



Review Article

Men's perceptions and preferences regarding prostate cancer radiation therapy: A systematic scoping review

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ABSTRACT

Purpose: To assess the literature on men's preferences and perceptions regarding prostate cancer radiation therapy.**Methods:** A scoping review was undertaken as per JBI guidelines. Searches were conducted in PubMed, CINAHL, Scopus and Science Direct with search terms including "prostate cancer," "radiotherapy," "radiation therapy," "radiation oncology," "patient preferences," "patient perceptions" and "patient experience." The resultant studies were mapped and grouped according to the emergent themes and pathway stages.**Results:** A total of 779 titles and abstracts were screened by two independent reviewers. Fifty-two full-text studies were reviewed, with 27 eligible for inclusion. There were 4 pre-treatment, 13 during treatment and 10 post-treatment studies covering broad themes of information needs (n = 3), preferences and decisions (n = 6), general experiences (n = 8), side effects (n = 6), and support (n = 4). There were a mix of methodologies, including 11 qualitative, 14 quantitative (including four preference studies), one mixed methods and one narrative review.**Conclusion:** There were only four preference studies, with the remaining 23 reporting on perceptions. Overall, there is a paucity of literature regarding patient preferences and perceptions of prostate cancer radiation therapy, particularly when considering how many clinical and technical studies are published in the area. This highlights opportunities for future research.

Background

Primary treatment for prostate cancer can include surgery (prostatectomy), hormones and radiation therapy, or a combination of these. Active surveillance is a further option for patients diagnosed with low-risk disease. The clinical efficacy and patient-reported outcomes of these primary treatments are well documented. [1–6].

The treatment options and pathway for each individual is negotiated between the patient and their health professional and is influenced by numerous factors. As reported in previous studies and systematic reviews, patients' choices of primary treatment(s) are influenced by both health and non-health related factors. [7–9] Perceptions of efficacy, side

effects and clinician recommendations influenced preference for primary treatment and management of localised prostate cancer. [7] Personal beliefs and the beliefs of others (such as clinicians, family and friends) about cancer, treatment efficacy and the severity of possible side effects have also been shown to influence treatment choice. [8] Even though treatment efficacy and side effects are influential factors, it has been reported that there are large variations in how men considered the importance of these two factors in relation to their treatment choice. [9] Systematic reviews on both decision aides and shared-decision making (SDM) demonstrate the complexity of the decision-making process following a prostate cancer diagnosis. [10–12] The existing systematic reviews on patient perceptions and preferences regarding

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prostate cancer radiation therapy treatment focus solely on the primary treatment choice, rather than the more nuanced aspects of radiation therapy. [7–9].

Choosing primary treatment is one of the most significant decisions for a patient with prostate cancer. However, it is just one of many decisions and experiences in the prostate cancer treatment pathway. Even when a patient chooses radiation therapy as their primary treatment, there are a number of aspects to the delivery of care where patient perception and preference are important. The radiation therapy treatment pathway is defined by three distinct phases: pre-treatment preparation, treatment and follow-up post-treatment. Pre-treatment preparation includes information needs, shared decision making and preparatory procedures such as fiducial marker insertion for image guidance. Treatment may include daily treatment preparation (such as bowel/bladder filling protocols) and fractionation schedules. Post-treatment follow-up may include decisions about who provides follow-up care (e.g. nurse or radiation therapist-led models), frequency of follow-up appointments and survivorship aspects. While most active decision-making occurs when choosing primary treatment, there are various points during the three following phases where patients have choices: for example, an individual may choose not to have fiducial markers inserted, a radiation oncologist may give the patient a choice on the fractionation schedule or a choice between in-person or telehealth follow-up appointments).

Our scoping review aims to answer the following question, “What is known about patients’ perceptions of prostate cancer radiation therapy from preparation to treatment and follow-up?.” This review seeks to identify patient perception and preference knowledge gaps so that future research can be undertaken to inform prostate cancer radiation therapy service delivery.

Methods

A scoping review, with supporting protocol, [13] was conducted as per JBI methodology. [14] The review question was developed using the Participants, Concept and Context (PCC) framework (Table 1). [14] Eligible sources included peer-reviewed studies, theses and grey literature such as professional guidelines. Inclusion and exclusion criteria are outlined in Table 1.

Search Strategy, Sources and Screening

Electronic databases of PubMed, CINAHL, Scopus and Science Direct were searched using combinations, synonyms and truncations of the following key search terms: “prostate cancer,” “radiotherapy,” “radiation therapy,” “radiation oncology,” “patient preferences,” “patient perceptions” and “patient experience” (Supplementary). Grey literature sources and government, policy and college websites (including the American Society for Radiation Oncology (ASTRO), the European Society for Radiation Oncology (ESTRO), and the Royal Australian and New Zealand College of Radiologists (RANZCR)) were also searched. No date limits were applied.

Each title and abstract were screened independently by two reviewers (AB, and SJ or JY) for eligibility in abstract. [15] Full-text review was undertaken by two reviewers (AB, and SJ or JY) of all eligible studies, with any uncertainty discussed with the third reviewer until consensus was reached.

Data extraction

A data extraction form was initially developed and tested on 3 studies, with all co-authors agreeing on the data inclusion. Data from all eligible studies were extracted by one author (AB) and verified by at least one other author (SJ or JY). Data extraction included: year of publication, country, major theme addressed, stage of radiation therapy described/studied (pre-treatment, during treatment, post-treatment

Table 1

Participants, Concept and Context of Scoping Review; with Inclusion and Exclusion Criteria.

Scoping Review	Inclusion	Exclusion
Participants	Men / Individuals with or who have had prostate cancer	<ul style="list-style-type: none"> • Comparisons/ Contrasts of primary treatments (e.g. surgery versus radiation therapy) • No clear indication of prostate cancer sub-population (i. e. general oncology perceptions) • Perceptions of carers, families, or other proxies (with no report of patient perceptions) • Perceptions of health professionals (with no report of patient perceptions) • Opinion pieces/ editorials • Language other than English
Concept	Perceptions – including experiences and preferences May include, but not limited to: <ol style="list-style-type: none"> 1. Pre-treatment preparation specifics such as information provision or needs 2. Treatment specifics such as side effects, fractionation schedules, image-guidance etc 3. Follow Up such as nurse or radiation therapist-led post treatment reviews; frequency of follow up; survivorship requirements 	
Context	Prostate cancer radiation therapy	

pathway), aim/s, population and sample size, key findings, and limitations and/or biases presented in the record. The results are presented grouped by major theme, across the treatment pathways.

Results

After removing duplicates, the initial search yielded 779 records with 727 excluded after title and abstract screening. No records were included from the grey literature. One record eligible in title/abstract screening could not be retrieved as it did not have an English translation. Of the 51 full-text records assessed, a total of 27 studies covering 25 study populations were eligible and were included in this review. Reasons for exclusion are detailed in the PRISMA flow diagram (Fig. 1).

The data extraction is presented in Table 2, grouped according to theme. The broad themes of information needs (n = 3) [16–18] preferences and decisions (n = 6) [19–24] general experiences (n = 8) [25–32] side effects (n = 6) [33–38] and support (n = 4) [39–42] are detailed in a matrix mapping the themes of each pathway (Fig. 2). Collectively, the three major stages of the prostate cancer pathway were described, with four addressing pre-treatment aspects; [16–19] 13 addressing during-treatment aspects; [20–22,25–28,33–35,39–41] and ten addressing post-treatment aspects. [23–24,30–32,36–38].

A range of methodologies were reported: 11 using qualitative methods, [16,27,40,31–32,34–37] 14 using quantitative survey-based methods, [26,28–29,33,38–39,19–24] one mixed-methods study [25] and one narrative review. [17] Of the studies using quantitative methods four were preferences studies (including three discrete choice experiments and one best-worst scaling survey). [21–22]

Many studies included perspectives of men who underwent a range of treatments including surgery and hormonal therapy. The majority of

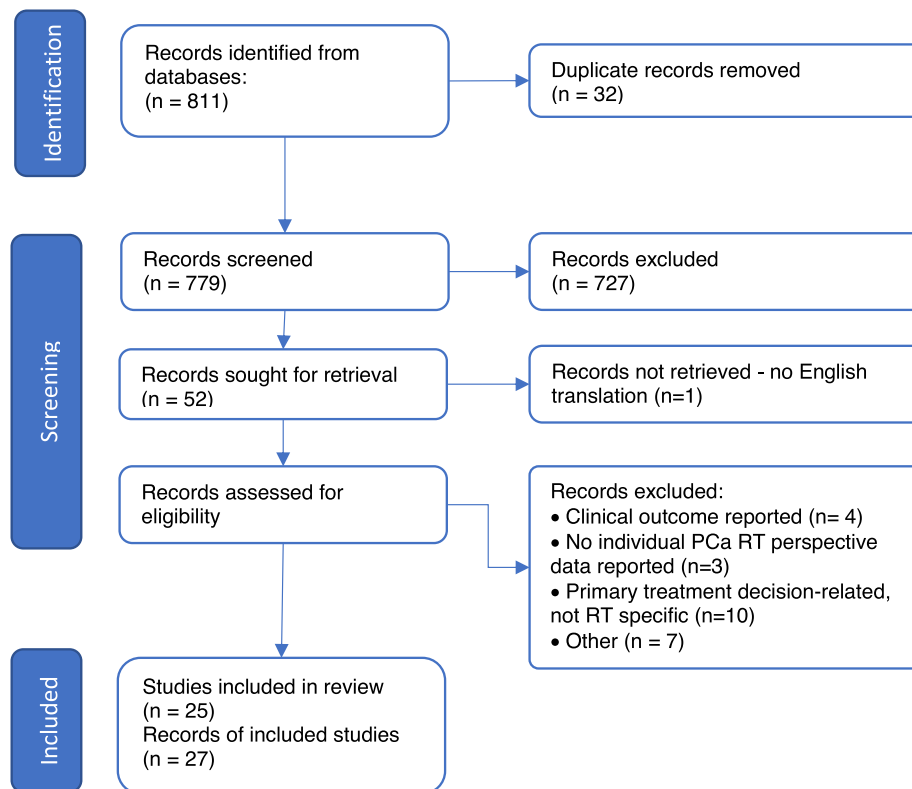


Fig. 1. PRISMA flow diagram; PCa: Prostate cancer; RT: Radiation therapy.

studies involved men who underwent external beam radiation therapy to the intact prostate, [18–19,29,32,35–36,42] and three of these studies also investigated stereotactic body radiation therapy (SBRT) and/or hypofractionation. [19,29,35] Six of these studies included other modalities such as brachytherapy [18,29,32,36,42] and one also included proton therapy. [29] One study focused on radiation therapy in the post-prostatectomy setting. [29] A number of studies included a range of treatments/modalities. [18,27,29,33] The complete details of treatment regimens were not specified [33] or were unclear in some studies, [18,27] usually when different treatment modalities were undertaken.

One study reported in two manuscripts included the perspective of the carer in addition to the patient, [16,42] and another included patients' partners at the patient's invitation. [30] Two studies each resulted in two separate records: Foley et al (2016, 2018) reported on 108 patients undergoing radiation therapy in Canada; [26,39] and Johnson et al (2021) and Chen et al (2021) reported on 216 men and 97 carers in the United Kingdom, [42] with a subset of 19 men and 6 carers interviewed. [16].

Countries represented in the studies included Australia, [21,28,24–25] Canada, [18,20,26,39] Denmark, [32] Germany, [37] Italy, [27] Netherlands, [19] Sweden, [34–35] United Kingdom [17,30–31,36,38,40–42] and United States of America. [22,29] The studies were published in a range of journals. Eleven were published in radiation therapy/radiation oncology specific journals and the remainder in varying oncology or other medical or supportive care journals. The earliest study was published in 2007, [19] with a noted increase in recent years.

Information Needs

Information needs were an important factor for patients undergoing radiation therapy. Three studies were focused on the pre-treatment phase (n = 3). [16–18] Across the studies, 247 men [16,18] and 97 carers [16] were surveyed and 25 men interviewed. [16] Additionally,

two studies covered information needs during treatment as a secondary focus with one in the post-treatment phase. [40–42].

Tailored information and the manner in which it was delivered was identified as important, not just at time of diagnosis but throughout the treatment journey. [16] The information needs of post-prostatectomy patients referred for radiation therapy were varied, with all domains presented (including diagnosis, decision making, radiation therapy procedures, benefits, side effects, and support network) in the survey deemed as essential by at least some participants. [18] These results were corroborated by the narrative review investigating information needs around radiation therapy for prostate cancer patients. In this review the authors argued that information needs, preferences and satisfaction varied, and noted that few records focussed only on prostate cancer. [17].

Patients reported they needed more information about radiation therapy processes such as bowel and bladder preparation as a secondary focus when discussing support. For example, some participants requested instructions in addition to the reasoning behind these requirements, however it is noted that while this information may be provided to patients, it may not be retained by all. [40–41] The information needs following treatment reflected the different phase of the treatment pathway, with a need for improved communication/information around survivorship and palliative care reported by both patients and carers. [42].

Preferences / Decisions

Preferences and decisions covered specific aspects of radiation therapy including fractionation and image-guidance, as well as understanding values and trade-offs made by participants. The preferences and decisions/decision making of participants were reported in six studies, with one focussing on pre-treatment, [19] three focussing on during-treatment [20,21] and two post-treatment. [23–24] 1055 participants were surveyed across the studies (survey population ranging

Table 2
Summary of included literature.

Reference	Country & Treatment Pathway Stage	Aim/s	Population and Sample Size	Methods	Key Findings	Considerations†
Information Needs						
Chen et al (2021) [16]	United Kingdom Pre-treatment	To gain an understanding of men's experience of and specific needs for information and communication	Prostate cancer men in United Kingdom Interviews: 19 patients and 6 carers *Interviewees invited from survey population of Johnson et al (2021)	<i>Study Design:</i> Qualitative descriptive Semi-structured interviews Framework analysis, with deductive and inductive approach	Four themes emerged: Information gaps Professional communication skills Individualisation of information Alternative information sources These were important not just at time of making a treatment decision, but throughout the cancer journey – e.g. understanding side effects of radiation therapy and what to do about them – the “real-life” implications of treatment.	Not clear how many participants had radiation – however the sampling frame indicates aiming for 3–4 patients. It is recognised that those who participated may be self-advocates and able to seek/engage with support
Gordon et al (2019) [17]	United Kingdom Pre-treatment	To identify, synthesise and analyse literature reporting the experiences of men with PCa related to information in radiotherapy	33 articles from 2000 to 2017 were identified	<i>Study Design:</i> Systematic literature review Quality assessment to assess validity and reliability Synthesis and thematic reporting	Many articles included radiation therapy patients more broadly than only focusing on PCa. Themes identified information needs information regarding adverse effects information and time information preferences satisfaction with information related to radiotherapy patient experience related to radiotherapy information	Many qualitative studies did not report on validity and reliability
Thavaraiah et al (2015) [18]	Canada Pre-treatment	To investigate patient opinions about information that should be discussed/provided to patients requiring radiation therapy post-prostatectomy.	New and follow-up patients who were referred for consultation N = 31 78% accrual rate Time of Survey Completion (to RT): Prior: 10 (32.3%) During: 12 (38.7%) After: 9 (29.0%)	<i>Study Design:</i> Quantitative Once-off survey Included domains of: understanding situation & diagnosis making a decision radiotherapy procedures potential benefits side effects supportive network during radiation therapy Likert-type scale rating importance, ranging from essential to avoid.	Variability between respondents with every question essential to at least some patients, and majority of questions were rated as either essential or important. However, no domains were deemed essential by 100% of respondents.	Generalisability as only one centre
Preferences & Decisions						
Stalmeier et al (2007) [19]	Netherlands Pre-treatment	To evaluate if radiation oncologists know what patient preferences are regarding two radiation dose options	150 patients from two different centres scheduled to undergo RT (50 did not consent)	<i>Study Design:</i> Qualitative Interview with Decision Aid (on 2nd visit to clinic having been provided with general radiation therapy information on 1st visit), with preferred treatment followed up by telephone 2 days later. Patients also indicated their decision-making preference. Choice between two radiation doses of 70 Gy or 74 Gy (trade-off between disease-free survival and adverse side effects).	79% of patients preferred an active participation role. 71% of patients favoured the less toxic treatment, whereas the radiation oncologist predicted only 51%. Overall agreement was 60% (k = 0.20) 31 patients did not want to choose, and 25 ROs did not provide substitute treatment preferences Agreement between patient preference and radiation	

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Table 2 (continued)

Reference	Country & Treatment Pathway Stage	Aim/s	Population and Sample Size	Methods	Key Findings	Considerations†
Sigurdson et al (2022) [20]	Canada During Treatment	To quantify patient preferences for toxicity and convenience of regimens of EBRT, to contribute to clinician counselling of treatment options with PCa patients	Prostate Cancer Patients who had either recently completed or were completing EBRT for PCa n = 58	Compared to radiation oncologist's substitute preferences, gauged at first clinic. Analysis: K statistic for agreement, with bivariate and multivariate analysis <i>Study Design:</i> Quantitative DCE – completed with interviewer 12 choice tasks completed 24 total choice sets Pilot: 6 patients Attributes/Levels: 1. Length of EBRT: 2 weeks (5#) / 4 weeks (20#) / 8 weeks (40#) 2. Marker implant Yes / No 3. PSA recurrence risk: 6% / 12% / 18% 4. Acute GI or GU toxicity risk: 20% / 35% / 50% 5. Late GI or GU toxicity risk: 10% / 15% / 20% Analysis: Multinomial logit and Mixed multinomial logit Latent Class analysis <i>Study Design:</i> Quantitative	oncologist prediction improved when patient was more hopeful and with RO experience Overall preference: • Lower recurrence risk • Lower side effects risk • No marker implantation • Shorter treatment time >70 years old preferred shorter EBRT Those living further away preferred shorter EBRT Reduction in risk of PSA recurrence – respondents more likely to be working Individuals were willing to increase length of EBRT to avoid fiducial markers and risk of worse efficacy or toxicity	Status quo bias / cognitive discordance recognised – i.e. that patients may “defend” their own treatment experience, particularly as partway through (43.1%) or recently completed treatment (56.9%)
Brown et al (2022) [21]	Australia During Treatment	To elicit preferences of men for IGRT techniques used in prostate radiation therapy	238 men with previous prostate cancer diagnosis 240 men from general population	DCE completed online or via paper Pilot: 27 men with PCa, 57 general population men Attributes/Levels: 1. Pain: No Pain / Low / Medium / High / Worst 2. Side Effects: Decreased / Same 3. Accuracy: Same / Increased 4. Additional Time: 5 / 15 / 30 min 5. Additional Appointments: No / One / Two Appointments 6. Cost: 0 / \$50 / \$150 / \$2500 Analysis: Multinomial logit modelling Latent Class Analysis (LCA) Marginal willingness to pay (mWTP) <i>Study Design:</i> Quantitative	Overall preference: • Less cost • Less pain • Improved accuracy PCa men valued accuracy more than general population PCa patients willing to pay more to avoid the worst pain than the general population, and willing to pay more for increased accuracy 3 sub-groups identified in LCA, concerned with: 1. Process-related attributes of pain, cost, as well as side effects 2. Process-related attributes of pain, cost as well as additional appointments 3. Clinical efficacy attributes of accuracy and side effects.	Different demographic characteristics between the two cohorts – differences between preferences of two cohorts must be interpreted with this in mind
Mishra et al (2020) [22]	USA During Treatment	Determined which bowel side effects prostate cancer patients find to be most impactful	174 PCa respondents – varied primary treatments EBRT: 81 ADT: 53 Prostatectomy: 51 Prostatectomy: 27 Brachytherapy: 24 AS: 15	Best-Worst scaling Orthogonal design – 18 tasks Attributes (with Levels of Moderate, Small and Very small for all) : • Urgency • Pain • Control	Most bothersome: Control Least bothersome: Frequency Proposed attribute bother weights: • Urgency 20.8% • Pain 18.7% • Control 29.5% • Bloody stools 17.6% • Frequency 13.4%	Demographics reporting was voluntary therefore a lot of missing data. Preference heterogeneity may be lacking as predominately Caucasian respondents Only 12 from one site, compared to 169 from other site.

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Table 2 (continued)

Reference	Country & Treatment Pathway Stage	Aim/s	Population and Sample Size	Methods	Key Findings	Considerations†
			Recruited from 2 institutions	<ul style="list-style-type: none"> Bloody stools Frequency 		
Eade et al (2021) [23]	Australia Post Treatment	To evaluate patient's treatment decision and decision regret in stereotactic body radiation therapy (SBRT)	112 out of 120 eligible patients consented and completed the survey	<p>Attributes/levels based on bowel subscale of the EPIC-26 short-form</p> <p><i>Study Design:</i> Quantitative</p> <p>Survey – patient reported outcome measures</p> <p>Treatment decision: How much did the option of having 5 stereotactic treatments (as compared to 20 to 40 visits of standard radiation) influence your decision to receive radiation treatment for your prostate cancer?</p> <p>Decision regret: Do you regret the choice of treatment (5 fraction stereotactic radiotherapy) for your prostate cancer compared to other treatment options?</p> <p><i>Study Design:</i> Quantitative</p>	<p>74% reported the SBRT regime was a significant factor in their decision making.</p> <p>Decision regret associated with toxicity, particularly urinary bother</p> <p>5 patients (4%) reported “quite a lot” of regret. 1 patient had biochemical control and no reported bother (bowel, bladder or sexual) – appeared to regret not having surgery.</p>	<p>Note: this article also evaluates treatment outcomes not presented here.</p> <p>An aim was not specified in the article.</p>
King et al (2021) [24]	Australia Post Treatment	To quantify the patient preferences of relative tolerability of adverse side effects or survival gains needed to make side effects worthwhile in the treatment of localised prostate cancer	<p>422 total</p> <p>Active surveillance (n = 64)</p> <p>Radical prostatectomy (n = 66)</p> <p>External beam radiotherapy (EBRT) (n = 29)</p> <p>Androgen deprivation therapy (ADT) (n = 31)</p> <p>EBRT + ADT (n = 37)</p> <p>LDR brachytherapy (n = 63)</p> <p>HDR brachytherapy (n = 66)</p> <p>Controls without PCa (n = 65)</p>	<p>Discrete choice experiment, with survival gains needed to justify persistent side effects estimated.</p> <p>Attributes: (Levels: No, Mild, Severe)</p> <p>Erectile dysfunction</p> <p>Loss of libido</p> <p>Urinary leakage</p> <p>Urinary blockage</p> <p>Bowel symptoms</p> <p>Fatigue</p> <p>Hormonal effects</p>	<p>Median survival benefit in months (with 2.5–97.5 percentiles):</p> <p>Severe erectile dysfunction: 4.0 (3.4, 4.6)</p> <p>Severe loss of libido: 5.0 (4.9, 5.2)</p> <p>Mild urinary leakage: 4.2 (4.1, 4.3)</p> <p>Severe urinary leakage: 27.7 (26.9, 28.5)</p> <p>Mild bowel problems: 6.2 (6.1, 6.4)</p> <p>Severe urinary and bowel symptoms were the least tolerable.</p> <p>Mild bowel problems were most prevalent after EBRT (30%)</p>	
General Experiences						
Brown et al (2021) [25]	Australia During Treatment	Explored experiences and preferences of patients undergoing IGRT - both fiducial marker (FM) insertion and Clarity ultrasound (US) procedures.	<p>Prostate Cancer</p> <p>Patients from single centre</p> <p>Survey = 40</p> <p>Interviews = 22</p>	<p><i>Study Design:</i> Sequential explanatory mixed methods:</p> <ul style="list-style-type: none"> Quantitative Surveys Qualitative Interviews <p>Surveys – investigator-developed; descriptive analysis</p> <p>Interviews – semi-structured with thematic analysis</p>	<p>Perceptions of invasiveness varied with 46% reporting FMs more invasive than US and 49% the same for the two procedures.</p> <p>Survey:</p> <ul style="list-style-type: none"> 46% FMs more invasive than US; 49% same invasiveness Mean scores for pain, physical & psychological discomfort were higher for FMs, only pain achieved significance (P < 0.05). <p>Three themes: Expectations versus Experience; Preferences linked to Priorities; and Motivations. Eleven patients (50%) preferred US; however, 10 (45%) could not illicit a preference.</p>	<p>Generalisability as only one centre</p>
Foley et al (2018) [26]		To describe the quality of personal care delivered to patient PCa		<p><i>Study Design:</i> Quantitative</p> <p>Questionnaire as for Foley et al (2016)</p>	<p>Top ranked elements included professionalism of ROs/RTs/Nurses to</p>	<p>Timing of questionnaires may reflect different timing in respondents'</p>

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Table 2 (continued)

Reference	Country & Treatment Pathway Stage	Aim/s	Population and Sample Size	Methods	Key Findings	Considerations†
		undergoing radiation therapy, to identify areas for improvement		, this article reporting on how quality of care was perceived	patients (including care, politeness, honesty and respect); knowledge of ROs/RTs, explaining and answering questions in a clear way, and taking the time to do so.	trajectories Generalisability as only one centre
Renzi et al (2017) [27]	Italy During Treatment	Assessed the experiences of prostate cancer men during radiation therapy treatment, with a particular focus on patient empowerment.	10 patients undergoing radiation therapy Radical: 3 Adjuvant: 3 Salvage: 4 (21 patients in total approached)	<i>Study Design:</i> Qualitative Semi-structured interviews, with thematic analysis Semi-structured interview guide was structured following explorative phase, examining department procedures/pathways and interpersonal dynamics experienced by the patients. 4 key theme areas identified: patient-healthcare providers' communication, decision-making, needs, and resources.	5/10 reported the possibility to share information and questions with at least one health care provider, and identified as having an active role in communication Burdens associated with radiation therapy were identified, including: travelling for treatment, being away from home, practical challenges with managing work around appointments, and preparation for radiation therapy including bladder and bowel. Resources which assisted included family and social support, economic resources, flexible appointment schedules around work commitments, supportive care including physiotherapists and case-managers.	Generalisability as only one centre. While interviewing patients undergoing radiation therapy, a lot was focused on diagnosis or pre- prostatectomy stages.
Hruby et al (2011) [28]	Australia During Treatment	To determine patient's ratings of physical and psychological discomforts associated with the brachytherapy procedure	58 men undergoing in-patient brachytherapy boost	<i>Study Design:</i> Quantitative Survey - adapted from a validated questionnaire for urodynamic and prostate biopsy "Prostate Brachytherapy Questionnaire" completed on consecutive days for 3 days during in-patient stay (during which, were bed-bound with brachytherapy template and catheter in place)	"Being stuck in bed" and "discomfort" were rated as most troublesome. Actual experience was rated better than expected by 60% of respondents. "Fear of opening my bowels" was rated to be worse than expected. These findings contributed to a change in protocol of 2 fractions delivered over 2 weeks, without the need for in-patient stay	Generalisability as only one centre
Shaverdian et al (2017) [29]	USA Post Treatment	Evaluation of treatment regret and patient perceptions of treatment experience between radiation modalities, including IMRT, SBRT and HDR.	276 prostate cancer patients (329 approached, 86% response) (IMRT, n = 74; SBRT, n = 108; HDR, n = 94) Single institution	<i>Study Design:</i> Quantitative Survey study, including decision-making experience, original expectations of toxicities versus realities, and treatment decision regret	87 % - fully informed about possible side effects Actual short term side effects less than originally anticipated: • IMRT: 56% • SBRT: 55% • HDR: 25%	A wide range of follow up: 12–93 months. Generalisability as only one centre

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Table 2 (continued)

Reference	Country & Treatment Pathway Stage	Aim/s	Population and Sample Size	Methods	Key Findings	Considerations†
				Analysis: chi-square or Wilcoxon test for comparing toxicity expectation with experience	Actual long term side effects less than originally anticipated: <ul style="list-style-type: none"> • IMRT: 20% • SBRT: 43% • HDR: 10% 	
					Long term side effects significantly more than expected in HDR and IMRT: self-reported problems with urinary, bowel and sexual functions.	
					Regret: 13% in total (19% IMRT, 18% HDR and 5% SBRT),	
Hackshaw-McGeagh et al (2017) [30]	England Post Treatment	To explore opinions, experiences and perceived acceptability of taking part in nutritional and physical activity interventions	16 men with PCa (4: Radiation therapy; 12: Surgery) 7 partners (4: Radiation therapy; 3: Surgery)	<i>Study Design:</i> Qualitative Semi-structured interviews Thematic analysis 6-month lifestyle intervention was described (30-min brisk walk, 5 days a week; and dietary changes or supplement).	Motivation for change: Diagnosis shock led to many taking stock of current lifestyle Motivated to reduce mortality and suffering, not specifically improving health/wellbeing. Facilitators of change Family support Health gains and clinical advice Rationale for change Anticipated enjoyment of lifestyle Barriers to change Poor weather Urinary incontinence (more so for post-prostatectomy patients) Time pressure Overall health Research considerations including participation, group versus individual interventions, data collection methods including digital etc were also explored	
Appleton et al (2015) [31]	United Kingdom Post Treatment	To explore how men receiving radiation therapy for PCa managed; and what aided/hindered their ability to adjust throughout	27 men in total n = 9 men prior to EBRT n = 8 men 6–8 months post EBRT n = 10 men 12–18 months post EBRT	<i>Study Design:</i> Qualitative Grounded theory approach Semi-structured interview	Impact of PCa and its treatment on daily life Living with PCa in the long term Painful biopsies were considered the worst part of the experience Radiation therapy preparation regimes caused discomfort and inconvenience. Side effects were often traded off against the benefits of radiation therapy	Cross-sectional sample – may have been different views if longitudinal

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Table 2 (continued)

Reference	Country & Treatment Pathway Stage	Aim/s	Population and Sample Size	Methods	Key Findings	Considerations†
Dieperink et al (2013) [32]	Denmark Post Treatment	Exploration of experiences with radiation therapy and ADT, and participation in a rehabilitation programme	Focus Groups × 2 Group 1 – spouse actively involved (n = 6 patients) Group 2 – alone (n = 7 patients)	<i>Study Design:</i> Qualitative Rehab programme – 2 nursing counsel sessions; two sessions of physio within 6 months post treatment Analysis of FG data: Phenomenological approach, with descriptive and meaning condensation analysis.	Influence on treatment on everyday life (including driving > 100 km per day for some) EBRT less complicated than expected. Handled mostly by themselves, but welcomed advice from health professionals. Rehabilitation was viewed as a way to return to normal life particularly after the months of treatment. Side effects – bother to bowel/bladder significantly decreased after EBRT “Accept things as they come” – particularly when told cured. Humour as coping strategy	
Side Effects Devlin et al (2019) [33]	Australia During Treatment	To investigate the association between patient response expectancies of side effects and subsequent toxicity experienced after prostate radiation therapy.	35 patients from two hospitals	<i>Study Design:</i> Quantitative Completed pre-treatment expectations survey; and repeated survey at 2 to 7 weeks during treatment Assessed 18 treatment-related side effects, health and hormonal status, emotional state and coping style Hierarchical multiple linear regression analysis	Men felt they had adequate information on side effects prior to commencing treatment Baseline expectancies predicted 6/18 toxicities at week 2 Week 2 expectancies predicted 7/17 toxicities at week 7 Sexual side effects expectancies had greater prediction, particularly “inability to reach orgasm” Some side effects were predicted and reported to occur at 2 weeks, prior to when medically expected, suggesting a psychological component	
Halleberg Nyman et al (2017) [34]	Sweden During Treatment	Explored PCa patient’s perceptions of participation during radiation therapy, with or without a smartphone app to manage symptoms and give self-care advice.	28 patients interviewed n = 17 app use group n = 11 standard care Two university hospitals (one rural, one suburban) n = 8 EBRT n = 20 Brachytherapy + EBRT	<i>Study Design:</i> Qualitative Open-ended interviews Analysed: “directed qualitative content analysis” utilising a analysis scheme developed for an emergency context	Four participation dimensions confirmed: • Mutual participation • Fight for participation • Requirement for participation • Participation in getting basic needs satisfied The app increased patient participation in their care in managing symptoms. It was seen as a point of contact, facilitating question/answers. Some participants reported frustration with unanswered questions, with radiation therapy staff only able to answer questions relating to radiation therapy rather than more broader questions around their illness or care.	It is noted that “participation in their care” was a difficult concept for some men.

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Table 2 (continued)

Reference	Country & Treatment Pathway Stage	Aim/s	Population and Sample Size	Methods	Key Findings	Considerations†
Blomberg et al (2016) [35]	Sweden During Treatment	To map and describe the symptoms and self-care strategies of patients undergoing prostate cancer radiation therapy	8 patients Recruited from a rural and urban centre 3 individual interviews, 1 focus group with 5 participants	<i>Study Design:</i> Qualitative Individual interviews (n = 3) and one focus group (n = 5) Open-ended question: “Can you describe your symptoms and concerns during and after radiotherapy?” Followed by questions about how they managed the symptoms they had, and how they felt about the support they had received. Qualitative content analysis	While the information received regarding radiation therapy was clear and provided in multiple forms, it was perceived that the health care staff set the conditions for when and how participation could take place. Symptom categories identified: urinary symptoms, bowel problems, pain, sexual problems, fatigue, and anxiety, depression and cognitive impairment, and irregular symptoms (incl weight gain, numbness, sweating, swollen feet, shivers, cyanosis). Self-care strategies rarely described but two identified: Urinary urgency – empty bladder prior to leaving the house Fatigue – trying to remain active Uncertainty reported by patients from around waiting to see health professionals; incomplete or limited information received and feeling unsure of information received	Sample size – although a breadth of EBRT modalities covered, and rural and urban centre included. Note: This was a mixed-methods study including professionals interviews and a scoping review, however the data extracted focuses solely on the patient qualitative interviews.
Kinnaird and Stewart-Lord (2021) [36]	England Post Treatment	To investigate men’s perceptions of sexual dysfunction caused by EBRT and ADT, and the impact of this on their life.	8 patients who were 18–24 months post treatment	<i>Study Design:</i> Qualitative Phenomenological study Semi-structured interviews Thematic analysis	Three themes: Priorities when making treatment decisions – with a strong focus on survival rather than side effects Information and support received about sexual side effects Perceptions and experiences of sexual dysfunction Life-disrupting side effects: urinary leakage, potency and libido loss	Selection bias recognised as those participating willing to discuss a sensitive issue
Schultze et al (2020) [37]	Germany Post Treatment	To capture the diverse range of experiences of having and having had prostate cancer Part of a larger project to add narratives to a website	44 men Recruited from health centres, support groups and consumer organisations 17 had radiation therapy and/or brachytherapy	<i>Study Design:</i> Qualitative Narrative interviews Thematic analysis	Life-disrupting side effects: urinary leakage, potency and libido loss Attributing losses to ageing and/or cancer – intertwining of ageing and cancer.	Recognised that because interviews were also going to be used online, there may have been a more positive prognosis consented
Dyer et al (2019) [38]	United Kingdom Post Treatment	To explore how erectile dysfunction is experienced by patients, and assessed and managed.	546 men, 137 (25%) received EBRT	<i>Study Design:</i> Quantitative Cross-sectional survey Recruited through Prostate Cancer UK’s communication channels Analysis: Proportions	*Results presented here represent the radiation therapy + ADT cohort only: 54% of men reported that no one asked about erections prior to treatment. 74% of men reported information regarding potential erectile dysfunction was given	Also included health professional perspective, not presented here Survey was co-produced with PCA patients Higher proportion of younger men than the prostate cancer population

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Table 2 (continued)

Reference	Country & Treatment Pathway Stage	Aim/s	Population and Sample Size	Methods	Key Findings	Considerations†
Support Foley et al (2016) [39]	Canada During Treatment	To identify the elements of nontechnical (personal) care that are most important to prostate cancer radiation therapy patients	108 patients undergoing prostate EBRT Exclusion: Nodes, prostatectomy or brachytherapy Inclusion: ADT	<i>Study Design:</i> Quantitative Questionnaires developed via cognitive interviews with 8 patients and 4 health professionals Aspect of care: Patient centeredness Empathy and respectfulness of caregivers Perceived competence of caregivers Adequacy of information sharing Accessibility of caregivers Continuity of care Comprehensiveness of services Treatment environment Privacy Convenience	41% reported not being offered treatment to help get or keep an erection Most important: perceived competence of their caregivers, the empathy and respectfulness of caregivers, and the adequacy of information sharing. Differences in patient's different priorities were not predictable by age, education or health status.	Timing of questionnaires may reflect different timing in respondents' trajectories Generalisability as only one centre
Clarke & Burke (2016) [40]	United Kingdom During Treatment	To ascertain PCa patient perceptions of support received during radiotherapy treatment course	13 patients, interviewed within last week of radiation therapy treatment (fractions 32 to 37)	<i>Study Design:</i> Qualitative Qualitative phenomenological approach, with Giorgi analysis Qualitative interviews	Quality of support overall positive. Many felt well supported during treatment sessions, not requiring additional on-treatment reviews Peer support found in the waiting room, building relationships with other men going through treatment. Mixed views regarding information and support prior to treatment commencement. Uncertainty around bladder and bowel preparation reported by 31% of participants. Requested to know why, not just instructions.	Generalisability as only one centre. No patient demographics are reported.
Ormerod & Jessop (2015) [41]	UK During Treatment	To evaluate if on-treatment review clinics were meeting patients needs during and at the completion of radiation therapy.	7 prostate cancer patients Convenience sample of all PCa patients completing treatment within 1 month	<i>Study Design:</i> Qualitative Phenomenology using semi-structured interviews	Two main themes emerged: Information giving Clinical assessment of symptoms Information was important to patients, with some specifics reported: 2/7 felt there had been information omissions at planning and treatment commencement, causing unnecessary anxiety However 6/7 were satisfied with information giving during and end of treatment 2/7 did not understand purposes of daily imaging All patients reported being	Generalisability as only one centre Note: Two health professionals were also interviewed, however their specific insights are not included here

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Table 2 (continued)

Reference	Country & Treatment Pathway Stage	Aim/s	Population and Sample Size	Methods	Key Findings	Considerations†
Johnson et al (2021) [42]	United Kingdom Post Treatment	To identify unmet supportive, palliative care and informational needs of people living with prostate cancer (patient and carers).	Prostate cancer men in United Kingdom Survey: 216 men, 97 carers Previous treatment: ADT: 42% RT: 39% Surgery: 37% AS: 28% Chemotherapy: 9% Palliative care: 1% Interviews: 19 patients and 6 carers	<i>Study Design:</i> Quantitative Survey including: Patient Supportive Care Needs Survey Carer Support Needs Assessment Tool Health Status (EQ-VAS) Free-text analysed thematically	aware of possible side effects 6/7 did not experience any that necessitated medication or required referral All patients' priority at the end of treatment was "to know how it's [the treatment] gone" with quality of life not commonly raised. Patients: 62% reported moderate-high needs Locally advanced/ advanced cancer diagnoses were associated with higher unmet needs. Carers: Chronic illness significantly predicted supportive care needs. Free-text analysis: Poor communication led to frustration High burden of symptoms, particularly hormone therapy Symptoms were "inevitable, to be borne stoically" Busyness of hospitals meant person-centred care was not always delivered, with some poor coordination or management noted	Cancer stage was self-reported, with 40.7% as "don't know/not to say"

†including limitations or biases; Abbreviations: ADT: Androgen Deprivation Therapy; AS: Active Surveillance; DCE: Discrete Choice Experiment; EBRT: External Beam Radiation Therapy; GI: Gastrointestinal; GU: Genitourinary; HDR: High dose rate brachytherapy; IMRT: Intensity Modulate Radiation Therapy; LCA: Latent Class Analysis; LDR: Low dose rate brachytherapy; mWTP: Marginal Willingness to Pay; PCa: Prostate Cancer; RO: Radiation Oncologist; RT: Radiation Therapy; SBRT: Stereotactic Body Radiation Therapy.

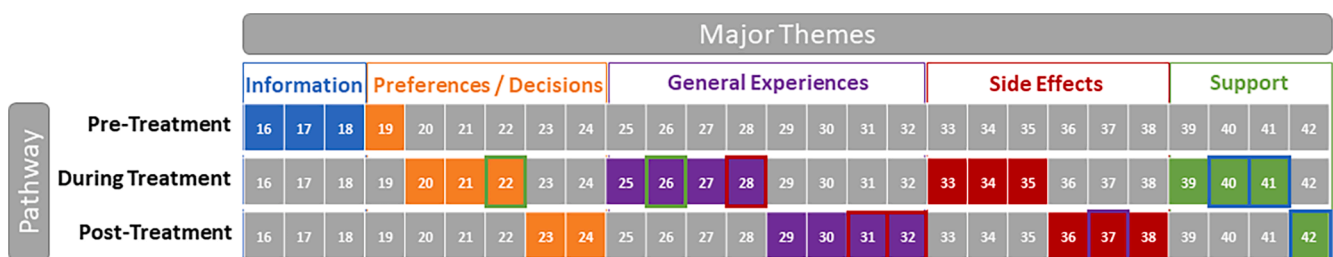


Fig. 2. Mapped matrix of major themes addressed across the treatment pathway continuum. Note: coloured squares indicate primary focus of the study, with coloured bordered squares indicating a secondary focus. Numbers denote the references.

from n = 58 [20] to n = 478[21]).

Results from a study utilising a decision aide to help patients decide on radiation treatment schedule (between 70 Gy and 74 Gy) found that 79% of men preferred active participation in the decision, with 71% favouring the less toxic treatment. [19].

Other treatment studies covered preferences of patients including: hypofractionation schedule preferences, [20] IGRT preferences [21] and bothersome bowel side effects. [22] Two studies elicited preferences

through discrete choice experiments, [20–21] and one through best-worst scaling. [22] One of these preference studies included a general population cohort in addition to a patient cohort, [21] and the other two focused on patient cohorts only. [20,22] Overall, men preferred shorter treatment regimens associated with lower recurrence risk, lower side effects risk and no FM implantation; [20] preferred IGRT with less cost, less pain and improved accuracy; [21] and perceived that bowel side effects of loss of control is most bothersome, and frequency least

bothersome. [22].

When quantifying the trade-offs between side effect tolerability and survival gains, respondents were least willing to tolerate severe bowel and bladder symptoms after EBRT, with a trade-off of 27.7 median months survival benefit required for severe effects [24] Decision regret in choosing SBRT over other treatment options was evaluated in 112 men, and found that 4% of men reported regret associated with side effects. [23].

General Experiences

General experiences related to any aspect of treatment interaction not covered by the other major themes. The experiences of participants were reported in five studies, with three focussing on during-treatment experiences, [25–28] and two focussing on post-treatment. [29–30] Across the studies, 36 men [25 27,30] and 7 partners [30] were included in interviews and 482 men surveyed, [25–26,28–29] (survey population ranging from $n = 40$ [25] to $n = 276$ [29]).

During treatment, the experiences of image guided radiation therapy (IGRT) procedures were explored, with participants describing fiducial marker insertion as more invasive compared to transperineal ultrasound monitoring. [25] The practical challenges of radiation therapy including time away from home/work were identified as a burden. [27] Following a high-dose brachytherapy (HDR) procedure, the most troublesome factors reported were “being stuck in bed” and “discomfort” by participants. [28] Men undergoing brachytherapy rated discomfort as most troublesome, however 60% rated their experience as better than expected. [28].

Treatment regret in choosing radiation therapy over other treatments and associated side effects was evaluated. Regret regarding their specific treatment was reported by a total of 13% of men surveyed (specific modality incidence: 19% intensity modulated radiation therapy (IMRT), 18 % HDR and 5% stereotactic body radiation therapy (SBRT)), with SBRT and IMRT patients reporting short-term side effects less than expected, and SBRT patients reporting long-term side effects less than expected. [29] Of those reporting regret, 71% regretted their decision for radiation therapy treatment, and instead wished they chose active surveillance. [29].

The acceptability of a proposed lifestyle intervention (dietary changes and physical activity) post-treatment was evaluated in interviews with patients and their partners. The main motivation identified was to participate in such interventions to reduce mortality and suffering rather than improve health and wellbeing. [30].

The care given by the multidisciplinary team (radiation oncologists, nurses and radiation therapists) during treatment was recognised by participants, with factors including politeness, respect, care and collaboration rated as important. [26].

Side Effects

Side effects included the experience of various symptoms, the impact of side effects and symptom management. Side effects were reported in seven studies, with three focussing on during-treatment side effects, [33–35] and four focussing on post-treatment. [36–38] 88 men were included in interview [34–37] and 172 men surveyed [33 38] (survey population ranging from $n = 35$ [33] to $n = 137$ [38]) across the studies. Additionally, two studies in the during-treatment phase [22 28] and two studies in the post-treatment phase [31 32] covered side effects as a secondary focus.

Urinary and bowel symptoms were identified in one study, as well as sexual problems and psychosocial problems such as anxiety and depression. [35] Life-disrupting side effects were described by some men including urinary leakage, lack of potency and libido loss. [37] Men reported the side effects were less than expected, with bowel/bladder both significantly decreasing after treatment, and there was a willingness to accept side effects for cure. [32] Similarly, side effects were

found to be traded off for the benefits of radiation therapy. [31].

Men identified self-care strategies in managing their symptoms, including practical measures such as emptying their bladder prior to leaving their house. [35] In one study, a smartphone app utilised during treatment increased the patient participation in managing their symptoms. [34] One study compared pre-treatment side effect expectancies to the experienced side effects in 35 men; the participant’s expectancies predicted seven out of 18 side effects near the completion of radiation therapy, that is, they experienced seven side effects that they expected. [33].

Erectile dysfunction (ED) is a known common side effect of prostate cancer treatment for men receiving EBRT. Almost three-quarters of respondents (74%) reported being given information on ED prior to treatment, but 41% reported they were not offered treatment for ED [38] Similarly, some men in interview reported a lack of information or overly optimistic outlooks were given by health professionals regarding sexual function. [36].

Support

Support included that provided by health professionals, peer support and unmet needs of patients and carers. The support needs of participants were reported in three studies in the during-treatment phase, [39–41] and one in the post-treatment phase. [42] Across the studies, 45 men were included in interview [40–42] and 324 men [39 42] and 97 carers surveyed. Additionally, one study included support as a secondary focus in the treatment phase. [26].

The perceived competence, empathy and respectfulness of health-care professionals was indicated as most important during treatment. [39] Support provided during the treatment phase and information (including access, type and volume) was considered important, with one study showing 28% of men did not understand the reason for imaging during radiation treatment. [41] Another study found men felt well supported during treatment, and aspects such as peer-support through meeting other men in the radiation therapy waiting room added to this feeling of support. [40].

The support needs in the post-treatment phase reflected the changed needs of patients and carers, higher needs were associated with more advanced prostate cancer diagnoses and chronic illness. [42] Poor coordination was a reported frustration and attributed to the demands of the health service, meaning patient-centred care was not always delivered. [42].

Discussion

This scoping review explored the literature pertaining to perceptions and preferences of prostate cancer radiation therapy. Overall, the 27 studies included in this review covered five themes: information needs, preferences and decisions, general experiences, side effects and support, spanning three stages of treatment (pre-, during, and post-treatment stages). These themes align with several of the domains of patient-centred care first described by the Picker institute and adopted by many international health services and systems, most notably: respect for preferences and values; emotional support; physical comfort; information, communication and education; and continuity and transition. [43].

The studies were categorised into five themes and pathway stage for this review. However, it is recognised that some studies may have addressed multiple pathway stages or themes. For example, two studies categorised as general experiences in post-treatment also covered side effects as part of those experiences. [31–32] The multiple categorisations reflect the interlinked nature of patient experience, perception and preference. The most overarching theme and pathway stage for mapping was determined through data extraction to keep the scoping results as clear and concise as possible, with secondary focus indicated as applicable.

The initial search revealed a number of pre-treatment studies focused on modalities (such as surgery versus radiation), but these were excluded during title and abstract screening as they were not radiation therapy specific. Of the full-text records assessed, an additional 19.6% of records were excluded as the focus was on primary treatment decisions. While the decision of treatment modality is a critical decision already well described in existing studies and systematic reviews, [7–9] there are many other factors for patients to consider once a particular treatment modality such as radiation therapy has been decided.

The focus on information particularly in the pre-treatment stage highlights the different information needs between patients at this pathway stage and the challenges faced by radiation oncology professionals in meeting these needs. The unknown environs of radiation therapy are documented, and help explain this “unknown” phenomenon often reported by patients about to start radiation therapy, influencing their need for information. [44] It is important for future research to recognise that “one size does not fit all” in meeting patient information needs, as there was a variance in information provision reported by men from “not enough” to “too much”. [17–18] There is a need for robust information at the time of diagnosis to guide overall treatment decisions as reported by treatment decision literature, [11,12,45] however information needs continue throughout the whole treatment pathway. [42].

In analysing general experiences, valuable perspectives are gained from the patients highlighting areas that could be immediately improved such as targeted information provision. [40] Additionally, preference studies highlight where patients place value, which may be different to the healthcare professional, such as preferring lower risk. [20] General experiences also provide insight into person-centred care aspects important to the patient – insights which can only be captured directly from the patient. [26,39].

The side effects and their management experienced by men were the focus of during-treatment studies and included other aspects such as support and logistics, unsurprising as these aspects are the most pressing during treatment. While shorter fractionation was found to be a preference by Sigurdson et al (2022), [20] so was lower side effect risk. This may reflect the increased advances in treatment since Stalmeier et al (2007) reported findings of patients opting for the less toxic (i.e. the lower dose of 70 Gy compared to 74 Gy) treatment. [19] The predominant theme of studies in the post-treatment phase was continued management of longer-term side effects, as well as treatment regret and survivorship with lifestyle modifications.

The importance of competence, empathy and respectfulness indicates the vital supportive roles expected of healthcare professionals in the prostate treatment pathways in providing patient-centred care. [39] Additional supports identified included peer-support and informational support. [40–41] Of note, while carers were included in some studies, none were included in studies around support, indicating this as a knowledge gap.

The paucity of radiation therapy specific literature suggests future potential areas for patient preferences research, particularly as the radiation oncology community seeks to increase and improve patient-centred care for men with prostate cancer. It is recognised that some records not included in this review may have relevant details, particularly studies about broad cancer populations that include a prostate cancer sub-cohort. Every effort was made to identify these studies, but where these sub-cohorts were not easily identifiable, studies may have been inadvertently excluded. This is a limitation of this review.

This review highlights that many factors influence the preferences and perceptions of prostate cancer patients receiving radiation therapy. More broadly, we believe the findings identify opportunities for radiation therapy services to further develop patient-centred practices, particularly around information needs, treatment procedures and the management of side effects. Delivering patient-centred care improves treatment adherence, better patient satisfaction and overall health system efficiency. [46–47].

Conclusion

This scoping review highlights the paucity of literature currently available describing the perceptions and preferences of men with prostate cancer regarding radiation therapy and related aspects. The varied perceptions reported in the literature demonstrates the complexity of delivering patient-centred care in a healthcare setting such as radiation oncology. Continued research in the areas of pre-treatment, treatment and post-treatment patient needs will further improve patient-centred care delivery in prostate cancer.

Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.ctro.2022.10.007>.

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