The decision-making role of the patient in localised prostate cancer treatment

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Abstract

Our objective was to review the current literature on patient participation and decision-making in the treatment selection process for localised prostate cancer, and to evaluate capacity for improvement. Methods: 42 articles from our literature search were deemed eligible and relevant for review. We reviewed studies on all facets of the treatment decision-making process with most number of articles (16) on treatment preferences. Results: The majority of the patients prefer an active or collaborative role in decision-making. Patients are seeking information from a myriad of sources but the recommendation from their treating physician is often the most influential on the final decision. Radical prostatectomy is more likely to be selected in patients who view a cure for cancer as being of the utmost importance and radiation therapy is preferred in patients who are concerned about treatment side effects. Conclusion: Currently no ideal tool exists to assist patients in making informed treatment decisions that also takes into account patients' values and preferences. We encourage collaborative partnership in a multidisciplinary setting to optimise this process and individualised risk-based decision-making tools may provide a better pathway to assist patients reach decisions.

Keywords: prostate cancer; patient participation; decisions; treatment

1 Introduction

Prostate cancer (PC) is the most common non-skin malignancy in Australia, accounting for 21,808 new diagnoses in 2009 (AIHW 2013). It is the fourth leading cause of mortality among Australian males, resulting in almost 3,300 deaths in 2011 (AIHW 2013). Approximately 90% of men have disease confined to the prostate gland or clinically localized disease (Wilt, MacDonald et al. 2008). While the incidence of PC in Australia is increasing, there is a decrease in the rates of cancer specific mortality (Wilt, MacDonald et al. 2008). While campaigns for greater public awareness, along with early detection and greater rates interventions have attributed to the improved PC outcomes, another significant contributor is the detection of low risk, low volume localised disease due to screening of asymptomatic patients (Jemal, Siegel et al. 2006, AIHW 2013). Thus, while screening for prostate cancer has shown some benefit in reducing PC specific deaths, this opened up the paradigm of over-diagnosis and over-treatment calling for uncoupling of screening from treatment (Heijnsdijk, Wever et al. 2012, Schroder, Hugosson et al. 2012).

As such, therapeutic management of localised prostate cancer has become complex, owing to comparable cure rates and varying risk profiles of each treatment option. Common treatment options include active surveillance (AS), radical prostatectomy (RP) and radiation therapy (by external beam or by radioactive seed implantation into the prostate, known as brachytherapy). Newly diagnosed patients are often faced with a complex decision in selecting a treatment. They must consider a number of factors such as evidence for treatment efficacy, differing profiles of short and long-term side effects, inputs from physicians, family members, or friends, economic consequences, prior medical care experiences, as well as other influencing factors (Zeliadt, Ramsey et al. 2006).

Three types of decision-making are usually distinguished: 1) active or autonomous decision making, when the patient is solely responsible for the decision; 2) collaborative or shared decision making, defined as a process of engagement in which physician and the patient work together, with available information, to understand the clinical issues and determine the best management options; 3) a passive role of the patient implies that the physician reviews the options and makes the decision on behalf of the patient (Fischer, Visser et al. 2006). In clinical setting, the decision making process is often affected by time and resource constraints, severity of illness and limitation of treatment options (O'Grady, Jadad 2010).

In this review we aim to compile the information from the studies that examine the different aspect of the decision making process in men with localised prostate cancer. By identifying and reviewing the current patient participation, pattern of information seeking, and different influences in treatment selection, we may recognise areas of deficiency and improve the decision making process for these patients.

2 Diagnosis and treatment options for localised prostate cancer

2.1 Diagnosis

The diagnosis of prostate cancer involves digital rectal examination (DRE), serum concentration of prostate specific antigen (PSA) and prostate biopsy (Heidenreich, Bastian et al. 2014). The need for prostate biopsies should be determined on the basis of the PSA level, a suspicious DRE, and the patient's biologic age and comorbidities. Single elevated PSA should not prompt immediate biopsy, except for high values of >20ng/ml (Heidenreich, Bastian et al. 2014). A persistently elevated or steadily rising PSA is more indicative of underlying malignancy. Ultrasound-guided transrectal or transperineal prostate biopsy has become the standard way to obtain histopathologic diagnosis. For each biopsy site, the proportion or length of tumour involvement of each biopsy core and the grading according to the Gleason score system should be reported (Heidenreich, Bastian et al. 2014). Further diagnostic and staging work-up is dependent on tumour grading and treatment options available to the patient.

2.2 Active surveillance

Aim of AS is to reduce overtreatment and the side effects of treatment such as incontinence and erectile dysfunction in patients with clinically confined low-risk PC. Low-risk prostate cancer has been defined as Gleason score of 6 or less, PSA less than 10 mg/ml, and a tumour that is either non-palpable or only palpable in less than half of one lobe of the prostate (D'Amico, Whittington et al. 1995). In these patients with low risk PC, radical treatment is delayed but are followed regularly with screening tests and examination, and treated with curative intent if progression or the threat of progression is detected during follow-up (Heidenreich, Bastian et al. 2014). Klotz et al (Klotz, Zhang et al. 2010) reported a cohort of 450 men with localised PC on active surveillance, and found disease-specific survival of 97.2% at 10-year follow-up and 30% of patients requiring curative treatment. Several other studies have now been published confirming a low rate of progression and cancer-specific death in well-selected patients with very-low-risk disease, making AS a reasonable approach in these patients (Klotz 2010, Klotz, Zhang et al. 2010).

However there are a number of negative aspects of AS such as the anxiety associated with a diagnosis of PC, the need for regular PSA testing and the complications associated with re-biopsy also place a significant burden on the healthcare system (Crawford, Black et al. 2010) While small scale studies have shown no increase in reported anxiety and good satisfaction rates amongst patients on AS (Burnet, Parker et al. 2007, Davison and Goldenberg 2011), as well as reduced sepsis rates owing to the transition to transperineal biopsy (Grummet, Weerakoon et al. 2014), the decision for AS is largely made on an individual basis.

2.3 Radical prostatectomy

In high risk localised or locally advanced PC radical prostatectomy still offers the best cancer specific survival benefit up to 92% at 10 years (Hsu, Joniau et al. 2007) and is advocated in men with intermediate or high risk localised or locally advanced PC life expectancy of >10 years. The increasingly popular nerve-sparing technique and robotic-assisted laparoscopic RP have seen improved urinary continence and erectile function in patients post-operatively (Ficarra, Novara et al. 2012, Ficarra, Novara et al. 2012). There are still, however, limited evidence to suggest an advantage of RP over other treatment options with regard to overall survival and metastasis-specific survival (Heidenreich, Bastian et al. 2014).

2.4 External Beam Radiation therapy

External beam radiation therapy offers an alternative curative modality for those with localised PC who do not want to undergo surgery with comparable results to a surgery (Potters, Klein et al. 2004, Nguyen, Aizer et al. 2014). Delivery of radiation treatment is much improved over the years in terms of accuracy, limiting exposure of surrounding tissue and rate long-term complications. Three-dimensional conformal radiation therapy (3D-CRT) is now the gold standard in external-beam radiation therapy (EBRT) in many institutions, with biochemical disease-free survival of 63% (Heidenreich, Bastian et al. 2014).

2.5 Brachytherapy

Brachytherapy, which involves implanting radioactive seeds in the prostate, also reports good 5 and 10-year survival rates of up to 93% and 85% respectively, with low incidence of genitourinary and gastrointestinal toxicities (Heidenreich, Bastian et al. 2014).

2.6 Morbidity comparison

Studies found that urinary dysfunction was more common in men treated with radical prostatectomy than in men treated with radiation therapy (Wilt, Shamliyan et al. 2008). Investigators reported incontinence rates for brachytherapy (2% to 32%), radical prostatectomy (5% to 35%), and radiation therapy (2% to 6%) (Wilt, MacDonald et al. 2008). Sexual dysfunction was common after all treatments. Impotence rates ranged from less than 5% to approximately 60% in the few studies reporting on men undergoing nerve-sparing radical prostatectomy (Wilt, MacDonald et al. 2008). Urethral stricture and haematuria were more frequent with radiation therapy. Bowel complications such as diarrhoea, faecal incontinence, and rectal bleeding occurred less frequently in men treated with radiation therapy (15% to 30%) (Wilt, MacDonald et al. 2008). At 15-year follow-up, no significant relative differences in disease-specific functional outcomes were observed among men undergoing prostatectomy or radiotherapy (Resnick, Koyama et al. 2013).

3 Literature search

We conducted an English language review of published reports concerning patient participation in the decision-making process for treatment of localized prostate cancer. Databases used for the search included PubMed and SCOPUS® (100% MedLine coverage). The search was conducted up to year 2015. Key words included '*prostate cancer*', '*patient participation*', '*prostate cancer treatment*' and '*decision making*'. We restricted our review to original, peer-reviewed studies that focused on patient participation in the decision-making process. We excluded studies of decision making for prostate-specific antigen (PSA) screening, studies of men with advanced prostate cancer and studies that focused on outcomes after treatment.

As a result, we identified 42 articles that met our criteria. (Figure 1) These include, 1 study examining influences of partners (Zeliadt, Penson et al. 2011), 2 studies examining influence of physicians (Fowler, McNaughton Collins et al. 2000, Stalmeier, van Tol-Geerdink et al. 2007), 16 studies comparing treatment preferences (Mazur and Hickam 1996, Hall, Boyd et al. 2003, Auvinen, Hakama et al. 2004, Berry, Ellis et al. 2006, Zeliadt, Ramsey et al. 2006, Block, Erickson et al. 2007, Cox and Amling 2008, van den Bergh, van Vugt et al. 2010, Davison and Goldenberg 2011, Ihrig, Keller et al. 2011, Davison and Breckon 2012, Davison and Breckon 2012, Hamilton, Wu et al. 2012, Penson 2012, Sidana, Hernandez et al. 2012, van Tol-Geerdink, Willem Leer et al. 2013), 4 studies on decision aids (Lin, Aaronson et al. 2009, Adsul, Wray et al. 2015, Violette, Agoritsas et al. 2015, van Tol-Geerdink, Leer et al. 2016), 7 studies examining role preferences (Cohen and Britten 2003, Davison, Goldenberg et al. 2003, Davison, Parker et al. 2004, Fischer, Visser et al. 2006, Deber, Kraetschmer et al. 2007, Pieterse, Henselmans et al. 2011, Song, Chen et al. 2013), 4 studies related to psychosocial issues of decision making (Wong, Stewart et al. 2000, Kraetschmer, Sharpe et al. 2004, Steginga, Turner et al. 2008, Birnie and Robinson 2010), 3 studies on demographic differences in decision making (Meyer, Talbot et al. 2007, Xu, Dailey et al. 2011, Palmer, Tooze et al. 2013), 2 studies examining decision making tools (Berry, Ellis et al. 2006, Henrikson, Davison et al. 2011), 1 cohort study on medical decision in general(Fowler, Gerstein et al. 2013), and 2 studies on multidisciplinary care (Strebel, Sulser et al. 2013, Hurwitz, Cullen et al. 2015).

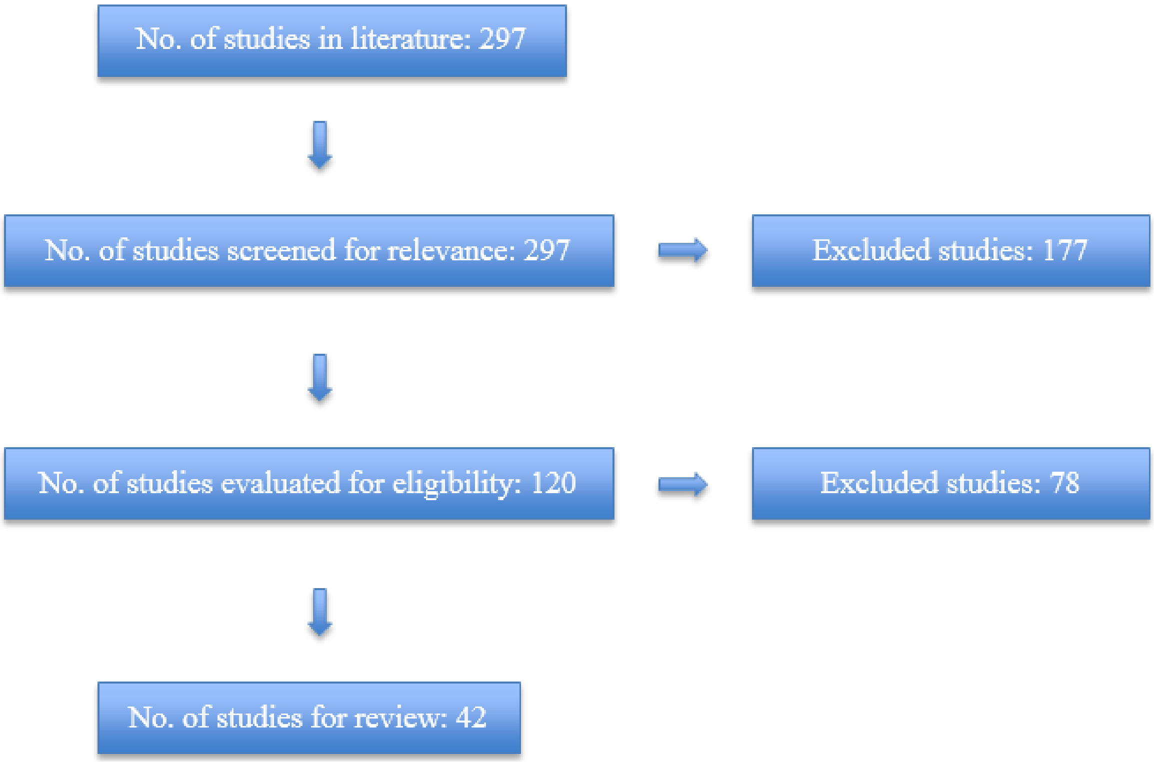

Figure 1: Flow chart of the recruitment of studies for review. Studies of decision making for PSA screening, studies of men with advanced prostate cancer and studies that focused on outcomes after treatment were excluded.

4 Results

4.1 Participation in treatment decision-making

Majority of the patients played either an active or a collaborative role in deciding the mode of treatment. Only a minority of the patients preferred a passive role in the decision-making process. Figures for men seeking active role in the decision making process range from 6-71%; shared decision making is in the range of 19 – 86; and 4-32% of the patients assumed a passive role in the decision making process (Davison and Goldenberg 2011, Hurwitz, Cullen et al. 2015). (Table 1)

Meyer et al (Meyer, Talbot et al. 2007) has identified that younger men (<60 years) were more likely to be an active decision maker compared to men older than 70 years of age. However, older adults were more likely to make immediate decisions than younger adults (Davison and Goldenberg 2011).

Frequently family members have been reported to actively participate in the discussion of treatment options and this greatly facilitates shared decision-making among physicians, patient and partners (Zeliadt, Penson et al. 2011). The desire of the family members to be involved did not, however, indicate a desire to make the final treatment decision; and most partners were determined that the final decision should be made by the patient (Zeliadt, Penson et al. 2011).

4.2 Information preference

Berry et al (Berry, Wang et al. 2012) identified that patients with diagnoses of PC used friends, the Internet, and pamphlets from the specialist's office as frequent information sources. Similarly, Xu et al (Xu, Dailey et al. 2011) conducted a small study of 21 men reported important information sources were professional advice from physicians, and family or friends, especially those with personal experience with prostate cancer. A number of articles, however, have identified Urologists as the most important source of information and the major factor influencing the treatment decision (Hall, Boyd et al. 2003). (Table 1) Urologists are often the specialists who diagnose prostate cancer and provide the initial treatment consultation. Therefore, it is not unusual that patients place great importance on recommendations offered at the first treatment discussion (Davison and Goldenberg 2011). Palmer et al further identified that even though most patients sought information about prostate cancer from physicians, active participants were significantly more likely to also seek information from the Internet (Palmer, Tooze et al. 2013). Surprisingly, spouses and fellow patients were relatively minor influences in this process (Hall, Boyd et al. 2003).

Decision aids (DA) are literature material developed to facilitate shared decision making by providing an understanding of the risks and benefits associated with treatment choices (Violette, Agoritsas et al. 2015). There has not been adequate evidence to suggest significant impact on patients' decision making (Violette, Agoritsas et al. 2015). However, patient participation was found to be increased in the patient population provided with decision aids, as well as the likelihood of patients choosing brachytherapy (Lin, Aaronson et al. 2009, van Tol-Geerdink, Willem Leer et al. 2013).

4.3 Reasons for selecting a treatment

Majorities of the studies investigated treatment options of active surveillance, surgery, brachytherapy and external beam radiotherapy (Table 1). Percentage of patients choosing radical prostatectomy have been quoted to be between 29-81.4%; 10.7 – 42% of patients elected to have radiation treatment and rate of active surveillance has been reported up to 42% (Mazur and Hickam 1996, Hall, Boyd et al. 2003, Fischer, Visser et al. 2006, Ihrig, Keller et al. 2011, Sidana, Hernandez et al. 2012).

A descriptive pilot study conducted by Hall et al (Hall, Boyd et al. 2003) described two major motivations underlying treatment decisions – best procedure to cure the cancer and treatment with best side effect profile. Over 97% of the patients who elected to undergo RP believed that it was the best procedure to cure their cancer, compared to 59.7% of the patient who chose EBRT (Hall, Boyd et al. 2003). In contrast, only 1.2% of the patients chose RP for its side effect profiles, which was the predominate reason given in patient who chose brachytherapy (40%) (Hall, Boyd et al. 2003).

Patients undergoing surgery were younger and more likely to report a family history of prostate cancer (Hurwitz, Cullen et al. 2015). Concerns over cancer control tend to drive patients towards surgical intervention and is a key barrier to acceptance of active surveillance (Penson 2012). Patients choosing EBRT tended to be older, African American, and have a major comorbidity (Hurwitz, Cullen et al. 2015). They also believed it offers equal efficacy of cure but fewer side effects than surgery (Xu, Dailey et al. 2011). Patients who chose brachytherapy are more concerned with convenience of the procedure and less concerned with risk of sexual dysfunction (van Tol-Geerdink, Willem Leer et al. 2013).

Urinary incontinence and sexual dysfunction were most commonly voiced concerns in all treatment types. This is especially of concern in younger patient cohorts. These side effects of treatment, however, are not the most influential factor when it comes to choosing treatment –

physicians' recommendation and the treatment option that was considered to offer the best survival were most influential (Table 1).

5 Discussion

Currently there is no 'gold standard' of therapy for treatment of localised prostate cancer with the contemporary treatment options demonstrating similar survival rates with variable side effect profiles. Treatment recommendation often differ according tumour grading, size and patient factors (Heidenreich, Bastian et al. 2014). An ideal decision-making process should involve providing patients with access to all relevant information in an unbiased manner, which encourages patients to make a decision according to their true preference. In reality, patient's decision making are often skewed by both the content and the method in which the information was delivered.

Review of the literature has shown a greater percentage of patients actively or shared a collaborative role in the treatment decision-making process. Active decision-making are seen more often in the younger men, who are more likely to choose the surgical pathway as they believe it offers the best chance of cure. In contrast, elderly patients often take up a passive role and are likely to choose non-surgical options. It is encouraging to see that patients are taking increasing interest in their cancer diagnosis and treatment, which may have contributed to the rising proportion of patients taking an active approach in the decision making process. However, the collaborative and the passive process are still often depended upon the clinicians' values and preferences. This is evident in a qualitative study conducted by Cohen et al (Cohen and Britten 2003) examining the decision-making models in NHS patients with localised prostate cancer - respondents' treatment plans were mostly decided on their behalf by their clinicians and that the patients' barriers to shared decision making included fear of appearing disrespectful to their doctors and of taking responsibility for the outcome of treatment. Similarly, A national survey of 2718 adults by Fowler et al (Fowler, Gerstein et al. 2013) investigating patient autonomy in the decision making for 10 common medical decision showed that there are still considerable paternalism in this process. Participants in the survey reported much more discussion of the pros than the cons of all tests or treatments and there are still clinical decisions being made without physician seeking patients' input (Fowler, Gerstein et al. 2013). Active or shared decision making, however, should be encouraged, as Stalmeier et al (Stalmeier, van Tol-Geerdink et al. 2007) pointed out that physicians often underestimated patients' preferences for active participation as well as misjudged patient's preference in treatment option.

Decision aids (DA) are a popular tool increasingly adopted by various centres designed to promote patient involvement in decisions by providing a common understanding of the risks and benefits associated with treatment choices (Violette, Agoritsas et al. 2015). Most DA's use multiple media to convey information; this includes videos, booklets, audio recordings and computer-based tools (Violette, Agoritsas et al. 2015). However, according to a systematic review by Adsul et al (Adsul, Wray et al. 2015), majority of the decision aids reviewed did not meet the international criteria – they often lacked thorough description of risks, benefits and outcome, lacked encouragement for partner involvement, or lacked readability owing to its complexity in content and language. Violette et al's (Violette, Agoritsas et al. 2015) systematic review and meta-analysis of DA from 14 trials revealed inconsistent effects on decision outcomes and demonstrated no effect on choice. This is was thought to be due to the fact that DA were used to purely provide information rather than to facilitate shared decision making through use in a clinical encounter (Violette, Agoritsas et al. 2015). Lin et al (Lin, Aaronson et al. 2009) reported, however, some non-randomized trials showed that DAs appear to increase the proportion of patients wanting and assuming a more active role in the treatment decision-making process.

There is a general lack of information regarding how a patient's personal values influence decision-making. A number of individualised risk calculators based on large datasets have been developed to aid treatment taking into account the risk of each patient. Development of similar risk calculators with decision-making aids based on datasets maybe useful to tailor treatments for individuals. A recent article suggested that there are often multiple approaches for patients to process data, occasionally focusing only on a subset of the available information, or systematically analysing individual information to make a decision (Polednak 1998). However, more research is needed to determine how personal values affect perceptions, biases, and the integration of information to eventually forming a decision on treatment. Equipped with such data, an information system or software can potentially be developed, not only providing patients with the essential baseline information on treatment options, but also catering to patients' diverse values and beliefs. Such system may also be modified in terms of treatment outcomes and morbidity rates of each institution and clinician to give patients more accurate outcome expectations.

In the current landscape, we believe that these patients may benefit most from a collaborative partnership with their clinicians in the process of deciding treatment options for localised prostate cancer. It would be difficult for any type of literature material in existence currently to cover all aspect of the process, tailored individual patient's values and needs, as well as providing comprehensive information. Therefore, a collaborative multidisciplinary approach is essential. Basic requirement is the obligation to present and discuss all newly diagnosed patients with prostate cancer at the multidisciplinary tumour board (Strebel, Sulser et al. 2013). What may make this process even more effective is for patients to be counselled in a clinic following the tumour board meeting where the patient has the opportunity to communicate with specialists of different fields to gain better insight into the different treatment options and to voice their concerns and preferences. This may help to eliminate the bias of a single consultation with clinician who is likely to promote treatment of his field of expertise.

Limitation of current review is that the literature mostly consists of patient cohorts from European and North American populations. This hence is not an accurate representation of the Australian cohort. Further studies are required in Australian centres on patient participation as well as current multidisciplinary practice for prostate cancer.

6 Conclusion

In the absence of a 'gold standard' therapy for localised prostate cancer, treatment recommendations to pursue active surveillance, radical prostatectomy, radiation therapy or brachytherapy are based on disease burden and patient preference. This process involves active participation from both the medical practitioner and the patient, and the decision making should be based on providing patients with relevant information in an unbiased fashion, allowing the patient to make an informed decision without being skewed by the content or the method of delivery. While studies have shown little benefit in generalised decision aids, a personalised decision making system based on datasets can provide increasing active participation of patients in the decision making process for treatment of localised prostate cancer. As the current evidence suggest that the personal aspects of the process and its influence on the final decision remain inadequately explored, future research is this area should be combined with ongoing study of multidisciplinary care and individualised risk based decision making tools which may provide a better pathway to assist patients reach decisions.

Author	Year	No.	Patient role	Treatment	Demographics	Side effects of concern	Influential factor
Mazur et al(Mazur and Hickam 1996)	1996	140	96% active or shared	53% RP, 42% AS	>70 y.o. more likely to prefer AS (59%)	Urinary incontinence	Complete tumour removal
Hall et al(Hall, Boyd et al. 2003)	2003	262	-	30.9% RP, 23.7% RT, 40.1% BT	No significant association found	Urinary incontinence and erectile dysfunction	Best procedure to cure cancer
Fischer et al(Fischer, Visser et al. 2006)	2006	126	18% active, 60% shared, 22% passive	29% RP, 18% RT	Younger age associated with active decision making	-	-
Berry et al(Berry, Ellis et al. 2006)	2006	260	71% active, 19% shared, 10% passive	-	For men >70yo - less likely surgery; <70yo surgery and BT equally likely	Bladder and sexual symptoms	Longevity
Sidana et al(Sidana, Hernandez et al. 2012)	2011	488	52.3% shared, 45.8% active	81.4% RP, 10.7% RT, 5.3% AS	All pt under 50y.o. More married men chose RP or RT	90% sexual function, 84% urinary function, 66% bowel function	Doctor's recommendation
Xu et al(Xu, Dailey et al. 2011)	2011	21	-	90% RP or RT	Younger men and men with good health more likely to choose active treatment	Impotence	Survival
Ihrig et al(Ihrig, Keller et al. 2011)	2011	31	6% active, 86% shared, 6% passive	58% RP, 42% RT	Surgical pts are younger	SE associated with EBRT	Physician's advice
Davison et al(Davison and Goldenberg 2011)	2011	25	27% active, 41% shared, 32% passive	-	Men older than 70 prefer to play a passive role	Impact of treatment on urinary function	Urologists' recommendation
Davison et al(Davison and Breckon 2012)	2012	258	35% active, 38% shared, 27% passive	-	44% of men under 60 assume active role; 44% men older than 70 assume passive role	Urinary and sexual function	Urologists' recommendation
Davison et al(Davison and Breckon 2012)	2012	150	38% active, 52.7% shared, 9.3% passive	58.7% RP, 20% RT, 16% AS, 0.7% cryosurgery	Younger men prefer to have active role in decision making	Urinary function	Survival
Palmer et al(Palmer, Tooze et al. 2013)	2012	181	44.2% active, 38.1 shared, 14.4% passive	63% RP, 17% RT	100% African-American population	Urinary incontinence and sexual dysfunction	Best chance of cure

van Tol-Geerdink et al(van Tol-Geerdink, Willem Leer et al. 2013)	2013	240		71% RP	No association with treatment received	Bowel and urinary side effects	Survival
Song et al(Song, Chen et al. 2013)	2013	788	41% active, 45% shared, 13% passive	67% RP	Younger men more likely to be active in the decision making process	General physical impact of treatment	Pt's age
Hurwitz et al(Hurwitz, Cullen et al. 2015)	2015	925	68% active, 29% shared, 4% passive	54% RP, 20% RT, 12% AS	Patients undergoing surgery were younger and more likely to report a family history of PC	-	Doctor's recommendation

Radical prostatectomy (RP); active surveillance (AS); radiation therapy (RT); brachytherapy (BT); prostate cancer (PC)

Table 1: Studies summarising patient participation and factors in decision-making.

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