
EXPERIENCES OF MEN WITH
PROSTATE CANCER
REGARDING INFORMATION
RELATED TO RADIOTHERAPY
IN THE UK

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Abstract

Approximately 52,000 men are diagnosed with prostate cancer each year in the UK with around 60% (~31,000) diagnosed at an early stage (locally advanced or localised disease). Around a third of men diagnosed with these locally advanced or localised prostate cancers will receive radical radiotherapy. Men will receive information and have discussions with health care professionals (HCPs) before, during and after radiotherapy related to decision making and management options, treatment procedures and the likely long term sequelae of their cancer management. Whilst previous studies have explored information across the course of a patient's prostate cancer diagnosis, none has previously focused specifically on the information related to radiotherapy for men with prostate cancer.

This study aims to explore the experiences of men with early-staged prostate cancer regarding information related to radiotherapy in the UK

A qualitative study situated within a social constructivist paradigm was devised, utilising patient and public involvement as an integral component of the early stages of development of the research design. Semi-structured interviews were undertaken with 20 men with prostate cancer who had received radiotherapy and 13 of their wives, to gain their perspectives regarding information exchanged before, during and after radiotherapy. Three focus-group interviews comprising 14 therapeutic radiographers across bands 5-8 recruited from one NHS Trust were carried out in order to provide context to the experiences reported by the men and their wives. Data were analysed using a thematic analysis approach.

Three distinct periods arose as being important regarding information related to radiotherapy: the pre-radiotherapy period from point of diagnosis through to just before the radiotherapy planning appointment, the peri-radiotherapy period covering radiotherapy planning and treatment, and the post-radiotherapy period from end of treatment to the time the patient was interviewed (from 3 to 18 months after the end of treatment). Across these three periods, 12 semantic themes were identified. In the pre-radiotherapy period these were a) information and being diagnosed and b) information and decision making. In the Peri-radiotherapy period themes were c) being prepared for

planning and treatment, d) information related to external beam radiotherapy procedures, e) retention of and compliance with information, f) information about practicalities, g) peer support and the “waiting room club” and h) therapeutic radiographers and information. In the post-radiotherapy period, the themes were i) the end of radiotherapy – information about what happens next and follow up, j) information on treatment-related outcomes, k) information and decision regret and l) information about sexual dysfunction. In addition, two latent themes of time and communication were identified as arising across all periods and underpinning the semantic themes. To demonstrate the interconnectedness of the themes within the chronology of the three identified periods, two contrasting cases are described to illustrate the impact and place of information in the experiences of two men.

The issues related to information reported by the participants had multiple mediating factors that differed across the three periods and so were considered with respect to Bronfenbrenner’s ecological systems theory. As a result, a new model of ecology of information in radiotherapy has been proposed to describe their experiences.

Patients’ experiences related to information and communication during their radiotherapy must be contextualised within the whole cancer journey, their personal ecological systems and changing needs over time. Information needs related to decision making during the pre-radiotherapy period can profoundly impact on longer term outcomes, particularly, with respect to sexual functioning. However, this could be mediated by improved opportunities for communication during the pre-radiotherapy period and further opportunities for specialist information and support in the post-radiotherapy period. This study has demonstrated that information before and after, as well as during radiotherapy is a crucial factor in determining the long-term quality of life outcomes for men with prostate cancer.

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List of abbreviations

ADT	Androgen Deprivation Therapy
AfC	Agenda for Change
ASP	Advanced or Specialist Practitioner
CAQDAS	Computer Aided Qualitative Data Analysis Software
CHHIP	C onventional versus H ypofractionated H igh-dose I ntensity-modulated radiotherapy for P rostate cancer
COVID-19	Coronavirus Disease 2019
CPG	Cambridge Prognostic Group
CRIPACC	Centre for Research in Public Health and Community Care
CT	Computed Tomography
EBRT	External Beam Radiotherapy
EORTC	European Organisation for Research and Treatment of Cancer
GDPR	General Data Protection Regulation
HCP	Health Care Professional
HCPC	Health and Care Professions Council
HDR	High Dose Rate
HYPRO	HYP ofractionated versus conventionally fractionated radiotherapy for patients with PRO state cancer
IMRT	Intensity Modulated Radiotherapy
LDR	Low Dose Rate
MPC	Men or Man with Prostate Cancer
NICE	National Institute of Health and Care Excellence
NHS	National Health Service
OAR	Organs At Risk
PC	Prostate Cancer
PIRg	Patient Involvement In Research group
PPI	Patient and Public Involvement
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analyses
PROMS	Patient Reported Outcome Measures
PSA	Prostate Specific Antigen
PTV	Planning Target Volume
RT	Radiotherapy

SD	Standard Deviation
TA	Thematic Analysis
TNM	Tumour, Node, Metastasis
TR	Therapeutic Radiographer

Glossary of terms

Active surveillance	A management approach where patients with low Gleason grade, localised prostate cancer undergo regular PSA testing and imaging rather than immediate definitive treatment.
Acute side effects	During and up to a few weeks after the end of radiotherapy.
Adjuvant	A treatment delivered after the primary treatment aimed at destroying remaining cancer cells.
Androgen deprivation therapy	Use of hormonal treatments to control hormone-mediated tumour progression by blocking the action of testosterone.
Brachytherapy	Refers to a form of radiotherapy where radioactive sources are introduced into the body or onto the skin surface in order to deliver radiation close to the target.
External beam radiotherapy	Refers to any radiotherapy where the origin of the beam of radiation is outside the body and slightly distant from it.
First day chat	Colloquial term used to describe the conversation between TR and new patients on their first day of radiotherapy. Usually used to explain procedures and give an overview of likely acute side effects.
Follow up	For radiotherapy, this relates to the first appointment after the end of treatment at which initial response to treatment and resolution of acute side effects is checked.
Homogeneity/homogeneous	When referring to radiation dose, this means that the measured dose is the same across a specific block of tissue.
Late/chronic side effects	Radiation-induced side effects that occur from a few months up to many years after the end of radiotherapy.
Localisation	Procedure during which images (usually CT) are obtained on radiotherapy-specific equipment, on which the treatment is planned. During the procedure relevant equipment parameters and immobilisation requirements are noted.
Neoadjuvant	Delivered before primary treatment method to reduce tumour size or begin treating microscopic, disseminated disease.
Palliative radiotherapy	Given with the intent of reducing unpleasant symptoms and thus improving quality of life.

Planning	A process by which the scans obtained during localisation are used to generate a map of radiation dose via sophisticated computer software. This process determines the high and low dose areas relative to the planned target volume.
Planning target volume (PTV)	A geometric concept that allows for uncertainties in planning or treatment delivery to ensure that the radiotherapy dose is delivered accurately to the tumour and a small margin around it. (for further explanation see text and diagrams in appendix 2)
Prostate Specific Antigen	A protein secreted by epithelial cells in the prostate gland as a component of ejaculate whose purpose is to allow sperm to swim freely. It is found in small quantities in the blood serum of healthy men but levels can be raised in men with prostate cancer.
Radical radiotherapy	A course of radiotherapy given with the intent to cure the patient.

Chapter 1. Introduction

This dissertation documents qualitative research that sought to discover the experiences of men with early-staged prostate cancer regarding information related to radiotherapy in the United Kingdom (UK). This chapter provides background to and rationale for the study, including an overview of management for early-staged prostate cancer in the UK with the place of radiotherapy highlighted. An overview of the research aims is provided. The Chapter will conclude with a summary of the dissertation structure, which includes brief details on the content of each chapter. Note that throughout this dissertation, unless otherwise indicated, the terms 'men' and 'man' refer to cisgendered individuals.

1.1 Background

1.1.1 Prostate cancer diagnosis and management

Between the years 2016 and 2018 around 52,300 new cases of prostate cancer were diagnosed in the UK (Cancer Research UK, 2022). This makes it the most common male¹ cancer, and overall, second only to breast cancer. It accounts for 14% of all new cancer cases and numbers of cases are rising, with rates projected to rise by 12% between 2014 and 2035 (Cancer Research UK, 2022). Unlike many other cancers, prostate cancer has no preventable risk factors, with the main risk being accumulated DNA damage associated with older age; a third of new cases arise in men aged over 75 years (Cancer Research UK, 2022). During the diagnostic process, men will have levels of prostate specific antigen (PSA) tested. This protein, produced by prostate epithelial cells and prostate cancer cells, can become elevated in a number of conditions. Normal PSA levels vary with age: up to 3ng/ml for men aged 50-59 rising to 5ng/ml for men aged 70-79 (Prostate Cancer Research, 2022; Prostate Cancer UK, 2022). Raised PSA is not usually considered as diagnostic for cancer unless reviewed alongside other clinical signs and symptoms; however, levels over 10ng/mL are considered highly suspicious and convey higher risk of cancer.

Prostate cancer is staged according to the TNM system. This represents the size of the primary tumour (T), the extent of any lymph node involvement (N), and whether distant metastases are present (M). Increasing T-stage, (the level of local invasion of the primary tumour) is related to risk of worse

¹ These statistics refer to biological sex at birth.

outcomes. More invasive tumours that have spread beyond the prostate capsule to the seminal vesicles and/or local lymph nodes, bladder and rectum are considered locally advanced cancers and staged as T3 or T4, with any evidence of nodal or metastatic spread considered as disseminated disease. Prostate cancer samples from biopsy are pathologically graded and allocated a Gleason score of between 6 and 10. The Gleason score relates to the degree of differentiation present in the biopsy samples: well-differentiated (very similar to normal prostate tissue) cancer samples are associated with lower risk of spread than those which are poorly differentiated or anaplastic (little or no similarity to normal prostate tissue), so a higher Gleason score indicates higher risk of spread. Therefore, management options for prostate cancer depend not only on the extent of the primary tumour, but on how likely it is to spread. Other management decisions will involve sociodemographic and medical factors, and patient preference.

So that management decisions can be made more effectively, each newly diagnosed patient is allocated a Cambridge Prognostic Group (CPG) category from 1 to 5, based on their risk according to a combination of Gleason score, PSA level and T-stage (see appendix 1). According to the National Institute of Health and Care Excellence (NICE), radical radiotherapy can be considered for men in CPG groups 1-3 where cure is the expected outcome and in groups 4-5 where it is likely that long-term control is achievable (NICE, 2021a). Other options available to men in groups 1 – 3 include radical prostatectomy and active surveillance. Active surveillance is not recommended for men in groups 4-5 due to the more aggressive nature of their cancers. Evidence related to prostatectomy suggests a higher risk of urinary incontinence when compared to radiotherapy (NICE, 2021a). All groups can be offered androgen deprivation therapy – (ADT, also called hormone therapy) for durations of 6 months up to 3 years. Around 60% of UK men with prostate cancer (MPC) are diagnosed at an early stage (T1 or T2)² and approximately 30% (9400) of these early-staged cases will receive radiotherapy with curative intent, either as a sole modality or as part of their overall management strategy (Cancer Research UK, 2022).

1.1.2 Radiotherapy

Radiotherapy (also called radiation therapy in countries other than the UK) is the use of high energy radiation to destroy cancer cells and therefore reduce the size of a tumour. High dose radiation is delivered with millimetre accuracy by technically complex equipment to ensure maximum dose is

² T1 refers to clinically unapparent tumour detected incidentally due to investigation of benign prostatic conditions or following biopsy due to raised PSA; T2 refers to tumours confined within the prostate gland.

received by tumour tissues and low dose to surrounding 'normal' tissues. External beam radiotherapy (EBRT) involves directing a beam of radiation from outside the body into the target tissue, hence it necessarily irradiates other non-tumour tissues in its path, and it is this latter which is responsible for most radiation-induced side effects. A variety of treatment units and techniques can be used to deliver EBRT (see appendix 2) depending on the requirements for the particular patient (e.g., tumour size and shape, patient size and shape). Typically for a man with localised or locally advanced prostate cancer, EBRT will normally be delivered in 20-37 fractions (treatments), for five days per week across 4-7 weeks³.

Intensity modulated radiotherapy (IMRT) is a method of delivering EBRT whereby the shape of the beam is modified in three dimensions. Conventional linear accelerators allow the beam to be shaped in two dimensions (the width and length of the beam); however, this cannot accurately account for irregular tumour shapes. With IMRT the intensity of the radiation beam can be adjusted across its profile, meaning it can be conformed to the volumetric shape of the tumour, rather than cross-sections as in previous conventional techniques. This high degree of conformity has allowed the margins of treated tissue to reduce, and radiation doses to be escalated, hence improving progression-free survival rates (Dearnaley et al., 2016; Dearnaley et al., 2014) and reducing the severity of some side effects.

Brachytherapy (from the Greek meaning "short distance") involves placing radioactive sources within body cavities or directly into tissues so that they are in close proximity to the tumour. Consequently, there is much less irradiation of non-tumour tissues, hence brachytherapy tends to be associated with fewer side effects than EBRT. However, placing brachytherapy sources often involves a surgical procedure, which itself can be lengthy - albeit occurring only once or twice - and conveys the usual surgical risks. For localised prostate cancer, brachytherapy is usually offered as two options: either by placement of radiation sources in the form of permanent seeds (use of 60-100 small pieces of radioactive isotopes of gold or iodine) often called low dose rate (LDR) brachytherapy, or by use of a high dose rate (HDR) afterloading brachytherapy unit. This is where 10-20 narrow catheters are inserted into the prostate gland transperineally, then a radioactive source attached to a guide wire is introduced into each catheter sequentially for a set period of time (see appendix 2). Following permanent seed implantation, the radioactive half-life of the isotope means that the prostate gland is irradiated over the course of several months, whereas with the HDR catheter option, treatment is

³ At the time of data collection for the present study, evidence from a number of trials was being implemented as a practice change in radiotherapy departments, with most departments changing to the shorter fractionation for localised, locally advanced disease.

given over 1-4 sessions during which time the patient remains an inpatient, as the catheters need to remain in place.

In order to prepare for radiotherapy, patients undergo radiotherapy-specific planning scans. For MPC prescribed EBRT this usually entails one scan appointment during which a scan of the pelvic area is taken, and reference marks (usually in the form of pinprick tattoos) are placed on the skin anteriorly and laterally to aid reproducible set up when treatment commences. The digital data provided by the scan are inputted to specialist computer software in order to produce a map of radiation dose that takes account of differing tissue densities and highlights the specific volume of tissue to be treated (usually the prostate gland with or without seminal vesicles, depending on staging) and any volumes of tissue that need to be avoided such as organs at risk (OAR)⁴ of radiation damage (See appendix 3). From this dose map the treatment machine parameters are determined and the patient's treatment prescription is constructed.

The planning procedure for patients undergoing brachytherapy is somewhat different, often occurring on the same day that treatment is delivered. Patients undergoing permanent seed brachytherapy will have an ultrasound scan either 2-4 weeks before seed insertion or on the same day. The purpose of the scan is to determine the volume of the prostate gland in order to calculate the number of seeds required for treatment. Patients undergoing HDR brachytherapy utilising catheter placement, will normally have a theatre visit for placement of the catheters under anaesthetic and will then have a planning CT scan which checks the position of the catheters and provides the tissue density information required to calculate the position and dwell-time⁵ of the radioactive sources. A dose map is also created from this scan (see appendix 3) with treatment following within around 2 hours of the CT scan being undertaken.

1.1.3 Therapeutic radiographers

In the UK, the protected title 'therapeutic radiographer' (TR) is given to the registered health professional whose responsibilities cover the planning and delivery of radiotherapy. In order to register with the Health and Care Professions Council (HCPC), a TR must achieve a BSc(Hons) or equivalent pre-registration, post-graduate diploma, and first posts for registrants are normally graded at Band 5 (National Health Service (NHS), 2020). In the planning stages the TR role involves using

⁴ An organ at risk (OAR) is defined as "normal tissues whose radiation sensitivity may significantly influence treatment planning and/or prescribed dose" (Symonds et al., 2019).

⁵ The length of time the radioactive source remains in a specific position in order to deliver the required radiation dose.

radiotherapy-specific computed tomography (CT) scanners to acquire images that are then used to create an intricate dose map for each patient, such that dose to tumour is maximised and dose to non-tumour tissues and organs at risk (OAR) is minimised. In the delivery of treatment, the TR interacts with patients, facilitating their positioning on the treatment couch so that radiotherapy is delivered with millimetre accuracy. They also communicate information⁶, advice and instructions throughout the patient's course of treatment aimed at ensuring the accuracy and reproducibility of treatment, and enabling side effect management, but also recognising social or welfare issues that may require referral to specialist services. Advanced practice and consultant radiographers have additional responsibilities. This makes the TR's role a unique blend of technological expertise and patient care.

1.1.4 The pathway for patients with localised or locally advanced prostate cancer

Men are usually diagnosed with prostate cancer either because unusual symptoms have caused them to seek medical advice, or they have undergone a PSA test that returns abnormal or unusual results. In either case, they would normally be referred to a urology clinic for further investigations, usually urinary flow tests, MRI and/or ultrasound guided biopsy, and other physiological testing designed to determine the absence or presence of cancer, and if present, how far it has disseminated. Once a definitive diagnosis is obtained, a period of decision-making ensues where various treatment options are considered within an overall management plan. This plan reflects a patient's age, fitness, presence of comorbid diseases, where they live and whether they have treatment preferences. Most patients are offered ADT straight away; in the UK this is often a drug called Goserelin (Zoladex™) given as a depot injection either every 4 weeks or every 12 weeks. Administration of ADT reduces levels of testosterone, therefore limiting progression of prostate cancer. Use of ADT can therefore allow more time to plan definitive treatments such as prostatectomy or radiotherapy. These often take place weeks or months after ADT commences. Assuming there is no disease progression (indicated by a raise in PSA from nadir point), patients remain on ADT for up to three years. Once definitive treatment finishes, patients are reviewed regularly by follow up, every 3-6 months. Follow up is usually managed via PSA testing and symptomatic review, with imaging reserved for investigating symptom development or increasing PSA.

⁶ Within the radiography standards of proficiency, the Health Care Professions Council (HCPC) refers to information communication and use as being core components of a therapeutic radiographer's role

Throughout this pathway and in accordance with NICE and NHS best practice (Department of Health, 2011; NICE, 2021c), patients should be given appropriate, timely information regarding diagnostic tests and treatment options to aid their decision making.

1.1.5 Information in cancer management

According to NICE, patients should have the opportunity to make informed decisions about their care and treatment, receiving individually tailored information in partnership with their healthcare professionals (HCP) (NICE, 2021b). Health policy has increasingly focussed much more closely on the needs of the patient, with several documents emphasizing the role of information in influencing the patient experience. They include those such as the Calman-Hine report, NHS Plan and NHS Cancer Plan which have done much to shape today's health services in the UK (Calman & Hine, 1995; Department of Health, 2000a, 2000b). This issue has gained further prominence since the unfortunate events at the Mid-Staffordshire Hospitals Trust investigated by Francis (2013). He reported that specific concerns were raised by families and carers regarding lack of information about patients' care or condition, involvement in decisions, provision of wrong information and a failure to listen. A recommendation of this report was that provision of information such that patients could make treatment choices and have a proper understanding of outcomes was the professional duty of HCPs (Francis, 2013). It is in the context of these issues that the original idea for this study was established.

More recent health policy and guidance has emphasised the importance of information in cancer management. In 2015 a new strategy for improving cancer outcomes was published (Independent Cancer Taskforce, 2015). It recognised that communication was the aspect of care in most need of improvement, particularly regarding information about diagnosis and treatment options, with a recommendation that information exchange should take place within shared decision-making conversations. However, some cancer patients felt that conversations were not meeting this principle and information and signposting was often confusing. It also recommended that patients required better support and information regarding living with and beyond cancer (Independent Cancer Taskforce, 2015). Similarly, the NHS long-term plan sets out a commitment to investing in online platforms to aid information seeking and sharing, with empowerment of people being driven by access to trustworthy, personalised health and wellbeing information and support (NHS, 2019).

1.1.6 Information for patients with prostate cancer

As a registered therapeutic radiographer, I have long been aware of my own role in exchanging information with patients and the part this plays in patient care and experiences during radiotherapy.

In 2012 when the rationale for this study was first proposed, there was plenty of literature in the evidence base related to the information needs of MPC (for example Boberg et al. (2003), Cohen & Britten (2003) and Echlin & Rees (2002)), and whilst some studies reported outcomes related to radiotherapy, none had radiotherapy information as the focus or were based on narrative accounts of patients who had received radiotherapy. Given that radiotherapy for prostate cancer is associated with very specific and potentially life-long side effects, and that information related to radiotherapy procedures is geared to reducing the impact of these long-term effects, I determined that there was a gap in the evidence base warranting further investigation and hence the present study was conceived.

1.2 Nomenclature used in this dissertation

1.2.1 Defining “information”

In analysing and synthesising the data, it became clear that I needed to carefully define what I understood the word ‘information’ to mean. The Chambers Dictionary (2021b) definitions of information are:

“1 knowledge gained or given; facts; news. Often shortened to **info**.

2 the communicating or receiving of knowledge.”

Given these definitions I have classified any interaction and/or exchange in any format from which the participants gained knowledge about their diagnosis, management and future outcomes as being ‘information’.

1.2.2 Terms used to classify the participants

Because there are three distinct groups of participants (MPC, their wives, and TR) I have used the following nomenclature throughout this dissertation:

- The MPC will be referred to as such. Although at the time of interview, most of the men were no longer on any active treatment, they were recalling experiences related to their diagnosis and subsequent treatment for prostate cancer.
- All but two of the MPC were married to female spouses with 12 contributing to interviews as participants. There were no non-married couples. Therefore, I will refer to female spouses as ‘wives’ or ‘wife’ throughout the dissertation.
- The therapeutic radiographers (TR) will be referred to as such as this is the protected title afforded to the profession in the UK as registrants with the HCPC.

- Where a point is explored with respect to more than one participant group, the word 'participant' will be used.

1.2.3 Stage of cancer

At the inception of this study in 2012 the terminology used commonly in practice and the wider literature referred to 'early' or 'late' staged prostate cancer to distinguish patients with potentially curable disease versus those with advanced disease where cure is unlikely. In 2021 a new method of categorising risk of prostate cancer progression was adopted. This Cambridge Prognostic Group (CPG) scoring system ranks individual risk from 1 (least risk) to 5 (highest risk) (see appendix 1) (NICE, 2021a). Patients who would formerly have been referred to as having early-staged prostate cancer are now categorised as CPG 1-3. The phrase 'early-staged' has been retained in this dissertation due to it being in use when participant recruitment and data collection took place.

1.3 Research aim and objectives

The principal research aim was to explore the experiences of men with early-staged prostate cancer regarding information related to radiotherapy in the UK.

The research objectives were to explore:

- the factors affecting the understanding of information received/exchanged by men undergoing radiotherapy for prostate cancer
- whether information received was exchanged in a timely manner, appropriate to, and sufficient for their needs
- what information for MPC was given/exchanged before, during and after radiotherapy
- whether MPC had unmet informational needs
- the perspectives of therapeutic radiographers related to information they give men undergoing radiotherapy for prostate cancer
- the role of patients' wives related to information given during the course of radiotherapy.

1.4 Structure of the dissertation

This dissertation comprises eight chapters. This introductory chapter has set out background information related to prostate cancer and its management, the role of the TR, and the context of UK health policy and guidance that demonstrate the place and importance of information in cancer care.

Chapter 2 provides an integrative review of literature, from which a peer-reviewed paper was published (Gordon et al., 2019). The search strategy is outlined, and literature is critically reviewed in relation to information needs, information regarding adverse effects, information and timing, satisfaction of information related to radiotherapy, information preferences and MPC experiences related to radiotherapy information.

Chapter 3 outlines the methodological approach and methods used in the study. It provides the rationale for the chosen qualitative approach, and details the methods used to determine the population and recruit the participants. Methodological considerations related to ethics and consent, the data collection processes, and the thematic analysis process are explored in detail with reference to relevant theory. An overview of the inclusion of patient and public involvement (PPI) is given. A section on reflexivity, focusing on exploration of several aspects of my position as therapeutic radiographer, educator and researcher concludes the chapter.

Chapter 4 is the first of two findings chapters. It is organised chronologically in sections reporting the findings related to the pre-, peri- and post-radiotherapy periods. Within these sections eleven semantic themes are explored, with the latent themes of time and communication highlighted throughout.

Chapter 5 is the second of the findings chapters. It presents the contrasting cases of two men with prostate cancer which demonstrate the influence of information across their trajectories from diagnosis until the time they participated in the study, illustrating key themes described in chapter 4 and noting the similarities and differences for each case.

Chapter 6 presents the discussion of key findings. It presents an examination of theories related to the latent themes of time and communication, within a theoretical framework informed by Bronfenbrenner's ecological systems and bioecological theories. A model representing the ecology of

information related to radiotherapy for MPC is proposed in order to help explain the findings. This model develops Bronfenbrenner's bioecological model (Bronfenbrenner & Morris, 2006), to incorporate communication as a dimension that is inherent in all aspects of the model, with the dimension of time expanded to overtly consider biographical disruption. The chapter concludes with an overview of this study's original contribution to knowledge, some limitations, recommendations for practice and recommendations for further research.

Chapter 2. Integrative review of literature

A peer-reviewed paper based on work presented in this chapter has been published as: Gordon, L., Dickinson, A., & Offredy, M. (2019). Information in radiotherapy for men with localised prostate cancer: An integrative review. European journal of cancer care, 28(3), e13085. The paper presents the results of the main literature search carried out between February and March 2017 (see appendix 4).

2.1 Introduction

A problem I encountered when considering the topic of information was how to manage the broad, diverse and extensive background evidence available in wider cancer care settings; therefore, a method of synthesising a more focussed literature base encompassing only information related to radiotherapy management of prostate cancer was required. According to Aveyard (2019) a literature review is a “comprehensive study and interpretation of literature that relates to a particular question” (p2). The aim of the present review was to identify, synthesise and analyse literature that reported the experiences of MPC related to information in radiotherapy. The search and review process was informed by the integrative review methodology of Whittemore & Knafl (2005). They describe an integrative review as “a specific review method that summarises past empirical or theoretical literature to provide a more comprehensive understanding of a particular phenomenon or healthcare problem” (p546). This type of review is useful where inclusion of studies using a broad range of methodologies is likely (Aveyard et al., 2016), in comparison to a systematic review where a highly focused research question is answered using specific and explicit methods for judging the quality of studies, often entailing exclusion of applied research in favour of randomised trial research (Whittemore & Knafl, 2005). The benefit, therefore, of an integrative review, is that it can synthesise a wide range of studies using a rigorous methodology that reduces bias. It is particularly useful where review of qualitative, mixed method and quantitative studies is required.

Because the original literature search and integrative review took place in 2017 an additional search for literature was carried out in late 2021 using the original search parameters to determine if any further useful literature had been published. The results of that search have been incorporated into the review presented below and detailed in section 2.6.

2.2 Search strategy

2.2.1 Integrative review process

For the main literature search and review carried out in 2017 the Whitemore & Knafel (2005) integrative review framework were used in order to provide a structured approach to the process; therefore it is useful to describe the stages of the process and how they were applied.

The integrative review process follows five stages. The first is problem identification. This involved determining a question that would be used to interrogate the literature and consequently identifying the search terms. In order to ensure full coverage of the evidence base, the search terms were defined using the SPIDER tool (Cooke et al., 2012) which is most useful for retrieving mixed methods and qualitative studies but in the context of an integrative review, will also capture quantitative studies. This process is described in section 2.2.2 below. The second stage is the literature search, where several electronic databases were searched systematically using search terms identified in stage 1. The search is detailed in section 2.2.2 below. The third stage is data evaluation. In this stage the final selection of evidence to be reviewed is evaluated for quality in order to enhance the validity and reliability of the review; however, in integrative review methodology, individual papers are not scored as they would be in a systematic review, rather they are assessed for authenticity, methodological quality, informational value and representativeness. For this process the checklist provided by Bowling (2014) was employed (see section 2.4 below). The fourth stage is data analysis. In this stage, articles were scrutinised in detail and summarised to elucidate commonly occurring themes within the literature and these themes were then used to structure the review and inform the research aims. The fifth and final stage is presentation of the findings in an ordered manner, i.e., presentation of this literature review. The following sections of this chapter detail the search, synthesis and analysis of literature.

2.2.2 Search method

A systematic search for literature was carried out using a research question structured with the SPIDER (Sample, Phenomena of Interest, Design, Evaluation, Research) tool. This was formulated by Cooke et al. (2012) to address the inherent deficiencies of the PICO (Patient, Intervention, Comparator, Outcome) tool when retrieval of qualitative and mixed methods literature is expected. Most qualitative studies do not necessitate interventions or comparisons and the word 'outcome' may presuppose a measurable endpoint. Hence use of the PICO tool to structure a literature search would mean exclusion of valuable and meaningful studies from the search results. Using the SPIDER

framework, the search question formulated was “What are the experiences of men with prostate cancer when receiving information related to a course of radiotherapy?”. Table 1 details the SPIDER framework used.

Table 1. SPIDER search strategy

Sample	men with prostate cancer
Phenomena of Interest	experiences of information related to a course of radiotherapy
Design	all designs and theoretical frameworks
Evaluation	all evaluation/analytic methods
Research	all research (quantitative, qualitative, mixed method, review)

Structuring the search in this way allowed several focussed search terms to be developed to carry out a series of electronic database searches. The main search terms used were “prostate cancer”, “radiotherapy”, “radiation therapy”, “information” and “patient experience”. Use of synonyms, truncations, wildcards and MeSH terms was employed (where allowed by the database) to expand the range of terms used, hence allowing more detailed searching. In particular, the use of wildcards (or alternative spellings where wildcards were not available) allowed consideration of variant spellings. This was important to reflect the international picture; for example, in the UK the word ‘tumour’ is used whereas in the USA it is spelt ‘tumor’. All search terms were used in numerous combinations by applying the Boolean operators ‘AND’, ‘OR’ and ‘NOT’.

Initial searches of electronic bibliographic databases for Pubmed, CINAHL plus, Cochrane library, Scopus, and Science Direct used a publication date range of the years 2000 - 2017. The rationale for choosing the earliest point in this timeframe was to account for advances in conformal radiotherapy and any associated changes in radiotherapy-induced side effect profiles that may have necessitated evolution of patient information. It is worth reiterating that the pace of technological change in radiotherapy is rapid, and indeed, across the course of this doctorate, the standard radiotherapy prescription for early-staged prostate cancer changed due to the findings of the CHHiP⁷ and HYPRO⁸

⁷ Conventional versus Hypofractionated High-dose Intensity-modulated radiotherapy for Prostate cancer

⁸ HYPofractionated versus conventionally fractionated radiotherapy for patients with PROstate cancer

trials (Aluwini et al., 2016; Dearnaley et al., 2016; Royal College of Radiologists, 2019). Prior to the year 2000 most radiotherapy would have been delivered using techniques that involved larger treatment volumes and hence would cause more significant side effect profiles than current techniques. Advice and information given to patients regarding side effects has evolved in parallel.

Animal and laboratory-based studies were excluded to ensure only studies with human participants were returned. A limit of English language was applied to reflect my first language. Hand-searches of individual journals (Journal of Radiotherapy in Practice, Radiography, European Journal of Cancer Care, PsychoOncology) were carried out to find articles not identified in database searches. This occurred following the initial database searches when it became apparent that I had not found papers known to be relevant as part of the database searches. The journals detailed above are specific to the discipline of radiotherapy. Additional searches of web-based resources were carried out to search for potentially useful, unpublished literature, including the Society and College of Radiographers, NHS research, NICE, British library thesis archive and OpenGrey websites. Searching for literature is an iterative process and throughout the remainder of the doctorate, searches using the same databases, terms and limits were carried out to identify further relevant literature published after March 2017. Any relevant literature discovered in this way was incorporated into the review presented in this chapter.

Separate searches were also carried out to identify relevant government and health policy documents. These are explored as part of the introduction chapter; hence this integrative review chapter reflects the peer-reviewed evidence base.

2.3 Search outcome

Initial database searches in February and March 2017 retrieved 4954 articles (after removal of duplicates). Initial examination of a selection of the articles' titles and abstracts noted that many were based on experimental studies, or studies involving MPC but without reference to information or radiotherapy, despite the correct application of the Boolean operators. For this reason and although time consuming, it was necessary to screen each of these against a further set of inclusion criteria to ensure relevance to the research question posed and inclusion of relevant papers. Thus, full-text articles were retrieved if they met one or more of the following inclusion criteria:

1. Prostate cancer/ radiotherapy/information/experience mentioned in article title

2. Radiotherapy referred to as a management option
3. Reported on patient experience related to information in radiotherapy.

This initial 2017 screening process resulted in retrieval of 105 full text articles. The individual journal searches returned a further 17 articles. The website and grey literature searches did not uncover useful papers or information sources that had not already been found during the database searching. Aveyard (2019) recommends searching of reference lists of articles retrieved to identify any further articles not retrieved in the main search. This was carried out but applying the same date range limits to acknowledge that articles published at the earliest point in the date range would reference older literature. This exercise retrieved a further 43 articles, giving a total of 165 full-text articles that were then subject to detailed inspection. On close reading, articles were excluded from further review for the following reasons:

- There was no focus on radiotherapy and/or information and/or prostate cancer and/or patient experience
- The articles comprised literature or narrative reviews of papers that had already been retrieved as primary sources, or that the papers reviewed in those articles had been published before the year 2000
- Articles written as essays were excluded due to the high risk of bias
- One article was a first-person narrative written by a patient, but was excluded as its focus was treatment decision-making
- One news article was excluded due to focus on diagnosis
- One discussion paper was excluded as the focus was on treatment consent

Following this final inspection 33 papers were considered relevant and selected for inclusion in the review. A summary of the search and review process can be found in the figure 1 PRISMA diagram below.

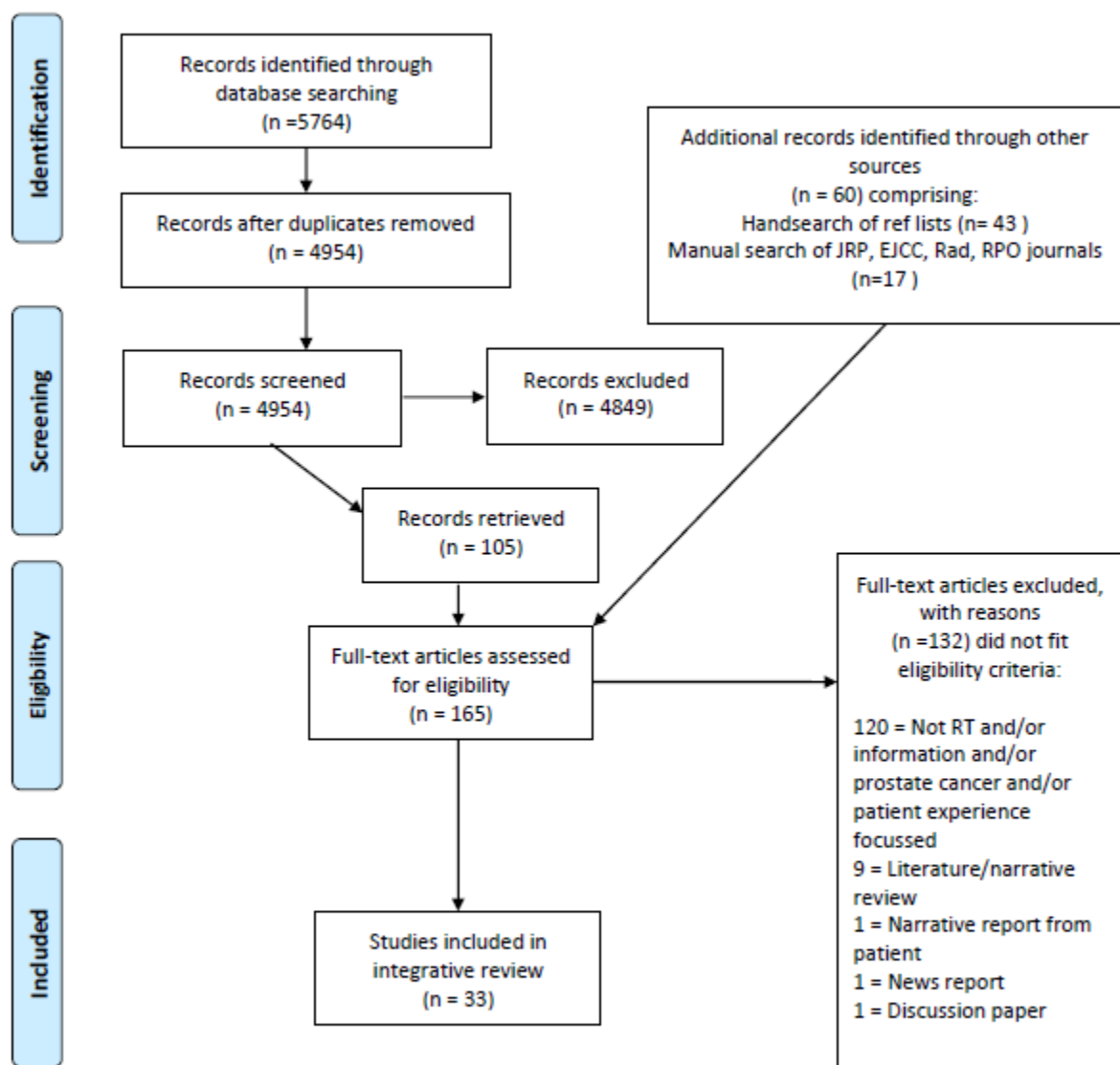


Figure 1. PRISMA diagram summarising results of searches carried out from February – March 2017

2.4 Quality assessment

Once the final selection of articles was determined, the next stage of the Whitemore and Knafel (2005) integrative review process was to evaluate the quality of the literature. A quality evaluation process is more conducive to reviews where the research designs are similar or identical (such as in systematic reviews), normally encompassing randomised controlled trials or other controlled study designs with measurable outcomes (Bowling, 2014) and the PRISMA checklist has emerged as the standard

evaluation to be used when conducting systematic reviews (Page et al., 2021). However, although several checklists exist for the evaluation of qualitative research (for example Northcote (2012)), there is currently no gold standard framework that enables a quality review of diverse sources including a range of methodologies. Therefore, an adaptation of Bowling's checklist was used to assess the selection (see table 2), thus ensuring validity and reliability of the literature review (Bowling, 2014).

Whilst some papers exhibited flaws related to reporting of sampling and aspects of method, overall, none were of poor enough quality to be excluded despite being ranked at a low level of evidence according to the traditional evidence pyramid (Offredy & Vickers, 2010). The final selection of 33 papers (based on 32 studies⁹) was confirmed following evaluation of relevance to the review aims and the inclusion and exclusion criteria applied during the search process.

⁹ To note: the Kelsey et al., (2004) and Owens et al., (2003) papers reported differing analysis/findings related to the same data set.

Table 2. Quality appraisal of studies utilising Bowling's checklist for critical appraisal of scientific literature (Bowling 2014)

Reference	Adler et al. 2009	Appleton et al. 2014	Barnett et al. 2004	Bennenbroek et al. 2003	Blomberg et al. 2016	Bolderston 2008	Boulton et al. 2015	Clarke & Burke 2016	Dale et al. 2004	D'Alimonte et al. 2011	Davison et al. 2002	Dieperink et al. 2013	D'Haese et al. 2000	Douma et al. 2012	Dubois & Loisele 2008	Eheman et al. 2009	Griffiths & Hodgson 2011	Kazer et al. 2011	Kelsey et al. 2004	Lamers et al. 2015	Lehto et al. 2015	Long 2001	Majumder et al. 2014	Nanton et al. 2009	Nicolaisen et al. 2014	Ormerod & Jessop 2015	Owens et al. 2003	Sinfield et al. 2008	Stewart-Lord et al. 2016	Sule-Suso et al. 2015	Thavarajah et al. 2015	Tomlinson et al. 2014	Wolpin et al. 2016				
Clearly stated aims	✓	✓	✓	✓	✓	✓	✓	x	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓		
Study design described	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	
Appropriate research methods	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	
country of study	✓	✓	✓	✓	✓	✓	✓	x	✓	x	✓	✓	x	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	
date of study	✓	x	✓	x	x	x	x	x	x	x	✓	✓	x	x	✓	x	x	x	x	✓	✓	✓	x	✓	✓	✓	x	x	x	✓	x	x	✓	✓	✓	✓	
site of study	✓	x	✓	✓	✓	✓	✓	x	✓	x	✓	✓	x	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Sample size & coverage reported	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	x	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	x	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
response rates/ sample attrition stated	✓	x	✓	✓	x	✓	✓	n/a	✓	x	✓	✓	x	✓	✓	✓	✓	✓	x	✓	✓	✓	✓	✓	✓	x	x	✓	x	✓	✓	✓	✓	✓	✓	✓	
sample characteristics given	✓	x	✓	✓	✓	✓	✓	x	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	x	✓	✓	✓	✓	✓	✓	x	x	✓	x	✓	✓	✓	✓	✓	✓	✓	
theoretical framework	x	✓	x	x	✓	x	✓	✓	x	x	✓	✓	x	x	✓	x	✓	x	x	x	x	✓	x	✓	x	✓	x	✓	x	x	x	x	x	x	x	x	
predictors & outcomes assessed	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	✓	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	
measurement tools with evidence of reliability and validity	x	n/a	✓	✓	n/a	✓	n/a	n/a	✓	✓	✓	n/a	x	✓	n/a	✓	✓	n/a	n/a	✓	✓	n/a	✓	n/a	✓	n/a	n/a	n/a	✓	✓	✓	✓	✓	✓	✓	✓	
outcomes/ results/ findings	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Generalisability considered	✓	✓	x	✓	x	✓	✓	x	✓	✓	x	✓	✓	x	x	✓	✓	x	x	✓	x	✓	x	x	✓	x	x	✓	✓	✓	x	x	x	x	✓	✓	

2.5 Data analysis & synthesis

To make sense of the studies and begin exploring the relevance to the research question, I developed a data charting form. For each of the 33 articles the following information was charted: Authors, year of publication, location (country) and setting/context of the study, research design, sample characteristics and sizes, data collection/generation measures, study aims, summary of outcomes and key findings (see table 3 in Gordon et al. (2019) provided in appendix 4). This was a time consuming and exacting process but allowed the immersion in the literature required to begin analysis. Data were synthesised with the intention of allowing thematic reporting to explore issues related to the literature review question: “What are the experiences of men with prostate cancer when receiving information related to a course of radiotherapy?”. As a result of the charting, synthesis and initial analysis process, six themes were identified: information needs, information regarding adverse (side) effects, information and time, information preferences, satisfaction with information related to radiotherapy, and experiences related to radiotherapy information. These themes are explored in section 2.7 below.

2.6 Follow up literature search

A follow up search was carried out in November 2021 to capture literature that had been published after the original integrative review had been carried out. This search used the same databases and search terms as the original search. This identified a further 878 articles published during the period from April 2017 to November 2021 inclusive. 108 duplicate articles were noted giving a total of 770. Detailed review of titles and abstracts according to the original inclusion and exclusion criteria excluded all but 27 articles as being not relevant. Review of full texts of these 27 articles determined that seven were relevant and review of reference lists identified one further article. These were incorporated into the literature review presented in this chapter. Note that two articles published as a result of the present study appeared in the search results but are excluded from the review. A PRISMA diagram giving an overview of this second literature search, tabulated summaries of the eight articles and a summary of the quality review of these articles can be found in appendix 5. Relevant findings from the literature are included in the review of literature presented in section 2.7 below.

2.7 Findings from the literature

2.7.1 Overview of article characteristics

Seventeen studies were carried out in the UK, seven in mainland Europe, six in Scandinavia, five in Canada, five in the USA and two in Australia. Two papers reported findings from the same data set (Kelsey *et al.*, 2004, Owens *et al.*, 2003) as previously stated. In 28 studies recruitment was from single centres including 12 of the 17 UK-based studies. This pattern of small, single centre studies is likely to reflect local needs and practicalities: all but three employed convenience or purposive sampling of local populations. Ten studies recruited from two to four settings, one recruited from 17 outpatient oncology clinics in the USA and one utilized national cancer registry data. Five studies reported sample sizes larger than n=500: a UK cross-sectional survey-based study (n=24101), a Dutch regional survey (n=697), a Finnish national survey (n=1239), an American multisite, longitudinal study (n=731) and a Swedish single-centre, cross-sectional survey (n=656). Eighteen studies utilised qualitative design with sample sizes ranging from n=9-127 participants; however, four of those reported the qualitative components of mixed-methods studies. The research design reported for qualitative studies comprised cross-sectional qualitative (n=2), qualitative framework (n=1), qualitative descriptive (n=7) and phenomenological (n=4) designs, with the remainder not specifying a particular qualitative approach. 21 quantitative studies comprised survey-based (n=14), longitudinal (n=3), pilot (n=2) randomised (n=1) and pre/post-test (n=1) designs. The sole randomised study reported a randomisation process but was not controlled: it reported survey-based, subjective reports from patients randomised to two groups, each receiving information at different time points. In 27 studies men with PC (and partners where applicable) were sampled, the rest sampled across a range of cancer diagnoses: three included sampling of both patients and HCP, and one sampled only therapeutic radiographers and assistant practitioners.

A limit applied to the original search was to retrieve only studies published between the years 2000 and 2017 in order to reflect conformal radiotherapy techniques. However, it was interesting to note that 18 studies sourced from this search did not include the dates/time frame of data collection. Potentially, therefore, some participants could have been reporting issues related to out-of-date radiotherapy techniques; however, for most of the studies where MPC were participants, the method sections reported when participants had received radiotherapy. In the majority of cases participants were recruited just before, during, or within 6 months of their radiotherapy; however, in two studies that explored longer term sequelae of treatment (Boulton *et al.*, 2015; Kazer *et al.*, 2011), participants had received treatment up to 11 years before their data were collected. Therefore, it is unlikely that

the overall findings of this literature review reflect issues with information related to historical radiotherapy procedures.

2.7.2 Information needs

This topic is explored widely in the literature across a range of health care settings. In papers retrieved early in the literature search process, several appeared relevant to the research topic but were then screened out due to the inclusion criteria applied. For example, a cross-sectional survey-based study by Valero-Aguilera et al. (2014) explored information needs of 269 patients with breast and urological cancers but focussed on their internet usage and with no focus on information needs during radiotherapy. Other examples reflected metastatic prostate cancer, information needs of cancer survivors, and treatment options other than radiotherapy (e.g. Diver et al. (2018), Jenkins et al. (2019) and Loeb et al. (2018)). A number of papers exploring patients' information needs as part of the primary research question reflected the wider prevalence of this topic in the literature (Ahamad et al., 2019; Bolderston, 2008; Chauhan et al., 2018; D'Alimonte et al., 2011; Dale et al., 2004; Douma et al., 2012; Thavarajah et al., 2015; Wolpin et al., 2016), with others mentioning information needs within background, findings and/or discussion sections (Adler et al., 2009; Blödt et al., 2018; Boulton et al., 2015; Dubois & Loiselle, 2008; Ehemann et al., 2009; Long, 2001; Majumder et al., 2014; Nanton et al., 2009; Owens et al., 2003; Sinfield et al., 2008; Smith et al., 2019; Sutton et al., 2021; Tomlinson et al., 2014).

The survey-based pilot study by D'Alimonte et al. (2011) explored information needs of ten MPC who had undergone prostatectomy at one cancer centre and were deciding whether to receive radiotherapy, and the social determinants affecting those needs. Due to the small number of participants, the findings must be treated with caution, but provide an interesting perspective. No correlation was found between information needs and the social determinants explored (income and educational level); however, they noted knowledge gaps about radiotherapy side effects related to a lack of information, which concurs with the findings of Nanton et al. (2009). Nanton's qualitative study explored experiences of uncertainty across the MPC patient journey, so did not specifically focus on aspects related to radiotherapy; however, the issue of lack of information about long-term side effects caused concern to several participants, reflecting their uncertainty regarding how to adjust to their 'new normal'. By comparing these two studies it is demonstrated that information requirements of patients can begin long before active management of their cancer commences and may also continue long after.

Two papers explored patients' changing information needs over time. In a longitudinal study of 104 patients with varying cancer diagnoses undergoing radiotherapy, Douma et al. (2012) reported that information needs decreased over time albeit remaining high. In another longitudinal study, Wolpin et al. (2016) explored changing information needs over time for 35 MPC. In Douma et al. (2012) one explanation given for this pattern of changing needs was that patients may have had difficulty recalling information given in their initial consultations. However, Douma et al. (2012) also pointed out that information needs might remain high due to initial information needs being unmet. This issue is also considered in Boulton's qualitative study exploring experiences of long-term side effects following pelvic radiotherapy where information initially provided was not sufficient to prepare some participants for the reality of undergoing radiotherapy, and that no amount of information would "make it any better" (Boulton et al., 2015, p.740), highlighting the complexity that HCP need to manage related to information giving. In the Douma et al. (2012) study, findings for MPC were not reported separately to other urological cancers; however, across diagnoses being male was statistically significantly associated with a decrease in information needs over time regarding procedures¹⁰ ($p=0.01$, $\exp b=0.28$, $95\%CI=0.10-0.76$), suggesting potential gender differences in the way information is needed and/or processed. In their study, Wolpin et al. (2016) reported findings in terms of information priorities rather than information needs, with patients asked to rank a selection of information topics according to their priority. This repeated measures study administered a survey at four time-points, beginning two weeks after the pre-treatment visit¹¹ and at fortnightly timepoints thereafter, with the last at 10 weeks (assuming a 6-7 week course, the last measurement point would occur within 2-4 weeks of radiotherapy finishing). Wolpin et al. (2016) found that information on prognosis became more important as treatment progressed, whereas information on side effects and treatment options became less important, suggesting that priorities can shift as treatment progresses through to the follow-up period. This pattern might reflect that information is given by therapeutic radiographers daily during treatment in response to side effect monitoring. For example, for MPC, it is expected that radiotherapy will cause changes to bowel habits, so radiographers will question patients daily so that appropriate interventions can be made should changes to bowel habits occur¹².

¹⁰ In this study, 'procedure' relates to localisation and treatment procedures

¹¹ Although not stated in the study, if the process of managing radiotherapy is similar to that in the UK, this would be the appointment for the localisation CT scan procedure

¹² This requirement to monitor the patient and act appropriately is one of the core practice skills set out in the HCPC standards of proficiency for UK radiographers

Dale et al. (2004) reported on the design and piloting of a scale used to assess the importance of specific items of information needed by MPC. The final scale was developed following a series of focus groups and interviews with urology staff and patients and comprised 20 items. Participants were asked to rank each item regarding the importance/amount of information needed from very important/too much information to not at all important/no information. The scale was subsequently piloted on 96 patients recruited from 17 different urology clinics. The highest rated need for information was regarding disease management; by inference, this included information on radiotherapy. As all participants had been diagnosed more than four weeks before completing the scale it might be expected that they would have received/sourced some information on treatment options. It should be noted that 66% of patients in the study were receiving palliative management where information needs are different from those undergoing curative treatment, and the mean duration since diagnosis for all patients was 32 (1 – 103) months. Because the sample was recruited from urology outpatient clinics it is possible that the sample was skewed towards patients undergoing ongoing management; MPC successfully treated with definitive surgery or radiotherapy would have less need to attend the clinics due to being discharged. It is worth noting that the final scale excludes reference to side effects other than sexual dysfunction despite one of the themes generated from the focus groups being the benefits and complications of treatment options, although this was mentioned as a limitation of the study. Given that 63% of participants were receiving ADT (an expected side effect of which is sexual dysfunction) it is interesting that the sexual functioning item on the scale was given lower levels of importance. However, other research has reported the reluctance of, or lack of opportunity for patients to discuss sexual functioning (Flynn et al., 2012; Griffiths & Hodgson, 2011; Kinnaird & Stewart-Lord, 2020), hence this lower score may reflect an unmet need for information about sexual functioning.

Bolderston (2008) used a Likert-scale survey to investigate education and information needs specific to radiotherapy for a range of cancers, comparing 183 patient and 42 radiation therapists' rankings regarding what patients want to know. Findings demonstrated that both groups ranked information needs about side effects highest. This contrasts with Thavarajah et al. (2015) who reported low ratings for information needs about radiotherapy side effects in their study of 31 MPC. These men were surveyed either before during or after receiving post-prostatectomy radiotherapy in order to gain their opinions on the topics that should be discussed between HCP and patients who may require post-prostatectomy radiotherapy for adjuvant or salvage intent. An earlier study by D'Alimonte et al. (2011) had focused on development of a Likert scale-based questionnaire tool aimed at addressing the informational needs of the patients in the same treatment category, with the Thavarajah et al. (2015)

survey focussing on the participants' judgements regarding the questions contained in the questionnaire. The questions rated most important reflected the patients' need to know about their prognosis/chance of cure with over 90% of patients ranking these highly. Although some questions about radiotherapy appeared in the top 10 most highly ranked, these also related to prognosis and/or impact of radiotherapy on overall outcomes. The low rating for information needs relating to side effects is interesting, considering that 68% of patients were either receiving or had received radiotherapy at the time of completing the survey, indicating perhaps that the information needs relating to side effects had been met, possibly due to the detailed information that is given by radiographers during a patient's course of treatment.

A factor to take into consideration for this theme is that of the research design implemented in the studies reviewed. Of the studies whose research questions considered information needs directly, all used quantitative, survey-based designs. All but one of the studies were single centre studies and four studies surveyed less than 100 participants each. There was heterogeneity in the study participants: two studies considered only post-prostatectomy patients, two included patients with a range of cancer diagnoses, with another two focussing on MPC but giving no details about whether they had received treatments other than radiotherapy. This means that although several issues related to information needs have been explored, none of the findings can be considered generalisable.

In summary it appears that patients' information needs vary across the course of their diagnosis, management and follow up, and furthermore are an important consideration before, during and after radiotherapy. It suggests there is a gap in the evidence base for qualitative research exploring in depth the information needs of MPC undergoing radiotherapy rather than exploring the cancer journey as a whole.

2.7.3 Information regarding adverse (side) effects

In studies exploring information needs, information concerning radiotherapy side effects emerged as an issue warranting further exploration, and this was also apparent in several other studies reviewed. Two studies focussed on views of participants regarding information on side effects of radiotherapy (Barnett et al., 2004; Boulton et al., 2015). Barnett et al. (2004) surveyed 82 cancer patients with a range of diagnoses on the amount of information that patients should be given at the time of treatment planning about the risk of developing mild, moderate, or severe radiotherapy side effects. Of the 82 participants, 16 were MPC. Although the participant characteristics were stratified

according to cancer type, other results were not which limits interpretation for the participants with prostate cancer. There was a trend in the data to suggest that participants had a higher information requirement as the severity of side effects increased (40%); however, the only statistically significant finding was that information requirements of patients under the age of 60 years for information on severe side effects tended to be greater ($\chi^2= 10.57$, $df= 2$; $P = 0.007$); however, it cannot be assumed that older patients need less information. The need for information on severity of side effects varied considerably across age groups and diagnoses, so the authors concluded that an individualised approach to information is required. Boulton et al. (2015) similarly concluded that patients need individually tailored or personally contextualised information on side effects. In their qualitative study using a framework approach 28 participants with a range of diagnoses who were between one- and eleven-years post-radiotherapy were interviewed about information on long-term side effects of pelvic radiotherapy. Five participants were MPC. Subsequent analysis of interview data identified two main themes: response to what information was given and response to how information was given. Within the overall findings, participants recognised the value of information related to long-term effects, but also acknowledged that it could cause undesirable effects and limit the way they dealt with treatment consequences. This is an important point that links to informed consent and a patient's right to receive specific information relevant to them (General Medical Council, 2020). Under the guidance, doctors are expected to make a judgement regarding what information is shared with a patient prior to gaining their consent to undergo a medical procedure. Such information includes potential benefits, harms and uncertainties, but this must be related to a patient's needs, priorities and values, and how well they understand the information being given. Therefore, the information provided by doctors during the consent process is designed to ensure patients fully understand the implications of treatments they are consenting to, and the potentially life-changing decisions they are making and yet giving too much information may adversely affect patients' decision making. This paradox of determining the information patients need/want regarding side effects is exemplified in the verbatim comments that Boulton et al. (2015) reported for four MPC. One participant valued the information he received about potential side effects as it relieved anxiety; however, another reported that receiving too much detailed information could be counterproductive as it was frightening and could deter people from having treatment. Another participant felt relieved that a booklet description matched his personal experience of side effects, providing reassurance and improving quality of life.

Several other studies noted information on side effects as being of high importance. Bolderston (2008) surveyed 183 patients and 42 radiation therapists in Canada to compare perceptions regarding patient educational needs. Fifty-eight of 183 patients surveyed received radiotherapy to the pelvis, some of

whom might have been MPC, although this is not specified. Patients and therapists were given a survey comprising 15 Likert scale questions and for each they rated on a 4-point scale from “not important at all” to “extremely important”. Information on side effects management was ranked the most important of 12 topics by both patient and radiation therapist participants (scores of 3.61 and 3.98 respectively). These results are perhaps unsurprising given that the patients were receiving radiotherapy when they completed the survey, and as previously stated, side effect management is a core component of the therapeutic radiographer’s role. In comparison, Davison et al. (2002) reported information on side effects as being the fourth most important topic in their survey of 80 men with PC and their partners to assess decision-making and information preferences at diagnosis. At the point of diagnosis, information on prognosis was the most important topic suggesting that when patients have chosen and are then receiving radiotherapy, information on side effects becomes more important to them. In contrast to these three studies, Thavarajah et al. (2015) reported that participants did not rate information about side effects as essential, perhaps because they had not yet reached the point of receiving radiotherapy. Furthermore, a noteworthy point raised in a study by Clarke and Burke (2016) was that some patients felt the information they received from radiographers in their first day chat was comprehensive enough that they could manage side effects on their own for the duration of treatment. One study specifically explored symptoms and side effects during and six months after radiotherapy for prostate cancer Blomberg et al. (2016). This study comprised a scoping review of the literature plus a qualitative component involving semi-structured interviews with 10 HCP and eight men with PC. Comments regarding information on side effects give a mixed picture. One patient complained that information contradicted their experience (suffering hard stools when they had been told to expect loose bowel movements) while another felt that information was lacking detail (experiencing pain due to a hormonal treatment was not expected as this was not given in the information). HCP were aware of the need to provide information, in particular about sexuality and intimacy, and had the impression that patients did not want to talk about these issues; however, the patients were concerned about the HCP focus on potency rather than wider issues related to longer term sexual problems. The focus of the Griffiths & Hodgson (2011) paper was to explore professionals’ attitudes and confidence in providing sexuality information to MPC. 42 therapeutic radiographers and assistant practitioners took part in a pre-post test design survey related to an educational intervention designed to provide knowledge and understanding about sexual issues in patients with prostate cancer. At the start of the study 73% of participants reported that they did not give patients any information on sexual issues, the main reason being their lack of knowledge and/or education on this topic, with the second most common reason being their own or the patients’ embarrassment. This reluctance of HCP to talk to patients about sexual functioning, or their lack of

knowledge on this subject has been the subject of several other studies (for example Gianotten (2021), Hordern & Street (2007), Kinnaird & Stewart-Lord (2020), O'Brien et al. (2011) and Ussher et al. (2013)). The issue of sexual dysfunction therefore appears to be the one of the side effect issues of most concern to both patients with prostate cancer and HCP.

Other studies mention side effects only briefly and do not report extensive findings related to information on side effects. The largest study reviewed is the national radiotherapy survey reported by Tomlinson et al. (2014) which includes findings related to 24101 cancer patients from 49 UK radiotherapy providers. Unfortunately, this survey does not stratify responses by type of cancer; however, given that prostate cancer is the most common male cancer in the UK and second only to breast cancer in terms of overall numbers (Cancer Research UK, 2021), it is likely that a large proportion of responders had a prostate cancer diagnosis. Positive findings from this survey were that, during the consent process, 99% of patients understood the benefits and side effects of radiotherapy and 95% reported being given information to manage side effects, indicating that some improvements in information may be required to ensure patient care is optimised. Tomlinson et al. (2014) point out that issues related to retention or recall of information, health literacy or timing may have contributed to the 5% of patients reporting they did not receive information about side effects, indicating that further research may be warranted to find out why these gaps occur. In a national cross sectional survey of 1723 Finnish men with PC, Lehto et al. (2015) reported that around half of the participants were satisfied with the information they received about side effects; however, the reporting does not distinguish between different types of treatment, therefore it is difficult to know whether this referred to radiotherapy side effects. As stated in section 2.7.2, Nanton et al. (2009) found that despite a lack of information regarding a range of long-term side effects, men were able to manage aspects of their own condition, thus adjusting and enabling them to continue with their usual routines. Interestingly Sutton's qualitative study exploring long-term side effects following radiotherapy for men with localised PC found that where men had longer term problems, it became difficult to distinguish between impact of comorbidities, normal ageing, and treatment side effects, and that those experiencing more severe side effects felt they had not been sufficiently prepared (Sutton et al., 2021). This indicates potential issues with patient expectations and further evidence that information requirements regarding survivorship and longer-term quality of life outcomes needs closer attention in future research. Two studies investigated the use of the Virtual Environment for Radiotherapy Training (VERT) (Vertual, 2021) for the delivery of radiotherapy information to patients (Stewart-Lord et al., 2016; Sulé-Suso et al., 2015). Both studies found increased patients' and relatives' knowledge and understanding related to side effects, with participants in the Sulé-Suso et al. (2015) study noting

that VERT enabled them to understand how and why side effects occur. Stewart-Lord et al. (2016) also found that treatment preparation information was rated highly so there is potential for use of this system to help improve patient compliance with information, thus helping to reduce some side effects, especially in the acute phase.

A number of qualitative studies mention side effects. The study involving 27 men with PC by Appleton et al. (2015) investigated the impact of prostate cancer on everyday life with some findings indicating participants' concerns about living with side effects in the longer term. In the qualitative study by Owens et al. (2003) focussing on experiences of 17 men with PC undergoing radiotherapy, the theme of 'side effects' was explored in some depth in the findings. Although in both studies some interesting points were made regarding the side effects experienced by the participants, this was not linked to the topic of information in either. In the study by Kelsey et al. (2004), which used the same data set as Owens et al. (2003), information about side effects is not mentioned directly; rather, it is referred to in terms of patients searching for information about treatments and their consequences. Dubois and Loiselle (2008) interviewed 20 newly diagnosed patients with either breast or prostate cancer regarding the role of informational support in relation to the use of health care services. They found that patients contextualise pieces of information, with one patient with PC reporting that if an information source contained information about side effects, they would see that as normal if that side effect happened to them. This lack of specificity regarding side effects for individual treatment options is unsurprising given that the study explores the cancer diagnoses in general terms. Ormerod & Jessop (2015) explored the support of patients with prostate cancer during radiotherapy, interviewing 7 men with PC and two staff members as part of their qualitative study. Following thematic analysis two main themes were generated. Whilst the topic of side effects was reported several times within the 'clinical assessment of symptoms' theme, it occurred only once as part of the 'information giving' theme as a verbatim quote related to treatment review clinics. In the qualitative study by Kinnaird & Stewart-Lord (2020) focussing on sexual dysfunction following radiotherapy and ADT, 10 men were interviewed. Not surprisingly, findings related to side effects focussed on sexual dysfunction, but an important finding to note was the inconsistency in amount and accuracy of information given. Men reported being surprised at the onset of symptoms and that a focus on physical side effects meant they were unprepared for psychosocial changes that developed. Overall men felt unprepared for long-term changes in quality of life echoing the findings of Sutton et al. (2021) who noted that men experiencing severe side effects reported that they had not been sufficiently prepared for the reality.

Finally, in two papers by Eheman et al. (2009) and Nicolaisen et al. (2014), information related to side effects was mentioned briefly in discussions, related to participants actively searching for information about treatment options and coping strategies; however, these issues were not explored in detail.

When considering the existing literature base related to information and side effects, it is clear that this is an important consideration for many patients and practitioners, especially related to sexual functioning. Patients need information on side effects in order to manage and cope with radiotherapy and there is a clearly defined role for a variety of HCP in ensuring their patients are given appropriate information; however, the current literature base also exposes a dearth of research focused on radiotherapy side effects, with findings suggesting that information about side effects is inconsistent and incomplete for a number of patients. Of particular concern is that many patients reported being unprepared for the longer-term side effects of treatment, pointing to lack of opportunity to discuss these or lack of information about long-term effects both before and during treatment. This may signify an area of unmet information needs warranting further investigation.

2.7.4 Information and time.

The temporal nature of information is reflected in two areas. Firstly, timeliness of information: whether information was given at the time it was needed, and secondly, time constraints: whether HCP have sufficient time to give appropriate and useful information.

Several papers reported the importance of timely information (Appleton et al., 2015; Boulton et al., 2015; D'Haese et al., 2000; Long, 2001). In their cross-sectional qualitative study Appleton et al. (2015) interviewed 27 men with PC before, during and after radiotherapy, noting that the nature of information and the timeliness in which it was received from HCP were factors contributing to the impact of PC on daily life and effective treatment decision-making. They noted that alongside being given information in a timely manner, having time to assimilate the information in order to make decisions was also important. Similarly, the qualitative study by Boulton et al. (2015) reported that timing of information impacted on decision-making and participants' understanding of side effects. Given the pressures on health services to initiate cancer treatment within 4 weeks of diagnosis (Department of Health, 2000) there is some tension in allowing patients enough time to decide on treatment options versus adverse impact on prognostic outcomes if the start of treatment is delayed. However, quality of life outcomes must also be considered; indeed, weak evidence from a systematic

review by Kashaf and McGill (2015) suggested that patient involvement in decision making has a positive impact on quality of life outcomes in cancer.

In a phenomenological qualitative study, Long (2001) interviewed 20 participants about their experiences of undergoing radiotherapy. Findings indicate that timing of information was crucial in allaying anxieties and was related to the pre-formed ideas patients had about radiotherapy. Timing was also an important factor related to retention of information. Some participants reported that they had difficulty retaining information given at their first consultation because it contained information that was irrelevant to their needs at that point. Further, there was some reporting of dissatisfaction when information was given later than would have been helpful. These issues are echoed in the randomised, repeated measures study by D'Haese et al. (2000) which investigated the effect of timing of information on anxiety and satisfaction of patients receiving radiotherapy by comparing a group receiving all information simultaneously with a group who received it at three time points (before, during and at the end of radiotherapy). Patients given two formats of information simultaneously at the initial consultation were significantly more anxious than those receiving the same information sequentially ($p=0.02$). However, the difference between groups had disappeared by the end of treatment. It is worth noting that this is the oldest study reviewed and information giving processes are likely to have changed in the 21 years since the study was published; nevertheless, receiving a cancer diagnosis and coping daily with the consequences, even years after the initial diagnosis, has been reported as common for many patients in more recent literature (Berry-Stoelzle et al., 2020).

In other studies, no empirical findings were generated; however, timeliness was variously noted as being associated with provision of supportive information (Tomlinson et al., 2014), impact on patient support (Clarke & Burke, 2016), impact on decision making (Thavarajah et al., 2015) and contributing to satisfaction with information (Grondhuis Palacios et al., 2019; Lehto et al., 2015). Clarke and Burke (2016) also reported findings related to on-treatment review, noting that one patient felt having a treatment review appointment would involve additional time spent in the department, therefore causing more stress than benefit. This indicates therefore, that the issue of time may also relate to the impact of radiotherapy on a patient's normal routine, even when additional opportunities to gain information from the HCP are provided. In the Lehto et al. (2015) study, timing of information was given as a cause of dissatisfaction with the way patients learned about their diagnosis; however, this finding was not explored further. A notable point made by Thavarajah et al. (2015) was that travel time may impact on decision making regarding treatments although no empirical evidence was given

to support this point. However, it is worth considering in terms of the geographic demography of patients – some patients who live in rural settings in the UK may regularly travel over an hour for radiotherapy and this is an issue being addressed in recent cancer strategies behind the building of satellite radiotherapy hubs so that radiotherapy is a more accessible option for more patients (Cullen et al., 2019).

Time constraint was mentioned in three papers as a reason for information quality being suboptimal (Griffiths & Hodgson, 2011; Lehto et al., 2015; Long, 2001). Griffiths & Hodgson (2011) investigated the attitudes and beliefs of 49 therapeutic radiographers and assistants before and after an educational intervention about information on sexuality for men with PC. The pre-intervention findings identified lack of time as the fourth most common reason for not giving patients information on sexuality. A statistically significant, moderate correlation was found between staff confidence in addressing sexual concerns and making time to give sexual information ($r= 0.453$, $p<0.01$). The issue of time constraints was also implicated by 8% of 1,239 men with PC responding to the Lehto et al. (2015) survey of patient experiences, where they reported dissatisfaction with how they learned of their diagnosis. However, 82% expressed satisfaction with the amount of time given by doctors at their first radiotherapy appointment; higher than for other treatment modalities. While this latter point may not be about information *per se*, consultations are normally designed around information exchange, suggesting that patients are very aware of time constraints of HCP. In the wider literature it has been noted that some physicians are also aware of time constraints; for example, in the study by Loeb et al. (2018), one pointed out that the time allowed for consultations is not enough to give all the information and explanations patients need. In the same study, another suggested that providing pamphlet-based information helps ameliorate some of the time issues. In the qualitative study by Long (2001), the issue of time constraints was noted in an emergent theme labelled “Staff demeanour” (p.466). Two participants described frustrations at not being able to get the information they desired due to time constraints of doctors. Other studies mentioned time constraints very briefly: Douma et al. (2012) noted that some patients may be afraid of taking up too much time with their physicians, Bolderston (2008) that time for patient interactions is limited which can impact on the amount of explanation that can be given, and Dubois and Loiselle (2008) reported that for some patients, consultations were rushed due to limited professional time. This indicates that patients are very aware of the limitations of some health services and practitioners in providing enough time for information to be shared, so this may be an issue that warrants further investigation.

In considering the evidence base related to information and time, it appears that once more, the issues are multifactorial and linked with information needs. The temporal nature of information in radiotherapy appears to be an important aspect, whether this is related to the timing of information seeking or giving, or the way information needs change over time. Timing of information may also reflect whether information needs are met or remain unmet, and how this impacts on the overall radiotherapy experience. It is important to note that patient satisfaction with information is influenced by staff time constraints, as well as whether information is provided at the right time in their management course. This issue warrants further research.

2.7.5 Satisfaction with information related to radiotherapy.

Satisfaction with information is one of the more well-documented topics in the wider evidence base. Numerous studies covering a multitude of health conditions, diagnostic processes and other clinical interventions exist, many designed as patient reported outcome measures (PROMS) or satisfaction surveys; hence, it is unsurprising that this topic was prevalent within the literature explored in this study. Satisfaction with information was reported in several studies reviewed (Adler et al., 2009; Cuypers et al., 2019; Douma et al., 2012; Grondhuis Palacios et al., 2019; Lamers et al., 2016; Majumder et al., 2014; Nicolaisen et al., 2014; Tomlinson et al., 2014), with some focussing on satisfaction with information in radiotherapy and others on satisfaction with information on prostate cancer. Only two explored satisfaction for MPC undergoing radiotherapy, both utilising cross-sectional survey designs (Majumder et al., 2014; Nicolaisen et al., 2014) and it is interesting to note that no studies utilising qualitative design were identified where this topic was explored, indicating that a study using qualitative methodology may be warranted.

Adler et al. (2009) surveyed 72 cancer patients receiving radiotherapy (6 of whom had prostate cancer) in a cross-sectional pilot study. Results were not reported according to cancer type. 74% of patients were moderately to very satisfied with the amount of information provided about medical issues although 61% wanted more. Interestingly, very satisfied patients had received more information than those less satisfied. Whilst reasons for this discrepancy were not determined, it perhaps accounts for their levels of satisfaction. However, given that 26% of patients were not satisfied with the amount of information, there may be some underlying reasons why this is the case. Other research has hinted at patients being overwhelmed with the amount of information (Boulton et al., 2015), or having difficulties with retention of information (Long, 2001), both issues that might affect satisfaction scores. A cross-sectional study involving 697 men with prostate cancer by Lamers et al. (2016) reported on

data collected in the Netherlands in 2011, with the study focussing on dissatisfaction with information provision. 35% of patients had received either external beam radiotherapy or brachytherapy and all patients were classed as cancer survivors, with the mean time since diagnosis being 4 years (SD 1.2). It is not stated whether any patients were still receiving active management (e.g. ADT which can continue for many years following diagnosis and definitive treatment). 34% of participants reported dissatisfaction with information provision, but the nature of information was found to be helpful by 72%. Satisfaction with information for patients who had received EBRT was 63% but much higher at 78% for brachytherapy patients although there was no statistically significant difference between the groups. The latter figure may reflect the specialised nature of brachytherapy, which may require more focussed processes for consent and information giving due to the surgical procedures involved. This study surveyed patients across all stages of prostate cancer, and it is interesting to note that fewer patients with late staged disease were dissatisfied with information when compared to those with earlier stage disease. Potentially this is because patients with late staged disease are reviewed and monitored frequently regarding their disease progression whereas patients with early-staged disease will be discharged from active management relatively quickly after definitive treatment. The later staged patients may therefore have more opportunities to discuss their information needs/access information due to this more frequent contact with HCP. Higher levels of dissatisfaction were apparent for patients with two or more self-reported co-morbidities (38%). It is possible that the information they received did not reflect the specific requirements of these comorbidities: For example, a diabetic patient undergoing radiotherapy may require different dietary advice to non-diabetics related to management of side effects; however, the general dietary information provided would not normally cover the more specialised information they need. Other findings from the Lamers et al. (2016) study demonstrated a statistically significant difference in satisfaction with information between high, medium and low educational levels ($P=0.002$) and a statistically significant positive association between satisfaction with information provision and emotional, social, physical and role functioning, and global health indicating that personal characteristics should be considered when providing information.

The studies by Majumder et al. (2014) and Lamers et al. (2016) are similar in that they used the same data collection instruments (EORTC QLQ-C30 and EORTC-INFO25 questionnaires designed to elicit information on quality of life and information preferences) and surveyed a similar number of MPC ($n=656$ versus $n=688$). Majumder et al. (2014) focussed on MPC treated with radiotherapy and Lamers et al. (2016) on MPC who had received any treatment type. There was broad agreement in the study findings with the mean scores for overall satisfaction with information being 69% and 66% respectively

which also compares well with the 74% reported by Adler et al. (2009). Additionally, Majumder et al. (2014) reported scores for satisfaction with information about treatment (65%), information about medical tests (70%) and written information (71%). A notable aspect of the Majumder et al. (2014) study was the finding that patients who had curative radiotherapy alone were more satisfied with the both the type of information and the amount of information received when compared with those undergoing surgery followed by salvage radiotherapy. The authors point this to being due to information from nurse specialists managing the hormonal treatment that non-surgical patients receive, with the extra clinic appointments required providing more opportunities to obtain information.

The Nicolaisen et al. (2014) cross-sectional survey of 143 men with PC explored long-term quality of life outcomes and information satisfaction 3-4 years after receiving either prostatectomy, radical radiotherapy or post-operative radiotherapy. They scored satisfaction on a scale from 0 to 100, broadly equivalent to the percentile scoring in other studies. Satisfaction scores were given for six different domains related to information. The overall mean score for information satisfaction in the radiotherapy groups was lower than in the previously mentioned studies at 53.7 and 56.7 possibly reflecting the different questions asked on the survey as the EORTC instruments were not used. For both radiotherapy groups the highest satisfaction with information was regarding format: the opportunity to ask questions and gaining written information. The lowest satisfaction scores for both groups were for information about the possibility of rehabilitation. This concurs with other research, especially related to sexual functioning, and indicates that perhaps patients are not being told enough about the long-term consequences of radiotherapy. This issue has become a focus of several recent initiatives by support charities and health policy (Macmillan Cancer Support, 2021; Macmillan Survivorship Research Group, 2021; NHS England, 2016) because many patients are living longer after radiotherapy and so may need to manage the long-term consequences for many years. Consideration of information related to information given at the end of radiotherapy regarding the longer-term side effects may therefore deserve exploration in the present study.

The pre-treatment consent process is a time where a large amount of information is given relating to the treatment process and likely effects and outcomes. Tomlinson et al. (2014) reported on a large national survey of the experiences of just over 24,000 patients undergoing radiotherapy in the UK. In this study data were not reported according to cancer type. 99% of patients indicated that the consent process was satisfactory, and although this does not also imply satisfaction with information as part of that process, 97% of participants did respond that the amount of written information given before

the start of radiotherapy was either excellent or satisfactory. This rose to 98% when all sources of information were considered, so overall it appears the majority of radiotherapy patients were well informed before they started their treatment. These findings concur with Douma et al. (2012) who reported that patient satisfaction with initial consultations was high (score of 89.7, SD 9.9) indicating information needs had been met at that point. In that study, information needs decreased by the end of radiotherapy; however, satisfaction with information was unrelated to the decrease in information need. An issue of concern is Tomlinson's finding that only 77% of participants reported being given information about what to expect after the end of treatment (Tomlinson et al., 2014). Although not strictly related to satisfaction with information, this figure is much lower than they reported for the amount of information at the beginning of radiotherapy, which is of concern at this important transition point as patients move on to the survivorship stage. This concurs with the Nicolaisen et al. (2014) findings regarding rehabilitation since most information given at the end of radiotherapy would normally relate to ongoing and longer-term side effects, therefore, as previously stated, information given at the end of radiotherapy may be an issue that warrants further exploration.

Information satisfaction is briefly mentioned in further studies in relation to a variety of issues, including satisfaction with information and support given by cancer information services (Dubois & Loiselle, 2008), dissatisfaction with timing/place/situation of information on radiotherapy side effects (Grondhuis Palacios et al., 2019; Lehto et al., 2015), satisfaction that information was interesting and complete (Bennenbroek et al., 2003) and satisfaction with amount of information provided (Bennenbroek et al., 2003; Lehto et al., 2015). Concerns reported in the findings of the qualitative study by Blomberg et al. (2016) included patients feeling unsure about the information they received and being given limited information. These issues may imply that quality of, or satisfaction with information was a factor, although this was not specifically reported. Additionally, Ahamad et al. (2019) reported overall patient satisfaction in their study exploring patient needs during oncology consultations, based on review of medical records. Whilst they did not refer to satisfaction with information overtly, written materials were reported to be associated with a small decrease in patient anxiety after consultations.

In summarising this section, it is interesting to note the plethora of survey-based quantitative studies that provide the bulk of the evidence and that few of these focus on information in radiotherapy for MPC. Based on this review of the literature, satisfaction with information in radiotherapy has not been fully explored via the qualitative accounts of MPC and as such, richness and depth of context to

support and explain the quantitative findings is missing from the evidence base. It is clear that issues related to satisfaction with information given at the end of radiotherapy warrant further investigation.

2.7.6 Information preferences

A few studies explored patients' preferences regarding information. Davison et al. (2002) assessed information and decision-making preferences of 80 MPC and their partners. Patients in this study had been diagnosed and had their initial treatment consultation. Patients and their partners were asked to rank the importance of nine categories related to aspects of their diagnosis and management, in terms of proximity to their personal information preferences. Information on prognosis, stage of disease, treatment options and side effects were the top four rated preferences at time of diagnosis by both men and their partners. Preference for information on sexuality was rated higher by men than their partners and was higher in younger age groups. It is worth noting that the role men and their partners took in decision making did not affect information preferences, with most preferring an active rather than passive role. This research was carried out before the patients had undergone any treatment; therefore, it should be noted that these preferences might not be maintained across the disease and management trajectory and may vary depending on the treatment option chosen. In Douma's study of 104 cancer patients, 30 had urological cancers; however, this included male and female patients and the number of MPC was not reported (Douma et al., 2012). The study was difficult to analyse with respect to preferences as the aim and findings were reported in terms of information needs as well as preference (the terms seemed to be used interchangeably), despite the questionnaire exploring preference. The overall findings demonstrated that information needs across all domains decreased between the baseline measurement at the beginning of treatment and the measurement at follow up. This is a potentially flawed finding – just because the need for information decreases, does not mean someone's preference for information also decreases. Dubois and Loisel (2008) carried out a descriptive qualitative study exploring the role of informational support. They interviewed 20 patients of which ten were MPC. They noted one point relating to preferences: that women appeared to prefer verbal information over written, with the converse being seen with male patients. No explanation for this was given and although other studies (e.g. Adler et al. (2009) and Kazer et al. (2011)) mention information format in findings and/or discussions, none indicate preferences. Bolderston's survey investigated differences between patient and radiation therapist perceptions of educational needs (Bolderston, 2008). She ranked what patients want to know in order of preference, comparing the top 15 ranked items for the 42 radiation therapists surveyed with those for 183 patients with a range of diagnoses. For both groups, information regarding side effects was ranked first in similar findings to the Douma et al. (2012) study. In reviewing how patients prefer to

receive information, talking to HCP was ranked first, above written information and video resources. Bolderston (2008) also reported that HCP preferred to provide printed materials to support discussions with patients and this possibly reflects patient preference for interactive information exchange and the opportunity to ask questions, also highlighting that patient needs and preferences for type and format of information varies considerably. A few other papers concluded that taking account of patients' information preferences is important but did not present empirical evidence or explore this topic further (Boulton et al., 2015; Dale et al., 2004; Kelsey et al., 2004; Owens et al., 2003; Sinfield et al., 2008).

The topic of preferences appears to be highly subjective and intertwined with information needs. Preferences may change over time, due to the patient's experiences and nature of their diagnosis. Only one of the studies reviewed focussed solely on MPC (Davison et al., 2002) and only one (Bolderston, 2008) had a radiotherapy focus, hence there appears to be a gap in the evidence base warranting focussed research related to information preferences for MPC undergoing radiotherapy.

2.7.7 MPC experiences related to radiotherapy information

It is difficult to review literature related to patient experiences because in many papers, experiences can be inferred by the way patients report many different factors. For example, the way patients interact with staff, their interactions with other people, their issues related to quality of life, social functioning and coping with their diagnosis are all aspects of their experiences. So, whilst numerous studies considered large number of topics related to experiences of patients related to radiotherapy (Appleton et al., 2015; Boulton et al., 2015; Clarke & Burke, 2016; Dieperink et al., 2013; Dubois & Loiselle, 2008; Kelsey et al., 2004; Kinnaird & Stewart-Lord, 2020; Long, 2001; Ormerod & Jessop, 2015; Owens et al., 2003; Sinfield et al., 2008; Sutton et al., 2021; Tomlinson et al., 2014) this section will focus only on those experiences that referred to information.

In the sole quantitative study reporting experiences relating to information, Tomlinson et al. (2014) reported the experiences of just over 24,000 patients attending for radiotherapy. Data on experiences related to information were gathered from 13 of the 60 questions, with 97% of respondents reporting that information given before treatment was either excellent or satisfactory. 80% reported finding attendance at an information session helpful. A point raised by this study was related to the 5% of patients who reported not receiving information related to side effects, bearing in mind this is a core topic of information therapeutic radiographers should give to all their patients. Tomlinson felt that a

proportion of these patients might be experiencing 'information overload' which concurs with Boulton et al. (2015); however, as Tomlinson et al. (2014) points out, there could also be an issue related to retention of information, something also noted by Long (2001).

In the papers using qualitative methodologies there was a range of positive experiences described. Patients reported receiving excellent support and information, in particular from specialist and advanced practice staff (Boulton et al., 2015; Clarke & Burke, 2016; Kelsey et al., 2004; Ormerod & Jessop, 2015; Sinfield et al., 2008). Lay networks of family and friends were integral to patients gaining and using information (Appleton et al., 2015; Long, 2001; Sinfield et al., 2008) with the value of experience-based information from other patients at support groups and in the radiotherapy waiting room highlighted as a positive source of help (Boulton et al., 2015; Clarke & Burke, 2016). The qualitative studies also reported a range of negative experiences related to information. Long (2001) reported that participants had held fear or preconceived ideas about radiotherapy related to inadequate information and that these fears were not alleviated by HCP once they had started their treatment. In two papers that reported different aspects of the same data set (Kelsey et al., 2004; Owens et al., 2003), each reported that patients found it difficult to gain independent advice about treatment options due to consultant bias. However, the patients were happy with the amount of time and support offered by their consultants. Conversations about treatment options were influenced by the professional background of the doctor (Kazer et al., 2011; Kelsey et al., 2004; Owens et al., 2003); i.e. surgeons recommended surgery and oncologists recommended radiotherapy. These recommendations particularly impacted on patient experiences of decision making about treatment options. Other issues were reported where information affected patient experience. These included the inadequacy of the amount and factual content of information being given, participants wanting more information regarding adverse effects and their decision making, patients wanting both written and oral information, the amount of information being overwhelming, conflicting information from HCP, and patients being misinformed prior to commencing radiotherapy due to their own or family members' prior experiences (Dieperink et al., 2013; Dubois & Loiselle, 2008; Long, 2001; Owens et al., 2003; Sinfield et al., 2008).

These examples from the literature demonstrate that information can have a profound impact on the experience of patients regarding their decision making and subsequent choice of treatment options; however, none of them considered experiences related to information in radiotherapy for MPC. Of those focussed on information, two reflected radiotherapy for a range of diagnoses (Boulton et al., 2015; Long, 2001) and one focussed on prostate cancer but not radiotherapy (Nanton et al., 2009).

This gives further evidence for the need for research focussed on the experiences of MPC related to information in radiotherapy.

2.8 Chapter summary

The aim of this chapter was to identify and synthesise literature reporting the experiences of men with PC related to information in radiotherapy. The review has identified that while many papers refer to information for cancer patients or to men with PC undergoing a variety of treatments and at different points in their management; there is no current qualitative evidence that focusses solely on the experience of men with PC related to information in radiotherapy.

The issues related to information that occur for some men with PC appear to be very specific to the nature of radiotherapy. That patients want detailed information regarding options for PC management, treatment procedures and radiotherapy side effects is relatively well-documented in survey-based studies; however, what is less well documented are the more personal and in-depth accounts of their issues.

It is perhaps unsurprising that information regarding radiotherapy side effects is important to many patients; however, such information was incomplete and/or inconsistent for a number of patients. In particular it is worth noting how many studies reported dissatisfaction from participants regarding information on late radiotherapy effects, demonstrating that this might be an area of unmet need requiring further investigation. During the consent to treatment process, clinicians are duty bound to inform their patients about all treatment options and the associated sequelae, including short- and long-term side effects. Additionally, therapeutic radiographers would normally inform patients of what to expect in the medium to long-term following completion of radiotherapy. Therefore, this topic informed the design of the study.

Satisfaction with information emerged as one of the most well-documented topics in the broader literature base and also within the literature reviewed in this chapter. The main finding for this theme is that most existing research was carried out using quantitative studies, mostly survey based, and therefore there is a clear gap in the evidence base for an in-depth qualitative study.

One of the difficulties encountered in carrying out this review was how interwoven the issues relating to information are. Patient experiences are multifactorial and are affected by temporal as well as individual characteristics. In reviewing the literature, it was clear that while the wider evidence base addresses many topics related to information, because there is no research that specifically addresses the experiences of MPC related to information in radiotherapy, this research is justified.

Chapter 3. Methodology

3.1 Overview of chapter

This study employs a qualitative methodology located within the social constructivist paradigm, with analysis of data carried out using Braun & Clarke's thematic analysis approach (Braun & Clarke, 2006). The aim of this study is to capture in-depth the experiences of MPC related to information during radiotherapy, hence the qualitative approach was deemed appropriate. To capture the rich data related to these experiences, semi-structured interviews with MPC were utilised, either alone or together with their wife, and focus group discussions with therapeutic radiographers. This chapter explains and justifies the research design and methodology, giving details of participant recruitment, data collection and analysis, patient and public involvement strategies and the strategies used to ensure rigour, quality and trustworthiness in the research process. The chapter ends with a reflexive review of factors that may have impacted on the research process.

3.2 Rationale for using a qualitative approach

Chapter 2 noted that although there was a wealth of literature reporting surveys and patient-reported outcome measure studies (PROMS) related to information for cancer patients, most was aimed at gauging information satisfaction or needs. Even before narrowing the focus to MPC and information related to radiotherapy, there appeared to be a dearth of purely qualitative studies, which meant that the in-depth experiences and context related to radiotherapy information had not been fully explored.

3.2.1 Theoretical and philosophical perspectives.

In considering theoretical perspectives I needed to consider my epistemological position. According to Saks & Allsop (2012) and Carter and Little (2007), epistemology concerns the nature and theory of knowledge and how we come to know what we know about the world. For qualitative research, epistemology has been considered in terms of what constitutes acceptable knowledge in a particular discipline (Bryman, 2012), what counts as knowledge and the relationship between researcher and subject (Creswell, 2012), and the process of thinking and the relationship between what we know and what we see (Denzin & Lincoln, 2013). Epistemologically, the use of a qualitative research approach negated the requirement to consider positivist or post-positivist assumptions, these being more

usually associated with quantitative research approaches where theories are developed *a priori* and tested in the research (Creswell, 2012; Denzin & Lincoln, 2013; Silverman, 2013). My epistemological position stems from several contexts: being female, my age, social and political contexts, my career as a therapeutic radiographer and educator, and my family experiences of cancer. These have undoubtedly influenced the nature and direction of my research and from an axiological perspective, were considered in the design, data collection, analysis and interpretation. These issues are considered reflexively in section 3.11.

Qualitative research is ideal for exploring situations that are socially constructed (Offredy & Vickers, 2010). Social constructivism (interpretivism) has been defined as a worldview in which individuals develop varied and multiple meanings to understand the world in which they live and work, with subjective meanings attributed to how situations are described and interpreted (Bryman, 2012; Creswell, 2012; Denzin & Lincoln, 2013; Saks & Allsop, 2012). According to Denzin and Lincoln (2013) the constructivist paradigm “assumes a relativist ontology... subjectivist epistemology... and a naturalistic ... set of methodological procedures” (p.27). Ontology in qualitative research is variously defined as the nature of reality (Creswell, 2012), nature of social phenomena (Bryman, 2012) or set of ideas (Denzin & Lincoln, 2013). At the root of these definitions are the assumptions of subjectivity and an individual’s construction of their own reality. In my research these facets are acknowledged in that the MPC whole cancer journey from diagnosis to beyond completion of treatment will affect their experiences related to information.

Within the social constructivist paradigm, several methodological approaches have been developed, for example phenomenology, grounded theory and ethnography (Atkinson et al., 2001; Strauss & Corbin, 1998; Wojnar & Swanson, 2007). What is common to all these approaches is the focus on the experiences and meanings these experiences have for individuals, constructed by, with and between people in the context in which they live; in other words, a naturalistic rather than experimental setting (Denzin & Lincoln, 2013). As will be explored later, this paradigm is where my research sits.

3.2.2 Rationale for qualitative approach

The research question is explored within a social constructivist framework. This framework explains the need for individuals to understand their world by developing meaning of their subjective experiences (Denzin and Lincoln, 2013; Creswell, 2012). In determining which qualitative approach was most suitable for the study a number of methodologies were explored, critiqued and discarded

as my knowledge and understanding developed. Many had elements that would be beneficial to the research; however, no single approach fitted comfortably. The following table presents the approaches considered and the rationale for discarding them as a sole methodology:

Table 3. Rationale for use or disregard for specific qualitative approaches

Qualitative methodology considered	Definition/explanation of the methodology	Rationale for discarding
Grounded theory	<ul style="list-style-type: none"> • Data are used to develop, generate or discover a theory. • Approaches to data collection may evolve and change as the research progresses and theories begin to emerge (theoretical sampling). • Data are coded and analysed thematically as the theories are generated/discovered. • Initial broad research questions/statements are systematically refined during the course of the research. 	<ul style="list-style-type: none"> • I needed to explore a well-defined and narrow topic. • The research needed to provide in-depth understanding rather than generate theory. • Findings needed to have real practical application, rather than the more abstract theoretical outcomes that are inherent in grounded theory.
Narrative research	<ul style="list-style-type: none"> • Encompasses the telling of stories in individual participants' lives. • Stories are told in participants' own words with little framing or direction from the researcher, other than prompting. • Tends to focus on one or two individuals' stories, rather than considering a sample more broadly. • Tends to focus on lives rather than incidents/objects. 	<ul style="list-style-type: none"> • The focus was on a specific component of the patients' radiotherapy experience. • Needed to make sense of many experiences rather than a few to ensure findings would have potential for practical application. • Acknowledgement of patients' life stories (in terms of their diagnosis and management) gives important context but is not the research focus.
Interpretive phenomenological analysis	<ul style="list-style-type: none"> • Explores how people make sense of their own life experiences. • Accepts that researchers' views etc. will influence the data. • May include close attention to language used. • Usually includes close, detailed attention to and initial coding of an initial transcript before progressing to further transcripts. • Has its roots within psychology. 	<ul style="list-style-type: none"> • Although drawn to making sense of people's experiences, I wanted to include the context of radiographers too. • Concern that this would be difficult to do effectively when considering a combination of single, dyad and focus group interviews.
Ethnography	<ul style="list-style-type: none"> • People are studied in their natural environment. • Data are generated through mainly observational processes where the 	<ul style="list-style-type: none"> • the context of information needed exploring before, during and after radiotherapy. In an ethnographic context this would involve multiple environments

	<p>researcher often immerses themselves into a culture or setting.</p> <ul style="list-style-type: none"> Concerns a holistic view and interpretation of a culture. 	<p>and encounters, not all of which were observable.</p> <ul style="list-style-type: none"> My focus was on a specific phenomenon related to the radiotherapy process, rather than the experience of radiotherapy itself.
Hermeneutic phenomenology	<ul style="list-style-type: none"> Concerned with human experience but explores details and experiences that may otherwise seem trivial or taken for granted. Interpretation of how things are understood by the people who experience them. Based in the work of Heidegger, who proposed 'Dasein' or the meaning of the human in the world. Consciousness is a historically lived experience. Context is a central concern. 	<ul style="list-style-type: none"> I was initially very drawn to this approach, but there were some aspects of my research where a more descriptive approach was required, especially in terms of application to practice.
Descriptive phenomenology	<ul style="list-style-type: none"> Sets aside the relationship of the phenomenon to the world in which we live. Researcher should consciously put aside previous experiences, knowledge and biases regarding the phenomenon – a process termed 'bracketing'. Context is a peripheral concern. Rooted in the work of Husserl. 	<ul style="list-style-type: none"> My experience as a therapeutic radiographer is closely intertwined with the research topic. Bracketing would potentially remove valuable insights provided by my professional background which were crucial in helping to develop the research.
Qualitative description	<ul style="list-style-type: none"> Deep or latent underlying meanings relating to the phenomena are not sought, rather, similar themes are topically grouped. Meanings are still interpreted but Analysis and interpretation remains 'data near'. The goal is descriptive and interpretive validity to produce a rich description. Uses data from multiple sources to describe the person's experience. 	<ul style="list-style-type: none"> Initially a very attractive option, due to how well qualitative descriptive studies translate to practice, this option was eventually discarded as it was determined that exploration of latent meanings in the data may be required. Data were generated via single or dual sources (participant ± wife), rather than multiple (the TR focus groups did not focus on individual participant experiences)

References for table: (Banister, 2011; Barbour, 2014; Laverty, 2003; Neergaard et al., 2009; Offredy & Vickers, 2010; Sandelowski, 2010; Silverman, 2016; Sullivan-Bolyai et al., 2005; Wojnar & Swanson, 2007)

Given the considerations in table 3 above, a qualitative approach underpinned by social constructivism but not explicitly conforming to an established methodology was deemed appropriate. This approach

that does not fit within an established qualitative paradigm has been described in the literature as being epistemologically social constructivist and highly inductive, and not guided by an explicit set of philosophical assumptions conforming to an established methodology (Caelli, Ray and Mill, 2008; Kahlke, 2014). Furthermore, Kahlke (2014) proposed that “researchers may choose to draw on a single established methodology, but deviate from its intent, rules, or guidelines in a way that they see as beneficial to the study” (p.39). In considering the methodologies in table 3 above, it became clear to me that the appropriate methodology needed to be a blend of approaches, explained by Creswell (2009) as a continuum of knowing drawing on qualitative descriptive, phenomenological and narrative traditions. These included hermeneutic phenomenology and qualitative description, with narrative aspects. Participant narratives provide rich description and data related to, and giving context to many aspects of their experiences and thus justify a descriptive approach, however, there can also be meanings and insights related to those experiences warranting a phenomenological approach (Bourgeault et al., 2010; Taylor et al., 2015). To exclude the meaning of these narratives could result in valuable context and therefore interpretation of that meaning being lost. An approach drawing on qualitative descriptive, phenomenological and narrative traditions was therefore appropriate.

3.3 Recruitment and sampling of participants

3.3.1 Recruitment and sampling of therapeutic radiographers

The purpose of recruiting therapeutic radiographers for inclusion in focus group discussions was to generate data likely to give additional context to data generated by patients and their wives. As stated in Chapter 1, TR are the registered health professionals responsible for the planning and delivery of radiotherapy and so are uniquely placed to narrate their experiences relating the patients they encounter. Egestad (2013) has explored how TR have a significant influence on patients undergoing radiotherapy and Owens et al. (2003) acknowledged that TR are ideally positioned to support patients while delivering radiotherapy such that opportunities for interactions between patients and TR are optimised, and information needs met. However, there is a dearth of literature reporting the TR perspective related to information in radiotherapy, hence it was important to include their experiences in this research, albeit in helping contextualise the reports of the patient and spouse participants. In particular the professional contexts of planning and delivery of radiotherapy were being sought. Because the requirement was to gain contextual data from the TR it was determined that focus groups would be preferable to individual interviews. Facilitation within a focus group means that the interactions between participants stimulate insight as they respond to each other, encourage

recall, and may encourage confidence in participants who might otherwise be reluctant to share their thoughts individually (Farnsworth & Boon, 2010; King & Horrocks, 2010; Silverman, 2016).

As all the TR were from a single institution, this meant that there was likely to be homogeneity in the data generated. In May 2018 the HCPC reported 4,616 TR on the UK HCPC register working in around 80 NHS and private radiotherapy centres (HCPC, 2018). During 2017 (when the focus group discussions took place) approximately 30 TR were employed at the NHS Trust chosen for the present study. The Trust is an accredited cancer centre providing cancer services to around 900,000 people, offering standard and specialist radiotherapy techniques. Therefore, the TR working there have suitable and relevant experience. Assistant practitioners and student radiographers also work within radiotherapy at this Trust; however, these groups were excluded from recruitment as, due to working to more limited protocols than their graduate colleagues, their knowledge, understanding and experiences of radiotherapy processes would be narrower, therefore limiting their contributions in the focus group discussions. Another reason for excluding student radiographers was to remove potential concerns regarding coercion due to my role as a Higher Education lecturer: the NHS Trust involved in the study regularly hosts students from my institution for practice placement experience. A summary of inclusion and exclusion criteria are shown in table 4 below.

Table 4. Inclusion and exclusion criteria for radiographer participants

Inclusion criteria for radiographer participants	Inclusion criteria for radiographer participants
Employed as a therapeutic radiographer at the study site	Student radiographer at the study site
	Assistant practitioner at the study site

A meeting with the departmental manager was organised to facilitate explanation and discussion of the purpose of the study and the proposed research design. Having gained her agreement, the invitation letter, participant information sheet and consent form were sent to her by email for forwarding to her staff (See appendix 6). This negated the need for storage of personal information about the staff, hence maintaining confidentiality and data protection for those who chose not to participate. The manager also agreed to organise the timing of the focus groups to minimise the impact on the staffing of the treatment units. I then attended the regular lunchtime staff meeting to further explain the purpose of the study and to answer any questions the radiographers might have.

Purposive sampling (Offredy & Vickers, 2010) was carried out to recruit a maximum 20 TR working at the Trust. All staff were invited to participate, and the final sample was n=14 from the maximum pool

of 30. In concordance with literature recommendations, it was agreed with the manager that three focus groups of 4-5 members would be appropriate in order to minimise clinical impact (Barbour, 2007; Bryman, 2012; Guest et al., 2017). Due to clinical scheduling, the focus group discussions were carried out over three consecutive weeks. I was unable to pre-determine the composition of each group as attendance depended on staff availability for each time slot. Therefore, although the groups were homogenous in terms of background (Barbour, 2007), they were not stratified by gender or banding/experience. Nevertheless, on reviewing the group composition there was reasonable spread of characteristics within each. Consent to participate was reconfirmed with each participant before the start of each focus group. All focus group discussions were carried out prior to recruitment of the first patient participant. This was coincidental rather than planned as recruitment information for both patient and radiographer participants was sent out at the same time. The focus groups were voice recorded with verbatim transcriptions being produced from those recordings. King and Horrocks (2010) recommend that focus groups should be conducted with two researchers: one to act as the moderator/facilitator - initiating and guiding discussions, and one to act as observer - noting down non-verbal messages and taking notes most other sources refer just to the moderator/facilitator and their role (e.g.: Bowling, 2014; Pope & Mays, 2020; Silverman, 2013). However, for practical purposes and because this was a doctoral study, I acted as the sole researcher conducting the focus groups. The nature of focus groups and why they were used is explored in more detail in section 3.5.1 below. An overview of radiographer participant characteristics can be seen in table 5 below.

Table 5. Summary of radiographer characteristics

Pseudonym	Gender	Focus Group Number	AfC Band	No. of Years Qualified	Role
Rebecca	f	1	7	20-25	ASP
Jane	f	1	7	26+	ASP
Clare	f	1	6	0-5	Research
Anne	f	1	8A	6-10	ASP
David	m	1	6	0-5	Rotational
Harry	m	2	6	6-10	Rotational
James	m	2	6	0-5	Rotational
Steph	f	2	5	0-5	Rotational
Laura	f	2	7	10-15	Research
Hannah	f	3	6	6-10	ASP
Sue	f	3	7	6-10	ASP
Paula	f	3	5	0-5	Rotational
Elaine	f	3	6	0-5	Rotational
Zoe	f	3	5	0-5	Rotational

Key: f - female; m- male; AfC – agenda for change ASP: advanced or specialist practitioner.

3.3.2 Sampling of men with prostate cancer and their wives

Purposive sampling was employed to recruit a maximum 25 MPC and a maximum 25 wives or partners. The primary population for the research was men diagnosed with early staged prostate cancer who had received either EBRT via IMRT, or brachytherapy, or both within the previous two years. The diagnostic/staging criteria reflected the NICE guidelines regarding eligibility for radical radiotherapy using IMRT or brachytherapy techniques (NICE, 2021a). Each radiotherapy option produces varying side effects for patients, hence the advice, information and support they receive will be tailored accordingly. By focussing on early-staged diagnoses treated with either IMRT or brachytherapy, some homogeneity was created in the population to be sampled. This choice was made to reduce the potential diversity in the data that can occur when using heterogeneous samples (Robinson, 2014). The timeframe was chosen to allow participants easy recall of the period related to their diagnosis and treatment and to limit inclusion of participants who had received outdated radiotherapy techniques. The chosen age limit of 50 years+ reflects the typical range for incidence of prostate cancer (Cancer Research UK, 2022). A further consideration was regarding comorbid diseases or conditions that may affect the way radiotherapy is delivered. Some musculoskeletal issues, or hip prostheses may change either the patient's position or the beam arrangement for delivery of radiotherapy, either of which has the potential to impact on side effects experienced and therefore the advice and information given to the patient. To further homogenise the population, patients with such conditions were therefore excluded from the study. So that participants would be able to engage in full and frank conversations during interview, people who did not have a good understanding and level of English language were excluded. A summary of inclusion and exclusion criteria are shown in table 6 below.

Table 6. Summary of inclusion and exclusion criteria for MPC

Inclusion criteria for patient participants	Exclusion criteria for patient participants
Patients prescribed intensity modulated external beam radiotherapy (IMRT) or high dose rate (HDR) brachytherapy	EBRT patients prescribed non-IMRT technique
Good level and understanding of English language	Poor spoken English or English comprehension; patients who would require a translator
Have no concurrent disease or disability which would require the standard treatment technique to be adapted such that organs at risk (OAR) receive radiation doses out of tolerance.	Patients with hip prostheses or musculoskeletal issues impacting on their treatment position (as these affect potential side effects and therefore change the standard information given)
Age range of 50years and above	

As each MPC was recruited, they were given the option of inviting their wives or partners¹³ to participate (the secondary population). Wives were included only if the MPC gave their consent and the MPC was given the choice of whether their wife was interviewed separately or as a dyad. The methodological considerations related to this choice are explored further in section 3.6.2 below. Inclusion/exclusion criteria for the MPC's wife's involvement were based on consent from the MPC and understanding of English language. These are summarised in table 6 below.

Table 7. Summary of inclusion and exclusion criteria for wives.

Inclusion criteria for wife participants	Exclusion criteria for wife participants
Consent given by husband for participation	Consent not given by husband for participation
Good level and understanding of English language	Poor spoken English or English comprehension; would require a translator

3.3.3 Patient participant recruitment

Initial ethics approval was gained for purposive sampling and recruitment of patient participants at one Trust's cancer centre. At this Trust around 400 new patients¹⁴ with early staged prostate cancer are prescribed radical radiotherapy annually, hence it was deemed an appropriate population to ensure recruitment of a maximum 25 MPC within the timeframe of the study. However, lack of interest at the study site caused delays in recruitment, therefore following amendments to ethics approvals, social media advertising was used to expand recruitment nationally.

Laminated posters were placed in waiting rooms and corridors in/near the Trust's cancer centre and copies printed as fliers were given to the clinic review radiographers and reception. The department manager had given permission for the review radiographers to act as gatekeepers – identifying any patients who fitted the inclusion criteria and signposting the study by giving them a copy of the flier. This was felt to be more appropriate than giving fliers to the treatment unit staff whose time was more limited for discussion. Regular contact was made with the review staff to ensure they had enough stocks of the fliers and to remind them about signposting the study.

Based on the inclusion criteria for patient participants given in section 3.3.2 it was anticipated that the final sample should be reasonably homogenous. The maximum sample size of 25 patients and

¹³ From this point onwards referred to as wives as all dyads recruited were married

¹⁴ Source: departmental statistics supplied by manager

maximum 25 wives was based on an original recruitment strategy aimed at potentiating theoretical data saturation within a one-year data collection period, with the actual number to be adjusted up or down depending on whether/when theoretical saturation was reached. Given my initial intention for theoretical data saturation to indicate an endpoint to recruitment, the rationale for this is worth further exploration. This will be covered in section 3.3.4 later in this chapter.

Over the course of the first six months of the data collection period, only three patient participants and one wife were recruited. This slow recruitment rate resulted in redesign of the flier to make it easier for participants to supply contact details. Within the next three months only one further participant and his wife had been recruited from the Trust, so a decision was taken to change the recruitment approach to recruit outside the NHS, at the same time requesting a six-month extension to the data collection period.

Following the decision to recruit outside the NHS, advertisement of the study was carried out via:

- social media (Facebook, Twitter, Instagram), in particular utilising community groups, pages and contacts based in three counties within easy travel distance of my home
- posters in local, large supermarkets (using the community noticeboards)
- community centres and local libraries (using the community noticeboards).

The Twitter advertising was shared by PCUK to the chairpersons of their prostate cancer support groups resulting in rapid recruitment of eight patients and five wives. A further five patients and two wives were recruited via social media and three patients and three wives from the original study site during the final six months. There was no recruitment from community noticeboard advertisements. Thus, my final sample was 20 patients and 12 wives. As this was close to the maximum potential sample for MPC and due to the extended time taken to recruit them, recruitment was halted at this point and a further extension was not sought. All MPC who contacted me about the study fitted the inclusion criteria and were recruited. The patient participant characteristics are summarised in table 8 below. The mean age of participants was 68.25 years (range 57 – 78, SD 5.8) with median age of 68.5 years.

Table 8. Patient participant characteristics

pseudonym	Where/how interviewed	Age at time of IV	How long after treatment participant was interviewed	Type of radiotherapy	Marital status	Interviewed alone or with wife	How recruited	Ethnic origin	(previous) occupation	NHS region of cancer centre where treated*
Andy	My workplace	67	2 months	EBRT	married	with wife	NHS study site	White British	retired project manager	Midlands
Jack	home	78	2 months	EBRT	married	alone	NHS study site	White British	engineer/senior manager	Midlands
Clive	phone	58	4 months	EBRT	single	alone	NHS study site	White British	not disclosed	Midlands
Murray	home	72	6 weeks	EBRT	married	with wife	NHS study site	White British	retired	Midlands
Victor	phone	75	5 months	EBRT	married	with wife	Social media	White British	retired	Wales
Adrian	My workplace	72	18 months	Both	married	alone	Social media	White British	retired engineer	South East
Gordon	Skype & phone	57	5 months	Brachytherapy	married	with wife	Social media	White British	retired	N. Ireland
Henry	home	70	6 months	Brachytherapy	married	with wife	Social media	White British	retired	Midlands
Ralph	home	67	3 months	EBRT	married	with wife	Social media	White British	engineer	East of England
Tom	home	66	7 months	Both	married	with wife	Social media	White British	self-employed landscaper	London
Paulo	home	69	8 months	EBRT	single (divorced)	alone	Social media	White British	retired printer/retail work	East of England
Bill	home	73	18 months	EBRT	married	alone	Social media	White British	MD small firm construction	East of England
Charles	home	74	12 months	EBRT	married	with wife_	Social media	White British	retired engineer	East of England
Philip	home	69	6 months	EBRT	married	with wife	NHS study site	White British	retired engineer	Midlands
Angus	home	68	7 months	EBRT	married	with wife	NHS study site	White British	retired - education	Midlands
Adam	phone	63	11 months	EBRT	married	alone	Social media	White British	electrical engineer	North East and Yorkshire
Bob	phone	60	12 months	EBRT	married	alone	Social media	White Irish	civil servant	Northern Ireland
Duncan	home	76	18 months	EBRT	married	with wife	Social media	White US/British	retired	East of England
Martin	phone	65	9 months	EBRT	married	alone	Social media	White British	retired maintenance supervisor	Midlands
Donald	home	66	6 months	EBRT	married	with wife	NHS study site	White British	retired sales engineer	Midlands

*NHS regions source: http://www.pmlive.com/_data/assets/image/0005/1274594/regions_980766_copy.JPG

3.3.4 Consideration of theoretical saturation of data as a recruitment end point

Many authors have discussed appropriate sample size for qualitative research (for example Boddy (2016), Guest et al. (2006), Malterud et al. (2016), Marshall et al. (2013) and Sim et al. (2018)) and all noted the concept of theoretical saturation of data, especially when applied to interview-based studies. Based on initial explorations of this concept, my goal of achieving 'data saturation' was developed as an indicator of when recruitment needed to cease. The concept emerged from consideration of methodology used in grounded theory studies (Glaser & Strauss, 2017). In these studies, recruitment of participants continues until thematic analysis and interpretation of the data shows that no new themes are being discovered. Hence it has been suggested that recruitment should stop when theoretical saturation occurs and this would dictate the final sample size (Bryman, 2012; Glaser & Strauss, 2017; Guest et al., 2006; Guest et al., 2017; Kumar, 2014; Lapan et al., 2011).

The number of participants required such that data saturation occurs depends on the heterogeneity of the sample, with literature suggesting that more heterogeneous samples require larger numbers of participants. Numbers from 5 to 200 participants have been reported depending on the methodology, but between 15-25 appears to be a common number (Guest et al., 2006) justifying my maximum sample size of 25 patient participants. However, other literature questions this "taken for granted" or "normalised" concept of saturation (Braun & Clarke, 2019), with O'Reilly & Parker (2013) suggesting that it is not appropriate in all instances of qualitative research. Braun & Clarke (2019) highlight that when analysing data, the way a theme is conceptualised impacts on whether saturation can be identified and links to whether themes are broad, semantic or latent etc. Furthermore, they suggest that coding quality arises from depth of engagement with the data and reflexive interpretation, neither of which align with the concept of saturation, which relates to frequency of codes occurring rather than their nature and meaning. In essence, meaning is context dependent, so 'saturation' may never be achievable especially in studies where thematic analysis is the chosen analytic method. This understanding of the discourse around theoretical data saturation helped me to question my own sampling methods and ultimately, I determined that striving for 'data saturation' was likely not possible or necessary for my study. Instead, I chose to continue with the more pragmatic aim of recruiting a maximum of 25 participants without assessment of thematic saturation. In taking this approach, considerations of rigour and trustworthiness were not abandoned, rather I considered that, within the scope of a time-limited doctoral study, placing restrictions on numbers and timeframes for data collection were practical solutions, and so long as data collection, analytic and interpretative processes were rigorous, the findings would be valid.

3.4 Pilot work

Carrying out pilot work is a desirable component of qualitative research. It enables questions to be tested, refined and modified and if necessary, but importantly for interview-based studies, allows the opportunity for the researcher to build their interviewing skills and familiarity with the topic guide, developing a process that allows both interviewer and interviewee to be comfortable with the process (Barbour, 2014; Bryman, 2012; Offredy & Vickers, 2010; Robson, 2011; Sampson, 2004). In this way, it enables the researcher to be sure that the research aims will be met based on the topics explored via the topic guide.

I conducted two pilot interviews – one with a patient and the other a spouse interview. The patient interview was held with a MPC whose diagnosis and radiotherapy schedule followed the study's inclusion criteria. The purpose of the first pilot interview was to test the research instruments and gain confidence in interviewing. The 'spouse' pilot interview was held with an individual who had supported her husband through cancer treatment, including radiotherapy, but not for prostate cancer. The purpose of the spouse interview was to prepare for any interviews where the MPC had preferred his wife to be interviewed separately. In both instances there were enough commonalities with my target population to give credibility and validity to the pilot. A voice recorder was not used in either interview in order to test my note-taking skills. The spouse interview took place in a noisy café making it difficult to concentrate and tested my active listening skills. As a result, the option of using public locations for interviews was not given to participants.

Feedback given by the pilot subjects was integrated into future interview technique, namely, allowing more time for participants to answer questions. Positive feedback judged the questions to be appropriate, complimented my sensitive approach and use of background to diagnosis to help settle participants into the interview.

I was not able to pilot the focus group topic guide before the focus group discussions; however, the feedback, preparation and interview skills development I gained from the individual interview pilots helped in the successful facilitation of the focus groups. Overall, the pilots ensured I was well-prepared for conducting the interviews, having allowed familiarisation with interviewing techniques, adding to the rigour of data collection.

3.4.1 Patient and public involvement (PPI)

Involvement of lay people in research has generally been as participants, rather than as contributors to the research process, but increasingly, involvement of people who are non-research trained in the design and implementation of research is seen as beneficial in improving research quality and applicability to the populations who will eventually benefit from the research (Boivin et al., 2018; Brett et al., 2014; INVOLVE, 2015; Stewart et al., 2011; Wilson et al., 2015). Nevertheless, it was noted in a recent paper that PPI processes and impact are rarely described in peer-reviewed papers that report aspects of doctoral research, citing the paper I published about PPI in the present research (Gordon et al., 2017)¹⁵ as a “notable exception” (Coupe & Mathieson, 2020) p.126).

In the early stages of planning the research design, it was vital that the topics I planned to explore with participants would be relevant and understandable to them. In early discussions with my supervisors, I queried how to determine what would be important. The response was to “ask the experts”, meaning I needed to consult with people in the demographic I would be recruiting from: men diagnosed with prostate cancer. Acknowledgement that people can be experts in their own disease and management, albeit from a different perspective to health care practitioners, is detailed in a government report that defined expert patients as: “people who have the confidence, skills, input and knowledge to play a central role in the management of life with chronic disease” (Department of Health, 2001). I had existing links with a cancer support group so arranged to attend some of their regular meetings. During conversations with group members, three men showed keen interest in my research and were invited to become my informal reference group.

An underpinning philosophy within the body of work on the expert patient gives recognition to the expertise and knowledge a patient will have of their condition, derived from their personal experiences (Wilson, 2001). The cancer experiences of the men in my reference group led to suggestions that were incorporated into the research design, and that would not have been considered without their input. One aspect that I had already considered was my tripartite status as a researcher, educator and registered health practitioner and therefore my positionality in relation to the study’s context. Positionality has been identified as the stance of the researcher in relation to the context of the study and the way it affects the research process, for example with respect to power and privilege (Fenge et al., 2019; Hampton et al., 2021; Moore, 2012). I had deliberated as to whether

¹⁵ A copy of the article can be found in appendix 8.

I should present myself to participants as a therapeutic radiographer and educator, as well as a researcher, and this led to wider consideration of insider/outsider status (explored further in section 3.9). The opinion of the reference group men was that they were more likely to 'open up' to me in an interview if they knew of my professional radiotherapy background as this (in their opinion) made me more trustworthy and knowledgeable about cancer and its management¹⁶. Based on these comments I decided that I would introduce myself as a registered therapeutic radiographer and lecturer who was undertaking doctoral research, but ensure I included a comment at the start of each interview stating that I could not advise participants on their health or cancer management and that any queries should be directed back to their HCP.

A second suggestion which changed the proposed research design was involvement of wives and partners. I had previously considered that when the interviews occurred relative to when patients had finished treatment might impact on how much detail participants would remember. This was discussed with the reference group members and one highlighted the importance of their wife's support and involvement and her role in taking on board information related to his diagnosis and subsequent treatment. He said: "*...no good asking me anything about [my initial consultation] but my wife knows everything, so to get the fullest picture she would need to be interviewed too*" with which the other members concurred. The importance of spousal support is detailed in the literature, which suggests that MPC and spouses face the diagnosis and adjust to the changes this causes together (Banthia et al., 2003; Boehmer & Clark, 2001b; Collaço et al., 2018; Schumm et al., 2010). Thus, the decision was taken to invite the wives or partners of recruited MPC to take part in the interviews. There was mixed opinion regarding whether interviews should be conducted as dyad or individual interviews. One man said he would feel uncomfortable talking about sensitive issues with his wife present, so interviews should be separate, whereas another stated that as he and his wife "*had no secrets*" the interviews could be conducted with couples¹⁷. This conversation concluded with all group members agreeing that participants should be given the choice of being interviewed together or separately. Therefore, the objectives of the study were changed to include involvement of spouses; however, it was made clear in the recruitment and consent process that only if the MPC agreed to their involvement would their wife be included.

The final aspect of PPI utilised was review of the research proposal by the University of Hertfordshire Public Involvement in Research group (PIRg) in March 2016, prior to submission to the University

¹⁶ This is explored further in Gordon et al., (2017) appendix 8

¹⁷ Advantages and disadvantages of dyad/couples interviews are considered in more detail in Gordon et al., (2017), appendix 8

ethics committee for approval for the study to commence. The PIRg was set up in 2005 and has a core membership of 15 lay people who are members of the public, service users and carers. The group advises on a variety of research activities including discussion of ideas, development or research tools and commenting on aspects of dissemination of research findings (University of Hertfordshire, 2022). Whilst the group had no comments regarding the proposed use of focus group interviews with TR, they strongly recommended I give the MPC and spouse participants the option of telephone interviews. This was in recognition that at the time of interview, the patients might still be suffering from radiation-induced bladder and/or bowel side effects that might require frequent access to toilet facilities, therefore they might not wish to travel to an interview or have a visitor to their home. Furthermore, at the time of planning the study, the limited literature available suggested that there might be some issues in judging body language when using telephone or other remote methods of interview, but that the amount and quality of data could be similar to that generated by face-to-face interviews (King & Horrocks, 2010; Novick, 2008; Sturges & Hanrahan, 2004). The final recommendation of the PIRg was to ensure a robust risk assessment of interviewing in participants' homes as a lone researcher. This was accepted as necessary and resulted in being guided by the Centre for Research in Public health and Community Care (CRIPACC) lone researcher policy, the Centre where my supervisors are based.

A further benefit of PPI is that it can give meaning and purpose to lay people who contribute to the research process, validating and giving value to their experiences, engendering respect, pride and satisfaction and feeling that they have made a difference as a result of their involvement (Aries et al., 2021; Froggatt et al., 2015; Gorbenko et al., 2022). The reference group members indicated that being diagnosed with cancer had been a difficult and stressful time in their lives and that being asked to contribute their thoughts and experiences meant that they had positively contributed to the care and experience of future cancer patients.

Overall, therefore, PPI has benefitted the design of this study, but also had a positive impact on the lay people who contributed their opinions and experiences.

3.5 Data collection

In this research I have combined the use of focus group discussions between TR, with semi-structured, individual or dyad interviews with MPC and their wives. This section will explore each method

individually in order to identify some of the issues that had the potential to affect the data collection process and hence the quality of data collected.

3.5.1 Focus group discussions

Focus group discussions allow a structured means of investigating a particular topic, capitalising on the interactions between group members as well as exploring issues of interest to the researcher (Barbour, 2007; Wright et al., 2012). The inclusion of the TR in my research allowed the participants to compare experiences, viewpoints and perceptions with each other, drawing on their shared radiotherapy knowledge and experience (Kvale, 2007). By analysing the focus group data alongside and in conjunction with the patient interview data, I gained context to the experiences of the patient participants and therefore was better able to interpret those experiences (King & Horrocks, 2010).

In conducting the focus groups, I was very aware of my tripartite roles as practitioner, educator and researcher. In the traditional facilitator/moderator role, the researcher ensures discussions are between the participants, providing probes or questions as necessary to stimulate conversation. By removing themselves from the empirical field, researchers are then able to retain objectivity; however, this creates issues of power and engagement that may impact on the quality of the data (Farnsworth & Boon, 2010). This semi-remote approach to facilitation would work well within groups where the participants did not know each other well, or where the researcher was unfamiliar with either the topic or the participants. However, for this research I had convened focus groups of people whose roles revolve around close teamwork, and therefore knew each other very well. Several were graduates from the programme I teach on, so I was also well-known to the groups as an educator. These aspects may have influenced the group interactions, and their interactions with me; however, I think it also meant that the discussions were comfortable and I did not encounter any issues related to discomfort with the proceedings. Hydén & Bülow (2003) describe this group 'comfort' as being due to development of a collaborative narrative as the participants have a common experiential background to draw from.

A potential issue was identified regarding hierarchy of the group members due to different grades of staff participating (see radiographer participant characteristics table 5) and the power dynamic this may cause. Research literature usually considers power in terms of the relationship between the research participants and the researcher, generally placing the balance of power with the researcher (see, for example Brinkmann and Kvale (2005). However, the issue of power dynamics between

participants is often overlooked. The issue receives some attention in papers reporting research involving couples in interviews (for example Valentine (1999)), usually attributing these to gender differences. However, in the focus groups this concern proved unwarranted with all participants able to give valuable contributions, possibly due to the close teamwork bonds they already held.

Three focus group discussions of 4, 5 and 5 participants were held. At the beginning of each session consent to participate was reconfirmed and a short explanation of the purpose of the study was given. Ground rules for conduct of the group were set out. Each focus group session was voice recorded.

The discussion was guided by use of a topic guide (see appendix 7). Development of the guide had been iterative, based on a number of discussions with my supervisors, some comments made by my reference group of former patients and literature on how to conduct interviews and discussions. Foremost among the literature was consideration of Tuckman's model for small group development initially described in 1965 as "forming, storming, norming and performing" with the addition of a fifth dimension of "adjournment" in a review of the model in 2010 (Tuckman & Jensen, 2010). This model was considered when planning the ordering of the questions, question styles and how to engage the group participants in conversation and discussion. The topic guide was composed of a series of potential questions and probes ordered chronologically in domains that reflect the typical cancer journey for a MPC. Before beginning the questioning, a short period of general chat was initiated to settle the group (forming). The domains used questions worded in open format to guide the discussions, with examples of probes also given. Questions were not asked in exactly the format they appeared on the guide but were modified to ensure each domain was fully considered during the course of the discussion (storming). For example, in focus group 2 I asked: *"So first of all can you tell me about the information that patients receive when they are first referred for their radiotherapy?"* instead of the topic guide suggestion of: *"Can we talk about what information patients receive at the new patient clinic –related to their radiotherapy"*. Subsequent questions reflected the responses of the participants and introduced the subsequent domains (norming and performing). Care was taken to ensure that each group member had an opportunity to respond, and if it was felt that someone wished to speak but had not had the opportunity, I made sure to address them directly, for example in focus group 1: *"David, you're based on the treatment units pretty much full time, have you got anything else you wanted to add?"* On reflection, the groups were very chatty, very respectful of each other's opinions and it was not difficult to keep the conversation flowing.

At the end of each session, I thanked the group and summarised the topics discussed and asked if they had any further comments to make (adjournment). This led to a few minutes more valuable discussion in two of the groups.

3.5.2 Interviews with patient participants and their wives

Data were generated via semi-structured interviews which are variously described in the literature as pseudo-conversations (Oakley, 1981) and conversations with a purpose (Offredy & Vickers, 2010), which go beyond a spontaneous exchange of views and are probably the most common method of generating qualitative data (Kvale, 2007; Mason, 2002). Most research texts will describe three main styles of qualitative interview: structured, semi-structured and unstructured (e.g., Bryman (2012), Creswell (2012) and Robson (2011)). This typology refers to the degree to which the questions are designed and structured in order to plan and format the interview.

Semi-structured interviews were determined as the data collection/generation method of choice as they allow some direction of topic domains whilst giving the interviewer and interviewee the opportunity to explore issues of interest and importance to both parties. This approach is widely used in qualitative research and has been critiqued by many authors (e.g., King & Horrocks (2010) and Kvale (2007)) and is used to gain insight into the context and meaning of phenomena described by the interviewee (Seidman, 2013).

In determining the issues that might impact on data generated from the interviews, there were some methodological considerations. I was advised by my reference group to include wives in the interviews if the patient participants desired. Twelve men wished their wives to take part, and all did so as dyad interviews, reflecting previous literature that suggests MPC and their wives typically face the challenges of the diagnosis together (Banthia et al., 2003; Boehmer & Clark, 2001a, 2001b). Strengths of joint interviewing are firstly, the production of a single collaborative account giving insights that might be difficult to identify in individual interviews (Valentine, 1999), secondly, that couples can create meaning or supplement each other's answers (Beitin, 2008) and thirdly, that they can promote a productive setting in which the couple can tell their stories (Bjornholt & Farstad, 2014). In contrast, interviewing apart gives each person the opportunity to air their own point of view unhindered by the other, but this may create anxiety if the couple is worried about what each might have said, especially regarding sensitive topics (Bjornholt & Farstad, 2014; Valentine, 1999). Another consideration was regarding the setting and method of the interview. My initial plan had been to interview in person,

either at a participant's home, or at the university. However, the PiRg members suggested that if I was interviewing within a few weeks or months of radiotherapy ending, I would need to consider the potential ongoing bladder and bowel side effects that might make travelling difficult. These issues are explored in more detail in section 3.4.1 and in my published paper focussing on the PPI aspect of this research (Gordon et al., 2017).

All potential participants were sent the study documents (participant information sheet, introduction letter and consent forms) by post or email. I spoke to each participant or had an email exchange to ensure their eligibility and also where relevant, regarding the potential involvement of their wife. If they indicated that they were happy to include their wife I also sent the information and consent forms for spouse participants (see appendix 9). I ensured there was at least 48 hours between initial contact and the interview to ensure participants had fully considered the information about the study. Face to face or telephone interviews were offered. Participants were given the option for face-to-face interviews to take place either at their home, the university or another suitably private location, to be mutually agreed. This led to two interviews being conducted on university premises, twelve at the participant's home and six by telephone (summarised in table 8, section 3.3.3 patient participant characteristics). For all home-based interviews, I followed the CRIPACC lone researcher policy to ensure my own safety.

For the face-to-face interviews the participants chose the location in the house where they would prefer us to hold the interviews. In most cases this was the living room, but in one case we used a seating area outdoors, due to very hot weather. For telephone interviews I used a private office with the telephone on speaker, placing the voice recorder close to the mouthpiece. For all participants I reconfirmed consent to participate and gave a short explanation of the purpose of the study and restated the right of withdrawal without prejudice. Once I was satisfied that they were fully informed and happy to proceed I switched on the voice recorder.

Each interview was guided by use of a topic guide (see appendix 10). It had been developed iteratively in parallel with that developed for the focus group interviews and ordered chronologically with the same domains and similar questions and probes, modified to be appropriate for the patient and spouse participants. In order to settle the participants, I began each interview with a question asking them to tell me about the story behind them being diagnosed with prostate cancer. This led naturally into chronologic consideration of the different domains I wished to explore. As with the focus groups, questions and probes were modified iteratively to ensure each domain was fully considered during

the interview, and to ensure that issues mentioned by the participants were explored. After the first couple of interviews were transcribed, I asked my supervisors to provide feedback. As a result, I became more comfortable with allowing participants to speak freely, relying less on the exact wording and script of the topic guide, whilst ensuring all domains were explored.

At the end of each interview, I thanked the participants and summarised the topics discussed and asked if they had any further comments to make. In my first interview, Andy carried on talking for ten more minutes after I had finished the interview and mentioned some potentially valuable information, so I quickly switched on the voice recorder to capture the remainder of the conversation. In further interviews I left the recorder running longer, to ensure valuable data was not missed. Once I had left the participants or ended the telephone calls, I took time to make some reflective notes regarding my initial observations and thoughts about what seemed important to that participant.

After each interview the voice file was uploaded to a folder on the University's secure server and then deleted from the voice recorder. Each interviewee was offered a transcript of the interview, to be sent by email or post.

3.6 Ethics and consent

3.6.1 Ethics approval

Ethics approval was given by the North of Scotland Research Ethics Service (ref: 17/NS/0044, amendments AMO1 and AMO2).

3.6.2 Informed consent

To ensure fully informed consent was obtained from participants, each was sent a copy of the consent form and participant information sheet along with an introductory letter¹⁸ at least 48 hours in advance of their interview or focus group discussion (see appendices 6 & 9). The participants were invited to return the signed consent form by post or secure email server, or to bring the signed form to the interview (if carried out in person). Consent to participate was reconfirmed for every participant at the beginning of each interview or focus group discussion following reiteration of the purpose of the

¹⁸ By post or email according to participant preference

research and explanations related to the participant information if requested/required. Emphasis was made of their right to withdraw from the study at any time without prejudice.

3.6.3 Ethics considerations

There was the potential for interviews with the MPC and their wives to elicit recall of upsetting, embarrassing or sensitive information, and difficult memories related to the participant's diagnosis and treatment. At the beginning of each interview, it was reiterated that the interview could be paused or halted at any time if participants needed a break or to compose themselves. The MPC were asked to contact their GP or specialist cancer team if issues related to their cancer management were raised during their interview, or for psychological support. Information was also provided or signposted about organisations such as Macmillan Cancer Support and Prostate Cancer UK (PCUK). The links to these resources were sent either by post, or by email.

Ethics issues considered for the radiographer participants related to standards of radiotherapy practice and confidentiality of the group discussions. I explained that any such issues would be noted and judged as to whether they contravened professional codes of conduct and/or standards of proficiency. For any unresolvable point of conflict, the discussion would be halted to check whether the group/individuals would like to continue. Participants were informed that if any group member wished to discontinue their involvement in the focus group, they could do so without prejudice.

As a HCPC registered practitioner, I have a duty of care to report instances of dangerous or poor practice, regardless of the otherwise confidential nature of the focus groups and interviews. This potential issue was discussed with participants at the beginning of each focus group or interview and would have been discussed at the end had poor practice been reported.

3.6.4 Confidentiality and data protection measures

Careful attention was paid to the issues of confidentiality and data protection in order to conform to General Data Protection Regulation (GDPR) requirements. Access to the unredacted voice recordings or transcripts of the interview was restricted to me, my supervision team and the professional transcription company. Where data in the form of quotations have been reported in this dissertation, pseudonyms have been allocated to protect the identity of participants. Similarly, names and locations

of departments/cancer centres have been anonymised or referred to in terms of their wider NHS region.

A key component of research governance is storing personal data of participants safely. Paper-based consent forms were stored in a locked cabinet at my workplace, which itself is accessible only by electronic key card. All electronic materials (voice files, transcripts, ethics documents, electronic consent forms) were stored on the University's secure server, access for which is via a password protected computer. Voice files were transferred from the voice recorder to the secure server on the same day that the interview/focus group took place and deleted immediately from the voice recorder. No materials are/were stored on removable storage devices (memory stick etc.). Transfer of any electronic written materials containing identifiable data was carried out via the university's secure file exchange server.

3.7 Transcription

All the interviews and focus groups were transcribed verbatim, and a copy was sent to each participant as a record of the interview. Carlson (2010) suggests that it is important that transcripts are checked for validity as an aspect of trustworthiness. This is commonly carried out via verification of transcripts by the participants, giving them the opportunity to verify accuracy, correct if necessary and clarify any issues that may have been unclear (Mero-Jaffe, 2011; Polit and Beck, 2017). Hence, I asked each participant to contact me if they had any queries or comments about the transcripts but received no responses.

I transcribed all focus group discussions and eleven of the interviews myself, the other nine interviews were transcribed by a university approved transcription service. Whilst it has been suggested that doing transcriptions yourself helps to immerse in the data (Barbour, 2014; Castleberry & Nolen, 2018), I found that I learned most from listening back to the recordings and reading through the transcripts that had been produced; the listening/typing process for me was fairly automatic and in typing fast I tended to concentrate just on hearing the words, rather than considering the context. During the transcription and checking processes, each transcript was fully anonymised by redacting names of people, hospitals and geographic locations and applying pseudonyms for the participants, the purpose being to ensure confidentiality for all participants and HCP they mentioned.

3.8 Thematic analysis

Thematic analysis (TA) is a flexible analytic method that is independent of theory and epistemology and has no stipulations regarding how populations are sampled, or data are collected (Braun & Clarke, 2006; Braun et al., 2016). The fundamental purpose of TA is to allow identification and analysis of patterns of meaning in the data. Although there are some similarities to content analysis in the way some themes are developed (Joffe & Yardley, 2004), there is less reliance on frequency of data occurrences and more consideration of the meaning of the data in context. This consideration of meaning was inherent in my decision to use a qualitative research approach and thematic rather than content analysis.

A number of authors have described and discussed TA (Braun & Clarke, 2006; Grbich, 2013; Guest et al., 2012; Joffe & Yardley, 2004) but it is Braun and Clarke who have developed a widely accepted analytic framework that is clear, simple and applicable across a range of qualitative research approaches. A theme can refer to a coding category of something directly observable or said (semantic), or to something with underlying meaning or not directly stated in the words used by the participants (latent) (Braun et al., 2016; Terry et al., 2017) and it was important for me to include both types when coding my data. Construction of a conceptual framework combining both semantic and latent themes requires interpretation. The Braun and Clarke TA model has been described within an analytic frame which ensures that issues related to research quality, rigour and trustworthiness are inherently addressed (Braun & Clarke, 2006). A summary of the model and how I applied it to my analytic process can be found in figure 2 below. The Braun and Clarke (2006) phases of thematic analysis are highlighted in bold text, with the description of processes I undertook highlighted in italicised text.



Figure 2. TA process adapted from (Braun & Clarke, 2006)

3.8.1 Coding

According to Richards (2005), the purpose of coding is to learn and revisit the data in order to develop understanding of the patterns, explanations and meanings. Coding is an interpretive process and is described as either inductive or deductive depending on whether *a priori* themes, theories or topics are used to guide the coding process (deductive) or the data gathered generates the themes (inductive). Given I had no preconceptions about what themes I might interpret from the data, an

inductive approach to coding was most appropriate. As previously stated, the coding process was carried out within the thematic analysis framework seen in figure 2 above.

Having reviewed the transcripts several times to become familiar with them, I used the computer aided qualitative data analysis software (CAQDAS) NVIVO 12™ to manage the process of applying and developing codes (step 1). NVIVO 12™ facilitates the management of data and implementation of several steps in the coding and analysis process in a way that I found more intuitive and efficient than manual coding methods. As Bryman (2012) states, it does not carry out the interpretation and analysis, but can help make the process more manageable when compared to manual coding methods. I began by coding the focus group discussion transcripts. An iterative process of generating, merging and re-coding of the documents resulted in 230 codes across these three transcripts (step 2).

I then moved on to coding the patient participant interviews. I had discussed with my supervisors whether to code these alongside or separately from the focus group data, and the consensus was that it would be best to consider the datasets together so that if similar/different codes were applied, it would be easier to see where there was difference or overlap between data generated in the two types of interview. In this way a form of triangulation was also employed (Lambert & Loiselle, 2008). Each time I created a new code, I reviewed previous transcripts using the NVIVO 12™ query function to see whether the new code needed applying to transcripts already coded. This was a time consuming and laborious process, but the constant reviewing and re-coding of all the transcripts had the added benefit of helping me become much more familiar with the data than if I had used a purely sequential approach (step 2). At the end of this initial coding process and including the codes generated from the focus group transcripts I had generated 467 codes. This number included many codes which had either one, two or three references associated with them and some similar or duplicate codes, so the next step was to review the coding to see if codes could be merged and to begin organising them into initial topic areas/themes using the parent/child node function within NVIVO12™ (step 3). Creation of parent/child nodes is the process of creating an ordinate node (parent) to which subordinate nodes (child) are linked. For example, the parent node 'patient factors or priorities' was linked to child nodes 'travel' and 'parking' (see image in appendix 12). Richards (2005) refers to this process of merging codes as 'dropping out of the document', as by reviewing all codes for a specific category, it helps to see the different meanings across the whole dataset. This coding process culminated in 31 parent nodes and 158 items in total across all focus group and interview transcripts (see appendix 12 for a screenshot of the NVIVO12™ node hierarchy and a table detailing the parent and child nodes).

3.8.2 Analytic process

The next phases of the Braun & Clarke (2006) TA process involve searching and reviewing themes in the data (steps 3 and 4). In undertaking these phases I began exploring the codes to look for themes and connections in order to create an initial conceptual framework. I initially reviewed the categories for the items that had been coded most frequently to begin thinking about similarities and differences and the importance of those as themes in consideration of my research aims. This was a manual process involving review of the electronic NVIVO12™ coded data, review of original voice files and transcripts alongside handwritten notes and use of a whiteboard in order to become more immersed in the data and enable initial thoughts, connections, concepts and themes to develop. Alongside this I ensured I revisited relevant literature and noted what I felt was important and interesting when considering the research objectives. This process of systematic thinking and reasoning, and assimilation of the data has been frequently highlighted as a core component of thematic analysis, allowing the researcher to interpret the data in a way that is understandable and reflective of the research question and objectives. (e.g. Braun & Clarke, 2006; Dey, 1993; Humble & Radina, 2018; Lapan et al., 2011). This resulted in production of an initial hand drawn concept map which is represented in figure 3 below (a photograph of the original hand drawn map is available for reference in appendix 10) (steps 3/4).

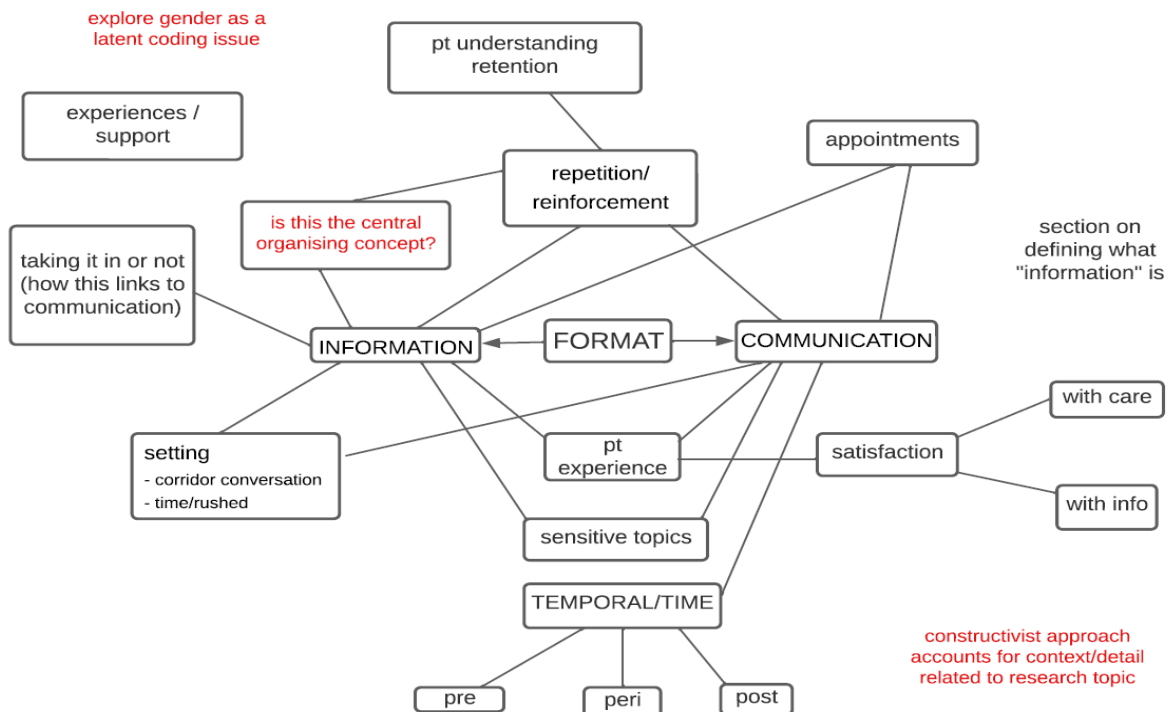


Figure 3. diagram representing initial hand-drawn concept map (see Appendix 10 for photograph of original)

This initial concept map had information and communication at the heart, with aspects of time/temporality, patient experience and satisfaction, retention of information and format of information being linked to these. These initial thoughts were shared with my supervisors in a ‘thinking out loud’ process as this is something I find valuable in helping to elicit hidden meanings or gaining a wider perspective on those initial ideas. This process highlighted the importance of the temporal aspects, and I undertook further reading of papers regarding aspects of temporality and cancer in order to understand the concept more fully (Braverman, 2020; Ervik, 2012; Kelly, 2009; Krumwiede & Krumwiede, 2012; Lindqvist et al., 2008; Nabisubi et al., 2020; Sidenius et al., 2020; Zerubavel, 1987). I also reconsidered the potential of ‘information’ as a theme. I was somewhat uncomfortable with this as a main theme, bearing in mind the focus of my research question relates to information and therefore the data were obviously going to generate many occurrences related to information. I deconstructed the parent node labelled ‘information’ to explore the child nodes more carefully (step 4). This proved a valuable exercise, and as a result I developed a second conceptual framework (see figure 4 below).

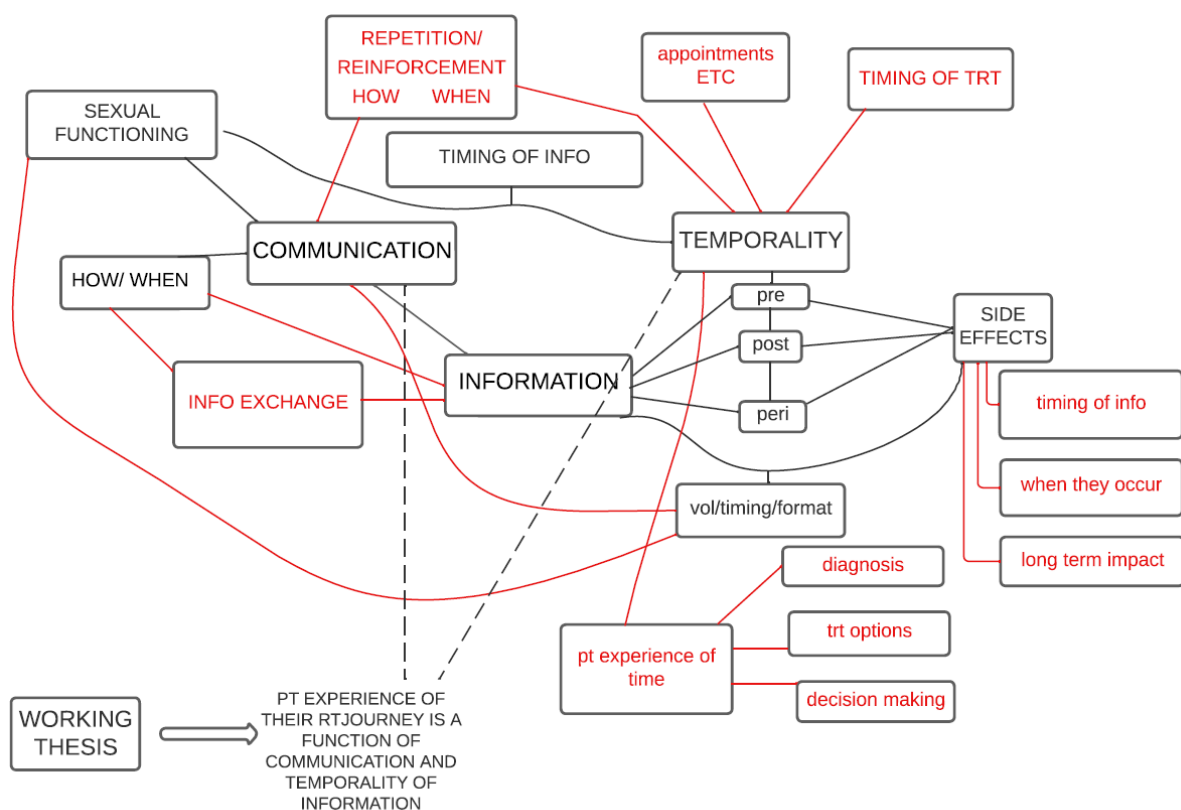


Figure 4. diagram representing second hand-drawn concept map (see Appendix 10 for photograph of original)

However, I was still uncomfortable with how disjointed and interconnected this map seemed. Having deconstructed the ‘information’ parent node I reviewed the new, more descriptive parent nodes.

These included nodes labelled according to the pre- peri- and post-radiotherapy periods. Increasingly, the theme of communication seemed important and alongside the theme of temporality appeared to underpin all other themes related to information. Within the context of time it has been suggested that men experience their cancer sequentially (Kelly, 2009) and in the present study three distinct, chronologically connected time periods became important in understanding the context of the findings: the pre-, peri- and post-radiotherapy periods. Pre-radiotherapy encompassed the period up to and including the decision to use radiotherapy as a treatment, peri-radiotherapy encompassed the localisation/planning process and treatment delivery, and post-radiotherapy encompassed the period from the last day of radiotherapy until the time they participated in the study. By reorganising the concept map according to these periods, related topics became much clearer, eventually being categorised as semantic themes, defined by Braun et al. (2016) as explicitly stated ideas and experiences. The semantic themes could therefore be considered and analysed in terms of the temporal and communication contexts. Because issues of time and communication were seen throughout all three periods, they were categorised as latent themes, defined by Braun et al. (2016) as ideas or concepts that underpin semantic themes. Reorganisation of the concept map into these time periods, enabled review and consolidation of the original coding, resulting in a modified concept map in which the three main themes of pre-, peri- and post- radiotherapy were associated with a total of 12 subthemes (see figure 5 below)(step 4).

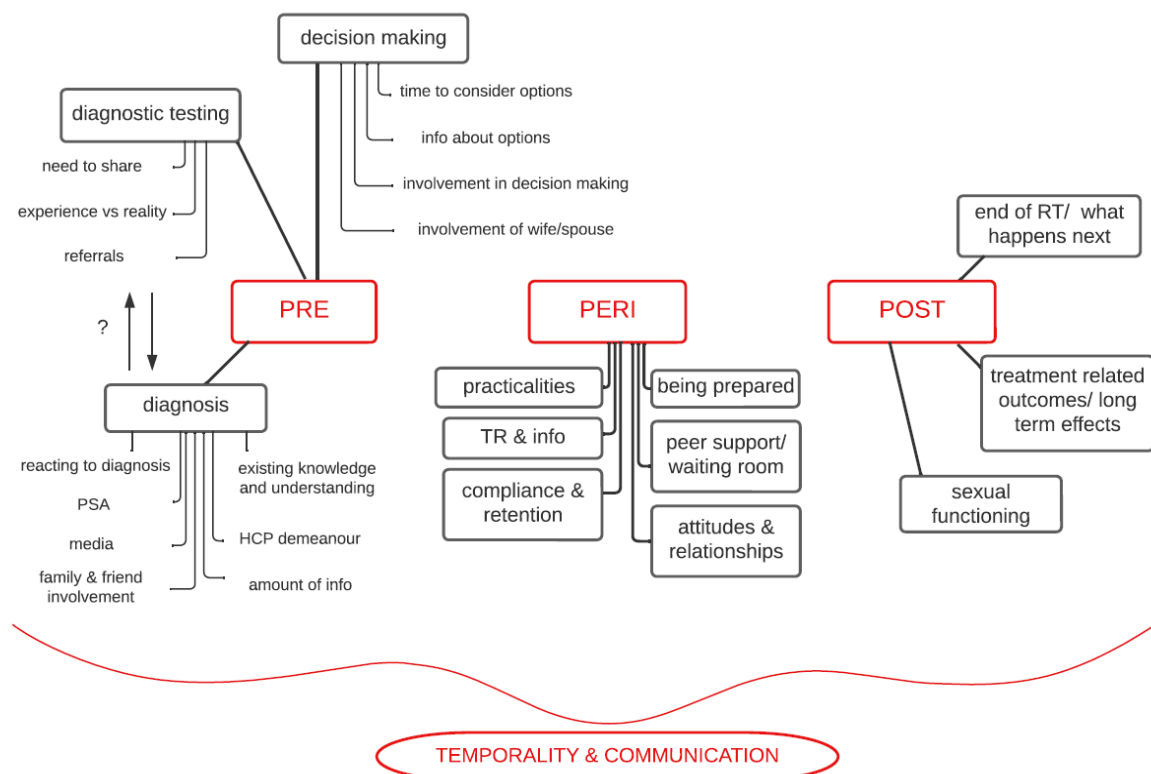


Figure 5. diagram representing third/ modified hand-drawn concept map (see Appendix 10 for photograph of original)

Part of the fifth step of TA is to interpret and analyse each theme in detail (Braun & Clarke, 2006). In the process of carrying this out and assimilating the findings, it became apparent that the diagnostic testing theme was better categorised within the diagnosis theme due to overlaps in context and 'fit' (Braun & Clarke, 2006). A final concept map was therefore produced reflecting this change and detailed in figure 6 below.

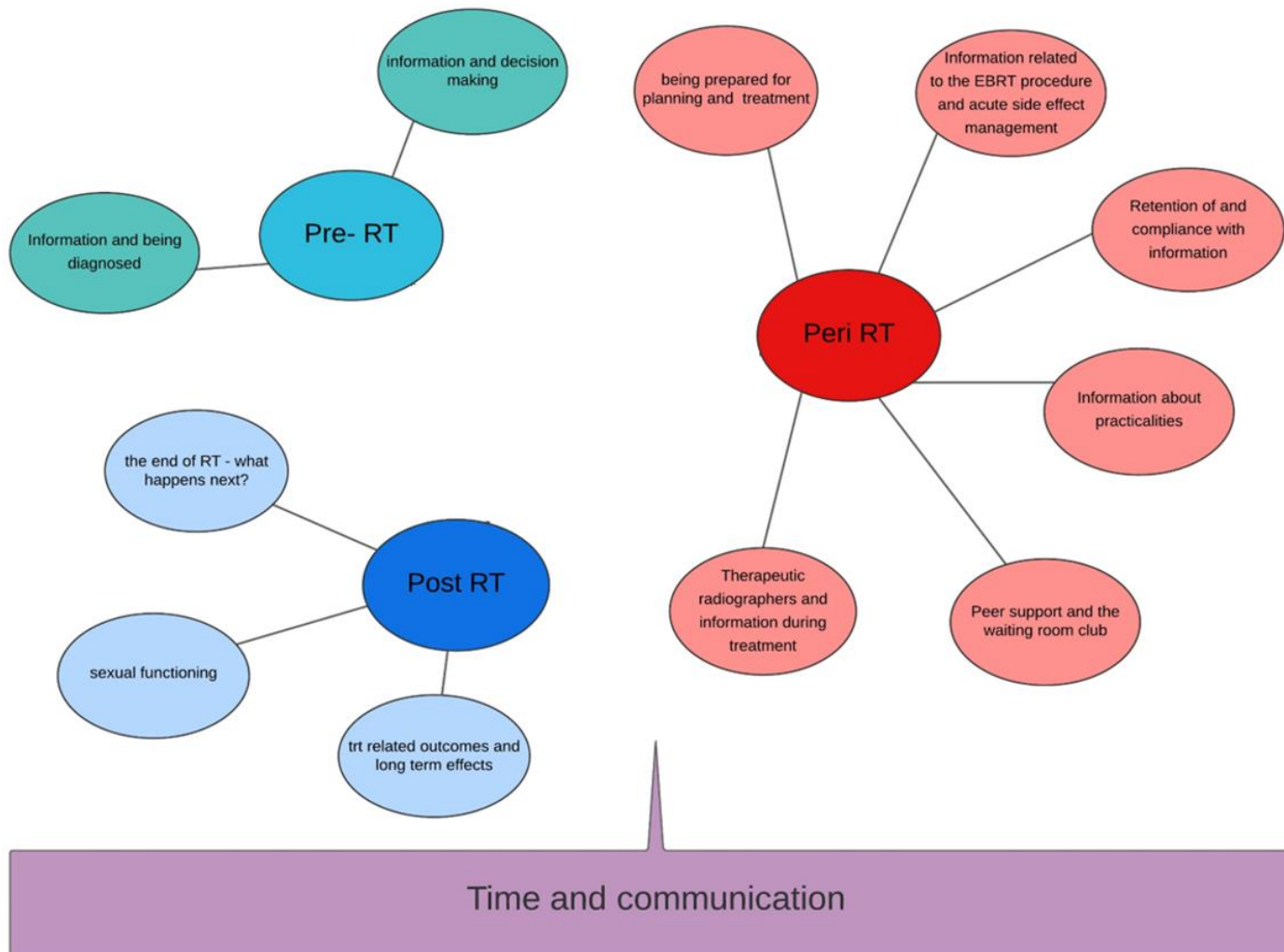


Figure 6. Final concept map

3.8.3 Quality, rigour and trustworthiness

Braun et al. (2016) stated that “quality has been a thorny issue in relation to qualitative research, and still is” (p.202), advocating rigorous, deliberate and reflective processes for researchers using thematic analysis. The issue of ‘measuring’ quality in qualitative research tends to stem from positivist research approaches where measures of validity, reliability and generalisability are standard indicators of research quality, rigour and trustworthiness (Bryman, 2012; Murphy & Yelder, 2010; Robson, 2011). However, in qualitative research, different criteria must be considered to demonstrate that the research has been rigorously carried out, is trustworthy and therefore is of high quality. Rigorous design is crucial to ensuring the validity and quality of a research project. The literature widely considers processes such as triangulation, member checking, negative case analysis and audit as being commonly used to ensure quality is both designed into the study and maintained throughout (e.g. Bryman (2012), Creswell (2012), King & Horrocks (2010) and Robson (2011)). Lambert & Loisel (2008) proposed that combining focus group and individual interview methods serves as a form of method triangulation which leads to enhanced description of phenomena. Tobin & Begley (2004) refer to this type of triangulation as “*offering completeness*” in that it allows a deeper and more comprehensive picture of the data rather than being seen as a validation tool and Mason (2006) refers to the potential for exploring the intersections between different dimensions of experience. In this study, TR and MPC were likely to offer differing perspectives regarding the radiotherapy process as well as each individual having subjective experiences. Drawing on social constructivism for this study meant it was important to use a methodology that acknowledged these individual subjective meanings and realities (Creswell, 2012). This supports my view that the research design was more rigorous as a consequence of using two participant groups. Nevertheless, there is also some consensus in literature on mixed methods research that the use of multiple methods can also introduce tensions and differences that are difficult to resolve and therefore potentially reduce rigour. For example, mixing methods may undermine, rather than increase methodological robustness as different methods do not necessarily lead to the building of one view of the phenomena (Mason, 2006; Tobin & Begley, 2004), or can cause over-compartmentalisation of the data (Barbour, 1998). It is worth noting Sandelowski’s concerns that applying rigorous approaches too rigidly can stifle the creativity, meaning and context that are hallmarks of qualitative research (Sandelowski, 1993). Indeed, dictionary synonyms for rigour include harshness and inflexibility (Oxford English Dictionary, 2020) which do not reflect most qualitative approaches. In my interpretation, rigour does not mean rigidly following a set of guidelines in order to discover the truths in the data; rather, by ensuring that the methodological approaches used are clearly described, justified and enacted, others will have little doubt that the research has been carried out with attention to quality and trustworthiness. I am confident that consideration of the shared

experience and contexts of radiotherapy of both TR and patients has created methodological robustness, especially as I analysed all data together.

Many authors have discussed and suggested criteria for ensuring trustworthiness in qualitative research (e.g., Emden and Sandelowski (1999) , Grbich (2013) and Lincoln & Guba (1985)); however, because I applied Braun and Clarke’s TA approach, I also followed their quality criteria checklist (Braun & Clarke, 2006). Table 9 below is an adaptation of the checklist which demonstrates how each of their criteria were applied in my study.

Table 9. 15-Point Checklist of Criteria for Good Thematic Analysis adapted from Braun & Clarke (2006)

Process	No.	Description	How/whether considered in my study
Transcription	1	Data have been transcribed to an appropriate level of detail, and the transcripts checked against recordings for “accuracy”.	Verbatim transcription undertaken. Recordings listened to at least three times to check accuracy /terminology /unclear sections
Coding	2	Each data item has been given equal attention in the coding process.	All transcripts fully coded – even if not directly relevant to the research aims, text was coded to ensure context was not lost. E.g. <i>“previous experience of healthcare”</i>
	3	Themes have not been generated from a few vivid examples (an anecdotal approach), but instead the coding process has been thorough, inclusive and comprehensive.	Single figure codes checked and removed/re-coded or left in place depending on context. Conceptual map 1 was not created until all 23 files had been coded.
	4	All relevant extracts for each theme have been collated.	Second coding process collated codes into the main themes. NVIVO 12™ used extensively to run queries, matrix coding and crosstabulation checks.
	5	Themes have been checked against each other and back to the original data set.	Extensive use of matrix and cross tabulation functions to check coding
	6	Themes are internally coherent, consistent, and distinctive.	Yes – they reflect the research aims and topic being explored: pre, peri, post radiotherapy
Analysis	7	Data have been analysed – interpreted, made sense of - rather than just paraphrased or described.	Suitable extracts have been used to help report a theme or subtheme, with explanation and analysis regarding the wider context/research aims Analysis began with writing of field notes taken at the time of the interviews; these have informed latter analytical and interpretative phases.
	8	Analysis and data match each other – the extracts illustrate the analytic claims.	Relevant participant quotations have been chosen to reflect themes and subthemes analysed and discussed.

	9	Analysis tells a convincing and well-organised story about the data and topic.	The analysis follows the chronology of pre, peri and post-radiotherapy
	10	A good balance between analytic narrative and illustrative extracts is provided.	As well as including analysis of pre-peri and post radiotherapy periods, two case studies have been explored and analysed.
Overall	11	Enough time has been allocated to complete all phases of the analysis adequately, without rushing a phase or giving it a once-over-lightly.	Analysis began with field notes and transcription and continued iteratively during coding and analysis phases, across many months
Written report	12	The assumptions about, and specific approach to, thematic analysis are clearly explicated.	Yes – detailed consideration in Chapter 3
	13	There is a good fit between what you claim you do, and what you show you have done – i.e., described method and reported analysis are consistent.	Yes – this is described in Chapter 3
	14	The language and concepts used in the report are consistent with the epistemological position of the analysis.	The epistemological position of the research sits within the social constructivist paradigm as detailed in chapter 3.
	15	The researcher is positioned as <i>active</i> in the research process; themes do not just “emerge”.	The coding process was iterative and repetitive to ensure that any new codes generated were re-visited in earlier transcripts. Active decisions were taken regarding epistemological, ontologic and reflexive aspects of analysis.

3.9 Reflexivity

Numerous authors have exhorted the value of reflexive approaches being both good practice and valuable in ensuring rigour and quality in qualitative research (for example Arber (2006), Mays and Pope (2000) and Ortlipp (2008)). Early in the development of my research proposal and study aims I noted several issues that would need consideration when designing and implementing the study. Firstly, I am a female researcher investigating a men’s health issue. Secondly, as a registered therapeutic radiographer, I am mindful that my experiences treating MPC will have shaped my consideration of the topic and my initial assumptions regarding issues that may arise. Thirdly, my father was diagnosed and treated for early-staged prostate cancer after I had commenced the doctorate but before I started data collection. Each of these factors will now be considered in terms of the potential impact on the evolution of the study.

3.9.1 Being a female researcher of a men's health issue.

Before commencing my current academic employment, I had worked in a radiotherapy department where there were only three male radiographers, although the majority of the medical staff were male. My current employment as a senior lecturer within a team of 12 is similarly female dominated – we have two male and 10 female staff. This female dominated demographic is echoed throughout healthcare in professions such as diagnostic radiography, nursing and physiotherapy (Chartered Society of Physiotherapy, 2021; Health and Care Professions Council, 2019). This is something I had always accepted as 'normal' so it was important for me to consider aspects of gender and how/whether they might influence my research process. As a female researcher planning to interview male participants about an aspect of their prostate cancer treatment, the impact of gender on the research process was something I considered very early on.

Communication related to health and illness has been widely documented as being gender specific and socially constructed (e.g., Courtenay (2000), Lohan (2007) and Street Jr (2002)) with Belur, (2014) reporting that gender strongly influences how research is conducted and experienced. Ahmed et al. (2011) postulated that female researchers may encourage female interviewees to be more open due to shared assumptions and experiences. Similarly, Arendell (1997) suggested that interviewees may assume that only a man would be interested in hearing men's stories, and act conventionally in respect of their gender belief system, thus gender is socially constructed (Seigfried, 1996, as cited in Denzin & Lincoln, 2013). This was considered because I was concerned that participants may not feel comfortable enough to speak freely about their experiences. Another consideration was whether participants in the interviews might display stereotypically gendered behaviours. For example, Broom et al. (2009) suggest that men respond according to the gendered performance of the interviewer, and men's 'talk' in an interview can be fundamentally shaped by the biography of the researcher. However, Lohan (2007) points out that they may also find it easier and more acceptable to discuss personal matters with a female interviewer. Thus, it should not be assumed that all participants will conform to a gendered stereotype. In female-to-female interviews with elite city workers, McDowell (1998) noted that some female participants were very forceful and had little time for a "sisterly exchange of views" (p.2137). This was in contradiction with Oakley (1981) who characterised women in interviews as sensitive and intuitive. In McDowell's paper the issue of gender is discussed in some detail but intertwined with age and power. This makes it difficult to determine whether gender is an isolated issue or something that, when combined with other factors such as age, race or class, shapes the conduct of the interview and associated disclosure of information (Dailey & Claus, 2001; Manderson et al., 2006). Although it seems that there is little consensus in the literature regarding

whether and how much the conduct of an interview might be mediated by gender, it was nevertheless a useful exercise in exploring my epistemological assumptions regarding this issue. When I questioned my reference group regarding how they would feel about sharing personal stories with a female researcher, they were very strongly of the opinion that gender was unimportant. What seemed more important was the trust they would have in me as a qualified health professional rather than someone who was “just a researcher”.

3.9.2 Being a therapeutic radiographer

Throughout my academic career I have maintained my state registration as a TR, having qualified in 1988. In considering my research journey I explored the duality of being a clinical practitioner and researcher. In their systematic review, Hay-Smith et al. (2016) describe this duality in terms of clinical patterns and connections: a research role can involve patterns of behaviour more typically seen in a clinical environment and the researcher may develop relationships with participants that mimic those they develop with their patients. This occurred on several occasions during interviews when patient participants asked my opinion regarding their management. In each case I was careful not to advise, but to give general information and a recommendation to contact their usual HCP or oncology team. Richards & Emslie (2000) noted the importance of reflection on one’s professional background to think about how it may influence the data. I frequently undertook reflection and critical thinking regarding my role and how to position myself when approaching the interviews with my participants in terms of whether to declare my professional background to my participants in case this was likely to change their perception of me. I similarly considered whether my professional background, knowledge and understanding of radiotherapy treatment pathways would impact on how I approached the design of the research as well as the way I interacted with participants. These issues were considered with respect to insider/outsider status which denotes how a researcher is similar or different to the group being researched (Lapan et al., 2011). My insider status as a registered TR conveys in-depth knowledge and understanding of radiotherapy and the typical cancer journey, but as I have never suffered cancer and am female, I am an outsider when compared to MPC. However, I am an insider when considering the focus group discussions with therapeutic radiographers. In the literature, discussion of the insider/outsider dilemma tends to focus on ethnographic and observational research (Dwyer & Buckle, 2009; Sherif, 2001) with Green & Thorogood (2009) referring to the tension between etic and emic perspectives, whereby the researcher must ensure that their insider account is made understandable to the outsider. This was a particular consideration when planning the content of the interview topic guides, the conduct of the interviews and analysis of the data generated. Davies & Dodd (2002) proposed that subjective positioning is an issue of both ethics and rigour in research; in other words,

how I presented and 'labelled' myself could have profoundly influenced the quality of the data generated, hence this critical consideration. Dwyer and Buckle (2009) point out that being an insider does not make for a better or worse researcher, merely a different one due to the perspective it may give.

3.9.3 My father's diagnosis of prostate cancer

During my father's prostate cancer diagnosis and subsequent radiotherapy, I accompanied him to all his initial appointments with the urology team, his biopsy and imaging appointments, his referral to his oncologist and to most of his radiotherapy appointments. My family relied on my expert knowledge and understanding to help them navigate my father's experiences. He is now well with no further evidence of cancer present. This was a completely unexpected diagnosis, but something that needed to be considered reflexively due to the potential impact on my study. The diagnosis and management plan coincidentally matched the inclusion criteria for my research. Most of my research instruments (such as the interview topic guide and participant information sheet) were finalised before my father's diagnosis; however, I was mindful of potential subtle changes to my perceptions in relation to insider/outsider status and also whether witnessing my father's experiences unconsciously changed my approach during the interviews with patients. I had not previously encountered the experience of being a close relative/carer of a person with cancer, and the paradigm shift in roles from professional to carer was something I identified as a potential source of researcher bias.

The literature exploring the impact of a researcher's influence on the data collection and analysis phases tends to be polar: some exponents of phenomenology suggest bracketing of experience to account for the roles that intense identification with the topic, prior assumptions and personal biases have in influencing the data (Mays & Pope, 2000; Offredy & Vickers, 2010; Silverman, 2016; Wojnar & Swanson, 2007). In descriptive phenomenology studies this is seen as focussing on the 'pure phenomenon' rather than what is already known about the phenomenon (Offredy & Vickers, 2010). The polar view is that researchers can find themselves as much part of the data as the researched (Al-Natour, 2011) and according to Banister (2011), bracketing is never completely achievable. This is mainly explored in the literature related to either the insider/outsider status discussed earlier, or in the wider literature on reflexivity. It is also reflected in Heidegger's hermeneutic phenomenology philosophy wherein hidden meanings are sought and interpreted within their respective contexts; in this case the context being my background and personal experiences (Gearing, 2004; Tufford & Newman, 2012; Wojnar & Swanson, 2007). Due to my professional background interrelating so closely

with this personal experience of a close family member's diagnosis and treatment, I felt uncomfortable with the concept of bracketing, and whilst I am not utilising a wholly phenomenological design for my study, the process of exploring these philosophies has helped me to understand how my own context may have influenced the research process. In reviewing my data, field notes and research diary, I have not found evidence that demonstrates overt bias. However, in a few recollections and notes I did reflect on whether particular participants reminded me of my father and his experiences.

In summary, reflection and reflexivity has been an important component of my research design and implementation. I developed an awareness of my role in the generation of data and this facet of research has aided my development as a researcher.

3.10 Chapter summary

This chapter has explored and justified the methods applied in answering the research question: the experiences of men with early staged prostate cancer regarding information related to radiotherapy in the UK. The use of a qualitative approach has been justified by critically exploring the literature on a range of qualitative methodologies. The research process has been described and justified with potential sources of bias identified. The thematic analysis approach has been detailed along with developments and decisions that led to the conceptual framework.

In chapters 4 and 5 the main findings will be reported and explored. Chapter 4 will explore findings relevant to pre-, peri- and post-radiotherapy periods respectively, drawing on the semantic and latent themes identified in the concept map presented in section 3.8.2 above. Chapter 5 will introduce two detailed case studies that contrast the experiences of two participants across their cancer journeys from diagnosis through to the time they participated in the study, in order to set in context the themes that were reported in chapter 4.

Chapter 4. Findings: pre-, peri- and post-radiotherapy

4.1 Introduction

This chapter presents the findings of the thematic analysis of data generated in the interviews and focus groups. Within this chapter it is important to address the original objectives of the study which were to explore:

- the factors affecting the understanding of information received/exchanged by men undergoing radiotherapy for prostate cancer
- whether information received was exchanged in a timely manner, appropriate to, and sufficient for their needs
- what information for MPC was given/exchanged before, during and after radiotherapy
- whether MPC had unmet informational needs
- the perspectives of therapeutic radiographers related to information they give men undergoing radiotherapy for prostate cancer
- the role of patients' wives related to information given during the course of radiotherapy.

Analysis of the data using a thematic analysis approach (Braun & Clarke, 2006) resulted in development of the concept map detailed on page 71, section 3.8.2 of the methodology chapter.

This findings chapter is organised chronologically into main sections that reflect the pre-, peri-, and post-radiotherapy periods. Within the main sections, the semantic themes that reflected the experiences of the MPC are explored. Where relevant, the perspectives and involvement of the men's wives are highlighted. Further context given by therapeutic radiographers is also explored. Due to the interconnectedness of many factors, and the latent themes related to time and communication, there is necessarily some overlap and repetition in the way the data are explored in these themes: in considering the data holistically, the 'whole' becomes "more than merely the sum of its parts or elements" (Chambers Dictionary, 2021a). Participant recollections around information related to ADT have been included, because these were inextricably linked to patients' overall radiotherapy

experience, in particular related to decision-making and long-term effects of treatment - all but one of the men had received ADT in line with NICE guidelines as well as radiotherapy (NICE, 2021a).

4.2 Pre- radiotherapy

Introduction to the theme

This section captures the experiences of participants related to what happened before they commenced radiotherapy. It explores their recollections of being diagnosed and the impact this had on them and their families, and the decision-making processes that led to them having radiotherapy determined as a treatment choice. The role, impact, and communication of information during this period is described.

4.2.1 Information and being diagnosed

One of the aims of this research was to explore the factors affecting the understanding of information received/exchanged by MPC undergoing radiotherapy. However, when analysing the data, it became clear that MPC experiences of information related to the 'on treatment' phase were inextricably linked to the initial diagnosis period. For many MPC, asking them to recall the time of their diagnosis identified a variety of information-related issues. For these men, this time point was when they first received information about their cancer, setting in motion the events that subsequently led to them undergoing radiotherapy. Exploring the background to experiences that led to them being diagnosed and receiving the diagnosis gives context to how information influenced their treatment decision making.

Knowledge and understanding about prostate cancer and its management before diagnosis varied between the MPC, as did their engagement with education-based resources and other information. Some were aware of where to find information and had accessed resources such as the NICE guidelines and had good understanding of the diagnostic processes involved, whereas others had little knowledge and understanding until they were diagnosed and either started looking for information or were given it. Most MPC had been symptomatic with either general or longer standing urinary symptoms prior to their diagnosis. Some had been diagnosed with benign prostate disease that had subsequently progressed and therefore were intimately aware of the differences between benign and

malignant disease, and the role of PSA testing in monitoring change. Others had been placed on an active surveillance¹⁹ pathway so their referral for radiotherapy had occurred due to progression of their disease, hence those were the MPC who tended to have greater existing knowledge and understanding. However, a few asymptomatic men approached their GP for testing, having learned about the importance of PSA testing. The UK prostate cancer risk management programme (PCRMP) sets out that GPs and other primary care professionals should counsel asymptomatic men over the age of 50 who ask about PSA testing, so that they can make an informed choice about whether to have the test/further examinations (Public Health England, 2020). In the present research, some men were given PSA tests on request; however, others felt GPs dismissed their concerns:

“Can I have a prostate check?” and my doctor... said, “What on earth do you want that for, do you know what it entails?” so I said, “Yes, unfortunately I am asking you to stick your finger up my bum and do a blood test” (Adam, MPC)

Adam had been knowledgeable about prostate cancer and as he fitted the PCRMP criteria, had been within his rights to request PSA testing, having weighed the evidence. Other MPC who had been asymptomatic at the point of diagnosis reported limited prior understanding or knowledge of prostate cancer, with most information being sought or gained as the diagnostic and treatment processes were arranged. For example, Martin had decided to seek a PSA test having watched an awareness programme on television, only seeking information once referred for biopsy. This type of condition-specific information seeking has been reported as being common in newly diagnosed cancer patients (Adjei Boakye et al., 2018).

For most MPC, recollections of information relating to diagnostic procedures tended to revolve around appointments or describing their experiences of the procedures and how long it took to receive the tests and consequently the diagnosis. For some men the pathway to diagnosis was uneventful and fairly swift, with a higher-than-normal PSA test result warranting referral for further procedures within the expected 2-week timeframe (Cancer Research UK, 2020):

“the GP said “I should refer you across”, it was a two-week referral and I went across, went through all the various tests - bone scan, MRI and the telephone pole up the backside (chuckle)” (Dan, MPC)

¹⁹ A management approach where patients with low Gleason grade, localised prostate cancer undergo regular PSA testing and imaging rather than immediate definitive treatment. It accounts for the fact that many prostate cancers are slow growing, with a low risk of spread. Definitive treatments can be offered at any time based on cancer progression or patient choice. The aim of active surveillance is to delay or avoid the side effects of the definitive treatments.

However, the reality of some of the diagnostic procedures was identified as being at odds with the men's expectations. MPC reflections on their experiences of the prostate biopsy suggest that some had received limited information, or that the information had been edited in order to make this investigation more acceptable. Having undergone the biopsy and found it either very painful or extremely uncomfortable, both physically and emotionally, they questioned whether there was deliberate withholding of information on the part of the HCP:

“you tell men all of the symptoms that you're going to get, they're going to go: I'm not having that done. So you know, you can't frighten someone away from having it done can you?” (Paulo, MPC)

MPC also wondered whether knowing the precise detail of what a biopsy entails might reduce the likelihood of some men to seek help and/or treatment and suggested they would be wary of sharing their true experience with other men in case it put them off having a biopsy. So, whilst they were critical of HCP limiting the amount of detail shared, the MPC acknowledged their own complicity in doing the same. These are important points to consider in terms of informed consent and the risk/benefit balance that is applied to all health care procedures, and how this balance can be addressed to ensure individual patient care and information needs are met.

Symptomatic men either requested PSA testing via their GP or were diagnosed after longer term monitoring of urinary symptoms. Some MPC noted the way the diagnosis was communicated to them and how this impacted on their understanding of the implications of their diagnosis. For example, the language used by a receptionist convinced Adrian of a poor prognosis; it was not the nature of the diagnosis that scared him, but the manner of the communication that made him assume a worse prognosis than was actually the case:

“She just said “can you come now”. So I immediately thought that if I don't, I'm going to be dead by tomorrow (chuckle)” (Adrian, MPC)

Other MPC mentioned similar issues with the way their diagnosis was communicated to them, with clues to a positive diagnosis being transmitted almost by stealth. They described being called in for an appointment rather than the normal practice of receiving a letter with results, receiving appointments for treatment or prescriptions for cancer drugs before having had the news broken to them, and noting that the body language of their clinician was avoidant, such as when Bill described how his GP: *“wouldn't look at me as I came in the door”*. Bill had previously had his concerns dismissed by this GP who told him he was *“wasting his time”* when approached for PSA testing and he reported having had

quite a battle to convince the GP to carry out the test: “‘Oh no, you’re not having one’. I said, ‘Yes, I am’. ‘No, no, no, you’re not having one’”. The general attitude of HCP was important to participants. For many, an efficient, direct or pleasant demeanour was associated with expertise, for example, Elsie, Angus’ wife described their consultant as: “*very nice and very direct, he knew his stuff, definitely*”. But for other participants such as Philip, that direct approach made them feel that their HCP was tending to “*talk at you rather than to you*” perhaps indicating a more didactic approach to information giving. For some participants the calm, caring and empathetic manner in which the information about the diagnosis was delivered by the HCP was often at odds with the emotions they felt, even though they understood why the HCP needed to remain calm, for example:

“as soon as they say it, it is cancer. ... They have to be, obviously very calm. But there is no emotion there. Which obviously, they can’t show anyway. Because it’s their job, but you’ve got this turmoil going on in your head and yes it is prostate cancer. And I think that was quite a shock, wasn’t it?” (Carol, Andy’s wife)

Whilst some participants commented on a few HCP whose demeanour was cold and brusque, most were at pains to explain that this was not a reflection of the competence of these HCP, but rather to be expected in a stressful or busy clinic environment, or due to cultural differences. Nevertheless, it impacted on their experiences at this time. Angus appreciated an approach where the clinician was “*matter of fact*” and told him “*exactly what [he] needed to know*” as this suited his own matter of fact personality. Donald provided an example of contrasting experiences with different clinicians throughout the path of his diagnosis. He reported the poor communication skills and arrogant approach of his urology consultant, who he said appeared to be “*either drunk or he hadn’t slept*” when giving his diagnosis, adding to an already stressful moment. This episode of poor communication with the consultant was in stark contrast to his experiences once referred to the oncology team, whose approach he described as discursive, competent, open and very positive, and made what he described as a “*massive difference*” to his transition to the treatment stage. Other participants also compared communication styles of HCP from different professions. For example, Henry’s wife Gail referred to a consultant whose attitude she described as “*horrendous*”, noting:

“he did nothing but yawn all the time, did he, and he was doing it by rote...it was a bit brutal wasn’t it?”

She contrasted this with the approach of the specialist radiographers they met:

“[the specialist radiographer] was brilliant, wasn’t she?... you rang her two or three times didn’t you? And she was just so lovely for help and advice... they were very good, they explained everything” (Gail, Henry’s wife)

The impact of emotional responses to their husbands being given the diagnosis was highlighted by several wives in the descriptive language they used. For example, Henry’s wife Gail spoke of feeling “shellshocked” and Tom’s wife, Heidi suggested that people “just freak out if they hear they’ve got cancer”. This level of heightened emotion adversely impacted on some participants’ ability to process the information they were being given, as in this example reported by Charles’ wife, Ruth:

“when you’re receiving the information, and you’ve got cancer going through your head, the word cancer going through your head, I think you’re, the taking up of that information is skewed ... I just thought, hang on a minute, he’s just been given a diagnosis of cancer, just ease back a bit and let him just talk it through” (Ruth, Charles’ wife)

Other participants were similarly aware of how the emotional aspects of receiving a diagnosis might impact on their understanding, retention and processing of information. Several MPC were told their diagnosis and given information about treatment options at the same appointment. They queried why they were not given time to review information or the opportunity for further discussion with a HCP, proposing that periods between one to three weeks after the initial consultation would have been helpful in enabling them to review information and carry out further research, as well as helping them to adjust to the reality of having cancer. Donald provided an example of how long it took him to adjust:

“When I got finally diagnosed it was like ‘yeah, okay’ but it was really only until about three weeks later that it went ‘shit, this is for real’” (Donald, MPC)

A further aspect of being able to assimilate information given at diagnosis, was the amount. The NHS has a policy of ensuring that every patient gives informed consent to either interventional investigations or treatments, hence clinicians are required to provide information accordingly (NHS, 2019). There were conflicting accounts regarding the impact of the amount of information given. Some MPC reported information overload, describing how information was often given in packs that covered a large variety of topics related to both diagnostic procedures and treatments, and the sheer volume of information caused issues, due to them being given too much information to make sense of. Ralph described this as a “juggernaut” of information, implying a large, unstoppable momentum. Similarly, Angus felt overloaded with information and in common with other participants suggested that more succinct information would have been beneficial:

“Tell me what I need to know and what I need to do. That’s it. Just condense it into that, don't give me too much information because too much information is going to be overload for me and anybody else.” (Angus, MPC)

Even when demonstrating that they had received a large amount of information, not all MPC felt overloaded, though it seemed they had received similar amounts to those who did. Some MPC were keen to show me how much information they had been given and gathered the information together ready for their interview (see figure 7 below). For example, Jack had created piles of the information he had received on his dining room table. This comprised books, leaflets and letters; however, he indicated that he was happy with the amount and had a pragmatic approach to dealing with it:

“I read them all, I just skipped the bits that... I mean, there were bits about surgery which I skipped over but I read everything that might have been relevant and then I tended to put ‘em on one side and just regard them as reference books. But I felt I’d got plenty of information there, and there is a lot of information in here that says where I can get more information if I need it. But I never actually felt I needed more, I felt they’d explained things well enough.” (Jack, MPC)



Figure 7. Photograph of one participant’s prostate cancer information

The perspective of radiographers is largely absent in terms of data relating to the time of diagnosis; however, a few commented on the amount of information that patients receive prior to radiotherapy, citing similar concerns about information overload. Jane, a specialist practitioner gave an example where she felt the plethora of information meant patients struggled to assimilate it:

“... it is another piece of paper that goes in their folder that never gets read because there is so much of it ... The booklet and their folders and they are absolutely rammed with different bits of information and you see them just put it in and it’s like, well, that’s gone, they won’t read it.” (Jane, specialist practitioner, FG1)

Jane’s perspective that the information was not being read is an issue that potentially gives rise to implications for successful radiotherapy, in that if some patients are not following or understanding the information they are given because they feel overloaded, they might not be fully informed, which could invalidate or affect informed consent. There is also the implication that if patients do not engage with the information made available to them, they risk opting for treatments that in the long term might impact their quality of life.

4.2.2 Information and decision making

In June 2021 NICE published its guidance regarding shared decision making (NICE, 2021b). In this guidance, expectations are set out that patients should receive information based on high quality evidence and that clinicians should check their patients understand the information given in order to take part in decisions about their care. The data demonstrate a variety of experiences regarding the MPC’s involvement in decisions about their management and treatment options, with some undergoing an active period of information seeking in order to make sense of their options, whereas others were more accepting of the choices suggested by their consultants and sought out little information, relying instead on what had been provided by their HCP. For some participants this time was characterised by initial ignorance or incognizance about their options as in this exchange between Philip and his wife Kim:

“Philip: And you know nothing.”

Kim: And you come in and you don’t know anything and you’re also concerned because of what’s happening to you, and it’s almost a little bit like it’s assumed that, or I don’t know whether it’s assumed, but they do sometimes talk as if you should know what they’re talking about, and actually you don’t”

In trying to become better informed about treatment options, some participants accessed a myriad of sources of information from their HCP, family and friends, and support groups, and described the research that they had carried out themselves, revealing that this process was often lengthy and involved several stages:

“And then you researched the options ... and you started then going to the prostate meetings, support group meetings, talking to people then, and you sort of like had three months where you were researching yourself” (Mary, Ralph’s wife)

This period of decision making was also characterised by concerns about the amount of information that MPC needed to navigate, and who to take notice of when advice or information was given. For example, Ralph noted that he was *“bombarded”* with information from family, friends and work colleagues even though they were not fully aware of his specific circumstances and therefore their information was likely to be erroneous. But despite the uninformed nature of this information, he admitted it had aided his decision making by allowing him to consider the implications of various treatment options more carefully. The influence of family and friends on the decision-making process was noted frequently, with MPC seeking information, support and advice from other people diagnosed with prostate cancer:

“the most important was talking to people who went through it or were going through the treatment and diagnosis themselves you know, because ... they knew, they were having the same reaction, it was just sort of how they felt whenever they heard what they heard and all this sort of thing, it was getting an affinity with them”, (Bob, MPC)

The concern regarding the amount of information was also noted by TR, with specialist radiographer Hannah (FG3) noting that she felt patients had *“a lot of information thrown at them”* before they went away to have a period of decision making. Some TR made assumptions about what happened at the decision-making stage as in this example from rotational radiographer Harry:

“So initially they will meet with the doctor, obviously with radiotherapy being one of the treatment options, so they will be made fully aware of what it involves. Obviously, I am assuming they will be in comparison with the other sorts of treatment modalities you know, so helping them make an informed decision in that case.” (Harry, rotational radiographer, FG2)

The language used in the example above demonstrates that TR may assume that their patients have accessed enough information to make an informed choice about all the potential treatment options,

when this may not always be the case. Indeed, several MPC commented that they were not given options, but were either told or strongly recommended as to what treatments they would be having:

“I don't think he sort of talked about choices ... he just said that we would start the hormone treatment straight away and you'll go to [hospital name] for radiotherapy. That was basically it.” (Murray, MPC)

In some cases, MPC were not aware of other options, even after discussions with their HCP about their cancer management. Jack described how he was unaware of brachytherapy until reading about it in information sent to him, despite having discussed radiotherapy at length with his consultant. Nevertheless, he was satisfied with the information and the choice that had been made on his behalf:

“I wasn't given any choice on type of radiotherapy but they decided what was best and that's what I agreed to. I mean at that point I probably didn't realise there were different types. It was only as these came through [pointed to booklets] that I realised ... I was quite happy the way it all went ... They told me enough, then they sent me some more and I learnt a bit more. I think it was all handled fine.” (Jack, MPC)

Even where MPC were aware of the treatment options available to them, some felt they were not given a choice and that consultants had a preference depending on their clinical speciality. Having read about several options available to him, Dan felt his oncology consultant gave him a *“sales pitch ... presented ... very nicely”* about radiotherapy but was given little information about other options.

MPC who were happy to rely on their clinician's suggestions for treatment tended to conceptualise this in terms of the clinician's expertise or specialist knowledge. Charles used a metaphor to explain his concerns about why he, as the uninformed patient, should be expected to make a choice rather than relying on the expert knowledge of his consultant:

“I don't know what the treatments are, you know, they talk about brachytherapy and all this sort of thing and it doesn't actually mean anything to me ... but you know, you don't get a plumber in and say 'fix my boiler' and he says 'well how do you want it fixed'? You know, he's the expert.” (Charles, MPC)

Other MPC felt the need to carry out further research, despite feeling that they had been given good advice from their consultants. They understood the information they had been given but felt under pressure to rationalise the longer-term impact of each option. Bob described how, despite having been

given further information and advice from the Prostate Cancer UK charity, he found it difficult to compare each option:

“I was getting pretty good advice ... also I made early contact with the Prostate Cancer charity and they were really good... then I suppose the hardest bit for me was ... there was physically three different options, there’s the brachytherapy, the external radiotherapy and the radical, the surgery ... and it then becomes a process of weighing up the pros and cons of each so that it’ll have the least effect on your life, and that was probably the hardest bit ... they give you objective advice but they don’t give you a recommendation ... you have to make that, assess the information yourself and make the decision and take ownership of the decision.” (Bob, MPC)

Consideration of likely long-term side effects of each treatment option, and the potential consequences on their future quality of life was mentioned by MPC as being a major factor in their decision making, but this created somewhat of a dichotomy for them. On the one hand they were being told there was a decision to be made about their treatment, but on the other, they felt they were presented with very little choice between having treatment that would likely cause long-term effects and the risk of not eradicating the cancer. These were men for whom an active surveillance approach was not suitable due to the risk of their cancer spreading if untreated. As they learned more about their options, a further anxiety for some MPC was the realisation that, even though they had accepted there was little choice but to have their prostate cancer treated, each option may have a profound impact on their future quality of life. Ralph gave an example where he felt that being asked to decide between surgery and radiotherapy was deciding on *“the lesser of two evils”*. The information MPC received indicated to them that the most likely severe, long-term side effects would be incontinence and sexual dysfunction regardless of which treatment they accepted. Some patients acknowledged that both side effects were inevitable consequences of being cured of their cancer; however, others felt they were being asked to weigh up which they were more prepared to live with in the long term, as in these examples provided by Ruth and Andy:

“they did mention that this could be a potential problem, I can remember that. You know, side effects but like you say, what’s the alternative? If you don’t have the radiotherapy, it doesn’t get treated, does it?” (Ruth, Charles’ wife)

“one of the leaflets I think it was, indicated that you could be incontinent or impotent. Impotent I wasn’t bothered about anyway ... I mentioned about incontinence because that was something... did I really want to live with that or would I rather put up with, if

there was an option, with having prostate cancer? ... that was why I did consider not doing it. Because I didn't want to end up incontinent" (Andy, MPC)

Concern regarding the demeanour of some HCP has already been noted in section 4.2.1 above as an issue during the diagnosis period and recurred as an issue with respect to decision making. During the decision-making period, MPC accessed information given to them by a variety of HCP and had conversations with consultant urologists, surgeons and oncologists, clinical nurse specialists and advanced practitioner or specialist radiographers. Building a good rapport with their HCP was important to them, and where some men felt this relationship was not good, they provided illustrations of negative experiences related to information which impacted on their decision making. For example, Philip suggested his consultant was “*elusive*” in that he did not give clear or specific responses. Having an engineering background, Philip was used to dealing with precise figures and was unhappy with the lack of clear guidance from his consultant regarding his options, reporting that his consultant had a “*sort of vague approach*” and was reluctant to give him the specific, detailed guidance he was expecting of someone with medical expertise. Likewise, Ralph described encounters with consultants where the manner of communication of information impacted on his decision making. He cited a surgeon’s approach to communication as a major reason why he did not choose the surgical option:

“the surgeon was talking, not talking to me, but just spilling the facts... didn’t seem to have any personal interest in me ... whereas [oncologist] seemed to talk to you more like a person” (Ralph, MPC)

In the UK the NHS sets a target for cancer patients of no more than 31 days from the date of the management plan being agreed to treatment starting (Cancer Research UK, 2020) due to the risk of the cancer progressing. All but one of the MPC in this study had been prescribed androgen deprivation therapy (ADT) therapy and had started it almost immediately following diagnosis, in line with NICE guidelines²⁰, as this is effective in halting the progression of primary prostate cancers and is associated with longer overall survival when compared to radiotherapy alone (Schmidt-Hansen et al., 2014). In terms of decision making; however, there was varied understanding regarding the role of ADT and how it related to the timing of other treatments. Gordon, the sole MPC not prescribed ADT had spoken at length with his consultant about the advantages and disadvantages of ADT as part of his decision-making process, and with the agreement of his wife had ultimately decided that “*it wasn’t something*

²⁰ Many prostate cancers grow more quickly in the presence of testosterone. The main androgen deprivation therapy (ADT) works by blocking luteinising hormone releasing hormone (LHRH), thereby preventing the testes from releasing testosterone.

we were going to entertain” due to concerns about mood-altering side effects. None of the other MPC mentioned decision-making with respect to ADT; however, for some there was surprise at the length of time between starting ADT and starting radiotherapy; they had not realised that their treatment had already begun as soon as the ADT was administered because the information they had received had not made this clear. This caused anxiety for some MPC who were concerned that this perceived delay in treatment may mean their cancer would spread. Murray gave an example of being informed that his cancer needed urgent treatment and yet he was being told his radiotherapy would not commence for three months:

“See I didn't realise that the hormone treatment is a treatment. I thought it was just to stabilize it and shrink it. You know it's like a pre-op if you know what I mean? No that wasn't explained about the hormones. About how important the hormone bit is and that it's a treatment on its own... nobody had told us that I'd got to be on hormone treatment for 3 months you know before the [radiotherapy]” (Murray, MPC)

Summary

In summary, the accounts of the participants have indicated that information is an integral part of the diagnosis and decision-making period for MPC. This pre-radiotherapy period was experienced as a time of profound biographical disruption with associated anxiety and stress. The examples provided by participants demonstrate that the nature, amount and sources of information were varied, and how information was communicated impacted not only on the treatment choices MPC made, but also on their well-being. Regardless of how much information HCP were giving to patients, it appears that for some, information needs at this time were not met, either because they were overwhelmed with information, or they did not receive enough to satisfy their information needs. The amount of time allowed for patients to absorb the implications of their diagnosis varied, with mixed consequences; some participants felt they needed more time to adjust to the disruption caused by the diagnosis in order to fully understand the consequence of the decisions they were being asked to consider, whereas others did not report this as an issue. Some reported confusion regarding the chronology of their management, having not been informed that ADT had signalled the commencement of treatment and thus experienced anxiety about perceived delays to the start of radiotherapy. A potentially negative issue was raised regarding HCP demeanour and relationships, with some participants reporting poor communication skills and attitudes in some HCP at a time when they were being asked to make potentially life changing decisions.

4.3 Peri radiotherapy

Introduction to the theme

This theme describes the experiences of participants related to the radiotherapy treatment process. This process comprises the time period covering the initial CT planning appointment through to attendance for their course of EBRT and/or brachytherapy. As reported in section 4.2, issues related to information in radiotherapy are apparent throughout the trajectory of diagnosis, decision making and treatment, with MPC reflecting on a variety of treatment-related issues that were influenced by the information they had received. This theme will explore how and when MPC received information related to planning and treatment processes, people and situations that influenced information exchange and aspects of their treatment experience that were influenced by information. Integral to this exploration is inclusion of the contexts of the MPC, their wives and the therapeutic radiographers.

4.3.1 Being prepared for planning and treatment

Once the decision to treat with radiotherapy had been reached, MPC can then expect to receive appointments for the planning of their treatment. The process for radiotherapy or brachytherapy planning is described in chapter 1 section 1.1.2 and for many patients this proceeded as expected. However, several participants referred to the uncertainty and anticipatory anxiety caused by what they perceived to be delays to their treatment starting and the lack of information they received about start dates. Carol, Andy's wife described being "*left in a little bit of a limbo*" because of the uncertainty regarding Andy's start date:

"we moved from February to March and then it's to May and then actually we are not starting till the end of June. I think that is the most worrying time because it's the unknown... you couldn't plan anything because you didn't know when things were going to start happening" (Carol, Andy's wife)

Whilst Carol's focus was on practical matters, for others the delay caused anxiety about the potential impact on treatment efficacy and what was happening to their cancer in the meantime:

"it was like I felt there was something growing, I don't know what it was, it was growing,... and if I could get to it before it got too bad; I wanted my treatment to start the next day or yesterday" (Angus, MPC)

MPC had normally received some information about radiotherapy as part of their decision making or discussion of treatment options, but the detailed information regarding what would happen during planning and delivery of radiotherapy was generally received as part of the appointment information for their planning scan (EBRT) or pre-surgery appointment (Brachytherapy). Only four of the MPC had received brachytherapy and there were few comments specifically mentioning information about the brachytherapy procedure, possibly as they had received this as part of their preparation for the surgical process and therefore their experience was somewhat different to the patients who underwent EBRT. These participants reported receiving information regarding preparation for brachytherapy that focussed on explanations of the procedure and likely side effects. In an example provided by Gordon, he described how the reality of his brachytherapy experience met his expectations:

“Everything happened just exactly the way he said it was going to happen, right down to how uncomfortable it would feel ... whenever you hear an expert saying that to you or explaining that to you and saying it in such a way that it’s very direct, very matter of fact and very sincere then why would you argue with it...” (Gordon, MPC)

Preparation for EBRT similarly focussed on management of the expected side effects of radiotherapy, and information about diet and fluid intake as these impact on bladder and bowel status²¹, which in turn dictate the radiation dose to both the prostate gland and organs at risk (OAR)²². So that the radiotherapy is reproducible, the size, shape and position of the internal organs surrounding the prostate gland at the planning scan will need to be replicated throughout the course of radiotherapy. In order to ensure this occurs, patients will often be sent information about diet and fluid intake that they need to follow for about a week leading up to the planning scan and then during their radiotherapy. MPC received this information once they had been notified of the appointment for their planning scan, with various forms of written information being mentioned by the MPC, for example: *“diet sheet”* (Bill, Donald, Paulo), *“introduction pack”* (Andy, Ralph), *“Booklet”* (Adam, Adrian, Clive) *“photos of the rooms”* (Tom). It is worth noting that practices related to bladder and bowel preparation vary between radiotherapy departments and some patients were aware of this due to comparing their experiences with friends who had undergone radiotherapy elsewhere. This

²¹ The dietary advice aims to reduce the amount of bowel gas as this causes positional changes of the bowels which can adversely impact the dose map. Similarly fluid intake is regulated so that the bladder volume is consistent at each treatment. A full bladder will displace small bowel away from the high dose volume, hence aiding reduction in bowel side effects.

²² Organs at risk (OAR) are structures close to the prostate gland that if irradiated to a high dose could cause unacceptable morbidity, both in the short and long term. By minimising dose to OAR long-term side effects are less likely and therefore a patient’s quality of life is likewise more likely to be improved.

introduced some uncertainty regarding whether the information they had been given was accurate, as in this example provided by Charles:

“I found that very confusing because we’d got another friend who was diagnosed just after me, he was sent to [hospital name]. And he got none of that, nothing about dietary constraints. Whereas mine were fairly strict and since then, there’s been another friend of ours who’s been diagnosed who ... wasn’t given any information at all about the dietary thing... his treatment was completely different. I mean he had to have an enema every day before he went...” (Charles, MPC)

For other MPC, the nature of the preparatory dietary information caused concern when they considered their usual diet, with Bill describing his instructions as an *“incredibly complicated list of things you can’t eat”*. Murray, a vegetarian, noted that he had not been given specific information that fitted with his usual diet and that the recommendation to switch, for example to foods lower in fibre may have a significant impact on the healthiness of his diet. Another was similarly concerned with switching to what he perceived was an unhealthy diet, lacking in fruit and vegetables and that *“all the healthy food we normally eat, you weren’t allowed”* (Ralph, MPC). TR spoke about the information they gave to prepare patients for their planning scans, stressing how much effort they put into ensuring patients are well informed but also remarking that sometimes there were issues with patients understanding why they are given the dietary information and why it is important for them to follow the changes during treatment. As described in this example from James (FG2) they noted how some patients could be confused regarding the dietary instructions if they had read different information elsewhere, or been given other advice from friends or family:

“it can become conflicting information when you talk to them about, you know, reducing their fibre and so on, or they may well have read somewhere that they are supposed to do something else. Quite often they may have a misunderstanding about what we have asked them to do or why we’ve asked them to do it.” (James, rotational radiographer FG2)

Here again, as with during the period of decision-making, the issue of the amount of information was raised. MPC appeared to be satisfied with the amount of information; however, TR were concerned that at the CT planning appointment some patients were overwhelmed by information and that by being given *“superfluous”* information on the day of the scan, unrelated to the scan procedure, they might struggle to assimilate the important information:

"sometimes there is too much information. They are trying so hard to take it in all the information ... they tend to miss out the most important bits" (Harry, rotational radiographer FG2)

4.3.2 Information related to the EBRT procedure and acute side effect management

When MPC mentioned the nature of the information they received during radiotherapy, the dominant topic was regarding treatment procedures and side effect management. They often reported this in conjunction with an account of their radiotherapy experiences. At the beginning of radiotherapy MPC were anxious to know what the procedure would be, and they noted whether information was helpful in allaying their concerns and whether or not their expectations had been met. In this example from Andy, he explains how his anticipatory anxiety was not warranted based on the reality of treatment:

"I was told I was gonna have three tattoos one in the middle and two at the sides. And we were told why. Because we have to set you up in the same position every time ... If you want the honest truth, the first one I had, I'm thinking is that it? Because I was in, on the bed. Once they had positioned me and the radiologist [sic] had gone out the room. Three minutes? Something like that. And I'm thinking. Well, is that it?" (Andy MPC)

Comments from some participants indicated they either may not have been as well informed as the TR assumed, or that the way the information was given had insufficiently prepared them. Tom reflected with some humour how he had misunderstood instructions regarding moisturising his skin (which can become dry due to being irradiated) and rather than moisturising in the treated area, had moisturised his whole body. Whilst this is an amusing anecdote, patients not understanding treatment instructions and information could have negative consequences for them. For example, HCP may make assumptions and expectations that their patients' understanding of terminology used in information is better than it actually is, a point made by Angus' wife, Elsie:

"I thought it was quite detailed. It's quite easy to... obviously I didn't know what radiotherapy was. All these words were all foreign to me really, all these sort of words" (Elsie, Angus' wife)

For many men, the focus was ensuring they were following the instructions regarding bladder and bowel preparation correctly. For some, the treatment experience itself was easy, whereas managing

the preparations was somewhat more difficult. The preparation procedures varied depending on where the MPC had received treatment. As indicated previously, much of the preparation revolved around dietary changes; however, some men were required to carry out daily mini-enemas 60-90 minutes before their treatment appointment, as well as drinking a set amount of fluid 30-60 minutes before the treatment. These preparations added a strict routine to the days of treatment and when these preparations did not work in the way they were meant to, some MPC became quite stressed. This example provided by Victor demonstrates how difficult he found it to prepare for each treatment, compared to the relatively straightforward delivery of radiotherapy:

“I’ve got, got this, this sheet here, Patient preparation for pelvic radiotherapy and all that, full bladder, empty rectum and that kind of stuff... this constant, especially drinking the amount of water and the enemas and everything, it really upset me several times. I couldn’t complete the treatment the first time because by the time I got in there I, I just couldn’t hang on and I couldn’t keep still and er they aborted the treatment ... the treatment itself of course is a doddle, I mean you just lie there and it happens ... that side of it was perfectly straightforward.” (Victor, MPC)

For some patients, the level of communication from TR was important when waiting their turn for treatment. Several described how they waited anxiously, having drunk their water allocation, and knowing that the timing of their radiotherapy was tied to this. However, when TR communicated well this anxiety eased somewhat, and they were better able to cope with the temporary discomfort caused by a full bladder. Philip developed what he described as a good working relationship with the radiographers because of this good communication:

“I would knock and I had my appointment time, they would always come out and say ... ‘Alright Philip, you know, have your drink now,’ So that was a great working perspective, well from my point of view I was able to work through it thinking I haven’t got that anxiety sitting here thinking, oh my god, like next few minutes, you know, because again I knew that it was maximum, but I was full up, you know, and they wouldn’t have done the radio, they wouldn’t have done the treatment I’m sure if the photo shot²³ they took hadn’t matched the others.” (Philip, MPC)

When commenting on the experience of EBRT and how prepared they had been, MPC reflected on whether their expectations regarding the reality of radiotherapy had been met, based on the

²³ Before administering radiotherapy on some days, radiographers will use on-board imaging to ‘match’ with planning images to ensure reproducibility and accuracy.

information they had received. As treatment progressed, many participants began to experience side effects. Most were prepared for this having been given information about side effects at their planning appointment and had it reiterated in a short consultation with a treatment radiographer on their first day of EBRT. Side effects ranged from tiredness, mild radiation cystitis and looser bowel motions to more severe effects and patients who reported these indicated that this was in line with their expectations. In a few cases the side effects were much more severe than the MPC had been led to believe by the information they had received, for example unexpected rectal bleeding, pain and very severe diarrhoea. In this example provided by Murray, he recounts how the pain he experienced was much more severe than he had expected and how concerned he was that his experience did not seem to match that of the other patients he encountered in the department. He described how the radiographers dealt with his concerns in a “*matter of fact*” way emphasising that they had “*seen this before*” and that he was unlucky, which went some way to alleviating his concerns, but nevertheless there was little practical or individualised help and advice given for the level of pain he was experiencing.

“There was no mention that I was going to have pain. And even in the books we only found one that mentioned pain... [the radiographers were] sort of like taking as matter-of-fact we've seen this before and we do know what you're going through and it's not good ... it's not normal but it happens. That's it. It's not rare, but it's not normal... so in a way that wasn't worrying, and in another way: why haven't the others got it?”
(Murray, MPC)

Patients who had received brachytherapy, reported mixed experiences regarding their expectations. They generally reported that the basic information regarding the procedure and preparation for it matched their experiences, but they were unprepared for the pain and discomfort caused by the procedure. In a similar comment to the one made by Paulo regarding the biopsy (detailed in section 4.2.1, page 82 above), Tom suggested his experience may make him wary of sharing too much detail with other men:

“I don't think I took in quite how brutal it was going to be... feeling a tad uncomfortable was quite a surprise. But, you know, would it have helped if I'd known? I'm quite careful about what I tell people who are going for it now” (Tom, MPC)

Although most MPC had been expecting some side effects and were happy with the information they had been given, some were nonetheless unprepared for the disruption to their sense of self caused by the manifestation of the side effects. Several MPC assumed that having been a ‘normal’ healthy

person, they would not suffer unduly and were unprepared for the moment the side effects developed. This example from Dan typified this response:

“I had been given all this information and they said this is what’s most likely to happen. But then I was thinking well, I’m superman so (laughter) slight exaggeration, but I’m super, extra fit, fitter than most so it won’t hit me like that. And... Oh yes it will!” (Dan, MPC)

It appears therefore, that whilst the information provided meant that most expectations of the reality of treatment were met, for a few men, there were individual issues that they were not expecting.

4.3.3 Retention of and compliance with information

Retention of and compliance with information was raised frequently as an issue by TR. They were concerned that despite the amount of detailed information patients were given, they would arrive for either their planning appointment or treatment unprepared or having interpreted the information differently to the radiographer expectations. A useful illustration of this issue is given in reports by both patients and TR regarding repeated planning CT scans. TR noted that some patients were needing to have three or four scans before their bladder and bowel status was deemed acceptable for treatment. The TR offered several explanations for why scans needed to be repeated. They questioned whether the patients had complied with the information that had been given in preparation for the scan, whether there was too much information given to the patients and whether the patients understood the information they were given. They were disappointed that their efforts with the preparations seemed to be ignored by some patients, or that patients did not tell the truth about the preparation they had done. Advanced practice radiographer Jane provided an example of the instructions patients are given and what happens if the first scan is not acceptable:

“We have the same issues because the patients who don’t pass their first CT scan because of bladder filling or the bowel protocol that we follow, we put them on a week of Senna, expecting, and we tell them, you take one every day for a week. The number of people that come back and when you quiz them and when they fail the second scan, they’ve only used it the night before... But we are scanning these people, a lot of these men at least three times but we have laboured long and hard about the drinking and making sure that you take the Senna every day” (Jane, advanced practitioner FG1)

Some patients also reported having had multiple planning scans and yet their perspective was that they had “failed” the scan and seemed to assume responsibility for this failure, even though they

explained how they had followed the instructions they had been given closely. They reported being given specific information, which was repeated and/or changed between each visit, and yet they were still subject to multiple scans. This example from Angus is typical of the patients' reports of repeated scans:

"I failed the assessment three times believe it or not ... the planning scan, 3 times. They kept saying "your bowel's too full" and then send me off. "I'll come back next week" "yeah ok then, take two senna everyday duh, duh, duh come back next week", failed it again and then the third time I failed it" (Angus, MPC)

There was also an expectation from the radiographers, that because patients had received information, they should be following it; for example, Rebecca stated that: *"technically they should know everything"*. This is an important point to note regarding the radiographer assumptions about MPC knowledge and understanding and how that related to their actions, given this was a time at which MPC received copious amounts of information about the whole radiotherapy process, not just the planning scan.

Whilst the involvement of wives at the planning scan appointments was not overtly referred to in the patient interviews, some participants did allude to it in the way they spoke about their experiences. Donald's wife Denise spoke about the team approach they had for managing the dietary instructions they had been given, saying they were *"slaves to that sheet"*, whilst other wives noted that they often took the lead in interpreting instructions and helping their husbands to prepare because of their husbands' reluctance to engage with details. Some noted that they deliberately avoided gaining too much information due to the impact on their emotional resilience as in this example from Andy's wife Carol:

"I didn't really want to know too much ... if I knew too much about it I might get worried about it and I didn't want Andy to feel worried about me worrying ... I did read some of it, but to me, the radiotherapy was a big thing. And I wasn't going to change it by knowing all the details." (Carol, Andy's wife)

Although little was noted regarding the role of wives leading up to and at the planning CT, the TR made some comments about the role wives may have had in supporting the MPC during their course of treatment, mentioning togetherness, practical and emotional support as well as the role wives had in ensuring their husbands retained information, and followed the treatment instructions and information:

“The partners or the wives tend to kind of take more of a lead in trying to get the guys to stick to the protocols that we ask. Particularly when they are in the chats, they’re quite useful to kind of um, kind of reiterate the information and they are often the ones that kind of drive the adherence to the policy rather than the men themselves” (James, rotational radiographer FG2)

Compliance with and retention of information continued to be an issue for TR throughout radiotherapy, not just at the planning stage. For TR the importance of ensuring patients can retain and comply with the information stems from their professional duty and standards of care requiring them to deliver highly accurate and reproducible radiotherapy to their patients (HCPC, 2013; Society of Radiographers, 2013). This relates directly to the likely success of treatment, as changes in internal organ position can impact on both the dose to the planning target volume (PTV) and the organs at risk, thus mediating outcomes in terms of both chance of cure and long-term bladder and bowel side effects (Chen et al., 2016). Consequently, when TR noted that treatment set up was difficult, they queried whether patients were retaining information. Despite TR recognising that there seemed to be an issue with respect to retention of information, some also provided explanations as to why this was occurring. They noted that a combination of factors contributed. This example provided by rotational radiographer James explains some of these factors which include the patients’ ignorance about radiotherapy, the amount of information they are expected to assimilate and as treatment progresses, managing the side effects:

“I think a lot of it they have no frame of reference to, so when you are talking about what we are gonna do in the room ... they’ve no idea what you are talking about. A lot of the information, they are trying to, kinda digest stuff that they have no inkling really of what’s gonna happen, amongst all the other stuff with side effects ... in terms of the actual planning procedure and the radiotherapy procedure I think they get an awful lot of superfluous information on the day” (James, rotational radiographer, FG2)

Some MPC accounts provide a different perspective. At diagnosis they felt overwhelmed with information, anxious about following instructions and were coping with a diagnosis which for many, had come as a complete surprise; however, they were grateful when radiographers *“reaffirmed it again”* at the beginning of radiotherapy. In this example provided by Angus, he explains how he felt when he received his diagnosis, and why it was important to have his wife with him when receiving information:

“once someone informs you that you have prostate cancer, you don't want to listen to anything else, you just want to basically get some fresh air... Elsie was with me... I wanted to get out of the room I didn't want to listen to anything. I'm not in the frame of mind to disseminate any information that came towards me. He could have been talking Dutch as far as I was concerned once you heard those words. And that sort of made me close down a bit. I suppose that's why they ask you to bring your wife, partner or a friend along” (Angus, MPC)

So far, the examples given in this section have exemplified what happens when it was perceived that MPC did not comply with or retain information related to treatment procedures. However, many MPC provided examples demonstrating how rigorously following treatment instructions caused them some anxiety. MPC were aware of the importance of following the treatment instructions in order to achieve the required set-up, but their concerns tended to be of a practical nature. The accounts of some patients showed how worried they became when trying to follow the required treatment instructions regarding diet and fluid intake, and cope with the treatment set up. They referred to their anxiety about being able to adhere to the drinking protocols and hold their bladder while on the treatment couch. In this example provided by Bob, he notes the anxiety he had in trying to make sure he complied with the treatment instructions as well as demonstrating his understanding of why he needed to follow them:

“I kind of quickly homed in on the fact that you got the least collateral damage would occur if your bladder was full during the treatment and then, so that was kind of the hardest bit in the first week or the first few days, was getting my timing right, about how much water I drank and then getting in you know, lying down and the urge to go to the toilet but knowing that all you had to go through was 5 or 10 minutes of the machine going round you and then quickly you were out and like the sense of relief just after that was kind of, that was the main bit just managing that” (Bob, MPC)

Some patients recalled that following the protocols precisely meant that they were unable to complete treatment without stopping part way through to empty their bladder. In such instances, although MPC were extremely conscious of the need to follow the treatment protocols, some explained why and how they had made modifications to the instructions that had been given to them by the TR:

“when I drank three cups of water, I couldn't always wait half an hour... in the end I made a decision I was gonna drink two cups of water, not three” (Andy, MPC)

Having been given precise information and instructions about the fluid routine, some mentioned difficulties with compliance with treatment protocols due to delays to appointment times. In this example provided by Adrian he explained his concerns regarding the accuracy of his treatment when delays meant his bladder was fuller than it should have been:

“they’ve measured in the prostate and they’ve measured the bladder and so on previously and if they’ve worked out that this is your watering time scale. ... So I’m thinking each time I’m delayed I’m not probably not getting the right dose in the right place” (Adrian, MPC)

4.3.4 Information about practicalities

Participants made frequent reference to information regarding the practicalities associated with having radiotherapy. Patients mentioned that alongside the preparatory information they received about treatment and side effects, they also received information about appointments, travel and parking arrangements. For some this included information about hospital arranged transport²⁴ and patients described how, not only was this a practical travel solution, but that the camaraderie and shared experience with other passengers was beneficial:

“It made my life a lot easier and it also made Lydia’s life a lot easier... it just literally pulled up outside the front door, I got in and there was that convenience ... the advantage far outweighed the disadvantage, absolutely. And also I think, as I travelled in the car there were usually 3 or 4 patients in the car as well as the driver we had a chance to talk” (Dan, MPC)

There were mixed experiences regarding parking arrangements at radiotherapy departments. Some MPC received information about dedicated parking bays, or reduced parking fees, whereas others reported not having received that information initially; they noted how much less stressed they felt on learning about dedicated parking as they did not have to worry about the time it might take to find a parking space. TR also noted that concerns about transport arrangements and parking were a source of stress for patients, as exemplified in this exchange between radiographers in focus group1:

“Anne: they have got other things on their mind.

²⁴ For patients who do not/cannot drive, or do not have access to public transport, or those who prefer not to drive themselves for treatment, radiotherapy departments often arrange transport that is booked and paid for by the hospital. This is often in the form of volunteer car drivers or minibus services.

Clare: I don't have my appointment list, I need transport...

Anne: I need transport, how am I gonna get here every day...

Jane: Where am I gonna park, that's another issue isn't it. They are more stressed about parking." (TR, FG1)

These concerns regarding parking seemed to be rooted in how MPC managed their travel arrangements to the departments and managing their normal, daily routine. Having received information about likely side effects and knowing they would need to have empty bowels and a full bladder for their treatment, timings related to travel arrangements became a priority for some MPC, with one participant commenting that knowing about parking arrangements was *"such a small thing"* (Andy, MPC) but made a big difference to his ability to cope. Many MPC were travelling between 30-50 miles to reach their radiotherapy centre, and several described how difficult it was to plan journeys knowing that they would need to stop along the way to urinate, sometimes devising original solutions:

"We've got a motor home, we went in that ...and just had to stop somewhere so that I could use the toilet in that ... and now, even on my phone I've got an app for where the nearest toilets are" (Victor, MPC)

"you know the great cardboard male 'me wee's'²⁵? Cheryl had a few of those in her car, and then you have your little wee in the hospital, and then you're halfway through rush hour of [town] traffic coming home and it's happening now, and you can't stop it, so we were already prepared ... we're in the middle of traffic and there's a bus parked at the side of us with people looking down just being nosy and I'm using this bloody me wee. Just a ridiculously funny but necessary thing" (Adam, MPC)

These examples demonstrate that perhaps there is an information gap regarding travel to radiotherapy departments where existing information seems to focus on hospital centric issues, rather than those that can be encountered by patients as the side effects of their treatment manifest.

Another practical issue that was mentioned frequently was the disruption to their normal routine while on treatment. Patients had received information about needing to have empty bowels and to drink a certain amount of water before treatment, therefore some created new routines to manage this. Therapeutic radiographers also commented on the MPC routine. From their perspective it was

²⁵ Disposable urine bottle. A non-disposable version marketed for female use is branded a 'She-wee'.

sometimes difficult to break patients out of their normal routine in order to follow treatment instructions. In these examples provided by TR James and Laura, stereotypes of ageing and male attitudes to health were given as explanations of this reluctance to change:

“when they get a bit older they get a bit set in their ways and when you try and deviate them out of that, then it, that’s when it becomes a bit difficult. They tend to get into a bit of a routine. And when you try and get them into a different routine that can be problematic.” (James, rotational radiographer FG2)

“Asking somebody to drink 2 litres of water when that’s not their norm...for some people is a massive change and they can’t deal with that ... the younger men... they’re controlled a bit more... because they are a bit more, you know, this has mucked up their routine and they wanna control it” (Laura, specialist radiographer FG2)

MPC on the other hand, noted how difficult it was to plan a routine. They have been informed that their bladder and bowel habits might change while on treatment, but some were unprepared as to how much their routines would change, and how much they would need to plan their day to day living around access to toilet facilities. Martin gave an example of how he needed to plan his travel around busy traffic and his fluid routine:

“from where I live and travelling over to where I had me treatment it’s about seven or eight miles or something, but if I went early morning, in the evening I’d get all the rush hour in the middle of [City], ... I found being on a regular time going every day that seemed to help, helped with the drinking the water as well, because I mean the last thing you can do is if you get up in the morning at half past six, seven o’clock and your appointment’s at nine you’re going to try and drink lots of water, it’s not working right is it” (Martin, MPC)

4.3.5 Peer support and the “waiting room club”

Although patients had received preparatory information from TR at the planning appointment and beginning of their course of treatment, they also mentioned other sources of information and support that were valuable in preparing them for radiotherapy, namely peer support via charity support groups and websites, plus the peer support gained from meeting other patients while attending for

radiotherapy. Two charities were mentioned frequently: Prostate UK (PCUK)²⁶ and Macmillan Cancer Support. Many of the leaflets and booklets the patients referred to are published by these charities and if HCP had not already signposted them, patients had found them via the internet or attendance at support group sessions. Patients were unanimously complimentary about the charity resources, finding them very useful in giving additional explanations of treatment side effects, providing extra detail and generally being supportive, which included being put in contact with other MPC to share experiences. In this example provided by Adrian, he explains why he found PCUK resources so helpful:

“A very, very good source is prostate cancer UK. They are amazing...I phoned their nurses and they’ll just chat away as long as you want to. And you end up sort of... not giving them your life story, but you end up pouring out all the things that you wanted to say and they’re quite happy to listen to you, apart from actual information just talking... And they arranged for a couple of ex patients to talk to me. All of these leaflets and if you go on the website site they’ve got a pamphlet for everything” (Adrian, MPC)

Some patients explained why they felt the charity internet pages were useful, stating that they did not want to indiscriminately search for information using “Dr Google” due to the inconsistency and potentially incorrect information they may find; however, the PCUK and Macmillan websites were seen as trustworthy and informative websites. Paulo explained he felt MPC were comfortable using these online resources because of the anonymity they afforded and that they would give a more realistic picture of what to expect from treatment. He also emphasised the benefit of being able to connect with people going through similar experiences, especially when exploring sensitive topics:

“that website that I’m on, Prostate Cancer UK ... they’re all people like me ... I could more likely get more information off of there, honest information than I could with say out of [town] Hospital ... the website I’m on very good, you know, because you’re comparing yourself with other people that have had exactly the same, you know? ... just people like me on there, because they’re normal people, and also maybe because they’re behind the computer they can say talk about their sex life, whereas they might not if you was, you know, having a conversation with them” (Paulo, MPC)

A commonly mentioned source of information and support was other patients the MPC met when attending for their radiotherapy. MPC, their wives and TRs variously referred to this as a “bit of a club”

²⁶ As well as producing written literature and funding support groups run by and for MPC, PCUK has MPC volunteers who can be contacted for support or who have provided testimonials for the website regarding various treatments and experiences. When men in this study referred to PCUK they tended to refer to these resources in an integrated way – it was the charity rather than the individual resources that seemed to be their focus.

(Clive), “*the morning gang*” (TR), “*club in the waiting room*” (Victor), and “*old boys’ club*” (Ruth). Several patients mentioned how they would converse and exchange information with other patients in the waiting room whilst awaiting their treatment slot. Some enjoyed interacting with their peers and creating social connections, valuing the shared experience and feeling something in common with people undergoing similar experiences but also exchanging information about treatment and how to cope, regardless of the type of cancer. Charles spoke about how he felt less alone in dealing with his cancer due to his waiting room interactions:

“you just feel part of, you’re not an isolated person when you get to these places if you’re meeting the same sort of people and people actually want to talk, you know, once you trigger it, they actually want to talk about things and I mean there were other people there having treatment, there were some ladies there having sort of treatment and even they wanted to chat generally. And of course, it eases the pain of just sitting and waiting.” (Charles, PMC)

Whilst many of the patients found these peer interactions useful, some patients and TR spoke about the issues that could sometimes arise when patients were sharing information. Some MPC described how either they, or other patients preferred not to interact with each other, perhaps reflecting their preferred coping mechanisms and social style/personality, comparing this to what happens in other social situations. TR noted that while this peer support and shared experience was beneficial for patients, there were potentially undesirable consequences in that it sometimes led to patients either questioning whether they were receiving the correct treatment or sharing incorrect treatment-related information. The data collection took place during a period of transition from a longer to shorter fractionation as a result of the CHHiP and HYPRO trials (Aluwini et al., 2016; Dearnaley et al., 2014; Royal College of Radiologists, 2019) and this meant that patients undergoing both the 20 and 37 fraction regimens were meeting in the waiting rooms. TR Clare provided an example of the assumptions patients made due to the number of treatments they were prescribed:

“It’s a very small waiting room. And they have obviously discussed and some of them are saying I’ve had 37 treatments so a couple of the 20 fractions have said oh, am I being short changed cause I’m only having twenty? ... When they chat, obviously some of them are feeling a bit short-changed rather than lucky they are not coming in for another seventeen” (Clare, specialist radiographer, FG1)

4.3.6 Therapeutic radiographers and information during treatment

In the previous sections, examples of the therapeutic radiographers' role in information exchange have been alluded to in both their own comments and those of the patients and their wives. Many participants specifically mentioned the information and support given by the therapeutic radiographers working on the treatment units, and in doing so they were unanimously complimentary. Patients spoke about the day-to-day advice received from treatment unit staff and, in conjunction with the written information they had received, were satisfied that their information needs regarding treatment procedures and side effect management had been met. Additionally, they cited the treatment review clinics as being a particularly valuable source of information and support. These sessions are normally run by advanced practitioner TR. MPC will typically be offered 2-4 opportunities to attend a treatment review clinic across their course of EBRT, often being referred by the treatment radiographers if issues regarding side effects are noted that require a longer conversation than is available during the radiotherapy appointment. MPC assumed seniority in the radiographers running these clinics referring to the "head honcho" or "head radiographer" and associating expertise and experience with them. This example provided by Angus details the scope of discussions he had at his review appointments and typifies those reported by other MPC:

"they'd go through: "everything seems to be ok Angus any side effects? How's your skin?" that sort of thing and "how's your diet coming on, your weight's good, how you feeling in yourself?" you know? And they'd say, "you know you're going to feel tired". I remember someone said the first fortnight there's no side effects, after the fortnight it starts kicking in and then I got the shock after the third meeting and he said "by the way just because your treatment finishes it's not the end it'll carry on" and I'm like Oh gosh..." (Angus, MPC)

It was while talking about treatment review that TR made the only reference to management of gay MPC. There was concern that TR generally assume their patients are heterosexual, and do not have enough knowledge and information to adequately support gay MPC, indicating that this could be an education opportunity for TR and observing that there are likely to be patients who want this information but do not ask for it:

"I think that is probably an area that's definitely not discussed and actually, that kind of area could be better informed. Or we could be better informed... I don't think it's a question that's asked, I think we assume that they are heterosexual... We had a gay man and I know the review radiographer had to look up specific information for all the questions he was asking and therefore we did research and we found out that prostate

cancer UK did provide that information so then we got that off for this gentleman. But I think it was a learning curve for the review radiographers because they hadn't been asked those questions before ...maybe there are people that want to ask those questions and never do" (Laura, specialist radiographer FG2)

None of the patients in this study identified as either being gay or men who have sex with men (MSM), although it is not unusual for older men to hide their sexuality due to fear of prejudice (Moore et al., 2019). Nevertheless, the therapeutic radiographers highlighted the heterocentric assumptions within their own practice, and therefore potentially this would have been echoed in much of the information being accessed by patients.

Therapeutic radiographers noted the variety of opportunities they have that allow information exchange, indicating that the setting could impact on the type of conversations they have. They were aware of the need to allow confidentiality for patients and outlined the usefulness of private spaces for distraction-free discussions; however, they were aware that some patients might believe that their only opportunity for discussion was during the walks in and out of the maze²⁷ to the treatment room. Even though a treatment room is a private space, it is still prone to interruptions from other staff members. TR Paula explained why she preferred private clinic rooms for conversations with patients:

"Cause it's just a little bit more one on one I think and it's like a secure environment. Whereas as we do sometimes reiterate in the treatment room there are still staff members coming in and out getting masks. So it's not like sit down, relax, open up"
(Paula, rotational radiographer FG3)

In contrast, only one patient mentioned whether he felt the environment had an impact on communication with HCP but in his experience thought it made little difference:

"I've been in many different rooms, little meeting rooms, little side rooms, things like that, and no problem whatsoever I'm there to speak to somebody and I'm not really bothered about furniture and things like that, and [hospital] is a very, very overused hospital, so I sympathise with the hospital but I'm there to speak to [doctor] and everybody else and not worry about a little tear on the floor" Adam

²⁷ Radiation can only travel in straight lines, therefore for radiation protection purposes, the entrance corridor to each treatment room is deliberately built with a number of turns that would help attenuate a radiation beam thus preventing radiation reaching waiting and control areas, hence being referred to as a 'maze'.

The issue of gender was raised by TR as a particular issue when treating MPC. In some instances, male TR felt that patients specifically targeted them for these conversations, especially when needing information or advice about embarrassing or sensitive topics. Similarly, female TR felt that some male patients were more likely to take notice of instructions and information from male therapeutic radiographers. It is worth noting for context, that approximately 18% of the UK TR workforce is male (Nightingale et al., 2020) which will impact on the number of opportunities MPC have to interact with male staff on a daily basis during their radiotherapy. David gave an example of where he had been targeted for support and information:

“I’d say when they are gonna do it, it is when you are walking them down the maze or when I’ve collected them from the waiting room, it’s like they are ooh, this is my chance now. Even if it’s something that happened last week, then it’s like they are waiting for a man to grab them from the waiting room or a man to walk them across to oncology where there’s, maybe not even the privacy but the, I guess the man to man” (David, rotational radiographer FG1)

Another aspect of gender raised by TR related to their perceptions of how MPC dealt with the information they were given. In this example of an exchange between two radiographers, David’s comments indicate aspects of male hegemony as being reasons why male patients were much less likely to seek support and information about medical matters, focussing on the technical aspects of radiotherapy, with his colleague Clare believing that this reluctance to seek advice impacted adversely on their day-to-day living:

David: “they’re stubborn, they don’t wanna be seen as... they think asking questions is weak ... you know that mind set of oh men are strong, they can’t ask questions because you find the first couple of days, they might ask a question or two but its more technical ... still that old-fashioned mind-set of man. Men are men, they’re steel, they are hardy, they’re... almost like they got a... outer armour that when you do break down that its almost... not too late in the treatment but it’s quite a way through before they actually start to realise how important it really is.”

Clare: “Yeah, then it turns out they’re not going out to the supermarket or something. Cause they need the toilet.”

Whilst a number of patients acknowledged how busy staff were across all aspects of their cancer journey, the only patient to directly mention the amount of time TR gave to care and communication

seemed satisfied with the amount of time therapeutic radiographers gave him: *“Communication was very good, everybody had time for me”* (Dan, MPC). Some of the TR seemed keenly aware that the time pressures innate in their roles impacted on how much information they could give to patients. They were concerned that they did not have time to give enough information, and that time constraints impacted on information quality and the ability of patients to retain information. Furthermore, lack of time meant TR were sometimes not able to address some of the more sensitive issues patients want and need to talk about, for example:

“If you are sort of talking as you are walking down the corridor to go in to the treatment room and just, they mention something and you’re just trying to be quick because you are on the way through to the treatment room and you don’t want to turn round again, and let’s have a proper chat with this, yes sometimes you probably do ... we are all guilty of giving it a little bit too smaller [sic] information to them. Sort of, just ‘cause we believe perhaps by the time they have got to treatment that they have been told everything” (Rebecca, specialist radiographer, FG1)

Summary

In summary the peri- radiotherapy period is dominated by detailed information about radiotherapy procedures and management of side effects. The examples provided by participants demonstrate that regardless of the amount, scope and format of information, anxieties about the procedures and treatment outcomes were still manifest. Most information needs regarding radiotherapy planning and treatment were met, and the MPC were highly complimentary of the skills and knowledge of the TR they met, and whilst initial ignorance or incognizance was noted, this disappeared as treatment progressed. Most patients felt their information needs were met and that their experiences met their expectations, even when side effects were much more severe than expected. Most MPC appreciated the opportunity to interact and exchange information with other patients and valued the support and information thus provided. They also highly praised information they had sourced from two cancer charities. MPC and TR highlighted the importance of having information about practicalities such as travel and parking arrangements, reporting that this type of information had a positive effect on stress and anxiety levels. Some potentially negative issues were raised. TR noted the numerous opportunities patients have to access information, but also highlighted where issues of gender and/or sexuality might impact on the information communication and exchange. They noted the impact of time constraints on the quality of information and the ability of patients to retain information in that context.

4.4 Post-radiotherapy

Introduction to the theme

A key transition point for MPC is when they finish their radiotherapy. For most MPC this signifies the end of definitive treatment although many will continue on ADT for up to three years afterwards, as long as no disease progression is detected (Cancer Research UK, 2022; Royal College of Radiologists, 2019). This section therefore focusses on information related to the end of radiotherapy and what the participants were expecting in the future regarding potential long-term side effects and other outcomes of treatment. Many of the patients started to consider their futures at the point of diagnosis and as part of their treatment decision making, so the topics explored in this section necessarily reflect on information given earlier in their cancer journey, as well as that given once radiotherapy was either complete or nearing completion.

4.4.1 The end of radiotherapy - Information about 'what happens next' and follow up

In my experience as a therapeutic radiographer the last week of EBRT would see a patient given the opportunity to attend a final treatment review or, on the last day of treatment, be given information about what to expect in the 3-4 weeks immediately following the end of treatment (related to the progress and resolution of acute side effects) and details regarding follow-up clinic appointments. As part of the interviews, I therefore questioned the participants to find out what the MPC's experiences and perspectives were relating to this transition period. There were a variety of experiences reported by both MPC and TR. NICE guidelines state that MPC with localised or locally advanced prostate cancer should have the opportunity to discuss the purpose, duration, frequency and location of follow up with either their urologist or specialist nurse (NICE, 2021a). A few MPC reported receiving information either in the treatment review clinic or on their last day about future avenues of support and follow up appointments, and had their questions answered by TR regarding the ongoing monitoring of the outcomes of treatment. None spoke of being given information about follow up by other HCP. Others had expectations of being given information explaining what would happen next; however, the reality was somewhat different; they reported that they had not been well informed and were unprepared for how little support would be provided in the weeks immediately following completion of radiotherapy. Adam provided an example in which his assumptions regarding information and support were not met:

“I didn’t think, when we’d been sent home for the last time, I thought we’d have had information, booklets, stuff like that, but somebody just said, “Right, your next appointment is in three months’ time,” and then you’re just left to swing for three months... and I’m thinking, why not in a week or a month’s time to just, no, it was three months, go away.” (Adam, MPC)

The TR reported that they routinely give end of treatment information, normally verbally rather than written/leaflet based, and gave lots of detail regarding the type of information patients are given. In some cases, this was given by the treatment radiographers, but they also emphasised the importance of what they described as the “*end of treatment review*” where a more comprehensive discussion was facilitated with an advanced practice radiographer. TR pointed out that the end of treatment can be difficult for some patients to accept as they are sometimes still adjusting to their diagnosis. They were very conscious that the focussed information, support and advice that is provided to patients when they attend daily for radiotherapy, disappears overnight after the last treatment. At the time of the interviews MPC could be undergoing EBRT for up to seven weeks. Whilst the TR accepted that it was likely that some patients might struggle to cope with this lack of support after the end of treatment, they were also concerned that they sometimes did not know who to refer patients to if they needed support or advice as there was no specific service for this point in time, thus highlighting a potential gap in service provision:

“quite often they’ve had all this attention, all this information and they’ve seen the team every day and then suddenly that’s bang! Ended. You know, and I often wonder how they get on really once they’ve left us... he’d had us for support for that seven and a half weeks and then when he finished you kind of think what’s he gonna do with himself now. Who is he gonna speak to about it ... There isn’t any... I wouldn’t know where to refer them on to.” (James, rotational radiographer FG2)

Caution should be taken when considering the TR data regarding the end of treatment information because the TR all worked at the same department, whereas the MPC had been treated at a range of departments in the UK. Some of the MPC reporting a lack of information at the end of radiotherapy had been treated at the TRs’ department, therefore a contradiction between TR and MPC reports is noted. There is the potential for reporting bias if the radiographers were wanting to convey best practice rather than regular practice in the interviews; however, there may also be an element of recall bias from the patients, or that they had not retained the end of treatment information.

When patients recalled what happened at their follow up appointments most described them as focussing on checking PSA levels and discussing side effects. The NICE guidelines recommend that patients with prostate cancer who are having radical treatment should have their PSA checked no earlier than 6 weeks after treatment and then at least every 6 months for the first two years (NICE, 2021a). In this study, the timescales for the gap between the end of treatment and the date of the first follow up appointment varied, with MPC reporting being given dates for between one and six months after the end of treatment. For some this date was further in the future than they had been led to expect. Regardless of the length of this gap, the time without contact with HCP concerned them, but this concern could have been alleviated if the timescales had been effectively communicated:

“it’s that length of time. You’re thinking you’ve finished your treatment, they’ve asked you how you are. Right, we want to check your PSA. But they don’t tell you they are not going to do it for six months. Which is a bit of a... I mean, it doesn’t bother me because what they’ve done is they’ve done ... and it won’t matter whether its four months, five months or six months. But it would have been useful if he had turned round and said, well, I’m not going to have you back. It came though on the letter, with the appointment. But there was no prior indication that it was going to be that length of time” (Andy, MPC)

4.4.2 Information on treatment-related outcomes and long-term side effects

Patients referred frequently to the expected outcomes of treatment, in particular related to side effects they would expect in the longer term. The most important of these for patients was the impact of treatment on sexual functioning, and this is such an important issue to highlight it is considered as a separate theme in section 4.4.4 below. Long-term issues other than sexual functioning are considered in this section.

When first diagnosed, information was key in helping MPC to determine which treatment they would be willing to have, and in particular for this group of patients, the decision between surgery and radiotherapy. They had either been given information or carried out research themselves, and some were eloquent in their reflections regarding their decision-making, indicating that they had read and understood the information they had accessed. Other than sexual functioning, the main long-term concerns for patients were urinary incontinence and/or long-term bowel effects. Some had chosen the radiotherapy treatment approach because their research and/or information given to them had

led them to understand that it was associated with less risk of long-term incontinence when compared to surgery, and they appreciated that they might live with the aftereffects of treatment for some years:

“I kind of was trying to narrow it down and the one that I did take off the agenda pretty quickly was the operation and that was for, with me taking my personal considerations into it, that was a number of considerations... and they took the prostate out but then they also, they couldn’t give any assurances that the damage they would cause to the sphincter muscle then there’s difficulty is bladder control afterwards ... and it was one of the kind of big concerns for me” (Bob, MPC)

Many of the MPC integrated their reports regarding information about long-term effects with whether they had developed the side effects mentioned in the information and if so, whether they were more or less severe than expected; some described how their expectations regarding their treatment had been met due to the nature and quality of the information they had received, and on reflection they were satisfied with their choices, considering themselves “lucky” to have avoided severe long-term effects:

“I’m totally comfortable with the choices because you know, the side effects, the literature and the advice that was given about the side effects they did clearly clarify to you that the worst that could happen ... my experience was that I didn’t experience that worst as such ... the bowels bit wasn’t as bad as it could have been under the literature and under the advice that was given you know... I was kind of preparing for the worst but expecting, hoping for the best and I’ve been, my experience has been that the best has happened more than the worst” (Bob, MPC)

Whilst many MPC reported that their experiences of late effects matched their expectations, a few men voiced their concerns about the longer term and their unease about what the future might hold. They had carefully considered the information given to them at the decision-making stage but even having made the decision to have radiotherapy, were worried about how they might cope in the long term. Bill provided an example where his research and exploration of the information uncovered implications related to incontinence that he had not previously known:

“The information about incontinence and things like that ... didn’t know about that until you start delving into it further, you know, there is implications of going down that avenue of being diagnosed and treated. ...you know, there are implications on what you have done, but you know, I’m grateful, touch wood, that I didn’t have any

incontinence and things like that because that would've, I don't know how I would've coped with that. That's not good." (Bill, MPC)

Similarly, other MPC shared how the information they had found made them fear the long-term side effects of both radiotherapy and ADT. They spoke about incontinence and feminisation of physical features as worrying treatment outcomes, referring to *"being a man"* as an important part of their identity. The embodiment of prostate cancer and side effects of treatment threatened their sense of masculinity, and they used a number of examples comparing to stereotypically female traits, sometimes using humour in their accounts:

"When you had your treatment did they tell you about your boobs might get more sensitive. I said, oh yeah, they warned me I might have to go to the lingerie department and buy a bra" (Andy, MPC)

"I have great sympathy with women going through the menopause because hot sweats, hot flashes sorry, night sweats, putting on weight, losing body hair as well. I didn't like that." (Bill, MPC)

Most of the information TR gave to MPC focussed on preparation for treatment and details of the acute side effects they might suffer, so perhaps unsurprisingly, since most TR are not involved with patient care once they have finished radiotherapy, very little information given by TR focussed on long-term side effects. When it was mentioned, it was either in the context of whether the patient had retained the information, or that they had referred the patient for a treatment review appointment so that long-term consequences could be discussed with an advanced practitioner. Some TR also assumed that the doctors had covered late effects of radiotherapy as part of the consent process, hence why they did not cover it themselves. In this example provided by radiographer James, he outlines the assumptions and practice of TR regarding information on late effects:

I don't think that really gets discussed when they have their pre-treatment or their treatment discussion. It's kind of the really long-term side effects that they might experience. So I don't think really we go through that at any stage per se unless they ask specifically about it ... I think sometimes that is something that we would probably get them to have a conversation with the review team... in terms of the others, the sexual function and the longer-term side effects we kind of think that the doctor probably would have spoken to them in a bit more detail about that in their decision to go ahead with the radiotherapy. So I think we tend to focus more on getting them

through the radiotherapy rather than focussing on the long-term aspects” (James, rotational radiographer, FG2)

Laura, an advanced practitioner, expressed surprise at how many patients report long-term effects when she reviewed them for long-term follow up, reiterating the focus TR have on acute side effects. This echoed previous points made by some MPC regarding the nature and amount of information potentially causing fear or anxiety about the reality of late effects, and she wondered whether this impacted on what TR told their patients. If this lack of focus on information about long term effects represents regular TR practice, it may need to be considered in the context of fully informed consent and in respect of whether provision of support and information for the post-radiotherapy period is adequate:

“I’ve seen some patients in long-term follow up and I didn’t realise so many had long-term side effects as do. Because you talk about it in radiotherapy as a minimal side effect but actually a lot of them have something of some kind. It might be minor compared to some people that have major, but they do have quite a bit. And I think it’s maybe... you don’t want to emphasise it because you don’t want to scare them but, I think potentially it’s played down about what could happen afterwards, especially bowel related symptoms.” (Laura, specialist radiographer, FG2)

Some patients explored their hopes, fears and uncertainties regarding the future and what life may hold after their diagnosis. They were concerned about their chance of cure, how their cancer would be monitored and what would happen if they developed further severe side effects. They spoke about the level of experience of their consultants and that gave them confidence in the information that they had been given, even when that information was inconclusive regarding possible outcomes; most were aware that their clinicians could not give them concrete answers about what the future may hold:

“how can a consultant sitting there give you any real information about moving forward? Erm... I mean I don’t know when I’ll be told when I’ll be completely clear. I don’t know whether they can ever tell you that.” (Andy, MPC)

“they’re ‘what ifs’ aren’t they? You know, and who can answer that question? The consultant can answer it no more logically than I could but he’s much more experienced and presumably would give the best advice he could at the time, and I mean, life’s not perfect, you know, things don’t always go to plan, do they?” (Charles, MPC)

4.4.3 Information and decision regret

A topic that was raised by only one participant regarding long-term effects but is nevertheless important to report is that of decision regret. In the literature being informed and involved in decision making have been associated with lower levels of decision regret for MPC (Albkri et al., 2018; Hoffman et al., 2017). Adrian reflected at length on how he regretted his decision to have brachytherapy followed by EBRT. He had been influenced originally by a close friend who persuaded him not to undergo surgery. However, Adrian's main concern was that at diagnosis he had not been given enough information or opportunities to explore the long-term side effects, in particular related to erectile dysfunction (ED). He had carried out further research during and after his radiotherapy and his increasing knowledge and understanding of the reality of his future led him to express anxiety, emotion and lack of hope. This was due to what he felt were his poor decisions based both on other peoples' influences and lack of high quality, detailed and timely information, when he had needed it most:

"he said well if you have the prostatectomy, we'll cut it open and we'll know exactly why. But I chose not to do that which I think was possibly my biggest mistake ... I'd kind of made up my mind because of other people I'd spoken to, but I really should have made up my own mind ... maybe one of the problems with discussing these things, is it's right at the beginning when your mind is full of everything but if you leave it and so will talk to him later, then you will have had to have made a decision ... some of those early meetings were a bit vague ... if there were discussions it wasn't much of a discussion ... when I found out that the ED could well be permanent, and they told me as if well everybody knows, and that was devastating to me. Because you know, they should have said at the beginning." (Adrian, MPC)

Adrian's example highlights how a lack of effective communication of crucial details related to treatment options can have a profound effect on outcomes for individuals. His experiences are given in more detail as part of one of the cases explored in Chapter 5.

4.4.4 Information about sexual dysfunction

All but one of the men in this study were prescribed ADT as part of their management. ADT is known to cause sexual dysfunction in the form of both erectile dysfunction (ED) and lack of libido due to the

effects of reduced testosterone. Recent evidence suggests that radiotherapy can cause erectile dysfunction in around half of men treated due to inflammatory damage to the cavernous nerve, fibrotic changes in blood vessels leading to reduced blood flow and smooth muscle atrophy in the corpus cavernosa, with radiotherapy-induced ED more likely to occur 3-5 years after treatment (Mahmood et al., 2016). The issue of sexual and erectile dysfunction (ED) was mentioned by many participants and described by Adrian as the “*biggest issue really, but not much you can do about it*”, alluding to this being an inevitable long-term side effect of prostate cancer management. Information about ED as a consequence of ADT had been given to most men, and they had also been informed that radiotherapy could cause ED. Some MPC were accepting of the changes to their sexual functioning and felt either that permanent sexual dysfunction was the compromise they needed to accept when balanced against the risk of their cancer recurring, or that at this stage of life, a sexual relationship was not important to them. However, for some men, the loss of sexual functioning was heavily disruptive when considering their future, especially when considering their relationship with their wife. Many men had discussed the likelihood of sexual dysfunction with their wives, as they felt that the impact would affect their wives as much as it would themselves, being more concerned with the overall effect on their relationship than they were the physical consequences. Adam provided an example in which he explains that he had not initially fully taken on board the wider consequences of treatment on sexual functioning, despite having been informed of the risk, only realising this later, especially in terms of his relationship with his wife:

“I don't want the relationship to suffer, but this is something that we both have to accept, and we can't bully each other into it... I thought it would be a reduced libido, but I didn't read into the lack of lubrication that obviously I'd made, that I never even thought about, and I certainly didn't realise that as deeply as it has affected me that there would be no ejaculation... yes, that's properly hit me for six... you sit there just praying that something does come back. But that is part of it, and I accept that, I don't have a problem with it, but in the meantime this part of the relationship has just stopped dead” (Adam, MPC)

Whilst the NICE guideline for prostate cancer management states that all patients receiving radical treatment for prostate cancer should be given access to specialist erectile dysfunction services, there is no recommendation about when and how information about the likelihood of sexual dysfunction should be discussed (NICE, 2021a). This may account for why there were contrasting experiences related to how well informed MPC were regarding the likelihood of ED/SF. Some patients recalled being given information about SF and ED alongside other information but found that they either had

to research it further themselves to fully understand the implications, or they had not been given information about ED. Bill noted that, despite the plethora of information he had been given, he did not initially fully understand the consequences of the treatment of his cancer until he looked into it further:

“There’s brochures on sex life and exercise and what else, well, all the other treatments you know, radiotherapy or brachytherapy and I mean there’s dozens and dozens of booklets and we’ve got a fairly good pile of them... The information about incontinence and things like that and ED and that, yeah, well you know, didn’t know about that until you start delving into it further, you know, there is implications of going down that avenue of being diagnosed and treated” (Bill, MPC)

Other patients felt well informed about the likelihood of ED/SF but gave differing experiences relating to how they obtained the information. Some had productive conversations with HCP who were able to give detailed information about both ADT and radiotherapy mediated ED; however, some, despite eventually being well-informed, felt they had to request the information and support, noting that HCP were reluctant to offer advice or that it was “*glossed over*”. Paulo explained how no-one had mentioned ED to him, and that having read about it in a booklet, wondered why he had not automatically been referred to an ED clinic:

“they can refer you to ED clinic, whatever, whatever, you know, it may be called. But what I’ve found is, and I mean even my GP see, he doesn’t volunteer things ... the hospital experience, you know, it’s not too bad, but they’re not volunteering a lot of information, like they should maybe say, well when you finish the course like you more than likely have ED, we can refer you or why don’t they refer you in the first instance, or would you like to be referred to them.” (Paulo, MPC)

Some patients recalled being given information about erectile dysfunction clinics and the support they had been given about ED, both practical and emotional. However, even though they appreciated the practical advice and access to equipment and medication, they were unprepared for the loss of libido caused by ADT and found it as difficult to deal with as the physical ED. They felt that their physical needs were well supported, but had not appreciated that the loss of libido would take away interest in sex as well as the ability to maintain an erection:

“Call a spade a spade once you’re on hormones, sex, what’s that? Not interested” (Bill, MPC)

Another aspect of change in sexual functioning that some MPC reported was how their body physically changed, and along with that their body image. They had accessed information about ADT causing changes such as gynaecomastia, weight gain, hot flushes and mood swings alongside the ED, but were nevertheless unprepared for the reality of how profound some of these changes would be. Donald provided an example where he explains how shocked he was by the penile shrinkage that occurred and that he felt patients should be better prepared for the reality of such changes:

“I put some weight on as well but it was the amount of weight I put on and my physical body changed, like my testicles and my penis had become extremely small, my breast, well I have boobs now and I’ve never had these before ... I think that is all explained in the documents that you get ... I’ve been through, looked at all of those things, but not enough I think, that should be more forefront to people rather than a bit of a shock, yeah ...the testosterone... it changes your body and I knew that was going to be happening. Admittedly I didn’t realise my penis was going to go smaller than it did and that was a shock! When it started going, I went “huh? Where’s it going?”” (Donald, MPC)

The point about MPC having to request information, or initiate conversations was similarly considered when the TR spoke about sexual functioning. They pointed out that often, initiation of conversations about any aspect of radiotherapy will depend on how comfortable a patient is with a particular member of staff, and with conversations about sexual functioning, this sometimes related to their gender, with MPC often seeking out male TR to talk to. Nevertheless, they accepted that it is part of their role to advise patients about sexual functioning but explained that they tend not to talk to patients about sexual functioning unless patients raise it as an issue. There were differing opinions in two of the focus groups regarding when patients are likely to speak about sexual dysfunction. One radiographer noted that patients rarely ask about sexual functioning on treatment and assumed that they save their discussions for review clinic appointments. However, another suggested that patients do not discuss in their pre-treatment or on treatment clinic appointments either:

“we don’t cover the sexual side of it enough which you mentioned earlier Laura, that people tend to gloss over...You know it’s very rare that they’d ask about something like that but some will. I don’t think that really gets discussed when they have their pre-treatment or their treatment discussion ... I don’t think really we go through that at any stage per se unless they ask specifically about it.” (James FG2)

This means that there is a potential gap in the information process related to information about and support for sexual dysfunction due to assumptions that HCP have made about who is giving this information, but also compounded by the reluctance of HCP to initiate discussions and the expectation from patients that it should be the HCP that initiate those discussions.

An interesting facet related to information regarding sexual function was the way in which information was communicated. Several MPC mentioned that the phrase “*chemical castration*”, was used by HCP to describe the effect of ADT, and this was shocking to them as in their minds this was linked with “*terrible consequences*” and associated with sex offenders or people wanting sex change. One patient reported that the way this information was delivered was “*brutal*” and led to them being unable to take in further information.

Summary

In summary, during the post-radiotherapy period, there seems to be a mismatch between what information TR assumed patients were being given and what patients reported they received. Whilst a few mentioned receiving information about late effects and follow up arrangements during treatment review or end of treatment chats, this was not universal, with many MPC feeling under-informed and ill-prepared for the reality of the late side effects they were beginning to experience, particularly regarding long-term bowel effects, incontinence or sexual dysfunction and the disruption this caused to their previous normality. In sections 4.2 and 4.3 MPC had consistently referred to making their treatment decisions based on the likelihood of these long-term effects occurring and for one participant this led to profound decision regret. The most concerning long-term side effect for many MPC was sexual dysfunction and they were resigned to this being an inevitable consequence of ADT and radiotherapy. This had been a concern for many MPC from the point of diagnosis, yet they reported that their information needs were not met, with information regarding likely effects on sexual functioning often not given, not volunteered or not accurately representing the reality. They reported that HCP seemed reluctant to talk about sexual functioning, something also noted by TR.

4.5 Chapter summary

This chapter has presented analysis demonstrating that the issues related to the post-radiotherapy period begin to manifest at diagnosis and continue into the treatment phase and beyond. The

experiences and issues shared by the MPC, were multifactorial and individual, with information being an important factor throughout. In order to give context to these experiences for individual MPC, the next chapter presents contrasting case studies that demonstrate similarities and differences in the experiences of two MPC and where information, or the lack thereof influenced those experiences.

Chapter 5. Information and radiotherapy – illustrative case studies

5.1 Introduction and background to chapter

In chapter 4, it was noted that the issues related to information in radiotherapy are complex and intertwined. There are many influences that impact on how a patient experiences their cancer diagnosis and subsequent management, and it is therefore difficult to describe and analyse them, especially as patients tend not to tell their stories in a linear fashion. In order to provide further understanding of how patients experience their prostate cancer diagnoses and use of information, in this chapter I have chosen to present two case studies/vignettes as illustrative examples of the influence of information from diagnosis and decision-making (pre-radiotherapy), through subsequent treatment (peri-radiotherapy) and living with and beyond the diagnosis (post-radiotherapy). Case studies are useful in allowing examination of data within specific contexts and allow exploration of complex issues when holistic investigation is required, by providing rich and detailed examples relating to the phenomenon being studied (Ghesquière et al., 2004; Zainal, 2007). These cases show both the temporality and biographical disruption of each patient's cancer journey, whilst emphasising the informational issues that were important to each patient, but also contrasting their experiences.

The concept of biographical disruption refers to the way an individual experiences the change in their expected life course when faced with a serious illness, how it changes the way that they engage in daily life as a consequence (Bury, 1982; Engman, 2019; Hudson et al., 2016). Bury (1982) also stated that this included a simultaneous disruption of social relationships and the ability to mobilise material resources. This theory is therefore useful in helping to contextualise the response of these men to their diagnosis and treatment. Similarly, although I have used the word 'temporality' to refer to the linear timeframe that spans the diagnosis, treatment and period beyond active treatment, it can also be considered phenomenologically. Husserl proposed that the present is impacted by both the preservation of the past and the anticipation of the future (Husserl, as cited in Stolorow, 2003); the meaning here being that past experiences and expectations of the future impact on how an individual experiences time, and also on how they progress through time and experience their reality. In reporting these cases therefore, it is important to highlight how the factors of time and biographical disruption impacted on each man.

Another factor that helps contrast these men's experiences has been described as incognizance, defined by St Jean (2017) as "having an information need that one is not aware of" (p309). Incognizance was identifiable as occurring early in one participant's trajectory but not in the other.

Thus, Adrian has been selected because of the distress he experienced regarding the probable permanent changes to his sexual functioning and the dissatisfaction he expressed regarding the nature, timing and communication of information he received. This manifested as profound biographical disruption, with the lack of information sought and received, and the decisions he subsequently made in the pre-radiotherapy period impacting on his sense of masculinity and causing decision regret in the post-radiotherapy period when he realised his sexual dysfunction was likely to be permanent. Martin has been chosen as a contrasting case which demonstrates his overt information-seeking behaviour, his wish to educate himself as fully as possible regarding prostate cancer and its management, which enabled him to feel fully informed with his decision making, and pragmatically accept the possibility of long-term changes to sexual functioning.

5.2 Case 1: Adrian – an example of biographical disruption having a major impact

At the time of interview Adrian was a 72-year-old married man whose prostate cancer was managed with ADT, brachytherapy and EBRT. He was interviewed approximately 18 months after completing his radiotherapy but was going to be on ADT for several more months. Adrian was initially diagnosed with prostate cancer after a visit to his GP with some minor urinary symptoms. His GP referred him to a urologist and following a number of investigations his prostate cancer was diagnosed. His initial PSA was measured at 31ng/ml (normal is around 4ng/ml). The urologist had a conversation with him about radiotherapy, ADT and brachytherapy and referred him to a surgeon who recommended prostatectomy. In this section I will illustrate how the timing of information, the way information was communicated, and the level of detail contained in the information impacted on the difficulties Adrian had in coming to terms with the potential long-term consequences of his cancer treatment.

5.2.1 Pre-radiotherapy – a period of incognizance

Very early on in his interview, when asked to recount what led to his diagnosis and subsequent treatment decisions, Adrian made reference to his lack of understanding of potential consequences of the various treatments, inferring that it was not until he had finished most of his treatments that he fully explored the implications of the choices made regarding his management, and that he regretted his decisions: *“Since then I've done an awful lot of research, but of course it's too late now”*. At the time of interview Adrian was still undergoing ADT and at that point it was not known whether some of his side effects would be permanent or temporary as it can take several years for the late effects of radiotherapy to manifest (Mahmood et al., 2016). His sense of decision regret was revisited many times in the interview. Adrian also recounted how emotional and confused he was when first hearing his diagnosis and the impact it had on his ability to remember details. For example, he showed me the letter he had been given that stated the urologist had given him *“all the information he needed”* and that they had discussed radiotherapy and side effects; however, he cannot remember being told about the side effects and wondered if the stress of being given the diagnosis affected his retention of information. He showed me some of the leaflets and booklets he had, some given to him by the nurse specialist and some he had sourced himself, but he also admitted that he had not accessed some of it until halfway through his radiotherapy *“because how could I know”*. This seems to indicate that rather than being ignorant of consequences, Adrian was incognizant; he had been unable to recognise the presence of a gap in his knowledge and was therefore unaware of the need to seek information.

When originally diagnosed, Adrian refused surgery, which he subsequently reflected on as his *“biggest mistake”*. He recalled that during the diagnostic processes, he did not carry out much research, describing himself as being *“a bit naïve”* and had waited for the medical professionals to tell him what to do, assuming that due to their *“medical experience...well, it'll be fine”* i.e., relying on their expertise and medical authority. Adrian also recalled basing some early decisions on a friend's experience, who convinced him that prostatectomy would not be a suitable option, because it was more likely to cause long-term side effects such as incontinence; however, he reflected that *“I really should have made up my own mind”* but that *“there's no point in talking about that now. It's gone”*. Adrian mentioned that during those early appointments he felt his HCP expected him to have already researched and/or accessed information about side effects, hence not talking him through those aspects in much detail and here again his incognizance and decision regret were apparent. His faith in one medical professional's opinion that his cancer had been *“caught in time”* contributed to this incognizance as

he felt that it was not necessary to access further information at that point, and this approach continued through the period when he was undergoing the diagnostic testing processes.

5.2.2 Temporality of change – coping with moving through diagnosis to treatment

Adrian had become very depressed as he tried to cope with his diagnosis. He described how, as he progressed through diagnosis and treatment, he had not shared what was happening with his wife who has significant health issues herself because *“she really doesn't understand it”*. Although he had friends who knew about his diagnosis, he did not feel comfortable talking to them about the more sensitive consequences of his diagnosis (such as ED) but described this peer support as *“brilliant”*. He admitted to having a typical male attitude to dealing with his diagnosis, keeping his concerns to himself and displaying hegemonic masculinity in his approach to coping. For example, he initially denied to himself that he was suffering from depression as a reaction to his diagnosis *“of course me red blooded male, no of course not, not me”*, eventually acknowledging that he needed further help and support, but sceptical about the beneficial effects of the anti-depressant medication he was given because of the potential for his ADT to have caused similar side effects:

“Once you have the Zoladex you assume everything that happens to you is the Zoladex. And of course, most of it is that some of it isn't... In the end I took the pills. Do they work? I don't know. You won't know unless you stop them, will you? Because they don't suddenly go bang (clicks fingers for emphasis)”

He described feeling that the HCP was *“fed up of me whingeing”* and that they *“argued and argued”* over whether he should continue to take antidepressants, stating that they engendered a sense of altered reality: *“it doesn't feel like real life”*.

Whilst this exploration of coping does not specifically relate to Adrian's use of information, it is important in that it highlights his state of mind at the time, how that impacted on his information seeking and communication behaviours, and the realisation post-treatment that he had missed opportunities for information that might have affected his decision making.

5.2.3 Adrian's peri-radiotherapy experience – expectation and process

Adrian was unusual amongst the participants in that he was one of only two men who had undergone both brachytherapy and EBRT. Adrian frequently compared his treatment experience with what he had subsequently read in his information sources. When describing his experience of brachytherapy, Adrian recalled that his experience had matched his expectations, based on the pre-treatment information he had been given. However, he queried whether the treatment had been accurately delivered due to experiencing some side effects which he had read would be unlikely with brachytherapy. His engineering background was apparent in the way he described this as his focus was as much about how it worked, as on the side effects:

“I didn't quite work out there, but you don't want radiation to go anywhere but where you want it. Now obviously you can't actually miss everything but they do the best they can, which is pretty good I expect by now. And then you stick these seeds in and leave them there and it's kind of going like this. And I didn't quite work out how that worked and now I know from the colonoscopy that it doesn't work because I now have radiation proctitis.”

I asked Adrian to describe his EBRT experience and his response focussed on appointments and the treatment process, rather than side effects:

“the information I got there was kind of about how it was going to happen more so than the side effects and I've probably got another piece of paper with ticks on for side effects. ... you're going 5 times, you're not going once a week are you, you're going five times a week and once a week you have a review.”

A sense of temporality pervaded this period. In the information he had been given, Adrian had noted the precise detail of the fluid intake protocol and whether this was observed exactly by the radiographers on his treatment days. He mentioned delays to treatment times caused by other patients and the impact this might have on his own treatment if his bladder was too full by the time he was called in. He had read about the precision of radiotherapy planning and queried how accurate his treatment had been if the timings given in his preparation information were not followed exactly, comparing it to a *“finger in the air kind of thing”*; *“I'm thinking each time I'm delayed I'm probably not getting the right dose in the right place or so on”*.

Adrian was complimentary about the on-treatment review where he was able to discuss side effects, assuming it was a *“head radiographer”* that carried out those clinics. He noted how she communicated

well with the treatment team, considering Adrian's family circumstances at that time. Overall, he felt the treatment review sessions helped him manage his expectations related to his treatment. This satisfaction with his communications with radiotherapy staff and the information they gave him contrasted starkly with the dissatisfaction he displayed regarding interactions with HCP in the pre-treatment period.

Adrian briefly mentioned talking with other patients in the waiting room, sharing and comparing experiences although, unlike other participants he tended not to exchange information with them. He did mention meeting a visually impaired patient being treated for a head and neck cancer, which seemed to make him consider his own disruption as being somewhat less profound:

"There was a guy there ... and he was now losing his voice because he's got cancer in his throat. So he's already blind and now he's losing his voice and I'm thinking, hang on I've just got a few urinary problems."

Apart from these few instances Adrian did not mention information related to his EBRT, focussing instead on issues related to ADT or prostate cancer management as a whole.

Adrian spoke about how careful he had been to access good quality sources of information "*I don't like to just kind of... Google*"; that he read papers about trials written by "*eminent people*" and also mentioned Prostate cancer UK (PCUK) as "*a very, very good source*". Through PCUK he had been able to speak to ex-patients about their experiences and found a number of leaflets on the website. However, much of this information had been sourced out whilst on active treatment and afterwards, rather than in the earlier stages of his diagnosis and decision making. It was here that he started building his knowledge and understanding that led to him questioning whether he had made the right choices.

5.2.4 Adrian's post-radiotherapy experience – the end of incognizance

Adrian recounted that since completing radiotherapy he had suffered some urinary and bowel effects in line with his informed expectations. However, he had also carried out much more research regarding what would happen to his sexual functioning when the ADT stopped and was intending to question his clinician at his follow up appointment. He was concerned about what information he would get and the outcomes that would be discussed with him as in past appointments he said he had "*forced her into giving me some true answers*". In particular he had researched the role of

testosterone in ED and was wanting to have his testosterone levels checked, questioning why this could be checked regularly during active treatment but not in the months and years following. He ascribed this to the difference in goals for clinicians vs patients: i.e. the clinicians were interested in cure, whereas he was concerned with long-term consequences as well as cure. He summarised this issue by saying that:

“the whole point of this, it's not about the treatment really it's about information, it's little things like that that can be really annoying”

Adrian reflected on his overall radiotherapy experience and described coming to terms with his diagnosis and treatment. He had started off: *“fine, but now you're not”*, describing his diagnosis as an *“accident”*. He emphasised his belief that to get *“real answers you really have to push to get them”* and that most statistics given regarding rates of potential side effects were *“from their side”*; i.e., designed to encourage patients towards particular treatment options, rather than giving the true picture. He said that HCP covered this vagueness with the phrase *“well, everybody's different”*. Another concern for the future was that he wanted to be assured that other patients be given enough time to reflect on treatment choices to ensure they are as fully informed as possible before committing to a particular treatment path, and that clinicians should *“man up and tell you”* the more undesirable consequences of treatment.

5.2.5 Reflecting on diagnosis and treatment – the evolving impact of biographical disruption

At the time of interview Adrian was 18 months post radiotherapy but still on ADT. He had begun to accept his ‘new normal’ and had begun to recognise some of the late radiation effects he had been warned about, but overall seemed quite positive:

“in my mind I'm feeling much better because, as I said many times I'm beginning to accept that it is what it is. I'm hoping that none of the late side effects get any worse, or if I get any more, I don't know”.

Adrian reflected at length on what happened when he first started on ADT, soon after his diagnosis. He insinuated that the information given to him at that time was to enable the consultant to *‘do her job’*; which was to *“get rid of the cancer”*; in other words, he was told didactically what treatment he would need to eradicate the cancer, rather than engaging in reciprocal communications that could have included his input regarding the pros and cons of each option. He mentioned feeling *“rushed”*

and felt that an opportunity to talk to a HCP a week or two after being given his diagnosis would have been beneficial as it would have allowed him to review and digest the information and recommendations, rather than making a quick decision while still trying to process the diagnosis. He also said he had not spoken to anyone about the options (i.e. family, friends etc.), therefore was trying to deal with the diagnosis alone.

When recalling the accuracy of the information he had been given, he felt that his expectations regarding brachytherapy and radiotherapy procedures and side effects had been met whereas the ADT was much worse than he expected. Something that profoundly affected him was learning that the erectile dysfunction due to ADT was likely to be permanent. Adrian felt very strongly that he had not initially been given information about the permanency of this side effect and he had assumed that at some point his sexual functioning would return to normal. The development of his depression was catalysed by his assertion that had he known about the permanence of this late effect of radiotherapy and ADT, he might have made different treatment choices. He felt that it was widely known amongst HCP that ED following prostate cancer treatment is frequently permanent, and he should therefore have been told of this prior to starting his treatment. He said this was “*devastating to me*” and:

“It probably wouldn't have made any difference but it would have been nice, this was the light at the end of my tunnel and suddenly she switched it off.”

He was also critical of the HCP demeanour when delivering this information, describing her approach as “*kind of an offhand thing*”, giving him lots of vague information that left him with “*all these false hopes*” early on although at the time of the interview he seemed to be much more accepting of his ‘new normal’. The profound biographical disruption he had experienced was thus clearly articulated.

One of Adrian’s points of contention was that the HCP had readily given him statistics related to cure or recurrence rates for each treatment option, but had not been more precise regarding the percentage chance of long-term ED, only that it might occur:

“[they said:] “you might get this”. “Oh might I?” (participant very emotional at this point). “But you might not get it”. Oh right! So the conversation has gone hasn't it? What's the point in telling me I might or I might not? You could tell me when I go out the campus and turn right, I might hit a truck, but I might not!”

He felt that some information was withheld, or there was a level of prevarication on the part of the HCP when he asked for more precise figures. He felt very strongly that had he been given more detailed and more precise information earlier he would either have made different choices regarding his treatment or been better prepared.

“if you can tell me every averages for the good side you can tell me averages for the bad side... I've asked several things from lots of people and they don't want to tell me... if I had known I wouldn't have had all these false hopes and I would have kind of planned around it and learnt to accept it”

Adrian's case demonstrates how the lack of communication of information or lack of detailed information at optimum points in a cancer trajectory can have a profound impact on a patient's wellbeing and biography. Although initially demonstrating incognizance, as he progressed to the post-radiotherapy period Adrian became more knowledgeable about his cancer and the consequences of each treatment option. Although the initial biographic disruption due to his diagnosis is clearly evident, as he moved through his trajectory the further disruption caused by his increasing knowledge impacted adversely on his wellbeing. His frustration with some HCP and their approach to information giving demonstrates how complex the communication of information can be and underlines the importance of considering a patient's information needs on a temporal basis as this has the potential to affect their overall radiotherapy experience.

5.3 Case 2: Martin - active information-seeking behaviours

Martin's case has been chosen because it contrasts well with Adrian's. Whereas Adrian had felt that initially he was not given enough information to make decisions about his treatment and the resultant consequences, Martin felt very well informed and also said that he had been given lots of information and plenty of time to carry out his own research in order to make his treatment decisions:

“had plenty information, and plenty, because I mean during all this time, because this was over a period of a couple of months or whatever, it was mulling around in me head all the time really and I was doing, like we do, we all Google everything nowadays don't we...?”.

This point is interesting as it reflects what Adrian said is needed. Martin was interviewed approximately 9 months after completing his radiotherapy. He had initially decided to go to his GP

regarding a PSA test having seen a TV programme about prostate cancer awareness. A PSA test result was 8.4ng/ml (normal is ~4.5ng/ml) so he was referred for biopsy resulting in a prostate cancer diagnosis with a Gleason score of 7. Like Adrian, Martin was married but slightly younger at age 65 years. In contrast to Adrian, Martin was an active seeker of information immediately he decided to see his GP and demonstrated none of the early incognizance that was a feature of Adrian's early trajectory. This enabled him to be fully involved in the treatment decision-making and having had time to consider options, chose radiotherapy and ADT. Whilst Martin's case also exemplifies biographical disruption, his way of coping by actively seeking information to ensure he was well-prepared is what contrasts with Adrian's experiences.

5.3.1 Pre-radiotherapy – a period of active information seeking and altruism

In contrast to Adrian, Martin recalled being well-informed very early on. His conversations with his urologist were useful and he was signposted to lots of resources to help him decide whether to undergo a biopsy:

"I was given a lot of leaflets, yeah, bits and pieces and everything, and told, told I could look it up on the internet as well"

This encouraged Martin to carry out his own research into the biopsy. As well as online research he consulted other people who had had prostate cancer treated but was mindful that other people's experiences would not necessarily reflect his own:

"of course everybody's different, everybody, it's a personal thing to everybody, you know, what they'd do"

This understanding of differing experiences contrasts with Adrian who had based some of his decision-making on the experiences of his peers. Martin describes feelings of positivity in that although pre-biopsy he was sure he had not got cancer, having the biopsy would be:

"a win-win situation really, because if a biopsy comes back negative and you haven't got cancer that's great, if you have got cancer they may have caught it early"

He described himself as a person who had nothing wrong with him: *"I felt absolutely well, I was still active, doing this, doing that and everything, and I felt fine ... and I went forward with that sort of mindset"*; however, when he was given the cancer diagnosis, he describes the feelings as being *"hit by an express train"*. The biographical disruption caused by his diagnosis is clear *"I was still quite*

confident that I hadn't got cancer". but what contrasts with Adrian is Martin's response. He was told that *"one thing you can't do and that's do nothing, you've got to have something done"* and similar to his approach pre-biopsy, engaged in a period of active researching. Unlike Adrian he was given a period of time to consider his options and during this time he carried out research into both surgery and radiotherapy. Something he noted from this research was a *"vein running through"* about the risk of incontinence being higher with surgery. Ultimately his knowledge and understanding of this risk dictated his decision to undergo radiotherapy rather than surgery

"I wouldn't have wanted that sort of thing ... once it's done it's done and if I've got to live with that I wouldn't want that."

At this point Martin also reflected on his biopsy experience, displaying a level of altruism and thinking ahead regarding how talking about his experience might influence other people. Despite the research he had carried out the reality of the biopsy was worse than his expectations:

"the worst part of the whole thing was the biopsy, but I would never tell that to a man, I wouldn't want to put a man off from having a biopsy because it could have saved his life, you know, so if I speak to any of my male friends I say, "Yeah, I had a biopsy and, you know, I went there like that," I'd never really go into details that it was uncomfortable and not nice"

Despite feeling well informed, Martin was mindful of the dangers of a lay person carrying out too much research:

"you can probably over-read it, you know, read too much into it then, and the why's and for's and against of everything"

This research was carried out over a period of a couple of months during which he had started ADT and was waiting for his radiotherapy planning appointment. Although he had made up his mind regarding his favoured treatment option, he carried on researching and found it very useful to talk to other people who had undergone radiotherapy, in particular complimenting the information from the Prostate UK charity which Adrian had also described as a useful resource but had accessed it later in his treatment trajectory. Martin's rationale for speaking to other patients was to *"rubber stamp"* his decision and seemed to reinforce and reassure him that the choice he had made was correct for him:

“I think I would have made my mind up anyhow if I’d spoke to nobody, no other people who’ve gone through it, so no, that probably didn’t sway me, I just needed a little bit reassurance”

This approach to finding out as much as he could contrasts with Adrian’s acceptance of medical authority and the expert knowledge of his clinicals driving his treatment decisions. Whilst Martin listened to his clinical team, he was also very careful to ensure he was as fully informed as possible as early as possible regarding outcomes before he embarked on definitive treatments, in contrast with the temporality of Adrian’s retrospective information seeking.

5.3.2 Peri-radiotherapy – preparation, expectation and compliance

Martin recalled being given information about his planning appointment by his consultant, who had advised him to begin drinking lots of water well in advance of the appointment so that he could get used to the volume that he would be asked to drink on treatment. Like Adrian, Martin spoke about his expectations and reality regarding the treatment process. He reported that he *“got into quite a good routine”* and was *“quite used to it”* by the time he started his treatment and felt very well prepared; however, he described feeling surprised that the treatment time was much shorter than he expected:

“I didn’t realise it would be so quick, they did say it was quick, you’re just on the machine for a couple of minutes, but I didn’t realise it would be that quick, I thought when they were saying a couple of minutes, I thought you’d be in there 20 minutes, half an hour per session, but sometimes it was only a matter of five minutes”

In many of Martin’s descriptions he detailed the information he was told and emphasised how much reading he carried out and that he made sure to read all information he was sent very carefully. He linked this to wanting to be sure what to expect especially as this was something he’d never undergone before, for example here he recalls the information he was given regarding the daily micro-enema:²⁸

“[they gave me] information about having the enema, which is something I’d never done before, so I was, I read up a lot about that, and the information was good on that because I mean I didn’t know what to expect with that really, or what would happen, or how you’d feel, never having one before, you know?”

²⁸ In some radiotherapy departments patients are given micro-enema packs and asked to use these just before undergoing their treatment in order to ensure an empty rectum. This helps ensure reproducibility of the treatment set up on a daily basis

He seemed anxious to ensure that he had followed the instructions correctly and was reassured at his first appointment that the radiographers said *“everything seems to be ok”*. At this timepoint his focus on active information seeking appeared to have changed to a focus on compliance with the treatment instructions. He was temporally in the present with his main concerns concentrated on the day-to-day treatment routine saying that *“when I was in a routine I found it a lot easier”*.

One example of this day-to-day compliance with instructions is regarding diet and fluid intake. Martin reported that he was initially told to keep to his regular eating habits. He described how his wife is a very good cook and had researched the nutritional value of their diet, *“looking up things [that are] supposed to be good”*. He commented that in comparison to the attention his wife normally paid to the nutritional value of their diet, the dietary information he received related to his radiotherapy seemed to be lacking detail.

“anything with reds or a vegetables in, red peppers and everything is supposed to be good and everything, but they didn’t, the information the hospital gave me didn’t put a great sway on that really”

He went on to describe some of the dietary changes he was asked to make such as cutting down on cabbage and beans etc. but described this as *“no big deal”* as the changes barely impacted on his usual diet. Martin also described being *“quite religious with drinking the water”* having been told this would help reduce side effects. He was *“quite pleased”* with his efforts in complying with this instruction, reporting very few radiotherapy side effects and was *“totally surprised I had very few side effects really”*. Those he did suffer, met with his expectations, based on the research he had carried out, for example:

“I read that you can get disturbed night’s sleep, but the slightest thing would wake me up, whereas normally I’m quite a good sleeper”

He also compared his experience with other patients, speaking about one who he felt had not complied with the instructions regarding fluid intake:

“I’m not trying to blow my own trumpet, but I don’t think he was drinking enough really, wasn’t drinking as much as I was”

In contrast to Adrian, Martin seemed to be accepting of the information he was given about the radiotherapy process, displaying active information-seeking behaviours to help inform him better,

whereas Adrian's information seeking seemed to focus on challenging his choices. This active seeking of information related to his treatment, seemed to help Martin make sense of his diagnosis and its management.

5.3.3 Martin's post-radiotherapy experience - acceptance and positivity

Martin was complimentary about the information received before and during his radiotherapy *"there was help there if I needed it"* but seemed less satisfied with the information given after the end of treatment. He described that at the end of treatment he *"just had a few leaflets really, that I picked up and I could read about what would happen after the treatment"* and that throughout the treatment he had relied on the research he had done before: *"a lot of the information I did have, I had before I started anything."* In the few weeks after the radiotherapy had finished, he described information received as *"nothing"* and *"I don't think I had much contact"* with the HCP after the treatment had ended. His experience of long-term side effects was generally positive in that he was *"expecting more than I did get"*, describing mild bowel effects and thus was reasonably satisfied with the initial outcomes.

Whereas Adrian's focus had been the impact of treatment on his sexual functioning, this was less of a concern to Martin. He briefly recalled being told about the risk of sexual dysfunction early on but accepted that this was a small price to pay when weighed against eradication of his cancer:

"the important thing really was to try and beat the cancer, part of that is losing a bit of, your erection or something so be it. And we're quite happy to go ahead on that basis...if this is the price to pay for trying to beat a bit of cancer I'm prepared to pay it"

5.3.4 Reflections on information across the treatment experience

Martin's experience came across as overwhelmingly positive, despite the biographical disruption he experienced. He was consistently complimentary of the information he received at different time points, and even when reporting a lack of information at the end of radiotherapy, was able to contextualise this positively as he had carried out so much research himself in the early stages of his diagnosis and treatment. He described himself as *"well-armed"* with information, adopting the 'battle' metaphor used commonly by patients diagnosed with cancer (Ellis et al., 2015). He reported obtaining most of his useful information online, describing the information given by the hospital as *"just the*

information I needed from what I was being treated with” highlighting that the information gap about his wider treatment options was something he addressed himself:

“you could Google every aspect of things ... I was reading a lot ... which wasn’t relevant to me, but it was handy to have it there, when I was making me choice”

In considering the information he received through the course of his diagnosis and treatment, Martin described it as “*concise*” and “*clear*” and that “*when you’re going through it it’s obviously clear to you then why you’re doing it, so it explains itself really when you start going through it*”. He did not question the information he was given, but by carrying out further research sought to educate himself as much as possible in order to understand the information given to him. For example, when recalling his bone scan he said: “*I wasn’t really sure why they were doing that... I wasn’t aware that prostate cancer can get into the bones quite easily, ... I didn’t link the two together, I didn’t link prostate cancer and bone cancer together ... but I do now*”. This example also demonstrates that Martin was very aware of the potential futures that could arise as a result of his diagnosis, but his information-seeking and research had helped him make sense of the probable outcomes.

Martin’s case is characterised by active information-seeking behaviours which formed a major part of his coping strategy. He took on board the information provided by the hospital, but supplemented this with his own, extensive research enabling him to become educated and informed about what was happening to him. This created a positive sense of wellbeing and acceptance of the changes to his biography, both at the time of diagnosis and when moving through treatment to consideration of the longer-term outlook.

5.4 Chapter summary

The participant cases highlighted in this chapter were selected as they demonstrated some similarities and differences in the influences of information throughout the course of their diagnosis and radiotherapy treatment. Every person diagnosed with cancer will experience their diagnosis and treatment individually but, in all cases, as exemplified in this chapter, some biographical disruption is inevitable.

Adrian and Martin mobilised different resources at different times in order to cope with and make sense of their diagnoses and subsequent treatment, Martin with a degree of acceptance and positivity,

Adrian with a sense of loss and anger. Whilst both men exhibited biographical disruption, the temporality of information seeking and information use was different. Adrian sought information reflectively and used information to make sense of choices that had been made for him (or that he felt he should have made), whereas Martin used information proactively to educate himself about what was happening to him and why, and to make fully informed treatment choices. The incognizance demonstrated by Adrian through the early stages of his diagnosis contrasts with Martin's early, extensive research efforts where incognizance was not evident; however, as the trajectory of their diagnosis and treatment progressed, both men gained more knowledge and understanding, with Adrian's early incognizance disappearing as he started to carry out more research. However, this path of education and gaining of knowledge had contrasting results: for Adrian it served to highlight insufficiencies of information, resulting in decision regret, depression and a sense of loss, especially regarding his sexual functioning, whereas for Martin, it enabled him to make reasoned treatment choices and early acceptance of the likely long-term consequences of those choices. Throughout both narratives, the nature of information required and acquired by each participant was consistent: information regarding investigations, planning and treatment procedures and their preparation, early and long-term side effects of treatment. What was less consistent was the perceived volume of information and how it was sourced.

In the next chapter, the discussion will explore the chapter 4 and 5 findings with respect to the research aims, revealing the latent themes of time and communication, and drawing on relevant theoretical perspectives to critically discuss and conceptualise the semantic themes identified.

Chapter 6. Discussion

6.1 Introduction

This research set out to explore the experiences of MPC regarding information related to radiotherapy. An integrative review (see chapter 2) demonstrated that whilst many studies had focussed on information for cancer patients there was a gap in the evidence base for qualitative research specifically focussed on information about radiotherapy for MPC. This research captured the experiences of MPC and wives during a series of semi-structured interviews conducted over a period of 18 months, with further context gained from therapeutic radiographers who participated in focus group interviews.

The research objectives were to explore:

- the factors affecting the understanding of information received/exchanged by men undergoing radiotherapy for prostate cancer
- whether information received was exchanged in a timely manner, appropriate to, and sufficient for their needs
- what information for MPC was given/exchanged before, during and after radiotherapy
- whether MPC had unmet informational needs
- the perspectives of therapeutic radiographers related to information they give men undergoing radiotherapy for prostate cancer
- the role of patients' wives related to information given during the course of radiotherapy.

Thematic analysis (Braun & Clarke, 2006) of the interview and focus group data identified 12 semantic themes which were organised into findings chapters relating to the three distinct time periods: Pre-radiotherapy, peri-radiotherapy and post-radiotherapy. In the pre-radiotherapy period two themes were identified where the focus of information related to the patient's diagnosis and the decision-making processes (where their overall cancer management plan was determined). In the peri-radiotherapy period six themes were identified: being prepared for planning and treatment, retention of and compliance with information, information about practicalities, peer support and the waiting room club, and therapeutic radiographers and information during treatment. In the post-radiotherapy

period, three themes related to information were identified: the end of radiotherapy and what happens next, treatment-related outcomes and long-term effects of treatment, and sexual functioning. (See concept map, section 3.8.2). These findings were organised and reported in a linear fashion that followed the chronology of the patients' cancer journey in order to represent the semantic themes identified, but also reflecting that men's embodiment of their cancer is experienced sequentially (Kelly, 2009). A holistic review of the data identified that underpinning these themes were two latent themes – those of time and communication. These themes provide the mechanism by which the interconnectedness and intertwining of the semantic themes can be explored in more depth and criticality. Throughout, nonconforming examples have been included to demonstrate views or experiences that were different to those commonly expressed (Silverman, 2015) in order to support the overall analysis.

This Chapter will critically explore and discuss the most important semantic themes discovered in the findings chapters and will be structured according to the pre-, peri- and post-radiotherapy periods. In order to ensure that the discussion would be carried out in appropriate depth and detail, a review of the themes was carried out to determine which should form the focus of the discussion. The themes presented in this chapter were determined as being those that were of most relevance to the overall research question and objectives, as well as being those that I interpreted to be of importance to the participants and their application to radiotherapy practice. The discussion will link to appropriate theory and literature, demonstrating where and why communication and time are essential components in deriving meaning and understanding in those themes. I will begin by briefly exploring the theoretical perspectives of the latent themes of time and communication in order to give some context to the semantic themes. Ecological systems theory will then be explored as a potential model that provides a structure to help explain the findings. Other theories of incognizance, uncertainty, transitions, embodiment, othering and social comparison will be referred to throughout the discussion in order to provide further critique and understanding and finally a model that provides a summary of the findings will be proposed.

6.2 Time

Every human being has a predictable life course: we are born and at some point we will die. The current life expectancy for men born in the UK in 2018-2020 in the UK is 79 years (Office for National Statistics, 2021), which has increased from 56 years for men born 100 years ago (The King's Fund,

2021). Bury (1982) reported that the life course an individual experiences is a “trajectory through chronological steps” (p171). This construct of time is usually marked in increasing years and a typical life course would see an individual progressing through biological developments of childhood, puberty, adulthood and aging processes, with social, cultural, psychological and medical factors impacting at various points in the life course. Time helps individuals make sense of the world and their lives (Haider et al., 2021); however, although a person’s life is marked in a chronological and linear way, people will experience time in different ways because life experience is unique to each person. The theory of time has been a subject of much debate in the literature, moving from the concept of time as an absolute, to one which Einstein theorised as relative and illusory (Urone et al., 2020). Sociologically, time - and in particular temporality - have formed the basis of much discussion in the literature, and have been conceptualised in various ways, for example in terms of continuity and discontinuity (Maines, 1987), construction and reconstruction of events in context (Martino & Freda, 2016), time disruption and appropriation (Rasmussen & Elverdam, 2007), and reflection and anticipation (Adams et al., 2009; Van Manen, 2016). What each of these concepts have in common is the individual way in which time is experienced.

6.2.1 Biographical disruption

Disruption of time is an important consideration in my study. In the chapter 5 case studies I referred to the theory of biographical disruption as being a common thread throughout not only the highlighted cases, but all the patients’ experiences. Bury’s seminal work on biographical disruption from 1982 questioned the concepts of illness and the sick role established by Parsons (1951) and defined biographical disruption not only in terms of the disruptive event(s), but also as a rethinking of self-concept and mobilisation of novel resources to help them cope with the disruption (Bury, 1982). Parsons’ original theory suggested that people who are ill deviate from their normal societal role and this has a dysfunctional effect on society. However, a crucial failing of this theory was its lack of consideration of the chronology of illness and the context of time, something that Bury’s paper highlighted: whilst chronic illness causes disruption to an individual’s life course, this is not a static or unchanging disruption. People with chronic illnesses experience peaks and troughs in the course of their illnesses thus disruption does not occur at only one time point and therefore must be given temporal context in order to make sense of a person’s experiences. A diagnosis of cancer might be considered as both acute and chronic disruption with acute disruption referring to the initial diagnosis and adaptation and the chronic relating to ongoing management and survivorship. In the acute phase, patients in my study experienced the biographical disruption caused by the diagnosis. Patients referred to being “*shellshocked*”, in “*turmoil*”, “*confused, emotional*”, and this distress at diagnosis is

echoed in other studies involving a number of long-term health conditions such as endometriosis (Hudson et al., 2016), cancer (Hubbard & Forbat, 2012; Liamputtong & Suwankhong, 2015) and Hepatitis C (Harris, 2009). Chronic disruption is exemplified in my research with patients coming to terms with their diagnosis and either pondering on or reporting their experiences of the long-term side effects of radiotherapy and ADT. It is worth noting that although all patients exhibited a degree of biographical disruption, responses regarding long-term consequences were varied. Some patients mentioned the *“collateral damage of treatment”* and *“preparing for the worst but... hoping for the best”* but others mentioned a level of acceptance, having balanced the risks and benefits of treatment options, for example: *“there’s nothing you can do about it. So you just have to accept it”*. In other words, they had adapted to the new reality that was consequent to the disruption they had experienced. This adaptation has been explored in the literature with respect to menopause (Johnston-Ataata et al., 2020) and similarities with this work can be seen in what patients reported in my study. In the Johnston-Ataata et al. (2020) study, biographical disruption caused by early menopause was characterised with a period of adaptation not only for the person experiencing it, but the wider family and this is also the case in my study where MPC shared their reflections about the impact of side effects on their wives. For example, when speaking about sexual dysfunction as a result of his treatment Adam said: *“I don’t want the relationship to suffer, but this is something that we both have to accept... But that is part of it, and I accept that”*. This indicates that whilst biographical disruption can be framed in a chronological fashion, temporally, patients may be experiencing their diagnosis in terms of simultaneous consideration of past experiences, their present circumstances and future hopes and fears, thus the nature of the information they receive can influence expectations regarding future treatment effects (Boulton et al., 2015; Stolorow, 2003) and hence mediate levels of biographical disruption.

6.3 Communication

Communication has been the subject of many studies with the wider literature proposing various theories to help explain how and why communication occurs; however, the fundamental process of communication is that it involves sending, receiving or exchanging information (Collins, 2021). Literature on communication theory focusses on mechanisms for the transmission/transfer of information, where messages are constructed and sent via a medium that conveys meaning (Stacks et al., 2019). The format of information varies and in some cases is sent with intent, in others more subliminally, such as in hidden messages in advertising (Littlejohn & Foss, 2010). Littlejohn & Foss

(2010) also note that the definition of communication has different meanings according to context, for example technological communication may focus on the equipment used to communicate such as digital media, television etc., whereas in health science, psychology and sociology disciplines the focus is on aspects of communication influenced by human behaviour, cultural and societal processes. Anderson (as cited in Craig, 1999) identified 249 distinct communication theories, noting the incoherence of the field of communication theory at that time, which gives some indication as to why it has also been difficult to clearly define what communication means. In the field of health and illness, research into communication has focussed on practical matters such as communication between staff and patients, communication barriers, and how to build more effective communication (Amalraj et al., 2009; Freimuth & Quinn, 2004; Park et al., 2009). Even noting these few examples, it can be seen that communication is a fundamental aspect of healthcare that is integral to a patient's experience.

6.3.1 Communication of information

As stated in chapter 1, it was difficult to define the term "information" and in that chapter I noted that any interaction and/or exchange in any format which the participants gained knowledge about their diagnosis, management and future outcomes would be considered as information. By using this definition, I have considered that communication was a facet of information for the participants. Whilst information can exist as an entity, it only gains meaning for an individual when it has been communicated with intent (Stacks et al., 2019), hence when analysing the data, it became clear that I needed to consider the subtext of the participants' narratives. Many participants referred overtly to information and its format, reporting that they had received booklets, or found information through internet research. However, others referred to occasions where information had been communicated, but it seemed that they had not recognised this as being information per se, such as radiographers having "*a little chat*", or when being given treatment instructions: "*they just went through what it would be like*". This communication of information was not subliminal; however, the communication behaviours involved meant that it was a subtle, almost automatic process, rather than being a tangible information exchange.

The importance of good communication of information for cancer patients has been explored in the evidence base, including focus on decision making, individualised communication, satisfaction with information, influence on psychosocial outcomes and patient understanding, all of which can have consequences when considering a patient's long-term outcomes (Adamson et al., 2018; Ahamad et al., 2019; Flynn et al., 2012; Gamble, 1998; Hyde et al., 2013; Papadopoulos & Lees, 2004; Thorne et

al., 2010). These aspects were present in my findings and differences in experiences were highlighted in the case studies of Adrian and Martin presented in chapter 5. For example, Adrian questioned the communication from his HCP regarding treatment options stating that to get *“real answers you really have to push to get them”* whereas Martin reported good communication from his HCP: *“he rang me up and just asked me... which one I’d chose to do... asked me why I’d chose that, I gave him the reasons”*.

6.3.2 Models of communication

Whilst a full discussion and evaluation of communication theories and models is beyond the scope of this dissertation, it is helpful to briefly review some that have been useful in exploring why communication has been identified as a latent theme in this research. Littlejohn & Foss (2010) suggested that communication theory can be considered as a prism, in that it is multifaceted and contextual. This explains why so many theories of communication have been postulated. Whilst there is a plethora of communication theories reported in the literature, there have also been attempts to describe the communication process in terms of models of communication. According to Littlejohn & Foss (2010) most of these models follow one of three basic designs: Firstly, there is the linear model, which is unidirectional which begins with the sender of, and ends with the receipt of the message. An example of a linear model is Berlo’s sender-message-channel-receiver (SMCR) model (Berlo, 1960), which expanded an earlier model developed by Shannon and Weaver (Shannon & Weaver, 1949; Shannon, 1948) to take account of the nature of each step of the communication process, and how each step may be influenced by personal and social factors. Secondly, there is the interactional model encompassing the cooperative sending, receiving, interpretation and impact of messages. An example of this model is that suggested by Schramm (1954) which exploits the bidirectionality of communication and takes into account the accumulated experience of those trying to communicate. By accounting for differences in experiences, difficulties in communicating outside an individual’s frame of reference could be incorporated into the model. Thirdly there is the transactional model which further builds on the interactional model by suggesting that individuals involved in communication are simultaneously sending and receiving messages, rather than receiving and decoding before sending a return message. An example of this is Barnlund’s Model. Barnlund suggested that communication is a continuous, complex and dynamic process in which the actors observe and interpret their own behaviours based on cues given by others involved in the communication (Barnlund, 2013). Each of these models could apply to the experiences of the

participants in my study: The linear communication model applies to written information sent to a patient with no expectation of response, for example:

“there would have been a little booklet or something like that” (Adam, MPC)

“We had the letter through; that came through from oncology” (Andy, MPC)

The interactional model applies to initial consultations where information about treatment options are discussed, for example:

“he went through everything for me and just talked me through it and basically I had to listen to verbal information, anecdotal information and I was allowed to ask questions so that I knew exactly what they were expecting” (Angus, MPC)

The transactional model applies to consultations or radiotherapy treatment appointments, where information is exchanged with an individual, but is tailored to that person’s individual needs and the response from each party will vary according to factors such as their personal circumstances, physical and psychological health. This applies to the daily treatment instructions given by the radiographers where radiographers will converse with patients to understand how treatment is affecting them and adjust their advice accordingly:

“I guess it’s continuing to adapt their drinking and their bowel habits really throughout the treatment ... kind of the right habit really and a lot of it is monitoring that process... so a lot of it is adapting their behaviour as we go through the treatment and being quite proactive in spotting that and dealing with that as we go along” (rotational radiographer James, FG2)

Whilst no particular model has been overtly applied to the findings of this study, understanding of the various models is helpful in exploring context of communication across the time periods identified in the chapter 4 findings.

6.3.3 Factors affecting communication

It has been well documented that communication strategies can be less effective when patients are suffering from distress or anxiety about their diagnosis (e.g. Maguire (1999) and Schofield et al. (2003). Several of the MPC in this study highlighted their shock and anxiety when given their diagnosis, with Angus describing how hearing his diagnosis made him “close down” and that the consultant “could have been talking Dutch as far as I was concerned once you heard those words”. There is also evidence

that a range of factors affect communication in health care. These include gender, age, social and personal factors, cultural and educational background, level of education and health literacy, and HCP perceptions about their patients' health beliefs (McCormack et al., 2011; Schiavo, 2013; Siminoff et al., 2006; Street Jr, 2002; Street Jr & Haidet, 2011; Thorne et al., 2010). The data in this study were not analysed against demographic factors; however, some of the MPC did report that issues regarding the demeanour of their HCP might be due to the HCP's cultural background. Similarly, Denise, Donald's wife pointed out that culture can impact on how people communicate about their health, calling on her own non-British heritage as an example that contrasted with a stereotypical British response where people tend not to communicate about their health issues.

From a sociological perspective these demographic and social factors also appear in Bronfenbrenner's ecological systems theory, later adapted and reconceptualised into the Process, Person, Context, Time (PPCT) bioecological model to explain human development (Bronfenbrenner, 1979; Bronfenbrenner & Morris, 2006) (see figures 9 and 10). These models will be explored in more detail in section 6.4 below.

6.4 Ecological systems theory

The ecological systems theory (EST) was originally developed by Bronfenbrenner to conceptualise the development of the human child within the context of its ecological environment, taking into consideration personal, cultural, subcultural, societal and governmental influences (Bronfenbrenner, 1979). He claimed that most previous research on child development did not take account of the two-way interactional nature of relationships in that he believed the individual had influence on other people and their environment as well as vice versa. He developed EST using a series of nested micro-, exo-, macro- and mesosystems to describe the close and wider influences on an individual, in which the interconnected settings, activities and individual factors were explained, with the systems close to the individual having the most impact. However, each system is not seen as discrete as each has influence on the others and the nature and level of influence of the systems will change over the course of an individual's life – the chronosystem. A description of each of the systems is given in figure 8 below (Bronfenbrenner, 1979; Bronfenbrenner & Morris, 2006; Härkönen, 2001).

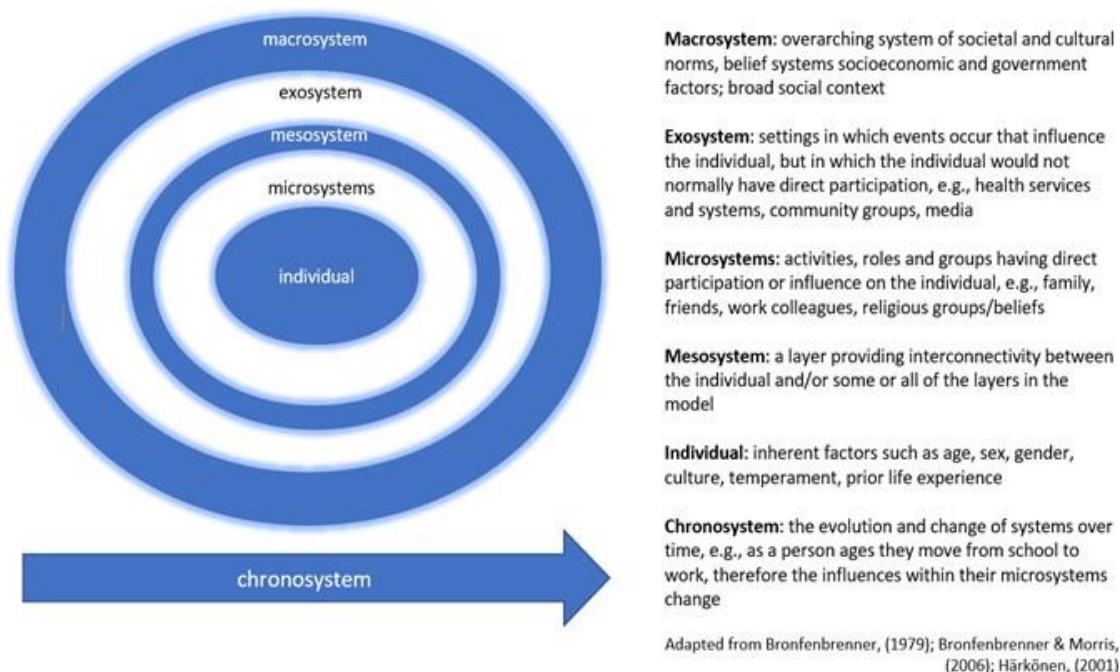
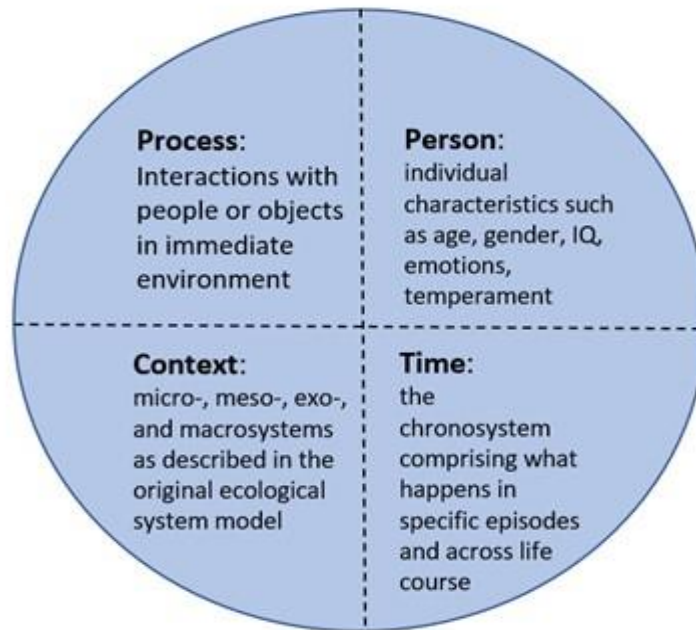


Figure 8. Model of Bronfenbrenner's ecological systems theory

Whilst the original EST model was constructed to explore and explain human development, the nested systems construct has been applied widely in other contexts for example, relationships of patients with breast cancer (Ginter & Braun, 2017), working with immigrant children (Paat, 2013) and the effects of mass trauma (Hoffman & Kruczek, 2011).

In his later work Bronfenbrenner noted that whilst he had applied the chronosystem to explain changes over time, the dynamic nature of temporality was not represented, and that not enough focus was given to the person at the heart of the model resulting in the evolution to what became his later bioecological model (Bronfenbrenner & Morris, 2006; Rosa & Tudge, 2013; Tudge et al., 2009) (see figure 9 below). The systems within this later model are still interlinked and bidirectional, but with the chronosystem fully incorporated.



Adapted from Bronfenbrenner & Morris, (2006); Tudge et al., (2009)

Figure 9. Model of Bronfenbrenner's PPCT bioecological theory

In chapter 4, MPC experiences related to information were influenced by many social and cultural factors, hence Bronfenbrenner's theories were helpful in conceptualising links to current knowledge and other theory to explain how, why, whether, what and when information enables MPC to adapt to changes in their lives and life course as a result of their diagnosis and radiotherapy. In the next four sections (6.5 to 6.8) of this discussion, themes arising from the data analysis in chapters 4 and 5 will be explored in detail by drawing on relevant previous literature and theory in order to demonstrate the multitude of factors that impact on how MPC experience information related to radiotherapy. These discussions helped conceptualise the development of a new explanatory model that will be detailed and explained in section 6.9.

6.5 Pre-radiotherapy

6.5.1 Being diagnosed

Receiving a diagnosis of cancer is known to be a shocking and distressful event that can adversely impact on a person's identity, sense of meaning, mental health and perceived quality of life regardless of whether they are expecting the diagnosis or not (Korfage et al., 2006; Roth et al., 2008; Thorne et

al., 2010; Vaartio et al., 2003). For MPC, their diagnosis is embodied in gendered social constructions related to masculinities and stereotyping about men's access to health care and the long-term disruptions caused by the diagnosis (Cayless et al., 2010; Chapple & Ziebland, 2002; Gough, 2006; Kelly, 2009; Tsang et al., 2019). Although most men in the study had been symptomatic prior to their diagnosis, the psychological impact on them was evident, for example reporting feeling "*shellshocked*" or that they might "*freak out*". Previous research has reported the high levels of distress and anxiety experienced at diagnosis (Gil et al., 2012) and that for some patients, memories of anxiety at diagnosis continue into the survivorship phase in the form of PTSD-like symptoms (Berry-Stoelzle et al., 2020). This demonstrates that how a patient experiences the communication of their diagnosis may have long-term consequences on their quality of life and mental health outcomes.

In the present study patients reported several issues regarding how their diagnosis was communicated and the information they received at that time. As in the Davidson & Mills (2005) study, most patients received their diagnosis from a consultant urologist, with a few being informed by their GP. They reflected on the communication process in terms of the demeanour and approach of the medical staff and how that affected their experience. Whilst some patients reported that their doctors were caring, calm and empathetic and gave them time to assimilate the diagnosis, others reported that the HCP were brusque, vague or cold in their approach. It is disappointing that these patients reported less than satisfactory communications with some HCP, given that the NHS has consistently placed high value on the impact of good communication on health outcomes (Department of Health, 2000; McDonald, 2016; NHS England, 2021) and previous studies have demonstrated that the quality of communication and clinician demeanour impacts on relationships with patients, their understanding, their feelings of being in control, the quality of their care and health outcomes (Davidson & Mills, 2005; Gamble, 1998; Jha et al., 2006; Long, 2001; Maguire, 1999; Prip et al., 2018).

Earlier research has emphasised the importance patients place on information about disease management (Dale et al., 2004). Even though most of the men in this study had been symptomatic prior to their diagnosis, few of them had accessed information about prostate cancer until their diagnosis was confirmed and described having little knowledge and understanding of prostate cancer and its management until then. Lack of knowledge/knowledge gaps have previously been described in terms of either ignorance or incognizance: participants either did not have the information or did not know they needed the information (D'Alimonte et al., 2011; Germeni & Schulz, 2014; Nanton et al., 2009; St Jean, 2017; St. Jean et al., 2017). However, St. Jean et al. (2017) also suggested that ignorance may stem from information avoidance or lack of health literacy: an individual may either

avoid information to control anxiety and retain hope, thus creating low health literacy, or they may not have the thinking and communication skills necessary to make sense of the available health-related information, hence impacting on health outcomes. From a practice perspective therefore and as suggested by Barnett et al. (2004) and Boulton et al. (2015), it is important to consider a personalised approach to information communication in order to ensure each patient's knowledge, understanding and information needs, especially in the context of the recent NICE guidelines which have emphasised the importance of, and requirement for shared decision making that takes account of individual patient needs (NICE, 2021b).

Whilst none of my participants admitted to avoidance of information, some did report that they deferred information seeking to their wife. This involvement of wives in making sense of the diagnosis and information related to treatment options was mentioned by many of the married participants, echoing earlier research which has demonstrated the dyadic approach of information seeking of couples (Ezer et al., 2006; Feltwell & Rees, 2004) and reflects early opinions from my reference group where one man stated that it was *"no good asking me anything about [my initial consultation] but my wife knows everything, so to get the fullest picture she would need to be interviewed too"*²⁹. This led directly to the inclusion of wives as research participants in this study and inclusion of the study aim related to wives' perspectives. Previously it has been noted that married men tend to be well-supported by their wives during consultations (Van Ee et al., 2018) and in the present study, most couples reported that they received information about the diagnosis together and dealt with processing the diagnosis together too. This involvement of family members exemplifies a microsystem (Bronfenbrenner, 1979; Bronfenbrenner & Morris, 2006) that describes how an individual experiences information exchange and therefore their experiences related to their diagnosis. Only Adrian reported that he actively withheld information about his diagnosis and management from his wife, due to her own health issues. Reeder et al. (2013) suggested that this type of withholding is a matter of timing and a matter of context; for Adrian, concern regarding his wife's issues outweighed his need to share information or include her in how he was managing his diagnosis. From a practice perspective therefore, offering active inclusion of partners/wives or other family members in the exchange of information about diagnosis and/or treatment decision making could ensure better communication and assimilation of information, but care must be taken to identify those patients who would prefer to manage alone. In their interview-based study reporting on the potential effectiveness of group-based treatment review, Chauhan et al. (2018) noted that some participants felt that inclusion of

²⁹ see (Gordon et al., 2017) for further exploration on the rationale for inclusion of wives/partners

partners could be beneficial, but that others might feel inhibited in conversations if a partner was present, hence reinforcing the importance of giving patients the choice as to whom they involve.

Once their diagnosis was confirmed, participants began receiving and/or accessing information about various management options and the likely short- and long-term side effects of these options. Topics referred to often were the timing/timeliness of information, the amount, or how difficult it was to take it all in. According to Boulton et al. (2015), Long (2001) and Lehto et al. (2015) the timing of information following diagnosis is important for decision-making. Although participants in the present study appreciated being given the information at the time they were diagnosed, the shock of the diagnosis meant that often they were unable to fully take on board what they were being told or to understand the implications of different options, which reflects findings by D'Haese et al. (2000), Long (2001) and Coyne et al. (2016). Cohen & Britten (2003) suggested that being told about the diagnosis in the same consultation in which they discussed treatment options impaired decision making for some men in their study. This reinforces the reflections of some participants in the present study who felt that they needed to have time to review information, do further research and come to terms with their diagnosis, and then attend a second appointment to discuss the options once the initial shock had worn off. When comparing the experiences of the two men profiled in Chapter 5 who were treated at different departments, this extra time to think and make decisions was seen as very valuable to Martin and was given as a suggestion by Adrian (who was given no time to decide), indicating that nationally, practice varies. This temporality of decision-making regarding treatment options is important and could be seen by patients as in conflict with current Department of Health requirements to initiate cancer treatment within four weeks of diagnosis (Department of Health, 2000). Whilst none of the men had questioned having to start ADT very quickly, thus appearing to fit within this four-week requirement, some were unaware that this meant their treatment had started or questioned issues related to temporal aspects.

Some participants expressed concern about ambiguity of language used by consultants in the communication of their diagnosis, with patients reporting being told their cancer needed an *“aggressive”* treatment approach or was *“high grade”*, terminology that to them signified that treatment needed to be urgent, and yet they then experienced anxiety due to what they perceived as delays to treatment. Understanding of terminology used by clinicians has been previously explored by Pieterse et al. (2013) who found that inappropriate use of terminology and other language cues impacted adversely on lay people’s understanding in consultations. Others recounted considering choices between brachytherapy, surgery and EBRT options, with some being told the best option for

them by their consultant while others were asked to review the options and then decide, so the uncertainty about what constituted the start of treatment and the urgency with which this needed to happen were evident. Here the issue of ignorance versus incognizance is raised; those men who exhibited decision regret or a wish to have had time to consider options did so on reflection of their experiences rather than being able to consider these options at the time of decision making. At the time of diagnosis, they did not have the knowledge and understanding to request time to consider options, or they did not know that they needed it. Bearing in mind that being well informed is associated with lower levels of decision regret and distress (Albkri et al., 2018; Castel et al., 2011; Hoffman et al., 2017), addressing either the ignorance or incognizance of MPC at diagnosis may positively impact on overall cancer experiences and improve satisfaction for those who eventually choose radiotherapy as an option.

The amount of information received was a frequent theme throughout the findings, but at the diagnosis timepoint, appeared to relate to whether a patient had been previously monitored for urinary symptoms, or had actively sought information about prostate cancer. Many participants referred to information overload or receiving information that they would not need until later in their cancer journey. This issue of amount of information has been considered frequently in previous research (e.g., Barnett et al. (2004), Boulton et al. (2015), Cuypers et al. (2019), Davison et al. (2004) and Matsuyama et al. (2013)) and is an issue that persists beyond the diagnosis and decision-making stage. This indicates that there is a potential to explore the timing and amount of information so that it is more effective for patient needs.

An information issue that concerned participants in these early stages was with respect to diagnostic processes. Some patients were concerned with the timing of appointments, how quickly they received them and the quality of communications, displaying what is known as anticipatory anxiety: the manifestation of uncertainty regarding future events (Grube & Nitschke, 2013). However, most were impressed by the speed at which they were referred for investigations and the level of communication they received. Adrian reported "*sailing through*" the diagnostic processes and Angus reported having had "*everything done*" within three weeks. This speedy response to referrals was welcomed by the participants and has been reported in previous literature related to information satisfaction, for example Davidson & Mills (2005) who reported some of their participants being dissatisfied with the time taken for them to be referred and diagnosed.

One concerning issue is that when mentioning the biopsy procedure, some participants reported differences in their expectations versus the reality, in that they had a worse experience of the biopsy than they had expected. This suggests that they may not have been given sufficient information about the biopsy which then has implications for the consent process. A standard view of informed consent holds that patients must be given adequate, accurate and relevant information and the disclosure of information must match the recipient's understanding of that information in order for informed consent to be valid (General Medical Council, 2020; Millum & Bromwich, 2021; Rao, 2008). However, Ploug & Holm (2013) point out that in some settings, consent can become 'routinised'; in that the consent process becomes almost automatic with little attention being given to the content of explanations or discussions, bringing into question how 'informed' the process is. Paulo pointed out that *"you tell men all of the symptoms that you're going to get, they're going to go, I'm not having that done"*, implying that there is the potential for HCP to have routinely withheld information that would deter acceptance of the procedure. However, Bolderston (2008) and Dubois & Loiselle (2008) noted that the time allowed for patient interactions is limited and that consequently some patients' consultations can be rushed, which can impact on the amount of explanation that can be given. While there is little doubt that correct processes for taking patients' consent were followed, questions remain as to how fully informed this process was. Again, it seems that a personalised approach to information is required in order to ensure patient needs are met, including active attention to information that covers unpleasant aspects of diagnostic procedures.

6.5.2 Decision making

The next tranche of information received by participants related to treatment options and decision making. Philip exemplified many of the participants when he stated *"and you know nothing"* to describe his initial feelings about his knowledge of treatment options, indicating that the early ignorance/incognizance can persist. Once participants started receiving information, they referred to conversations, discussions, written information, and information gleaned by carrying out their own research. However, the format of information was less of a concern than the amount, with some participants seeming overwhelmed with the amount of information they received. This concern regarding *"information overload"* was noted by radiographers who expressed concern that patients were given so much information, it became difficult to navigate in order to make appropriate informed decisions about the options presented. A similar point was raised in Boulton's study where one participant suggested that too much detailed information could deter people from having treatment; however, in the same study it was noted that no amount of information *"would make it any better"* (Boulton et al., 2015). This sentiment was echoed in a patient narrative article by Gebhard (2001) who

recalled that “there is never enough information available, either in the form of literature or from the doctor, to help patients to make the right choice about treatment” (p. s56). In the present study, although participants commented on the sometimes overwhelming amount of information they received, they were generally satisfied that this was appropriate and were happy that they were able to make informed decisions about their treatments, fully understanding the consequences.

Kashaf & McGill (2015) pointed out that becoming informed is reliant on communication processes where information is shared between patients and their HCP; a HCP cannot know whether their patient is ignorant/incognizant unless there is effective communication with them. The wider evidence base indicates that many HCP and patients advocate a shared decision-making approach (Elwyn et al., 2012; Gwede et al., 2005; Holmes-Rovner et al., 2015; Stiggelbout et al., 2015; Walsh et al., 2010), something that was recommended in the recent NICE document on shared decision making (NICE, 2021b). However, many patients reported that they have been “*told*” what treatment they would be having and felt excluded from the decision-making process. For patients like Angus, this was expected and welcomed, and he was keen to emphasise his reliance and trust in “*the experts*”, whereas other patients such as Jack reported being given no choice; “*they decided what was best*”. For some men those decisions would have been made due to specific clinical indications; however, participants reported that there was an illusion of choice packaged as “*a nicely presented sales pitch*” indicating that for some patients, shared decision making had not taken place. This again raises the issue of whether informed consent has taken place, as without full exploration of the treatment options, patients may be ignorant as to what they are agreeing to. Donald pointed out that there may be generational contexts to decision making as in the past patients were very used to having medical decisions made unilaterally by their clinicians; however, he felt “*forearmed*” by the information he had been given and therefore felt confident in the decisions he had made. Nevertheless, some participants mentioned feeling uncomfortable about making decisions about treatment, wanting to leave this to their clinicians, “*the experts*”, echoing findings of other literature (Tombal et al., 2013; Wagland et al., 2019)

As illustrated in the cases examined in chapter 5, the temporal aspect of information related to decision making is important. Adrian had reflected that he had felt rushed into decision making, whereas Martin reported having had two weeks to make those decisions. An interesting assumption made by one of the radiographers regarding decision making was that patients are given time to make decisions about their treatment and yet for some patients this did not seem to be the case. The point regarding having time to assimilate information was made by Appleton et al. (2015) and Pinquart and

Duberstein (2004) as being important for patients to have effective treatment decision making and has also been mentioned by cancer patients in articles about their experiences published on support websites (e.g., Gagnon, (2022)), so as stated in the 'being diagnosed' section, there seems to be a tension between the clinical services requirement to initiate treatment within 4 weeks and patients having time to consider their treatment options. It could be argued that because these men effectively started their treatment when commencing ADT, the 4-week requirement has been met and yet findings from the present study suggest that not all patients are being given time to fully explore and understand the implications of the choices available to them.

Evidence shows that the survival outcomes for early staged, localised prostate cancer are almost identical between radical radiotherapy and prostatectomy (National Institute for Health and Care Excellence (NICE), 2021a), so for most men the decision they needed to make was between these two options and centred on the risk and acceptability of a number of long-term side effects. ADT is used as an adjuvant treatment option that improves outcomes for patients undergoing radiotherapy (Schmidt-Hansen et al., 2014), and is almost universally administered to men with early staged prostate cancer. All but one of my participants were prescribed long-term ADT immediately after diagnosis, a major side effect of which is alteration or loss of sexual functioning; however, because this can also be a long-term consequence of both radiotherapy and prostatectomy, I have taken into account the combined effects of management options rather than trying to separate them, both when considering the findings and in this discussion. The other side effects that tend to have long-term consequences and that caused most concern to participants were incontinence of bowel and incontinence of urine. The patients' consideration of these side effects and fear of managing an incontinent body (Kelly, 2009) clearly demonstrates the temporality of decision making alongside the biographical disruption that had been initiated. Earlier research has extensively documented that patient concerns regarding long-term effects have been a factor in their decision making (e.g., Grondhuis Palacios et al. (2019), Ihrig et al. (2011), Orom et al. (2016), Steginga et al. (2002) and Zeliadt et al. (2006)). Not surprisingly, this aspect of decision making caused a great deal of anxiety for many patients as they navigated the information in order to try to make the best choice for themselves. Some patients such as Adrian and Tom compared experiences with, and asked advice from friends about long-term side effects in order to help their decision making, an approach to information gathering that has been documented in previous research (Berry et al., 2003; Blödt et al., 2018; Van Ee et al., 2018), whilst as previously stated, other patients such as Angus and Clive were happy to rely on the expertise and direction of their consultants in line with findings from Owens et al. (2003). Some patients were very keen to ensure their cancer was cured and so the side effects were perceived as

less important to them; however, it must be noted that many of the participants were interviewed within 18 months of being diagnosed so at that time may not have begun to develop some of the longer term side effects, which can manifest any time from three months to several years after irradiation (Abayomi et al., 2009; Hauer-Jensen et al., 2014; Henson, 2010).

Martino & Freda (2016) described a concept of meaning making in breast cancer diagnoses as “the time of illness, an illness of time” (p. 625), suggesting that the diagnosis and disruption can become all-encompassing of a patient’s past, present and future. This concept applies to the patients in the present study as they needed to make decisions about treatments that could have long-term consequences on their lives, many of which could involve permanent, embodied change, notwithstanding that their decision-making was framed in their past attitudes to dealing with health and illness. Whilst Martino’s concept helps explain the temporal nature of a diagnosis, it does little to explore the individual factors such as cultural and societal norms that dictate someone’s response to a diagnosis. In the present study, the cohort of MPC demonstrated very little cultural and racial diversity, nevertheless they did exhibit individual responses to their diagnosis that were framed by their family circumstances, religious and spiritual support and their general sociodemographic factors. In this sense, a response to the diagnosis of prostate cancer and the informational needs a patient has in embodying that diagnosis can also be explored in terms of Bronfenbrenner’s ecological systems theory.

In summary, the period of time surrounding a patient’s diagnosis and the decision-making that is required has been identified as crucial in determining the extent of biographical disruption that patients experience. The temporal nature of information and how it is communicated impact on decisions that will ultimately affect a patient’s long-term outcomes and quality of life and yet takes place at a time when patients are highly anxious and vulnerable emotionally. Further attention to patients’ information needs and the communication processes required to ensure fully informed consent is required.

6.6 Peri-radiotherapy

Radiotherapy planning is meticulously carried out to ensure production of a three-dimensional dose map that ensures the radiation dose to the planned target volume is homogeneous³⁰ and high enough to be tumoricidal, whilst ensuring that normal tissues and organs surrounding the target receive low doses (Symonds et al., 2019). However, even with careful planning, some normal tissues will receive enough radiation dose to disrupt normal functioning and give rise to side effects. For patients undergoing EBRT, efforts to reduce dose to normal tissues include techniques designed to immobilise the patient and give reproducible accuracy on a daily basis within a few millimetres of tolerance. Whilst externally this is done using a range of physical immobilisation and fixation devices, the size, shape and motion of abdominal and pelvic organs also need to be considered. Motion of bowel and bladder in particular can lead to geographical miss³¹ causing higher dose to normal tissues which then increases the likelihood of both acute and chronic radiation reactions (Hauer-Jensen et al., 2014; Symonds et al., 2019). Patients are given specific information regarding intake of bladder and bowel to help mediate these internal organ motion effects. Hence in the period covering the radiotherapy planning and treatment processes, the dominant topics involved preparing for treatment, peer support and information related to side effect management.

6.6.1 Being prepared

Patients in the present study had been given some information about radiotherapy as part of the diagnostic and decision-making processes, but most of them reported receiving radiotherapy-specific information when their planning scan³² (prior to EBRT) or pre-surgery appointment (prior to brachytherapy) was booked. A variety of experiences was noted with some patients satisfied with the amount of information received, but others feeling unprepared or lacking detailed information. Hovey et al. (2012) noted that transmission and reception of medical information is neither linear nor straightforward and for MPC is mediated by emotions such as fear and anxiety. Whilst most men had already received information when diagnosed, they noted issues related to the radiotherapy process. Some were unprepared for the temporal nature of information. Having received so much at the diagnosis stage, they developed anxiety about how long it took to receive information about their radiotherapy and what they perceived as delays to treatment starting or made assumptions that their

³⁰ Please see appendix 2 for diagrams and explanations of these radiotherapy dose concepts

³¹ Where the beam(s) of radiation do not fully cover the intended target. Often occurs because the treatment units are fixed in position and the patient and/or their organs move relative to the treatment set up parameters.

³² A radiotherapy-specific CT scan whose purpose is to provide the detailed anatomical information required to create the individualised map of dose that forms the basis of the radiotherapy technique that will be used during a patient's treatment.

cancer was not serious otherwise the treatment would not have been delayed. This assumption has been noted previously, suggesting that 'delay messaging' has reinforced the societal expectation that if cancer is not treated swiftly, prognosis is likely to be compromised (Aronowitz, 2001).

From both the patient and radiographer perspectives there was a need to be prepared for treatment. There was an expectation from therapeutic radiographers that patients would have received information, understood its importance, and have followed it. In some cases, the scan of the patient revealed that there was too much gas in the rectum, too much stool in the rectum or that bladder filling was not optimal, all of which impact on ideal dosimetry, therefore requiring patients to be given a further period of time to follow instructions and optimise these anatomical requirements. Usually, they are given an appointment to return for a repeat scan around seven days after the first. When referring to these repeat scans, patients reported that they had "failed" them. This language indicates that patients took responsibility for this requirement for a repeat. In these cases, or when treatment set up was difficult, radiographers attributed this requirement to patients not complying with or retaining information. The language used by the radiographers implies a sense of 'othering'; that is, seeing the patients as different from themselves (Canales, 2000; Johnson et al., 2004). Patients were referred to as 'they': "*we tell them*" "*We quiz them*" and by placing the responsibility for failed scans with the patient, they were perhaps excluding themselves from responsibility for this task but also demonstrating the power relationship that exists between practitioner and patient. Johnson et al. (2004) describes practitioner/patient relationships presenting as othering in which the ideal patient should realise what is important and listen to the expert practitioner, mirroring the radiographers in the present study who expressed concern when they felt the patients were not taking on board the information they had been given, suggesting they "*don't realise how important it is*". This sentiment may also point to a mismatch in expectations related to communication of information, with previous literature suggesting that sometimes HCP make unwarranted assumptions about patient knowledge (Salt et al., 2012; Towle et al., 1999). Patients referred to the anxiety they felt in anticipating treatment, making it difficult to remember details and were concerned about adhering to instructions, also reporting that when the planning or treatment process did not go smoothly, they were at fault and had in some way 'failed' the HCP concerned. The wider evidence base refers to retention of information, for example MPC reported receiving information but not remembering what was said (Öster et al., 2013), the amount and timing as factors affecting retention of information (Long, 2001; Tomlinson et al., 2014), high anxiety caused by anticipation of diagnostic testing impacting on patients' ability to process information (Feldman-Stewart et al., 2018) and giving too much information in one session increasing initial levels of anxiety thereby affecting retention (D'Haese et al., 2000). Here it

seems there are linked issues of both communication and time. The fact that some patients required repeat scans seems to suggest a potential issue related to whether information had been communicated effectively and in a timely enough fashion for instructions to be carried out successfully. As previously stated, assimilating large amounts of information can be difficult for some patients, and findings from D'Haese et al. (2000) demonstrated that levels of anxiety were less for patients who received information sequentially rather than all in one go suggesting that a staged approach to information-giving might improve retention. However, merely retaining information does not mean a patient understands the importance of that information (Bobridge et al., 2015), something the radiographers commented on when they found out that patients had started following information the night before their scan, rather than for the required week before. From a practice perspective therefore, there is scope for therapeutic radiographers to consider how information is communicated and what processes are in place to ensure patients' understanding.

6.6.2 Peer support - the "waiting room club"

An important part of the patients' experience was their interactions with other patients, either while waiting for their treatment slot, or as part of structured support groups. Some patients referred to the value they placed on "*the waiting room club*" or "*old boys' club*" and how they had gained support and information - good and bad - by communicating with fellow patients. This peer support has been reported previously as the 'little social club' (Clarke & Burke, 2016) and was characterised by sharing of information regarding diet and fluid intake, comparison of treatment schedules and comparison of side effects often exchanged with a great deal of humour: "*if there's a funny side we tried to find it*". For those who valued meeting other MPC, encountering people who had gone through similar experiences seemed to help them make sense of their embodied prostate cancer, and whilst it did not seem to reduce the biographical disruption experienced, they seemed to benefit from being able to share experiences and build camaraderie. Bennenbroek et al. (2002) suggested that this need to compare with others is a form of social comparison, which in the present study was rooted in a desire to gain information from others who are relatively similar and being more reticent in comparing with people who have not experienced this diagnosis (Wenger & Oliffe, 2014). However, as previously mentioned, whilst men were keen to share and compare experiences, these were limited to the acute side effects of treatment, treatment schedules, and diet and fluid intake with conversations regarding emotional and psychological sequelae not being mentioned. This does not mean that the conversations regarding emotional and psychological issues did not take place, or that they were not important topics for the participants. A common perception is that men are less likely than women to talk about emotional or embarrassing issues that might impact on either their own or others'

judgment of their masculinity (Chapple & Ziebland, 2002); however, bearing in mind the distribution and reconstruction of their embodied selves due to prostate cancer and its treatment, their stereotypical construct of masculinity may have changed (Owens et al., 2003). Whilst not admitting to speaking about their emotions with peers, several men had mentioned that knowing other people were going through what they were helped them manage emotionally. It may be that the waiting room was not a suitable environment for them to discuss these issues, or that hegemonic masculinities related to suppression of emotions and stoicism (Emslie et al., 2006; Wall & Kristjanson, 2005) prevented them from doing so, therefore suggesting that further opportunities for discussion of the emotional or psychological sequelae of treatment are required. As stated at the beginning of this section, the information exchanged in the waiting room was both good and bad. With MPC interacting with patients undergoing treatment for a range of cancers, sometimes information was exchanged that was not relevant to a particular diagnosis, leading to patients being misinformed. For example, a radiographer reported one patient being treated for a brain tumour who had been told by the wife of a MPC to drink water, which is not required unless the pelvis is being irradiated. Misinformation has been reported in the context of internet sources, video sharing networks or cancer support groups, but associated with decision-making and general cancer information rather than on-treatment protocols (Black & Penson, 2006; Steginga et al., 2007; Xu et al., 2021). Given that only the radiographers reported instances of misinformation, it is likely that MPC generally adhere to their treatment protocols and whilst they may share and compare experiences in the waiting room, findings from this study suggest they are not deviating from the daily treatment protocol information they are given.

6.6.3 Peer support - support group and charity information

The reliance on information from support group and charity resources was articulated frequently and many men spoke of the importance of the information from the charity Prostate Cancer UK (PCUK), either obtained from their website or from support groups, as has been reported in other literature (e.g., Boulton et al. (2015)). Most men seemed to access this information to reinforce and supplement what they gained from HCP, in some cases to reinforce and corroborate the information already gained, but in others because they had not been satisfied with either the amount or level of detail of information gained from HCP. Most men found the PCUK website information extremely valuable and liked that they could access it whenever they needed as well as download or order documents in order to have physical copies. Haider et al. (2021) suggested that time plays an integral part of information seeking because physical manifestations of documents imply permanence and stability, giving provenance and gravitas to this type of information, adding trustworthiness for the reader. A further

layer of trustworthiness was implied by the patients when they reported that HCP also supplied them with information published by PCUK. This is an interesting paradox from a temporal perspective. As previously noted, some patients had been critical in perceived delays in receiving information from HCP and yet some of the information supplied by those same professionals would be instantly available to patients wishing to search and retrieve from the internet. Here again is manifestation of incognizance; if patients did not know that PCUK was a source of information that would be helpful to them, they would not know to access it.

6.6.4 Information about side effects and their management

This desire to seek information in order to further understand and make sense of their diagnosis and management began for many in the diagnosis phase; however, for others it was the development of side effects that led them to seek reassurance that what was happening was expected and 'normal'. In this they displayed combinations of ignorance and incognizance: they were aware of the types of side effects they might expect; however, they may not have appreciated the severity or temporal nature of the effects and there were some side effects they were not expecting at all. For example, Murray had not been told to expect pain and had not found reference to treatments causing pain in the booklets he had been given, so was completely unprepared for the severity of pain when it occurred, despite having reviewed a large amount of information. Albeit his symptoms were dealt with swiftly by the treatment team, Murray felt that even though the radiographers had "*seen it all before*" he was alone in experiencing this level of pain, reflecting that other patients had much less severe or zero pain and that "*it would have helped if somebody else had suffered*". Murray embodied this pain by comparing it to "*what you ladies go through*", demonstrating both hegemonic masculinity and social comparison in his personal expectation of toughness and stoicism (Bennenbroek et al., 2002; Emslie et al., 2006; Wall & Kristjanson, 2005). At the time of his interview, he was still recovering from the acute side effects of treatment and was keen to point out how little his experiences had matched those he had been led to expect based on the information he had received.

Historically, patients undergoing pelvic radiotherapy have been required to change their diets in order to reduce acute side effects of diarrhoea and excess bowel gas caused by radiation damage to the bowel mucosa. With the advent of IMRT and conformal radiotherapy techniques, the likelihood of severe bowel side effects has reduced; however, excess gas in the bowel has implications for reproducibility and accuracy, therefore having patients make dietary changes as a method of reducing bowel gas during radiotherapy has often been employed (Henson et al., 2013) and still occurs in many

departments. Many patients mentioned dietary issues, with some patients advised to follow a diet that aimed to reduce bowel gas, whereas others were told to keep to their normal diet. However, for some, communication about these changes was contradictory or made them anxious about general health and wellbeing or comorbid chronic conditions. As the only patient interviewed to follow a vegetarian diet, Murray found that if he followed the dietary information, it would mean excluding many of the foods he knew as healthy. He found that the information lacked detail and it was only his own knowledge and understanding of his normal diet that meant he was able to find his “*own balance*”. As a diabetic, Philip found that changing his diet to reduce bowel gas had longer term implications for his diabetes control. Having complied with the radiotherapy diet, and then having returned to his usual diet, he was finding it difficult to get his diabetes back under control. He described how his radiotherapy and diabetes care were compartmentalised and questioned why it could not be a more holistic approach. The radiotherapy staff did not consider his diabetes management, indicating either a lack of education regarding this comorbid condition, or a blinkered approach to radiotherapy advice and information. There is some literature considering the impact of comorbidities on radiotherapy management of patients, most in terms of the comorbidities dictating treatment options and survival outcomes (Hall et al., 2005) but few mention quality of life outcomes or the impact of radiotherapy on management of comorbid diseases. However, Rodrigues & Sanatani (2012) noted that complication patterns can be impacted by comorbidity status, hence holistic consideration of all health needs of individual patients should be key in both treatment decision making and delivery. Indeed, evidence demonstrates improvements in care and patient satisfaction when care is integrated such that clinicians are able to consider all aspects of a patient’s health (Baxter et al., 2018; Stoves et al., 2010), therefore this should be possible for patients undergoing radiotherapy if this approach is developed as normal radiotherapeutic practice. The examples given above from Murray and Philip demonstrate where a more holistic approach and more personalised information and communication would have been beneficial to them.

6.6.5 Practical matters

Whilst patients were critical regarding their perceptions of whether they had been prepared for the reality of radiotherapy, they were complimentary and positive about their on-treatment experiences and communications with the therapeutic radiographers. They praised being given detailed explanations from the radiographers on each day of treatment and had the right amount of information for their needs during this period, which included information about appointments,

parking and travel options. Much focus was on the bladder and bowel preparation protocols, and patients' main concerns were based on whether they would be able to follow the specific timing requirements, especially related to fluid intake. Maliski et al. (2002) suggested that a diagnosis of prostate cancer represents a lack of control for some patients, with other literature suggesting that being in control is a hegemonic masculinity (Wall & Kristjanson, 2005) and this seems to have been demonstrated with the men's diligence in following the treatment protocols; taking this responsibility appears to be one way the men in the present study perceived they took back some control. The issue of timing of fluid intake was a source of great anxiety to some patients. They worried about managing the journey to the radiotherapy departments and developed strategies to cope, such as planning routes to include toilet stops and carrying urine bottles in the car. This focus on the logistics of radiotherapy was also noted by Ahamad et al. (2019). Adam coped by creating what he called his "*disaster bag*" containing everything he needed to manage episodes of incontinence. Even while in the department, some patients worried about timing of fluid intake, having had it communicated to them by the radiographers on how important it was to drink a set amount of water, at a set time before treatment to ensure a full bladder and developed a new routine to cope "*I worked out my system and it was quite complicated*". If patients felt timings were wrong (for example if their treatment was delayed) and radiographers had not effectively communicated the reasons why, they would become agitated and concerned that their treatment would not be accurately delivered. It is interesting to consider this perspective by applying Bronfenbrenner's bioecological theory (Bronfenbrenner & Morris, 2006), where the radiotherapy department, its staff and patients could be considered a microsystem, in which a patient's personal characteristics and the impact of the treatment, contextualised with temporality and treatment processes frame their experience. Patients who did not become anxious at these times reported being regularly updated by the radiographers, suggesting that in this microsystem, good communication went some way to ameliorating anxieties related to fluid intake, for example Philip who felt the good relationship he built with the radiographers helped him manage to complete his treatment each day: "*have your drink now ... you've got more confident ... that they were keeping to it... that that was a great working perspective*".

Overall, the peri-radiotherapy time period was characterised by patients reporting high levels of satisfaction with information received from the radiographers during their treatment. They had overcome the acute need for detailed information demonstrated in the diagnosis and decision-making period, and the transition to active treatment switched focus to the immediate issues of following protocols in order to assure accurate treatment. This change of information needs as treatment progresses has been documented elsewhere (Wolpin et al., 2016) and in this section is typified in the

change from needing information regarding treatment options, to focus on information about side effects of treatment, and practical matters related to treatment protocols. The embodiment of their prostate cancer had progressed from the disease itself to manifestation of treatment side effects and how to manage them.

6.7 Post radiotherapy

Kelly (2009) noted that prostate cancer is a uniquely male experience and that mens' embodiment of prostate cancer occurs within a sequentially experienced trajectory, incorporating transformation and mediation. This sequential nature of the embodied history of a cancer diagnosis has been reported by Ogle & Ullstrup (2006) related to female breast cancer, however they focussed on social roles, world views and other contextual factors. Nevertheless, they acknowledged the re-framing of self-concept and identity that takes place, therefore demonstrating parallels with Kelly's noting of transformation and mediation for MPC. Furthermore, in the present study, the role of the mens' wives in helping them make sense of the diagnosis and management of their cancer must be recognised. As in other studies (Banthia et al., 2003; Harden et al., 2006; Lavery & Clarke, 1999) men and their wives tended to face the challenges of the prostate cancer diagnosis together. The roles of wives included taking on board information, helping their husbands follow treatment related instructions and generally providing a supportive presence. These roles were acknowledged by both radiographer and patient participants as factors helping patients to cope day to day during radiotherapy and then when adjusting to the longer-term changes and biographical disruption.

In the present study the temporal changes from diagnosis through to the post-radiotherapy period were characterised by patients' changing information needs and focus. Whereas before and during radiotherapy, their focus was on treatment options and side effect management, by the end of radiotherapy the focus had changed to consideration of "what happens next" with patients concerned with knowing the outcomes of radiotherapy and the expectations of their future lives. These concerns have been noted in previous literature where it was observed that information needs change over time with information on prognosis becoming more important as treatment progresses (Baverstock et al., 2015; Douma et al., 2012; Wolpin et al., 2016).

The end of EBRT marked an important transition point for patients. They had become accustomed to daily communication and support from the radiographers across a period of four to seven weeks and needed to adjust to life without their regular visits to the radiotherapy department. Several patients mentioned this transition, missing contact with people they had made friends with and the daily reassurance they had become used to receiving from the radiographers. For several weeks during and immediately after the end of radiotherapy some patients reported suffering from effects of treatment such as diarrhoea or pain, so this transition was embodied in an acute period of discomfort due to the side effects and uncertainty about the future. Uncertainty has been conceptualised as a patient's inability to determine the meaning of illness-related events (Mishel, 2014), which for MPC in this study manifested in two linked areas, firstly with respect to longer-term outcomes and secondly in terms of whether an individual had made the right decisions about treatment - as detailed in Adrian's case in chapter 5. Patients' decision-making had been carried out at a time when they had little knowledge of either prostate cancer or the treatment options available and as already discussed previously, those decisions have implications for patients regarding survival and the impact on quality of life due to long-term morbidity. It has been suggested that persistent uncertainty regarding outcomes can adversely impact on quality of life (Clark et al., 2003; Nanton et al., 2009) and that access to information helps patients manage their uncertainty (Appleton et al., 2019; Nanton et al., 2009), hence it is important that patients' needs for information about their outcomes are met throughout and after their treatment course, not just at the decision-making stage. Generally, this information need is met via the use of follow-up appointments, as recommended by NICE (NICE, 2021a). Most patients reported receiving some information about follow up and what to expect following completion of radiotherapy; however, several patients reported receiving no information at this time leaving them feeling poorly supported. This lack of information and support at the end of EBRT has been noted in previous research involving patients with a range of diagnoses (Corner et al., 2013; Halkett et al., 2010; Hendry, 2011; Wells, 1998). These studies noted that the period immediately after radiotherapy signified a time when patients reflect frequently on their treatment but also had limited access to specialist HCP for discussion of their concerns. It seems therefore, that a paucity of information at the end of treatment has been a long-standing issue common across several diagnoses and not unique to patients with prostate cancer. The radiographers in the present study reported that they routinely give information to patients at the end of EBRT; however, this was a group from one department, whereas patient participants had been recruited nationally, indicating that information-giving practices may vary by location. Information that was most consistently given at the end of EBRT and also to patients who had received brachytherapy was that regarding follow-up appointments. At follow-up patients are normally given the opportunity to discuss initial outcomes of radiotherapy

concerning resolution of acute side effects and planning for future monitoring; however, anticipation of the appointment can cause a great deal of anxiety for patients because an additional purpose of these consultations for HCP is to detect recurrence (Lewis et al., 2009; Vieira et al., 2014). Several studies have addressed the benefit of follow up, in particular via telephone (e.g., Anderson (2010), Leahy et al. (2013), O'Brien et al. (2011) and Verma et al. (2015)). The reported benefits of follow up mentioned in the studies included satisfaction with care, improvements in service delivery and benefits of remote follow up, but consistently focussed on physical outcomes such as levels of toxicity and/or long-term physical side effects, and this was the case for patients in the present study who reported the focus being on PSA checks and side effect monitoring. Although there is this body of literature exploring follow up, there is a dearth of literature that focusses on patients' wellbeing and/or information needs in the 6–8-week period immediately between completion of radiotherapy and follow up. Wells (1998) highlighted this period as a "hidden experience" (p.840) and referred to the disruption and uncertainty that patients feel as being "largely swept under the carpet" (p.846), with the first month after the end of treatment being of particular significance because patients have moved beyond the immediate focus of the HCP. In essence patients experience temporally what has been described as 'sustained liminality'; the uncertainty of whether they are healthy or ill, the incorporation of uncertainty into their new view of life and the biographical disruption that arises from this (Mishel, 2014; Pietilä et al., 2018). Given that some patients in the present study reported a lack of information at this crucial transition stage, the end of EBRT therefore seems to be important in terms of patients' unmet informational needs and because of their unique knowledge and experience, therapeutic radiographers are well-placed to adapt their practice to 'plug' this information gap. This may warrant exploration in future research.

The second period of uncertainty occurs as a gradual transition process, which marks a return to normal life, or rather a 'new normal' for some patients potentially framed in the uncertainty of their new sense of order (Mishel, 2014). This transition often occurs with no medical intervention other than continuation of ADT, during which patients are generally reviewed at follow up appointments no earlier than six weeks after the end of radiotherapy and thereafter no less than every 6 months (NICE, 2021a). Patients in the present study were interviewed between 3 and 18 months after the end of radiotherapy and so reported varying experiences related to their experiences of acute and longer-term side effects, the ending of radiotherapy and their transition to their new normal. They had been treated prior to 2017 at a time when many departments were reviewing their dose fractionation regimens for EBRT in light of the findings of the CHHiP and HYPRO trials (Aluwini et al., 2016; Dearnaley et al., 2016). Current EBRT in the UK has been standardised to the shorter regimen of 60Gy in 20

fractions delivered with IMRT for early, localised prostate cancer, which has generally replaced the longer schedule of 78Gy in 37 fractions (Morgan et al., 2018; Royal College of Radiologists, 2019). The findings therefore reflect a combination of patients who had undergone both EBRT schedules and seed brachytherapy. Regardless of the type of treatment patients had received, the issues they reflected on were similar, with the most important topic in this gradual transition period identified as uncertainty regarding sexual functioning and the lack of information and communication about this long-term side effect. The transition from active treatment to managing new normal has been documented in previous literature (Nanton et al., 2010) where for wives of MPC, striving for normality was undertaken in order to maintain some semblance of control as well as providing emotional support. This level of support was apparent for the married men in the present study; however, perhaps due to the information they had received, their transition was more accepting of the biographical disruption and change, and less focussed on returning to the pre-treatment status.

6.7.1 Sexual functioning

Sexual dysfunction following treatments for prostate cancer (radiotherapy, surgery or ADT) has been documented as a frequently occurring consequence (Barsouk et al., 2020; Fergus et al., 2002; Katz, 2005; Wittmann et al., 2009) and emerged from the literature review in chapter 2 as a topic requiring further exploration. The loss of sexual functioning in the form of either erectile dysfunction, loss of libido and/or loss of ability to ejaculate was experienced by many men in this study, with most men attributing the dysfunction to ADT. In some cases, they assumed that when the ADT stopped, their sexual functioning would begin to return. Many men in the present study reported how unprepared they were for facing this as a longer-term issue, citing lack of information being given at the decision-making stage and reluctance for HCP to speak to them about sexual dysfunction as their treatment progressed; the information was “*glossed over*” or “*they’re not volunteering a lot*” even though “*everybody knows [it] will happen*”. This reluctance of HCP to discuss sexual functioning, sex and intimacy has been the subject of previous research, with participants in those studies wanting their HCP to initiate conversations about sexual problems and feeling unprepared for bodily changes due to the lack of information and poor communication about these issues (Appleton et al., 2019; Flynn et al., 2012; Forbat et al., 2012; Kelly et al., 2015; Kinnaird & Stewart-Lord, 2020; O’Brien et al., 2011)). A recent study suggests that around 50% of patients with prostate cancer may not be receiving information on sexual functioning; something that is likely to have a profound impact on their long-term quality of life outcomes (Watson et al., 2021). Adrian spoke about the lack of absolutes and lack of detail regarding the risk of long-term sexual dysfunction. He noted that clinicians were able to give reasonably precise figures for outcomes such as cure rates or disease-free intervals but were much

less willing to give figures for prevalence of long-term effects, even though he was later able to source this information himself. And yet best practice literature related to shared decision making suggests that discussion of uncertainty in medical decisions – of which communicating uncertainty of adverse reactions and/or functional outcomes is a part – is crucial for patient centred care (Barnett et al., 2004; Simpkin & Armstrong, 2019). Other patients in the present study reported being given booklets about sexual and erectile dysfunction but did not understand the long-term implications until they researched it themselves in more detail (and often after the treatment had occurred rather than before), while others reported having to request advice and support.

Griffiths & Hodgson (2011) found that many radiographers reported a lack of education and therefore a lack of confidence in communicating with patients about sexual functioning. Whilst therapeutic radiographers in the present study accepted that giving advice on sexual functioning was part of their role, they did not report feeling under-educated, but in agreement with the patients mentioned that information on sexual function could be “*glossed over*” or not given attention unless patients specifically asked about it. Additionally, they assumed medical staff would have covered the issue as part of wider management conversations or that they would refer patients to a review team as this would give more time for the patients to discuss their concerns. This concurs with a Dutch study that reported 75% of radiation oncologists agreeing that discussion of sexuality was their responsibility and that 97% regularly or often informed their patients of the risk of ED after radiotherapy (Krouwel et al., 2015). One radiographer in the present study pointed out that issues of sexual functioning are not discussed with patients either at the pre-treatment scan or during discussions about treatment, because it is seen as a long-term issue. They intimated that information focus for radiographers was on the acute, physical side effects of treatment. This concurs with (Kinnaird & Stewart-Lord, 2020) who suggested that the focus is on physical symptoms and that lack of emphasis on emotions and relationships could have long-term implications for many patients. This indicates that information at the end of radiotherapy is an area of practice that is in need of further attention.

The impact of sexual dysfunction in terms of biographical disruption on some patients’ sense of self, their sense of masculinity and the effect on their relationships was profound, as detailed in Adrian’s case study. Even where the disruption appeared not so profound, and patients seemed to have acknowledged sexual dysfunction as an acceptable consequence of their treatment it was an issue that mattered. Participants in a previous study described future impotence as a ‘small price to pay’ (Chapple & Ziebland, 2002) and in the present study, patients had clearly considered their changed future but with a pragmatic understanding that it was either accept these changes or risk their cancer

not being cured: “...I can live without ... I’m still here... but maybe in five years’ time I might not” (Paulo). It is disappointing that for some patients, opportunities were not taken to provide information to ameliorate some of these issues. It seems there may be a ‘perfect storm’ of conditions that have been documented over many years that points to many patients receiving insufficient information and support regarding the effect of prostate cancer treatments on sexual functioning, but that the present study demonstrates are still not being addressed satisfactorily.

Patients described a number of other physical changes that accompanied sexual dysfunction such as gynaecomastia, bodily changes, weight gain and mood swings, often referring to stereotypically female body appearances such as “bingo wings”, “boobs” and “body shape changed...like an old woman”. The description of these changes in feminine language demonstrates how their embodied masculinity had been challenged and yet information about these changes had either not been given or had not been in sufficient detail to prepare them for the reality. The language also reflects the hegemonic masculinities that persist in many cultures; men are expected to be stoic, controlled, unemotional and tough (Chapple & Ziebland, 2002; Emslie et al., 2006; Gough, 2006; Wall & Kristjanson, 2005). Some men, such as Andy understood that it was difficult for HCP to predict the nature and severity of such bodily changes because “until they start treating you they don’t know” and yet the findings suggest that as with the sexual dysfunction issues, there were opportunities for these discussions to take place that were missed, primarily at the decision-making point. However, it has been noted that at the time of decision-making, patients are often not emotionally prepared to retain this information (Long, 2001). Halkett et al. (2010) referred to the “repertoire of information” with some of their participants reflecting on the difficulty in remembering information, a sentiment shared by participants in the Öster et al., (2013) study, who reported being “calmed” and having their information needs met by further conversations with HCP.

6.7.2 Urinary incontinence and long-term bowel effects

Other long-term side effects of radiotherapy that were of concern were urinary incontinence and long-term bowel effects such as radiation enteritis. Previous research has suggested that bodily control is important to self-identity and masculinity (Chapple & Ziebland, 2002; Tsang et al., 2019) therefore concerns about incontinence move beyond the physical inconveniences to social and self-esteem issues too, further reinforcing the long-term biographical disruption faced by MPC. Patients appeared to be well-informed about the potential of these side effects, often having used information comparing the risk of these effects to determine that radiotherapy was a better treatment choice for

them than surgery. Andy was typical of a number of patients who reflected that the information they were given indicated a stark choice between being impotent or incontinent. His treatment choice had therefore considered what he could cope with in the long-term: *“do I want to spend the rest of my life incontinent or ... live with what I’ve got?”* This was echoed in other studies where some MPC reported being ill-informed and unprepared for the impact that incontinence and other long-term side effects would have on their lives (Carter et al., 2014; Corner et al., 2013; Sutton et al., 2021). Paulo linked incontinence as one of the potential issues that might impact on his “being a man”, an example of where it was not just the sexual dysfunction effects that were likely to challenge a patient’s sense of masculinity. He and others described a lack of information at the diagnosis stage as impacting on understanding of the “collateral damage” of radiotherapy and that on reflection, they were unprepared for the longer-term effects and how they might impact on daily life. In Corner’s study, patients reported a lack of preparation regarding long-term effects with some suggesting they may not have proceeded with treatment had they been more fully informed (Corner et al., 2013). At the time of interview, an unknown for participants in the present study was whether they would develop those longer-term effects which often manifest some years after treatment. Whilst some patients had been concerned about the long-term effects, others noted that so far, they had not been as bad as anticipated; however, they framed this as feeling “lucky” rather than considering lack of effects as an expected outcome. Recent investigation of long-term outcomes suggests that most studies comparing radiotherapy with surgery or active surveillance focus on survival and function-based long-term effects, with little attention on those affecting quality of life, with participants reporting they would have liked more information about the potential of these effects (Corner et al., 2013; Donovan et al., 2016). Whilst there has been advice communicated to practitioners regarding radiation enteritis and how to manage it (Andreyev et al., 2014), the continued concern of patients in the present study regarding these effects indicates that the information needs of MPC regarding long-term effects of radiotherapy are still not being met despite the wealth of evidence over a significant period of time highlighting this as an issue.

6.8 Summary of discussion

This chapter has provided an in-depth discussion of the experiences of MPC related to information in radiotherapy, which appear to be rooted in issues related to communication and time. As noted by Owens et al. (2003), it is difficult to separate a patient’s radiotherapy experience from their overall diagnosis and management, and the narratives of participants in the present study covered elements

related to what happened before, during and after their radiotherapy, so the issues related to radiotherapy information are unavoidably intertwined within a temporal consideration that starts with a patient's diagnosis and management decisions. This background context needed to be considered holistically in the analysis and discussion.

It became clear that events and information needs at the diagnosis and decision-making stage had a profound impact on patients in the longer term, especially in consideration of the biographical disruption they experienced, and whilst information for the duration of radiotherapy focussed on ensuring accuracy and reproducibility of treatment techniques, its longer-term aim was to ensure patients had information that would help minimise chronic adverse outcomes, in particular related to bladder, bowel and sexual functioning. It was not always certain that the participants understood the importance of the information they were given, especially at the point of diagnosis and when decisions were made about treatments. Here, the high emotions and biographical disruption caused by the diagnosis impacted on patients' ability to take on board the information they were given. This combined with some less than optimum communications from HCP meant that some patients were either under-informed or not aware of information that might have impacted on their decision-making. For some men, dealing with the potential long-term consequences caused profound distress or decision regret and whilst being able to access the right information at the right time might not have changed their treatment approach, at least it may have satisfied their information needs enough to reduce the amount of distress they encountered. Married men frequently relied on their wives to recall information that had been given. During radiotherapy patients were generally satisfied with the amount and scope of information, praising the radiographers for their communication and support. Information needs during this period focussed on the daily preparations required for accuracy and reproducibility to minimise both acute and chronic effects of treatment. During this period patients valued the peer support they gained from meeting other patients in the waiting room, and also supplemented their knowledge and understanding via information sourced from charities such as PCUK. A few patients reported feeling unprepared for the reality of some rare side effects, but this related to the broader information received before the radiotherapy began, rather than the more specific treatment-related information.

6.9 Proposing an explanatory model

In this section I will draw on the ecological systems and bioecological theories of Bronfenbrenner in order to propose a new model which helps to explain the issues explored in the previous sections of this discussion chapter. The purpose of the model is to provide a graphic representation of the multitude of factors that impact on how a man with prostate cancer experiences information related to radiotherapy – those that have a direct impact and those that are more socially or systemically constructed and the acknowledgement that the influence of factors may change over or be mediated over time.

In deciding to structure presentation of the findings and discussion according to the three defined time periods of pre-, peri- and post- radiotherapy, it was interesting to note the changing information needs over time, but also the factors that influence those information needs. I previously referred to the ecological systems and bioecological theories developed by Bronfenbrenner, and these helped develop my understanding of the interactional nature of the contextual issues that impact on an individual's diagnosis, treatment and beyond. The value of the original Bronfenbrenner ecological systems theory (EST) is that it puts the individual at the heart of nested systems that contextualise their experiences and development. As stated in section 6.4 above, in the context of a MPC, the model fits as a means of explaining my findings to some extent, as many of the factors that influence an individual's human development also apply to how a MPC processes his diagnosis and subsequent management of prostate cancer. However, as noted when reflecting on development of the original EST into the bioecological model, Bronfenbrenner placed more emphasis on personal factors, context and proximal processes, noting the mutual influence and interconnectivity of each aspect (Bronfenbrenner & Morris, 2006; Rosa & Tudge, 2013; Tudge et al., 2009). An important part of the bioecological model was to consider the biological attributes and potential changes for an individual, which may relate to, but not necessarily be caused by social and other contextual factors. Biological changes related to disease development and progression, and side effects related to disease management typified the prostate cancer experience for all men in the present study, especially in terms of biographical disruption. Additionally, they drove the proximal processes associated with the people MPC interacted with and influenced the information they sourced across the course of their diagnosis, management and life beyond cancer. Note, that in the bioecological model, Bronfenbrenner defines proximal processes as "enduring forms of interaction in the immediate environment" (Rosa & Tudge, 2013) p. 317) placing most emphasis on the actors closest to individuals;

in the present study, this being the HCP, friends and family they interacted with directly within each stage of their prostate cancer journey.

When considering the latent themes that were identified in this research (communication and time) the bioecological model cannot be applied unless communication is overtly represented, as this was a mediating factor throughout the MPC experiences. In his original EST, Bronfenbrenner introduced the concept of the mesosystem – a layer providing interconnectivity between some of, or all other nested layers (see figure 8 section 6.4) and initially it seemed that applying communication as a mesosystem within the EST model would provide the interconnectivity required. However, in the later bioecological model the mesosystem was incorporated into the contextual factors and suggesting communication as a contextual mesosystem underplays its importance in the present study. Therefore, an adaptation of the bioecological model aimed at representing the ecology of information related to radiotherapy for MPC is proposed in which communication is incorporated as an essential factor inherent in all other components. Another limitation of both original models is that although they present the context of temporal factors and acknowledge the changing development of an individual over time, there is limited detail in terms of what the particular temporal issues might be. The proposed model incorporates biographical disruption as a major temporal contextual influence and considers the chronology and temporal change related to information across a patient's prostate cancer journey and on into the survivorship period.

In his early work on child development, Bronfenbrenner highlighted how ecological research had developed from consideration of dyadic and triadic environments through to more complex studies that incorporated environment, relationships and activities in a reciprocal manner, that human beings adapt and change in response to a variety of ecological conditions and across time (Bronfenbrenner, 1975). In developing the graphic of the proposed model, I aimed to capture this adaptability but also to identify some examples of factors that illustrate the specific ecology related to information in radiotherapy. Although the graphic of the model (figure 10 below) shows clearly defined sections, this is merely to help illustrate how the various factors fit together. In practice the individual components are multidirectional and may have different emphasis at different times in the patient's cancer journey. For example, a person's emotions and temperament might be linked to their development within a particular religious or cultural context. Similarly, the proximal processes involving information related to appointments, or information communicated by various HCP at various times may need to be considered in the context of information received from family and friends, or related to particular cultural norms. Therefore, the blurred and dotted lines in the graphic aim to convey that factors given

in an individual section in the model are not discrete entities, but influence and are influenced by the other sections and components.

The new model representing the ecology of information related to radiotherapy for MPC is presented in figure 10 below:

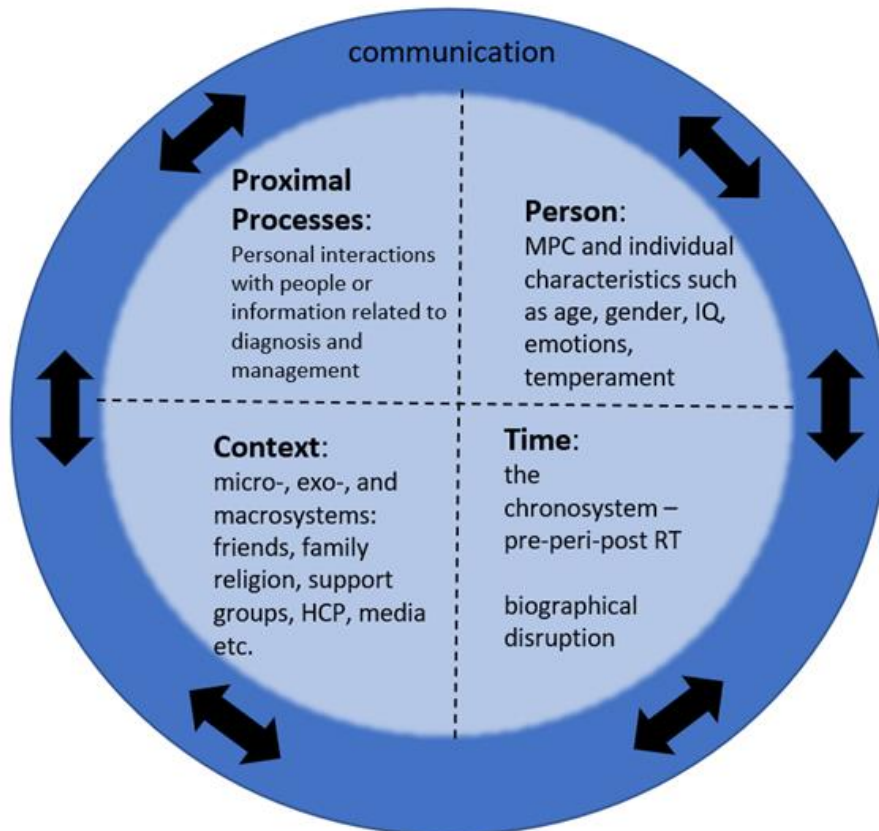


Figure 10. The ecology of information related to radiotherapy for MPC

This new model utilises the original components of Bronfenbrenner’s bioecological model (proximal processes, person, context and time) but applies them specifically to the issue of information in radiotherapy (Bronfenbrenner & Morris, 2006). Table 10 below compares the sections on the new model compared with the original:

Table 10. Comparison of new model with Bronfenbrenner’s bioecological model

Component	Bioecological model	Ecology of information related to radiotherapy for MPC
Proximal Processes	Interactions with people or objects in immediate environment	Personal interactions with people or information related to diagnosis and management
Person	Individual characteristics such as age, gender, IQ, emotions, temperament	MPC and their individual characteristics such as age, gender, IQ, emotions, temperament
Context	Micro-, meso-, exo- and macrosystems as described in the original ecological system model	Micro-, exo- and macrosystems: family, religion, support groups, HCP, media etc.
Time	The chronosystem comprising what happens in specific episodes and across life course	The chronosystem: pre-, peri- and post-radiotherapy; biographical disruption
Communication	Not present	A mesosystem inherent in all other components of the model

In order to demonstrate the operation of the model I have applied it to the case study for Adrian described in chapter 5. This is presented in table 11 below:

Table 11. Application of the new model to one case

Component	Ecology of information related to radiotherapy for MPC	Applying the model to Adrian’s case
Proximal Processes	Personal interactions with people or information related to diagnosis and management	Interactions with GP, urologist, surgeon, clinical nurse specialist, TR
Person	MPC and their individual characteristics such as age, gender, IQ, emotions, temperament	72 year old male, Caucasian, retired engineer, active volunteer, suffering depression, emotional, hegemonic male
Context	Micro- exo- and macrosystems: family, religion, support groups, HCP, media etc.	Wife, family, friends with cancer, PCUK, GP, urologist, surgeon, clinical nurse specialist, TR, colleagues at volunteering site,
Time	The chronosystem: pre-, peri- and post-	Lack of information seeking pre-radiotherapy and reliance on information from friends; focus

	radiotherapy; biographical disruption	on following information in protocols during radiotherapy; reflection and information seeking post-radiotherapy leading to decision regret. Biographical disruption throughout all phases: shock at diagnosis, managing acute side effects of radiotherapy, growing distress and depression regarding likely long term sexual dysfunction in the post-radiotherapy period
Communication	A mesosystem inherent in all other components of the model	Conversations regarding treatment options with urologist and surgeon; lack of recall of details that had been communicated; communication with his friend and the impact on decision making; communication with HCP and their assumptions of his knowledge and understanding contributing to incognizance; lack of communication about his diagnosis with his wife due to her health issues; discussion of side effects in treatment review clinics; interactions with other patients in the waiting room; sharing experiences with fellow volunteers; reflecting that he did not communicate enough with HCP early enough to obtain accurate and detailed information; critical of HCP demeanour when delivering information.

In order to test the model, it is worth considering whether it can be used to show how the situation for Adrian, and other men like him could have been improved. For example, the proximal processes component on the model above concerns interactions with people and processes related to diagnosis and management. Adrian spoke about a clinical nurse practitioner he interacted with and how that impacted on his experience. He noted that this person's dismissive response regarding his query regarding sexual functioning led to profound distress, adversely contributing to the biographical disruption he experienced. This example suggests that clearer and more compassionate communication of information about the long-term effects of his cancer management earlier on in his cancer trajectory, may have ameliorated some of the longer-term psychological consequences. As discussed in section 6.5.1 the manner in which information regarding prostate cancer diagnosis was imparted was important to many of the participants and reported in previous literature. Hence consideration of the proposed model might have the potential to help HCP to reflect on their own

practice and the wider impact their interactions with patients might have. Evaluation of the utility of the model could form the basis of future studies.

In summary the new model effectively captures the ecology of information related to radiotherapy for MPC and provides a novel approach to explain their experiences related to information in radiotherapy. This is a first step in development of understanding of information specifically focussed on radiotherapy and the model will require further testing with other populations of MPC to examine its usefulness and application.

6.10 Original contributions to knowledge

This is the first study utilising qualitative methodology that focusses on information related to radiotherapy for MPC, hence providing an original contribution to the knowledge and evidence base. Previous studies had examined information in radiotherapy using quantitative methods, utilised samples that included people with a range of cancer types, reported radiotherapy findings incidentally or had considered information related to a range of treatment options for MPC. This study's unique contribution is that it has demonstrated that information for MPC related to radiotherapy is mediated by communication and time. A new model that enables explanation of this contribution has been proposed.

I argue that information for patients undergoing radiotherapy cannot be seen as a discrete entity and that it must be contextualised within an individual's experiences of diagnosis and decision making during the pre-radiotherapy period, and factors that impact on daily living and a patient's expected life course. An unexpected finding was that the biographical disruption caused by a diagnosis of prostate cancer can impact on patients' treatment decision making and subsequently how patients use and process information related to radiotherapy.

Other contributions to knowledge as a result of this study were firstly an understanding that patients have unmet informational needs during the pre-radiotherapy period that can impact profoundly on their longer-term outcomes, and secondly that there was a dearth of detailed information about the reality and likelihood of the long-term adverse effects, in particular related to sexual functioning. Although both these issues have been highlighted in previous studies, this has not been explored in

the specific context of radiotherapy. Both these issues were mediated by communication from HCP during the pre-radiotherapy period, and a dearth of information and support in the weeks and months immediately following the end of treatment.

A strength of this research was the early decision to “ask the experts” when designing the study to ensure inclusion of patient and public involvement (PPI). Very early in the process I approached a cancer support group and the University of Hertfordshire patient involvement in research group (PIRg) to review my research approach and the feedback received from both groups was incorporated into the study design (see section 3.4.1). At the time I began my research journey in 2012, PPI was rarely reported in health research and less so in doctoral dissertations. A recent study which cited my research note paper described the inclusion and reporting of PPI in my doctoral studies as a “notable exception” (Coupe & Mathieson, 2020) (p.126). My paper was also cited as a good practice example within level 8 learning units delivered by my university. Hence this paper has provided an additional original contribution to the evidence base and the education of current and future doctoral candidates.

6.11 Limitations of the study

A few limitations were identified regarding this study regarding recruitment, sample demographics and changing radiotherapy practice:

- The initial recruitment of the sample was revised from a local approach at one hospital site to national recruitment via social media. Whilst a twitter advert was successful from a numbers perspective, it was potentially responsible for some bias in the sample demographics: mainly well-educated and computer literate Caucasian responders, many of whom were already users of information from PCUK, and whose demographics have previously been noted as factors that increase use of social media, and are associated with higher levels of knowledge, understanding and health literacy (Meeking, 2020; Oliffe et al., 2011; Xu et al., 2016).
- The final sample indicated a lack of demographic diversity. All but one respondents and final recruits were of White British ethnicity, none identified as other than cis-gender and all identified as heterosexual.

- The recruitment of participants took place across a period of time when many radiotherapy departments were in the process of changing from an established 74Gy in 37 fractions treatment prescription to 60Gy in 20 fractions as a result of the CHHiP and HYPRO trials (Royal College of Radiologists, 2019) so participants in the study had received either regimen. Practices regarding treatment preparation and thus the informational needs of patients may therefore also have changed since the data collection period.
- All participant recruitment took place before the start of the COVID-19 pandemic began in early 2020, therefore information and support practices that have been put in place since then are not reflected in this study's data.

6.12 Recommendations for practice

In 1995 the Calman Hine report set out strategies to improve quality of patient care and Current NHS policy recommends a person-centred approach to service delivery and recommends individualisation of information given at the right time (Calman & Hine, 1995; NICE, 2012). Findings from the present study indicate that this occurs during the planning and delivery of radiotherapy and that patients appreciate the quality of information and support given by therapeutic radiographers. However, there was less satisfaction with information during the pre- and post-radiotherapy periods, in particular related to decision making and understanding of long-term implications of the treatment choices made. Patients felt under-informed of the scope, severity and timeframe of sexual dysfunction therefore **a recommendation of this research would be to ensure patients are given enough time to consider the different options by being offered the opportunity for further discussion of the long-term effects before their final treatment choices are made.** Current NICE guidelines recommend that clinicians need to ascertain the extent to which a person wishes to be involved in their decision making and that people should be supported in making treatment decisions (NICE, 2021a). However, **a recommendation arising from this study is that where there is a choice to be made between several treatment options, the guidelines should also indicate that a period of time should be given to allow decision making.** This may have the result of decreasing the levels of biographical disruption experienced and reducing levels of decision regret.

The roles of advanced practice and consultant radiographer are characterised by both role expansion and extension (Eddy, 2008) and have extensive and in-depth knowledge and understanding of both acute and long-term radiation effects, therefore are well-placed to utilise their expertise at the decision-making stage; however, recent literature suggests advanced practice radiographers may be under-utilised at this point, with most being involved in the patient pathways once patients are referred for radiotherapy (Yeo et al., 2019). Patient narratives in their interviews appeared to corroborate this point, with plenty of reference to clinical nurse practitioners but not therapeutic radiographers. **A recommendation arising from the study would therefore be for service changes that allow advanced practice therapeutic radiographers to expand their practice to be more included as part of decision-making, perhaps as suggested by participants in the present study by being available for supplementary consultations once the initial diagnosis has been conveyed.** However, it is appreciated that there may be service need and cost implications related to this suggestion. According to a paper by Duffton et al. (2021) that post-dates my data collection period, involvement of consultant therapeutic radiographers is occurring across the full patient pathway, therefore this recommendation is likely already being more widely implemented than was apparent at the point of data collection.

Many patients in the present study reported limited information and support in the immediate aftermath of radiotherapy, leading to uncertainty regarding future outcomes and avenues of support regarding side effects, both those that manifest acutely in the first few weeks following treatment, but also about possible late effects. **A recommendation arising from this study is development of specialist services that give patients access to focussed support in the weeks between end of treatment and first follow up.** This could take the form of a telephone helpline or online service. Evidence has shown TR led telephone follow up to be effective (Taylor & Shuttleworth, 2021; Verma et al., 2015), therefore a similar remote service that bridges the time between the end of treatment and first follow up could provide effective support.

In line with other literature, some TR in the present study reported being under educated, under confident and ill-equipped for conversations about sexual functioning therefore **a recommendation for practice is that further education of all HCP who care for MPC regarding long-term sexual dysfunction is required.** This research demonstrated a general reluctance for TR to inform patients of the late effects of treatment, as well as assumptions that other HCP would already have done this as part of the consent process. Patients reported that they would have liked more information on this issue as they were finishing treatment. **More attention needs to be given to information and support**

needs of patients in the few months immediately after radiotherapy to improve quality of life for patients.

6.13 Recommendations for future research

None of the men were asked about or volunteered their sexual orientation at recruitment, and during the interviews none identified themselves as a gender other than male, non-heterosexual or as men who have sex with men (MSM). This lack of diversity created a homogenous sample. However, the disadvantage of this homogenous cohort is that the voices and narratives of minority and under-represented groups are missing. Other research has demonstrated that LGBTQ+ people and those from minority ethnic backgrounds have particular information needs often not reflected in the information available (Hammick et al., 2001; Ralph, 2021; Webster & Drury-Smith, 2021). **Therefore, the information needs of under-represented groups undergoing radiotherapy for prostate cancer is an area that needs to be addressed in future research.**

Treatment preparation practices related to, for example, dietary advice or use of enemas to clear the rectal contents and fluid intake may have changed since the data collection period in response to radiotherapy prescription changes (Royal College of Radiologists, 2019). Any changes in treatment protocols may have led to changes in information, therefore the context of the information utilised by patients interviewed in my study must be viewed with respect to the short historical context. **Further research may elucidate whether these changes in treatment protocols and prescriptions have impacted on information needs of MPC.**

The data collection period took place before the COVID-19 pandemic and since then patient support practices have changed with more services following a telemedicine approach. **A follow up study exploring patient experiences with respect to information post-COVID may illustrate the impact of these changes on MPC.**

6.14 Conclusion

This dissertation has explored the experiences of MPC regarding information related to radiotherapy, from the perspectives of the men who had undergone radiotherapy and given context by the inclusion of wives of the participants and therapeutic radiographers from one radiotherapy department.

Two central but latent themes which underpinned all other findings: communication and time. Findings were explored by consideration of how information needs and communication varied across three distinct time periods: pre-, peri- and post- radiotherapy. Across these time periods, eleven semantic subthemes were identified.

The study identified that TRs made assumptions about why patients did or did not take note of information and whose responsibility it was to ensure patients were informed and supported. Unmet informational needs were identified including the desire for more personalised or individualised information. Findings were consistent with previous literature but unique in exploring MPC experiences with a focus on information in radiotherapy. A strength of this study is the richness of context that was gained from aspects of each patient's cancer journey that preceded their radiotherapy. A model to explain the ecology of information related to radiotherapy for MPC is proposed on the basis of the findings. An important aspect of this study is that it has demonstrated how information related to radiotherapy is significant at all stages of the cancer journey for a man with prostate cancer and the experiences related to information that begin at diagnosis continue to impact long into the future.

In concluding this study, I would like to use the words of Adrian, a MPC, who said:

"it's not about the treatment really, it's about information"

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Appendices

Appendix 1 - Risk stratification of prostate cancer

Risk stratification for people with localised or locally advanced prostate cancer (National Institute for Health and Care Excellence (NICE), 2021a)

Cambridge Prognostic Group	Criteria
1	Gleason score 6 (grade group 1*) and prostate-specific antigen (PSA) less than 10 microgram/litre and Stages T1–T2
2	Gleason score 3 + 4 = 7 (grade group 2) or PSA 10 microgram/litre to 20 microgram/litre and Stages T1–T2
3	Gleason score 3 + 4 = 7 (grade group 2) and PSA 10 microgram/litre to 20 microgram/litre and Stages T1–T2 or Gleason 4 + 3 = 7 (grade group 3) and Stages T1–T2
4	One of: Gleason score 8 (grade group 4), PSA more than 20 microgram/litre, Stage T3
5	Two or more of: Gleason score 8 (grade group 4), PSA more than 20 microgram/litre, Stage T3 or Gleason score 9 to 10 (grade group 5) or Stage T4

* International Society of Urological Pathology Grade group as shown in the table below (Prostate Cancer Foundation, 2022):

Risk Group**	Grade Group	Gleason score
Low/Very Low	Grade Group 1	Gleason score ≤ 6
Intermediate (Favourable/Unfavourable)	Grade Group 2	Gleason score 7 (3 + 4)
	Grade Group 3	Gleason score 7 (4 + 3)
High/Very High	Grade Group 4	Gleason score 8
	Grade Group 5	Gleason score 9-10

**Risk Groups are defined by the Grade Group of the cancer and other measures, including PSA, clinical tumour stage (T stage), PSA density, and number of positive biopsy cores.

NB. High-risk localised prostate cancer is also included in the definition of locally advanced prostate cancer.

Appendix 2 – Overview of radiotherapy equipment and explanation of radiotherapy dose concepts

Image 1 - Truebeam™ linear accelerator used to deliver IMRT EBRT. Utilises high energy Xray photons for treatment of prostate cancer.



Image retrieved from <https://www.varian.com/products/radiotherapy/treatment-delivery/truebeam>

Image 2 – TomoTherapy™ : delivers EBRT in a helical pattern, simultaneously imaging the patient for more precise conformation of dose to the target.



Image retrieved from: <https://www.hhmglobal.com/knowledge-bank/news/studies-support-use-of-accuray-tomotherapy-system-for-advanced-rectal-cancer>

Image 3: Cyberknife™: A robotic system that delivers the radiation in hundreds of pencil-thin beams from multiple angles allowing for high levels of accuracy and conformity.



Image retrieved from: <https://www.itnonline.com/content/cyberknife-system-provides-long-term-disease-control-prostate-cancer-patients>

Image 4: HDR brachytherapy afterloading. Catheters are inserted transperineally using a template to guide the position. A guidewire with radioactive source at the distal end is inserted sequentially into each catheter remaining in place for a set amount of time before being moved to the next position. The timing and position of the source dictates the dose distribution.

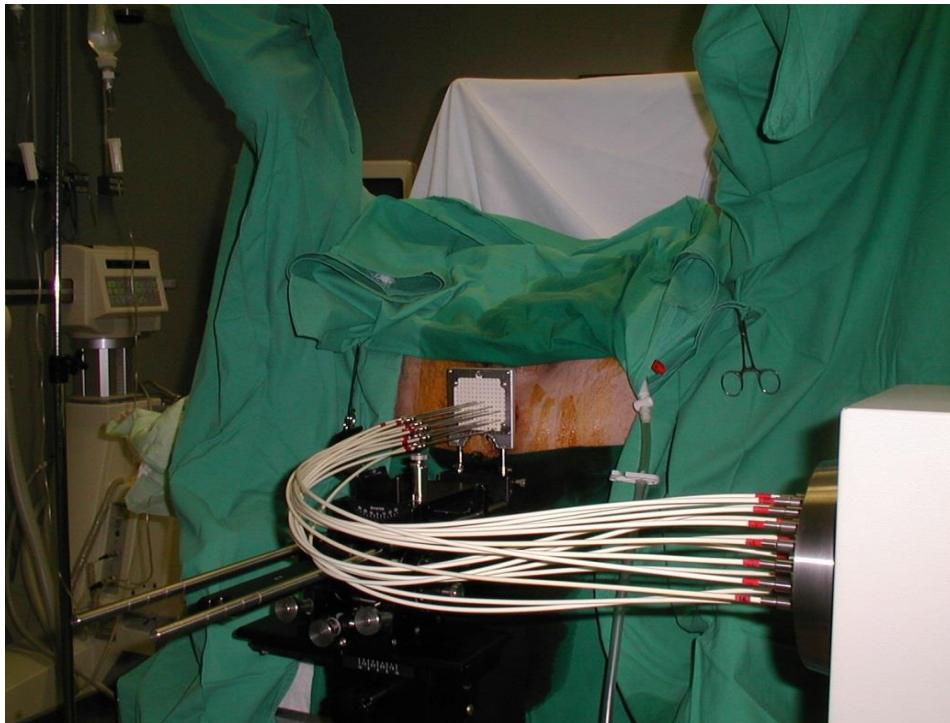
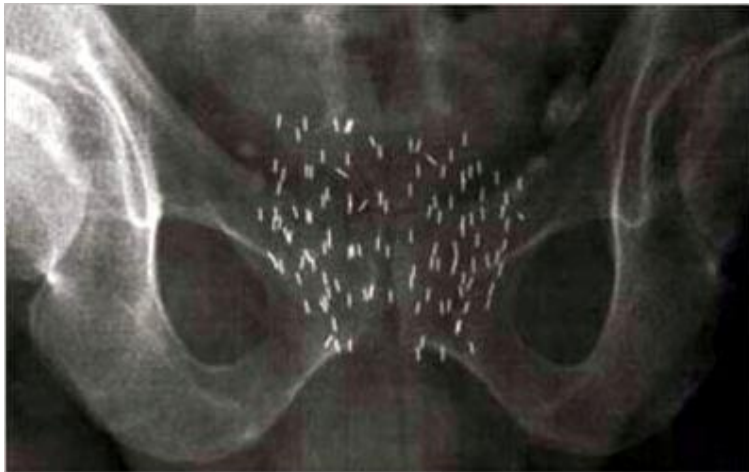


Image retrieved from: <https://www.intechopen.com/chapters/41799>

Images 5a and b: Permanent seed brachytherapy. A large bore needle is inserted through a template and transperineally into the prostate gland and each time it is triggered, a seed is deposited. Typically, 60-100 seeds are deposited evenly throughout the gland, with positioning guided by ultrasound. Image a) shows a radiograph of seeds in position and image b) shows the size of the seeds in comparison to a USA 1 cent coin.

a)



b)

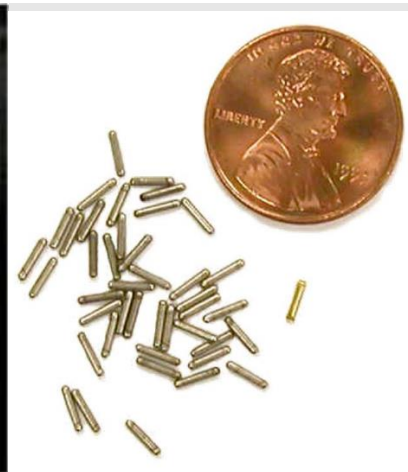


Image a) retrieved from: <https://sites.wustl.edu/m3inradmed/research/geneticalseeds/> Image b) retrieved from: <https://nrl.mit.edu/facilities/medical-isotope-irradiations>

Image 6 a and b: How volumes of irradiated tissue are defined from a geometric perspective. In radiotherapy the volume of tissue receiving a dose of radiation can be described in a number of different ways. The diagram below along with the definitions explain how the different volumes are defined according to reports 50 and 62 published by the International Commission on Radiation Units and Measurements (ICRU). These definitions are adhered to when any radiotherapy is planned.

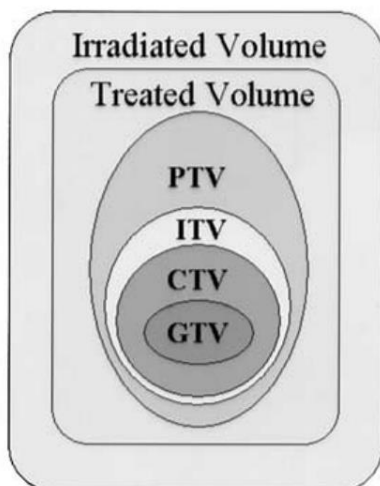


Image 6a source: Purdy (2004)

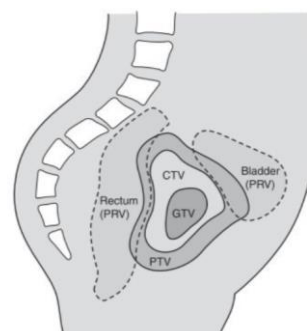


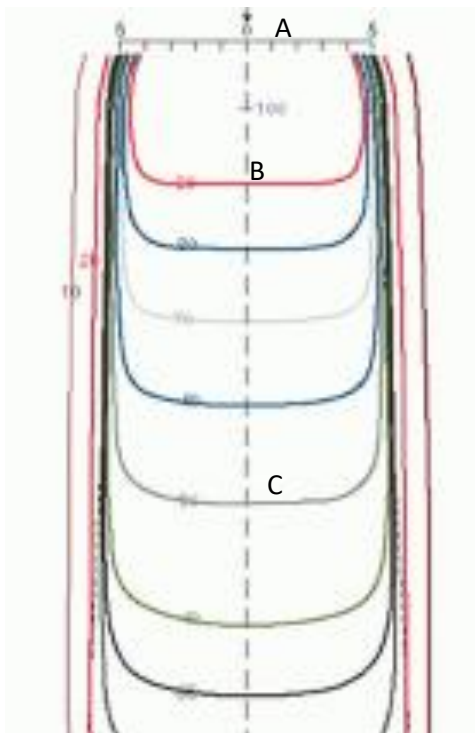
Fig. 10.2 Prostate showing clinical target volume (CTV), gross tumour volume (GTV), planning organs at risk volume (PRV), planning target volume (PTV), bladder and rectum.

Image 6b source: Symonds et al (2019)

Definitions related to image 6a taken from Symonds et al (2019) page 156 and Purdy (2004):

GTV	Gross tumour volume	the gross palpable or visible/demonstrable extent and location of the malignant growth
CTV	Clinical target volume	a tissue volume that contains a GTV and/or subclinical microscopic malignant disease, which has to be eliminated. This volume thus has to be treated adequately in order to achieve the aim of therapy: cure or palliation.
ITV	Internal target volume	Comprises the CTV plus an internal margin that takes account of variations in size, shape, and position of the CTV due to organ motion.
PTV	Planning target volume	a geometrical concept, defined to select appropriate beam size and beam arrangement, taking into consideration the net effect of all the possible geometrical variations and inaccuracies in order to ensure that the prescribed dose is actually absorbed in the CTV.
	Treated volume	the volume enclosed by an isodose surface, selected and specified by the radiation oncologist as being appropriate to achieve the purpose of treatment.
	Irradiated volume	the volume that receives a dose considered significant in relation to normal tissue tolerance

NB: an isodose surface is defined as any surface on which the percentage of radiation dose is the same. In the image below, the isodose chart shows several isodose surfaces for a single beam of radiation passing through a block of tissue of uniform density. Note that in Appendix 3 the dose distribution charts show the dose maps that are achieved by adding together several beams of radiation.

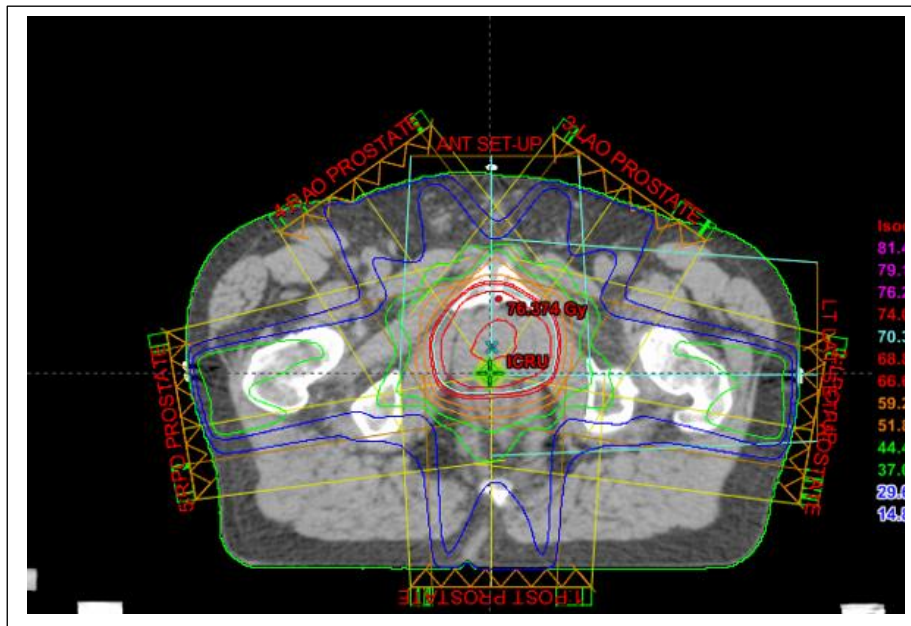


This isodose chart represents a beam of 10MV Xray photons applied as a 10 x 10cm beam where the target producing the beam is 100cm from the surface of a block of tissue (point A on the diagram). The red line (point B) indicates a dose surface where every point on that surface (or isodose line) measures at 95% of the dose delivered by the treatment unit. The reduction in dose as the beam travels through the block of tissue is due to absorption of some dose in the tissue. The dose along all points of the grey line (point C) measures 50% of the dose given at the surface.

Image source: <https://radiologykey.com/treatment-planning-i-isodose-distributions/>

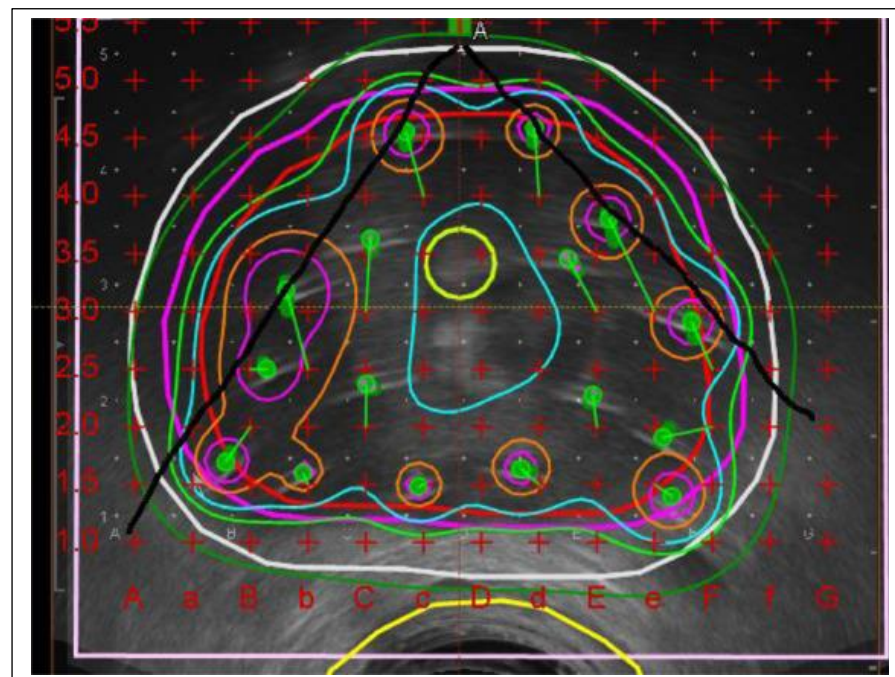
Appendix 3 – Example dose distributions for prostate radiotherapy

IMRT dose distribution



Source: University of Hertfordshire radiotherapy teaching materials

HDR brachytherapy dose distribution



Source: Crook et al. (2020)

Appendix 4 - (Gordon et al., 2019) Integrative review


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FEATURE AND REVIEW PAPER

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Information in radiotherapy for men with localised prostate cancer: An integrative review

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Abstract

Introduction: Men with prostate cancer may receive radiotherapy as part of their management. They encounter a range of information related to radiotherapy, and a crucial role for therapeutic radiographers and other healthcare practitioners is ensuring patients receive appropriate information related to their treatment. This integrative review aims to identify, synthesise and analyse literature reporting experiences of men with localised prostate cancer related to information in radiotherapy.

Methods: A systematic literature search encompassing database and hand searches was carried out between February and March 2017 with date limits of 2000–2017 applied. Initially, 4,954 articles were identified. Systematic screening and detailed examination identified that 33 met the inclusion criteria. Data were synthesised and analysed thematically.

Results: Few studies explicitly addressed the issue of information in radiotherapy for men with localised prostate cancer. Themes that emerged and were explored are information needs, information regarding adverse effects, information and time, information preferences, satisfaction with information related to radiotherapy and patient experience related to radiotherapy information.

Conclusion: This review suggests that although several aspects related to information for men with localised prostate cancer have been documented, few were explored in detail with respect to radiotherapy indicating that further research in this area is warranted.

KEYWORDS

information, integrative review, prostate cancer, radiation therapy, radiotherapy

1 | INTRODUCTION

Every year 30% of men diagnosed with prostate cancer (PC) receive radiotherapy as part of the management of their disease (Cancer Research UK, 2019). Radiotherapy for PC can be delivered in a variety of ways, dependent on the grade and extent of disease. External beam radiotherapy (EBRT) for PC prescribed with curative intent is normally delivered using intensity-modulated radiotherapy (IMRT) techniques. The 5-year findings of the

CHHiP (Conventional or Hypofractionated High Dose Intensity Modulated Radiotherapy for Prostate Cancer) trial demonstrated that hypofractionated radiotherapy delivered in 20 fractions was non-inferior to the conventional 37-fraction regimen when considering long-term outcomes (Dearnaley et al., 2016). Therefore, the shorter fractionation is now being accepted as the gold standard for patients whose disease is confined to the prostate gland. Some patients who have local extension outside the prostate capsule may still receive radiotherapy using the longer fractionation.

For patients with small, low-risk tumours, low-dose brachytherapy using permanent iodine 125 seed implants may be a more suitable radiotherapy approach. For those with intermediate- or high-grade disease, high-dose-rate (HDR) brachytherapy using removable radioactive sources in combination with EBRT may be a suitable option. Regardless of which radiotherapy approach is chosen, patients receive focussed information before, during and after their prescribed radiotherapy, which typically lasts for 4–7 weeks for EBRT and 1–4 days for HDR brachytherapy. Much of this information is given by therapeutic radiographers who in the UK are the key clinical practitioners delivering radiotherapy to men with PC, regularly exchanging information with patients regarding radiotherapy planning, treatment, side effects and post-treatment care, with other healthcare professionals (HCP) also being involved in information exchange from cancer diagnosis through to follow-up and beyond. The therapeutic radiographer's role in giving patients information during EBRT has been documented (Halkett & Kristjanson, 2007; Jenkins, Fallowfield, & Poole, 2001) with patients reporting the importance of being given information relating to technical aspects, the experience of radiotherapy and its side effects as providing reassurance. This core component of the therapeutic radiographer's role is outlined in the UK Radiography Standards of Proficiency (Health & Care Professions Council, 2013) but is common to radiographers and radiation technologists elsewhere in the international radiotherapy community (e.g., American society of radiologic technologists, 2017, Australian Institute of Radiography, 2013).

Information provision is explored in the literature widely with respect to PC management for both localised and disseminated disease, for example, regarding PC patient satisfaction with information, information needs, information for decision-making and the information gap. However, many of these papers focus on surgical or hormonal management and reference to radiotherapy is either minimal or absent (Boberg et al., 2003; Davies, Kinman, Thomas, & Bailey, 2008; Echlin & Rees, 2002; Posma, Weert, Jansen, & Bensing, 2009; Rutten, Arora, Bakos, Aziz, & Rowland, 2005; Snow et al., 2007). Much of the evidence refers to information for radiotherapy in passing, for example, findings are explored in comparison with other management methods or cancer types, or focus on satisfaction with information, using surveys with quality of life outcomes (e.g., Davies et al., 2008); this focus misses the valuable patient experience-based context. Thus, whilst it appears that there is a wide body of evidence and knowledge regarding information for men with PC who undergo radiotherapy, there are very few papers that explicitly explore this issue. We could identify

no reviews which specifically addressed the topic of information in radiotherapy for men treated curatively for localised or locally advanced PC. This paper therefore reports on an integrative review to ascertain the nature and extent of current knowledge related to the topic. The aim was to identify, synthesise and analyse literature reporting the experiences of men with PC related to information in radiotherapy. With this, we aim to provide evidence that might be useful in supporting the information dissemination practices of HCP involved in the care of men with PC undergoing radical radiotherapy.

2 | METHOD

The integrative review process was informed by the methodology of Whitemore and Knafelz (2005), following their five-stage framework of problem identification, literature search, data evaluation, data analysis and presentation. This type of review is particularly useful where inclusion of both qualitative and quantitative studies is required.

2.1 | Search strategy

A systematic search was carried out by LG during February and March 2017, structured using the SPIDER (Sample, Phenomena of Interest, Design, Evaluation, Research) tool (Cooke, Smith, & Booth, 2012) due to the inherent deficiencies of the PICO (Patient, Intervention, Comparator, Outcome) tool when retrieval of qualitative and mixed-methods literature is expected (see Table 1). The primary search question thus formulated was "What are the experiences of men with prostate cancer when receiving information related to a course of radiotherapy?".

Electronic bibliographic databases for PubMed, CINAHL plus, Cochrane library, Scopus and Science Direct were searched using combinations, synonyms and truncations of the following terms: "prostate cancer," "radiotherapy," "radiation therapy," "information" and "patient experience." A limit for publication date from the year 2000 onwards was applied to account for advances in conformal radiotherapy and any associated changes in radiation side effect profile that may have necessitated evolution of patient information. Animal and laboratory-based studies were excluded. A limit of English language was applied to reflect the authors' first language. Hand searches of individual journals (*Journal of Radiotherapy in Practice*, *Radiography*, *European Journal of Cancer Care*, *Psychooncology*) were carried out to find articles not identified in database searches.

Sample	Men with prostate cancer
Phenomena of Interest	Experiences of information related to a course of radiotherapy
Design	All designs and theoretical frameworks
Evaluation	Thematic content analysis
Research	All research (quantitative, qualitative, mixed method, review)

TABLE 1 SPIDER search strategy

Full-text articles were retrieved if they met one or more of the following inclusion criteria:

1. Prostate cancer/radiotherapy/information/experience mentioned in article title
2. Radiotherapy referred to as a management option
3. Reported on patient experience related to information in radiotherapy.

Government and professional documents, abstracts and dissertations were excluded as the intention of the review was to focus on primary, peer-reviewed evidence sources. At each stage of the search, the results were checked and verified by AD.

2.2 | Search outcome

The total number of papers returned from all database searches (after removal of duplicates) was 4,954 (see PRISMA diagram Figure 1). Titles and abstracts were screened for relevance with 4,849 papers excluded. This initial screening retrieved 105 full-text articles deemed suitable for closer examination. Individual journal searches returned a further 17 articles. A hand search of reference lists of these 122 articles resulted in identification of a further 43 articles, giving a total of 165 full-text articles that were then subject to detailed inspection. Articles were excluded from further review for the following reasons:

- No focus on radiotherapy and/or information and/or prostate cancer and/or patient experience
- Literature or narrative review of papers already retrieved as primary sources, of papers published before the year 2000, those written as essays
- First person narrative written by a patient
- News article
- Discussion paper

Following this final inspection, 33 papers were considered relevant and selected for inclusion in the review. The screening of articles was carried out by LG and independently verified by AD. There were no articles on which consensus was not reached.

2.3 | Quality assessment

According to Whittemore and Knaf (2005), a quality assessment process is more conducive to reviews where the research designs are similar or identical, but currently, there is no gold standard framework that enables a quality review of diverse sources. Therefore, the checklist provided by Bowling (2014) was used to assess the selection (see Table 2) and thus validity and reliability. Whilst a few papers exhibited flaws related to reporting of sampling and method, overall none were of poor enough quality to be excluded despite being ranked at a low level of evidence according to the traditional evidence

FIGURE 1 PRISMA flow chart for search process

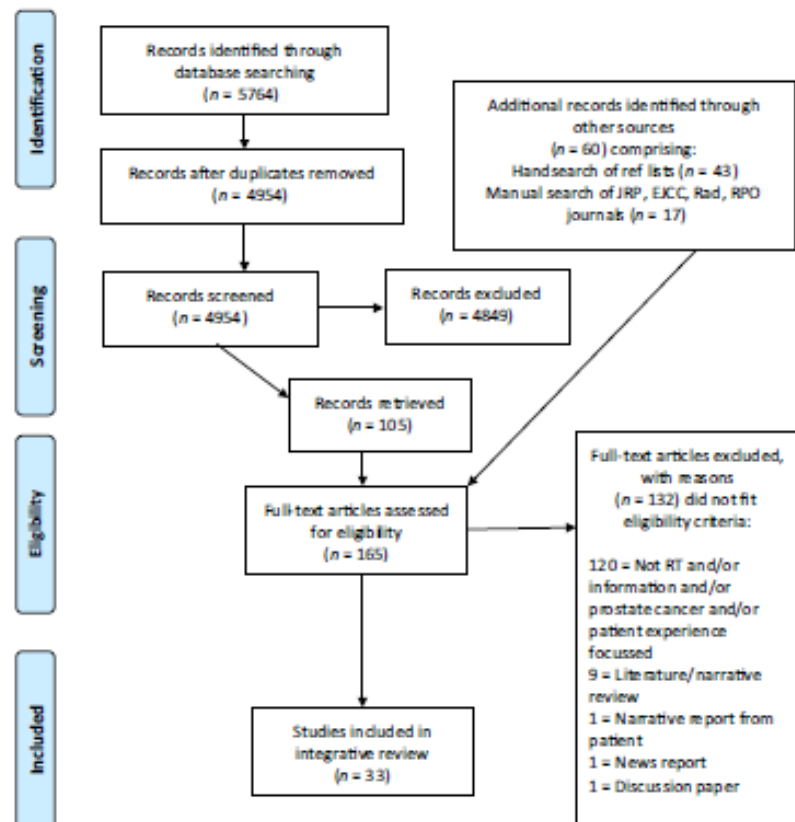


TABLE 2 Quality appraisal of studies utilising Bowling's checklist for critical appraisal of scientific literature (Bowling, 2014)

Appraisal Items	Adler et al. (2009)	Appleton et al. (2013)	Barnett et al. (2004)	Bennenbroek et al. (2005)	Blomberg et al. (2016)	Bolderston (2008)	Boulton et al. (2013)	Clarke and Burke (2016)	Dale et al. (2004)	D'Allmona et al. (2011)	Devton et al. (2002)	Dieperink et al. (2013)	D'haese et al. (2000)	Douma et al. (2012)	Dubois and Loizele (2008)
Clearly stated aims	✓	✓	✓	✓	✓	✓	✓	x	✓	✓	✓	✓	✓	✓	✓
Study design described	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Appropriate research methods	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Country of study	✓	✓	✓	✓	✓	✓	✓	x	✓	x	✓	✓	x	✓	✓
Date of study	✓	x	✓	x	x	x	x	x	x	x	✓	✓	x	x	✓
Site of study	✓	x	✓	✓	✓	✓	✓	x	✓	x	✓	✓	x	✓	✓
Sample size and coverage reported	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	x	✓	✓
Response rates/sample attribution stated	✓	x	✓	✓	x	✓	✓	n/a	✓	x	✓	✓	x	✓	✓
Sample characteristics given	✓	x	✓	✓	✓	✓	✓	x	✓	✓	✓	✓	✓	✓	✓
Theoretical framework	x	✓	x	x	✓	x	✓	✓	x	x	✓	✓	x	x	✓
Predictors and outcomes assessed	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	✓	n/a
Measurement tools with evidence of reliability and validity	x	n/a	✓	✓	n/a	✓	n/a	n/a	✓	✓	✓	n/a	x	✓	n/a
Outcomes/results/findings	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Generalisability considered	✓	✓	x	✓	x	✓	✓	x	✓	✓	x	✓	✓	x	x
Measurement tools with evidence of reliability and validity	x	n/a	✓	✓	n/a	✓	n/a	n/a	✓	✓	✓	n/a	x	✓	n/a
Outcomes/results/findings	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Generalisability considered	✓	✓	x	✓	x	✓	✓	x	✓	✓	x	✓	✓	x	x

pyramid (Offredy & Vickers, 2010). The final selection of 33 papers (reporting on 32 studies) was confirmed following evaluation of relevance to the review aims and the inclusion and exclusion criteria applied during the search process. During the search, data extraction and consideration of findings, the results were reviewed and verified independently by the second author to ensure quality and reliability.

2.4 | Data extraction and synthesis

A data charting form was developed in Microsoft Word. For each article, the following information was charted: authors, year of publication, location (country) and setting/context of the study, research design, sample characteristics and sizes, data collection/generation measures, study aims, summary of outcomes and key findings (see

Table 3). Data were then synthesised and are reported thematically to explore the issues related to men with PC experiences of information in radiotherapy.

3 | RESULTS

3.1 | Overview of article characteristics

Fourteen studies were carried out in the UK, five in mainland Europe, five in Scandinavia, five in Canada, three in the United States and one in Australia. Two papers reported findings from the same data set (Kelsey, Owens, & White, 2004; Owens, Kelsey, & White, 2003). Most studies were based on single centres with eight studies recruiting from two to four settings. One study recruited

Ehman et al. (2009)	Griffiths and Hodgson (2011)	Kazar et al. (2011)	Kelzay et al. (2004)	Lamers et al. (2016)	Lehto et al. (2015)	Long (2001)	Majumder et al. (2014)	Nanton et al. (2009)	Nicolizan et al. (2014)	Ormerod and Jessop (2015)	Owens et al. (2005)	Sinfield et al. (2008)	Stewart-Lord et al. (2016)	Subi-Suso et al. (2015)	Thavarajah et al. (2015)	Tomlinson et al. (2014)	Wolpin et al. (2016)
✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
x	x	x	x	✓	✓	x	✓	✓	✓	x	x	x	✓	x	x	✓	✓
✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	x	✓	✓	✓	✓	✓	✓	✓
✓	✓	✓	x	✓	✓	x	✓	✓	✓	x	x	✓	x	✓	✓	✓	✓
✓	✓	✓	x	✓	✓	✓	✓	✓	✓	x	x	✓	x	✓	✓	✓	✓
x	✓	x	x	x	x	✓	x	✓	x	✓	x	x	x	x	x	x	x
n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a
✓	✓	n/a	n/a	✓	✓	n/a	✓	n/a	✓	n/a	n/a	n/a	✓	✓	✓	✓	✓
✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
✓	✓	x	x	✓	x	✓	x	x	✓	x	x	✓	✓	x	x	x	✓
✓	✓	n/a	n/a	✓	✓	n/a	✓	n/a	✓	n/a	n/a	n/a	✓	✓	✓	✓	✓
✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
✓	✓	x	x	✓	x	✓	x	x	✓	x	x	✓	✓	x	x	x	✓

from 17 outpatient oncology clinics in the United States, and one study utilised national cancer registry data. Five studies reported sample sizes larger than $n = 500$: national cross-sectional survey-based studies carried out in the UK ($n = 24,101$), the Netherlands ($n = 697$) and Finland ($n = 1,239$); one American multisite longitudinal study ($n = 731$) and one Swedish single-centre, cross-sectional survey ($n = 656$). Thirteen studies used qualitative design with sample sizes ranging from $n = 9$ –58 participants. These encompassed cross-sectional qualitative ($n = 2$), qualitative framework ($n = 1$), qualitative descriptive ($n = 7$) and phenomenological ($n = 3$) designs. Nineteen quantitative studies comprised survey-based ($n = 12$), longitudinal ($n = 3$), pilot ($n = 2$), randomised ($n = 1$) and pre/post-test ($n = 1$) designs. The sole randomised study reported a randomisation process but was not controlled. There was one mixed-methods study

(sample $N = 117$). Twenty-one studies sampled only men with PC (and partners where applicable), and the rest sampled across a range of cancer diagnoses.

3.2 | Themes

3.2.1 | Information needs

Six papers explored patients' information needs (Bolderston, 2008, Dale, Jatsch, Hughes, Pearce, & Meystre, 2004, D'Alimonte et al., 2011, Douma, Koning, Zandbelt, Haes, & Smets, 2012, Thavarajah et al., 2015, Wolpin et al., 2016) with ten more mentioning information needs within the background, findings and/or discussion sections but without offering empirical information (Adler et al.

TABLE 3 Studies included in the integrative review according to authors, year and country, setting/context, design, sample, data collection/generation method, study aim/purpose and summary of outcomes/findings related to information/experiences

Authors, year, country	Setting/context	Design	Sample	Data collection/generation method	Study aim/purpose	Summary of outcomes/findings related to information/experiences
Adler et al. (2009) Germany	One RT centre	Cross-sectional observational	94 pt undergoing RT	Questionnaire	To evaluate the perception of cancer patients undergoing radiotherapy regarding the information received on different areas of the disease, diagnosis, treatment and care and the importance of different media, especially the Internet	72 pts responded. 74% moderately to v. satisfied with amount of information but 61% wanted more and 6% wanted less. 50% found information helpful and 6% not helpful; very satisfied patients had received more information than less satisfied. Most important media information types were brochures, television and Internet. Least important was self-support groups. 41% pts had obtained information from the Internet; 39% discussed Internet information with clinicians. High educational status, females and younger age were associated with higher rate of Internet use
Appleton et al. (2015) UK	One specialist cancer centre	Cross-sectional qualitative using constructivist grounded theory approach	Purposive sample of 27 men with PC receiving/curative RT	One individual, semi-structured interview (voicerecorded)	To explore how men receiving curative treatment managed their disease on a daily basis and what aided and hindered their Ability to adjust to events and occurrences throughout the PC pathway	4 main themes generated: the pathway to diagnosis; the diagnosis; the impact of PC; and its treatment on daily life and living with PC. Some differences in expectations regarding radiotherapy. Pts interviewed before RT voiced concerns about process and how they would feel during treatment. Those interviewed after RT had concerns about treatment side effects and living with PC in the long term
Barnett et al. (2004) UK	One cancer centre	Structured interview-based survey	All (n = 82) pts attending planning for RT within a 3-month period	Structured interview based on 3-point questionnaire	To determine the amount of information that patients felt they wanted to know about the adverse effects of radiotherapy at the time that they attended for treatment planning	No. of respondents was 82. 38 males, of which 16 were men with PC. Findings were not analysed with respect to diagnosis. 28% wanted to be informed if the risk of a side effect was as small as 0.1%, and 31% would only want to be informed if there was either a 50% or a 100% chance of a mild side effect occurring. For severe side effects, 44% wanted to be informed of a 0.1% risk, whereas 16% only wanted to be informed if the risk was either 50% or 100%. 40% had increasingly higher information requirements as the severity of the side effects increased. The information requirements of patients aged <60 years were greater for severe side effects. No association was detected between treatment intent and information requirements
Bennenbroek et al. (2003) Netherlands	Three RT departments	Cross-sectional survey	319 pts with breast, head and neck, PC about to receive curative RT	Pts allocated to one of three experimental groups (each with different audiotape allocated) or control group. All groups given the same questionnaire control: no tape	To examine whether information on different dimensions would indeed serve different goals, and thus yield different effects, by provided information on three potentially relevant comparison dimensions, namely procedures, emotions and coping	n = 226 agreed to participate; n = 61 were men with PC. Responses not reported according to diagnosis. Pts were very satisfied with information and found it interesting, sufficient and complete. 87% reported that there was no new information on the tapes. ANOVA revealed significant difference in understanding between the three tapes $F(2,163) = 3.59$ $p < 0.05$ mainly due to higher increase in understanding in the procedural tape group. Procedural and coping tapes increased understanding and knowledge of RT, self-efficacy and the feeling of validation of emotions

(Continues)

TABLE 3 (Continued)

Authors, year, country	Setting/context	Design	Sample	Data collection/generation method	Study aim/purpose	Summary of outcomes/findings related to information/experiences
Blomberg et al. (2016) Sweden	Two hospitals 1 rural, 1 urban	Qualitative framework approach	Stratified sampling of: men with PC having RT (n = 8) and oncology HCP (n = 10)	Individual semi-structured interviews (n = 3) and focus groups (n = 1) with patients and HCP (n = 3) plus scoping literature review of 26 articles	To map and describe symptoms and self-care from the perspective identified by (a) newly diagnosed pts with PC during and 6 months after RT alone or in combination with hormonal treatment, (b) healthcare professionals caring for these patients and (c) the literature	Scoping review identified 26 articles for inclusion. Qualitative content analysis of interview and focus group data combined with literature findings identified seven categories that were reported: urinary symptoms; bowel problems/pain; sexual/problems; fatigue; anxiety, depression and cognitive impairment; irregular symptoms). HCP were aware that pts needed information about intimacy and sexuality but pts reported information as mainly about potency. Pts reported incomplete information about symptoms and self-care and being unsure about information they did receive
Bolderston (2008) Canada	One urban cancer centre	Quantitative survey	77 radiation therapists and 324 RT pts (mixed diagnoses)	Self-administered questionnaires	Aims not stated; study hypothesis was that radiation therapists might be incorrect in their assessments of their patients' educational needs regarding what patients want to know and how they prefer to receive this information	183 pts responded (56%). 81 were male, 58 were having pelvic RT, but their diagnosis and gender were not reported. 42 radiation therapists responded (5.9%). Both patients and therapists ranked information on side effects highest in terms of what patients want to know. Pts also ranked what happens after RT is finished highly. The biggest difference in ranking was for if a pt can work during treatment (therapists ranked 3rd and patients ranked 14th) and for how RT works (therapists ranked 15th and pts ranked 4th). Pts and HCP reported one-to-one information sessions with HCP as the most popular way to receive information. This was twice as popular as receiving written information. Hypothesis not answered in findings
Boulton et al. (2015) UK	One RT department	Mixed-methods study paper reports the qualitative component undertaken using the framework approach	A maximum variation sample of 30 cancer survivors who had received RT from 418 who had returned a questionnaire	One-to-one semi-structured interviews	To explore participants' experiences of the long-term and late effects of pelvic radiotherapy and their views on and responses to information provided in relation to these	28 participants completed interviews of which five were men with PC. Data analysis generated two main themes each with three subthemes as follows: Main theme 1: response to what information was given; subthemes: values information, concerns about potential undesired consequences, encountered its limitations in meeting their support needs. Main theme 2: response to how information was given; subthemes: timing of information, the amount and context of information, unique value of experience-based information from other patients. Men with PC reported valuing information received as it relieved anxiety. Receiving too much detailed information was counter-productive, and there was relief that a booklet descriptor matched personal experience of side effects
Clarke and Burke (2016) UK	Not stated	Qualitative phenomenological approach.	13 men with PC undergoing radical RT	One-to-one semi-structured interviews	To ascertain men with PC perceptions of the quality of physical and emotional support they receive as standard during their course of RT	Data are reported numerically. Individual quotes not reported, instead percentage of participants reporting an issue are given. Main themes reported were as follows: happy with the support received; the waiting room "support group"; on-treatment review; information and support before treatment; and bowel and bladder preparation.

(Continues)

TABLE 3 (Continued)

Authors, year, country	Setting/context	Design	Sample	Data collection/generation method	Study aim/purpose	Summary of outcomes/findings related to information/experiences
Dale et al. (2004) UK	Seventeen hospital urology outpatient clinics	Mixed methods	Qualitative part: 21 urology clinics Quantitative part: 96 urology pts completed the scale/questionnaire	Focus group interviews to generate themes; scale prototype based on those themes	To report on the initial development of a scale tool which could provide HCP with a straightforward means of identifying patients' information needs	The themes that emerged from focus groups were as follows: (i) general information needs for patients with PC, including prostate function, and causes, types and stages of PC; (ii) disease monitoring and screening; (iii) treatment options, their benefits and complications; (iv) quality of life, sexuality and problems with self-management; (v) clinical deterioration and emergencies; (vi) access to information; and (vii) healthy lifestyle, nutrition and complementary medicine. Prototype scale comprised set of 20 items related to specific items of information, loosely or derived to reflect the major themes identified from the focus group study, each with four-point Likert scales
D'Alimonte et al. (2011) Canada	One cancer centre	Quantitative pilot study	10 men with PC purposively sampled	Closed format questionnaire	To explore post-prostatectomy men with PC informational needs and experiences going through the decision-making process of salvage or adjuvant RT	Results reported as modes for each of 11 4-point Likert-scale responses with correlations of Likert scores with individual demographic features also given. No correlation found between knowledge of PC and income or educational level. Oncologist and urologist opinions were reported as important factors in deciding to have RT
Davison et al. (2002) Canada	One cancer centre	Quantitative survey	convenience sample of 80 couples where one partner has PC diagnosis	Conceptual framework based on transactional model of stress and coping. Computerised questionnaire	To identify and compare information and decision preferences of men with PC and their partners at the time of diagnosis	92% of men prefer an active or collaborative role in decision-making with their physician. 51% wanted a collaborative role with their partner in decision-making versus 48.8% active. Preferred role in decision-making did not affect information preferences. Information preferences favoured combinations of prognosis, stage of disease, treatment options and side effects as being most important at time of diagnosis. Men ranked information on sexuality more important than partners. Main sources of information for men with PC were reported as talking to a friend or relative. Talking to someone with PC and information leaflets
Dieperink et al. (2013) Denmark	One cancer centre	Qualitative	17 PC survivors who had received RT and hormone therapy purposively sampled	Semi-structured focus group interviews	To explore patients' perspectives on treatment and participation in a rehabilitation programme. To explore the participants' thoughts and approach to spousal involvement in the rehabilitation process	13 patients participated in two focus groups. 1st main theme: treatment with radiotherapy and androgen deprivation therapy. Subthemes: "Like a working day" adverse effects, embracing life, masculinity and identity change, network. 2nd main theme: rehabilitation. Subthemes: meeting the professionals, to make an effort, to cope with everyday life. 3rd main theme: spousal involvement. Subtheme: coplayer or line player. Importance of having both oral and written information about adverse effects was highlighted. Patients felt they had to rely on information from HCP regarding prognosis after RT. Patients reported inconsistencies in information given by different groups of HCP

(Continues)

TABLE 3 (Continued)

Authors, year, country	Setting/context	Design	Sample	Data collection/ generation method	Study aim/purpose	Summary of outcomes/findings related to information/experiences
D'haese et al. (2000) Belgium	One RT department	Randomised repeated measures study	68 cancer pts referred for RT, randomised to either simultaneous or stepwise information timing groups	Anxiety measured using state-trait anxiety inventory	The importance of time sequence of provision of information on the anxiety and satisfaction of patients undergoing RT	<p>Pt satisfaction was defined as ability of an intervention to meet need and expectations of the pt related to timing and amount of written information. 27 patients completed evaluation at all three time points. Mean values of anxiety and satisfaction at three time points (T1, T2 and T3) reported.</p> <p>Significantly less anxiety at T1 when information was given stepwise rather than simultaneously. No difference at T3. RT was found to be an anxiety-provoking event.</p> <p>Satisfaction at T2 and T3 was high with a significant increase over time in the stepwise group ($p = 0.005$)</p>
Douma et al. (2012) Netherlands	One RT department	Prospective, longitudinal study	293 consecutive new cancer pts of nine oncologists and six trainees	Baseline questionnaire before 1st RT consultation; checklist immediately following consultations; questionnaire 1 week before follow-up appt	Aim to gain understanding of how patients' information needs change from visit to visit in order to better tailor information giving	<p>159 pts agreed to participate, and 154 completed the base line questionnaire. 104 also complete the follow-up questionnaire. 62 were male. 30 had urological cancers (across both sexes) of which some were men with PC, but the actual number was not specified.</p> <p>Information needs decreased significantly over time in all domains except psychosocial issues (still a decline but not significant). Highest need was for information about side effects at both baseline and follow-up.</p> <p>Being male was significantly associated with decreased information needs about procedures and expected side effects. Lower health literacy was significantly associated with a decreased need for information about treatment</p>
Dubois and Loiselle (2008) Canada	One urban teaching hospital	Qualitative descriptive	Planned sample size of 10 breast cancer and 10 PC pts purposively sampled	Face-to-face semi-structured individual interviews	Explore the perceived role of informational support in relation to the use of healthcare services among women and men newly diagnosed with cancer	<p>Three main experiences emerged: 1. a positive experience with informational support to guide service use; 2. an unsupportive experience with informational support to guide service use; and 3. a mixed experience with informational support although tolerated was less than optimal in guiding service use.</p> <p>Examples given are as follows: men tended to normalise their cancer situation through reliance on literature provided routinely by staff. When participants received information they had not expected or did not understand, they experienced anxiety. Some participants reported that they had received contradictory information from healthcare professionals at different stages</p>

(Continues)

TABLE 3 (Continued)

Authors, year, country	Setting/context	Design	Sample	Data collection/ generation method	Study aim/purpose	Summary of outcomes/findings related to information/experiences
Eheman et al. (2009) USA	Seventeen outpatient oncology clinics	Longitudinal study	1,004 cancer patients prescribed chemotherapy or RT	Three self-administered surveys at 2 weeks before, 2 weeks after and 6 months after treatment	Examined information-seeking preferences in relation to demographic characteristics and cancer type among men and women who responded to the questionnaires before and after they underwent chemotherapy or radiotherapy	Analysis restricted to participants for whom data about information-seeking style were available in both time periods. 731 pts completed both pre- and post-treatment questionnaires. 128 were men with genitourinary cancers. At pre-treatment, 86% were active or moderately active information seekers. Participants in professional or managerial occupations showed higher levels of active or moderate seeking behaviours than those in technical or clerical jobs. Men with genitourinary cancers were more likely to actively seek information than those with other types. At post-treatment, more patients were passive information seekers than in the pre-treatment period. Married patients were less likely to be passive
Griffiths and Hodgson (2011) UK	One RT Centre	Quant: pre-post-test design	56 TR and assistants	Questionnaire administered pre- and post-education intervention	To measure the attitudes and beliefs of radiotherapists and assistants both before and after an educational intervention, to ascertain whether education in sexuality improves their attitudes and beliefs and ultimately their confidence in meeting their obligatory and supportive role to patients with PC	49 participants responded. Prior to the education intervention, 85% did not recall receiving any professional education about patient sexuality. 74% reported that they did not provide patients with sexuality information. Understanding about how PC might affect patient sexuality correlated with confidence in ability to address concerns. In turn, this is correlated with making time to give information and referring back to the consultant for more information. Overall, lack of knowledge and education were the main barriers to giving sexuality information
Kazer et al. (2011) USA	Multisite	Qualitative	53 unpartnered PC survivors who had previously participated in a longitudinal study	Semi-structured qualitative interview	To explore how men without partners manage a PC illness	26 men with PC agreed to participate. The study target was 20. Analysis began after 17th interview and indicated that data saturation had been reached so further recruitment was halted. Themes reported: 1. going it alone; 2. diagnosis and PC treatment decision-making; subtheme 2a: effects of the PSA blood test; subtheme 2b: role of the healthcare team; 3. sources of information and support; 4. the aftermath of PC treatment; 5. coping strategies; subtheme 5a: positive attitudes; subtheme 5b: confidence in healthcare team. Under theme, three participants reported books, the Internet and family as frequent sources of information. Experiences of Internet sources were mixed. Two participants reported attending support groups

(Continues)

TABLE 3 (Continued)

Authors, year, country	Setting/context	Design	Sample	Data collection/generation method	Study aim/purpose	Summary of outcomes/findings related to information/experiences
Kelsey et al. (2004) UK	One cancer centre	Qualitative	Purposive sampling of men with PC who had completed either brachytherapy (n = 10) or EBRT (n = 17)	Semi-structured focus group interviews	To explore men's experiences of radiotherapy for PC; to consider if current services meet the needs of these men	<p>Themes reported:</p> <ol style="list-style-type: none"> the journey to diagnosis; 2. a satisfactory choice; 3. experiences of radiotherapy; 4. support encountered; and 5. dealing with the future. <p>Men reported wanting more realistic information about the biopsy. Confirmation of diagnosis led to more information gathering activity, but the information found could be unhelpful and overwhelming. Men who had received brachytherapy seemed more informed and proactive.</p> <p>Gaining information alleviated anxiety and men desired straightforward information with regard to progress and long-term outcomes</p>
Lammers et al. (2016) Netherlands	A national cancer registry	Cross-sectional survey	Random sampling of 1,053 patients diagnosed with PC listed in the cancer registry	Questionnaire	To determine the satisfaction with information received by PC survivors and associations with health-related quality of life (HRQOL) and illness perception	697 men with PC responded to the invitation to complete the questionnaire. 34% reported dissatisfaction with information provision and 27% reported wanting to receive more information. Information was found helpful by 72% lowest satisfaction (63% was regarding information provision for EBRT
Lehto et al. (2015) Finland	National	Cross-sectional survey	1723 men with PC (taken from a 50% population sample)	Questionnaire	To investigate the experiences and psychological well-being of a population-based sample of PC patients of all ages who received any of the current treatment types (prostatectomy, external beam radiation, brachytherapy, surveillance)	<p>1,239 patients completed the questionnaire.</p> <p>Patients more often informed of diagnosis in an impersonal way (telephone or letter) when intended treatment was prostatectomy or brachytherapy. More often informed by the doctor during an appointment when intended treatment was hormone therapy. Most common reason for dissatisfaction with learning about their diagnosis was that they found out in an impersonal way (35%). Other reasons for dissatisfaction included the doctor's behaviour and communication (15%), crudeness (5%), timing/place/situation of the information (5%), insufficient information (9%), delay in scheduling medical examinations (8%) and too little time available (8%).</p> <p>Half of pts were fully satisfied with information received about radiotherapy. Poorer well-being was associated with insufficient information.</p>

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TABLE 3 (Continued)

Authors, year, country	Setting/context	Design	Sample	Data collection/generation method	Study aim/purpose	Summary of outcomes/findings related to information/experiences
Long (2001) Australia	One cancer centre	Qualitative hermeneutic phenomenological approach	20 pts undergoing RT for cancer or benign tumours	Unstructured individual interviews	To give insight into the experience of an intensive course of radiation therapy and relate the findings to the nurses working with individuals receiving radiation therapy. The purpose of this article was to describe and interpret the experiences of individuals undergoing radiation therapy in the cancer centre of a large teaching hospital (NB aims only present in abstract)	Data saturation reported as occurring at 17th participant and 51 interviews, but other 3 had already been recruited so remained in the study. Final number of interviews not stated. The main theme that emerged from this study was "Being informed," with subthemes of being supported, everydayness and regaining a sense of self (patient to person). Information enabled individuals to have more sense of being in control. Some reported confusion caused by mixed messages from HCP, especially related to decision-making. Information was a significant factor in coping with treatment. Many had pre-formed ideas related to inadequate or misleading information, and these were not satisfactorily addressed by HCP. Type and level of information did not meet the needs of some patients, and timing of information was crucial. Some reported problems in the way HCP present information and respond to questions. This relates to staff demeanour
Majumder et al. (2014) Sweden	One oncology department	Cross-sectional survey	640 men with PC	Questionnaire	To compare patients after RP + salvage RT with those who underwent curative RT alone with respect to their perception of received information and satisfaction with that information	606 participants complete the questionnaire fully. Mean score for satisfaction with information was 62 (on a scale of 1–100). Younger patients reported receiving more information about other treatments as compared to younger patients. Patients receiving curative RT were more satisfied with all elements of information and received more information when compared to the salvage RT group
Nanton et al. (2009) UK	Two hospitals and one PC support group	2 phase, qualitative cross-sectional design with constructionist perspective	Phase 1: 26 pts randomly sampled from urology clinic register (UCR) and 26 attending a local support group approached Phase 2: 64 randomly sampled from UCR	Semi-structured focus group discussions and individual interviews	To explore the experience of uncertainty at different stages of the disease trajectory and to investigate the interrelationship of information, problem-solving and cognitive reframing in mediating its effects in relation to the personal patient journey	58 men with PC participated: 40 in phase 1 and 18 in phase 2 in a total of seven focus groups and 22 individual interviews. Broad themes relating to "information" and "uncertainty" and the "patient journey" were identified. Men with PC reported difficulty in absorbing information due to the shock of the diagnosis. Having a point of contact at the hospital was seen as almost more important than the information they might get from that content. There was mixed opinion regarding amount of detail in information; some required basic facts, others purposefully sought more detail. Timing of information between having tests done and the next appointment. Some noted a lack of information on responsibility of care and the impact this had on stress and confusion. There was a lack of information on the extent and persistence of major side effects. Social support was an important source of information

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TABLE 3 (Continued)

Authors, year, country	Setting/context	Design	Sample	Data collection/generation method	Study aim/purpose	Summary of outcomes/findings related to information/experiences
Nicolaisen et al. (2014) Norway	One hospital	Cross-sectional survey design	176 men with PC who had undergone either RP (n = 65) or radical EBRT (n = 111)	Mailed questionnaires	The aims of this study were thus to compare long-term quality-of-life (QOL) outcomes and satisfaction with information received from health care, three to four years after RP, REBRT and post-op EBRT, and to analyse to what extent disease-specific QOL, health-related QOL and satisfaction with information affect overall QOL	143 participants returned questionnaires. Men with PC who had RP reported higher satisfaction with information than those who had EBRT. Patients with impaired general QOL and urinary function who were not treated with surgery alone reported lower scores for satisfaction with information
Ormerod and Jessop (2015) UK	One RT department	Qualitative phenomenological approach	Convenience sample of all men with PC completing RT within 1 calendar month (actual figure not stated). 2 TR purposively sampled	Individual semi-structured interviews	To investigate both patients and staff perceptions of on-treatment review clinics in meeting patients' needs during and at the completion of radiotherapy treatment	Seven men with PC accepted interviews. 2 themes of information giving and clinical assessment of symptoms emerged. Information in all forms emerged as the most important theme related to review clinics. TR reported concerns that pts do not take in information at the start of treatment; therefore, repetition is required, and consistent information is needed. Some pts reported a lack of information prior to the planning appointment which caused anxiety. Most were satisfied with information given during and at the end of treatment. Family and peer support were important in accessing and understanding information. Specialist staff were an important source of information
Owens et al. (2003) UK	One hospital	Descriptive qualitative approach	17 men with PC recently completing EBRT purposively sampled.	Semi-structured focus group interviews	To explore the experiences of men with PC as part of a needs-based analysis into the services offered to men undergoing brachytherapy and external beam radiotherapy	Data saturation was achieved after 3 focus groups involving 17 participants so further recruitment was halted. The four emergent themes were as follows: 1. making decisions and feeling prepared and informed; 2. the experience of having radiotherapy; 3. side effects of treatment; and 4. sources of support. The amount and factual content of information was seen as hugely important by most men when deciding to choose RT. Most men said seeking good information was difficult. The role of the doctor with whom they discussed their treatment options was repeatedly a source of frustration, with the background of the doctor influencing the conversation and the speed at which they were expected to make a decision, often on little information was a source of anxiety. Lack of written information was commonly reported. Some received conflicting information from HCP. Family support was important

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TABLE 3 (Continued)

Authors, year, country	Setting/context	Design	Sample	Data collection/generation method	Study aim/purpose	Summary of outcomes/findings related to information/experiences
Sirfield et al. (2008) UK	Two hospitals in the East Midlands	Qualitative	Purposive sampling of men with PC on one hospital's pt register and from urology outpatient clinics. Partners were also invited	Semi-structured interviews	To identify the aspects of care patients and their partners report as important	35 Patients and 10 female partners interviewed. Not stated if this was dyad or individual interviews. Results presented under the following themes: 1. experiences of information provision and communication; 2. patients' experiences of making decisions; and 3. experiences of partners. Only 1 patient reported being given written information related to PSA test and diagnosis. Problems were reported with information provision and communication in secondary care: pts were unprepared for the biopsy procedure. Inconsistent and poor communication from consultants was highlighted. And some were unaware they were being tested for PC. Shock of diagnosis impacted on ability to take in information. Some reported contradictory information and lack of information on treatment arrangements and dealing with incontinence. Urology nurse was important in providing information not given by consultants. Partners found written information useful but that their own information needs were often unmet
Stewart-Lord et al. (2016) UK	One RT department	Cross-sectional survey	Total population sample of men with PC referred for EBRT within a 6-month period (n = 40)	Survey following attendance at a VERT session	To explore the prostate patients' perceptions of Virtual Environment for Radiotherapy Training (VERT) as an information giving resource prior to radiotherapy delivery	Overall response rate was 38 men with PC. 97% reported high levels of satisfaction with VERT as an information giving tool that adequately prepared them for treatment. HCP were also rated highly as sources of information. Information on treatment preparation received during the VERT session was important as was information about bladder and bowel preparation
Sulé-Suso et al. (2015) UK	One cancer centre	Quantitative pilot study	152 cancer pts prescribed radical RT. Sampling strategy not reported	Pt viewed their own CT data using VERT. Then completed questionnaire at home	To understand the needs of patients from planning of RT up to treatment delivery and to assess whether using VERT increases patients and relatives' knowledge of RT planning and delivery	104 patients participated of which 90 were men with PC. All cited better understanding as a result of the VERT session. Procedural information in particular was greatly improved. General comments only were reported, with no detailed descriptive statistics available
Thavarajah et al. (2015) Canada	One cancer centre	Cross-sectional survey	40 men with PC referred for RT purposively sampled	Questionnaire survey	To investigate patient opinions regarding the questions that should be discussed between healthcare professionals and post-prostatectomy patients who may require radiation therapy with a curative or salvage intent	31 completed the survey. Participants were asked to rate 74 questions about PC and radiotherapy in terms of their importance. The most important topics were those about prognosis, cancer spread and chance of cure, and others related to understanding their diagnosis. The least important questions were regarding parking, becoming radioactive and asking about a specific type of scan. Other concerns noted were regarding side effects of treatment and further testing after receiving RT.

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TABLE 3 (Continued)

Authors, year, country	Setting/context	Design	Sample	Data collection/generation method	Study aim/purpose	Summary of outcomes/findings related to information/experiences
Tomlinson et al. (2014) UK	National	Quant survey	Population sample of all adult cancer pts from 50 RT departments	Questionnaire survey	To obtain a meaningful picture about patient experience across the 50 radiotherapy centres within NHS trusts within England, and to understand patients' views about this experience, at every step from referral to follow-up across the radiotherapy pathway	Study aimed to receive 500 responses per department. 24,101 individual returns from a total of 49 departments were received. Data on diagnoses were not reported. 13 questions on the survey were specifically about information. (97%) said that the amount of information given to them before their radiotherapy was either excellent or satisfactory. 80% found attending an information session before starting treatment useful; however, 16% were not invited to one. 35% did not respond to questions about reading information on cancer charity websites. 30% looked at website for information. Of those who did not look at websites, 44% said they did not need to and 28% did not want to. 98% found the overall amount of information at the beginning of treatment was excellent or satisfactory. 9.5% were given information on side effect management. 23% were not given written information about what to expect after treatment had finished. 75% were given information about support groups
Wolpin et al. (2014) USA	One RT department	Longitudinal repeated measures pilot study	Convenience sampling of 35 pts with stage I–III prostate cancer	Survey at 2, 4, 6 wks of RT trt	To describe how information needs change over the course of receiving radiation therapy for PC	28 patients completed the first assessment; 6 patients completed all four survey time points. Information on treatment options and prognosis was highest priority at all four time points although information on treatment options became less important over time. Information on family risk became more important as time went on, and information on side effects became less important. Overall, information priorities shift over time

Abbreviations: pt or pts, patient/patients; RT, radiotherapy; men with PC, men with prostate cancer; HCP, healthcare practitioner; EBRT, external beam radiotherapy; RP, radical prostatectomy; TR, therapeutic radiographer.

2009, Boulton et al., 2015, Dubois & Loisel, 2008, Ehemann et al., 2009, Long, 2001, Majumder, Brandberg, Johansson, Nilsson, & Bergenmar, 2014, Nanton, Docherty, Meystre, & Dale, 2009, Owens et al., 2003, Sinfield, Baker, Agarwal, & Tarrant, 2008, Tomlinson, Samuels, Murphy, James, & Beardmore, 2014).

The survey-based pilot study by D'Alimonte et al. (2011) explored the information needs of ten men with PC who had undergone prostatectomy at one cancer centre and were deciding whether to receive radiotherapy, and the social determinants affecting those needs. They found some knowledge gaps about radiotherapy side effects related to a lack of information. No correlation was found with the social determinants explored.

Two papers explored patients' changing information needs over time. In a longitudinal, patient preference study of 104 patients with a range of cancer diagnoses, Douma et al. (2012) reported that information needs decreased over time albeit remaining high. Findings for men with PC were not reported separately; however, being male was statistically significantly associated with a decrease in information needs over time regarding procedures ($p = 0.01$, $exp\ b = 0.28$, 95% CI = 0.10–0.76) but not regarding levels of health literacy or levels of anxiety. In another longitudinal study, Wolpin et al. (2016) explored changing information needs over time for 35 men with PC. Findings were reported in terms of information priorities rather than information needs, with patients asked to rank a selection of information topics. Information on prognosis became more important as treatment progressed, whereas information on side effects and treatment options became less important suggesting that priorities can shift as treatment progresses through to the follow-up period.

Dale et al. (2004) reported on the design and piloting of a scale used to assess the importance of specific items of information needed by men with PC. The scale was developed through a series of focus groups and interviews with urology staff and patients. The scale was piloted on 96 patients recruited from 17 different urology clinics. The highest rated need for information was regarding disease management; by inference, this includes information on radiotherapy. It should be noted that 66% of patients in the study were receiving palliative management of PC where information needs are different to patients undergoing curative treatment.

Bolderston (2008) used a Likert-scale survey to investigate education and information needs specific to radiotherapy for a range of cancers, comparing 183 patient and 42 radiation therapists' rankings regarding what patients want to know. Findings demonstrated that both groups ranked information needs about side effects highest. This contrasts with Thavarajah et al. (2015) who reported low ratings for information needs about side effects in their study of 31 men with PC in a follow-up to the D'Alimonte et al. (2011) study. The earlier study had focussed on the development of a scale tool, and Thavarajah et al. (2015) surveyed men with PC regarding the importance of questions contained in the scale. The low rating for information needs relating to side effects is interesting, considering that 68% of patients were either receiving or had received radiotherapy at the time of completing the survey.

3.2.2 | Information regarding adverse (side) effects

Two studies focussed on views of participants regarding information on side effects of radiotherapy (Barnett, Charman, Sizer, & Murray, 2004; Boulton et al., 2015). Barnett et al. (2004) surveyed 82 cancer patients with a range of diagnoses about the amount of information patients should be given on the risk of developing certain side effects. Only 16 of the participants were men with PC. Results were not reported according to cancer type, and the main finding suggested that information requirements of younger patients tended to be greater; however, it cannot be assumed that older patients need less information. The need for information on severity of side effects varied considerably, so the authors concluded that an individualised approach to information is required. Boulton et al. (2015) similarly concluded that patients need individually tailored or personally contextualised information on side effects. In their qualitative study using a framework approach, they interviewed 28 participants with a range of diagnoses who were between one and eleven years post-radiotherapy, about information on long-term side effects. Five participants were men with PC. Subsequent analysis of interview data identified two main themes: response to what information was given and response to how information was given. These themes were further subdivided to aid reporting and findings. Verbatim comments were reported for four men with PC. Some valued the information received as it relieved anxiety; however, others reported that receiving too much detailed information could be counter-productive as it was scary and created anxiety. One participant felt relieved that a booklet description matched his personal experience of side effects.

Two further studies noted information on side effects as being of high importance. Fifty-eight of 183 patients surveyed by Bolderston (2008) received radiotherapy to the pelvis, some of whom might have been men with PC. Information on side effect management was ranked most important of 12 topics by both patient and radiation therapist participants (scores of 3.61 and 3.98 respectively). Davison et al. (2002) reported information on side effects as being the fourth most important topic in their survey of 80 men with PC and their partners to assess decision-making and information preferences at diagnosis. At the point of diagnosis, information on prognosis was the most important topic suggesting that when patients choose treatment with radiotherapy, information on side effects becomes more significant.

The remaining ten papers mentioned side effects only briefly and did not report empirical findings related to information on side effects (Clarke & Burke, 2016; Dubois & Loisel, 2008; Ehemann et al., 2009; Kelsey et al., 2004; Lehto, Helander, Taari, & Aromaa, 2015; Nicolaisen, Muller, Patel, & Hanssen, 2014; Ormerod & Jessop, 2015; Owens et al., 2003; Sulé-Suso et al., 2015; Tomlinson et al., 2014).

3.2.3 | Information and time

The temporal nature of information is reflected in two areas: timeliness of information and time constraints.

Four papers reported the importance of timely information (Appleton et al., 2015; Boulton et al., 2015; D'haese et al., 2000; Long, 2001). In a cross-sectional qualitative study, Appleton et al. (2015) interviewed 27 men with PC before, during and after radiotherapy, noting that the nature of information and the timeliness in which it was received from HCP were factors contributing to the impact of PC on daily life and effective treatment decision-making. Similarly, the qualitative study by Boulton et al. (2015) reported that timing of information impacted on decision-making and participants' understanding of side effects. In a phenomenological qualitative study, Long (2001) interviewed 20 participants about their experiences of undergoing radiotherapy. Findings indicate that timing of information was crucial in allaying anxieties and was related to the pre-formed ideas patients had about radiotherapy. Long (2001) also reported some dissatisfaction with timing of information, with some being given later than would have been helpful. These issues are echoed in the randomised, repeated measures study by D'haese et al. (2000) where the impact of time sequence in provision of information on levels of anxiety and satisfaction was noted. Patients given two formats of information simultaneously at the initial consultation were significantly more anxious than those receiving the same information sequentially ($p = 0.02$). However, the difference between groups had disappeared by the end of treatment. In five further studies, no empirical findings were generated; however, timeliness was variously noted as being associated with provision of supportive information (Blomberg et al., 2016; Tomlinson et al., 2014), impact on patient support (Clarke & Burke, 2016), impact on decision-making (Thavarajah et al., 2015) and contributing to satisfaction with information (Lehto et al., 2015).

Time constraint was mentioned in three papers as a reason for information quality being suboptimal (Griffiths & Hodgson, 2011; Lehto et al., 2015; Long, 2001). Griffiths and Hodgson (2011) investigated the attitudes and beliefs of 49 therapeutic radiographers and assistants before and after an educational intervention about information on sexuality for men with PC. The pre-intervention findings identified lack of time as the fourth most common reason for not giving patients information on sexuality. A statistically significant, moderate correlation was found between staff confidence in addressing sexual concerns and making time to give sexual information ($r = 0.453, p < 0.01$). The issue of time constraints was also implicated by 8% of 1,239 men with PC responding to the Lehto et al. (2015) survey of patient experiences, where they reported dissatisfaction with how they learned of their diagnosis. However, 82% expressed satisfaction with the amount of time given by doctors at their first radiotherapy appointment, higher than for other treatment modalities. Whilst this latter point may not be about information per se, consultations are normally designed around information exchange, suggesting that patients are very aware of time constraints of HCP. In the qualitative study by Long (2001), the issue of time constraints was noted in an emergent theme labelled "Staff demeanour" (p. 466). Two participants described frustrations at not being able to get the information they desired due to time constraints of doctors.

3.2.4 | Information preferences

Three studies reported findings related to information preferences. Davison et al. (2002) assessed information and decision-making preferences of 80 men with PC and their partners. Patients ranked the importance of nine categories related to aspects of their diagnosis and management, in terms of proximity to their personal information preferences. Information on prognosis, stage of disease, treatment options and side effects were the top four rated preferences at time of diagnosis by both men and their partners. Preference for information on sexuality was rated higher by men than their partners and was higher in younger age groups. However, these preferences might not be maintained across the disease and management trajectory. In Douma's study of 104 cancer patients, 30 had urological cancers; however, this included male and female patients and the number of men with PC was not reported (Douma et al., 2012). The study was difficult to analyse with respect to preferences as the aim and findings were reported in terms of information needs despite the questionnaire exploring preference. Dubois and Loiseau (2008) carried out a descriptive qualitative study exploring the role of informational support. They interviewed 20 patients of which ten were men with PC. They noted one point related to preferences: that women appeared to prefer verbal information over written, with the converse being seen with male patients. No explanation for this was given, and although other studies (e.g., Adler et al., 2009; Kazer et al., 2011) mention information format in findings and/or discussions, none indicate preferences.

Other papers concluded that taking account of patients' information preferences is important but did not present empirical evidence or explore this topic further (Bolderston, 2008; Boulton et al., 2015; Dale et al., 2004; Kelsey et al., 2004; Owens et al., 2003; Sinfield et al., 2008).

3.2.5 | Satisfaction with information related to radiotherapy

Satisfaction with information was reported in six studies (Adler et al., 2009; Douma et al., 2012; Lamers et al., 2016; Majumder et al., 2014; Nicolaisen et al., 2014; Tomlinson et al., 2014). Adler et al. (2009) surveyed 72 cancer patients receiving radiotherapy (six of whom had PC) in a cross-sectional pilot study. Results were not reported according to cancer type. 74% of patients were moderately to very satisfied with the amount of information provided about medical issues although 61% wanted more. Interestingly, very satisfied patients had received more information than those less satisfied, but reasons for this discrepancy were not determined. A cross-sectional study involving 697 men with PC by Lamers et al. (2016) reported on data collected in the Netherlands in 2011, with the study focussing on cancer survivors, rather than patients undergoing active treatment. 34% of participants reported dissatisfaction with information provision, but the nature of information was found to be helpful by 72%. Satisfaction for patients who had received EBRT was 63% but interestingly much higher at 78% for brachytherapy patients although

there was no statistically significant difference between the groups. The latter figure may reflect the specialised nature of brachytherapy, which may require more focussed processes for consent and information giving due to the surgical procedures involved. Other findings demonstrated a statistically significant difference in satisfaction with information between high, medium and low educational levels ($p = 0.002$) and a statistically significant positive association between satisfaction with information provision and emotional, social, physical and role functioning, and global health indicating that personal characteristics should be considered when providing information.

Studies by Majumder et al. (2014) and Lamers et al. (2016) are similar in that they used the same data collection instruments (EORTC QLQ-C30 and EORTC-INFO25 questionnaires designed to elicit information on quality of life and information preferences) and surveyed a similar number of men with PC ($n = 656$ vs. $n = 688$). Majumder et al. (2014) focussed on men with PC treated with radiotherapy and Lamers et al. (2016) on men with PC who had received any treatment type. There was broad agreement in the study findings with the mean scores for overall satisfaction being 69% and 66%, respectively, which also compares well with the 74% reported by Adler et al. (2009). Additionally, Majumder et al. (2014) reported scores for satisfaction with information about treatment (65%), information about medical tests (70%) and written information (71%).

The Nicolaisen et al. (2014) cross-sectional survey of 143 men with PC explored long-term quality-of-life outcomes and information satisfaction 3–4 years after receiving either prostatectomy, radical radiotherapy or post-operative radiotherapy. They scored satisfaction on a scale from 0 to 100, broadly equivalent to the percentile scoring in other studies. The mean score for information satisfaction in the radiotherapy groups was lower than in the previously mentioned studies at 53.7 and 56.7 possibly reflecting the different questions asked on the survey as the EORTC instruments were not used.

Tomlinson et al. (2014) reported on a large national survey of the experiences of just over 24,000 patients undergoing radiotherapy in the UK. Data were not reported according to cancer type. Information given before the start of radiotherapy was reported by 99%, with 97% reporting it as either excellent or very good. Further, 98% felt satisfied with the amount given at the start of treatment. However, only 77% of participants reported being given information about what to expect after the end of treatment. This figure is much lower than at the beginning of radiotherapy which is of concern at this important transition point as patients move on to the survivorship stage. Douma et al. (2012) reported that patient satisfaction with initial consultations was high (score of 89.7, *SD* 9.9) indicating information needs had been met at that point. Information needs decreased by the end of radiotherapy; however, satisfaction with information was unrelated to the decrease in information need.

Information satisfaction is briefly mentioned in four studies in relation to a variety of issues, including satisfaction with information and support given by cancer information services (Dubois & Loisel, 2008), dissatisfaction with timing/place/situation of information on radiotherapy side effects (Lehto et al., 2015), satisfaction that information was interesting and complete (Bennenbroek et al., 2003)

and satisfaction with amount of information provided (Bennenbroek et al., 2003; Lehto et al., 2015). Concerns reported in the findings of the qualitative study by Blomberg et al. (2016) included patients feeling unsure about the information they received and being given limited information. These issues may imply that quality of information was a factor, although this was not specifically reported on.

3.2.6 | Men with PC experiences related to radiotherapy information

Eleven studies considered experiences of patients related to radiotherapy (Appleton et al., 2015; Boulton et al., 2015; Clarke & Burke, 2016; Dieperink, Wagner, Hansen, & Hansen, 2013; Dubois & Loisel, 2008; Kelsey et al., 2004; Long, 2001; Ormerod & Jessop, 2015; Owens et al., 2003; Sinfield et al., 2008; Tomlinson et al., 2014). Because of the large number of topics related to patient experience mentioned across these studies, this section will focus on only those regarding information.

In the sole quantitative study, Tomlinson et al. (2014) reported the experiences of just over 24,000 patients attending for radiotherapy. Data on information were gathered from 13 of the 60 questions, with 97% of respondents reporting that information given before treatment was either excellent or satisfactory. 80% reported finding attendance at an information session helpful.

In the qualitative papers, there was a range of positive experiences described. Patients reported receiving excellent support and information, in particular from specialist and advanced practice staff (Boulton et al., 2015; Clarke & Burke, 2016; Kelsey et al., 2004; Ormerod & Jessop, 2015; Sinfield et al., 2008). Lay networks of family and friends were integral to patients gaining and using information (Appleton et al., 2015; Long, 2001; Sinfield et al., 2008) with the value of experience-based information from other patients in the radiotherapy waiting room highlighted as a positive source of help (Boulton et al., 2015).

The qualitative studies also reported a range of negative experiences related to information. Long (2001) reported that participants had held fear or pre-conceived ideas about radiotherapy related to inadequate information and that these fears were not alleviated by HCP once they had started their treatment. In two papers that reported different aspects of the same data set, Kelsey et al. (2004) and Owens et al. (2003) each reported that patients found it difficult to gain independent advice about treatment options due to consultant bias. However, the patients were happy with the amount of time and support offered by their consultants. Conversations about treatment options were influenced by the professional background of the doctor; that is, surgeons recommended surgery, oncologists recommended radiotherapy, and these recommendations particularly impacted on patient experiences of decision-making about treatment options. Other reported issues where information affected patient experience included the inadequacy of the amount and factual content of information being given, participants wanting more information regarding adverse effects and their decision-making, patients wanting both written and oral information, the amount

of information being overwhelming and patients having misinformation prior to commencing radiotherapy due to their own or family members' prior experiences and conflicting information from HCP (Dieperink et al., 2013; Dubois & Loisele, 2008; Long, 2001; Owens et al., 2003; Sinfield et al., 2008).

4 | DISCUSSION

The aim of this integrative review was to identify and synthesise literature reporting the experiences of men with PC related to information in radiotherapy. This was in order to provide evidence that might be useful in informing the information dissemination practices of HCP involved in the care of men with PC undergoing radiotherapy. This review has revealed that whilst many papers refer to information for men with PC undergoing radiotherapy and to various aspects of patient experience, there is no in-depth, detailed evidence solely focussing on patient experience related to information in radiotherapy. From the papers reviewed, issues related to information appear to be complex and intertwined.

There is a wide range of useful evidence that relates to information across the wider PC trajectory and management; however, the range of issues for men with PC appears to be very specific to the radiotherapy course. Patients' desire for detailed information regarding options for PC management, treatment procedures and radiotherapy side effects is relatively well-documented. Nevertheless, individual information requirements may depend on a patient's coping mechanisms or demographic characteristics so these need to be considered by HCP such that patients can be given individualised or personalised information.

It is perhaps unsurprising that information regarding radiotherapy side effects is important to many patients, for example appropriate timing of this information was crucial for patients to make effective decisions about treatment (Appleton et al., 2015; Boulton et al., 2015). However, in many of the studies reviewed, reference to information on side effects was mentioned incidentally and was not well documented in study findings.

The temporal nature of information in radiotherapy appears to be an important aspect, whether this is related to the timing of information seeking or giving, or the way information needs change over time. Timing of information may also reflect whether information needs are met or remain unmet, and how this impacts on the overall radiotherapy experience. It is important to note that patient satisfaction with information is influenced by staff time constraints, as well as whether information is provided at the right time in their management course. This issue warrants further research.

Information satisfaction has emerged as an important element of the information process, and whilst men with PC undergoing radiotherapy generally report relatively high satisfaction with information (e.g., Lamers et al., 2016; Majumder et al., 2014), there is a paucity of evidence about whether the format of the information impacts on satisfaction. Given that this issue was so infrequently mentioned, it may be a topic worth exploring in more detail in future research.

An important finding of the Tomlinson et al. (2014) survey was that satisfaction with information is lower at the end of radiotherapy compared to the beginning. Given the increasing focus on survivorship and rehabilitation by organisations such as Macmillan Cancer Support (2014), this is an area worth exploring further to ensure that patients understand the longer-term sequelae of radiotherapy.

One of the difficulties encountered in carrying out this review was how interwoven the issues relating to information are. Timing is dependent on patient needs, patient need is dependent on where patients are in their cancer journey, satisfaction is dependent on whether information was given at the right time in that journey and so on. However, what is clear from this review is that further research focussed on experiences related to information in radiotherapy for men with PC is required.

4.1 | Strengths and limitations

To our knowledge, this is the first review to explore experiences of men with PC regarding information related to radiotherapy. The strength of this review is that it was carried out in a systematic and rigorously structured manner. However, there are some limitations to be acknowledged: first, only English language studies were retrieved meaning that some useful studies may have been excluded; second, most of the studies were of cross-sectional or qualitative design where purposive or convenience sampling was employed, which may have introduced selection bias; third, reported findings tended to be either self-reports which can introduce social desirability and recall bias, or thematic interpretations of data where researcher bias may be a factor, especially as most qualitative studies reviewed did not report on how validity and reliability were ensured.

5 | CONCLUSION

Our review has identified a gap in the evidence base related to in-depth exploration of the experiences of men with PC related to information during radiotherapy. The issues identified within this review demonstrate that further research is warranted in order to contribute to the knowledge specific to information in radiotherapy for men with PC. Greater understanding of these issues will allow healthcare professionals to better tailor the individual information needs of men with PC who are prescribed radiotherapy, from the point of decision-making through to living with and beyond cancer.

CONFLICT OF INTEREST

The authors declare that there are no conflicts of interest regarding the publication of this paper.

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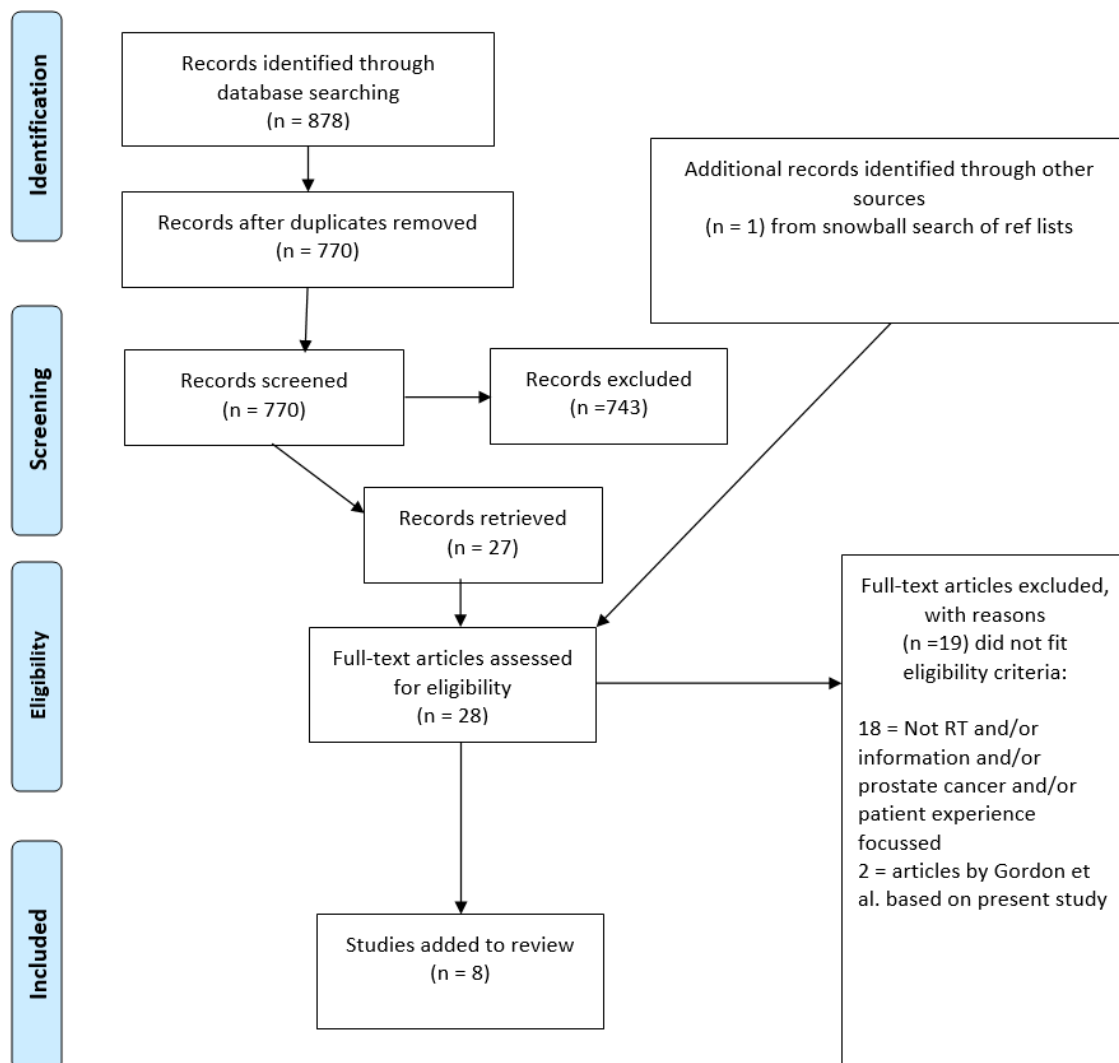
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Appendix 5 – PRISMA diagram, quality assessment and summary of articles sourced in search carried out in November 2021

i) PRISMA diagram of articles published between April 2017 and November 2021



ii) Summary of studies sourced in November 2021 covering the period April 2017 to November 2021

Authors, year, country	Setting/context	Design	sample	Data collection/generation method	Study aim/purpose	Summary of outcomes/findings related to information/experiences
Ahamad et al (2019) USA	One cancer centre	Retrospective review of medical records	medical records of 579 consecutive patients	documentary review and extraction of data	<p>To assess the quantity of questions that were asked when the radiation oncologist dedicated unlimited time and effort to this portion of their initial consultation</p> <p>To evaluate the nature of patients' questions to estimate whether generic information materials could be sufficient</p>	<p>A total of 2386 questions were asked with median number of questions asked per patient of 6</p> <p>two broad areas identified: radiation modality-related questions (56.9%) and disease-related questions (36.7%)</p> <p>nine subjects were identified as follows:</p> <ol style="list-style-type: none"> 1. schedule and logistics; 2. side effects, symptom control effect of treatment on life, and follow-up; 3. radiotherapy details, effectiveness, and technique; 4. disease characteristics: diagnosis, pathology, stage, results, biology, and symptoms; 5. pertaining to other specialties; 6. lifestyle, complementary subjects, nutrition, supplements, stress, physical activity, and quality of life; 7. other topics; 8. Cost; 9. epidemiology or aetiology. <p>Concluded that Increasing patient age, being underinsured, and having certain tumour types may be potential barriers to the amount of information that patients request.</p> <p>Suggest that radiation oncologists need to address questions that are disease-related, radiotherapy-related, and details requested about patients' case. They may use generic materials but also need to provide customized information. Results may differ for radiotherapy patients.</p>
Blödt et al (2018) Germany	National maximum variation recruitment across Germany	secondary analysis of data from a qualitative interview study	127 men and women with either prostate, breast or colorectal cancer	narrative interviews	To analyse the role and meaning of health information in individuals' experiences with either breast, colorectal or prostate cancer in order to better understand unmet information needs of people with a cancer diagnosis	<p>4 Themes were explored under the overarching topic of: Role of information in illness narratives. Themes were:</p> <p>Becoming confident in one's treatment decision: Importance of up to date information, information that allowed evaluation of experience and quality of HCP and health services. Noted avoidance of some info seeking once treatment decision had been made.</p> <p>Taking responsibility for one's situation: Noted how info prepared interviewees for communications with physicians and insurance companies, facilitated informed decision making, gave sense of control</p> <p>Understanding the consequences of the disease and treatment for one's life: long term consequences, info that helped assessment of the meaning of the disease, using experiences of others to further understanding.</p> <p>Dealing with fear: tension between info seeking and avoidance, importance of info in helping maintain control of emotions, role of info in giving hope. Acknowledgement of hindsight in considering info choices.</p>

Chauhan et al (2018) UK	one RT dept	UK service evaluation	60 completing RT chemo, hormones, surgery	MPC +/-	60 surveys and 11 interviews	<p>To establish the effectiveness of the current service in relation to patient's information and support needs including their individual treatment review.</p> <p>To identify opportunities for service improvement and in particular the value of group-based treatment review.</p>	<p>Concluded that Information was never a simple, neutral fact in the interviewees' narrative, but something that was cognitively used to make treatment decisions. Rather, information was crucial as a means of gaining a sense of control in a seemingly uncontrollable situation. Evaluation of one's own information behaviour and the information received change over time and are closely linked to how the illness unfolds.</p> <p>Pts were satisfied with information provision before and after treatment. Most were happy with the amount given about bladder and bowel prep. 10% felt they needed extra info before treatment.</p> <p>Thematic analysis of interviews raised some issues and concerns regarding info provision, in particular about how RT works, prep procedures and suggested visual info would be useful. They suggested peer support could be useful. Several patients recognised that relatives or carers may need to be involved for practical reasons alternatively others were less positive suggesting this would make them feel inhibited. Taboo topics for group discussion were noted as sex life, impotence and bowel habits.</p>
Gronhuis-Palacios et al (2019) Netherlands	3 hospitals	Dutch multicenter, cross-sectional survey	412 MPC	MPC	questionnaire	<p>To evaluate possible discrepancies between patients' expectations concerning sexual side effects related to prostate cancer treatment, based on the obtained information prior to treatment.</p> <p>To determine if demographic or clinical factors may have an effect on the accuracy of patients' expectations concerning sexual side effects after treatment.</p>	<p>Before treatment information was most commonly received verbally (62.1%, n = 252) and from a urologist (74.9%, n = 301). The internet was most frequently used as a source for self-gathered information concerning sexual side effects (34.7%, n = 140). Almost half of men (46.5%, n = 188) had no desire to search for additional information, eg if they already had received sufficient information (20.2%, n = 38).</p> <p>Twenty-four percent (n = 99) reported to have received insufficient information prior to treatment concerning sexual side effects after treatment, whilst 63.5% (n = 261) stated they had received sufficient information.</p> <p>Of men with sexual side effects after treatment, 1 in 3 reported them as worse than expected, based on the received information before treatment (32.5%, n = 109). Sixty percent reported no discrepancies between their expectations and developed sexual side effects (n = 199). A small group reported their sexual side effects as less severe than expected (8.1%, n = 27). Men who reported to have received insufficient information prior to treatment, described their sexual side effects significantly more often as worse than expected than men who had received sufficient information.</p> <p>Pts receiving radiotherapy +ADT reported less discrepancy between expectation and info than those who underwent surgery.</p>
Kinnaird & Stewart-Lord (2020) UK	One hospital	UK qual phenomenology	10 completing EBRT 18-30 months previously	MPC	semi-structured interviews	<p>To explore men's perceptions of sexual dysfunction, including factors such as self-perception, relationships and information and support needs</p>	<p>The three main themes identified through thematic analysis of the data were</p> <p>(i) Priorities—sexual issues were not perceived to be a priority when making treatment decisions</p> <p>(ii) Information and support—men described unmet information/ support needs relating to sexual dysfunction: Most said they were not told enough or given an unrealistic picture. While some described being given comprehensive and accurate information, others described being surprised and shocked by the onset of problems.</p>

							(iii) Impact—sexual side effects had a wide-ranging impact on their self-perception and relationships
Öster et al (2014) Sweden	One RT department	qualitative	9 MPC	group discussion analysis	To describe the experiences of men living with prostate cancer shared within conversational support groups during a course of radiotherapy	Most findings focussed on side effects and the procedures. Findings related to information are: Getting information or having knowledge was crucial to being able to make decisions Information on a proper level was claimed as important. The men said that they had got information but then did not remember what was said. A combination of verbal and written information was easier to integrate than only a verbal. The men appreciated the information that they had gotten and felt that they needed it Knowledge was valuable and made the men understand better	
Smith et al (2019) Australia	One hospital	qualitative	Twenty-five men recently diagnosed with localised prostate cancer	semi-structured interviews	To understand how to best support men diagnosed with LPC in choosing the treatment that best suits their values/preferences, when robotic prostatectomy and radiotherapy are equally appropriate to offer them, in that they offer equivalent cure rates	TA revealed 4 themes: 1. Trust in clinicians and the information they provide is critical for treatment choice: info from clinicians is seen as reliable due to expertise 2. The perceived fit between treatment characteristics and personal preferences: judgement was largely made based on information provided to men in consultation with clinicians, but some men sought information from other sources, namely other men with LPC, family and friends, the internet, and pamphlets. 3. Additional considerations: Specific side effects, socio-emotional and financial factors 4. Need for balanced and tailored information delivery: no unanimous preferences regarding information content, format or amount, indicating a need for tailored information delivery	
Sutton et al (2021) UK	4 centres	qual arm following a previous trial	16MPC who had EBRT	interviews	To investigate men's experiences of receiving external-beam radiotherapy (EBRT) with neoadjuvant Androgen Deprivation Therapy (ADT) for localized prostate cancer (LPCa) in the ProtecT trial.	All men reported experiencing some bowel, sexual, or urinary side effects Difficulties with sexual function were common, with adverse impacts including lack of "sex drive" or desire, inability to maintain an erection or achieve a climax There were some aspects of timing of info and details of treatments they felt could be improved Those who experienced more or serious side effects felt they had not been sufficiently prepared – suggesting that information should be provided on an ongoing basis Many men described in positive terms the support and information they had received from healthcare professionals Findings highlight the importance of providing clear, concise, and timely information and supportive resources in the short term, and more targeted and detailed information and care in the longer term to maintain and improve treatment experiences for men undergoing EBRT	

iii) quality appraisal of studies sourced in November 2021 covering the period April 2017 to November 2021 utilising Bowling's checklist for critical appraisal of scientific literature (Bowling 2014).

Appraisal items	Ahamad et al (2019)	Blödt et al (2018)	Chauhan et al (2018)	Grondhuis-Palacios et al (2019)	Kinnaird & Stewart-Lord (2020)	Öster et al (2014)	Smith et al (2019)	Sutton et al (2021)
Clearly stated aims	✓	✓	✓	✓	✓	✓	x	✓
Study design described	✓	✓	✓	✓	✓	✓	✓	✓
Appropriate research methods	✓	✓	✓	✓	✓	✓	✓	✓
country of study	✓	✓	✓	✓	✓	✓	x	✓
date of study	✓	x	✓	✓	x	x	✓	x
site of study	✓	✓	✓	✓	✓	✓	x	✓
Sample size & coverage reported	✓	✓	✓	✓	✓	✓	✓	✓
response rates/ sample attrition stated	✓	✓	✓	✓	✓	✓	✓	✓
sample characteristics given	✓	✓	✓	✓	✓	✓	✓	✓
theoretical framework	x	x	x	x	x	x	x	x
predictors & outcomes assessed	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a
measurement tools with evidence of reliability and validity	n/a	n/a	n/a	✓	n/a	n/a	n/a	n/a
outcomes/ results/ findings	✓	✓	✓	✓	✓	✓	✓	✓
Generalisability considered	x	x	x	x	x	x	x	x

Appendix 6 - Materials related to radiographer recruitment and consent

- i) Radiographer invitation letter
- ii) Radiographer participant information sheet
- iii) Radiographer consent form

i) Radiographer invitation letter

Date

Dear

The experiences of men with prostate cancer regarding information in radiotherapy.

My name is Lynne Gordon, and I am a senior lecturer in Radiotherapy and Oncology who is also a state registered therapeutic radiographer (registration number RA30098). I am studying for my Doctorate and as part of this I am carrying out a research study about what men think and feel about the information they receive during a course of radiotherapy.

I would like to invite you to take part in the study. I would like you to take part in a focus group with other therapeutic radiographers during which you will discuss issues related to the information received by men with prostate cancer just before and during their radiotherapy. I am hoping that the findings of the study will help to better understand the issues regarding information and therefore help improve the standards of care of men with prostate cancer in the future.


The focus group will be arranged so that it does not clash with your normal working hours and will last about an hour. I will facilitate the group by asking questions and there will be a research assistant present who will take some notes. I hope that it will be a positive experience for you to share your views and experiences.

I have attached an information sheet about the study for you to read. I am happy for you to contact me if you have any further questions you would like to discuss. Contact details for me and my academic supervisor can be found on the last page of the information sheet. If you feel you would like to take part in the study, please contact me either by telephone or by email. I will then contact you to arrange your attendance at a focus group – there will be several dates/times available once I know how many people wish to participate.

Although I would be very grateful for your help, you do not have to take part in the study if you do not want to. Your choice whether to take part will not affect your work or any professional relationship with the University of Hertfordshire.

Many thanks for your time.

Kind regards



Lynne Gordon
Doctoral student, University of Hertfordshire

|

ii) Radiographer participant information sheet

LG V6. 5/17 

The lived experiences of men with early-stage prostate cancer when receiving information related to a course of radiotherapy in the UK.



Participant information sheet (radiographers)

UH HHSEDA protocol no: HSK/PGR/NHS/02450

IRAS project ID: 166436

Introduction

You are being invited to take part in a research study. Before you decide whether to do so, it is important that you understand the research that is being done and what your involvement will include. Please take the time to read the following information carefully and discuss it with others if you wish. Do not hesitate to ask me anything that is not clear or for any further information you need to help you make your decision. Please do take your time to decide whether or not you wish to take part. Thank you for reading this.

What is the purpose of this study?

During a course of radiotherapy patients are given or told a lot of information. This study will allow in depth exploration of the experiences of men with prostate cancer regarding the information they receive during a course of radiotherapy. Your views as a therapeutic radiographer are being sought in order to help set in context the experiences of the men who will be interviewed as part of this study. The study forms the basis of my Doctorate in Health Research.

Why have I been invited?

Because you have been identified as a therapeutic radiographer who works at a department where men with a diagnosis of prostate cancer receive radiotherapy as part of their management.

Do I have to take part?

It is completely up to you whether or not you decide to take part in this study. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. You are free to withdraw at any stage without giving a reason. A decision to withdraw at any time, or a decision not to take part at all, will not affect your work with your department or any professional association with the University of Hertfordshire.

What are the possible disadvantages of taking part?

There is a small possibility that in answering some questions during the interview you may become upset. If this occurred I would halt the interview until you felt able to continue.

LG V6. 5/17 

What are the possible advantages of taking part?

I cannot promise the study will help you directly, but the knowledge gained from this study may help improve the radiotherapy management of men with prostate cancer by increasing the awareness of issues regarding information they receive. In this way it will add to the body of knowledge specifically related to men with prostate cancer who undergo radiotherapy treatment.

What will happen to me if I take part?

You will be invited to participate in a focus group interview (FGI) with other radiographers from your department which will be facilitated by me. A range of suitable dates and times will be identified and agreed with the radiotherapy manager. The FGI will take place on the hospital premises. Before the date of your FGI I will arrange to visit the department so that I can go through this information sheet with you and so that you have the opportunity to ask any questions about the study. If you are happy to proceed I will arrange for you to read and sign a consent form at the start of the FGI.

It is expected that the FGI will take no longer than 60 minutes to complete but may be a little shorter or longer depending on the issues we discuss. During the interview I will ask the group to talk about matters related to information given/exchanged with patients undergoing treatment for prostate cancer. I will use a digital voice recorder to record the interview and also take some notes. A research assistant may be present to take notes, but only with your prior knowledge and consent. Once the transcript of the focus group has been created it will be forwarded to so you have the opportunity to review the content for accuracy.

What will happen to the results of the research study?

The findings of this study will be written up as my Doctoral Thesis. The findings will be presented at conferences related to radiotherapy and/or research and published in reports in professional journals. To ensure your anonymity, you will not be identifiable in any presentations and reports.

Who has reviewed this study?

All research in the NHS is looked at by independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by the NHS Research Ethics Committee, reference number: 17/N5/0044

How will my taking part in this study be kept confidential?

All information collected about you during the course of the research will be kept strictly confidential. Any personal data (such as that needed to identify you while booking interviews) will be strictly controlled and kept in a secure location within my office at the University. Any electronic documents will be password protected. A transcription company will be employed to convert the recording file into text, however they will not be sent any information that could identify you. University secure servers will be used to transfer any electronic documents. The only persons other than myself who will be able to access personal data will be my Doctorate supervisors. If, during our conversation you tell me about an incident that involves, for example poor patient care or other poor professional practice, I would need to report the incident to my supervisor, and the head of radiotherapy which may then require confidentiality to be breached. However this would be done with the utmost discretion and would follow guidelines from the appropriate professional body. Direct quotes from your focus group will be included in reports of the research but these will be given pseudonyms or codes in order to protect your identity.

Who can I contact if I have any questions?

If you would like further information or would like to discuss any details personally, please get in touch with me or my primary supervisor, in writing, by phone or by email:

Lynne Gordon Doctoral student University of Hertfordshire, College Lane, Hatfield, Herts, AL10 9AB Tel: 01707 285088 Email: l.gordon@herts.ac.uk	Dr Angela Dickinson Doctoral supervisor Centre for Research in Primary and community Care University of Hertfordshire Tel: 01707 285993 Email: a.m.dickinson@herts.ac.uk
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Although I hope it is not the case, if you have any complaints or concerns about any aspect of the way you have been approached or treated during the course of this study, please write to the University Secretary and Registrar, Mrs Sue Grant at s.c.grant@herts.ac.uk.

Thank you very much for reading this information and giving consideration to taking part in this study.

iii) Radiographer consent form

University of Hertfordshire
College Lane
Hatfield
Herts
AL10 9AB

UH HHSEDC protocol no: HSK/PGR/NHS/02450. IRAS project ID: 166436

Participant Identification Number for this study:

CONSENT FORM (Radiographers)

Title of Project: The lived experiences of men with early-stage prostate cancer when receiving information related to a course of radiotherapy in the UK.

Name of Researcher: Lynne Gordon

Please initial all boxes

1. I confirm that I have read and understand the information sheet dated 5/17 (version LG V6 5/17) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my employment or legal rights being affected.
3. I agree to the use of voice recording equipment during the research interviews.
4. I understand that the recorded interview will be transcribed into a written format by either the researcher or commercial transcription service
5. I agree that direct quotes from the interview can be used anonymously as quotations in the presentation of the research.
6. I understand that the researchers will contact the senior manager if I tell the interviewer about an incident involving, for example, poor patient care.
7. I agree to take part in the above study.

Name of Participant Date Signature

Name of Person taking consent
(if different from researcher) Date Signature

Name of Researcher Date Signature

Consent form date of issue: 5/17
Consent form version number: 8

Page 1 of 1

Appendix 7 - Radiographer interview topic guide

<p>Focus group number: Facilitator Initials LG Note-taker Initials</p> <p>Date</p> <p>Introduction</p> <p>I am Lynne Gordon from the University of Hertfordshire (Facilitator)</p> <p>I am _____ from _____ (note-taker – if present)</p> <ul style="list-style-type: none"> ✓ Ask group to introduce themselves using first names only ✓ Capture demographic details (provide proforma) – using first name for discussion ✓ Explain general purpose of the study: <ul style="list-style-type: none"> • <i>For FGD:</i> to understand the lived experiences of men with early-stage prostate cancer when receiving information related to a course of radiotherapy (RT) in the UK ✓ Aims of the discussion and expected duration (1 hour) ✓ Who is involved in the process (other participants) ✓ What will happen with the collected information and how the participant/target group will benefit ✓ Ask group to define their own ground rules, for example: <ul style="list-style-type: none"> • Only one person talks at a time. • It is important for us to hear everyone’s ideas and opinions. There are no right or wrong answers to questions – just ideas, experiences and opinions, which are all valuable. • It is important for us to hear all sides of an issue – the positive and the negative. • Confidentiality is assured. “What is shared in the room stays in the room.” ✓ Any questions? ✓ Check position and functioning of tape recorder ✓ Check for everyone’s consent to participate and be recorded ✓ Refreshments will be served after the discussion <p>Now I am going to introduce some topics one at a time related to information that men with prostate cancer receive during radiotherapy, and I hope you can discuss them together.</p>	
Domain	Topic and Probes
<i>Information given about RT at new patient stage</i>	<p>Can we talk about what information patients receive at the new patient clinic –related to their radiotherapy</p> <p>How do you give information?</p> <p style="text-align: center;"><i>Probe: nature and format of information</i></p> <p>How much of this information do you think patients understand?</p>

	<p><i>Probe related to format, professional groups, content, amount</i></p> <p>Tell me about the quality of this new patient information.</p> <p><i>Probe – how well do you think it meets the patients' needs at that point in time?</i></p> <p>What do you think patients want to know at this point in time?</p> <p>How well prepared do you feel that patients are as they start their radiotherapy?</p> <p>Where do you give the information (environment)?</p>
Information given during the RT planning and treatment process	<p>Tell me about the information that radiographers <u>give</u> to patients during their course of radiotherapy.</p> <p><i>Probe: if not mentioned question participants regarding information on side effects, treatment instructions, ongoing care, immobilisation/bowel/bladder prep, treatment review clinics and follow up</i></p> <p>Are there any particular issues that you have encountered when giving this information?</p> <p>What challenges are there to delivering high quality information?</p> <p>Is there anything that makes a difference to the way information is given to patients</p> <p><i>Probe on numbers and grades of staff, presence of students/other professional groups, any reliance on site specialists, time available, environment</i></p> <p>What is the most important aspect of the information you give?</p>
Information related to the end of RT and immediate follow up period	<p>Tell me about the end of treatment and the information given at that point.</p>
Perception of information exchange	<p>How would you describe the nature of the information exchange?</p> <p>Why do you think this is?</p> <p>If you reflect on how information is given, what if anything would you change?</p>
<p>Closing</p> <p>We are now approaching the end of our discussion. Is there anything else anyone would like to add about information for men with prostate cancer that we have not talked about?</p> <ul style="list-style-type: none"> ✓ Summarise ✓ Thank participants ✓ Provide extra/ support information and contacts to participants 	
<ul style="list-style-type: none"> ✓ Offer refreshments <p>Collect participant demographic proformas</p>	

Appendix 8 (Gordon et al., 2017) Research note paper

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A research note on the benefit of patient and public involvement in research: The experience of prostate cancer patients regarding information in radiotherapy



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ABSTRACT

Aim: To explore the inclusion of patient and public involvement (PPI) in a qualitative study on the experiences of men with prostate cancer regarding information in radiotherapy.

Method: The application of PPI to one doctoral research study is explored with respect to two perspectives: firstly, involvement of a patient reference group who informed the research design and materials, and secondly, the involvement of a public involvement in research group (PIRG) in advising the researcher during the design process.

Discussion: PPI is recognised as an important component of contemporary health research. PPI is becoming a common and essential requirement for high quality research projects and yet literature exploring or reporting the involvement and influence of PPI is sparse. Consideration is given to the national PPI landscape that has shaped public involvement in health research.

Conclusion: The contribution of PPI to this study appears to have been beneficial to the development and evaluation of the study design, the self-worth of the reference group participants and demonstrates that the value of PPI in health research should not be underestimated.

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Introduction & background

Increasingly there is a requirement for researchers to involve patients and the public in the design and implementation of their studies. This has been labelled 'patient and public involvement' (PPI).¹ While this requirement has been seen positively from a political perspective,^{2,3} there has been criticism that some researchers accord little value to PPI and often, because of the way it was implemented, conclude that it made little difference to their research instead paying so called 'lip service' to the requirements of funding bodies or trial steering committees.⁴ Public involvement in research has been defined as "research carried out 'with' or 'by' members of the public rather than 'to', 'about' or 'for' them".¹ This definition moves beyond describing public or lay involvement in research merely in terms of those involved as research participants and recognises that non-academic and non-health professional

people can have a valuable and sometimes profound influence on research design and processes.

As far back as 1995 an article in the British Medical Journal stated that "patients should be at the front of researchers' minds when they design, conduct, and report medical research".⁵ It gave seven ways in which patients and public can be involved: to help set the research agenda, be the best people to advise on the outcomes to be studied, comment on the design of the study, assess the quality of consent to be sought, help with publicity to encourage recruitment, insist on publication of research, and counter the issue of results of research not being put into practice. Since then an increasing body of work has considered the role of PPI in research, variously reporting on its impact, values and benefits.^{6–9} There is consensus in the literature that inclusion of PPI is empowering to the PPI contributors^{4,10} and that the quality of the relationship between researchers and PPI contributors is important in determining the impact of inclusion of PPI.^{4,11} Additionally, a prospective case study reported the following emergent themes when considering service users: trust and commitment, impact on the wider study, mutual learning and timing of service user involvement.⁹ Yet regardless of the growing evidence related to PPI in research, it is

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still the case that most peer reviewed reports of UK-based health research do not mention how or whether PPI informed the research process. One systematic review of health and/or social care studies found only 66 studies across a 15 year period that reported the impact PPI had on the research.¹² This is despite the fact that applications to many research funders are expected to demonstrate inclusion of PPI as an integral part of the research design and that the Department of Health recommends that “relevant service users and carers or their representative groups should be involved ... in the design, conduct, analysis and reporting of research”.¹³ For example, National Institute for Health Research (NIHR) decisions on whether to consider funding a study may in part be influenced by whether and how PPI has been integrated into the study design¹⁴ and one of the requirements for applicants to the CoRIPS (College of Radiographers Industrial Partnership scheme) fund is to demonstrate how PPI has informed the study design.¹⁵

One of the disadvantages highlighted by previous literature on PPI is the difficulty in monitoring the impact it has had on individual studies. In particular, Staniszewska et al. highlighted the lack of quantitative measurement of impact.⁸ Other research has indicated a general perception of the importance of evaluating impact but acknowledged the complex evaluation process and the impetus linked to accountability.⁹ Furthermore, in one qualitative study where chief investigators (CI), trial managers and PPI contributors were interviewed, over half of informants indicated that PPI had made a difference within a trial but that this was influenced firstly by whether the CI had goals/plans for PPI and secondly by the quality of the relationship between the research team and PPI contributors.⁴ The authors of the study acknowledged the inherent limitation related to quantification in qualitative research. The message from these studies therefore is that although the impact of PPI is not easily measurable quantitatively, there is evidence to support the inclusion of PPI as being beneficial to PPI contributors, researchers and the participants.

The aim of this paper is to consider PPI in one piece of research being carrying out in fulfilment of a Doctorate of Health Research offered at the University of Hertfordshire. It will explore the development of a reference group and how the group informed and commented on aspects of the research design. It will also explore how advice from a local Public Involvement in Research group (PIRG) further refined the research documentation in preparation for submission for ethics review.

Overview of the doctoral research study

The doctoral research will explore the experiences of men with prostate cancer (MPC) regarding information they receive related to their course of radiotherapy. Previous research has addressed information in cancer, information in prostate cancer and information in radiotherapy but mainly using quantitative or review-based research methods.^{16–19} An extensive search and review of literature identified no evidence related to in-depth exploration of the experience of prostate cancer patients specifically related to information received during a course of radiotherapy. The research has a qualitative descriptive methodology, which allows an approach that is not guided by a specific set of established philosophical assumptions and allows rich, straight description of experiences in language similar to the participants' own.^{20–23} The research will recruit participants from a single radiotherapy department in England. There will be two participant groups: firstly, MPC who have radiotherapy as part of their management will participate in semi-structured individual interviews and secondly, therapeutic radiographers will participate in semi-structured focus group interviews. Data generated will be analysed thematically within and between the participant groups.

Discussion

The following section discusses the implications of recommendations made firstly by an informal reference group of patients and secondly by the formal Public Involvement in Research group (PIRG) based at the University of Hertfordshire. Interestingly, both groups focussed their comments and advice only on the patient participant involvement. Throughout this section the doctoral student is referred to as ‘the researcher’.

Involvement of the informal patient reference group

Very early on in the design and development of the research, it became clear that there were questions related to the method that could not be answered by using the usual literature based resources. Wilson states that when defining what makes an expert patient, knowledge and understanding is derived from experience.²⁴ Therefore given this definition, it seemed practical to ‘ask the experts’, i.e. a selection of people who had been diagnosed with prostate cancer and experienced radiotherapy. Contact was therefore made with the St Neots Acom Cancer Support group who gave permission for the researcher to attend the group to talk about and invite comment on the proposed research. This particular group is a social support group that offers a venue once a month for people who have been affected by a range of cancers (whether as patients or relatives/carers) so that they can socialise together over tea, coffee and sandwiches and receive advice and support as they require. A holistic therapist is available for reflexology/massage; representatives from other support organisations attend and guest speakers are regularly invited to deliver short presentations related to living with and beyond cancer.

A core group of three MPC offered to comment on the proposed research and subsequently made general comments that influenced the design of the research. The conversations about the research were held during the regular group meetings. The first topic they were asked to comment on was whether they felt that there would be an issue for interviews with men to be conducted by a female researcher. This issue was identified for consideration due to noting some potentially sensitive topics that might arise during interviews. With prostate cancer being inextricably linked to the function of the male genitourinary system, some of the information received by MPC is likely to involve reference to urinary continence or sexual functioning which are potentially embarrassing or sensitive topics to discuss with someone of the opposite gender. The issue of gender in the interview situation has been discussed at length in the literature. For example, Broom, Hand and Tovey argue that men may mediate their response depending on the gendered performance of the interviewer,²⁵ and Henderson and Weisman reported that sensitive or personal issues can be difficult for men to discuss with physicians of the opposite gender.²⁶ Some research suggests that men may find it easier and more acceptable to discuss personal matters with a female interviewer, with the ‘traditional discourse of femininity’ meaning that a female interviewer is viewed as unthreatening by male participants.^{27,28} However other research suggests there is an assumption that only a man would be interested in hearing men's stories.²⁹ The men in the Acom reference group felt that the gender of an interviewer was not as important as being confident that the interviewer had a knowledge and understanding of cancer and its management. One member stated that ‘if you weren't a radiographer I probably wouldn't talk to you as I wouldn't be sure you knew your stuff’. Therefore for this small group, the researcher's positioning as a health care professional (HCP) was more important than concerns about their gender. This led to considerations concerning the conduct of interviews with regard to the researcher's ‘insider/outsider’ status. This phrase

is generally accepted to denote how a researcher is similar or different to the group being researched.³⁰ In relation to the patient participants, the researcher's insider status as a state-registered therapeutic radiographer conveys in-depth knowledge and understanding of radiotherapy and the typical cancer patient pathway, but as the researcher has never suffered cancer and is female, they are an outsider in terms of the experiences of the participants who will be recruited to the study. The insider/outsider dilemma has been discussed by other authors but tends to focus on ethnographic and observational research.^{31–34} Dwyer and Buckle point out that being an insider does not make for a better or worse researcher, merely a different one due to the perspective it may give, however in the same paper they note that participants may question an outsider's capacity to understand their experience, which in part contradicts the comment from the Acorn reference group.³¹ Nevertheless the insight gained from the reference group's comments regarding positioning as a HCP was valuable and the researcher will introduce herself to potential participants as a researcher who is also a state-registered radiographer. Consideration of insider/outsider status will be integrated in the reflexive interpretation and analysis of the data generated during the study. Without these comments from the reference group this aspect of reflexivity might have received less consideration.

The other main influence of the reference group was on the design of the study, which was amended to allow the option for the patient participants' wives/partners to take part in the interviews. There was very strong opinion in the reference group that wives/partners should be included, with one member stating that it would be "no good asking me anything about [my initial consultation] but my wife knows everything, so to get the fullest picture she would need to be interviewed too". This opinion is echoed in the literature indicating that MPC and their spouses typically face the challenges of the diagnosis together.^{35,36} The point was mentioned by other group members but there was some disagreement as to whether they would want to be interviewed as a couple or individually. All the men in the group stated that it was important for the choice to be offered and given this consensus it became an issue requiring further investigation.

The methodological issue of interviewing couples together or apart is one which has been debated in the literature. Strengths of joint interviewing are the production of a single collaborative account giving insights that might be difficult to identify in individual interviews³⁷ and that couples can create meaning or supplement each other's answers.³⁸ Interestingly, Bjornholt and Farstad point out that the ethical issue of anonymity and confidentiality is lessened in the joint interview scenario and can promote a productive setting in which the couple can tell their stories.³⁹ Interviewing apart gives each person the opportunity to air their own point of view unhindered by the other, but this may create anxiety if the couple is worried about what each might say, especially regarding sensitive topics.^{37,39,40} There are also issues of one person dominating the conversation due to the power dynamic within the relationship,³⁷ the dynamic between interviewer and interviewees changing due to the interaction between the couple³⁹ and ethical issues related to inclusion, intrusion and difference.⁴¹ These are not necessarily negative issues, but may affect the data generated and will need to be considered both at the time of the interview (in terms of interview style and approach) and at the analysis stage. Because of the strong opinion of the group in favour of inclusion of wives/partners, a research aim was added to reflect their experiences and contribution. During the recruitment phase, participants will be given the option to have their wife/partner involved and the choice of being interviewed together or separately. The methodological consequences will be examined carefully during the analysis and post analysis phases.

This contribution of an informal reference group at the design stage appears to be relatively rare (or at least rarely reported) but should be considered as an integral part of research design due to the unique and personal perspective lay contributors can give.⁴² The Acorn reference group is not likely to be offered further involvement in the design of the study, however any reports and findings will be sent to the group and their involvement has been, and will continue to be acknowledged in all conference materials and publications.

Involvement of a Public Involvement in Research group (PIRg)

The University of Hertfordshire PIRg was established by the Centre for Research in Public and Community Care in 2005 with a 'hub and spoke' design comprising 15 core 'hub' members and various networks, service users and PPI groups as the 'spokes'.⁴³ The PIRg was approached for advice and support regarding the documentation to be submitted for ethics review and the researcher was subsequently invited to present an overview of the proposed research at a PIRg meeting in March 2016. The 20 min presentation was followed by a discussion of around 30 min during which the PIRg members questioned various aspects of the study design. The PIRg members were complimentary regarding the general design of the study but felt strongly that the patient participants should be given the option of telephone interviews or interviews in their own home. This would reflect the likelihood that patients might still be experiencing the side effects of radiotherapy (e.g. frequency of urination, loose bowels, fatigue) and therefore feel less anxious if they were able to remain in their home environment. The method of telephone interviewing is addressed in a small body of literature. Advantages are cited as being cheaper cost, easier with dispersed populations, easier to ask sensitive questions due to lack of face-to-face contact and potential reduction of bias due to interviewer characteristics. Disadvantages are given as being the inability to judge body language, technical difficulties related to recording of interviews and generational differences in the way telephones are used (factually vs socially).^{44–47} In one qualitative study very little difference between face-to-face and telephone interviewing was found, with the amount, quality and themes of data being similar.⁴⁸ Therefore should a mix of telephone and face to face interviews be undertaken in the study, the evidence suggests that the interview method might not have a significant impact on the nature of the data generated. The issue of interviewing in a participant's home generated some discussion on practical aspects of participant and researcher safety and these have been addressed by the drafting of a detailed risk assessment which complies with the researcher's host department's lone worker policy. Further involvement of the PIRg is planned as members also offered to review all ethics documents prior to final submission to IRAS.

Conclusion

This paper has outlined two facets of patient and public involvement in one piece of research. The involvement of patient reference and public involvement in research groups has been an integral part of the doctoral student's research journey and has provided insight into the value of patients and lay people giving practical and common sense advice to researchers. The involvement of PPI in this study has so far been extremely beneficial in strengthening the study design and informing methodological issues that would not otherwise have been considered. Indeed, the patient reference group members all mentioned that being asked to participate has given meaning and value to an otherwise difficult and stressful point in their lives. Involvement of PPI should be seen

as standard practise to both ensure and support well-designed, robust research processes.

Conflicts of interest

None.

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Appendix 9 - Materials related to MPC and spouse recruitment and consent

- i) invitation letter
- ii) participant information sheets
- iii) consent forms

i) invitation letter

University of Hertfordshire
College Lane
Hatfield
Herts
AL10 9AB

Date:

Dear

Re: The experiences of men with prostate cancer regarding information in radiotherapy.

My name is Lynne Gordon, and I am a senior lecturer in Radiotherapy and Oncology who is also a state registered therapeutic radiographer (registration number RA30098). I am studying for my Doctorate and as part of this I am carrying out a research study about what men think and feel about the information they receive during a course of radiotherapy.

I am contacting you as you have expressed an interest in taking part in this study.

This letter is to provide further information and to invite you to take part in the study. I want you to tell me, in your own words, about the information you received about your radiotherapy treatment, who gave it to you, what format it was in and what you thought about it, along with any other views you have that are important for me to know regarding the information you received. I am hoping that the findings of the study will help to better understand the issues regarding information and therefore help improve the standards of care of men with prostate cancer in the future.

The study will involve me asking you some questions and listening to your answers in an interview that will last about an hour. Because the wives or partners of men with prostate cancer are often involved in their support, you can choose for them to be involved in the interviews too. They could take part in your interview, or if you and they prefer, I can arrange a separate interview. I hope that your interview will be a positive experience for you to share your views and experiences.

I have attached an information sheet about the study for you to read and discuss with your family and friends. I am happy for you to contact me if you have any further questions you would like to discuss. Contact details for me and my academic supervisor can be found on the last page of the information sheet. If you feel you would like to take part in the study, please contact me either by telephone or by email. I will then contact you to arrange a good time to meet and complete the interview.

Although I would be very grateful for your help, you do not have to take part in the study if you do not want to. Your choice whether to take part will not affect the care and treatment you are receiving.

Many thanks for your time.

Kind regards



Lynne Gordon
Doctoral student, University of Hertfordshire

ii) Participant information sheets

The lived experiences of men with early-stage prostate cancer when receiving information related to a course of radiotherapy in the UK.



Participant information sheet (patients)

UH HHSEDC protocol no: HSK/PGR/NHS/02450.

IRAS project ID: 166436

Introduction

You are being invited to take part in a research study. It is important to understand why the research is being done and what it involves. Please take the time to read the following information carefully and discuss it with others if you wish. If anything is not clear or for any more information, Lynne Gordon will be happy to talk to you.

Who has reviewed this study?

All NHS research is looked at by an independent group called a Research Ethics Committee, to protect your interests. This study was reviewed and given favourable opinion by the NHS Research Ethics Committee.

What is the study about and who is involved?

During radiotherapy patients are given or told a lot of information. This study will allow you to tell me, in your own words, about information you received during your radiotherapy for prostate cancer. It forms the basis of my Doctorate in Health Research, which I am studying at the University of Hertfordshire.

Why have I been invited?

Because you have been identified as someone with a diagnosis of prostate cancer who will be having radiotherapy as part of the management of your cancer.

Do I have to take part?

It is completely up to you whether or not you take part in this study. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. You can withdraw at any stage without giving a reason and any data collected from you will be destroyed. A decision to withdraw at any time, or not to

take part at all, will not affect any treatment or care that you may receive. If you would prefer, your wife/partner can also take part.

What will happen to me if I take part?

I will arrange to talk to you about the information you received before and during your course of radiotherapy and what you considered important about this. This should take no longer than 90 minutes but may vary depending on the issues you talk about. I will use a digital voice recorder to record the conversation and also take some notes.

Who else will take part in the study?

I aim to include 20 patients plus any wives/partners interested in being involved. I will also interview some therapeutic radiographers to gain their views on information they give to patients having radiotherapy for prostate cancer.

What are the possible disadvantages of taking part?

There is a very small possibility that answering some questions may cause you to become upset, or feel embarrassed, especially if the answer you want to give is of a personal nature. However if this happened I would stop until you felt ready to continue, or rearrange another visit. **You do not have to answer if you do not want to.**

What are the possible advantages of taking part?

I cannot promise the study will help you directly, but the knowledge gained from this study may help us to understand issues regarding radiotherapy information for patients with prostate cancer and therefore improve the experience of patients in the future.

What will happen to the results of the research study?

The findings of this study will be written up as my Doctoral Thesis. The findings will be presented at conferences related to radiotherapy and/or research and published in reports in professional journals. To ensure your anonymity, you will not be identifiable in any presentations and reports. The raw data from the study will be destroyed 3 years after the end of the study (this is standard University practice).

How will my taking part in this study be kept confidential?

Information collected about you will be kept strictly confidential. Any personal data (e.g. contact details while booking interviews) will be strictly controlled and kept in a secure location within my office at the University. Electronic documents will be password protected. A transcription company will be employed to convert the recording file into text, however they will not be sent any information that could identify you. University secure servers will be used to transfer any electronic documents. Only I and my Doctorate supervisors will be able to access your personal data. If, during our conversation you tell me about something that involves, for example poor patient care or other poor professional practice, I would need to report the incident to my supervisor and the head of radiotherapy. However this would be done with the utmost discretion and would follow guidelines from the appropriate professional body. Direct quotes from your interview will be included in reports of the research but these will be given a pseudonym or code in order to protect your identity.

Who can I contact if I have any questions?

If you would like further information, or to discuss any details personally, please get in touch with me or my primary supervisor in writing, by phone or by email:

Lynne Gordon(Doctoral student) University of Hertfordshire, College Lane, Hatfield, Herts, AL10 9AB Tel: 01707 285088 Email: l.gordon@herts.ac.uk	Dr Angela Dickinson (supervisor) Centre for Research in Primary and community Care University of Hertfordshire Tel: 01707 285993 Email: a.m.dickinson@herts.ac.uk
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Although I hope it is not the case, if you have any complaints or concerns about any aspect of the way you have been approached or treated during the course of this study, please write to the University Secretary & Registrar, Mrs. Sue Grant at s.c.grant@herts.ac.uk.

Thank you very much for reading this information and giving consideration to taking part in this study.

How will my taking part in this study be kept confidential?

Information collected about you will be kept strictly confidential. Any personal data (e.g. contact details while booking interviews) will be strictly controlled and kept in a secure location within my office at the University. Electronic documents will be password protected. A transcription company will be employed to convert the recording file into text, however they will not be sent any information that could identify you. University secure servers will be used to transfer any electronic documents. Only I and my Doctorate supervisors will be able to access your personal data. If, during our conversation you tell me about something that involves, for example poor patient care or other poor professional practice, I would need to report the incident to my supervisor and the head of radiotherapy. However this would be done with the utmost discretion and would follow guidelines from the appropriate professional body. Direct quotes from your interview will be included in reports of the research but these will be given a pseudonym or code in order to protect your identity.

Who can I contact if I have any questions?

If you would like further information, or to discuss any details personally, please get in touch with me or my primary supervisor in writing, by phone or by email:

Lynne Gordon (Doctoral student) University of Hertfordshire, College Lane, Hatfield, Herts , AL10 9AB Tel: 01707 285088 Email: l.gordon@herts.ac.uk	Dr Angela Dickinson (supervisor) Centre for Research in Primary and community Care University of Hertfordshire Tel: 01707 285993 Email: a.m.dickinson@herts.ac.uk
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Although I hope it is not the case, if you have any complaints or concerns about any aspect of the way you have been approached or treated during the course of this study, please write to the University Secretary & Registrar, Mrs. Sue Grant at s.c.grant@herts.ac.uk.

Thank you very much for reading this information and giving consideration to taking part in this study.

The lived experiences of men with early-stage prostate cancer when receiving information related to a course of radiotherapy in the UK.



Participant information sheet (partner/wife)

UH HHSEDC protocol no: HSK/PGR/NHS/02450.

IRAS project ID: 166436

Introduction

You are being invited to take part in a research study. It is important to understand why the research is being done and what it involves. Please take the time to read the following information carefully and discuss it with others if you wish. If anything is not clear or for any more information, Lynne Gordon will be happy to talk to you.

Who has reviewed this study?

All NHS research is looked at by an independent group called a Research Ethics Committee, to protect your interests. This study was reviewed and given favourable opinion by the NHS Research Ethics Committee.

What is the study about and who is involved?

During radiotherapy patients are given or told a lot of information. This study will allow you to tell me, in your own words, about information your partner/husband received during his radiotherapy for prostate cancer. It forms the basis of my Doctorate in Health Research, which I am studying at the University of Hertfordshire.

Why have I been invited?

Because you have been identified as the partner or wife of someone with a diagnosis of prostate cancer who will be having radiotherapy as part of the management of their cancer.

Do I have to take part?

It is completely up to you whether or not you take part in this study. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. You can withdraw at any stage without giving a reason and any data collected from you will be destroyed. A decision to withdraw at any time, or not to take part at all, will not affect any treatment or care that you may receive. If you would prefer, your wife/partner can also take part.

What will happen to me if I take part?

I will arrange to talk to you about the information your partner/husband received before and during his course of radiotherapy and what you considered important about this. This should take no longer than 90 minutes but may vary depending on the issues you talk about. I will use a digital voice recorder to record the conversation and also take some notes.

Who else will take part in the study?

I aim to include 25 patients plus any partners/ wives interested in being involved. I will also interview some therapeutic radiographers to gain their views on information they give to patients having radiotherapy for prostate cancer.

What are the possible disadvantages of taking part?

There is a very small possibility that answering some questions may cause you to become upset, or feel embarrassed, especially if the answer you want to give is of a personal nature. However if this happened I would stop until you felt ready to continue, or rearrange another visit. **You do not have to answer if you do not want to.**

What are the possible advantages of taking part?

I cannot promise the study will help you or your partner/husband directly, but the knowledge gained from this study may help us to understand issues regarding radiotherapy information for patients with prostate cancer and therefore improve the experience of patients in the future.

What will happen to the results of the research study?

The findings of this study will be written up as my Doctoral Thesis. The findings will be presented at conferences related to radiotherapy and/or research and published in reports in professional journals. To ensure your anonymity, you will not be identifiable in any presentations and reports. The raw data from the study will be destroyed 3 years after the end of the study (this is standard University practice).

iii) Consent forms

University of Hertfordshire
College Lane
Hatfield
Herts
AL10 9AB

UH HHSEDC protocol no: HSK/PGR/NHS/02450. IRAS project ID: 166436

Participant Identification Number for this study:

CONSENT FORM (Patients)

Title of Project: The lived experiences of men with early-stage prostate cancer when receiving information related to a course of radiotherapy in the UK.

Name of Researcher: Lynne Gordon

Please initial
all boxes

1. I confirm that I have read and understood the information sheet dated 5/17 (version LG V7 5/17) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected. If I withdraw from the study any data from me will be destroyed.
3. I agree to the use of digital voice recording equipment during the research interview.
4. I understand that the recorded interview will be transcribed into a written format by either the researcher or commercial transcription service.
5. I agree that direct quotes from the interview can be used anonymously as quotations in the presentation of the research.
6. I understand that the researchers will contact the senior manager if I tell the interviewer about an incident involving, for example, poor patient care.

Consent form date of issue: 5/17
Consent form version number: 8

Page 1 of 1

7. I agree that my wife/partner can take part in the study and will be interviewed at the same time/ at a different time to me (delete as appropriate)

8. I agree to take part in the above study.

Name of Participant Date Signature

Name of Person taking consent
(if different from researcher) Date Signature

Name of Researcher Date Signature

Consent form date of issue: 5/17
Consent form version number: 8

Page 1 of 1

UH HHSEDC protocol no: HSK/PGR/NHS/02450. IRAS project ID: 166436

Participant Identification Number for this study:

CONSENT FORM (Partner/wife)

Title of Project: The lived experiences of men with early-stage prostate cancer when receiving information related to a course of radiotherapy in the UK.

Name of Researcher: Lynne Gordon

Please initial
all boxes

1. I confirm that I have read and understood the information sheet dated 5/17 (version LG V3 5/17) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my legal rights being affected. If I withdraw from the study any data from me will be destroyed.
3. I agree to the use of digital voice recording equipment during the research interview.
4. I understand that the recorded interview will be transcribed into a written format by either the researcher or commercial transcription service.
5. I agree that direct quotes from the interview can be used anonymously as quotations in the presentation of the research.
6. I understand that the researchers will contact the senior manager if I tell the interviewer about an incident involving, for example, poor patient care.

7. I agree to take part in the above study.

Name of Participant Date Signature

Name of Person taking consent
(if different from researcher) Date Signature

Name of Researcher Date Signature

Appendix 10 - MPC and spouse interview topic guide

Research title: The lived experiences of men with early-stage prostate cancer when receiving information related to a course of radiotherapy (RT) in the UK.

Patient/spouse topic guide

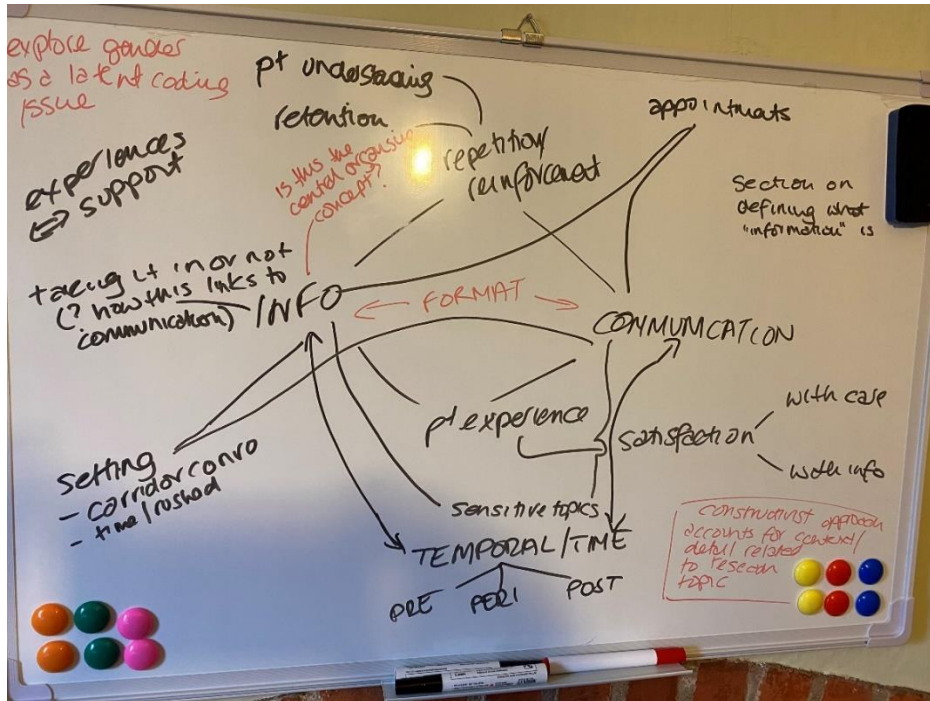
Participant IDNO	Spouse/partner present Y/N	Researcher Initials
Date		
Introduction		
I am Lynne Gordon from the University of Hertfordshire		
<ul style="list-style-type: none"> ✓ General purpose of the study ✓ Aims of the interview and expected duration ✓ Who is involved in the process (other participants) ✓ What will happen with the collected information and how the participant/target group will benefit ✓ Any questions? ✓ Consent 		
(Start voice recorder here)		
Warm up [demographic & brief history related to diagnosis]		
Can I ask some details about you and your prostate cancer?		
Ethnic/cultural background		
When diagnosed.....		
Date of birth		
Marital status:.....		
Address (for transcript checking/results)		
<p>Now I am going to ask you some questions about your experiences related to the information received relating to your radiotherapy treatment.</p>		
Domain	Topic and Probes	
Information given about RT at new patient stage	<p>Can you tell me about the first time you met your consultant?</p> <p>What information did you receive at that time?</p> <p>Who gave the information?</p> <p style="padding-left: 40px;"><i>Question further about the nature of the staff</i></p> <p>What format was the information in?</p> <p style="padding-left: 40px;"><i>Question further about usefulness of format, content, amount of info.</i></p> <p>Did you have some understanding of what you were being told? <i>(or read – probe according to format mentioned in previous question)</i></p>	

	<p>Tell me about your expectations regarding information you thought you would be given.</p> <p>What were your feelings at the time?</p> <p>In what way (if at all) did this impact on your understanding of the information?</p> <p>Had you looked anywhere else for information about radiotherapy before this meeting? (<i>probe what/where from</i>)</p> <p>What was your understanding of radiotherapy before you were diagnosed?</p> <p>How did the information you received influence your understanding of radiotherapy?</p> <p>How well did the information meet those expectations?</p> <p>Was it what you needed?</p> <p><i>Why was this?/ If not why not?</i></p> <p>At that time, what was most important for you to know about the radiotherapy?</p> <p>What is your opinion about the quality of the information given?</p> <p>Tell me about the environment you were in when you received the information?</p> <p>Can you recall any particular issues that might have impacted on the consultation; for example noise, comfort?</p> <p>Tell me about any aspect of this appointment that particularly stands out in your memory.</p> <p>If you think overall about the information that was given at that point, do you have any comment about whether anything could have been done better?</p> <p><i>Probe:— either about the way it was given or the content of the information.</i></p> <p>Tell me what happened after the consultation: did you discuss the information with anyone? If so, who? What did you discuss?</p> <p>Did you feel that the information was what you needed at that time?</p> <p><i>Probe further depending on answer. —</i></p> <p><i>Was it enough or too much?</i></p> <p><i>Did you have enough time to act on the information?</i></p> <p><i>Was there anything that you felt was not addressed?</i></p>
<p>Information given during the RT planning and treatment process</p>	<p>Tell me how the radiotherapy went for you.</p> <p>Thinking back to the information you were given before you started, did you feel prepared for the treatment?</p> <p>How did the reality of treatment compare to the expectation?</p> <p><i>Probe on how well prepared they felt</i></p> <p>How did the information you received contribute to how you felt about having radiotherapy?</p> <p>Is there anything you were not told that in retrospect, you think you should have been? And conversely, is there anything you were told that in retrospect, you wish you had not been told?</p> <p>Tell me about the information you received on your first day of treatment.</p> <p><i>Probe who, what where, when</i></p> <p>Did you receive any other information during the course of treatment? If so what was it?</p> <p>Did you have to ask for information? Did you understand what was being told to you?</p>

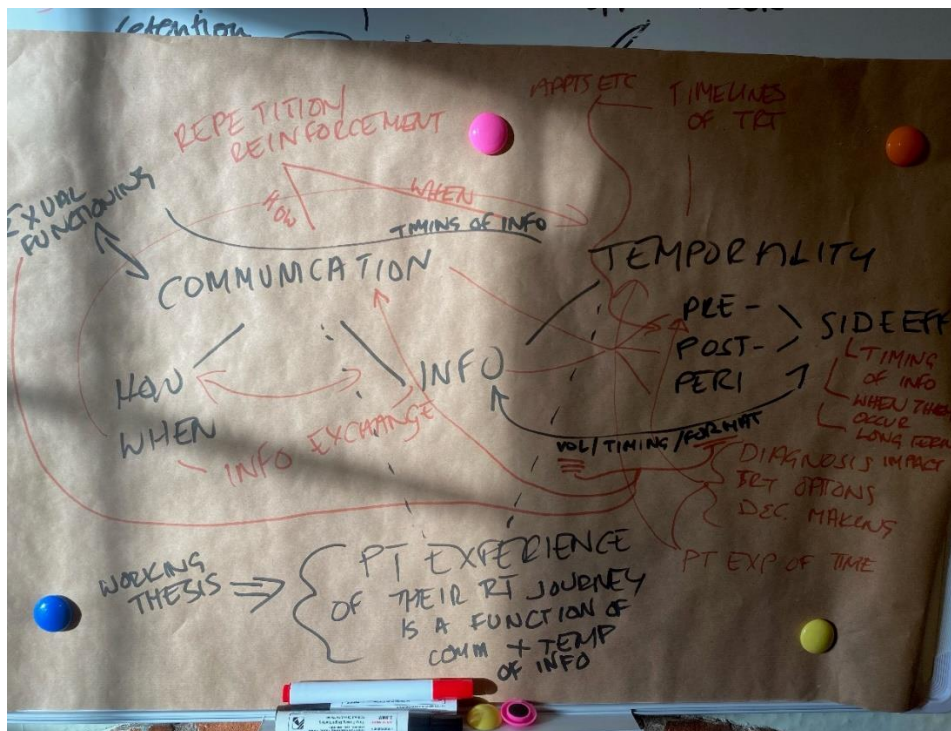
	<p><i>probe answers to these questions.</i></p> <p>Who gave the information? <i>Question further about the nature of the staff</i></p> <p>What format was the information in? <i>Question further about usefulness of format, content, amount of info.</i></p> <p>Did you have some understanding of what you were being told? <i>(or read – probe according to format mentioned in previous question)</i></p> <p>How useful was the information? <i>Probe according to negative/positive answer</i></p> <p>Can you think of anything that would have made a difference to the information you received? <i>(probe according to answer but might include– format, timing, staff, explanation, content)</i></p> <p>Is there anything else you would like to tell me about the information you received?</p>
<p>Information related to the end of RT and immediate follow up period</p>	<p>Tell me about the end of your course of treatment – what information were you given. <i>How useful was it?</i></p> <p><i>Is there anything you think you should or could have been told about?</i></p> <p>If you look back over your course of treatment, what would be your overall opinion about the information you received?</p>
<p>Closing</p>	<p>Is there anything else you would like to tell me about your experiences of radiotherapy?</p> <p>Would you like to receive a summary of the findings? Yes <input type="checkbox"/> No <input type="checkbox"/></p> <ul style="list-style-type: none"> ✓ Summarise ✓ Thank participant ✓ Provide extra/support information and contacts to participants

Appendix 11 – original concept map photographs

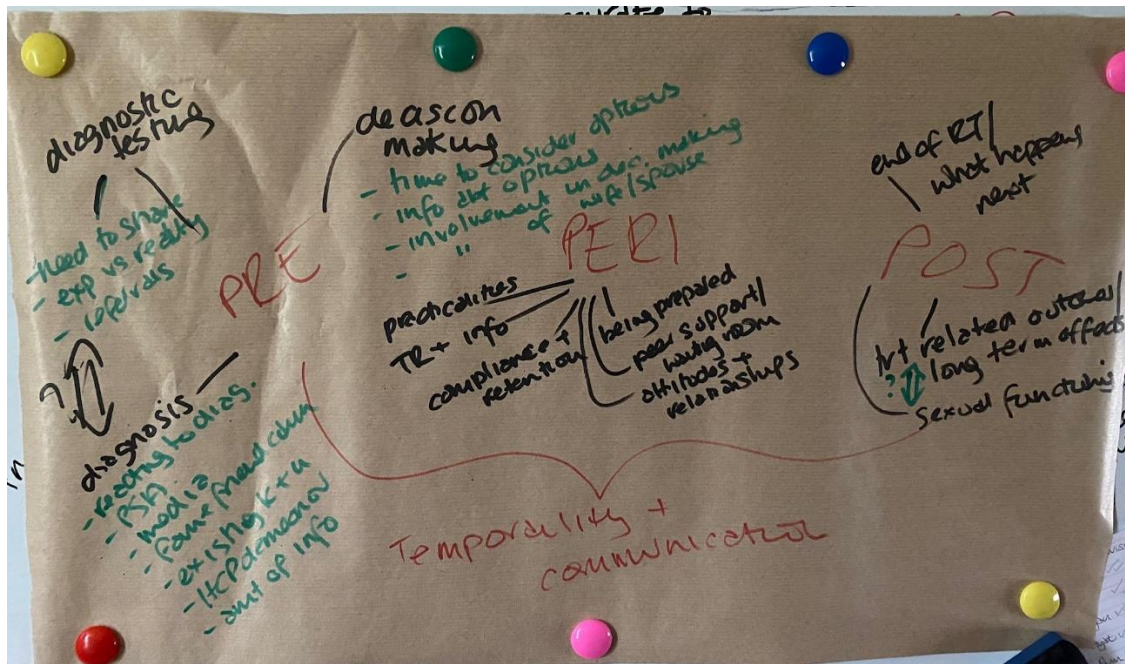
Original hand drawn concept map – redrawn as figure 4 in chapter 3



2nd concept map redrawn as figure 5 in chapter 3



3rd concept map redrawn as figure 6 in chapter 3



Appendix 12 – NVIVO 12™ screenshots

Screenshot relating to patient factors/priorities and car parking as an example of parent/child nodes:

The screenshot shows the NVIVO 12 interface with the 'Nodes' list on the left and a detailed view of the 'car parking & travel issues' node on the right.

Name	Files	References	In Folder	References	Coverage
equipment, technology	18	56	Adam	2	2.84%
expectations related to diagnosis, treatment and outcomes	23	168	Adrian	1	1.10%
explanations	21	130	Andy & Carol	5	2.08%
general health, comorbid conditions or comparison with ot	14	75	Angus & Elsie	2	2.41%
get it done or get on with it	13	26	Bill	5	5.15%
HCP rad or staff issues	23	322	Bob	2	2.89%
info exchange	23	444	Charles & Ruth	2	1.13%
info format	23	558	Clive	2	2.59%
information and issues during local & trt period	8	15	Dan & Lydia	3	4.70%
information and issues related to the post- or end of treat	23	318	Donald & Denise	1	0.70%
information and issues related to the pre-treatment period	23	958	Henry & Gail	1	0.43%
positivity	15	42	Jack	2	3.94%
pt factors or priorities	23	654	Martin	1	2.43%
outside influences	3	10	Murray & Beryl	2	1.00%
patient to blame	4	13	Paulo	1	0.40%
practicalities	21	99	Philip & Kim	5	2.61%
car parking & travel issues	20	50	Radiog FG 1	1	0.17%
financial info or advice	3	8	Ralph & Mary	3	1.56%
pragmatism or acceptance or not	19	81	Tom & Andrea	3	1.77%
psychological impact	13	45	Victor & Victoria	6	7.14%
pt experience	19	59			
relationships	23	156			
routine, change in routine or normality	23	156			
statistics or numbers	2	16			

Screenshot of node hierarchy

The screenshot shows the NVIVO 12 interface with a node hierarchy on the left and a treemap visualization on the right. The treemap is titled 'Compared by number of coding r' and displays a complex hierarchy of nodes and their relationships, color-coded by category.

Table detailing parent and child nodes used to code data in NVIVO 12™

Final NVIVO coding			
Parent node (n=31)	Child node (n=87)	Subnode (n=40)	
Amount of info	Info overload		
	Lack of info		
assumptions about pt k & u or info needs	assumed and or pre-existing knowledge		
communication	being treated as an individual		
	communication about or concerns regarding appointments	manner of communication of info thrown at them	
	impact of language on communication		
	issues with HCP that impact on communication	communication between staff or teamwork effectiveness of communication record keeping and admin staff demeanor whether HCP is helpful	
	negative aspects of communication		
	point of contact to communicate re. advice or info		
	talking and listening to people		asking or answering questions communication in meetings or discussions with HCP difficult conversations negative aspects of talking and listening taking advice
comparing or relating experiences	shared experience		
	went through it		
demographic or diversity issues impacting on info communication or exchange	age as influence		
	culture as influence		
	family history		
	gender issues		
emotions or psych issues	empathy		
	humour		
	negative emotional responses related to their cancer management		
equipment, technology			
expectations related to diagnosis, treatment and outcomes			
explanations			
general health, comorbid conditions or comparison with other medical issues			
get it done or get on with it			

HCP rad or staff issues	acknowledging staff pressures	
	collaborative approach	
	everyday occurrence for staff	
	experience, expertise or professionalism of staff	HCP lack of knowledge
	reference to specialist rad or other staff	
info exchange	how info is used or shared	
	info barriers	
	info needs	
	reading info	
info format	info quality	tailored or individualised information
information and issues during local & trt period		
information and issues related to the post- or end of treatment	consequences	
	follow up	
	new normal	
	not knowing or uncertainty	
	outcome of treatment	
	what the future holds	
information and issues related to the pre-treatment period (before localisation)	decision making	choices available to patients
		lack of choice
		lack of info for decision making
	diagnosis	background to diagnosis
		confirming suspicions
		diagnostic testing and procedures
		misdiagnosis
		PSA
		pt initiating diagnosis
		shock or shellshocked
	signs and symptoms of prostate cancer	
	pre treatment info	
	regular monitoring pre diagnosis	
treatment options		
waiting or anticipation		
pt factors or priorities	outside influences	
	patient to blame	
	positivity	
	practicalities	car parking & travel issues
		financial info or advice
	pragmatism or acceptance or not	
	psychological impact	
	pt experience	previous experience of health care
	relationships	impact on family & relationships
		relationship with staff
		waiting room club
routine, change in routine or normality	getting to the toilet or frequency of use	
statistics or numbers		
pt factors related to info use or understanding	awareness of cancer mgt and info sources	
	compliance with info	
	info seeking	
	retention of info	
	review, reflection and interpretation	

	of info	
pt knowledge & understanding		
quality of patient care		
satisfaction		
sensitive topics	sexual functioning	
setting or impact of environment		
side effects	hormones and side effects	
	impact of side effects or cancer on lifestyle	
	incontinence	
	radiotherapy side effects and management	bladder and bowel prep long term side effects short term side effects
sources of info	charity info sources	
	HCP sources	
	media or internet sources of info	
	patient sourced info	
temporal aspects	delays to treatment or start of trt	
	time constraints	
	time to consider options	
	timing of info giving	
the support received or required for RT pts	daily and or ongoing support	lack of support
	fitness or exercise	
	on-treatment review	
	organised or group based support	
	peer support & education	
	referral on to specialist support services	
	related to support needed from- or for- family	concern for spouse emergency support or info family spouse or friends involvement family support
treatment or localisation procedure	being prepared or not for treatment	
	pt failing or repeating scan	
	pt feels at fault or fear related to set up issues	
	radiation and dose multiple scans related to the localisation process	
treatment related information	standardisation	
	students and info giving	
usefulness of info	accessibility or availability	
	doesn't really tell you anything	
	inaccurate or incorrect info	
	whether information is used	