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The impact of supportive nursing care on the needs of men with prostate cancer: a study across seven European countries

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Background: Prostate cancer is for many men a chronic disease with a long life expectancy after treatment. The impact of prostate cancer therapy on men has been well defined, however, explanation of the consequences of cancer treatment has not been modelled against the wider variables of long-term health-care provision. The aim of this study was to explore the parameters of unmet supportive care needs in men with prostate cancer in relation to the experience of nursing care.

Methods: A survey was conducted among a volunteer sample of 1001 men with prostate cancer living in seven European countries.

Results: At the time of the survey, 81% of the men had some unmet supportive care needs including psychological, sexual and health system and information needs. Logistic regression indicated that lack of post-treatment nursing care significantly predicted unmet need. Critically, men's contact with nurses and/or receipt of advice and support from nurses, for several different aspects of nursing care significantly had an impact on men's outcomes.

Conclusion: Unmet need is related not only to disease and treatment factors but is also associated with the supportive care men received. Imperative to improving men's treatment outcomes is to also consider the access to nursing and the components of supportive care provided, especially after therapy.

Prostate cancer is a significant health burden within Europe with recent survival data suggesting that the number of men with this disease will increase over the next 20 years (Berrino *et al*, 2007; Siegel *et al*, 2012). Prostate cancer is being detected earlier, and as a consequence more men receive treatment and subsequently face adverse effects of therapy (Resnick *et al*, 2013b). Despite improvements to cancer treatment, some men will continue to experience long-term consequences. Population-based studies have highlighted that prostate cancer survivors report significant chronic illness compared with age-matched controls, with poorer health status and reduced quality-of-life (Van Hemelrijck *et al*, 2010; Elliott *et al*, 2011; Khan *et al*, 2011; Higano, 2012; Lustberg *et al*, 2012). Increasingly, there is recognition that lifestyle factors correlate with the risk of late pelvic symptoms after prostate cancer treatment (Thomas *et al*, 2013) and can have an impact on men's overall survival (Kenfield *et al*, 2011).

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Such survivorship results in an enduring requirement for health-care monitoring and challenges providers of cancer care to effectively respond to men's long-term supportive care needs (Simonelli *et al*, 2008; Harrison *et al*, 2009; McCabe *et al*, 2011). Critical to health service planning is the need to recognise the factors that contribute to men's poorer health and the ability to identify what supportive care packages, such as nursing, are needed and at what time in the treatment and recovery pathway.

Although studies of prostate cancer often focus on functional outcomes of therapy, the extent to which adverse effects bother men also needs careful evaluation (Luckett *et al*, 2009; Pachman *et al*, 2012; Seklehner *et al*, 2012). Understanding the importance of comprehensive patient outcomes is essential in delivering whole-patient cancer care (Jacobsen *et al*, 2012; Stanton, 2012). Studies exploring unmet needs of men with prostate cancer consistently show that these needs are highest in relation to psychological and sexuality issues, as well as information about treatment and care in the health-care setting (Steginga *et al*, 2001; Boberg *et al*, 2003; White *et al*, 2012). Several predictive analyses from unmet needs studies have found significant associations between unmet need and factors of age, education, marital status, treatment variables, disease characteristics and mental affect (Smith *et al*, 2007; Ream *et al*, 2008). None of these studies have explored unmet need against the type or nature of supportive care these men received. Identifying the characteristics of unmet need and nursing outcomes over the cancer pathway can contribute to the evidence of the impact of specialist nurses as well as clarify quality parameters in providing good after-care. In this study, we examine the relative predictive impact of prostate-specific dimensions of nursing care on the scope and extent of men's unmet supportive care needs across seven countries within Europe.

MATERIALS AND METHODS

We surveyed men with a diagnosis of prostate cancer living in Denmark, France, Ireland, Netherlands, Spain, Turkey and the UK via on-line and paper questionnaire. Pre-survey information, together with the on-line link, was posted on support group, charity and nursing organisation websites, and leaflets were distributed through support networks and clinic settings. The questionnaire was translated and the response was anonymous. The survey was available on-line for one month in October/November 2011 during which time 1131 eligible men started the questionnaire and 558 (49%) completed. Between October 2011 and early January 2012, 2111 paper questionnaires were also made available to centres for use where paper completion was preferred (numbers of questionnaires distributed within the individual countries were not recorded). A total of 443 (21%) completed paper questionnaires were returned to the United Kingdom. Consent information was given within the survey before the start of both on-line and paper questionnaire and consent was indicated by commencement of the survey.

Three patient-reported outcome scales were included in the questionnaire.

The Supportive Care Needs Survey (SCNS) is a valid and reliable 34-item tool for assessing cancer patients' unmet needs. It assesses five domains: psychological; sexuality; health system and information; physical and daily activity and patient care and support (Boyes *et al*, 2009). Need for help is rated on a five-point scale: 1 = not applicable, 2 = satisfied, 3 = low need, 4 = moderate need and 5 = severe need. Five items from the SCNS prostate-specific module were also used related to urinary function, bowel function and hormonal effects.

The EuroQol EQ-5D-3L is a standardised, valid and reliable measure of health status for clinical and economic use (Pickard *et al*, 2007). It measures five dimensions: mobility, self-care, usual activities, pain/discomfort and anxiety/depression. Each is scored on a three-point scale representing no problem, some problem and extreme problem. A self-rating scale of Health State is scored from 0–100 on a visual scale, 0 representing the 'worst imaginable health state' and 100 representing the 'best imaginable health state'.

Experience of supportive nursing care was measured using a scale developed by the authors. It contained nine dimensions of supportive care commonly provided by hospital nurses (see column 1 in Table 4). The items were developed based on research literature utilising evidence from specialist nursing domains (Eicher *et al*, 2012) and clinician and patient consultation in each of the seven countries. Response was measured on a four-point scale by participants indicating for each dimension if they strongly agreed, agreed, disagreed or strongly disagreed that they had received advice and support. If they had not seen a nurse at all for that dimension of care, they were asked to check a fifth column. These questions aimed to provide patient-reported data for nursing provision and covered supportive care across the disease journey.

We also collected demographic characteristics (age, education, living status, ethnicity and country of residence), and disease and treatment characteristics (time since diagnosis, treatment modality, time since treatment, time last assessed by a clinician and stage of disease).

We hypothesised that demographic and treatment characteristics, patient-reported outcomes of quality-of-life (mental affect and health state) and patient experience would be associated with unmet needs of men with prostate cancer. Descriptive analysis examined sample characteristics and patient-reported outcome measures. Analysis for SCNS domains was conducted on an overall response of no need (all item responses of not applicable or satisfied) *vs* some need (at least one item response of low, moderate or high unmet need). Within each domain, missing item responses were imputed using multiple imputations (Markov Chain Monte Carlow method) in IBM SPSS Statistics version 19.0 (London, UK).

Predictive modelling for some need was developed using the backwards elimination selection procedure to identify suitable logistic regression models for each of the five domains based on the pooled model results. Where possible, interactions were included in the models but none were found to be significant. All testing was conducted at the 5% significance level. Covariates incorporated into the models included known predictors of need from other published studies: age, country of residence, education, living status, stage of disease, time since diagnosis, time since last assessed, treatment modality, treatment status nested within treatment degree, mental affect (measured by the EuroQol item on depression and anxiety) and health state (Table 1). Nine variables relating to supportive nursing care across the disease journey were introduced to the final analysis to assess whether men's experience of nursing care could explain any variation over and above that explained by the initial models. Backwards elimination was used to remove non-significant terms. The resulting final models were all statistically significant $P<0.001$ for all domains. The Youden indices ranged from 0.316 to 0.564. Sensitivity and specificity were higher comparing the models with nursing care variables to the initial models for the psychological, health system and information and the patient care and support domains.

RESULTS

Study participants. Data was based on 1001 complete questionnaires. The majority of participants were aged between 61–80, of white ethnic origin and living with others, and there were similar

Table 1. Derived variables

Variable	Definition
Treatment modality	Created for all separate treatments received, defined as not had treatment *vs* received/currently receiving treatment
Treatment degree	Considering treatment or monitoring *vs* had a single treatment modality *vs* had multiple treatment modalities
Treatment status	Considering treatment or monitoring *vs* currently on-treatment *vs* finished treatment <1 year ago *vs* finished treatment more than1 year ago
Mental affect	Derived from the EuroQoL EQ-5D anxiety/depression dimension, where a response of not anxious or depressed = 0 and moderately or extremely depressed = 1
Health state	A continuous variable represented by participant rating on the EuroQoL EQ-5D VAS scale

numbers of men in each of the education categories (Table 2). Over one-quarter of the sample had been diagnosed within the last year, and one-quarter 1 and 2 years previously. A total of 36.9% of men were receiving treatment at the time of the survey, 20.5% were <1 year out of treatment and 40.4% were ⩾1 year out of treatment; few were considering treatment. Equal numbers of men had received radical prostatectomy, radiotherapy or hormone therapy (43.6%/ 44.6%/43.8%), fewer men had experience of active surveillance (16.2%) and watchful waiting (12.2%), 57.7% of men had received multiple treatments. Moderate or extreme anxiety or depression (mental affect) was reported by 33.7% of men: normative data are only available in three countries (Netherlands, Spain and the United Kingdom) indicating percentage ranges for men over 40 years of age to be 18–33%, 7–20% and 16–26%, respectively (Svende and Williams, 2004) and mental affect measured by the EQ-5D for men with prostate cancer in the United Kingdom has been reported at 30% (Ream *et al*, 2008). Mean self-rating for health state was 74.3 (s.d. 17.6 median 80, 65/90) (Table 2): normative data for men in Netherlands, Spain and the United Kingdom indicate mean ranges across age groups for men over 40 years of age to be 69–82, 67–78 and 71–85, respectively.

Prevalence of unmet supportive care needs. More than 80% of men in the sample had some unmet need across the five domains measured; psychological needs, sexuality needs, and health system and information needs had the greatest prevalence (Table 3). Prostate-specific symptoms were reported by over half the participants: incontinence or dysuria was the most prevalent, followed by hormonal symptoms and then bowel problems (Table 3). Over 45% of men indicated that they had not seen a nurse at all for one or more dimensions of care during their pathway (Table 4). When men had seen a nurse, support and advice was highest in pre-treatment and immediate treatment-related care: over 80% had received advice and support for screening, diagnosis, side effects and treatment after-care. However, fewer men reported advice and support for longer-term effects, home care, choosing treatment options, referral and emotional support (Table 4).

Predictors of unmet supportive care need. Dimensions of post-treatment nursing care significantly and independently predicted unmet need. The most common aspect was for longer-term effects: men who had not seen a nurse about longer-term effects were twice as likely to have health system and information needs and patient care and support needs. Similarly, men who had not received advice and support from a nurse for longer-term effects were three times as likely to have health system and information needs and patient care and support needs. In addition, men who had not received advice about longer-term effects were twice as likely to have psychological need (Table 5).

Three further areas were significantly associated with unmet need: not seeing a nurse for treatment side effects was associated with psychological need, lack of advice and support for after-care was associated with patient care and support need, and lack of advice and support for home care was associated with sexuality and health system and information need. Nursing care did not predict need in the physical and daily living domain (Table 5). A number of further factors had an impact on unmet needs. The country a man lived in, the stage of his disease and the type of treatment he had experienced were the most common demographic and treatment predictors of unmet need (Table 5). Men in Spain were more likely to have psychological and health system and information needs, and together with men in France, they had a higher probability of sexuality-related needs than men in Denmark (reference category). Men with more extensive disease were more likely to have psychological and health system and information needs and to require help with patient care and support issues. Treatment modality was a significant predictor of unmet need in three respects. Having had chemotherapy was strongly predictive of unmet physical and daily living needs, and having had radical prostatectomy was predictive of unmet sexuality need, whereas men who had had radiotherapy were less likely to have psychological need than men who had not (Table 5).

Men who had finished treatment 1 or more years ago were significantly less likely to have physical and daily living needs compared with men on treatment. The more recently a man had been assessed by a clinician the more likely he was to have health system and information needs, although this was not influenced by time since diagnosis. Conversely, men diagnosed 1–2 months ago were ten times more likely to need help with sexuality issues than men at diagnosis (within the last month) and this changed over time. Neither age nor education nor living status was found to be a significant predictor of unmet need in any domain having included the nursing care variables.

Patient-reported parameters of mental affect and health state were each associated with unmet need for all domains (Table 5). Increasing health state by one unit produced an estimated decrease in odds of reporting need ranging between 1.7 and 4.2% across domains. Men with moderate or severe anxiety or depression were approximately twice as likely to have sexuality, health system and information, patient care and support or physical and daily living needs, but in line with previous studies, this association was greatly increased in relation to psychological need (odds ratio = 7.604). The questionnaire format was significantly associated with unmet need: men who completed the survey in paper format were less likely than men who had completed it on-line to have unmet psychological physical and daily living needs (Table 5).

DISCUSSION

This study makes an important contribution to the understanding of the role of supportive care in addressing survivorship needs for men with prostate cancer and the significance of nursing in reducing men's unmet needs. In addition to disease and treatment characteristics, lack of contact with a nurse or advice and support from a nurse was associated with men's unmet needs. The greatest areas of need reflect other survey data (Boberg *et al*, 2003; Feldman-Stewart *et al*, 2010; Harrison *et al*, 2011), which suggest that current services may not be addressing on-going concerns that have an impact on men's long-term distress (Foster *et al*, 2009; Davies and Batehup, 2011). This provides evidence that access to supportive nursing care can influence patient outcomes, and importantly indicates that there are areas of care, in particular after cancer treatment, that nursing could improve.

Table 2. Sample characteristics

Base	1001	%
Country response		
The Netherlands	319	31.9
UK	180	18.0
Spain	179	17.9
Denmark	125	12.5
France	95	9.5
Ireland	53	5.3
Turkey	50	5.0
Questionnaire format		
On-line	558	55.7
Paper	443	44.3
Age		
50 or less	17	1.7
51–60	142	14.2
61–70	531	53.0
71–80	279	27.9
81 +	31	3.1
Total[a]	1000	
Education		
Finished before 18 without qualifications	271	27.3
Finished at 18 with qualifications	274	27.6
Gained a diploma/certificate after 18	207	20.8
Gained a degree (bachelor's, master's or doctorate)	240	24.1
Total[a]	992	
Living status		
Living with other (s)	907	90.6
Living alone	94	9.4
Ethnic origin		
White	975	98.0
Black - Caribbean	2	0.2
Black - African	1	0.1
Mixed ethnic origin	1	0.1
Other ethnic group	4	0.4
Prefer not to say	12	1.2
Total[a]	995	
Time since diagnosis		
Within the last month	24	2.4
1–2 month ago	20	2.0
3–6 months ago	92	9.2
7–12 months ago	120	12.0
1–2 years ago	246	24.6
3–4 years ago	189	18.9
5–10 years ago	237	23.7
More than 10 years ago	70	7.0
Total[a]	998	
Stage of prostate cancer		
Stage I	112	16.4
Stage II	112	16.4
Stage III	93	13.6
Stage IV	63	9.2
Don't know/can't remember	305	44.5
Total[a]	685	
Treatment modality[b]		
Received/currently receiving		
Prostatectomy	436	43.6
Radiotherapy	446	44.6
Brachytherapy	99	9.9
Hormone therapy	438	43.8
Chemotherapy	101	10.1
High-intensity ultrasound	16	1.6
Active surveillance	162	16.2
Watchful waiting	122	12.2
Treatment degree		
Considering treatment or monitoring	22	2.2
Had a single treatment modality	398	40.1
Had multiple treatment modalities	573	57.7
Total[a]	993	
Treatment status		
Considering treatment or monitoring	22	2.2
On treatment	366	36.9
Finished treatment up to 1 year ago	204	20.5
Finished treatment 1 or more years ago	401	40.4
Total[a]	993	
Last assessed by clinician		
Within the last year	657	66.8
One year ago	93	9.5
2 years ago	64	6.5
3 years ago	40	4.1
4–13 years ago	130	13.1
Total[a]	984	
Health state (rating 0–100)		
Rated under 50	76	8.0
Rated 50–74	319	33.6
Rated 75–100	554	58.4
Total[a]	949	
Anxiety/depression (mental affect)		
Not anxious or depressed	635	66.3
Moderately or extremely depressed	323	33.7
Total[a]	958	

[a] Total excludes missing data.
[b] Participants may have had more than one treatment.

Relatively few studies have hitherto researched how supportive nursing intervention can have an impact on men's outcomes after prostate cancer treatment (Ream *et al*, 2009; Cockle-Hearne and Faithfull, 2010; Chambers *et al*, 2011; Faithfull *et al*, 2011; Sussman *et al*, 2011). Systematic reviews on efficacy of specialised oncology nursing interventions offer evidence that nurse provision leads to improvements in the management of chronic problems and increases patient knowledge and self-management; it can also lead to reduced use of acute services and improve patient symptoms (Corner, 2003; Sussman *et al*, 2004). Subsequently, nurse-led care and coordination roles have been promoted as an important component of breast cancer services (Eicher *et al*, 2012) and have been embraced by cancer teams as part of quality care provision (Roselli Del Turco *et al*, 2010). Strong evidence that the provision of breast cancer clinical nurse specialists has a psychological impact on women has come from randomised trials both during and after treatment. These studies indicate that nurse intervention reduces anxiety (Wengstrom *et al*, 2001; Yates *et al*, 2005), distress and depression (Strong *et al*, 2008; Fors *et al*, 2011) and increases satisfaction in women compared with usual care (Aranda *et al*, 2006; Beaver *et al*, 2012). However, in a randomised trial of specialist nursing support for women compared with that provided by a psychologist there were no significant differences in outcome (Arving *et al*, 2006). This would suggest that it is the quality of contact and/or the intervention targeted against the need, rather than necessarily the role, that has an impact on patient experience. Such a targeted intervention model has been evaluated in Canada with specialist community nurses providing care coordination: this led to a marked improvement in patients' unmet supportive care needs (Sussman *et al*, 2011). Defining the individual dimensions of supportive care required by men in this present study has provided potential targets for cancer nursing intervention within Europe. Fundamental to this is a comprehensive understanding of patient-specific need as an essential precursor to appropriate interventions and for facilitating access to relevant supportive care services as well as training staff to meet those needs (Stricker *et al*, 2011; Chubak *et al*, 2012).

Table 3. Prevalence of unmet need

	No need		Some need	
N **= 1001**	***n***	**% of total**	***n***	**% of total**
Total need	**186**	**18.6**	**771**	**80.6**
Supportive care need domains				
Psychological	325	34.9	607	65.1
Sexuality	377	39.7	573	60.3
Health systems and information	380	40.3	563	59.7
Physical and daily living	559	59.0	388	41.0
Patient care and support	566	59.3	389	40.7
Prostate-specific symptoms				
Urinary incontinence/difficulties in passing urine	583	60.5	380	39.5
Hot flushes/feeling as if you are going through a change of life like women do	644	66.3	327	33.7
Problems with your bowel habits	710	73.6	255	26.4
Totals exclude missing data				

It is clear that treatment factors remain important predictors of patient outcome. Men in this study reported higher levels of unmet need in relation to specific treatment modalities, including chemotherapy, which was strongly predictive of need for help with physical and daily living issues, and radical prostatectomy, which was predictive of unmet sexuality needs. Men, who had had radiotherapy, were less likely to have psychological need than men who had not. These unmet needs are consistent with recent prospective clinical studies comparing radiotherapy and prostatectomy; men who underwent radical prostatectomy were five times more likely to have urinary incontinence and twice as likely to have erectile dysfunction at 5 years than those men in the radiotherapy group (Resnick *et al*, 2013b). Late effects from prostate cancer treatment are often time-dependent and men's lifestyle and co-morbidity can have an impact on rectal, urinary and erectile dysfunction (Thomas *et al*, 2013). Sexual dysfunction is common in the older population and co-morbidities have an impact on the complexity of predicting erectile problems post treatment (Nelson *et al*, 2010). It is therefore important to have discussions with men about prevention and possible management of erectile dysfunction before and after therapy (Salonia *et al*, 2012).

The potential weakness of this study was that it was a 'snap shot' in time of symptoms and unmet needs; it was therefore not possible to differentiate co-morbidities from those of prostate treatment effects. We did not find a relationship between age, education or living status and unmet need, which has been found

Table 4. Dimensions of supportive nursing care

	Did not see a nurse at all			When a nurse was seen support and advice received		
Total		**1001**	**%**		**1001**	**%**
Advice about screening	Did not see a nurse Total^a	421 931	45.2	Had support Total^b	426 510	83.5
Information and support at the time of diagnosis	Did not see a nurse Total^a	303 919	33.0	Had support Total^b	515 616	83.6
Help choosing treatment options	Did not see a nurse Total^a	415 897	46.3	Had support Total^b	320 482	66.4
Provided enough immediate care after treatment	Did not see a nurse Total^a	198 962	20.6	Had support Total^b	683 764	89.4
Information and advice about side effects that occur after treatment	Did not see a nurse Total^a	284 935	30.4	Had support Total^b	524 651	80.5
Information, advice and support about longer-term side effects	Did not see a nurse Total^a	432 926	46.7	Had support Total^b	307 494	62.1
Gave emotional support to me and/or my family and friends	Did not see a nurse Total^a	378 956	39.5	Had support Total^b	436 626	69.6
Referral to other services	Did not see a nurse Total^a	533 952	56.0	Had support Total^b	239 419	57.0
Advice about home care	Did not see a nurse Total^a	523 956	54.7	Had support Total^b	286 433	66.1

[a] All participants who responded to question.
[b] All participants who indicated they had seen a nurse for that aspect of care.

Table 5. Predictors of unmet supportive care needs

Domain	Predictor	Estimate[a]	Standard error[a]	*P*-value[a]	Odds ratio[a] (95% confidence interval)
Psychological	Country (reference: Denmark)	–	–	–	–
	France	−0.377	0.649	0.561	0.686 (0.192, 2.447)
	Ireland	0.701	0.614	0.253	2.016 (0.605, 6.716)
	The Netherlands	0.006	0.484	0.990	1.006 (0.390, 2.598)
	Spain	1.539	0.446	0.001	4.658 (1.942, 11.170)
	Turkey	0.426	0.675	0.528	1.531 (0.407, 5.751)
	UK	−0.390	0.533	0.464	0.677 (0.238, 1.923)
	Stage (reference: Stage I)	–	–	–	–
	Stage 2	1.166	0.364	0.001	3.209 (1.573, 6.548)
	Stage 3	1.095	0.404	0.007	2.988 (1.353, 6.599)
	Stage 4	1.168	0.497	0.019	3.216 (1.214, 8.515)
	Do not know; cannot remember	0.785	0.309	0.011	2.192 (1.196, 4.019)
	Receiving/received radiotherapy(reference: not had)	−0.471	0.232	0.043	0.625 (0.396, 0.985)
	Mental affect (reference: not anxious or depressed)	–	–	–	–
	Moderately/extremely anxious or depressed	2.029	0.323	<0.001	7.604 (4.037, 14.325)
	Health state	−0.040	0.008	<0.001	0.961 (0.945, 0.976)
	Nursing care (reference: had advice and support)	–	–	–	–
	No nurse advice for treatment side effects	0.124	0.366	0.735	1.132 (0.553, 2.319)
	No nurse contact for treatment side effects	0.912	0.315	0.004	2.490 (1.343, 4.616)
	No nurse advice for longer-term effects	0.747	0.344	0.030	2.111 (1.076, 4.144)
	No nurse contact for longer-term effects	−0.050	0.293	0.865	0.951 (0.536, 1.690)
	Paper format (reference: on-line)	−0.914	0.379	0.016[a]	0.401 (0.191, 0.842)
Sexuality	Country (reference: Denmark)	–	–	–	–
	France	0.748	0.355	0.035	2.112 (1.053, 4.235)
	Ireland	0.093	0.375	0.803	1.098 (0.526, 2.291)
	The Netherlands	−0.070	0.243	0.774	0.933 (0.579, 1.502)
	Spain	1.144	0.307	<0.001	3.138 (1.720, 5.727)
	Turkey	0.330	0.457	0.470	1.391 (0.568, 3.406)
	UK	−0.328	0.260	0.208	0.720 (0.432, 1.200)
	Time since diagnosis (reference: within last month)	–	–	–	–
	1–2 months	2.322	0.960	0.016	10.199 (1.553, 66.955)
	3–6 months	0.974	0.618	0.115	2.649 (0.788, 8.901)
	7–12 months	1.028	0.602	0.088	2.796 (0.857, 9.127)
	1–2 years	0.782	0.585	0.182	2.186 (0.693, 6.897)
	3–4 years	0.802	0.589	0.174	2.230 (0.702, 7.085)
	5–10 years	0.625	0.581	0.282	1.869 (0.597, 5.850)
	More than 10 years	0.686	0.624	0.272	1.986 (0.583, 6.758)
	Receiving/received prostatectomy (reference: not had)	0.453	0.160	0.005	1.573 (1.150, 2.153)
	Mental affect (reference: not anxious or depressed)	–	–	–	–
	Moderately/extremely anxious or depressed	0.560	0.183	0.002	1.751 (1.225, 2.505)
	Health state	−0.022	0.005	<0.001	0.978 (0.969, 0.988)
	Nursing care (reference: had advice and support)	–	–	–	–
	No nurse advice about home care	0.734	0.260	0.005	2.083 (1.252, 3.466)
	No nurse contact about home care	0.105	0.187	0.574	1.111 (0.770, 1.605)
Patient care and support	Stage (reference: Stage I)	–	–	–	–
	Stage 2	0.691	0.335	0.039	1.997 (1.035, 3.850)
	Stage 3	0.502	0.357	0.160	1.652 (0.820, 3.329)
	Stage 4	0.663	0.406	0.103	1.940 (0.875, 4.303)
	Do not know/cannot remember	0.485	0.284	0.088	1.624 (0.930, 2.836)
	Mental affect (reference: not anxious or depressed)	–	–	–	–
	Moderately/extremely anxious or depressed	1.038	0.220	<0.001	2.823 (1.833, 4.348)
	Health state	−0.019	0.006	0.002	0.981 (0.969, 0.993)
	Nursing care (reference: had advice and support)	–	–	–	–
	No nurse advice for after-care	1.614	0.395	<0.001	5.020 (2.316, 10.882)
	No nurse contact for after-care	0.153	0.263	0.560	1.166 (0.696, 1.953)
	No nurse advice for longer-term effects	0.995	0.278	<0.001	2.706 (1.570, 4.664)
	No nurse contact for longer-term effects	0.571	0.234	0.015	1.770 (1.119, 2.800)

Table 5. (Continued)

Domain	Predictor	Estimate[a]	Standard error[a]	*P*-value[a]	Odds ratio[a] (95% confidence interval)
Health system and information	Country (reference: Denmark)	–	–	–	–
	France	0.421	0.479	0.380	1.523 (0.595, 3.898)
	Ireland	– 0.380	0.540	0.481	0.684 (0.237, 1.970)
	The Netherlands	– 0.153	0.362	0.672	0.858 (0.422, 1.744)
	Spain	1.325	0.448	0.003	3.764 (1.563, 9.067)
	Turkey	0.483	0.627	0.441	1.621 (0.474, 5.542)
	UK	0.071	0.386	0.854	1.074 (0.503, 2.289)
	Stage (reference: Stage I)	–	–	–	–
	Stage 2	0.788	0.334	0.018	2.199 (1.142, 4.236)
	Stage 3	1.220	0.369	0.001	3.389 (1.645, 6.979)
	Stage 4	1.169	0.451	0.010	3.219 (1.330, 7.791)
	Do not know/cannot remember	0.734	0.280	0.009	2.083 (1.203, 3.607)
	Time since last assessed	– 0.130	0.044	0.004	0.878 (0.805, 0.958)
	Mental affect (reference: not anxious or depressed)	–	–	–	–
	Moderately/extremely anxious or depressed	1.000	0.253	<0.001	2.718 (1.654, 4.465)
	Health state	– 0.017	0.007	0.012	0.983 (0.970, 0.996)
	Nursing care (reference: had advice and support)	–	–	–	–
	No nurse advice for longer-term effects	1.264	0.318	<0.001	3.539 (1.899, 6.596)
	No nurse contact for longer-term effects	0.937	0.255	<0.001	2.553 (1.549, 4.205)
	No nurse advice about home care	1.018	0.354	0.004	2.769 (1.383, 5.544)
	No nurse contact about home care	0.130	0.259	0.615	1.139 (0.686, 1.892)
Physical and daily living	Receiving/received chemotherapy (reference: not had)	1.716	0.316	<0.001	5.561 (2.995, 10.324)
	Treatment status (reference: on treatment)	–	–	–	–
	Finished treatment up to 1 year ago	0.260	0.215	0.226	1.296 (0.851, 1.974)
	Finished treatment 1 or more years ago[b]	– 0.489	0.185	0.008	0.613 (0.427, 0.881)
	Mental affect (reference: had advice and support)	–	–	–	–
	Moderately/extremely anxious or depressed	0.866	0.170	<0.001	2.377 (1.704, 3.315)
	Health state	– 0.043	0.005	<0.001	0.958 (0.948, 0.968)
	Paper format (reference: on-line)	– 0.489	0.165	0.003	0.614 (0.444, 0.848)

Based on observed data: psychological domain specificity 57.9%, sensitivity 85.7% Youden index 0.436; sexuality domain specificity 51.6% sensitivity 78.2% Youden index 0.564; health system and information domain specificity 55.0% sensitivity 82.5% Youden index 0.375; patient care and support domain specificity 81.4% sensitivity 50.2% Youden index 0.316; physical and daily living domain specificity 84.1% sensitivity 58.4% Youden index 0.425.

[a] Pooled multiple imputation results.

[b] For patients who have received treatment (those considering treatment have been taken into account in the modelling – no significant difference was found between patients considering treatment and those who have received treatment (physical and daily living *P*-value 0.823).

in other studies (Steginga *et al*, 2001; Lintz *et al*, 2003; Smith *et al*, 2007; Ream *et al*, 2008). However, living in Spain was associated with a higher probability of unmet sexuality, psychological and health system and information need, and living in France was also associated with a higher probability of unmet sexuality need. This may be the result of differing cultural expectations in relation to sexual attitudes in these two countries. Men with cancer are less likely than women to recognise the need for help because of cultural and societal barriers especially in relation to sexual issues (Courtenay, 2000; Tamres *et al*, 2002; Hautamaki-Lamminen *et al*, 2013). It should also be emphasised that the association of unmet need with the country of residence in this study was independent of the effect of supportive nursing care as measured.

An important theme emerging from the analysis was the lack of support for on-going symptoms and concerns after treatment and their association with unmet need. Evidence from a recent patient-reported outcome study within the United Kingdom (DoH, 2012) suggested information and preparation for cancer follow-up is limited. Patients described being ‘cut adrift’ by the health system after active therapy (Corner *et al*, 2013). Patient satisfaction with health-care provision is an important measure in assessing the structure and process of cancer care, and is associated with reduced quality-of-life including decline in post-treatment physical function (Resnick *et al*, 2013a). In this present study, recent assessment by a clinician and being a year or more out of treatment were significant predictors of unmet need, indicating that clinician contact paradoxically did not always address men’s needs. This is also confirmed in a longitudinal study of patients after cancer treatment, despite follow-up checks over 30% of patients, who had symptoms at the end of therapy, continued to experience such symptoms 12 months later (Armes *et al*, 2009). Providing long-term care for prostate cancer patients has been reported as challenging especially in primary care (Zhou *et al*, 2010). In the United States of America, studies have shown that only a minority of physicians feel able to manage the consequences of cancer treatment (McCabe *et al*, 2011; Skolarus *et al*, 2011; Chubak *et al*, 2012). Oncologists in the UK have also shown concern that primary care doctors have little experience of follow-up and longer-term effects of prostate cancer treatment (Watson *et al*, 2011). The predictive model in this study shows that unmet need can change over time in that men were much more likely to need help with sexuality issues when they had been recently diagnosed; however, as stage of disease progressed, unmet psychological, patient care and information needs remained.

Despite this being the first study in Europe to examine the relationship of supportive nursing care to patients' unmet needs, and the comparatively successful response to the survey, there are strengths and weaknesses. In using the SCNS, we have examined some need *vs* no need; in contrast, some studies have categorised only moderate-to-severe need (Armes *et al*, 2009). We believe that it is important for defining supportive care packages to consider the range of unmet need since, if not supported, low need can become moderate or even high need at a later stage. A further strength of this study is that it is based on the more sensitive measurement of unmet need, that is, assessing where help is needed, rather than on quality-of-life, which in this population may not consistently differentiate from the norm. A limitation with the SCNS is that it has been validated for paper and electronic administration via touch-screen computer (Boyes *et al*, 2002), but not currently for on-line use. There is evidence from this study that the tool could perform differently on psychological and physical and daily living domains when administered on-line: the statistical modelling indicated that men who completed the paper version were significantly less likely to have unmet need in these domains than men who completed the survey via the internet. This difference in performance is unlikely to be the result of format selection bias, as choice of format in this survey was not given at the point of completion. However, there may have been some bias in the clinic setting where paper was more easy to complete. Further research would need to clarify this variation in the tool. A potential limitation of this study is that the outcomes are based on reported measures of nursing care, rather than on observed practice. However, the patient perspective is important in that it tells us what patients value in managing their care, and this is a crucial aspect to incorporate in evaluating cancer services within a patient-centred care framework (Velikova *et al*, 2002; Luckett *et al*, 2009).

A fundamental shift is required in survivorship care to improve outcomes for men with prostate cancer, especially after treatment is completed. Furthermore, more consistent provision of nurses across the care pathway, with training to address sexual dysfunction and psychological care, should be a priority for enhancing supportive care. The provision of information, symptom management and long-term side effects are areas in need of improvement. Recognition of specialist nurses within cancer multidisciplinary teams is not consistent across Europe and their inclusion should be essential in defining quality prostate cancer care. As the population of men increases, so will the need for monitoring and management. Whether after-care is received from oncology, urology or primary care, it is important that all health-care professionals recognise the extent of long-term consequences experienced by cancer patients. Health-care services therefore need to provide effective and targeted supportive care for men after prostate cancer treatment to meet this growing population of survivors.

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CONFLICT OF INTEREST

The authors declare no conflict of interest.

AUTHOR CONTRIBUTIONS

JC-H and SF conceived the design of the study and acquisition of the data. JC-H, SF, DK, FC-S, LD, HEF and BTJ were responsible for the design and analysis of the study. JC-H, KL, EvM, FC-S, PF-O, BTJ and SK were responsible for undertaking data collection within their respective European countries. The initial draft of the paper was produced by JC-H, HEF and SF, and circulated between all authors for critical revision. All authors read and approved the final manuscript.

ETHICS APPROVAL

This work was reviewed in the UK by the South East Coast Surrey Research Ethics Committee (Rec Ref 11/LO/0738) and approval given on 8 June 2011.

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