No time for reflection. Patient experiences with treatment-related decision-making in advanced prostate cancer

Abstract:

Aim: This study explored how patients with advanced prostate cancer experience the communication with health professionals and their experiences of how and by whom treatment-related decisions were made.

Background: The rationale of the study was the predominant understanding that patient involvement in treatment-related decision-making is essential and that communication with cancer patients can affect their quality of life, satisfaction with care, and psychosocial and medical outcomes positively.

Methods: A phenomenological-hermeneutic research design was applied, and data was collected using qualitative interviews supplemented with participant observations in a urological outpatient clinic at a regional hospital in Denmark. Thirteen patients participated. Data were analysed using Ricoeur’s theory of interpretation.

Findings: The patients experienced the course as being routine and that decisions related to treatment were made in advance. Three themes were identified: (1) Fast track diagnosing and treatment (2) Off course I should have this treatment (3) They don't ask about existential issues.

Conclusion: The study concluded that patients experienced communication primarily revolved around disease- and treatment-related issues and that it was characterised as efficient, and straightforward, but insufficient. The patients experienced that the doctors made treatment-related decisions without involving them.

Keywords:
Advanced prostate cancer, communication, health care communication, person centred healthcare, patient involvement, treatment-related decision-making, shared decision-making, phenomenology-hermeneutical, interviews.
Introduction

With an estimated incidence of almost 1.3 million worldwide in 2018, prostate cancer is the second most common cancer disease in men (1), and approximately 14% present with advanced prostate cancer (APC, i.e. metastatic disease) (2). Currently, there is no curative treatment for APC. The primary treatment of APC is androgen deprivation with medical or surgical castration. 90% of the patients are treated with androgen deprivation therapy (ADT). In some cases, patients are treated with early initiated (up-front) chemotherapy (3, 4).

The ADT is used to palliate symptoms and to prevent progression of the disease and thereby reduce the risk of serious sequela, e.g. ureteral obstruction, spinal cord compression, and pathological fractures. However, ADT is associated with severe side-effects, including erectile dysfunction, loss of libido, penile volume loss, fatigue, hot flashes, weight gain, osteoporosis, reduced muscle mass, and muscle tones (5, 6).

ADT is also known to cause mood swings, decrements in cognitive functioning, sleep disturbances, anxiety, depression, and low perception of one’s self-body image.
Furthermore, ADT causes significantly increased risks of heart disease, obesity, and diabetes (7).

Chambers et al. found that men with APC experience that their disease and the treatment thereof have a tremendous impact on their quality of life, their relationships, and their ability to do everyday tasks. They state that the effects of the physical changes are essential, and since men especially associate their sexuality and sexual capability with their male identity, changes affecting this play a crucial existential role. Furthermore, they found, that many worry about their future, including their ability to work and their financial situation. They also found that to understand potential long-term effects when choosing a treatment, men need more guidance and support as well as clear information about possible treatment options (8).

Due to the far-reaching side-effects, patient involvement in treatment-related decision-making seems to be essential. In this context, efficient cancer treatment pathways place high demands on health professionals' communication skills, which are fundamental and have considerable influence on patient experience (9). Studies have shown that empathic and effective communication with cancer patients and their family can affect patient quality of life, satisfaction with care, and psychosocial and medical outcomes positively (10, 11). However, as discussed by Baile & Aaron, many have described that verbal and non-verbal exchanges between patients and health professionals are complex (10). Studies have shown that time constraints in busy clinics may leave patients with unmet needs of communication and cause patient dissatisfaction (12).

Accordingly, health professionals’ communication skills are also an essential key to success when it comes to patient involvement and decision-making (10, 11). Since the 1990s, the concept of shared decision-making (SDM) has been a key concept in research related to patient involvement; and based on convincing evidence, the desire for patients to be actively involved in decisions about their care has increasingly been on the political agenda (13). However, it has been found that SDM is rarely accomplished in clinical
practice. Accordingly, Elwyn et al. (2012) published a model as a guide to how to achieve SDM containing three-steps: choice talk, option talk, and decision talk (14).

Studies have shown that most patients with APC do not experience being sufficiently informed nor involved when decisions are made concerning the course of their disease (15, 16). Still, only a few studies have focused on experiences by patients with APC related to communication with health professionals and their experience concerning involvement in treatment-related decision-making.

**Aim**

This study aimed to explore how patients with advanced prostate cancer experience the communication with health professionals as well as to explore their experiences of the decision-making processes during their course of treatment.

**Methods**

**Design**

The study employed a phenomenological-hermeneutic research design. To gain knowledge, broad and open-ended qualitative interviews as described in the phenomenological literature by Kvale and Brinkmann and Fog were used (17, 18). To prepare and qualify the interviews participant observations of the hospital's environment and patient consultations were conducted (19). Data were analysed using Ricoeur’s theory of interpretation (20, 21).

**Participants and setting**

Thirteen men with APC aged between 60-89 participated in the study. Participants were recruited immediately after being referred to the Urological outpatient clinic of Lillebaelt Hospital, Vejle, Denmark with suspicion of prostate cancer. Initially, 27 men were recruited, thirteen of which didn’t have advanced disease and therefore excluded, and one declined for emotional reasons. Of the remaining thirteen, one died before the study ended. Age and characteristics are presented in table 1.
Table 1: Characteristics of the 13 participants

<table>
<thead>
<tr>
<th>Participants</th>
<th>Age</th>
<th>Type(s) of treatment(s)</th>
<th>Number of interviews</th>
<th>Minutes per interview</th>
</tr>
</thead>
<tbody>
<tr>
<td>#1</td>
<td>74</td>
<td>Leuprorelin</td>
<td>3</td>
<td>64, 52, 58</td>
</tr>
<tr>
<td>#2</td>
<td>73</td>
<td>Degarelix, Triptorelin, Docetaxel</td>
<td>3</td>
<td>60, 76, 84</td>
</tr>
<tr>
<td>#3</td>
<td>82</td>
<td>Degarelix</td>
<td>2</td>
<td>66, 33, (died)</td>
</tr>
<tr>
<td>#4</td>
<td>81</td>
<td>Degarelix, Docetaxel</td>
<td>3</td>
<td>53, 78, 72</td>
</tr>
<tr>
<td>#5</td>
<td>89</td>
<td>Leuprorelin</td>
<td>3</td>
<td>51, 86, 60</td>
</tr>
<tr>
<td>#6</td>
<td>83</td>
<td>Degarelix, Leuprorelin</td>
<td>3</td>
<td>46, 47, 24</td>
</tr>
<tr>
<td>#7</td>
<td>81</td>
<td>Degarelix, Docetaxel</td>
<td>3</td>
<td>32, 56, 32</td>
</tr>
<tr>
<td>#8</td>
<td>60</td>
<td>Triptorelin, Degarelix, Orchiectomy</td>
<td>3</td>
<td>104, 37, 72</td>
</tr>
<tr>
<td>#9</td>
<td>85</td>
<td>Triptorelin</td>
<td>3</td>
<td>44, 43, 43</td>
</tr>
<tr>
<td>#10</td>
<td>80</td>
<td>Degarelix, Docetaxel</td>
<td>3</td>
<td>49, 40, 54</td>
</tr>
<tr>
<td>#11</td>
<td>63</td>
<td>Degarelix, Docetaxel</td>
<td>3</td>
<td>27, 72, 34</td>
</tr>
<tr>
<td>#12</td>
<td>67</td>
<td>Degarelix</td>
<td>3</td>
<td>49, 29, 10</td>
</tr>
<tr>
<td>#13</td>
<td>70</td>
<td>Bicalutamid</td>
<td>3</td>
<td>42, 36, 29</td>
</tr>
</tbody>
</table>

Data collection

Using broad and open-ended qualitative interviews (17, 18) and participant observations (19), data was collected from January 2017 to September 2018 in the urological outpatient clinic. To gain knowledge about the participants' experiences of treatment-related decision-making, both in the introductory part and in the subsequent course of treatment, data related to individual participants were collected for up to 13 months. Figure 1 illustrates the course of the study.

Participant interviews were conducted 3 to 19 days after they were diagnosed with APC and initiated with ADT. Next, depending on which type of ADT the participants received, they were interviewed after 1, 3 or 6 months, and again 9 to 12 months later. Twelve participants completed all the way to the end of the study. The participants were asked to describe how they experienced the communication with health professionals as well as their experience of how and by whom the treatment-related decisions regarding their APC were made. The interviews primarily took place in the participants’ homes. However, following the participants' wish, a few interviews took place at the hospital. The interviews were recorded and transcribed verbatim.

Participant observations were conducted during the diagnostic phase and preceding each interview to gain an impression of what is at stake in the consultations and as a basis for
asking specific questions in the qualitative interviews. Inspired by Spradley’s theory (1980), a non-participatory approach was used, i.e. any involvement by the observer was avoided. Field notes were made during the observations and later transcribed for use in the analysis (19).

**Ethical considerations**

The participants received verbal and written information about the purpose of the study from the first author. They were also informed that participating was voluntary, and they could withdraw from the investigation at any time without influencing their treatment. Moreover, they were told that their identity would be anonymised, that collected data would be treated confidential, and that recordings of the interviews would be deleted, when the study was completed. The interviewer was experienced as an interviewer. She did not know the participants before commencement.

The study was approved by the Danish Data Protection Agency (journal number 2008-58-0035), and data kept by applicable rules. Inquiries to the Research Ethics Committee were made, but given the character of the study, obligation of notification was not required.

**Data analysis and interpretation**

Ricoeur’s phenomenological-hermeneutical theory of interpretation was used analysing and interpreting the data (21). According to Ricoeur, interpretation proceeds through three phases, *a naïve reading, structural analysis*, and *comprehensive understanding*. It is through a dialectic process alternating between explanation and understanding and between the surface and in-depth levels of the text, interpretation is achieved (21).

*By the naïve reading*, an immediate interpretation, creating an overall idea of the meaning of the text is achieved. With this, an initial, spontaneous assumption of what the text is generally about is created, which supplements the interviewer’s first-hand impressions when meeting the patients. Hence, the focus of the interpretation is changed from the participants’ opinions, and intentions to what the text is about. By this, new aspects of the
patients’ narrative are unveiled potentially leading to new ways of understanding the narratives (20, 21).

According to Ricoeur, the structural analysis is an essential stage, guiding the investigator between the first naïve reading and the comprehensive understanding (21). Through a more objective semantic analysis, the purpose of this phase is to validate the naïve reading (21). Based on what is said in the interviews and a succeeding interpretation of what the text speaks about, meaning units, i.e., quotations, are extracted from the transcribed interviews. By this, the meaning units are “de-chronologized” from the text, before assembled with other meaning units from which themes and sub-themes are derived. According to Ricoeur, it means a movement from “what the text says” to “what it speaks about” (21).

To gain a deeper understanding, the derived themes are the foundation for the comprehensive understanding including relevant theoretical perspectives on patient involvement and SDM as described by the English researcher Angela Coulter, by the German philosopher Hans-Georg Gadamer’s (1900-2002) theoretical perspectives on treatment and dialogue, and by the Canadian physician Tom A. Hutchinson’s anthology on Whole Person Care. Furthermore, in the discussion other research is included comparatively (13, 20-23).

Findings

Naïve reading

Several themes that seemed meaningful to the patients were revealed in the naïve reading. The patients told about effective, routine courses in which it was mainly doctors who made the treatment-related decisions. The communication between patients and health professionals in the diagnostic phase primarily focused on examinations, tests, test results, diagnosis, and initiating treatment. The health professionals telling about the chosen treatment was predominantly positive and contained only limited information about possible side-effects. The subsequent treatment course primarily focused on providing
treatment and watching the status of the disease. There was rarely focus on how patients experienced living with their changed life situation with a life-threatening disease.

**Structural analysis**

In the *structural analysis*, the themes revealed in the naïve reading are elucidated through the elaboration of the three main themes: (1) *Fast track diagnosing and treatment* (2) *Off course I should have this treatment* (3) *They don’t ask about existential issues*. Table 2 illustrates the structural analysis from interview data to the themes.

### Table 2: Illustration of the structural analysis from interview data to themes

<table>
<thead>
<tr>
<th>What the text says</th>
<th>What the text speaks about</th>
<th>Theme and sub-themes</th>
</tr>
</thead>
</table>
| There was not so much patient attention. That is, too much “running through” without asking “are you with me?” or “anything else you need?” That was missing. Right?! No eye contacts! And it was served in a quite rough way. After I’m called in, they look at the screen, I get an injection, and then I leave. I’m not even there for 5 minutes. That’s all there is to it. | The patients experience the diagnostic phase as being routine, effective, and intense. The diagnosis is given as soon as possible in a straightforward way. The patients experience that during the treatment course consultations focus only on the status of the disease and treatment. | Fast track diagnosing and treatment  
An effective and intense routine course  
A quick follow-up on the status |
| I would say that I have been dictated this treatment. Actually, they didn’t mention anything about other treatments. The doctor said: “The medication can keep it calm. We will go with that for now. You’ll get the injections now, and again in one month. We’ll do that once a month and see if we can switch to a different treatment which lasts for three months.” | The patients experience that doctors make all decisions regarding ADT. Often, the treatment is perceived as being pre-arranged with no consideration of patients’ preferences or needs and without the patients having an opportunity to influence the course. The patients are not presented with alternative treatment options than the chosen ADT nor that the choice not to undergo treatment is an option. | Off course I should have this treatment  
Doctors independently decide regarding ADT throughout the course  
Treatment with ADT is prearranged |
| Usually, it’s about how I am. But, last time, the doctor didn’t really need to ask because looking at the number [PSA level], she could see that I should be fine. At least physically, right?! Well, mentally that’s something completely different. They ask: “How is it going?”?, “How much do you weigh”?”, “Do you have any symptoms?” and so forth. But they don’t ask about mental health and things like that. No, they don’t give a shit. They don’t care what the Cardiac Unit has done to me, and don’t ask about that either. They’re only interested in their own area. To hell with it! | The patients experience that health professionals mainly focus on disease and treatment-related issues. Almost no health professional show interest in patients’ feelings or existential issues. Hence, patients had unmet needs and dissatisfaction. | They don’t ask about existential issues  
Focus on disease and treatment  
No interest in feelings or existential issues  
Unmet needs |

**Fast track diagnosing and treatment**

This theme is related to the patients’ experiences of communicating with the health professionals during their course in the clinic ranging from the diagnostic phase with initiating of treatment to the subsequent course of treatment. Common to all patients was their experience of the diagnostic phase as being an effective and quite intense period as well as their experience of the overall course as being routine as if it was a part of a pre-arranged patient-course. One patient described it as “a small factory that has some routines you must go through.”
The patients experienced that the diagnosis was given as soon as possible and in a rather straightforward way. Thus, almost half of the patients were diagnosed with APC at their very first appointment in the clinic, and some were informed of their diagnosis already while lying on the examination couch and the doctor examined their prostate. Observations showed that these patients got injected with ADT with the associated risk for severe side-effects on the same day. Though, being informed about a few of the possible side-effects prior to being injected, the patients did not experience being involved in this decision. Others were informed that they most likely did have prostate cancer and waited one or two weeks until relevant test results were available before they received the treatment. Despite the patients’ experience of a very fast and for some overwhelming course, most were happy about the process. Some patients stated their satisfaction with the doctors’ straight communication:

They don’t sugar-coat anything. But, I'm fine with that! Getting a clear message, cause it's worse not knowing.

Others felt that the doctor had passed the message without any compassion and in a non-empathetic way as if it had been a rather unimportant standard message. Few felt somewhat offended by this approach. A patient expressed:

There wasn’t so much patient attention. That is, too much "running through" without asking "are you with me?" or "any questions?" That was missing. No eye contact! And it was served in quite a rough way.

Notably, during the first consultations, the patients experienced that the doctors spoke very quickly. Loads of standardised information about treatment, possible side-effects, and the following course of treatment most often was given within a few minutes, and in some cases, in just one or two long sentences. One patient said:

It was a bit like machine-talk! She's said it a thousand times. She knows exactly how it goes.
Some patients appreciated the effectiveness of this practice whereas others indicated that it was difficult to follow and that they didn’t understand all of it. Though, common to the patients was the experience that the effective design of the consultations and the massive flow of information usually left them with no time for reflection.

While the diagnostic phase focused on finding the exact diagnosis and starting-up treatment, the patients experienced that the following consultations mostly focused on the status of the disease and the treatment, which mainly meant keeping an eye on the PSA level, injecting the ADT as planned, and when needed making decisions regarding side-effects. A patient told:

    After I’m called in, they look at the screen, I get an injection, and then I leave. I'm not even there for 5 minutes. That's all there is to it.

The patients experienced that the doctors along with the news about their serious diagnosis presented the chosen treatment to them and often at the same time reassuring them not to worry cause “we can and will help you”. Using positive phrases like “the very best”, “calming the disease”, “keeps the disease from progressing”, the health professionals described ADT as being a very efficient therapy. Bearing this in mind, a patient with a very high PSA level and widespread bone metastases said:

    Then it sounds like it's not all that bad. There are several who have this [disease]. As far as I understand, they slow it down, so it doesn’t spread.

Thus, several patients found comfort in the positive assertions and because of this, some felt that it might be, that they were incurably ill but given the efficient ADT, perhaps it wasn’t that bad after all. Others felt that the health professionals by talking so positively neglected the fact that they were incurably ill.

Despite getting a large amount of information, several patients experienced that they had not received all relevant information such as how the ADT works, possible side-effects of the ADT and chemotherapy, or all test results. Though, wondering why, most patients,
owing to their general trust in the doctors, stated that it did not make them feel unsafe. However, a few patients who experienced unknown side-effects felt differently. One patient told about the emotional storm he suffered because of insufficient information about possible side-effects:

I had some severe stomach aches and it really hurt! 24 hours a day, I was in pain, slept badly, and couldn't eat anything. I was so nervous that my cancer perhaps had spread to my stomach. I was scared shitless!

Off course I should have this treatment

This theme refers to the patients' experiences of how the treatment-related decisions were made during their course of treatment. Common to all patients was their experience when receiving the diagnosis that the doctors independently decided which ADT to administer. Moreover, most often the decisions were made without any consideration to the patients’ preferences or needs. Hence, the patients received a specific type of ADT without being involved in the various kinds of treatment; nor were they informed that the choice not to undergo treatment was an option. The doctor usually just asked the patient if he “accepted it.” A patient who experienced this course of action elaborated:

I would say that I have been dictated this treatment. Actually, they didn't mention anything about other treatments.

To most patients, it seemed as if their course of treatment was planned before they entered the door, and sometimes even before they had met the doctor. And though they experienced doctors asking for their acceptance, the patients didn’t "really" feel that it was up to them to make treatment-related decisions. A patient said:

The doctor said: "The medication can keep it calm. We will go with that for now. You'll get the injections now, and again in one month. We'll do that once a month and see if we can switch to a different treatment which lasts for three months.”

The patients also experienced that it was the doctor who decided whether to switch to another type of ADT. Some patients knew why the doctor had decided to switch, namely increased PSA levels, or if a patient experienced some unexpected side-effects like severe stomach pain, but most didn’t know. With a few exceptions, patients did not try to
influence the doctors' decisions related to ADT, and those who did, experienced that the doctor declined their requests. A patient said:

A friend of mine gets injections every six months. I would have liked that as well and then get rid of all that bloody running around! I told the doctor, but I had to continue with the same dose once a month.

While the patients didn’t experience being involved when decisions were made related to ADT, some patients to a greater extent felt that it was their choice to make when they were involved in decision-making about treatment for side-effects and chemotherapy. It was not in the same way experienced as if it was a matter of course. Hence, primarily based on the doctors’ positive view on the ADT, a few patients declined when offered early initiation of chemotherapy.

Regardless, with only a few exceptions, the patients did not feel like they "really" had a choice but to accept treatment. Partly, because they were incurably ill, and getting treatment offered hope for a future. Partly, because the doctors had offered or even recommended ADT or chemotherapy which they thought they wouldn’t if it had been meaningless. A patient stated that “I have no choice but to trust them. But why shouldn't I?” Besides, some patients did not see it as a real offer, but as something, they had to get. A patient told:

Of course, I needed treatment. I wouldn’t accomplish anything by questioning him and then destroying it for myself. That would be stupid! So, no matter what it takes and how long it lasts, I'm interested in getting as much out of my life as possible.

Like this patient, most patients expressed their trust in the doctors whom they considered to be experts and capable of making the right decisions. Though, after having received ADT for a period, some patients began questioning if there had been other relevant options in their situation.

They don't ask about existential issues
Throughout the diagnostic phase and the subsequent course of treatment, the patients experienced that health professionals mainly focused on disease and treatment-related
issues. According to the patients, almost no health professional showed any interest in knowing about their feelings about being seriously ill, nor did they ask about their existential issues. Whenever health professionals asked how they were, all patients perceived that they only asked for their physical condition:

Usually, it's about how I am. But, last time, the doctor didn't really need to ask because looking at the number [PSA level], she could see that I should be fine. At least physically, right. Well, mentally that's something completely different.

Observations showed that health professionals often acknowledged to the patients that it was difficult to receive such a serious diagnosis. Hence, they sometimes informed about the importance of talking to someone about their situation. Despite this, patients experienced that health professionals during the consultations did not invite them to talk about issues related to getting seriously ill. Nor did they experience the health professionals taking an interest in any existential issues about the patients living with an incurable disease. A patient said:

It’s strange, really, that they don't ask how I feel. They only ask how you are doing.

Although the health professionals recognised the importance for patients to talk about these issues, observations showed, that they left the responsibility for this to others. Thus, they recommended that patients spoke with family members or to someone at the Cancer Counselling.

Most patients found this acceptable, but others expressed a need for more than just “the standard” care, and few patients stated that they were unhappy with the health professionals’ narrow focus. One patient firmly expressed his dissatisfaction:

They ask: "How is it going?", "How much do you weigh?", "Do you have any symptoms?" and so forth. But they don't ask about mental health and things like that. No, they don't give a shit. They don't care what the Cardiac Unit has done to me, and don’t ask about that either. They're only interested in their own area. To hell with it!
Discussion – a comprehensive understanding

Whole person care

The interviews showed that many patients experienced that the health professional didn’t show interest in the patients’ feelings about being seriously ill or in their existential issues.

According to Coulter (2011), factors as health professionals’ attentiveness to patients’ physical, emotional, and social needs, as well as taking their values and preferences into account when making clinical decisions, are core values in patient-centred care. It is considered essential that health professionals have a patient-centred approach, partly because patients want it, and partly because their experiences can influence the effectiveness of treatment and health outcomes (13).

Based on these perspectives, it is obvious that patients were not met with patient-centred care. However, due to the severity of their disease, it would most likely not impact the patients’ treatment and health outcomes.

The interviews indicated that the busy consultations, particularly in the diagnosis phase, were characterised by the short time allocated in which patients received a large amount of information. In most cases it left no room for patients' reflections or a genuine dialogue between the patient and the health professionals. It was difficult for some patients to comprehend the amount of information.

According to Gadamer (22), the dialogue must be seen as an important part of the treatment itself and not just as an introduction or preparation for it. To determine a patient’s diagnosis for certain, it is not enough to examine the body functions, it requires the doctor’s attention to the patient's condition and their story as a whole. Moreover, to sense and respond appropriately to a patient’s needs requires suitable attentiveness as well as dialogue with and involvement of the patient (22). Based on this, it is problematic when patients do not understand the information they receive about ADT as they may miss out on an essential part of treatment. Likewise, it is just as problematic when doctors do not understand the patients.
We found that health professionals generally had a narrow focus on issues related to disease and treatment. Similarly, Hack et al. (2012) found in their study of consultations in prostate oncology, that communication primarily was characterised by biomedical information giving to patients and that only little attention was paid to psychosocial issues (24). Concordantly, a systematic review showed that men with prostate cancer experienced poor communication with health professionals and having unmet needs for emotional support and information (25).

Hutchinson (2011) distinguishes between the concepts of "cure", which is about treating and curing disease and "healing", which has a broader and more holistic approach, including focusing on the patients’ wellbeing in general. Hutchinson suggests that the approach should be combined whereby patients will be met with “whole person care” instead of a narrow biomedical approach (23). This requires health professionals to be more aware of psycho-social and existential needs than in this case. Our study showed that the patients did not experience being met by "whole person care". However, such an approach would seem to have difficult conditions in this clinic characterised by short and busy consultations due to an overwhelming patient-flow.

**Treatment-related decision-making**

The interviews showed that the patients experienced that doctors independently made the decisions concerning the ADT without asking about patients’ preferences or needs. Likewise, Christoffersen et al. (2018) found that most patients with breast cancer experienced not having a choice regarding treatment-related decisions and that they merely gave their consent to a course of treatment organized by health professionals (26).

Coulter (2011) describes SDM as a process in which patients and professionals as partners decide on acceptable treatment, talk about prioritisations and goals, as well as make plans for and implement the preferred plan of action. SDM presupposes that patients are provided with evidence-based information about treatment options, outcomes, and uncertainties (13). Our study showed, that doctors informed the patients very quickly and
straightforwardly about diagnosis and that they predominantly emphasised positive stories about ADT before initiating the treatment within minutes. Most patients appreciated this approach, but some found it difficult to understand the received information. Concordantly, several studies have found that most cancer patients prefer doctors to deliver bad news about cancer diagnosis and treatment in a clear and honest way and just as important, that the patients fully understand the given information (27).

Based on the above experiences and perspectives, the patients did not participate in an SDM process; it would have required doctors to give patients the opportunity to play a greater role in organising their course. However, the interviews showed that the patients did not request this either. On the contrary, most patients trusted the doctors and were satisfied that they made the decisions. According to a systematic review, patients actually assume it is expected that they remain passive and leave decision-making to the doctors, and furthermore that patients often underestimate their expertise compared with doctors’ and thus do not believe their knowledge is of value to the decision-making process (28). However, some patients in our study, experiencing having unmet needs because of the narrow focus on treatment-related issues, requested to be seen as a whole human being.

**Methodological considerations - strengths and limitations**

This study was carried out by interviewing 13 patients with APC, in total 38 interviews were conducted. Averagely, the interviews lasted 51 minutes, which corresponds to 22 pages of transcription, i.e. 836 pages in total. Moreover, 89 participant observations were conducted, comprising 47 consultations with the included patients. This can be said to be a large foundation for a qualitative study. Some may argue that the amount is too large to achieve thorough analyses. However, performing repetitive interviews was of great value to achieve nuanced knowledge of the participants' experiences. Since no new themes emerged in the last interviews, we find it reasonable to assume that data saturation was achieved (17).

Furthermore, choosing method triangulation using both interviews and participant observation strengthens the study (29).
We believe that by using Ricoeur's theory of interpretation (20, 21) and with great effort, we have achieved a comprehensive understanding of the themes. However, from a phenomenological hermeneutic perspective, our interpretations cannot be seen as the only possible interpretations (21).

Using method triangulation and the transparent description of analysis and interpretation contributed to the trustworthiness of the study. For the sake of study reliability, the interviewer strived to ask clarifying questions during the interviews. Likewise, the dialectic process through the analysis and interpretation and the consequent consistency systematisation of data contributed to reliability (17).

Health professionals might have other views than patients, which are not taken in to account in this article, nor are organisational factors that may have an impact on the issues discussed.

**Conclusion and implication for practice**

The patients with advanced prostate cancer experienced that health professionals predominantly focused on disease- and treatment-related issues. The doctors quickly, and straightforwardly, informed them about diagnosis and ADT. Some patients appreciated this practice, but for half of the patients, it was difficult to follow and understand. The patients experienced the course as being routine and that decisions related to treatment were made in advance. The health professionals mainly emphasised the positive effect and expectation for the chosen treatment, and the patients felt they didn't have any choice but to receive ADT.

The patients experienced time-limited and routine consultations characterised by insufficient information and by lack of dialogue, of interest in their existential issues, and room for reflections, which could lead to frustrations, emotional distress, and unmet needs. Conclusively, the patients experienced that the doctors made the treatment-related decisions without involving them sufficiently.
The findings of this study can by exemplifying patients' experiences contribute knowledge that health professionals can use as a basis to support and encourage patients to participate more actively when making treatment-related decisions and thereby achieve a more person-centred approach in the treatment of patients with advanced prostate cancer.

Acknowledgements

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Author contributions

The first and last author were responsible for designing the study. The first author collected data. All authors were responsible for the analysis and interpretation of data, for drafting the manuscript, and for critical revision of the manuscript.

(i) References:


5 American Cancer Society. What is Prostate Cancer? 2016


12 Hack TF, Degner LF, Parker PA, Team SC. The communication goals and needs of cancer patients: a review. Psychooncology 2005; 14: 831-45.


17 Kvale S, Brinkmann S. Interview: det kvalitative forskningsinterview som håndværk [Interview: The qualitative research interview as craft]. 3rd edn. 2015, Hans Reitzels Forlag, Copenhagen, Denmark.


