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Exploring the acceptability and feasibility of patient initiated follow up for women treated for Stage I endometrial cancer

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Exploring the acceptability and feasibility of patient-initiated follow up for women treated for Stage I endometrial cancer

ABSTRACT

Purpose: There is a strong shift away from hospital-based approaches to follow-up after active treatment for cancer with supported self-management being promoted as an approach to long term recovery. We aimed to determine the acceptability and feasibility of patient-initiated follow-up (PIFU), supported by a self-management approach, for patients treated for Stage I endometrial cancer.

Methods: A mixed methods study was undertaken. Participants were asked to forego hospital outpatient follow-up appointments, supported by a self-management approach. Outcome measures included satisfaction with information and service, psychological morbidity, quality of life and preferences for follow-up. Qualitative interviews were carried out with study participants to determine their views on follow-up in general and PIFU in particular.

Results: We recruited 17 patients. High levels of satisfaction were evident with no physical or psychological detriment. Self-management was a favoured option. Participants questioned the value of hospital follow-up and were willing to engage in self-management if they knew who to contact if they had a problem and were aware of the signs and symptoms of recurrence. However, uptake to the study was low and further work is needed to explore if recruitment to a randomised controlled trial (RCT) is a viable option.

Conclusions: Alternative approaches to hospital-based follow-up need to demonstrate that patients feel supported, knowing what symptoms to report and to whom. This study shows acceptability of a supported self-management approach but raises some concerns about the feasibility of recruitment to a future RCT.

KEYWORDS

Endometrial cancer

Self-management

Patient-initiated follow-up

Feasibility study

Survivorship

Gynaecological cancer

HIGHLIGHTS

Increasing numbers of endometrial cancer survivors puts pressure on hospital-based approaches to follow-up

This study examined a patient-initiated approach to follow-up, aimed at enabling self-management

Patients on patient-initiated follow-up need to be aware of the signs and symptoms of recurrence and how to self-refer if they have concerns.

BACKGROUND

The incidence of endometrial cancer is rising, linked to the global problem of obesity and diabetes (Arnold et al., 2015; Nagle et al., 2018). Endometrial cancer is the sixth most commonly occurring cancer in women globally with 380,000 news cases reported in 2018 (World Cancer Research Fund, 2019). In the United Kingdom (UK) there are approximately 9,300 new cases reported each year; the fourth most common female cancer (Cancer Research UK, 2019). However, most patients (75%) present with Stage I disease (confined to the uterus) and five-year survival is over 70% (Baekelandt and Castiglione, 2009). The risk of recurrence is approximately 3% or less for low risk patients and most recurrences are symptomatic (Fung-Kee-Fung et al., 2006). Therefore, although incidence is rapidly rising, treatment is highly effective for early stage disease and worldwide there are increasing numbers of endometrial cancer survivors. The National Health Service (NHS) in the UK has traditionally provided long term follow-up care for women treated for endometrial cancer, in the form of hospital clinic visits at regular but decreasing intervals over a period of years. The intention is to detect recurrent disease at an early stage, before symptoms develop, and improve survival (Nordin, 2006). However, a one-size fits all approach does not take account of individual needs and preferences, cancer stage or risk of recurrent disease.

Mortality rates for cancer are falling globally (Hashim et al., 2016) and it is predicted there will be four million cancer survivors in the UK alone by 2030 (Maddams et al., 2012). Hence, a hospital-based approach to follow-up care is arguably unsustainable from a practical, workforce and financial perspective and there have been recent moves towards alternative follow-up strategies for different cancer diagnoses, including nurse-led models (Monterosso et al., 2019; Taylor et al., 2019) nurse-led telephone follow-up (Beaver et al., 2009; Beaver et al., 2012; Beaver et al., 2017; Cox et al., 2008; Kimman et al., 2010; Shaida et al., 2007), General Practitioner (GP) follow-up (Murchie et al., 2010; Grunfeld et al., 1996), technological approaches using, for example, telemedicine, smartphones and computer touchscreen technology to monitor symptoms and concerns (Dickinson et al., 2014;

Schougaard et al., 2016; Semple et al., 2018), and patient-initiated follow-up (PIFU) (Kirshbaum et al., 2017, Koinberg et al., 2004). In PIFU, there are no routine scheduled hospital clinic appointments. On completion of primary active treatment, when patients are considered to be in the 'follow-up' stage, patients are informed about signs and symptoms to look out for and who to contact for self-referral back to specialist services

For gynaecological cancers, evidence to date indicates that routine clinical review has little survival benefit and early detection of recurrence does not improve outcomes or reduce morbidity (Baekelandt and Castiglione, 2009; Jeppesen et al., 2017; Kew, Roberts and Cruickshank, 2005; Lajer et al., 2010; Tjalma et al., 2004). Hence, less resource intensive approaches may be suitable for this patient group. The first randomised controlled trial (RCT) of nurse-led telephone follow-up for women treated for Stage I endometrial cancer (ENDCAT trial, n=259) indicates non-inferiority to hospital-based follow-up in terms of psychological morbidity, satisfaction with information and service, quality of life, and time to detection of recurrent disease (Beaver et al., 2017). Therefore, telephone follow-up presents a viable alternative to hospital follow-up, although clinical nurse specialists are unlikely to have the resources to provide follow-up care to all patients diagnosed with early stage endometrial cancer.

A patient-initiated approach to endometrial cancer follow-up may also be a viable option, if patients have the information they need to self-manage their recovery. A recent UK study has reported that PIFU is well received by women treated for endometrial cancer, although younger women (median age 57 years) initiated more contact with health care staff, indicating they needed a higher level of support (Kumarakulasingam et al., 2019). A study carried out in Denmark reported that PIFU for endometrial cancer patients (n=156) was feasible and potentially cost effective but patients in the PIFU arm indicated significantly higher levels of fear of recurrence than in the hospital follow-up arm of the study (reported difference of -5.9; 95% CI -10.9 to -0.9, p=0.02) (Jeppesen et al., 2018). It was

speculated that the increased responsibly put on women to detect signs of recurrence may have increased levels of stress (Jeppesen et al., 2018).

The Living With and Beyond Cancer programme in the UK advocates a Recovery Package for all patients treated for cancer to promote self-management and improve outcomes and co-ordination of care, including better and earlier identification of the consequences of treatment (National Cancer Survivorship Initiative, 2013; Independent Cancer Taskforce, 2015). The Recovery Package is intended to support all patients who have completed active treatment for cancer and includes holistic needs assessments (HNA) and care planning, treatment summaries for GPs and patients, cancer care reviews in primary care, and health and wellbeing events (National Cancer Survivorship Initiative, 2013; Macmillan Cancer Support, 2018). Full implementation of the Recovery Package is proposed for 2020 but, as reported in 2018 at one of the largest teaching hospitals in the country, implementation is challenging due to clinical and workload pressures, and more resources are required to support implementation (Greenfield and Proctor, 2018). If some patients receiving PIFU have a continued need for information and support, then the addition of the Recovery Package could reduce any potential distress and enhance confidence to self-manage. PIFU may become standard practice in the future and evidence is required to demonstrate that supported self-management approaches are acceptable to patients, as well as clinically effective, to ensure that patients feel supported throughout the survivorship period. While it may be assumed that minimalist approaches would lead to cost savings for health services, this may be a false economy if patients have unresolved and unmet needs and use alternative services. The aim of the present study was to determine the acceptability and feasibility of PIFU supported by the UK's Recovery Package for patients who have completed active treatment for Stage I endometrial cancer. More specifically, we addressed the following research questions: 1) what are patients views on follow-up? 2) will patients accept PIFU as an alternative to hospital-based follow-up? 3) Will patients feel supported by the Recovery Package? 4) What are patient preferences for follow-up after completion

of active treatment? 5) will patients be willing to accept randomisation in a future trial of hospital-based follow-up versus PIFU and what outcome measures will be suitable?

METHODS

A convergent parallel design mixed methods approach was utilised (Cresswell and Plano Clark, 2018). We collected both qualitative and quantitative data concurrently, without prioritising one particular method. In the analysis we brought findings from both approaches together, to present an overall interpretation of feasibility. We utilised multiple data sources, including quantitative measures and qualitative semi-structured interviews with patients to explore their views on hospital-based follow-up, PIFU, the Recovery Package and supported self-management. The combination of both qualitative and quantitative approaches provided more evidence for feasibility than one single approach (Cresswell and Plano Clark, 2018). We investigated patient satisfaction with care and service provision, psychological morbidity and quality of life. We also examined preferences for follow-up and willingness to be randomised into a future RCT on PIFU versus hospital-based follow-up. There were a number of elements to the study, in terms of exploring acceptability, as we wanted to look for explanations and reasoning behind patient responses and also wanted to determine if there was sufficient support, in terms of feasibility, for a future RCT. Ethical approval was granted by the National Research Ethics Service (11/NW/0648) and approval from the Research & Innovation departments of all participating centres was obtained prior to recruitment. Informed verbal and written consent was obtained from all individual participants included in this study.

Sample and Sample Size

Inclusion criteria were: a known diagnosis of Stage I endometrial cancer, completed primary treatment (e.g. surgery, radiotherapy), scheduled to attend outpatient clinics for the purposes of routine monitoring and surveillance, and scheduled to attend appointments 3-4 monthly. Exclusion

criteria were: a known diagnosis of stage II, III or IV endometrial cancer, currently receiving active treatment, taking part in a clinical trial with a pre-defined follow-up regime, and attending appointments 6-12 monthly. The focus of the study was on acceptability and feasibility and it was not designed as a fully powered study to detect statistical significance. It is not a requirement to carry out a sample size calculation for a feasibility study, although it is important that the sample is representative of the target study population (Thabane et al., 2010). As 75% of women are diagnosed with Stage I disease (Baekelandt and Castiglione, 2009), our sample was representative in that respect. We carried out the entire study over a 12-month time period (November 2016 – October 2017) to gain an understanding of how many participants could be recruited at two locations in England over a three-month time period, allowing time for patients to miss one or two appointments.

Access and recruitment

Patients were primarily recruited from the outpatient clinics of consultant gynaecology oncologists at two study locations in the UK; London (South East England) and Preston (North West England). Clinicians (gynaecology oncologists and clinical nurse specialists) were asked to identify suitable patients and a brief introductory letter was provided to eligible patients at this stage. The introductory letter gave a brief overview of the study and had a tear off slip for patients to indicate interest and provide their preferred contact details. We asked potential participants to return this slip in a pre-paid envelope to a researcher at a university address so that patients did not feel coerced to participate and had time to consider whether they wanted more information about the study. To enhance recruitment, clinical staff also identified suitable patients from their records and sent a letter by post to patients, describing the study and asking if they would be willing to participate. A researcher discussed the study with those who indicated an interest and provided a patient information sheet and consent form for consideration. The patient information sheet explained the stages of the study that included: completion of a set of outcome measures (including

a socio-demographic questionnaire) to be returned by post in a pre-paid envelope at two time points, agreement to replace 1-2 forthcoming hospital appointments with a supported self-management approach, consent to one interview on patient views of cancer care follow-up, and attendance at a hospital outpatient follow-up appointment at study end for clinical assessment. All patients received a very detailed patient information sheet that described each element of the Recovery Package. Both study locations were working towards full implementation of all elements of the Recovery Package.

Patient outcome measures

Satisfaction with information and service: we used two 10-point scales (one for satisfaction with information and one for satisfaction with service) ranging from 'very unsatisfied' to 'very satisfied'. Higher scores indicated higher levels of satisfaction. There was an open response question to expand on what could have been improved for those who had indicated 'yes' to a question asking if anything could have been done better.

Preferences for follow-up and willingness to be randomised: Participants were presented with 12 alternative approaches to follow-up (including hospital, telephone, GP, self-management, no follow-up) and were asked to indicate their liking for each item using a five point Likert type scale ranging from 'Like a lot' to 'Dislike a lot'. Participants were also asked to indicate their willingness to be randomised to a future RCT that compared hospital-based follow-up (control arm) with a patient-initiated self-management approach (intervention arm).

Socio-demographic questionnaire: participants were asked to provide details on age, level of education, occupation (used to determine socio economic status) (Standard Occupational Classification, 2010), employment status, marital status, and ethnic group.

Psychological Morbidity: We used the State Trait Anxiety Inventory (STAI), one of the most widely used measures of anxiety in clinical research with high levels of validity and reliability distinguishing between anxiety as a personality trait and short-term anxiety initiated by current life events (Spielberger et al., 1983; Bowling, 2001).

Quality of Life: We used the European Organization for Research and Treatment (EORTC) QLQ-C30 (version 3) (Aaronson et al., 1993). This 30 item scale has five functional scales (physical, role, cognitive, emotional, social), a global health and quality of life scale, three symptom scales (fatigue, nausea and vomiting, pain) and six single items (dyspnoea, insomnia, appetite loss, constipation, diarrhoea, financial difficulties). We also used the specific module for endometrial cancer (QLQ-EN24) (Greimel et al., 2011). The QLQ-EN24 contains 24 items; five multi-item scales and eight single-item scales (four related to chemotherapy; one to pelvic pain; three to sexuality).

Medical notes review: At the end of the study, all participants were invited to return to a hospital-based appointment for consultation; the outcome was recorded on a study proforma. A medical notes review was also carried out to record any indicators of recurrence during the study period, with patient consent.

Interview Guide

An interview guide was developed to explore views on hospital-based follow-up, self-management and the different elements of the Recovery Package. The questions included in the interview guide are shown in Box 1.

Insert Box 1 here

Procedures

For patients who consented to participate, their next scheduled hospital appointment was cancelled. Depending on time of recruitment, and frequency of follow-up appointments, participants missed one or two hospital appointments. Patients did not return to hospital-based follow-up until the study end point and, depending on date of recruitment, did not have a follow-up consultation for a period of between 7 and 10 months. Participants would have been scheduled to return in three months if not taking part in the study. Outcome measures were completed at two time points; at recruitment (T1) and prior to returning to a hospital consultation (T2). A convenient date and time was arranged to interview participants over the telephone, a minimum of 6 months post recruitment. All interviews were audio-recorded with consent and fully transcribed.

ANALYSIS

Quantitative data were entered into SPSS (Version 24). It is not the intention of feasibility studies to report on statistically significant outcomes (Thabane et al., 2010). However, we carried out statistical analyses to obtain useful information on the suitability of the outcome measures. For the STAI we used a cut off score of 41 to indicate high levels of anxiety, based on normative mean values for women aged 50-69 (Spielberger et al., 1983) and setting the cut off at one standard deviation above the mean (Millar et al., 1995). Prior to analysis of the EORTC QLQ C30 and EN24 data, raw scores were linearly transformed to scales of 0 to 100. Higher scores on functional scales indicated higher levels of functioning and higher scores on symptom scales indicated higher symptom burden (Aaronson et al., 1993; Greimel et al., 2011). Paired samples t tests were used where possible to make comparisons between scores on scaled items at T1 and T2. For the question on preferences for follow-up, we used frequencies and percentages to report data. Detection of disease recurrence during the study (ascertained from medical notes review) was coded as a dichotomous variable.

All interview transcripts were anonymised prior to data analysis. All qualitative data were analysed using content analysis (Graneheim and Lundman, 2003; Morse and Field, 1998). Themes and categories were identified which captured the overall meaning and substance of the data. Reliability of the coding was established through independent coding by two researchers. Any discrepancies were resolved through review of the data and discussion until consensus was reached. Measures were undertaken to ensure the rigour of the research process including line-by-line analysis and regular review and de-briefing involving coders (Denzin and Lincoln, 2000; Sandelowski, 1995).

RESULTS

During the recruitment period, 65 patients were identified as eligible. Seventeen agreed to participate (26%); seven in London and 10 in Preston. The socio-demographic characteristics of the sample are shown in Table 1. A typical participant was married, with formal qualifications and retired from work. Mean age was 59.41 years (SD 10.82, range 34 - 79 years). All participants had received surgery and were a mean of eight months from diagnosis and a mean of six months from end of treatment. There were some differences between participants at the two sites as more were retired from work at the Preston site and more had qualifications and were from a higher socio-economic group at the London site.

Insert Table 1 here

Satisfaction with information and service

Mean scores for satisfaction with care were high at both T1 (9.25) and T2 (9.00). Similarly, with mean scores for satisfaction with information at T1 (9.00) and T2 (7.83). However, participants were significantly less satisfied with the information they had received at T2 ($t=3.63$, $df = 11$, $p=0.004$). At T1, five participants indicated 'yes' to the question 'is there anything that could have been done better?' and provided additional comments; all related to a need for more information. At T2, four participants responded 'yes' (including three who had responded 'yes' at T1). Two of the comments

related to misunderstandings about the design of the study, one comment related to wanting more information on risk of recurrence and one participant asked for better communication with primary care.

Preferences for follow-up and willingness to be randomised

Preferences for different types of follow-up at T1 and T2 are shown in Table 2. Findings have been ordered from most to least favoured based primarily on the combined categories of 'like a lot' and 'like'. The most popular options at T1 were a mix of hospital and telephone appointments, early discharge from hospital supported by the Recovery Package, follow-up appointments with a GP, and telephone appointments with a specialist nurse. At T2, the most popular options were early discharge from hospital supported by the Recovery Package and follow-up appointments with a GP.

The majority of participants (12/17, 71%) said they would be willing to be randomised in a future trial at T1; three indicated 'no' and two were 'not sure'. At T2, nine of the 12 who answered the question (75%) indicated that they would be willing to be randomised; two indicated 'no' and one was 'not sure'. Preferences had altered for two participants; one had indicated 'yes' at T1 and changed to 'not sure' and one had indicated 'not sure' at T1 and changed to 'yes'.

Insert Table 2 here

Psychological morbidity

The overall mean STAI score at T1 (n=16) was 33.81 (range 20-60). The mean STAI score at T2 (n=12) was similar (30.25, range 20-50). For the Trait measure, the overall mean score was higher at 39.19 (range 21-65). The STAI mean scores did not meet the cut off score of 41 to indicate high levels of

anxiety. A paired comparison between those who had returned the STAI at both T1 and T2 (n=12) showed no statistically significant differences between scores (t=0.761, df= 11, p=0.463).

Quality of life

Overall, scores on the EORCT QLQ C30 indicated high levels of functioning and low symptom burden (Table 3). A total of 14 participants completed the EORTC QLQ C30 at both time points. There were no statistically significant differences between T1 and T2 for any of the items on the EORTC QLQ C30 (Table 3) apart from the item relating to role function. Role function had significantly improved at T2 (t= -2.474, df=3, p=0.028). Scores on the QLQ-EN24 indicated low symptom burden but also indicated low levels of sexual interest and sexual activity (Table 4). Only two women (2/14, 14.28%) who completed the QLQ-E24 at both time points indicated that they were sexually active. The only statistically significant differences between scores at T1 and T2 were in relation to lymphoedema and tingling/numbness; scores for both items had increased at T2 indicating a higher symptom burden at T2 (Table 4).

Insert Table 3 here

Insert Table 4 here

Medical notes review

At the end of the study, all participants were invited to return to a hospital-based appointment. All those recruited to the study were reviewed and none presented with signs of recurrent disease, no investigations were ordered and no further referrals were made. Participants were a median time of 9 months between recruitment and attending the medical review (range 7-10 months).

Patient interviews

Fourteen of the 17 participants recruited to the study were interviewed; two were not contactable, one had been diagnosed with a different cancer and one no longer wanted to be interviewed. Three main themes emerged from the analysis of the patient interview data: 'the value of hospital follow-up', 'self-management', and 'the Recovery Package'.

The value of hospital follow-up

Hospital-based follow-up was viewed as inconvenient in terms of travelling to appointments, car parking, financial cost and time out of work. The value of returning to scheduled hospital appointments was questioned, especially if no clinical problems were apparent. Anxiety levels were raised when appointments were imminent, with fears that cancer recurrence would be detected at the visit. However, hospital-based follow-up was also perceived as reassuring, especially in the early stages post-treatment. As time from the end of treatment increased, participants were less reliant on hospital follow-up for reassurance and were accepting of less frequent appointments.

> *'Well obviously, I thought it [hospital follow-up] is necessary, very necessary. Of course, I am nervous but I also want to check that nothing has come back, which is what I find helps. But as time has gone on, I feel it is not as necessary to go as often… I am very, very anxious when I am coming [to hospital follow-up] and probably for a couple of days before.' (ID 02)*

Returning to hospital repeatedly for appointments could bring back painful memories and emotions from the time of initial diagnosis. Fears of cancer recurrence were raised by impending appointments, whereas this fear may not have become tangible if the appointment had not been scheduled.

'It's kind of very much in your mind that it can come back or that you know … and I think if I didn't have the appointment, I'd just kind of assume that everything was okay, unless I had a problem.' (ID 09)

Self-management

Participants were positive about self-management as an approach to follow-up if the appropriate support and information was in place. Most participants were pleased to be given the opportunity to self-manage and were confident in their ability to recognise a potential problem or sign of recurrence and self-refer back to hospital. All participants reported that they knew who to contact if they had any concerns or developed symptoms indicative of recurrent disease, and this was usually a clinical nurse specialist.

'I will go back if I need to, I think the top and bottom of it is, if people have got a phone number to ring, they are more confident, aren't they? Like I have got [name of specialist nurse], it is just there if you need it.' (ID 03)

Three patients reported that they had self-referred during the study after identifying a potential problem and experienced an effective and rapid response which instilled confidence in the systems that were in place. The clinical nurse specialist had responded quickly to concerns and fast tracked patients back into the system.

'It was dead easy. I developed a discharge that was unusual for me and I went… I didn't even go to the doctors [GP] … I think the first thing I did was ring the hospital. They saw me the next day.' (ID 07)

Most participants reported awareness of signs and symptoms of recurrence and knew what to look out for in this respect but this did not apply to all participants. Some participants did not recall receiving information on alarm symptoms, which could limit their ability to self-manage. Despite the perceived differences in information provision, participants did advocate taking responsibility for their own health and being pro-active in making contact if any problems arose.

> *'I kind of go in there and I feel like it's a bit of a waste of their time and my time. If I had symptoms you kind of would call them ... if you had any problems you could possibly ring up anyway and say "I don't feel well" so it's basically like when you self-assess, you are the one that is going to be self-assessing anyway aren't you?' (ID 11)*

Receiving information on signs and symptoms of recurrence, from gynaecology oncologists and clinical nurse specialists, was considered vital to being able to effectively self-manage. Although some participants reported that they would find information on the Internet, they preferred evidence based information, provided by healthcare professionals.

> *'And I think just kind of getting all of the right information from experts who kind of know the difference between a rubbish piece of research that you have read about online and a more robust piece of research, that they can actually give you those informed responses … The more informed you are, the better you are at dealing with it emotionally I think.' (ID 16)*

The Recovery Package

Participants had been asked their views on the different elements of the Recovery Package. Participants reported some awareness of certain aspects of the Recovery Package but there was poor recollection and much confusion about what the Recovery Package involved. The HNA tended to be confused with the outcome measures used in the study. When clarification was given, most

participants could not recall a formal assessment or care plan but some did recall having an informal discussion about their concerns, usually with a clinical nurse specialist.

> *'I remember having an informal chat, I do remember having an informal chat about how any issues that I had, and we did go through a few things … I remember now, I thought it was a chat, it wasn't rushed, it was nice, informal and I think if I'd have any issues, I wouldn't have had any problems raising them'. (ID 10)*

Only two participants recalled receiving a treatment summary, although five participants commented that a treatment summary would have been beneficial. There was some confusion regarding the treatment summary, which was confused with copies of clinic letters sent to GPs and copied to patients.

> *'I think you are kind of given information on a day and you kind of lose track of what was said to you, so to have something in writing that states this, this and this, is a very good idea.' (ID 12)*

Participants were unsure what a cancer care review entailed and how this would differ to making an appointment with a GP to discuss a problem that had arisen. Only those who reported a strong relationship with a familiar GP were positive about the cancer care review. Others were reluctant to attend an additional appointment with a new doctor that they had not seen previously in relation to their cancer diagnosis.

> *'Well the thing is, I don't feel comfortable with my GP because the one I had is retired. And every time I go to phone up now, I get somebody different. And I've built no relationship up with them. They don't know me, they don't really know my condition.' (ID 11)*

Six participants could recall receiving information about a health and wellbeing event and, of those, two thought they were support groups or a place where they could go for a massage. Most participants did not appear to understand the nature of the event and had misperceptions that included being required to discuss their personal problems in a public arena.

> *'I felt like I already knew if I needed support where I would get it from. I didn't feel like it would have been useful for me to attend [a health and wellbeing event]. I am not someone who is going to go up to a stall and lay out my problems and say "what can you do for me?". Do you know what I mean? I would feel uncomfortable doing that when there are a lot of different people milling around'. (ID 06)*

DISCUSSION

This study aimed to determine the feasibility and acceptability of implementing PIFU for patients who had completed active treatment for Stage I endometrial cancer, supported by a Recovery Package. Some findings were encouraging and outcome measures appeared to be suitable and informative, although additional measures could be considered in future work that relate more directly to self-management (e.g. self-efficacy, health literacy). High levels of satisfaction were reported and no physical or psychological detriment was evident. Receiving information on the signs and symptoms of recurrence and knowing who to contact if any concerns arose was essential to participants. They felt able to self-manage if they were provided with this information prior to commencing PIFU and the majority indicated a willingness to accept randomisation in an RCT that would compare hospital follow-up with PIFU. No recurrences of disease were detected in the sample but it is unlikely that recurrences would have been detected over such a short duration as participants had early stage disease with a median time of only nine months between recruitment and medical review

Participants did not experience more anxiety as a result of missing appointments and mean anxiety levels were low. It may be that only those patients who were confident in their ability to self-manage, and had confidence in the self-referral systems in place, agreed to recruitment. However, participants also talked about the hospital appointments triggering fear of recurrence, negative memories of cancer experiences and acting as a reminder of the cancer diagnosis. In contrast, a recent RCT carried out in Denmark found that fear of cancer recurrence in endometrial cancer patients was reduced significantly more in those randomised to hospital-based follow-up than those randomised to PIFU (Jeppesen et al., 2018). In the Danish study, women in the PIFU arm had been given verbal information on alarm symptoms that would require examination and were provided with a contact number for a project nurse for self-referral. The responsibility of detecting symptoms of recurrence may have caused distress and the complete withdrawal of clinic visits may have been too drastic (Jeppesen et al., 2018). Our qualitative findings indicated that women found hospital-based follow-up more reassuring in the early months post treatment. A gradual transition to PIFU, rather than a complete withdrawal of hospital-based appointments, may provide opportunities for health care professionals to make a full assessment of needs, provide reassurance, appropriate information, and key contact details prior to implementing supported self-management approaches.

Our findings indicated a high level of functioning and low symptom burden. Hence, it may be appropriate to implement PIFU for low risk patients without adverse effects on quality of life. However, study participants indicated low levels of sexual activity and sexual functioning. This is perhaps surprising in a relatively young sample of women; mean age was 59 years with about half the sample being under the age of 60 years. It is not clear if sexual activity and functioning was a concern for patients and this warrants further investigation in future studies. Other studies have shown that women experience serious problems with sexual function after treatment for endometrial cancer (Becker at al., 2011). A Chinese study reported that 55.9% of 118 women treated for endometrial cancer did not have sexual intercourse post-surgery (Gao et al., 2017). The most

common reasons for this were psychological problems and a lack of interest in sex (Gao et al., 2017). Difficulties with sexual activity and function have been addressed and an RCT reported that psychosexual counselling by a clinical nurse specialist can lead to improved sexual function for gynaecological cancer patients (Maughan and Clarke, 2001). Hence, a more detailed assessment of psycho-sexual needs and concerns is warranted prior to discharge from hospital-based follow-up to ensure women have their needs addressed and are given the information they need to self-manage.

Early discharge from hospital with the Recovery Package was a favourable option for participants; the most favoured option at T2 alongside follow-up with a GP. However, 'no follow-up' was highly unpopular at both T1 and T2, indicating that participants could see a difference between a supported self-management approach and a 'no follow-up' option. There is a distinction to be made between discharge from hospital follow-up, effectively 'no follow-up', relying on patients to make contact if they have a problem or concern, and supported self-management approaches that ensure patients perceive that they have the information and support mechanisms in place to address any problems that may arise. The Recovery Package was designed to provide information and support for all cancer patients and when fully implemented this may prove to be an enabling factor in shifting away from hospital-based approaches to follow-up care, although there were clear misunderstandings about the Recovery Package and what it entailed that will need to be addressed. However, the Recovery Package is only one aspect of a sustained and committed approach by NHS England in the UK to adopt a patient centred approach to care that considers quality of life to be just as important as clinical outcomes (NHS England, 2019).

Less encouraging findings arose in relation to the low uptake rate in this study. Only 26% of eligible patients participated. A recent trial on PIFU versus hospital follow-up, carried out in Denmark, had an uptake of approximately 69% (Jeppesen et al., 2018). It is not clear why our uptake was low as we did not have data on reasons for non-participation. This may reflect a problem with the recruitment

process and/or with the design of the study. The recruitment period was of a short duration (3 months) to align with the 12 months funding for the study; a longer study duration would have allowed more time for recruitment. Also, recruitment commenced just prior to the Christmas holiday period and this may have deterred patients from participating. The identification of suitable participants was undertaken by busy clinicians and a more pro-active approach in identifying suitable individuals may have increased the number of eligible patients. For those who consented to participate, few knew about the elements of the Recovery Package and there was confusion and misunderstanding over what this involved. The full Recovery Package is scheduled to be in place by 2020 (Macmillan Cancer Support, 2018) and the UK is currently in a transition period where different locations are implementing different elements at different times. Even though both study locations were taking active steps towards full implementation of the Recovery Package, participants did not report full access to all aspects of the Recovery Package. However, at a minimum, a detailed HNA, providing information on signs and symptoms of recurrence and a contact number should ensure patients know what to look out for and who to contact in the transition period. Terminology may also raise issues as there was confusion over what a HNA was and participants did not understand the nature of the health and wellbeing events. Clearer information and guidance is needed on how the elements of the Recovery Package fit together to support patients. Findings from this study indicate that it cannot be assumed that the Recovery Package will equip women with the information they need to self-manage and it is not clear if women will identify serious symptoms and know how to respond.

To date, there have been no published economic evaluations comparing hospital-based follow-up with PIFU for endometrial cancer patients. However, evidence is emerging that patient-initiated approaches result in fewer hospital appointments, whilst maintaining high levels of patient satisfaction, quality of life and clinical outcomes across differing conditions (Taneja et al., 2014). More work is needed in this area as the number of patients diagnosed with endometrial cancer is

likely to increase; 30-50% of endometrial cancers diagnosed worldwide are linked to lifestyle factors (Cancer Atlas, 2018) and more efficient services are needed that will reduce the number of hospital-based appointments.

Limitations

The generalisability of findings is limited by the small sample size and our sample size reflected a pragmatic approach to sampling within a defined study period. However, a sample size calculation using a confidence interval approach would have strengthened the arguments for and against feasibility in this study. Sample bias is evident as participants were well educated and from higher socio-economic groups (particularly at the London site), as well as being predominantly White British; not representative of the demographic makeup of the study locations. More work is needed to establish if more highly educated individuals are more confident to self-manage. Our sample was also not representative in terms of age. In the UK, incidence is highest in those aged between 75 and 79 years (Cancer Research UK, 2019). Although we recruited participants from a broad age range (34-79 years), the mean age was only 59.41 years and only three women were in the 70+ age group. Findings are subject to selection bias as the sample had already agreed to forego hospital-based appointments to take part in this feasibility study. Hence, this approach was arguably only suited to the small number who agreed to participate. Participants were asked a hypothetical question about trial participation and responses may not be predictive of actual behaviour in a real recruitment situation. The study was conducted over a short time frame and participants were aware that they would be returning to a hospital clinic for review at study end point. The addition of clinicians' perspectives would have been beneficial but was not within the remit of the reported study and should be considered in further work.

CONCLUSIONS

As health care services increasingly struggle to meet demand, alternatives to hospital-based follow-up need to be evaluated and PIFU is increasingly viewed as a more appropriate and efficient alternative to hospital-based appointments (Taneja et al., 2014). However, any alternative approach needs to demonstrate that patients feel well supported, knowing what symptoms to report and who to report them to. Our study aims were intended to address acceptability and feasibility. While we have support for acceptability to the small number of women who participated, we do not have strong evidence of feasibility in terms of being able to recruit to a fully powered RCT.

Conflict of interest

None declared

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Box 1. Semi-structured interview guide

- What do you think about the hospital-based approach to follow-up care for patients treated for endometrial cancer? (i.e. asking patients to come back to hospital outpatient clinics at regular intervals)
- Do you think this hospital approach has any advantages for patients?
- Are there any disadvantages?
- What do you think about the Recovery Package?
- Do you feel confident that you know who to contact if you have a problem?
- Have you had any problems or symptoms since you have been in the study? (if yes, what was the problem, who was contacted and what was the outcome)?
- What are your views on holistic needs assessments (i.e. a nurse asking you questions about your needs)?
- What are your views on treatment summaries being given to patients and their GPs?
- What are your views on health and wellbeing clinics?
- What are your views on the cancer care review at your GP practice?
- What sort of follow-up would suit you best if you could choose any sort of follow-up (reasons why)?

Table 1. Characteristics of the study sample

Variable	Both sites combined n=17		London (South East) site n=7		Preston (North West) site n=10	
Age (n=17)	n	%	n	%	n	%
<50 years	2	11.76	1	14.3	1	10.0
51-60 years	6	35.29	2	28.6	4	40.0
61-70 years	6	35.29	3	42.9	4	40.0
70+ years	3	17.65	1	14.3	1	10.0
Marital status (n=17)						
Married/co habiting/civil partnership	10	58.82	4	57.1	7	70.0
Divorced/separated	2	11.76	0	14.3	1	10.0
Widowed	1	5.88	1	0.0	0	0.0
Single (never married)	4	23.53	2	28.6	2	20.0
Employment status (n=17)						
Working full time	5	29.41	2	28.6	3	30.0
Working part time	1	5.88	1	14.3	0	0.0
Retired from work	8	47.06	2	28.6	6	60.0
Unemployed at present	2	11.76	2	28.6	0	0.0
Long term sick	1	5.88	0	0.0	1	10.0
Educational qualifications (n=17)						
Yes	14	82.35	5	71.4	9	90.0
No	2	11.76	2	28.6	0	0.0
Not sure	1	5.88	0	0	1	10.0
Socio-economic status[1] (n=15)						
1. Managers, directors and senior officials	0	0.00	0	0.0	0	0.0
2. Professional Occupations	7	46.67	4	66.7	3	30.0
3. Associate professional and technical occupations	2	13.33	1	16.7	0	0.0
4. Administrative and secretarial occupations	3	20.00	0	0.0	3	30.0
5. Skilled trades occupations	0	0.00	0	0.0	0	0.0
6. Caring, leisure and other service occupations	1	6.67	0	0.0	1	10.0
7. Sales and customer service occupations	0	0.00	0	0.0	0	0.0
8. Process, plant and machine operatives	0	0.00	0	0.0	0	0.0
9. Elementary occupations	2	13.33	1	0.0	1	10.0
Ethnic group (n=17)						
White	16	94.12	6	85.7	10	100.0
Indian	1	5.88	1	14.3	0	0.0
Completed measures						
Completed baseline (T1) measures	17	100.00	7	100.00	10	100.00
Completed follow-up (T2) measures	14	82.35	7	100.00	7	70.00

[1]based on Standard Occupational Classification, Office of National Statistics [12]. Data were collected on current or previous occupation if the participant was retired from work. Two retired participants did not provide information on previous occupation

Table 2. Preferences for follow up at T1 (n=17) and T2 (n=12)

Type of follow-up	Like a lot/like		Neither like/dislike		Dislike/dislike a lot	
T1	%	n	%	n	%	n
A mix of hospital and telephone appointments depending on how I feel at the time	58.82	10	41.18	7	0.00	0
Early discharge from hospital with the Recovery Package	58.82	10	23.53	4	17.65	3
Follow up appointments with my GP	58.82	10	23.53	4	17.65	3
Telephone appointments with a specialist nurse	58.82	10	23.53	4	17.65	3
Hospital appointments with either a doctor or nurse	47.06	8	41.18	7	11.76	2
Hospital appointments with a doctor	41.18	7	47.06	8	11.76	2
Hospital appointments with a specialist nurse	41.18	7	47.06	8	11.76	2
Telephone appointments with either a doctor or nurse	41.18	7	41.18	7	17.65	3
Follow-up appointments with a nurse at my GP practice	41.18	7	23.53	4	35.29	6
Telephone appointments with a doctor	35.29	6	41.18	7	23.53	4
Text messages only	23.53	4	23.53	4	52.94	9
No follow up	5.88	1	17.65	3	76.47	13
T2	%	n	%	n	%	n
Early discharge from hospital with the Recovery Package	58.33	7	16.67	2	25.00	3
Follow up appointments with my GP	58.33	7	16.67	2	25.00	3
A mix of hospital and telephone appointments depending on how I feel at the time	50.00	6	33.33	4	16.67	2
Hospital appointments with a specialist nurse	50.00	6	16.67	2	33.33	4
Telephone appointments with a specialist nurse	50.00	6	25.00	3	25.00	3
Follow-up appointments with a nurse at my GP practice	50.00	6	5.88	1	41.67	5
Telephone appointments with either a doctor or nurse	41.67	5	33.33	4	25.00	3
Telephone appointments with a doctor	41.67	5	33.33	4	25.00	3
Hospital appointments with a doctor	33.33	4	50.00	6	16.67	2
Hospital appointments with either a doctor or nurse	33.33	4	33.33	4	33.33	4
No follow up	16.67	2	33.33	4	50.00	6
Text messages only	5.88	1	16.67	2	75.00	9

Table 3. EORTC QLQ-C30 subscales at T1 and T2

	Mean score T1 (n=14)[1]	**Mean score T2 (n=14)**	**t**	**df**	**P**
Global health status/ quality of life					
Global health status and quality of life	70.24	73.81	-1.104	13	0.290
Functional scales					
Physical functioning	84.29	86.19	-0.409	13	0.689
Role functioning	82.14	95.24	-2.474	13	**0.028**
Emotional functioning	84.52	92.26	-1.509	13	0.155
Cognitive functioning	84.52	89.29	-1.000	13	0.336
Social functioning	86.90	97.62	-1.883	13	0.082
Symptom scales/single items					
Fatigue	22.22	15.08	1.351	13	0.200
Nausea and vomiting	1.19	2.38	-0.563	13	0.583
Pain	17.86	7.14	1.883	13	0.082
Dyspnoea	11.90	11.90	0.000	13	1.000
Insomnia	9.52	7.14	1.000	13	0.336
Appetite loss	9.52	4.76	1.472	13	0.165
Constipation	16.67	7.14	1.170	13	0.263
Diarrhoea	7.14	11.90	-0.806	13	0.435
Financial difficulties	7.14	9.52	-1.000	13	0.336

[1] Although 17 participants completed the T1 measures, we analysed data for complete sets of data that were completed at both T1 and T2

Table 4. EORTC QLQ-EN24 subscales at T1 and T2.

	Mean score T1	Mean score T2	N	t	df	P
Functional Scales						
Sexual interest (item 49)	7.14	9.52	14	-0.434	13	0.671
Sexual activity (item 50)	4.76	7.14	14	-1.000	13	0.336
Sexual enjoyment (item 54)[1]	66.67	33.33	2	1.000	1	0.500
Symptom Scales						
Lymphoedema (items 31-32)	10.26	23.08	13	-2.540	12	**0.026**
Back/pelvis pain (item 33)	17.95	33.33	13	-1.585	12	0.139
Urological symptoms (items 34-37)	24.36	26.28	13	-0.294	12	0.774
Gastrointestinal symptoms (items 38-42)	13.33	14.36	13	-0.313	12	0.760
Tingling/numbness (item 43)	0.00	12.82	13	-2.132	12	**0.054**
Muscular/joint pain (item 44)	23.08	35.90	13	-1.806	12	0.096
Hair loss (item 45)	0.00	7.69	13	-1.000	12	0.337
Taste change (item 46)[2]	2.56	2.56	13	-	-	-
Body image problems (items 47-48)	8.33	5.95	14	1.482	13	0.165
Sexual/vaginal problems (items 51-53)[1]	5.56	0.00	2	1.000	1	0.500

[1] Items 51-54 to be answered if sexually active during past 4 weeks
[2]the t value could not be computed because the standard error of the difference was zero