

BJUI PCA: Prostate Cancer, Patient-Centred Approach or both?

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To evaluate differences and similarities in opinions on and expectations of prostate cancer management between physicians and patients. Two surveys on patient-specific opinions and expectations in prostate cancer management were done in 2011 among European prostate cancer specialists and patients with prostate cancer. Survey results were complemented with existing published data and with the authors' opinion. Most specialists spent 15–29 min on delivering the diagnosis, and about the same amount of time on explaining treatment options. This time was considered insufficient by 35% and 48% of patients, respectively. There was a large discrepancy between physicians' and patients' opinions about the type of provided prognostic and therapeutic information, indicating that patients may not have completely understood this information. Shared decision-making was preferred by both patients and specialists. Treatment efficacy was the most important factor determining treatment choice for both groups, while the physician's opinion or experience also had a great impact on patients' treatment choice. Patient-support groups have an important role in providing

What's known on the subject? and What does the study add?

Several studies have explored patient-specific expectations of prostate cancer management, while others have investigated physicians' perceptions. However, the opinions of both groups have seldom been compared in one study. Therefore, the present study compares the results of two surveys, one among physicians and one among patients, on patient-physician communication and patients' expectations of prostate cancer management.

The present review aims to highlight the differences and similarities in opinion on prostate cancer management between physicians and patients. It reflects the most important results of two surveys on patient-specific expectations in prostate cancer management, done among European prostate cancer specialists and patients with prostate cancer. These results are compared with published data. In addition, the authors' opinion on the survey results and on optimal prostate cancer management is included.

relevant information and in exchanging experiences between patients. The supportive role of partners/relatives was more appreciated when discussing treatment options than during diagnosis. Although patients' expectations are generally matched by their caring physician(s), physicians can still improve quality of care by taking adequate time for their patients, by using terminology that is easily understood by patients and by

encouraging shared decision-making. A multidisciplinary team may be an important part of the treatment paradigm, with the individual patient's needs and preferences as the centre of care.

KEYWORDS

counselling, multidisciplinary approach, patient support, physician-patient relations, prostate cancer, shared decision-making

INTRODUCTION

Current prostate cancer management includes many aspects that may surpass the competence of individual prostate cancer specialists. Therefore, managing patients with prostate cancer in a multidisciplinary/multiprofessional team (MDT) is now considered the best approach [1,2] and has

been implemented in several European countries (e.g. Belgium, Germany, UK) [1,3].

Given the wide variety of treatment options, patients with prostate cancer have to make difficult choices during the varying phases of their disease. Unfortunately, they may be confronted with differing information and little understanding to make these choices.

This often leads to confusion [4]. This 'lost patient syndrome' may get even worse if there is a lack of communication or feedback between the different MDT members [4].

Consequently, patients need clear, objective and relevant information. Good communication between all involved parties,

TABLE 1 The physicians' characteristics

Characteristic	n (%)
Main specialty:	
Urology	291 (96)
Radiation oncology	8 (2.6)
Medical oncology	2 (0.7)
Other	2 (0.7)
Experience in clinical practice, years:	
≤5	26 (8.6)
6–10	46 (15.2)
11–15	37 (12.2)
>15	194 (64.0)
Main practice setting:	
Academic hospital	163 (53.8)
Community hospital	60 (19.8)
Private practice	55 (18.2)
Governmental	22 (7.3)
Other	3 (1.0)
% of time spent on patient care:	
<25	11 (3.6)
50	51 (16.8)
>75	168 (55.4)
100	73 (24.1)

i.e. the different MDT members, the caregivers outside the hospital (e.g. general practitioner; GP) and the patient [4,5], is an absolute prerequisite. However, most physicians have been taught a disease-centred approach, with eradication of the tumour being the main goal. Patients, on the other hand, also take the risk of treatment-related morbidity and impact on their health-related quality of life (HRQL) into account when making treatment decisions [6,7]. Thus, there may be differences in opinion on prostate cancer management between patients and physicians [8]. Consequently, patients' information needs might not be fully met, leading to some dissatisfaction with the decision-making process [9–11].

Here, prostate cancer patient-support groups such as Europa Uomo, the European Prostate Cancer Coalition representing 23 national, autonomous patient-support groups, might play a role, both by establishing networks of relevant information and by pleading for a balance between optimal medical treatment and patient-tailored care [4].

Several studies have explored patient-specific expectations of prostate cancer

management [6,7,9–15], while others have investigated physicians' perceptions [16]. However, the opinions of both groups have seldom been compared in a single study [8]. Therefore, the present study compares the results of two surveys, one among physicians and one among patients, on patient-physician communication and patients' expectations of prostate cancer management.

METHODS

The present review aims to highlight the differences and similarities in opinion on prostate cancer management between physicians and patients in three ways:

1. It reflects the most important results of two surveys on patient-specific expectations of prostate cancer management done (February 2011), i.e. a web-based questionnaire sent to a random sample of European prostate cancer specialists, and a paper-based questionnaire sent to a random sample of patients with prostate cancer
2. It compares these results with published data. To that purpose, a literature search was performed in MEDLINE (June 2011) using the Medical Subject Headings (MeSH) terms: 'prostatic neoplasms' and 'physician-patient relations'. Relevant English-language articles were selected and reference lists were screened for complementary publications.
3. The present review reflects the authors' opinion on the survey results and on optimal prostate cancer management.

RESULTS

DEMOGRAPHICS

In all, 303 prostate cancer specialists and 48 patients with prostate cancer completed the web-based and the paper-based surveys. The physicians' questionnaire was mainly completed by experienced urologists from all European countries, of whom half were working in academic hospitals (Table 1). As many patients with prostate cancer are seen by non-academic experts in real life, the survey results may not be fully representative for the opinion of the treating physician of patients with prostate cancer in general. Despite this limitation, the

survey outcome may give a relatively good indication of the current situation.

The patients' questionnaire was principally completed by educated European patients aged 65–74 years, who were married or living with a partner and who had been diagnosed with prostate cancer ≥5 years previously (Table 2). There were few patient respondents, of whom most were living in Belgium, and no questions were posed about their disease stage, both constituting survey limitations.

DIAGNOSIS AND PROGNOSIS

From our surveys, it is clear that the urologist is generally responsible for telling the patient that he has prostate cancer: only 8.3% of patients heard the diagnosis from their oncologist or radiation oncologist, while the GP was responsible in <5% of cases. About half of the specialists indicated that they felt (very) comfortable during this conversation. In contrast, about two-thirds of patients did not feel comfortable, and ≈40% found that their physician was not sufficiently supportive or sensitive. Discussing the patient's emotions was not common for physicians: >50% only did so if the patient expressed his feelings, vs 42.6% doing it routinely. Lack of adequate skills and time constraints might be the most important barriers for not initiating such a discussion [16]. Although most specialists (58.7%) usually take 15–29 min and 30% even take more time, more than one-third of patients indicated that this time was insufficient (Fig. 1). The best way to overcome this perceived lack of time is probably not by prolonging a single consultation, but giving the diagnosis gradually during several consultations. Indeed, patients might be 'shocked' when hearing the diagnosis, making it difficult for them to absorb any further information or to ask questions during a single consultation [9]. Therefore, it also helps if the patient is accompanied by a relative or friend, as those persons might be more receptive to the provided information after hearing 'bad' news.

Although most specialists stated that they provide the patient information about tumour characteristics (87.5%) and prognosis (83.2%), only about half of the patients said they had actually received prognostic information, while only one-third

indicated that the physician had explained their tumour characteristics (Fig. 2). In general, >60% of patients were not satisfied with the amount of information they received after the initial diagnosis (Fig. 3). This major discrepancy between physicians' and patients' opinion (Fig. 2) indicates that the patient may not have completely understood the information provided by the physician. Possibly, the terminology used might not have been adequate for these discussions. Indeed, a previous study already highlighted the importance of using language tailored to the patient's level of understanding [9]. The observed discrepancy might also be partially explained by patients' 'recall bias': as >80% of patients were diagnosed with prostate cancer ≥ 5 years previously, they might have forgotten exactly what information they were given.

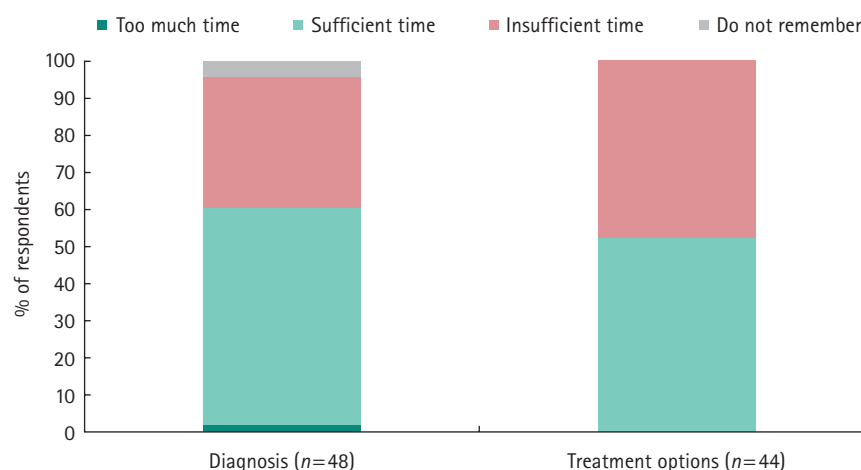
TREATMENT DECISION-MAKING

There was also a discrepancy between physicians' and patient's opinion for the provided information on the available treatment options. Nearly all specialists indicated that they informed their patients about differences in effectiveness/prognosis and in side-effects, while only 56.3% and 29.2% of patients remembered actually receiving this kind of information (Fig. 2). Thus, it is not surprising that about one-third of patients were not satisfied with the amount of information provided (Fig. 3), consistent with results from semi-structured interviews [9] and an extensive survey among 75 patients with prostate cancer [11]. In general, the time that specialists spent on explaining the available treatment options was about the same (usually 15–29 min) as the time for delivering the diagnosis. Half of the patients felt that this was insufficient (Fig. 1). This perceived 'rush' in explaining the information might be one of the reasons why patients had difficulties in capturing the provided information. Again, it might be overcome by spreading the treatment-decision process over several consultations [15], preferentially in accordance with the hospital's examination and treatment schedules. This approach will also reinforce the patient's feeling that there is sufficient time to take a well-considered treatment decision.

The fact that printed information, which allows the patient to quietly read the information at home [9,17], was only seldom

Characteristic	n (%)	TABLE 2 The patients' characteristics
Age, years (n = 46):		
55–64	6 (13.0)	
65–74	25 (54.3)	
75–84	14 (30.4)	
≥ 85	1 (2.2)	
Nationality (n = 46):		
Western Europe	36 (78.3)	
Belgium	31 (67.4)	
United Kingdom	2 (4.3)	
Other (Ireland, Germany, Netherlands)	3 (6.5)	
Northern Europe (Norway, Sweden)	2 (4.3)	
Southern Europe (Cyprus, Spain, Portugal)	3 (6.5)	
Eastern Europe (Bulgaria, Lithuania, Romania, Slovakia, Poland)	5 (10.9)	
Highest education level (n = 45):		
Primary school	4 (8.9)	
Secondary school	13 (28.9)	
Bachelor degree	10 (22.2)	
Master degree/University	15 (33.3)	
Post-university (PhD, etc.)	3 (6.7)	
Years since prostate cancer diagnosis (n = 48)		
<1	1 (2.1)	
1–4	8 (16.7)	
5–9	24 (50.0)	
≥ 10	15 (31.3)	

FIG. 1. Patients' opinion on amount of time spent by the caregiver on delivering the diagnosis/prognosis of prostate cancer and discussing the treatment options.



given to patients (10% in our survey) might be another reason why they did not capture all the information. Ideally, the patient should be offered a written decision-aid during a first consultation, followed by a second consultation shortly afterwards. In the meantime, the patient has time to reflect on his preferences and to formulate

questions to be asked during the second interview, preferentially to several MDT members. As such, a written decision-aid increases patients' knowledge about the disease, creates more realistic treatment expectations and improves discussion between patients and partner/relatives. Most importantly, it also improves the quality of

FIG. 2. Comparison of patients' and physicians' opinion on type of information on prostate cancer received by the patient/provided by the physician. ('Other' information includes: degree of treatment urgency, influence on partner, psycho-oncological effects and possible treatment, advice on coping strategies, contact information to ask for a second opinion, invitation for additional consultation(s) allowing further clarification of the provided information.)

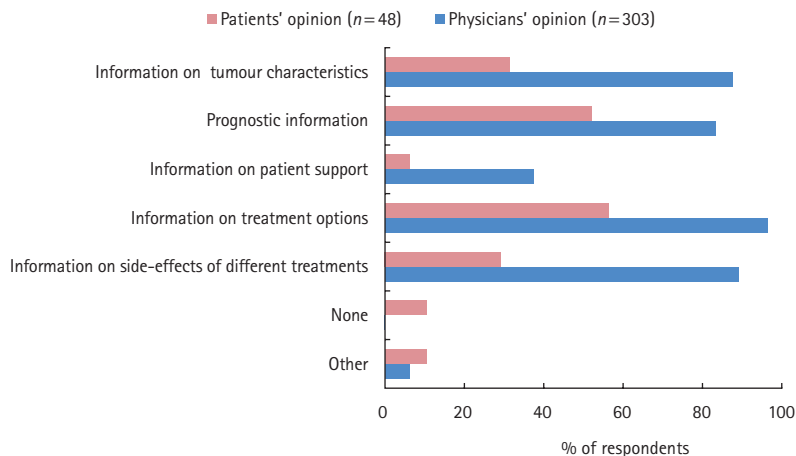
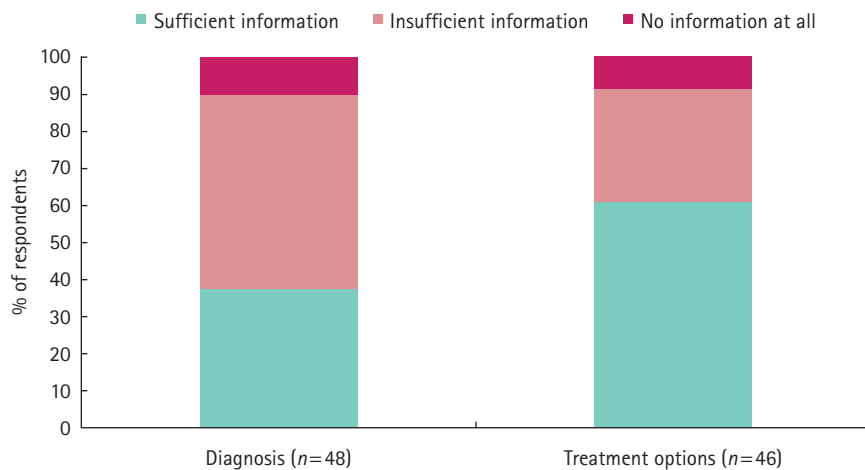


FIG. 3. Patients' opinion on amount of information given by the caregiver when delivering the diagnosis/prognosis of prostate cancer and discussing the treatment options.



communication between physicians and patients: as patients are better informed during a second consultation, specialists will have to explain less basic information, allowing them to focus more on patients' preferences [17]. Thus, although physicians have to invest some extra time in explaining the decision-aid at an early stage, it may be advantageous during all next management stages and can improve patients' satisfaction.

Indeed, patients' satisfaction with the treatment decision greatly depends on their involvement in the treatment-decision

process. This was nicely shown in a study among 126 Dutch patients with prostate cancer [10]. If the treatment decision was made by the doctor (passive), only about half of the patients were satisfied afterwards. Conversely, if patients had taken the treatment decision themselves (autonomous) or in collaboration with the physician, i.e. 'shared decision-making', >90% of patients were satisfied. Interestingly, the percentage of patients that felt 'very satisfied' was twice as high for the collaborative than for the autonomous approach, indicating that shared decision-making is preferred from the patients' point

of view. These results were confirmed both in a survey among 101 patients with prostate cancer [13] and in our own survey, with ≈50% of patients preferring shared decision-making, and another one-third preferring autonomous decision-making (Fig. 4). Remarkably, shared decision-making was even more preferred among physicians than among patients. The latter difference might be explained by the fact that >80% of patients were diagnosed with prostate cancer ≥5 years previously, when shared decision-making was not yet common practice. As such, it would be interesting to compare physicians' current opinion with the opinion of a large group of patients who were recently diagnosed with prostate cancer.

If physicians and patients were asked about the most important factor determining their treatment choice, most chose high treatment efficacy (Fig. 5). The risks of urinary and sexual dysfunction were the most concerning treatment-related side-effects for both groups. However, only 6% of patients indicated that this risk of treatment-related morbidity was the major decisive factor (Fig. 5). This finding seems to contradict previous study results, which showed the risks of urinary, gastrointestinal and sexual problems and their impact on HRQL, strongly influenced patients' treatment decisions [6,7,12]. This discrepancy might be explained by differences in formulation of the question between the present survey (asking to choose only one factor) and previous ones (asking to assign relative weights to all influencing factors). Indeed, in another study, where patients were asked to select only one most important decisive factor [14], outcomes were comparable to the present results. In addition, the low score of treatment-related morbidity might also be partly explained by a recall bias, as discussed before.

For physicians, treatment-related morbidity and patients' HRQL before/after treatment were clearly less important in treatment decision-making than treatment efficacy and tumour and biological characteristics (stage, grade, presence/location of metastases, etc.; Fig. 5), despite the strong advocacy of patient-support groups [4] and professional organisations [5] to consider patients' HRQL and preferences during the MDT discussion. This is especially

important for patients for whom treatment guidelines are not straightforward, such as patients with locally advanced prostate cancer. Indeed, in pT3b patients, therapeutic decisions taken by a MDT were only reproducible in 29% of cases, if based only on TNM stage, Gleason score and margin status [18].

Interestingly, the experience or the opinion of the treating physician was the most important decisive factor for almost 30% of patients (Fig. 5). This finding is in agreement with previous surveys [6,14], with >90% of patients indicating that the physician had influenced their treatment decision to some extent [6]. Given this extremely high impact of doctors on treatment choice, the specialist's experience with each treatment option (including success rate) should be a standard aspect of the information provided to the patient.

PATIENT SUPPORT

Treating physicians do not only have a huge impact on patients' treatment decision, but they are also the most important information source for the patient. Indeed, verbal information from the urologist was the most commonly used source, both in our survey ($\approx 75\%$ of patients) and in a previous one [11]. As such, treating physicians have the responsibility to provide patients with relevant, objective and up-to-date information. The MDT plays a crucial role here. Indeed, whereas individual specialists tend to favour their own discipline if they act autonomously [14], discussing each patient case in a MDT results in less biased decision-making [15]. As such, the multidisciplinary approach increases patients' feeling of being informed, facilitates decision-making and therefore increases patients' satisfaction [15].

The second most commonly used information sources were prostate cancer patient-support groups and relevant websites (38.5% and 30.8% of patients). Here, it should be stressed that the information provided by patient-support groups is generally more reliable than the disseminated and often confusing information posted by individuals on the internet. Indeed, spreading evidence-based, factual and up-to-date information on prostate cancer is one of the major goals of Europa Uomo, next to striving for optimal

FIG. 4. Comparison of patients' and physicians' opinion on preferred way of patient counselling and decision-making about prostate cancer. Only patients who had a real treatment choice (more than one treatment option appropriate) were considered.

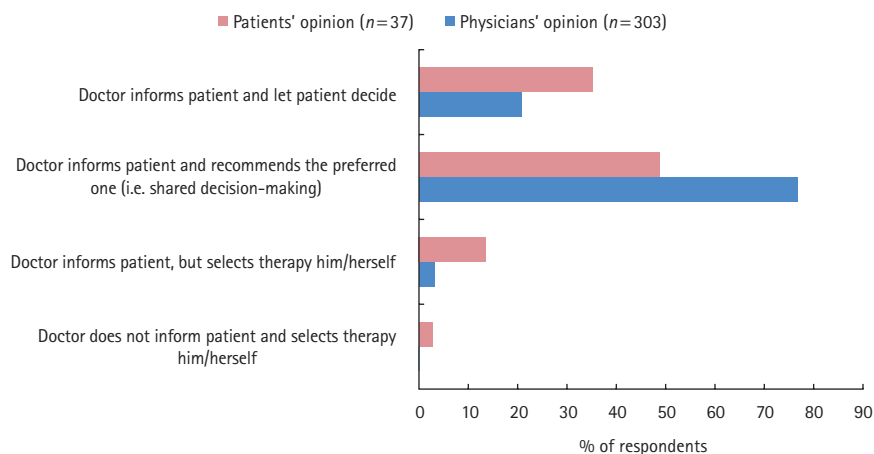
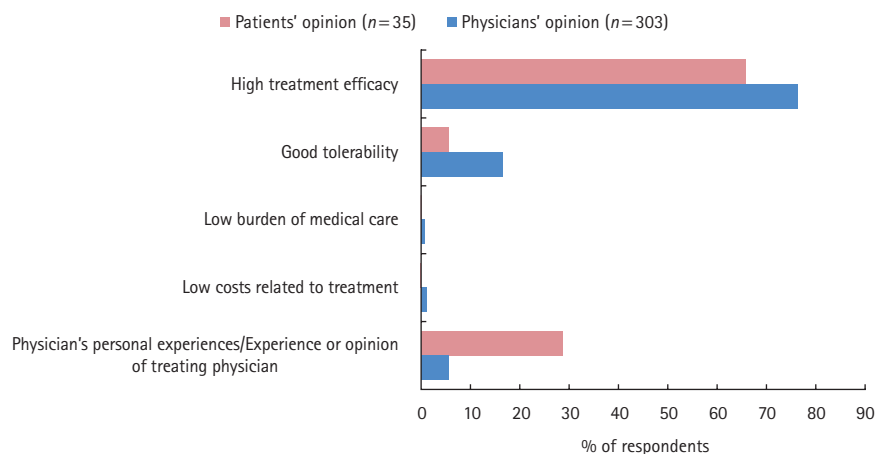


FIG. 5. Comparison of patients' and physicians' opinion on the most important treatment characteristic that influences their treatment choice. Patients who selected more than one option were excluded from the analysis.

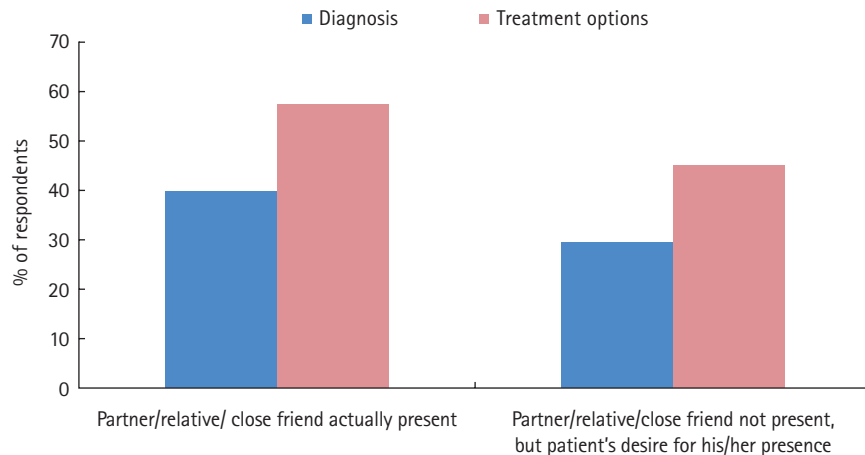


HRQL for patients with prostate cancer and their families, ensuring optimal multiprofessional tailored treatment and supporting prostate cancer research and active partnerships [4]. The multiple supportive roles of patient groups were also evident in the present patient survey: 40% of patients used support groups as an information source, and $\approx 70\%$ said that it was (very) important for them to share their experiences or to get the opinion of other patients with prostate cancer. Given this considerable role of patient-support groups, it is interesting that, according to the patients, only 6% of physicians informed them on ways to find patient-specific

support (Fig. 2); although this percentage might be partially explained by patients' 'recall bias', it remains remarkably low.

Next to patient-support groups, partners or relatives also play a crucial role in supporting the patient. As expected from a previous survey among patients with prostate cancer and their family members [19], partners/relatives were more often present when discussing the treatment options than during diagnosis (Fig. 6), and their supportive role was more appreciated during decision-making. Consistent with patients' opinion, >90% of physicians indicated that it was (extremely) important

FIG. 6. Patients' opinion on presence of partner/relative/close friend when hearing the diagnosis/prognosis of prostate cancer and discussing the treatment options.



for them to have the patients' partner/relatives present when explaining the treatment options. Indeed, participation of partners in the treatment discussion greatly facilitates shared decision-making between patients and partners, thereby improving patients' satisfaction [19].

Finally, the supportive role of the physician should not be neglected. In the present survey, >80% of patients could ask their doctor any question about prostate cancer, showing that physicians are generally very approachable and empathetic. However, continuous effort is needed to maintain and improve patients' degree of satisfaction with care.

CONCLUSIONS

Despite some methodological limitations, from the present study (one of the first comparing patients' and physicians' opinions on prostate cancer management), it is clear that patients' needs are generally matched by their caring physician(s). However, physicians may still improve quality of care by:

1. Taking adequate time for their patients, by using appropriate terminology and by providing verbal and written information in a gradual way during several subsequent consultations.
2. Providing patients with relevant and up-to-date prognostic and therapeutic information. MDT discussion is a good way

to exclude biases and to increase patients' feeling of being informed.

3. Informing patients on where to find additional information and patient-specific support.
4. Encouraging shared decision-making, between patients and physicians and between patients and partners/relatives.
5. Building the MDT around the patient, with his individual needs and preferences as the centre of care and by providing a permanent contact person within the MDT.

In this way, a patient-centred approach (PCA) will become synonym for optimal prostate cancer (PCA) management.

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CONFLICT OF INTEREST

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Abbreviations: MDT, multidisciplinary/multi-professional team; GP, general practitioner; HRQL, health-related quality of life.