

ENDCAT Qualitative paper

Target journal; EJONS

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

Authors: S Williamson, K Beaver, A Gardner, P Martin-Hirsch.

Background

Endometrial cancer is the sixth most common female cancer worldwide (WCRF 2016) and the most common gynaecological cancer in developed countries (CRUK 2014). Most endometrial cancers are diagnosed at an early stage with a five-year survival rate of over 91% (WCRF 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 & 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 & 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) 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 & 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 & 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 2014). 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 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 & Clarke 2001, Sekse 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.

Aim

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

Methods

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.

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.

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.

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.

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 & 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.

Findings

Sample characteristics were representative of the 259 trial participants and are presented in Table 1. Most participants were receiving follow-up consultations 3-4 monthly (Table 1). CNS's from all five study sites were interviewed. Patient and CNS views of TFU were positive; all patient participants stated a preference for TFU and all CNSs wanted to continue to provide TFU. Three themes emerged from the patient interviews; Convenient Care, Discrete Personalised Care and Confidence and Reassurance. The themes arising from the CNS interviews were Patient Centred Care, Holistic Care and, Confidence and Skills.

Patients Views

Convenient Care

TFU was more convenient for patients than HFU. Patients did not have to rely on, or feel they were inconveniencing relatives or friends who would usually take them to hospital appointments, which promoted independence. Punctual appointments made it easier for patients to organise their day

and they did not need to arrange time off work or, for some, arrange care for dependents. Some participants mentioned their relief at no longer having the economic and physical burden of travelling while most mentioned how stressful they found trying to find a car parking space at the hospital.

Well we couldn't park and we were driving round and round and round, eventually he had to go and park on a retail park ... and then he [husband] came back and had to find me in hospital you know. Oh it was terrible, so based on that the telephone I mean you're sat in your own home it's much better...and she's [CNS] always bang on time. (ID235)

...my daughter had to get time off work and she's on the district team across a busy area and I thought that was good cos it'll spare [daughter's name] getting time off work. (ID 10)

it's got many advantages you can take the phone call at work you, you don't have to go down there [hospital] do other things you know, so from a personal point of view it is a time saver. (ID158)

The patients were not anxious as a result of no longer going to the hospital for appointments or foregoing a physical examination. They were confident that their gynaecology-oncology surgeon would not have supported TFU if it would be detrimental for them and had confidence that TFU with the CNS would elicit any potential problems. Others felt it was a waste of their time going to the hospital for a follow-up appointment when they felt well, indicating that this group of patients felt confident in their ability to self-manage.

I mean it's a waste of time if you're feeling fine, it seems a waste of time going. (ID11)

So it's easier for me to answer the questions and watch myself for anything that might change. (ID 184)

Discrete Personalised Care

The patients felt TFU provided them with privacy that they perceived was not available at their hospital appointments. If relatives accompanied patients to appointments, it could be difficult to broach sensitive issues or answer questions of a personal nature. For others, the busyness of the hospital clinics and seeing a male doctor inhibited them.

I could ask her like intimate things. Which I, no way I would of ever asked [doctor's name]. As lovely as he is and he was lovely. (ID142)

...she was sat here [daughter] and um, I felt I couldn't talk about some of the questions, um sexual health questions so I just said to her you know oh it's the telephone clinic today so don't come up... (ID 235)

None of the patients minded being asked questions that they perceived as intimate and personal even though they might not have initiated such a conversation. All welcomed the opportunity to discuss issues relating to sexual function or attractiveness even if they did not currently have a partner or were no longer having a sexual relationship with their partner.

I've not got a fella but I thought, you never know, I always live in hope (ID137)

I mean even though my husbands died and um I've not got a partner but you know I just thought I wonder if I've, would you get feelings now that you know, you've had a hysterectomy? (ID142)

Patients felt that TFU provided the opportunity for them to ask questions and that they shared information with the CNS's over the telephone that they would not have shared in a hospital appointment. They felt that TFU provided them with care and information that was tailored to their needs. Whilst patients recognised that hospital clinics were busy, it made them feel that they were on a conveyor belt being processed through the system. Many felt that the clinical examination was a priority at their hospital appointments and that, in contrast to TFU, they were not provided with opportunities to discuss or ask questions about issues that were important to them.

You know she [CNS] answers questions and asks things about, ... and tells me different bits of information so yeah I think going to the hospital you're just concentrating really on the examination and there's so many people there. That you're just a number really aren't you... Whereas with [nurse's name] it's a more personal, it feels more personal um so it's more individual, it's nice. (ID184)

...in hospital it was so um, you know in and out. Quite frankly I think the phone probably elicited more information out of you than, than the hospital would have done... there is something that people will, if there's no faces involved, will be more frank perhaps, perhaps it's the anonymity. (ID29)

Confidence and Reassurance

Patients found TFU reassuring and said they found it easier to self-manage than when they were receiving HFU. While a clinical examination that detected no abnormalities was reassuring, with TFU patients had responsibility for reporting symptoms and concerns. The patients found the structure of the intervention and the repetition of the questions beneficial. They felt the intervention acted as an aide memoire and ensured that the CNSs assessment of their needs, or any symptoms they might have noticed, was thorough.

I think sometimes with your telephone one you've more time if you're worried about something, to talk to somebody individually whereas the hospital you feel as though you know it's, it's, you're on a conveyor belt. It's get you in and get you out. (ID 36)

“Well to me the telephone was, was more, was easier because I could, I was in charge of myself if you know what I mean.” (ID 64)

Participants were confident that if they had a concern they would be given the time to discuss it as their appointments were about them and their information needs. Although patients described the staff at their hospital appointments as “kind” or “lovely” nonetheless they felt they were busy and not able to establish trusting relationships required to provide personalised care. No longer having a face to face consultation or physical examination did not worry these patients and they felt confident that they would be referred back to the hospital if they had a problem.

...it’s a good thing because I’m at my ease at home. And um, if I have any problems I can discuss them and then I can be referred to whoever. (ID179)

I would certainly prefer not to go into the hospital, it’s harder for them in hospital because they’re seeing so many people one after the other. I don’t know how many minutes they give you but whatever it is they’re not in the practice of establishing a relationship. Um, in hospital it’s very much tied up to the examination and they blow in and they fiddle around and they blow out. (ID29)

CNS Views

Patient Centred Care

Before participating in the ENDCAT trial only two of the CNSs had routinely provided hospital nurse-led follow-up for patients who had completed treatment for endometrial cancer. The nurses who did not routinely provide HFU indicated that they only saw patients at follow-up appointments at a doctors request. Since conducting TFU the CNSs realised that patients would not always inform the doctor that they had a problem, either because they felt uncomfortable broaching a sensitive issue or because they felt they were not given the opportunity.

...our priority in a clinic is often the new patients coming through, so you don’t always get to see the follow-up patients coming through, unless they actually report a problem to the doctor...but you’re reliant on the patient actually bringing something up with the doctor, that they may not always do... (CNS 05)

Although 20 minutes was allocated to TFU, nurses found the majority of patients reported no problems and the appointments were usually quite short. They were confident that repeating the questions at the next appointment provided the patients with another opportunity to discuss an issue that they might not have been ready to discuss yet.

“...the previous appointment might have been a short one but then they’ll bring something up the next time...the patients know the questions, know what you’re gonna ask them and

actually they are doing very well and they don't have any, any issues, and perhaps they feel a bit more comfortable with it as well, with a telephone follow-up, but yeah sometimes you do get a surprise, you look at their previous appointment and you think that was all fine and then they just then ask something about the diagnosis or the cancer or something like that.” (CNS 05)

All the nurses felt that the structure of the intervention helped the patients to prepare for their appointments. It also provided reassurance that nothing would be missed and patients were given time to talk about anything that was concerning them. CNS's reported that they frequently had to provide information or send out leaflets to patients who had previously experienced HFU.

“...when you initially see a patient you're giving her lots of information and at follow-up you don't tend to give out very much information cos they've had everything... whereas I've had quite a few ask, I've sent, I've sent out pelvic information, I've sent out diet recipes all, you know and also on eating, what else have I sent out, one was a support group information, which she had initially I know she had initially, but she wanted more information and all that, so yeah probably sending out more to the long term follow-up's than I would give if we were in the hospital.” CNS 04

The CNS's felt that TFU enabled them to build a relationship with the patients and that this helped the patients to have confidence in them. They found that patients discussed issues on the phone that they did not usually talk about in a hospital clinic and perceived this was because patients were trusting of the developing relationship.

“sometime maybe they tell us more on the telephone perhaps cos they can't see us they may expand a little bit more.” (CNS 06)

Holistic Care

The CNSs felt that using the intervention and asking patients about their physical and psychosocial needs at every TFU appointment was possibly more time consuming than relying on patients to be proactive and ask for information. However, they all felt their provision of TFU using the intervention enabled them to assess and meet patient's holistic needs. The CNS's felt that TFU was an opportunity to conduct a HNA using the intervention as a guide. Until delivering TFU and having the opportunity to enquire about patients' information and support needs following treatment, some acknowledged that they had not appreciated how important the HNA was in order to provide personalised care.

“I concentrate on the new patients and then patients all have my number and they'll ring me if they've got a problem, so because of the limitations of time I don't do holistic needs on follow-up patients.” CNS 02

"I think because we've had that proforma [intervention] to go through it has, as a learning curve for me personally it's made me realise the holistic assessment is very important..."CNS 06

Other ways in which the CNSs felt that TFU met patients' individual needs was the choice of location of follow-up. This was entirely in the control of patients and the CNSs perceived that patients chose to have TFU in convenient locations. They perceived that patients seemed relaxed during TFU even though some chose to have their appointments at work and others seemed quite happy to have TFU in public places.

"and I've had [laughs] probably a couple of patients that have been in the most strange place and have still wanted to answer the questions when I've phoned them like in the coffee shop which to me didn't seem appropriate because of the questions I was asking, but they've still wanted to do it, and I phoned somebody and she was on the bus and I said I, you know I really think I need to phone you back and, but she would have been quite happy [laughs] to answer the question on the bus now, I suppose that's her, but yeah so I've had a couple of those." (CNS 05)

Some of the nurses felt uncomfortable and conflicted about asking questions relating to sexual function and attractiveness and suggested they were unnecessary. However, they all acknowledged that the patients did not mind and, in some instances, were grateful that the issue had been broached. Moreover, they recognised that patients information needs changed over time and that it was important to ask the questions even if that made them personally uncomfortable because the patient may have a new partner in their lives.

"...and to be honest at first I felt slightly uncomfortable asking you know, an eighty year old lady how she felt with her own sexual function and her body awareness, and it was me who felt more uncomfortable than she did at the, or than the patients did, at the beginning, but they would talk quite openly ... I've got one of the ladies who comes to my support group and she's spoke to me more about it, about she said I'm glad you brought it up on the phone clinic..." (CNS 02)

"I mean I know we say we've got to ask, we've got to talk about it to everybody but, I don't know it's just something that you do with patients sometimes and sometimes it's just, but I don't think you have to ask all the questions about the sex bit." (CNS 01)

"...you have to ask the question because it may be something that's bothering them and you know it, things may have changed, they may have got a new partner." (CNS 06)

Confidence and Skills

All the CNS's felt that they had the skills and knowledge to provide TFU for patients but that they had lacked confidence initially. During the training in delivering the intervention they had thought

that repeating the questions at each appointment was unnecessary and solely for the purposes of retaining the integrity of the intervention for the ENDCAT trial. However, they all said that not only had the intervention helped them to assess patients holistic needs outside the trial but they would continue to use the same format when the trial finished. The CNSs initial concerns that they might not be able to answer the questions posed by patients or that patients would prefer to attend hospital to see a doctor were unsubstantiated. The nurses felt that they fully utilised their skills whilst providing TFU and that their initial concerns about missing the non-verbal cues of a face to face consultation were unfounded. Their knowledge and ability to listen were key components in gaining the trust and confidence of patients.

"I mean I thought it was a really good idea but you just kind of, in your head, in your nursing head you kind of think that the patients want to see the doctor and they want to get examined but then when you actually do it, it actually works really well as long as you do it in a proper setting, use a nice quiet room, not disturbed, you can give your full attention to the patient and it's, the more you do it, at first you're a bit clinical with the questions and the template that you've got, once you've done it a few times it's really good and it's really natural and you actually just feel like you're having a nice chat so it's good." (ID 01)

"I think initially you kind of think am I going to miss any cues you know the non-verbal communication, but actually you get quite astute at picking up changes in voices and things when you've spoke to them and ask more searching questions." (ID 06)

The nurses enjoyed the autonomy that providing TFU gave them and wanted to continue with it when the trial finished. They knew from feedback they had received from patients that they valued their TFU appointments; the structured approach of the intervention would make it suitable for other gynaecology oncology patients.

"I love it, I think it yeah, I think it's really, really good I, I really enjoy and I look forward to doing the clinic and once the trials finished I certainly will carry on with it and I will see other patients as well I so I will be extending the clinic to, to suit all gynae patients rather than just endometrial." (CNS 02)

"I still get as much job satisfaction I guess by talking over the phone as being in the clinic...I think it's probably because there is time to ask all those questions and you are kind of doing more of an holistic assessment than you are doing with a routine follow-up's in the clinic." (CNS 05)

Discussion

That patients found TFU convenient and less stressful than hospital follow-up and that nurses enjoyed providing TFU has been reported previously (Beaver et al 2010, Kimman et al 2010, Williamson et al 2015). Furthermore, some patients in this study regarded going to the hospital for follow-up, when they felt it was not necessary, as a waste of their time, suggesting that a more

flexible approach to follow-up would suit these patients who demonstrated confidence in their ability to self-manage. None of the patients interviewed minded the repetition of the questions in the intervention and valued the opportunity to access information and support when they needed it. This is corroborated by the findings from the nurse interviews, which indicate that the structured nature of the telephone intervention effectively assessed patients holistic needs, enabling provision of information to patients at relevant time-points. This illustrates the importance of such questioning not becoming a tick box exercise, as using routine standardised questioning has been found to have a negative impact on patients if needs identified are not then addressed (Ahmed et al 2014). The UK's Achieving World-Class Cancer Outcomes Report (DoH 2015) recommends that the care of people living with and beyond cancer should be tailored to individual needs and that the Recovery Package and stratified care pathways be rolled out as quickly as possible. However, until all elements of the recovery package (HNA, treatment summary, cancer care review, health and wellbeing clinics) are embedded into practice and, in the UK, funding secured for patient centred rather than face to face HFU, this may take time to happen outside of research studies (Davies & Batehup 2011, Frew et al 2010, Jefford et al 2013).

It has been suggested that CNSs should play a pivotal role in meeting the psychosocial needs of patients and their roles should be examined more closely to ensure that their skills are being utilised effectively (DoH 2010, Macmillan 2014). As CNSs report feeling over-burdened and unprepared for providing complex psychosocial support for patients (Maguire & Pitceathly 2003, Jenkins et al 2010, Biddle et al 2016) it would be premature to advocate TFU as a suitable alternative for all. Although Biddle et al (2016) reported patients being unwilling to discuss psychosocial difficulties with CNSs, TFU appears to provide an environment conducive to discussions about psychosocial difficulties. Supporting people to regain control of their lives following treatment for cancer will be problematic unless CNSs and patients feel comfortable and confident having conversations relating to psychosocial issues. The CNSs providing TFU were clear that, whilst they might have felt uncomfortable, patients appreciated the opportunity to receive information and discuss sensitive issues such as sexual wellbeing. Notably, patients stated that the relaxed nature and privacy afforded by TFU made it easier to discuss psychosocial and sexual difficulties with CNSs and this has been reported previously (Beaver et al 2010, Williamson et al 2015).

There is a growing body of evidence that the needs of cancer survivors are complex and are not being met through traditional hospital outpatient follow-up appointments. Importantly, information needs to enable self-management, are not being met at appropriate time points in their care pathway. The CNS's who routinely provided HFU were surprised at the information patients requested whilst receiving TFU as they had provided this information at diagnosis. Moreover, as

those patients who were interviewed felt that TFU helped them to regain a sense of normalcy and manage themselves it is worth considering that alternative models of follow-up such as TFU could be more beneficial than HFU to some groups of patients.

Implications for Practice

This study adds to the growing body of evidence that patients at low risk of recurrence receiving TFU, whose information needs are met, have confidence in their ability to self-manage and confidence that systems are in place for rapid access to hospital care if necessary. Furthermore, CNSs observed that asking patients about their information needs at each appointment frequently resulted in them repeating advice or re-sending leaflets months and years after provision of new patient information-packs. This has implications for workforce planning as recognition needs to be afforded to the growing body of evidence that many patients have psychosocial information and support needs for some years following treatment which can be effectively met by CNSs. In addition, CNSs need training and support to enable them to feel confident in the provision of psychosocial support for patients (Olsson et al 2012, Moore et al 2013).

Limitations

The study was conducted in the North West of England so the geographical and social diversity of the UK was not completely represented. The sample of patients who agreed to be interviewed were White British and, had also agreed to be randomised so the views of those patients with different cultural or social backgrounds who had not agreed to participate are unknown. Whilst the range of educational attainment in the sample was broad, most were well educated and thus more likely to report problems (Jeppeson et al 2017).

Conclusion

The findings from this study suggest that a flexible appointment pattern could be taken with patients who have been treated for endometrial cancer at low risk of recurrence. Patients found that TFU with CNS's was convenient, provided in an environment of their choosing and enabled discussion of issues and information provision at relevant time-points. The CNS's found that using a structured format enabled them to utilise their skills and knowledge and identify and meet patients holistic needs. Alternative models of care such as structured TFU provided by CNS's are effective, do not cause distress and assist self-management but thus far have only been tested following the appointment pattern of HFU.

References

- Ahmed N, Ahmedzai SH, Collins K, Noble B, (2014) Holistic assessment of supportive and palliative care needs: the evidence for routine systematic questioning. *BMJ Supportive & Palliative Care* 2014;0:1–9.
- Baekelandt MM, Castiglione M; on behalf of the ESMO Guidelines Working Group. Endometrial carcinoma: ESMO clinical recommendations for diagnosis, treatment and follow-up. *Ann Oncol* 2009; 20(suppl 4): iv29–31.
- Beaver K, Bogg J, Luker KA (1999) Decision-making role preferences and information needs: a comparison of colorectal and breast cancer. *Health Expectations*. 2. 266-276
- Beaver K, Campbell M, Williamson S, Procter S, Sheridan J, Heath J, et al. An exploratory trial comparing telephone and hospital follow-up after treatment for colorectal cancer. *Colorectal Dis* 2012;14:1201–9.
- Beaver K, Williamson S, Sutton C, Hollingworth W, Gardner A, Allton B, Abdel-Aty A, Blackwood K, Burns S, Curwen D, Ghani R, Keating P, Murray S, Tomlinson A, Walker B, Willet M, Wood N, Martin-Hirsch P. (2016) Comparing hospital and telephone follow-up for patients treated for Stage I endometrial cancer (ENDCAT Trial): a randomised, multicentre, non-inferiority trial. *BJOG: an international journal of obstetrics & gynaecology*. DOI: 10.1111/1471-0528.14000. (IF 3.728) ISSN 1470-0328
- Beaver K, Tysver-Robinson D, Campbell M, Twomey M, Williamson S, Hindley A, et al. Comparing hospital and telephone follow-up after treatment for breast cancer: a randomised equivalence trial. *BMJ* 2009;338:a3147.
- Beaver K, Williamson S, Chalmers K. (2010) Telephone follow-up after treatment for breast cancer: views and experiences of patients and specialist breast care nurses. *Journal of Clinical Nursing* 19(19); pp 2916-2924
- Biddle L, Paramasivan S, Harris S, Campbell R, Brennan J, Hollingworth W, (2016) Patients and clinicians experiences of holistic needs assessment using a cancer distress thermometer and problem list: A qualitative study. *European Journal of Oncology Nursing* 23. 59-65
- Cancer Research UK. *Cancer incidence for common cancers 2015*.
- Davies NJ, Batehup L (2011) Towards a personalised approach to aftercare: a review of cancer follow-up in the UK. *J Cancer Surviv* 5: 142–151.
- Department of Health (2007) Cancer reform Strategy
- Department of Health (2010)
<http://www.macmillan.org.uk/documents/aboutus/commissioners/excellenceincancercarethecontributionoftheclinicalnursespecialist.pdf> (Accessed October 2017)
- Department of Health (2013). *Living With and Beyond Cancer: Taking Action to Improve Outcomes*
- Department of Health (2015). *Achieving World-Class Cancer Outcomes. A Strategy for England 2015-2020. A report of the Independent Cancer Taskforce.*

Ekwall, E., Ternestedt, B-M., Sorbe, B (2003) Important aspects of Health care for Women With Gynaecologic Cancer: *Oncology Nursing Forum*. **30**:2. 313-319

Foster, C., Fenlon, D., (2011) Recovery and self-management support following primary cancer treatment. *British Cancer* 105, 521-528

Frew G, Smith A, Zutshi B, Young N, Aggarwal A, Jones P, Kockelbergh R, Richards M, Maher EJ (2010) Results of a quantitative survey to explore both perceptions of the purposes of follow-up and preferences for methods of follow-up delivery among service users, primary care practitioners and specialist clinicians after cancer treatment. *Clin Oncol* 22: 874–884.

[Jefford M](#), [Rowland M](#), [Grunfeld E](#), [Richards M](#), [Maher J](#), [Glaser A](#) (2013) Implementing improved post-treatment care for cancer survivors in England, with reflections from Australia, Canada and the USA. *Br J Cancer*. Jan 15; 108(1): 14–20.

[Jenkins K](#), [Alberry B](#), [Daniel J](#), [Dixie L](#), [North V](#), [Patterson L](#), [Pestell S](#), [North N](#). (2010) Beyond communication: the development of a training program for hospital and hospice staff in the detection and management of psychological distress--preliminary results. *Palliative and Supportive Care*. 8(1):27-33.

Jeppesen M M, Mogensen O, Hansen D T, Iachina M, Korsholm M & Jensen P T (2017) Detection of recurrence in early stage endometrial cancer – the role of symptoms and routine follow-up, *Acta Oncologica*, DOI:[10.1080/0284186X.2016.1267396](https://doi.org/10.1080/0284186X.2016.1267396) (Accessed October 2017)

Kew FM, Roberts AP, Cruickshank DJ. The role of routine follow-up after gynaecological malignancy. *Int J Gynecol Cancer* 2005;15:413–9.

Kimman ML, Bloebaum MMF, Dirksen CD, Lambin P, Boersma LJ (2010) Patient satisfaction with nurse-led telephone follow-up after curative treatment for breast cancer. *BMC Cancer*. 10. 174-183

Knowles G, Sherwood L, Dunlop MG, Dean G, Jodrell D, McLean C, Preston E (2007) Developing and Piloting a nurse-led model of follow-up in the multidisciplinary management of colorectal cancer. *European Journal of Oncology Nursing*. 11. 21-223

Lajer H, Jensen MB, Kilsmark J, Albæk J, Svane D, Mirza MR, Geertsen PF, Reerman D, Hansen K, Milter MC, Mogensen O. *International Journal of Gynecological Cancer* 2010; 20:8, 1307-1318

Lewis R, Neal RD, Williams NH, France B, Wilkinson C, Hendry M, Russell D, Russell I, Hughes DA, Stuart NSA, Weller D (2009). Nurse-led vs. conventional physician-led follow-up for patients with cancer: systematic review

Lewin S, Glenton C, Oxman AD (2009) Use of qualitative methods alongside randomised controlled trials of complex healthcare interventions: methodological study. *British Medical Journal*. 339: 3496 doi:[10.1136/bmj.b3496](https://doi.org/10.1136/bmj.b3496)

Macmillan (2011) *Cancer Clinical Nurse Specialist: An evidence review*

<http://www.macmillan.org.uk/Documents/AboutUs/Research/ImpactBriefs-ClinicalNurseSpecialists2014.pdf> (Accessed October 2017)

Maguire P & Pitceathly C. Improving the psychological care of cancer patients and their relatives: The role of specialist nurses. *Journal of Psychosomatic Research*. 2003. 55; 469–474.

Maughan K and Clarke C (2001) The effect of a clinical nurse specialist in gynaecological oncology on quality of life and sexuality. *Journal of Clinical Nursing*. 10:2 221-229

Mistry A, Wilson S, Priestman T, Damery S, Haque MS (2010) How do the information needs of cancer patients differ at different stages of the cancer journey? A cross-sectional survey. 1-10

Moore, A., Higgins, A. Sharek, D., 2013. Barriers and facilitators for oncology nurses discussing sexual issues with men diagnosed with testicular cancer. *European Journal of Oncology Nursing*, 17(4), pp. 416-422.

Morse JM, Field PA (1998) *Nursing research: the application of qualitative approaches* (2nd ed.) Cheltenham: Stanley Thornes.

Olsson, C., Berglund, A., Larsson, M. Athlin, E., 2012. Patient's sexuality – A neglected area of cancer nursing? *European Journal of Oncology Nursing*, 16(4), pp. 426-431.

Pennery E. Mallet J (2000) A preliminary study of patients perceptions of routine follow-up after treatment for breast cancer. *European Journal of Oncology Nursing*. 4: 138-145

Saldana J. (2009) *The Coding Manual for Qualitative Researchers*. Los Angeles. Sage

Sekse RJT, Raheim M, Blaka G, Gjengedal E, (2012) Living through gynaecological cancer: three typologies. 21, 2626-2635

Shenton, A.K., 2004. Strategies for ensuring trustworthiness in qualitative research projects. *Education for Information* 22, 63e75.

Stead, M.L., Brown, J.M , Fallowfield, L, Selby, P. (2003) Lack of communication between healthcare professionals and women with ovarian cancer about sexual issues. *British Journal of Cancer*. 88, 666-671.

Tariman JD, Doorenbos A, Schep KG, Singhal S, Berry DL (2014) Information needs priorities in patients diagnosed with cancer: A systematic Review. *Journal of the Advanced Practitioner in Oncology*.5. 115-122

Tjalma WAA, Van Dam PA, Markar AP, Cruikshank DJ. The clinical value and the cost-effectiveness of follow-up in endometrial cancer patients. *Int J Gynecol Cancer* 2004;14:931–7.

Reis N, Kizilkaya Beji N, Coskun A, (2010) Quality of life and sexual function in gynaecological cancer patients: Results from qualitative and quantitative data. *European Journal of Oncology Nursing*. 14:2, 137-146

Wells M, Donnan PT, Sharp L, Ackland C, Fletcher J, Dewar JA (2008). A study to evaluate nurse-led on-treatment reviews for patients undergoing radiotherapy for head and neck cancer. *Journal of Clinical Nursing*. 17, 1728-1439

Williamson S, Chalmers K, Beaver K (2015) Patient experiences of nurse-led telephone follow-up following treatment for colorectal cancer. *European Journal of Oncology Nursing*.19: 237-243

World Cancer Research Fund International <http://www.wcrf.org/int/cancer-facts-figures/data-specific-cancers/endometrial-cancer-cancer-lining-womb-statistics> (Accessed October 2016)

Table 1**Sample characteristics of interview cohort (n=25)**

Age at recruitment to ENDCAT trial	Median 67	Range 52-82
Marital status	Number	Percent
Married/co-habiting/civil partnership	19	72%
Divorced/separated	1	4 %
Widowed	3	12 %
Never married	2	8 %
Ethnic Group		
White	25	100%
Employment status		
Full time	2	8%
Part time	3	12%
Retired	18	72%
Long term sick	1	4%
Never worked	1	4%
Qualifications		
No formal qualifications	5	20%
O/A Level	16	64%
Vocational	5	20%
Diploma/Degree	8	32%
Follow-up status at recruitment to trial		
3-4 months	17	68%
6 months	7	28%
12 months	1	4%
Months from Diagnosis		
1-12 months	13	52%
14-43 months	12	48%