

## Doctors' Approaches to Decision Support in Counseling Patients with Localized Prostate Cancer: An Asian Perspective

(Pendekatan Doktor untuk Menyokong Keputusan dalam Memberi Kaunseling kepada Pesakit Kanser Prostat Setempat: Perspektif Asia)

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### ABSTRACT

*There are many treatment options for localized prostate cancer, and there is clinical equipoise in relation to the treatment outcomes. This study aimed to explore doctors' approaches to decision support in counseling patients with localized prostate cancer in a country with a less established system of support and care delivery for cancer treatment. Four in-depth interviews and three focus group discussions were conducted with seven government policy makers/consultant urologists, three oncologists, four private urologists and six urology trainees in Malaysia between 2012 and 2013. Doctors facilitated the treatment decision by explaining about the disease and the treatment options, which included monitoring, side effects and complications of each treatment option. Paper-based (charts and diagram drawings) or electronic (ipad apps and websites) illustrations and physical models were used as patient education aids. Further reading materials and websites links were often provided to patients. Patients were given time till subsequent follow up to decide on the treatment and family involvement was encouraged. Referral to other healthcare professionals (oncologist, radiotherapist or other urologist) for second opinion was offered to the patients. The doctors would recommend patients to speak to prostate cancer survivors for peer support but official support groups were not easily accessible. This study highlighted a multi-faceted approach to support patients with localized prostate cancer in making a treatment decision. It not only involved the doctors (urologist or oncologist) themselves, but also empowered the patients and their social network to support the decision making process.*

*Keywords: Decision making support; prostate cancer; qualitative; treatment*

### ABSTRAK

*Terdapat banyak pilihan rawatan untuk kanser prostat setempat, dan terdapat soal keseimbangan faedah klinikal berhubung dengan pelbagai hasil rawatan. Kajian ini bertujuan untuk meneroka pendekatan doktor dalam menyokong pesakit kanser prostat setempat untuk membuat keputusan rawatan semasa kaunseling di negara yang kekurangan sistem sokongan yang mantap untuk rawatan kanser. Empat temu bual mendalam dan tiga kumpulan perbincangan fokus telah dijalankan dengan tujuh orang penggubal dasar kerajaan/perunding urologi, tiga orang pakar onkologi, empat orang pakar urologi swasta dan enam orang pelatih urologi di Malaysia antara tahun 2012 dan 2013. Doktor memudahkan keputusan rawatan dengan menjelaskan mengenai penyakit tersebut dan pilihan rawatan, di mana ia termasuk cara pemantauan, kesan sampingan dan komplikasi setiap pilihan rawatan. Ilustrasi berasaskan kertas (carta dan lukisan rajah) atau elektronik (aplikasi ipad dan laman web) dan fizikal model telah digunakan sebagai alat bantuan pendidikan pesakit. Bahan-bahan bacaan lanjut dan laman web pautan sering diberikan kepada pesakit. Pesakit telah diberi masa sehingga susulan berikutnya untuk membuat keputusan mengenai rawatan dan penglibatan keluarga adalah digalakkan. Rujukan kepada profesional kesihatan yang lain (pakar onkologi, radioterapi atau pakar urologi yang lain) bagi memperolehi pendapat kedua telah ditawarkan kepada pesakit. Para doktor akan mengesyorkan pesakit untuk berbual dengan bekas pesakit kanser prostat untuk mendapat sokongan rakan sebaya tetapi kumpulan sokongan rasmi tidak mudah didapati. Kajian ini menekankan pendekatan yang pelbagai untuk menyokong pesakit kanser prostat dalam membuat keputusan rawatan. Ia bukan sahaja melibatkan doktor (pakar urologi atau pakar onkologi) diri mereka sendiri, tetapi juga menggalakkan pesakit sendiri dan rangkaian sosial mereka untuk menyokong proses membuat keputusan.*

*Kata kunci: Kanser prostat; kualitatif; rawatan; sokongan membuat keputusan*

### INTRODUCTION

Prostate cancer is the most common cancer in men in developed countries and the incidence is increasing in developing countries as a result of an aging population

(Jemal et al. 2011). The treatment options for prostate cancer vary according to the disease stage, healthcare professionals' and patients' preferences and availability and accessibility of treatment. In localized diseases,

there are a number of treatment options, such as watchful waiting, active surveillance, surgery or radiation therapy with none showing a significant advantage over the other (Management of Localised Prostate Cancer 2012; Wilt et al. 2008). This is because the 10-year disease specific survival rates are quite similar for the different options but the side effects vary (Wilt et al. 2008).

There were wide variations in how doctors support the patients in making an informed decision which may affect the patients' decisional quality and outcome (Wyatt et al. 2014). Shared decision-making between patient and doctor was increasingly considered the preferred way for making decisions, especially in a scenario with no single best option such as the case of localized prostate cancer (Elwyn et al. 2000; O'Connor et al. 2005).

Various methods and materials has been used by healthcare professionals in helping patients to choose their treatment options (Spiegle et al. 2013). Different types of support methods were reported in the literature to assist patients in decision-making. These include patient decision aids, patient decision boards, question prompt lists, pamphlet and disease information booklet (Spiegle et al. 2013). A systematic review reported that these decision supports method were effective in improving patients' knowledge, but not significant in improving patients' satisfaction with decision making process and reduced decision conflict (Spiegle et al. 2013). Most of the studies on this aspect of care were from the perspective of Western countries with more established systems of support and care delivery in counseling patients for their treatment options for cancer (Spiegle et al. 2013). However, little is known about how doctors support the patients in making decisions about localized prostate cancer treatment in an Asian country such as Malaysia.

Malaysia is a developing country in South East Asia with a population of 25 millions. The incidences of prostate cancer in this country are increasing though it is much lower than the West (Sothilingam et al. 2010). It was the 4th commonest cancer in Malaysian men (Zainal Ariffin & Nor Saleha 2011). In Malaysia, doctors (urologist and oncologist) are usually the key personnel in helping the patients in making a decision on treatment options. They are the professional personnel who provide information and also directly treat the patients. Thus, their support to the patient is important and this could translate into a better decision- making process that will benefit the patient.

This paper aimed to explore the doctors' approaches to decision support in counseling patients with localized prostate cancer. Data from this study will help in planning the policy and strategies of information giving to support patients with localized prostate cancer, especially in an Asian country with low incidence of prostate cancer and limited experience and resources (Zainal Ariffin & Nor Saleha 2011).

## MATERIALS AND METHODS

### DESIGN

A qualitative method was used as it allowed us to explore in more depth the various approaches used by doctors in supporting patients to make decisions about the treatment of localized prostate cancer (Pope & Mays 1995). Thematic analysis was used as the approach of the analysis in this study (Braun & Clarke 2006). This study was part of a larger study that aimed to develop a patient decision aid for supporting patients with localized prostate cancer.

### SETTING

The healthcare system in Malaysia is supported by both public and private sectors. The public hospital is provided and highly subsidized by the Ministry of Health, whereas patients need to pay out-of-pocket when seeking treatment from a private hospital.

There is limited number of urologists in the country (one urologist for 250,000 population) and some of the states do not have a urology service (Urologist Directory 2015). This study involved healthcare professionals (HCPs) from both public and private hospitals from all the states in Malaysia (Kuala Lumpur, Selangor, Penang, Sabah, Sarawak, Kelantan, Pahang, Terengganu and Johor) with a urology service.

### RECRUITMENT OF PARTICIPANTS

Purposive sampling was used to identify the HCPs who were involved in the management of patients with prostate cancer. The HCPs include seven government policy makers/consultant urologists, three oncologists, four private urologists and six urology trainees. Six public consultant urologists were also involved in the policy making of their respective states' main hospitals. One key policy maker was involved in developing and implementing the government national prostate treatment plan.

The data collection and analysis were done iteratively until no new theme emerged. The recruitment was stopped when the researchers came to a consensus that the analysis had reached thematic saturation (Braun & Clarke 2006).

### DATA COLLECTION

Individual in depth interviews and focus group discussions were used to explore the doctors' approaches to decision support in counseling patients with localized prostate cancer (Bogdan & Taylor 1975; Patton 1980; Pope & Mays 1995). The interviews were conducted between November 2012 and January 2013. The sociodemographic details of the participants were collected using a structured questionnaire. A semi-structured interview guide was used to guide the interviews. This interview guide was developed based on literature review, the Ottawa Decision Support Framework and expert opinion (O'Connor et

al. 2005). In-depth interview were conducted with the key policy maker and the oncologists because of time constraints on the participants in attending a focus group. The focus group discussions were arranged according to the HCPs' background to capitalize on their shared experiences for interactive discussions (Kitzinger 1995). The interviews and focus groups discussions were conducted by four trained researchers (PYL, CJN, KA and ATC). Open-ended questions were used during the interviews, and prompts were used only if the essential key issues did not emerge spontaneously. The HCPs were asked about their approach in counseling patients about treatment decisions relating to localized prostate cancer. An assistant took field notes on non-verbal cues and participants' dynamics. Each interview lasted between 60 and 80 min. All participants were assured of anonymity and confidentiality and signed a written consent prior to the audio recorded interview sessions.

#### DATA ANALYSIS

The recorded data was transcribed verbatim by a trained research assistant. Non-verbal cues from the field notes were used to verify and validate the participants' responses. Data saturation was reached after four individual interviews and three focus groups discussions (Braun & Clarke 2006). Three researchers (PYL, CJN and LYK) initially coded two transcripts independently. A list of free nodes was created. These free nodes were repeatedly reviewed before grouping them into categories. Main themes were then emerged from these categories. This served as the initial framework for subsequent data analysis. During subsequent coding, new categories and themes that emerged were added to the list after consensus among all the researchers. The research team members underwent constant reflection and open

discussion throughout the data analysis to reduce possible bias in interpretation of the data. The data was managed using the Nvivo 10 software.

#### ETHICS APPROVAL

This study was approved by the Medical Research and Ethics Committees of the Ministry of Health, Malaysia (KKM/NIHSEC/08/0804/P12-735).

#### RESULTS

We conducted four in-depth interviews and three focus group discussions. The 20 participants were healthcare professionals from government and private hospitals. There were 16 male and three female participants. The focus groups comprised of urologists in private practice ( $n=4$ ), government policy makers/consultant urologists ( $n=6$ ) and urology trainees ( $n=6$ ). The sociodemographic characteristics of the participants are shown in Table 1.

We identified four main themes which describe the doctors' approaches to decision support in counseling patients with localized prostate cancer: information support, giving time to decide, referring for counseling and second opinion and engaging family and peers in the decision-making process.

#### INFORMATION SUPPORT

The information supports are as follows:

##### *Providing information about each treatment option*

Doctors facilitated the treatment decision by explaining about the disease and its natural history and the treatment

TABLE 1. Sociodemographic characteristics of the participants

ID	Age	Duration of practice in Urology	Position	Place of practice
CU1	53 years old	16 years	Consultant urologist/key policy maker	Government hospital
CU2	42 years old	6 years	Consultant urologist/ policy maker	Government hospital
CU3	47 years old	14 years	Consultant urologist/ policy maker	Government hospital
CU4	41 years old	9 years	Consultant urologist/ policy maker	Government hospital
CU5	39 years old	5 years	Consultant urologist/ policy maker	Government hospital
CU6	44 years old	8 years	Consultant urologist/ policy maker	Government hospital
CU7	44 years old	9 years	Consultant urologist/ policy maker	Government hospital
OC1	38 years old	10 years	Oncologist	Government hospital
OC2	41 years old	6 years	Oncologist	Government hospital
OC3	36 years old	7.5 years	Oncologist	Government hospital
TU1	33 years old	2 years	Trainee urologist	Government hospital
TU2	37 years old	3.5 years	Trainee urologist	Government hospital
TU3	36 years old	3 years	Trainee urologist	Government hospital
TU4	35 years old	0.5 years	Trainee urologist	Government hospital
TU5	37 years old	3 years	Trainee urologist	University hospital
TU6	36 years old	2 years	Trainee urologist	Government hospital
CU8	54 years old	23 years	Consultant urologist	Private hospital
CU9	49 years old	18 years	Consultant urologist	Private hospital
CU10	52 years old	15 years	Consultant urologist	Private hospital
CU11	53 years old	17 years	Consultant urologist	Private hospital

options which included monitoring, side effects and complications of any chosen management option. Other issues such as cost were also addressed.

“I usually explained about the options, tell them this is it and this is the side effect and this is the outcome, the risk of survival and if they can decide, that’s fine. If they ask me for my opinion, then I’ll tell ..what’s associated with the best outcome. I’ll tell them but I’ll still let them decide”

government trainee urologist

“.....And then I said after the operation, and I explained to them exactly how the operation is done, ..... Then I tell them after when you see me after the operation in about three months, I would do a PSA. You know what the PSA now is now about 8 or 10 or whatever it is. After the operation, if I’ve cured you, your PSA must be less than 0.1...”

government consultant urologist/policy maker

“..... so definitely cost is important. So we do tell them.. you know.. if they go to private... maybe it’s other range of cost.. you know.. compared to when they go to government... so we do discuss about cost”

government consultant oncologist

#### *Delivering personalized information*

They emphasized the importance of delivering the information in a simple way that the patient can understand and is tailored to the patient’s education level.

“Just based on guidelines alone we follow, the options are already there. The pros and cons, what’s the risk associated with each option are already there, how many percent it worked. ..It’s all there to guide us. These options are explained in layman terms. I think that’s the most important thing for those depending on the education level of the patient ....”

government trainee urologist

#### *Using decision support tools*

The doctors used various educational aids in delivering the information in order to enhance the patients’ understanding of prostate cancer. The aids used include paper-based (chart, diagram drawing) or electronic (website) illustrations and models.

“ ..... I write down certain things, certain keywords clearly. And I will give this paper and the drawing to them, so that they go back, they look at the drawing, they remember the discussion that we had”

government urologist

“Illustration basically, whether it’s on the computer, or it’s on the model in the clinic”

government trainee urologist

#### *Empowering patients to seek information*

Further reading materials from the internet and books (e.g. ABC of prostate cancer) were often shared with patients. Patients, who were information technology savvy, were

provided with keywords and website (e.g. Cancer.Net) to encourage information search.

“Well, one thing they are very savvy... sometimes I give them the website, they will go.... So you go do some reading, you come back, you have some questions, you list down, and then I can give the answers. This is for well educated patients. ”

government consultant urologist

#### GIVING TIME TO DECIDE

Most doctors give time for patients to decide as there was no urgency to make a decision immediately for localized prostate cancer. Most doctors felt that information overload could happen in the first session, so the patient was given time to decide on the treatment in the following sessions after exploring the options with family members, friends or opinions from other doctors.

“ ..... I always find that usually one time doesn’t do good, you know. Normally they have a first session then come back again and you got more questions. So, I gave them an outline first and then if they have more questions I will go for more detail. Because I think that if you give them too much in one go, it will be overload.”

private consultant urologist

#### REFERRING FOR COUNSELING AND SECOND OPINION

Healthcare professionals often refer a patient to another discipline, i.e. the oncologist, for better explanation of the different treatment options. The urologist felt that the options of radiotherapy and its related complications are better discussed by the oncologist. On the other hand, the oncologist would also refer patients to the urologist to counsel on surgery. Besides that, they also encourage patients to seek a second opinion.

“..... So since you’re coming to see me, of course I will sell you my operation, I’m a surgeon, I’m bias to all surgery. So of course I will sell you all the good points about surgery. If you go and see the radiotherapist, he’ll try to sell you radiotherapy. So basically, to get a balance view, you must see a lot of guys. You must read a lot, talk to your friends you know, get second opinion.....”

government consultant urologist/policy maker

“Would not have discussed with them (about surgery). That’s not my field. I’m not going to... go beyond what I know. So the risk of surgery yes, normally I’ll refer them to the urologists, you know, ...I don’t want to give them the wrong information. So I leave it to the urologists. What I tell them mostly focus on the radiotherapy part.”

government consultant oncologist

#### ENGAGING FAMILY AND PEERS IN DECISION-MAKING PROCESS

Family and peers are important social supports to the patients. Doctors often encourage the patients to discuss with their family members and peers before making the

treatment decision. The doctors would recommend patients to speak to prostate cancer survivors for peer support but official support groups were not easily accessible.

“I’ve some good patients of mine, who have done well, and they are willing to talk to other patients. So I keep the numbers and of course I remember to get their consent saying in future if I got any patients, I will ask them to talk to him”

government urologist

“.....That’s why it’s good to discuss with the family members around at the same time. If they are not there, ask them to come next time, discuss, explain everything openly, let them decide”

government trainee urologist

## DISCUSSION

In this study, we found that the strategies doctors used to support patients with localized prostate cancer are in the area of information giving. In addition, they provide time and follow up for the patient to think about their treatment options, refer the patients to other healthcare providers and involve family members and peers to support the patients. Providing information to support patients in decision making is a major task for any doctor who diagnoses and offers treatment options to patients. The urologist is usually the source of information in 95-100% of men diagnosed with prostate cancer (Cox & Amling 2008) as he is usually the first doctor who breaks the news. Beside survival rates, each treatment has its potential benefits and side effects which could affect the patients’ decision in choosing their treatment. Thus, it needs to be explained in detail. The patient’s view of which information items affect his decision differs from one patient to the other and changes over time (Feldman-Stewart et al. 2011). Furthermore, the patient might have information overload at the first session (Gebele et al. 2014). Thus, the doctors have to prepare themselves to repeat the information for the patients in subsequent discussions. From our interview, we found that most doctors provide time for patients to think about their treatment choice, to discuss with their family members or to gather further information through second opinion.

Family members such as spouse and children are significant others who might influence the decision about treatment (Shaw et al. 2013; Zeliadt et al. 2011, 2006). It was reported that family members were encouraged to participate in patient treatment decisions by doctors and that this facilitated shared decision making (Zeliadt et al. 2011). In Malaysia, as an Asian country, the family members’ roles are important in sharing the responsibilities of care and financial support to the patients (Lee et al. 2015). Thus, the doctor encouraged the patient to discuss with family members before making decision.

This study showed that the doctors are aware of the patients’ needs to understand the available treatment before making a decision. Both the urologist and the oncologist acknowledged their limited ability to provide detailed information for treatment which was not within their

field, thus it was not uncommon for them to refer patients to another healthcare provider for a second opinion. A possible explanation for this practice may be the lack of an established multi-disciplinary combined clinic in Malaysia. In certain developed countries, a combined clinic consists of multidisciplinary team members such as urologist, radiotherapist and oncologist, who provide an opportunity for the patients to consult various experts (Nieder 2009; Steginga et al. 2008). Besides that, the multi-disciplinary team meeting is also a common practice in many countries to reach consensus on the treatment for oncology patients.

In this study, the aids doctors used were mainly for educational purposes, to improve the patients’ understanding of the disease rather than to support decision making. Decision aids (DAs), tools which assist patients in making a decision, were found to be lacking in the current study. Literature showed that use of DAs can improve patients’ knowledge, encourage more active patient involvement in decision-making and decrease decisional conflicts (Lin et al. 2009). This tool is helpful especially in preference-sensitive decision-making such as choosing treatment in localized prostate cancer. However, there is no decision aid for localized prostate cancer at this moment in Malaysia. A similar situation is also faced by other countries in this region.

Other decision support strategies such as question prompt lists and audio recording of the consultation were less complex and study showed that the effectiveness of these strategies is similar to patient decision aids in knowledge, satisfaction, anxiety and decision conflicts (Spiegel et al. 2013). These are alternatives which our healthcare professionals could possibly adopt and tailor to individual needs in supporting the patients in addition to what they have done to facilitate the shared decision making.

Data from this study will help in planning the policy and strategies of information giving to support patients with localized prostate cancer especially in an Asian country with low incidence of prostate cancer and limited experience and resources. With the gaps identified in this study, decision aids and disease related materials which are relevant to the local communities could be prepared to help the affected patients and their families. Promotion of a multi-disciplinary approach will be useful to achieve this effort. This information can then be promoted to all healthcare providers who deal with localized prostate cancer to familiarize them with each treatment option. In this way, the patients will be able to receive consistent and reliable advice, e.g. which treatment option is appropriate and available for the individual patient in the community. This study has the strength of including policy makers and also healthcare professionals from both private and public sectors. However, the limitation is that we did not collect any data from the patients. Data from both parties would provide a more comprehensive picture about this issue. This could be addressed in future studies.

## CONCLUSION

This study highlighted a multi-faceted approach to support patients with localized prostate cancer in making a treatment decision. It not only involves the urologists themselves, they also empower the patients, patients' social network and other physicians who treat prostate cancer. Personalized decision support tools might be a useful aid for healthcare professionals to facilitate patients with localized prostate cancer to make an informed decision.

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