e. a 'care' compared to a 'treatment' perspective (Steginga and Dunn, 1997; Butler et al., 1998; Velji and Fitch, 2001; Ekwall et al., 2003; Reis et al., 2010).

Current literature mainly focuses on patients' perceptions of their interactions with the health-care system (Bradley et al., 1999; Velji and Fitch, 2001; Ekwall et al., 2003) or issues related to sexuality (Lamb and Sheldon, 1994; Butler et al., 1998; Juraskova et al., 2003; Reis et al., 2010). Women's concerns change as they recover from treatment. Initially fears for survival, the stress of treatment procedures and short-term side effects cause anxiety (Steginga and Dunn, 1997; Ekwall et al., 2003). Vaginal brachytherapy is particularly unpleasant (Velji and Fitch, 2001; Wray et al., 2007). The most distressing side-effects reported across all treatments are fatigue, pain and disruption of urinary and bowel function (Steginga and Dunn, 1997). Longer-term difficulties relate to restoring self-concept and dealing with the perceived threat of recurrence (Lamb and Sheldon, 1994; Bradley et al., 1999; Wray et al., 2007).

Sexual difficulties result from reduced vaginal lubrication, vaginal stenosis, dyspareunia, fatigue and diarrhoea caused by surgery but more commonly radiotherapy (Lamb and Sheldon, 1994; Butler et al., 1998; Juraskova et al., 2003; Reis et al., 2010). Some studies describe a distressing sense of androgeny related to hysterectomy, particularly in young women where femininity is associated with child-bearing (Lamb and Sheldon, 1994; Butler et al., 1998; Juraskova et al., 2003; Reis et al., 2010). Older women report less change in body image (Juraskova et al., 2003).

Women find the process of treatment less distressing if they have confidence in the quality of their care (Ekwall et al., 2003). Specifically, women are reassured if staff show understanding of the treatment and recognise that patients respond to the experience of treatment in different ways (Velji and Fitch, 2001; Ekwall et al., 2003). It has been suggested that women receive inadequate information on what to expect from treatment and the impact it will have on their lives (Velji and Fitch, 2001; Ekwall et al.,

2003; Wray et al., 2007). Many women have poor understanding of their anatomy, cancer pathology and prognosis but do not ask for further details (Butler et al., 1998; Bradley et al., 1999; Juraskova et al., 2003; Wray et al., 2007). A lack of opportunities to discuss sexual functioning is universally reported (Lamb and Sheldon, 1994; Butler et al., 1998; Juraskova et al., 2003; Wray et al., 2007; Reis et al., 2010).

This study aimed to discover, i) Which issues affect EC patients' HRQoL during treatment and recovery (in comparison to other gynaecological cancers)? ii) What areas other than sexuality are important? iii) How does delivery of treatment and after care influence women's experiences? and iv) What opportunities exist for service improvement?

## Methods

We conducted a qualitative study using semi-structured interviews. All patients referred to a single tertiary referral centre with a new diagnosis of EC from January 2007 to December 2008 were approached to participate in a longitudinal quantitative questionnaire study on the impact of treatment on HRQoL and a one-off qualitative in-depth interview. The qualitative study reported here was generated as part of the longitudinal questionnaire study. Women received written information about the interviews including the voluntary nature of involvement and could discuss the study with the research nurse before consenting to participate.

Attempts were made to interview all consenting participants. Purposive sampling was used to stratify participants across four follow-up points, at three, six, nine, and 12 months post-treatment, with the intention of interviewing at least five patients at each time point. Interviews were then arranged by telephone and letters.

Interviews were conducted in hospital clinics or participant's homes by one of two interviewers (either HB or SH), neither of whom was involved in participants' care. Participants were told they could ignore issues which they did not wish to discuss.

The interview schedule was based around concepts emerging from the literature (Jones et al., 2006). As the study progressed, additional topics were added as they arose. The final interview schedule is shown in Table 1. Open questioning was used initially allowing participants to direct the interview towards their personal experience, followed by specific questions to ascertain further details. Interviews were tape recorded, then digitalised and transcribed by administrative staff. Transcriptions were checked against the tapes by the interviewer and then were organised and coded using the QSR NVivo 8 Computer-Assisted Qualitative Data Analysis Software.

**Table 1**  
Interview schedule.

Diagnosis
Details of diagnosis, emotional impact
Treatment received
Type, experience including hospital stay, understanding of, fears/anxieties
Treatment impact on health-related quality of life
Treatment impact on how you feel as a woman
Side effects, positive impacts, how others view you
Treatment impact on relationship with partner
If no partner, ideas about impact on future relationships
Treatment impact on sexual relationships
Side effects, priority of sex, anxiety, partner's feelings
Ways of coping with previous three topics
Information received
Source, type, adequacy, other types required
Experiences of support
In hospital, at home; health-care staff, family, friends
Recommendations for service improvement re: support/information/interventions required

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