European Journal of Cancer Care

Review article

A review of prostate-specific antigen screening prevalence and risk perceptions for first-degree relatives of men with prostate cancer

M.E. MCDOWELL, BPSYCH (HONS), *School of Psychology, Griffith University, Brisbane*, S. OCCHIPINTI, PHD, *School of Psychology, Griffith University, Brisbane*, R.A. GARDINER, MBBS, MD, FRACS, FRCS, PROFESSOR, *Department of Surgery, University of Queensland; Consultant Urologist, Department of Urology, Royal Brisbane Hospital; Australian Prostate Cancer Collaboration, Brisbane*, P.D. BAADE, SENIOR RESEARCH FELLOW, *Viertel Centre for Research in Cancer Control, The Cancer Council Queensland, Brisbane and* ADJUNCT ASSOCIATE PROFESSOR, *School of Public Health, Queensland University of Technology, Brisbane* & S.K. STEGINGA, PHD, *General Manager Programs and Research, Viertel Centre for Research in Cancer Control, The Cancer Council Queensland; School of Psychology, Griffith University, Brisbane, Australia*

MCDOWELL M.E., OCCHIPINTI S., GARDINER R.A., BAADE P.D. & STEGINGA S.K. (2009) *European Journal of Cancer Care* **18**, 545–555

A review of prostate-specific antigen screening prevalence and risk perceptions for first-degree relatives of men with prostate cancer

First-degree relatives of men with prostate cancer have a higher risk of being diagnosed with prostate cancer than men without a family history. The present review examines the prevalence and predictors of testing in first-degree relatives, perceptions of risk, prostate cancer knowledge and psychological consequences of screening. Medline, PsycInfo and Cinahl databases were searched for articles examining risk perceptions or screening practices of first-degree relatives of men with prostate cancer for the period of 1990 to August 2007. Eighteen studies were eligible for inclusion. First-degree relatives participated in prostate-specific antigen (PSA) testing more and perceived their risk of prostate cancer to be higher than men without a family history. Family history factors (e.g. being an unaffected son rather than an unaffected brother) were consistent predictors of PSA testing. Studies were characterized by sampling biases and a lack of longitudinal assessments. Prospective, longitudinal assessments with well-validated and comprehensive measures are needed to identify factors that cue the uptake of screening and from this develop an evidence base for decision support. Men with a family history may benefit from targeted communication about the risks and benefits of prostate cancer testing that responds to the implications of their heightened risk.

Keywords: family history, prostate cancer, screening, review.

INTRODUCTION

Prostate cancer is one of the most frequently diagnosed cancers in men with 543 000 new cases diagnosed worldwide in 2000, representing over 10% of new cancers diagnosed in men each year (Parkin 2001; Parkin *et al.* 2001). Although recently there has been a decrease in prostate cancer mortality, the incidence of prostate cancer remains high (e.g. 104 new cases per 100 000 men in North America; Parkin 2001; Parkin *et al.* 2001; Baade *et al.* 2004). Furthermore, the prevalence of this condition is certain to escalate over the next few years with ageing populations throughout most of the western world and an increasingly long natural history.

Correspondence address: Stefano Occhipinti, School of Psychology, Griffith University, Nathan QLD 4111, Australia (e-mail: S.Occhipinti@griffith.edu.au).

Accepted 22 August 2008
DOI: 10.1111/j.1365-2354.2008.01046.x

European Journal of Cancer Care, 2009, **18**, 545–555

Prostate cancer risks more than double for first-degree relatives of men with prostate cancer; and risk increases threefold when more than one first-degree relative has prostate cancer (Bruner *et al.* 2003; Johns & Houlston 2003; Staples *et al.* 2003). As well, the risk of being diagnosed with prostate cancer for first-degree relatives increases further when their relative is diagnosed prior to the age of 60 years (Johns & Houlston 2003). Much of the high familial rate of prostate cancer is due to hereditary factors that are thought to play a greater role in prostate cancer than in any other cancer (Lichtenstein *et al.* 2000). Although there have been recent advances in the identification of prostate cancer susceptibility genes (Pomerantz *et al.* 2007), a clearly identifiable gene has not yet been found.

Problematically, genetic testing for prostate cancer susceptibility is not yet a practical option (Gronberg 2003; Schaid 2004; Langeberg *et al.* 2007), and opinions differ as to whether prostate-specific antigen (PSA) screening should be offered to all men with a family history (Neal *et al.* 2000; Gambert 2001; Kiemeney *et al.* 2008). In this regard, the efficacy of screening for the general population of men has not yet been confirmed as there is insufficient evidence to conclude that mortality will be reduced as a result of early detection (Neal *et al.* 2000; Harris & Lohr 2002;Postma and Schroder 2005; Ilic *et al.* 2006). The PSA blood test used to detect prostate cancer has low specificity and sensitivity, and it does not differentiate between clinically significant and indolent cancers. Furthermore, there are competing causes of mortality for older men, and treatment for prostate cancer carries with it enduring iatrogenic effects that range from erectile dysfunction and urinary incontinence to hot flushes, loss of bone substance and muscle mass, cognitive impairment and induced metabolic syndrome (Neal *et al.* 2000; Gambert 2001; Harris & Lohr 2002; Loblaw *et al.* 2007). Randomized control trials are currently underway to establish whether prostate cancer screening for asymptomatic men is efficacious (Prostate, Lung, Colorectal and Ovarian, Andriole *et al.* 2005; European Randomized study of Screening for Prostate Cancer, Schroder *et al.* 2003). Hence, it is broadly held by most professional and statutory bodies that until there is evidence that screening is efficacious, screening should not be offered to asymptomatic men, but that men should be informed of the risks, benefits and uncertainties associated with prostate cancer screening and make individual decisions about testing for prostate cancer (Neal *et al.* 2000; Harris & Lohr 2002; Wilt and Wilt 2002; Postma and Schroder 2005; Ilic *et al.* 2006).

However, while public health policies do not yet endorse screening for first-degree relatives, many family members seek testing (Bratt *et al.* 2000; Hemminki *et al.* 2005; Kiemeney *et al.* 2008). Consistent with this, Bermejo and Hemminki (2005) and Hemminki *et al.* (2005) reported that the diagnosis of prostate cancer in a sibling leads to an early diagnosis of prostate cancer in siblings of the affected brother. Examining pairs of affected brothers, Bermejo and Hemminki (2005) and Hemminki *et al.* (2005) found that the diagnosis of the second sibling occurred within 5 years from the diagnosis of the first sibling and around half of these diagnoses occurred within 1 year of the first siblings' diagnosis. These results suggest that having a family member diagnosed with prostate cancer prompts male family members to participate in prostate cancer screening. Thus, while it is important to acknowledge that there remains considerable controversy and debate about whether first-degree relatives should screen for prostate cancer, these men are currently faced with and are making decisions about screening. Therefore, the need to understand how first-degree relatives are currently reasoning about their risk and making screening decisions in light of this uncertainty is paramount. Accordingly, primary care physicians and health educators will increasingly need to respond to the information and decision support needs of these men as prostate cancer prevalence continues to rise, and more men find themselves with a family history of prostate cancer.

In order to develop targeted and effective patient education materials and decision aids to help such men make informed decisions about testing, a clear understanding of the cues that prompts relatives to undergo testing is needed (O'Connor *et al.* 1999; Myers 2005). The present review examines the prevalence of testing in first-degree relatives, predictors of testing and perceptions of prostate cancer risk. Knowledge about prostate cancer and the psychological effects of testing are also reviewed. From this, how a family history of prostate cancer influences first-degree male relatives' decisions about participating in screening is discussed.

METHODS

Literature searches were conducted in CINAHL, Medline and PsycINFO for the period 1990 to August 2007. The search combined prostate cancer and a first-degree family history of prostate cancer (first-degree relative, family history, high risk, son, father, brother or sibling) in addition to using combinations of keywords relating to: prostate cancer screening ('screen*' or 'test*', 'prostate specific antigen', 'early detection' or 'preventive health'), risk perceptions (perceived risk, susceptibility or vulnerability),

knowledge or psychosocial issues (psychological, psychosocial, worry or distress). An ancestry search of the reference lists of eligible articles and a Web of Science cited reference search were conducted to identify any additional studies meeting the review criteria. Studies were included in the review if they specifically examined a sample of first-degree relatives of men with prostate cancer and the risk perceptions or screening practices of first-degree relatives and were published in peer-reviewed journals in the English language. Studies were excluded if they examined primarily biomedical aspects of prostate cancer screening (e.g. examining PSA serum levels), prostate cancer diagnoses or hereditary or genetic testing for prostate cancer.

RESULTS

The search identified 1218 articles using the search terms, and 23 articles met all the inclusion criteria and were considered for the review. The majority of articles were excluded on the basis that they examined biomedical aspects of prostate cancer and were reviews of prostate cancer screening, or they examined risk estimates and the genetic determinants of prostate cancer risk. On reading the articles a further five studies were excluded on the basis that: two were qualitative and did not specifically examine men with a family history of prostate cancer (Arar *et al.* 2000; Sanders *et al.* 2003), two focused on issues associated with genetic inheritance and genetic testing (Bratt *et al.* 1997; Cormier *et al.* 2002c) and two described overlapping results and therefore one was excluded (Cormier *et al.* 2002b). The remaining 18 (see Table 1) were included in the review, representing 16 390 participants (2817 first-degree relatives). The included studies were predominantly North American.

Participants and recruitment

The majority of studies (77%) recruited first-degree relatives through contact with their probands (affected relatives) who were often participating in prostate cancer programmes or who were identifiable through national cancer registries (Bratt *et al.* 2000, 2003; Miller *et al.* 2001; Cormier *et al.* 2002a, 2003; Bock *et al.* 2003; Beebe-Dimmer *et al.* 2004; Jacobsen *et al.* 2004; Roumier *et al.* 2004; Vadaparampil *et al.* 2004; Bloom *et al.* 2006; Pruthi *et al.* 2006; Sweetman *et al.* 2006; Weinrich 2006). Three of these studies recruited participants for involvement in annual prostate cancer screening programmes (Cormier *et al.* 2002a; Roumier *et al.* 2004; Sweetman *et al.* 2006). Four surveyed participants as part of population-based health surveys (Ross *et al.* 2005; Schnur *et al.* 2006; Spencer *et al.* 2006; Weinrich 2006; Shah *et al.* 2007) recruited participants who attended for a prostate cancer screening appointment at a general urology clinic and Bloom *et al.* (2006) obtained part of their sample through contact with African-American community groups. Four studies examined participants who were recruited from or who were participating in projects associated with hereditary risk (Bratt *et al.* 2000, 2003; Bock *et al.* 2003; Weinrich 2006). Excluding studies examining annual screening programme adherence or the psychological effects of the screening process only Vadaparampil *et al.* (2004) included a follow-up assessment. Beebe-Dimmer *et al.* (2004) and Pruthi *et al.* (2006) limited their assessment to brothers of men with prostate cancer. Furthermore, fewer than half of the studies made direct comparisons between first-degree relatives and the general population.

Prostate cancer screening prevalence

Eleven studies report screening prevalence for first-degree relatives (see Table 1). For those examining lifetime screening prevalence (e.g. have you *ever* participated in prostate cancer screening), most found that prevalence exceeded 50% (Miller *et al.* 2001; Cormier *et al.* 2003; Vadaparampil *et al.* 2004; Ross *et al.* 2005; Shah *et al.* 2007) with the exception of one study conducted in the UK (Sweetman *et al.* 2006), finding that just over 40% of first-degree relatives reported some previous PSA testing, and another finding that only 44% of African-American men with a family history had ever screened (Weinrich 2006). Of those studies examining recent PSA testing prevalence, one reported that 56% of first-degree relatives had been tested within the last 12 months (Spencer *et al.* 2006), 69% had been tested within the last two years (Cormier *et al.* 2003) and 68% of first-degree relatives tested regularly (Bratt *et al.* 2000). According to one North American study (Bock *et al.* 2003), almost all first-degree relatives with hereditary risk of prostate cancer participated in prostate cancer screening (95%).

Three studies make direct comparisons between the screening prevalence rates of first-degree relatives and men from the general population (Miller *et al.* 2001; Spencer *et al.* 2006; Shah *et al.* 2007), and only two report that first-degree relatives are more likely (1.5–2.2 times more likely) to have participated in prostate cancer screening (Spencer *et al.* 2006; Shah *et al.* 2007). Two of the three studies examining screening prevalence for African-American men reported that African-American first-degree relatives were more likely to have participated in PSA testing (2.3–3.0 times more likely) than African-American men without a family history (Ross *et al.* 2005;

Table 1. Articles examining first-degree relatives of men with prostate cancer

Reference	Country	Sample	PSA	Screening	Prevalence	Main Findings
Beebe-Dimmer *et al.* (2004)	USA	• 111 FDR brothers recruited through contact with affected sibling				• Majority perceived risk to be ≥ 50% • Younger brothers had higher risk estimates than brothers who were older than their affected sibling • Long-term risk greater than short-term risk estimates
Bock *et al.* (2003)	USA	• 64 FDR of families participating in PCGP who had an affected father and an affected brother	FDR	95%	Ever	• Majority of unaffected men had prior PSA test • Half of first-degree relatives received first PSA test prior to the age of 50 years
Bratt *et al.* (2000)	Sweden	• 110 FDR recruited from prostate cancer families with 3+ connected cases of prostate cancer and who had pedigree consistent with hereditary prostate cancer	FDR	68%	Regularly	• Screening associated with the number of relatives with prostate cancer • Majority of men estimated risk to be high with 40% overestimating their risk • Risk associated with number of relatives deceased from prostate cancer
Bratt *et al.* (2003)	Sweden	• 57 FDR participants in Bratt *et al.* (2000) who indicated that they screened frequently				• No significant experiences of psychological adverse effects as a result of participating in prostate cancer screening
Cormier *et al.* (2003)	USA	• 138 FDR recruited through contact with affected relative	FDR	72% 69%	ever last 2 years	• Perceived risk not associated with screening • Age, having regular physician, number of men first-degree relatives knows with prostate cancer, knowledge of PSA, and discussing screening with physician predicted prostate cancer screening
Cormier *et al.* (2002a)	France	• 220 FDR recruited through contact with affected relative • Recruited for screening programme				• Moderate deterioration in anxiety and minimal deterioration in health-related quality of life for 20% of first-degree relatives over the course of PSA screening process
Jacobsen *et al.* (2004)	USA	• 83 FDR recruited through contact with affected relative and 83 GP through peer nomination				• Perceived vulnerability to prostate cancer mediated relationship between family history and PSA intentions • Intention to have PSA test predicted by number of past PSA tests, time since last PSA test and perceived vulnerability
Miller *et al.* (2001)	USA	• 56 FDR recruited through contact with affected relative 100 GP community group members	FDR GP	63% 61%	Ever	• No difference in screening for first-degree relatives and general population men • First-degree relatives had greater perceived vulnerability to prostate cancer and lower expectations about prevention of prostate cancer
Pruthi *et al.* (2006)	USA	• 112 FDR recruited through contact with affected sibling (42% African-American)				• 31% of brothers improve prostate cancer knowledge after their sibling's diagnosis • Improvements in knowledge predictive of screening • 85% of brothers did not begin screening
Roumier *et al.* (2004)	France	• 640 FDR recruited through contact with affected relative • Annual screening programme (3 years)				• Men under 60 were 2.3 times more likely to participate in screening programme; sons were 1.4 times more likely to participate than brothers; men with several relatives with prostate cancer 1.5 times more likely to participate • 88% adherence rate (69% initial participation rate)

Table 1. *Continued*

Reference	Country	Sample	PSA	Screening	Prevalence	Main Findings
Schnur *et al.* (2006)	USA	• 33 FDR and 176 GP attendees at screening appointment in urology clinic				• Relationship between family history of prostate cancer and perceived risk of prostate cancer • Perceived risk of prostate cancer mediated relationship between family history of prostate cancer and prostate cancer worry
Shah *et al.* (2007)	USA	• 226 FDR and 3769 GP sampled as part of a population-based health survey	FDR GP	52%‡ 35%	Ever	• First-degree relatives aged 50+ years almost twice as likely to have participated in screening than general population men
Spencer *et al.* (2006)	USA	• 492 FDR and 8221 GP sampled as part of a population-based health survey	FDR GP	56%‡ 42%	Last 12 months	• First-degree relatives more likely to have participated in screening than general population men • Men with multiple high-risk factors (African-American men with family history) no more likely to screen than men with only one high-risk factor were
Sweetman *et al.* (2006)	UK	• 128 FDR recruited through contact with affected relative • Recruited for screening programme	FDR	41–46%	Some previous	• Past screening behaviour only reliable predictor of adherence to screening programme • Prior screening associated with having a father and brother with prostate cancer, having realistic or elevated risk, higher perceived benefits of testing, higher social class and agreeing to take part in screening programme to get more information about prostate cancer
Vadaparampil *et al.* (2004)	USA	• 82 FDR recruited through contact with affected relative	FDR	50% 50%	At any time 14 months follow-up	• 63% of men who had prior PSA test had a PSA test during 14-month follow-up • Risk perceptions did not predict prior or follow-up screening behaviour
African-American Studies						
Bloom *et al.* (2006)	USA	• 88 FDR and 120 GP recruited through contact with affected relative and peer nomination or from churches and African-American social groups	FDR	3.03 OR‡	Last 12 months	• African-American men with a family history of prostate cancer were more likely to report having a recent PSA test • First-degree relatives did not perceive their risk to be higher than men without a family history
Ross *et al.* (2005)	USA	• 43 FDR and 693 GP sampled as part of a population-based health survey	FDR GP	64%‡ 42–50%	Ever	• African-American men with a family history of prostate cancer more likely to have heard of a PSA test and to have had a PSA test than African-American men without a family history
Weinrich (2006)	USA	• 134 FDR participants in the AAHPC who had 4+ relatives with prostate cancer and 411 GP African-American participants from population-based health survey (NHIS)	FDR GP	44% 65%	ever	• Comparison between screening prevalence in AAHPC participants and NHIS African-American participants indicated that African-American men with a strong family history of prostate cancer reported lower PSA testing behaviour

‡Significant difference in prevalence rates between first-degree relatives and general population men.
AAHPC, African-American Hereditary Prostate Cancer Study; FDR, First-Regree Relatives; GP, General Population men; NHIS, National Health Interview Survey; OR, odds ratio; PCGP, Prostate Cancer Genetics Project; PSA, prostate-specific antigen.

Bloom *et al.* 2006). By contrast, Spencer *et al.* (2006) reported that men with multiple high-risk factors (African-American men who also have a family history) were no more likely to screen than men with just one high-risk factor. The one study that examined screening over a 14-month period reported that of the first-degree relatives who reported having participated in prior prostate cancer screening at baseline (50%), 63% of these men also participated in screening within a 14-month follow-up assessment period (Vadaparampil *et al.* 2004).

Predictors of prostate cancer screening

Eleven papers report on the predictors of prostate cancer screening. Older age predicted participation in prostate cancer screening in almost all studies that examined screening predictors (Miller *et al.* 2001; Cormier *et al.* 2003; Jacobsen *et al.* 2004; Roumier *et al.* 2004; Vadaparampil *et al.* 2004; Ross *et al.* 2005; Bloom *et al.* 2006; Spencer *et al.* 2006; Sweetman *et al.* 2006), as well as higher socioeconomic factors (Cormier *et al.* 2003; Vadaparampil *et al.* 2004; Ross *et al.* 2005; Spencer *et al.* 2006; Sweetman *et al.* 2006). Physician discussion and having regular access to health care were associated with increased screening (Cormier *et al.* 2003; Bloom *et al.* 2006; Spencer *et al.* 2006). Having undergone prostate cancer screening in the past predicted future prostate cancer screening intentions (Jacobsen *et al.* 2004) and adherence to annual prostate cancer screening programmes (Sweetman *et al.* 2006).

Although not all studies reported on the relationship between family history characteristics and study variables, the type of family history of prostate cancer among first-degree relatives predicted prostate cancer screening among men. Men were more likely to participate in screening if they had more than one first-degree relative with prostate cancer (Bratt *et al.* 2000; Cormier *et al.* 2003; Roumier *et al.* 2004; Sweetman *et al.* 2006). Sons of men with prostate cancer were more likely to participate in prostate cancer screening than brothers of men with prostate cancer were (Roumier *et al.* 2004), and younger brothers of men with prostate cancer were more likely to participate in screening than older brothers were (Beebe-Dimmer *et al.* 2004).

Risk perceptions and screening behaviour

Nine studies assessed first-degree relatives' perceptions of prostate cancer risk; however, not all studies reported the average risk perceptions for their samples. Three different types of measures were used to assess perceived risk. Five studies report risk perceptions measured by single-event probability scales (e.g. 0–100%; Bratt *et al.* 2000; Miller *et al.* 2001; Beebe-Dimmer *et al.* 2004; Jacobsen *et al.* 2004; Schnur *et al.* 2006), and these results suggest that on average first-degree relatives perceive their lifetime risk of being diagnosed with prostate cancer to be around 50%, and more than a third of first-degree relatives overestimated their lifetime risk. Three studies examine comparative risk perceptions (e.g. personal risk comparable with that of the average man; Bratt *et al.* 2000; Miller *et al.* 2001; Cormier *et al.* 2003; Beebe-Dimmer *et al.* 2004), reporting that the majority of first-degree relatives perceive their risk to be greater than that of the average man. However, approximately 40% of first-degree relatives underestimate their risk as being the same as or less than the average man. Risk perceptions were predicted by family history characteristics. Beebe-Dimmer *et al.* (2004) found that brothers who were older than their affected sibling had lower risk perceptions than brothers who were younger than their affected sibling. Bratt *et al.* (2000) reported that the number of relatives deceased from or diagnosed with prostate cancer increased risk perceptions. Only two studies used more reliable multi-item measures to assess risk perceptions (e.g. 4-item summated scale measures that assess both comparative and numerical risk perceptions; Jacobsen *et al.* 2004; Vadaparampil *et al.* 2004), and these showed that first-degree relatives indicated greater perceived risk.

Three of the nine studies made direct comparisons between the risk perceptions of first-degree relatives and men from the general population (Miller *et al.* 2001; Jacobsen *et al.* 2004; Schnur *et al.* 2006). These studies are consistent in reporting that first-degree relatives estimate both their comparative and lifetime risk as being higher than that reported by men from the general population. However, African-American first-degree relatives did not have higher risk perceptions than African-American men without a family history of prostate cancer (Bloom *et al.* 2006). Three studies found that higher risk perceptions were associated with increased screening (Beebe-Dimmer *et al.* 2004; Jacobsen *et al.* 2004; Sweetman *et al.* 2006) while three found that risk perceptions were not associated with increased screening in first-degree relatives (Miller *et al.* 2001; Cormier *et al.* 2003; Vadaparampil *et al.* 2004).

Knowledge, beliefs and information needs

Three studies examined first-degree relative's prostate cancer knowledge. One utilized a multi-item measure to

assess knowledge of a variety of issues associated with prostate cancer (e.g. prostate cancer anatomy, risk factors) and reported that prostate cancer knowledge was high among first-degree relatives (Cormier *et al.* 2003). However, the assessment measure applied did not examine knowledge of screening efficacy. One study examined retrospective, perceived knowledge (e.g. poor, fair, good) prior to and following a diagnosis of prostate cancer in a sibling (Pruthi *et al.* 2006). Men who improved their self-assessed knowledge following their sibling's diagnosis were more likely to begin screening, and African-American first-degree relatives were less likely to improve their knowledge (Pruthi *et al.* 2006). However, 69% of first-degree relatives did not improve their prostate cancer knowledge, and 85% did not begin participating in prostate cancer screening. The third study assessed whether there were differences in awareness of PSA testing between African-American first-degree relatives and African-American men without a family history of prostate cancer (Ross *et al.* 2005). African-American first-degree relatives were more likely to be aware of PSA testing than African-American men without a family history (Ross *et al.* 2005).

First-degree relatives reported a need for more information about prostate cancer and prostate cancer screening. Jacobsen *et al.* (2004) found that first-degree relatives were more likely to indicate that they would like to receive information about prostate cancer than men from the general population do. Sweetman *et al.* (2006) reported that men who stated that they agreed to participate in their screening programme to get more information about prostate cancer were more likely to have participated in prostate cancer screening in the past.

Psychological effects of screening

Participation in PSA testing appears to have little effect on anxiety, depression and health-related quality of life (HRQOL) for first-degree relatives (Cormier *et al.* 2002a; Bratt *et al.* 2003). One study reported no change in depression or anxiety during the screening process (Bratt *et al.* 2003) while another stated that approximately 20% of first-degree relatives showed moderate deterioration in anxiety and a small deterioration in HRQOL across the screening process (from pre-screening to post-screening and after receiving a negative result; Cormier *et al.* 2002a). Men with more than two relatives with prostate cancer, a higher education, an anxious personality, no children living at home and between the ages of 50 and 60 years were more likely to demonstrate deterioration in anxiety and HRQOL (Cormier *et al.* 2002a).

DISCUSSION

The findings of the review indicate that the prevalence of screening in first-degree male relatives appears to be high, at least in North America. Furthermore, men with a family history of prostate cancer appear to screen more than men without a family history of prostate cancer; two of the three studies comparing the screening practices of first-degree relatives with men from the general population found that first-degree relatives are more likely to screen. Such men have heightened risk perceptions; however, their risk perceptions are often inaccurate with men both overestimating and underestimating their risk. Risk perceptions do not consistently predict screening with only half of the studies that examined the relationship between risk perceptions and screening finding that higher risk perceptions predicted screening. Rather, screening is predicted by older age, access to health care, higher socioeconomic status, previous involvement in screening, having more than one first-degree relative with prostate cancer and the nature of the familial relationship with the affected relative. Specifically, being a younger versus an older sibling or a son as opposed to a brother of a family member with prostate cancer predicted screening. In summary, two key themes emerge as influencing the testing behaviour of these men. First, having a more extensive family history and a paternal rather than fraternal history was related to more testing, suggesting that the more personally significant the history, the greater the effect on behaviour. Second, socioeconomic factors that influence access to health care also influence testing in first degree male relatives. This finding is consistent with research showing poorer prostate cancer treatment decisions and health outcomes for men who report socioeconomic barriers and poorer access to health care (Hall *et al.* 2005; Zeliadt *et al.* 2006; Gallina *et al.* 2007).

Not surprisingly, the predictors of risk perceptions are similar to the factors that predict screening, viz. having multiple first-degree relatives diagnosed with or deceased from prostate cancer, a paternal family history or a younger versus an older sibling (Bratt *et al.* 2000; Beebe-Dimmer *et al.* 2004). These findings are of particular interest as brothers are at an actual greater risk of being diagnosed with prostate cancer than are sons (Bruner *et al.* 2003; Johns & Houlston 2003), and one of the main risk factors for being diagnosed with prostate cancer is older age. Thus, first-degree relatives may not have an accurate understanding of familial risk and may be making assumptions about risk based principally on the nature of their relationship to their affected relative. These results highlight the need to ensure that first-degree relatives are

appropriately counselled about their actual risk of being diagnosed with prostate cancer based on their individual family histories. Despite the finding that having a family history raises men's awareness of prostate cancer, actual knowledge has been poorly assessed. Specifically, researchers have relied on examining men's personal perceptions of their knowledge, and the one study that did assess actual knowledge did not examine men's understanding of screening efficacy. As well, prostate cancer knowledge assessments have not examined men's knowledge of the benefits and limitations of prostate cancer screening. Hence, it is unclear whether these men are making informed decisions about screening consistent with public health policies (USPSTF 2002; RACGP 2006). Furthermore, first-degree relatives report unmet needs for information about prostate cancer. In the light of inaccurate risk perceptions and these unmet needs it is proposed that work is needed to educate both the community and the families of men with prostate cancer about the implications of a family history of prostate cancer and the potential benefits and limitations of screening for first-degree relatives.

In interpreting the results of this review, there are a number of methodological issues that need to be taken into consideration. First, the different types of assessments of perceived risk led to differences in how men rated their prostate cancer risk. Approximately 40% of men underestimated or overestimated their risk depending on the assessment of risk (e.g. comparative versus single-event probability scales respectively). This finding is consistent with research showing that women estimating breast cancer risk overestimate their risk when utilizing single-event probability scales and underestimate their risk when utilizing comparative rating scales (Eibner *et al.* 2006). As different measures of risk perception have the capacity to influence the risk levels reported by first-degree relatives, it is important for future studies to utilize comprehensive and multi-item measures to gauge less assessment-biased perceptions of risk. The different assessments of perceived risk may also provide some explanation as to why risk perceptions were not found to consistently predict screening for first-degree relatives.

Second, there were inconsistencies in the assessment of prevalence (e.g. have you *ever* participated in PSA testing versus have you participated in PSA testing in the *last 12 months*; see Table 1), limiting the extent to which prevalence can be compared across studies. Where possible, screening prevalence assessments should examine comprehensive and consistent timeframes to enhance the potential for comparisons to be made between recent and lifetime screening prevalence across studies. As well, additional studies should utilize more population-based sampling methods as first-degree relatives recruited from prostate cancer screening programmes may represent a biased sample of first-degree relatives. Third, the majority of studies have been retrospective limiting the conclusions that can be drawn from the data. Prospective studies are needed to identify predictors of prostate cancer screening clearly and to describe screening behaviours and psychological outcomes for these men over time.

Finally, as nine of the 11 studies examining screening prevalence were conducted on a North American sample of first-degree relatives, the generalizability of these findings to other countries may be limited. The uptake of PSA testing in the UK is lower than in North America, and there is a considerably greater incidence of prostate cancer in North America compared with the UK (Hsing & Devesa 2001; Parkin *et al.* 2001; Melia 2005). As well, a recent examination of clinical practice guidelines for prostate cancer screening found that national and international medical entities vary in their endorsement of prostate cancer screening (Peters *et al.* 2001). Thus, there is the potential for attitudes towards prostate cancer screening to differ across these countries. Future research to assess cross-cultural differences in screening attitudes and behaviours for men with a family history of prostate cancer is needed.

This review illustrates the need for additional research on first-degree relatives of men with prostate cancer to gauge the extent to which having a family history of prostate cancer influences screening and to describe better the factors that lead such men to undergo screening. Although the literature suggests that men with a family history participate in PSA testing more than the general population and identify their higher risks of being diagnosed with prostate cancer, results are inconsistent. Socioeconomic factors and the nature of the family history appear to be influential for screening behaviour and risk perceptions. These men do not appear to experience negative psychological consequences as a result of testing but do report unmet needs for information. Prospectively, longitudinal assessments that use both consistent and comprehensive measures of screening are needed to establish what factors cue the uptake of prostate cancer screening in these men and how they fare over time.

In order to develop effective educational materials and decision aids for men with a family history of prostate cancer, it is essential to first understand what factors predict testing. This review found that consistent predictors of screening were aspects related to a first-degree relative's personal family history. If a diagnosis of prostate cancer in the family is acting as a trigger for screening, it

is important to ensure that first-degree relatives are appropriately informed about prostate cancer risk and screening efficacy following their relatives' diagnosis. For example, it may be beneficial for general practitioners and nurse counsellors to seek permission to approach first-degree relatives following a diagnosis of prostate cancer in the family to provide prostate cancer education and support to family members. As well, written or electronic (e.g. websites) counselling and education materials could be passed on to prostate cancer patients to pass on to their unaffected male relatives as a means of providing information and support to family members. As well, educational materials for patients should focus on ensuring that there is effective and accurate communication about familial risk with referral for in-depth information and support tailored to the needs of family members.

Furthermore, there may be some benefit in examining how families communicate about prostate cancer risk and how this relates to participation in prostate cancer screening. The influence of families on the performance of preventive health behaviours has been recognized; particularly, the positive effect a partner can have on one's health status (Zimmerman & Connor 1989; Joung *et al.* 1995; Joutsenniemi *et al.* 2006). With research examining the possible familial aggregation of prostate cancer with other cancers in the family, such as breast cancer (Schaid 2004), the potential for cancer diagnoses in the family to prompt prostate cancer screening in male relatives could be of interest. Further, the influence of changing family structures on the communication between family members may need to be examined to ensure that family members are aware of the implications of prostate cancer risk and the importance of communicating risk information to family members.

Finally, African-American men with a family history of prostate cancer have multiple risk factors for developing prostate cancer: race and family history (Catalona *et al.* 2002; Bloom *et al.* 2006). Future research to determine both the individual and the combined influences of race and family history on risk perceptions and screening behaviours is needed, particularly in light of the greater barriers to general health care, facing African-American men by comparison with Caucasians (Talcott *et al.* 2007).

REFERENCES

Andriole G.L., Levin D.L., Crawford E.D., Gelmann E.P., Pinsky P.F., Chia D., Kramer B.S., Reding D., Church T.R., Grubb R.L., Izmirlian G., Ragard L.R., Clapp J.D., Prorok P.C. & Gohagan J.K. (2005) Prostate cancer screening in the Prostate, Lung, Colorectal and Ovarian (PLCO) cancer screening trial: findings from the initial screening round of a randomized trial. *Journal of The National Cancer Institute* **97**, 433–438.

Arar N., Thompson I., Sarosdy M., Harris M., Shepherd D., Troyer D. & Plaetke R. (2000) Risk perceptions among patients and their relatives regarding prostate cancer and its heredity. *Prostate Cancer and Prostatic Diseases* **3**, 176–185.

Baade P.D., Coory M.D. & Aitken J.F. (2004) International trends in prostate-cancer mortality: the decrease is continuing and spreading. *Cancer Causes and Control* **15**, 237–241.

Beebe-Dimmer J.L., Wood D.P., Gruber S.B., Chilson D.M., Zuhlke K.A., Claeys G.B. & Cooney K.A. (2004) Risk perception and concern among brothers of men with prostate carcinoma. *Cancer* **100**, 1537–1544.

Bermejo J.L. & Hemminki K. (2005) Familial risk of cancer shortly after diagnosis of the first familial tumor. *Journal of the National Cancer Institute* **97**, 1575–1579.

Bloom J.R., Stewart S.L., Oakley-Girvans I., Banks P.J. & Chang S. (2006) Family history, perceived risk, and prostate cancer screening among African-American men. *Cancer Epidemiology, Biomarkers and Prevention* **15**, 2167–2173.

Bock C.H., Peyser P.A., Gruber S.B., Bonnell S.E., Tedesco K.L. & Cooney K.A. (2003) Prostate cancer early detection practices among men with a family history of disease. *Urology* **62**, 470–475.

Bratt O., Kristoffersson U., Lundgren R. & Olsson H. (1997) Sons of men with prostate cancer: their attitudes regarding possible inheritance of prostate cancer, screening, and genetic testing. *Urology* **50**, 360–365.

Bratt O., Damber J.E., Emanuelsson M., Kristoffersson U., Lundgren R., Olsson H. & Gronberg H. (2000) Risk perception, screening practice and interest in genetic testing among unaffected men in families with hereditary prostate cancer. *European Journal of Cancer* **36**, 235–241.

Bratt O., Emanuelsson M. & Gronberg H. (2003) Psychological aspects of screening in families with hereditary prostate cancer. *Scandinavian Journal of Urology and Nephrology* **37**, 5–9.

Bruner D.W., Moore D., Parlanti A., Dorgan J. & Engstrom P. (2003) Relative risk of prostate cancer for men with affected relatives: systematic review and meta-analysis. *International Journal of Cancer* **107**, 797–803.

Catalona W.J., Antenor J.A.V. & Roehl K.A. (2002) Screening for prostate cancer in high risk populations. *Journal of Urology* **168**, 1980–1984.

Cormier L., Guillemin F., Valeri A., Fournier G., Cussenot O., Mangin P. & Litwin M.S. (2002a) Impact of prostate cancer screening on health-related quality of life in at-risk families. *Urology* **59**, 901–906.

Cormier L., Kwan L., Reid K. & Litwin M.S. (2002b) Knowledge and beliefs among brothers and sons of men with prostate cancer. *Urology* **59**, 895–900.

Cormier L., Valéri A., Azzouzi R., Fournier G., Cussenot O., Berthon P., Guillemin F. & Mangin P. (2002c) Worry and attitude of men in at-risk families for prostate cancer about genetic susceptibility and genetic testing. *The Prostate* **51**, 276–285.

Cormier L., Reid K., Kwan L. & Litwin M.S. (2003) Screening behavior in brothers and sons of men with prostate cancer. *Journal of Urology* **169**, 1715–1719.

Eibner F., Barth R., Helmes A. & Bengel J. (2006) Variations in subjective breast cancer risk estimations when using different measurements for assessing breast cancer risk perception. *Health Risk and Society* **8**, 197–210.

Gallina A., Karakiewicz P.I., Chun F.K.H., Briganti A., Graefen M., Montorsi F., Walz J., Jeldres C., Erbersdobler A., Salonia A., Suardi N., Deho F., Schlomm T., Scattoni V., Haese A., Heinzer H., Valiquette L., Rigatti P. & Huland H. (2007) Health-insurance status is a determinant of the stage at presentation

and of cancer control in European men treated with radical prostatectomy for clinically localized prostate cancer. *BJU International* **99**, 1404–1408.
Gambert S.R. (2001) Screening for prostate cancer. *International Urology and Nephrology* **33**, 249–257.
Gronberg H. (2003) Prostate cancer epidemiology. *The Lancet* **361**, 859–864.
Hall S.E., Holman C.D.A.J., Wisniewski Z.S. & Semmens J. (2005) Prostate cancer: socioeconomic, geographical and private-health insurance effects on care and survival. *BJU International* **95**, 51–58.
Harris R. & Lohr K.N. (2002) Screening for prostate cancer: an update of the evidence for the U.S. preventive services task force. *Annals of Internal Medicine* **137**, 917–929.
Hemminki K., Rawal R. & Bermejo J.L. (2005) Prostate cancer screening, changing age-specific incidence trends and implications on familial risk. *International Journal of Cancer* **113**, 312–315.
Hsing A.W. & Devesa S.S. (2001) Trends and patterns of prostate cancer: what do they suggest? *Epidemiologic Reviews* **23**, 3–13.
Ilic D., O'Connor D., Green S. & Wilt T. (2006) Screening for prostate cancer. *Cochrane Database of Systematic Reviews*, **3**, 1–25, CD004720.
Jacobsen P.B., Lamonde L.A., Honour M., Kash K., Hudson P.B. & Pow-Sang J. (2004) Relation of family history of prostate cancer to perceived vulnerability and screening behavior. *Psycho-Oncology* **13**, 80–85.
Johns L.E. & Houlston R.S. (2003) A systematic review and meta-analysis of familial prostate cancer risk. *BJU International* **91**, 789–794.
Joung I.M.A., Stronks K., Vandemheen H. & Mackenbach J.P. (1995) Health behaviors explain part of the differences in self-reported health associated with partner marital-status in the Netherlands. *Journal of Epidemiology and Community Health* **49**, 482–488.
Joutsenniemi K.E., Martelin T.P., Koskinen S.V., Martikainen P.T., Harkanen T.T., Luoto R.M. & Aromaa A.J. (2006) Official marital status, cohabiting, and self-rated health-time trends in Finland, 1978–2001. *European Journal of Public Health* **16**, 476–483.
Kiemeney L.A., Broeders M.J., Pelger M., Kil P.J., Schröder F.H., Witjes J.A. & Vasen H.F. (2008) Screening for prostate cancer in Dutch hereditary prostate cancer families. *International Journal of Cancer* **122**, 871–876.
Langeberg W.J., Isaacs W.B. & Stanford J.L. (2007) Genetic etiology of hereditary prostate cancer. *Frontiers in Bioscience* **12**, 4101–4110.
Lichtenstein P., Holm N.V., Verkasalo P.K., Illiadou A., Kaprio J., Koskenvuo M., Pukkala E., Skytthe A. & Hemminki K. (2000) Environmental and heritable factors in the causation of cancer: analyses of cohorts of twins from Sweden, Denmark, and Finland. *New England Journal of Medicine* **343**, 78–84.
Loblaw D.A., Virgo K.S., Nam R., Somerfield M.R., Ben-Josef E., Mendelson D.S., Middleton R., Sharp S.A., Smith T.J., Talcott J., Taplin M., Vogelzang N.J., Wade J.L., III, Bennet C.L. & Scher H.I. (2007) Initial hormonal management of androgen-sensitive metastatic, recurrent, or progressive prostate cancer: 2007 update of an American society of clinical oncology practice guideline. *Journal of Clinical Oncology* **25**, 1596–1605.
Melia J. (2005) Part 1: The burden of prostate cancer, its natural history, information on the outcome of screening and estimates of ad hoc screening with particular reference to England and Wales. *BJU International* **95**, 4–15.
Miller S.M., Diefenbach M.A., Kruus L.K., Watkins-Bruner D., Hanks G.E. & Engstrom P.F. (2001) Psychological and screening profiles of first-degree relatives of prostate cancer patients. *Journal of Behavioral Medicine* **24**, 247–258.
Myers R.E. (2005) Decision counseling in cancer prevention and control. *Health Psychology* **24**, S71–S77.
Neal D.E., Leung H.Y., Powell P.H., Hamdy F.C. & Donovan J.L. (2000) Unanswered questions in screening for prostate cancer. *European Journal of Cancer* **36**, 1316–1321.
O'connor A.M., Fiset V., Degrasse C., Graham I.D., Evans W., Stacey D., Laupacis A. & Tugwell P. (1999) Decision aids for patients considering options affecting cancer outcomes: evidence of efficacy and policy implications. *Journal of the National Cancer Institute*, Monographs 67–80.
Parkin D.M. (2001) Global cancer statistics in the year 2000. *Lancet Oncology* **2**, 533–543.
Parkin D.M., Bray F.I. & Devesa S.S. (2001) Cancer burden in the year 2000. The global picture. *European Journal of Cancer* **37**, S4–S66.
Peters S.M., Jovell A.J., Garcia-Altes A. & Serra-Prat M. (2001) Screening and clinical management of prostate cancer. A cross-national comparison. *International Journal of Technology Assessment in Health Care* **17**, 215–221.
Pomerantz M.M., Freedman M.L. & Kantoff P.W. (2007) Genetic determinants of prostate cancer risk. *BJU International* **100**, 241–243.
Postma R. & Schroder F.H. (2005) Screening for prostate cancer. *European Journal of Cancer* **41**, 825–33.
Pruthi R.S., Tornehl C., Gaston K., Lee K., Moore D., Carson C.C. & Wallen E.M. (2006) Impact of race, age, income, and residence on prostate cancer knowledge, screening behavior, and health maintenance in siblings of patients with prostate cancer. *European Urology* **50**, 64–69.
RACGP (Royal Australian College of General Practitioners) (2006) Prostate screening: policy endorsed by the 48th RACGP council, 19 April 2006. Retrieved 30 November, 2006. Available at: http://www.racgp.org.au/Content/NavigationMenu/Advocacy/RACGPpositionstatements/20060911Prostatescreening.pdf
Ross L.E., Uhler R.J. & Williams K.N. (2005) Awareness and use of the prostate-specific antigen test among African-American men. *Journal of the National Medical Association* **97**, 963–71.
Roumier X., Azzouzi R., Valeri A., Guillemin F., Fournier G., Cussenot O., Mangin P. & Cormier L. (2004) Adherence to an annual PSA screening program over 3 years for brothers and sons of men with prostate cancer. *European Urology* **45**, 280–286.
Sanders T., Campbell R., Sharp D. & Donovan J. (2003) Risk constructions among people who have a first-degree relative with cancer. *Health Risk and Society* **5**, 53–69.
Schaid D.J. (2004) The complex genetic epidemiology of prostate cancer. *Human Molecular Genetics* **13**, R103–121.
Schnur J.B., Dilorenzo T.A., Montgomery G.H., Erblich J., Winkel G., Hall S.J. & Bovbjerg D.H. (2006) Perceived risk and worry about prostate cancer: a proposed conceptual model. *Behavioral Medicine* **32**, 89–96.
Schroder F.H., Denis L.J. & Roobol M. (2003) The story of the European randomized study of screening for prostate cancer. *BJU International* **92**, 1–13.
Shah M., Zhu K., Palmer R.C. & Wu H. (2007) Family history of cancer and utilization of prostate, colorectal and skin cancer screening tests in U.S. men. *Preventive Medicine* **44**, 459–464.
Spencer B.A., Babey S.H., Etzioni D.A., Ponce N.A., Brown E.R., Yu H.J., Chawla N. & Litwin M.S. (2006) A population-based survey of prostate-specific antigen testing among California men at higher risk for prostate carcinoma. *Cancer* **106**, 765–774.

Staples M.P., Giles G.G., English D.R., Mccredie M.R.E., Severi G., Cui J.S. & Hopper J.L. (2003) Risk of prostate cancer associated with a family history in an era of rapid increase in prostate cancer diagnosis (Australia). *Cancer Causes and Control* **14**, 161–166.

Sweetman J., Watson M., Norman A., Bunstead Z., Hopwood P., Melia J., Moss S., Eeles R., Dearnaley D. & Moynihan C. (2006) Feasibility of familial PSA screening: psychosocial issues and screening adherence. *British Journal of Cancer* **94**, 507–512.

Talcott J.A., Spain P., Clark J.A., Carpenter W.R., Do Y.K., Hamilton R.J., Galanko J.A., Jackman A. & Godley P.A. (2007) Hidden barriers between knowledge and behavior: the North Carolina prostate cancer screening and treatment experience. *Cancer* **109**, 1599–606.

USPSTF (U.S Preventive Services Task Force) (2002) Screening for prostate cancer: recommendations and rationale. Retrieved 30 December, 2007. Available at: http://www.ahrq.gov/clinic/3rduspstf/prostatescr/prostaterr.htm

Vadaparampil S.T., Jacobsen P.B., Kash K., Watson I.S., Saloup R. & Pow-Sang J. (2004) Factors predicting prostate specific antigen testing among first-degree relatives of prostate cancer patients. *Cancer Epidemiology Biomarkers and Prevention* **13**, 753–758.

Weinrich S.P. (2006) Prostate cancer screening in high-risk men: African-American hereditary prostate cancer study network. *Cancer* **106**, 796–803.

Wilt T.J. & Wilt T.J. (2002) Clarifying uncertainty regarding detection and treatment of early-stage prostate cancer. *Seminars in Urologic Oncology* **20**, 10–7.

Zeliadt S.B., Ramsey S.D., Penson D.F., Hall I.J., Ekwueme D.U., Stroud L. & Lee J.W. (2006) Why do men choose one treatment over another? *Cancer* **106**, 1865–1874.

Zimmerman R.S. & Connor C. (1989) Health promotion in context – the effects of significant others on health behavior-change. *Health Education Quarterly* **16**, 57–75.