Helen Melling

CoRIPS Research Grant 165

£9,918 awarded

Title: AIRPORT: Assessment of Information Required by Patients Or relatives who have undergone radical lung Radiotherapy Treatment

Principle Aim

To audit the information and support needs of radical lung cancer patients on completion of their radiotherapy treatment, in order to optimise the content of our department's EoTD.

Primary research question

What information and support do radical lung radiotherapy patients and their carers need and want as they approach the end of radiotherapy?

Secondary research questions

How and when can we best deliver this information and support to patients?

Can we use this information to help develop national guidelines for an EoTD proforma?

Outcomes

The primary outcome is a patient and radiotherapy professionals' co-designed EoTD proforma to ensure the information and support given at the end of radiotherapy meets the needs of these patients.

The secondary outcome is to use this proforma to inform potential new national guidelines with regard to the content, format and delivery of information for EoTD.

Review of literature and identification of current gap in knowledge

Patient education is essential in today's radiotherapy department [1]. The ability for patients to ask and receive treatment information is paramount in order to reduce their distress and increase their compliance during their radiotherapy treatment [2]. This is even more important than ever due to plethora of information in the public arena (e.g. internet and social media) which may or may not be accurate. The ease of access and quantity of information should not be seen as an excuse for departments to minimise accurate tailored advice to our patients [3].

First day chats are used universally in radiotherapy departments throughout the United Kingdom [2]. The need for efficiency for increasing compliance by reducing the amount of wasted ‘machine time’ has driven the use of ‘first day chats’. Routine ‘first day chats’ are built into the patient pathway to enable patients to be informed and supported throughout their treatment, have specific preparation procedures explained to them and provide an opportunity to ask any outstanding questions [4, 5]. An ad hoc continuation of patient education on set may take place, providing a signposting mechanism for further medical intervention or support, depending on the needs of the patient. Unfortunately, this support and information ceases at the end of the treatment. Currently the use of ‘end of radiotherapy treatment discussions’ is not seen as a mandatory element in our radiotherapy pathway and the information given to patients varies tremendously.

It has been identified that patients need and want information at the end of their radiotherapy treatment, to provide them with the knowledge to react to and minimise the effect of any potential side effects. Davidson et al [6] eloquently highlighted the paucity of follow-up information given to radiotherapy patients:

‘. . everything was explained to me in detail about my treatment for the 13 weeks I would be receiving it. Nothing was mentioned as to what to expect after it was over. (A 56-year-old breast cancer patient)’ [6] page 88.

This sentiment has been recently re-emphasised in the Society of Radiographers’ ‘Patient public and practitioner partnerships within imaging and radiotherapy; Guiding principles’ document [7]:

‘I need to feel assured that when I leave I am not forgotten and that I am well-informed about what will happen to me next’ [7] page 4

The quantity and quality of information delivered to patients has historically been decided on by the treating clinicians [8]. ‘Medical paternalism’ is no longer appropriate nor fit for purpose in the 21st century [9]. Co-production of decision making tools and information giving, with the patient as the centre of this process, must now be seen to be the norm [8]. Despite this gap in the patient information being identified, little has been done to establish what is actually required by the patient [10].

Experience based co-design (EBCD) has successfully been used to improve patient services in a variety of scenarios [11]. Charlotte Weston (Royal Marsden Hospital, London) presented her experiences of EBCD to improve teenage cancer patients’ satisfaction at the 2018 UKRO conference in Liverpool. This two-way approach enhanced the patients experience and also enlightened the treating clinicians to exactly what the patient wanted/needed to know.

Methodology

Overview

This project has been deemed service evaluation by our Trust's Research and Innovation (R and I) department thus obviating the need for ethical approval. An email from the Trust's R and I department has been included with the completed application.

An audit of patient and carer experiences throughout and up to six weeks after their radiotherapy treatment pathway will be conducted. Common themes obtained from this will inform a new EoTD proforma which will be piloted in a similar group of patients. The results of this will be used to influence changes in patient pathways and help inform national guidelines.

Method

We will employ a mixed methods approach based on experienced based co-design methods, comprising of:

Work stream 1: Qualitative components (semi-structured interview)

A group of patients (n= 12) and their carers (n =6) will be asked to take part in a semi-structured interview to detail their experiences of the radiotherapy treatment. The patients will be recruited from the radical lung cancer follow up clinics at our hospital, six weeks after completing their radiotherapy. A purposive sampling strategy will be used for the interview study to approach a representational group of our patient demographics and to ensure Stereotactic Ablative Radiotherapy (SABR), chemo radiotherapy and conventional radiotherapy only treatments are represented.

Work stream 2: Quantitative component (questionnaire analysis)

A cross-sectional study of patients will be performed. A quantitative questionnaire exploring patients' (n=50) views based on the information provided in work stream one will be used.

Work stream 3: Delphi evaluation of the proposed proforma.

Evaluation of the proposed new information will be achieved by completing a Delphi evaluation using lung cancer patients (n = 12) and radiotherapy staff representatives (n= 12).

Recruitment process

Patients being treated radically for lung cancer will be identified using the report function of our radiotherapy software. These patients and their carers will be given patient information sheets on the study by the treating radiographers during their course of treatment. The patients and carers who have expressed an interest in participating in this audit will be approached by the study radiographers. Consent will be obtained despite this being an audit project. Our lung cancer support group and Patient Carers and Public Information (PCPI) group will be used to advertise this work at their various meetings. Patients suffering from any overt psychopathology will not be approached.

Sample size

Work stream 1: Twelve patients (dependent on data saturation) and six carers will be recruited to take part in a semi-structured interview. Selection of the sample size has been pragmatic due to the possible volume of data that could be obtained. If data saturation occurs, the number of subjects recruited will be reduced.

Work Stream 2: A questionnaire will be used to gain opinion from patients and carers regarding the proposed information. Fifty participants will be recruited over a four-month period. In our department 467 lung cancer patients are treated with radical intent (Department figures 2017). Our overall population of patients typically returns 40% of general departmental questionnaires which would suggest this number is achievable in this period.

Work stream 3: Twelve radiographers and 12 patient representatives will be invited to perform the Delphi evaluation.

Data collection method

Work stream 1: Semi structured interviews

Interviews will be audio-recorded and transcribed verbatim and take place in a private area of the radiotherapy department.

Work stream 2: Quantitative assessment of the proforma

Paper questionnaires will be used and participants and their carers invited to complete these in a quiet space in the radiotherapy waiting areas. Participants who wish to complete the questionnaire at home will be provided with a stamped addressed envelope to post their questionnaires back to the department.

Work stream 3: Delphi evaluation of the proforma

Online data collection (Bristol On Line Services) will be used to collect the staff and patient responses by evaluating the percentage of agreement on the content of the proforma. The option of a proxy will be available to those who are unfamiliar with on line computer surveys.

Data analysis

An experienced researcher (P Holch) will analyse the interview data using thematic analysis [12] method which has no alignment to an epistemology. The proforma will be subject to Delphi consensus methodology [13] where through a series of iterative stages, preference for the suitability of the content will be affirmed with staff and patient groups.

Quantitative responses on the newly developed EoTD proforma will be analysed descriptively using Statistical Package for Social Scientists (SPSS) providing a descriptive summary of frequencies and mean scores. Free text message will be collated and charted under themes.

Reliability and validity/credibility/ trustworthiness of data

Qualitative analysis: Inter rater-reliability on a sub section of the analysis will be achieved via consensus for identification of themes of qualitative interviews with a second researcher.

P. Holch, a published quantitative and qualitative researcher, will lead the analysis.

Quantitative descriptive analysis will be led by P. Holch and the thematic coding of free text comments will be agreed with a second researcher.

Endorsement and usability of the new proforma will be established through the Delphi consensus methodology where patient groups and radiotherapy staff will have the opportunity to endorse the final proforma.

Ethical implications of the study

This study has been deemed as service development by the Trust's R and I department and therefore ethical approval is not required (see attached). Despite this, all investigators in the study will have undergone good clinical practice (GCP) training and the evaluation will be conducted under ethical guidelines of informed consent and right to withdraw at any time.

Anonymity and confidentiality will be maintained and as members of staff are identifying patients they will ensure the approach to patients is appropriate at that time. All participants will be given a study number and will only be identifiable by that. Consent forms will be kept separately from study numbers in a locked cabinet, such that neither questionnaire nor interview participants can be identifiable.

We acknowledge that there is a potential for patients to become upset whilst reflecting on their treatment journey. All the investigators have specialised training /skills to enable them to assess and support patients through this and to signpost to specialist multidisciplinary services across the region. They have direct access to Clinical Psychology for regular clinical supervision and expert advice.

Potential impact

The development of the EoTD for lung radiotherapy patients will transform the content of these discussions locally in our department and we hope to translate lessons learnt for other cancer diagnoses within our radiotherapy department. We will be able to measure the immediate local impact of this intervention by auditing patients who have had their EoTD via the new proforma. We will also audit the number of telephone enquiries made to our review clinic by lung cancer patients to measure the frequency and content of the calls.

We intend to share our work with other radiotherapy departments nationally through existing networks and publications. The ultimate aim is to create the foundation for the development of national guidelines regarding the information provided to patients at the end of a course of radiotherapy treatment.

Dissemination Strategy

We will produce peer reviewed publications from our study for possible publication in Acta Oncologica (impact factor 3.156) and Radiography (impact factor 0.706). We will submit abstracts to both national and international radiographic conferences; UKRC, The Annual Radiotherapy conference and the European Society of Radiotherapy and Oncology conference. We will report back locally to our patient population via means of our departmental patient information screens, via leaflets in the waiting area and at our local PCPI groups.

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