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Not All Prostate Cancer is the Same - Patient perceptions: An Asia-Pacific study

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Abstract

Introduction and Objective:

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. Such research is particularly lacking in reference to the Asia Pacific Region.

Patients and Methods:

Initial 45 minute 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 cancer underwent 30 minute online (Australia) or computer-assisted/personal interviews categorized on the 5 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: a) patients' feelings and emotional state change during their disease journey, b) patients lack of

knowledge about prostate cancer and disease progression prior to diagnosis, c) patients felt shared decision making was uncommon, d) patients have misperceptions about surgery, e) 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 Asia- Pacific region appear to have gaps in knowledge about their disease and wish for greater information, support and public awareness about prostate cancer.

Introduction

Prostate cancer (PC) is the second most common cancer in men worldwide, and the fifth leading cause of cancer death.[1] In Asia PC 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 PC diagnosis.

As prostate cancer progresses from localized to advanced disease patients experience different symptoms and receive treatments that variably impact quality of life.[4,5,6,7] Treatments including androgen deprivation therapy (ADT) and chemotherapy may have significant negative impacts on physical and psychological health related quality of life (HRQoL).[6,8,9] Up to 90% of men with non-metastatic castrate resistant prostate cancer (nmCRPC) will eventually develop bone metastases.[8] Multiple new drugs for metastatic CRPC (mCRPC) and metastatic hormone sensitive PC (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 cancer patients about treatment, side effects, and self-care behaviours can minimize the side effects of chemotherapy, reduce symptom distress, and improve QoL.[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 PC among males in order to improve PC awareness, ensure early diagnosis, and improve HRQoL among PC patients in Asia. Studies have previously investigated perceptions [13–16] and knowledge of PC in men from the US[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. This study sought to explore the perceptions of patients living with different stages of PC 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 disease.

Patients and Methods

Exploratory phase

Using qualitative research interragatory interview techniques an initial exploratory phase using open-ended questions was conducted with 45 minute face-to-face interviews with 12 PC patients 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 APAC (Asia Pacific and China) 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 minute online (Australia) or computer-assisted/personal interviews. Interviews were 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 categorized in 5 themes to uncover patients' perceptions and unmet needs in living with PC: 1) patients' diagnosis pathway including symptoms experienced and duration before visiting the doctor; 2) patients' knowledge about disease stages and attitudes towards PC; 3) patient's emotional state of mind and key concerns from time of diagnosis and onwards; 4) seeking support and unmet needs, including who patients discuss PC with,

satisfaction with Health Care Professional (HCP) interaction and what type of support is needed; 5) 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 predefined options, or answered how strongly they agreed with a given statement on a scale from 1-5, 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 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 PC advocacy groups. All open-ended answers were translated to English and all responses coded for analysis purpose. Data was tabulated based on analysis specifications and statistical descriptive analysis used to identify trends and insights.

Table 1. Overview of study participants and disease characteristics

	Exploratory phase n=12		Main Study n=150					
Countries	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	Localized, stage I-III	1 each country	Localized, stage I-III	49	9	9	9	10	12
		1 each country	Stage IV, M0 nmCRPC	46	12	12	12	3	7
	Recently progressed from M0 to M1	1 each country	Stage IV, M1, mCRPC	29	3	4	3	8	11
	Stage IV, M1, mCRPC	1 each country	Stage IV, M1, mHSPC	26	6	5	6	9	N.A.

Abbreviations: N.D. = not detected; N.A. = not available; mCRPC = metastatic castration resistant prostate cancer; nmCRPC = non-metastatic castration resistant prostate cancer; mHSPC = metastatic hormone sensitive prostate cancer

Recruitment

PC patients 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 among PC patients: a) patients' feelings and emotional state change during their disease journey, b) patients lack knowledge about symptoms and disease progression, c) 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 PC, which are presented in detail below.

i. Patients state of mind and key concerns vary as the disease progresses

Across the APAC region, patients with advanced PC, including M0 nmCRPC, M1 mCRPC and M1 mHSPC, experienced a greater extent of negative emotions than with localized 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 localized 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 high concern, whereas patients at early stages were mostly concerned about life expectancy and impact on sexual life.

ii. There is a low level of patient knowledge about PC prior to 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 PC prior to their diagnosis and 33-53% to have heard of PC but not having any understanding of the disease (Supplementary Table 1). 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 PC as a condition for older men.

Australian men demonstrated the highest awareness of PC prior to diagnosis where all interviewed patients (100%) had heard about PC, however, 17% of these patients had no understanding of PC, 30% of them reported having reasonable amount of knowledge, and 53% limited knowledge (Supplementary table 1). A higher awareness about disease stages after PC diagnosis was also present in Australia and Taiwan (Supplementary table 1). Elsewhere such knowledge was poor with between 60-80% having no knowledge of PC at all prior to diagnosis.

iii. ***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 PC 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 (Supplementary table 1). 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 PC and definitions of disease progression.

Across cohorts, patients reported not feeling sufficiently informed by their doctors about PC disease stages and disease progression. Only 33% and 23% of patients in China and Japan reported receiving in-depth information about PC stages and 37% and 33% respectively that disease progression was clearly defined to them (Supplementary table 1).

iv. **Patients trust and mainly rely on their HCPs for support in prostate cancer management.**

Health Care Providers (HCP) 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 general practitioner (85%). In contrast, in China, Korea and Japan only a minority of patients received support from medical oncologists or other types of HCPs.

v. 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 (Supplementary table 1).

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.

vi. 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%) (Supplementary table 1).

vii. Patients have unmet needs for greater information and support to manage their condition.

Patients reported wishing they had known more about PC 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 w*ith my doctor"*. Gaps observed in disease understanding differed across disease stages (Supplementary table 2). Patients with localized disease and mCRPC regularly reported not having a clear understanding of PC 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*"*, *"*PC is not talked about as much as other diseases (i.e. diabetes, hypertension)*"* and *"*PC does not have as much visibility and support from the community as other cancer types (i.e. breast cancer)*"*.

Discussion

The results of this study revealed trends and insights in patient's perceptions of living with PC 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 PC, symptoms and the different stages of PC, 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 stages of disease where emotions are characterised by fear and uncertainty of the future. Our findings of increasing negative emotions as disease progresses, is in line 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 PC could also explain the differences in motivation observed between countries.[29]

The low level of PC knowledge among patients in this region is comparable with findings from other studies in the US[17–19] and Europe[20–23]. However higher levels of PC knowledge was 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 in television, radio and online commercials featuring well-respected celebrities.[30] Similar benefits have also been noted in Europe.[36]

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[31] there appears to be an unmet need among PC patients 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-to-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 were present 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[32] 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 this 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 health care 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 this study had undergone surgery despite their reservations prior to consenting to it. Importantly a US 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.[33]

***Potential interventions toward improving public awareness and patients' knowledge about* PC**

The results throughout this study emphasized that there is a clear gap of PC 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[34-36], PC 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 PC knowledge.[12] Internet and social media resurces 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 PC.[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 assessements become available[39-44].

The novel nature of this study lies in the qualitative approach in identifying patients' perceptions and unmet needs in living with PC. Although mltinational registries have been created[45], to our knowledge this is the first study of its kind including patients across the Asia-Pacific region. The sample size however 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 for the general population of men living with PC in the APAC region. Further research on a larger sample size including more detailed patient information for descriptive statistical analysis would enhance knowledge in this area.

Conclusion

Overall patients with Prostate Cancer in the Asia- Pacific region appear to have gaps in knowledge about their disease and wish for greater information, support and public awareness about prostate cancer.

This knowledge gap in PC 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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