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CoRIPS Research Grant 171

£8,605 awarded

Title: How to radiographers care and manage patients with dementia referred for radiotherapy?

Principle Aim

To investigate how Therapy Radiographers (TR) care and manage patients with dementia undergoing radiotherapy.

Primary research question

What are the experiences of therapeutic radiographers when providing care to patients with dementia?

Secondary research questions

What are the facilitators and barriers faced by therapeutic radiographers when providing care to patients with dementia?

What are the training and support needs of therapeutic radiographers to allow them to confidently manage patients with dementia?

Outcomes

The outcomes of the study are to establish and generate theory of the facilitators and barriers to the provision of good care from therapy radiographers in caring for and managing patients with dementia undergoing radiotherapy. This knowledge will inform clinical practice guidelines and seek to improve patient care and experience by recognising the support needs of therapy radiographers to confidently manage patients with dementia. The knowledge and insight gained from this study will be used to develop education and training packages for undergraduate and postgraduate therapy radiographers.

Review of literature and identification of current gap in knowledge

In later life dementia is one of the main causes of disability, more disabling than some cancers, cardiovascular disease and stroke (1) and is the leading cause of death for women in the UK (2). At present there are approximately 850,000 people living with dementia in the UK, of whom 808,000 are aged 65 years or over (3). This number is expected to rise to 1.14 million by 2025 and by 2051 the projections are estimated to exceed 2 million people living with dementia (4).

Advancing age is recognised as the highest dementia risk factor (5) a position parallel to cancer. There are more than 360,000 new cancer cases in the UK every year (6) and more than a third (36%) of all cancer cases in the UK are diagnosed in people aged 75 and over (7).

Dementia is a syndrome encompassing a number of progressive conditions which affect the brain (8). The 5 most common forms of dementia include: Alzheimer's disease, vascular dementia, dementia with Lewy bodies, frontotemporal dementia and mixed dementia, although there are 200 subtypes (9). Symptoms include but are not limited to, problems with memory, thinking speed, mental agility, language, understanding and judgement (10). Symptoms of mild cognitive dementia interfere with daily living and may progress to severe cognitive disabilities which result in the inability to self-care (10). There are a number of social studies of professional work addressing the wide-ranging challenges that can arise for professionals in a number of specialist roles, and all levels of experience, during face-to face interactions with patients with dementia (11, 12). As radiotherapy is a common treatment for cancer, it is estimated that, 50% of people with cancer would benefit from a course of radiotherapy (13). It is expected that as there is an increase in the age of the population therapy radiographers are likely to be caring for an increasing number of patients with dementia. However, it is unknown if they have yet accrued the levels of direct professional experience conventionally thought to be key to developing expertise' in clinical performance (14). To date many studies have focused on interactions between the patient and practitioner where dementia remains the reason for the interaction taking place (15, 16). The importance of radiotherapy as a treatment for cancer cannot be underestimated. Radiotherapy requires the patient to consent to, and be compliant during treatment. People with dementia may find their usual activities of little interest and may experience difficulties expressing and managing their emotions, in particular when trying to communicate what they are thinking or what they want (19). As dementia affects a person's mental abilities, decision making, planning and organising can become challenging (17). This can pose a challenge in radiotherapy as someone with dementia may be unable to cope with the demands of the positioning required or understand instructions given during radiotherapy. Similarly, they may have difficulty coping with any potential side effects of treatment. The requirement for healthcare professionals in the radiotherapy department is to understand and support the needs of people with dementia and their carers to manage the treatment, their symptoms and side effects as well as their general well-being. In people with dementia not all the symptoms manifest in each person or in the same way. The severity of symptoms may vary and progress over time. In addition how an individual experiences dementia will be influenced by a number of factors such as: their personality, biography, physical health, environment, and social and cultural factors (18, 19). The College of Radiographers published clinical practice guidelines for

radiographers who care for people with dementia and their carers undergoing imaging and/ or radiotherapy in 2015 (19). However, it is recognised within these guidelines and noted in the literature that there is no substantial research undertaken to date examining how a patient's dementia can impact upon the clinical requirements of radiotherapy.

While many studies have focussed on incidence and prevalence rates there is scarce evidence that reports on situations when diagnoses of dementia and cancer coexist and the subsequent implications for healthcare services (20). However, from the limited literature those patients who have an existing diagnosis of cancer and dementia (henceforth referred to as cancer–dementia) have when compared with other cancer patients, cancer diagnosed at a later stage, receive less treatment, are more likely to experience complications from treatment and have poorer survival (21 - 23) and therefore understanding and meeting the care needs of people with dementia will ensure the best outcomes in radiotherapy.

This study aims to address the current research gap as the literature review identified no primary studies that have specifically investigated the impact of dementia on treating patients with cancer undergoing radiotherapy.

Methodology

Due to the lack of existing research in this area the study will use a grounded theory approach namely Kathy Charmaz's 'Constructivist Grounded Theory' (24) using open interviews as the method to generate theory.

Method

Sampling Strategy

Purposive sampling will be used to identify therapy radiographers with experience of treating patients diagnosed with dementia. The aim is to recruit at least 20 - 25 therapeutic radiographers across 3 UK radiotherapy departments or until data saturation occurs. This sample should provide insight to a range of experiences and challenges of caring and managing patients with dementia. By recruiting participants from different centres it should be possible to examine differences in local policies or training that may influence staff confidence or capability in supporting dementia patients during radiotherapy.

Saturation of Themes

Recruitment of therapy radiographers will continue until saturation is reached. The point at which no new information or themes are observed in the data is the concept of “saturation” which will form the purposive sample (25). Guidance on saturation suggests that this will occur once there are no new answers or themes

being observed (26). Furthermore, in using grounded theory Thomson (2010) in his content analysis of one hundred articles that explored grounded theory and interviews as a data collection method indicated the point of theoretical saturation can be affected by the scope of the research question, the sensitivity of the phenomena, and the ability of the researcher. However, the average sample size was twenty-five, but it was recommended to plan for thirty interviews to fully develop patterns, concepts, categories, properties, and dimensions of the given phenomena. (27)

Inclusion criteria:

- Therapy Radiographers involved in the treatment and management of patients diagnosed with cancer that have dementia which will include the following:
 - Therapy radiographers who have consented to take part in the study
 - Therapy radiographers grades 5 and above
 - Year 3 Student therapy radiographers
- Therapy radiographers who have cared or managed a patient with dementia within the last 6 years (this is to reflect the time when the College of Radiographers dementia guidance was published)

Recruitment

The project will be conducted within three radiotherapy centres. Once local approvals have been granted therapeutic radiographers will be approached to take part in the study and to ensure open and inclusive recruitment a presentation will be delivered to staff about the study and awareness through distribution of flyers within the staff rooms.

Potential participants will be provided with a study pack containing a covering letter, participant information sheet, an interview reply slip and a consent form.

Data Collection

Once the researcher receives the interview study reply form they will contact the therapeutic radiographers to arrange a convenient time and place for the interviews. Interviewing will take place in a quiet hospital room or via other means depending on participant preferences. All interviews will be digitally recorded, confidential, anonymised and transcribed verbatim for analysis. All participants will be able to terminate or pause the interview at any time without stating a reason. Demographic details such as and including age, experience,

length of time in the department, grade will be collected from each participant in addition to their experiences of working with patients with dementia.

Patient and Public Involvement in the Research

The researcher has actively involved the patients, public and their carers' in developing this research by engaging with the South Yorkshire Dementia Advisory group (SYDAG).

With the involvement of PPI using the SYDAG it has reinforced the importance of this research as it has ensured this research is relevant to the needs of patients, carers and service users with dementia by matching the needs of the patient to the exploration of the therapy radiographer's experiences of managing and caring for patients with dementia.

Patients and their carers will be involved in all stages of the research process including:

- The design and management of the study: pre data collection to include review of the lay summary, including a member of the group in the study team, highlighting any potential themes which could be explored in the interview.
- The data collection and analysis: mid-way through and at the end of the data collection to enable comments on the theory emerging.
- The dissemination of findings: at the end of the data collection and having created theory.

Data Analysis

The study will use Grounded Theory using a Constructivist approach (24). In order to explain the data that is collected which develops the theory coding will be used and Charmaz (2006) describes this as the 'pivotal link'. At the coding stage meaning will emerge through looking into the data.

Coding occurs in stages. In initial coding, using early data the generation of many ideas occurs inductively (28). In focused coding, a set of central codes is selected and sought throughout the entire dataset and the study (28). The decision is to determine which initial codes are most prevalent or important, and which contribute most to the analysis (28). At the theoretical coding stage the final categories are refined to their theory and they are related to one another (28). In Charmaz's method actions or processes are depicted by using gerunds as codes (verbs ending in 'ing'); Charmaz also puts emphasis on coding quickly, and keeping the codes as similar to the data as possible.

Quality

In order to ensure quality in keeping with grounded theory procedures and general principles of qualitative research the following points describe what is crucial for this study to achieve quality and minimise opportunities for researcher bias.

During data collection

1. All interviews will be digitally recorded, professionally transcribed in detail and the transcripts checked against the recordings.
2. The interview transcripts will be analysed as soon as possible after each interview. This will allow the process of theoretical sampling to occur (28).
3. Writing memos after each interview allows for the researcher to capture initial ideas and make comparisons between participants' accounts. These memos will aid in comparing among reflections, which will enrich data analysis and guide further data collection (28).
4. Member checking after interviews to clarify concepts will aid in refinement of theoretical concepts, thus forming part of theoretical sampling. (29)
5. Phone interviews due to participants' preference will be used in this study to allow for a greater range of participation. (28)

During data analysis

1. Detailed analysis records will be kept.
2. Throughout the research process peer debriefing will take place with the supervisory team in particular in discussing and contextualising emerging interpretations, introducing a wide range of disciplinary perspectives.
3. Keeping an audit of concept development
4. Using direct quotes from transcripts to indicate how concepts/constructs have been developed from the data.
5. Going back to the field once theory development has started to identify negative cases and to test the emerging theory.
6. Use of member checking to ensure theories and concepts which have emerged are reflective of the accounts given (29).

Ethics

This study will require NHS ethics and local Research and development approval from the three participating radiotherapy centres. The study will be conducted in accordance with the principles of Good Clinical Practice. Ethical Approval for the study is currently being sought through Sheffield Hallam University Research Ethics Committee; Sheffield Hallam will act as sponsor to the study.

Informed written consent will be obtained from therapy radiographers prior to entry into the study. The consent process will include reassurance about confidentiality, and if at any point in the interview, participants express concerns about confidentiality or discomfort in discussing these issues, and they may withdraw from the study or request that the recorder is turned off.

If an issue arises that is deemed mal practice or a concern about the care of any future patients is identified from the comments of participants, the head of radiotherapy department will be informed; participants will be aware of this prior to consenting to the study.

All person-identifiable data, such as consent forms and contact details will be stored in the study site file, kept in a locked area on Sheffield Hallam University premises. Any electronic data that contains participant-identifiable information will be stored on the researchers SHU secure J drive that is password protected and accessible only by the researcher. Only the researcher will have access to person-identifiable data during the study. Only data that is anonymised will be transferred out for the purposes of data analysis by the researcher with the support of the supervisory team.

Potential impact

The theory developed through this study around how practitioners currently care for patients with dementia in the radiotherapy department will be used to inform the Radiotherapy community about:

1. The facilitators and barriers in managing patients with cancer who have dementia in the radiotherapy department. This knowledge will facilitate the development of learning resources to upskill radiographers in order to provide better care for patients with Dementia. The facilitators and barriers will also be important for informing policy makers and department managers on how to use resources to improve care for this patient group.
2. The issues which may be in need of attention to inform future practice guidelines when managing patients with dementia in the radiotherapy department.

Further Research is intended:

To explore the radiotherapy experiences of patients with cancer who have dementia.

Dissemination Strategy

To ensure that the outputs from the research inform practice and thereby maximise the benefit to patients and the service, the following dissemination strategy has been developed.

It is known that research is most effectively disseminated using multiple channels, ideally with face to face interaction. So, in addition to giving written feedback to study participants, dissemination activities will include:

- Open access peer review publication of the research including Full, Executive Summary and Plain English summary reports of the research in a related journal such as 'Radiography'
- Conference poster and/or presentation at the Annual Radiotherapy Conference
- Development of links with key organisations such as the College of Radiographers, Health and Care Professions Council, NHS England, Dementia UK and Alzheimer's Support to contribute to and capitalise on their networks
- South Yorkshire Dementia Group
- Use of electronic media such as websites and social media such as Twitter

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