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ONCOLOGY/RECONSTRUCTION REVIEW

Multi-disciplinary and shared decision-making approach in the management of organ-confined prostate cancer



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KEYWORDS

Prostate cancer; Decision-making; Multi-disciplinary team (MDT); Patients' preferences

ABBREVIATIONS

ADT, androgendeprivation therapy; AS, active surveillance; CCI, Charlson Comorbidity Index; Abstract Decision-making in the management of organ-confined prostate cancer is complex as it is based on multi-factorial considerations. It is complicated by a multitude of issues, which are related to the patient, treatment, disease, availability of equipment(s), expertise, and physicians. Combination of all these factors play a major role in the decision-making process and provide for an interactive decision-making preferably in the multi-disciplinary team (MDT) meeting. MDT decisions are comprehensive and are often based on all factors including patients' biological status, disease and its aggressiveness, and physician and centres' expertise. However, one important and often under rated factor is patient-related factors. There is considerable evidence that patients and physicians have different goals for treatment and physicians' understanding of their own patients' preferences is not accurate. Several patient-related key factors have been identified such as age, religious beliefs, sexual health, educational background, and cognitive impairment. We have focused on these areas and highlight some key factors that need to be taken considered whilst

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ECE, extracapsular extension; MDT, multidisciplinary team; mpMRI, multiparametric MRI: NCCN, National Comprehensive Cancer Network: QoL, quality of life; RCT, randomised controlled trial; RP, radical prostatectomy; (EB)RT, (external beam) radiotherapy

counselling a patient and understanding his choice of treatment, which might not always be match with the clinicians' recommendation.

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Introduction

With ∼181 000 new cases diagnosed in 2016, prostate cancer is the most frequently diagnosed cancer in men in USA. However, there has been a small drop in the incidence in the last few years. The drop in prostate cancer incidence has been attributed to decreased PSA testing from 2008 to 2013 in the wake of the USA Preventive Services Task Force recommendations against routine use of the test to screen for prostate cancer (Grade D) in those aged >75 years in 2008 and in all men in 2011 because of growing concerns about over diagnosis and over treatment [1]. More than 80% of men diagnosed with prostate cancer have clinically localised disease [2]. Patients with localised disease can be treated by a variety of options including radiotherapy (RT), surgery, or active surveillance (AS). Decision concerning these options is often based on physician's preference or patient preference. Either of these ways have inherent deficiencies.

The decision-making in localised prostate cancer is complicated by variability in the biological potential (clinical aggressiveness), age at diagnosis, comorbid conditions, patients' perception and life style, social set up and available help at home, physicians' preference (often influenced by financial incentives, ego, enthusiasm for a particular management option amongst other factors), and not least of all the spectrum of management options from AS to major surgery.

According to the National Comprehensive Cancer Network (NCCN) guidelines 2018, organ-confined prostate cancer can be classified into six different categories and decision-making in general, and patient participation in particular, can vary according to different categories (Table 1).

Prostate cancer is a unique entity amongst urological cancers. Not only because of its importance as the most common cancer in males [3], but also due to the variety of available treatment modalities, which include: watchful waiting, AS, radical prostatectomy (RP; open

or minimally invasive), external beam radiotherapy brachytherapy, cryotherapy, and high-(EBRT), intensity focused ultrasound, as well as palliative hormonal and medical therapy [4]. In the decision-making process, meticulous assessment of the patient diagnosed with prostate cancer is of utmost importance. An accurate medical history should include current symptoms, such as bone pain for example could hint towards bone metastases, making a curative approach impossible. A history of previous abdominal operations might make laparoscopic/robot-assisted surgery difficult, and history of medical illness e.g. severe cardiac or respiratory illness would compromise fitness for surgery overall and possibly make active treatment in general inadequate. In addition, a complete physical examination is essential to assess fitness for surgery and a DRE to assess the local disease and the pelvic floor muscle. Investigations such as TRUS, CT, MRI and bone scan for selected cases are tools for proper assessment before presenting the case to the multi-disciplinary team (MDT). The information so gained needs to be considered whilst evaluating the variety of treatment options in view with the constantly changing guidelines and evidence-based changes in prostate cancer treatment. Consequently, the role of a multi-disciplinary approach to find the most suitable treatment in each individual case cannot be underestimated [5]. However, these scientific aspects are not the only key factors in decisionmaking, as the patients choice is majorly influenced by factors such as age, religious beliefs, sexual health, educational background, and cognitive state. This can be demonstrated in patients, who are in the same risk group, yet they decide on different treatment modalities.

Studies have shown that surgeon characteristics are associated with patients' treatment strategy after controlling for patient and tumour characteristics. The various surgeon factors include: gender, academic/private training, and type of medical degree. However, further work is needed to confirm the associations to determine

Risk group	Clinical/pathological features	Initial therapy
Very-low-risk group	T1c AND Gleason score ≤ 6/ Grade Group 1 AND PSA level < 10 ng/mL AND < 3 prostate biopsy/cores positive, ≤50 cancer in each fragment/core AND PSA density < 0.15 ng/mL/mL	Expected patient survival ≥ 20 years: AS EBRT or brachytherapy RP ± pelvic lymph node dissection (PLNE Expected patient survival 10–20 years: AS Expected patient survival < 10 years: Observation
Low-risk group	T1–T2a AND Gleason score $\leq 6/G$ rade Group 1 AND PSA level $< 10 \text{ ng/mL}$	Expected patient survival ≥ 10 years: AS EBRT or brachytherapy RP ± PLND Expected patient survival < 10 years: Observation
Favourable-intermediate-risk group	T2b-T2c OR Gleason score 3 + 4 = 7/Grade Group 2 OR PSA level 10-20 ng/mL AND % positive cores < 50%	Expected patient survival ≥ 10 years: AS EBRT or brachytherapy alone RP ± PLND Expected patient survival < 10 years: EBRT or brachytherapy alone Observation
Unfavourable-intermediate-risk group	T2b-T2c OR Gleason score 3 + 4 = 7/Grade Group 2 or Gleason score 4 + 3 = 7/Grade Group 3 OR PSA level 10-20 ng/mL	Expected patient survival ≥ 10 years: RP ± PLND EBRT + ADT OR EBRT + brachytherapy ± ADT Patient expected survival < 10 years: EBRT + ADT OR EBRT + brachytherapy ± ADT Observation
High-risk group	T3a OR Gleason score 8/Grade Group 4 or Gleason score 4 + 5 = 9/Grade Group 5 OR PSA level > 20 ng/mL	Patient expected survival > 5 years: EBRT + ADT OR EBRT + brachytherapy + ADT RP + PLND
Very-high-risk group	T3b-T4 OR Primary Gleason pattern 5 OR > 4 cores with Gleason score 8–10/ Grade Group 4 or 5	As for high-risk category

whether they reflect surgeon behaviour, patient response, or physician–patient interactions [6].

Treatment options for localised prostate cancer

Patients with organ-confined prostate cancer have several potentially curative options to choose from including RP, EBRT, and brachytherapy [4,7,8].

There is no consensus for the optimal treatment strategy for organ-confined prostate cancer and current guidelines do not indicate the best choice of therapy with regards to oncological and survival outcome. The active treatment options (surgery, RT, hormonal therapy) all have a potential to significantly impact quality of life (QoL). This includes impaired urinary, sexual or bowel functions besides an association with psychological distress such as uncertainty and social (relationship) problems [9,10]. The efficacy and complications vary widely even within one treatment modality making decision-making complex [11]. In the literature it is evident that

side-effect profiles differ between the treatment modalities analysed; men after RP more commonly report urinary and sexual side-effects vs bowel symptoms following RT. In a recent report, notable findings from the analysis of emotions expressed, indicates that age has an important bearing. Patients with prostate cancer aged < 40 years expressed significantly high positive and negative emotions compared with other age groups. Partners of patients expressed more negative emotions than the patient himself [12]. In a recent French study, the authors noted that the main reasons for decisional regret were the fact that patients received incomplete information about prostate cancer (40%) and the impact of treatment on continence (34%). The information on the oncological outcome was considered adequate by 32.3% of the satisfied group and 14.3% of the decisional-regret group (P = 0.003), and with regard to urinary incontinence the information received was considered complete in 41.4% and 17.4%, respectively (P < 0.01) [13].

The NCCN and AUA have recommended AS for selected patients in whom treatment is considered safe to defer with the intention of avoiding over treatment of low-risk disease [5,6]. However, these patients live with a constant fear and stress of disease progression [14].

To improve the efficacy—morbidity profile, minimally invasive treatment options, such as laparoscopic and robot-assisted RP, have evolved; similarly RT has also modified to deliver higher doses of radiation to more tightly defined anatomical regions. Three-dimensional conformal and intensity-modulated RT with or without androgen-deprivation therapy (ADT), low- and high-dose-rate brachytherapy and stereotactic radio-surgery helps this [15].

Patients who are old and have significant medical comorbid conditions are less fit surgical candidates and benefit from RT. In a population-based cohort study, Daskivich et al. [16] analysed the data of patients with prostate cancer from the Surveillance, Epidemiology and End Results (SEER) and found that older men diagnosed with prostate cancer are at risk of both over and under treatment of their cancer and appropriate management in these less fit patients can be challenging as co-existing medical conditions can impact treatment tolerance and the likelihood of benefitting from aggressive treatment.

Lunardi et al. [17] analysed a population-based cancer registry for the impact of age and comorbidity on prostate cancer treatment choices and on multivariate analysis showed that the chosen definitive treatment for localised prostate cancer was influenced by age and comorbidities. There was a significant reduction in RP practice compared to EBRT in order to avoid the surgical complications in unfit patients.

Decision-making process in organ-confined (localised) prostate cancer

Informed decision-making based on patient preferences is a key component to ensure effective, patient-centred care [18]. Decision-making is complex and difficult in patients with organ-confined prostate cancer. This is due not only to the variable biological potential of the cancer but also due to patients' factors such as life expectancy and medical comorbid conditions [4,5], as treatment can have a significant impact on patient's QoL and length of life [9].

The information needs of patients with localised prostate cancer are enormous and there is evidence that their needs are not being met through usual care [19]. It is also important to understand how and why patients make their treatment decisions and the effect that these treatment choices have on long-term outcomes [13]. Over treatment of low-risk cancers remains a concern. Various clinical parameters such as age, PSA level at

diagnosis, cores involved, and PSA density, are currently utilised predictors. More recently, the Prostate Health Index (PHI), the 4 Kallikrein (4K) score, and patient-related factors (e.g. age, race, and family history) have been assessed for applicability to differentiate indolent from aggressive prostate cancers. The life expectancy is a commonly used metric to decide between treatment options. Age, comorbidities (as objective assessed by Charlson Comorbidity Index, CCI) are used to determine life expectancy. Boehm et al. [20] recently reported that in patients with non-metastatic prostate cancer, neither age nor CCI can accurately estimate overall mortality or life expectancy in excess of 10 years. All guidelines consider life expectancy as an important determinant for devising a management strategy; it is not easy to identify tools that could be appropriately used into a point-of-care decision aid [21].

The biological potential of prostate cancer is variable, nearly one-third have low-risk tumours that are not lethal and remain asymptomatic during their lifetime. Currently, various nomograms are in use to predict positive surgical margins, particularly extracapsular extension (ECE). ECE has a significant impact on the management strategy and patient prognosis. Identification of ECE before surgery is therefore pivotal in clinical decision-making. It not only influences surgical decision-making, but also if nerve sparing will be performed. Sacrificing the neurovascular bundle negatively impacts QoL by increasing the chances and recovery period of both continence [22] and potency [23]. Currently, available models and nomograms are based on clinical staging based on ultrasonography, which significantly under stages ECE in over one-quarter of patients [24]. Recently, multiparametric MRI (mpMRI)-based staging has been proposed to minimise understaging [17]. It has been noted that mpMRI improved accuracy of existing clinical nomograms for prediction of pathological ECE [25]. With the introduction of mpMRI during the last decade, significant advances have been made in prostate cancer pre-therapy staging, with consequent risk stratification and hence its integration into clinical decision-making with the goal of preventing over treatment of low-risk disease and selection of optimal aggressive treatment in high-risk disease [26]. mpMRI also provides the highest clinical value when used as part of a multi-disciplinary collaboration between the treating physician and interpreting radiologist.

Biological markers [urine prostate cancer antigen 3 (PCA3), transmembrane protease serine 2:v ets erythroblastosis virus E26 oncogene homolog (TMPRSS2-ERG) gene fusion, or PSA isoforms] are promising; along with genomics on the tissue sample itself. However, further data are needed in order to use these markers in standard clinical practice [27]. In the recent years, significant progress has been made in the mutational landscape in the development and progression of

prostate cancer. This has opened new avenues for development of molecular markers in predicting prognosis, diagnosis, and monitoring drug response. However, currently their clinical applicability is limited due to a lack of clinical validation, limitations, and cost [28].

Physicians' bias and perceptions about treatment decisionmaking in prostate cancer

Evidence suggests that patients and physicians have different goals for treatment and physicians' understandings of their own patients' preferences are not accurate [29].

Treatment decision is highly variable and is influenced by non-clinical factors, such as patient's demographics, geography and physicians' own specialty (urologist, radiation oncologists) [30], as they would intentionally or unintentionally reveal their treatment preferences at the time of diagnosis.

A recently published study identified physicians' (including urologists, radiation oncologists and primary care physicians) perceptions of patients' considerations, which are important for decision-making in prostate cancer [31]. Physician recommended AS for patients' with characteristics, such as older age, fear of treatment side-effects, comorbidities, life expectancy, anxiety, and willingness and ability to follow a surveillance protocol. Physicians also reported that their decision and recommendation were also influenced by patients' anxiety about cancer and the healthcare setting of physicians with recommendation of active treatment in fee-forservice settings (financial incentive) compared to integrated healthcare settings [16].

Various factors also contribute towards shared decision-making in prostate cancer. These include not only patient demographics such as age, comorbidity and performance status, but also their life expectancy and family history of longevity. Various guidelines recommend use of population-based scales such as mortality tables to estimate life expectancy, as only chronological age should not be considered as the main decision factor. Nomograms and tools are devised to define the optimal treatment options for patients diagnosed with cancer after weighing the individual's risk of disease progression against risk of non-cancer death [32].

Patients' bias and preferences for treatment selection and subsequent decision regret

Studies have shown that patients with prostate cancer do not receive the necessary information needed for understanding of the disease and treatment options, with fear and misconceptions prevailing in their minds. They therefore rely on the treatment decision of their physicians, family, anecdotes, and opinions of others [33]. Patients often report high levels of decision-related stress both at the time of diagnosis and at the completion of treatment [7].

Patients' experiences differ markedly between and within the treatment options, and they sometimes experience regret about not only the choice they made but also the way the decision was made regarding a particular treatment option [9]. Up to a quarter of patients report regrets about their treatment decision, this is more prevalent amongst men who assume a more passive role during decision-making [7].

A systematic review of regret following treatment of localised prostate cancer identified that treatment-related toxicity especially urinary, sexual and bowel dysfunction were the most common factors for regret followed by old age and longer time since treatment. A higher level of regret was found after RP than after ERBT or brachytherapy [9].

Patients who undergo RT could experience significant side-effects including urinary incontinence, gastrointestinal side-effects, erectile dysfunction, and serious sequelae requiring urological procedures and hospital admissions which could impact QoL and be associated with significant regret. RT is associated with even serious side-effects such as formation of urinary fistula and development of secondary malignancy. These complications vary according to the institution, RT dose, and technique of RT [34].

Patient-centred approach with consideration of values, preferences and perceptions

To facilitate a decision, physicians need to tailor intervention according to patients' age and cancer aggressiveness and should develop strategies to reduce patient's concerns and misconceptions. Patients should also be given sufficient time to consider treatment options, which helps them to balance the information, received from various sources [35]. Patients should be given choices of treatment options with a detailed discussion on potential advantages and disadvantages that they must consider based on their lifestyle, values, and preferences. Treatment should be selected based on patients own perceptions of risks and benefits rather than selected from a predominantly medical perspective [13].

Patient-related factors for decision-making in the management of organ-confined prostate cancer

Age

The risk of developing prostate cancer increases with age, but it can occur in a wide spectrum of age groups. Age is also an important prognostic factor in treating prostate cancer. Within the younger age group

(the working labour group) the socioeconomic concerns need to be considered, e.g. the patients employment status. In this regard it has been shown that the younger patient is more likely to opt for a surgical treatment, whereas the older patient tends to receive a nonsurgical treatment [36], although this has slightly changed after remarkable improvement in outcomes following laparoscopic and robotic surgery. Younger patients were also found to be more willing to be involved in the decision-making process and more hopeful, whereas older patients were found to be avoiding being involved and were found to be less participatory in the decision-making process [37].

Religious beliefs

Amongst urological surgeons there is a tendency towards seeing robotic RP a 'gold standard' for treatment of organ-confined prostate cancer [38]. However, every once in a while we face the situation that a patient refuses surgical or even all treatment due to religious beliefs. The classical example of Jehovah's witnesses, despite being rare, should be kept in mind, as this will leave the decision maker no option for a curative treatment but RT. In scenarios where RT is contraindicated (e.g. previous pelvic irradiation or inflammatory bowel diseases) the options left would be hormonal therapy and watchful waiting or embarking on a high-risk surgery. However, there seems to be some kind of flexibility amongst Jehovah's witnesses emerging in the past few years, especially if the patient is well-informed about the surgical option and the risk of blood transfusion. There are even reports that a few patients have even accepted blood transfusions if inevitable [39]. Indeed, these patients accept surgery with allogenic blood transfusion. Fregonesi et al. [40] reported use of transfusion-free radical robotic surgery in this group. As RP is historically associated with the potential for significant blood loss, patients who refuse allogeneic blood transfusion such as Jehovah's Witnesses can be challenging surgical candidates. Various strategies are described in the literature to prevent or reduce the need for blood transfusion, such as preoperative haemoglobin boost utilising erythropoietin, normovolemic haemodilution, and intraoperative cell salvage [41].

Sexual health

Since the concept of focusing on QoL rather than purely on survival for patients with cancer was introduced to modern cancer therapy, much has changed in decision-making. It has been shown that patients may prefer and appreciate a better QoL, even at the cost of poorer survival rates [42].

In this respect maintenance of a healthy sexual life after radical treatment is an increasing concern for patients. Nowadays, it is not uncommon to be asked directly by the patient about the possibility of a nervesparing surgery or to see patients concerned about penile shortening after RP. Changes in sexual function should therefore routinely be discussed during patient counselling. Since all radical treatment options have an impact on sexual health, AS and focal therapies have become the methods of choice for some patients.

In our practice the assessment of sexual health is now a standard preoperative measure. A widely accepted method for this assessment is through International Index of Erectile Function score. The patient is also thoroughly educated about the treatment options for erectile dysfunction postoperatively. These include phosphodiesterase type-5 inhibitors, intracavernosal injections, vacuum erectile devices, and medicated urethral systems. Use of penile prosthesis is the last line of therapy for erectile dysfunction following radical prostate surgery. In a recent study, Pillay et al. [43] assessed QoL, psychological functioning, and treatment satisfaction of men who underwent penile implantation after RP. They noted that patients reported good sexual function and treatment satisfaction.

Educational background

Understanding the details of the different prostate cancer treatment modalities and their potential complications requires a certain level of educational and cultural background. Not only should the patient understand the potential complications after surgery (e.g. incontinence, erectile dysfunction) but should also have sufficient educational background to understand the principles of pelvic floor training for example or penile rehabilitation. This educational background may be the key factor that drives a patient to undertake a prostate-screening test for example [44], as the benefit of having a national prostate cancer screening programme remains controversial. Patients with a family history of prostate cancer are by far better informed and it is easier to educate them about treatment modalities. Nevertheless, regardless of the patients educational background, every effort should be made by the medical team to achieve an adequate understanding of all information given, as studies show that many patients fail to make the best decision because they were affected by the experience of others and gathered information from unreliable sources [45,46].

Online risk-prediction resources for prostate cancer are now easily accessible and widely used by patients for informed decision-making concerning screening and diagnosis. Often these tools are not regularly updated to incorporate newer biomarkers, imaging studies etc. Of the many prediction tools, nomograms provide superior, individualised, disease-related risk estimations that facilitate management-related

decisions. Nevertheless, many more predictive tools, comparisons between them, and improvements to existing tools are needed [47].

There are many web-based patient-education materials, we often refer to the one provided by the European Association of Urology (EAU). Compared to conventional educational tools such as booklets, online web-based resources provide more prospects to tailor information to patient's individual needs [48].

Cognitive impairment

To achieve best possible treatment outcome an assessment of psychological status is mandatory. Together with educating the patient about his disease, qualified psycho-oncological counselling should be initiated to reveal any cognitive impairment, e.g., as this is associated with increased mortality [49]. Emotional state and secondary depression were shown to improve in elderly patients after surgical treatment but a pre-existing cognitive impairment would not change, hence the importance of the initial assessment. Many methods for assessment are available. The most widely accepted method to date is the mini-COG [50,51]. The International Society of Geriatric Oncology recommends performing a comprehensive geriatric assessment in elderly population including identifying comorbidities, functional status (dependent or independent performance), nutritional status and overall QoL [50]. AS/watchful waiting are the chosen options for elderly patients with dementia and limited life-expectancy. Various factors also need to be considered when choosing curative treatment options, such as patient's support and independent performance.

Brachytherapy (if not contraindicated by a much enlarged prostate or history of urinary retention) can also be a safe option with good patient tolerance and minimal gastrointestinal or genitourinary functional disturbance.

Data on ADT resulting in cognitive impairment are conflicting. However, a discussion on the negative impact on cognitive function of ADT should be part of patient counselling prior to the start of treatment. Due consideration should be given to explaining the pros and cons in the light of comorbid conditions, life-expectancy, and disease risk. There is dearth of data on counselling patients about treatment options in patients who have pre-existing dementia. It is clear that a truly informed consent cannot be obtained under such situations [52] and further aggravation of cognitive dysfunction is expected.

Decision-making framework

Patients' participation in decision-making for medical care ranges within three categories of framework according to a Control Preference Scale (CPS) describe by Degner et al. [53]:

- Active (patient's autonomy): patient makes treatment decision alone.
- Collaborative (shared decision-making): patient and physician make the treatment decision together and share the responsibility
- 3. Passive (medical paternalism): Physician makes treatment decision for patients [30]. Medical paternalism is based on the belief that physicians know more than patients about what is good for them [30] and therefore endorses physician's authority. However, physicians who make decisions on behalf of patients are often poor judges of patients' values, preferences, QoL and life expectancy [54]. Shared decision-making ensures better quality of care and increased satisfaction for both the patients and medical staff [7].

Shared care/shared decision-making

This concept comprises an intentional and co-operative communication between the patient and a clinician with the aim of delivering high-value, patient-centred care [55].

Due to the complexity of prostate cancer diagnosis, risk stratification, and the multitude of available treatment options, patients themselves are not in a position to take responsibility for treatment [12]. Shared decision-making ensures that healthcare decision combines physician's knowledge and expertise about a treatment option with each individual patient's preferences, values, and life priorities [32], thus reducing decisional conflicts [56]. The AUA guidelines encourage both urologists and patients to participate in shared decision-making for prostate cancer [6].

A recently published randomised controlled trial (RCT) 'Procare' criticised the current model follow-up strategy for men with low- to intermediate-risk prostate cancer [57]. It randomised patient's care into shared care vs usual care. Patients with usual care described more distress and ongoing side-effects including psychological issues compared to shared care. A study by Davison et al. [58] showed that men who prefer a more collaborative role are aware of more information about prostate cancer and test results, treatment options, and their impact on OoL. Patients with newly diagnosed localised prostate cancer and low health literacy levels were more vulnerable to mental distress than those with a high health literacy level [59]. To promote shared decision-making, online health information like e-health programmes can provide patients and their families' opportunity to improve their health education and knowledge.

Decision aids

Background

Decision aids are particularly useful when there is no consensus about best practice/'gold standard' for a particular condition (like organ-confined prostate cancer) and judgments about treatment risk and benefits are

more or less subjective [33]. Decision aids are tools designed to improve shared decision-making and to complement counselling from healthcare professionals [33].

They facilitate patient participation and support them making specific and deliberative choices amongst treatment options and risk perceptions by reducing decisional conflict through evidence-based description of benefits and risks of different treatment options [60].

Content and types of decision aids

These aids contain numeric and graphic information to describe possible outcomes of each option, helping patients to reach a decision based on their own values and preferences [37].

These aids convey balanced information about different treatment options in their understandable language and encourage them to pursue treatment options appropriate to their situation. They are therefore different from conventional educational materials and should be implemented in daily clinical care of patients [37]. Decision aids use various media to convey information and include personal interviews, written and printed materials, audio recordings, videos and multimedia presentations, and interactive computer-based tools [61].

Rationale for decision aids

A Cochrane review studied 115 decision aids to assess those used in RCTs and concluded that compared to usual care, patients who used decision aids have greater knowledge of treatment options, better understanding of treatment risks, and their decisions were consistent with individual values and preferences [33].

A systematic review showed that for localised prostate cancer the use of decision aids is feasible and acceptable, and have been shown to improve care in key domains of decision-making, i.e. active participation, gain in patients' knowledge, alleviation of anxiety, and improved satisfaction with the decision [62].

Adsul et al. [63] in a systematic review of decision aids studied their role for helping make specific choices amongst the options and outcomes relevant to health status specific to prostate cancer treatment.

Role of multidisciplinary care and clinics

Dimensions needed for multidisciplinary care and shared decision-making in patients with prostate cancer

Different dimensions such as content to be discussed (type, detail of information), a facilitative environment, and emotional support are important for the multidisciplinary clinic when involved in shared decision-making.

Multidisciplinary clinics

Multidisciplinary clinics are an effective tool to facilitate the decision-making process. Contrary to consultation with individual practitioners, the treatment patterns of patients who attend multidisciplinary clinics are different [64]. In MDT clinics, patient (with family members) are informed about the full overview of the possible treatment options available, along with the alternatives at a particular setup after complete review of imaging and pathology reports (staging). The patient's risk profile is determined to help them to choose the best possible option whilst maintaining QoL and a structured follow-up care plan is given. A discussion of potential risks and benefits of each treatment is made [65]. Studies have shown that this real-time collaboration between urologists, radiation oncologists, medical oncologists, pathologists and radiologists helps in the adherence to clinical guidelines and hence improved quality of care. This also results in high satisfaction rate as appreciated by the patient and their families [58].

A scheduled appointment in a multidisciplinary clinic is often difficult, as coordination between specialties is required [66]. Often the experts involved are working in other hospitals and even across continents and this introduces further complexity [67].

A multidisciplinary approach includes a thorough assessment about patient characteristics such as potential longevity, medical and psychological concerns, and patient's tumour characteristics. Patients are educated about their cancer and management choices by the urologists, radiation oncologists and other healthcare professionals, and then the team makes a joint recommendation about the treatment options [41].

These clinics help in appropriate communication with patients about treatment options and prevent any omission of information availability, thus improving their knowledge, fostering active participation in decision-making, and reducing the level of anxiety and distress [68]. Through the multidisciplinary and a patient-inclusive approach an appropriate (shared) decision can be made.

Conclusions

Decision-making in localised prostate cancer is difficult as there is no 'gold standard' treatment. Often the condition is asymptomatic and the patient is subjectively worse after treatment. This results in an unhappy patient, unless he is actively involved in the decision-making process. There are forums like MDT, decision aids etc. to facilitate this process. There are many

personal factors such as age, religion, education, sexual activity and psychological status, which can have a major impact on the decision-making process and should be considered whilst trying to counsel the patient about the best treatment option. After all, the patient is the only decision maker, we just provide him with the choices.

Conflict of interest

None.

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References

- Jemal A, Fedewa SA, Ma J, Siegel R, Lin CC, Brawley O, et al. Prostate cancer incidence and PSA testing patterns in relation to USPSTF screening recommendations. *JAMA* 2015;314: 2054–61.
- [2] American Cancer Society. Cancer Facts & Figures 2017. Available at; https://www.cancer.org/content/dam/cancer-org/research/cancer-facts-and-figures-2017.pdf [accessed June 2018].
- [3] Ferlay J, Soerjomataram I, Dikshit R, Eser S, Mathers C, Rebelo M, et al. Cancer incidence and mortality worldwide: sources, methods and major patterns in GLOBOCAN 2012. *Int J Cancer* 2015;136:E359–86.
- [4] Ruchlin HS, Pellissier JM. An economic overview of prostate carcinoma. *Cancer* 2001;**92**:2796–810.
- [5] Mottet N, Bellmunt J, Bolla M, Briers E, Cumberbatch MG, De Santis M, et al. Guidelines on prostate cancer. Part 1: Screening, diagnosis, and local treatment with curative intent. *Eur Urol* 2017;71: 618–29. https://doi.org/10.1016/j.eururo.2016.08.003.
- [6] Hershman DL, Buono D, McBride RB, Tsai WY, Joseph KA, Grann VR, et al. Surgeon characteristics and receipt of adjuvant radiotherapy in women with breast cancer. J Natl Cancer Inst 2008;100:199–206.
- [7] National Comprehensive Cancer Network. NCCN Guidelines in Oncology - Prostate cancer, version 2, 201. Available at: https://www.nccn.org/professionals/physician_gls/pdf/prostate.pdf>.
- [8] American Urological Association. Guidelines Early Detection of Prostate Cancer. Available at: https://www.auanet.org/guidelines/early-detection-of-prostate-cancer-(2013-reviewed-and-validity-confirmed-2015) [accessed June 2018].
- [9] Davison BJ, So AI, Goldenberg SL. Quality of life, sexual function and decisional regret at 1 year after surgical treatment for localized prostate cancer. *BJU Int* 2007;**100**:780–5.
- [10] Jarosek SL, Virnig BA, Chu H, Elliott SP. Propensity-weighted long-term risk of urinary adverse events after prostate cancer surgery, radiation, or both. *Eur Urol* 2015;67:273–80. https://doi. org/10.1016/j.eururo.2014.08.061.
- [11] Christie DR, Sharpley CF, Bitsika V. Why do patients regret their prostate cancer treatment? A systematic review of regret after treatment for localized prostate cancer. *Psychooncology* 2015;24:1002–11.
- [12] Bandaragoda T, Ranasinghe W, Adikari A, de Silva D, Lawrentschuk N, Alahakoon D, et al. The Patient-Reported Information Multidimensional Exploration (PRIME) Framework for investigating emotions and other factors of prostate cancer

- patients with low intermediate risk based on online cancer support group discussions. *Ann Surg Oncol* 2018;**25**:1737–45.
- [13] Albkri A, Girier D, Mestre A, Costa P, Droupy S, Chevrot A. Urinary incontinence, patient satisfaction, and decisional regret after prostate cancer treatment: a French national study. *Urol Int* 2018;100:50–6.
- [14] Parker PA, Davis JW, Latini DM, Baum G, Wang X, Ward JF, et al. Relationship between illness uncertainty, anxiety, fear of progression and quality of life in men with favourable-risk prostate cancer undergoing active surveillance. *BJU Int* 2016;117:469–77.
- [15] Weiner AB, Patel SG, Etzioni R, Eggener SE. National trends in the management of low and intermediate risk prostate cancer in the United States. J Urol 2015;193:95–102.
- [16] Daskivich TJ, Lai J, Dick AW, Setodji CM, Hanley JM, Litwin MS, et al. Variation in treatment associated with life expectancy in a population-based cohort of men with early-stage prostate cancer. Cancer 2014;120:3642–50. https://doi.org/10.1002/cncr.28926.
- [17] Lunardi P, Ploussard G, Grosclaude P, Roumiguié M, Soulié M, Beauval JB. Current impact of age and comorbidity assessment on prostate cancer treatment choice and over/under treatment risk. World J Urol 2017;35:587–93. https://doi.org/10.1007/s00345-016-1900-9.
- [18] Makarov DV, Chrouser K, Gore JL, Maranchie J, Nielsen ME, Saigal C, et al. AUA White Paper on implementation of shared decision making into urological practice. *Urol Pract* 2016;353:355–63.
- [19] Hurwitz LM, Cullen J, Elsamanoudi S, Kim DJ, Hudak J, Colston M, et al. A prospective cohort study of treatment decision-making for prostate cancer following participation in a multidisciplinary clinic. *Urol Oncol* 2016;34:e17–25.
- [20] Boehm K, Dell'Oglio P, Tian Z, Capitanio U, Chun FK, Tilki D, et al. Comorbidity and age cannot explain variation in life expectancy associated with treatment of non-metastatic prostate cancer. World J Urol 2017;35:1031–6.
- [21] Fontanella P, Benecchi L, Grasso A, Patel V, Albala D, Abbou C, et al. Decision-making tools in prostate cancer: from risk grouping to nomograms. *Minerva Urol Nefrol* 2017;69:556-66.
- [22] Michl U, Tennstedt P, Feldmeier L, Mandel P, Oh SJ, Ahyai S, et al. Nerve-sparing surgery technique, not the preservation of the neurovascular bundles, leads to improved long-term continence rates after radical prostatectomy. *Eur Urol* 2016;69:584–9.
- [23] Nguyen LN, Head L, Witiuk K, Punjani N, Mallick R, Cnossen S, et al. The risks and benefits of cavernous neurovascular bundle sparing during radical prostatectomy: a systematic review and meta-analysis. *J Urol* 2017;198:760–9.
- [24] Feng TS, Sharif-AfsharAR WuJ, Li Q, Luthringer D, Saouaf R, et al. Multiparametric MRI improves accuracy of clinical nomograms for predicting extracapsular extension of prostate cancer. *Urology* 2015;86:332–7.
- [25] Martini A, Gupta A, Lewis SC, Cumarasamy S, Haines KG, Briganti A, et al. Development and internal validation of a side specific, multiparametric MRI-based nomogram for the prediction of extracapsular extension of prostate cancer. *BJU Int* 2018. https://doi.org/10.1111/bju.14353 [Epub ahead of print].
- [26] Nazim SM, Ather MH, Salam B. Role of multi-parametric (mp) MRI in prostate cancer. J Pak Med Assoc 2018;68:98–104.
- [27] Lamy PJ, Allory Y, Gauchez AS, Asselain B, Beuzeboc P, de Cremoux P, et al. Prognostic biomarkers used for localised prostate cancer management: a systematic review. *Eur Urol Focus* 2017. https://doi.org/10.1016/j.euf.2017.02.017 [Epub ahead of print].
- [28] Boström PJ, Bjartell AS, Catto JW, Eggener SE, Lilja H, Loeb S, et al. Genomic predictors of outcome in prostate cancer. *Eur Urol* 2015;68:1033–44.

[29] Steginga SK, Turner E, Donovan J. The decision-related psychosocial concerns of men with localized prostate cancer: targets for intervention and research. World J Urol 2008;26:469-74.

- [30] Fowler Jr FJ, McNaughton Collins M, Albertsen PC, Zietman A, Elliott DB, Barry MJ. Comparison of recommendations by urologists and radiation oncologists for treatment of clinically localized prostate cancer. *JAMA* 2000:283:3217–22.
- [31] Davis K, Bellini P, Hagerman C, Zinar R, Leigh D, Hoffman R. Physicians' perceptions of factors influencing the treatment decision-making process for men with low-risk prostate cancer. *Urology* 2017;107:86–95.
- [32] Kutikov A, Cooperberg MR, Paciorek AT, Uzzo RG, Carroll SA, Boorjian SA. Evaluating prostate cancer mortality and competing risks of death in patients with localized prostate cancer using a comprehensive nomogram. *Prostate Cancer Prostatic Dis* 2012;15:374–9. https://doi.org/10.1038/pcan.2012.21.
- [33] Denberg TD, Melhado TV, Steiner JF. Patient treatment preferences in localized prostate carcinoma: the influence of emotion, misconception, and anecdote. *Cancer* 2006;107:620–30.
- [34] James M, McLean G, Williams S, Robinson B, Yi M. Complications of curative radiation treatment for early prostate cancer. Asia Pac J Clin Oncol 2018. https://doi.org/10.1111/ajco.12839
 [Epub ahead of print].
- [35] Song L, Chen RC, Bensen JT, Knafl GJ, Nielsen ME, Farnan L, et al. Who makes the decision regarding the treatment of clinically localized prostate cancer—the patient or physician? Results from a population-based study. *Cancer* 2013;119:421–8.
- [36] Harlan LC, Potosky A, Gilliland FD, Hoffman R, Albertsen PC, Hamilton AS, et al. Factors associated with initial therapy for clinically localized prostate cancer: prostate cancer outcomes study. J Natl Cancer Inst 2001;93:1864–71.
- [37] Cassileth BR, Zupkis RV, Sutton-Smith K, March V. Information and participation preferences among cancer patients. *Ann Intern Med* 1980;92:832–6.
- [38] Chopra S, Srivastava A, Tewari A. Robotic radical prostatectomy: the new gold standard. *Arab J Urol* 2012;10:23–31. https://doi.org/10.1016/j.aju.2011.12.005.
- [39] Trzciński R, Kujawski R, Mik M, Berut M, Dziki Ł, Dziki A. Surgery in Jehovah's Witnesses our experience. Prz Gastroenterol 2015;10:33–40. https://doi.org/10.5114/pg.2014.47496.
- [40] Fregonesi A, Ciari C, Melotti L, Zani EL, Ferreira U, Reis LO. Strategies for transfusion-free radical retropubic prostatectomy in Jehovah's witnesses. *Actas Urol Esp* 2010;34:440–3.
- [41] Nieder AM, Simon MA, Kim SS, Manoharan M, Soloway MS. Intraoperative cell salvage during radical prostatectomy: a safe technique for Jehovah's Witnesses. *Int Braz J Urol* 2004;30:377–9.
- [42] van Tol-Geerdink JJ, Stalmeier PF, van Lin EN, Schimmel EC, Huizenga H, van Daal WA, et al. Do patients with localized prostate cancer treatment really want more aggressive treatment? J Clin Oncol 2006;24:4581–6. https://doi.org/10.1200/JCO.2006.05.9592.
- [43] Pillay B, Moon D, Love C, Meyer D, Ferguson E, Crowe H, et al. Quality of life, psychological functioning, and treatment satisfaction of men who have undergone penile prosthesis surgery following robot-assisted radical prostatectomy. *J Sex Med* 2017;14:1612–20.
- [44] Kilpeläinen TP, Talala K, Raitanen J, Taari K, Kujala P, Tammela TL, et al. Prostate cancer and socioeconomic status in the Finnish randomized study of screening for prostate cancer. Am J Epidemiol 2016;184:720–31. https://doi.org/10.1093/aje/kww084.
- [45] Berry DL, Ellis WJ, Woods NF, Schwien C, Mullen KH, Yang C. Treatment decision-making by men with localized prostate cancer: the influence of personal factors. *Urol Oncol*. 2003;21:93–100.
- [46] Aning JJ, Wassersug RJ, Goldenberg SL. Patient preference and the impact of decision-making aids on prostate cancer treatment

- choices and post-intervention regret. *Curr Oncol* 2013;**19**:S37–44. https://doi.org/10.3747/co.19.1287.
- [47] Shariat SF, Karakiewicz PI, Roehrborn CG, Kattan MW. An updated catalog of prostate cancer predictive tools. *Cancer* 2008:113:3075–99.
- [48] Schaffert R, Dahinden U, Hess, T,Bänziger, A,, Kuntschik, P,, Odoni F,, et al. Evaluation of a prostate cancer E-health tutorial: development and testing of the website prostata-information.ch. *Urologe A* 2018;57:164–71. https://doi.org/10.1007/s00120-017-0552-8.
- [49] Namiki S, Ishidoya S, Tochigi T, Ito A, Arai Y. Quality of life after radical prostatectomy in elderly men. *Int J Urol* 2009;16:813–9. https://doi.org/10.1111/j.1442-2042.2009.02371.x.
- [50] Droz JP, Albrand G, Gillessen S, Hughes S, Mottet N, Oudard S, et al. Management of prostate cancer in elderly patients: recommendations of a task force of the International Society of Geriatric Oncology. Eur Urol 2017;17(72):521–31. https://doi.org/10.1016/j.eururo.2016.12.025.
- [51] Borson S, Scanlan JM, Chen P, Ganguli M. The Mini-Cog as a screen for dementia: validation in a population-based sample. J Am Geriatr Soc. 2003;51:1451–4.
- [52] McHugh DJ, Root JC, Nelson CJ, Morris MJ. Androgendeprivation therapy, dementia, and cognitive dysfunction in men with prostate cancer: how much smoke and how much fire? *Cancer* 2018;124:1326–34.
- [53] Degner LF, Sloan JA, Venkatesh P. The control preferences scale. Can J Nurs Res 1997;29:21–43.
- [54] Walz J, Gallina A, Perrotte P, Jeldres C, Trinh QD, Hutterer GC, et al. Clinicians are poor raters of life-expectancy before radical prostatectomy or definitive radiotherapy for localized prostate cancer. *BJU Int* 2007;100:1254–8.
- [55] Fried TR. Shared decision making finding the sweet spot. N Engl J Med 2016;374:104–6.
- [56] Stacey D, Légaré F, Lewis K, Barry MJ, Bennett CL, Eden KB, et al. Decision aids for people facing health treatment or screening decisions. *Cochrane Database Syst Rev* 2017;12:CD001431.
- [57] Emery JD, Jefford M, King M, Hayne D, Martin A, Doorey J, et al. ProCare trial: a phase II randomized controlled trial of shared care for follow-up of men with prostate cancer. *BJU Int* 2017;119:381–9.
- [58] Davison BJ, Parker PA, Goldenberg SL. Patients' preferences for communicating a prostate cancer diagnosis and participating in medical decision-making. *BJU Int* 2004;93:47–51.
- [59] Song L, Mishel M, Bensen JT, Chen RC, Knafl GJ, Blackard B, et al. How does health literacy affect quality of life among men with newly diagnosed clinically localized prostate cancer? Findings from the North Carolina-Louisiana Prostate Cancer Project (PCaP). Cancer 2012;118:3842–51.
- [60] O'Connor AM, Bennett CL, Stacey D, Barry M, Col NF, Eden KB, et al. Decision aids for people facing health treatment or screening decisions. *Cochrane Database Syst Rev* 2011;10: CD001431.
- [61] Taylor KL, Davis KM, Lamond T, Williams RM, Schwartz MD, Lawrence W, et al. Use and evaluation of a CD-ROM-based decision aid for prostate cancer treatment decisions. *Behav Med* 2010;36:130–40.
- [62] Lin GA, Aaronson DS, Knight SJ, Carroll PR, Dudley RA. Patient decision aids for prostate cancer treatment: a systematic review of the literature. *CA Cancer J Clin* 2009;**59**:379–90.
- [63] Adsul P, Wray R, Spradling K, Darwish O, Weaver N, Siddiqui S. Systematic review of decision aids for newly diagnosed patients with prostate cancer making treatment decisions. *J Urol* 2015;194:1247–52.
- [64] Aizer AA, Paly JJ, Efstathiou JA. Multidisciplinary care and management selection in prostate cancer. Semin Radiat Oncol 2013;23:157–64.
- [65] Colasante A, Augurio A, Basilico R, Cotroneo AR, Di Sciascio G, Gaspari G, et al. A multidisciplinary group for prostate cancer

- management: A single institution experience. *Oncol Lett* 2018;**15**:1823–8. https://doi.org/10.3892/ol.2017.7506.
- [66] Leeftink AG, Vliegen IM, Hans EW. Stochastic integer programming for multi-disciplinary outpatient clinic planning. *Health Care Manag Sci* 2017. https://doi.org/10.1007/s10729-017-9422-6 [Epub ahead of print].
- [67] Brown ER, Bartlett J, Chalulu K, Gadama L, Gorman D, Hayward L, et al. Development of multi-disciplinary breast
- cancer care in Southern Malawi. Eur J Cancer Care (Engl) 2017;26:1. https://doi.org/10.1111/ecc.12658.
- [68] Korman H, Lanni Jr T, Shah C, Parslow J, Tull J, Ghilezan M, et al. Impact of a prostate multidisciplinary clinic program on patient treatment decisions and on adherence to NCCN guidelines: the William Beaumont Hospital experience. Am J Clin Oncol 2013;36:121-5.