Clinical research coordination: a non-traditional health information management role

Tammy Corica

Since graduating in 1999 with a degree in health information management, I have worked in a ‘non-traditional’ health information management role in radiation oncology, where I have had the good fortune to become involved in the design and implementation of an international randomised controlled trial. The aim of the trial was to determine whether an experimental once-off dose of radiotherapy delivered intra-operatively (IORT) would offer a non-inferior risk of cancer recurrence when compared to standard external beam radiotherapy (EBRT), which requires daily doses for six weeks. The trial was driven by doctors who wanted to improve treatment options for women with early, low risk breast cancer. Fast forward ten years: we have now published two key papers in the Lancet, suggesting that IORT can be considered a safe and effective treatment option. While this is a fantastic outcome, IORT will continue to be considered experimental in Australia until a Medicare item number has been granted. I hope my current work, within the scope of my PhD research, will contribute towards turning this aim into a reality.

My doctoral research is focused on investigating how patients (and to some extent, health professionals) feel about intra-operative treatment through a patient preference, quality-of-life and cosmetic outcome study. Some of my work has been published; some is still being churned through a statistical software package; and some data are simply waiting patiently for me to get to them! What is taking up most of my time at the moment is the ongoing data collection for the second phase of my patient preference study.

I am currently inviting women, those who have recently had breast-conserving surgery for early breast cancer, to complete a hypothetical patient preference and demographics questionnaire. The questionnaire is designed to find out what risk of breast cancer recurrence women would accept in order to have the more convenient experimental IORT in the place of standard EBRT. Sounds easy enough; but the challenge lies in inviting these women to complete the questionnaire on the day they have had their diagnosis of breast cancer confirmed post-surgery (or as close to this day as possible). This is naturally a tricky time; however, I need to approach the women as soon as this because the questionnaires need to be completed before they even meet with a radiation oncologist to discuss radiotherapy. Why? Because I need their unbiased answers. The questionnaires have detailed information about radiotherapy so they can make their decision based on consistent information.
I, therefore, need to build strong relationships with the breast surgery teams (surgeons, nurses, administrators) in Western Australia. Each week, I screen the pathology results of women who have had breast-conserving surgery at one of the participating hospitals and identify those who may be suitable for the study. I then attend the multi-disciplinary breast meetings at each of the hospitals to request permission to flag the patient for the study (so that when she attends her post-operative visit, the surgeons and nurses can hand out preliminary information about the study). Then I await the patients’ responses: are they interested – yes or no? I contact those who are interested by telephone the next day to describe the study in more detail. If they are happy to proceed, I mail a questionnaire pack to them (with a reply paid envelope, and a decline card should they change their minds). It is imperative they receive the pack and have time to complete it before they see a radiation oncologist! If completed questionnaires have not been returned within one week, I telephone the patients to ensure the questionnaires arrived in time and to ask if they need assistance to complete them.

I have created a database to track the patients’ progress through each step of the process, and for entering the research data when the questionnaires are returned. The aim is to identify how accepting patients would be of the ‘experimental’ IORT if it was currently available as a standard treatment option, and whether there are any demographic drivers that assist them to make that decision. We hope that this will assist patients and their doctors to make better informed decisions when IORT becomes available in the future.

One of the most rewarding aspects of my work has been my involvement with the amazing, strong, brave and loyal research participants, whom I cannot thank enough for making themselves available for this research. I have thoroughly enjoyed the last 15 years and am looking forward with excitement to the next 15 years!