The patient perspective on a first raised PSA test

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ABSTRACT

INTRODUCTION: Approximately 350 000 prostate-specific antigen (PSA) tests are undertaken in New Zealand on a quarter of a million men each year. A number of studies have looked at PSA testing done by general practitioners (GPs) and subsequent outcomes. Few have looked at the patient perspective after a raised PSA result.

AIM: To explore patient experiences up to and following a raised PSA test.

METHODS: Thirty-one general practices within the Midland region were recruited. Community laboratory databases were used to identify all men with a first raised PSA test during 2010. Questionnaires were sent to these men.

RESULTS: One hundred and ninety-four (63%) eligible responses were received from 307 eligible men delivered questionnaires. For 54% of men this was their first PSA test. Most men (66%) identified that their PSA test was initiated by their GP. Forty-three percent of men identified having symptoms at the time of their first raised PSA test. A digital rectal examination (DRE) was performed on 73% of men at the time of the test. Fifty-eight percent of men were referred to see a specialist. Māori men were less likely to be referred after a raised PSA. Of all men referred, 61% received a biopsy.

DISCUSSION: PSA testing is predominantly initiated by GPs. We found the care pathway is variable for men after an elevated PSA result. Standardisation of the pathway prior to and post diagnosis would assist patients in knowing what to expect and would aid in GP management of men being investigated for prostate cancer.

KEYWORDS: Patient care; prostate-specific antigen; screening, opportunistic

Introduction

Increasing emphasis is being placed on timely, structured and appropriate patient pathways for men suspected of having prostate cancer.[1] Screening asymptomatic men for prostate cancer by New Zealand general practitioners (GPs) is widespread.[2–6] However, population-based screening is not recommended because of the potential for avoidable harm.[7,8] Whilst pre- and post-diagnosis pathways are generally agreed between general practitioner and specialist, the patient perspective is also pivotal.[9,10] Learning about what men know, how they were diagnosed, and the pathway of care they took is ever more important to ensure that men are receiving appropriate care and are provided with enough information to adequately assess the benefits and risks related to their decision to embark on the screening pathway.[11–18]

There are approximately 350 000 prostate-specific antigen (PSA) tests done on approximately 250 000 men in NZ, with around 3000 prostate cancers registered every year.[19] One in five of these men will die from their prostate cancer.[20] PSA testing identifies a significant proportion

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of men who have no evidence of cancer, as well as some men who have evidence of cancer but in whom it is unlikely they will ever become symptomatic. Approximately 70–80% of testing is done in asymptomatic men and can be considered opportunistic screening.[2,4,6]

The New Zealand Prostate Cancer Taskforce (Taskforce) recommends that primary health care provide high-quality, culturally appropriate information on prostate cancer and PSA testing to men aged 50 to 70 years, and that systems to facilitate the informed consent process be introduced into practices.[3] However, there is evidence of variation in GP attitudes to PSA screening. For example, 20–55% of GPs indicated they would not initiate screening discussions at any age, while 30% of GPs admit they would initiate discussions in a 79-year-old asymptomatic man.[19] Anecdotally, we have received information that some men are tested without their knowledge, as part of a general 'health screening'.

The Taskforce recommends that all patients should have a digital rectal examination (DRE) when they are PSA tested, although again there are anecdotes that this is a barrier to testing for some men. There is also controversy as to the value of PSA testing when assessing a man with lower urinary tract symptoms (LUTS) and prostate-related symptoms.[21,22] Finally, the Taskforce has developed age-related recommendations concerning referral. These are different and higher than the values recommended by some laboratories in NZ and higher than those used in the randomised controlled trials (RCTs) of prostate cancer screening.[23]

The aim of this study was to explore patient understanding of their care leading up to and following a raised PSA test. The study sought to find out why patients with a raised PSA test thought they had been tested in the first place.

Methods

Practice recruitment

During April to December 2011, 31 general practice clinics in the Midland region (Waikato, Lakes and Bay of Plenty District Health Boards [DHBs]) were recruited for a study of PSA testing on men aged 40 years and over with a test between 1 January and 31 December 2010. This accounted for approximately 25% of general practices in our region. The study team gained community laboratory access through Pathlab to all PSA tests undertaken during 2010 for all enrolled men aged 40 years and over within participating general practices.[24] Patients were tracked from their GP to Pathlab via their National Health Index (NHI) number.

Accessing patients

For men tested during 2010, PSA tests undertaken between 2007 and 2009 were also reviewed to identify those with a first raised PSA. Questionnaires (see Appendix in the online version of this paper) were mailed out to men by their general practices and posted back to the practice by the men. In total, 391 men were identified as having a first raised PSA within 2010.

Ineligibility/exclusion

From the patients identified with a first raised PSA, a number were excluded from follow-up by their GP. Patients were identified as ineligible based on their vital status, comorbidities, having died, transferred out of the practice, or having previous prostate problems not identified from their current record.

Definition of raised PSA level

It is important to note that the range of normal PSA levels differs between national guidelines and local laboratory reporting. The community laboratory Pathlab uses the age-specific PSA levels, which are lower and start earlier than those more recently recommended by the Ministry of Health Prostate Cancer Taskforce (Table 1).[5,24] We utilised the Pathlab community laboratory levels as the standard for normal/raised.

Questionnaire pilot

A questionnaire was developed by the lead GP (FH) and pilot tested on patients in five clinics in the Midland region.[5] No changes were made to the questionnaire as a result of the pilot study,

so the questionnaires from the pilot clinics were included in the final analysis.

Ethical approval for the Midlands Prostate Cancer study was gained through the Northern Y Ethics Committee (Ref. NTY/11/02/019).

Results

Patient characteristics

In total, 391 patients were identified and 307 men were mailed questionnaires. There were 194 eligible responses (63%). Table 2 shows that, out of the eligible responses, 17 self-identified as Māori (9%) and 177 as non-Māori (91%). Most men (68%) were aged 50–69 years.

PSA testing history

To understand if men knew their PSA testing history, we asked if this was their first PSA test. About half of the men (54%) reported that this was the first time they had been PSA tested. Māori men were more likely to identify this as their first PSA test than non-Māori men, at 82% vs 50% respectively. Younger men were less likely to have been tested previously.

Patients were asked who initiated the test done in 2010: himself, the GP, or some other reason.

WHAT GAP THIS FILLS

What we already know: Screening for prostate cancer is regularly undertaken in NZ. However, little is known about the management of patients following a raised PSA result.

What this study adds: We have explored the self-reported patient experience from receiving a PSA test to the outcomes following a raised PSA result. We highlight the variability in the patient pathway, including by ethnicity (Māori/non-Māori), and illustrate the need for standardising the pathway post a raised PSA result.

Twenty-seven percent of men identified that they had asked for the PSA test, while 66% of men indicated that the GP initiated the testing. Fifty-three percent of Māori men identified that the GP had initiated their PSA test, compared to 67% of non-Māori men. Table 3 identifies the differences in testing initiating by age-range, in particular highlighting that GP initiating of testing increased with age. However, of men who reported their GP had initiated the test, 48% identified that they had some form of urinary symptom at the time the test was taken.

Self-initiating testing

Thirty-five percent of Māori men self-initiated the PSA test, compared to 27% of non-Māori men. For the 53 men who self-initiated having a

Table 1. Comparing the PSA normal range by community laboratory and national recommendations

Age range	Normal PSA range[24] (Pathlab)	Age range	Normal PSA range[3] (Prostate Cancer Taskforce recommendations)
40–49 years	0–2.5 ng/ml	**50–70 years**	0–4.0 ng/ml
50–59 years	0–3.5 ng/ml	**71–75 years**	0–10.0 ng/ml
60–69 years	0–4.0 ng/ml	**≥76 years**	0–20.0 ng/ml
70–79 years	0–6.5 ng/ml	Palpable abnormality and/or significant rise in PSA level warrant referral	
80+ years	0–7.0 ng/ml		

Table 2. Age and ethnicity of respondents

Ethnicity	Age					
	40–49 years n/N (%)	50–59 years n/N (%)	60–69 years n/N (%)	70–79 years n/N (%)	80+ years n/N (%)	Total n/N (%)
Māori	1/17 (5.9%)	5/17 (29.4%)	9/17 (52.9%)	2/17 (11.8%)	0	17/194 (8.8%)
Non-Māori	9/177 (5.1%)	49/177 (27.7%)	69/177 (39.0%)	36/177 (20.3%)	14/177 (7.9%)	177/194 (91.2%)
Total	10/194 (5.2%)	54/194 (27.8%)	78/194 (40.2%)	38/194 (19.6%)	14/194 (7.2%)	194/194 (100.0%)

Table 3. Who suggested the PSA test?

	40–49 years n/N (%)	50–59 years n/N (%)	60–69 years n/N (%)	70–79 years n/N (%)	80+ years n/N (%)
Patient	3/10 (30.0%)	18/54 (33.3%)	29/78 (37.2%)	3/38 (7.9%)	–
GP	5/10 (50.0%)	31/54 (57.4%)	47/78 (60.3%)	32/38 (84.2%)	13/14 (92.9%)
Other	2/10 (20.0%)	5/54 (9.3%)	2/78 (2.6%)	3/38 (7.9%)	1/14 (7.1%)

GP General practitioner

PSA test, we asked what their main reason was for doing this. Men identified that 'having a family history of the cancer' or 'being prompted by the media, a friend or family member' were the main reasons at approximately 19% (10/53) and 47% (25/53) respectively. Only six men (approximately 11%) requested to be tested because of what they believed were symptoms of prostate cancer or previous prostate problems. Table 4 identifies the different reasons for men requesting a PSA test by age range and ethnicity.

Symptoms at time of test

In addition to understanding if symptoms were a motivator for requesting a PSA test from the GP, we were interested in finding out if men felt that they were symptomatic at the time of the PSA test. As well as the six men who requested the test because of their symptoms, another 77 men (83 in total) felt that they were symptomatic at the time of their test (Table 5). Men aged 70+ years were slightly more likely than their younger counterparts at <70 years to have symptoms at the time of presentation to their GP, at 50% and 40% respectively.

Digital rectal examination

Men were asked if they had received a digital rectal examination (DRE) by their GP at the time of their PSA test. Most men (73%) said they had received a DRE. Māori and non-Māori men were just as likely to receive a DRE at the time of the test, at 71% and 73% respectively. Men aged 60–69 years (86%) were most likely to receive a DRE by their GP.

Post–raised PSA level: what occurred next?

After the result of the PSA was identified as raised, we wanted to know what occurred next. Fifty-eight percent of men were referred to a specialist by their GP; 40% of men stated that they were not referred. Table 6 shows an increase in GP referral to a specialist as the man's age increases. Māori men were significantly less likely to be referred (p=0.04) than their non-Māori counterparts, at 35% and 61% respectively.

Post-referral: location of first specialist appointment

Of the 58% of men who were referred, we asked if they had seen a specialist urologist and, if so, had they seen them in a public or private setting. One hundred and thirteen men identified that they had their first specialist appointment (FSA) with a urologist. The split between the public and private setting was close to even, at 47% and 44% respectively. In addition, three men (all non-Māori) saw specialists in both the public and private setting.

Table 4. Patient-identified reasons for self-initiating the first PSA test (n=53)

Reasons	40–49 years n/N (%)	50–59 years n/N (%)	60–69 years n/N (%)	70–79 years n/N (%)	80+ years n/N (%)	Māori n/N (%)	Non-Māori n/N (%)	Total
Family history	–	4/18 (22.2%)	6/29 (20.7%)	–	–	–	10/47 (21.3%)	10/53 (18.9%)
Symptoms	–	2/18 (11.1%)	2/29 (6.9%)	2/3 (66.7%)	–	1/6 (16.7%)	5/47 (10.6%)	6/53 (11.3%)
Media, friend, family awareness	3/3 (100%)	9/18 (50.0%)	12/29 (41.4%)	1/3 (33.3%)	–	3/6 (50.0%)	22/47 (46.8%)	25/53 (47.2%)
Not identified	–	3/18 (16.7%)	9/29 (31.0%)	–	–	2/6 (33.3%)	10/47 (21.3%)	12/53 (22.6%)

Post–first specialist appointment

Men were asked what the specialists did next: organise a biopsy, decide to monitor, arrange for an operation, or something else. For those men who did see a specialist, 69 men (61%) received a biopsy. Māori men who were referred were slightly more likely to have a biopsy (67%) compared to 61% of non-Māori men. Of the men biopsied, 38 (55%) had a positive biopsy result. Some men (19%) identified that surgery was undertaken post-FSA. Two-thirds of these surgeries were radical prostatectomies and one-third of surgeries were for symptomatic management. Half of the men referred felt that they were not being monitored. For men who were monitored, there was some confusion about who was doing this, as shown in Table 7.

Wait times between referral and first specialist appointment

The wait times for men between GP referral and FSA varied (Table 8). Most men (82%) identified that they were seen by a specialist within 8 weeks of their referral. Māori men were just as likely to be seen within the first 2 weeks (17%) as non-Māori men (21%), but more likely to be seen within 2–4 weeks (50%) than non-Māori (30%). Most men who went privately for their FSA waited 4 weeks or less (approximately 78%). Twenty-nine percent of the men who went to a public hospital waited 2–4 weeks, and nearly half of the men having their FSA in a public hospital were seen after a wait of 4–8 weeks (approximately 44%). Māori men identified slightly more often than non-Māori that they attended privately—50% and 44% respectively.

For men who had symptoms at the time of presentation to the GP, wait times to see a specialist varied. The majority of men (64%) seen in the 4 weeks following referral had symptoms. Fifty-three percent of men seen in the 4–8 week time period were also symptomatic at the time of GP referral. For men who identified that their

Table 5. When you went to the doctor did you have any symptoms relating to your prostate?

	Non-Māori n/N (%)	Māori n/N (%)	Total n/N (%)
Had symptoms	77/177 (43.5%)	6/17 (35.3%)	83/194 (42.8%)
No symptoms	94/177 (53.1%)	11/17 (64.7%)	105/194 (54.1%)
Unknown	6/177 (3.4%)	–	6/194 (3.1%)

Table 6. Referral to specialist post first raised PSA

	40–49 years n/N (%)	50–59 years n/N (%)	60–69 years n/N (%)	70–79 years n/N (%)	80+ years n/N (%)
Yes	5/10 (50.0%)	27/54 (50.0%)	47/78 (60.3%)	24/38 (63.2%)	10/14 (71.4%)
No	5/10 (50.0%)	25/54 (46.3%)	31/78 (39.7%)	14/38 (36.8%)	3/14 (21.4%)
Don't know	–	2/54 (3.7%)	–	–	1/14 (7.1%)

Table 7. Patient identified monitoring after first specialist appointment

	40–49 years n/N (%)	50–59 years n/N (%)	60–69 years n/N (%)	70–79 years n/N (%)	80+ years n/N (%)	Total
By specialist	–	8/27 (29.6%)	8/47 (17.0%)	4/24 (16.7%)	2/10 (20.0%)	22/113 (19.5%)
By GP	1/5 (20.0%)	4/27 (14.8%)	2/47 (4.3%)	4/24 (16.7%)	3/10 (30.0%)	14/113 (12.4%)
By specialist and GP	–	2/27 (7.4%)	4/47 (8.5%)	2/24 (8.3%)	–	8/113 (7.1%)
Don't know if monitored	1/5 (20.0%)	1/27 (3.7%)	–	3/24 (12.5%)	1/10 (10.0%)	6/113 (5.3%)
Monitored but don't know by whom	–	3/27 (11.1%)	2/47 (4.3%)	2/24 (8.3%)	–	7/113 (6.2%)
Not monitored	3/5 (60.0%)	9/27 (33.3%)	31/47 (66.0%)	9/24 (37.5%)	4/10 (40.0%)	56/113 (49.6%)

GP General practitioner

Table 8. Wait times from referral to first specialist appointment

	Private n/N (%)	Public n/N (%)	Public and private n/N (%)	Somewhere else n/N (%)
0–4 weeks	40/51 (78.4%)	16/55 (29.1%)	1/3 (33.3%)	0
4–8 weeks	7/51 (13.7%)	24/55 (43.6%)	2/3 (66.7)	3/4 (75.0%)
8–16 weeks	1/51 (2.0)	9/55 (16.4%)	0	0
16 weeks+	2/51 (3.9%)	2/55 (3.6%)	0	1/4 (25.0%)
Unknown	1/51 (2.0)	4/55 (7.2%)	0	0
Total	51/113 (45.1%)	55/113 (48.7%)	3/113 (2.7%)	4/113 (3.5%)

wait time was 8 weeks or more, 60% of these men identified that they had one or more related symptoms. However, 19% of men who had symptoms were not referred on to a specialist.

Discussion

In this study, we found that PSA testing is regularly carried out on asymptomatic men, with a significant amount of screening being undertaken on men outside of the age range recommended for testing (i.e. <50 years and >70 years). The bulk of the initiation and frequency of PSA testing undertaken in the Midland region is not driven by men, but rather by the GP. While New Zealand's Ministry of Health has recommended that no population-based screening programme is implemented, it is clear that unorganised screening is continuing to be undertaken by GPs.[6,24]

For men who self-initiated the test, most identified that this was as a result of influence from the media, family and/or friends. Family history was also a strong motivator for requesting a PSA test from the GP, with 19% of men acknowledging this was their motivating factor for requesting a PSA test. None of the Māori men identified a family history within their responses, nor saw this as a motivating factor for requesting the test from their GP.

Age is a contributing factor in testing. We found that 27% of testing undertaken is on men 70 years plus. Nearly 85% of testing on those 70–79 years and 93% of the testing on 80-plus-year-olds was GP initiated, with just over 44% of men aged 70 years plus asymptomatic at the time of the test. Ten patients were under 50 years when they were tested and, of these, half were initiated by the GP, despite this being outside the recommended age range; none of these men reported a family history of prostate cancer.

Recent research recommends that men 70 years and over (depending on their life expectancy and level of health) should generally be advised that they do not require further PSA testing.[24,25] This is primarily because as men age, the benefits of early diagnosis decrease and the harms of intervention can increase.[26] More recently, the Ministry of Health Prostate Cancer Working Group has developed management and referral guidance based on the implementation of the Taskforce-developed Prostate Cancer Awareness and Quality Improvement Programme.[1,26] This reflects the standpoint that men 70 years and over with previously normal PSA results and a normal DRE should be advised that they do not require further PSA testing, with caveats for men with longer life expectancy and a known family history, etc.

Following on from an elevated result, most men reported having a DRE performed by their GP at the time of their PSA test. The Taskforce has previously recommended that all consenting men who are tested receive a DRE at the time of their PSA test.[3] However, for over a quarter of men in our study, this did not occur.

Referrals to specialists occurred for half the men. Overall, the wait between GP referral and FSA identified by men was timely. Men who went to a private FSA were more likely to have that appointment within the first month after referral. For those in the public system, this took about one month longer—4 to 8 weeks.

The ongoing monitoring of men post–positive PSA result varied, with nearly 50 men being actively monitored by either the GP or specialist, or by both. However, the majority of men believed that they were not being currently monitored. Approximately a quarter of all men tested in the 70–79 year age range and 36% of all 80+ men tested are continuing to be routinely monitored, while only 10% of men aged 40–49 years and 17.9% of men aged 60–69 years were being monitored. It would seem appropriate in men with a known raised PSA, aged under 70 years, that if referral does not occur, that patients should be regularly monitored.

A limitation of this study is that our data collection was only focused on patients with an elevated PSA, not men diagnosed with prostate cancer by another method (e.g. DRE). Although we focused on recruiting higher numbers of Māori men, we were only able to achieve 8.8% of the total group. While Māori make up 14% of men aged over 40 years in our region, Māori are half as likely to be tested.[24,27] Additionally, Māori have had a lower response rate than non-Māori to patient questionnaires. Our sample may have been biased by those who responded versus those who did not.

Strengths of this study are that, although this is a patient perspective, we were able to cross-reference each patient's testing history with their responses. In this manner, we were able to follow up on patient monitoring, confirm aspects of the patient's pathway, and collate a bigger picture of their care. We did not assess whether men had been informed at the time of the test that they were being PSA tested (informed consent). We have identified differences in the pathway identified by men based on ethnicity. For example, Māori men were less likely to have their PSA test initiated by their GP and more likely to request the test themselves. The study provides insights into the way opportunistic testing is occurring in New Zealand.

There is little uniformity in the pathway of care from raised PSA test to diagnosis. Most PSA testing is GP initiated and much of this is in older men, in whom testing is not recommended. Despite the recommendation for the use of DRE to aid diagnosis, nearly a quarter of men tested did not receive a DRE at the time of their test. Referral to specialists after a raised PSA result was variable, perhaps because of the differences in recommended criteria between national guidelines and local laboratories.

Although the debate for and against screening continues, it is difficult to deny that standardising the pathway would ensure that all men receive timely, high-quality and equitable care. We recommend that general practices have a clear strategy for the management of men with an elevated PSA result, which includes regular follow-up and/or referral.[24] The Prostate Cancer Working Group management and referral guidance are timely and can assist in making the management of suspected and diagnosed prostate cancer more standardised and transparent for patients and practitioners alike.

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COMPETING INTERESTS
None declared.

APPENDIX A

The Patient Questionnaire

Thank you for filling in this questionnaire. We would be most grateful if you could answer the following questions and sign the consent form at the bottom of the form. Please return the form in the stamped addressed envelope provided.

In 2010 our records show you had a blood test to check your prostate (a PSA test).
Please could you answer the following questions?

1. Was this the first time you had a PSA test?

☐ Yes ☐ No ☐ Not sure

2. Did you ask for the test or was it suggested by your GP?

☐ I asked for the test

☐ The test was suggested to me by my GP

☐ Other

3. If you asked for a PSA test can you tell us what prompted your request?

_____

_____

_____

_____

4. When you went to the doctor did you have any symptoms relating to your prostate (such as difficulty passing urine, blood in the urine, etc)?

☐ Yes ☐ No

Could you please tell us what the symptoms were?

_____

_____

_____

_____

5. At the time of the test did your GP examine your prostate with his/her finger?

☐ Yes ☐ No

6. Since the test have you been referred to a specialist?

☐ Yes ☐ No

(If yes please continue)

If you have seen a specialist urologist, where did you see the specialist?

☐ In private?

☐ At a public hospital (which one): _____

☐ Somewhere else?

Did the specialist

(1) Organise a biopsy of the prostate? ☐

(2) Decide to monitor:

a. By specialist? ☐

b. By GP? ☐

c. Don't know ☐

(3) Arrange for an operation? ☐

(4) Do something else ☐

Do something else *(please explain)*:

_____

_____

_____

_____

7. How long did you wait between being referred by your GP to seeing your specialist?

☐ 0–2 weeks ☐ 2–4 weeks

☐ 4–8 weeks ☐ 8–16 weeks

☐ 16–26 weeks ☐ more than 26 weeks

Would you like to make any other comments that might help this research?
(Please write on back if needed):

_____

_____

_____

_____

Can you please tell us a little about yourself:

How old are you? _____

Can you tell us which ethnic group you belong to?

- ☐ NZ European
- ☐ Māori
- ☐ Pacific *(please specify)* _____
- ☐ Asian *(please specify)* _____
- ☐ Other *(please specify)* _____

Can you please sign this form to indicate that you are happy for the researchers to use this information and to check the data against your hospital records and the records held by your general practice. This information will be kept completely confidential and no personal or identifiable information will be passed to anyone else.

Signed _____ Name in full _____

Date _____

Would you be interested in being part of ongoing research into prostate cancer and be happy for us to contact you again?

☐ Yes ☐ No