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Key factors associated with social distress after prostate cancer: Results from the United Kingdom Life after Prostate Cancer diagnosis study

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ABSTRACT

Background: More men are living following a prostate cancer (PCa) diagnosis. They may need support to maximize the quality of their survival. Physical and psychological impacts of PCa are widely documented. Less is known about social impacts. We aimed to identify key factors associated with social distress following PCa.

Methods: The Life After Prostate Cancer Diagnosis study is a UK national cross-sectional survey of men 18–42 months post diagnosis of PCa. Men (n = 58 930) were invited to participate by their diagnosing cancer centre including 82% of English NHS Trusts (n = 111) and 100% of all Health Boards in Northern Ireland (n = 5), Scotland (n = 14) and Wales (n = 6). Social distress was measured using the Social Difficulties Inventory (SDI-21), 16 item Social Distress scale with men assigned to 'socially distressed'/'not socially distressed' groups, according to published guidelines. Clinical and sociodemographic variables were collected from self-report and cancer registries.

Results: Response rate 60.8% (n = 35 823) of whom 97% (n = 29 351) completed the Social Distress scale (mean age = 71.2; SD = 7.88). The proportion of 'socially distressed' men was 9.4%. Multivariable logistic regression analysis revealed unemployment versus employment (odds ratio (OR): 11.58 [95% CI 9.16–14.63]) and ≥3 co-morbidities versus none (OR: 5.37 [95% CI 4.61–6.27]) as key associations. Others were Androgen Deprivation Therapy, External Beam Radiotherapy in combination with another treatment, age, prior mental health problems and living in a socio-economically deprived area.

Conclusion: Most men following PCa are socially resilient. A simple checklist could help clinicians identify men at risk of social distress.

1. Introduction

Prostate cancer (PCa) is the second most common cancer in men in the developed world. Over recent decades PCa incidence and prevalence has increased considerably across Europe and in the United States (US) following introduction of prostate-specific antigen (PSA) testing [1]. The physical symptoms and late effects of the disease and treatments are widely documented, particularly concerning sexual, urinary and bowel function [2,3]. Depression and anxiety are recognised psychological issues [4]. Less is known about the social impact of PCa diagnosis and treatment on everyday life, at home, at work, financially and recreationally [5]. As cancer patients surviving longer, they must be supported to maximise their rehabilitation [6].

In the United Kingdom (UK), large scale Patient Reported Outcome

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Measure (PROM) surveys linked with clinical data have been recommended to examine the scale of psychosocial issues faced by cancer survivors and to inform delivery of clinical care, service planning and policy decision making [7,8]. An English national survey of colorectal cancer survivors allowed for complex predictive analyses of social distress using the Social Difficulties Inventory, (SDI-21) [9,10], a questionnaire designed to measure everyday social impacts following cancer diagnosis [11]. Major associations with social distress were multi-morbidity, unemployment, advanced disease, younger age and living in more deprived areas. Pilot surveys have included social distress assessment but the numbers surveyed precluded detailed multivariable analyses [12]. The National Health Service (NHS) England pilot of 866 men with PCa, one to five years post diagnosis, demonstrated a trend for men with PCa to be less socially distressed than patients from other tumour groups [12].

Ideally, screening programs integrated into routine care might identify men who would benefit from psychosocial support or rehabilitation. The UK National Cancer Survivorship Initiative promoted including social assessment as part of comprehensive programmes of supportive care [8]. In the United States, a taskforce examined evidence and made recommendations regarding cancer rehabilitation to meet the needs of cancer survivors [13]. One barrier identified to integrating rehabilitation into oncology care was a lack of PROMs for assessment within the social domain (e.g. communication, employment, community and social participation). In Canada, the Distress Assessment and Response Tool (DART) program has overcome many challenges faced in routine distress screening, including choice of assessment tools [14]. DART includes the SDI-21 which covers the social domain issues outlined above, and has demonstrated usefulness by being a key indicator of suicidal ideation and intention [15]. However, many cancer care services may be unable to introduce routine psychosocial and rehabilitation screening due to practical and financial challenges. Identifying ‘at risk’ patients using known factors associated with social distress may be a more realistic option for many clinicians. As PCa is one of the most common cancers with which men may live for many years following diagnosis, early identification of men who may benefit from support and rehabilitation must become a key component of follow-up care.

The Life After Prostate Cancer Diagnosis (LAPCD) study is a large UK-wide evaluation of quality of life (QoL) in men diagnosed with PCa [16]. The aim of this sub-study is to utilise LAPCD data to identify key factors associated with social distress in men with PCa, thus informing clinical practice and enabling prompt recognition of the most vulnerable men likely requiring support to optimise their quality of survival.

2. Material and methods

2.1. Study design

The LAPCD study design has been detailed previously [16]. In brief, men with PCa between 18 and 42 months post diagnosis identified through national cancer registration systems in England, Wales and NI, and through hospital activity data in Scotland, were eligible to participate. They were invited to participate by their diagnosing cancer centre. Two reminders were sent to non-responders. The survey was run between October 2015 and November 2016. Ethical approval was provided by: Newcastle & North Tyneside 1 Research Ethics Committee (15/NE/0036), Confidentiality Advisory Group (15/CAG/0110), NHS Scotland Public Benefit and Privacy Panel (0516-0364), and NHS R&D approval from Wales, Scotland and Northern Ireland. Informed consent was accepted as given on return of a completed survey.

2.2. Main outcome and measures

The survey comprised validated PROMs covering generic and PCa specific domains alongside psychological and social outcomes. Participants were asked to provide information about their cancer diagnosis and treatment in addition to a number of sociodemographic questions. For full survey content see supplementary file 01.

2.2.1. The Social Difficulties Inventory (SDI-21)

The main outcome of social distress was measured using the SDI-21, developed specifically for cancer patient assessment [11]. The SDI-21 has been positively reviewed [17] and used in a number of previous national surveys [10,12]. The 21 items have four response options (0 – no difficulty through to 3 – very much difficulty). Sixteen items form a scale named Social Distress (SD-16) with a range of scores of 0–44 with a cut-point indicating “meaningful Social Distress of ≥10 (derived following social worker assessment) [18].” Men were categorised into one of two groups (socially distressed/not socially distressed) based on this cut-point. Within the SD-16 there are three subscales: Everyday Living (6 items), Money Matters (5 items) and Self and Others (5 items) [19]. There are five single items, of which two were included in the LAPCD survey (Plans to have a family and Holidays). Three single items (Sexual matters, Where you live, Other) were omitted with permission of the originators (PW, PS) to avoid item duplication within other included scales and to reduce participant burden. The items are numbered 31–48 in supplementary file 01.

2.2.2. Clinical and sociodemographic variables

Cancer stage grouping (I–IV) at time of diagnosis was provided from national population-based cancer registries. A measure of area-based socio-economic deprivation was derived from postcodes of residence using Index of Multiple Deprivation (IMD) [20–23]. Participant self-reported Long Term Conditions (LTCs) from a list of 14 (e.g. diabetes, heart disease) (supplementary file 01, question 84) were counted and categorised as 0 1, 2,or ≥3 comorbidities, height and weight (to generate Body Mass Index (BMI)), ethnicity, marital status, employment status, sexuality, carer status and whether or not in the past they had consulted a health-care professional for problems with emotions or nerves or use of alcohol or drugs (referred to from here on as mental health-related problems). Age at the time of the survey was self-reported, and where missing supplemented by cancer registration records. Four age groups were generated (years: < 60, 60–69, 70–79, 80 +). PCa treatments (e.g. surgery, radiotherapy, androgen deprivation therapy (ADT), systemic (chemotherapy/Abiraterone/Enzalutamide) and monitoring (active surveillance (AS), watchful waiting)) were participant self-reported. Based on these self-reports, several groups of men were excluded from the analyses where their responses indicated they were unsure about the specific treatment type (s) received (supplementary file-02).

2.3. Statistical analyses

Analyses were performed using Stata version 15.0 (StataCorp, TX, USA). Missing SDI-21 data were imputed with the mean responses within each SDI-21 subscale if ≥50% of items on the subscales were complete.

Descriptive statistics were used to compare the characteristics of responders and non-responders to the SDI-16, SD-16 subscales and the two single items. Chi-square analyses compared categorical variables. Univariable analyses assessed associations between the sociodemographic and treatment variables described above and social distress. Multivariable logistic regression analyses were performed to assess associations with the independent sociodemographic and treatment variables and distress according to SD-16 (binary outcome < 10 vs. ≥10) and each of the subscales (cut-points for each derived from earlier work: Everyday Living ≥5, Money Matters ≥2, Self and Others ≥3) [10].

Table 1
Characteristics of the men who completed the SD-16.

Variables		UK-wide men with prostate cancer (N = 29,351)		
Characteristics		N	(%)	Missing
Age	< 60 years	2,163	7.4	2
	60–69 years	10,191	34.7	
	70–79 years	12,644	43.1	
	80+ years	4,351	14.8	
Deprivation (Quintile of socio-economic deprivation)	Most affluent 1	7,960	27.8	668
	2	7,788	27.1	
	3	6,021	21	
	4	4,192	14.6	
	Least affluent 5	2,722	9.5	
Ethnicity	White	27,813	97.3	752
	Non-White	786	2.7	
Long term conditions	0	8,577	29.2	0
	1	10,353	35.3	
	2	5,798	19.8	
	3+	4,623	15.8	
Consulted for mental health related problem	Yes	4,932	17.2	682
	No	23,737	82.8	
Caring responsibilities	Yes	6,846	24.2	1025
	No	21,480	75.8	
Legal marital status	Married/Civil Partner	23,411	80.5	264
	Separated/ Divorced	2,109	7.3	
	Widowed	2,126	7.3	
	Single	1,058	3.6	
	Other	383	1.3	
Employment status	Employed	5,974	20.9	784
	Unemployed	582	2	
	Retired	21,804	76.3	
	Other	207	0.7	
Body Mass Index (Kg/m^2)	< 25	8,409	30.9	2096
	25–30	13,126	48.2	
	> 30	5,720	21	
Prostate cancer stage at diagnosis	I/II	16,338	64.6	4061
	III	5,801	22.9	
	IV	3,151	12.5	
Treatment	Active surveillance	2,869	9.8	0
	Surgery alone	6,919	23.6	
	EBRT alone	2,442	8.3	
	Brachytherapy alone	1,190	4.1	
	ADT alone	2,990	10.2	
	Watchful waiting	2,211	7.5	
	EBRT & ADT	7,337	25	
	Surgery & EBRT/ ADT	2,279	7.8	
	ADT & systemic	609	2.1	
	EBRT & systemic	505	1.7	

Key: SD-16: Social Distress scale. EBRT: External beam radiotherapy. ADT: Androgen deprivation therapy. Systemic (chemotherapy/Abiraterone/ Enzalutamide). Long term conditions reported were counted from a list of 14 and categorised into one of the four groups (0, 1, 2, ≥3).

3. Results

3.1. Response rates

All health boards in Scotland, Wales, NI and 111/136 NHS Trusts in England participated (supplementary file-03) resulting in inclusion of 58,930 men, which is approximately 82% of all men diagnosed in the UK with PCa during the study period. The response rate was 60.8% (35,823/58,930). After excluding the men who did not report or were unsure about their received treatments, (n = 5709; 15.9%), 30,114 survey responses were available for analysis. Of those, 97% (n = 29,351) contained the full SD-16 and completion rates for single items were: plans to have a family (87.8%); plans to travel or take a holiday (97.7%). Of the men not providing treatment information, 14.3% (n = 772) were above the SD-16 cut-point indicating significant social distress (supplementary file-02).

3.2. Characteristics of SD-16 respondents

SD-16 respondent' characteristics are presented in Table 1. The mean age of the men was 71.2 years (SD = 7.88) with most ≥60 years old (92.6%) and white (94.4%). The proportion of men under 60 years old who were unemployed was 10.6% compared with the older men (1.3%). Those living in affluent areas were over-represented compared with non-responders. Non-responders to the SD-16 were more likely to be non-white ($p < .001$) and living in areas of greater deprivation ($p < .001$). The percentage of missing data was less than 3% for participant characteristics, barring BMI (calculated from participant self-reported weight and height) at 7.2% and for stage of PCa at the time of diagnosis (from cancer registration records; 13.8%).

3.3. SD-16

The median SD-16 score was 1, range 0–44 and Interquartile range (IQR) 0–4. Just under 10% of men (2766/29,351) indicated social distress (SD-16 score ≥10). The proportion of men indicating social distress and univariable associations are shown in Table 2. Table 3 presents results of the multivariable logistic regression. Being unemployed at the time of survey was most strongly associated with social distress, followed by having ≥3 comorbid LTCs. Other clear associations with social distress included External Beam Radiotherapy (EBRT) in addition to another treatment, ADT, being under 60 years old, having ever consulted a healthcare professional for mental health-related problems and living in areas of greater socio-economic deprivation. To a lesser extent, separated/divorced, having stage IV disease, having caring responsibilities, and a BMI > 30 were also associated with social distress.

3.4. SD-16 subscales

Multivariable logistic regression indicated unemployment was most strongly associated with distress on all three subscales (Table 4). Having ≥3 comorbid LTCs was related to significant distress across all subscales but especially Everyday Living. Type of treatment impacted on all subscales, with systemic therapy and ADT alone having a greater influence on Everyday Living and Self and Others than Money Matters. Other factors independently associated with distress on all three subscales included having seen a healthcare professional for mental health-related problems, living in an area of greater socio-economic deprivation, having caring responsibilities, being diagnosed with stage IV PCa and having a BMI > 30. Older age (80+) was a significant risk factor for distress on the Everyday Living subscale but had a protective effect on the other two subscales. Being of non-white ethnicity was associated with distress on the Money Matters subscale only. See Table 4 for full results.

3.5. Single items

The percentages of men reporting 'quite a bit of difficulty' or 'very much difficulty' were 4.2% for "Plans to have a family" and 12.3% for "Holidays".

4. Discussion

This is the largest study we know of to date, examining the social impact of PCa on those living with and beyond the disease. Reassuringly, and of importance, is the finding that most men were socially resilient following a diagnosis of PCa. The key associations with social distress were non-cancer related, such as unemployment and

Table 2
Proportion of respondents who scored ≥10 on SD-16 by characteristics.

Characteristic		UK men with prostate cancer (N = 2,766)		
		N	%	p
Age	< 60 years	325	15	< 0.01
	60-69 years	956	9.4	
	70-79 years	899	7.1	
	80+ years	586	13.5	
Deprivation (Quintile of socio-economic deprivation)	Most affluent 1	480	6	0.07
	2	608	7.8	
	3	584	9.7	
	4	529	12.6	
	Least affluent 5	498	18.3	
Ethnicity	White	2,101	8.9	< 0.01
	Non-White	126	15.4	
Long term conditions	0	403	4.7	< 0.01
	1	660	6.4	
	2	668	11.5	
	3+	1,035	22.4	
Consulted for mental health related problem	No	1,795	7.6	< 0.01
	Yes	883	17.9	
Carer status	No	1,855	8.6	< 0.01
	Yes	766	11.2	
Legal marital status	Married/Civil Partner	1,986	8.5	< 0.01
	Separated/ Divorced	331	15.7	
	Widowed	229	10.8	
	Single	130	12.3	
	Other	55	14.4	
Employment status	Employed	376	6.3	< 0.01
	Unemployed	343	58.9	
	Retired	1,928	8.8	
	Other	36	17.4	
Body Mass Index (Kg/m^2)	< 25	623	7.41	< 0.01
	25-30	1,005	7.66	
	> 30	824	14.41	
Stage	I/II	1,331	8.1	< 0.01
	III	548	9.4	
	IV	489	15.5	
Treatment	Active surveillance	188	6.6	< 0.01
	Surgery alone	503	7.3	
	EBRT alone	196	8	
	Brachytherapy alone	50	4.2	
	ADT alone	469	15.7	
	Watchful waiting	181	8.2	
	EBRT & ADT	702	9.6	
	Surgery & EBRT/ ADT	274	12	
	ADT & systemic	105	17.2	
	EBRT & systemic	98	19.4	

Key: SD-16: Social Distress scale. EBRT: External beam radiotherapy. ADT: Androgen deprivation therapy. Systemic (chemotherapy/Abiraterone/Enzalutamide). p values represent level of significance in a chi-squared test, significance was indicated at the 0.05 level.

Table 3
Logistic regression analyses for Social Distress.

		Odds Ratio	95% Confidence interval	p
Age	< 60 years	1		
	60–69 years	0.55	0.45–0.67	< 0.01
	70–79 years	0.41	0.33–0.51	< 0.01
	80+ years	0.69	0.54–0.88	< 0.01
Deprivation (Quintile of socio-economic deprivation)	Most affluent 1	1		
	2	1.28	1.11–1.49	< 0.01
	3	1.43	1.23–1.66	< 0.01
	4	1.66	1.42–1.95	< 0.01
	Least affluent 5	2.3	1.95–2.72	< 0.01
Ethnicity	White	1		
	Non-White	1.29	0.99–1.67	0.06
Long term conditions	0	1		
	1	1.38	1.18–1.61	< 0.01
	2	2.63	2.25–3.08	< 0.01
	3+	5.37	4.61–6.27	< 0.01
Consulted for mental health related problem	No	1		
	Yes	2.23	2.00–2.48	< 0.01
Carer status	No	1		
	Yes	1.32	1.19–1.47	< 0.01
Legal marital status	Married/Civil Partner	1		
	Separated/ Divorced	1.48	1.26–1.74	< 0.01
	Widowed	1.07	0.89–1.29	0.46
	Single	0.89	0.70–1.15	0.37
	Other	1.56	1.10–2.23	0.01
Employment status	Employed	1		
	Unemployed	11.58	9.16–14.63	< 0.01
	Retired	1.19	1.02–1.39	0.02
	Other	2.39	1.55–3.7	< 0.01
Body Mass Index (Kg/m^2)	< 25	1		
	25-30	1.01	0.89–1.15	0.87
	> 30	1.52	1.33–1.75	< 0.01
Stage	I/II	1		
	III	1.09	0.96–1.23	0.18
	IV	1.44	1.24–1.67	< 0.01
Treatment	Active surveillance	1		
	Surgery alone	1.1	0.89–1.36	0.36
	EBRT alone	1.19	0.93–1.54	0.17
	Brachytherapy alone	0.54	0.36–0.81	< 0.01
	ADT alone	2	1.58–2.53	< 0.01
	Watchful waiting	1.2	0.92–1.56	0.17
	EBRT & ADT	1.4	1.14–1.73	< 0.01
	Surgery & EBRT/ ADT	1.83	1.44–2.33	< 0.01
	ADT & systemic	2.79	2.01–3.87	< 0.01
	EBRT & systemic	3.59	2.58–5	< 0.01

Key: EBRT: External beam radiotherapy. ADT: Androgen deprivation therapy. Systemic (chemotherapy/Abiraterone/Enzalutamide). The odds ratios with their 95% confidence intervals were estimated by multivariate logistic regression after controlling for the sociodemographic and clinical variables listed. An odds ratio greater than 1 represents a greater odds than the first group listed (reference category) of reporting social distress. To check for multi-collinearity between stage and treatment, two models were run. The first, shown above, included 'stage at diagnosis' in the model and the second excluded 'stage at diagnosis' from the model. The Odds Ratios for both models changed very little.

multi-morbidity.

As found in the colorectal cancer English national survey, being in either the youngest (< 60 years) or oldest (≥80 years) age groups was associated with higher levels of distress [10]. This may well be a reflection of 'life stage', with younger men more likely to have financial commitments (e.g. paying a mortgage, needing to provide an income) and having responsibilities for children [24]. In this study, younger men recorded higher levels of distress in the Money Matters subscale. They were also much more likely to report being unemployed than men over 60 years. Many of the younger men had changed employment status since diagnosis [25]. Unemployed men had almost twelve times higher odds of experiencing social distress than their employed or retired counterparts. The median age of men in Europe and in the United States of America (USA) at the time of their PCa diagnosis is decreasing [1]. This means more men of employment age will receive a PCa diagnosis than previously. This expanding group of younger men, and the smaller number of unemployed older men may benefit from information, signposting and advice regarding employment and financial matters from key trained staff [26]. This would need careful introduction, as research suggests men may be resistant to intervention for fear of losing control or due to striving for 'normality' [27]. For

Table 4
Logistic regression analyses for three SD-16 subscales.

Subscale		Everyday living			Money Matters			Self and others		
	Characteristics	Odds Ratio	95% Confidence interval	p	Odds Ratio	95% Confidence interval	p	Odds Ratio	95% Confidence interval	p
Age	< 60 years	1			1			1		
	60–69 years	0.87	0.70–1.08	0.2	0.61	0.53–0.71	< 0.01	0.49	0.42–0.57	< 0.01
	70–79 years	1.04	0.82–1.31	0.75	0.44	0.37–0.51	< 0.01	0.34	0.29–0.4	< 0.01
	80+ years	1.98	1.55–2.53	< 0.01	0.49	0.40–0.6	< 0.01	0.44	0.36–0.54	< 0.01
Deprivation (Quintile of socio-economic deprivation)	Most affluent 1	1			1			1		
	2	1.27	1.12–1.43	< 0.01	1.31	1.15–1.48	< 0.01	1.14	1.01–1.28	0.03
	3	1.36	1.20–1.55	< 0.01	1.36	1.20–1.55	< 0.01	1.08	0.95–1.23	0.23
	4	1.56	1.36–1.79	< 0.01	1.69	1.48–1.94	< 0.01	1.36	1.19–1.56	< 0.01
	Least affluent 5	2.26	1.96–2.61	< 0.01	2.19	1.89–2.53	< 0.01	1.6	1.38–1.85	< 0.01
Ethnicity	White	1			1			1		
	Non-White	1.04	0.81–1.33	0.79	1.79	1.46–2.19	< 0.01	1.08	0.85–1.36	0.53
Long term conditions	0	1			1			1		
	1	1.55	1.35–1.77	< 0.01	1.2	1.07–1.34	< 0.01	1.14	1.01–1.27	0.03
	2	2.77	2.42–3.18	< 0.01	1.7	1.50–1.92	< 0.01	1.78	1.57–2.01	< 0.01
	3+	6.29	5.50–7.2	< 0.01	2.34	2.06–2.67	< 0.01	2.44	2.15–2.78	< 0.01
Consulted for mental health related problem	No	1			1			1		
	Yes	1.77	1.60–1.95	< 0.01	1.66	1.51–1.83	< 0.01	2.5	2.28–2.74	< 0.01
Carer status	No	1			1			1		
	Yes	1.16	1.06–1.28	< 0.01	1.53	1.39–1.67	< 0.01	1.48	1.35–1.62	< 0.01
Legal marital status	Married/Civil Partner	1			1			1		
	Separated/Divorced	1.21	1.04–1.41	0.02	1.64	1.43–1.88	< 0.01	1.45	1.26–1.67	< 0.01
	Widowed	1.12	0.97–1.29	0.14	1.24	1.05–1.47	0.01	1.38	1.18–1.62	< 0.01
	Single	1.05	0.85–1.3	0.64	0.99	0.81–1.22	0.94	1.15	0.94–1.4	0.18
	Other	1.34	0.96–1.88	0.09	1.42	1.04–1.94	0.03	1.44	1.05–1.96	0.02
Employment status	Employed	1			1			1		
	Unemployed	13.18	10.36–16.75	< 0.01	5.81	4.69–7.19	< 0.01	4.55	3.68–5.63	< 0.01
	Retired	2.12	1.81–2.49	< 0.01	0.57	0.51–0.63	< 0.01	1.02	0.90–1.15	0.77
	Other	3.1	1.99–4.83	< 0.01	1.98	1.40–2.8	< 0.01	1.79	1.22–2.62	< 0.01
Body Mass Index	< 25	1			1			1		
	25-30	0.98	0.88–1.09	0.67	1.01	0.91–1.12	0.86	1.01	0.91–1.12	0.82
	> 30	1.65	1.47–1.85	< 0.01	1.29	1.15–1.46	< 0.01	1.4	1.24–1.58	< 0.01
Stage	I/II	1			1			1		
	III	1.13	1.02–1.25	0.02	1.08	0.97–1.2	0.14	1.12	1.01–1.25	0.03
	IV	1.44	1.27–1.63	< 0.01	1.47	1.28–1.68	< 0.01	1.26	1.10–1.45	< 0.01
Treatment	Active surveillance	1			1			1		
	Surgery alone	1.24	1.02–1.5	0.03	1.21	1.02–1.43	0.03	1.36	1.14–1.62	< 0.01
	EBRT alone	1.29	1.04–1.61	0.02	1.41	1.14–1.73	< 0.01	1.33	1.07–1.65	0.01
	Brachytherapy alone	0.8	0.57–1.12	0.19	0.85	0.64–1.13	0.27	0.9	0.67–1.21	0.48
	ADT alone	2.15	1.75–2.63	< 0.01	1.55	1.25–1.91	< 0.01	1.74	1.41–2.15	< 0.01
	Watchful waiting	1.34	1.07–1.67	0.01	1.17	0.93–1.47	0.17	1.32	1.05–1.66	0.02
	EBRT & ADT	1.53	1.27–1.84	< 0.01	1.37	1.15–1.63	< 0.01	1.65	1.38–1.97	< 0.01
	Surgery & EBRT/ADT	1.58	1.27–1.98	< 0.01	1.8	1.47–2.21	< 0.01	1.96	1.59–2.41	< 0.01
	ADT & systemic	3.31	2.49–4.4	< 0.01	1.8	1.33–2.45	< 0.01	2.71	2.01–3.64	< 0.01
	EBRT & systemic	4.63	3.46–6.19	< 0.01	2.07	1.51–2.83	< 0.01	2.65	1.95–3.6	< 0.01

Key: SD-16: Social Distress scale. EBRT: External beam radiotherapy. ADT: Androgen deprivation therapy. Systemic (chemotherapy/Abiraterone/Enzalutamide).

older men, their 'life stage' maybe reflects struggling with age-related fatigue and general physical decline, impacting recovery from treatment [24]. Multi-morbidity is strongly associated with older age, with the proportion of people in England with one or more diagnosed disease (s) increasing with age until plateauing at over 90% in the 85-plus age groups [28]. Having ≥3 comorbid LTCs increased the odds of social distress, almost five-fold. This echoes findings that multi-morbidity tends to be negatively associated with health related quality of life in men with PCa [29]. Similarly, a Danish study demonstrated the expressed need for rehabilitation was significantly increased in cancer patients with multi-morbidity and this was particularly marked in men with PCa [30].

There were a number of other health related factors independently associated with social distress but to a lesser extent: Men who had consulted a health/social care professional for mental health related problems and those with a BMI > 30 had greater odds of being socially distressed. PCa related clinical and treatment factors of most importance concerning social distress were being diagnosed with Stage IV disease and/or receiving systemic treatment or ADT. There may well be a case for, in addition to PCa related factors, multi-morbidity and other health related problems to be included in modelling for risk-stratified care planning. Referral for specialist rehabilitation (e.g. occupational therapy, physiotherapy, social work) may need to be a consideration for those with complex health problems.

The odds of men who lived in the areas of greatest socio-economic deprivation reporting significant social distress were almost twice compared with their most affluent counterparts. The proportion of distressed men increased across the socio-economic deprivation trajectory. The link between deprivation and poorer QoL has been observed elsewhere with role, social and emotional functioning, measured using the EORTC-QLQ-C30 at 12 months post radical prostatectomy, found to be influenced by income at the time of diagnosis [31]. Other indicators of greater social distress included being separated or divorced and having caring responsibilities. Having caring responsibilities impacted all three Social Distress subscales. As the population ages, 'mutual caring' is likely to become commonplace. Men with PCa

Box 1
Social distress checklist for men with prostate cancer.

Sociodemographic risk factors
Unemployed
Under 60 years old
Living in an area of socio-economic deprivation
Separated or divorced
Caring responsibilities
Non-White ethnicity
Clinical risk factors
Multiple co-morbidities
Has consulted a health/social care professional for a mental health, alcohol or drug related problem
Body Mass Index > 30
Prostate cancer related risk factors
Combination therapies
Androgen deprivation therapy
Advanced disease

caring for someone else may have to make difficult choices regarding treatment, based in part on their caring responsibilities. Checking ‘carer status’ across the patient pathway may help ensure discussion and support are provided in a timely manner. Being of non-white ethnicity was not associated with overall social distress, with Everyday Living or Self and Others subscales, but was of significance in the Money Matters subscale. In the UK, medical costs are paid for by the NHS. Where health costs are not part of a national health system the disparity between white and non-white ethnic groups may be wider. A qualitative metasynthesis of ethnicity and the experience of PCa highlighted the marked financial burden arising from the cost of treatment and services experienced by minority ethnic groups in the USA [32].

Although this survey included a very large sample, there are a number of limitations. The data reported are cross-sectional and therefore, although associations between variables may be strong, causation cannot be inferred. The data provide a ‘snap-shot’ of the experience of men between 18–42 months post PCa diagnosis. Stage of disease at the time of the survey was not known, therefore no measure of disease progression was available. The ProtecT study demonstrated that by 12 months, men with clinically localised disease at diagnosis had relatively stable physical and mental health scores which remained steady over the following five years [2]. In the LAPCD study almost two thirds of men were diagnosed with stage I or II disease, and therefore it seems possible that, as with physical and mental health, social distress may be relatively stable over this time period. Men with advancing disease may experience greater levels of social distress but this cannot be ascertained from the available data. Likewise, ongoing treatments may influence social distress but data were unavailable to test this. Self-report was the only way to collect all treatment information. Although less reliable than medical record review, agreement between self-report and record review has been found to be excellent for surgery and radiotherapy, with decreasing agreement for hormone therapies [33]. Many different treatment combinations were reported; some combinations too small to report separately. Based on clinical feedback, ten single and combination treatment groups with the largest numbers of men and highest clinical relevance were included in analyses. As data were missing both from cancer registration systems (e.g. stage at diagnosis) and from participant self-report (e.g. height and weight for BMI calculation), generalisation of the results should be undertaken with some caution. However, as the overall response rate was reasonably high (> 60%) and the sample size large, these findings remain the most comprehensive and highest quality available to date. As the response rates of non-white men and of men living in areas of greater socio-economic deprivation were lower than that of white men and of men living in less deprived areas, respectively, the level of social distress reported may be an underestimate. Co-morbidities were self-reported, which may be thought unreliable. However, a recent study demonstrated comorbidities reported by men with PCa were similar to those extracted from medical records [34]. Lastly, men who did not self-report or were unsure about their treatment were not included in the analyses; however, the pattern in the results was similar when all respondents were included in the analyses (results not shown). Ideally, we would have liked to obtain general population data from across the UK but this was beyond the scope of this research.

5. Conclusions

This study has highlighted that the majority of men living 18–42 months following a diagnosis of PCa report little social distress. We have been able to identify common factors associated with social distress which mirror closely our earlier findings from a PROMs survey of people following a diagnosis of colorectal cancer in England [10]. The identification of these factors has direct and valuable clinical application. Awareness of the most vulnerable groups of men is essential to ensure appropriate provision of support. The social distress risk factors identified in this study can easily be ‘flagged’ in the clinical setting without any major resource expenditure. Reference to a simple checklist (Box 1) to remind clinicians of men at greatest risk of social distress may inform judicious and risk-stratified utilisation of frequently stretched psychosocial support and rehabilitation resources. For policy-makers, commissioners and providers of health and social care, an understanding of these risk factors will support delivery of appropriate targeted interventions to maximise quality of survival.

Author contributions

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Declarations of interest

None.

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Appendix A. Supplementary data

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