Facing life-prolonging treatment: The perspectives of men with advanced metastatic prostate cancer – An interview study

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ABSTRACT

Purpose: Several life-prolonging treatment options have recently become available for metastatic castration-resistant prostate cancer. However, research regarding patient experiences while undergoing these treatments is scarce. The aim was to explore the perspectives of men when facing life-prolonging treatment of metastatic castration-resistant prostate cancer.

Method: Qualitative interviews were conducted with 16 men as they were starting, undergoing or had completed their first life-prolonging treatment. Interpretive description was used for analysis.

Results: The results illuminate the complexity of facing life-prolonging treatment, with interlaced dimensions beyond just the outcome, and where the men described other dimensions of their lives in relation to the treatment. The results are presented as 4 themes; Considering treatment when the remainder of life is at stake, Preparing for the life-prolonging treatment after deciding to go through with it, Considering the prospect of the life-prolonging treatment not being successful and Reflecting on death and dying in the light of a life-limiting illness.

Conclusions: The quality and content of the remainder of life are central for men when facing life-prolonging treatment of metastatic castration-resistant prostate cancer. This is important when weighing desired treatment outcomes against side effects, and when reflecting upon whether going through with treatment would be worth it or not. The results illuminate the importance of encouraging men at this stage to express expectations, hopes and fears regarding the treatment and the future when considering life-prolonging treatments. Nurses working with these patients are important in the decision-making process and in evaluating treatments, to detect needs for interventions.

A R T I C L E  I N F O

Keywords: Nurse-patient relations Nursing Oncology nursing Palliative care Patient-centered care Prostatic neoplasms Castration-resistant Prostatic neoplasms Castration-resistant Quality of life Therapeutics

1. Introduction

Prostate cancer (PC) has a high global incidence (Siegel et al., 2018; Ferlay et al., 2013). In Sweden, 10,288 men were diagnosed with the disease in 2017 (National Board of Health and Welfare, 2019). The most advanced, incurable stage of the disease, metastatic castration-resistant prostate cancer (mCRPC), is defined by a resistance to castration treatment (Cornford et al., 2017). In this palliative phase, health-related quality of life (HRQoL) is rapidly deteriorating and the symptom burden is often severe (Burbridge et al., 2020), even for patients receiving disease-directed treatments (Sullivan et al., 2007; Lindqvist et al., 2008a). Patient-reported outcome measures have been shown to be important for evaluating quality of life (QoL) and function in men with mCRPC (Eton et al., 2010).

Today there are no curative treatments available for mCRPC. However, several options for treatment with disease-inhibiting and life-prolonging intent have been developed, such as chemotherapy or hormone-regulating drugs (Tannock et al., 2004; Petrylak et al., 2004;
Shore et al., 2017; Sumanasuriya and De Bono, 2018). Men with localized PC tend to overestimate the increased survival with treatment and underestimate their life expectancy without treatment (Xu et al., 2016; Mohan et al., 2009). To our knowledge, treatment expectations have not been studied specifically in men undergoing life-prolonging treatment of mCRPC. However, research on patient expectations on chemotherapy treatment of other advanced cancers suggest that a substantial number of patients may not have understood that the chemotherapy would not cure their cancer (Weeks et al., 2012; Nowicki et al., 2015).

Given the severity of mCRPC, it is important to consider the possible negative effects of specific treatments on the patients’ HRQoL and weigh these against the desired positive effects. Controlling pain from skeletal metastases has been shown to be important for men with mCRPC when considering treatment, whereas side effects such as fatigue, memory loss and cognitive impairment are viewed as worrying potential costs of treatment (Eliasson et al., 2017). A review of the needs and experiences of men with PC ranging from localized disease to an advanced, palliative phase highlights the men’s need for information about treatment options as well as the expected severity and duration of side effects (King et al., 2015). Still, it has been shown that men with mCRPC lack enough information about the treatments and their possible impact on their life (Jenkins et al., 2019). Further, QoL has been shown to be more important to men with mCRPC than extending life expectancy with the risk of experiencing debilitating treatment complications (Jones et al., 2018). Considering the often long course of the disease, the severe symptom burden and the decline of QoL in the advanced stages, it has been argued that palliative care might be especially suitable for men with PC, even in conjunction with life-prolonging treatments (Sanford et al., 2013).

Research has shown that nurses play an important part in the treatment of advanced cancer; in the decision-making process, where they provide emotional support as well as information or clarification of information to the patient. Similarly, they are also active in follow-ups and treatment evaluation with the patients (McCullough et al., 2010). Chemotherapy treatment, which is also one of the most common life-prolonging treatments for mCRPC, is usually administered by nurses (Buiting et al., 2011). The important role of nurse specialists in the PC care team member comprises patient support (emotional and practical), information provision, planning and follow-up as well as holistic assessments of the patient’s situation (Lamb et al., 2017). Even if the role of, and access to, specialist nurses in prostate cancer care may vary in between regions and nations, the Swedish national guidelines for the management of PC (National Board of Health and Welfare, 2015) state that all PC patients should have a designated nurse as a continuous contact at the oncology- or urology clinic. The contact nurse should serve as a valuable source of information for both the patient, the patient’s family and the rest of the health care team involved in the patient’s cancer care.

In summary, existing research regarding patient perspectives in the context of life-prolonging treatments of mCRPC is scarce. The severity of the disease and the relative novelty of the life-prolonging treatments make it important to further explore patient perspectives to better understand and improve the care of these patients. Thus, the aim of this study was to explore the perspectives of men when facing life-prolonging treatment of mCRPC.

2. Methods

2.1. Design

The study had a qualitative approach using qualitative interviews for data collection (Kvale and Brinkmann, 2014) and interpretive description for analysis (Thorne, 2016).

2.2. Procedure and participants

The present study is part of an ongoing longitudinal, multicenter study exploring patient expectations and experiences in the context of life-prolonging treatments of mCRPC. One hundred and fifty patients about to start their first life-prolonging treatment and who understand the Swedish language are recruited from oncology clinics at three hospitals in rural and urban areas in Sweden. They receive QoL- and symptom questionnaires every three months for up to two years and data from medical records is also collected at each follow-up. A subsample of the men is also invited to participate in individual interviews. All participants receive oral and written information, and written informed consent is obtained from all participants.

In the present study, a subsample of men from the longitudinal study was invited to take part in interviews. The men were asked by a research nurse/coordinator about being contacted by a researcher for an interview and those who agreed were contacted via telephone. Inclusion criteria were: men with mCRPC who were about to start, were currently undergoing or had finished their first life-prolonging treatment. A purposeful sampling strategy was used to ensure variation among the participants regarding characteristics such as age, relationship status, level of education, and current type of life-prolonging treatment. Two men declined to participate due to not feeling well enough; a total of 16 men agreed to participate.

The participants’ age ranged from 60 to 82 (mean: 73) years. Twelve were married or cohabitating with a partner, one lived with his child, and three lived alone. The participants’ highest level of education was: 9-year elementary school (n = 3), high school degree (n = 5) and university degree (n = 8). Fourteen were retired, one was working part-time and one was on sick leave. At the time of the interview, three participants were about to start their first life-prolonging treatment, nine were currently undergoing their first treatment and four had completed their first treatment - either chemotherapy (Docetaxel, n = 11) or hormone-regulating treatment (Abiraterone acetate, n = 1, Enzalutamide, n = 4). At the interview, the participant’s overall condition was assessed by the interviewer using the ECOG Performance Status (ECOG PS) (Oken et al., 1982). The ECOG PS uses a numeric scale ranging from 0 to 5, with a higher number indicating a higher level of involuntary daily restrictions and difficulties carrying out everyday tasks and pre-disease activities. Fourteen participants were scored with either 0 or 1, while two participants scored 2 and 3 respectively.

2.3. Data generation

Data were generated through qualitative interviews (Kvale and Brinkmann, 2014) conducted between March 2016 and August 2017. All interviews used the opening question “Would you like to tell me about your situation with prostate cancer?” Thereafter, the interview adhered to the unfolding of the man’s narrative. Open (e.g. “Tell me about the treatment you are about to receive now”, “What are your thoughts on the future?”), probing (e.g. “Tell me more about that”) and follow-up (e. g. “What did you think when you heard this?”) questions were formed based on what came up naturally in the interview. In accordance with the participants’ wishes, 13 face-to-face and 3 telephone interviews were conducted. Face-to-face interviews were conducted either in the participants’ homes, in a conference room at the first author’s workplace or at the oncology clinics. All interviews were conducted by the first author except for one performed by the last author and one performed by a research nurse. Notes on the content and ideas for follow-up questions were taken by the interviewer during all interviews. The face-to-face interviews were also audio-recorded and transcribed verbatim. The median length of the interviews was 56 min, ranging from 22 to 160 min.
2.4. Data analysis

An interpretive descriptive methodology (Thorne, 2016) guided the analysis. Firstly, to achieve a sense of the entirety and closeness to data, all transcripts were read several times while simultaneously listening to the interviews. Text segments corresponding to the study aim were thereafter extracted. This was performed inclusively to make sure that each segment had its original context and framing intact. An inductive approach was applied while coding segments and identifying themes and patterns within and between interviews. The segments and codes were thoroughly discussed between the first author and co-authors, moving back and forth between each segment and its wider context in the interview text during the analysis. The software QSR NVivo 9 (QSR International Pty Ltd, Doncaster, Victoria, Australia) was used to facilitate sorting of data.

2.5. Ethical considerations

The study was performed in accordance with the ethical principles stated in the Declaration of Helsinki (WMA, 2013). The study was approved by the Regional Ethical Review Board in Stockholm, Sweden (Dnr, 2014/341-31/2, Dnr, 2016/851-32 and Dnr, 2016/2230-32).

3. Results

The results illuminate the complexity of facing life-prolonging treatment, with interlaced dimensions beyond just the outcome of the life-prolonging treatment, and where the men described other dimensions of their lives in relation to the treatment. The results are presented as four themes; Considering treatment when the remainder of life is at stake, Preparing for the life-prolonging treatment after deciding to go through with it, Considering the prospect of the life-prolonging treatment not being successful and Reflecting on death and dying in the light of a life-limiting illness.

3.1. Considering treatment when the remainder of life is at stake

When speaking of their illness and the treatment they were starting or undergoing, the men spontaneously described that they knew the life-prolonging treatments provided no possibility for cure and that the remainder of their life was at stake. In relation to this, they explained the importance of weighing possible treatment benefits, such as increased survival or relief of symptoms, against possible treatment side effects. Weighing possible treatment outcomes, the benefits and risks, against the desired quality and content of the remainder of their lives was also described as important. They expressed hope that the life-prolonging treatment would be “successful”, in the sense that it would slow down the progression of the disease and hence, prolong life. One man said:

“In no way have I imagined that I will all of a sudden be completely cured. But … that … well, that I can … keep going and feel well a little longer than I would otherwise have done [without treatment]”

When considering the treatment, the men described how they discussed the treatment benefits and risks with family and friends. Some described searching for more information about the treatment and its possible effects, and trying to keep themselves up to speed with the development and medical advancements in the field, whereas others tried to limit the amount of information they received and relied mainly on the information given by their oncologist or contact nurse at their oncology clinic. The men’s previous experiences of cancer and cancer treatments, either their own, a relative’s or a friend’s, influenced their expectations regarding treatment success and side effects. Prior experiences of distressing treatment side effects could reinforce feelings of fear or worry whilst prior experiences of successful outcomes, symptom relief or disease inhibition supported feelings of hope. One man described this as follows:

“My thoughts about that … they are that you’re going to end up with problems and … become bald, and feel unwell and … feel really sick and … and … things like that. But then I’ve also thought that you don’t have to become bald … or lose all your hair here [on the head], my father didn’t. So I thought … that doesn’t have to happen to me”

When speaking about the remainder of life and the impact the treatment had already had or possibly could have, the men emphasized how they wanted and intended to prioritize spending time with family, relatives and friends. They spoke of how they hoped to reach certain future “milestones” they had set for themselves, e.g. to reach a certain age or to be around to witness a grandchild graduate from school. They also expressed that they wanted and planned to take up interests they had previously been engaged in, such as riding motorcycles or playing instruments. They also had plans to try to start working again. The men emphasized the importance of still having enough energy and feeling well enough to carry out their everyday lives as they wished throughout the treatment, although this was not expressed as a condition for undergoing the treatment. While voicing concerns and worries about possible unwanted treatment side-effects, the men also expressed a willingness to accept a certain amount of discomfort from side effects in the hope that the treatment would prolong their life. Still, they noted how they could not know or predict in advance whether going through with the treatment would ultimately be worth it or not, especially since a successful treatment outcome could not be guaranteed and treatment side effects not fully predicted.

“After all … life is worth more than the discomfort. I think so. Then, in the end, you’ll never know if it was worth it or not”

3.2. Preparing for the life-prolonging treatment after deciding to go through with it

After deciding to undergo treatment, the men described how they prepared mentally, physically and practically. Their preparing was influenced by their expectations of the treatments, based on the information they had received or obtained and their prior experiences. Their preparations comprised different actions and measures, where the men described spending time thinking about the treatment and looking for further information about what could be expected when undergoing it. They described how their preparation involved planning and re-arranging everyday activities to fit around the treatment schedule and appointments. They also described elements of self-care, such as cutting down on their normal amount of work, as one man expressed:

“I probably won’t… do as much work now when going through the chemotherapy because the body, it needs to be … be as stable as possible. That’s the most important thing of all”

The men also contemplated how far ahead in time they should or could prepare and make plans. One man stated, “I guess you can plan 6 months ahead” whereas another man said, “I’m just taking it one day at a time”, showing the somewhat different views on this. In some interviews, the men gave voice to both perspectives when reasoning about how they tried to live day by day while simultaneously making long term plans for several months ahead.

3.3. Considering the prospect of the current life-prolonging treatment not being successful

The men’s considerations also comprised scenarios where the life-prolonging treatment would not be successful, meaning it would not impede the disease progression or that the effect would eventually cease. They considered what it would be like if additional life-prolonging
treatments were to become an option or a necessity after the first one, or if there would be no further treatment options. They described both fear and hope when thinking about the different treatment options that might come into question; whether they would be able to “buy” additional time, the side effects that might occur and whether the next treatment would be more or less intrusive than the current one. One man reflected:

“For some, it [the treatment] just works for a couple of months but for some it can apparently work for ... longer than for others. And I must hope ... and believe that I’m in that category at least. No ... but of course, if it comes to it ... then I will have to ... undergo radiotherapy or ... chemotherapy and so on”.

Expectations on the healthcare services were also addressed in relation to the possibility of having to consider additional life-prolonging treatments. Some men expressed feelings of hope and confidence in “the medical advancements” and that new treatments would be made available for them if wanted and needed. Others described feeling less confident in the healthcare services and the availability of treatments after their current treatment, and instead worried about whether they would get the “right” treatment next time and if treatment would be initiated “in time”. This worry was associated with prior experiences of not being listened to when seeking medical attention, or that previous PC treatments had been unnecessarily delayed due to “system errors”, such as lack of resources at the clinics or miscommunication between healthcare providers.

3.4. Reflecting on death and dying in the light of a life-limiting illness

Thoughts and expectations about death and dying were addressed in relation to the remainder of the men’s lives. When reflecting upon death, the men returned to a sense of uncertainty and described feeling worried that they could not know or predict how, when or how fast their health and overall condition would deteriorate. Some described how they were not afraid of death and not particularly occupied with the thought of their own impending death. Still, the men who described that they were at peace with their own death also expressed feelings of fear and unease when thinking about the dying process and the end of life. Other men described their thoughts about death and dying with fear and anguish. One man said:

“So of course you think about ... what the end will be like, if it’ll be the pump [heart] that stops or if it’s ... a prostate cancer death, it’s not that merciful, you’ve read many gloomy stories about that.”

I: do you think about that a lot?

“No, I can’t say I do. It’s on and off, off and on. But no, not a lot. In some weird way I keep it at a distance. But sure it comes to mind sometimes ...”

The men who spoke about the fear of death and dying explained how frightening and painful memories of a family member or friend dying in agony or pain generated anxiety and fear of unmanageable symptoms at the end of life. They also expressed a fear of becoming dependent on others and not being able to care for themselves. In relation to this, thoughts were also expressed about suicide and euthanasia in order to be able to “end things in a dignified way” in the sense of dying without being in pain or agony. Some men described how they tried to distance themselves from thoughts about the end of life, believing that there was little they could do to influence this anyway. Other men described how they regularly worried and how they tried to manage their worry by talking to their family, most commonly their spouse. Some men reflected on their death in terms of a “fear of missing out”, where they expressed sadness over things that they knew they would not participate in.

“I’m not afraid to die, no it’s ... I don’t think I am. I haven’t come that far yet so ... I don’t think so ... it’s more that ... am I going to be around for things?”

The men explained how they took actions to make things easier for their families after their death. One man put it “I’m not planning to die but I’m not ruling it out” and reasoned about how he felt hopeful about the treatment while still making sure that he was as prepared as possible in the event of his demise. The actions described by the men involved gradually clearing their homes of “unnecessary” papers and items, getting legal documents in order and reflecting on how they would like their memorial service to be.

4. Discussion

The results show that the quality and content of the remainder of life are central for men when facing life-prolonging treatment of mCRPC. These were important factors when weighing desired treatment outcomes against unpredictable, distressing side effects. This also raised thoughts and reflections about whether going through with treatment would be worth it or not, especially since the treatment provided no possibility for cure. While expecting some treatment side effects, the men also expressed a willingness to tolerate varying amounts of treatment side effects in the hope of a disease-inhibiting and life-prolonging effect. After deciding to undergo treatment, the men prepared themselves practically and mentally for the treatment ahead. They also reflected on the possibility of the treatment being unsuccessful as well as the end of life and their impending death.

The men in the present study considered the life-prolonging treatment an opportunity to inhibit the disease progression but expressed awareness of that they would not be cured, which is in line with the results of another interview study by Catt et al. (2019). However, this contrasts against previous research showing that palliative and life-prolonging treatments of cancer might be misunderstood by patients as being curative (Weeks et al., 2012; Nowicki et al., 2015; Mitera et al., 2012). The present study shows that the men’s hopes for the treatment outcome was an impeding factor of the disease progression, while simultaneously hoping to avoid debilitating side effects from the treatment. Previous research shows a complex relationship between these two aspects, as the patients’ hopes for a life-prolonging effect might cause them to underestimate the severity or negative impacts of treatment side effects, making the treatments difficult to evaluate (Daneault et al., 2010). The fact that the treatment will not cure their disease, further underlines the importance of taking men’s priorities and wishes into account when making decisions concerning life-prolonging treatments in this palliative phase, especially considering their severe symptom burden (Lindqvist et al., 2008a) and limited survival (Sullivan et al., 2007).

The careful weighing of quality of life against quantity of life, benefits against risks, described by the men has also been previously illustrated, showing that it varied as to whether patients were willing to endure side effects to buy some time knowing that their disease could not be cured (Havlířský et al., 2014; Wright et al., 2010; Mack et al., 2010). When men are facing life-prolonging treatments, it is, therefore, important to consider and discuss both the benefits and possible harmful effects of the treatments when communicating with the patient (Winkler et al., 2012; Haun et al., 2017). In a recent study, men with mCRPC reported lacking enough information on how the treatment might affect them and their life situation and also on how to access supportive resources (Jenkins et al., 2019). A majority of the men in the present study received chemotherapy as their first life-prolonging treatment but all types of treatments the men received require regular follow-ups and treatment evaluation, something that is commonly handled by contact nurses at the oncology clinics in the Swedish context. Since nurses are involved in the initiation and administration of life-prolonging treatments, they become important gatherers and providers of information to the patient as well as the rest of the health care team (Mccullough et al., 2018; Buiting et al., 2013; Lamb et al., 2017), as also stated in the Swedish National Guidelines for PC (National Board of Health and Welfare, 2015). Assessment forms have also been developed to assist nurses in evaluating treatments that might cause more harm than good (Nappa et al.,
In this study, we found that the men made a distinction between how they expressed their hopes and their expectations in the current situation. The men expressed hope of e.g. avoiding treatment side effects while they simultaneously expected to experience a certain degree of side effects. The differentiation between the two concepts hopes and expectations is explained by a conceptual model (Leung et al., 2009) where health hopes are described as preference-driven and health expectations as probability-driven. These concepts are also described as being linked, and the distance between them increases the more the probability differs from the desirability of an outcome. The men in the present study described how their previous experiences regarding cancer treatments were influential in their current situation. This is also illustrated in the model through a cyclical movement where experienced outcomes affect the formation of hopes and expectations in new, similar or related situations (Leung et al., 2009).

The results in this study show that the men, while already being in a palliative phase, worried about unmanageable symptoms later in the course of the disease and at the end of life as well as becoming dependent on others. Similar results are shown where especially men in advanced stages described concerns about unmet support needs at the end of life (Paterson et al., 2015). Further, a recent interview study also showed that men with mCRPC commonly worried about feeling like a burden to their families and friends (Burbridge et al., 2020). Along with the fear of unmanageable symptoms, the men in the present study talked about the uncertainty of what the end of life would be like, which is also in line with previous research on how men with mCRPC reason regarding their impending death (Lindqvist et al., 2008b). In the light of the results in this study, a perspicuous and functional regimen for continuity of nursing care seems imperative for men with advanced PC who receive life-prolonging treatments. A continuous contact with a nurse or contact nurse at the oncology clinic throughout the disease trajectory (Mcullough et al., 2010; National Board of Health and Welfare, 2015) provides an opportunity for the patient or nurse to raise issues like these and talk about fears the patient might have. In contexts where the nurse’s role is viewed as a salient part of the health care team around the patient, it is reasonable to believe this gives the nurses a unique position in continuously discussing and evaluating the life-prolonging treatment together with the patient as well as the rest of the cancer care team. It also gives the nurses an opportunity to detect early needs for nursing interventions, such as symptom management, psychosocial or emotional support.

A number of measures have been taken to achieve trustworthiness (Lincoln and Guba, 1985) in this study. To strengthen credibility and reflexivity, analysis was continuously discussed in close collaboration within the research group. The credibility and basis for assessing transferability were strengthened by recruitment from different study sites, variation in participants’ characteristics, the open interview approach, as well as methodological transparency and the use of quotations in the results.

Rather than striving to create a subsample that was representative of the entire group of participants in the main study, we used a purposeful sampling strategy to include a variation in background characteristics among the men in the subsample. Even though the men were mostly older, as men with mCRPC usually are (Collins et al., 2019), we managed to achieve an age range in the sample from 60 to 82 years, meaning that the men were both of working age and retired. Another strength of the study is that different life-prolonging treatments are represented even if a majority of the men received Docetaxel, which until recently served as the standard first-life-prolonging treatment in Sweden. The men in the sample mostly had a high functional level. This may be attributed to the fact that men with lower functional level do not receive life-prolonging treatments to the same extent. It is possible that more participants might have added further perspectives. Also, inclusion of participants who were not fluent in Swedish could have enriched the results. Three out of the 16 interviews were conducted via telephone as this was preferred by these participants. Telephone interviews may be easier for some people and more challenging for others compared to face-to-face interviews. However, the telephone interviews in this study generated rich data.

### 5. Conclusion

When facing life-prolonging treatment of mCRPC, men’s perspectives concern not only the treatment outcome but their entire lives in relation to the treatment. The present study highlights the importance of care continuity and allowing men with mCRPC to communicate their expectations, hopes, fears and previous experiences of cancer treatments when considering life-prolonging treatments in this palliative phase of their disease. Here, nurses have significant professional responsibilities and opportunities.

### CRediT authorship contribution statement

Sandra Doveson: Conceptualization, Investigation, Data curation, Formal analysis, Project administration, Writing - original draft, Writing - review & editing. Maja Holm: Conceptualization, Formal analysis, Writing - review & editing. Lena Axelsson: Formal analysis, Validation, Writing - review & editing, Supervision. Per Fransson: Conceptualization, Validation, Writing - review & editing, Supervision, Funding acquisition. Agneta Wennman-Larsen: Conceptualization, Investigation, Data curation, Formal analysis, Project administration, Writing - review & editing, Supervision, Funding acquisition.

### Declaration of competing interest

None declared.

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