Meeting of the SWAG Network UGI / HPB Site Specific Group (SSG)

Friday 15th May 2015 at The Academy, Holiday Inn, Bristol City Centre, 12:30-16:30

This meeting was sponsored by Pfizer and Celgene

Chair: Mr Richard Krysztopik

Notes

(To be agreed at the next SSG meeting)

1. Welcome and apologies

Please see the separate list of attendees and apologies uploaded on to the South West Strategic Clinical Network website here.

2. Administrative update

As there were no amendments or comments following distribution of the minutes from the meeting on the 9th December 2014, the notes were accepted.

A retrospective application for the meeting to be CPD accredited will be made to the Royal College of Physicians. Attendees are to complete the evaluation form provided for this to be validated.

The recent Be Clear on Cancer National Oesophago-Gastric Cancer campaign was noted to have been a success, significantly increasing OGD referrals. The extra workload was managed by organising extra lists.

3. The Somerset Cancer Registry

Please see the presentation uploaded on to the SWSCN website

Presented by Catherine Donnelly and Saiwah Man

The Somerset Cancer Register releases updates twice yearly in line with any changes that are required to be made to the National audit datasets. The SCR are contractually bound to prioritise this work stream before all other product developments, one of which will be implementation of the National HPB audit. The new high grade dysplasia dataset will be upgraded by November 2015. A biopsy section will be included, and ambiguous fields, such as the ‘not known’ options will be removed. This National audit upload is due in October, so users of the SCR will be a month behind. It was felt that the new dataset would significantly increase the workload of gastroenterologists. Projects are currently underway to create interfaces between the SCR and different information systems so that data on chemotherapy, radiotherapy, pathology and PAS will be automatically imported into the registry. An e-tertiary referral function has
also been developed that will allow demographic, diagnosis and referral information to be transferred between Trusts SCR systems. In the near future, UH Bristol and Taunton will be pilot hospitals for testing the second phase of this project. Further product developments are to be planned over the next 5 to 10 years in collaboration with clinical teams. Members of the UGI / HPB SSG were invited to join the SCR working groups to ensure that any site specific requirements are designed into the register in a way that supports the SCR user’s standards of record keeping.

A new intuitive NOGCA user guide is currently being developed. It will be updated with the frequently asked questions obtained from the user helpline. Members of the group were invited to provide feedback on the guide.

In order to extract data from the SCR, the SCR user needs to be granted access to the reports / data view function which, once logged into the system, should appear as a tab. This can be arranged by sending a request to the employee’s Cancer Manager to change the user permissions associated with an individual’s login. From the data view screen, every data field that is entered into the register can be manipulated to create different reports. There are 6 UGI specific report templates. These can be filtered to check for data completeness and used for audits. Webinars that explain how to do this are available on the SCR website. The group was asked to inform Catherine Donnelly (CD) if any additional data fields or interfaces were required. The SCR was written in a language that allowed data to be transferred to other IT systems.

The MDT Coordinator at UH Bristol frequently runs a report to check for missing data fields and completes this with support from the Clinical Nurse Specialists (CNSs).

Read only access to other Trusts’ SCR systems can also be made available by requesting the relevant user permissions.

4. Radio Frequency Ablation (RFA) for Low Grade Dysplasia (LGD)

Please see the presentation uploaded on to the SWSCN website

Presented by Dan Titcomb (DT)

Gloucestershire Hospitals have already instigated the process of RFA provision for LGD. The importance of identifying and treating patients with dysplasia in as timely a way as possible to prevent the possibility of undergoing an oesophagectomy was emphasised. SSG members viewed a video (available on YouTube) that showed how treatment is delivered using HALO technology. This involves inserting a catheter which is attached to a radiofrequency generator into the oesophagus. The catheter has a small balloon which is then expanded. A controlled dose of heat is then administered which removes the diseased tissue. Patients are re-examined 6 weeks later, and the procedure is repeated if diseased tissue is still present. David Hewin (DH) is in the process of writing local guidelines for the procedure. DT is currently the only surgeon performing this procedure in UH Bristol.

Results from the 31 people treated at Bristol Royal Infirmary (BRI) revealed that it was possible to ablate 92% of patients in one procedure. A couple of patients required a
repeat procedure after one year. Three of the 31 patients had disease progression and required an oesophagectomy. Two patients developed strictures, and one patient had chest pain that resolved shortly after the procedure. NICE guidelines published this year recommend that patients with LGD are offered ablation, but this is currently not commissioned. The commissioners advise that it should only be offered to the patients that would have otherwise been offered an oesophagectomy. There are 4 patients under surveillance with LGD that would be eligible for the procedure. The number of LGD patients eligible for ablation across the region is to be determined. While surveillance of the patients is to continue in the short term, some patients have been discharged from follow up as they no longer have Barrett’s disease.

The risk of a cancer nodule developing under the squamous cell was raised. A patient would be deemed unsuitable for the procedure if there was any doubt that a nodule might be present. Follow up data on patient outcomes will be available from the USA in the near future.

Gloucestershire Hospitals have similar data to the BRI results, but conduct the treatment under sedation rather than general anaesthetic.

The MDTs will work collaboratively to agree referral criteria for RFA.

5. Chemo-radiation

Please see the presentation uploaded on to the SWSCN website

Presented by Stephen Falk

Brachytherapy:

The Brachytherapy service commenced in UH Bristol four months ago. The procedure provides a palliative treatment option by ablation of diseased tissue with high dose radiotherapy directly into the oesophagus wall. The top and bottom of the tumour are clearly marked prior to the procedure to minimise the exposure of healthy tissue to the dose. Ablation is achieved in one application. There is a rare potential for the treatment to result in haematemesis. Two research trials that compared brachytherapy with stent placement have shown that long term relief from dysphagia was better and incidence of complications were reduced in the patient groups treated with brachytherapy. Patients who are unsuitable for radical surgery or chemotherapy who have a reasonable swallowing capacity, and would otherwise later require a stent, are eligible to be referred. It would replace the use of external beam therapy which involves 5-10 treatments over 11 hospital appointments. The results of the treatment are very similar when comparing the responses of both squamous and adenocarcinomas.

Neoadjuvant chemo-radiation prior to curative surgery:

The research trials OE 05 and ST 03 are due to be published by ASCO in 2015. Both are well designed trials that will lead to informed advances in the management of oesophago-gastric cancer.
In the OE 05 trial, 897 patients were randomised between 2005 and 2011 by 72 UK centres. Patients would receive either the standard chemotherapy treatment, or a more aggressive regime, to determine whether increasing the amount of chemotherapy given prior to surgery improved overall survivorship. The results will be fed back to the group.

After publication of the results of the MAGIC trial recommending peri-operative chemotherapy for gastric tumours, the ST03 trial assesses the safety of adding bevacizumab to the chemotherapy regime. For safety reasons, the trial now excludes patients with lower oesophageal cancers.

The results of the CROSS trial confirmed that chemo-radiation prior to surgery for resectable oesophageal cancer can prolong survival. RO resection was achieved in 92% of patients in the chemo-radiation plus surgery group, compared with 62% in the surgery alone group. Patients in the chemo-radiation arm were given weekly carboplatin and paclitaxel as opposed to the more established regimen. It may be that there will be a shift to trimodality in the future, but there is a need to continue to be subjective until further evidence has been analysed. All eligible patients are to be offered entry into the following trials in order to help establish the correct treatments:

- DEBIOC
- CROSS v MAGIC
- ST03 sub-study.

6. The use of pancreatic enzyme replacement therapy

Please see the presentation uploaded on to the SWSCN website

Presented by Georgina Giebner

A case study was presented that highlighted the importance of utilising pancreatic enzyme replacement therapy (PERT) to manage patients’ symptoms, and improve outcomes. It had been found that the dose prescribed needed to be increased to ensure that patients benefited from the treatment. The recommended starting dose was 25,000 units, with 2-3 of the capsules to be taken with each meal, and 1-2 with snacks and milky drinks. Results of the research trial Survival of patients with unresectable pancreatic cancer: Impact of the treatment of pancreatic exocrine insufficiency and malnutrition, has shown that treatment with Creon significantly lengthens survival by approximately 7 months. The following patient groups should also be considered for treatment with PERT:

- Loss of Pancreatic tissue
- Asynchrony of enzyme delivery
- Changes to pH of gut
- Loss of neural pancreatic stimulation (changes in gastric fundus function)
- Abnormal/altered Cholecystokinin release
- Obstruction of pancreatic anastomosis.
Any post UGI surgery patient should be considered for the treatment. There is a faecal elastase test that can establish who requires it. It is pork based, but has been approved by a High Imam for Muslim patients.

7. The normal unpleasant psychology of cancer treatment and recovery

Please see the presentation uploaded onto the SWSCN website

Presented by Mike Osborn (MO)

There is a need to dispel folk beliefs, and cultural ideas associated with cancer, to assist patients in managing their expectations as, frequently, confusion and negative self-critical feelings emerge, such as guilt and shame about the time they are taking to recover, adding to the unpleasant experience that has been inflicted upon them during treatment.

Processing the psychological effects of cancer treatment often only begins once treatment has finished, and people may hide how they are feeling about it to protect the people around them. The burden on the brain caused by undergoing chemotherapy, known as ‘chemo fog’, can undermine everyday confidence. The intense fatigue, which is the inevitable, primal, protective reflex response to anxiety, plus metabolic fatigue, is unavoidable. People often think that they need to push through the fatigue using will power, which only results in increasing the levels of fatigue. The presentation contains pictorial representations of the different kinds of emotions that people might experience. What can help with this is to be prepared for what is to come, and realise that feeling some or all of these emotions is a normal, inevitable consequence which requires managing with a flexible approach. Patients are to be encouraged to treat themselves with the same patience, compassion, respect and dignity that they would give to a friend, and look forward to some kind of comfort and of peace of mind in the future.

The ideal time to broach this subject with patients should be guided by the information that they want and can absorb at a given time, given in a candid, open and honest manner. When people are seen very intensely during treatment, and then move into follow up, they often feel very lost. Health and Wellbeing days can help with this, but more are needed, and often some people need more individual care. To assist with spreading the message of the normal unpleasant psychology of cancer, MO has developed films that can be prescribed to patients, prior to moving into follow up, in the hope that treating misery can become routine. Access to the films can be granted by emailing MO. These are going to be available on the Macmillan website in the near future, but it would be more beneficial to prescribe for a patient via direct contact rather than direct them to a link on a website.

8. The pancreas pathway, potential changes and developments

Meg Finch-Jones (MF-J)

Mandatory completion of a dataset for a quality indicator dashboard relating to HPB services is now required following the decision to commission the service on a
nationally basis. The dataset, which is surgically oriented, has been submitted for 2014 / 15. In the future, the data fields need to be added to the SCR to improve the data collection process. The adenocarcinoma criterion was removed when calculating many of the required denominators, as this would have skewed the results by the elimination of non-histological reported cases. There were issues with recording the bilirubin data due to the units of measure being incorrect. Suggestions for improvements to the dashboard for next year were submitted. It was not currently possible to identify the correct number of patients with colorectal liver metastases that were discussed at MDT due to the way that things were coded on the SCR. This information is now being collected on a weekly basis.

The results showed that the mortality rate at UH Bristol is lower than the national average, but the majority of patients were admitted with jaundice and were therefore not flagged for managing within the 62 day cancer waiting time target. The current time to treatment was around 100 days. Issues with the capacity of the service need to be identified and improved. The process of referrals to the HPB service will be simplified to address any delays that may be caused by referring between MDTs. The patient’s pathway from referral onwards will be audited by Tom Walker, who would require a Consultant UGI surgeon to sponsor him. Sponsorship by RUH was agreed. The current two week wait (2WW) referral form was not adequate and should be separate from the Upper GI 2WW form. MF-J will send a revised version to Helen Dunderdale (HD) to circulate. Waiting for MDT meetings to occur should not slow down the decision making as decisions could be made outside the meeting. For example, the mechanism for referring a patient for an EUS is to speak to a member of the MDT.

Simulation training will be provided for CNSs and Junior medical staff on how to accept referrals and ensure that all the correct information is collected and properly disseminated.

Date of next meeting: 29th January 2016

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