

Supportive care needs of men with prostate cancer after hospital discharge: multi-stakeholder perspectives

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ABSTRACT

Purpose: This study explored the supportive care needs of men with prostate cancer (PCa) after hospital discharge based on the perceptions of multiple stakeholders.

Methods: Eight semi-structured focus groups and three individual interviews were conducted between September 2019 and January 2020, with 34 participants representing men with PCa, primary and secondary healthcare professionals, and cancer organizations in western Norway. Data was analysed using systematic text condensation.

Results: Four categories emerged: 1) men with PCa have many information needs which should be optimally provided throughout the cancer care process; 2) various coordination efforts among stakeholders are needed to support men with PCa during follow-up; 3) supportive care resources supplement the healthcare services but knowledge about them is random; and 4) structured healthcare processes are needed to improve the services offered to men with PCa. Variations were described regarding priority, optimal mode and timeliness of supportive care needs, while alignment was concerned with establishing structures within and between stakeholders to improve patient care and coordination.

Conclusions: Despite alignment among stakeholders' regarding the necessity for standardization of information and coordination practices, the mixed prioritization of supportive care needs of men with PCa indicate the need for additional individualized and adapted measures.

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Introduction

An estimated 1.3 million men worldwide were diagnosed with prostate cancer (PCa) in 2018, making it the second most common cancer in men (Bray et al., 2018). There is a wide international variation in prevalence of PCa due to differences in diagnostic methods, treatment, lifestyle, social, and genetic factors (Center et al., 2012). Due to the prevalence and high survival rates of PCa, and the long-lasting side effects of treatment, many of these men need consistent follow-up supportive care post-hospitalization (Appleton et al., 2015) though shortcomings in follow-up care have been reported (O'Brien et al., 2010).

Supportive care is a person-centred provision of services throughout the cancer care process (Hui, 2014). Being holistic, individualized, respectful, and empowering are attributes of supportive care (Ekman et al., 2011; Morgan & Yoder, 2012; Zhao et al., 2016). Patients' supportive care needs are defined as "informational, emotional, spiritual, social, or physical needs during their diagnostic, treatment, or follow up phases" (Hui, 2014, p. 378).

Several studies have explored the supportive care needs of men with PCa from a patient perspective. A study across seven European countries found that 81% of the men with PCa had unmet psychological, sexual, health system and information needs (Cockle-Hearne et al., 2013). Two systematic reviews also highlighted the importance of management of treatment side effects and other physical needs (King et al., 2015; Paterson et al., 2015).

In a study of urologists, primary and secondary healthcare nurses, nurse coordinators and research coordinators, Carter et al. (2014) identified four areas of supportive care needs for men with advanced PCa: information, pain and symptom management, emotional support, and practical assistance. Blomberg et al. (2016) found that the perceptions of men with PCa undergoing radiotherapy were well aligned with those of urologists, oncologists, urology nurses, oncology nurses, and medical social workers on some side effects of treatment.

Support groups, peer workers or peer navigators, helplines, patient organizations and associations, and rehabilitation centres complement the healthcare system to meet the supportive care needs of men along

the PCa care process and are often voluntary in nature (Jones & Pietila, 2020). A qualitative systematic review showed that one-to-one peer support or local support groups are important to men with PCa in offering information and emotional sharing (King et al., 2015). In addition to their empowering and supportive role, peer support workers advocate for men with PCa by increasing awareness of PCa among healthcare professionals (Jones & Pietila, 2020). However, there is no systematic referral of men with PCa to these support groups (Maharaj et al., 2018) and provision of information about supportive care services is either lacking (Carter et al., 2011) or rare (Kam et al., 2012). Another study showed that referral from healthcare professionals motivates patients to use peer support groups as a complement to medical care (Maharaj et al., 2018).

In summary, the supportive care needs of men with PCa from a patient perspective is well documented, but fewer studies have sought the perspectives of healthcare professionals and cancer organizations. With few exceptions (Blomberg et al., 2016; Carter et al., 2010, 2011, 2014), no studies have explored supportive care needs from a multi-stakeholder perspective. To our knowledge, ours is the first study to explore the perceptions of supportive care needs among men with PCa, primary and secondary healthcare professionals, and cancer organizations, regardless of treatment and follow-up stage.

The aim of the study was to explore the supportive care needs of men with PCa after hospital discharge based on the perceptions of multiple stakeholders. The following research question has guided the study: How can the perceptions of supportive care needs for men with PCa after hospital discharge be described across patients, primary and secondary healthcare professionals, and cancer organizations?

Method

Design

This study used a descriptive qualitative research design (Polit & Beck, 2018) with focus group interviews as the primary data collection method supplemented by a few individual interviews when focus group interviews could not be formed for practical reasons. Focus group interviews were chosen as they offer rich understanding of participants experiences and beliefs (Morgan, 1997) and facilitate interaction and memory recall among participants (Krueger & Casey, 2014). Our study was reported according the COREQ (COnsolidated criteria for REporting Qualitative studies) checklist (Tong et al., 2007) (Supplement 1).

Setting

The Norwegian healthcare is publicly funded and run. A Regular General Practitioner Scheme was implemented in 2001, and more than 99% of the population are contracted to a general practitioner (GP). A referral from a GP is mandatory for service in secondary healthcare and hospitalization is free. If PCa is suspected, the GP refers the patient to the hospital for further evaluation. If the suspicion is confirmed, the patient enters the PCa clinical pathway, which consists of all the clinical processes, allocation of responsibility and management of PCa from diagnosis, to treatment, follow-up care and control (Norwegian Directorate of Health, 2015a, 2015b).

After treatment at the hospital, men with PCa are reassigned to primary healthcare for follow-up by the GP with regular control according to disease stage and treatment described by hospital urologists. If the patient has problems after hospital discharge, he is expected to contact his GP. Primary healthcare in the municipalities may also include primary care cancer coordinators. Secondary healthcare includes somatic hospitals, outpatient clinics, centres for physical training, and rehabilitation and is the responsibility of the four regional health authorities (Norwegian Directorate of Health, 2012). At six weeks and then one year after surgical treatment for PCa, the patient should present for a consultation at the urology outpatient clinic.

Sample and recruitment

A purposive sampling strategy was used to select stakeholders that were especially knowledgeable about or experienced with the supportive care needs of men with PCa after hospital discharge (Patton, 2015).

Recruitment was based on the following inclusion criteria: Men diagnosed, treated and discharged from hospital with PCa regardless of disease stage and treatment modality, healthcare professionals from primary (GPs and cancer coordinators) and secondary (urologists, urology nurses, urology outpatient clinic nurses, urology pathway coordinator, physiotherapist and clinical nutritionist) healthcare with experience in treating and supporting patients with PCa in western Norway, and representatives from Norway's three major cancer organizations. Those who could not participate in the interviews due to insufficient proficiency in the Norwegian language or reduced cognitive capacity were excluded.

Men with PCa were recruited through user representatives of the patient cancer organization; secondary healthcare professionals (urologists, urology nurses, urology outpatient clinic nurses, urology pathway coordinator, physiotherapist and clinical

nutritionist) were recruited through their departmental leaders; representatives of cancer organizations and primary care cancer coordinators were recruited through their organization. For GPs, a call for recruitment was made through a digital newsletter to regional GPs.

Eight focus group interviews with 31 participants were conducted: Three focus group interviews with men with PCa (n = 14), one with urologists (n = 5), one with nurses (n = 5) from department of urology, from the urology outpatient clinic and the urology pathway coordinator, one with GPs (n = 3), one with physiotherapist and clinical nutritionist (n = 2) and one with primary care cancer coordinators (n = 2). During the focus group interview with urologists, two participants were unexpectedly called away in the middle of the interview. No other dropout or withdrawals took place. Three interviews with representatives from three cancer organizations were decided for mobility issues. For a detailed description of participants, see [Table I](#).

Data collection

Data was collected between September 2019 and January 2020. The interviews lasted from 45 to 90 minutes. The eight focus group interviews adopted a broad-involvement approach (Krueger & Casey 2015). An experienced focus group

moderator, who was a native Norwegian with knowledge of PCa (SEH) conducted the first six focus group interviews with patients (n = 3), urologists (n = 1), nurses (n = 1) and GPs (n = 1) with the first author (FTK) as assistant moderator. FTK moderated the remaining two focus group interviews with primary care cancer coordinators (n = 1) and with physiotherapists/nutritionists (n = 1) and conducted the three individual interviews with representatives of the cancer organizations. An assistant note taker attended six focus group interviews. One moderator (FTK) had met two of the cancer organizations representatives, the physiotherapist, and the clinical nutritionist when volunteering with one of the cancer organizations but her volunteer services had ceased prior to this study.

The focus group interviews and individual interviews were conducted at the most convenient place for each participant group or individual. For patients it was at the office of a cancer organization; for health-care professionals it was their hospital or GP clinic; and for representatives of cancer organizations it was their workplace or their home. For practical reasons the focus group interviews with primary care cancer coordinators, the physiotherapists, and clinical nutritionists took place at the headquarters of the cancer organization.

All interviews were semi-structured and conducted according to an interview guide, which was developed by the first author based on previous research and to the aims of the study. It included discussions with co-authors (SEH and SRK) and user representatives (patients, partner, physiotherapist, cancer organization, and GP). The user representatives' advisory role was to strengthen the relevance of the interview guides; they did not participate in data collection. The interview guide included both open-ended and facilitating questions. It was organized around six main themes with belonging questions and were adapted to each stakeholder group ([Table II](#)).

Data analysis

The raw data material included digital audio files of focus group interviews and individual interviews, notes taken during the focus group interviews and discussion notes after the interviews between moderators and assistant note takers. All interview audio files were transcribed verbatim by two ethnic Norwegian transcriptionists. Both transcribers anonymized data by assigning a code number for each participant and by removing local dialect. Prior to the analysis, the first author checked the verbatim transcriptions for errors and inconsistencies. Any errors or inconsistencies found were discussed with the transcriber. If no agreement was reached, a second researcher was asked to listen.

Table I. Participant characteristics (N = 34).

Characteristics	Number of participants
Gender	
Male	22
Female	12
Age	
20–39	7
40–59	11
60–79	14
n/a	2
Men with PCa	
PCa Stage	
Local	8
Advanced	6
Treatment type	
Surgery	5
Surgery with adjuvant* therapy	5
Hormone & radiation	4
Year of PCa diagnosis	
2000–2009	1
2010–2015	4
2016–2019	6
n/a	3
Healthcare Professionals	
Urologist	5
Urology nurse	3
Urology outpatient clinic nurse	1
Urology pathway coordinator	1
Clinical nutritionist	1
Physiotherapist	1
Primary care cancer coordinator/Oncology nurse	2
General practitioner	3
Cancer organization representatives	3

* radiation and/or hormone

Table II. Main themes of the interview guides.

Theme	Questions
Hospital discharge and follow up practices	<ul style="list-style-type: none"> • What do you remember when you were discharged from hospital after surgery or after the first treatment at the urology outpatient clinic and the time after that? a • What is your experience with hospital discharge and follow up practices when it comes to patients with PCa? b, c, e
Hospital discharge quality	<ul style="list-style-type: none"> • What was particularly positive about the hospital discharge? f • What do you think is missing during hospital discharge? f • Was there anything challenging or problematic during hospital discharge? f
Patient preparedness after hospital discharge	<ul style="list-style-type: none"> • In what way were patients with PCa prepared to deal with their illness and its consequences after discharged from the urology department/outpatient clinic? a, d
Supportive care offers during follow-up care	<ul style="list-style-type: none"> • What other resources (such as patient organizations and/or patient services, cancer coordinators or psychologists) were/do you recommend/d if you/patients encounter problems after discharge? a, b, c, e • How does the organization prepare/support patients with PCa so that they can best deal with illness and the consequences that may arise after discharge from the urology department/outpatient clinic? d
Coordination between services	<ul style="list-style-type: none"> • How are patients with PCa referred to you before they are discharged from the hospital? Are there any routines? d, e • How can communication and collaboration between you and the hospital or urology outpatient clinic be improved? b, d • What experiences does the organization have with collaborating with the hospital? d
Quality improvement	<ul style="list-style-type: none"> • Is there anything you think can help improve discharge from hospital or urology outpatient clinic? a, d • Do you have any recommendations for how the discharge process for patients with PCa can be quality assured? c, e • Do you have any recommendations on what information and interventions should be included at discharge? b, e

a- Men with PCa, b- Primary healthcare professionals, c- Secondary healthcare professionals (urologists, nurses, urology pathway coordinator), d- Cancer organizations, e- Physiotherapists & clinical nutritionists, f- All stakeholder groups

Systematic text condensation was used as the data analysis method, because as a pragmatic phenomenological approach focusing on describing the perceptions of participants per se rather than finding underlying meanings, it was well aligned with the aim of this study (Malterud, 2012).

The analysis process consisted of first grouping the transcripts according to four stakeholder groups: men with PCa, primary healthcare professionals, secondary

healthcare professionals, and cancer organizations. For each of the four groups a within-group analysis with the following stages were conducted: 1) reading of the transcribed interviews to get an impression of the material content and identify five to eight preliminary themes (chaos to themes); 2) developing code groups based on the preliminary themes and identifying meaning units related to each code group (themes to codes); 3) finding subgroups for the code groups and condensing the subgroup content into a summary description with a “golden citation” as an example (code to meaning).

All co-authors participated in identifying and agreeing on the preliminary themes during stage 1. Stages 2 and 3 were an iterative and negotiated process among FTK, SEH and KA. An across-group analysis to find variations in perspectives across the four stakeholder groups was done for stage 4 where the content of the code groups was synthesized (condensation to descriptions and concepts). Data coding, synthesis and across case comparison during stage 4 were performed by the first author with input from all co-authors. An excerpt of the analysis process for stages 1–3 can be found in Table III and for stage 4 in Table IV.

User involvement

User involvement was essential to this research study. Our six user representatives had an advisory and consultancy role to strengthen its relevance to men with PCa (Greenhalgh et al., 2010). We included men with PCa, partners, physiotherapists, GPs, and cancer organizations as user representatives. Prior to the data collection three meetings with the user representatives were organized. During those meetings they checked the relevancy of the interview guides. With their input the guides were revised to include specific questions relevant for each stakeholder group. For example, questions related to sexual health and pelvic floor exercises were added (patients and physiotherapist interview guide respectively).

Ethical considerations

The study was approved by the Norwegian Centre for Research Data (No. 949368 on 14.5.2019) and by the hospital’s research department (12/2019 on 24.04.2019). For primary healthcare professionals, approval was obtained from their immediate employers. All participants were informed about the project both in writing and verbally and signed a written consent before the interviews took place. Voluntary participation, anonymity, and confidentiality were ensured and the right to withdraw at any time from the study without consequences, especially for men with PCa was repeated before the interviews started.

Table III. Example of within-group analysis process (Stages 1–3) using STC.

Preliminary theme	Code group	Subgroups	Condensate	Citation
Information needs	Patients' information needs vary throughout the cancer care process	<ol style="list-style-type: none"> 1. Practical things 2. Side effects of treatment 3. Do not remember what the doctor said 4. Optimal provision of information 5. Social support, training and other needs 	I would like to be prepared to handle practical stuff that come afterwards, for example, issues with pain, treatment of wounds and everything related to the catheter. It is also important for me to know the services and rights I have as a patient with regards to driving a car and the use of public transportation or taxi.	"one was to some extent prepared that there would be pain and such, and the practical issues" (<i>Patient:129–130</i>)

Table IV. Example of across-group analysis process (Stage 4) using STC.

Secondary healthcare		Primary healthcare		Cancer Organizations		Men with PCa	
Code group	Subgroups	Code group	Subgroups	Code group	Subgroups	Code group	Subgroups
Patients' information needs vary throughout the cancer care process	<ol style="list-style-type: none"> 1. Provision of information 2. Treatment, complications side effects and their management 3. Managing everyday life, physical activity and relationships 	Patients' information needs vary throughout the post-discharge follow-up care process	<ol style="list-style-type: none"> 1. Physical, psychological and other needs 2. Optimal provision of information 	Patients' information needs vary throughout the cancer care process	<ol style="list-style-type: none"> 1. Sexual help 2. Psychosocial and other needs 3. Repetition of information 4. Optimal provision of information 	Patients' information needs vary throughout the cancer care process	<ol style="list-style-type: none"> 1. Practical things 2. Side effects of treatment 3. Do not remember what the doctor said 4. Optimal provision of information 5. Social support, training and other needs

Results

The analysis identified four categories that were central to stakeholders' perceptions of the supportive care needs of men with PCa after hospital discharge: 1) men with PCa have many information needs which should be optimally provided throughout the cancer care process; 2) various coordination efforts among stakeholders are needed to support men with PCa during follow-up; 3) supportive care resources supplement the healthcare services but knowledge about them is random; and 4) structured healthcare processes are needed to improve the services offered to men with PCa. In the following section, the content of the categories is described with quotations from the participants.

Men with PCa have many information needs which should be optimally provided throughout the cancer care process

All stakeholder groups expressed that patients with PCa need a great deal of information throughout the cancer care process and that there should be optimal communication of this information. However, stakeholder groups somewhat varied in their perspectives

of the content of the information, the quantity, mode, timing, and the need for repetition.

Stakeholders described patients' **information needs in several domains**: practical after treatment, treatment outcomes and follow-up processes, side effects of treatment, sexuality, psychosocial support, and activities of daily life.

Often, they [patients] have an extensive information need after surgery and before they go home, what will happen next, how they will handle having a catheter and how to manage in the period following surgery. (Urology nurse: 11-13)

All stakeholder groups with the exception of GPs were aligned to patients' need for information about treatment side effects, especially to incontinence, declines in sexual function and sexual help. However, there was variation between stakeholder groups about who assumes responsibility and whether information about sexual help should be systematically provided whether requested or not. The patient education course "Living with prostate cancer" offered by the secondary healthcare provider Learning and Mastery Centre, was described as important by all stakeholder groups except for primary healthcare professionals. [Table V](#) gives a detailed description of the information contents by stakeholder group.

Table V. Information contents by stakeholder group.

Information content	SG ^a		SG ^b			SG ^c			SG ^d
	Pat ¹	GP ²	CaC ³	UR ⁴	NU ⁵	PthC ⁶	CN ⁷	PH ⁸	CaO ⁹
Information content									
Practical after-treatment									
Catheter management	x	x		x	x				
Wound management	x			x	x				
Pain management	x								x
Medication management	x	x	x	x					x
Incontinence management	x	x		x					x
Transportation issues and rights	x								x
Treatment outcomes and follow-up processes									
Surgery outcomes	x			x	x				
Histology results	x			x	x				
PSA results	x			x		x			
Follow-up processes	x			x		x		x	x
Treatment side effects									
Urinary incontinence	x	x	x	x	x				x
Bowel incontinence	x						x		
Sleep	x								
Fatigue	x	x					x	x	
Weight loss							x		
Lymphoedema and general swelling	x		x	x	x	x			
Erectile dysfunction and impotence	x	x	x	x	x	x			x
Sexuality									
Sexual help	x	x	x	x	x	x			x
Masculinity and identity	x		x						x
Psychosocial support									
Psychological support	x	x	x			x	x		x
Social support	x						x	x	x
Patient education course*	x			x	x	x	x	x	x
Cancer organizations	x			x	x		x		x
Primary care cancer coordinator			x						x
Daily life									
Daily physical activity	x				x			x	x
Exercise (training and PFE**)	x			x	x	x		x	x
Work		x	x	x				x	
Nutrition	x						x	x	x

Stakeholder group (SG): ^a Men with PCa, ^b Primary healthcare professionals, ^c Secondary healthcare professionals, ^d Cancer organizations

¹ Men with PCa, ² General practitioner, ³ Primary care cancer coordinator, ⁴ Urologist, ⁵ Nurse, ⁶ Urology pathway coordinator, ⁷ Clinical nutritionist, ⁸ Physiotherapist, ⁹ Cancer organizations

* Patient education course "Living with prostate cancer"

** Pelvic floor exercise

All stakeholder groups expressed that patients need to receive information in an optimal way, however mixed opinions emerged in the particulars of information provision in terms of quantity, mode, timing, and repetition.

Hospital nurses perceived that a sufficient **quantity of information** was being provided to the patient group. The urology outpatient clinic nurse stated that "they are the best-informed patient group in which nobody receives that many consultations pre- and post-surgery". However, for all other stakeholder groups the information patients received was either insufficient (patients, cancer organizations) or excessive (patients, primary care cancer coordinators, clinical nutritionists). Patients expressed a desire for balance.

It is a balancing act, how much they [healthcare professionals] should inform about the consequences, because at the same time they neither want to make us [patients] insecure nor convey the feeling that all this can happen. (Patient: 879-880)

Stakeholder groups expressed that patients need to receive **information in an optimal way** with concrete, detailed and specific written information about

treatment, practical issues, side effects and follow up from the beginning of the cancer treatment process because patients often misunderstand and forget what they are told. As the physiotherapist stated, "in any case there should be written information so that patients can go back to it". Although patients expressed their ability to locate information online, they preferred "one to one personal communication" with healthcare professionals "who are the specialists", who explain issues with "sympathy and empathy, without pressure and time restrictions", both orally and written through e.g., brochures. Moreover, patients preferred doctors to be completely transparent, positive and direct.

One thing is that you [the patient] get a bag with brochures and samples and things like that, but it is really required that you are in contact with a healthcare professional, someone who sits there and talks to you, and who is open for such a conversation to take place. (Patient: 83-85)

There was a variation between nurses' and patients' perceptions about **when information should be provided**. Nurses at the urology outpatient clinic offer patients practical advice after hospital discharge

when patients return to have the catheter removed, and to receive brochures from cancer organizations during their one-year follow-up visit. However, patients would like to receive information about practical issues and follow up much earlier and attend the patient "Living with prostate cancer" course before treatment "to avoid surprises".

For the patient who is discharged from the hospital everything is unknown, it is an unfamiliar situation and he is burdened more or less with difficult thoughts about the future [...] one should more or less grab the men at the hospital door when they leave to go through all the practical stuff. (Cancer organization 3: 241-258)

All stakeholder groups stated that **"information must be repeated"** because patients do not remember everything that healthcare professionals tell them.

Yes, because at different points in time they [patients] are concerned with specific issues. If they receive everything [information] at once then there are only parts of it they can manage and that is of concern to them at the beginning and right afterwards, and then other things come later on, something like that. (Urology pathway coordinator:143-145)

Various coordination efforts among stakeholders are needed to support men with PCa during follow-up

All stakeholder groups described variations in the coordination efforts, resulting in fragmented follow-up supportive care services for men with PCa. The stakeholders described lack of coordination, but there were mixed views about the reasons.

This systematization I think is the most important. Because the services are there, but they are very fragmented and split up and everyone works a little for themselves and there is not a good [information] flow between GPs, primary healthcare, secondary healthcare, low-threshold services, the Prostate Cancer Society, and the Norwegian Cancer Society. So, there is a lot that needs to be coordinated, and that is where it may fail, that those in most need, do not receive the information and do not show up, while those with less need receive the information and drop by. Everyone has a need, but, as a starting point, everyone should get the same offer. (Clinical nutritionist: 368-375)

Stakeholders varied in their explanation of the lack of coordination. GPs experienced "the transition gap between the different healthcare services due to a lack of systems." For physiotherapists it was "lack of hospital referral routines". GPs' referrals to clinical nutritionists "must fulfil very rigid and strict criteria"; for cancer organizations it was the "tendency of healthcare services to focus on their own services". For primary care cancer coordinators it "depends on

the hospital unit routines and the size of municipalities, in bigger ones it is more difficult to get hold of their GPs", for urology pathway coordinator it was due to "adapting the referrals to patients" individual needs; and for patients who experienced problems after hospital discharge it was because urologists were "neither interested in collaborating with other healthcare professionals nor in listening to the patient". According to one patient, "They [urologists] each sit on their own turf and are terrified that someone else might find something".

Moreover, all stakeholders except patients, had similar experiences that **recommendations** of men with PCa to cancer organizations **and referrals to other supportive care services is part of coordination** but a bit random and can depend on the person, the capacity of the hospital and the cancer organization. The cancer organizations stressed the need for an improved coordination among all supportive care services for men with PCa and between the cancer organizations themselves.

I think it [referrals to supportive care services] very much depends on the person, who is at work at the ward or at the outpatient clinic [...] it is very person dependent on the other available services apart from those that the patient must have, what is the patient being informed about? Because it's about who is at work that day, how much experience they have, and what do they know? (Cancer organization 1: 83-90)

The **optimal mode of coordination** was described by urologists and primary healthcare professionals preferring electronic messaging because it is practical, easier and they can reply when they have time. However, urologists believed that GPs were satisfied with the electronic information they sent GPs at six weeks from the outpatient clinic.

Yes, we try to call and write letters so that the GPs are also informed of what we have found before they [patients] go to them. I think they are very satisfied with getting feedback [outpatient clinic note] about it. (Urologist: 92-93)

An opinion not shared by GPs who were dissatisfied with the content of hospital discharge letters, which "lack concrete usable information" for GPs to "properly follow up men with PCa". Primary care cancer coordinators also preferred to "automatically receive patient information from the urology outpatient clinic instead of reading the hospital discharge letter or asking the patient".

The issue of **optimal timing** of the coordination efforts along the cancer care process was important for most stakeholder groups. Hospital nurses said that the "Living with prostate cancer" course should be offered to patients earlier. Primary care cancer coordinators noted that GPs' referrals were not made until the patient's condition had already deteriorated,

which was the opposite of GPs' perception. GPs experienced that hospital discharge letters still arrived too late, but for urologist's early coordination with GPs in the form of follow-up care guidelines in the discharge letter was neither needed nor urgent and "therefore there is no pressure to inform GPs like within a week". However, such delay for GPs:

Is unfortunate when they [patients] visit right after discharge for one or another problem and I have not received the hospital discharge letter and I don't know what has taken place. (GP: 417-418)

Supportive care resources supplement the healthcare services but knowledge about them is random

There are several supportive care resources like cancer organizations, rehabilitation centres, courses, peer navigators, and primary care cancer coordinators. These valuable resources meet patients' supportive care needs and many patients use their services. Even though these services are supplementary to healthcare services, information about these services to men with PCa is randomly provided and usually not from healthcare professionals.

Cancer organizations stressed that their **role** and offers during the patient cancer care process is **supplementary** to that of the healthcare services who are responsible for patient treatment and follow-up. Patients described using cancer organizations, associations, centres, and courses. Many were already members of a cancer organization. All these supportive care resources were considered valuable because they offer "information, security, social support and a sense of belonging". One patient noted that a visit to the cancer organization "changed the rest of the [care] process because they understood me and cared about me as a human being, I absolutely needed that." Even though some patients expressed concern due to a feeling that there is competition among the cancer organizations, they still believed that all men with PCa should take advantage of supportive care services. As one patient suggested, "it should not be if you want to go, you must!" However, primary care cancer coordinators suggested balancing the need for using supportive care services.

One must not make people more in need of help than they actually are, either that one must push on them all kinds of stuff if they do not need it. So, it's a balancing act. (Primary care cancer coordinator: 212-213)

All stakeholder groups experienced that **knowledge** about these resources varies among primary and secondary healthcare professionals. According to patients and cancer organizations, patients receive

information about supportive care resources randomly and usually not from healthcare professionals.

My experience is that men with prostate cancer to a large extent make contact on their own, and as you say, they have found out by themselves, or they have heard from someone else or the partner made contact on their behalf or both of them together [...] and I think that's good, but I do not think it's good enough that they should hear about important services through other fellow patients. It should come from healthcare professionals and again, it should of course come from the hospital, as part of the treatment apparatus. (Cancer Organization 2: 102-110)

The patients stated that "doctors think that cancer organizations only talk about problems and sickness and therefore do not recommend them". However, this is not the case according to the representatives of these organizations. Moreover, GPs expressed the lack of referral or recommendations to supportive care services because the various offers and resources are not available to GPs, their personal knowledge about them varies and added that GPs need "an overview over the actual services these patients have".

Structured healthcare processes are needed to improve the services offered to men with PCa

Stakeholder groups gave a variety of suggestions for improving the services offered to men with PCa like checklists and GP follow-up guidelines, having one healthcare professional responsible for the patient, and urologist's preparation prior to patient follow-up consultation.

All stakeholder groups were aligned in the importance of **establishing routines and structural efforts** both within and between healthcare services and cancer organizations. Most stakeholder groups suggested that these efforts should be a hospital checklist or a pathway, used especially during the patient's discharge where urologists can provide all information with phone numbers, contact persons, supplementary offers from organizations and routines for consistently recommending support for example, about sexual health, contacting primary care cancer coordinators and local peer navigators.

Pilots have a checklist[...] Doctors can have that too, but if they do not have them then they may forget something [...], in the checklist there is everything you need to know and do, tick what you have done. So, it is some kind of quality assurance missing there. Something is forgotten, and something you get, something you do not. (Patient: 357-360)

GPs however, emphasized that because they are not specialists, they need their **own clear, usable, practical follow up guidelines**, to minimize practice variation during patient follow-up. These guidelines "which will outline the most common problems" could be

provided either in the hospital discharge letter or through a “pathway out” or as a checklist or at an electronic platform.

If you ask what the hospital should do, they should create a module that is compatible with the national health portal and with the GP’s journal system. [...] This type of solution helping us to follow up cancer patients, so that there are ways to get the electronic medical patient journal at the hospital to communicate with that of the GP clinic and the national portal [...] by having one place to find the information and making it as relevant as possible for each patient, that’s what we’re really looking for. (GP: 374-381)

Patients experienced as difficult the fact that there was not **one urologist responsible** who followed them up throughout the cancer care process. The constant change of urologists was felt as troublesome and did not build a sense of security. Moreover, patients also described the need for **urologist’s preparation before follow-up consultations**, that “they remember them and what has happened to them, that they are men with PCa”.

it is difficult to ask for the same doctor all the way, but, there was one doctor who performed the surgery, there was one at the first consultation then there was a third at the second consultation, so there were three different people, and it would have been desirable if there was one person who followed you up all the way. (Patient: 76-79)

Discussion

The results of this multi-stakeholder study demonstrate variation of perspectives across patients, primary and secondary healthcare professionals, and cancer organizations with regards to priority, optimal mode and timeliness of supportive care needs, the factors influencing coordination efforts, and suggestions for improvement.

There are various supportive care needs but stakeholders have mixed opinions as to their priority

The findings show that only patients expressed the need for all types of supportive care needs but especially practical support and psychosocial care for disease management (Gordon et al., 2019; Huntley et al., 2017). By contrast, primary and secondary healthcare professionals described as important mainly the physical aspects of care that were linked to their professional roles, responsibilities and everyday practice when following up men with PCa. Watson et al. (2016) found that patients with PCa reported that healthcare professionals focused only on the physical aspects of their care. Our study adds to their findings by offering the perceptions of several stakeholders.

Our findings suggest that men with PCa have multiple supportive care needs in similar domains as reported elsewhere (Paterson et al., 2017, 2015). However, those studies explored the supportive care needs from a patient-only perspective, while we have included the views of several stakeholders. Similarly, Carter et al. (2014) explored the perspectives of primary and secondary healthcare professionals, but our study added perspectives from several other healthcare professional groups including cancer organizations. With their peer support workers, centres, volunteers and offers, cancer organizations have an ongoing, active, and supportive role for patients with cancer, which to our knowledge is missing in the literature. Blomberg et al. (2016) found alignment between patients and secondary healthcare professionals perspectives related to treatment side effects for men undergoing radiotherapy; our study included men with all stages and treatment modalities in addition to the perspectives of healthcare professionals and cancer organizations.

Stakeholders consider optimal provision and timeliness of supportive care needs as equally important

Our findings show that the optimal mode of provision of information should be concrete, written, provided early, in an appropriate amount and repeated throughout the cancer care process because men with PCa often misunderstand and forget the information they are receiving. This is consistent with the findings by Allchorne and Green (2016) and Carter et al. (2011) but in our study the need for repetition throughout the PCa care process was reiterated to overcome these issues. Our patient stakeholder group stressed that they can and do find information through the internet, but this is not always recommended as they are not specialists and cannot evaluate the quality of online content and their own symptoms (Steinberg et al., 2010; van Ee et al., 2018). Moreover, our findings are consistent with Huntley et al. (2017) who found that men with PCa would like urologists to communicate in a more empathic, personalized way. Our patient stakeholders also stressed the need for fewer pressure and time restrictions, which are common in consultations with urologists.

Coordination gaps with multiple explanatory factors are common

All stakeholder groups expressed coordination problems between healthcare services due to lack of systematic referral practices, or due to strict referral criteria, or because of the tendency of healthcare services to promote their own services. However, some stakeholders viewed this variation not as a lack of coordination but as an adaptation of referrals to patients’ individual needs. Some added the factor of municipality size. Bigger

municipalities have more healthcare professionals, so the lack of capacity adds to the difficulty of coordination.

Men with PCa who experienced complications after hospital discharge described coordination gaps due to urologists "lack of interest in collaborating with other healthcare professionals". This finding contrasts with those of Watson et al. (2010) who found that most oncologists supported shared responsibility with GPs for follow-up of cancer patients. However, Watson and colleagues' findings were not limited to PCa.

Our study also showed coordination gaps between healthcare services and cancer organizations despite their supplementary role and importance for men with PCa. Our findings, like those of Ettridge et al. (2018) suggest that not all men know about supportive care services because information about them is fragmented and not due to reduced accessibility as described by other studies (Chambers et al., 2018; Paterson et al., 2020). Moreover, our findings show that urologists and GPs may not refer men with PCa to these services due to misunderstandings over the content of the services offered, particularly the belief that they focus only on disease. On the contrary, Oliffe et al. (2010) found that PCa supportive care groups focus on health promotion and less on the illness itself.

Suggested improvements are related to routines and systems

The stakeholders in our study stressed the importance of establishing routines and setting systems in place both within and between healthcare services and cancer organizations as a means of improving patient care and coordination. This included recommendations and/or referrals to supportive care services. Moreover, coordination efforts should stress timely and useful contents of the hospital discharge letters as Dossett et al. (2017) suggested. Checklists, pathways, or an electronic platform to which primary and secondary healthcare professionals have common access, should be prioritized. The GPs in our study requested their own follow-up guidelines for men with PCa and/or an electronic platform as a way of offering improved follow-up care and minimizing practice variation. This result is in contrast to the findings by Watson et al. (2011) where specialists were concerned with GPs' lack of knowledge and experience with PCa follow up and that clear follow-up guidelines are not easy because PCa is a complicated condition for GPs to monitor.

Limitations

Even though the literature has shown the importance of carers' supportive care role and their own needs during the PCa care process, for practical reasons we were unable to recruit this important stakeholder group. Including them would have added a perspective to our

analysis that could have expanded our understanding of the supportive care needs of men with PCa.

Another limitation of the study is the geographical representativeness of primary and secondary healthcare professionals, all of whom were recruited from one urban area in western Norway. Research designs using random sampling or other recruitment approaches from a wider geographical distribution would increase the generalizability of the results. For patient stakeholder groups, however, the sample included men ranging in age from 59 to 77 years from both rural and urban areas, with all treatment types and disease stages. Many had received treatment in hospitals in different regions of Norway thus covering a broader spectrum of experiences. We are confident that the sample provides enough information power (Malterud et al., 2016) to answer the research question and generate new knowledge.

Conclusions

Even though perceptions of supportive care needs of men with PCa after hospital discharge were aligned across stakeholder groups in the necessity for standardization of information and coordination practices during follow-up care, the mixed priorities of supportive care needs among stakeholders shows that setting systems in place is necessary but not enough. There is no single way to meet the supportive care needs of men with PCa. Future studies need to explore the possibility of a combination of standardization and individual adaptation of supportive care needs for men with PCa, perhaps in the form of an intervention consisting of several information and coordination practices. Moreover, despite alignment of opinions as to the importance of supportive care resources for men with PCa after hospital discharge, the variations in recommendations suggest a need for further research.

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Availability of data and material

Data is not available due to ethical restrictions

Authors' contributions

Through an iterative process FTK, SEH and SRK designed the study and developed the interview guides. All co-authors participated in identifying and agreeing on the preliminary themes during stage 1. Stages 2 and 3 were an iterative and negotiated process between FTK, SEH and KA. Data coding, synthesis and across case comparison during stage 4 data analysis was performed by the first author with input from all co-authors. All authors contributed to developing the manuscript and all authors checked and approved the final manuscript.

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