

Post-treatment impact and needs of prostate cancer survivors in Malaysia; a qualitative study

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Abstract

Introduction and Objectives There are limited studies conducted on the needs of cancer survivors in developing countries like Malaysia. This qualitative study aimed at exploring the post-treatment impact and needs of prostate cancer survivors.

Method: A qualitative study design was used. One in-depth interview and four focus group discussions were conducted with 24 prostate cancer survivors (age range: 58–79 years) from government and private hospitals in Malaysia in 2013. Trained researchers used a topic guide to guide the interviews, which were audio-recorded, transcribed verbatim, checked and managed with Nvivo 10 software. A thematic approach was used to analyse the data.

Result: Three main themes emerged from the analysis: (a) impact of prostate cancer on the survivors, (b) support needed for coping and (c) information needs. Prostate cancer has an important impact on the survivors' lifestyle after treatment. Some of them have to live with the post-treatment side effects. They were anxious about the possibility of relapse. In addition to family and peer support, there were participants who felt that spiritual support was important in helping them cope with the possibility of relapse. The survivors felt that they did not receive enough information about post-treatment care, dietary measures and supplements for relapse prevention, treatment and prognosis.

Conclusion: Prostate cancer has a significant impact on the survivor's lifestyle, emotional and physical health. They need information and emotional support from the healthcare professionals, family and peers. Therefore, it is important for healthcare providers to explore the needs of prostate cancer survivors and provide the necessary support.

Introduction

Prostate cancer is the second most common cancer diagnosed in males worldwide, and it accounts for 15% of all cancers in the male population.¹ In Malaysia, prostate cancer is the fourth most common cancer among the male population.² Although it is common, it has a relatively low mortality rate compared to other cancers.¹ Hence most prostate cancer survivors live with the disease for many years. More studies are focused on patients with prostate cancer before or during treatment rather than the survivors. Therefore, it is important to study the impact of prostate cancer and its treatment on the survivors' lives in terms of side effects, psychosocial implication and quality of life. This is more relevant to primary care physicians as prostate cancer survivors may be on follow-up in general practice for other co-morbidities.

The needs of cancer survivors have been explored in many studies, and they include needs related to psychology, health system and information, physical and daily living, patient care and support, and sexuality.³ However, most of these studies were done in developed countries and only a few studies have reported the impact and needs for prostate cancer survival in developing countries like Malaysia, which has a diverse culture and lower health literacy.^{4–6} In addition, Malaysia has a much lower prevalence of prostate cancer (6.2 per 100,000 population age-adjusted incidence rate) compared with a developed country like the United States of America (160 per 100,000 population age-adjusted incidence rate).^{2,7} Healthcare professionals and the healthcare system are thus less equipped with the skills and knowledge require to support the needs of prostate cancer survivors. Hence, this qualitative study aimed at exploring the post-treatment impact and needs of prostate cancer survivors.

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Methods*Design, setting, participants, recruitment and sampling*

A qualitative methodology was used to explore the range of post-treatment impact and needs of prostate cancer survivors.⁸⁻¹⁰ This study recruited prostate cancer survivors from both public and private hospitals in Klang Valley between January and April 2013. The participants were identified through linkage with the prostate cancer support group of the National Cancer Society and by the recommendations of urologists in Klang Valley. Purposive sampling was used to identify prostate cancer survivors from different ethnicities, education levels, health sectors and those who had chosen a range of treatment options. Sampling and analysis were conducted iteratively until thematic saturation. The analyses were done after each focus group discussion till no new theme emerged. Issues that were raised were incorporated into subsequent focus group discussions. For example, use of complementary and alternative medicine to prevent relapse was raised in the first focus group discussion and this issue was incorporated into the interview guide for the later groups.

Data collection

In-depth interviews and focus group discussions were conducted using a topic guide. The development of the interview topic guide was guided by a conceptual framework developed from literature review and consultation with experts. The focus groups were organised according to the patient's duration of cancer from the onset of disease (1-5 years and more than 5 years post diagnosis of prostate cancer) to facilitate discussion based on shared experience.¹¹ The single individual in-depth interview was conducted separately with a prostate cancer survivor who was also an influential national leader in the prostate cancer patient's support group to avoid his opinion influencing the rest of the participants in a focus group. This key person is a national leader and founder of the national prostate cancer patient's support group. He had more than 10 years of experience in developing and chairing various prostate cancer patient's support groups meetings in private and government

hospitals around Klang Valley. Open-ended questions were used during the interview, and prompts were only used if the critical issues did not emerge spontaneously. Prostate cancer survivors were asked about the impact of the disease on them and their needs.

The participants were informed that their data would be anonymised and kept confidential. Written consent was obtained from the participants. Four experienced researchers (PYL, CJN, KLA and ATC), comprising three family physicians and one nursing lecturer, conducted the interviews. 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 and focus group discussions as well as field notes were used in the analysis.

Data analysis

A descriptive thematic approach was used for data analysis.¹² Two researchers (PYL, CJN) coded two 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 was subsequently used by three independent researchers (YKL, ATC, KLA) to code the same two transcripts. All researchers were involved in the analysis discussion and consensus was 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 it 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 with the consensus of all research team members. Consensus could not be reached, an independent researcher (TAO) who had not participated in the analysis was asked to analyse the data. For the results, all quotations were screened and those that best captured the essence of the themes were extracted. Reflection and open discussion were used by the researchers throughout the interviews and analyses to reduce possible biases in data collection and interpretation. This study is a part of larger project to develop a patient decision aid to support patients with early prostate cancer in making treatment decisions.

Ethical approval

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

Results

One in-depth interview and four focus group discussions were conducted with 24 prostate cancer survivors (age range: 58–79 years) from government and private hospitals in Malaysia. Each interview lasted approximately 60 to 90 minutes. The demographic data and disease profile of the participants are shown in **Table 1**.

Table 1. Demographic data and disease profile of patients

Demographic or disease profile	Categories of demographic or disease profile	Number of participants = 24 (%)
Age (years)	56–65	6 (25.0)
	66–75	15 (62.5)
	>75	3 (12.5)
Ethnicity	Chinese	16 (66.7)
	Indian	6 (25.0)
	Malay	2 (8.3)
Education level	Primary	1 (4.1)
	Secondary	4 (16.7)
	Diploma	6 (25.0)
	University	13 (54.2)
Treatment decision	Radiotherapy	12 (50.0)
	Surgery	10 (41.7)
	Active	2 (8.3)
	Surveillance	
Years since diagnosis	1–5 years	15 (62.5)
	>5 years	9 (37.5)

Three main themes emerged from the analysis: (a) impact of prostate cancer on the survivors, (b) support needed for coping and (c) information needs.

(a) Social, emotional and physical impact on survivors

Change of lifestyle

Most patients changed their lifestyle after treatment. They became very careful with their diet, intake of organic food, regular exercise, using alternative medicine, avoiding alcohol and maintaining better sleep habits.

“If not for prostate cancer, most probably

I’d be drinking and enjoying myself! Now I changed my lifestyle, food, friendship, sleeping habits.” 73 years old, diagnosed prostate cancer 12 years ago.

Anxious about cancer relapse

Most patients expressed anxiety and uncertainty about the possibility of relapse. In addition, they felt that healthcare professionals did not give enough emotional support to them.

“Then after another year, 3rd time, it (PSA) went to 19. And that time I got worried. And then they first said no need to do biopsy because you are already old or you may die. That’s what they always say which is a bad thing to tell a patient, you know.” 79 years old, diagnosed prostate cancer 23 months ago.

Living with post treatment side-effects

Some survivors had to live with the long-term post-treatment side effects such as strictures and urinary incontinence. It was troublesome and caused distress. However, erectile dysfunction seemed to be less of a bother to them.

“Yes, yes ... not exactly difficult, it’s slow, the stream is slow. See, since the stream is slow, he felt that I should ... because they’ve been asking me to use the self-insertion catheter, daily, you know. In the beginning, I was doing it nicely, you know, a self-insertion catheter, where you insert a catheter in the morning, and then you take out the urine, you know. Of course, the advice was a wonderful advice, but it’s very troublesome.” 73 years old, diagnosed prostate cancer 12 years ago.

“Now I come in to clinic I’m still wearing a diaper. You see, cannot control. Day time is difficult. I leak when I cough, I sneeze, I blow my nose. Or I sit too long.” 74 years old, diagnosed prostate cancer 14 months ago.

“(When discussing about erectile dysfunction) But then my wife said that sex is secondary. She said I want you to live, we are not bothered, you are already old. Not so keen on that thing.” 75 years old, diagnosed prostate cancer 6 and a half years ago.

(b) Support needed for coping*Family and social support*

Support from friends, family and support group helped patients cope with their cancer and treatment. The support were important in helping them come to terms with their cancer and motivated them to fight against the disease to continue living.

“Family level. My wife of course I told the family and all, a lot of sympathy here and there, wife quiet. Children completely, you know, not sure. But my daughter was very positive. She didn't tell me good or not good, she just gave me a book, 'dad, read this.' Because I'm a sports person. So I looked at it what is this book? Lance, the cyclist, Armstrong, Lance Armstrong, the victory and all he was fighting testicular cancer and all that. So I read that book, very happy. Because she was telling me in another way that it's okay, fight it.” 68 years old, diagnosed prostate cancer 3 years ago.

This particular group (cancer support group) is the one that put me back on the right track. Alright. They told me you don't withdraw after you are diagnosed, you continue living the life you want.” 58 years old, diagnosed prostate cancer 5 years ago.

Spiritual support

In addition, most of them resorted to spiritual support to help them cope with uncertainty. They surrendered their health outcomes to divine protection or purpose.

“I mean hopefully it (relapse of cancer) will not come also. I don't know, maybe like actually, I think a lot of cancer patients, inside their heart, they feel, just see what is it like, there's nothing much we can do. Leave our fate to God like he says. You know. Just pray more and leave it to God. Because this is one sickness whereby there's no actual cure yet.” 58 years old, diagnosed prostate cancer 5 years ago.

(c) Information needs*Information about cancer relapse*

Patients felt that they did not receive enough information from the doctors about cancer relapse and prognosis. They were not given information about relapse prevention and its best treatment option.

“What we want to know is relapse. You see, we are back to square one again. When we relapse, again there are so many routes, one you have abiraterone, zytiga (hormone therapy), you have all these types of things coming in. What is the best? So that part is lacking. Also how to prevent relapse” 69 years old, diagnosed prostate cancer 2 years ago.

Diet and supplements

Patients wanted to know more about suitable diet, vitamins and supplements after treatment to prevent relapse and to improve their health. However, most doctors would just give general advice about balanced diet. Some survivors used complementary and alternative medicine to prevent relapse.

“(about prevention of relapse) Don't believe in doctors, they say the food you eat is good enough. What kind of food we're eating we don't know! Oh, they said balanced diet. I don't believe in all these balanced diet, I just pop in some vitamins ...” 73 years old, diagnosed prostate cancer 12 years ago.

“Yeah I avoid seafood and I take supplements. Recently I take the 'snake leaf', one green apple and a glass of tomato juice. ... Snake grass is good for people who have cancer, so I just want to be double sure (to prevent relapse), I also take supplement like energy powder and organic oat, and lemon juice from US (United State), I also take another one, the named start with E, it's a type of juice, white colour.” 77 years old, diagnosed prostate cancer 5 years 42 months ago.

Status of disease after treatment

Some patients felt that doctors did not explain clearly about the status of their disease after treatment. They wanted to know the outcome of the treatment and the next steps.

“After my treatment (radiotherapy). I called Dr. XX. What is the results now? I meant tell me what’s stage. I say, I spend 35 times (number of times for radiotherapy) you know and I want to know,’ he can’t tell me exactly,” 72 years old, diagnosed prostate cancer 1 year ago.

Discussion

This study provides an overview of the post-treatment impact on patients and needs for prostate cancer survivors in Klang Valley, Malaysia. The three main themes that emerged from this study are: (a) impact of prostate cancer on the survivors (change of lifestyle, living with post-treatment side effects and anxious about relapse), (b) support needed for coping (family, social and spiritual) and (c) information needs (post-treatment care, relapse prevention, diet, treatment and prognosis). These findings were similar to those from developed countries. This could be because the study participants were from well-educated urban population; hence, they may have a similar thinking process and knowledge with patients from developed countries.

The impact of the disease and treatment on prostate cancer survivors in this study were similar to those from western countries, where the survivors reported that they have to live with post-treatment side effects, were anxious about cancer relapse and forced themselves to change their lifestyles to prevent relapse.^{13–15} Prostate cancer survivors have a higher level of psychological distress due to issues, such as urinary incontinence, bowel changes, fatigue, pain, hot flushes, body image changes and forced lifestyle changes.^{13–15} The elevation of PSA tumour marker that may indicate relapse of cancer can be a significant source of anxiety for the prostate cancer survivors.¹³ However, in contrast to the findings of most studies,^{16–18} male patients in this study seemed to be less bothered about the surgical complication of erectile dysfunction. This may be related to the Asian culture and belief where traditionally, older people are not expected to have active sex lives. Hence older people are

more prepared to live with sexual dysfunction as they perceived it as being a part of the normal ageing process.^{19–20}

Similar to other studies,^{21–24} we found that family, social, religious and peer support were viewed by the participants as important reinforcements that help them to cope with their psychological needs. Spiritual or religious support was important to help them cope with the uncertainty of a relapse. Spirituality and religion for the coping of cancer survivors has been increasingly recognised among survivors. When patients have to deal with uncertainty, religious system which is usually integrated in the patient’s social and cultural context may offer a more acceptable explanation for their disease.^{22,25} In a qualitative study by Aquino et al.²², religion was viewed as playing a role in helping patients to gain new strength in the fight for survival and as a solution to their uncertainty. Hence, it is important for health professionals to be aware of and consider the importance of religiosity while planning and delivering care to cancer survivors. This will help to maintain trust and respect in relation to the patients’ religious beliefs.²² This is especially relevant in a multi-cultural and multi-ethnic society like Malaysia.

In this study, it was found that information needs were not fulfilled. The main gaps in information needs include post-treatment care, relapse prevention, diet, treatment and prognosis. Similarly, other studies have reported unmet information needs for post-treatment care, relapse prevention, treatment and prognosis.^{3,26,27} More pertinent to Asian cultural beliefs, cancer survivors in this study demanded more information about diet and supplements to prevent relapse. Most patients were not fully satisfied with general advice about balanced diet and nutrition; they wanted more information on ways to prevent cancer recurrence. Some of them resorted to trying alternative medicines. The use of complementary and alternative medicine (CAM) is common among cancer survivors.^{28,29} A review on the role of CAM therapies in the management of cancer has reported that CAM being used to “complement” the conventional therapies of radiotherapy, chemotherapy, hormone therapy and surgery can contribute to improving the quality of life of cancer patients and their general well-being.²⁹ However, there may be drug interactions between complementary and alternative medicine with patient’s medications.³⁰ Healthcare professionals

should discuss these issues with patients who are considering complementary and alternative medicine, address their concerns and provide unbiased information to them.

The strength of this study is that we recruited participants from all ethnic groups who had prostate cancer from 1 to 13 years. However, we did not collect any data from patients who are from the more rural area. Future studies may need to look into the perspective of patients from a rural area as their needs may differ. In addition, the data of this study are mainly from focus group discussions as this will facilitate the participants to discuss shared experience; however, this method may hinder participants to raise certain issues that may be sensitive or personal. Future study may need to involve more in-depth interviews to explore certain personal issues.

This study found that prostate cancer survivors' lifestyle, emotional and physical health were affected after cancer treatment. They need information and emotional support from

healthcare professionals, family and peers. This study highlights the important role of a healthcare provider in exploring and addressing the needs of prostate cancer survivors and supporting them throughout their illness.

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Conflicts of interest

Nil

How does this paper make a difference to general practice?

- Prostate cancer survivors need information and emotional support from healthcare professionals, family and peers. However, there are gaps in the provision of these needs.
- Primary care physicians can play an important role in exploring and addressing the needs of prostate cancer survivors and supporting them throughout their illness.

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