Kent and Medway Cancer Collaborative

Follow Up for Gynaecological Cancers

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GYNAECOLOGICAL CANCER FOLLOW-UP

Guidelines

1.0 Background

Traditionally, gynaecological cancer patients are followed on a regular clinical review schedule in outpatient clinics, generally for a period of 5 years. Follow-up regimes vary across Kent & Medway, but generally involve regular review on a 3 – 4 monthly basis during the first 2 years, followed by 6 monthly or annual review to a total of 5 years. In most places within the region, follow-up is uncoordinated between different disciplines of the multi- disciplinary teams. Some patients are seen regularly in cancer unit follow-up clinics, cancer centre gynaecological follow-up clinics and clinical oncology follow-up clinics, producing a large number of uncoordinated visits to various hospitals.

Cancer follow-up has been addressed by clinicians in other cancer site specialities, and there are a number of publications which questioned the value of regular follow-up for gynaecological oncology patients. British publications in follow-up in endometrial, cervical and vulval carcinoma have suggested there may be little or no benefit from regular follow-up. It has also been suggested that regular routine clinic follow-up may even be harmful for patients in terms of delaying their presentation for review at the onset of symptoms suggesting possible recurrence and also in terms of anxiety caused by attendance in the clinic. Unfortunately there is no high quality evidence as to the value of follow-up in gynaecological oncology. A multi-disciplinary multi-centre research proposal to assess the value of follow-up in comparison to patient initiated follow-up, in the form of a large randomised control trial, has unfortunately failed to obtain the necessary funding. Several local clinical trials are presently being run within the United Kingdom to assess innovative forms of follow-up but in the absence of the power required to identify benefit of one form or the other in terms of survival, detection of recurrence or quality of life, these studies perhaps should best be viewed as feasibility and acceptability studies for alternative forms of follow-up.

The alternative model of follow-up proposed in these studies is a patient initiated follow-up, in which detailed patient information is provided at an “exit” interview at the end of the episode of care (i.e. the clinic visit shortly following the completion of surgery, chemotherapy or radiotherapy). This consultation and the accompanying written information aims to educate the patient regarding symptoms suggestive of possible disease recurrence. She is given contact details to a nurse specialist and is encouraged to telephone at any time to discuss any concerns she may have regarding symptoms suggestive of recurrent disease or potential treatment related side effects. In response to a call from the patient, the nurse specialist triages the patient appropriately, for urgent review by clinicians in a follow-up clinic, to the general practitioner, to a specialist service such as a lymphoedema clinic, or perhaps initially lists the patient for discussion in the multi-disciplinary team meeting. This model of care appears very attractive as it empowers patients and enables them to access care at short notice when required. It also helps patients to progress beyond the “sick role” as soon as they have recovered from treatment. Unfortunately, at the present time, effectiveness of this model remains unproven.

The British Gynaecological Cancer Society (BGCS) has published guidelines (June 2019) on patient initiated followup (PIFU) for patients with endometrial, ovarian and cervical cancers, who are at low risk of recurrence.

The following purposes of follow-up were discussed and agreed via the Tumour Site Specific Group (TSSG) and subsequently the Non-Surgical Oncological Group (NOG)

1) Detection of disease recurrence:

   The intention is that regular clinic follow-up may enable early detection of disease recurrence. Depending on the disease site, stage and previous treatment, early detection

of recurrence may improve the chance of salvage (ie disease cure). It was generally acknowledged that disease recurrence beyond 3 years post treatment is extremely uncommon in any gynaecological oncology disease sites.

2) Symptom management:

Gynaecological cancer follow-up clinics enable expert management of symptoms associated with treatment side effects as well as symptoms of active disease.

3) Patient reassurance:

Some patients definitely feel that they benefit from regular "check-up" and are reassured when no evidence of recurrent disease is identified. Clearly, however, another group of patients appear to be psychologically harmed by follow-up, developing very real anxiety during the days and weeks preceding clinic appointments.

4) Outcome Data:

Regular review in follow-up clinics enables accurate outcome data to be measured. However, documentation of gynae oncology patient status on a cancer database is not presently performed on a routine basis anywhere within the network.

5) Benefit to clinicians:

It was widely acknowledged that oncology clinicians benefit from reviewing successfully treated patients in clinic. These patients "brighten" oncology clinics. Trainees also benefit from seeing living proof of effective cancer treatments.

It was acknowledged that the advent of the clinical nurse specialist within gynaecological oncology teams has provided a resource which until several years ago was unavailable within Kent. Most patients develop a relationship with the clinical nurse specialist before and during their period of treatment and therefore find the nurse specialist to be a very appealing link with the clinical team. It was agreed that this resource needs to be harnessed and incorporated into management guidelines for gynae oncology patients within the network.

2.0 Proposal

It was agreed by the TSSG that at the present time, in the absence of quality evidence, we should not dispense with the strategy of routine regular follow-up clinic reviews for the majority of gynaecological oncology patients. Instead, it is proposed to rationalize the schedule of routine clinic reviews, and supplement this with an integrated model of patient initiated follow-up, along the lines described above. Each patient would carry a care diary in which the nurse specialist or clinician would clearly document the proposed follow-up protocol.

2.1 The minimum standard routine clinic review regime would be as follows:

Endometrial

1. Adjuvant stage 1 and 2. Discharge to surgical follow up
   NOTE: post TAH patients who have MDM recommendation for further nodal surgery or consideration of radiotherapy AND decline both imaging at 6 mths and 18 mths post operative, unless clinical indication for earlier.

2. Stage 3c1:
   - 1 year follow up CT
   - 2 year follow up CT
3. Stage 4 clinical follow up as felt appropriate

The BGCS recommends-
Patients initiated follow-up (PIFU) for five years from treatment for the following:

- low risk (<10% risk of recurrence ROR) from end of treatment HNA by 3/12
- Intermediate risk (10-20% risk of recurrence)- offer from end of treatment or 2 years for all
- High risk (>20% risk of recurrence)- offer from 2 years from end of treatment

Remote/telephone based follow up for the following:
- Intermediate risk up to 2 years and
- high risk up to 5 years in place of CBFU (clinic based follow-up)

Clinic based follow-up for the following:
Intermediate risk up to two years
High risk up to 5 years in the place of remote follow-up

Cervical

Primary Surgery:
MRI – at 6 months post-surgical treatment

Primary Chemo-radiotherapy:
Alternate oncology follow up with surgical follow up
Follow up Imaging:
1. Patients with minimal/ no residual tumour on MRI at week 5 of chemoradiotherapy. Consider follow up MRI at 3-4 months post Chemo -Radiotherapy
2. Patients with significant residual tumour on MRI scan at week 5 of chemoradiotherapy. Follow up MRI and PET Scan to be done 3 months from last brachytherapy insertion, prebook date for hysterectomy 4 months from last brachytherapy insertion (pending results of follow up scans and MDM discussion).

The BGCS recommendation for follow-up in cervical cancer is as follows:

Patient initiated follow-up to be offered for five years from treatment to low risk patients (<10% of recurrence) from 2 years post treatment. This excludes patients who have had fertility sparing surgery or LLETZ.

Clinic based follow up is recommended for intermediate and high risk patients.

Ovary

1. Disease free post adjuvant, 3- 6 monthly alternate oncology/surgical follow up.
Individual clinician based guided by clinical history examination and CA125 as felt clinically appropriate
2. Disease present – as per clinical guidelines for follow up
3. Aim alternate oncology and surgical follow up

Initial post treatment clinic review (eg 6 weeks post-op, post chemotherapy) Patients may need to attend each of these in turn.
6 months post-completion of treatment.
12 months post-completion of treatment.
18 months post-completion of treatment.
30 months post-completion of treatment.
42 months post-completion of treatment.

Where patients have undergone treatment by more than one speciality (eg surgery and chemotherapy), the routine scheduled clinic appointments will generally alternate between follow-up clinics. Ideally, multi-disciplinary follow-up clinics will be established and patients will be reviewed within these joint clinics at every visit.

A formalized patient information interview would be held at the end of treatment, at the post treatment clinic appointment if not before. Formalized disease specific patient information would be provided at this time, with contact details for the nurse specialist, to be used in the event of disease or treatment related concerns or symptoms. A nurse specialist would be able to arrange for the patient to be reviewed at any time on an urgent basis in a follow-up clinic when required, in addition to the standard regime as described.

BGCS recommendation for follow-up of ovarian cancer patients is as follows:

Offer patient initiated follow-up for five years from treatment for the following group of patients:

- **Low risk** (<10% risk of recurrence: stage 1a/b fully staged) from end of treatment (surgery +/-chemotherapy). This excludes patients who have had fertility sparing surgery.

Offer remote/telephone based follow-up to the following group of patients:

- For FIGO stages 2-4 give patients the option of standardised remote follow-up for years 4&5 post first-line treatment completion (clinic based follow-up 1-3 yrs)

Offer clinic based follow-up for patients with FIGO stage 2-4 ovarian cancer.

- 1-3 years clinic follow-up and if suitable & elects, remote follow-up for years 4 & 5
- 1-5 years if not suitable or declines remote follow-up for years 4&5

2.2 Exceptions:

2.2.1 Very Low Risk Patients

It was agreed by the gynaecology GNAT that the following specific patient groups do not require any structured routine clinic reviews beyond the initial post treatment appointment. Disease recurrence in

these particular patient groups is so rare, it was agreed that integration of these patients into long term routine follow-up is perhaps more likely to be harmful than beneficial, causing unnecessary anxiety and prolongation of the “sick role”.

1) Endometrial cancer FIGO stage 1A grade 1/grade 2

2) Adequately staged FIGO stage 1 ovarian tumours of borderline malignant potential.

   - These 2 groups should be managed with patient initiated follow-up alone.

3) Carcinoma of the cervix, FIGO stage 1A1

   - These patients should be managed as per high grade CIN under the NHS CSP cytology guidelines.

2.2.2 Other carcinoma of the cervix

1) Carcinoma of the cervix.

   - MR at 6/12 post radical surgery/chemo-radiation

2.2.3 Clinical Trials

Patients involved in clinical research and trials should undergo follow-up as prescribed by the trial protocol. They should also be offered “patient initiated follow-up” as described above, unless it contravenes the trial protocol.

2.2.4 Disease and Treatment Related Morbidity

Review in follow-up clinic will remain available on a basis of need. In addition to patient initiated review, more frequent review can be initiated by any members of the multi-disciplinary team on the basis of need. For example, patients with treatment-related morbidity may require frequent regular review in a follow-up clinic, and would therefore deviate from the standard protocol described above.

2.2.5 Patient Concerns including Psychosexual Advice

It is widely recognised that an amount of Follow Up should be delivered by the CNS Team. This allows for issues to be discussed/dealt with that would not otherwise as easily be addressed. This includes psychosexual issues as a result of treatment.

3.0 Revision History

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April 2016	1.1	Amendments noted following consultation with CNS' and review of all content	A.Papdopoulos
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