



# A qualitative exploration of Maltese couples' care experiences of prostate cancer diagnosis and radiotherapy treatment

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## ABSTRACT

**Introduction:** Although prostate cancer is male-specific, the diagnosis and treatment also affect close family members, particularly spouses. Following diagnosis, treatment choices have to be made and this may lead to a period of stress and confusion for both patient and their family. This study investigated couples' care experiences with prostate cancer from diagnosis to radiotherapy treatment in Malta.

**Methods:** A qualitative descriptive methodology was adopted using semi-structured interviews with twelve couples and two men. Data were collected between January and December 2019. The participants were recruited from a local oncology hospital in Malta. Data were analysed thematically and included the identification of potential contrasts and overlaps between men and their spouses.

**Results:** A prostate cancer diagnosis and treatment was a significant source of distress for men and their spouses. Healthcare professionals did not consistently attend to the couple's concerns, such as perceived delays in the management of prostate cancer and the treatment decision-making process. Most couples did not disclose the diagnosis to wider family and friends and several men valued the experience of men who previously underwent prostate cancer treatment.

**Conclusion:** Ensuring that these couples receive the right information, support, and resources is crucial to assisting couples in navigating the challenges of the cancer journey effectively. When experiences were less positive, the communication process with healthcare professionals was not perceived as adequate, which negatively impacted their emotional well-being.

**Implications for practice:** Additional communication training for healthcare professionals may improve their recognition and response to the needs of service users. Information tailored to the needs of men and spouses may also be considered such as the use of digital tools or involving men who previously underwent treatment.

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## Introduction

Prostate cancer is the most commonly diagnosed male cancer in Malta.<sup>1</sup> Five-year survival rates have substantially increased from the early 2000s in Malta, reflecting earlier diagnosis and more effective treatment.<sup>2</sup> Men diagnosed with localised prostate cancer are presented with various treatment options, including radical prostatectomy, external beam radiotherapy, brachytherapy, or active surveillance.<sup>3</sup> Individuals undergoing treatment for prostate cancer may encounter chronic complications related to erectile

dysfunction, urinary issues, and bowel function. However, the frequency of physical side effects differs depending on the chosen treatment approach.<sup>3</sup>

Since there is no consensus regarding the optimal treatment option, prostate cancer treatment guidelines recommend that patient's preferences should be considered.<sup>4</sup> The central consideration of an informed treatment decision involves weighing the expected benefits against the cost of likely side effects.<sup>3</sup> Treatment decisions often have to be made quickly after a diagnosis and this naturally can be a stressful and confusing time for the cancer patient and their family.<sup>5</sup> Treatment decisions for prostate cancer commonly occur within patients' family network, with spouses often facilitating men's choice of treatment.<sup>6</sup>

Although unique to men, a prostate cancer diagnosis and subsequent treatment also impacts their partners.<sup>7</sup> The literature concerning relationships and cancer highlights the mutual

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influence that partners exert on each other, demonstrating that the experiences of one partner significantly affect the other within the dyadic relationship.<sup>8</sup> Studies suggest that men with prostate cancer and their partners may have unmet needs. For example, an online survey across seven European countries reported that 81 % of the men had some unmet supportive care needs that encompassed psychological, sexual and health system and information needs.<sup>9</sup> Partners of men with prostate cancer have reported unmet informational needs related to therapeutic side effects, availability of support services and the anticipated course of disease.<sup>10</sup> Furthermore, partners frequently experience a sense of being left alone and not adequately included in the patient care process by hospital staff.<sup>11</sup>

To tackle the entire disease pathway, the EU drafted the Europe's Beating Cancer Plan which proposes a holistic approach to improving the quality of life of cancer patients, survivors and their carers.<sup>12</sup> This plan highlights the important role of family members in supporting and providing care to cancer patients. In addition, the Maltese National Cancer Plan (2017–2021) aimed to increase the participation of cancer patients in the care process and proposes that cancer services should be patient-centred and take into account the patients', families' and carers' views and preferences.<sup>1</sup> While there is a lack of in-depth detail and information from patients' and families' participation in the care process, no studies have been conducted in Malta, which may have a distinct social and cultural setting.<sup>13</sup>

This study therefore explored the experiences of men who completed external beam radiotherapy treatment in Malta in the last two years, together with their spouses. This paper focuses on the following research question.

- How do couples experience and navigate the diagnosis and radiotherapy treatment of prostate cancer in Malta?

In particular, this paper will focus on the early phase including diagnosis, the treatment decision-making process and the radiotherapy treatment experience. All men in this study had received radiotherapy treatment, with some also undergoing multimodal treatment including either surgery and/or hormone treatment. This focus allows for a detailed examination of both patient and partner experiences, highlighting areas for potential improvement in patient and partner support and decision-making processes.

## Methods

To explore men and spouses prostate care experience in Malta, a qualitative descriptive approach using semi-structured interviews was adopted. Ethical approval was granted by the local research and ethics committee in July 2018 (FREC\_1718\_148).

### Participant recruitment

Patients were purposively recruited from a radiotherapy out-clinic department in a Malta oncology hospital between December 2018 and December 2019. Patients were eligible if they were between 64 and 74 years of age at the time of diagnosis and had completed external beam radiotherapy treatment between 6 months and 2 years previously. The age group was based on a qualitative study which examined the experience of men with prostate cancer and their partner by life-stage cohort,<sup>14</sup> and adapted to the local setting. The time period since radiotherapy criterion ensured that acute side effects from radiotherapy had subsided<sup>15</sup> and allowed some time for couples to adjust following prostate cancer treatment. Furthermore, the men had to be married

or cohabiting with a partner/significant other (regardless of gender) and be able to communicate in English.

Eligible patients were contacted by intermediaries (therapeutic radiographers) via a phone call. Interested participants were sent an information pack. Prospective participants were required to complete and return an expression of interest form to the researcher (using a freepost envelope). This prompted a telephone call from the researcher to screen for eligibility and answer questions about the study.

### Procedure

A semi-structured interview guide, developed following a review of the literature focussed on the study aim, was piloted for appropriateness and understandability with the first two couples. Minor changes were made to include more probing and follow-up questions. The interviews were conducted by the lead researcher who is a qualified therapeutic radiographer but unknown to the participants. Interviews were conducted in the local hospital or the home of the participants depending on their preference. The couple's interviews were conducted with both partners present, often referred to as dyadic interviews. Dyadic interviews allow participants to cross-probe, correct, challenge, or introduce new themes for discussion which could not be identified during individual interviews.<sup>16,17</sup> Interviews were audio-recorded and transcribed verbatim by the lead researcher.

### Data analysis

The inductive approach to data analysis was grounded in the data itself. Thematic analysis followed the six-phase process described by Braun and Clarke<sup>18</sup> using a qualitative data analysis software programme (QSR International's NVivo 12). A unique aspect of dyadic analysis is the examination of the themes emerging from the couple's individual narratives. This is performed by assessing contrasts and overlaps between the different accounts of the men and their spouses.<sup>19</sup>

Trustworthiness and credibility were promoted through peer reviews and debriefing. Using multiple coders was particularly beneficial in a reflexive manner to sense-check ideas and to explore multiple assumptions in the interpretation of the data.<sup>20</sup>

## Results

### Participant characteristics

A total of 52 men were approached and 14 interviews were subsequently conducted with couples ( $n = 12$ ) and individual men ( $n = 2$ ). The most common reasons for decline were a lack of interest ( $n = 20$ ) and being unable to be interviewed in English ( $n = 12$ ). Two men attended the interview alone. Since this study also explored differences between men and their spouse, and these men were part of a marital dyad, their opinion and views could offer additional insight into their experiences of the healthcare system. Although all men underwent external beam radiotherapy treatment, most men received this in combination with hormone treatment ( $n = 9$ ) or after surgery ( $n = 3$ ) (Table 1 - Participants characteristics).

The study findings report on the detailed experiences of men undergoing prostate cancer radiotherapy treatment and their partners. Several overarching themes were identified and this paper will present three main themes: 'Getting to grips with prostate cancer', 'Making a treatment decision' and 'Navigating the radiotherapy treatment process'. These themes will be further presented in this section.

**Table 1**  
Participants characteristics.

Interview	Gender	Age	Employment status	Marital status (Years of marriage)	Months since completing RT	Management option(s)
01	M	70	Retired	Married (14)	7	RT only
	F	57	Clerk			
02	M	69	Part-time catering	Married (47)	12	RT + ADT
	F	69	Housewife			
03	M	72	Retired	Married (48)	16	RT + ADT
	F	68	Housewife			
04	M	70	Retired	Married (12)	16	RT + ADT
	F	40	Cleaner			
05	M	71	Retired	Married (49)	24	RT + ADT
	F	73	Housewife			
06	M	74	Retired	Married (49)	18	RT + ADT
	F	71	Housewife			
07 <sup>a</sup>	M	64	Retired	Married (40)	12	RT + ADT
	F	63	Housewife			
08	M	73	Retired	Married (47)	6	RT + ADT
	F	71	Part-time cleaner			
09	M	64	Retired	Married (39)	9	RT only
	F	69	Housewife			
10	M	66	Gardener	Married (35)	22	RT + ADT
	F	59	Housewife			
11 <sup>a</sup>	M	65	Retired	Married (33)	14	Post-op RT
	F	59	Housewife			
12	M	65	Retired	Married (40)	16	Post-op RT
	F	58	Housewife			
13	M	64	Retired	Married (40)	9	Post-op RT
	F	63	Retired			
14	M	72	Retired	Married (52)	12	RT + ADT
	F	71	Retired			

Abbreviations: M = Male, F=Female, RT = External Beam Radiotherapy, ADT = Androgen Deprivation Therapy, Post-op = post operative.

<sup>a</sup> Men attended alone to the interview.

### Getting to grips with prostate cancer

Getting to grips with prostate cancer presents the initial experiences of men and spouses with a potential prostate cancer diagnosis. Findings illustrate that the period from initial referral to a specialist until the actual diagnosis was particularly challenging for them. This period was often associated with uncertainty, and this affected their emotional well-being:

*‘I was downcast the first time the GP told me that it could be cancer. It could be! it could be! Listen, it could be cancer! Because it is the unknown if they told me it is definitely cancer then you know.’*

(M03, 72 years)

The initial elevated PSA levels and the need for further tests and examination also caused a negative emotional impact on the spouse. Several spouses highlighted the emotional toll, particular the worry and fear associated with the possibility of a cancer diagnosis.:

*‘That affects you I am sure just the word cancer it puts a fear in you’*

(F03, 68 years)

Participants expressed concerns about prolonged waiting times and delays in receiving a prostate cancer diagnosis, which many felt increased their distress. This led to a number of men chose to seek private healthcare to receive a more timely assessment:

*‘They say it is a slow process but I can still not understand why they say that because in December the PSA was Ok but in February it*

*wasn't anymore and when they did the biopsy it was an aggressive Gleason 8 cancer so WoW. It moves fast it doesn't move slowly and we were wasting time in my opinion.’*

(M03, 72 years)

Findings revealed that there was disagreement between the couples and healthcare professionals centred on the potential growth and progression rate of prostate cancer. Whereas the healthcare professionals often reportedly indicated to participants that prostate cancer tended to be a relatively slow-growing disease, the couples perceived that any delays could have a negative impact on the outcome of their treatment and prognosis.

*‘You shouldn't say, because that is the first thing. They tell us: ‘listen, don't worry, this takes long, it can take years’. I mean you cannot tell if it is aggressive or not and I got frightened, and Ok, they mentioned that this is a slow-growing tumour. But I was feeling that this long wait could have a negative impact on the outcome and that the cancer may grow during this period.’*

(F13, 63 years)

Beyond the medical challenges, participants also expressed challenges in managing the socials aspect of the condition. Their responses highlight that most couples in the local setting did not disclose their diagnosis to friends and wider relatives. Most couples only informed direct family members (typically their children). Participants explained that this choice was often based on concern about causing unnecessary worry or altering their relationships with others.

*'I know that I could have getting support but I would rather not be pitied so just my family knows, my kids.'*

(M07, 64 years)

Findings illustrate that spouses often agreed with the limited disclosure, with a slightly different emphasis noted that others have their own families and concerns and therefore they did not want to add any additional worry or distress to them.

*'What is the use, they got their families, and they got their worries.'*

(F02, 69 years)

#### Making a treatment decision

Following the diagnosis, men faced the challenge of making a treatment decision, particularly whether to undergo surgery or radiotherapy, and whether to opt for standard surgery locally or robotic-assisted surgery abroad. Findings revealed that this decision was difficult, and men often consulted close family members, particularly their spouses, for support.

*'I was given to understand that I had an option, and it is not easy to decide on an option. I mean, it wasn't easy at all. I discussed it with my wife and my son and daughter - I mean everybody had their opinion to do it in Malta or over in England. I went through a lot of thinking and finally I decided for an operation locally.'*

(M03, 72 years)

To make an informed decision about the available treatment options, most men sought information from other sources, such as healthcare professionals, the internet and family and friends. However, many men expressed a preference to receive information from previous patients who already had undergone the treatment before recommended.

*'Somebody had told me that this particular doctor had passed through this experience, and after me he had about 20 people waiting. When I entered, I told him that I have nothing but that I wanted to speak to him about his experience of the surgery and I think I spend about 45 minutes. He explained to me everything, his experience and what I have to do to prepare myself and I wanted to pay him and he told me: 'no you came here patient to patient' and I came out of that meeting as a lion! That is why I told you that I was prepared for it.'*

(M09, 64 years)

In addition to the anxiety and stress associated with making a management decision, four of the men (M09, M03, M07, M12) experienced an unexpected change in their treatment plans. Initially, they decided to undergo a surgical procedure, but they were subsequently informed that surgical intervention was no longer appropriate. Findings revealed that it was not always clear why a change in their treatment plan had been made, and participants expressed frustration and confusion due to a lack of clear information about the reason for the change:

*'That was very bad as it was not an option as they first said you go for surgery and I prepared everything I prepared the family and at the last minute and I was just waiting for the day and it was coming in a week time. And then suddenly a phone call it was not going to*

*happen. Why I asked? and they told me we don't know. So I asked who knows and they told me nobody knows. What do you mean nobody knows?'*

(M07, 64 years)

In the absence of appropriate information, some men assumed that their cancer had progressed to a more advanced stage and therefore an operation was no longer appropriate and the future was bleaker:

*'The initial reaction was very bad and your initial reaction is very bad I thought they were not going to do it because it is too late that the cancer has spread.'*

(M07, 64 years)

#### Navigating the radiotherapy treatment process

Following the decision-making process, all men were referred for radiotherapy treatment. However, several men revealed that they were initially unaware of the specifics of this treatment or the treatment reactions.

*'The radiotherapy, when someone tells you that, you, radiotherapy, you do not know what is going to happen. And I was thinking that I will get burned because of this treatment. So, in your mind, you have a lot things going on'*

(M12, 65 years)

While the men received information regarding treatment and side effects before the start of treatment, from the oncologist and treating radiographer, some men suggested that information from previous patients would have complemented this, if given before starting their radiotherapy treatment. Participants felt that such first-hand information would have better prepared them for treatment.

*'I spoke to another person who underwent the radiotherapy before I went. and he explained the procedure and that really gave me the courage to go ahead with this treatment and I was prepared for what I was going to face, you know.'*

(M09, 64 years)

Whilst the men appeared to prefer information from first-hand experiences, findings revealed that spouses often searched the internet for further information to prepare them for their support role.

*'Reading till 2 or 3 in the morning on the internet looking around what am I going to do what can they give him what kind of treatments are out there because I am like that, I have to know everything from A to Z what is going to happen.'*

(F10, 59 years)

Response highlights that not all men were aware of the nature of treatment-related side effects, especially the timing and long-term impacts. Although they often recalled having received information about potential side effects before the commencement of treatment, on reflection they were not always aware that acute side effects could occur for several months following the completion of the treatment, nor the course or likelihood of longer-term effects.

*'We had a meeting before, obviously before the commencement of treatment. And they told us the possible consequences, but I always thought that these possible consequences were during the treatment. I was not aware of things to come out five months after. Nobody said, 'Listen, this may take a period of 1 year or 2 years.' Nobody said that this might happen when you take this radiotherapy. It was logically for me - I mean, today was the last day of the therapy and thank God I feel fine. I was not aware that the problems will start afterwards.'*

(M07, 64 years)

## Discussion

This study indicates that one of the greatest consequences of a prostate cancer diagnosis and treatment is the emotional impact on both men and their spouses. Specifically, perceived delays in diagnosis and treatment were common concerns during the initial phase. Participants also felt that healthcare providers often did not seem to understand their concerns about the urgency of a potential prostate cancer diagnosis. For them, prostate cancer felt like a life-threatening illness and therefore associated with significant distress for the couple, especially in the early phase of engagement. However, their concerns did not seem to be adequately addressed by the healthcare professionals, which further compounded participants' anxiety, resulting in unmet supportive care needs.

Unmet psychological and information needs in prostate cancer patients<sup>21</sup> and spouses<sup>22</sup> have been associated with negative emotional consequences.<sup>23</sup> Couples in this study also indicated that the provision of information was not always perceived as adequate, in particular when a change in treatment plan was recommended by the healthcare professionals. This may indicate some unmet supportive care needs in patient-provider communication. Patient-provider communication plays a critical role in diagnosis, treatment and prognosis of critical health conditions such as cancer.<sup>24</sup> Effective communication among cancer patients, spouses and providers can facilitate shared decision-making, and foster patient-centred health outcomes,<sup>25</sup> decreasing anxiety and distress<sup>26</sup> and improving satisfaction about the offered services.<sup>27,28</sup> The most recent Maltese Cancer Plan highlighted that cancer services should be patient-centred and that the model of care should be based on communication with patients and shared decision-making, whenever possible.<sup>1</sup> However, findings suggest that such an approach was not always perceived as adequate, in particular when a change in treatment was given over the phone, with a lack of sufficient information and detail which had a negative impact on their emotional health. The decision-making process is a critical phase in the cancer care pathway, however, the ineffective communication increased couples' anxiety and distress and this aligns with previous research, which noted that ineffective communication has also been related to deficiencies in patient experiences with cancer care.<sup>29</sup>

The findings of this study also revealed differences in information needs between men and spouses. Whilst spouses in this study appeared to use more digital informational tools, men more commonly valued the opportunity of listening to other men who had previously undergone prostate cancer treatment. Such differences may be important for healthcare professionals to consider and may be linked to the differences in roles such as being a patient versus support provider. Partners often play an important role in providing physical, emotional and informational support throughout the illness<sup>30</sup> and therefore may have different information needs when compared to their husbands. While spouses

commonly use the internet to gather their information, this information may not be accurate or reliable.<sup>31</sup>

Men in this study appeared to value first-hand lived experience information, which resulted in several men actively seeking other men who underwent prostate cancer treatment. As there is no formal support group established in the local setting that focuses on prostate cancer, this may be challenging for other men. Peer support groups have been indicated to be an important source of support for both men and their spouses during prostate cancer treatment.<sup>30</sup> Peer support programs have become acknowledged as a beneficial form of psychosocial support<sup>32</sup> and peer support services have also begun operating in conjunction with healthcare services in clinical environments.<sup>33,34</sup> These programs may be adopted in the local setting to enhance the treatment experience and potentially improve support for men and their partners during the initial phases of prostate cancer.

The social and cultural context in which this study was undertaken may also have a profound impact on participant experiences. In particular, findings from this study revealed that most couples did not disclose their prostate cancer diagnosis to friends and/or wider relatives, possibly due to cultural norms and concerns about maintaining privacy. This may impact the ability of couples to engage in meaningful social activities and/or access wider support networks. While the men appear to be more conscious about their self-image, as prostate cancer may be received as a threat to their masculine identity,<sup>35</sup> spouses did not want to put an additional emotional burden on others. These differences may relate to traditional gender roles that are the norm in the local socio-cultural setting. As can be seen from the demographic characteristics (Table 1), spouses were commonly housewives which could indicate the more traditional roles adopted by men and spouses in this particular context. Due to the relatively small size of the island and close interaction with other family members, Malta could be considered a face-to-face community in which anonymity is unusual.<sup>36</sup> This may therefore suggest that some of the efforts by the couples to prevent disclosure, were, perhaps, a way of maintaining anonymity within the community.

## Limitations

This study involved men and their spouses who were in long-term heterosexual relationships, which may limit the transferability of the findings to participants with other types of relationships. Additionally, the focus on men receiving radiotherapy, with or without multimodal therapies, means that the experiences of those who only underwent surgery or other treatments were not included. Findings should therefore be considered accordingly. The characteristics of the sample and the specific context of the study, conducted between 2018 and 2019, may also impact the wider generalizability of the results, particularly as the context and delivery of services may have changed since then.

## Conclusions

The study highlights significant emotional distress experienced by both men and their spouses, which is grounded in prostate cancer, but exacerbated by perceived delays in care and insufficient communication from healthcare providers. Effective, clear and timely communication are crucial to addressing these concerns. Tailoring support to individual needs, such as through peer support programs and customized informational resources, is likely to enhance the care experience. Patient-centred communication and



more meaningful, integrated peer support can better meet the needs of patients and their families, with potential for leading to improved satisfaction and outcomes.

### Conflict of interest

None.

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