

**David Finn**

**CoRIPS Research Grant 143**

**£5,997.25 awarded**

**Title:** Experiences of palliative care for patients with advanced lung cancer at the Edinburgh Cancer Centre

### **Principle Aim**

To examine palliative care given to patients with advanced lung cancer at the Edinburgh Cancer Centre. This gathering of patient experience and stories will allow us to explore themes of care and areas of unmet need for this patient group. This information is crucial to identify future areas of service development by identifying gaps in care, designing more efficient ways of working and most importantly tailoring care needs to the individual.

### **Primary research question**

What is the experience of care of patients with advanced lung cancer who are offered radiotherapy at the Edinburgh Cancer Centre?

### **Outcomes**

The project will evaluate the scope of the unmet need for care in patients with advanced lung cancer and in so doing a new model of care will be developed.

### **Review of literature and identification of current gap in knowledge**

For the two-year period 1 Jan 2014 to 31 Dec 2015, the most common stage of disease at diagnosis for lung cancer in Scotland was stage 4, which accounted for 46.2% of all lung cancer patients (ISD Scotland, 2016). At stage 4 the cancer has metastasised and this makes it much more likely that this patient cohort will at some

point follow the pathway to non-curative or palliative treatment and care options. Currently the palliative care pathway for lung cancer patients has not been formally evaluated for fitness of purpose or whether it meets the needs of the individual patients.

This means nearly half of all diagnosed lung cancer patients attending the Edinburgh Cancer Centre experience a care path that has little data pertaining to its fitness for purpose.

Adequate and timely patient centred palliative care is vital and has been shown to improve quality of life (QOL), reduce symptom burden and depression symptoms. Temel et al. (2016) found that early integrated palliative care interventions such as dedicated and regular contact with palliative care services, had a significant positive effect on QOL, as measured by the Functional Assessment of Cancer Therapy-General (FACT-G) scale. Baseline FACT-G scores for usual care vs early care were 77.79 and 78.84 respectively (mean adjusted scores) and over 24 weeks the early care score increased to 82.15 whereas the usual care saw a decrease (75.62). To evaluate mood and anxiety, patients completed Patient Health Questionnaire-9 (PHQ-9), which detects symptoms of major depressive disorders. Over the 24 weeks of care those receiving early interventions saw their scores drop (6.39 – 5.54) while usual care demonstrated an increase in depression (6.5 – 6.71)

In addition, multiple studies have demonstrated a strong association with patient-reported QOL and survival. Sloan et al. (2012) reported that patients with a clinically deficient scored (CDS) QOL (measured using the Lung Cancer Symptom Scale) had a median survival of 1.6 years vs 5.6 years for patients with a non-CDS-QOL. Similarly, Braun, Gupta and Staren (2011) found that every 10 point increase in global QOL (using EORTC core quality of life questionnaire) correlated with a 9% increase in survival. More specifically one randomized controlled trial by Temel et al. (2010) looking at early palliative care in patients with metastatic non-small cell lung cancer, found a positive correlation between early care and survival.

Patients given early palliative care intervention, as described previously, and measured using the FACT – Lung (FACT-L) scale, had longer median survival (11.6 months vs 8.9 months)

This project aims to collect data on current practice through means of exploring patient experience of care. NICE guideline CG121 section 1.6 addresses follow up and patient perspectives. In particular section 1.6.4 states that the opinions and experiences of lung cancer patients should be collected and used to improve the delivery of lung cancer services (NICE, 2017).

## **Methodology**

As we have no initial hypothesis, and the goal is information gathering, the project will adopt a Grounded theory methodology. Gathering qualitative data through interviews and diaries, the aim being to develop a theory around how current patient management influences patient experience and quality of care. Using a Grounded Theory approach will enable a model of current care to be identified from the emergent data. The use of interviews and observational methods such as patient diaries are well documented approaches to collect this data (Polgar & Thomas, 2013). In a study by Wu and McSweeney (2007) semi structured interviews were used in conjunction with diaries to gather rich data on patients experience of cancer related fatigue. The method fits the methodology as interviewing focuses the topic while providing the interactive space and time to allow the participants views and insights to emerge (Charmaz, 2014). Diaries allow for the collection of more quantitative structured data by allowing the participants to record variables of when, how and who they interacted with, and also allow triangulation of data from the interviews. Browall et al. (2016), used diaries to acquire data through a mixture of open ended questions and Likert scales to focus the participant on certain aspects of the event. In a similar way, the diary in this study can be used to focus the interview guide in the next round of data collection.

## **Potential impact**

If it is identified that there is an unmet need, literature points to the potential benefits of improved care through early integrated palliative care. Improved quality of life, less depression symptoms and even prolonged survival. The patient experience of this service will be enhanced.

A similar study which has led to such improvements in a neighbouring health board, also found a higher probability of patients dying at home, their preferred location. They also found hospital stays were reduced which led to significant cost savings (NHS Fife, 2016).

## **Dissemination Strategy**

On a local level the results of this study will be presented at the Edinburgh Cancer Centres Lung Team meeting and then the Radiotherapy management group as this is attended by all site specialist teams. The information will be shared with radiographer colleagues locally and then on a wider level to colleagues across the country at the UK Radiological and Radiation Oncology Congress.

A paper based on the study will be submitted to the journal Radiography and a summary of the work will be available to patients attending the clinics at the cancer centre.

Patient forums are also relevant as part of the dissemination strategy, and a presentation of the research will be offered to the Roy Castle Lung Cancer Foundation and the Scottish Government Health Service.

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