

Original Article

Not all prostate cancer is the same – patient perceptions: an Asia-Pacific region study

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Objective

To explore the perceptions of patients living with different stages of prostate cancer across the Asia-Pacific (APAC) region, as while extensive quantitative research has been undertaken into outcomes of treatments for prostate cancer, little in the way of qualitative research has been performed looking at subjective perceptions of patients in regard to their perceived deficits in the treatment of this condition and such research is particularly lacking in reference to the APAC region.

Patients and methods

Initial 45-min qualitative research interrogatory interviews were conducted with 12 patients from Australia, China and Japan to identify themes that were significant to patients in the management of prostate cancer. Thereafter, 150 patients with different stages of prostate cancer underwent 30-min online (Australia) or computer-assisted/personal interviews categorised on the five key themes identified, in order to more fully clarify the nature of patient perceptions of how their prostate cancer had been treated and the issues they felt could be more fully addressed in order to improve the management of this condition.

Results

Interviews indicated common challenges and unmet needs among patients, including: (i) patients' feelings and emotional state change during their disease journey, (ii) patients lack of knowledge about prostate cancer and disease progression prior to diagnosis, (iii) patients felt shared decision-making was uncommon, (iv) patients have misperceptions about surgery, and (v) patients have unmet needs for greater information and support to manage their condition.

Conclusions

These patient perceptions of unmet needs in prostate cancer management stand in contrast to patient awareness of other common diseases such as heart failure and diabetes. Such unmet needs vary across disease stages and between different nationalities. Patients with prostate cancer in the APAC region appear to have gaps in knowledge about their disease and wish for greater information, support and public awareness about prostate cancer.

Keywords

prostate cancer, disease stages, disease progression, patient awareness, patient knowledge, #PCSM, #ProstateCancer

Introduction

Prostate cancer is the second most common cancer in men worldwide, and the fifth leading cause of cancer death [1]. In Asia, prostate cancer prevalence has been rapidly increasing during recent decades in parallel with economic growth, increased life expectancy and lifestyle changes. From 2007 to 2009 incidence grew at a rate of 7.2% per year [2]. Prostate cancer incidence in Asia is projected to increase by 100%

from 2018 to 2040, and by 46% in Australia in the same period [3]. This expected increase underlines the growing need for awareness about implications of prostate cancer diagnosis.

As prostate cancer progresses from localised to advanced disease, patients experience different symptoms and receive treatments that variably impact health-related quality of life (HRQoL) [4–7]. Treatments including androgen-deprivation

therapy and chemotherapy may have significant negative impacts on physical and psychological HRQoL [6,8,9]. Up to 90% of men with non-metastatic castration-resistant prostate cancer (nmCRPC) will eventually develop bone metastases [8]. Multiple new drugs for mCRPC and metastatic hormone sensitive prostate cancer (mHSPC) have been launched with the objective of delaying or limiting disease progression and increasing overall survival, while reducing symptoms and improving HRQoL [2,9]. In parallel, studies have found that educating patients with cancer about treatment, side-effects, and self-care behaviours can minimise the side-effects of chemotherapy, reduce symptom distress, and improve HRQoL [10,11].

Additionally, poor cancer awareness, delays in seeking health information, and lower healthcare utilisation influence the cancer mortality rates in men [12]. This highlights the importance of understanding the current knowledge of prostate cancer among males in order to improve prostate cancer awareness, ensure early diagnosis, and improve HRQoL among patients with prostate cancer in Asia. Studies have previously investigated perceptions [13–16] and knowledge of prostate cancer in men from the USA [17–19] and Europe [20–23]. Limited studies have been performed in Japan [24,25] and Korea [26]; however, little such research has been done in the Asia-Pacific (APAC) region as a whole. The present study sought to explore the perceptions of patients living with different stages of prostate cancer across the APAC region, to identify gaps in disease knowledge and unmet needs that could be addressed, so as to empower patients and improve management and outcomes of the disease.

Patients and Methods

Exploratory Phase

Using qualitative research interrogatory interview techniques an initial exploratory phase using open-ended questions was conducted with 45 min face-to-face interviews with 12 patients with prostate cancer from Australia, China and Japan (Table 1). The key themes were identified by individual evaluation of responses rather than by automated software, and these then were used to design the elaborated questionnaire for the main phase of the study, which sought to substantiate and quantify these findings on a larger sample size ($n = 150$) across the APAC region.

Main Study

A total of 150 patients diagnosed with different stages of cancer (Table 1) from Australia, China, Japan, Korea and Taiwan were recruited for 30-min online (Australia) or computer-assisted/personal interviews. Interviews were

Table 1 Overview of study participants and disease characteristics.

Countries	Exploratory phase, $n = 12$					Main study, $n = 150$					
	China, Japan, Australia					All	China	Japan	Korea	Taiwan	Australia
Number of patients	12, 4 each country					150	30	30	30	30	30
Average age, years	N.D.					69	65	65	72	70	73
Stages of disease	Localised, Stage I–III	1 each country				49	9	9	9	10	12
	Recently progressed from M0 to M1	1 each country				46	12	12	12	3	7
	Stage IV, M1, mCRPC	1 each country				29	3	4	3	8	11
		1 each country				26	6	5	6	9	N.A.

N.A., not available; N.D., not detected.

conducted in the native language of the patient from December 2018 to March 2019. Based on the findings in the exploratory phase, the interview questions were categorised in five themes to uncover patients' perceptions and unmet needs in living with prostate cancer: (i) patients' diagnosis pathway including symptoms experienced and duration before visiting the doctor; (ii) patients' knowledge about disease stages and attitudes towards prostate cancer; (iii) patient's emotional state of mind and key concerns from time of diagnosis and onwards; (iv) seeking support and unmet needs, including who patients discuss prostate cancer with, satisfaction with healthcare professional (HCP) interaction and what type of support is needed; and (v) knowledge and experience with prostate cancer treatment, including knowledge related to PSA and attitudes towards treatment decision. Depending on the question, patients selected the answer among pre-defined options, or answered how strongly they agreed with a given statement on a scale from 1 to 5, where 1 = strongly disagree, 2 = disagree, 3 = neutral, 4 = agree, 5 = strongly agree. Patient responses were captured in a digital platform. The final translated question list and the detailed project was reviewed by a project suitability assessment process within Kantar Health Singapore, as an industry accepted surrogate for quantitative research across national boundaries, and then by the national prostate cancer advocacy groups. All open-ended answers were translated to English and all responses coded for analysis purpose. Data were tabulated based on analysis specifications and statistical descriptive analysis used to identify trends and insights.

Recruitment

Patients with prostate cancer were recruited via physician referral. To fulfil a desirable sample size in Taiwan, patients were additionally recruited via patient support group referral, assisted by Taiwan Prostate Cancer Prevention Association. All patients provided written informed consent prior to participating.

Results

The exploratory interviews indicated three common challenges and unmet needs amongst patients with prostate cancer: (i) patients' feelings and emotional state change during their disease journey, (ii) patients lack knowledge about symptoms and disease progression, (iii) patients rely greatly on HCPs, but felt shared decision-making was uncommon. These findings formed the basis of the elaborated questionnaire used in the main study, that sought to substantiate and quantify these findings on a larger sample size ($n = 150$).

The responses from patient interviews of the main study revealed a pattern of seven themes related to patients'

challenges, disease knowledge and unmet needs in living with prostate cancer, which are presented in detail below.

Patients State of Mind and Key Concerns Vary as the Disease Progresses

Across the APAC region, patients with advanced prostate cancer, including M0 nmCRPC, M1 mCRPC and M1 mHSPC, experienced a greater extent of negative emotions than with localised disease, including: 'I feel restricted as I am not able to do what I want, e.g. being physically active, travel without limitation, etc.', 'I feel overwhelmed by living with prostate cancer', 'I feel that I have lost control of my own life', 'I feel frustrated because there is no cure'. More patients with localised disease felt calm, under control and hopeful and had few negative emotions such as 'I feel embarrassed as a man having prostate cancer'. Country specific differences were observed in Australian and Chinese patients with mCRPC and mHSPC, who were overwhelmed by negative emotions. In Japan, patients in general experienced a wide range of negative emotions regardless of disease stage and had very few positive emotions related to their disease.

Disease progression, treatment effectiveness and side-effects were the overarching concerns consistent across any disease stage. Additionally, pain and impact on daily life were of great concern, whereas patients at early stages were mostly concerned about life expectancy and impact on sexual life.

There is a Low Level of Patient Knowledge About Prostate Cancer before Diagnosis and a Delay Between Onset of Symptoms and Visiting HCP

With the exception of Australia, between 23–40% of patients sampled reported not having heard of prostate cancer before their diagnosis and 33–53% to have heard of prostate cancer but not having any understanding of the disease (Table S1). Men who reported having limited and reasonable knowledge prior to diagnosis reported their knowledge was lacking about symptoms (0% in China, 22–36% other countries) and of different disease stages. Patients generally perceived prostate cancer as a condition for older men.

Australian men demonstrated the highest awareness of prostate cancer prior to diagnosis, where all interviewed patients (100%) had heard about prostate cancer; however, 17% of these patients had no understanding of prostate cancer, 30% of them reported having reasonable amount of knowledge, and 53% limited knowledge (Table S1). A higher awareness about disease stages after prostate cancer diagnosis was also present in Australia and Taiwan (Table S1). Elsewhere such knowledge was poor with between 60–80% having no knowledge of prostate cancer at all prior to diagnosis.

There is a Low Level of Patients' Current Understanding of Disease Progression

Investigating the patients' current level of disease understanding and knowledge (i.e. after prostate cancer diagnosis) revealed the majority of patients were aware of the different disease stages (63–97%), but reported having low knowledge about them. Some patients reported no understanding of what it means when progressing from one stage to another and how treatment options are different in each stage of the disease (Table S1). Interestingly, patients in Taiwan and Australia had a higher awareness of treatment options and disease progression compared to China, Japan and Korea (43–53% vs 13–23%). Despite the higher awareness in Taiwan and Australia, only 50–57% had received in-depth information about prostate cancer and definitions of disease progression.

Across cohorts, patients reported not feeling sufficiently informed by their doctors about prostate cancer disease stages and disease progression. Only 33% and 23% of patients in China and Japan reported receiving in-depth information about prostate cancer stages and 37% and 33% respectively that disease progression was clearly defined to them (Table S1).

Patients Trust and Mainly rely on their HCPs for Support in Prostate Cancer Management

The HCPs were routinely noted by patients to be the most important source of support in managing prostate cancer. When asked regarding the type of HCP they contacted for support, patients mainly sought support from urologists (70–100%). In both Australia and Taiwan, a high proportion of patients sought professional support from medical oncologists (85% and 50%), and in Australia additionally from their GP (85%). In contrast, in China, Korea and Japan only a minority of patients received support from medical oncologists or other types of HCPs.

Surgery is a common Treatment Option but Patients have Reservations and Misperception About It

Surgery (radical prostatectomy or surgical castration) was the most common form of therapy reported by participants, and generally, patients felt that doctors had sufficiently involved them in the decision-making process and that enough time had been provided for this purpose. However, 53% had consented to surgery despite having expressed reservations to their doctor (Table S1).

Differences were observed in Japan where most patients did not feel sufficiently involved in the treatment decision-making process and did not believe they would be cured. In Australia, fewer patients voiced their concerns about surgery to their doctor. Geographical variations in patterns of treatment

practice were also apparent; noteworthy being the higher number of patients in China and Japan receiving chemotherapy and surgical castration, respectively.

The Majority Of Patients Claim to be Aware of how PSA is Linked to Disease Progression

A majority of patients (67–90%) had been provided with explanations of the role of PSA by their HCPs upon diagnosis, with exception of Japan (50%), and were aware of how PSA levels are linked to disease progression (>77%) (Table S1).

Patients have Unmet Needs for Greater Information and Support to Manage their Condition

Patients reported wishing they had known more about prostate cancer before diagnosis. Patients desired more knowledge about symptoms, what doctor to visit, PSA and what it means, different stages of prostate cancer, disease progression and its impact, treatment options and how to select treatments. Regardless of current disease stage, the majority of patients expressed sentiments like 'I am determined to take control of my condition', 'I want to have more information about my disease and my options to enable me to discuss how to manage my condition with my doctor'. Gaps observed in disease understanding differed across disease stages (Table S2). Patients with localised disease and mCRPC regularly reported not having a clear understanding of prostate cancer disease stages and future treatment options. In Japan, patients had similar gaps in disease understanding across all cancer stages, and less than half of patients were motivated to take control of their condition and wanted more information.

When asked what support would help them better manage their disease, patients regardless of disease stage wished for more simplified language in discussions with doctors, patient education materials and greater psychological support. Multiple patients also expressed views like 'I wish there was an intervention program to help with early detection', 'Prostate cancer is not talked about as much as other diseases (i.e. diabetes, hypertension)' and 'Prostate cancer does not have as much visibility and support from the community as other cancer types (i.e. breast cancer)'.

Discussion

The results of the present study revealed trends and insights in patient's perceptions of living with prostate cancer and their level of disease knowledge. The underlying theme in the qualitative research assessment was that patients have a gap of knowledge about their disease and wish for greater information, support and public awareness about prostate cancer, although differences were observed between countries (Table 2).

It appears that patients across the region had low knowledge of prostate cancer, symptoms and the different stages of

Table 2 Summary of similarities and differences observed in patient perceptions and unmet needs in living with prostate cancer across APAC and disease stages.

Themes	Similarities across APAC	Differences across APAC
(i) Patients state of mind and key concerns vary as the disease progresses	<p>Disease management</p> <p>Late Stage IV prostate cancer (M0 nmCRPC, M1 mCRPC and M1 mHSPC):</p> <ul style="list-style-type: none"> patients experienced a greater extent of negative emotions pain and impact on daily life were of high concern <p>Localised disease:</p> <ul style="list-style-type: none"> patients felt calm, under control, hopeful and only had few negative emotions patients were concerned about life expectancy and impact on sexual life <p>Disease management and treatment</p> <p>Any disease stage:</p> <p>Disease progression, treatment effectiveness and side effects were the main concerns at any disease stage.</p>	<p>Disease management</p> <p><i>Japan:</i> Patients experienced a wide range of negative emotions regardless of disease stage and had very few positive emotions related to their disease</p> <p><i>Australia and China:</i> Patients at late stage prostate cancer, M1 mCRPC and M1 mHSPC, were especially overwhelmed by negative emotions compared to early stage prostate cancer.</p>
(ii) There is a low level of patient knowledge about prostate cancer prior to diagnosis and a delay between onset of symptoms and visiting HCP	<p>Prostate cancer Awareness</p> <p>Low awareness of prostate cancer, symptoms and disease stages prior to diagnosis</p> <p>Perception that prostate cancer is a condition for older men</p> <p>Diagnosis</p> <p>There was a delay between onset of symptoms and first visit to HCPs</p>	<p>Prostate cancer Awareness</p> <p><i>China:</i> 0% of patients had heard about prostate cancer symptoms prior to their diagnosis</p> <p><i>Australia:</i> 100% of patients had heard about prostate cancer prior to diagnosis</p> <p>Diagnosis</p> <p><i>Japan:</i> Up to > 2 years delay between onset of symptoms and first visit to HCP</p> <p><i>China and Australia:</i> Patients immediately visited the doctor or had delays between 1–3 months</p>
(iii) There is a low level of patients' current understanding of disease progression	<p>Prostate cancer awareness</p> <p>Patients were aware of the different prostate cancer disease stages but had low knowledge about them:</p> <ul style="list-style-type: none"> Did not understand what it means when progressing from one stage to another Did not know how treatment options are different in each stage of the disease <p>Disease management</p> <p>Patients did not feel sufficiently informed about prostate cancer disease stages and disease progression by their doctors</p>	<p>Prostate cancer awareness</p> <p><i>Taiwan and Australia:</i> Had a higher awareness of treatment options and disease progression</p> <p><i>China, Japan and Korea:</i> Had a lower awareness of treatment options and disease progression</p> <p>Disease management</p> <p><i>Taiwan and Australia:</i> More patients received in-depth information about prostate cancer and definitions of disease progression from their doctors</p>
(iv) Patients trust and mainly rely on their HCPs for support in prostate cancer management	<p>Disease management</p> <p>HCPs were the most important source of support in managing prostate cancer</p>	<p>Disease management:</p> <p><i>China, Taiwan and Australia:</i> Patients also talked with their family members about the disease</p> <p><i>Australia:</i> More than half of the patients relied on friends for support, and also sought support from their GP</p> <p><i>Australia and Taiwan:</i> A high proportion of patients sought support from medical oncologists</p> <p><i>China, Korea and Japan:</i> Only a minority of patients received support from medical oncologists</p>
(v) Surgery is a common treatment option while patients have reservations and misperception about it	<p>Treatment</p> <p>Surgery was the most common treatment among patients</p> <p>Patients felt involved in the treatment decision-making process</p> <p>More than half of the patients had consented to surgery despite having expressed their reservations</p> <p>Patients were of the belief that they would be cured by the treatment</p>	<p>Treatment</p> <p><i>China:</i> A high number of patients received chemotherapy</p> <p><i>Japan:</i> A high number of patients received surgical castration</p> <p><i>Japan:</i> Patients did not feel sufficiently involved in the treatment decision making process and did not believe they would be cured</p> <p><i>Australia:</i> Few patients voiced their concerns about surgery to their doctor</p>
(vi) Majority of patients claim to be aware of how PSA is linked to disease progression	<p>Diagnosis</p> <p>Patients were provided explanations of the role of PSA by their HCPs upon diagnosis</p> <p>Disease management</p> <p>Patients were aware of how PSA levels are linked to disease progression</p>	<p>Diagnosis</p> <p><i>Japan:</i> only 50% of patients were provided explanations of the role of PSA by their HCPs upon diagnosis</p>

prostate cancer, and that after diagnosis a gap in knowledge persists especially related to disease stages, disease progression and treatment options. We also found that as disease progresses to later advanced stages, patients more commonly

experience negative emotions alongside having key concerns about disease progression and treatment. There appears to be a need to provide more information to patients on these topics, as well as psychological support, especially at later

Table 2 (continued)

Themes	Similarities across APAC	Differences across APAC
(vii) Patients have unmet needs for greater information and support to manage their condition	<p>Prostate cancer awareness</p> <p>Patients wished they had known more about prostate cancer before their diagnosis</p> <p>Patients wished for more knowledge about:</p> <ul style="list-style-type: none"> • symptoms • what doctor to visit • PSA and what it means • different stages of prostate cancer • disease progression and its impact • treatment options and how to select treatments <p>Treatment</p> <p>Patients had gaps in knowledge related to understanding current and future treatment options, which varied across disease stages (see Table S2)</p> <p>Disease management</p> <p>Patients had gaps in knowledge related to understanding disease stages and how to manage disease, which varied across disease stages (see Table S2)</p> <p>Patients had an unmet need for:</p> <ul style="list-style-type: none"> • simplified language in discussions with doctors • patient education materials • greater psychological support 	<p>Disease management</p> <p><i>Japan:</i></p> <ul style="list-style-type: none"> • Patients had similar gaps in disease understanding across all disease stages • Less than half of patients were motivated to take control of their condition and wanted more information

stages of disease where emotions are characterised by fear and uncertainty of the future. Our present finding of increasing negative emotions as the disease progresses, is consistent with other studies showing that physical and functional wellbeing is a significant predictor for levels of psychological distress in men with prostate cancer [27,28]. Negative orientation towards prostate cancer could also explain the differences in motivation observed between countries [29].

The low level of prostate cancer knowledge among patients in this region is comparable with findings from other studies in the USA [17–19] and Europe [20–23]. However, higher levels of prostate cancer knowledge were observed among patients in Taiwan and Australia, both before and after diagnosis, which could be a result of public awareness campaigns. In Australia, such campaigns have been broadcast on television, radio and online commercials featuring well-respected celebrities [30]. Similar benefits have also been noted in Europe [31].

Despite the low level of knowledge related to disease progression, patients claimed to be aware of PSA and its linkage to disease progression through the conversations with their doctor. Despite published data on this topic [32] there appears to be an unmet need among patients with prostate cancer of in-depth information to gain deeper understanding of disease progression, how it impacts their life, prognosis and treatment options.

There is a Gap in HCP–patient Communication

Patients' low level of disease and symptom awareness prior to diagnosis coincided with a delay between onset of symptoms and first visit to HCPs. Long delays up to

6 months were present in Korea and Taiwan and up to >2 years in Japan. Studies have shown that Japanese men were inadequately aware of prostate cancer and of the means available for its early detection, with only 8% of men having heard of PSA testing [24]. Additionally, previous studies have found a low acceptance of PSA testing among Taiwanese men [33] and that 58% of Korean men were not willing to take screenings because of the belief that they were healthy [26].

The low level of disease understanding after diagnosis found in the present study could possibly be linked to the observed gap in HCP–patient communication. The dissatisfaction with information from HCPs was pronounced in patients from China and Japan, in contrast to Taiwan and Australia where both disease awareness and satisfaction with information from HCPs were higher. Differences in access to specialised healthcare resources may impact on the information regarding disease stages and progression that patients received. Studies have similarly shown that receiving support from their partner or family is important for navigating the medical system [13] and improves patients' HRQoL [27].

The majority of patients in the present study had undergone surgery despite their reservations prior to consenting to it. Importantly a USA study on implications of improvement of patient–physician communication, especially for prostate cancer, showed that a positive patient–HCP communication was related to satisfaction of healthcare services. These relationships can also help patients navigate challenging situations such as uncertainty about the variety of treatment options [34].

Potential Interventions Toward Improving Public Awareness and Patients' Knowledge About Prostate Cancer

The results throughout this study emphasised that there is a clear gap in prostate cancer knowledge, and that patients across the region have an unmet need for greater information and support to manage their condition. Compared to heart disease and diabetes, for which public awareness and patient knowledge has been reported to be on a more adequate level [31,35,36], prostate cancer awareness is less developed. Studies have shown that multimodal approaches of patient educational materials such as printed materials (e.g. brochures, leaflets, and calendars), education sessions, interactive video, online, and audio intervention components effectively increased men's prostate cancer knowledge [12]. Internet and social media resources may be of benefit [37,38]. Also, workplace-based intervention such as 'Take the Wheel' interactive video/audio and 'Help a Mate' intervention significantly increased participants' awareness of prostate cancer [12]. Interaction with specialised nurses could also be a source for great potential support, especially as treatment patterns change and relevant peer-reviewed information on diagnosis and treatment outcomes that could function as research-justified assessments become available [39–43].

The novel nature of the present study lies in the qualitative approach in identifying patients' perceptions and unmet needs in living with prostate cancer. Although multinational registries have been created [44], to our knowledge the present study is the first of its kind including patients across the APAC region. However, the sample size was relatively small and patients were recruited based on a pre-determined set of characteristics to capture men at all disease stages, and thus this sample may not be representative of the general population of men living with prostate cancer in the APAC region. Further research on a larger sample, including more detailed patient information for descriptive statistical analysis, would enhance knowledge in this area.

Conclusion

Overall, patients with prostate cancer in the APAC region appear to have gaps in knowledge about their disease and wish for greater information, support and public awareness about prostate cancer. This prostate cancer knowledge gap stands in contrast to patient awareness of other common diseases, such as heart failure and diabetes. The unmet needs vary across disease stages. Nationally specific differences also exist, which are important to consider for patient education, counselling and provision of information materials.

Conflicts of Interest

Naomi Mermod is an employee at Janssen Pharmaceutical Companies of Johnson & Johnson, Asia Pacific. Kantar Health Division received funding from Janssen for the conduct of the study and the development of the manuscript.

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Abbreviations: (m)(nm)CRPC, (metastatic) (non-metastatic) castration-resistant prostate cancer; APAC, Asia-Pacific; HCP, healthcare professional; HRQoL, health-related quality of life; mHSPC, metastatic hormone-sensitive prostate cancer.

Supporting Information

Additional Supporting Information may be found in the online version of this article:

Table S1. Patient knowledge and communication with HCPs.

Table S2. Patient knowledge gaps and unmet needs across disease stages.