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# Laboratory or Sanctuary? Patients' Perceptions and Experiences of Diagnostic Imaging and Radiotherapy - a qualitative study

### Lay summary

A limited number of published studies have explored diagnostic imaging and radiotherapy via the first hand personal accounts of patients. Previous studies have mainly employed audits and structured questionnaires, relating to specific procedures, leaving untapped a rich vein of individual narratives relating to patients' expectations, perceptions, and experiences of diagnostic imaging and the radiotherapy process. A qualitative study is needed, based on patient experience "as lived" as there is a general shortage of qualitative research within radiography, some of which has focused on the perceptions of radiographers rather than patients. The views of patients as service users are of vital importance as an indicator of the quality of health service delivery.

Study themes will explore:

- Patients' perceptions of the environment of the imaging or radiotherapy department. Factors which generate fear and uncertainty, or promote reassurance and confidence;
- Patients' perceptions of the diagnostic or therapeutic radiographer;
- Factors contributing to positive or negative patient experiences;
- Issues affecting communications between patients and staff;
- Patient awareness of the risks and benefits of diagnostic imaging and radiotherapy

The study will utilise individual interviews conducted by the co-investigators with patients at three district general hospitals and two tertiary radiotherapy centres.

### Aim

The principal aim of the study is to explore patients' understanding and lived experiences of diagnostic imaging or radiotherapy pre-treatment and treatment procedures.

### Primary research question

What are patients' experiences of diagnostic imaging or radiotherapy pre-treatment and treatment procedures?

### Secondary research questions

1. Are these perceptions and experiences generally positive? If not, what steps may be taken by clinical departments and staff in order to enhance their positivity?
2. How are diagnostic and therapeutic radiographers perceived by patients?
3. What are patients' prior conceptions of the nature and risks of diagnostic imaging or radiotherapy procedures? How do their subsequent lived experiences compare with this?
4. How does the type of procedure undertaken influence patients' understanding and experiences?
5. Do patients' clinical conditions and demographic status affect their views and experiences?

## Outcomes

The study will portray the features and diversity of the beliefs, feelings and perceptions expressed by patients regarding diagnostic imaging and radiotherapy pre-treatment and treatment procedures. Any emerging themes will be explored in the light of the environment of the clinical department, the characteristics of staff, communications between staff and patients, the nature of the procedure and the patient's personal circumstances.

## Literature review

The small number of existing qualitative studies in the diagnostic imaging field include explorations of patients' attitudes to screening mammography. Trigoni et al (2008) in a study of Cretan women, noted poor patient knowledge of the risks and benefits of mammographic screening, fear of the procedure itself, embarrassment and stress. Feelings of fear and lack of knowledge of mammography were also expressed in focus group study of women with learning disabilities, conducted by Truesdale-Kennedy, Taggart and McIlfatrick (2011). Cultural beliefs regarding death from cancer may be a factor influencing attitudes towards mammography, as evidenced by a study of Samoan women (Ishida, Toomata-Mayer and Braginsky, 2001).

Communication between patients and radiographers has been studied by Booth (2008) who noted that a number of factors, such as radiographer confidence and extraversion, patient age and the demands of obtaining a good diagnostic image, sometimes interfered with good communication. In challenging situations, radiographers often reverted to standardised behaviours such as parenting or nurturing. Farmer and Davis (2009) found that the radiographers within their study had a poor knowledge of patients' psychiatric conditions and were fearful of interactions.

A recent quantitative questionnaire-based study (n =698) by Blomberg et al (2010) is one of the few to consider quality of care in diagnostic imaging from a patient perspective. This study noted that adverse quality of care experiences, chiefly centred around waiting times, were much alleviated by good communication and waiting area facilities. Patients of a lower educational level were more likely to perceive quality of care to be poor. Halkett and Kristjanson (2007) have explored patients' perceptions of radiotherapists using a grounded theory approach and noted that relationships, information and emotional comfort were key aspects of the role. However there is no equivalent study available for diagnostic radiography.

A small number of questionnaire-based studies have explored patient experiences of specific imaging procedures, albeit from a standpoint of acceptability rather than from an experiential perspective. Glueker et al (2003) and Taylor et al (2005) noted that patients preferred CT colonography to a barium enema examination in terms of comfort and convenience.

There is a wealth of qualitative literature available which has examined quality of life issues for cancer patients who are undergoing radiotherapy, but little has been written about the experiences of those patients and what their perception or experience of the role of the radiographer is in the radiotherapy process, other than that related to treatment outcomes and side effects.

In 2006 a study examined the factors that influence cancer patients’ overall perceptions of the quality of care and the major themes that emerged centred around communication of information (Sandoval et al., 2006). Issues highlighted by radiotherapy patients included long waiting times, information needs regarding psychosocial issues (e.g. sexual activity, emotional change, relationship change), physical issues (e.g. nutritional requirements) and who to go to for different types of information. A Finnish study indicated that patient satisfaction scores rated staff characteristics most highly and environment lowest, with younger patients, employed patients and those with a higher levels of education giving the lowest quality ratings. (Siekkinen et al., 2008). Thind et al, (2010) found that patients with greater involvement in the treatment decision-making process, those perceiving high-quality information giving and those perceiving greater emotional support were more satisfied with their care. However it is not possible to tell from these studies which staff groups were referred to in these satisfaction scores. Much of the literature used by the authors in these studies focuses on general quality of life, perception of radiotherapy and information needs, or has its base in nursing practice.

Therefore it appears that there is an identified gap in the literature regarding the patients’ perceptions of radiotherapy radiographers and their role in treatment planning and delivery.

## Methodology

The study will consist of a qualitative, phenomenological investigation of the understanding and experiences of individual patients undergoing diagnostic imaging or radiotherapy procedures. Schwandt (2007: 225) summarises phenomenology as a rejection of the empiricist study of “mere appearance” and an acceptance of “the ordinary conscious experience of everyday life”. Each person's personal journey and perception can be expected to be unique. Carel (2010) notes that phenomenology could help to record patients’ experiences of health care systems, and contribute to evidence based practice. To many people working in healthcare, “evidence-based” means empirical evidence, and Carel’s view seems a timely reminder of the additional need for qualitative research. The proposed research will adopt an inductive rather than a deductive stance, without prior conceptions or hypotheses.

The data collection method will employ individual semi-structured face-to-face interviews, which will explore patients' narrative accounts of their journeys through a diagnostic imaging procedure or a course of radiotherapy treatment. Purposeful sampling will be employed, in order to ensure that the range of patients and procedures included within the study is as representative as possible of diagnostic imaging and radiotherapy practice. In the case of diagnostic imaging, the sample should include patients attending for "plain X-ray", fluoroscopic, CT, MRI and ultrasound examinations. Patients who are children, acutely unwell (for example following serious trauma, stroke or cardiac arrest)], severely incapacitated, emotionally upset or in a reduced state of alertness will be excluded from the study. In the case of radiotherapy, patients attending for both palliative and curative localisation and treatment will be included, and with a representative range of tumours. Once again, children, the acutely unwell, the severely incapacitated, emotionally upset or those with reduced alertness will be excluded. It is proposed that at least 30 patients (10 per hospital site) should be recruited from diagnostic imaging, and at least 20 from radiotherapy (10 per hospital site). Patients will be invited to participate by one of the co-researchers at the time of their arrival or appointment, when the purpose and nature of the research will be explained to them. Patients will have the opportunity to consider the invitation to accept or decline as they see fit. Should they accept, the timing and venue for a subsequent interview will be discussed.

Key areas of exploration within the interviews will include: personal narrative histories and accounts; knowledge, awareness and expectations; the experience of the diagnostic imaging or radiotherapy process; fears, anxieties; confidence and reassurances; positive and negative aspects; communication; patient perceptions of relevant hospital staff and of their related health professions. Interviews will take place as soon as possible after the diagnostic procedure or course of radiotherapy. Interviews will take place in a quiet and private environment, either in an appointment room at the hospital or in the patient's own home (or a neutral alternative venue) should that be preferred by them. Each interview will be recorded (if patient permission is obtained) and will last no longer than 60 minutes.

The verbal accounts from the individual interviews will be examined for emerging themes, using an iterative-inductive approach (O’Reilly, 2005, p178). Hence themes arising will be revisited and re-interpreted in the light of ongoing additional data. The researchers will apply the process of “bracketing” or phenomenological reduction, (Holloway, 2005, p 107) suspending preconceptions and external beliefs, focusing on the experiences of the participants themselves.

Experiences, opinions and perceptions will be sorted and categorized within the process of coding. This will help to name and define the thoughts and meanings present in the text and will be undertaken using a CAQDAS (computer assisted qualitative data analysis software) package such as NVivo. Three stages of coding have been identified, as devised by Strauss and Corbin (1990) and reported on by Gibbs (2007, p 50) and others:

1. Open coding – identification of possible categories, without prior conceptions
2. Axial coding – development and linking of categories
3. Selective coding – determination of core or central categories

Both co-researchers will examine the transcripts of every verbal account within the coding process, in order to confirm the developing themes and prevent the personal perspective of one researcher from becoming a potential source of bias.

## Challenges to rigour

The transferability of the study will be maintained by taking steps to ensure the diversity of the patient sample. There will be purposeful recruitment of patients with a range of social and cultural backgrounds, undergoing a variety of investigations or treatments. Recording of interviews will help to maintain the dependability of data, as analysis will not be reliant on the researcher's personal notes. The Hawthorne effect ("guinea pig" effect) within interviews will be reduced by maintaining a friendly, relaxed and private atmosphere, in which the researchers have no "vested interest" in the research outcomes. Patients will be invited to be as honest and free-ranging as possible in their verbal narrative accounts. The credibility (validity) of the study will be maximized by conducting interviews as soon as possible after the patients' experiences in order to enable recall and by minimising patient "self-selection" during recruitment. Self-selection might bias the study towards respondents with particularly vocal attitudes towards imaging or radiotherapy and might occur if online or postal recruitment was employed. It is possible that other underlying personal factors might affect patients' perceptions of imaging or radiotherapy and the analysis of verbal accounts will consider this.

## Ethical implications

The study will involve individual face-to-face interviews with patients undergoing clinical investigations and treatments for conditions including cancer. Discussions will include narration of personal perceptions and feelings. Thus it will be essential to conduct the interviews in an empathetic and supportive environment, with the facility to offer additional help and advice if needed. The co-researchers are HPC registered radiographers working in education, with much previous clinical experience. Any research undertaken will only be with the full co-operation and consent both of the patients themselves and the clinical departments concerned. No personal identifying data such as name, date of birth or hospital record number will be recorded. Brief notes will be made of demographic information and summary clinical history, as well as the procedure(s) undertaken in order to inform the analysis. All verbal narrative information received will be confidential and both the respondents and clinical sites will be anonymised. Patients and clinical sites will have the right to decline to participate in the study or withdraw at any time.

## Potential impact of the study

It is hoped that the study will give voice to patients as service users and provide insights and perspectives which should inform future service delivery. There is little previous published research in this field and a need for more qualitative research in radiography generally

## Dissemination strategy

The findings will be disseminated via suitable conferences such as UKRC and UKRO, as well as key publications such as Radiography, Clinical Radiology and The Journal of Radiotherapy in Practice. The intention will be to communicate findings to the relevant clinical professionals who are in a position to act on the information.

## Proposed timeframe

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| **September to November 2011** | NREC ethics approval, full literature search, permissions from clinical sites |
| **December 2011 - March 2012** | Face to face interviews with patients |
| **April 2012 - May 2012** | Analysis and write-up |
| **June 2012** | Dissemination of findings (UKRC), write up articles for publication |

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