Resisting ethnic inequities in advanced breast cancer: a call to action

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ABSTRACT

Māori women with advanced breast cancer are less than half as likely as their Pākehā counterparts to reach the five-year survival mark. We argue that this inequity is unacceptable. We trace the inequity back to i) inadequate screening and risk assessment, ii) lack of support for patient navigation, iii) failure to offer accessible state-of-the-art treatments, and iv) delays in receiving life-prolonging care. We posit that each of these factors is a site of institutional racism and privilege as they cause Māori women to experience significantly worse outcomes than non-Māori. In the active pursuit of justice, cancer survivors, women living with cancer and their supporters across the country have been engaging in passionate advocacy to address inequities. As the Ministry of Health develops a new cancer control plan, in this viewpoint opinion piece, we seek to amplify these distressing inequities and offer evidence-based recommendations to improve the quality of care and ultimately survival rates. Breast cancer inequities are modifiable. We recommend prioritising breast cancer screening and risk assessments for Māori women, reducing treatment delays, providing Māori-centered patient navigation, increasing funding for treatments and drugs to align with the OECD standard of care, and holding health providers accountable for ethnic inequities. We call on policy makers drafting the new cancer control strategy, and those working across the cancer continuum, to take action to improve breast cancer outcomes so Māori women will gain valuable life-years.

Cancer is the leading cause of death in Aotearoa New Zealand.[1] There are systemic ethnic inequities across the cancer continuum, from diagnosis and receiving treatment, through to mortality rates.[2] This pattern is repeated within advanced breast cancer (ABC), which is the focus of this paper.[3] Research commissioned by the Breast Cancer Foundation New Zealand found Māori women in Aotearoa with a diagnosis of ABC (stage IV) have a 5% five-year survival rate; while New Zealand European women have a 15% survival rate.[4] The evidence suggests these rates persist even when all factors except ethnicity are controlled for.[5] As Wiki Mulholland, while advocating on behalf of women with ABC, highlighted in her 13 March 2019 Health Select Committee submission, we need to recognise that Māori women are the heart of the whānau and wider community and we need to keep them well.

Through *te Tiriti o Waitangi,* international human rights agreements and core health policy and legislation, the New Zealand Government has an obligation to protect and promote Māori health and pursue health equity.[6,7] Systemic ethnic inequities in cancer outcomes suggest a failure of the Ministry of Health in its role of stewardship.[2] If, as the data suggest, all other factors are controlled for and ethnic inequities persist, we argue it is likely to be institutional racism—a pattern of behaviour that benefits one ethnic group and disadvantages another. Institutional racism can manifest through policy, investment decisions, mono-cultural structures and inaction. Critically, racism does not need to be intentional.

In this viewpoint paper, written by Māori and non-Māori breast cancer survivors (and allies), we overview some of the modifiable contributing factors to ethnic inequities experienced by Māori in ABC. Our focus on breast cancer rather than cancer more generally is due to our lived experience. We focus on i) risk assessment and screening, ii) delays and deficiencies in treatment and iii) limitations in drug and treatment funding. We then outline some of the resistance to ABC policy and clinical practice led by highly motivated cancer patients and supporters. Finally, we outline some key recommendations around reducing racism, privilege and ethnic inequities in ABC to be considered for the forthcoming cancer control strategy. These recommendations may be applicable for addressing ethnic inequities in other types of cancer.

Sites of inequities

As we will show, Māori women experience worse ABC outcomes than other New Zealanders. However, it also worth noting that all New Zealand women experience worse ABC outcomes than women in other developed nations.[4] While we believe that ABC care in New Zealand should be improved overall, we believe that the three sites of inequities presented here are critical to eliminating the ethnic survival gap.

Breast cancer screening

Breast cancer screening has been proven to reduce breast cancer mortality.[3] Women diagnosed via screening are more likely to have positive prognostic factors and less likely to have ABC than women diagnosed outside screening.[3] As of June 2019, BreastScreen Aotearoa reports that nationally 66.1% of eligible Māori women and 73.7% of Pākehā women had received a mammogram in the last two years.[1,9] However, only 52.6% of eligible Māori women had been appropriately rescreened over the same time interval, while 67.7% of non-Māori, non-Pacific women had been rescreened. Without appropriate screening, women are at risk of being diagnosed at a later stage and thus at higher risk of developing advanced breast cancer.

Between 1981 and 2004, Māori women had the highest breast cancer incidence of any New Zealand ethnic group.[10] A 2005 analysis found that because Māori women experience lower screening and higher incidence, Māori women have the potential to benefit from increased screening more than their non-Māori counterparts.[11] However, an increase in breast screening for Māori women is expected to result in better outcomes as evidenced by a cohort study published in 2015 that found no significant difference in breast cancer survival by ethnicity provided the cancer is screen detected.[12] Thus, the potential for health equity is greater when Māori women are adequately screened.

Epidemiological studies regarding ethnic differences in age at breast cancer diagnosis have yielded variable results. A 2010 analysis found that Māori women are significantly more likely than European New Zealanders to be diagnosed with breast cancer before the age of 45.[10] However, a 2005 analysis found no significant differences between age at diagnosis for Māori and non-Māori women, except in the 25–29 age group.[11] Māori women experience higher breast cancer rates, however, the data on differences in age at diagnosis are inconclusive. The higher incidence of breast cancer among Māori women is also poorly understood; a genetic link is frequently hypothesised but has not been adequately evaluated. Further evidence in this area could allow screening recommendations to be better-tailored to the needs of Māori.

New Zealand currently funds biennial screening for women aged 45–69, with no assessment to determine a woman’s individual risk. Women at an elevated risk of developing breast cancer may receive survival benefit by beginning annual screening as early as age 25.[13] There are various validated risk assessments for different patients. A 2013 study found that Māori women, on average, have higher volumetric breast density than Pākehā.[14] High breast density both contributes to a higher risk of developing breast cancer and a lower likelihood that breast cancer will be detected via mammography. In higher-risk patients other screening modalities such as ultrasound or magnetic resonance imaging (MRI) may be warranted.[13] However, current screening policies do not incorporate individualised risk assessment for supplementary screening.

Delays and deficiencies in treatment

Māori women have to wait significantly longer than other women to see a specialist after diagnosis, to begin treatment, receive surgery and receive adjuvant chemotherapy and radiation following surgery.[5] A 2014 study found that a delay in initiation of first adjuvant therapy was associated with an increase in mortality by 45%.[15] Evidence suggests Māori women are significantly less likely than other women to receive the treatment within international guidelines.[16] These delays and deviation from guidelines contribute to the likelihood that primary breast cancers will progress to ABC.

Māori women also experience lower rates of completion of adjuvant therapies for primary breast cancer, which again puts them at higher risk for developing ABC.[17] Following clinical treatment of primary breast cancer, patients with endocrine receptive positive cancer are typically placed on long-term endocrine therapy to lower the risk of recurrence or progression to ABC. Non-completion of endocrine therapy is again associated with increased mortality. Māori women complete endocrine therapy at a rate of 62.1% compared with 72.5% for European women.[18]

Potential reasons for the lower completion rates include systemic barriers from inequitable access to the determinants of health[19] such as access to general practitioner and prescriptions and experiences of personally-mediated racism.[20] There is also a need for greater research into how these barriers contribute to differences in ethnic survival rates. The Ministry of Health and district health boards (DHBs) do not currently provide adequate support for Māori health providers, who deliver culturally and clinically safe care for Māori.[2] There is considerable scope to develop the cultural and political competencies of individual health practitioners and allied staff and to strengthen organisational expertise and responsiveness to Māori.

Access to transport to attend appointments remains a factor in both the quality and consistency of care for women with ABC. A 2016 study found that rural Māori have lower rates of breast cancer survival than urban Māori, suggesting that treatment location may play a role in survival.[21] Receiving cancer treatment in an accessible location may affect treatment completion and ultimately reduce mortality. Services must be accessible for Māori whānau, who often cannot afford to be away from paid employment or incur the additional costs of being away from home. Further research is needed to evaluate how accessibility can be improved.

Drug/treatment funding

Māori women are much more likely to receive breast cancer treatment in the public healthcare system than privately. Māori women account for 12.9% of breast cancer patients in the public system and just 2.6% of patients in the private system.[22] A 2016 study found that patients who receive breast cancer treatment in the public system have a 14% higher risk of mortality even after baseline differences, particularly related to ethnicity, stage at diagnosis and type of loco-regional therapy, are accounted for, than those going privately.[22] More research is warranted to better understand this discrepancy.

The Breast Cancer Foundation New Zealand reports that 33% of ABC patients have accessed private care, with 18% of those patients spending more than $50,000 on treatment.[4] The average Māori household income in 2013 was $22,500.[23] Since Māori women are much less likely than their Pākehā counterparts to have the necessary finances to access private healthcare, any failings of the public system affect Māori disproportionately.

A weakness of breast cancer treatment in the public system is the lack of funding for state-of-the-art medicines. In its 2017 briefing to the incoming Minister of Health, PHARMAC reported that of the 36 OECD countries, only Mexico spends less per capita on medicines.[24] In recent years, a class of drugs known as cyclin-dependent kinase (CDK) 4/6 inhibitors have become widely used in the treatment of ABC, achieving 42–58% improvements in progression-free and overall survival over conventional treatments.[25–27] So CDK 4/6 inhibitors offer women with ABC significantly longer and significantly healthier lives. However, New Zealand does not fund these drugs, which cost more than $5,000 per month when purchased privately.

Resistance to inequities

It has been apparent for decades at tangi across the country and from the Ministry of Health's mortality data that Māori women die younger and at higher rates from ABC. But what has been done by women (and allies) to resist these inequities?

In order to achieve access to medicines recommended by oncologists (but not publicly funded), women and their families have been going to extraordinary lengths. At a personal level, many families have sought to resist the inequities by turning to their communities for help with medication costs via crowdfunding websites. People have described the mixed feelings they experience in asking others for money, while many know the costs are beyond the resources of their own communities. Crowdfunding has been described as a new form of health insurance in Aotearoa, given the number of unfunded medicines.

This kind of resistance has been required repeatedly, over years lobbying for medicines such as Herceptin; used to treat HER2-positive breast cancer of which Māori have a higher rate. As noted above, the lack of public funding for effective medicines is a barrier for all advanced breast cancer patients, but impacts Māori and low-income women at greater rates due to income disparities.

Women seeking to maximise quality time with their friends and families as they come to terms with a terminal diagnosis have also been committing their time and energy to organising petitions, writing to and speaking at Health Select Committees, writing open letters to politicians and conducting media interviews. Fighting inequality while fighting a terminal diagnosis has meant many women have died before seeing the changes to public policy that they seek. The umbrella organisation of Breast Cancer Aotearoa Coalition (BCAC), Hei Ahuru Mowai and the patient group Metavivors NZ work to ensure that more women are able to keep giving voice to the injustices even when others are silenced in death.

BCAC has also highlighted to the health minister the need for targeted screening for younger Māori and Pacific women. Travel distance and parking costs have been identified as particular barriers to full treatment. Women have challenged these inequities through seeking chemotherapy infusion at more locations and lobbying BreastScreen Aotearoa for advertising and community-based engagement tailored for Māori. For example, BCAC continues to lobby the DHB for South Auckland to provide chemotherapy infusion locally rather than requiring women to travel to Auckland City Hospital. There have been briefings and meetings with Ministers and the Ministry of Health asking for strengthening of Māori screening efforts and the funding of medicines beyond the reach for many Māori women.

Recommendations for new cancer strategy

In order to narrow the ethnic survival gap for ABC, we recommend adopting and resourcing a systemic approach to change and increasing accountability for outcomes. By addressing institutional racism and strengthening engagement with *te Tiriti o Waitangi*, the healthcare system will be better able to address specific sites of inequity identified in this article through a planned approach.[28] The sites identified are risk assessment and screening, timely treatment completion, and enhanced public provision of medicines and other treatments.

We maintain that to eliminate racism and achieve health equity and improved Māori health outcomes the health sector must engage authentically with its *Tiriti o Waitangi* obligations. The recent Waitangi Tribunal[2] report on the WAI 2575 health kaupapa (agenda) claim clearly articulates the historic and contemporary failure of the health sector to protect and promote Māori health and offers direction for improvement. Going forward, we need co-design with Māori in decision making, policy making, sector design, implementation and evaluation of all aspects of the breast cancer continuum.

To increase rates of screening, we suggest that policy-makers draw on strategies that have proven successful in the past. From 2003 to 2007, a general practice in rural New Zealand serving a predominantly Māori population was able to increase participation in breast screening from 45% to 98%.[29] The practice improved rates by facilitating appointment scheduling, disseminating information and providing transport, using a multidisciplinary approach. They also issued appointment reminders and followed-up missed appointments.[29] Further research on actionable interventions in this space is greatly needed.

We suggest the implementation of more individualised screening guidelines, with a focus on providing patients with risk assessments to determine screening commencement age, frequency and screening method. Currently, the higher incidence of breast cancer in Māori women is poorly understood. Additionally, there is a lack of understanding about the causes of breast cancer in Māori. Further research is needed to determine why Māori women experience breast cancer at higher rates than European women in order to design prevention and treatment services. Expanded research will allow for the creation of improved screening guidelines.

A 2016 study in the US found that for low-income and minority patients with breast cancer, access to a free patient navigation programme significantly increased treatment completion rates and reduced treatment delays.[30] ABC patients surveyed by Breast Cancer Foundation New Zealand[4] reported a marked interest in this type of navigation. A 2008 study reported that Māori patients undergoing cancer treatment believed that navigators would improve their experience.[31] Further research on addressing unmet need and solutions is urgently required.

To address treatment delays, we recommend that DHBs be required to engage in equity-focused reporting of median diagnosis time frames and treatment delays by ethnic group. This reporting will make ethnic inequities transparent. A new performance measure could encourage providers to explicate reasons for delays and respond. We recommend that existing transport assistance programmes be improved and that local delivery of care be achieved with a focus on reaching predominantly Māori communities and that such programmes be co-designed with Māori.

Finally, we recommend that funding for advanced breast cancer drugs and treatments in the public system be increased to reduce ethnic inequities. Currently, high-cost modern medicines and other timely treatments available in the private system are disproportionately accessible to New Zealand Europeans. As Māori women are more likely to be treated in the public system, they are currently denied treatments that are the standard of care in developed countries.

Conclusion

Under *te Tiriti o Waitangi,* the New Zealand Government should work comprehensively towards Māori health equity. As we have shown, Māori women experience inequity across the ABC continuum, from a lack of adequate risk assessment and screening to a denial of life-prolonging drugs in the public system. Evidence suggests if these inequities are reduced, the survival gap between non-Māori and Māori women will narrow. We propose that ethnic inequities can be improved by implementing individualised risk assessments, increasing screening coverage, reducing treatment delays, increasing funding for drugs and treatments, offering patient navigation services and mandated reporting of ethnic cancer data by DHBs. We also recommend further research into the incidence patterns of breast cancer among Māori women to better guide future efforts. Patients with metastatic breast cancer have given enough of their lives fighting the system, it’s time for the system to fight for them. We believe that implementing the recommendations presented here will help Māori women with ABC to live longer and healthier lives, thus improving Māori health equity and bringing the New Zealand Government closer to fulfilling its obligations under *te Tiriti o Waitangi.*

Competing interests:

Dr Came is co-chair of STIR:Stop Institutional Racism—this is a nationwide network of activist scholars and public health practitioners committed to eliminating institutional racism in the health sector.

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REFERENCES:

1. Ministry of Health. Mortality: Historical summary 1948–2015. 2018.
2. Waitangi Tribunal. Hauora report on stage one of the health services and outcomes inquiry. Wellington, New Zealand 2019.
3. Morrell S, Taylor R, Roder D, et al. Mammography service screening and breast cancer mortality in New Zealand: a National Cohort Study 1999–2011. Br J Cancer. 2017; 116(6):828–39.
4. Breast Cancer Foundation New Zealand. “I’m still here”: Insights into living- and dying- with Advanced Breast Cancer in New Zealand. New Zealand; 2018.
5. Tin Tin S, Elwood JM, Brown C, et al. Ethnic disparities in breast cancer survival in New Zealand: which factors contribute? BMC Cancer. 2018; 18(1):58.
6. United Nations. Declaration on the Rights of Indigenous Peoples. New York, New York 2007.
7. Ministry of Health. New Zealand health strategy: Future directions. Wellington, New Zealand: Author; 2016.
8. Came H. Sites of institutional racism in public health policy making in New Zealand. Soc Sci Med. 2014;106:214-20.
9. BreastScreen Aotearoa. BSA New Zealand All District Health Board Coverage Report. 2019.
10. Cunningham R, Shaw C, Blakely T, et al. Ethnic and socioeconomic trends in breast cancer incidence in New Zealand. BMC Cancer. 2010; 10.
11. Curtis E, Wright C, Wall M. The epidemiology of breast cancer in Maori women in Aotearoa New Zealand: implications for screening and treatment. N Z Med J. 2005; 118(1209):U1297.
12. Seneviratne S, Campbell I, Scott N, et al. Impact of mammographic screening on ethnic and socioeconomic inequities in breast cancer stage at diagnosis and survival in New Zealand: a cohort study. BMC Public Health. 2015; 15:46.

13. Barke LD, Freivogel ME. Breast Cancer Risk Assessment Models and High-Risk Screening. Radiol Clin North Am. 2017; 55(3):457–74.
14. Ellison-Loschmann L, McKenzie F, Highnam R, et al. Age and Ethnic Differences in Volumetric Breast Density in New Zealand Women: A Cross-Sectional Study. PLoS ONE. 2013; 8(7).
15. Seneviratne S, Campbell I, Scott N, et al. Ethnic differences in timely adjuvant chemotherapy and radiation therapy for breast cancer in New Zealand: A cohort study. BMC Cancer. 2014; 14(1).
16. Latt PM, Tin Tin S, Elwood M, et al. Receipt of radiotherapy after mastectomy in women with breast cancer: Population-based cohort study in New Zealand. Asia-Pacific Journal of Clinical Oncology. 2018.
17. Seneviratne SA, Campbell ID, Scott N, et al. Risk factors associated with mortality from breast cancer in Waikato, New Zealand: A case-control study. Public Health. 2015; 129(5):549–54.
18. Seneviratne S, Campbell I, Scott N, et al. Adherence to adjuvant endocrine therapy: Is it a factor for ethnic differences in breast cancer outcomes in New Zealand? Breast. 2015; 24(1):62–7.
19. Chin MH, King PT, Jones RG, et al. Lessons for achieving health equity comparing Aotearoa/New Zealand and the United States. Health Policy. 2018; 122(8):837–53.
20. Harris RB, Cormack DM, Stanley J. Experience of racism and associations with unmet need and healthcare satisfaction: the 2011/12 adult New Zealand Health Survey. Aust N Z J Public Health. 2019; 43(1):75–80.
21. Lawrenson R, Lao C, Elwood M, et al. Urban rural differences in breast cancer in New Zealand. International Journal of Environmental Research and Public Health. 2016; 13(10).
22. Tin Tin S, Elwood JM, Lawrenson R, et al. Differences in Breast Cancer Survival between Public and Private Care in New Zealand: Which Factors Contribute? PLoS One. 2016; 11(4):e0153206.
23. Statistics New Zealand. 2013 Census QuickStats about income. 2013.
24. PHARMAC. Briefing to the incoming Minister of Health. 8 November 2017. http://www.pharmac.govt.nz/assets/briefing-to-incoming-minister-2017-11.pdf
25. Hecht K, Selby C. Review of Cyclin-Dependent Kinase 4/6 Inhibitors for the Treatment of Hormone Receptor-Positive Advanced Breast Cancer. Annals of Pharmacotherapy. 2019; 53(2):195–203.
26. Im SA, Lu YS, Bardia A, et al. Overall survival with Ribociclib plus endocrine therapy in breast cancer. N Engl J Med. 2019; 381(4):307–316.
27. Turner NC, Slamon DJ, Ro J, et al. Overall survival with Palbociclib and Fulvestrant in advanced breast cancer. N Engl J Med. 2018; 379:1926–1936.
28. Came H, Griffith D. Tackling racism as a “wicked” public health problem: Enabling allies in anti-racism praxis. Social Science & Medicine. 2017.
29. Thomson RM, Crengle S, Lawrenson R. Improving participation in breast screening in a rural general practice with a predominately Maori population. New Zealand Medical Journal. 2009; 122(1291):39–47.
30. Castaldi M, Safadjou S, Elrafei T, et al. A Multidisciplinary Patient Navigation Program Improves Compliance With Adjuvant Breast Cancer Therapy in a Public Hospital. Am J Med Qual. 2017; 32(4):406–13.
31. Walker T, Signal L, Russell M, et al. The road we travel: Maori experience of cancer. N Z Med J. 2008; 121(1279):27–35.