

## Ylva Hellstadius: final report- EONS Research Travel Grant 2013

### Report on visit to St Thomas's Hospital, London, and ongoing research

#### Emotional distress following oesophageal cancer surgery

My thesis entitled '*Emotional distress following oesophageal cancer surgery*' at Karolinska Institutet in Stockholm aims to investigate the development of anxiety, depression and post-traumatic stress symptoms (PTSS) following a diagnosis of oesophageal cancer and during curatively intended treatment. The thesis includes data from a large nationwide clinical cohort study, *The Swedish Oesophageal and Cardia Cancer study (SECC)*, collected in Sweden between 2001 and 2005. Data from an ongoing large prospective cohort study at St Thomas' hospital in London, UK entitled *Guy's and St Thomas' Gastric and Oesophageal Tissue and Data Bank (GSTT)* is also being used. The database in London provides longitudinal high quality data on self-reported measures of anxiety, depression and PTSS, outcomes of greatest importance for my thesis.

The European Oncology Nursing Society (EONS) made it possible for me, by their generous financial support, to travel to London, UK, to undertake a 10-week research exchange at the Department of Upper Gastrointestinal Cancer Research, St Thomas' Hospital, as one of the recipients of the *EONS Research Travel Grant 2013*. The research exchange was successfully carried out and I have learned so much more than I could have imagined when I initially planned the research exchange in spring 2013. The outcomes from this invaluable learning experience are outlined in this final report.



**What is known about emotional distress in oesophageal cancer patients?**

Oesophageal cancer is a devastating disease with an extremely poor prognosis<sup>1</sup>. At diagnosis, only 25 % of patients are considered fit enough to survive curatively intended treatment<sup>2</sup>. The curatively intended treatment to date includes neo-adjuvant treatment in combination with extensive surgery<sup>3</sup>. Oesophagectomy, the removal of the whole gastric tube and the upper part of the stomach, is a highly demanding surgical procedure and the only chance of cure for these patients. Even after curatively intended surgery the risk of death from tumour recurrence is high<sup>4</sup>. The literature investigating emotional distress following oesophageal cancer surgery is limited<sup>5</sup> even though indications of the psychological trauma experienced by patients diagnosed with oesophageal cancer have been published recently<sup>6</sup>. A handful of studies have found elevated symptoms of anxiety and depression from the time of diagnosis and throughout the first year of illness<sup>7,8</sup>. One recent large-scale representative cohort study, included in my thesis, showed that approximately 50% of patients who undergo surgery for oesophageal cancer report problems with emotional distress 6 months post-operatively<sup>9</sup>. These problems also appear to persist in the majority of patients even after 5 years. Despite these findings, the emotional distress experienced by oesophageal cancer patients during curatively intended treatment is an area of research that has received little attention thus far. Therefore, high quality data including longitudinal assessments of emotional distress in this vulnerable patient group is highly warranted in order to contribute to a new body of evidence and reduce patient suffering. Such data is available in the GSTT cohort at St Thomas' hospital in London.

### **Purpose of the research exchange**

The purpose of the research exchange was to participate in the ongoing data collection that my research group in Sweden (Surgical Care Science) runs together with the Department of Upper Gastrointestinal Research at St Thomas' hospital in Central London. The work included taking part in the clinical data collection: that is, approaching patients and seeking consent, administering self-report measures and collecting blood and tumour tissue during surgery. This work provided full insight into all details of this comprehensive data collection. The work also included data cleaning and data entering to put together a full dataset for one of the studies included in my thesis. I also participated in clinical work with the oesophageal cancer patients treated at St Thomas' Hospital in order to broaden my clinical knowledge about the assessment, treatment and management of oesophageal cancer.

### **Description of the ongoing data collection**

Patients willing to participate in the study are assessed by a comprehensive questionnaire including, for instance, measures of anxiety, depression and PTSS to be filled in by the patients at baseline (on the day before surgery). Patients are then followed up with self-reported questionnaires posted to their homes at 6, 12 and 36 months following surgery.

The collection of data at St Thomas' Hospital is unique due to the number of oesophageal cancer cases treated at the hospital, the administration of the data collection (two full-time research coordinators are employed), the comprehensive collection of information on patient and tumour characteristics, as well as the ongoing collaboration with the clinical network at St Thomas'. Since 2013, the data collection has been included in a large network of high-quality clinical cohort studies including oesophageal cancer data, carried out in the UK and coordinated by Cambridge University.

### **Exceptional learning experience**

#### ***High volume centre***

St Thomas' Hospital is one of the highest volumes centres in the world regarding oesophageal cancer surgery, with a yearly rate of 100 surgical cases. Thus, the oesophageal cancer team at St Thomas' Hospital including surgeons, nurses, oncologists, dieticians and research coordinators represents a unique source of competence and knowledge. To have the opportunity to be a part of the team and follow the patients from referral to discharge has been highly significant for my understanding of oesophageal cancer and the continuation of my thesis work at KI.

#### ***Curatively intended pathway***

Patients on a curatively intended treatment pathway are regularly assessed in the outpatients' clinic at St Thomas' Hospital before surgery, during the neo-adjuvant treatment and later up to 5 years post-surgery. During these appointments they frequently meet the surgeons, oncologists, dieticians and specialist nurses. The team supports them with appropriate interventions during their treatment pathway as well as the post-operative phase, which can be highly demanding. At the oncological assessments of the patients during neo-adjuvant treatment, I witnessed how the patients struggled with eating difficulties and loss of appetite, which often resulted in adverse weight loss. The demanding procedure of undergoing neo-adjuvant treatment could sometimes postpone the scheduled surgery due to complications caused by the chemotherapy or the fact that the patients were too fragile after the treatment.

This vulnerable situation was difficult for the patients and their relatives and appeared to trigger strong feelings of anxiety.

Attending theatre and observing the extensive procedure of an oesophagectomy has given me a new perspective of the extremely demanding treatment of oesophageal cancer. One patient I followed during his stay at St Thomas' told me when he woke up at the intensive care unit (ICU) following surgery, that the best way he could describe how he felt was "having been run over by a bus". Further, the clinicians, the patients and the relatives often underlined the severe post-operative battle that followed the surgery. Firstly, the risk of medical and surgical complications and later the struggle back to an everyday life where everything was different from before. The patients and their relatives explained the continuous overhanging threat of disease recurrence and the anxiety before the post-operative assessments such as x-ray and endoscopy. A few patients described the feeling of depression that usually came a few months following surgery when the treatment was finished and they had to adapt to a totally new life situation. I am sincerely grateful to EONS who made it possible for me to share all these experiences with the patients and their relatives.



## **Outcomes from the research exchange**

### ***Preliminary results***

Preliminary results from the data I entered during my research exchange to St Thomas' Hospital showed that up to a third of the patients reported anxiety and about a fifth reported depression at baseline. Women appeared to be more anxious and those of poorer physical status seemed to be more depressed. These patients were assessed on the day before surgery (baseline) using the self-report questionnaire the *Hospital and Anxiety and Depression scale*

(HADS). The preliminary results indicate that patients with oesophageal cancer are affected by emotional distress (i.e. anxiety and depression) before curatively intended treatment and it may be that psychological interventions are needed at this early time point. However, large, representative longitudinal studies are needed to clarify the course of emotional distress from diagnosis up to several years post-treatment to investigate at what time point additional psychological support is most required.

### ***Combining qualitative and quantitative data***

Large scale studies using self-reported questionnaires when screening for psychological outcomes have provided us with a broader picture of a situation. They have enabled us to draw conclusions on a group level and facilitated generalisation of the results to other groups with similar characteristics in a comparable context. However, at the same time we miss some important information, namely, the individuals' variability. When we care for people in the clinic we consider the patient's individual needs and adjust our interventions according to the person in front of us. Unfortunately, the patients' perspective is to some extent excluded when we use large data sources and calculate psychological outcomes on mean score levels. I therefore encourage that all quantitative studies investigating psychological outcomes in larger groups, should be combined with a qualitative study. Consequently, when we combine methods and different sources of data, we will benefit from richer information about a problem or phenomenon and we can interpret the data in a fuller way. The problem with losing the individuals' variability is a valuable experience I take with me from the research exchange in London. It will be a future challenge for me to bring forth the 'patients' voices' behind the numbers.

### ***Measuring emotional distress – the challenge***

The last valuable outcome I experienced during the research exchange that I will mention in this report is the challenge of assessing emotional outcomes with pre-defined questionnaires. During my time in the outpatients' clinic and the ward where the patients stayed before surgery, I continuously experienced a high proportion of the patients and their relatives expressing feelings of fear, anxiety and depressed mood. These emotions were rarely captured in the questionnaires and could, to some extent, explain the rather low proportion of patients reporting anxiety and depression at baseline in the preliminary results presented above. I discussed this issue with the research-coordinators who administer the questionnaires, and with the clinical team, who confirmed my observation.

However, a questionnaire used to screen for emotional outcomes in the clinic needs to be suitable for the clinical context where it is used. This usually requires a rather short questionnaire that the patient finds easy to understand and fill in themselves. At the same time it needs to be valid and capture the emotional status of the patient. Yet screening tools for emotional distress used in the clinic for research purposes do not have to be comparable to clinical interviews yielding a diagnosis of mood disorders. At the same time, when psychological variables more often are included as outcomes in cancer research, a further discussion about appropriate assessments in the field of emotional distress in cancer patients would be highly beneficial.

In conclusion, I send my sincerest thanks to EONS who made it possible for me to complete this valuable research exchange and for believing in my research about emotional distress in oesophageal cancer patients. I would also like to express my warmest thanks to Janine Zylstra and Sarah Stone, research manager and research coordinator at the upper GI team at St Thomas' in London, for taking care of me and making my research exchange very successful. Also, a special thank you for their excellent work with the data collection.

### **Current status**

- I will be presenting the outcomes of my 10-week research exchange to London during the EONS-9 conference in Istanbul on 19 September 2014.
- The preliminary results mentioned in this final report have been summarised in a manuscript entitled '*Risk factors for emotional distress among oesophageal cancer patients prior to surgical treatment*' and will be submitted to a scientific journal during autumn 2014.
- I will visit the department in London again in June 2015 and enter the longitudinal data for the two last studies included in my thesis, enabling me to complete my thesis at Karolinska Institutet in Stockholm by December 2016.

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