

CoRIPS Research Award 97

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**Palliative Radiotherapy for Bony Metastases: A qualitative, exploratory study of prostate patients and their families' expectations and lived experiences of palliative radiotherapy treatment**

**Awarded £3,800**

**Description of the project:**

[Palliative Radiotherapy for Bony Metastases: A Qualitative, Exploratory Study of Prostate Patients and Their Families Expectations and Lived Experiences of Palliative Radiotherapy Treatment.](#)

This study arose out of a perceived local need to involve patients, family and health professionals to review and improve the quality of the entire Radiotherapy experience offered when palliating painful bony metastases, as it has long been recognised that;

*'...if a patient needs palliative Radiotherapy, we can be fairly certain that Radiotherapy is not all the patient needs'<sup>1,p6</sup>*

[Principal aims of the study](#)

-To explore the lived experiences of prostate patients' and families throughout the palliative Radiotherapy pathway

-Consider how current Radiotherapy services can meet the needs and expectations of advanced prostate patients and their families

[Research Question](#) - How do advanced prostate cancer patients, their families and radiotherapy professionals perceive their experience of palliative radiotherapy treatment for bony metastases?

[Objectives](#)- Patient Issues (using diary and semi- structured interviews)

- Explore the patients' lived experience of receiving palliative Radiotherapy for the first time
- Establish patients perceptions of their expectations of palliative Radiotherapy
- Explore coping strategies employed by patients in the weeks following Radiotherapy

[Objectives](#)- Family/Friend issues (using diary and semi-structured interviews)

- Explore the psycho-social impact of accompanying a family member or close friend through the palliative Radiotherapy journey
- Identify the perceptions of family members on their personal needs and expectations of Radiotherapy treatment
- Explore coping strategies employed by family members in the weeks following Radiotherapy treatment

[Objectives](#)- Radiotherapy Professional Issues (via focus groups)

- To identify whether (and if so, how) Radiotherapy Professionals recognise needs and expectations in advanced prostate cancer patients and their families
- Establish perceptions of Radiotherapy professionals on current palliative Radiotherapy service provision and discuss possible service improvements

[Study Outcomes](#)

-Production of a report on the lived experience and expectations of palliative prostate cancer patients and their families when receiving Radiotherapy for painful bony metastases.

-Production of final thesis to submit towards a Professional Doctorate in Health.

[Literature Review](#)

Despite a 60 year history and widespread use, the optimum dose-fractionation regime to effectively palliate painful bony metastases remains controversial and is still the main focus of contemporary studies due to wide variations of treatment practice worldwide<sup>2-7</sup>. There is a stark lack of studies exploring the lived experiences of these palliative patients. Pain relief is typically used as the primary end-point<sup>3-7</sup> despite the impact of metastatic disease and Radiotherapy treatment extending beyond pain control<sup>1,5-7</sup>.

Radiotherapy outpatient clinics are often busy and demanding for the palliative patient, family and health professional which can be a barrier to delivering in-depth comprehensive support. The location of Radiotherapy centres within large cities means patients and their families may have travelled long distances, be anxious and in pain, possibly waiting for many hours for consultation and treatment. Radiotherapy professionals may be under pressure to complete multiple tasks within each appointment potentially overlooking patient and family treatment needs and expectations.

The general public is largely poorly educated about Radiotherapy. Although much is being done to improve Radiotherapy awareness to reduce anxiety and fear for some patients their

information and support needs are un-met. Although treatment completion is often eagerly anticipated by patients<sup>8,9</sup>, when Radiotherapy treatment ends, patients can experience negative impact on wellbeing and health, increased use of medical services, anxiety, fatigue and a loss of confidence<sup>8-10</sup>. How patients with bone metastases and their families currently manage these problems in the weeks following treatment is not clear or addressed in previous studies.<sup>2-10</sup>

The literature is starting to identify prostate cancer impacts on both the patient and family; however there is still a paucity of research seeking the direct views of patients and family members. Separately ascertaining and comparing the families views to the patients could further fulfil the needs and expectation of the patient<sup>11</sup>. Family members may not discuss feelings of helplessness and isolation directly with the patient and can play down financial difficulties due to the cancer diagnosis<sup>11-15</sup>. Indeed, some studies have identified the psychological impact of the disease is greater for partners<sup>15</sup>. Unfortunately, due to radiation protection, families are unable to escort the patient during treatment, compounding the lack of awareness of family needs during Radiotherapy. Understanding these unvoiced needs and concerns of both patient and family during and after Radiotherapy is relatively unexplored within the literature<sup>13-14</sup>.

Although the scope for clinical research in Radiotherapy is large<sup>16-17</sup>, there is a necessity to address the poorly articulated needs of palliative prostate Radiotherapy patients and their families<sup>18-19</sup> and the lack of consensus on collaborative management<sup>4,5-7,20</sup>. Using semi-structured interviews, diaries and focus groups, this qualitative study will aim to explore the lived experience of the trio involved at point of care in palliative Radiotherapy, the patient, family and Radiotherapy professional. Greater attention can be given in a practice environment to the needs that patients and families may have previously been reticent to raise within a treatment appointment. It is hoped that information from the study will help Radiotherapy professionals reassess how they interact with the prostate patient and family member from diagnosis to first follow up. Understanding the lived experience of palliative Radiotherapy and the impact on the everyday life on its users could help healthcare providers identify and respond to patient and family member needs and expectations in a timely and effective manner.

**Study Design** - A qualitative design will be used. Data will be collected from 3 sources to provide a broad understanding of issues relating to palliative Radiotherapy from the perspective of patient, family member (or friend) and Radiotherapy professional.

**Service User Input** - Service users have already contributed towards and commented on the study design and study information. Potential interview questions will shortly be discussed at a local prostate cancer support group to add towards enhanced study quality, relevance and integrity, developing a study that is more ethically acceptable<sup>21</sup>. The decision to use different users at pre-determined stages of the research is to reduce the burden of taking part on palliative user group participants.

**Setting** - One research setting serving a varied population of approximately one million people within 3 counties will be used during the study duration.

**Study Participants** are separated into 3 distinct groups; advanced prostate cancer patients, family or close friends and Radiotherapy professionals. The sample size will be kept small and reasonably homogeneous to ensure analysis is suitably penetrative. It is anticipated 6 patient and 6 family/friends will be recruited. Wherever possible patient and family members will be matched pairs but patients/family members who would like to participate alone will NOT be excluded from the study. Interpretive phenomenological analysis (IPA) is the qualitative approach proposed for this study. IPA is a phenomenological-focussed approach, where we perceive the world by engaging in it<sup>21</sup>. Therefore, purposeful sampling will be used to recruit patients, as it is important that all participants can offer a meaningful perspective on Radiotherapy and are willing to reflect on their experiences. Two Radiotherapy professional focus groups will also take place consisting of approximately 5-8 participants recruited into each group. The Professionals will represent a range of experience and professional role representative of multi-disciplinary staff supporting patients and carers throughout Radiotherapy.

**Patients** - Prostate cancer patients have been selected as the patient population as; 75% of advanced prostate cancer patients will unfortunately experience metastases of their disease to bone<sup>2,3</sup>. This patient group have a median survival of 40 months, 25% reach 5 years survival after diagnosis of bone metastases<sup>19</sup>. Treatment for prostate cancer bony metastases is commonly single modality, either Radiotherapy or surgery alone<sup>4</sup>

**Inclusion/exclusion Criteria** - All adult, advanced prostate patients referred for their first course of Radiotherapy to bony metastases will be initially screened by a health professional to assess study suitability. Patients who meet the eligibility criteria will be sent information about the study with their Radiotherapy appointment letter. An 'opt-in' slip will be included for interested patients to contact the researcher for more information.

Patients will not be sent information about the study if;

- participation is deemed detrimental to their well-being by a medical professional
- they present to the department as an oncological emergency
- in the opinion of health professionals they are too sick or fatigued to participate
- they require translation services (due to limited funding for this study)

**Family or Friend** - Included within the study information will be a request for patients to nominate a supportive family member or close friend to also participate in the study. Wherever possible patient and family members will be matched pairs but patients/family members who would like to participate alone will NOT be excluded from the study.

**Inclusion/exclusion Criteria** - The family member or friend needs to be over 18 years old, willing to participate, self-caring and able to communicate in English. They need to attend the initial Radiotherapy appointment and support the patient through the Radiotherapy journey.

**Radiotherapy Professional** - All Radiotherapy professionals supporting this patient group who work within the research setting will be invited to attend one of two focus groups. Participation is voluntary with no obligation or incentive offered.

**Focus group 1** – maximum 8 participants taking place BEFORE patient and family member data collection, the participants will consider what they feel palliative prostate patient and family needs, expectations and experiences of Radiotherapy treatment are.

**Focus group 2** – maximum 8 participants taking place AFTER patient and family member data collection, the participants will discuss ideas on how the Radiotherapy service can be improved for this patient group.

## Measures

**Diary** Patient and family member participants will each be provided with a study 'manual' or 'diary'. This will include copies of the study information, researcher contact details and diary sheets. Participants will be asked to maintain a regular, short written record within the manual of how they think, feel and behave during Radiotherapy treatment and in the weeks following the treatment. Using a written record allows participants to accurately 'catch hold' of thoughts and feelings when they occur. Drawing will also be encouraged. Although diaries have not previously been used in similar studies, they are widely used in both health care and palliative care as they can aid recollection of events and interactions and allow accurate recording of thoughts, feelings and discussions which can be complex in a palliative care setting.

**Interview** - Due to the limited existing evidence base and exploratory nature of the study, qualitative, semi-structured interviews are deemed appropriate to determine patients' and families' detailed and nuanced expectations and experiences of Radiotherapy. The interview will be conducted 4 weeks after treatment finishes as side-effects from treatment should have dissipated and the positive benefits from Radiotherapy should be apparent<sup>7</sup>. This short timescale can also enhance recollection and reflection of experiences. A one hour, in-depth semi-structured interview will be carried out individually with each participant to fully explore their lived experience of Radiotherapy allowing;

- Exploration of the factors affecting the decision to have Radiotherapy
- Identification of potential sources of Radiotherapy related anxiety, expectations and hopes
- Reflection on the reality and lived experience of the Radiotherapy treatment
- Discussion of post-treatment phase and identification of any coping strategies used

**Professionals Focus Group** - The groups will be organised after 4pm to avoid disruption of the working day. Demographic information will be taken to outline the age, professional grade and clinical experience of each participant. A qualitative focus-group (FG) design will discuss of participants' own professional and experiential knowledge to allow a trio of perspectives, relatively unexplored in the literature.

**Aims of the focus group 1** – before patient/family interviews;

- To explore staff experience of treating and supporting advanced prostate cancer patients
- Consider what staff feel the needs and expectations of patients and their families could be

**Aims of focus group 2** – after completion and analysis of patient/family interviews;

- To explore the themes arising from the interviews and the implication on clinical practice
- To identify possible areas of service improvement

**Ethical Considerations** - relating to this qualitative study are;

- The patient population are palliative cancer patients undergoing treatment for painful bony metastases, therefore they and their family member are vulnerable
- Simply talking about an experience could raise sensitive issues for any of the participants
- Staff may feel the research will criticise their current practice, this is not the case as the research is allowing discussion of possible service developments

Ethical research is a dynamic process and needs to be continually monitored<sup>21</sup>. All participants will be informed prior to data collection and within the study information that if the researcher becomes concerned about the immediate safety or distress of any

the researcher becomes concerned about the immediate safety or distress of any participant, in addition to the researcher's qualification and skills, robust referral processes are already in place; NO participant will be knowingly left in a distressed state. The researcher will maintain a reflexive diary throughout the study to ensure personal beliefs do not cloud analysis.

**Analysis Aim** - To develop an organized, detailed, plausible and transparent account of the meaning of the data.<sup>21</sup> Interpretive phenomenological analysis (IPA) is suited to this new exploratory study as it will provide detail about the participant's experiences to produce a narrative account that expresses the participants Radiotherapy journey, rather than make premature general claims. With IPA, the researcher's beliefs are not seen as biases to be eliminated as in Grounded Theory, but necessary to make sense of the participant's personal world.<sup>21</sup> However, a reflexive diary will be kept as reflexivity can help reduce personal beliefs clouding analysis. Peer-debriefing through the analysis stage with an experienced IPA researcher will also help ensure consistency of data interpretation.

Sufficient time between data collection episodes will be allocated to allow rapid transcribing of data, reading and reflection whilst the essence of each interview/focus-group is easily recalled. All diary, focus group and interview data will be subjected to Systematic analysis, one case at a time. Analysis will adhere to a series of steps<sup>21</sup> comprising of: first impressions, initial notes, descriptive, linguistic, theoretical comments and emergent themes. IPA is committed to idiographic analysis, which means that the analysis of each individual is undertaken in complete isolation and then the findings between participants are compared and common themes identified. Through theoretical generalizability, Radiotherapy professionals within the second focus group can then assess the study against their own professional and experiential knowledge thus increasing the trustworthiness of the data. IPA can be used to develop models to offer up recommendations that can inform clinical practice and allow consideration of new, collaborative ways of working.

**Dissemination** - this study will concentrate on services within a single large NHS foundation trust and as such may not directly translate to other Radiotherapy departments. However, many of the issues and themes arising from the study should be considered by the wider Radiotherapy community. National conference presentations will be made and the results of the work will be submitted to a peer review journal.

**Gantt chart**

| Milestones                         | Oct-Dec 2013 | Jan-March 2014 | April-June 2014 | July-Sept 2014 | Oct-Dec 2014 | Jan-March 2015 |
|------------------------------------|--------------|----------------|-----------------|----------------|--------------|----------------|
| Submit ethics                      |              |                |                 |                |              |                |
| Lit review/method for final thesis |              |                |                 |                |              |                |
| Recruitment Rads/patient/family    |              |                |                 |                |              |                |
| Focus Group(FG) 1 Radiographers    |              |                |                 |                |              |                |
| Interviewing and analysing data    |              |                |                 |                |              |                |
| Recruit and carry out FG 2         |              |                |                 |                |              |                |
| Final analysis, complete write up  |              |                |                 |                |              |                |
| Disseminate                        |              |                |                 |                |              |                |