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Patients' and partners' views of care and treatment provided for metastatic castrate resistant prostate cancer in the UK

Short running title: Patients' and partners' views of care for mCRPC

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Abstract

Objective

Documentations of the experiences of patients with advanced prostate cancer and their partners are sparse. Views of care and treatment received for metastatic castrate resistant prostate cancer (mCRPC) are presented here.

Methods

Structured interviews conducted within 14 days of a systemic therapy for mCRPC starting and 3 months later explored: treatment decisions, information provision, perceived benefits and harms of treatment, and effects of these on patients’ and partners’ lives.

Results

Thirty-seven patients and 33 partners recruited from UK cancer centres participated. The majority of patients (46%) reported pain was their worst symptom and many wanted to discuss its management (baseline-50%; 3 months-33%). Patients and partners believed treatment would: delay progression (>75%), improve wellbeing (33%), alleviate pain (≈12%) and extend life (15% -patients, 36% -partners). At 3 months most men (42%) said fatigue was the worst treatment-related side effect (SE), 27% experienced unexpected SEs, and 54% needed help with SEs. Most patients received SE information (85% written; 75% verbally); many additionally searched the internet (33%-patients; 55%-partners). Only 54% of patients said nurse support was accessible.

Conclusion

Pain and other symptom management is not optimal. Increased specialist nurse provision and earlier palliative care links are needed. Dedicated clinics may be justified.

Keywords

Advanced prostate cancer; interviews; supportive care

Introduction

For men who present with, or progress to, advanced (metastatic) prostate cancer the mainstay of treatment is Androgen Deprivation Therapy (ADT) alone or in combination with docetaxel chemotherapy [Sweeney et al, 2015; James et al, 2016; Cornford et al, 2017; Morris et al, 2018]. Unfortunately the development of resistance to ADT is inevitable in most cases [Debres & Tindall, 2004] and is known as metastatic castrate resistant prostate cancer (mCRPC). Adding therapies sequentially to ADT such as first-line, second-line, or re-challenge with chemotherapy (docetaxel and cabazitaxel) [Petrylak et al, 2004; Tannock et al, 2004; De Bono et al, 2010] or bone targeted agents (Radium -223) [Parker et al, 2013)] have demonstrated gains in overall survival (OS). Moreover, the last decade has seen the understanding of castrate resistance change; it is not uniform and has multiple underlying pathways [Karantanos et al, 2015]. In some cases control of disease progression is possible by hormonal manipulation with drugs such as abiraterone acetate (androgen biosynthesis inhibitor) and enzalutamide (antiandrogen). Both have demonstrated significant advantages for OS, progression free survival (PFS) and quality of life (QoL) in the pre and post docetaxel settings [Nuhn et al, 2018]. The exact sequencing of these further therapies for any individual man remains uncertain. Factors influencing this include: - heterogeneity of the prostate cancer and tumour factors such as Gleason Grade, PSA kinetics, the sites of recurrence (visceral, bone or nodal), patient co-morbidities, potential toxicities of drugs, and importantly patient choice depending on an individual's circumstances. Also of note is a current lack of sufficiently robust biomarkers that predict response or toxicity/tolerability of any individual treatment [Armstrong 2017].

This is a complex backdrop for treatment decision making and not surprisingly the management of mCRPC requires a multidisciplinary team (MDT) approach. For the process to be truly patient centred, men with mCRPC need to receive information and counselling about all of the available therapy options at each stage of their disease. Different and multiple specialties will be providing information which makes it essential that MDT members are aware of each other's roles so that patients receive accurate and consistent information to guide treatment decisions. The American Society of Clinical Oncology (ASCO) guidelines for survivors of prostate cancer recommend that an individual's information needs at all stages of disease are assessed and patients provided with or referred to the appropriate sources for information and support [Resnick et al, 2015]. The little evidence that exists shows a shortfall in services provision [Jenkins & Fallowfield, 2016]. Three studies from Canada [Carter et al, 2010; Carter et al, 2011; Carter et al, 2014] with men most of whom had castrate resistant disease, their partners, and health professionals found information provision was less than optimal for key topics such as treatments and associated side effects (SE), progression of disease and available supportive care services. Many patients did not understand the treatment information, especially how treatments worked, and had difficulty getting answers to questions; equally worrying oncologists and specialist nurses acknowledged an awareness of these shortcomings. A qualitative study of Australian men diagnosed with advanced prostate cancer [Chambers et al, 2018] also identified difficulties with accessible informational support about the disease and treatment. The study revealed that the partner was the catalyst for seeking information and getting help from the supportive services and that they needed to be involved and supported too. The influence of factors such as age, expression of masculinities and models of coping with illness also emerged which has implications for the design of care models. Our own recent UK clinician survey showed men with mCRPC are managed mostly in general urological oncology clinics where the mix and level of staffing is not ideal for focussing on their complex needs [Jenkins et al, 2018a]. Minimal availability of specialist nursing and palliative care staff created a situation where achieving optimal QoL for patients was challenging. Similar to the Canadian findings, important topics such as prognosis, SE amelioration, patient's current goals and access to supportive care were frequently identified by the UK clinicians as omissions, in what were time restrained consultations with patients. This suggests more evidence based research into meeting the specific needs of men with mCRPC and their families is required.

As part of a UK prospective study examining the EXperiences, TREatments and Quality Of Life (EXTREQOL) in men diagnosed with mCRPC structured interviews were conducted with patients and their partners. This was to explore experiences of treatment decisions, information provision, perceived benefits and harms of treatment and the effects of these on their lives; the findings are presented here.

Methods

A prospective longitudinal mixed-methods observational design was used in EXTREQOL and included structured interviews with patients and their partners. Twenty hospitals in 19 Trusts in England, Scotland and Wales provided access to men considered suitable for systemic treatment for mCRPC between July 2016 and July 2017. Exclusion criteria were not having a diagnosis of mCRPC, those with current or historical anxiety and/or depression or psychiatric illness. Ethical approval (16/LO/0403) was granted by the London-Surrey Boarder Research Ethics Committee and sponsorship and all local NHS R&D permissions were obtained for the study.

Procedures

Eligible patients were identified and initially approached by a member of the clinical team who briefly explained the study together with providing the Information Sheet. Neither being interviewed, nor having a partner willing to be interviewed, was a pre-requisite of the study, but it was made clear that there was opportunity for this within the study. Interested patients completed an expression of interest form with their contact details and gave permission for researchers to phone them no sooner than 24 hours later to discuss the study. Written informed consent was obtained prior to participation. Consecutive sampling was used with a pragmatic target of interviewing 30 men and if applicable their partners.

Interviews

Taking into account preference, interviews took place either in-person at home, or by telephone and were carried out within 14 days of a systemic therapy [any line] being initiated for mCRPC, and after 3 months of treatment. Patient and partner interviews were conducted independently of each other, were undertaken by three researchers (SC, VJ, LM) experienced in interviewing and lasted between 15-45 minutes. The interview schedules, four in total (patient baseline & 3 months and partner baseline &

3 months), were developed and piloted. Patient demography was collected and questions asked about treatment history, experiences of treatment decisions, symptoms (particularly pain) and related side effects, information provision, perceived benefits and harms of treatment, effects of these on patients' and partners' lives, supportive care and follow up provided by the clinical team. All answers were recorded directly onto the printed interview schedules. A majority of questions had pre-assigned response categories. Replies to the open-ended questions were written verbatim and then read back for confirmation of accuracy and understanding.

Analysis

The written material generated by open-ended questions was initially read and then independently coded into categories by both SC and LM with discrepancies resolved through discussion and if necessary adjudicated by VJ. All of the categorical data were summarised as counts and percentages and collated in tabular or graphic format, comparisons across patients and partners are presented where useful.

Results

193 men returned expression of interest forms , after further consideration 52 declined participation and 8 were ineligible (not mCRPC=2, too ill=1, a systemic treatment not started=2, had been on treatment for >14 days=4). 132 men consented to the study of whom 33 together with their partners and 4 single men were interviewed.

Table 1 summarises the demography for those interviewed and patients' medical history, 22% (8/37) of whom were presenting with mCRPC for the first time, which was representative of the study sample as a whole (23%;30/132). The majority had bone metastases (60%, 22/37), a similar proportion to that of the whole study sample (62%, 82/132). The single men interviewed were on average older, none were University educated nor employed.

Table 1 here

Views from the consultation about commencing treatment for mCRPC

Table 2 presents a summary of the perceived worst symptom, language used by the doctor to convey the status of the cancer, and the decision time and perceived patient involvement at the consultation where the new treatment for mCRPC was discussed.

Patients and partners views for the worst presenting prostate cancer symptom were only moderately congruent (Kappa value = 0.4). Pain was the worst presenting symptom from the perspective of a majority of the men, (though only one of the four single men), whilst partners more often reported the patient’s worst symptom as psychological distress and other urinary problems (i.e. incontinence).

Few patients or partners recalled reference to mCRPC during the “new “treatment consultation to convey the disease status. Most recollected hearing the terms “advanced” or “progressive” prostate cancer used and/or the phrasing “the cancer has spread”, “the cancer is metastatic”, “treatment has stopped working”.

Over a third said the treatment decision was made at the consultation when mCRPC was confirmed, others were given a longer time to decide. In most cases treatment decision making was viewed as a joint doctor-patient decision, with partners also involved.

Table 2 here

Figure 1 shows that most thought the aim of treatment was to delay cancer progression (>75%), and just over a third of partners, but fewer patients (15%) to extend life and around a third of both patients and partners to improve QoL.

Figure 1 here

Experiences of information provision

Table 3 gives an overview of the information leaflets and websites used by the patients. The majority of leaflets were from Macmillan and drug companies, which provided "very" or "fairly" useful information about SEs. However, a third of patients and 55% of partners had searched the internet for additional SE information. Few recalled website recommendations being made by the healthcare professionals and it was more likely for partners than patients to have visited websites.

Table 3 here

Pain management and treatment related side effects

Table 4 shows at baseline 16/37 (43%) of men needed and had the opportunity to discuss pain management. One man did not find this very useful and a further three required a discussion, but this had not happened.

By 3-months a third had discussed their pain recently with a healthcare professional; most (11/12, 92%) had found this very/fairly useful. However, nearly a fifth (7/37, 19%) made comments attributing the pain to causes other than prostate cancer, for example:-

> "I think the pain in my hip could be rheumatic" (P14, 56yrs)
>
> "My pain in the lower back and shoulder are due to degeneration" (P1, 73yrs)
>
> "I put the backache down to gardening" (P33, 73yrs)

A majority of men (16/37, 42%) reported fatigue as the worst SE at 3 months, and nearly a third had experienced some unexpected SEs, over 50% had sought help to manage them.

Table 4 here

Support for patients and partners

Figure 2 reveals inequitable provision of access to specialist nurse resources with nearly half of patients and partners reporting there was no specialist nurse available to talk to.

Figure 2 here

Around a third of patients (13/37, 35%) and partners (10/33, 30%) said they had received details of a local support group. Many of those not provided with this information said they were not interested (20/24, 83% patients; 20/23, 87% partners). About half (16/33, 49%) of the partnered men and three quarters (3/4, 75%) of the single men accessed supportive services, the types of help are shown in figure 3. There was evidence of why some men were reluctant to, or had not used supportive services, for example:-

"I prefer to keep things in the family, I get all my support from the family" (P4, 66yrs)

"For me I think not wanting to have help from the hospice might be a male thing, wanting to keep going on your own" (P2, 68yrs)

"He is a man he doesn't like to look weak and ask for help, he has had a couple of breakdowns at home, coping with the nausea & vomiting, pain and diarrhoea" (S6, 68yrs)

Figure 3 here

Requests for improvements

On reflection 11/37 (30%) of men and 12/33 (36%) of partners commented on how care might be improved for future patients. Suggestions for improved communication and information provision were prominent, for example:-

"Consistency in information is vital, differing opinions from the doctor and nurse" (P28, 76yrs)

"Improvement of continuity of passing on information, across healthcare professionals and different hospitals, important points do sometimes seem to go missing" (P11, 72yrs)

"They (the healthcare professionals) don't seem to recommend any websites" (P12, 70yrs)

"Initially we struggled for information, only after the specialist referred us to the hospice did we get the support, information and help we really needed" (S3, 67yrs)

There was also evident desire for improvements to be made to supportive care and the resource allocation that underpins this, comments such as:-

"Very over worked staff, no opportunity to discuss my incontinence issues with a nurse" (P13, 69yrs)

"I'm so tired, hot flushes, restless legs, feel exhausted, something to help all of these" (P9, 68yrs)

"I feel particularly unsupported as a partner, we are a relatively young couple, I am worried about the future, I feel very much in the dark" (S2, 57yrs)

"Help with psychological issues,… I am very worried about leaving my wife and son, …I feel there should be psychological support for them too" (P14, 56yrs)

"More help and support with incontinence, I'm pretty much house bound now, I'm worried about having an accident while I'm out and about" (P37, 91yrs)

"I think more contact with the nurse would give my husband more confidence. We feel at the clinic that we are on a bit of a conveyor belt and time is short with the doctor & nurse" (S6, 68yrs)

Discussion

The interviews from EXTREQOL highlight the ongoing challenges facing mCRPC patients, their partners and HCPs in terms of finding treatment and care models to maximise survival and QoL.

Three quarters of the patients in EXTREQOL had metastatic bone disease and pain was a commonly reported presenting symptom recognised by 43% of clinicians [Jenkins et al, 2018a]. This is important though not surprising and it fits with previous evidence showing that men with mCRPC experience poorer QoL and more pain than men at other stages of disease [Chambers et al, 2018]. Patients who managed to have a pain management discussion were in the main satisfied, however, some attributed their pain to their older age, or other conditions other than cancer e.g. arthritis, or an activity like gardening. Evidence from the Brief Pain Inventory data for the whole EXTREQOL study sample showed only 39% (22/57) of those with moderate/severe pain experienced ≥70% pain relief from their analgesia, and these proportions dropped to 37.5% (15/40) and 36.5% (15/41) at 3 & 6 months follow-up respectively [Jenkins et al, 2018b]. The overall picture from EXTREQOL and other studies is one of less than optimal pain management in this group of men. A recent qualitative study of Australian men’s experiences of advanced prostate cancer documented similar findings on the influence men’s age and the expression of masculinities have on response to and coping with illness. They found a reluctance to seek help which the men ascribed to male values (being strong, capable, independent or stoic) and used avoidant coping, covering up or ignoring side-effects or a need for support [Chambers et al, 2018].

Fatigue was a common SE of the mCRPC treatments and was difficult to manage by patients and staff as the EXTREQOL survey data showed. Doctors were less confident in being able to ameliorate fatigue compared to most specialist nurses (71%) who were confident [Jenkins et al, 2018a]. However, an imbalance in nurse support suggests many patients will miss out on such vital management discussions. In a report by the UK charity ORCHID (2012) a similar proportion, of around 50% of men, was highlighted as missing out on nurse support as found in the current study.

This coincides with an appeal from the prostate cancer workforce for more specialist nurses, which needs to double to equal the existing provision given to breast cancer patients [Prostate Cancer UK, 2014; Trevatt & Leary, 2010].

The striking feature in regard to accessing supportive services was the relatively low level of usage and the expression of no interest in peer support groups from many men (20/37, 54%). Comments regarding their lack of engagement with services revealed a preferential reliance on spouses and family for primary support and masculinity influencing help seeking/acceptance. Another qualitative study revealed low emotional support-seeking and a similar preference for informal networks (i.e. partners, family & friends) [Ettridge et al, 2018]. Even men with localised prostate cancer are reluctant to seek help for their prostate-related concerns within the year following diagnosis (40%) and few had accessed psychological support [Hyde et al, 2017]. This sits within a context where men's general help-seeking behaviour is known to be low for both health and psychological problems [Yousaf, Grunfeld & Hunter, 2015]. The pattern is replicated in the general cancer setting where men compared to women are less likely to utilise support [Forsythe et al, 2013].

In men generally and those with cancer, psychological barriers to seeking help have been identified as including: - restricted emotional expression, need for independence and control, gender role conflict and embarrassment [Yousaf, Grunfeld & Hunter, 2015; Fish et al, 2015]. Awareness of these factors is vital for supportive services to be designed to meet the needs of men with mCRPC and maximise their quality of life. It also flags up the interconnectedness of patients with partners and for their need to be involved and supported too.

Without question the men and their partners were overwhelmingly grateful and complimentary of the treatment and care they had received. It was therefore in the spirit of improving things for future patients that requests for changes were articulated and broadly these were for improved communication and information provision and better supportive care underpinned by adequate resource allocation (specifically access to specialist nurse and palliative staff).

Conclusions

More help to manage pain and other symptoms is required. Better specialist nurse access and earlier palliative care links would help to optimise symptom control, dedicated clinics maybe warranted.

Limitations of the study

The study sample lacked ethnic diversity and the experiences of black men in the UK, who are three times more likely to be diagnosed with prostate cancer than white men, have not been represented. Adoption of purposive sampling could help to address this in any future study.

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Table 1: Demography and patients’ medical history

Demography	**Partnered men (n=33)**		**Single men (n=4)**		**Partners (n=33)**
Age(yrs): Mean, SD, min-max	70.8, 6.81, 56 - 89		80.5, 9.56, 71 - 91		67.6, 6.18, 54 - 79
University educated: n (%)	12 (36)		0		9 (27)
Employed: n (%)	6 (18)		0		9 (27)
Medical history					
First presentation of mCRPC					
yes	8		0		
Site of metastasis: n (%)					
bone	18 (55)		4 (100)		
visceral	8 (24)		-		
both	6 (18)		-		
missing	1		-		
New treatment for mCRPC (baseline status):	Started	Awaiting	Started	Awaiting	
abiraterone (Zytiga)	5	1	-	-	
enzalutamide (Xtandi)	10	1	1	1	
docetaxel (Taxotere)	5	2	-	1	
radium-223 (Xofigo)	3	1	-	-	
cabazitaxel (Jevtana)	2	-	-	-	
steroid switch + abiraterone	1	-	-	-	
goserelin (Zoladex)	-	-	1	-	
docetaxel + AZD5363	1	-	-	-	
enzalutamide & radium-223	-	1	-	-	
Concurrent treatments: n (%)					
hormone injections	31 (94)		3 (75)		
bisphosphonate	1 (3)		1 (25)		
analgesia	16 (49)		2 (50)		
radiotherapy for bone mets	2 (6)		2 (50)		
Clinical trial offered: n (%)	5 (15)		1 (25)		

Table 2: Worst symptom, disease status and treatment decision-making

	Partnered men(n=33) n (%)	Single men (n=4) n (%)	Partners (n=33) n (%)
Worst symptom:			
none	5 (15)	0	3 (9)
pain	15 (46)	1 (25)	11 (33)
fatigue	5 (15)	1 (25)	3 (9)
psychological distress	1 (3)	0	3 (9)
reduced physical function	0	1 (25)	0
increased urinary frequency	4 (12)	0	4 (12)
other urinary problem (incontinence)	3 (9)	1 (25)	6 (18)
Terms used to convey disease status:			
multiple responses possible			
none			
advanced prostate cancer	2 (6)	2 (50)	4 (13)
progressive advanced prostate cancer	16 (49)	1 (25)	17 (55)
metastatic castrate resistant prostate	7 (21)	1 (25)	8 (26)
cancer (mCRPC)	3 (9)	0	4 (13)
castrate resistant prostate cancer (CRPC)	0	0	1 (3)
hormone resistant prostate cancer (HRPC)	1 (3)	0	1 (3)
treatment has stopped working	8 (24)	1 (25)	5 (16)
the Cancer has spread	16 (49)	0	13 (42)
aggressive prostate cancer	4 (12)	0	3 (10)
cancer is metastatic	7 (21	0	5 (16)
mCRPC/CRPC written in a summary letter	3 (9)	0	3 (10)
Time available for treatment decision:			
decision made at consultation	11 (33)	2 (50)	9 (27)
decision made at follow-up consultation	9 (27)	0	9 (27)
however long needed	13 (39)	2 (50)	15 (46)
Treatment decision was made by:			
patient alone	1 (3)	1 (25)	
patient considering the doctor's opinion	8 (24)	0	
doctor and patient decided together	18 (55)	2 (50)	
doctor considering the patient's opinion	3 (9)	0	
doctor alone	3 (9)	1 (25)	
How involved are partners in the treatment decision-making process?:			
Very much	25 (76)		20 (61)
Quite a bit	7 (21)		3 (9)
A little	0		4 (12)
Not at all (partner did not wish to be involved)	1 (3)		1 (3)

Table 3: Information provision

	Partnered men(n=33) n (%)	**Single men (n=4) n (%)**	**Partners (n=33) n (%)**
Type of written leaflets provided: multiple responses possible			
None	3 (9)	1 (25)	4 (12)
Macmillan	15 (46)	1 (25)	13 (39)
Cancer Research UK	3 (9)	0	0
Prostate Cancer UK	0	0	1 (3)
Hospital own	8 (24)	0	5 (15)
Drug company own	16 (49)	2 (50)	15 (46)
Other	2 (6)	0	1 (3)
Written side effect information provided:			
Yes, very useful	21 (64)	2 (50)	20 (61)
Yes, fairly useful	8 (24)	1 (25)	8 (24)
Yes, not very useful	0	0	0
No written information received	4 (12)	1 (25)	4 (12)
Don't know			1 (3)
Side effects explicitly discussed:			
Yes	29 (88)	1 (25)	29 (88)
No	4 (12)	3 (75)	4 (12)
Looked side effects up on the internet:			
Yes	11 (33)	0	18 (55)
Websites recommended: multiple responses possible			
None	29 (88)	4 (100)	31 (93)
Macmillan	4 (12)	0	1 (3)
Cancer Research UK	1 (3)	0	0
Prostate Cancer UK	1 (3)	0	1 (3)
Hospital own	0	0	0
Drug company own	0	0	0
Websites utilised: multiple responses possible			
None	21 (64)	3 (75)	12 (36)
Macmillan	4 (12)	0	7 (21)
Cancer Research UK	5 (15)	1 (25)	6 (18)
Prostate Cancer UK	5 (15)	0	4 (12)
Hospital own	0	0	0
Drug company own	0	0	0
Other	6 (18)	0	17 (51)

Table 4: Pain management and side effects experienced

Patients, n=37	Baseline n (%)	3-months n (%)
Pain discussed with a healthcare professional?		
Yes, very useful discussion	13 (35)	8 (22)
Yes, fairly useful discussion	2 (5)	3 (8)
Yes, not very useful discussion had	1 (3)	1 (3)
No, discussion not required	18 (49)	25 (67)
No, but wanted a discussion	3 (8)	0
Worst side effect		
None		8 (22)
Fatigue		16 (42)
Nausea/vomiting		3 (8)
Hot flushes		3 (8)
Diarrhoea		2 (5)
Dizziness		1 (3)
Hypertension		1 (3)
Poor kidney function		1 (3)
Increased bone pain		1 (3)
Indigestion		1 (3)
Had unexpected side effect/s occurred?		
Yes		10 (27)
Asked for help with side effects?		
Yes		20 (54)

Figure 1: Understanding of the aims of treatment

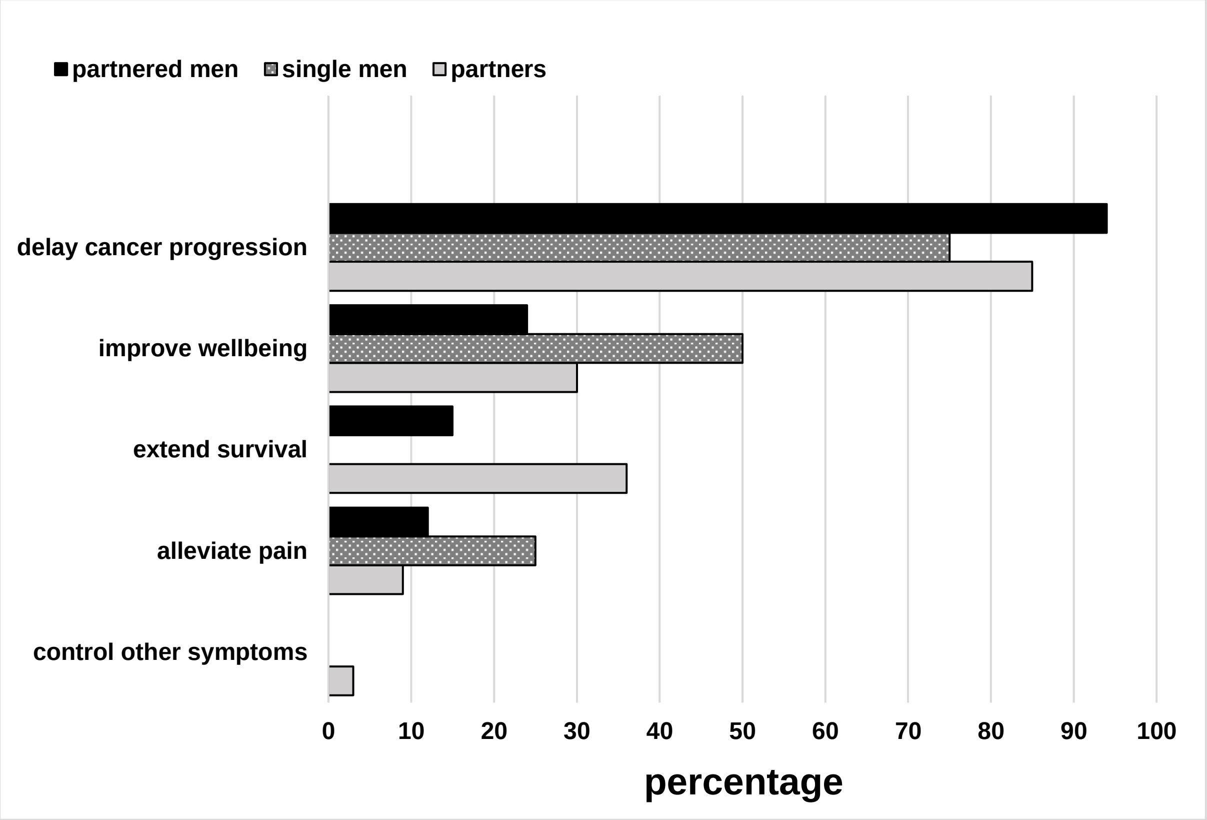

Figure 2: Patient and partner views of specialist nurse provision

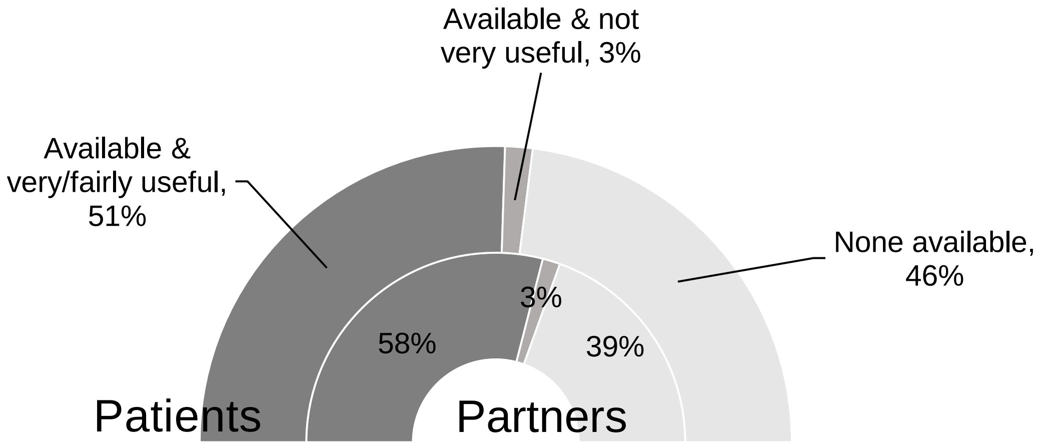

Figure 3: Summary of the help men were accessing