

Financial toxicity: a potential side effect of prostate cancer treatment among Australian men

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The purpose of this study was to understand the extent, nature and variability of the current economic burden of prostate cancer among Australian men. An online cross-sectional survey was developed that combined pre-existing economic measures and new questions. With few exceptions, the online survey was viable and acceptable to participants. The main outcomes were self-reported out-of-pocket costs of prostate cancer diagnosis and treatment, changes in employment status and household finances. Men were recruited from prostate cancer support groups throughout Australia. Descriptive statistical analyses were undertaken. A total of 289 men responded to the survey during April and June 2013. Our study found that men recently diagnosed (within 16 months of the survey) ($n = 65$) reported spending a median AU\$8000 (interquartile range AU\$14 000) for their cancer treatment while 75% of men spent up to AU\$17 000 (2012). Twenty per cent of all men found the cost of treating their prostate cancer caused them 'a great deal' of distress. The findings suggest a large variability in medical costs for prostate cancer treatment with 5% of men spending \$250 or less in out-of-pocket expenses and some men facing very high costs. On average, respondents in paid employment at diagnosis stated that they had retired 4–5 years earlier than planned.

Keywords: prostate cancer, out-of-pocket expenses, medical costs.

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INTRODUCTION

An experience of prostate cancer can have a significant personal, work-life and financial impact on men and their families. Despite the prolific body of evidence on prostate cancer diagnoses and treatments, little research exists on the economic burden faced by those directly affected by prostate cancer. Two US studies showed that the majority

of expenses occurred during the first 6 months of treatment (Jayadevappa *et al.* 2010) and men felt reasonably comfortable in paying up to US\$5000 in medical payments (Jayadevappa *et al.* 2010; Markman & Luce 2010). Economic burden covers the out-of-pocket medical and non-medical expenses of receiving medical care, the impact on an individual's employment situation and on a caregiver's employment. Cancer treatments can be prolonged and fragmented across health services and unexpected medical and related expenses can rapidly accrue. Understanding these impacts is important to educate patients about treatments, to support individual health care choices, to help plan and implement social support services and enable equitable and sustainable health policy.

However, in Australia research into out-of-pocket expenses is challenging because patterns of care and resource information are not routinely collected in a centralised and linked way. Furthermore, 47% of Australians have optional private health insurance in addition to being covered by national health care insurance (Medicare) and patient out-of-pocket costs should be net of this coverage. Despite being open to recall bias, patient self-report is a practical method of collecting out-of-pocket expenses. Self-reported data have previously occurred through traditional postal and telephone surveys but the development of online survey tools offers new opportunities. Here we report the feasibility, methods and descriptive results of an online cross-sectional survey on the economic burden experienced by men after a diagnosis of prostate cancer.

METHODS

Survey development

A number of relevant studies related to this topic were identified (Krahn *et al.* 1999, 2009; Wilson *et al.* 2006; Yabroff *et al.* 2007; Warren *et al.* 2008; Fourcade *et al.* 2009; Roehrborn *et al.* 2009; Crawford *et al.* 2010; Jayadevappa *et al.* 2010; Markman & Luce 2010; Skolarus *et al.* 2010; Stokes *et al.* 2010, 2011; Andersson *et al.* 2011; Mollinier *et al.* 2011) and helped structure our survey, identify the types and sources of expenses incurred and provided guidance on the types and phrasing of questions in our survey. The survey was intended to combine the health situation of respondents and the key economic issues specific to Australian men diagnosed with prostate cancer. To this end, the survey comprised 68 questions over seven domains including: medical history, employment, household finances, out-of-pocket expenses of prostate cancer, private health insurance status, quality of life and general socio-demographic variables. For the questions on out-of-pocket expenses, participants were asked

how much they spent that was not already covered by Medicare and, if they had one, their private health insurer. A copy of the survey is provided in File S1. The content was informed both by questions used in previous social surveys and developed or adapted by the researchers (Table 1). A final open-ended question inviting the respondents to provide further information about their experience and/or feedback on the survey was included. The draft survey was circulated to consumers and Prostate Cancer Foundation of Australia (PCFA) executives, with modifications made to structure and wording. The final survey was then pre-tested online with 15 PCFA members, men with prostate cancer and researchers.

Sampling and recruitment

We undertook a national online survey of men who self-reported they had previously been diagnosed with prostate cancer. Sample size calculations indicated 300 respondents were required to detect a large effect size (0.35) in mean costs between equal subgroups with an alpha = 0.05 (two tails) and 80% power. Eligible participants were approached via PCFA and associated support groups, with PCFA hosting a web link to the survey as well as inviting PCFA support group members by email and social media to complete the survey. The membership of PCFA support groups during 2013 included approximately 5000 active members. To capture a broad cross-section of cancer survivors, no restrictions were made to the time since diagnosis therefore men could be at any time since their diagnosis. Participants were anonymous to the researchers and PCFA staff; no names or other identifying information were collected. The survey period was open until no further responses were received. This happened at 6 weeks after two reminders. Ethical clearance was obtained from Griffith University Human Research Ethics Committee (MED/31/12/HREC).

Data collection and analysis

Data were collected online using *LimeSurvey* hosted by the Survey Research Centre at Griffith University. The online survey opened on 8 April 2013 and ran for 6 weeks until 16 May 2013 at which point, after two reminder emails, no further responses were received. Participant consent via a front-screen information/consent sheet was required to proceed to the survey. Survey results were exported from *LimeSurvey* and analysed in Stata SE/11. Duplicate surveys were manually identified and removed. Subgroup analyses were undertaken between men who were diagnosed prior to January 2012 (more than 16 months prior to the survey date) and since January 2012

Table 1. Survey content and sources

Section	Question content	Source of questions
Medical history	Diagnosis date, treatments, whether cancer had spread, last PSA test details, concurrent health conditions	Researchers' own questions used in cancer surveys (Gordon <i>et al.</i> 2009, 2011), tailored to prostate cancer
Employment	Work status, hours of work, leave taken, job performance, major changes at work, retirement choices	Questions used on previous ABS surveys, HILDA surveys Researchers' own-developed questions
Household finances	Income, benefits, cost impact on family, distress, cost influence on treatment choice, financial hardship indicators, strategies to raise extra funds	ABS social surveys, questions used in Markman and Luce (2010)
Cost of prostate cancer	Costs in the last 3 months, itemised costs, total costs since diagnosis, complications and associated costs, PBS and Medicare Safety Net, CAPS eligibility	Adapted from previous research in Jung <i>et al.</i> (2012) Researchers' own-developed questions
Health insurance	Current status, policy duration, treatment coverage, type of hospital treated in, waiting time	Researchers' own-developed questions
Quality of life	Five questions on mobility, self-care, usual activities, pain/discomfort, anxiety/depression, 1 ranking question 0–1 on overall wellbeing	EuroQol-5D-3L (Viney <i>et al.</i> 2011) scored using Australian weights
General characteristics	Age, ethnicity, rurality, language, marital status, education	Standard socio-demographic questions
Free-text box	One open-ended question on any other comments participants wished to make on the financial impact of prostate cancer	Researchers' own-developed question

ABS, Australian Bureau of Statistics; CAPS, Continence Aids Payment Scheme; HILDA, Household, Income and Labour Dynamics in Australia; PBS, Pharmaceutical Benefits Scheme; PSA, prostate-specific antigen.

(hereafter termed 'recently diagnosed'); between men with and without private health insurance; and by state of residence. Pearson's chi-squared and Student's *t*-tests at $P < 0.05$ were used to test for significant differences in participant characteristics among subgroups. Skewness was considered for the cost data. Non-parametric bootstrapped statistics using 1000 repetitions and the bias-corrected approach was applied to out-of-pocket mean costs by subgroups.

RESULTS

Responses and missing data

A total of 297 survey responses were received. Note that because of the distribution method, which included a web link to the survey, it is not possible to determine the exact number of men who were aware of the survey and hence to calculate the response rate. Respondent self-reported diagnosis dates ranged from October 1991 up to April 2013, when the survey was completed. Not all participants fully completed the survey, and eight responses were identified as duplicates and subsequently removed from the analysis. Overall, there were 289 individual survey participants, comprising 239 (83%) full and 50 (17%) partial responses. No significant differences in baseline characteristics were found between full and partial responders, except a higher proportion of partial respondents (68%) were diagnosed more than 3 years prior to the survey compared with full responders (51%) $P = 0.033$.

Feasibility of the survey

The online survey was acceptable to those respondents who replied with respect to content, format and duration. There were a few exceptions that related to technical issues (in less than 10 men) such as computer 'freezes' or 'crashes', issues hampering the respondent progressing through the survey (related to mandatory responses), and in some cases low computer literacy. While five paper surveys were requested and posted to one support group leader with reply-paid envelopes, none were returned. A few participants telephoned the researchers to clarify questions, obtain technical support, and in one case provide detailed itemised records of expenses over an 18-month period.

Respondent characteristics

The mean age of respondents was 65 years old. The majority were married or partnered, owned their home and were living in a metropolitan area (Table 2). Thirty-nine per

Table 2. Socio-demographic and clinical profile of respondents

	All participants (<i>n</i> = 289)	Diagnosed after January 2012† (<i>n</i> = 65)	Diagnosed before January 2012 (<i>n</i> = 224)
Age group			
Mean years (SD)*	65.1 (8.4)	59.5 (7.5)	66.9 (7.9)
<60 years*	64 (22)	30 (46)	34 (15)
60–70 years*	110 (38)	21 (33)	89 (40)
70+ years*	69 (37)	5 (8)	64 (28)
Not stated	46 (16)	9 (14)	37 (17)
Total	289 (100)	65 (100)	224 (100)
Marital status‡ (<i>n</i> , %)			
Married or <i>de facto</i>	220 (90)	50 (89)	170 (90)
Divorced	13 (5)	2 (4)	11 (6)
Single/Never married/widowed	11 (4)	4 (7)	7 (4)
Education‡			
Primary School (Grade 7 or below)	4 (2)	0 (0)	4 (2)
High School (Grade 8 or above)	46 (19)	10 (18)	36 (19)
Dip./Certificate/Trade Qualified	86 (35)	15 (27)	71 (38)
University degree	108 (44)	31 (55)	77 (41)
Household income‡			
<\$18 000	13 (5)	3 (5)	10 (5)
\$18 201–\$37 000	48 (18)	7 (12)	41 (20)
\$37 001–\$80 000	100 (38)	20 (33)	80 (39)
\$80 000–\$180 000	66 (25)	20 (33)	46 (22)
>\$180 000	23 (9)	4 (7)	10 (5)
Unanswered	17 (6)	7 (12)	19 (9)
Private health insurance, yes	206 (71)	47 (72)	159 (71)
Region‡			
Metropolitan	177 (61)	41 (63)	136 (61)
Regional	40 (14)	9 (14)	31 (14)
Remote	13 (4)	2 (3)	11 (5)
Unclear locality	14 (4)	4 (6)	10 (5)
State‡			
New South Wales	87 (30)	16 (25)	71 (32)
Queensland	42 (15)	13 (20)	29 (13)
Victoria	41 (14)	10 (15)	31 (14)
South Australia	18 (6)	4 (6)	14 (6)
Western Australia	13 (5)	1 (2)	12 (5)
ACT	16 (6)	6 (9)	10 (5)
Tasmania	8 (3)	1 (2)	7 (3)
Northern Territory	5 (2)	1 (2)	4 (2)
Unknown	59 (26)	13 (20)	46 (16)
Most recent PSA score§ (ng/mL)	Mean (SD)		
Metastasised <i>n</i> = 48	10.10 (19.6)	–	–
No metastasis <i>n</i> = 207	1.5 (5.0)	–	–
Unknown spread of disease <i>n</i> = 8	3.5 (6.9)	–	–
Diagnosed in last 3 years	132 (46)	65 (100)	67 (30)
Diagnosed in last 5 years	189 (65)	65 (100)	124 (55)
Prostate cancer metastasised§	53 (18)	11 (17)	42 (19)
Comorbidities			
Other cancer	28 (10)	3 (5)	25 (11)
Heart disease	24 (8)	2 (3)	22 (10)
Osteoporosis	22 (8)	2 (3)	20 (9)
Stroke	5 (2)	0 (0)	5 (2)
Diabetes*	23 (8)	1 (2)	22 (10)
Arthritis	59 (20)	9 (14)	50 (22)
High blood pressure	112 (39)	20 (31)	92 (41)
High cholesterol	88 (30)	20 (31)	68 (30)
Chronic lung disease	7 (2)	1 (2)	6 (3)
Depression/anxiety	49 (17)	10 (15)	39 (17)
Other comorbidities	34 (12)	8 (12)	26 (12)
No. comorbidities per person (<i>n</i> , mean)*	207 (2.2)	41 (1.9)	166 (2.3)
Treatment completed or current¶			
Watchful waiting	26 (9)	3 (5)	23 (10)

Table 2. *Continued*

	All participants (<i>n</i> = 289)	Diagnosed after January 2012† (<i>n</i> = 65)	Diagnosed before January 2012 (<i>n</i> = 224)
Active surveillance	38 (13)	10 (15)	28 (13)
Radical prostatectomy	199 (69)	43 (66)	156 (70)
Cytotoxic chemotherapy	9 (3)	1 (2)	8 (4)
Radiotherapy*	89 (31)	13 (20)	76 (34)
Brachytherapy	18 (6)	2 (3)	16 (7)
Androgen Deprivation therapy	81 (28)	15 (23)	66 (29)
Immunotherapy	1 (<1)	0 (0)	1 (<1)
Other	22 (8)	5 (8)	17 (8)

Values are expressed in *n* (%).

**P* < 0.05.

†Diagnosed in last 16 months prior to survey (January 2012–April 2013).

‡Data were missing on socio-demographic and clinical characteristics for 45 (16%) men, including 9 (14%) who were recently diagnosed.

§This question is whether a doctor has told the respondent if their cancer has spread 'to other parts of their body' which we assume to mean metastases.

¶This includes any treatment and therefore the total *n* does not equal 289.

cent of the men were aged younger than 65 years and most men had other comorbid conditions (e.g. high blood pressure 39%, high cholesterol 30%, arthritis 20%, depression/anxiety 17%). A high proportion of men were university or trade qualified and 38% had household incomes between AU\$37 000 and AU\$80 000. A total of 71% held private health insurance and the mean time with their current insurer was 22.4 years. Just under one quarter (*n* = 65) were recently diagnosed (within 16 months prior to the survey date), with 65% diagnosed in the last 5 years for a median of 3.9 years. The majority had undergone a radical prostatectomy (69%) as primary treatment for their cancer, and many were currently receiving ADT (40%). Less than one fifth indicated their cancer had metastasised.

Out-of-pocket costs

Men who were recently diagnosed reported mean out-of-pocket expenditure of 2012 AU\$11 077 (SD \$10 096), with a median of AU\$8000 (interquartile range AU\$14 000) (Table 3). Three quarters of respondents diagnosed since January 2012 reported having spent up to AU\$17 000. Overall, expenditure was largely for specialist fees, hospital services, medical equipment and supplies and medicines. The mean total out-of-pocket expenditure reported between diagnosis and survey date by all respondents was AU\$9205 (SD AU\$14 567) with a median \$5000 (interquartile range AU\$10 000). Three quarters of respondents had spent up to AU\$12 000. Respondents with private health insurance reported double the out-of-pocket

Table 3. Out-of-pocket costs by subgroups of patients (Australian dollars)

	<i>n</i>	Mean (SD)	Median (IQR)	Bootstrapped 95% CI*
Total expenses since diagnosis (all patients)	245	\$9205 (\$14 567)	\$5000 (\$10 000)	\$7350–\$11 059
Diagnosed since January 2012†‡	56	\$11 077 (\$10 096)	\$8000 (\$14 000)	\$8395–\$13 759
Diagnosed in previous 3 years	116	\$8923 (\$8750)	\$5500 (\$11 650)	\$7322–\$10 534
Diagnosed in previous 5 years	161	\$8937 (\$10 442)	\$5000 (\$11 500)	\$7401–\$10 473
Treatment: watchful waiting	24	\$5492 (\$5119)	\$3000 (\$8750)	\$3450–\$7534
Treatment: active surveillance	31	\$10 302 (\$12 982)	\$5000 (\$8000)	\$5892–\$14 711
Treatment: radical prostatectomy	171	\$10 996 (\$16 681)	\$6000 (\$11 000)	\$8493–\$13 500
Treatment: Androgen Deprivation Therapy	67	\$11 471 (\$24 119)	\$3375 (\$10 300)	\$5765–\$17 177
Private health insurance	196	\$10 052 (\$15 460)	\$6000 (\$9000)	\$7849–\$12 255
No private health insurance	36	\$5103 (\$8022)	\$2000 (\$4000)	\$2458–\$7747
State: NSW	80	\$10 165 (\$12 038)	\$5750 (\$10 715)	\$7539–\$12 792
State: Queensland	40	\$14 035 (\$27 290)	\$6500 (\$12 385)	\$5708–\$22 363
State: Victoria	39	\$5451 (\$5095)	\$5000 (\$6900)	\$3944–\$6959
State: South Australia	18	\$3458 (\$7088)	\$875 (\$2100)	\$323–\$6592
Advanced prostate cancer	43	\$12 328 (\$15 977)	\$5000 (\$10 000)	\$7498–\$17 159

*Non-parametric bootstrapping with 1000 repetitions and the bias-corrected approach – 95% confidence interval around mean.

†Diagnosed in last 16 months from survey January 2012–April 2013.

‡\$AUD 2012. For all other subgroups, the dollars are unadjusted for inflation as we do not have information in which years the costs were incurred.

costs (AU\$10 052, 95% CI: AU\$7849–AU\$12 255) than those without insurance (AU\$5103, 95% CI: AU\$2458–AU\$7747) regardless of time since diagnosis. Reported out-of-pocket costs were highly right-skewed with 5% men having high medical expenses (\geq AU\$30 000). At the other end of the scale, 5% of the men spent \$250 or less out-of-pocket for their prostate cancer treatments. Men who had radical prostatectomy also tended to have higher costs than those managed by active surveillance, watchful waiting or androgen deprivation therapy (Table 3). Reported expenses also tended to be higher among men recently diagnosed (median \$8000) compared with those for men diagnosed within the last 3 years (median \$5500).

We found a statistically significant difference in reported cost (unadjusted) between states of residence with the highest median cost being in Queensland (AU\$6500) and the lowest in South Australia (AU\$875).

Employment impact

A total of 107 (39%) participants reported that they were in the workforce at the time of the survey. Approximately one quarter of men stated that they chose an earlier retirement age, and had stopped work, as a result of their diagnosis (Table 4). On average, respondents who had retired early had retired 4–5 years earlier than planned. There was

Table 4. Employment status and impact from prostate cancer

	All participants (<i>n</i> = 289)	Diagnosed after January 2012† (<i>n</i> = 65)	Diagnosed before January 2012 (<i>n</i> = 224)
Current work status*			
Retired	152 (55)	21 (33)	131 (61)
Employed	107 (38)	36 (50)	71 (33)
Unemployed/Other	19 (7)	6 (20)	13 (6)
Missing	11 (–)	2 (–)	9 (–)
Work status prior to diagnosis			
Retired	71 (26)	13 (21)	58 (27)
Employed	196 (71)	47 (75)	149 (70)
Unemployed/Other	10 (4)	3 (5)	7 (3)
Missing	12 (–)	2 (–)	10 (–)
Impact on retirement age			
Did diagnosis affect retirement age?			
No, retired when I expected / expect to retire as planned	196 (71)	42 (67)	154 (72)
Yes, my cancer meant I chose a later retirement age	16 (6)	5 (8)	11 (5)
Yes, my cancer meant I chose an earlier retirement age	64 (23)	16 (25)	48 (23)
Missing	13 (–)	2 (–)	11 (–)
Change in work since diagnosis‡§			
Decreased work hours	41 (14)	11 (17)	30 (13)
Increased work hours	10 (3)	3 (5)	7 (3)
Change in income	40 (14)	8 (12)	32 (14)
Change in role/responsibilities	28 (10)	5 (8)	23 (10)
Change in employer	17 (6)	2 (3)	15 (7)
Stopped work*	77 (27)	11 (17)	66 (29)
No change to work	138 (48)	34 (52)	104 (46)
Work environment experience‡			
Colleagues treated me differently*	20 (7)	10 (15)	10 (5)
Passed over for promotion	6 (2)	2 (3)	4 (2)
Demoted	1 (0)	0 (0)	1 (<1)
Made redundant	9 (3)	4 (6)	5 (2)
Treated with respect and support	109 (38)	30 (46)	79 (35)
Did not reveal prostate cancer at work	5 (2)	1 (2)	4 (2)
Other work impact	36 (12)	8 (12)	28 (12)
Not applicable (i.e. not working)	125 (43)	23 (35)	102 (40)

Values are expressed in *n* (%).

* $P < 0.05$.

†Diagnosed within 16 months prior to survey (January 2012–April 2013).

‡Not mutually exclusive categories.

§The question was phrased 'since your diagnosis of prostate cancer' therefore it is possible that changes may not have been 'due to' the prostate cancer.

also a reduction in employment among respondents diagnosed in the 16 months prior to the survey with 17% reducing their work hours and 17% stopping work. Also, those recently diagnosed reported longer usual work hours but more had missed work for illness compared with all respondents. In their workplace, most respondents indicated that they had been treated with respect and support when diagnosed with prostate cancer. In a few instances, respondents indicated that they had been passed over for promotion (six men, 2%), had not told their employer about their cancer (five men, 2%) or had been made redundant (nine men, 3%).

Financial impact

In assessing participants who were recently diagnosed, 57% of respondents indicated that their financial position was 'reasonably comfortable'. However, six men (9%) stated that they decided against treatment due to its high expense. Even so, 70% had spent more for their cancer treatment than they expected to, 20% said that the cost of treating their prostate cancer had caused them 'a great deal' of distress. One-third of participants (34%) reported they were 'just getting on' or 'struggling' financially. To pay for their treatment, respondents reported they had drawn on savings (38%), sold assets (8%) and increased a credit card limit (22%). Reporting unfavourable financial impacts of prostate cancer treatment appeared to be worse for men who were recently diagnosed compared with the responses of all respondents. In total, 206 (71%) had private health insurance and most of these men were treated in a private hospital (171 or 83%) with the remainder treated in the public sector (35 or 17%). General comments received from respondents add further insight to the survey results and provide useful supplementary data to understanding respondents' experience with the financial impact of prostate cancer (File S2).

DISCUSSION

Our study found that 50% of men diagnosed during 2012 reported out-of-pocket expenses of up to AU\$8000 for their prostate cancer treatment while 75% of men spent up to AU\$17 000 (2012). Despite the caution required when interpreting our findings from a select group of men with prostate cancer, they suggest a large variability in out-of-pocket medical costs for prostate cancer treatment with some men facing very high costs. Notably, many study participants were well-educated, financially comfortable and two-thirds were privately insured but this did not provide adequate protection for the costs related to

this unexpected but common disease. It is known that patterns of treatment vary between the public and private systems and between states (Evans *et al.* 2013). Many experts also believe that consumerism has had an impact on treatment choices for prostate cancer, which has in turn impacted costs (Alkhateeb & Lawrentschuk 2011). It seems likely that these factors contribute, at least to some degree, to the variability of costs in our study.

While the financial considerations of health care will naturally be of secondary importance when a person is told he has cancer and needs treatment, these findings highlight this to be an additional source of distress at a vulnerable time. Some individuals face considerable financial consequences after a diagnosis of cancer and they are unable to work or face high out-of-pocket expenses. When addressing supportive care needs, it is becoming increasingly important to consider the patient's financial position and where necessary, provide adequate support and/or referrals to local support agencies. When diagnosed with prostate cancer men should be made aware of their financial options and the sources of assistance that may alleviate this distress and avoid later decisional regret. Earlier awareness of what services are or are not covered by private health insurance policies and switching private health insurers to obtain improved coverage may also be advisable.

Private health insurance is designed to help consumers manage health care expenses but it does not protect them from open-ended co-payments (e.g. specialist fees, hospital fees) leaving individuals exposed to unlimited costs (Doggott 2014). There has also been a trend towards private health insurance policies with lower premiums, but more restrictions and exclusions for selected treatments, leading to higher co-payments when insurance is used (Doggott 2014). A recent patterns of care study in Victoria (Evans *et al.* 2013), that recruited men with prostate cancer from the Victorian registry, reported the changes in treatment during the past decade. They identified declines in the proportion of men treated with first-line ADT (6% from 39%), increases in curative treatments such as surgery, radiotherapy or brachytherapy (71% from 25%), increases in EBRT and high-dose brachytherapy (26% from 12%) and expected increases in robotic surgery (currently 20% of all radical prostatectomies). These trends were similar to those reported in Queensland and NSW studies (Evans *et al.* 2013) but may be different to those in South Australia which has experienced stable rates in prostatectomy (23%). What is different across states is the level of private health insurance coverage (i.e. ACT 58%, NSW 48%, QLD 45%, VIC 45% NT 39% and Australia-wide 47% in 2014) (www.phiac.gov.au). In combination with

the different fees charged by doctors, the varied hospital costs passed on to patients and different gap schemes of private health insurers, this is likely to influence the variation in patient co-payments.

Latest figures indicate that average household expenditure on goods and services in Australia was \$1236 per week in 2009–2010 which rose \$343 per week (38%) since 2003–2004 (Australian Bureau of Statistics 2003). Although the spending on 'medical care and health expenses' also rose during this time by 40%, it is still below spending on housing, food, transport, miscellaneous goods and services (which includes education costs), and recreation categories (Australian Bureau of Statistics 2003). On average, individual medical out-of-pocket expenses in Australia are higher than those in most European countries, are growing on average 6.7% annually, and represent 17.8% of overall health care funding (Australian Institute of Health and Welfare 2013). Also, due to Australia's geography, travel and accommodation expenses would not affect most Europeans. These factors suggest that the findings presented here are high relative to those experienced by most European residents. Co-payments are known to be a less equitable form of health funding and will potentially increase health inequality across socio-demographic groups (Pisu *et al.* 2010; Meneses *et al.* 2012; Lauzier *et al.* 2013; Doggett 2014). Calls have been made for a national framework for co-payment policy which currently does not exist (Doggett 2014).

Despite there being a paucity of research in this area, US researchers have examined the direct and indirect health care expenditures for cancer (Pisu *et al.* 2010; Meneses *et al.* 2012; Lauzier *et al.* 2013) and have recently called it the 'financial toxicity' of cancer treatment (Mcdougall & Ransey 2014). Our research complements two US-based studies quantifying the personal cost of prostate cancer treatment to patients (Jayadevappa *et al.* 2010; Markman & Luce 2010). One found approximately 80% of patients with prostate cancer experienced average out-of-pocket costs of up to US\$5000 (Markman & Luce 2010). However, cost varied with treatment type (Jayadevappa *et al.* 2010), with the majority of treatment costs occurring soon after diagnosis for younger men, those with advanced cancer, and those undergoing surgical interventions.

The retrospective and cross-sectional nature of survey leaves the results open to recall bias to an unknown degree. There was a wide variation between respondents in the time between diagnosis and survey date, making the accurate recall and interpretation of cumulative costs difficult. The variation across respondents in the time between diagnosis and survey date is likely to contribute to the range of costs reported. However, we designed the

survey to focus on the actual impact of the financial burden to individuals rather than strive for accuracy of the dollar value. Clearly, an improvement to our design would be to prospectively capture medical expenses at frequent intervals (e.g. 3 monthly), validate with receipts and anchor participants at recruitment to a common starting time (e.g. within 3 months of diagnosis). This more intensive design would incur a high burden on participants and may lower completion rates.

Our survey captured a sample of 289 men covering a broad spectrum of ages, geographic regions and socio-economic status. However, while it drew from the entire nation, the study was not population-based and generalisability is not guaranteed. Compared with an Australian population-based sample in study (Evans *et al.* 2013), the mean age was 66.2 years compared with our study mean age 56 years, 44% had radical prostatectomy versus our study of 66% and 50% had private insurance versus 72% in our study. The questions on costs were framed specifically to minimise inaccuracies (e.g. 'SINCE DIAGNOSIS, how much would you estimate to have spent in TOTAL for your prostate cancer out of your own money? I.e. the amount you paid that was not covered by Medicare or your health insurance.'). However, we cannot rule out problems with the accuracy (over or under estimates) of the expenses reported by the participants. Some men said they had referred to receipts, tax and other written documents to support their answers. There was higher participation among those with private health insurance and those with good computer literacy. Also, participants were drawn from PCFA prostate cancer support groups and they are likely to have been more interested and engaged with the topic, and potentially had higher-than-normal medical expenses. The PCFA only attracts a very small proportion of the overall Australian men living with prostate cancer (~5000 members from at least 120 000 prevalent cases). On the other hand, the study did provide a balanced view with many men saying they had had low financial burdens. Finally, we relied on self-report of prostate cancer and had no way of verifying the diagnosis of prostate cancer among respondents. However, a targeted approach was taken and we have no reason to believe that respondents did not have prostate cancer.

We have demonstrated that an online format is acceptable and feasible to some men with prostate cancer. Advantages include online surveys are quickly, widely and cheaply disseminated, require no data entry, allow privacy and mandatory response types can minimise missing data. However, these advantages come at the expense of still requiring data cleaning, survey incompleteness, some technical difficulties and men required to be

competent using a computer. We found that providing space for respondents' free comments resulted in a deeper understanding of responses. Until further assessment of the psychometric properties of this survey is undertaken, the complexity of this topic, combined with the variation in participant experiences here suggests a mixed methods approach is optimal.

There are significant research gaps in our understanding of how medical out-of-pocket expenses and other economic burdens impact on individuals. This study provides a starting point and snapshot into this area for men with prostate cancer. Although, it is not traditionally viewed as a chronic disease, high survival rates mean there is ongoing health care resources beyond the upfront primary treatment (e.g. secondary treatments, bone scans, PSA tests). Furthermore, many men in our survey had other chronic illnesses such as diabetes, arthritis, depression and heart disease. The financial burden imposed by prostate cancer for these individuals was compounding. This study highlights the problem of cumulative out-of-pocket costs and the need for policy debate ahead of proposed changes in Australia to Medicare doctor and medication co-payments. Financial hardship did exist for some men in our study and many had a reduced capacity to work, exacerbating the individual's financial distress.

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CONFLICT OF INTEREST

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SUPPORTING INFORMATION

Additional Supporting Information may be found in the online version of this article:

File S1. Survey questions.

File S2. Open comments from respondents.