A qualitative study of Pacific women’s knowledge and awareness of gynaecological cancers in Auckland, New Zealand.

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ABSTRACT:

Background: The aim of this paper is to understand knowledge and awareness of gynaecological cancer among Pacific women. The key objectives are to examine the level of awareness Pacific women have about gynaecological cancers, to identify the barriers to accessing gynaecological services and to obtain feedback on what would be the best way of educating and informing Pacific women.

Methods: Data was collected through semi-structured interviews which took place in Auckland. Twenty Pasifika women were interviewed during 2015-2017. A general inductive approach was used to analyse the data. Ethical approval was granted by the University of Auckland Human Subjects Committee Ethics Reference Number 016670.

Findings: The definitions of gynaecology varied with many Pacific women never hearing of the term gynaecological cancers. The women identified that their primary sources of information for health and gynaecological health were; personal experiences, relatives that were previously diagnosed, health professionals, pamphlets and posters, school sex education, referrals through the health system, website searches, friends and family. There were a number of barriers to accessing gynaecological services. These included a lack of awareness of services, personal fear, shame, busy schedules, physical examinations, and attitudes, preference for a female doctor, poor health literacy, language difficulties, costs and public health system versus private health system. Participants identified a number of key areas strategies for gynaecological cancers. There needs to be more information about the types of services that are available, accessing services, community outreach programmes and services, flexible opening hours and culturally appropriate information.

Conclusion: Given the multi-faceted and complex nature of this project, the recommendations provided are multi-levelled and will require inter-sectoral partnerships for community and education awareness is needed to enhance Pacific women’s access to gynaecological services in New Zealand.

Key words: Pacific women, Gynaecological cancer, Gynaecology, Gynaecology awareness, Gynaecology services.

BACKGROUND

Gynaecological cancer, with the exception of cervical cancer, in New Zealand is a growing health problem. Inequity in gynaecological cancer, including cervical cancer, incidence and mortality is also a problem. Pacific women have the highest rates of endometrial cancer (69.7/100,000 (95 % CI 55.1–84.2)) in New Zealand with a risk over double that of European/Other women (RR, 2.61; 95 % CI, 2.22–3.05). Known risk factors for this disease are obesity, diabetes, nulliparity, early menarche, late menopause, and exogenous unopposed estrogen. Incidence of cervical cancer amongst Pacific women (32.9/100,000) is also higher compared to European/Other women (16.0/100,000).
Pacific women, aged 45 years to 64 years, have a mortality rate from cervical cancer of 14 per 100,000 compared with the national average rate of 8 per 100,000. Finally, ovarian cancer incidence is also highest amongst Pacific women (25.4/100,000) compared to European/Other women (18.7/100,000).

Cervical cancer incidence has been declining in New Zealand since the implementation of a screening programme in 1990. Between 1998 and 2010 age-standardised cervical cancer mortality has declined from 3.2 to 1.7 per 100,000 women of all ethnicities. In New Zealand, total population participation rate in the National Cervical Screening Programme (NCSP) was 74.5% in early 2018, with participation of Pacific women now at 74.4%. There is considerable variation across New Zealand with recent declines in screening for Auckland District Health Board and ongoing lower participation for Capital and Coast (66.7%), Hawkes Bay (70.4%) and Hutt Valley (70.3%). The proportion of Pacific women accessing screening in 2002/2003 was considerably lower, only just over 50% compared to European/Other women (around 76%).

The increased incidence and mortality due to cervical cancer amongst Pacific women has been reported to reflect the historical lower cervical screening rate among Pacific women. Improving screening rates is a step towards reducing these health disparities.

Like many other forms of cancer for which screening is available, cervical cancer outcomes are negatively associated with socioeconomic status, a trend evidenced by the dominance of this type of cancer amongst women within developing countries. Studies within developed countries show that women from more affluent areas are likely to have cervical cancer detected earlier, resulting in higher chances of survival. Lower cervical screening rates and negative attitudes towards cervical screening are more common in lower socioeconomic groups. Pacific women are four times over-represented in lower socioeconomic areas.

Seeking knowledge to reduce these inequities in screening and cancer outcomes, the aim of this study was to understand the level of awareness of gynaecological cancer among Pacific women. We examined the knowledge Pacific women have about gynaecological cancers, have outlined the barriers accessing gynaecological services and have identified future strategies to inform Pacific women about gynaecological cancers.

METHODS

Twenty semi-structured interviews of Pacific women were conducted during 2015 through to 2017. Interviews were conducted by one of the authors who is Tongan. There were 10 scheduled questions (Table 1). The responses to questions were taped and transcribed. A general inductive approach was used to analyse the data. Two Pacific Island researchers iteratively read and drew themes from the interview transcripts. The interviews were in the homes of participants, shopping malls, fast food outlets and work places. A convenience sample of twenty women of Pacific descent residing Auckland were recruited through the researchers’ networks. A retail voucher worth NZ$20, as a token of appreciation, was provided for each participant at the end of each interview. Ethical approval from the University of Auckland Human Participants Ethics Committee (UAHPEC) was granted in 2016, Ethics Reference Number 016670.

RESULTS

Participants spanned a wide age range, nine were aged 18–29 years, seven were aged 30–49 years and 4 were 50 years or older. Pacific ethnicities of the women were Niuean (5), Cook Island (5), Samoan

Table 1: Interview questions used to structure discussion of gynaecological health issues.

<table>
<thead>
<tr>
<th>Interview Questions</th>
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<tr>
<td>1. What do you know about gynaecological health issues for women?</td>
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<td>2. What do you know about gynaecological services that are available for women and Pacific women?</td>
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<td>3. Have you discussed gynaecological health issues with your health professionals?</td>
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<td>4. Are you comfortable to discuss a gynaecological health issues with your health professionals?</td>
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<td>5. Do you know of anyone who has discussed gynaecological health issues with their health professionals?</td>
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<td>6. What service information or recommendations would you like to see with a Pacific culturally appropriate gynaecological service?</td>
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<td>7. If you could change the way services were delivered to Pasifika women, how would you?</td>
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8. What are some of the barriers for Pacific women for not accessing gynaecological services?

9. What are some recommendations you have for how gynaecological service and treatment services should be delivered?

10. What are effective ways Pasifika women can be informed of gynaecological cancer and services they may benefit from?

(5) and Tongan (5) descent. The places of birth were New Zealand born (9), Cook Island born (2), Niuean born (2), Australian born (1), Samoan born (3), Tongan born (2) and Fijian born (1).

Knowledge and sources of information

Participants defined gynaecology based on personal understanding and experiences. Some of the women had never heard of the term gynaecology. They explained that in their respective languages, gynaecology was never heard of as there is no literal translation of gynaecology in Samoan or Tongan.

“Not quite sure, that is a medical term and I haven’t heard it before, so I don’t know what it means, sorry.”

“Sorry, I speak mainly Tongan so I do not know what is the understanding of that word, we don’t have a word like that in our language.”

The majority of the participants were informed or made aware of gynaecological cancers through personal experiences or relatives that were diagnosed.

“There is someone who knows someone. For me, I knew about it with family members on my mum’s side and even my dad’s mum with ovarian cancer, though they call it different in Tongan. And then there’s also a small Tongan church community so some people find out about it through that. You learn from some of these stories.”

Most of the women mentioned that a source of information were the posters, pamphlets and print-outs on display at their doctor’s clinic.

“Sometimes in the waiting room of my doctors or GP, I see that there are a lot of posters and a whole area where they have like all these hand-outs so pamphlets and sheets or forms and just a lot of stuff to go through.”

A few of the women noted that they recalled going through sexual education in secondary school as a part of their health or physical education syllabus.

“I remember for credits in science and even physical education (PE) we would have to talk about female and male anatomy and so there was like introduction to gynaecology and just knowing what’s what and what it does back in high school.”

Many of the participants stated that they were informed of various gynaecological cancers when they would attend preventative check-ups such as the cervical smear test or when they were recommended to receive the HPV vaccination in intermediate or secondary school.

“I remember in fourth form we have to have the HPV vaccination and that’s when the school nurse talked to us about cervical cancers and this went hand in hand with what my health teacher would say about having to go in for a smear test and so it was all in those topics that I began to be more aware of cancers.”

More than half of the women used online websites such as YouTube and search engines Google and Yahoo to learn more about their bodies, reproductive system and overall health.

“Currently if you want to know things, you get your phone out and jump on google, punch in some of the things that are happening and you will get loads of information – it really is at the touch of a button now.”

Barriers and enablers

Main themes arising relating to barriers and enablers were the nature of health professionals and first experiences, shame or fear and finally cost and convenience.

Health professionals and experiences

A few of the women identified that long-standing relationship with local GPs or family doctors were preferential as these doctors knew their medical history and family history.

“I have been with my GP for years and he knows what has happened to me and has all my records so I go back to him because with all the stuff that has happened with me, and he’s proved himself over and over like when he referred me for a colposcopy and we were able to get treatment done sooner, I just trust him.”
More than half of the women spoke about experiences building trust with health professionals.

“If I have a good experience with a GP or a gynaecologist or my midwife, I will prefer to go back to them and it won’t be such a stress freaking out about whether you’re going to get a dodgy or rude doctor, because you have history with this one.”

“How they are treated through the process, how important it is for them to do it. How the nurse might treat them for their first test that can determine whether they will go back again.”

All of the participants preferred to see a female health professional. Female health professionals were thought of by the participants to be more compassionate and caring when discussions took place about female health issues.

“I only feel comfortable talking about this stuff with a woman health professional. In my culture, it is only women’s business so if it is a male then I don’t feel comfortable. Like my gynaecological health issues. One time they told me to take off my top and just have on my bra and I didn’t even feel comfortable with that.”

Many of the women spoke about the differences between the public health system and the private health care system when they were referred for gynaecological care.

“There is absolutely a difference between public and private. I have tried both. My gynaecologist now is private and I currently see her every year since 2009. Her service is so different. She knows me and we have a relationship. It is a nicer place to have my checkups done, they seem to be more attentive. I just had an ultrasound done last week and that was a referral from my gynaecologist. I don’t know if just definitely feels like there’s more attention to detail in private, than when I’ve gone public.”

More than half of the women did not understand what the health professionals was discussing with them in terms of their health conditions.

“Sometimes I just go along to the medical consult and I’ll just nod and say yes, even if I don’t understand because they’re talking to me about my body and I feel stupid that I don’t even know what’s happening. I feel it but can’t say what’s going on. There’s uncertainty but it also does a lot of negative things to your confidence as well. They ask me questions and I don’t know how to answer.”

“Health literacy may be a barrier as to why these women are not receiving the service. A lot of them don’t even know what gynaecology mean. And then it is what will their experience be if they used it? That’s part of the reason why people don’t go any further because of the knowledge and experience.”

For most of the Islands born participants language difficulties was a problem as English is not their first language.

“English isn't my first language and so it's hard to know what is going on or where I must go. I need time to be able to understand these things and if I am only there for ten to twenty minutes, I can't go through everything properly.”

**Stigma, shame and fear**

Most of the women spoke about the stigma associated with accessing gynaecological services because of traditional moral perspectives about sex, particularly outside of marriage.

“Traditional Tongans are quite big on waiting until you’re married to have sex and I do go by that too but at the same time, there are people who make up their mind to not go and sometimes that can lead to an infection but then they’re too embarrassed to go or even tell their family because that’s what we call fakama or shaming. It is changing but I think with a woman’s reputation those kinds of clinics are a no-no because of the judging and ideas and rumors that follow if you get seen.”

More than half of the women stated that a barrier for accessing gynaecological services was the shame attached to their families knowing that they had a health problem.

“Shame – that’s a barrier, like for one of my friends who was quite reckless with her body when she was in her teens had trouble getting pregnant later with her partner and sometimes people don’t know the implications of STIs and some of the impacts until ten years later and you’re trying for a baby and so for her, she didn’t want to have that shame and felt it was her fault to a large extent.”

Most of the women identified that many gynaecological screening tests and treatment requires revealing private parts was a barrier for many women and were uncomfortable showing their personal body parts.
“It’s nerve wrecking and just the idea that you have to show them down there or your breasts and then it’s not only just seeing but they really go in and it is so embarrassing and humiliating, I don’t even like seeing myself with the light on and a spotlight and everything out there, that’s a huge barrier as to why I find it tricky accessing the doctor for smears or gynaecology troubles.”

Most of the women identified that personal fears and concerns were a barrier to accessing services and accepting treatment.

“Pelvic examinations hurt, like physically it stings when they’re telling you to get into this position and they start putting the equipment in you. They say that it shouldn’t cause pain but it hurt and so I can imagine for other women and myself… It’s scary, going somewhere like the GP or gynaecologist where you know they may perform a test that hurts are very scary – if I can avoid it, I do.”

Convenience and cost

Most of the women stated that Pacific women had competing demands of family, work, church and other social commitments were barriers to accessing gynaecological services.

“I am a single mum and so for my daughter who is just in high school – she comes first – if I have an appointment it can be pushed back if she needs me to take her to practice or pick her up after school, sometimes at the time, other things and other people are more important”

Many of the women discussed costs as an issue to accessing gynaecological services.

“It’s not cheap to go doctors. It costs me $17.50 every time I go, that’s a lot of money. I’m not working anymore so where am I supposed to get that money, and then on top of that the medications for being unwell and they always say if I don’t get better then come back. That is money again.”

Future Strategies

Services need to be promoted.

“A big motivating factor would have to be knowing. Our women need to know that the services are out there for breast, vagina, uterus – whatever the problem there needs to be an ability or knowledge of services and why the services are there for those services to even be used. For example, a woman isn’t just going to rock up and have people start looking at her private parts but if she knows to have screening done once she is sexually active, she is more likely to go get a smear done than say someone who has no idea that’s what you have to do once you have sex”.

Most of the women recommended that Pacific women need to be made aware of the dangers of avoiding or delaying gynaecological preventative care or services.

“My recommendation is pretty simple; women need to be aware of symptoms and whether it’s normal or abnormal. Sometimes we don’t know the difference and just wait it out but we need to be able to tell the difference, for example an extremely heavy period or missing it, it’s about knowing. This can be done through IG, Facebook or even launching a campaign. It can be through testimonies or online, but either way health professionals and role models need to relay to women that inaction and delay isn’t good enough, if you notice it, if it’s not normal for you, go in.”

Most of the participants wanted culturally appropriate information in their own languages.

“It would be good to have gynaecological information in our own languages so we understand what they are talking about. This would be very uplifting for our people if our way of seeing things were taken on board.”

More than half of the participants wanted information about where to go for support and advice about gynaecological services.

“Going through the health system can be so daunting, for me it is. So it’s about teaching women of where, why, what, when and how – the basics. This can be done through workshops and for specific symptoms there can be like a flow chart of where to go and so forth.”

A number of women wanted the services to be in the community so they can be easily accessed.

“Services need to go to where our people are as well. Because otherwise there’s a million things that pacific women do and their needs just fall off the priority list, so that is addressing an issue for them, finding time, and going to schools, churches and work to give them access to the services.”

The majority of the women also wanted services that had flexible opening hours as this would allow them to attend these clinics.
“There needs to be more flexible hours. I work shifts and so by the time I’m done, my local GP is closed and I can’t afford to go after hours somewhere else. There needs to be more time availabilities for screenings and smears for women like me, otherwise it’s just too much hassle having to take leave or sick leave from work.”

DISCUSSION

This research has outlined a number of key areas of concern and many of the Pacific women were not aware of or did not understand gynaecological cancer. Participants identified a wide range of primary sources including; health professionals, personal experiences with family members and friends who were diagnosed with a gynaecological illness, pamphlets in waiting rooms, sexual education in school and internet searches. Earlier research based in one of New Zealand’s smaller urban centres, Palmerston North, reported similar sources of information on cervical screening. Whilst many sources of information on gynaecological cancer were identified, the majority of participating women in this study stated that lack of awareness of services and knowing how to navigate the health system was a barrier.

There were practical barriers to attending screening or appointments related to gynaecology. Cost was a barrier. This study and other research has identified a need for after-hours services and local, community based services. Having more services delivered locally and in primary care is a recommended path for improving Pacific people’s health and well-being.

A strong theme evolving from this study was that shame, stigma and embarrassment create reluctance to seek help or access screening for gynaecological issues. This is generally consistent with New Zealand and international work. Within this are three subthemes of morality and cultural concept of tapu associated with women’s reproductive anatomy and finally shame of having a health problem recognised by other community members. There are elements of health provider services that may help to counteract these barriers such as having a female doctor or nurse. However, it has been suggested it is better, for anonymity, if the person taking a smear was not part of the Pacific community. Trust developed as part of a long standing relationship is considered a key to effective primary health care for Pacific people in New Zealand. There were aspects of private health care that women felt gave them more reassurance than the public health service. In other studies, support from male household and community members for screening has been a positive influence on women’s attendance particularly for Tongan women and therefore may help counteract the influence of stigma and embarrassment.

Health literacy and language barriers were discussed. Health literacy was weaker amongst Māori across all income quintiles compared to non-Māori. A specific examination of health literacy amongst Pacific Island ethnicities in New Zealand is not available. Ongoing provision of Pacific Island language resources with accessible information about gynaecological cancers and screening is important and has been recognised in other research work.

Limitations

This was a qualitative analysis of a convenience sample of women of different Pacific Island ethnicities and not necessarily representative of the entire spectrum of barriers and enablers for this large and diverse community. However, there were a number of consistencies between this and other similar research. The sample was also collected using researcher networks which may bias the sample towards a more health literate and well educated Pacific perspective. Nonetheless, there were issues raised of not understanding health professionals which suggests the problems may be more widespread and acute.

CONCLUSION

Whilst there has generally been improvement in participation in cervical screening by Pacific women there are some regions of New Zealand that are struggling to reach equity or have declining participation by Pacific women. Health professionals need to deliver key messages around gynaecological cancers that are meaningful and that patients can easily understand. Further research is needed around the concepts and definitions of gynaecological cancers that are suitable for the Pacific community.

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