

Prevalence and predictors of cancer specific distress in men with a family history of prostate cancer

M. E. McDowell^{1*}, S. Occhipinti¹, R. A. Gardiner^{2,3} and S. K. Chambers^{2,4}

¹Griffith Health Institute, School of Applied Psychology, Griffith University, Brisbane, Queensland, Australia

²Centre for Clinical Research, University of Queensland, Brisbane, Queensland, Australia

³Consultant Urologist, Department of Urology, Royal Brisbane Hospital, Brisbane, Queensland, Australia

⁴Griffith Health Institute, Griffith University, Brisbane, Queensland, Australia

*Correspondence to:

School of Applied Psychology,
Griffith University, Mt Gravatt
QLD 4111, Australia. E-mail:
M.McDowell@griffith.edu.au

Abstract

Objective: To examine prevalence and predictors of cancer-specific distress in undiagnosed men with and without a family history of prostate cancer, and to examine the contribution of perceptions of an affected relative's cancer experience on the distress of unaffected male relatives.

Methods: Men with a first degree relative with prostate cancer ($n = 207$) and men without a family history ($n = 239$) from Australia completed a Computer Assisted Telephone Interview. Participants completed the Prostate Cancer Anxiety Subscale of the Memorial Anxiety Scale for Prostate Cancer, measures of perceived risk, and socio-demographic information. Men with a family history provided details about their family history (number of relatives diagnosed with and dead from prostate cancer, relationship to affected relative, months since diagnosis) and reported their perceptions of their affected relative's prostate cancer experience including perceptions of threat related to the relative's diagnosis and perceived treatment phase and prognosis.

Results: Cancer-specific distress was low for all men and there was no significant difference in the distress experienced by men with and without a family history. Regression analyses showed that for all men, cancer-specific distress increased with urinary symptoms and decreased in those with higher education and in older participants. For men with a family history, having a relative who died from prostate cancer and perceiving greater threat from a relative's diagnosis was associated with greater cancer-specific distress.

Conclusions: Interventions would benefit from examining appraisals of familial risk and examining prospective assessments of distress in the unaffected male relatives of men with prostate cancer over the course of the cancer trajectory.

Copyright © 2013 John Wiley & Sons, Ltd.

Received: 20 November 2012

Revised: 17 April 2013

Accepted: 25 April 2013

Introduction

A diagnosis of cancer is associated with significant psychological distress not only for the person diagnosed but also for their unaffected family members [1,2]. People with a family history of cancer are not only confronted with a relative's illness experience but family members may also need to cope with additional risk that can accrue to them as a result of a cancer diagnosis in the family. For instance, a diagnosis of prostate cancer in a family member results in an increased risk for unaffected first degree relatives that is greater than twofold that of men without a family history [3,4]. It is not clear how a family member's diagnosis of prostate cancer or perceptions of personal disease risk impact on the cancer-specific distress experienced by unaffected male relatives. Although cancer distress is reportedly high in people with a family history, much of this research has been conducted in predominantly female cancers [e.g. breast and ovarian; 2,5], whereas distress is often reported to be lower in men and suggests a possible gender difference [1]. Further, many

studies of prostate cancer distress in men with a family history examine general distress rather than cancer-specific distress associated with risk of diagnosis [6]. This study sought to identify whether men with a first degree family history of prostate cancer reported greater cancer-specific distress than men without a family history, and to identify potential predictors of distress. Understanding the relationship between family history of cancer, perceptions of risk, and psychological distress is crucial should interventions seek to target distress in family members following the diagnosis of a relative.

Prostate cancer-specific distress in men with a family history

The potential for men with a family history of prostate cancer to experience psychological distress as a result of their family history has been investigated across a number of studies. Specifically, psychological distress has been investigated with respect to examining the prevalence of general distress in men with a family history [e.g. trait

anxiety; 7], as a predictor of screening programme attendance or adherence [8,9], in relation to attitudes towards genetic testing [7], or as an outcome associated with the prostate specific antigen (PSA) testing process or referral for biopsy [10–12]. Notably, no study has addressed whether men with a family history experience greater prostate cancer-specific distress than men without a family history.

The prevalence of psychological morbidity in men with a family history of prostate cancer has been reported to be within the normal population range for middle-aged men [13]. For instance, Bratt *et al.* [14] reported that the average anxiety and depression levels of men with a family history were below the population average for Dutch and Swedish samples. However, assessments of psychological morbidity in these studies have utilised general psychological distress measures that do not specifically examine distress related to prostate cancer risk. Cancer-specific distress is more likely to be elevated in people with a family history, and general distress measures may underestimate the degree or prevalence of distress associated with the risk of diagnosis [6,15]. For instance, women who have a greater risk of cancer do not differ from women at average risk in terms of general health anxiety but report greater cancer-specific distress [16]. For men with a family history of prostate cancer, measures of distress have included measures of general anxiety such as the State-Trait Anxiety Inventory [8,17,18] or Hospital Anxiety and Depression Scale [10,12,14,19], or measures of general health-related anxiety [20,21]. Only three studies [9,10,14] have used cancer-specific distress measures [e.g. Impact of Events Scale, 22] that assess distress related to prostate cancer risk, specifically. Of these three studies, none has compared samples of at-risk men with and without a family history of prostate cancer directly. Only one study compared distress experienced by men with and without a family history at the time of biopsy and found no significant difference in distress levels experienced across groups at biopsy [12], a finding consistent with studies examining distress during the PSA screening process [10,11].

Further, many of the family history samples used in studies examining psychological distress include men who are at high hereditary risk or recruit men from a screening setting where distress may be linked to the specific health context. For instance, many samples are composed of men who are from families with a known histological or hereditary risk, men who were recruited for the purposes of attending prostate cancer screening programmes, or men who were participating in studies examining interest in genetic testing [8–11,14,18]. Cancer distress has not been examined in men with a family history more broadly.

Predictors of prostate cancer-specific distress in men with a family history

Few studies have examined predictors of distress, including socio-demographic or other factors such as urological

symptoms [23] or risk perceptions [24] that have been associated with cancer fear or worry. Further, there is evidence to suggest that cancer distress may be influenced by the specific cancer experiences of an affected relative, such as perceiving a relative's cancer prognosis to be deteriorating (versus stable), or observing a relative experience treatment side effects [15]. Experience with an affected relative may increase or attenuate distress such that distress may fluctuate in response to perceptions of illness prognosis, side effects and outcomes. As well, emotional or affective responses to a relative's cancer experience, such as perceiving the cancer experience to be personally threatening, may also contribute to distress regarding one's personal risk of cancer. To our knowledge, there have been no studies to examine these cancer experience predictors empirically.

In a study that examined family relationship factors in men with a family history of prostate cancer, Bratt *et al.* [14] reported greater cancer-specific distress was correlated with the number of relatives diagnosed with or deceased from prostate cancer. These results are consistent with predictors of distress in the other cancer domains. In a review of indicators of psychological distress in women with an increased risk of breast cancer, Thewes *et al.* [2] surmised that the following cancer experience factors were associated with psychological distress: having a mother diagnosed with breast cancer, being a caregiver to a relative, having a relative die from breast cancer, and overestimating personal risk of developing breast cancer. Thus, perceived risk and family relationship factors (e.g. relationship to and perceived closeness to an affected relative) appear to be associated with greater distress in other cancer domains such as breast, ovarian, and colorectal cancer [1,2,5,25,26]. Identifying the characteristics associated with the experience of distress in relatives with a family history of prostate cancer is an important first step in determining how best to target distress about prostate cancer in unaffected male relatives.

The present study assesses cancer-specific distress in men with and without a family history of prostate cancer and examines how socio-demographic characteristics, perceived risk, and family history predict distress. Further, the contribution of cancer experience characteristics (as perceived by the unaffected relative) to the prediction of cancer-specific distress is also explored.

Method

Participants

First degree relatives of men with prostate cancer (FDRs) and a sample of men from the general population of Queensland, Australia (PM) participated in a Computer Assisted Telephone Interview (CATI) as part of a broader study examining decision making about prostate cancer

screening. Details of the recruitment process and study protocols can be found in the study of McDowell *et al.* [27] and McDowell *et al.* [28] and are summarised below. FDRs were recruited from probands (affected relatives) who were part of a longitudinal decisional intervention randomised controlled trial (RCT), ProsCan [29]. A convenience sample of PM was recruited by a market research firm. Ethical clearance was obtained from Griffith University Human Research Ethics Committee and the study was funded by the Cancer Council Queensland.

The participants were eligible for the study if the proband was diagnosed prior to the age of 65 years (FDR sample), and if the participant was aged between 40 and 65 years, lived within Australia, did not have a prior history of cancer (including prostate cancer), and had Basic English literacy. PM who reported a first degree family history of prostate cancer were excluded from the study ($n=32$). For the FDR sample, permission to contact was obtained from probands for 293 FDRs and 207 consented to participate (70.6% consent rate). Of the 246 PM who answered all eligibility questions, 239 (97.2% consent rate) completed the study (440 households had a man in the eligible age range and exclusions were based on subsequent eligibility criteria or the occupant was away for the study duration). The total sample size was 446 participants.

Materials and procedure

The participants completed the CATI guided by research officers. The CATI was conducted as part of a larger study and took approximately 35 min to complete.

Background variables

The participants completed socio-demographic information (marital status, countries of birth, ethnic background, work status, education, and annual income) and urinary symptoms assessed by the International Prostate Symptom Score [30]. The International Prostate Symptom Score is a widely used and validated instrument to evaluate lower urinary tract symptoms and demonstrated good internal consistency in the current study ($\alpha=0.73$).

Perceptions of affected relative's cancer experience

FDRs reported the number of first degree relatives (i.e., father, brothers and sons) diagnosed with as well as the number who had died from prostate cancer. For the most recently diagnosed relative, FDRs reported an estimate of months since diagnosis. To assess perceptions of an affected relative's cancer experience, FDRs indicated perceptions of the status of their relative's prostate cancer (*stable*, *improving* and *deteriorating*); current treatment phase (*completed*, *undertaking* or *having no active treatment*); the severity of treatment side effects experienced by their relative (1 = *no side effects* to 6 = *very severe*); and whether they felt threatened by their relative's prostate cancer

(1 = *not at all threatened* to 5 = *very threatened*). If the participant reported more than one affected relative, these questions referred to their most recently diagnosed relative.

Perceived risk

A composite of a 4-item measure based on the perceived susceptibility measure used by Gerend *et al.* [31] assessed perceived risk of prostate cancer. Details of the measure are described in the study of McDowell *et al.* [28] and are summarised in the succeeding text. Two items assessed absolute risk (e.g. perceived susceptibility and chance of developing prostate cancer in one's lifetime) utilising 5-point Likert scales (e.g. very low chance to very high chance). The third absolute risk item assessed perceived risk with respect to natural frequencies with the same numeric denominator (e.g. 1 in 1000 to 100 in 1000 or greater), and the final item asked men to indicate their risk in comparison with other men of their age (1 = *a lot lower* to 5 = *a lot higher*). The Percent of Maximum Possible score method [32] created a composite scale score ranging from 0 to 100.

Cancer-specific distress

Cancer-specific distress was assessed with the 11-item Prostate Cancer Anxiety Subscale of the Memorial Anxiety Scale for Prostate Cancer [MAX-PC-PCAS; 33] as validated by Dale *et al.* [34] for undiagnosed men at the time of biopsy. For the present study (undiagnosed men not currently undergoing biopsy), a single item that referred to going to get PSA test results was reworded to ask more generally about going to get a PSA test (*I was afraid that going to get a PSA test would show me that I could have prostate cancer*). Items were measured on a 4-point Likert scales assessing frequency of thoughts (0 = *not at all*, 3 = *often*) with a total scale score ranging from 0 to 33. The MAX-PC-PCAS has demonstrated reliability and validity [34] and showed good internal consistency in the current study ($\alpha=0.88$).

Statistical methods

Treatment of missing data

The dataset contained small amounts of missing data across a range of variables, and multiple imputation was employed to retain incomplete cases in the analyses. Unlike other missing data techniques (e.g. listwise or pairwise deletion and mean replacement) that can underestimate standard errors and overestimate parameters, multiple imputation incorporates variances in parameter estimates in the calculation of standard errors across multiply imputed datasets. Multiple imputation is considered to be current best practice in dealing with missing data in surveys and clinical trials. Extensive simulation evidence is reported in the study of Shafer and Graham [35]. The pattern of missing data was assumed to be

Missing at Random and multiple imputation (using STATA version 12 *mi impute mvn*, StataCorp. 2011. Stata Statistical Software: Release 12. College Station, TX: StataCorp LP.) was conducted on the complete dataset that included auxiliary variables that would contribute to the prediction of missing data on relevant variables. Prior to imputation, dummy variables were created for categorical variables with missing data, and whole scale scores were imputed when they met the conditions set by Graham [36]. Analyses were run on two multiple imputed datasets (10 imputations were run for each file). First, a data file containing only those variables with measures assessed for both FDR and PM was used to impute missing data for analyses involving comparisons between the two groups, and missing data patterns are described in detail in the study of McDowell *et al.* [27]. For analyses involving family history cancer experience characteristics (only asked of FDRs), a second data file containing only data for the FDR sample was imputed. Missing data patterns for this file were as follows: 38% of variables contained no missing data, 35% contained missed data for <5% of cases, and 5% contained missing data for between 6% and 22% of cases (skip patterns accounted for missing data for the remaining variables and were retained to preserve hierarchical relationships between variables). Unless otherwise specified, descriptive statistics are reported for raw data.

Statistical analyses

Where appropriate, univariate analyses using logistic or ordinary least squares (OLS) regression examined group differences between FDRs and PM on socio-demographic

variables, urinary symptoms, and cancer-specific distress. Predictors of cancer-specific distress were examined using standard OLS regression.

Results

Sample descriptives

As reported in the study of McDowell *et al.* [28],¹ most participants were born in Australia (84.3%). FDRs were more likely to be born in Australia than PM ($F(1, .) = 20.43$, $p < 0.0001$)² and to identify with a British/Scottish/Welsh/Irish ethnicity compared with other ethnicities ($F(1, .) = 9.28$, $p = 0.002$). The majority of the participants were married or in a cohabitation relationship (82.3%), had completed tertiary education or a trade certificate (66.8%), were employed full-time (70.0%), and earned >AUD \$60,000 per year (53.6%). Compared with the 2006 Census data, the current sample tended to be composed of men who were more likely to be married, report a high income, to be born in Australia and less likely to be employed full-time [37]. On average, FDRs were older ($M = 54.0$, $SD = 7.47$) than PM ($M = 52.5$, $SD = 7.37$; $F(1, 442) = 4.63$, $p = 0.032$) and were more likely to be recruited from a regional location ($F(1, .) = 8.96$, $p = 0.003$). Less than 3% of men reported experiencing severe urinary symptoms with the majority reporting only mild symptoms (76.9%).

Perceptions of affected relative's cancer experience

Approximately, a third (30.9%) of FDRs reported having multiple affected first degree relatives. The majority of FDRs were recruited from ProsCan men who were brothers (83.1%) and over 40% reported having a father

Table 1. Descriptives for FDR family history experience variables

Variable	FDR (%)
Brother of ProsCan proband (vs son)	172 (83.1)
No. first degree relatives diagnosed with PCa	$M = 1.37$, $SD = 0.60$
No. FDRs who have a relative deceased from PCa	16 (7.7)
Relationships of affected relative/s	
Father	37 (17.9)
Brother/s	122 (58.9)
Father and brother	48 (23.2)
Most recently diagnosed relative	
Father	37 (17.9)
Younger brother	54 (26.1)
Older brother	116 (56.0)
Perceived phase of treatment of affected relative	
Undertaking treatment	15 (7.3)
Completed treatment	183 (88.4)
Not having active treatment (e.g. watchful waiting)	3 (1.5)
Perceived progression of affected relative's cancer	
Stable	161 (77.8)
Improving	34 (16.4)
Deteriorating	4 (1.9)

Percentages may not equal 100% owing to missing data and do not know responses.
FDR, First-degree relatives of men with prostate cancer.

with prostate cancer (Table 1). The most recently diagnosed relative was most frequently reported to be an older brother, and the relative was diagnosed on average over 26 months prior to the study ($M=26.08$, $SD=12.97$; range 3–72). Less than 10% of FDRs reported having a relative who had died from prostate cancer. Most FDRs perceived that their most recently diagnosed relative had completed their prostate cancer treatment, experienced mild–moderate side effects as a result of their treatment ($M=3.55$, $SD=1.34$), and were reported to be in a stable condition with respect to their cancer progression. On average, FDRs felt slightly threatened by their relative's prostate cancer ($M=1.90$, $SD=1.04$).

Perceived risk

Greater overall perceived risk was reported for FDRs ($M=55.9$, $SE=1.58$; 95%CI 52.77–59.02) in comparison with PM [$M=41.0$, $SE=1.34$; 95%CI 38.31–43.60, $F(1, 408.3)=52.90$, $p<0.0001$, $R^2=0.110$; 28]

Prostate cancer-specific distress

Levels of cancer-specific distress were low for both the FDRs ($M=5.84$, $SE=0.45$; 95%CI 4.95–6.73) and PM ($M=4.85$, $SE=0.39$; 95%CI 4.08–5.63), and the difference was not significant ($F(1, 427)=2.74$, $p=0.098$). Although there are no published clinical cut-offs for distress

Table 2. Predictors of cancer specific distress

Variable	Total sample		FDR	
	Coef (SE)	95% CI	Coef (SE)	95% CI
Constant	1.65 (1.67)	[−1.64–4.93]	6.44 (4.11)	[−1.70–14.57]
Socio-demographics				
Age [‡]	−0.09 (0.04)*	[−0.17–0.01]	−0.01 (0.10)	[−0.19–0.21]
Marital status [‡]	0.24 (0.80)	[−1.33–1.81]	−0.57 (1.08)	[−2.69–1.56]
Country of birth (not Australia)	0.46 (0.87)	[−1.24–2.19]	−1.00 (1.91)	[−4.77–2.76]
Metro location (regional)	0.01 (0.60)	[−1.16–1.19]	−1.03 (0.91)	[−2.82–0.76]
Ethnicity (non-British)	−0.08 (0.80)	[−1.65–1.50]	−1.32 (1.61)	[−4.57–1.94]
Education – Senior high ^b	0.56 (1.09)	[−1.60–2.69]	−1.46 (2.15)	[−5.70–2.78]
Education – Trade Cert ^b	0.20 (0.79)	[−1.36–1.75]	0.57 (1.10)	[−1.61–2.74]
Education – Tertiary ^b	−2.05 (0.91)*	[−3.84–0.26]	−2.33 (1.26)	[−4.82–0.17]
Income AUD\$20–39,999 ^c	1.46 (1.33)	[−1.16–4.08]	−0.66 (1.95)	[−4.51–3.18]
Income AUD\$40–59,999 ^c	0.59 (1.29)	[−1.94–3.12]	−0.85 (1.89)	[−4.59–2.88]
Income AUD\$60–79,999 ^c	0.10 (1.37)	[−2.60–2.80]	−1.10 (2.02)	[−5.09–2.88]
Income AUD\$80,000+ ^c	−0.82 (1.26)	[−3.31–1.66]	−2.76 (1.88)	[−6.48–0.95]
Urinary symptom total score	0.19 (0.06)**	[0.08–0.31]	0.12 (0.09)	[−0.05–0.29]
Perceived risk	0.05 (0.01)**	[0.02–0.08]	−0.01 (0.02)	[−0.05–0.03]
FDR status	0.42 (0.65)	[−0.86–1.70]	—	—
Relative experience				
Treatment phase – completed ^d			1.39 (1.77)	[−2.11–4.90]
Treatment phase – no active ^d			1.42 (4.68)	[−7.82–10.67]
PCa progression – improving ^e			1.54 (1.18)	[−0.79–3.87]
PCa progression – deteriorating ^e			−3.30 (3.06)	[−9.34–2.74]
Recent diagnosed – younger brother ^f			−8.30 (4.65)	[−17.47–0.87]
Recent diagnosed – older brother ^f			−7.37 (4.45)	[−16.16–1.42]
Relationship – brother ^f			2.49 (4.57)	[−6.53–11.52]
Relationship – brother and father ^f			5.57 (4.36)	[−3.03–14.17]
Number relatives PCa [‡]			0.61 (1.07)	[−1.50–2.71]
Months since relative's diagnosis			−0.02 (0.03)	[−0.08–0.05]
Perceived Tx side-effects			−0.22 (0.36)	[−0.93–0.48]
Perceived threat			3.09 (0.46)***	[2.19–3.99]
Relative's deceased from PCa			4.29 (1.88)*	[0.57–8.00]
Model	$R^2=0.113$		$R^2=0.375$	

Reference category for binary variables shown in parentheses.

[‡]Reference category is never married/divorced/widowed.

^bReference category is no greater than junior high school.

^cReference category is <AUD\$20,000.

^dReference category is undertaking treatment.

^eReference category is stable.

^fReference category is father.

[‡]To facilitate interpretation, participant age was centred at the mean for each analysis (Total sample, $M=53.19$; FDR sample, $M=54.00$) and number of relatives diagnosed was centred at 1.

FDR, First-degree relatives of men with prostate cancer.

* $p<0.05$.

** $p<0.01$.

*** $p<0.001$

for the MAX-PC-PCAS, only 9.7% of FDRs and 8.8% of PM exceeded a total score cut-off value of 16.5 [equating to an average score of 1.5 on each item; 33].

Regression analyses

Table 2 presents the results for OLS regression analyses examining risk perceptions and socio-demographic predictors of prostate cancer-specific distress for the total sample, and for a model that included family history diagnosis characteristics for the FDR sample.

Predictors of cancer-specific distress

For the total sample, the only socio-demographic predictors of distress were age, education, and urinary symptoms. Less distress was reported with increasing age and for men with tertiary education (compared with men who were educated to junior high school), whereas the experience of greater urinary symptoms predicted greater distress. Greater perceived risk was a significant predictor of distress. Consistent with the univariate analysis for distress reported earlier, FDR status did not predict distress. The overall model was significant ($F(14,419.9)=3.60$, $p < 0.001$) and explained 11.3% of the variance in distress.

For the FDR sample, family history cancer characteristics added to the prediction of distress and explained 36.6% of the variance ($F(26,168.7)=3.62$, $p < 0.001$). In contrast to the regression analysis for the total sample, education, age, and urinary symptoms were not significant. Perceived risk did not significantly predict distress in this model. Rather, FDRs who perceived their relative's cancer as more threatening and FDRs who reported having a relative deceased from prostate cancer reported greater distress.³ There was a trend for FDRs whose most recently diagnosed relative was a younger brother or older brother as opposed to a father to report less distress, however, these differences did not reach significance ($p=0.072$ and $p=0.089$, respectively).

Discussion

This is the first study to assess and compare prostate cancer-specific distress experienced by men with and without a family history of prostate cancer. Prostate cancer-specific distress in the present study was low for all men, and men with a family history did not report greater distress than men without a family history. These results support and extend the findings of previous studies on men with a family history of prostate cancer that generally show first degree relatives do not report high or significant levels of general distress or cancer worry [7,14]. This contrasts with research in other cancer domains where psychological distress is considered to be high in family members of affected relatives [2,5,26]. However, not all studies find that family history is

associated with high cancer-specific distress [25], suggesting that the presence of a family history may not be a sufficient condition to increase distress or concern about cancer risk in isolation of other factors. For instance, family relationship factors, such as playing a caregiving role or reporting a close personal relationship to the affected relative, are key determinants of distress in women with a family history of breast cancer [2,25,26]. Men with a family history of prostate cancer may not play a similar caregiving or supportive role as unaffected female relatives, particularly given that support offered to men with cancer is purportedly mediated by spousal support [38]. Gender differences in emotional closeness, support, and caregiving on distress in unaffected male relatives of men with prostate cancer warrants further exploration.

Alternately, Benyamini *et al.* [39] found the lowest levels of cancer worry in people with vicarious cancer experience (e.g. living with someone with cancer) compared with those with a personal or no experience with cancer, yet they were just as vigilant about monitoring bodily signs of cancer as those who had a personal cancer history [39]. Emotional coping and response to health threats (e.g. taking action) may be independent, and men with a family history of prostate cancer may deal with cancer risk through more problem-focused as opposed to emotion-focused coping [40]. First-degree relatives do not report significant distress regarding prostate cancer risk but report greater screening behaviours compared with men with no family history [27,41]. In this connection, although in the present study, men with a family history reported greater risk perceptions than men without a family history, perceived risk was not associated with distress for men with a family history but did predict cancer-specific distress in men with no family history. Additional research is needed to address this finding as well as to explore the reasons why ratings of perceived risk were high for both groups and may be incongruent with population risk levels.

Although not significant when analyses included cancer experience factors for FDRs, older men reported lower distress when examined as a predictor of distress for all men. This result would seem counterintuitive given that age is a known risk factor for prostate cancer [42] and there is an increase in screening behaviour with age [28]. It is possible that older men who have not been diagnosed with prostate cancer feel less anxious or concerned each year they remain undiagnosed. It is unclear why higher education was associated with lower anxiety in men or why education was not a significant predictor of anxiety in FDRs. Future research could explore how education may relate to seeking or attending to information about prostate cancer that serves to alleviate concern about prostate cancer, and this may explain why education was not associated with anxiety in men who are at heightened

familial risk. The relationship between urinary symptoms and cancer-specific distress is not surprising considering that the experience of urinary symptoms can be associated with multiple urological conditions (e.g. benign prostatic hyperplasia) and men with urological conditions do report greater cancer worry [23]. This finding is also consistent with the Common Sense Model of Health and Illness where urinary symptoms are interpreted as a sign of an underlying health threat [43]. Reassuring men with urological conditions that they have a similar risk of prostate cancer to asymptomatic men improves their capacity to cope with symptoms [23]. Similar strategies may reduce prostate cancer distress in symptomatic men.

Consistent with Bratt *et al.* [14], greater cancer-specific distress was found in men who reported having a relative who died from prostate cancer, and this finding is consistent with research in other cancer domains [e.g. 2]. However, few other cancer experience factors predicted distress. Contrary to Bratt *et al.* [14], having multiple affected relatives did not increase distress. However, the sample of men in Bratt *et al.* was unaffected men from families identified as having a strong heredity basis with three or more connected cases of prostate cancer in the family, and unaffected relatives were informed that they were at substantially increased risk of prostate cancer during their recruitment to the study. Further, time since diagnosis, perceptions of disease prognosis and type of relationship to an affected relative were not associated with distress. In the present study, the majority of the participants reported that their relative had completed treatment and that the average time since diagnosis was over 24 months prior to the study. It is possible that fluctuations in cancer distress may be more apparent in earlier stages of the cancer experience and future research would benefit from examining these factors at different stages of the illness trajectory. Further, only four participants rated their affected relative's cancer prognosis to be deteriorating, with the majority of the participants stating that their relative was currently stable. In a qualitative study examining risk constructions of people with a family history of cancer, Sanders *et al.* [44] reported that perceiving the disease experience of an affected relative to be stable presented a low threat to the affected relative and absolved family members of responsibilities to offer support.

Perceived threat associated with a relative's prostate cancer was a predictor of prostate cancer distress, which suggests that FDRs make an evaluative judgement about how their relative's prostate cancer experience may make them more vulnerable to or concerned about developing prostate cancer. The individual items used to assess the relative's cancer experience in the current study may have been too specific (e.g. perceptions of side effect severity and disease prognosis)

and may have focused attention on specific illness characteristics rather than on an overall evaluation of the illness experience. Rather, the more general evaluative assessment, perceived threat, may have allowed FDRs to make a more global evaluation about the prostate cancer experience of their affected relative and appraise the experience in terms of an overall judgement about threat. This explanation is consistent with appraisal theories of stress and coping [e.g.40] that suggest that people cognitively appraise health threats which in turn influences coping resources.

Limitations

The present study was retrospective and cross-sectional and utilised a convenience sample of population men, which may limit the representativeness of the sample. The majority of FDRs reported that their relative had been diagnosed on average over 2 years prior to the study and had finished their cancer treatment. Potential relationships between cancer experience factors and prostate cancer distress may not be evident so long after the relative's diagnosis. Prospective studies that capture unaffected male relatives close to their relative's diagnosis may provide a better test of these relationships. Further, FDRs were recruited from their probands, and it is possible that FDRs may have been less likely to participate in the present study if they perceived their relative's cancer was not progressing well. As well, the contact details of unaffected family members who did not have close contact with the proband may not have been provided, and FDRs of probands who died from aggressive disease may not be represented in the sample and thus may contribute to a selection bias.

Conclusions

Similar to all men, first degree relatives of men with prostate cancer did not report experiencing distress associated with the risk of prostate cancer. Rather, the results of the present study suggest that interventions would benefit from examining appraisals of familial risk and targeting relatives who feel threatened by a diagnosis of prostate cancer in the family or following the death of a relative. Future research would benefit from prospective assessments of prostate cancer distress in unaffected male relatives over the course of the cancer trajectory. Further, an investigation of the inter-relationship between perceived risk, cancer-specific distress, and health behaviour would improve our understanding of the psychological and behavioural coping strategies men use following a prostate cancer diagnosis in the family.

Conflict of interest

The authors have declared that there is no conflict of interest.

Notes

1. McDowell *et al.* [27] reports socio-demographic data in detail for FDR and PM samples separately. Significant differences between the samples are reported previously.

2. Owing to multiple imputation, degrees of freedom for error are not always available for *F* statistics (in such cases a decimal point is included in the reporting of degrees of freedom).
3. Analyses exploring potential moderation and mediation effects for the relationship between perceived risk, threat, and cancer-specific anxiety for FDRs were not significant.

References

1. Rabin C, Rogers ML, Pinto BM, Nash JM, Frierson GM, Trask PC. Effect of personal cancer history and family cancer history on levels of psychological distress. *Soc Sci Med* 2007;**64**(2):411–416. DOI: 10.1016/j.socscimed.2006.09.004.
2. Thewes B, Meiser B, Tucker K, Schnieden V. Screening for psychological distress and vulnerability factors in women at increased risk for breast cancer: a review of the literature. *Psychol Health Med* 2003;**8**(3):289–304. DOI: 10.1080/1354850031000135731.
3. Bruner DW, Moore D, Parlanti A, Dorgan J, Engstrom P. Relative risk of prostate cancer for men with affected relatives: systematic review and meta-analysis. *Int J Cancer* 2003;**107**(5):797–803. DOI: 10.1002/ijc.11466.
4. Johns LE, Houlston RS. A systematic review and meta-analysis of familial prostate cancer risk. *BJU Int* 2003;**91**(9):789–794. DOI: 10.1046/j.1464-410X.2003.04232.x.
5. Geirdal AO, Reichelt JG, Dahl AA, *et al.* Psychological distress in women at risk of hereditary breast/ovarian or HNPCC cancers in the absence of demonstrated mutations. *Fam Cancer* 2005;**4**(2):121–126. DOI: 10.1007/s10689-004-7995-y.
6. Lindberg NM, Wellisch DK. Identification of traumatic stress reactions in women at increased risk for breast cancer. *Psychosomatics* 2004;**45**(1):7–16. DOI: 10.1176/appi.psy.45.1.7.
7. Cormier L, Valéri A, Azzouzi R, *et al.* Worry and attitude of men in at-risk families for prostate cancer about genetic susceptibility and genetic testing. *Prostate* 2002;**51**(4):276–285. DOI: 10.1002/pros.10092.
8. Roumier X, Azzouzi R, Valeri A, *et al.* Adherence to an annual PSA screening program over 3 years for brothers and sons of men with prostate cancer. *Eur Urol* 2004;**45**(3):280–286. DOI: 10.1016/j.eururo.2003.09.022.
9. Sweetman J, Watson M, Norman A, *et al.* Feasibility of familial PSA screening: psychosocial issues and screening adherence. *Br J Cancer* 2006;**94**(4):507–512. DOI: 10.1038/sj.bjc.6602959.
10. Bratt O, Emanuelsson M, Gronberg H. Psychological aspects of screening in families with hereditary prostate cancer. *Scand J Urol Nephrol* 2003;**37**(1):5–9. DOI: 10.1080/00365590310008604.
11. Cormier L, Guillemin F, Valeri A, *et al.* Impact of prostate cancer screening on health-related quality of life in at-risk families. *Urology* 2002;**59**(6):901–906. DOI: 10.1016/S0090-4295(02)01552-2.
12. Macefield RC, Lane JA, Metcalfe C, *et al.* Do the risk factors of age, family history of prostate cancer or a higher prostate specific antigen level raise anxiety at prostate biopsy? *Eur J Cancer* 2009;**45**(14):2569–2573. DOI: 10.1016/j.ejca.2009.03.016.
13. Wakefield CE, Meiser B, Gaff CL, *et al.* Issues faced by unaffected men with a family history of prostate cancer: a multidisciplinary overview. *J Urol* 2008;**180**(1):38–46. DOI: 10.1016/j.juro.2008.03.020.
14. Bratt O, Damber JE, Emanuelsson M, *et al.* Risk perception, screening practice and interest in genetic testing among unaffected men in families with hereditary prostate cancer. *Eur J Cancer* 2000;**36**(2):235–241. DOI: 10.1016/S0959-8049(99)00272-5.
15. Zapka J, Fisher G, Lemon S, Clemow L, Fletcher K. Relationship and distress in relatives of breast cancer patients. *Fam Syst Health* 2006;**24**(2):198–212. DOI: 10.1037/1091-7527.24.2.198.
16. Rees G, Fry A, Cull A, Sutton S. Illness perceptions and distress in women at increased risk of breast cancer. *Psychol Health* 2004;**19**(6):749–765. DOI: 10.1080/08870440412331279764.
17. Spielberger CD, Gorsuch RL, Lushene R, Vagg PR, Jacobs GA. Manual for the State-trait Anxiety Inventory. Consulting Psychologists Press: Palo Alto, CA, 1983.
18. Cormier L, Kwan L, Reid K, Litwin MS. Knowledge and beliefs among brothers and sons of men with prostate cancer. *Urology* 2002;**59**(6):895–900. DOI: 10.1016/S0090-4295(01)01657-0.
19. Zigmond AS, Snaith RP. The hospital anxiety and depression scale. *Acta Psychiatr Scand* 1983;**67**(6):361–370. DOI: http://www.ncbi.nlm.nih.gov/pubmed/6880820.
20. Luccock M, Morley S. The health anxiety questionnaire. *Br J Health Psychol* 1996;**1**:137–150. DOI: 10.1111/j.2044-8287.1996.tb00498.x.
21. Goldberg DP, Hillier VF. A scaled version of the General Health Questionnaire. *Psychol Med* 1979;**9**(1):139–145. DOI: http://www.ncbi.nlm.nih.gov/pubmed/424481.
22. Horowitz M, Wilner N, Alvarez W. Impact of event scale: a measure of subjective stress. *Psychosom Med* 1979;**41**(3):209–218. DOI: http://www.psychosomaticmedicine.org/content/41/3/209.long.
23. Brown C, O'Flynn E, Van Der Meulen J, Newman S, Mundy A, Emberton M. The fear of prostate cancer in men with lower urinary tract symptoms: should symptomatic men be screened? *BJU Int* 2003;**91**(1):30–32. DOI: 10.1046/j.1464-410X.2003.04013.x.
24. Schnur JB, DiLorenzo TA, Montgomery GH, *et al.* Perceived risk and worry about prostate cancer: a proposed conceptual model. *Behav Med* 2006;**32**(3):89–96. DOI: 10.3200/BMED.32.3.89-96.
25. Erblieh J, Bovbjerg D, Valdimarsdottir H. Looking forward and back: distress among women at familial risk for breast cancer. *Ann Behav Med* 2000;**22**(1):53–59. DOI: 10.1007/BF02895167.
26. Fletcher KE, Clemow L, Peterson BA, Lemon SC, Estabrook B, Zapka JG. A path analysis of factors associated with distress among first-degree female relatives of women with breast cancer diagnosis. *Health Psychol* 2006;**25**(3):413–424. DOI: 10.1037/0278-6133.25.3.413.
27. McDowell ME, Occhipinti S, Gardiner RA, Chambers SK. Patterns of PSA testing in Australian men: the influence of family history. *BJU Int* 2012;**109**(3):S64–S70. DOI: 10.1111/j.1464-410X.2012.11050.x.
28. McDowell ME, Occhipinti S, Chambers SK. Heuristics, risk perception, and prostate cancer screening: the influence of family history. *Health Psychol* 2013 [Advance online publication]. DOI: 10.1037/a0031622.
29. Chambers SK, Ferguson M, Gardiner RA, *et al.* ProCan for men: randomised controlled trial of a decision support intervention for men with localised prostate cancer. *BMC Cancer* 2008;**8**:207. DOI: 10.1186/1471-2407-8-207.
30. Barry MJ, Fowler FJ, Jr., O'Leary MP, *et al.* The American Urological Association symptom index for benign prostatic hyperplasia. *J Urol* 1992;**148**(5):1549–1557. DOI: http://www.ncbi.nlm.nih.gov/pubmed/1279218.
31. Gerend MA, Aiken LS, West SG, Erchull MJ. Beyond medical risk: investigating the

- psychological factors underlying women's perceptions of susceptibility to breast cancer, heart disease, and osteoporosis. *Health Psychol* 2004;**23**(3):247–258. DOI: 10.1037/0278-6133.23.3.247.
32. Cohen P, Cohen J, Aiken LS, West SG. The problem of units and the circumstance for POMP. *Multivar Behav Res* 1999;**34**(3): 315–346. DOI: 10.1207/S15327906MBR3403_2.
 33. Roth A, Nelson CJ, Rosenfeld B, et al. Assessing anxiety in men with prostate cancer: further data on the reliability and validity of the Memorial Anxiety Scale for Prostate Cancer (MAX-PC). *Psychosomatics* 2006;**47**(4): 340–347. DOI: 10.1176/appi.psy.47.4.340.
 34. Dale W, Hemmerich J, Meltzer D. Extending the validity of the memorial anxiety scale for prostate cancer (MAX-PC) at the time of prostate biopsy in a racially-mixed population. *Psycho-Oncology* 2007;**16**(5):493–498. DOI: 10.1002/pon.1107.
 35. Schafer JL, Graham JW. Missing data: our view of the state of the art. *Psychol Methods* 2002;**7**(2):147–177. DOI: <http://www.ncbi.nlm.nih.gov/pubmed/12090408>, <http://psycnet.apa.org/journals/met/7/2/147.pdf>
 36. Graham JW. Missing data analysis: making it work in the real world. *Annu Rev Psychol* 2009;**60**(1):549–576. DOI: 10.1146/annurev.psych.58.110405.085530.
 37. Australian Bureau of Statistics. Census data 2006, 2012. Available from: <http://www.abs.gov.au/websitedbs/censushome.nsf/home/Census> (accessed 28 June 2012).
 38. Goldzweig G, Andritsch E, Hubert A, et al. Psychological distress among male patients and male spouses: what do oncologists need to know? *Ann Oncol* 2010;**21**(4):877–883. DOI: 10.1093/annonc/mdp398.
 39. Benyamini Y, McClain CS, Leventhal EA, Leventhal H. Living with the worry of cancer: health perceptions and behaviors of elderly people with self, vicarious, or no history of cancer. *Psycho-Oncology* 2003;**12**(2):161–172. DOI: 10.1002/pon.637.
 40. Lazarus RS, Folkman S. Transactional theory and research on emotions and coping. *Eur J Pers* 1987;**1**(3):141–169. DOI: 10.1002/per.2410010304.
 41. McDowell ME, Occhipinti S, Gardiner RA, Baade PD, Chambers SK. A review of prostate-specific antigen screening prevalence and risk perceptions for first-degree relatives of men with prostate cancer. *Eur J Cancer Care (Engl)* 2009;**18**(6):545–555. DOI: 10.1111/j.1365-2354.2008.01046.x.
 42. Parkin DM, Bray F, Ferlay J, Pisani P. Global cancer statistics, 2002. *CA Cancer J Clin* 2005;**55**(2):74–108. DOI: 10.3322/canjclin.55.2.74.
 43. Leventhal H, Brissette I, Leventhal EA. The common-sense model of self-regulation of health and illness. In *The Self-regulation of Health and Illness Behaviour*, Cameron LD, Leventhal H (eds). Routledge: London, 2003; 42–65.
 44. Sanders T, Campbell R, Sharp D, Donovan J. Risk constructions among people who have a first-degree relative with cancer. *Health Risk Soc* 2003;**5**(1):53–69. DOI: 10.1080/136985031000066005.