Aotearoa New Zealand Deaf women's perspectives on breast and cervical cancer screening.

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ABSTRACT

AIMS: Since the introduction of both cervical and breast screening programmes in Aotearoa New Zealand, mortality rates have dropped. Both screening programmes track women's engagement, but neither capture the level of engagement of Deaf women who are New Zealand Sign Language users or their experiences in these screening programmes. Our paper addresses this knowledge deficit and provides insights that will benefit health practitioners when providing screening services to Deaf women.

METHODS: We used qualitative interpretive descriptive methodology to investigate the experiences of Deaf women who are New Zealand Sign Language users. A total of 18 self-identified Deaf women were recruited to the study through advertisements in key Auckland Deaf organisations. The focus group interviews were audiotaped and transcribed. The data was then analysed using thematic analysis.

RESULTS: Our analysis indicated that a woman's first screening experience may be made more comfortable when staff are Deaf aware and a New Zealand Sign Language interpreter is used. Our findings also showed that when an interpreter is present, extra time is required for effective communication, and that the woman's privacy needs to be ensured.

CONCLUSION: This paper provides insights, as well as some communication guidelines and strategies, which may be useful to health providers when engaging with Deaf women who use New Zealand Sign Language to communicate. The use of New Zealand Sign Language interpreters in health settings is regarded as best practice, however their presence needs to be negotiated with each woman.

Aotearoa New Zealand was one of the first signatories of the United Nations Convention on the Rights of Persons with Disabilities,[1] which identified access to the highest attainable standard of health without discrimination as a right. This right is echoed in Aotearoa New Zealand's Disability 2016–2023 Strategy.[2] Even though internationally Deaf communities identify themselves as a linguistic and cultural minority group and not as disabled,[3] Aotearoa New Zealand policy includes them under the umbrella of disabled.

Since the introduction of the cervical and breast screening programmes in Aotearoa New Zealand, mortality rates have dropped for cervical cancer[4] and breast cancer.[5] While both programmes track women's engagement, neither capture details regarding Deaf women who are New Zealand Sign Language users.

The New Zealand Disability Survey[6] identified that 380,000 people reported having a hearing impairment, which includes both Deaf and hard of hearing. New Zealand Sign Language (NZSL) is one of Aotearoa's official languages and according to the 2018 Census, NZSL was used by approximately 23,000 people. Of these, approximately 4,599 use NZSL as their main means of communication.[7] While this indicates that screening service providers may rarely encounter these women, such infrequency does not justify ignoring their rights to dignity, respect, full communication and informed consent. Little is known about women who use NZSL's experiences of Aotearoa New Zealand's screening programmes; hence, our study aimed to provide some insights into this knowledge deficit.

In consultation with a Deaf-identified academic and others from the Auckland Deaf community, and in accordance with Deaf Aotearoa, our use of the word 'Deaf' with a capital 'D' refers to those people who identify as being part of a Deaf community with a shared culture, beliefs and values and language. From this perspective deafness is not a disability or disease, but rather a difference in human experience.[8]

Literature review

International studies identify that women with disabilities have a higher cancer mortality rate than other groups, especially with regards to breast cancer.[9–11] They are less likely to participate in regular

preventative cancer screenings[12] as the financial, structural and attitudinal barriers often prove too much.[9,10,13–15] These barriers include: lack of funds to pay for non-urgent medical care,[9,14] and medical practices' inaccessibility to disabled or Deaf people.[9,11,16,17] Most of these studies either focus on women with physical disabilities or do not differentiate between women with physical and sensory disabilities. As a result, there is a lack of knowledge about the experiences with preventive screening among Deaf women.

Deaf people are reported as often less satisfied with their healthcare provision than hearing patients.[18,19] The reported main issue was communication barriers, as most practitioners were not aware of Deaf culture or trained to communicate with patients who identify as Deaf.

Deaf women may experience educational disadvantage and may have lower literacy levels than hearing people.[20,21] These factors may impact on their health literacy[22] and their ability to fully comprehend information being communicated to them by forms other than NZSL. An Aotearoa New Zealand study[22] investigated both Deaf NZSL users' access to general, mental health and addiction secondary healthcare and health professionals' experiences of communicating with Deaf NZSL users. Authors found the following communication issues: inconsistent interpreter provision, problems with informed consent, and decreased access to general health information. These systemic issues contributed to Deaf people's inability to understand and hence consent to treatment.

Deaf women's knowledge about breast[23] and cervical cancer is generally insufficient. A study[24] found fewer than half of their Deaf women participants were able to explain what a PAP smear was. While there is research on some of the difficulties Deaf women experience with general healthcare and some access issues in cancer screening, there is minimal research on Aotearoa New Zealand Deaf women's experiences with the two screening procedures. As well, there is little research on the complexities of NZSL interpreter provision in both cervical and breast screening encounters. Our paper aims to address these gaps and to provide insights that may benefit health practitioners providing screening services to Deaf women who use NZSL.

Methods

The study's objectives were to investigate the experiences of women living with a physical/sensory disability when engaging breast and/or cervical cancer screening services in Aotearoa New Zealand, and to identify any barriers encountered. Mixed methods were used—a questionnaire that was distributed nationally[25] and an Auckland-based qualitative component.

The research team consisted of a: Deaf researcher, Māori researcher who lives with a physical disability, research officer, women's health researcher and an international disability studies researcher.

Participants for the qualitative component were recruited through advertisements in Auckland organisations: Te Roopu Waiora, Auckland Deaf Society and Deaf Aotearoa, CCS Disability Action, and Blind Low Vision NZ. All participants were provided with an information sheet prior to making their decision to participate.

The inclusion criteria were women between 20 and 69 years, who lived with a physical or sensory disability and could converse in English or NZSL. We wanted to determine if these women faced barriers when engaging with the screening services. We invited women who met the screening criteria but had not been screened and those who had accessed breast and/or cervical screening services.

The qualitative component employed an interpretive descriptive approach.[25] Data were generated through semi-structured focus groups. Six focus groups with women (n=31) living with physical or sensory disabilities were held. Of the Deaf or disabled women who participated, 18 identified as Deaf. Two focus groups consisted solely of Deaf women (n=14). In one other group, which included women with a mix of different sensory and physical disabilities, four women identified as Deaf (n=4). Of the 18 Deaf women, one identified as Māori, two as Asian and 15 as Pākehā/European. All three focus groups had NZSL interpreters to ensure clear communication between the moderators and the women.

For the two focus groups solely with Deaf women, the moderator was the Deaf researcher. The third group was moderated by the Māori disability researcher. The first author was the note taker for all groups. Ethical approval was obtained from the Auckland University of Technology's Ethics Committee. Written consent was obtained from all participants and their agreement to maintain confidentiality and to not divulge the identity and any personal information of fellow participants.

The moderators used a semi-structured interview guide, asking participants who had engaged

with cervical or breast screening services to discuss their experiences and any barriers encountered (see Appendix 1). Women who had not been screened were asked to discuss their experiences and reasons for not engaging with services. All focus groups' interviews were audio recorded, and data was transcribed verbatim. Data analysis focussed on recurring themes following the process set out by Braun and Clarke.[27] The researchers familiarised themselves with the transcripts, independently coded the data and then came together to engage in detailed data coding. Coded segments were clustered together by the researchers based on underlying similarities. From these clusters larger overarching themes were generated. The thematic findings centre on Deaf women's experiences of cervical and breast screening, in particular the exchange of information with service providers and use of NZSL interpreters.

Results

Table 1 denotes some key socio-demographic and screening details of participants. There were mainly younger aged women (35–40 years), with the majority Pākehā/European. All 18 Deaf women had engaged with cervical screening. Seventeen women had been screened every three years, with the exception of one woman. This was because she was uncertain about the criterion of **ever** having been sexually active. Four women had engaged with mammography services and had been screened within the last two years. The key issue from the focus groups was the communication between the women and the cervical screening practitioners and mammographers

The significance of Deaf aware staff

Four of the Deaf participants attended the same general practice, as it was located where many members of the Deaf community reside, and, importantly, because its fees were relatively low. Given this, the reception and nursing staff have become adept at communicating with Deaf patients (Deaf aware). R spoke of her first experience of a cervical smear with Deaf aware general practice staff:

> *R: I mean for me they (the nurse) had quite a positive attitude and I explained that I was Deaf and they were like "ok" and so then they showed me, they told me that, I could leave my top on but needed to take my pants off. So they explained to me what I needed to do and I just followed along with it and it was fine.*

For S, who attended another practice where the staff were not aware of how to communicate with Deaf clients, her first experience of cervical screening and understanding what was involved was not so positive:

> *S: The first time there weren't enough interpreters around. I went by myself. It wasn't a comfortable experience for me at all.*
>
> *I: And so you mean it was difficult, the communication was difficult? Or difficult to follow? Or what was happening?*
>
> *S: Well, you just go in there and you have just got to open the pants and just end up having. So it's kind of an interesting experience without an interpreter.*

Comparing these two excerpts, when clinic staff were aware of R's communication needs as a Deaf woman and were able to use gestures effectively, R was able to understand what she was required do. The procedure was not perceived as so uncomfortable. In comparison, S, who would have preferred to have had an interpreter present at her first cervical smear, was not at ease and did not understand fully what was involved. Her experience indicates the importance of both Deaf aware staff and the role a NZSL interpreter has in these examinations.

Use of interpreters

Using NZSL interpreters is seen as best practice in effective communication for Deaf people. Currently, NZSL interpreters in the healthcare setting are funded via iSign. iSign is contracted by Manatū Hauora – Ministry of Health to provide this service.[28] Our participants identified when going through the public hospital/health system they expected that the hospital would arrange for the NZSL interpreters. However, going to see their GP the women would organise this for themselves:

> *A: If it's the private system then I would organise my own interpreter. If it was in the public then, when they texted me the appointment or sent me the letter I would reply and say "please arrange*

Table 1: Demographic information of participants.

	Age of participants			Ethnicity of participants			Type of screening experienced by participants	
	35–40yrs	45–50yrs	60–65yrs	Māori	Asian	Pākehā/ European	Cervical cancer screening/ PAP smear	Breast cancer screening/ mammography
Number of participants	9	5	4	1	2	15	18	4

an interpreter." And then they would book an interpreter. And when I would arrive there would be one there.

The issue of privacy

Engaging a NZSL interpreter for either mammography or cervical cancer screening was not routinely practiced by all the women. One factor influencing whether the women wanted an interpreter present was the issue of privacy. For NZSL interpreting to be effective, both the woman and the interpreter need to clearly see one another's faces and hand movements.

Both cervical screening and breast cancer screening involve exposure of highly intimate parts of the woman's body. In using a NZSL interpreter for a mammography or cervical PAP smear, the woman needs to be comfortable in having an interpreter present who might see her exposed body. "SZ" spoke about an interpreter service that provided her with a male NZSL interpreter:

SZ: I have had problems with bookings. They have booked the wrong interpreter. For example, they have brought a male interpreter.

The sex of the interpreter can also be perceived as potential threat to maintaining one's privacy. For all the women, ensuring that they had a female interpreter at their mammography or cervical screening was important, as indicated by P:

P: Yes, well for me sometimes I do prefer a woman interpreter rather than a male interpreter. Especially if it's a private woman's issue. So I will ask for a female interpreter.

For some women, the need to maintain their privacy took precedence over their communication needs. These women relied on the health practitioner's ability to communicate what they needed the women to do and to read the woman's body language. Sometimes this was a satisfactory experience for women and for others not. R related her experience of having a mammography:

R: I feel like I don't need an interpreter to come in and see everything. I mean it's my privacy that I want to keep as well. I just work with a radiographer and we use gestures and I watch her body language. Once I tried to tell the radiographer that I had pulled a muscle in my shoulder and to just be gentle, but she didn't understand. And so I was actually in a lot of pain the last time. I have actually had it [my shoulder] pulled twice, and I was saying to the radiographer "Can you please stop because it's really painful in my shoulder" but she just didn't listen to me.

Mammography screening often requires women to adopt uncomfortable positions: draping their arms over or around the machine and having their breasts compressed. R's reliance on gestures to communicate with her radiographer about her injured shoulder failed. Her experience demonstrates the limited nature of gestures as a main

means of communication. It also highlights the need for practitioners to be observant of their clients' expressions and movements.

The effective use of interpreters: extra time and complexity of issue

For the effective use of NZSL interpreters, increased time and energy was needed for good three-way communication by participant, interpreter and provider. One participant stated:

> *S: …communicating through the interpreter you know it takes longer. And because I am Deaf I feel that I have to communicate to the interpreter and it takes longer for the three-way communication and for things to be clarified and signed back to me. And I think the clarification time takes more of the time. So it is better if I have got longer than 15 minutes [for an appointment].*

GP visits are usually scheduled for about 15 minutes. For mammograms it is approximately 20 minutes. In the above account, S suggests that standard medical appointment times may be a barrier to Deaf women in seeking health information as the presence of an interpreter slows the direct communication between the practitioner and the woman as they relay the information from the woman to practitioner and then the practitioner back to the woman.

Besides additional time, other participants identified the complexity of the reason for seeing their doctor as to whether or not they require an interpreter present:

> *P: It depends on the issue as well. If it is just a small thing you are seeing the doctor for then 15 minutes is just enough. And it depends on the interpreter you are working with as well. I always pick an experienced interpreter, not a new graduate, you know, never for the doctor because there are just too many communication breakdowns.*

If the health issue is perceived as relatively minor, then a woman might decide to communicate directly to her doctor using other modes of communication. Both mammography and cervical cancer screenings, because of their respective three- and two-yearly occurrences, and each following a standard procedure, have the potential to become known to the women and may not require the repeated presence of an interpreter.

However, if her health issue is a major or complex health issue, such as the presence of cancer, not only is more time required but also the need for an experienced NZSL interpreter, and very often the need for the same interpreter, to provide continuity of communication.

Several participants discussed this:

> *N: If you are going to the doctor perhaps and then if you are talking about cancer or something really serious, you want the same interpreter for continuity.*
>
> *P: Yeah definitely.*
>
> *T: So maybe it doesn't really matter at the start but when you find out that you have got a serious condition you want the same interpreter every time.*

More complicated and nuanced consultations were seen by the women to warrant an interpreter. Having the same interpreter appeared to provide some surety for the women in that they would not have to explain their circumstances/medical history to a new interpreter. More importantly, having the same interpreter for complex medical issues, treatment or procedures allows the interpreter and Deaf woman to have a shared understanding of terms they will use to promote communication. Major, McKee, McGregor and Pivac[29] note that NZSL does not have an exact vocabulary for many medical terms, therefore this shared understanding is crucial.

Discussion

Our findings highlight the importance of effective communication during these sensitive health encounters, which is enabled through staff aware of how to communicate effectively with Deaf women (for suggestions, see Appendix 2) and the use of NZSL interpreters.

While NZSL is often seen as the "gold standard" with respect to communication with Deaf clients, the context of the clinical setting and the wishes of the Deaf woman herself are essential with respect as to when to employ NZSL. Ideally, Deaf women need to be consulted on their communication preferences prior to their cancer screening encounters. This could be ascertained directly with the woman when booking appointments so that at the

appointment staff are prepared, and the preferred mode of communication is used. Such preparations could be facilitated by having a note on the woman's file that she identifies as Deaf. As indicated in our findings, should the women request a NZSL interpreter be organised, they may have a specific NZSL interpreter whom they use. In the case of GP visits, the woman may prefer to book these herself through iSign. However, with hospital appointments the hospital is responsible for booking the NZSL. Should the woman choose not to have an interpreter, then health practitioners need to be aware of the possible limitations that gestures and lip reading have as the main means of communication. Researchers have shown experienced lip-readers only understand about 30–45% of what is being said.[30] This percentage is likely to be less when the Deaf person is ill.[19] Reliance on written material may also be problematic as people who have been Deaf from birth or early childhood may have low literacy levels.[31]

When interpreters are requested and used by Deaf clients, practitioners still play an important role in ensuring communication throughout the encounter. For example, visual aids were identified as a significant means of communication by Deaf participants in an Australian study.[32] For example, NZSL could be augmented with appropriate models and diagrams to ensure full understanding of the procedures.

Regardless of whether an interpreter is present or not, our findings suggest that additional time should be allocated for Deaf women in the setting up of appointments. This would facilitate the exchange of full information and for the service to be given equitably. In addition, practitioners could make Deaf women aware of available accessible resources related to cancer screening, such as those on the Health Education webpage for NZSL resources.[33] Information about how and when the screening results are made available to the woman and her practitioner could also be given. Any additional national resources to support Deaf women's understanding of cancer screening procedures, timing of results, etc. should be developed in consultation with Deaf women.

Currently in Aotearoa New Zealand no information is gathered regarding the participation levels of Deaf (and disabled) women in these screening programmes. However, the Office for Disability Issue's Disability Data and Evidence Working Group's research may make this possible. There is a need for disaggregated data on Deaf women's engagement with screening and other health services. Such information would help direct, at a public health level, cancer screening knowledge/education and screening procedures that must be accessible to Deaf women and their community. This should be done in partnership with Deaf organisations.

Conclusion

Our findings were based on Deaf women's experiences with breast and cancer screening. We suggest they are applicable to other health national screening programmes' services. Ensuring Deaf clients have full information while balancing privacy and effective communication should be seen as best practices for all health practitioners and their staff. In this way we may hope to achieve health equity for this population.

COMPETING INTERESTS
Nil.

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Appendix 1: Semi structured Focus Group Interview Guide

Following welcome, introduction and establishment of ground rules:

Cervical Screening

- Who of you has not had a cervical smear test?
- Can you tell us why you have not had one, please?
- Who of you has had cervical smear test?
- How were you notified?
- Did you have an NZSL interpreter?
- Tell us about your experiences of having a cervical smear.
- Did you encounter any barriers?
- If so, explore further as to what kind, how they overcame them.

Breast Cancer Screening

- Who of you has not had a mammography?
- Can you tell us why you have not had one, please?
- Who of you has had a mammography?
- How were you notified?
- Did you have an NZSL interpreter?
- Tell us about your experiences of having a mammography.
- Did you encounter any barriers?
- If so, explore further as to what kind, how they overcame them.

Appendix 2: Some suggested resources

- Making health care more accessible for Deaf patients, Medical Assurance Society. https://www.mas.co.nz/hub/making-health-care-more-accessible-for-deaf-patients/.
- Say that again, Deaf Aotearoa. https://www.deaf.org.nz/translation/say-that-again/.
- Guidelines for working with people who are Deaf or hard of hearing, Queensland Government. https://www.health.qld.gov.au/__data/assets/pdf_file/0032/1098842/dmhs-guidelines.pdf.
- HealthEd has NZSL versions of both Breastscreen Aotearoa and cervical screening pamphlets available at https://healthed.govt.nz/collections/all/language-nz-sign-language.