

Original Article

Uterine cancer: exploring access to services in the public health system

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Background: Māori are the indigenous peoples of New Zealand and experience higher rates of uterine cancer and poorer survival rates. Postmenopausal bleeding (PMB) is the most common presenting symptom for uterine cancer. Prompt investigation is essential with 28 days being viewed as an appropriate time from first medical contact (FMC) to first specialist appointment (FSA).

Aims: To compare access to services for the investigation of PMB between Māori and non-Māori women.

Materials and Methods: The time interval between FMC to FSA was obtained from medical records for women presenting to gynaecology clinics for PMB. Dates of first bleeding symptoms, knowledge and access issues were collected in a nurse-administered questionnaire.

Results: A total of 154 women ($n = 27$ Māori and 127 non-Māori) participated in the study. 23% of women had their FSA from FMC within 28 days and 67% waited more than six weeks. The 75th percentile was approximately two weeks longer for Māori women. 25% ($n = 37$) of women were not aware that they needed to see a doctor about PMB, and this was significantly more common for Māori women (44%; 95% CI 25–65) than non-Māori women (20%; 95% CI 13–28; $P = 0.011$).

Conclusions: The majority of women were not seen for FSA within 28 days of their FMC. Māori women were more likely to experience lengthy delays and to report that they did not know they should see a doctor about PMB. Further investigation into reasons for delays and initiatives to improve access to services and health information appears warranted.

Key words: access to services, disparities, indigenous peoples, investigation, uterine cancer.

Introduction

Māori are the indigenous peoples of New Zealand, and there is clear evidence demonstrating that Māori have poorer survival than other ethnic groups for most types of cancer.¹ Māori women are more likely to present with advanced uterine cancer² and have higher incidence and mortality from uterine cancers than non-Māori women.³ Māori are also more likely to have an unmet need for primary health care.⁴ Postmenopausal bleeding (PMB) is the most common presenting symptom for uterine cancer. Prompt investigation is essential with 28 days being

viewed as an appropriate time from first medical contact (FMC) to first specialist appointment (FSA).⁵ Because there is a discrete pathway from an early symptom to diagnosis, it is appropriate to examine the patient journey from the time of PMB to identify the barriers to accessing appropriate care that may be contributing to uterine cancer inequalities. Our study aimed to explore access to services for the investigation of PMB for Māori and non-Māori women.

Materials and Methods

Health care provided by the public hospital system is free in New Zealand (for NZ citizens/permanent residents) if the patient is referred by a GP. GP services may require co-payment. Recruitment for this study took place between 1 July 2009 and 1 September 2010 at publicly funded specialist gynaecology clinics in two adjacent District Health Board (DHB) regions (Wellington and

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Hutt Valley, New Zealand serving approximately 435,000 people).⁶ The Central Regional Ethics Committee granted ethics approval in December 2008 (REF CEN/08/09/044).

Eligibility criteria included as follows: aged 45 years and over; referred for and attended for investigation of postmenopausal bleeding (PMB); and deemed by hospital staff to be able to participate in a thirty-minute interview. PMB was defined as vaginal bleeding occurring 12 or more months after the final menstrual bleed.

At the hospital, the referral triage clerk, specialist, or nurse identified women attending appointments for the investigation of PMB, briefly advised them about the study and sent notice of their appointment times to the study coordinator. The research nurse responsible for conducting the interviews then determined whether the woman was eligible, fully explained the study, obtained informed consent and conducted the interview.

The primary outcome measure was the proportion of Māori and non-Māori women attending their FSA within 28 days (measured in days by the time interval between FMC to FSA calculated from medical records). As secondary outcomes, and using illustrative time points (56 and 84 days), we sought to determine: (i) time from PMB to FMC (self-report); (ii) time from PMB to FSA (self-report); (iii) number of contacts with the GP and types of procedures prior to FSA (GP and hospital notes); (iv) patient's knowledge of PMB, its significance as a possible sign of cancer and key factors related to access to and acceptability of care (patient interview).

The questionnaire was adapted from previous national surveys and research^{3,4,7} and customised for the present study. Drafts of the questionnaires were piloted on 5 women attending the gynaecology clinic prior to the start of data collection and modified where necessary for clarity. The questionnaire recorded as follows: socio-demographic data, including age, ethnicity and educational qualifications. Ethnicity refers to the ethnic group to which an individual belongs and was collected via self-report using the standardised New Zealand 2001 census question 1.^{3,7,8} Categorisation was based on prioritised ethnicity for those women reporting multiple ethnicities as per Ministry of Health guidelines.⁷ Non-Māori was used as the reference and included those who did not report ethnicity. Dates of first bleeding symptoms, cervical screening attendance and patient's knowledge of PMB were collected by self-report. Unique patient identifiers (National Health Index (NHI) numbers) were used to match to nationally held data to obtain a measure of socio-economic deprivation using the New Zealand Deprivation index, an area-based measure of socio-economic deprivation, with areas ranked in deciles from 1 (least deprived) to 10 (most deprived).⁹

Structured interviews were conducted face-to-face in a private room at the clinics using the questionnaire. When time was limited, interviews were completed by phone as soon as possible after the appointment. Interpreters were used where required or requested ($n = 6$ women).

Participants' permission was sought to collect relevant information from their GP and from their hospital medical records three months after their initial specialist visit. Information obtained from the notes related specifically to PMB, including dates of first medical contact (FMC) and first specialist appointment (FSA), referral and appointment dates for subsequent investigations, procedures performed and any clinical outcomes (including histology).

Sample size calculations were based on detecting differences in the proportion of Māori attending their first specialist assessment within 28 days compared with non-Māori. To have 80% power to detect an absolute difference of 20% attendance within 28 days between Māori (e.g. 40% attending in 28 days) and non-Māori (e.g. 60% attending in the same time frame), required a sample size of 107 women per group (total = 214; 80% power, $\alpha = 0.05$).

Data from interviews and medical records were collected on paper and entered into a customised Access database (Microsoft® Office Access 2003 SP3, Redmond, WA, USA). Descriptive and inferential data analyses were conducted in R (R 2.15.2, R Institute, Vienna, Austria).

Analyses for the treatment-timing primary and secondary outcomes were conducted using Kaplan–Meier survival analysis methods.¹⁰ Hypothesis testing of contact/assessment time differences between Māori and non-Māori women used log-rank tests; estimates and 95% confidence intervals for proportion of women seen within a particular time frame were derived from the Kaplan–Meier estimates. As women were recruited at the time of their FSA, there was no censoring of this outcome in the data analysis (i.e. everyone had the event in question.)

For the secondary outcomes not related to timing of appointments, confidence intervals were calculated for reported proportions, and differences between Māori and non-Māori women were formally examined with chi-squared tests.

Results

Of the 210 women approached to participate in the study, 190 (89%) were deemed eligible and of those 154 (81% of all eligible) consented to participate. Recruitment was halted when it became apparent that the majority of women were unlikely to have a FSA within 28 days and that lower-than-expected numbers of Māori women presented with PMB. Hence, to reach the numbers required for a statistical difference would have required extended recruitment beyond the time frames of this study. In total, 27 women self-identified as being of Māori ethnicity (18%), while the remaining 127 women (82% of total) self-identified as being of non-Māori ethnicities (76% European, 9% Pacific, 3% Asian and 12% 'Other'). Mean age for Māori participants was 56.2 years (SD = 5.5); mean age for non-Māori participants was 61.1 years (SD = 9.6).

Table 1 describes key clinical characteristics and knowledge of PMB as self-reported by women when

interviewed. There was a significant difference between the self-reported bleeding amounts between Māori (37% reporting more bleeding than a usual period) and non-Māori (13% reporting more bleeding than a usual period) women ($P = 0.013$), although not in terms of the length of bleed (median days).

With regard to prior screening participation, 30% of the women did not have regular smear tests (19% for Māori women, and 32% for non-Māori women). One in four women reported not knowing that PMB was abnormal ($n = 39$, 26%) or that they should see a doctor about PMB (25%). Lack of awareness on this latter point was reported significantly more for Māori women (44%; 95% CI 25–65) than for non-Māori women (20%; 95% CI 13–28).

Table 2 describes the waiting time in days between FMC and FSA (also Fig. 1), as well as waiting times from self-reported PMB to the FMC and to FSA. 23% of women received their FSA within four weeks of first medical contact; by six weeks, this had increased to 32.5%, more than two-thirds of women had to wait at least six weeks for their FSA. Figure 1 is the Kaplan–Meier curve showing the timing of FSA appointments relative to FMC by ethnicity. The log-rank test for this curve was suggestive of differences by ethnic group in time from FSA to FMC (χ^2 (1 df) = 3.7, $P = 0.053$). As

shown in Fig. 1, differences by ethnicity begin to appear around the 12-week time point, with 75% of women receiving their FSA by 16.1 weeks for Māori and 13.6 weeks for non-Māori.

Looking at time intervals between first evidence of symptoms and medical contacts (Table 2), 55% of the women had their FMC within 28 days of having PMB, while 11% of the women had attended their FSA within four weeks of PMB (22.7% by eight weeks). Ethnic differences in times from PMB to FMC/FSA are also presented in Table 2; as the study had very few Māori participants, there was not enough evidence to draw robust conclusions regarding ethnic differences for these outcomes (as can be seen from the confidence intervals and hypothesis tests).

For the majority of women ($n = 142$, 92%), a GP was their first medical contact regarding PMB (Table 2). The majority of women were referred after their first visit ($n = 112$, 74%) and 26% of all women ($n = 39$) saw a GP more than once. There were no statistically significant differences between the two ethnic groups for the type of procedures and investigative tests (see Table 2). An ultrasound was the most common procedure carried out for the investigation of PMB (81% of all women), and 67% of all women either had just an ultrasound or no investigative tests prior to FSA ('no further tests' in Table 2).

Table 1 Self-reported clinical characteristics and knowledge of postmenopausal bleeding (PMB) presented by ethnic group

Clinical characteristics and PMB knowledge	Ethnic group						<i>P</i> -value* comparing ethnicity
	Māori ($n = 27$)		Non-Māori ($n = 127$)		Total ($n = 154$)		
	<i>n</i>	% (95% CI)	<i>n</i>	% (95% CI)	<i>n</i>	% (95% CI)	
Heaviest bleeding†							
Less than usual period	12	44 (25, 65)	84	67 (58, 75)	96	63 (55, 70)	0.013
Same as usual period	5	19 (6, 38)	25	20 (13, 28)	30	20 (14, 27)	
More than usual period	10	37 (19, 58)	17	13 (8, 21)	27	18 (12, 25)	
First bleeding episode‡: median duration in days (interquartile range)		4 (2–5)		3.5 (1–5)		3.5 (1–5)	0.548 (Wilcoxon)
Cervical smear testing							
Reports having regular smears	22	81 (62, 94)	86	68 (59, 76)	108	70 (62, 77)	0.156
Reports not having regular smears	5	19 (6, 38)	41	32 (24, 41)	46	30 (23, 38)	
Knew postmenopausal bleeding was abnormal§							
Yes	17	63 (42, 81)	94	75 (67, 82)	111	73 (65, 80)	0.194
No	10	37 (19, 58)	29	23 (16, 32)	39	26 (19, 33)	
Don't Know	0	0 (0, 13)	2	2 (0, 6)	2	1 (0, 5)	
Knew that needed to see Doctor about PMB¶							
Yes	15	56 (35, 75)	98	79 (71, 86)	113	75 (67, 82)	0.011
No	12	44 (25, 65)	25	20 (13, 28)	37	25 (18, 32)	
Don't Know	0	0 (0, 13)	1	1 (0, 4)	1	1 (0, 4)	

*Hypothesis tests are chi-squared tests unless otherwise noted.

†Not available for one non-Māori participant.

‡Missing data for 3 Māori, 10 non-Māori participants.

§Missing data for two non-Māori women. No and Don't Know answers combined for chi-squared test.

¶Missing data for three non-Māori women. No and Don't Know answers combined for chi-squared test.

PMB = postmenopausal bleeding

Table 2 Proportion attending first medical contact (FMC) and first specialist appointment (FSA) following postmenopausal bleeding (PMB), as estimated from Kaplan–Meier survival curve presented by ethnic group, and characteristics of initial investigations

Outcome measure	Ethnic group			P-value comparing ethnicity
	Māori (<i>n</i> = 27)	Non-Māori (<i>n</i> = 127) Proportion† (95% CI)	Total (<i>n</i> = 154)	
Timing of postmenopausal bleeding and medical visits*				
First medical contact to first specialist assessment‡				
Within four weeks (28 days)	25.9 (7.4–40.7)	22.6 (14.9–29.6)	23.2 (16.1–29.6)	0.053
Within six weeks (42 days)	37 (15.9–52.9)	31.5 (22.8–39.2)	32.5 (24.6–39.5)	
Postmenopausal bleeding to first medical contact§				
Within four weeks (28 days)	64 (39.3–78.7)	53.3 (43.5–61.3)	55.1 (46.3–62.5)	0.690
Within twelve weeks (84 days)	76 (51.8–88.1)	75.4 (66.4–82)	75.5 (67.5–81.6)	
Postmenopausal bleeding to first specialist assessment¶				
Within four weeks (28 days)	16 (0.3–29.2)	10.4 (4.9–15.6)	11.3 (6.1–16.3)	0.894
Within eight weeks (56 days)	32 (11–48)	20.8 (13.4–27.6)	22.7 (15.7–29.1)	
Contacts made and investigations performed**				
First contact regarding PMB††				
GP	96 (81, 99.9)	91 (85, 95.6)	92 (86.8, 95.9)	0.592
Nurse	4 (0.1, 19)	6 (2.2, 11)	5 (2.3, 10)	
Other	0 (0, 12.8)	3 (0.9, 7.9)	3 (0.7, 6.5)	
Total number of contacts with GP				
One	77 (56.4, 91)	74 (65, 81.1)	74 (66.4, 80.9)	0.521
Two	23 (9, 43.6)	22 (14.7, 29.8)	22 (15.5, 29.3)	
Three or more	0 (0, 13.2)	5 (1.8, 10.2)	4 (1.5, 8.4)	
Tests/procedures				
Ultrasound	78 (57.7, 91.4)	81 (73.2, 87.5)	81 (73.4, 86.5)	0.692
Further tests/procedures‡‡				
No further tests	77 (56.4, 91)	65 (55.4, 72.9)	67 (58.5, 74.1)	0.276
Endometrial biopsy	4 (0.1, 19.6)	3 (0.9, 8.1)	3 (1.1, 7.6)	
Blood test	12 (2.4, 30.2)	22 (14.9, 30.1)	20 (13.9, 27.3)	
Urine sample	4 (0.1, 19.6)	9 (4.5, 15.3)	8 (4.2, 13.6)	
Smear or swab	0 (0, 13.2)	1 (0, 4.4)	1 (0, 3.7)	
Polyp removed	0 (0, 13.2)	1 (0, 4.4)	1 (0, 3.7)	
STI profile	4 (0.1, 19.6)	0 (0, 2.9)	1 (0, 3.7)	

*P-value from log-rank test comparing time to event by ethnicity. **P-value from chi-squared test.

†Proportions and 95% CI calculated from Kaplan–Meier survival curves at specified time points.

‡Missing FMC dates for 3 non-Māori women.

§Missing FMC or PMB dates for two Māori women, and five non-Māori women.

¶Missing PMB dates for two women from each ethnic group.

††No GP visits recorded for 1 Māori and 2 non-Māori participants.

‡‡Answers provided as free text and coded into categories here. Missing data for 1 Maori and 3 non-Maori women.

GP = general practitioner; PMB = postmenopausal bleeding; STI = sexually transmissible infections

Discussion

This analysis of access to services for the investigation of uterine cancer from PMB to FSA for Māori and non-Māori women highlights two main areas of concern. Firstly, there was marked delay in accessing a specialist appointment for all women with 77% of women not seen for their FSA within 28 days of FMC. Secondly, a lack of awareness of the importance of PMB was commonly reported, with 26% unaware that PMB was an abnormal symptom requiring further investigation; this was more common for Māori women.

Although the women in our study had comparable services (type of procedures and investigative tests) for the

investigation of PMB, the access to FSA failed most women. Māori women did experience more lengthy delays – with the 75th percentile for FMC to FSA being about two weeks longer for Māori women than for non-Māori women. This suggests that for some Māori women, the current system is failing to provide equitable follow-up. Rebooking and non-attendance is likely to play only a small part in the delay as our prior study¹¹ showed that 9% of women (19/210) had appointment changes, with half of these hospitals initiated. Delays to FSA can occur both from the referral from FMC to hospital and within the hospital, related to the hospital booking system.¹¹ A recent report from another New Zealand hospital has also

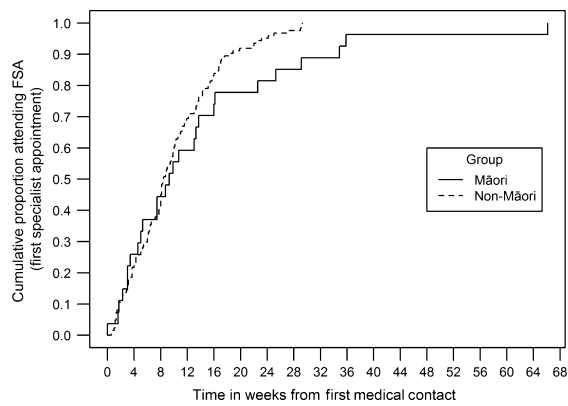


Figure 1 Kaplan–Meier plot showing cumulative proportion attending first specialist appointment (FSA) in weeks since first medical contact (FMC).

shown that there are delays from the initial referral to first treatment (and to FSA).¹²

These findings suggest that there are barriers to timely access to services for the investigation of PMB. These barriers may contribute to inequity of access for some Māori women. Further investigation into the more proximal reasons for delays and initiatives to improve access to services and health information appears warranted.

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