Quality of life three years after diagnosis of localised prostate cancer: population based cohort study

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ABSTRACT

Objective To quantify the risk and severity of negative effects of treatment for localised prostate cancer on long term quality of life.

Design Population based, prospective cohort study with follow-up over three years.

Setting New South Wales, Australia.

Participants Men with localised prostate cancer were eligible if aged less than 70 years, diagnosed between October 2000 and October 2002, and notified to the New South Wales central cancer registry. Controls were randomly selected from the New South Wales electoral roll and matched to cases by age and postcode.

Main outcome measures General health specific and disease specific function up to three years after diagnosis, according to the 12 item short form health survey and the University of California, Los Angeles prostate cancer index.

Results 1642 (64%) cases and 495 (63%) eligible and contacted controls took part in the study. After adjustment for confounders, all active treatment groups had low odds of having better sexual function than controls, in particular men on androgen deprivation therapy (adjusted odds ratio (OR) 0.02, 95% CI 0.01 to 0.07). Men treated surgically reported the worst urinary function (adjusted OR 0.17, 95% CI 0.13 to 0.22). Bowel function was poorest in cases who had external beam radiotherapy (adjusted OR 0.44, 95% CI 0.30 to 0.64). General physical and mental health scores were similar across treatment groups, but poorest in men who had androgen deprivation therapy.

Conclusions The various treatments for localised prostate cancer each have persistent effects on quality of life. Sexual dysfunction three years after diagnosis was common in all treatment groups, whereas poor urinary function was less common. Bowel function was most compromised in those who had external beam radiotherapy. Men with prostate cancer and the clinicians who treat them should be aware of the effects of treatment on quality of life, and weigh them up against the patient's age and the risk of progression of prostate cancer if untreated to make informed decisions about treatment.

INTRODUCTION

Survival after diagnosis of prostate cancer has increased substantially in the past two decades. Five year relative survival for localised prostate cancer is almost 100% in Australia¹ and the United States.² Observational studies show that different treatment options offer nearly equal survival rates³; therefore, quality of life after treatment should be a major consideration in treatment decision making. Dissatisfaction with care in some men may be owing, in part, to a lack of accurate and representative information on the long term effects of treatment.⁴

The primary aims of the New South Wales Prostate Cancer Care and Outcomes Study (PCOS) were to document the care given to men with newly diagnosed prostate cancer and to measure three year and five year health related quality of life.

METHODS

Study population

All men aged less than 70 years, resident in New South Wales, diagnosed with histopathologically confirmed prostate cancer—that is, clinical stage T1a to T2c with no evidence of lymph node or distant metastases—between October 2000 and October 2002, and notified to the population based New South Wales central cancer registry by May 2003 or no more than 12 months after their diagnosis, were eligible for this study. We enrolled only men aged less than 70 years at diagnosis because radical treatment is generally not offered to men with less than 10 years life expectancy.⁵ Of all the Australian men diagnosed with prostate cancer during the study period, 45% were aged less than 70 years.⁶ Pathology companies, hospitals, radiotherapy centres, day therapy centres, and the registrar of births, deaths, and marriages are legally required to notify all cancer cases to the cancer registry.¹ Rapid ascertainment procedures were implemented by the central cancer registry to minimise the time between diagnosis and recruitment for the study.

Patient participation was sought as soon as possible after the central cancer registry received notification of a case, but not less than one month after diagnosis.

Treating doctors were asked to allow our research team to approach their recently diagnosed patients. Doctors were also asked to confirm that each patient was aware of his diagnosis and physically and mentally capable of a 30 minute telephone interview in English. A total of 254 doctors were contacted regarding the participation of 3195 men. Eight doctors, managing the care of 336 patients, refused any approach to their patients. A further 246 doctors denied on an individual basis consent to approach an additional 152 potentially eligible patients, and doctor's consent was still pending at the close of the study for 49 men. Permission was granted to approach 2658 patients (83% of those notified to the central cancer registry). Of those approached, 2031 agreed to take part in the study (63.6% of those identified and 76.4% of those approached; fig 1).

A total of 1347 potential controls, matched by age and postcode of residence to cases, were randomly selected from the New South Wales electoral roll. The intention was to enrol 500 matched controls into the study. Potential controls were first checked against the central cancer registry to exclude those with a diagnosis of prostate cancer, then cross referenced using

telephone directory listings to identify those with a listed telephone number. In total, 947 men with directory listings were sent an invitation letter. A follow-up phone call was made after two weeks to obtain the consent of invited controls and to book a telephone interview. Of those contacted, 281 men refused to participate and 41 were found to be ineligible because they could not complete a 30 minute telephone interview in English or were not residents of New South Wales. In addition, 118 potential controls could not be contacted. A total of 507 men agreed to participate and 495 completed a baseline interview (62.8% of men contacted and eligible).

Data collection

Clinical data for men diagnosed with prostate cancer

A trained field worker or the treating doctor completed a data collection form for each participant with prostate cancer. Data on clinical stage at diagnosis and management during the first year after diagnosis were obtained. Data were collected no sooner than 12 months after diagnosis in order to obtain a complete description of treatment during the first year.

Initial primary treatment was defined as the treatment given within six months of diagnosis. Treatment was classified into one of the following categories: active surveillance, radical prostatectomy, external beam radiotherapy, androgen deprivation therapy, low dose rate brachytherapy, high dose rate brachytherapy, or any combination of these. If a man was first recommended to have active surveillance but had active treatment within six months of diagnosis, he was coded as having had active treatment.

Clinical data were obtained for 1874 men (94% of the sample). A total of 80 men (4%) who gave telephone interviews did not consent to collection of clinical information; access to clinical notes for a further 41 men (2%) could not be obtained. Of the 1874 men with clinical information, 1642 had localised disease and were included in this analysis (fig 1).

Two field workers collected data independently on a random subsample of 60 cases from five doctors. Fair to very good agreement between field workers was observed for the following key variables: prostate specific antigen level at diagnosis (90% agreement); Gleason score (70% agreement, Cohen's kappa score for inter-rater agreement $\kappa=0.56$); tumour stage (80% agreement, $\kappa=0.62$), and type of initial primary treatment (100% agreement, $\kappa=1$). In two thirds of cases where Gleason scores disagreed, a report on pathology of a repeat biopsy or a prostatectomy sample that gave a different score to the original biopsy report was available to the second field worker.

Self reported health related measures for cases and controls

Trained interviewers interviewed each case and control using a computer assisted telephone interview. Validated measures were included, with some minor wording changes to suit the Australian context and telephone administration. The final survey instrument is available from the authors on request.

Fig 1 | Flow diagram showing case participation and follow-up

Health related quality of life outcomes

Health related quality of life was measured using the domain specific items of the long form University of California, Los Angeles prostate cancer index.⁷ This is a well validated instrument suitable for both cases and controls and has good reliability for recall of prediagnosis symptoms when administered within six months of diagnosis.⁸ The University of California, Los Angeles prostate cancer index contains all items in the 12 item short form (SF-12) health status instrument. SF-12 has excellent reliability and validity.⁹

The University of California, Los Angeles prostate cancer index also includes 20 items that measure the domains of urinary, bowel, and sexual function, yielding three function scales; higher scores indicate better function. In addition, the index includes a single item measure of “bother” for each domain (“what was the level of bother for (urinary/bowel/sexual) function?”); higher scores indicate less bother. These six scales plus the physical component score and the mental component score from the SF-12 comprised the eight quality of life outcomes used in this study.

Other health related measures

The international prostate symptom score¹⁰ was used at baseline to measure obstructive or irritative urinary problems. Participants were also asked about 12 chronic comorbid conditions. A total comorbidity score was calculated for each man, with one point contributed by each of the following conditions that limited their activity or required prescription medicine: cerebrovascular disease; inflammatory bowel disease; liver disease; gastric ulcers; arthritis; diabetes; depression; hypertension; chest pain; heart attack; heart failure; and chronic lung disease. Questions were also asked on tobacco use and alcohol intake.

Timing of interviews

For cases, “baseline” was defined as the month before diagnosis; however, data were collected after diagnosis in all cases because of the observational study design. The baseline interviews for cases were done as soon as practicable after recruitment (mean 3 months after diagnosis (range one to 12 months)) and, in the majority of cases, occurred after primary therapy had begun. Four cases who did not complete a baseline interview but completed later interviews were excluded from analysis because baseline outcome was a necessary covariate. We excluded 205 men who were diagnosed more than 12 months before the date of identification to reduce the likelihood of error in self reported baseline health status. Controls were asked to recall their baseline health status three months before the date of interview; this approach was used to standardise the recall time for cases and controls and to minimise differential recall bias.

Follow-up interviews were scheduled one, two, and three years after diagnosis for cases and one, two, and five years after baseline interview for controls. As most treatments carry short term adverse effects we concentrated on outcomes at three years after diagnosis, when

effects on quality of life would generally have stabilised.¹¹ To reduce both costs and responder fatigue, the three year assessment in controls was omitted and values were estimated on the basis of outcomes at five years. A total of 380 (79%) controls completed an interview at five years; however, 22 controls were diagnosed with prostate cancer during the study period and were censored from the analysis at the time of their diagnosis. The majority (93%) of interviews were conducted within one month (± 4 weeks) of the anniversary of diagnosis (cases) or baseline interview (controls).

Data analysis

Data were analysed with SPSS and STATA software. The physical component scores and mental component scores were calculated according to the user manual¹² and on the basis of Australian population norms¹³ and scoring weights. Scores were normalised to a population mean of 50 and a standard deviation of 10. Higher scores reflect better quality of life.

Scores for the six disease specific domains were calculated according to the instructions for the prostate cancer index¹⁴ and ranged from 0 to 100, with higher scores indicating better function or less bother. The scores for each domain were divided into ordinal categories because of their asymmetric distributions. Proportional odds ordinal logistic regression models were fitted for each domain and treatment group, with the controls used as the reference group. Cluster robust variance estimators and independence working correlation matrices were used to provide unbiased estimated standard errors in the presence of correlation between repeated observations on the same subjects. Domain scores were grouped into three to five categories to provide a relatively even balance of observations in each category.

Our primary interest was in the effect of treatment at yearly intervals up to three years after baseline, so the interaction between treatment type and time was examined. Treatment comparisons at three years were complicated by the fact that data were not collected for controls at this time point. However, we modelled the case and control log odds trajectories as linear from year two onwards by using control group responses measured at five years after baseline, so that the model effectively interpolated treatment group and control comparisons at year three. Furthermore, the log odds trajectory from years one to two for a given treatment group was allowed to differ from the subsequent log odds trajectory for that treatment group through the inclusion of an additional segmented regression parameter.

All demographic and clinical variables were considered as potential confounders for quality of life and were included in the multivariable models. A common model selection process was used for each of the eight quality of life outcomes. First, a “full model” was fitted to the data using the categorised quality of life score as the dependent variable. For each domain, the baseline quality of life score was treated as a continuous covariate and was included in the “full model,” along with the

following other prespecified covariates of interest: time after baseline measurement (one, two, and three years); age (<55, 55-59, 60-64, and 65-69 years); and all other demographic and clinical variables except tumour stage, Gleason score, and prostate specific antigen concentration (all of which were very strongly correlated with treatment type (data not shown)).

A “reduced model” was then derived from the full model. We adjusted for the confounders that were significantly associated with treatment group outcomes ($P>0.05$) or changed their odds ratios by 10% or more when included in the model. Baseline score, time after baseline, treatment group, and age were all retained in the reduced model. The proportional odds assumption was checked for each “reduced model” and if not met (as was the case for three of the eight domains), additional analysis including partial proportional odds models was used to assess the effect of the violation. Following this approach had little effect on the conclusions, and thus results from the proportional odds models are reported for ease of interpretation.

Generalised estimating equations for longitudinal binary outcomes were used to examine the potential influence of missing data. For each of the eight domains, a binary indicator of outcome measurement attainment at time t (0=missing, 1=attained) was regressed on the most recent outcome value before time t and all significant covariates from the corresponding “reduced model.” Although these analyses identified that missing data was sometimes associated with covariates included in the corresponding “reduced model,” there was little evidence that this was independently associated with the most recent previous outcome value (P values ranged from 0.14 to 0.98).

RESULTS

The 1642 men with localised prostate cancer included in this study were 37 to 69 years of age (mean 61.2 years) when diagnosed (table 1). A total of 981 cases (60%) had radical prostatectomy, and most of the remainder had external beam radiotherapy, with or without androgen deprivation therapy (289/1636 (18%)) or active surveillance (200/1636 (12%)). Just over half of the radical prostatectomies were nerve sparing in intent (494/981). Four men who had orchidectomy as primary therapy and two with unknown primary therapy were excluded from further analysis.

There was significant heterogeneity within treatment types of all demographic characteristics—except country of birth and comorbidity—and all disease characteristics (all $P<0.001$). Cases who had radical prostatectomy or low dose rate brachytherapy tended to be younger and have earlier stage disease, lower prostate specific antigen levels, and lower Gleason score than cases in other treatment groups, and tended to have higher incomes and better education. Cases who had nerve sparing prostatectomy were younger and more likely to have higher baseline sexual function than those who did not have it. Cases who had external beam radiotherapy or androgen deprivation therapy, or the two combined, were older, had later stage

disease, and had more comorbidity than those who received other treatments. There were no substantial differences in the demographic profiles of the controls and the cases (pooled across treatments).

A total of 1493 (91%) patients with prostate cancer interviewed at baseline were also interviewed at three years; 1530 (93%) cases and 433 (87%) controls completed the two year interview. Completion rates differed across treatment groups and ranged from 97% (low dose rate brachytherapy) to 77% (androgen deprivation therapy (fig 2)). The smallest number of cases remaining at three years in any group was 43 in the group who had been treated with high dose rate brachytherapy. When all variables in table 1 were included in a logistic regression model, only being born overseas (odds ratio (OR) 1.52, 95% confidence interval (CI) 1.02 to 2.27) and not having private health insurance (OR 1.85, 95% CI 1.21 to 2.83) increased the likelihood of withdrawal from the study.

At the three year interview, 99 cases (6.6%) reported that they had been diagnosed with “recurrent disease or disease that had spread after diagnosis.” None of the men who had received low dose rate brachytherapy reported this outcome, whereas two (2%) who had undergone external beam radiotherapy, five (3%) on active surveillance, 64 (7%) who had been treated with radical prostatectomy, and four (30%) who had received androgen deprivation therapy alone reported recurrent disease or disease spread. Of the variables in table 1, only Gleason score (OR 1.87, 95% CI 1.47 to 2.38) and the log of prostate specific antigen level (OR 1.96, 95% CI 1.42 to 2.72) were independent, statistically significant predictors of recurrence or spread.

General quality of life

Table 2 presents the mean scores for each quality of life domain and treatment group at baseline and at year three. Given that these scores are not adjusted for clinical and demographic characteristics, they reflect the combined impact of disease, treatment, and age on long term quality of life. Mental component scores of cases at baseline were similar to those of controls for all groups, except those having non-nerve sparing radical prostatectomy (table 2). Overall, men with localised prostate cancer had higher baseline physical scores than controls, in particular men who had nerve sparing radical prostatectomy (OR 1.85, 95% CI 1.48 to 2.32) or low dose rate brachytherapy (OR 2.36, 95% CI 1.43 to 3.89). Men who had androgen deprivation therapy, however, had lower scores than controls.

After adjustment for baseline physical component score, age, income, area of residence, and comorbidity, men who had androgen deprivation therapy alone were least likely to have better physical scores than controls at three years after diagnosis (fig 3).

Cases who had radical prostatectomy or high dose rate brachytherapy were unlikely to have a higher mental component score than controls in the first year (fig 3). However, mental component scores for cases in all treatments groups were similar to those of controls at three years.

Urinary function and bother

At baseline, few cases (33/1636 (2.0%)) reported urinary incontinence—that is, few agreed that they experienced “urinary leakage that required one or more pads per day to control.” This single measure of incontinence, which does not include all forms of incontinence, was most prevalent at baseline in men who subsequently had androgen deprivation therapy (4/61 (6.6%)) or active surveillance (12/200 (6.0%); table 3). After diagnosis, the highest rate of incontinence was in the group who had radical prostatectomy: 156 men (16.3%) reported incontinence at one year and 111 (12.3%) at three years.

All men except those who had undergone nerve sparing radical prostatectomy or low dose rate brachytherapy had lower urinary function scores than controls at baseline (table 2). Urinary function scores fell significantly below control scores in all groups between baseline and year one, except for in cases on

active surveillance, androgen deprivation therapy, or high dose rate brachytherapy (fig 4). The odds ratio was lowest in those who had radical prostatectomy (OR 0.17, 95% CI 0.13 to 0.22). For all groups except those on androgen deprivation therapy or high dose rate brachytherapy, the adjusted odds ratio increased or stabilised between year one and year three. All treatment groups had worse urinary bother at baseline than did controls (table 2), and this persisted up to three years in most groups (fig 4).

Urinary bother at baseline in all men was highly correlated with their international prostate symptom score ($R^2=0.56$; $P<0.001$), more so than with the University of California, Los Angeles prostate cancer index urinary function score ($R^2=0.21$; $P<0.001$). Of the men who reported less urinary bother than controls three years after diagnosis, 68 men (64%) on active surveillance and 22 men (34%) on androgen deprivation therapy had a transurethral resection of the prostate. The fact

Table 1 Baseline demographic and clinical characteristics of cases of prostate cancer and baseline demographic characteristics of controls

	Treatment group (n (%))							Overall (n (%))		P value for heterogeneity among groups
	Active surveillance (n=200)	Radical prostatectomy (n=981)	EBRT (n=123)	ADT (n=61)	Combined EBRT/ADT (n=166)	LDR brachytherapy (n=58)	HDR brachytherapy (n=47)	Cases (n=1636)	Controls (n=495)	
Age at diagnosis (years)										
<55	20 (10.0)	163 (16.6)	5 (4.1)	4 (6.6)	13 (7.8)	8 (13.8)	4 (8.5)	217 (13.3)	82 (16.6)	<0.001
55-59	38 (19.0)	273 (27.8)	13 (10.6)	8 (13.1)	19 (11.4)	18 (31.0)	13 (27.7)	382 (23.3)	68 (13.7)	
60-64	54 (27.0)	275 (28.0)	35 (28.5)	14 (23.0)	52 (31.3)	17 (29.3)	12 (25.5)	459 (28.1)	142 (28.7)	
65-69	88 (44.0)	270 (27.5)	70 (56.9)	35 (57.4)	82 (49.4)	15 (25.9)	18 (38.3)	578 (35.3)	203 (41.0)	
Mean (95% CI)	65.8 (62.5 to 69)	60.2 (59.9 to 60.6)	63.9 (63 to 64.7)	64.0 (62.8 to 65.2)	63.3 (62.5 to 64)	60.0 (58.6 to 61.4)	62.2 (60.7 to 63.6)	61.2 (61 to 61.5)	61.2 (60.7 to 61.7)	
Private health insurance status										
Insured	131 (65.5)	755 (77.1)	55 (44.7)	25 (41.7)	84 (50.6)	49 (84.5)	43 (91.5)	1142 (68.4)	312 (63.3)	<0.001
Uninsured	69 (34.5)	224 (22.9)	68 (55.3)	35 (58.3)	82 (49.4)	9 (15.5)	4 (8.5)	491 (31.6)	181 (36.7)	
Comorbidity score										
0	62 (31.0)	427 (43.5)	33 (26.8)	13 (21.3)	46 (27.7)	24 (41.4)	18 (38.3)	623 (37.9)	184 (37.2)	<0.001
1	59 (29.5)	311 (31.7)	39 (31.7)	22 (36.1)	64 (38.6)	20 (34.5)	14 (29.8)	529 (32.1)	154 (31.1)	
2+	79 (39.5)	243 (24.8)	51 (41.5)	26 (42.6)	56 (33.7)	14 (24.1)	15 (31.9)	484 (30.1)	157 (31.7)	
Clinical stage at diagnosis										
T1a	58 (29.0)	4 (0.4)	1 (0.8)	1 (1.6)	1 (0.6)	0 (0.0)	0 (0.0)	65 (4.0)	n/a	<0.001
T1b	19 (9.5)	15 (1.5)	4 (3.3)	5 (8.2)	2 (1.2)	0 (0.0)	1 (2.1)	46 (2.8)	n/a	
T1c	83 (41.5)	516 (52.6)	56 (45.5)	16 (26.2)	51 (30.7)	43 (74.1)	13 (27.7)	778 (47.6)	n/a	
T2a	26 (13.0)	239 (24.4)	31 (25.2)	9 (14.8)	33 (19.9)	12 (20.7)	10 (21.3)	360 (22.0)	n/a	
T2b	6 (3.0)	120 (12.2)	19 (15.4)	10 (16.4)	55 (33.1)	2 (3.4)	18 (38.3)	230 (14.1)	n/a	
T2c	8 (4.0)	87 (8.9)	12 (9.8)	20 (32.8)	24 (14.5)	1 (1.7)	5 (10.6)	157 (9.6)	n/a	
Gleason score										
2 to 6	172 (89.1)	539 (55.1)	57 (47.1)	9 (14.8)	49 (29.5)	53 (91.4)	15 (31.9)	894 (55.0)	n/a	<0.001
7	19 (9.8)	356 (36.4)	55 (45.5)	26 (42.6)	71 (42.8)	5 (8.6)	25 (53.2)	557 (34.3)	n/a	
8 to 10	2 (1.0)	83 (8.5)	9 (7.4)	26 (42.6)	46 (27.7)	0 (0.0)	7 (14.9)	173 (10.7)	n/a	
Mean (95% CI)	5.6 (5.5 to 5.8)	6.5 (6.4 to 6.5)	6.5 (6.4 to 6.7)	7.4 (7.1 to 7.7)	7.1 (6.9 to 7.2)	6.0 (5.9 to 6.1)	6.9 (6.6 to 7.1)	6.5 (6.4 to 6.5)	n/a	
PSA at diagnosis										
<4	59 (32.4)	77 (8.0)	8 (6.5)	2 (3.4)	2 (1.2)	2 (3.4)	2 (4.3)	152 (9.5)	n/a	<0.001
4 to 9.9	93 (51.1)	643 (66.8)	67 (54.5)	5 (8.5)	48 (29.1)	46 (79.3)	18 (38.3)	920 (57.6)	n/a	
10 to 19.9	22 (12.1)	195 (20.2)	38 (30.9)	13 (22.0)	51 (30.9)	8 (13.8)	17 (36.2)	344 (21.5)	n/a	
20+	8 (4.4)	48 (5.0)	10 (8.1)	39 (66.1)	64 (38.8)	2 (3.4)	10 (21.3)	181 (11.3)	n/a	
Median (range)	5.7 (0.3 to 41.5)	7.2 (0.3 to 602)	8.2 (0.2 to 45)	28.2 (1.5 to 250.9)	14.6 (2.7 to 190)	7.2 (2.1 to 23.3)	10.5 (2.5 to 75.9)	7.7 (0.2 to 602)	n/a	

Abbreviations: ADT, androgen deprivation therapy; EBRT, external beam radiotherapy; HDR, high dose rate brachytherapy; LDR low dose rate brachytherapy; PSA, prostate specific antigen.

Table 2 | Mean unadjusted physical, mental, urinary, bowel, and sexual domain scores at baseline and three years after diagnosis for patients with prostate cancer and for controls

	University of California, Los Angeles prostate cancer index score (mean (standard deviation))								
	Active surveillance (n=200)	Nerve sparing RP (n=494)	Non-nerve sparing RP (n=476)	EBRT (n=123)	ADT (n=61)	Combined EBRT/ADT (n=166)	LDR brachytherapy (n=58)	HDR brachytherapy (n=47)	Controls (n=495)
Physical component score (normalised to mean of 50 and SD of 10; higher scores indicate better function)									
Baseline	47.7 (10.8)	52.3 (7.6)	50.6 (8.7)	49.3 (9.9)	44.2 (10.6)	46.7 (11.3)	52.6 (7.9)	51.4 (8.5)	49.4 (9.6)
3 years	46.9 (11.9)	50.1 (9.0)	48.7 (9.5)	46.5 (10)	38.8 (12.7)	44.1 (11.7)	49 (9.6)	48.5 (11.2)	47.9
Mental component score (normalised to mean of 50 and SD of 10; higher scores indicate better function)									
Baseline	51.4 (9.5)	53.6 (7.7)	54.4 (7.4)	53.1 (9.0)	53.4 (8.8)	53.5 (8.6)	51.7 (9.9)	52.6 (8.4)	52.5 (9.1)
3 years	53.1 (9.2)	53.3 (8.5)	53.7 (8.5)	52.9 (9.1)	53.2 (9.7)	52.8 (9.7)	54 (7.8)	51.5 (10.0)	54.1
Urinary function (score range 0-100; higher scores indicate better function)									
Baseline	85.7 (19.7)	95.6 (10.7)	94.2 (12.4)	92.9 (13.8)	87.5 (19.4)	90.7 (15.1)	96.8 (7.2)	92.9 (13.3)	95.2 (11.8)
3 years	91.6 (14.7)	85.5 (17.0)	83.3 (19.2)	92.6 (15.2)	92.8 (14.1)	89.9 (16.5)	93.5 (14.3)	89.8 (15.3)	95.4
Urinary bother (score range 0-100; higher scores indicate less bother)									
Baseline	58.3 (36.4)	80.5 (28.5)	80.6 (28.6)	77.2 (30.2)	59.2 (35.9)	69.9 (35.3)	80.6 (26.9)	83.0 (30.0)	89.2 (22.6)
3 years	84.1 (25.5)	84.8 (23.5)	83.1 (25.3)	81.4 (27.6)	73.4 (34.3)	79.3 (28.5)	84.4 (24.6)	76.7 (29.1)	89.7
Bowel function (score range 0-100; higher scores indicate better function)									
Baseline	83.9 (17.9)	89 (12.0)	87.1 (15.7)	86.4 (16.5)	84.7 (17.9)	87 (14.5)	91.8 (9.3)	88.4 (10.5)	88.4 (12.3)
3 years	86.7 (16.4)	88.1 (13.9)	88.5 (12.3)	84.5 (15.8)	82.1 (18.3)	81.8 (19.0)	88.8 (11.5)	87.8 (16.0)	89.8
Bowel bother (score range 0-100; higher scores indicate less bother)									
Baseline	84.3 (28.3)	93 (18.4)	90.4 (22.1)	87.6 (25.9)	83.8 (27.2)	88.1 (24.7)	94.4 (14.8)	93.1 (17.8)	89.2 (23.3)
3 years	88.1 (23.2)	90 (20.9)	90.5 (18.7)	79.8 (28.2)	87.2 (23.8)	78.8 (29.0)	91.1 (14.6)	84.3 (28.4)	93.8
Sexual function (score range 0-100; higher scores indicate better function)									
Baseline	61.0 (24.8)	71.8 (21.7)	63.3 (26.8)	57.4 (28.0)	45.0 (31.9)	50.6 (28.6)	69.8 (25.2)	66.3 (23.5)	66.0 (25.7)
3 years	44.1 (29)	34.7 (27.7)	22 (23.6)	32.0 (29.0)	8.3 (16.6)	22.1 (25.9)	54.0 (25.7)	30.3 (32.4)	57.1
Sexual bother (score range 0-100; higher scores indicate less bother)									
Baseline	67.0 (37.2)	78.9 (32)	71.1 (36.5)	74.6 (33.5)	64.8 (40.0)	65.1 (37.9)	81.9 (29.5)	70.2 (36.4)	75.3 (34.0)
3 years	65.9 (37.9)	52.2 (39.7)	53.6 (42.2)	57.6 (41.9)	66.5 (44.0)	58.4 (42.2)	66.8 (32.7)	60.5 (37.9)	78.5

Scores not adjusted for differences in demographic or clinical characteristics. Three year means for controls were extrapolated using two and five year data; standard deviations for year three controls were not estimated.

Abbreviations: ADT, androgen deprivation therapy; EBRT, external beam radiotherapy; HDR, high dose rate; LDR, low dose rate; RP, radical prostatectomy; SD, standard deviation.

that these men underwent this procedure might explain the reduction in bother.

Bowel function and bother

Bowel problems were defined as responding to the question “Overall, how big a problem have your bowel habits been?” with either “moderate” or “big.” Although bowel function of cases at baseline was generally similar to that of controls (table 2), men who had external beam radiotherapy, both with and without androgen deprivation therapy, had worse bowel function than controls at one year (OR 0.51, 95% CI 0.34 to 0.74) and at three years (OR 0.58, 95% CI 0.39 to 0.86) after diagnosis (fig 4). Bowel bother was persistently worse in all treatment groups relative to controls, with the greatest impact in the groups who received treatment that included external beam radiotherapy either alone at one year (OR 0.24, 95% CI 0.15 to 0.36) and three years (OR 0.22, 95% CI 0.14 to 0.34) or in combination with androgen deprivation therapy at one year (OR 0.24, 95% CI 0.16 to 0.35) and three years (OR 0.19 95% CI 0.13 to 0.28).

Sexual function and bother

Sexual function at baseline differed between groups (tables 2 and 3)—15.6% (76/494) of men who

subsequently had nerve sparing radical prostatectomy were impotent at baseline compared with 42.1% (24/61) of those who had androgen deprivation therapy. On the other hand, 109 controls (22.3%) and 128 men (27.6%) who had non-nerve sparing radical pros-

Fig 2 | Percentage of quality of life interviews completed annually by each group. Abbreviations: ADT, androgen deprivation therapy; EBRT, external beam radiation therapy; HDR, high dose rate; LDR, low dose rate

tatectomy stated at baseline that they were unable to obtain an erection firm enough for sexual intercourse (table 3). At three years, 67.9% (307/494) of men who had nerve sparing radical prostatectomy, 86.7% (379/476) of men who had non-nerve sparing radical prostatectomy, 67.9% (72/123) of men who had external beam radiotherapy, and 36.4% (20/58) of men who had low dose rate brachytherapy were impotent.

After adjusting for age, baseline function, income, area of residence, and comorbidity score, all treatment groups had worse sexual function than controls at one, two, and three years (fig 4), although in all groups there was some improvement between the score at one year and that at three years. The treatment with greatest adverse impact on sexual function was androgen deprivation therapy (OR 0.02, 95% CI 0.01 to 0.07). Cases who had nerve sparing radical prostatectomy had a better outcome at three years (adjusted OR 0.10, 95% CI 0.08 to 0.13) than those who had non-nerve sparing surgery (adjusted OR 0.05, 95% CI 0.04 to 0.07; $P<0.001$).

All treatment groups, with the exception of men on androgen deprivation therapy (who had poor baseline function), persistently reported more sexual bother than controls (fig 4). At three years, 494 men (33% of cases) reported that they had used some form of treatment to achieve an erection. Use of such treatments was highest in cases with good baseline sexual function and, therefore, considerable motivation to return to baseline function. Of the men who reported seeking assistance for erectile function, 383 (77.5%) stated that they used a phosphodiesterase type 5 inhibitor (for example, sildenafil, tadalafil, or vardenafil (Viagra, Cialis, and Levitra, respectively)), although 168 (43.9%) of these individuals stated that such agents were of “little or no use.” After adjusting for age, baseline potency, and treatment type, use of a phosphodiesterase type 5 inhibitor appeared to have no effect on potency at three years.

DISCUSSION

We have shown in a representative sample of reasonably young men that treatment for early prostate cancer has important and persistent adverse effects on quality of life. The adverse effects of treatment for prostate cancer tended to be most pronounced in men who underwent radical prostatectomy, external beam radiotherapy, or any treatment involving androgen deprivation. Only men who had primary androgen deprivation therapy had poorer general physical or mental quality of life than controls at three years.

Treatment for prostate cancer caused urinary problems in the majority of treatment groups, which became less notable over time. Men who had radical prostatectomy continued to have poor urinary function three years after diagnosis. It is important to note, however, that men with prostate cancer had worse urinary function than controls at baseline. Poor bowel function was a persistent problem for men who received external beam radiotherapy together with androgen deprivation therapy, and all men who underwent treatment for prostate cancer reported bowel bother.

Decreased sexual function was the most prevalent reduction in quality of life three years after diagnosis of localised prostate cancer. After adjustment for confounders, all active treatment groups had significantly lower odds of better sexual function than controls, with some variation by type of treatment.

For each of the three quality of life domains specific to prostate cancer, a comparison of the degree of loss of function following treatment with the “bothersomeness” of the change in function is of interest. For the group who had radical prostatectomy, urinary and sexual function and bother scores were significantly below those of controls after treatment; however, bother did not seem to be as great a problem as impaired function. Although 12% of men who had prostatectomy reported prolonged incontinence, an improvement from 16% at year one, at three years less than 50% of them considered it any more than a “small” problem.

Table 3 | Unadjusted proportion of men with localised prostate cancer who reported incontinence, moderate or severe bowel problems, or impotence at baseline and three years after diagnosis

	Active surveillance (n=200)	RP (n=981)	Nerve sparing RP (n=494)	Non-nerve sparing RP (n=476)	EBRT (n=123)	ADT (n=61)	Combined EBRT/ADT (n=166)	LDR brachytherapy (n=58)	HDR brachytherapy (n=47)	Controls (n=495)
Urinary incontinence (n (%))*										
Baseline	12 (6.0)	11 (1.1)	3 (0.6)	7 (1.5)	0 (0.0)	4 (6.6)	5 (3.0)	0 (0.0)	0 (0.0)	5 (1.0)
3 years	6 (3.4)	111 (12.3)	43 (9.4)	66 (15.1)	3 (2.7)	2 (4.3)	6 (3.9)	3 (5.4)	3 (7.0)	—
Moderate or severe bowel problems (n (%))†										
Baseline	27 (13.5)	43 (4.4)	18 (3.6)	25 (5.3)	13 (10.6)	6 (10.0)	15 (9.0)	0 (0.0)	1 (2.1)	31 (6.3)
3 years	11 (6.3)	32 (3.5)	19 (4.1)	12 (2.7)	16 (14.5)	3 (6.4)	19 (12.5)	0 (0.0)	4 (9.3)	—
Impotence (n (%))‡										
Baseline	53 (27.3)	206 (21.5)	76 (15.6)	128 (27.6)	35 (30.2)	24 (42.1)	63 (39.1)	11 (19.0)	12 (25.5)	109 (22.3)
3 years	94 (54.3)	695 (77.4)	307 (67.9)	379 (86.7)	72 (67.9)	45 (97.8)	121 (82.3)	20 (36.4)	31 (72.1)	—

Number at baseline includes men with missing data for individual questions (three cases and one control did not answer questions on bowel problems, and 42 cases and six controls did not answer the question on impotence). Controls were not asked these questions at year three.

*Incontinence defined as needing to wear one or more pad per day to control urinary leakage.

Bowel problems defined as responding to the question “Overall, how big a problem have your bowel habits been?” with either “moderate” or “big.”

‡Impotence defined as being unable to obtain an erection sufficient for sexual intercourse.

Abbreviations: ADT, androgen deprivation therapy; EBRT, external beam radiotherapy; HDR, high dose rate; LDR, low dose rate; RP, radical prostatectomy.

Fig 3 | Adjusted odds ratios and 95% confidence intervals for the likelihood of having higher physical or mental component scores than controls at one to three years after diagnosis.

*Adjusted for age, baseline physical score, region of residence, income, education, and comorbidity score.

†Adjusted for age, baseline mental score, country of birth, and comorbidity score. Abbreviations: ADT, androgen deprivation therapy; EBRT, external beam radiotherapy; HDR, high dose rate; LDR, low dose rate; RP: NS, nerve sparing radical prostatectomy; RP: non-NS, non-nerve sparing radical prostatectomy

Greater urinary bother, particularly at baseline in the active surveillance and androgen deprivation therapy groups, appeared related to the cases' generally poor international prostate symptom score (over 30% reported "severe" symptoms). The majority in these two groups with severe problems experienced improvements in urinary bother between baseline and year one, most likely as a result of transurethral resection of the prostate or drug treatments for lower urinary tract symptoms.

Of the cases who reported prolonged impotence after radical prostatectomy, only 48% described the disorder as any more than a "small" problem at three years. Cases who had non-nerve sparing surgery had worse sexual function than those who had nerve sparing techniques, but were slightly less bothered by their loss in sexual function. The expectations of better function after nerve sparing surgery may partly explain this disparity. It is also possible that response shift explains some or all of this difference at three years; that is, individuals may adapt to a change in health by adjusting their internal standards, values, or conceptualisation of quality of life.¹⁵

Interestingly, the health status of men who chose radical prostatectomy, especially nerve sparing surgery, tended to be better than that of matched controls, particularly at baseline. Men who chose radical prostatectomy were more likely to have been diagnosed with early stage disease: 47% of those who had surgery had T1c stage prostate cancer at diagnosis (generally a cancer detected as a result of elevated prostate specific antigen levels) and 63% reported that their diagnosis occurred in the absence of symptoms. Men who participate in screening are generally healthier than other men in the population from which they come.¹⁶ A "healthy screenee" effect can be inferred from the lower prevalence of smoking among study participants with T1c stage cancer (11.7%) than in all other men with localised disease (15.1%; $P=0.04$).

This report presents data on three year quality of life in men diagnosed with localised prostate cancer—that is, clinical stages T1a to T2c with no evidence of lymph node or distant metastases. This restriction was applied so that the quality of life comparisons could be made among men who had a high probability of remaining disease free during the follow-up period. More immediate outcomes, at two and six months after diagnosis, have been described elsewhere.¹⁷ We therefore concentrated on outcomes to three years after diagnosis to allow quality of life to stabilise and thus to reflect persistent adverse effects of treatment. We achieved good follow-up rates in most treatment groups: 91% of all cases interviewed at baseline also completed an interview at three years.

Strengths and limitations of the study

This study has a number of important strengths. Not only did we measure quality of life outcomes at one, two, and three years after prostate cancer diagnosis, we also measured quality of life at baseline and had control data for comparison. Very few observational studies of quality of life in patients with prostate cancer have a control arm.¹⁸

The ability to adjust quality of life data for the underlying effects of ageing, baseline function, comorbid conditions, and other important confounders is another major strength of our study. The population based sample of men with prostate cancer that we used and the broad range of centres at which men received treatment further strengthen our study findings and their relevance to young men with prostate cancer.

Our study comprises one of the largest series of men on active surveillance ($n=200$). As more younger men with low stage disease are being diagnosed, active surveillance is more frequently being promoted as a management option.¹⁹ Our cohort also includes meaningful numbers of men treated with low dose rate or high dose rate brachytherapy.

Greater surgical experience and higher patient volumes are associated with better outcomes at institutions treating patients with prostate cancer;²⁰ however, not every man who is diagnosed with the disease can be offered this level of expertise. Our results realistically

portray the quality of life the average man diagnosed with localised prostate cancer can expect three years after being treated.

There are also some important limitations to this study. Although the study is population based, the 64% participation rate among eligible cases notified to the New South Wales central cancer registry detracts from its representativeness. The multistep consent process and the delay in notification of some cases to the registry accounts for most of the participation loss. Eight urologists managing the care of 336 men chose not to participate in the study. These eight had higher than average patient volumes. Thus, if patient volume

is associated with better outcomes after treatment, it is possible that we have overestimated the detrimental effects of treatment on quality of life in this population.

Compared with all patients with prostate cancer registered during the recruitment period, our cases did not differ much in age, area of residence, or socioeconomic status. For example, study participants were a little less likely to be born outside Australia than individuals not included in the study. Controls were selected from the electoral roll and matched with electronic listings of residential telephone numbers. In 2003, 95% of Australian households had a landline telephone connection and 83% had a white pages

Fig 4 | Adjusted odds ratios and 95% confidence intervals for urinary, bowel, and sexual function and bother scores higher than those in control group—that is, better function and less bother than controls—by primary treatment group one to three years after diagnosis. *Adjusted for age, baseline urinary function, country of birth, and comorbidity score. †Adjusted for age, baseline urinary bother, and comorbidity score. ‡Adjusted for age, baseline bowel function, country of birth, and comorbidity score. §Adjusted for age, baseline bother, and comorbidity score. ¶Adjusted for age, baseline sexual function, accessibility of residence, income, and comorbidity score. **Adjusted for age, baseline sexual bother, marital status, and comorbidity score. Abbreviations: ADT, androgen deprivation therapy; EBRT, external beam radiotherapy; HDR, high dose rate; LDR, low dose rate; RP: NS, nerve sparing radical prostatectomy; RP: non-NS, non-nerve sparing radical prostatectomy

listing.²¹ Thus, selection bias may have been introduced into the control sample by requiring that they have a listed number. Such a bias would be small, however, because sociodemographic and quality of life variables for controls at baseline were generally similar to those for cases, implying that the controls were well matched to cases in most respects.

The participation rate in controls, 63% of those both eligible and contacted, was less than is desirable, and there were significantly fewer participating controls aged 55-59 years, unmarried, and living in major cities than among those initially approached. To control for this selection bias and for other personal and disease characteristics that might affect outcomes (table 1), we based our inferences about associations of treatment with outcomes on confounder adjusted odds ratios.

Baseline assessment of quality of life occurred after primary therapy had begun in a large proportion of cases. Baseline data were collected a median of three months after diagnosis, and participants were asked to recall their quality of life in the month before diagnosis. At this first assessment, 96% of men who had androgen deprivation therapy, 88% who had radical prostatectomy, 75% who had external beam radiotherapy, 40% who had high dose rate brachytherapy, and 36% who had low dose rate brachytherapy had received treatment. This delay may have caused bias in the recall of prediagnosis quality of life in cases.²²

Research suggests, however, that a high percentage of men accurately recall prediagnosis quality of life up to six months after diagnosis when using the University of California, Los Angeles prostate cancer index,⁸ although recall is poor between seven and 36 months after treatment.²² We tested for differences in baseline scores among men who had their initial interview before or after initiation of treatment and found no material differences in any of the domains after adjusting for age and comorbid status (results not shown). We attempted to reduce differential error in the controls' baseline response by asking them to recall quality of life three months before interview. We think these sources of error had only a small impact on outcome assessments, because reported baseline levels for overall quality of life and urinary, bowel, and sexual function in cases were generally little different from those in controls (table 2).

We report here on the three year outcomes. In some treatment groups, particularly the active surveillance group and the intermittent androgen deprivation therapy group, quality of life may fluctuate depending on the type, timing, and duration of treatment after the first year. A total of 27 men (14%) who were defined as receiving active surveillance moved to radical treatment between six months and two years after diagnosis, most of whom (n=19) had a radical prostatectomy. Their urinary and sexual function scores at three years resembled those of the radical prostatectomy group.

Generalisability of the results

The people in New South Wales make up approximately one third of the Australian population and

adequately represent the ethnic, economic, and health status mix of the whole country. In addition, given Australia's largely publicly funded health system, New South Wales offers quality of care similar to that in other parts of the country. Five year relative survival for cancer patients diagnosed in New South Wales is generally equal or close to the best reported rate from other developed countries.²³ In principle, our findings can be generalised to men in other developed countries who were treated for localised prostate cancer in the early 2000s.

The patterns of care described in this cohort reflect the care given in 2000 to 2003; however, treatment patterns have changed somewhat since this time, which may affect the generalisability of our results. Open prostatectomy is the most common treatment for early prostate cancer, but new techniques such as laparoscopic approaches and robot assisted methods have now become available. The outcomes from these new approaches, however, have not yet been well described. Both high dose rate and low dose rate interstitial brachytherapy have become more popular treatment choices since 2003, and techniques for delivering external beam radiotherapy have changed, with more widespread use of conformal therapy and image guidance.

Our results, however, will probably be for some time a good guide to outcomes from open radical prostatectomy and the other therapies we were able to document in sufficient numbers. Newer therapies cannot be assumed to produce better outcomes unless demonstrated to do so by randomised controlled trials²⁴ or by follow-up of large, well documented, and representative patient cohorts.

The results of this study may not be generalisable to older men with prostate cancer, as age is associated with both baseline function and comorbidity, which in turn are independently strongly predictive of poorer outcomes.²⁵

Comparison with other studies

Although there have been a number of studies on quality of life after prostate cancer,²⁶⁻²⁷ we believe ours is the first prospective population based study to assess long term quality of life among men receiving different treatment options for localised prostate cancer and to compare quality of life with that of men randomly selected from the general population.

One randomised trial has directly compared the quality of life of patients who had surgery (n=189) with that among patients on active surveillance (n=178)²⁸: 80% of men who had surgery were impotent and 18% had moderate to severe urinary leakage five years after surgery compared with 45% and 2%, respectively, in the active surveillance group. A recent study of 1201 cases who underwent prostatectomy, external beam radiotherapy, or brachytherapy and 625 spouses described outcomes of a similar direction and magnitude to ours, and found that changes in quality of life were associated with overall level of satisfaction of care.¹⁷

WHAT IS ALREADY KNOWN ON THIS TOPIC

Previous observational studies have shown that the common therapies for localised prostate cancer can affect quality of life, but the majority of such studies are from single centres or examine short term outcomes only

There is little evidence regarding long term outcomes of prostate cancer therapy from population-wide studies that compare patients with normally aging men

WHAT THIS STUDY ADDS

Relative to a normal aging population, men on each of the main treatments for localised prostate cancer have persistently altered quality of life

Although general physical and mental health of men with prostate cancer is comparable with that of controls at three years, sexual function is compromised in men receiving any of the main treatments

Bowel and urinary problems three years after diagnosis vary in severity and frequency on the basis of treatment type

Men with prostate cancer and the clinicians who treat them should weigh up the effects of a treatment on quality of life against the patient's age and the risk of progression of prostate cancer if untreated

The general health status of our patients with prostate cancer, as reflected by mental and physical scores and reported comorbidities, was eventually similar to, if not slightly better than, that of our controls. European and American studies have similarly shown that the quality of life in patients with prostate cancer returns to baseline or exceeds the health status of the age related population six to twelve months after diagnosis.^{29,30}

The continence and potency outcomes of some frequently quoted studies appear better than those in our study; however, this disparity may be because participants in other studies were drawn exclusively from large teaching hospitals and centres of excellence.^{31,32} In addition, overly favourable outcomes in some studies may be owing, in part, to variation in the definitions of outcomes and methods used across studies. A recent review identified 112 published definitions of incontinence and 79 definitions of erectile dysfunction.³³ Furthermore, when data are collected by doctors, patients' reported sexual function can be overestimated by as much as 30%³⁴ and urinary function by 13% to 65%.³⁵ In our study, independent interviewers collected outcome data directly from the men by using a validated instrument.

The selection of patients for various treatment options is likely to be influenced by the characteristics of the disease, patient, doctor, and healthcare system. Quality of care for localised prostate cancer and the way in which care is delivered may differ between regions and countries, so the differences in outcomes between treatment types observed in this study may not reflect, at least quantitatively, differences in outcomes in, for example, European or American men. However, our results are similar in a number of respects to those of other published series from population wide samples of men with prostate cancer.^{17,18,36-38} For example, the five year outcomes for men in the American prostate cancer outcomes

study who had radical prostatectomy or external beam radiotherapy were similar to those at three years in our sample.³⁹

Conclusions and implications

The aim of treatment of any early stage cancer is to eradicate the malignancy with the smallest possible impact on quality of life. We have shown in a population representative sample of men that treatment for early prostate cancer has important and persistent adverse effects on quality of life, particularly in men who undergo radical prostatectomy, external beam radiotherapy, or any treatment involving androgen deprivation. The extent to which these adverse effects are balanced by reduced risk of recurrence and better survival will be seen with further follow-up, within the limits of what can be inferred from an observational study. Men with prostate cancer and the clinicians who treat them need to be aware of the effects of treatment on quality of life, and weigh them up against the patient's age and the risk of progression of prostate cancer if untreated in order to make informed decisions about treatment.

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Contributors: DPS conceived and designed the study. He had full access to all the data, interpreted the data, and wrote the manuscript. DPS takes responsibility for the integrity and accuracy of the data and the analysis, and is the guarantor. SE had full access to all the data, contributed to its interpretation, and commented on drafts of the manuscript. MPB and JW contributed to the study design, interpretation of the data, and writing of the manuscript. DLO and MTK provided statistical advice, analysed and interpreted the data, and commented on drafts of the manuscript. PDS and PC provided clinical and methodological advice and commented on drafts of the manuscript. BKA conceived and designed the study, interpreted the data, critically revised the manuscript, and oversaw the conduct of the study. All authors declare that they accept full responsibility for the conduct of the study and the decision to publish.

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