

Supporting Patients in Making Treatment Decisions for Early Prostate Cancer: A Qualitative Study of Healthcare Professionals' Views on Barriers and Challenges in an Asian Country

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Abstract

Background: The aim of this study is to explore the challenges faced by healthcare professionals (HCPs) in Malaysia in supporting patients with early prostate cancer in making treatment decisions.

Methods: Four in-depth individual interviews and three focus group discussions were conducted with urologists (n=11), urology trainees (n=5), oncologists (n=3) and policy makers (n=1) in Malaysia in 2012-2013. A semi-structured interview guide was used to facilitate the interviews, which were audio-recorded, transcribed verbatim and checked. Thematic approach was used to analyze the data.

Results: Challenges reported by HCPs in supporting patients in making decisions about prostate cancer treatment consisted of patient, social, healthcare professionals and health system factors. Patient-related challenges were: distrust of HCPs, difficulty in communicating information, preconceptions, attitudes to treatment, preparedness for decision making, viewing prostate cancer as taboo and fear of treatment complications, or side-effects. Social factors, such as influence of family or others, also posed a problem for HCPs seeking to support patients' decision-making. HCP-related challenges included: differences of opinion among HCPs, uncertainty about the best treatment option and lack of interdisciplinary cooperation. Healthcare system factors challenges included: lack of support staff, time constraints, treatment availability and treatment costs. HCPs suggested that delivery of care by multi-disciplinary teams, and more use of audio-visual media, would help patients to make decisions.

Conclusions: HCPs faced various challenges in supporting patients with prostate cancer in making decisions about treatment. Delivery of care by a supportive team in a specialist centre may improve the support patients receive in making decisions.

Keywords: Cancer, decision, prostate, support, treatment.

List of abbreviations: HCP: Healthcare professional; PSA: Prostatic specific antigen.

Introduction

Making a decision about treatment for early prostate cancer is challenging. There are several treatment options (surgery, radiotherapy, active surveillance and watchful waiting) with comparable mortality rates, but there are different side-effects that impact on quality of life.¹ This is a preference-sensitive decision with no single best option which depends on the clinical profile of the patient as well as the preferences of the patient and healthcare professionals (HCPs) involved.^{2,3}

Studies in Western countries that have investigated patients' participation in decision-making with regard to medical treatment, have reported various challenges relating to patients, clinicians and the healthcare system factors that may influence the support of informed decision-making. Cognition, emotion, personal preference, cultural, literacy and knowledge of disease may affect patients' active participation in decision making.⁴⁻⁷ Clinicians may not be able to avoid personal bias and have limited time to discuss and consider the patient's risk profile and preference.^{8,9} Furthermore, in the health care systems, the information and communication systems that are needed to encourage the implementation of informed decision-making are limited.¹⁰

Most of the studies related to challenges faced by HCPs, in supporting patients in making decisions about treatment, have been done in Western countries and do not relate specifically to prostate cancer.⁴⁻¹⁰ Only a limited amount of research has been done in multi-cultural Asian countries such as Malaysia.^{11,12} There are social and cultural differences between Malaysian and Western patients, so findings based on Western samples may have only limited applicability in Asian contexts. In addition, Malaysia has a dual-sector healthcare system (pay-per-service private sector vs. subsidized public sector). For access of specialists in the public sector, patients need referral from primary care doctors. However, in the private sector, patients have the freedom of choosing any specialist they prefer. The HCPs involved in the care of prostate cancer patients in the country mainly consist of urologists and oncologists, while primary care doctors and nurses play very little role. These differences may affect the challenges faced by HCPs in supporting patients in treatment decision-making.

HCPs are strategically well-placed to support patients in decision making.¹³ Their views on the barriers and challenges

they face in supporting patients in decision-making will inform our understanding of how best to support patients to enable them to make informed decisions. The aim of this study is to explore the challenges faced by HCPs in Malaysia in supporting patients choosing between the various treatments for early prostate cancer.

Methods

Design, Setting, Participants, Recruitment and Sampling

Qualitative methods, namely in-depth interviews and focus group discussions with a topic guide, were used to explore the range of views among HCPs.¹⁴⁻¹⁶ This study involved HCPs from both public and private hospitals. HCPs were recruited from 8 states in Malaysia as there are differences in ethnicity compositions and cultural background in these states. A policy maker involved in developing and implementing the government's national prostate treatment plan was also included.

We used purposive sampling to identify stakeholders (urologists, oncologists and policy makers) involved in the treatment of prostate cancer. Participant recruitment was carried out using a 'snowball' technique: we asked participants to identify HCPs who were involved in prostate cancer treatment. Interviews and analyses were conducted iteratively until no new themes emerged. Recruitment was stopped when the researchers agreed that the analysis had reached thematic saturation after 4 in-depth individual interviews and 3 focus group discussions were conducted with 11 urologists, 5 urology trainees, 3 oncologists and a policy maker.

Data collection

The development of the interview topic guide was guided by a conceptual framework based on a literature review and in consultation with experts. The focus groups were organized by practice background to facilitate discussion that came from shared experience.¹⁷ For logistical reasons, we conducted individual in-depth interviews with policy makers and oncologists. Interviewees were informed that the interview would focus on patients diagnosed with early prostate cancer. The interview was structured around a series of open-ended questions; prompts were only used if the critical issues did not emerge spontaneously. HCPs were asked about the challenges they faced in supporting patients diagnosed with early prostate cancer to enable them to make choices about treatment.

Individual interviews and focus group discussions were conducted between November 2012 and January 2013. All participants provided written consent and they were informed that their data would be anonymous and confidential. Four experienced researchers (PYL, CJN, KLA and ATC) who are family physicians or nursing lecturers conducted the interviews guided by an interview topic guide. An assistant took field notes on non-verbal cues and interview dynamics. All interviews were audio-recorded and transcribed verbatim. The transcripts from the in-depth interviews, focus group discussions and field notes were considered together in the analysis.

Data analysis

We used a thematic approach to data analysis.¹⁸ The themes were inferred from the data. Two researchers (PYL, CJN) each coded 2 transcripts independently, creating a list of free nodes. The free nodes were later merged to form larger categories and the categories were merged to form the main themes. This framework, consisting of nodes, categories and themes, was subsequently used by 2 independent researchers (YKL, ATC) to code another 2 transcripts. Inter-rater consistency of coding across all transcripts was examined and any discrepancies were resolved by discussion between the two researchers (PYL, ATC). When the researchers involved in the coding could not reach a consensus, an independent researcher who had not participated in the analysis was asked to analyze the data. All researchers involved in the analysis discussed the results and consensus was reached on the final list of nodes, categories and themes with their descriptions. This final list of revised nodes, categories and themes was imported into Nvivo 10 software and served as the framework for coding the rest of the transcripts. New themes that emerged during coding of the remaining transcripts were added to the list following consultation with the rest of the research team. All the quotations were screened and those that best captured the essence of the themes were extracted for presentation in the results. The team used reflection and open discussion extensively throughout the interviews and analysis to reduce possible biases in the collection and interpretation of the data. This study was part of a larger project to develop an aid to support treatment decision-making by patients with early prostate cancer.

Ethics approval

Ethical approval for this study was obtained from the Medical Research and Ethics Committee of the Ministry of Health, Malaysia (KKM/NIHSEC/08/0804/P12-735).

Results

Each interview lasted between 60 and 80 minutes. Twenty HCPs: 11 urologists, 5 urology trainees, 3 oncologists and a policy maker participated in this study. There were 17 male and 3 female participants.

The challenges faced in supporting patient decision-making were divided into 4 categories: patient-related challenges, social factors, HCP-related challenges and healthcare system factors.

Patient-related challenges

Distrust of HCPs

Participants reported that some patients distrust the HCPs. This is more likely when patients are asymptomatic and they doubt the diagnosis. Respondents felt that these patients are more likely to be lost to follow-up.

“Well, I think that usually it’s the one that’s had no symptoms who is the most difficult to deal with ... ‘I do not have any symptoms, are you sure?’ These are the people who may just disappear, actually because they had doubts about your diagnosis.” (49-year-old consultant urologist, private hospital)

HCPs also felt that some patients only listened to the doctors and did not trust the nurses or paramedics to give accurate information. Some patients were reluctant to discuss sexual problems with female HCPs.

Difficulty in communicating the information

HCPs found it difficult to explain the various treatment options and potential complications of prostate cancer, especially to less educated patients. Patients who did not understand about the disease will tend to ask their doctors to decide for them.

Preconceptions

Patients with preconceptions about prostate cancer and its treatment posed a challenge to doctors. HCPs felt that these patients’ ideas had often been influenced by media, social contacts and information found on the Internet. They

were unable to accept information given by the doctors and sometimes wanted treatment that was unavailable.

Patient attitude to treatment

Patients' attitudes to treatment also presented HCPs with a challenge. Some patients wanted to pursue complementary and alternative treatments including spiritual healing. Other patients who were anxious wanted many opinions and this process of seeking other opinions was likely to delay their treatment.

Preparedness for decision making

Doctors reported that supporting patients who were indecisive presented a challenge; this group of patients needed a lot of guidance and may have preferred to trust their doctors to make the decision. The doctors found it challenging dealing with patients who delegated decision-making to them. They felt that this had to be dealt with responsibly.

“And of course that is something that you sometimes have to constantly remind yourself about. Because they have a good opinion of you, you can actually change their decision process. And you have to handle that responsibly.” (54-year-old consultant urologist, private hospital)

Patients view prostate cancer as taboo

HCPs felt that some men with prostate cancer do not disclose their illness because they consider it as a taboo. Hence, these patients will tend to make their own decisions without support from others.

“Men keep a lot of things to themselves. So they do not tell other people about it (their prostate cancer). Because prostate cancer sometimes becomes like a taboo. So they do not say anything, so no-one knows and no-one can advise them on which treatment to have.” (36-year-old trainee urologist, government hospital)

Fear about side-effects of treatment

Some patients refuse certain treatments because they fear the side-effects. Patients who want to get rid of their cancer altogether were willing to put up with more severe side-effects; whereas others based their choice of treatment on a desire to avoid certain side-effects. Patients with symptoms are more likely to accept the side-effects of surgery.

Social factors

Family and other social influences

HCPs reported that patient's decision were often influenced by information and advice from family members (especially their children) and other doctors (such as their family doctor). HCPs would be expected to discuss a patient's treatment with other family members and sometimes the patient himself was excluded from the discussion.

HCP-related challenges

Different opinions within the HCP community

HCPs felt that one of the challenge was that patients with early prostate cancer often sought second opinions from various urologists and oncologists. These specialists' treatment preferences tended to depend on their personal expertise. Patients may get confused after seeing several HCPs, each with a different opinion. HCPs also felt it was a challenge to deal with patients who had made a decision with which they disagreed.

Lack of a multi-disciplinary approach to care

HCPs reported difficulties in coordinating multi-disciplinary care and discussing problems with other HCPs. HCPs suggested that these problems could be addressed by establishing multi-disciplinary teams including other HCPs and trained nurses, and having a centre with audio-visual media resources which could be used to support patients in decision making.

“I wish I could have a clinic for instance, where there is a radiotherapist, an oncologist, a physiotherapist sitting there. That would be ideal. The patient also would feel ‘I'm not seeing one guy whose opinion may be right, may be wrong. I'm seeing a team, I can ask everyone the question.’” (53-year-old policy maker, government hospital)

Uncertainty about the best treatment

HCPs had to deal with uncertainty when applying guidelines about treatment options in individual cases.

“I must admit that at the back of my mind, I'm not sure which is the best option. Really, speaking about this particular patient, because I can only go by statistics. But exactly what is good for this patient, I wouldn't really know.” (53-year-old consultant urologist, private hospital)

Healthcare system factors

Cost

Cost of treatment is usually not a major issue in public hospitals, however for patients in private hospitals, it is an important issue that the doctors have to discuss with patients, as some of the treatment options are expensive. Patients are given the option to be referred to a public hospitals if they can't afford to be treated in a private hospital.

Availability of treatment

Some patients may face limited treatment options because of lack of resources. For example, robotic surgery is only available in two public hospitals and one private hospital in Malaysia.

Lack of support staff

Currently urologists and oncologists are the main HCPs that support patients in making decisions about treatment for prostate cancer. There are no nurses or paramedical staff trained for this role.

“We do not have enough nurses to discuss with them. Probably there's a role for urology nurses or medical assistants in doing this.” (47-year-old consultant urologist, government hospital)

Limited time

Doctors have to manage time constraints. A doctor may need to spend at least an hour with a patient to discuss treatment options and counsel the patient appropriately. HCPs felt that this is often impossible, especially in the government setting where the patient load is high.

Discussion

Challenges reported by HCPs in supporting patients in making decisions about prostate cancer treatment include: patient, social, healthcare professionals and health system factors. Similar to studies from Western countries, patient-related challenges, including patients' emotion, personal preference, cultural, literacy and knowledge of disease, may affect patients' active participation in decision-making.⁴⁻⁷ Findings from this study are consistent with other studies which reported HCP-related challenges like personal bias, time constraints, and health system-related challenges from limited information and communication systems which discourage the implementation of informed decision making.⁸⁻¹⁰ However, this study highlighted a few issues which is more exclusive to Asian culture.

Patients' distrust of HCPs, highlighted by the participants in this study, is an issue less discussed in other studies about patients' involvement in decision-making. Distrust of HCPs is a growing problem and this may have a negative effect on treatment compliance.¹⁹ As stated by the HCPs in this study, patients who have a good rapport with the doctors as well as those who have less education will trust the doctor to make the decision for them. This had been reported in other studies.^{20,21} However, the HCPs in this study highlighted the pros and cons of this 'trusting' attitude. While it makes the decision-making process easier for both parties, patients may not fully understand the implications of the choices.

The other important issue, highlighted by the HCPs in this study, which is more exclusive to Asian society, is viewing cancer as a taboo. Similar studies in Western countries had reported doctors' challenges in dealing with Asian patients who viewed cancer as taboo.^{22,23} This is a big challenge for doctors in Asian cultures like Malaysia, since patients tend to avoid discussing their disease with others, including peers, and thus have fewer sources to support them in making decisions about treatment.

We found that social influence, especially the opinions and advice of family members, is an important element of the challenges faced by HCPs in supporting men with prostate cancer in their decision-making. Other studies have also reported that men relied heavily on the opinions and history of other people (family and peers) in finalizing their decisions about prostate cancer treatment.^{24,25} It is, therefore, important that HCPs engage a patient's family in decision-making as their views are likely to play a significant role in the decision making process.²⁶

There are no easy solutions for patient-related challenges. Patients with a diagnosis of prostate cancer come from very different educational levels, socio-cultural, and economical backgrounds. It is thus important for HCPs to be aware of this and tackle the consultation accordingly. HCPs must counsel the patients in a language and tone that the patients could understand. Misconceptions and taboos of the patients must be explored by the HCP who could then explain to the patients and their family the proper treatment plan. A few consultations might be necessary to establish a trusting rapport and offer a chance for the patients to clarify any queries.

In Western countries, nurses provide patients with comprehensive information about a prostate cancer diagnosis, treatment plan, and management of the side effects of treatment. These specialist nurses support patients in making complex decisions about treatment as well as providing emotional and psychological support.²⁷ Hence this may help to ease the doctor's consultation time constraints.

In Malaysia, however, nurses do not play an important role in supporting decision-making about treatment for prostate cancer. The HCPs in this study have related the problem to a shortage of trained nurses in this field, and the patients' preference of getting advice from doctor. In addition, as some of the participants pointed out, patients may be reluctant to discuss sexual problems like erectile dysfunction with a female HCP. The majority of nurses in Malaysia are female, hence, patients may not want to discuss treatment and side-effects with them. Therefore, in Malaysia, especially for gender specific cancer, these issues may need to be considered in the planning of multi-disciplinary care teams where the involvement of nurses is critical in providing information and support for treatment decision-making.

It is not an easy task for the doctors to discuss the most appropriate treatment option for patients with localized prostate cancer. Many factors have to be considered before an informed decision is made – for example, the age, quality of life, life expectancy and the preferences of the patient. It is also important for the doctor to realize that there is no 'best treatment'; the decision is based on what is important to patients (patient values) after discussing with them the treatment options. Doctors should be able to accept uncertainty about the treatment options and convey this clearly to the patient. Decision aids, which are designed based on the local setting, would be helpful.

The availability of treatment facilities is very much dependent on the health care system and budget. This is particular acute in a developing country such as Malaysia. The difficulties faced by both the patients and HCPs should be relayed to the health care authorities in order for them to provide the basis for improvement in service. However, treatment options that can be offered to patients should not be limited to the availability at one centre; instead, a range of treatment options should be discussed with patients, and if the option they prefer is not available at the

centre, the patient would have the option of being referred to another centre where the treatment is available.

The strength of this study is that we recruited participants from all the groups of stakeholders involved in caring for men with prostate cancer and from both the public and the private sector in Malaysia. We did not, however, collect any data from patients; future studies looking into primary evidence of patients' views and experiences is needed to provide an integrated, more valid picture of the issues surrounding decision-making about treatment for prostate cancer. The other limitation is the nature of snowballing recruitment in qualitative study which may limit the generalization of the findings. The research team included urologists and primary care physicians whose professional expertise may have biased their conduct of interviews and interpretation of the data; however, the data, and their interpretations, were discussed extensively during meetings in an attempt to ensure that our results would be credible.

Conclusion

HCPs faced various challenges in supporting patients with prostate cancer in making decisions about treatment. There is huge variation in how doctors support patients in decision-making, due to differences in doctors' personal treatment preferences and patients' attitude toward treatment, their preparedness for decision making, and their psychological states. Delivery of care by a supportive team in a specialist centre may improve the support patients receive in making decisions.

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Conflicts of interest

No conflict of interest

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