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PHD
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The Journal of Pacific Research

Pacific wellbeing through the researchers lens

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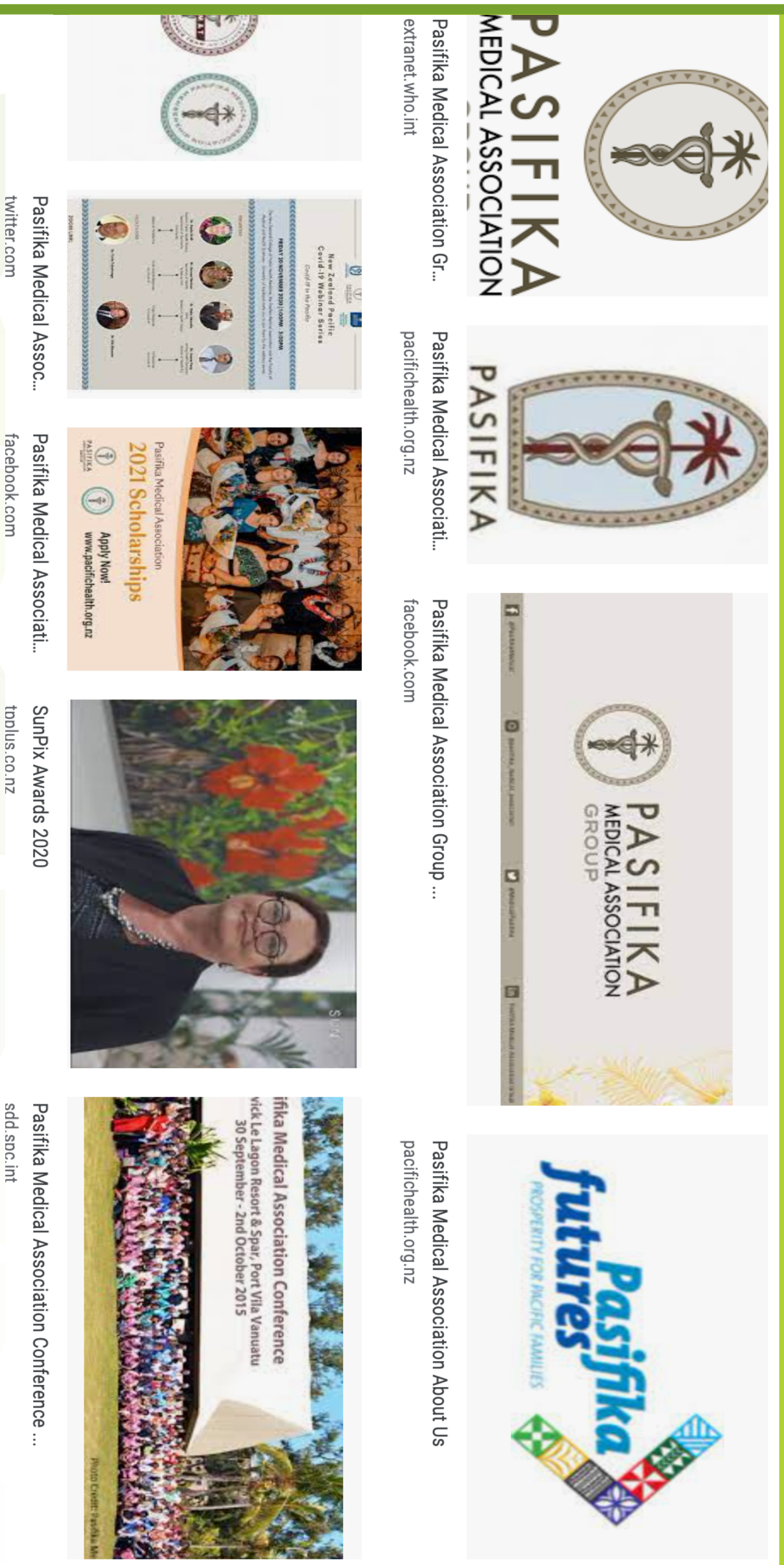

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The Journal of Pacific Research

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Editorial **OPEN ACCESS**

Wealth of Pacific research

Alec J EKEROMA

Editor in Chief, Pacific Health Dialog, a.ekeroma@nus.edu.ws

In this issue of the Pacific Health Dialog, we have continued to attract a diverse submission of manuscripts as we provide an essential platform for Pacific research dissemination. The manuscripts, spanning from original research to commentary and literature reviews provide a rich tapestry of interwoven themes between health and our cultures and all those other determinants of health that are not limited to social, economic and political impacts.

Kokaua *et al* [1] have continued to utilize the rich data in the New Zealand Integrated Data Infrastructure to analyse and meaningfully comment on issues that affect Pacific Health. In their paper, they explored the value of the parent's education on their children's health. It makes sense that when parents are educated the children do better both academically and health wise. But some hard evidence is needed. They found that there was a modest reduction in severe mental illness with an additional year of the parent's education and other co-variates such as economic deprivation do not fully moderate the effects of parental education. After adjusting for covariates, they found a 6% reduction in MHC for every additional year of both parent's education. These findings confirm the protective effect of parent's education on their children's mental health.

The COVID-19 pandemic has caused significant economic and social distress in the Pacific Islands [2] and the recent surge of cases in Fiji and Papua New Guinea stresses the importance of quarantine, detection and isolation to prevent and halt transmission. A study from Samoa by Olayemi *et al* [3] found that medical and nursing students at the National University of Samoa were well-informed of COVID-19 which is important for the prevention of COVID-19. The constant barrage of information and news about the COVID-19 in the last 16 months may well have many people well-informed, which may lead to better prevention strategies and vaccine utilisation.

Three manuscripts explored various research methods with some uniquely designed for the Pacific setting or Pacific people. For instance, family-tree mapping and interviews conducted using blended narrative-Talanoa explored gender-based violence in Niue and it seemed to have bridged a gap in using genealogy and ancestry in understanding gender and violence issues.[4] The level of violence disclosure was controlled by the participants within the confines of the family setting. The two manuscripts by Thomsen *et al* explored the challenges of service access by the Pacific Rainbow community by using research methods such as relationality, co-community embeddedness and co-design. The methods engaged the participants from conception to completion and captured the genealogical and social relationships to understand the notion of self as one relates to others to illustrate "interconnectedness of Pacific communities, cultures and people."[5] The socially marginalized Rainbow Community groups often suffer violence and are treated unfairly by a host of service providers such as the medical profession.[6] The manuscript by Boon-Nanai *et al* [7]used the Fonofale research model to framework abuse as reported by twelve elderly Samoans. The Fonofale model gives a wide definition of abuse to include cultural and spiritual abuse. For example, failing to take an elderly relative to church is considered spiritual abuse. Hence, Pacific researchers have continued to create new research methods and explore the use of established ones to gather and validate results that are culturally relevant for our research in our diverse Pacific communities, paving the way for more impactful research.

We decided to publish a couple of papers with dated datasets as the findings may remain relevant despite the years. As we continue to attract more and good quality manuscripts, we are on the constant lookout for reviewers to strengthen the peer review process by improving turnaround times. Let us know if you are interested.

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Kokaua J. Pacific Health Dialog 2021; 21(7): 361-372. DOI: 10.26635/phd.2021.112

The Journal of Pacific Research
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Original Research **OPEN ACCESS**

Is parent education protective of mental wellbeing in Pacific young people? A cohort study of mental health and census data in Aotearoa/New Zealand's integrated data infrastructure.

Jesse KOKAUA,[1] Seini JENSEN,[2] Reremoana THEODORE,[3] Nicholas BOWDEN,[4] Russell BLAKELOCK,[5] Debra SORENSEN,[6] Wilmason JENSEN,[7] Rosalina RICHARDS[8]

ABSTRACT:

Aim: The aims of this paper are to quantify the impact of parental education on the five-year incidence of mental health conditions (MHC) in Pacific young people and to investigate the influence of other factors.

Method: The analyses in this paper used data extracted from Aotearoa/New Zealand's Integrated Data Infrastructure (IDI). Data relating to 383,595 young people (48,768 Pacific), identified in the 2013 Census, aged 12-24 years, and their parents' were used. Logistic regression models were used to investigate the incidence of children with MHC from 2013-2018.

Results: Mental health conditions were identified in one of five Pacific young people. Irrespective of ethincity, increased parental education was associated with decreased MHC. However, the association was only significant for those in specialist mental health care (OR=0. 897, 95%CI:0.881-0.913) but not for those seen in other health settings (OR=0. 989, 95%CI:0.974-1.004). The association, for specialist settings, was not mediated by the contribution of other factors (OR=0.941, 95%CI:0.926-0.958). However, increased parents education with the addition of social, cultural and economic advantages the number of Pacific children seen in the specialist mental health setting could be nearly halved.

Conclusion: The findings show that a parental educational advantage exists for children who access specialist mental health care. However, there are more complex but far greater opportunities for the health of Pacific families if a coordinated education, housing, employment and health solution were possible. The gains from a multi-disciplinary Pacific solution exist in terms of reduced severity for and level of care to Pacific children with MHC.

Key words: Ethnicity, Mental Health, Parental Education, Population data

BACKGROUND

New Zealand's *Pasifika Education Plan 2013-2017* characterises successful Pasifika learners as vibrant, dynamic, secure and confident in their identities, languages and cultures, across all curriculum areas.[1] Such a vision of educational success implies that benefits of education extend beyond career aspirations to support better social or health outcomes for individuals and their families. The subsequent and current 10-year action plan[2] for Pacific education aspires to respond to the needs and expectations of diverse communities or ethnic groups within Pasifika, guided by four key values: reciprocity; diversity; commitment; and collective action.

Corresponding author: Jesse Kokaua
Jesse.kokaua@otago.ac.nz

1. Research Fellow, Centre for Pacific Health, Va'a O Tautai, Division of Health Sciences, University of Otago, Dunedin, New Zealand (NZ)
2. Director of Performance & Evaluation, Pasifika Futures Limited, Auckland, NZ
3. Co-Director, National Centre for Lifecourse Research, University of Otago, Dunedin, NZ
4. Big Data Theme, A Better Start National Science Challenge, Women and Children's Health, Dunedin School of Medicine, University of Otago, PO Box 56, Dunedin, NZ
5. Specialist psychiatrist, Canterbury District Health Board, Christchurch, NZ
6. Chief Executive Officer, Pasifika Futures Limited, Auckland, NZ
7. Deputy Chief Executive, Pasifika Futures Limited, Auckland, NZ
8. Centre for Pacific Health, Va'a O Tautai, Division of Health Sciences, University of Otago, Dunedin, NZ

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These values are reflected strongly in the priority areas, which address diversity, challenging racism and discrimination, and improving the established pedagogies to respond to the needs of Pacific children and young people.

The current Pacific Education Action Plan acknowledges its contribution to the nation's strategy for the wellbeing of children and young people with particular focus on diverse Pacific communities.[3] The plan has prioritised initiatives to mitigate the effects of poverty and socioeconomic hardship with a determined intent to address social inequalities and key determinants of health and wellbeing, including racism and discrimination. Other studies have documented Pacific peoples' socio-economic status and related poorer health.[4] None have sought to understand what factors contribute to improved Pacific health and socio-economic wellbeing nor how they interact. For education, this means exploring intergenerational associations with health among Pacific peoples and starting to unpack how this works and impacts. This includes considering the pathways that Pacific families have available to them to support health gains - how these might be maximised or whether there are alternative ways to access these benefits.

Given the literature that suggests achievement in higher education is related to better health,[5] it is not surprising that Pacific children from families with educated parents may also display these patterns. Internationally, evidence suggests that children of parents with few qualifications are less likely to attain higher qualifications and also less likely to rate their health positively. International studies have presented strong evidence that parental education is protective for many health conditions.[6-,9,11-19] This is inclusive of mental health conditions, where there is an associations between parental education and their children's mental health diagnoses and issues,[8,9,20-22] as well as neurodevelopmental conditions like autism and Attention-deficit/hyperactivity disorder (ADHD).[12] Conversely, a systematic review showed that less parental education had a stronger impact on their children's and adolescent's mental health than unemployment or occupation.[21]

A large study from the United States of parents of children under 18 years showed significant parental advantage for their child's overall health but not for their socio-emotional domain, difficulty with emotions or getting along with others.[23] Another study of DSM-IV disorders in children in the United States confirmed no association between parental education and any prevalence of disorder.[24] However, they found that higher parental education was associated with reduced persistence and severity of disorder.

Studies have found that the association between parental educational status and improved physical and psychological wellbeing changed with the age of their children.[25,26] Other studies note that parents' education had a stronger influence than household income, and both were the strong contributors to their children's mental health, compared to other factors like employment, sole parenting, or nationality. [27]

To date there are few studies that have explored the value of education for Pacific parents to their child's health or whether that value is consistent across different Pacific groups. One longitudinal study of Pacific children in Aotearoa found a strong association between parental education and childhood depression.[8,9] While, a study linked parental and child administration data in Aotearoa showed potentially avoidable hospitalisations of Pacific children displayed a clear parental educational advantage.[11]

This paper is an output from *Meitaki te Api'i*: A study of the benefits of education to health outcomes for Pacific families in Aotearoa.[28] Its focus is on mental health conditions (MHC) in Pacific young people using data from the Aotearoa integrated data infrastructure (IDI).[29] The main aims for this paper are: (H1) to identify any parental education advantage to the five-year incidence of MHC in Pacific and other young people; (H2) to investigate if other factors mediate or moderate parental education advantage to their children's MHC; (H3) to see how other factors influence MHC beyond parental education.

METHODS

Participants

This paper, part of the *Meitaki te Api'i* study of the influence of education on Pacific families, includes young people aged from 12 to 24 years in 2013, and their parents, restricted to those who filed a Census return. The data used are described in full in a publication of the study protocol for *Meitaki te Api'i*.[28] This study uses data from linked datasets in the IDI for children who met the inclusion criteria, and their parents. These include ethnicity from personal details, the 2013 census, and relevant health datasets as indicated below.

The IDI reflects the whole population in Aotearoa. By focusing on the 2013 Census population, this study is using a snapshot of the total Aotearoa population at that point in time. Thus, establishing a baseline for parents education and other covariate characteristics and allows for a 5 year follow up period to observe mental health outcomes. In 2013, more than 1.2 million children and young people, under 25 years of age, were identified from the census of that year (**Figure 1**). From that group, 334,827 non Māori-non Pacific (NMNP) and 48,768 Pacific children between 12 and 24 years of age met the criteria for inclusion in this study.[29] Of the latter, 12,375 Pacific children were identified with lower parental education, social, cultural and economic supports than other families in the study.

Measures

Ethnicity: Ethnicity for children in the study has been categorised in the personal details table of the IDI that includes an ID number, gender, birthdates and links to parents ID numbers. The personal details set also include six main ethnic groups, including Pacific or Pasifika, collated from multiple sources of data in the IDI. In this study we have used the terms Pacific and Pasifika interchangeably to refer to those descended from peoples indigenous to Pacific nations. Pacific children in the study represent a non-prioritised cohort of children who identified with any Pacific ethnicity, irrespective of any other group co-identified with. This approach will allow us to get a complete picture of Pacific children that will benefit other under-represented groups beyond those in this study. For comparison purposes, those who were neither Pacific nor Māori were assigned to a composite non Māori-non Pacific (NMNP) group.

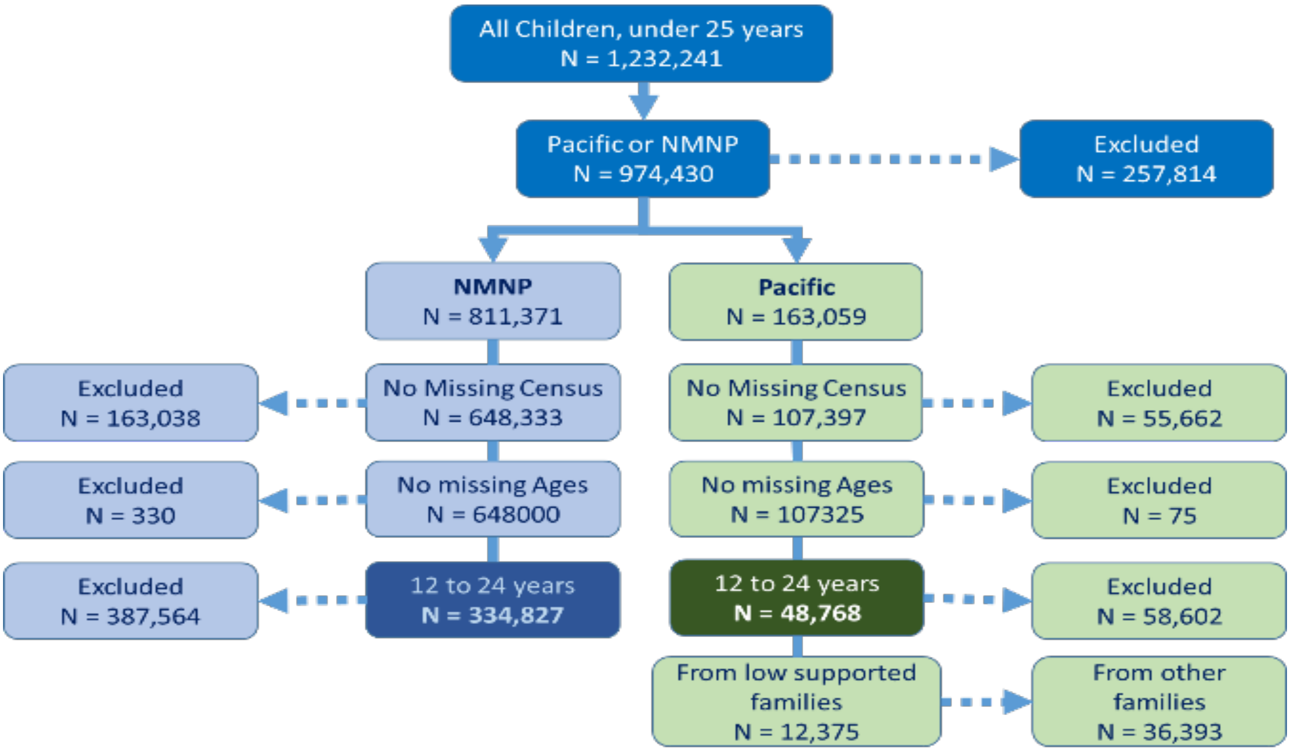
We have excluded Māori except for those, included in the Pacific cohort, who are Pacific and Māori. As indigenous peoples, Māori command a unique position in Aotearoa and are deserving of independent research. However, their shared heritage with peoples from the Pacific, yet their very different colonisation experiance in Aotearoa, means their presence in a comparison non-Pacific cohort would introduce systematic bias to many characteristics inherent in Pasifika.

Mental health conditions (MHC): Mental health cases were identified in the Meitaki O Te Apii cohort using the method devised by E Tipu Rea: A Better Start National Science Challenge Big Data team.[29] A mental health case identification method based on service use, designed to identify clinically meaningful cases of MHCs among children and young people minimising false positives. The method utilised available datasets that identified MHC such as psychotic, mood, anxiety, and substance use disorders. The specific datasets were Programme for integration of Mental Health Data (PRIMHD, specialty mental health services), national minimum dataset (NMDS, hospital admissions), pharmaceutical collection (PHARMS, medication dispensing) and national needs assessment and service coordination information (Socrates). In the present study, we have divided our analyses into three high level categories: any MHC, MHC identified via specialist mental health settings (PRIMHD only), MPH identified in other "community" settings (PHARMS, Socrates, NMDS).

Years of parental education: Parental education is represented by the highest maternal and paternal qualifications gained that were recorded in the 2013 Census. Aotearoa and international qualifications were acknowledged, however, international qualifications were translated to New Zealand equivalent qualifications. The years of each parent's education were estimated by calculating the standard number of years' study required to attain their highest educational qualification. The average parental years studied was obtained by dividing their combined years of education by number of parents for each child.

Other covariate factors: Other variables available in the IDI considered to influence a child's health are parent's birthplace/migration status, languages spoken in the home, parents smoking status, employment and home ownership. Factors associated with families included household income, church membership, numbers of adult and child household occupants and a measure of local area deprivation (NZDep2013). Household income was equivalised to reflect the total income for the household that a child lives in, adjusted to reflect the number of people living in their home. A separate study protocol for this study reports a breakdown of the study cohort by the variables used.[28]

Figure 1: Omissions from the study cohort



Statistical Models

This paper investigates the influence of education of parents upon the mental health outcomes for their children. The outcomes in this study are indicated with binary variables over a five-year period from 2013-2018. These were summarised by frequencies and crude rates with chi-squared tests for unadjusted ethnic differences. To investigate data over the five-year period starting from 2013, the year of the previous Census, logistic regression models were applied to each outcome. Thus, two models were used:

- a baseline model of parental education with age and sex of the child to establish a baseline association between parental education and mental health;
- Adjusted, other covariate variables were included to examine the influence of variables included in the previous section.

The adjusted model was used to predict marginal proportions of Pacific children with MHC for each year of parental education. Finally, the model was used to predict, in a cohort of children with few education, cultural, and socio-economic supports, how many children would be seen with MHC in two health settings.

All analyses were run in the IDI Datalab environment using SAS.

Ethical Approval

This study uses anonymised data in the IDI which fall outside the scope of the national Health and Disability Ethics committee (HDEC). Ethics approval for the study was obtained through the University of Otago ethics committee (HD18/042). In addition, a Tivaivai research framework, applied to Pacific health research using the IDI in Aotearoa. This framework has been developed to clearly link the study to Pacific research values.[30]

RESULTS

Comparisons of 5-year cumulative incidence of MHC

In 2013, there were around 383,595 children and young people (48,768 (13%) Pacific), aged between 12 and 24 years of age, who met the criteria for inclusion in this study (**Table 1**). Small but significant ethnic differences were found in the incidence of overall MHC in Pacific and non-Maori, non-Pacific (NMNP) children in the five years following the 2013 census ($p<0.0001$), affecting around one in five Pacific and NMNP children. Nearly half of children's MHC were seen in a specialist mental health setting (10% of Pacific children, 9% of NMNP children).

Projected percentages of Pacific children with MHC shows slight ethnic differences in the gradients across years of parent's educational qualification (**Figure 2**). The difference between children with MHC seen in a specialist mental health setting, at the two ends of the parental education spectrum show a reduction in incidence of between 50% and 65% for NMNP and Pacific respectively. In contrast, there is little or no increase observed for MHC in other health settings. Peculiarly, for specialist mental health, if Pacific children shared the socio-demographic patterns of NMNP, their incidence increased. In contrast to their actual number shown in **Table 1.**

Table 1 : Five-year cumulative incidence of MHC by child's ethnicity.

		Pacific	**NMNP**
Total	**N**	48,768	334,827
Any MH Problem	**n (%)**	10,164 (20.8%)	65,880 (19.7%)
	χ^2 (p-val)†	36.5 (<.0001)	
Specialist MH Setting	**n (%)**	4,893 (10%)	28,605 (8.5%)
	χ^2 (p-val)†	1,508 (<.0001)	
Other Health Setting	**n (%)**	6,672 (13.7%)	46,524 (13.9%)
	χ^2 (p-val)†	1.6 (0.2002)	

†Chi squared (χ^2) tests and p-values for a difference between ethnic groups.

A single year of education for parents of Pacific and NMNP young people yields a 5% reduction in the odds of any MHC (**Table 2**). As shown in Figure 2, the gradients for specialist mental health settings were much steeper than other health settings, 13% and 10% reductions to Pacific and NMNP young people respectively. Other covariate factors, attributed for 43% and 72% of odds of any advantage from parents education to MHC in specialist settings for Pacific and NMNP young people, respectively. After adjusting for all covariates, Pacific young people reported a 6% and NMNP a 3% reduction in odds of specialist MHC for every additional year of their parent's education.

No significant associations were found between education for parents of Pacific young people and their unadjusted odds of MHC in other health settings. NMNP alone had a significant unadjusted gradient, other factors attributed fully for parental education advantage (PEA) in other settings.

Overall, in five years from 2013, 10,164 Pacific children were identified with at least one MHC, 4,893, in specialist settings and 6,672 in other settings. Of those, 1,683 and 1,716, respectively, were from 12,375 Pacific families living in areas of high socio-economic deprivation and with at least one parent without a qualification higher than school. Adjusted regression model results predicted the numbers of children from those families if different combinations contributing risk factors were no longer an issue.

Figure 3 summarises the hypothetical numbers of Pacific children who, if nothing else changed for those children, increasing their parents education, to both parents with at least a school qualification, would prevent 357 (21%) children seen in specialist and 84 (5%) in other settings. For mental health specialist services, addressing social and cultural barriers as well as education would reduce by half the MHC for children in families with few advantages.

Social and cultural factors outweigh economic barriers, the latter preventing as much as a further 237 (14%) of Pacific young people seen in mental health specialist services. Education and, social and cultural factors, by comparison, reduce 225 (13%) of community MHC, from other health settings. Improved economic status increased Pacific child's use of community MHC in families with low economic advantages and little influence on their incidence of specialist care. If all factors were addressed for Pacific children from families with least means and support, as much as half of MHC in specialist services could be avoided with a minimal decrease and possibly an overall increase in community MHC.

DISCUSSION

Given the need to find holistic approaches to support wellbeing among Pacific families, this study offers a unique opportunity to explore the potential positive impact of parental education on a number of child health outcomes, while taking into account a range of contributing other family, social and economic factors. Measuring health outcomes for children is difficult even without considering the complexities of Pacific concepts of health, which incorporate multiple domains. [20,21] This paper investigated the influence of parental education to their children's outcomes of *Tu manako* (mental wellbeing) and (family or parents) and *Aorangi* (household and geographic socio-economic status).

It is important to note that MHC are not a definitive indicator of mental ill health in Pacific children as these conditions have been identified by interactions through government funded health related interventions. Two contexts of mental health care have been investigated in this paper, children identified in specialist mental health settings and those identified in other community settings. The former is more likely to represent more severe diagnosed mental illness in recent treatment in mental health services.

Figure 2: Five-year incidence of MHC by years of parental education by ethnicity of child.

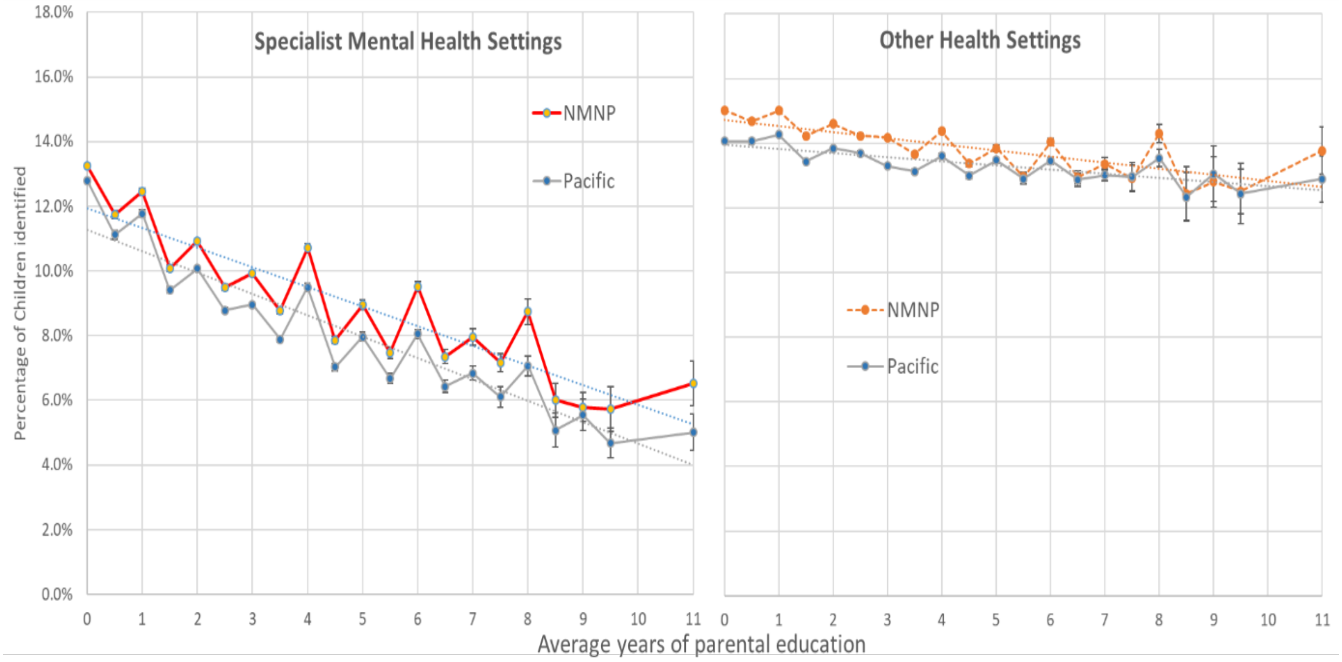
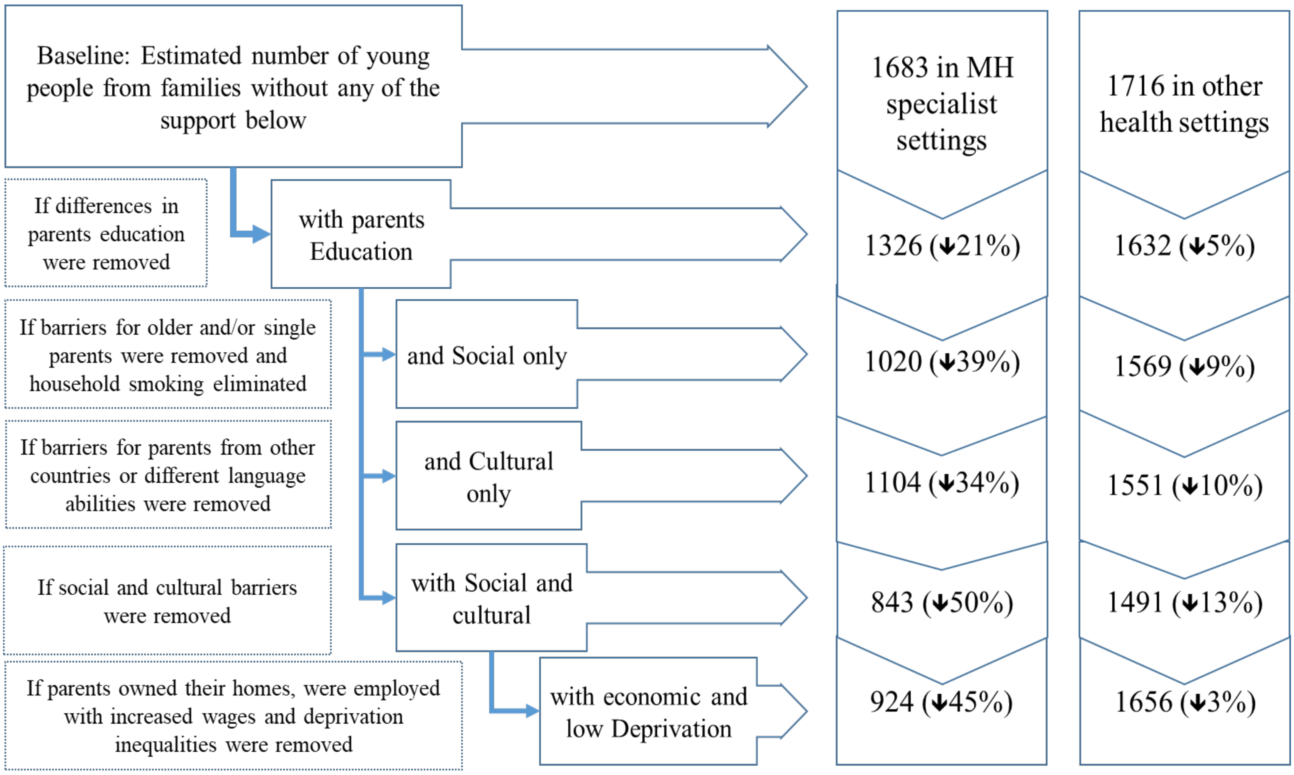


Table 2: Odds ratios for Parental educational influence on children's MHC by child's ethnicity.

			Pacific	**NMNP**
Total		**N**	**48768**	**334827**
Any MH Problem	Baseline	OR (CIW)	0.948(0.013)***	0.948(0.004)***
	Adjusted	OR (CIW)	0.966(0.013)***	0.985(0.005)***
	%attr		35.6%	70.8%
Specialist MH Setting	Baseline	OR (CIW)	0.897(0.016)***	0.901(0.006)***
	Adjusted	OR (CIW)	0.941(0.017)***	0.972(0.007)***
	%attr		42.8%	71.7%
Other Health Setting	Baseline	OR (CIW)	0.989(0.015)ns	0.977(0.005)***
	Adjusted	OR (CIW)	0.987(0.016)ns	0.995(0.006)ns
	%attr		-	-

*__CIW__ reports the width of one side of the 95% confidence interval for the odds ratio. __%attr__ is the proportional reduction in baseline odds ratio by introducing other covariates to the regression models. ***An odds ratio is significantly different from parity with a p-val<0.001, "ns" is not significant.*

Figure 3: Predicted numbers of children from families with little socio-economic support and at least one MHC with different cultural, social and economic scenarios.



Parental education and MHC in Pacific young people

The first part of the overall aims of this paper was to quantify the impact of parental education on the five-year incidence of MHC. The findings show that parental education advantage exists for the incidence of overall MHC in young Pacific people (H1), but that advantage extended only to specialist identified MHC and not to those identified in other community settings. A key finding from this study is a modest reduction in MHC incidence in specialist settings (i.e. more severe cases), for each additional year of parent's education. These findings are somewhat supported by previous research evidence that also suggest that parent's education was protective of their children's diagnosed mental illness. [8,9,21] They also are reflective of another study's findings that parental education was not associated with overall prevalence of mental disorders but with severity.[24]

Influence of other factors on MHC in Pacific children

Overall, there is a clear advantage to the mental health of Pacific young people from their parents' education. However, that advantage is perhaps less about the avoiding the condition, but more about influencing the severity of their condition and the setting at which a young person with a mental health problem is cared for. Studies have shown that children of better-educated mothers are more likely to receive medical or dental care than other children, regardless of the family's income.[6] Whether by increased health literacy or other means, the influence of parental education would appear to extend beyond improved economic position or other factors. Pacific peoples in Aotearoa are currently over-represented in many poorer outcomes related to socio-economic, health and educational status.[4] In the past decade there has been a growing recognition, within the education sector, that current programmes may not meet the needs of Pacific learners and new and innovative approaches are being developed to support Pacific learners in primary, secondary and tertiary education.[2]

These findings from the present study show that, for specialist mental health, household income or other covariates are moderators of, but do not fully mediate, the influence of parents' education on the incidence of their children's MHC (H3). Household income only had a marginal effect upon the role of parental education. Other covariate factors attributed for much of the influence of parental education particularly for specialist MHC. However, for specialist MHC, parental education remained significantly advantageous.

Our findings support the approach taken bv the Child and Youth Wellbeing Strategy in that they suggest multi sectoral approaches that, if addressed, will optimise the influence of increased parental education advantage. If nothing else changed for those Pacific children in families with the greatest need, increasing their parents' education would result in 28% of children being seen in settings other than in specialist mental health care. While some care must be taken with interpreting the findings, however, there appear to be opportunities to prevent many Pacific young people, with serious mental disorders, from requiring specialist mental health treatment, if inter-sectoral approaches could address cultural and social barriers. Such as, successfully engaging parents who have difficulties communicating in English as well as Pacific families with single parents, older Pacific parents, or parents not born in Aotearoa.

These findings have many implications for promoting education as an investment to family health irrespective of ethnicity. Nevertheless, in spite of education sector initiatives, challenges still exist for Pacific young people to engage with learning institutions with implications for education institutions to engage with continuing education for young parents who may have disconnected from an education pathway. In addition, a more complex but far greater opportunity to the health of Pacific families is available. While we have to be careful about advocating for one setting over another for the care of MHC, our findings suggest that, potentially, as many as four out of five MHC in specialist mental health settings could be prevented if education, social, cultural and economic support could be addressed. This finding highlights the importance of such service configurations as those promoted by the Whanau Ora Pasifika programmes that seek to address Pacific family wellbeing across multiple domains. The gains from a multi-disciplinary Pacific solutions exist in terms of reduced severity for and level of care to Pacific children with MHC.

Strengths and weaknesses of the study

The findings of this paper are part of a wider study of the benefits of education to health outcomes for Pacific families in Aotearoa. Its findings are hoped to inform Pasifika communities in terms of health and education with the intent to produce better outcomes for Pasifika families.[21] Models of Pacific health emphasise the need for inclusive views of life, success and wellbeing. This study has adopted a Tivaivai research framework and applied it to quantitative methodologies to incorporate Pacific values and community practices in the analyses and presentation of it results. To that end, this paper is a product of a study design with Pacific communities at its core, upholds Pacific leadership, respect of cultural values, researcher development and is part of a wider process of reciprocity and seeking Pacific led solutions.

For this study, strengths of using the IDI include: it uses population data providing increased statistic power; it has more consistent ethnicity data from multiple sources, which is an improvement over using ethnicity captured in any single data collections; it enables researchers to look at Pacific sub-ethnic groups; it uses a method of identifying the MHC outcomes captured across a range of service areas. However, the mental health case identification method is yet to be fully validated and is based on service utilisation. Therefore, it is likely to identify more severe MHC and therefore undercount the true community prevalence of MHC. This study is a reflection of patterns of MHC in Pacific children prior to 2019. The 2020 COVID-19 pandemic will influence the collections of data as well as mental illness in Aotearoa.

Two factors, not included in this study, that have been suggested reduce the influence of parental education were parental morbidity and children's own education.[18] Additionally, in contrast to one study that suggested better-educated parents with better access to healthcare in studies using administrative health data may inflate education and income advantage on health conditions.[4] In this study, the omission of privately funded hospitalisations is more likely to potentially lead to an under-estimation of the impact of people with high socio-economic status. Affluent parts of the population, with private insurance, may have greater access to private hospital services.

The statistical models displayed modest performance. The models Hosmer-Lemshov statistic was below the threshold of what is considered having acceptable predictive strength but their patterns still hold valid ability to draw some important conclusions.

CONCLUSION

The findings above show that, in spite of some ethnic differences, a parental educational advantage, in terms of a reduction in severe MHC, exists for Pacific children who access specialist mental health care. That remained significant even taking into account the contribution by other factors. There are many implications for promoting education as an investment to family health irrespective of ethnicity. However, a more complex but far greater opportunity to the health of Pacific families is available if a coordinated education, housing, employment and health, solution were possible. The gains from a multi-disciplinary Pacific solution exist in terms of reduced severity for and level of care to Pacific children with MHC.

Statistics New Zealand Disclaimer

These results are not official statistics. They have been created for research purposes from the Integrated Data Infrastructure (IDI) which is carefully managed by Stats NZ. For more information about the IDI please visit https://www.stats.govt.nz/integrated-data/.

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Author contributions:

All authors have contributed to the idea, and discussion. JK and NB contributed to the methodological sections relating to the IDI. All authors contributed to the drafting of the article and reviewing significant content and all have approved the final version to be published.

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Pasifika preferences for mental health support in Australia: focus group study

Roman KINGI,[1] Wani ERICK,[2] Vili H NOSA,[3] Janine PAYNTER,[3] Debra DE SILVA[4]

ABSTRACT

Introduction: Mental wellbeing is a growing health issue for Pacific Islands communities (Pasifika), particularly amongst people who have resettled in a different country. We explored whether Pasifika people living in Australia think mental health services meet their needs.

Methods: We ran eight two-hour focus groups with 183 adults living in Queensland, Australia. There were representatives from the following ethnic groups: Cook Islands, Fiji, Maori, Niue, Papua New Guinea, Samoa, Tokelau and Tonga. We also included mental health providers. We analysed the feedback using thematic analysis.

Findings: Pasifika people welcomed having an opportunity to discuss mental wellbeing openly. They said that economic issues, social isolation, cultural differences, shame and substance use contributed to increasingly poor mental health amongst Pasifika communities in Australia. They wanted to work with mainstream services to develop culturally appropriate and engaging models to support mental wellbeing. They suggested opportunities to harness churches, community groups, schools, social media and radio to raise awareness about mental health.

Conclusions: Working in partnership with Pasifika communities could strengthen mainstream mental health services and reduce the burden on acute services in Australia. This could include collecting better ethnicity data to help plan services, empowering community structures to promote mental wellbeing and training staff to support Pasifika communities. The key message was that services can work 'with' Pasifika communities, not 'to' them.

Key words: Pasifika, mental health, cultural, spiritual values

INTRODUCTION

More than 200,000 Pasifika people currently call Australia home. About one third of these live in Queensland, mostly around Brisbane.[1] Throughout this article we use the term Pasifika to refer to Pacific Island communities in general, but we recognise that there are multiple communities, each with their own culture, perspectives and needs.

Pasifika communities in Australia are vibrant and varied. They contribute heavily to seasonal working schemes, sporting activities and churches. However, Pasifika communities also have higher than average rates of hospital admissions, chronic conditions. criminal offences and mental health issues.[2,3] Pasifika people often have poor health literacy and are in low paying jobs. If they are not Australian citizens, they are ineligible for some job seeking services, unemployment benefits or superannuation.[4,5] All of these issues can impact on mental wellbeing. Research has found links between social and economic deprivation, unemployment, mental wellbeing, access to mental health services and suicide.[6,7,8]

Corresponding author: Roman Kingi, roman.avaiki.kingi@gmail.com

1. Multi-link Community Services Inc, Brisbane, Australia.
2. PhD Student, Faculty of Health, Queensland University of Technology, Australia
3. Pacific Health Section, School of Population Health, Faculty of Medical and Health Sciences, University of Auckland.
4. Professor, The Evidence Centre, London, United Kingdom

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Mental health is increasingly recognised as fundamental to a person's experience of day-to-day life and their overall sense of wellbeing. The Australian government has identified improving mental health as a national priority. Mental illness, combined with neurological and substance use, constitutes 13% of the global burden of disease and is a leading cause of death and disability. [9] Amongst the general population, one in five adult Australians reported having a mental health condition.[10] However, the incidence of mental illness is not equal across the population. Indigenous peoples, migrants and members of culturally and linguistically diverse communities are particularly vulnerable. [11]

In Australia and New Zealand, Pasifika and Māori people have higher rates of mental illness compared to the general population.[12,13] This is compounded by cultural and logistical barriers to accessing health services. In both Australia and New Zealand, Pasifika people use health services less than others and often delay seeking treatment for serious conditions.[14,15,16]

There is little research about the mental health needs of Pasifika people in Australia or their experience of mental health services. We wanted to find out what people using and working within mental health services thought of the support available for Pasifika people, and whether Pasifika communities would be willing to actively engage to develop supportive services.

METHODS

Approach

We conducted eight two-hour focus groups with Pasifika members of the public and the mental healthcare workers supporting them.

We recruited people from across south-east Queensland by inviting them to attend a one-day Pasifika and Māori mental health forum in 2015. We distributed fliers, emails and social media invitations and advertised through community groups. The forum included speakers, cultural dance performances and Polynesian food to encourage people to attend. We invited everyone to take part in a focus group on the day.

We provided participant information sheets and gained signed consent to participate. This was a developmental grassroots event, designed and run by the community for the community. As such, we did not apply to a research ethics committee for approval.

We ran one focus group for each of the following groups: Cook Islands, Fiji/Tokelau, Maori, Niue, Papua New Guinea/Tonga, Samoa, service providers (non-Pasifika) and youth. Each group was facilitated by two people from the specific ethnic group, fluent in that community's language and culture. The facilitators used either English or community languages as desired by the group. A note-taker took verbatim notes during the sessions. Facilitators and note-takers were trained in advance.

Topics of discussion included definitions of mental health and wellbeing; existing community support structures; barriers to using health services; and desired characteristics of culturally specific mental health services.

Participants

A total of 183 people took part, 75% of whom were female. Participants ranged in age from 18 to 70-plus years. **Table 1** shows the ethnic breakdown.

Table 1: Focus group participant characteristics

Group	Number female	Number male	Total number
Cook Islands	5	3	8
Fiji	5	1	6
Tokelau	2	0	2
Niue	8	6	14
Maori	56	12	68
Papa New Guinea	2	0	2
Samoa	17	9	26
Tonga	38	6	44
Service providers	4	4	8
Younger people	1	4	5
Total	138	45	183

Note: People from 1) Fiji and Tokelau and 2) Papua New Guinea and Tonga took part in combined focus groups due to small numbers.

Analysis

We analysed the themes using an inductive approach.[17] A group of Pasifika researchers, community leaders and service developers reviewed the transcripts to identify and categorise key themes. We identified recurring patterns and grouped these into categories, or subthemes. We produced thematic maps to visually represent the categories. We examined relationships between the themes and explored similarities and differences across the groups.

We checked back with community representatives to ensure that the themes we identified resonated.

In this article we focus on themes that applied across the focus groups. We do not break down the views by ethnic group as there were not enough people from each community to allow us to make robust comparisons.

FINDINGS

Is mental wellbeing important for Pasifika people?

Participants were from diverse ethnic groups across the Pacific. However, Pasifika and Maori were united in having a strong holistic perspective about what health was. Health in general was seen to comprise the body, mind, spirit, social and environmental elements. An individual's health was linked to communal wellbeing.

People had more varied definitions of mental health and wellbeing. Some focused on something being physically 'wrong' with people's brain. Others focused on personality traits. But the most common definition of mental health involved issues related to abnormality, difference, stigma, judgement and fear.

> *"[Mental health is] a person that is crazy, possessed… someone who belongs in the loony bin… family isn't interested and not ready to understand what is happening to the person, someone that can be very aggressive and not able to process all issues or surroundings."* (Cook Islands participant)

Focus group participants believed that mental health was important to the wellbeing and spirituality. People commonly believed that mental illness was characterised by 'weakness' or confusion. They emphasised that mental health issues affected the family and community, not solely an individual.

Many Pasifika groups thought that substance or alcohol use was a major influence on the mental wellbeing of their families and communities. They linked substance and alcohol use with physical violence within the family, trauma and mental distress. This was an area that people wanted prioritised for support from mainstream services.

They also acknowledged that younger people faced special pressures, compounded by trying to adapt to a different culture.

> *"[Pasifika] children brought up in Australia and New Zealand seem to have self-conflict or self-doubt of their own identity and expectation. [They are caught between] expectations from their 'Aussie mates' and their own parents, family and elders."* (Tongan participant)

Why don't Pasifika people access mental health services?

Many participants said that mental health conditions were not usually discussed openly due to shame, stigma, fear of being judged and fear of bringing embarrassment to the family. Mental health was viewed as a taboo topic.

> *"Culturally, mental health is an issue which impacts upon the wider family. Mental health is not spoken about in homes due to private shame of the family, and the stigma associated with it. There's a sense of embarrassment and a lack of understanding of what mental health is about. Due to lack of knowledge, it's not openly discussed, but often ridiculed."* (Niuean participant)

People said that Pasifika societies have a communal or collectivist structure, with large extended families the norm. Individuals usually have a strong desire to remain accepted as part of the extended family and community. Those with a mental illness may be viewed as "weak" or "abnormal" so there was significant social pressure to avoid losing status in the eyes of the community.

Some people said that families and communities shunned mental health issues due to a lack of health literacy, education and understanding. Some participants said that mental illness was confused with disability in their community. Others said that it was common to say that someone experiencing distress was 'cursed by God'. The sense of shame in being perceived in this way and desire to remain accepted meant that issues were kept 'hidden' and people did not seek help.

Another barrier to seeking help is that many Pasifika communities spoke about not wanting to express their feelings or emotions. They said that it was culturally ingrained to use humour to deflect issues.

If people did seek support for mental health issues, they commonly approached family members, schools and radio programmes and printed resources in their own language. It was less common for Pasifika people to seek out formal mainstream services in the first instance. If they did access these services, they tended to be referred by a family member, teacher, minister or friend.

One reason that people may not seek support is because healthcare services did not match people's cultural models of health and wellbeing. Participants suggested that services were medicalised and focused heavily on the individual, rather than their family or community. A perceived lack of cultural understanding and respect for Pasifika within services meant people delayed or avoided seeking assistance during times of mental distress.

An example of this was provided in terms of elder care. Participants said that mental health issues were "dumped together with old age and dementia" in healthcare services, whereas in Pasifika communities growing older was respected, valued and seen as an important and natural part of the life course, not something to be 'fixed' or 'medicated'.

What would help meet Pasifika people's needs?

Participants wanted to work with health services to improve the mental wellbeing of their communities. They thought it was vital to consider what having good mental health looks like in order to be clear about the end goal. To our participants, good mental health, and thus the support systems in place, needed to cover physical, social, emotional and behavioural elements.

Queensland has a variety of mental health services, but participants were often not aware of the range of formal and informal support available. They said that Pasifika communities had limited understanding of the usefulness of medical mental health treatment and how health professionals could help. This knowledge varied based on how familiar people were with the Australian health system, which was influenced by people's age and length of residency. Younger people were more likely than their elders to know about the range of services, the words used by health professionals to describe mental health and the potential benefits from support.

> *"The older Samoan generation believe that there is no such thing as mental health disorders. They would more likely relate someone's odd behaviour to being lazy, or being a liar to get out of chores. So, the definition differs between generations. For example, mood disorders are referred to by the younger generation, while the older generation calls an individual 'paie' [lazy]. Also, while one generation refers to psychotic disorders, the other refers to individuals as 'vale's' [dumb]." (Samoan participant)*

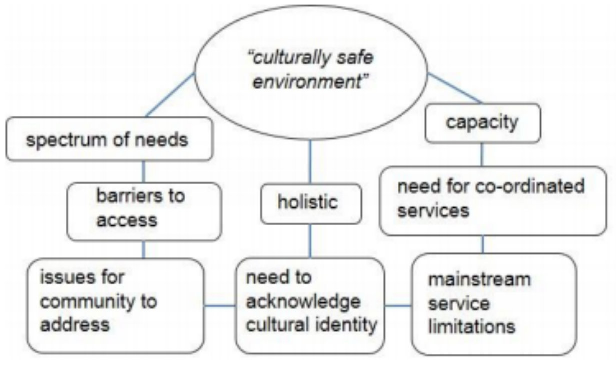
People suggested that it would be helpful to raise awareness about services, including those that may be accessible to non-Australian citizens. They suggested that community groups, schools, social media, churches and cultural radio stations could help spread the word.

There was a consensus that whilst healthcare professionals do their best to cope with high demand and multiple ethnic groups, some basic cultural training would help Pasifika people feel more comfortable approaching and using mental health services. Mental health therapies often encourage people to discuss things openly, sharing intimate details of their lives, thoughts and behaviours. This requires trust, and participants said that it was difficult to attend services and speak freely when they did not feel that providers understood or respected them. Using non-stigmatising language was deemed particularly important so people do not feel 'laughed at' or judged.

Most of all, Pasifika communities wanted to work side by side with health services and with other ethnic groups to help each other with mental health. Participants suggested that health services could allocate ringfenced time to plan health education and build more culturally aware services. Nurturing existing community networks would give access to support groups of like-minded people and build unity for solving communitywide problems.

There were many elements that participants believed influenced culturally safe mental health services (**Figure 1**). Pasifika mental health issues often originate outside the direct control of the health sector, including the financial and housing pressures experienced by migrants, challenges to cultural identity and involvement in criminal activities. People attending the focus groups thought that there should be more cross-sectoral collaboration to achieve cultural safety.

Figure 1: Focus group themes related to culturally safe mental health services[18]



The church was mentioned throughout the focus groups as having a central role in fostering a supportive community. This is also a place where there are high trust relationships that could be built on to provide mental health support more formally.

Participants also wanted representatives to have a seat at the table at regional or institutional healthcare planning. They said that, like other groups, Pasifika communities can be excluded from mainstream planning processes and become increasingly marginalised as a result.

Part of being respected and valued by institutions involves being 'counted'. The healthcare professionals and policy makers who took part said that there was a lack of data about the number and needs of Pasifika people and so it was difficult to include them in service planning. Taking part in the focus groups helped Pasifika communities and health professionals learn more about each other's perspectives. Each group valued the other's perspective on areas for development.

DISCUSSION

Culturally and linguistically diverse groups such as Pasifika communities often suffer from poor physical and mental health. This is influenced by factors such as socio-economic disadvantage, loss of cultural identity, and under-utilisation of health services.[19] This may mean that the mental health needs of Australia's Pasifika communities are not being met, but little research is available about what community members think about this and their preferred solutions.

Our study suggests that members of Pasifika communities are eager to talk about mental wellbeing and work with mainstream services to develop supportive and culturally appropriate approaches.

Pasifika people are over-represented in statistics about mental illness and suicide, but make up less than 1% of the Australian population. We therefore need to be realistic about the amount of time and resource that health services have to develop approaches that are most supportive for these communities, especially given the range of other culturally diverse groups in Australia. Rather than relying on mainstream services to adapt wholly to Pasifika needs, our research suggests that it may be effective for community groups and the voluntary sector to work side by side with health services to maintain Pasifika health and wellbeing.

An important step may be collecting data about the ethnic groups of people using or in need of services. At present we do not have a clear picture of what proportion of mental health service users are from Pasifika communities or the community prevalence of depression, alcohol or substance misuse and similar. This information would help decide whether targeted support approaches may be feasible.

Another implication for practice is that more could be done in Pasifika communities to increase understanding of mental health and wellbeing. Community champions could be developed in churches or cultural groups who are able to help people speak openly in their own language in a comfortable context.

Participants in our focus groups often saw mental illness as a form of weakness and a source of shame. Individuals may avoid talking about mental wellbeing out of fear of bringing shame to their family. This is backed up by other research.[20] The culture of shame and silence is unlikely to be addressed simply by encouraging Pasifika people to visit mainstream services.[21] Instead, health services could upskill and help community groups and local champions to facilitate open discussions and promote wellbeing. Churches, schools, community centres, family groups, community radio and social media may all have a role to play. Studies in New Zealand have found success from this community empowerment approach.[22]

Empowering community support structures could go hand in hand with supporting mainstream services to offer culturally aware services. Australia is multicultural, but healthcare teams receive relatively little training and refresher sessions about people's cultural and spiritual beliefs and expected behaviours. In mental health services, where building trust and compassion can be a lifeline, further awareness training for staff may be especially important. Our research mirrors others who have found that Pasifika people are more likely to access services which consider different cultural perspectives and seek to deliver more holistic care.[23,24,25]

Official resettlement support programmes could include discussions of mental health issues and support. This would help newly arriving families know what to expect from acculturation and where to seek help.

This is one of the first published accounts of a grassroots initiative seeking feedback about Pasifika mental health needs in Australia. A strength is that our approach was developed as a collaboration between community groups and health and care services. Facilitators and participants from many Pasifika communities took part.

However, we have just scratched the surface of the complex issues related to mental wellbeing in Pasifika communities. A limitation of our approach is that we are relying on feedback from people who were interested enough and had the time available to take part in our forum. This self-selected sample may not represent the views and characteristics of the wider communities.

A second limitation is that, due to spatial constraints, in this article we have focused on sharing themes that resonated across all the Pasifika communities and with healthcare professionals. We acknowledge that each Pacific culture is unique and there may be differences between the communities in the most appropriate way to promote and support mental wellbeing.

CONCLUSION

Pasifika people in Australia are at risk of poor physical and mental health outcomes. This can have debilitating impacts for individuals and families, as well as using valuable healthcare resources. The proportion of Pasifika people in the population is relatively small, but the potential burden of poor mental health on healthcare systems and communities is large. It would be unrealistic to expect healthcare services to completely tailor care to Pasifika communities. Healthcare services can however work in partnership with local schools, churches and community groups to raise awareness of mental wellbeing, collect data about mental health needs and train staff to understand cultural perspectives. Our research has shown that communities and health services appear willing to engage. We recommend:

1. improving processes to collect data so services can identify and track Pasifika people's health needs
2. increased health promotion in local communities to de-stigmatise mental illness and educate people about the support available
3. empowering community support structures, to make best use of local resources and knowledge, whilst reducing the burden on formal health services
4. communities and health services working together to train staff to understand the beliefs and needs of Pasifika communities, to support culturally safe and holistic care from the consumer's perspective.
5. resources and knowledge, whilst reducing the burden on formal health services
6. communities and health services working together to train staff to understand the beliefs and needs of Pasifika communities, to support culturally safe and holistic care from the consumer's perspective.

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Family-tree mapping and gender-based violence (GBV) in Niue: research method and intervention

Erin THOMAS,[1] Charlene TUKIUHA,[2] Yvonne UNDERHILL-SEM,[3] Jama'l TALAGI,[4]

ABSTRACT

Introduction: Gender-based violence (GBV) is a product and manifestation of gender relations that inflicts harm disproportionately on those who identify as women and girls. In the Pacific island country of Niue, there is a lack of research and attention on the issue. The aim of this research paper is to examine the use of the family-tree mapping method to research and interpret GBV in Niue with the goal of eliminating violence in social relations and promoting healthy relationships.
Methods: The research involved 14 family-tree mapping interviews using blended narrative-Talanoa methods. Guided by a genealogical approach, this family-tree mapping approach was piloted as a tool for in-depth exploration of how the family space functions around GBV. The research described in the paper did require ethics approval which was granted by the University of Auckland Human Participants Ethics Committee (reference 023589).
Findings: This family-tree mapping framework presents a new way of engaging with the issue of GBV in terms of research and intervention through family-tree mapping in a way that illuminates the dynamics around disclosure, accountability, education, and Talanoa/ gossip, but also protects the privacy of participants.
Conclusion: By making space within families through family-tree mapping to discuss GBV, local advocates and researchers can better understand the complexity and intimacy of family dynamics, uphold the imperatives for privacy and safety important to GBV research, and guide communities towards prevention and accountability.

Key words: gender-based violence, family tree, family violence, domestic violence.

INTRODUCTION

Gender-based violence (GBV) has been a key focus area for gender and development because, by World Health Organisation (WHO) estimates, up to 70 percent of women have experienced physical or sexual violence by men in their lifetimes. [1] In the Pacific, WHO prevalence studies report particularly high rates. In the Cook Islands, Samoa, Tonga, and Tuvalu, these prevalence studies indicate that 38-60% of women have experienced physical, sexual, and/ or emotional intimate partner violence alone. [2]

Pacific women have led change in many spaces related to GBV from community organising efforts in Papua New Guinea [3] to the Fiji Women's Rights Movement winning legislation change.[4] Individual women and children, their families, and communities in the Pacific who have lived with the effects of violence have developed various ways of managing, but the pressures and stresses are enormous.

Corresponding author: Erin Thomas, etho548@aucklanduni.ac.nz

1. Development Studies, University of Auckland
2. Head of Community Affairs/ Services, Ministry of Social Services, Government of Niue, charlene.tukiuha@mail.gov.nu
3. Development Studies/ Pacific Studies, University of Auckland, y.underhill-sem@auckland.ac.nz
4. School of Public Policy, University of Auckland, jtal025@aucklanduni.ac.nz

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GBV includes all tactics employed predominantly by men to control predominantly women. It may involve "physical, psychological, sexual and/or economic abuse, in domestic environments and public spaces, with known or unknown assailants". [5] It occurs as a result of social relations that normalise violence as a tool to reinforce gender roles and norms. GBV does not occur in exactly the same way around the world, and the central theme of this research is that GBV cannot be essentialised, nor can its respective interventions. [6]

In all of the GBV research in the Pacific, Niue has fallen through the cracks. In the Pacific, as well as other parts of the world, prevalence studies have been the main source of research on GBV. [7] These studies rely on the WHO standard methodology [8] that employs surveys to capture the quantitative prevalence of different types of GBV. These studies provide valuable insights into the scope of the problem in a given place and context-specific risk and protective factors but are often not enough to craft effective interventions. Further, the small population on Niue poses ethical challenges in using quantitative methodologies. In particular, protecting the privacy of individuals is a significant challenge.

The 2017 research undertaken by the first author with the International Center for Advocates Against Discrimination (ICAAD), found that GBV is a persistent problem in Niue and that it remains a gap in existing literature. [9] Further, a report from the South Pacific Community [10] highlighted domestic violence as a problem and the conflicting challenge of the perception that gender inequality is not a problem in Niue. Available research comes primarily from reports from international and regional organisations[11] , and the academic research to date has only focused on Niueans living in New Zealand. [12]

Public health research on Niueans in New Zealand provided guidance in how to conceptualise the spaces in which GBV is prevented and addressed. [13] This research as well as that of the first author in 2017 [14] pointed to the family as a crucial space in terms of understanding and addressing GBV in Niue. Building on these findings, the present research pilots a new approach in using family-tree mapping as a tool to consider the intricacies of the family space. The *magafaoa,* family and extended family, is where guidelines for gender relations are socialised, where burdens are shared, and where ancestry lives. [15] In this research, it is both a space in which GBV is addressed as well as a research method through family-tree mapping.

Genealogy is a major thread in many Pacific research methodologies as well as recent research in Niue. In Pasisi's research [16] , Niue women's stories about climate change included stories of their genealogies which allowed Pasisi to access the richness of women's knowledge embedded in ancestry. Stories of how gender expression is understood within ancestry can provide context for understanding gender today. Because gender is socialised, with the family being a major social space, the lessons from our families, including our elders, speak to the way our families understand and express gender.

This methodology is in the spirit of *Fakatupuolamoui,* the Niuean conceptual framework developed by Niueans in New Zealand for addressing family violence which leans on positive aspects of *Aga Fakamotu* (Niuean culture, the Niuean way). [17] In this sense, the research design is focused on the positive development of the *magafaoa* in preventing and addressing GBV.

METHODS

The research took place over four weeks from 19 October to 15 November 2019 in Niue with interviews led by American researcher Erin Thomas (hereinafter, primary researcher) with support from co-author Niuean counsellor and Head of Community Affairs/ Services Charlene Tukiuha. The research involved two parts: 27 fact-finding interviews with 32 participants and 14 family-tree mapping interviews with a woman from each village. The fact-finding interviews with government and community leaders provided crucial relationships and context to understand the recurring narratives around GBV, but the focus of this article will be on the second part: the 14 family-tree mapping interviews.

Family-tree interview participants were recruited through the village women's councils with one in each of the 14 villages. Chairpersons of each women's council were given the details of the research in English and Vagahau Niue and asked to select a participant in a manner appropriate for their group. The council could refuse to participate as a collective, and if they did choose to participate, the selected participant could also withdraw at any point. If the selected participant withdrew, we contacted the Chairperson again to, if their council still wanted to participate, select another participant. This approach was chosen in order to include a range of families and to ensure that the data collected was exhaustive enough to be publicly accepted in Niue, meaning as representative as possible.

There was a total of 14 interviews ranging from 60-180 minutes, averaging 120 minutes. There were no age restrictions, but members of the village women's councils were mainly women over 40. Participants were all between 40 and 80 years old with an average age of 64 years. At the start of the sessions, it was explained that the focus would not be on any situations or events whereby the participant was directly involved in violence. After each interview, participants were given a small gift and thank you card in reciprocity for their time.

During the interviews, we mapped their social family tree focusing on family members living in Niue (**Table 1**). We drew the family tree no more than two generations. This took 30 minutes on average in each interview. Similar methods have been used most notably in anthropology and psychology as well as in the process of post-mortems by the New Zealand Family Violence Death Review Committee. [18] Then, questions were asked around the areas of disclosure, accountability, education, and Talanoa/ gossip in the family (see Table 2). Disclosure involves when and how the participant became aware of the situation. Education is about lessons shared within the family about relationships, gender roles, and GBV. Accountability refers to if and how the person who caused harm was held accountable. Talanoa/ gossip in this use involves the gossip and discourse in the family around a specific GBV situation.

For the family-tree mapping interviews, the primary researcher used Doucet and Mauthner's [19] Listening Guide to do a four stage review of each transcript. The first review involved a reflexive reading for immediate reactions and interpretations. The second review traced the participant and how she spoke about herself. The third review mapped her relations with others in the narrative. The fourth review was a conceptual narrative that wove all of those reviews together. In the practice of empathic apprenticeship, it was important for the goal of the analysis to learn about and understand the participant's narrative.[20] Through the research, this meant developing place-specific cultural competency and an attunement to participants' talanoa.

This approach derives from the theoretical framework. The literature as well as the primary researcher's positionality as a non-Pacific researcher, advised closely by Niuean collaborators, culminated in a narrative-Talanoa style for the family-tree mapping which is a hybrid of the Pacific research methodology, talanoa[21], and a feminist narrative approach. [22]

Talanoa is Pacific-specific "storying" [23], and many indigenous communities throughout the Pacific note that storytelling is a powerful methodological tool because "it facilitates the expression of experiences and fits well with feminist research methods and Indigenous oral history traditions". [24]

This aligns, in many ways, with a feminist narrative framework in which, as Somers[25] has articulated, narratives allow the narrators many ways to draw from other societal narratives, including cultural practices and values, to construct something that is uniquely their own. Still, it is important to account for the ontological barriers for non-Pacific researchers to interpret Pacific talanoa.[26] As such, the methodology employed in this research is not purely Talanoa. In order to honour Niue knowledge and ways of knowing, elements of the Talanoa approach including empathic apprenticeship, cultural competency, and relationships were prioritised. [27]

RESULTS

There are numerous methodological and ethical challenges to publishing the findings of this research, as two authors are outsiders to the community in Niue. The small population of Niue means quotes and examples could easily identify participants. In response to this challenge, the family-tree mapping interviews were storied as a dialogue between the primary researcher and two women who had been interviewed.

The story[28] was an imaginary composite of the narratives heard in the interviews and meant that individuals identities and stories were protected. However, it also provided critical nuances of some of the major themes including the meaning of marriage, gender roles and expectations, domestic violence within marriages, sexual violence and marital rape, and family education.

In this paper, we share learnings from the family-tree mapping approach and the potential application of the approach in research and interventions. In order to assist in using or learning from this method in the future, we will discuss some of the lessons learnt in using this approach. We will also share how this family-tree mapping approach can be used in both formal research and as an intervention to address GBV within families and communities.

Table 1. Family-tree Mapping Interview Framework

Phase 1. Family-tree Mapping	Co-design participant's social family tree visually on paper.
Phase 2. Discussing Family Relationships	Moving through different relationships at different generational levels to learn about events or incidents that changed family dynamics.
Phase 3. In-Depth Discussion About Specific Situations (depending on relationship with participant)	Revisiting situations raised in phase 2 to explore disclosure, education, Talanoa, and accountability related to GBV within the family.

Table 2. Family-tree Mapping Interview Thematic Areas.

Disclosure	How/where/when/with whom do individuals come forward about their experiences with GBV?
Education	How/where/when/with whom does education about healthy relationships happen within families?
Accountability	What does accountability look like for perpetrators of GBV in the formal system? In the family? Were the accountability measures effective? What does accountability within the family look like?
Talanoa/ Gossip	How is the family discussing incidents of GBV and gendered relations in relationships? Is it furthering our family's values? How is the broader community discussing these incidents of GBV? How can we contribute to shaping these broader discussions?

Family Tree Mapping in Practice

These lessons come from field notes and reflections. At the end of each interview, the primary researcher asked how the interview went, leaving it open for the participant to share their thoughts. These lessons included the healing potential of interviews and the importance of valuing the participant's knowledge of her own experiences. One of the major concerns with this approach was the possibility of retraumatisation if participants had experienced violence in the past. This is a common concern when conducting research on GBV, and the psychological research on the topic is mixed.[29] Fontes[30] argues that there are several risks even beyond psychological risk that can affect participants in the short and long term, and it is difficult to assess the full impact of GBV research on participants. However, others have described the potential therapeutic benefits of GBV research that involves qualitative interviews.[31]

To minimise potential retraumatisation in these family-tree mapping interviews, there was plenty of space in the interview to avoid any of the participants' direct experiences with GBV. However, some participants shared their personal experiences unprompted. While the primary researcher was initially concerned about this, the feedback from participants suggested that the interviews were more therapeutic than anything else. As one participant expressed when the primary researcher followed up a few days after the interview:

"I told my husband about the interview. I didn't realise how therapeutic it would be. These were things all in the back of my head that I was able to let out."

That being said, there will always be concerns about the immediate and long-term impacts of GBV research on interview participants. When conducting these interviews, the narrative-talanoa approach made it clear that the relationship and the person being interviewed was much more important than the data collection. This was both to produce rich information and to protect the safety and wellbeing of participants. Further, before and after the interviews, participants were reminded about their referral options for counselling which may be accessed for any reason and any point in time. They were also reminded that these conversations can raise experiences that have delayed emotions.

In their feedback, most participants shared that they felt they could open up. One participant said the primary researcher was easy to talk to because they seemed genuine and not like a "researcher." That was the balance that was sought in the narrative-Talanoa approach. When it came to opening up and sharing sensitive topics, another participant said she was fine to talk about her family because everyone in the community already knew the stories about her family. Others, like the participant who shared the quote above, had not shared these types of stories with anyone but close confidants. While we are sure participants felt different levels of comfort with opening up based on numerous factors including their relationship to the primary researcher, this is the part of empathic apprenticeship[32] that is crucial to unearthing participants' realities.

Some participants shared their anxieties about saying the "right things." One participant curiously asked, "did other people laugh as much as we did?" The interpretation of this feedback was two-fold. First, it reflected participants' comparisons of their family to other families and curiosity about how their family measured up in Niue. The other interpretation was that it suggested participants believed there were "right things" to say in the first place. This is perhaps a shortcoming of the narrative parts of the approach which might have come across as too formal and not based enough on relationships which would have generated a sense of ontological pluralism, where there are no "right things" to say but only what is right to the participant.

DISCUSSION

One of the major challenges in GBV research is striking the balance between centering lived experiences with, at the same time, the participants' wellbeing in discussing this sensitive topic.[33] Examples of GBV research that balance these dynamics in the Pacific are common in recent arts based approaches like sociodrama in Samoa,[34] community theatre in Vanuatu[35], and photo voice in Papua New Guinea.[36]

In this research, the family-tree mapping methodology engaged in a familiar practice where a range of family relations are discussed while avoiding directly raising personal experiences with GBV. Some participants found a level of comfort to discuss more intimate details - either their own or that of members of their family but the level of disclosure was controlled entirely by the participant.

Insights from the use of this family-tree mapping method to study GBV suggest that it could be applied in other contexts as both a research and intervention tool. The strength of this approach is that it creates a space to talk about GBV that honours women's knowledge and authority while centering the family as context for disclosure, education, accountability, and Talanoa/ gossip. By building empathic spaces for understanding ourselves and relationships in the complex social webs of our families and beyond, we can better understand patterns of GBV across the continuum of violence.

In terms of research practice, the family-tree mapping approach is complicated in that the resulting data is crucially situated within the relationships discussed in each interview, and writing about those relationships with any specificity risks breaching anonymity. However, the data illuminates some of the dynamics of addressing GBV within the family space which is often rendered invisible in public policy. It comes at the high cost of needing to maintain privacy and participant safety.

This approach can be a powerful research tool for local advocacy efforts. Local advocates interested in women's rights and reducing GBV in the Pacific, and potentially beyond, can find deeper understanding of the dynamics within families while also creating spaces for such discussion.

For Pacific researchers and advocates, feminist Pacific research methodologies[37] point to the use of group Talanoa which could create an opportunity to discuss GBV in a different way and collectivise the issue. Group sessions were not done in this research for logistical and time reasons, but a local advocate would be better positioned to facilitate these and pursue this line of inquiry.

Local advocates would also be in a strong position to apply the insights from the family-tree mapping to further community programming and interventions. The approach can allow advocates to collect stronger data that captures the often hidden family dynamics around GBV. It can also be a pathway for community organising to orient to the social unit of the family with the goal of shifting gender relations. As with anyone leading this type of research, there must be established trust, privacy, and safety for participants and advocates. Insiders can potentially face unique challenges in maintaining this privacy and safety.

For community outsiders conducting this type of research, community partnerships are needed to ensure the research will be useful and that it is designed appropriately for the community. Because this approach is highly context-specific, these relationships that guide the culturally-specific design of the project are an essential starting point. For all applications of this research method, multiple Talanoa sessions with participants would be helpful in building researcher-participant relationships and digging deeper into participants' felt and lived experiences.

There are several possible uses of the family-tree mapping interview as a tool for intervention. These include individual and group counselling and more decentralised practices of the approach. The potential for a counselling setting lies in the approach's unique way of unpacking intergenerational family dynamics alongside an individual's own relationships. While it may not be as helpful for clients dealing with personal experiences of GBV at that moment, it can help provide a framework for thinking about how the family is involved in incidents of GBV.

An important barrier here is that there is resistance to help-seeking through counselling in Niue because of privacy concerns. Counselling through faith-based leaders emerged as a common practice in fact-finding and family-tree mapping interviews. The use of family-tree mapping with faith-based leaders is another area for further exploration.

In terms of a more decentering approach, the family-tree mapping approach does not have to be a formal interview. The family-tree mapping approach is about using our understanding of our social families to critically contemplate relationships, particularly romantic and sexual relationships, and the broader family involvement and history while centering and valuing women's knowledge and authority. Family-tree mapping helps us position ourselves in the network of family relationships and employ our values to guide a path forward on how to give meaning to our own experiences, and those of our family members, with GBV.

In applying this decentering approach, it could be a part of an awareness campaign demonstrating how to start such conversations. These conversations are not exclusively for women or one-on-one; however, expectations of respect, safety, and privacy must be established to build trust in the space and to minimise potential for harm. It is helpful to break down these conversations into the themes of disclosure, education, accountability, and Talanoa.

These areas provide a framework for reflection on the past, contemplation of the present, and planning for the future. These questions do not need to come up formally and are not age-specific. While barriers to having these conversations is often a lack of disclosure or intergenerational respect, there are opportunities for learning about relationships and their gendered dynamics at any time even if GBV is not apparent. For example, if appropriate, a young woman could ask her mother about some aspects of her dating life when she was young. The conversation can expand to the daughter's aunties and make space for curiosity where the mother and daughter can consider the family's values as they measure up in different situations. Instead of gossiping about an incident of GBV, siblings or cousins can discuss the meanings that the community has given to the incident and how they might contribute to shaping those broader discussions.

When the family-tree mapping approach is applied as an intervention, ideally it should be led by local women's rights advocates who have an understanding of cultural protocols who can ensure the cultural and ethical sensitivity of the programme. Part of this must be a determination about expectations of accountability, the legal implications of disclosure, and support for community accountability processes if needed. Being culturally-specific also involves the knowledge of historical trauma specific to the community in focus. Language is also a key concern. If this type of intervention were to be used in Niue, it is essential that it is conducted in Vagahau Niue to capture the emotions and meanings for those participating.

CONCLUSION

While there are challenges to researching and addressing GBV, the family-tree mapping method presents several opportunities for addressing the enduring negative impacts of this problem. Spaces within families offer opportunities to support one another when they disclose experiences with GBV; to learn and educate each other about healthy relationships among all genders; to hold space for accountability in the community; and to critically consider how to respond and contribute to community discourses about GBV-related gossip. For many participants, engaging with family around this topic was familiar. Examples of disclosure, education, accountability, and Talanoa/ gossip could all be found in their stories. As we map it out together, we see how genealogies live through descendants and families, chosen and biological, and have always been spaces where our stories are shaped, together.

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Ethnic Identity Buffers the Effect of Discrimination on Family, Life, and Health Satisfaction for Pacific Peoples in New Zealand

Sam MANUELA

Senior Lecturer, School of Psychology, University of Auckland, Auckland, New Zealand

ABSTRACT

Introduction: The effect of discrimination on health and wellbeing varies. Mixed findings show that greater ethnic identity can make one more susceptible to the harmful effects of discrimination, or that ethnic identity can protect one against discrimination. This study tests how ethnic identity moderates the relationship between ethnic discrimination and a range of wellbeing measures for Pacific peoples in Aotearoa New Zealand.

Methods: Two independent studies, The Pacific Identity and Wellbeing Study (N = 752) and the New Zealand Attitudes and Values Study (N = 472), surveyed Pacific peoples in New Zealand across measures of ethnic identity, perceived discrimination, family satisfaction, life satisfaction, and health satisfaction.

Findings: Moderated regression analyses for both studies showed a significant identity x discrimination interaction. Across all analyses, for those with lower ethnic identity scores, there was a significant negative relationship between discrimination and the health and wellbeing measures. For those with higher ethnic identity scores, there was no significant relationship between discrimination and wellbeing measures.

Conclusions: These results suggest that higher scores of Pacific ethnic identity buffer the negative effects of discrimination on satisfaction with family, life, and health. These findings offer support for the protective properties of Pacific ethnic identities. As such, initiatives that seek to bolster Pacific ethnic identities and culture will support a multifaceted approach for enhancing Pacific health and psychological wellbeing.

Keywords: Pacific; Ethnic identity; Discrimination; Wellbeing; Health

INTRODUCTION

Ethnic identity has been posited as a protective factor for the health and wellbeing of Pacific peoples in New Zealand. However, wider psychological research on the effects of ethnic discrimination and ethnic identity on psychological wellbeing has shown mixed findings across a diverse range of ethnic groups.[1] This paper presents two studies that test how Pacific peoples' ethnic identity moderates the relationship between perceived ethnic discrimination and ethnic identity on measures of wellbeing and health satisfaction.

Discrimination, health, and wellbeing

Meta-analyses across multiple ethnic groups internationally show that self-reported experiences of discrimination are associated with negative physical and mental health outcomes.[2,3] Likewise, a recent systematic review of quantitative racism and ethnic discrimination research in New Zealand shows discrimination is associated with negative health outcomes.[4] Overall, as Talamaivao *et al*. note, discrimination is a key determinant of health, and the differential experiences of ethnic discrimination endured by Pacific peoples in Aotearoa can explain health inequities that exist between ethnic groups.

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Pacific peoples have contended with overt and subtle discrimination in NZ since the initial waves of migration. The 'Dawn Raids' during the 1970's saw Pacific peoples unfairly targeted in a government crackdown on immigration. Discriminatory acts are often fuelled by negative stereotypes in media[5], and perceptions of Pacific peoples as generally warm peoples but with low competence[6]. Pacific students often experience discrimination, in spite of their academic success.[7] In terms of health, those that report experiences of discrimination are more likely to report lower health satisfaction, poor mental health, more likely to report cardiovascular disease[8] and more likely to report unfair health treatment.[9] Pacific experiences of ethnic discrimination are also associated with increased psychological distress, lower subjective wellbeing, and lower self-esteem.[10] These studies highlight Pacific peoples experience discrimination in Aotearoa across a broad range of contexts and settings, which have direct negative effects on health and wellbeing.

Ethnic identity, health, and wellbeing

Ethnic identity refers to a range of feelings and attitudes that one has about the ethnic group/s they belong to. Phinney[11] describes ethnic identity as identification with an ethnic group, a sense of belonging, positive/negative attitudes towards that ethnic group, and ethnic behaviours. Ethnic identity is generally associated with positive outcomes such as self-esteem, academic achievement,[12] and lower depressive symptoms.[13] A meta-analysis of 184 studies of people of colour found an overall positive relationship between ethnic identity and multiple indicators of wellbeing.[14] There is increasing interest in how ethnic identity can enhance health[15] where it is likely that the relationships that inform identity also contribute to a social environment that facilitates support and agency.

Broader Pacific understandings of identity emphasise an interconnected self, with focus on relationships, family, and spirituality.[16] Pacific identities can be understood through vā – the sacred relational space between that connects. Thus, the self is who you are in relation to others in a given context, and the nature of the relatedness between the self and the other. For instance, it is understanding the nature of the vā between, say, a husband and wife, and how this differs from the vā between a brother and sister. It is recognising one's identity is a combination of the vā between the self and multiple others.[17] Likewise, psychological wellbeing can be understood as the nature and quality of the vā. It is here that efforts to tauhi vā (Tongan) or teu le va (Samoan), to nurture the space between, are a way to understand what wellbeing is. Because the self is consists of the vā between self and others, damage to the vā can result in damage to the self. It is through this understanding then, that wellbeing for Pacific can be understood through the quality of the relationships between self and others, where damage to the vā can be the same as damage to wellbeing, whilst efforts to repair or nurture the vā can be the same as bolstering or enhancing wellbeing.

Ethnic Identity and Discrimination

With general research consensus showing ethnic identity is positively related to health and discrimination negatively related to health, what happens when someone experiences discrimination on the basis of their ethnicity? The interaction between ethnic discrimination and ethnic identity has shown mixed findings; (i) ethnic identity buffers the effects of discrimination, (2) ethnic identity exacerbates the effects of discrimination. Yip's[1] synthesis of ethnic identity and discrimination research suggests that they both inform each other. Yip points out that identity can both protect and exacerbate the effects of discrimination on mental health, however this seemingly contradictory role of identity can be understood through how identity develops, and different dimensions of identity. For example, people who are exploring or trying understand what their identity means to them (identity exploration) might be more prone to the negative effects of discrimination. However, those that have a secured understanding of their identity and show a commitment to it (identity commitment) may be protected against it.[18] Furthermore ethnic affirmation may also be positively related with mental health, which may be stronger for those that view their ethnicity as a more centrally defining aspect of the self, and have a secure ethnic identity.[19]

Overall Study Aims

Two studies are presented here that will each test how ethnic identity moderates the relationship between perceived ethnic discrimination and a range of wellbeing indicators, for Pacific peoples in NZ. Study 1 will used data from The Pacific Identity and Wellbeing Study and will identify if and how ethnic identity can moderate the relationship between discrimination and wellbeing. Based on the review of literature above, it is hypothesised that ethnic identity will have a buffering effect. Study 2 will use data from an independent study (The New Zealand Attitudes and Values Study) to see if the same pattern of results in Study 1 will be replicated.

STUDY 1

METHOD

Participants and Procedure

Participants (N= 752, 166 male, 586 female, mean age = 29.65, SD = 10.50) responded to an email advertisement inviting them to be part of an online study on Pacific identity and wellbeing. Participants responded to an email advertisement inviting them to be part of an online study on Pacific identity and wellbeing. The email was sent to a variety of Pacific groups, organizations and community networks. A snowball sampling method was also used, where participants were asked to invite others in their networks to participate in the study, thus the data cannot be considered as representative of the Pacific population in NZ. Participants were entered into a draw to win $300 worth of grocery vouchers.

Measures

Ethnic identity

Ethnic identity was assessed using the identity related factors of the Pacific Identity and Well Being Scale.[20] Participants were asked to rate how they agreed with statements on a 1 (strongly disagree) to 7 (strongly agree) Likert scale. Our identity factor of interest is the Group Membership Evaluation factor (5 items, $\alpha = .88$). Example items participants responded to include: "Being a Pacific Islander gives me a good feeling" "Being an Islander is an important part of how I see myself" "I am proud to be a Pacific Islander". Additional identity factors include Pacific Connectedness and Belonging (6 items, $\alpha = .79$), Religious Centrality and Embeddedness (6 items, $\alpha = .84$), and Cultural Efficacy (4 items, $\alpha = .74$). Scores for each factor were created using the average scores of the items.

Discrimination

Perceived Discrimination was assessed using 1 item where participants were asked to rate the item "I feel that I am often discriminated against on the basis of my ethnicity" on a 1 (Strongly Disagree) to 7 (Strongly Agree) Likert scale.

Perceived Ethnic Discrimination was assessed using 1 item where participants were asked to rate how their thoughts on the question "Do you think people from your ethnic group are discriminated against in NZ?" on a 1 (Definitely Not) to 7 (Definitely Yes) scale.

Wellbeing measures

Perceived Familial Wellbeing (PFW) was assessed using the respective factor from the Pacific Identity and Wellbeing Scale[20] Participants were asked to rate how satisfied they were (1 completely dissatisfied, 7 completely satisfied) on seven domains of family relationships. Examples include satisfaction with "Communication with your family", "Your family's happiness" and "Your position within your family" ($\alpha = .86$). PFW was calculated by averaging the responses to each item.

Satisfaction with Health was assessed using an item taken from the Personal Wellbeing Index. Participants were asked "How satisfied are you with 'Your health'" and were instructed to respond on a 0 (completely dissatisfied) to 10 (completely satisfied) scale.

Demographics Participants were asked to indicate their gender (coded as 0 = male, 1 = female), age in years and their country of birth (coded as 0 = born overseas, 1 = born in NZ).

Ethics

The Pacific Identity and Wellbeing Study was approved by The University of Auckland Human Participants Ethics Committee on 26 June 2009 and renewed on 3 June 2012 until 3 June 2015 Reference Number: 6071.

Analysis

A moderated, multivariate regression using Bayesian estimation was performed using MPlus (version 7.4). The key predictor variables of interest were Group Membership Evaluation (GME) and Perceived Discrimination (PD). An interaction term was created by first mean centering the two predictor variables, then multiplying them together (PD x GME). The mean centred GME, PD, and the PDxGME interaction term were all entered into the model as predictor variables. Demographic information (Gender, age, country of birth), and Group Discrimination were entered as covariates. Perceived Familial Wellbeing and Satisfaction with Health were simultaneously entered as outcome variables. An additional regression model was performed (**Model 2**), including the additional identity related measures of the Pacific Identity and Wellbeing Scale. These results are presented in **Table 2**.

RESULTS

STUDY 1

Perceived Familial Wellbeing

Descriptive statistics and correlations are presented in **Table 1**. Results of the moderated multivariate regression are presented in **Table 2**. As seen in Table 2, the effect of gender was significant, with males scoring lower than females. PD was associated with familial wellbeing. Of key interest, the PD x GME interaction was significant. Simple slopes were calculated and showed a significant negative slope for those with lower GME scores (*b*slope = -.094, *Post.SD* = .026, 95% CI [-.156, -.043], *p* < .001) and not significant for those with higher GME (*b*slope = -.014, *Post.SD* = .024, 95% CI [-.62, .034], *p* > .05). A plot of these slopes can be seen in the left panel of Fig 1. As seen in Model 2 in Table 2, when controlling for other facets of Pacific ethnic identity, CEF was positively associated with familial wellbeing. The GME x PD interaction also remained significant where the negative effect of perceived personal discrimination on familial wellbeing was significant for those with lower GME (*b*slope = -.091, *Post.SD* = .026, 95% CI [-.142, -.040], *p* < .001), and not significant for those with higher GME (*b*slope = -.014, *Post.SD* = .024, 95% CI [-.062, .033], *p* > .05).

Satisfaction with Health

As shown in **Table 2**, there was a significant, negative main effect of both perceived and personal discrimination. A significant, positive main effect of GME was also found. The PD x GME interaction was significant. As shown in the right panel of **Figure 1**, the negative effect of perceived personal discrimination on satisfaction with health was significant for those with lower GME (*b*slope = -.135, *Post.SD* = .046, 95% CI [-.224, -.045], *p* = .002), and not significant for those with higher GME (*b*slope = -.016, *Post.SD* = .043, 95% CI [-.100, .068], *p* > .05).

When controlling for other facets of Pacific ethnic identity, the PD x GME interaction was not significant. However negative main effects were observed for perceived group and personal discrimination and a significant, positive main effect was found for CE.

Figure 1: The moderating effect of Group Membership Evaluation on the relationship between Personal Ethnic discrimination and Perceived Familial Wellbeing (left) and Satisfaction with Health (right). Note: the y axis on the right begins at 4.

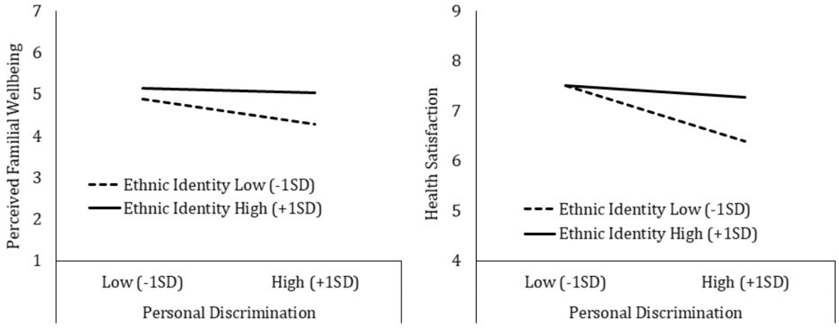

Table 1: Descriptive statistics, bivariate correlations and Cronbach's alphas for Pacific identity, wellbeing and discrimination variables

	1.	2.	3.	4.	5.	6.	7.	8.	9.	10.	11.
1. Gender (0M, 1F)	-										
2. Age	.04	-									
3. NZ Born (0N, 1Y)	.07	-.08*	-								
4. PFW	-.11*	.06	-.04	-							
5. Health Satisfaction	-.01	.05	.03	.42*	-						
6. GME	-.02	-.01	.01	.28*	.09*	-					
7. PCB	-.03	.05	.02	.23*	.03	.58*	-				
8. RCE	-.06	-.07	.04	.17*	.04	.29*	.31*	-			
9. CEF	-.02	.10*	.02	.30*	.18*	.42*	.48*	.27*	-		
10. Personal Discrimination	-.08*	.00	-.2	-.17*	-.18*	-.01	.04	-.02	-.08*	-	
11. Group Discrimination	.01	.08*	.01	-.16*	-.22	-.02	.05	-.05	-.09*	.43*	-
M	-	29.55	-	5.91	5.07	6.40	5.76	5.37	5.40	3.73	4.43
SD	-	10.46	-	.94	1.59	.90	1.03	1.43	1.24	1.91	1.92
Cronbach's Alpha				.86		.88	.79	.84	.74		

N = 472

Table 2 - Estimates for multivariate moderated regression model using Bayesian estimation assessing Perceived Familial Wellbeing and Health Satisfaction

				95% Credible Interval					**95% Credible Interval**	
	Estimate	**Post.*SD***	***p***	**Lower 2.5%**	**Upper 2.5%**	**Estimate**	**Post.*SD***	***p***	**Lower 2.5%**	**Upper 2.5%**
Model 1										
Gender	-.216	.078	.003	-.370	-.062	-.034	.137	.403	-.30.	.236
Age	.005	.003	.068	-.002	.011	.007	.006	.095	-.004	.018
NZBorn	-.140	.074	.029	-.284	.005	-.229	.128	.037	-.482	.022
GD	-.052	.019	.003	-.089	-.015	-.151	.033	.000	-.222	-.087
PD	-.054	.019	.002	-.091	-.017	-.076	.033	.012	-.140	-.010
GME	.286	.036	.000	.215	.357	.135	.063	.016	.012	.258
PDxGME	.045	.019	.009	.008	.081	.066	.033	.022	.002	.130
Model 2										
Gender	-.201	.077	.005	-.352	-.049	-,035	.136	.399	-.299	.233
Age	.004	.003	.137	-.003	.010	.005	.006	.166	-.006	.017
NZ Born	-.106	.073	.074	-.248	.038	-.196	.128	.064	-.446	.056
CE	.126	.031	.000	.066	.187	.198	.054	.000	.092	.304
PCB	.053	.041	.098	-.027	.133	-.090	.072	.106	-.231	.052
RCE	.027	.024	.132	-.020	.074	-.013	.043	.384	-.096	.071
GME	.167	.045	.000	.079	.255	.088	.079	.132	-.066	.242
GD	-.046	.019	.007	-.082	-.009	-.140	.033	.000	-.204	-.075
PD	-.052	.019	.003	-.089	-.016	-.069	.033	.018	-.133	-.004
PDxGME	.043	.019	.011	.006	.079	.062	.033	.029	-.002	.126

N = 752. Perceived Familial Wellbeing is measured on a 1-7 scale and Health Satisfaction 0-10. Post.*SD* = posterior standard deviation. *p* = proportion of the posterior distribution below 0 for a positive effect, and the proportion of the posterior distribution above 0 for a negative effect. NZ Born = 0 No, 1 Yes; GD = Group Discrimination; PD = Personal Discrimination; GME = Group Member Evaluation; CE = Cultural Efficacy; PCB =Pacific Connectedness and Belonging; RCE = Religious Centrality and Embeddedness.

STUDY TWO

Having identified that GME moderates the relationship between discrimination and wellbeing, Study Two will test the same identity x discrimination interaction using data from an independent study – The New Zealand Attitudes and Values Study. The aim of this study is to replicate the same pattern of results found in Study 1; that ethnic identity will moderate the association between discrimination and wellbeing measures.

METHOD

Participants and Procedure

Study Two uses data from Time 4 (2012) of the New Zealand Attitudes and Values Study (NZAVS). The analyses presented here focus on a subset of the overall sample that identified their ethnic affiliation with a Pacific Nation (*N* = 472). The Pacific participants in these analyses are 156 men and 316 women, with an overall average age of 39.24 years (*SD* = 13.58). Participants were initially sampled from the 2009 New Zealand electoral roll, and this sample includes those that were retained from this initial sampling wave, those that were retained from additional waves using booster samples, and unsolicited opt-ins. Please see Sibley[22] for a detailed explanation of the sampling procedures used.

Materials

Ethnic identity

Ethnic identity was assessed using three items from a subscale of ethnic identity centrality.[21] The items were asked to rate the items "I often think about the fact that I am a member of my ethnic group." "The fact that I am a member of my ethnic group is an important part of my identity" and "Being a member of my ethnic group is an important part of how I see myself" (α = .73). Participants rated items from 1 (strongly disagree) to 7 (strongly agree). An ethnic identity score was calculated using the mean of all three items.

Discrimination

Perceived Discrimination was assessed using 1 item where participants were asked to rate the item "I feel that I am often discriminated against on the basis of my ethnicity" on a 1 (Strongly Disagree) to 7 (Strongly Agree) Likert scale.

Perceived Ethnic Discrimination was assessed using 1 item where participants were asked to rate how their thoughts on the question "Do you think people from your ethnic group are discriminated against in NZ?" on a 1 (Definitely Not) to 7 (Definitely Yes) scale.

Wellbeing Outcomes

Satisfaction with life was assessed using two items "I am satisfied with my life" and "In most ways my life is close to ideal" from the Satisfaction With Life Scale.[23] Participants were asked to rate the items from 1 (strongly disagree) to 7 (strongly agree). A satisfaction with life score was calculated using the average of both items (α = .79).

Satisfaction with Health was assessed using an item taken from the Personal Wellbeing Index.[24] Participants were asked "How satisfied are you with 'Your health'" and were instructed to respond on a 0 (completely dissatisfied) to 10 (completely satisfied) scale.

Demographics

Participants were asked to indicate their gender (coded as 0 = male, 1 = female), age in years and the country in which they were born (coded as 0 = born overseas, 1 = born in NZ).

Ethics

The New Zealand Attitudes and Values Study was approved by The University of Auckland Human Participants Ethics Committee on 9 September 2009 until 9 September 2012, and renewed on 17 February 2012 until 09 September 2015. Reference Number: 6171.

Analysis

A moderated, multivariate regression using Bayesian estimation was performed using MPlus (version 7.4). The key predictor variables of interest were Ethnic Identity Centrality (EIC) and Perceived Discrimination (PD). An interaction term was created by first mean-centering the two predictor variables, then multiplying them together (PD x EIC). The mean centred EIC, PD, and the PDxEIC interaction term were all entered into the model as predictor variables. Demographic information (Gender, age, country of birth), and Group Discrimination were entered as covariates. Life Satisfaction and Satisfaction with Health were simultaneously entered as outcome variables.

RESULTS

Life Satisfaction

Descriptive statistics and correlations are presented in **Table 3**. Results of the moderated multivariate regression are shown in Table 4. As shown in Table 4, there was a significant positive main effect of age and ethnic identity). There were also significant negative main effects of both perceived group discrimination and personal discrimination. Critically, the PD x ID interaction was significant. Simple slopes were calculated, and show the negative effect of perceived personal discrimination on satisfaction with life was significant for those with lower ethnic identity (*b*slope = -.170, *Post.SD* = .047, 95% CI [-.261, -.078], *p* < .001) and not significant for those with higher ethnic identity (*b*slope = -.029, *Post.SD* = .047, 95% CI [-.121, .062], *p* > .05). A plot of the slopes are presented in the left panel of **Figure 2**.

Health Satisfaction

As show in Table 4, there was a significant main effect of country of birth where those born in NZ reported lower satisfaction with health relative to those born overseas. There was also a significant negative main effect of perceived personal discrimination. Critically, the PD x ID interaction was significant . Simple slopes were performed and show the negative effect of perceived discrimination on health satisfaction was significant for those with lower ethnic identity (*b*slope= -.315, *Post.SD* = .086, 95% CI [-.483, -.146], *p* < .001) and not significant for those with higher ethnic identity (*b*slope= -.066, *Post.SD* = .086, 95% CI [-.234, .103], *p* > .05). A plot of the slopes are presented on the right panel of **Figure 2**.

Figure 2: The moderating effect of ethnic identity centrality on the relationship between Personal ethnic discrimination and Life Satisfaction (left panel) and Health Satisfaction (right panel). Note: the y axis on the right begins at 4

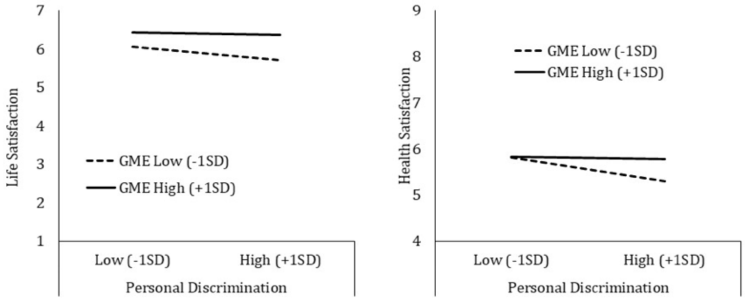

Table 3: Descriptive statistics, bivariate correlations and Cronbach's Alphas for ethnic identity centrality, wellbeing and discrimination variables

	1.	2.	3.	4.	5.	6.	7.	8.
1. Gender (0M, 1F)	-							
2. Age	.22*	-						
3. NZ Born (0N, 1Y)	-.08	-.29*	-					
4. Life Satisfaction	.02	.14*	-.08	-				
5. Health Satisfaction	.04	.05	-.15*	.44*	-			
6. Ethnic Identity	.02	.00	.06	.14*	.05	-		
7. Personal Discrimination	.11*	-.01	-.04	-.14*	-.14*	.14*	-	
8. Group Discrimination	-.02	-.13*	.15*	-.13*	-.13*	.22*	.23*	-
M		39.24		4.88	6.22	5.40	3.16	4.48
SD		13.58		1.29	2.37	1.40	1.77	1.79
Cronbach's Alpha					.73	.79		

TABLE 4: Estimates for multivariate moderated regression model using Bayesian *estimation assessing Life Satisfaction and Health Satisfaction.*

	Life Satisfaction					Health Satisfaction				
				95% Credible Intervals					95% Credible Intervals	
	Estimate	Posterior *SD*	*p* value	Lower 2.5%	Upper 2.5%	Estimate	Posterior *SD*	*p* value	Lower 2.5%	Upper 2.5%
Gender	.010	.127	.467	-.237	.259	.259	.233	.131	-.196	.720
Age	.011*	.005	.009	.002	.020	-.003	.008	.357	-.020	.013
NZBorn	-.085	.127	.251	-.335	.165	-.723*	.236	.001	-1.186	-.261
GD	-.078*	.035	.012	-.146	-.010	-.109	.064	.044	-.234	.017
PD	-.099*	.034	.002	-.166	-.033	-.190*	.063	.001	-.313	-.067
ID	.179*	.044	.000	.094	.265	.156	.080	.025	-.001	.313
PD x ID	.050*	.023	.014	.005	.095	.089*	.042	.018	.006	.172

N = 472. Satisfaction is measured on a 1-7 scale and Health Satisfaction 0-10. Post.*SD* = posterior standard deviation. *p* = proportion of the posterior distribution below 0 for a positive effect, and the proportion of the posterior distribution above 0 for a negative effect. Gender (0 M, 1 F); NZBorn (0 No, 1 Yes); GD = Group Discrimination; PD = Perceived Personal Discrimination; ID = Ethnic Identity Centrality

DISCUSSION

This paper sought to test how Pacific peoples' ethnic identity moderates the relationship between perceived ethnic discrimination and a range of wellbeing outcomes. This was done across two independent studies using both Pacific and general measures of ethnic identity. The two studies and multiple analyses presented within them provide evidence that ethnic identity is a protective factor against the negative effects of ethnic discrimination for Pacific peoples in NZ. Study One showed that people that reported lower Group Membership Evaluation would also report lower satisfaction with their family relationships and satisfaction with their health, if they reported more ethnic discrimination. However those that reported higher Group Membership Evaluation, there was no effect on satisfaction with family relationships, and satisfaction with health. This pattern of results was replicated in an independent study, using different a more general measure of identity. Similarly, those that reported lower ethnic identity reported lower life and health satisfaction when reporting greater discrimination. Those that reported higher ethnic identity centrality, there was no significant effect. Taken together, the results of these two studies provide evidence that for Pacific peoples in NZ, ethnic identity will provide some protection against the negative effects of discrimination for their satisfaction with family relationships, satisfaction with life, and satisfaction with their health.

These findings are in support of the protective properties of Pacific peoples' ethnic identity, providing a psychological mechanism to protect the self against the harmful effects of discrimination. It is likely these results reflect the suggestions of Yip[1] who posits that those with a secured understanding of their identity and a commitment to their identity may be protected against discrimination. The identity measures used in each study (GME from the Pacific Identity and Wellbeing Scale[20] and Identity Centrality[21]) reflect commitment and positive affirmations of ones' identity. Furthermore, the participants in both studies are adults, and are more likely to have negotiated what their ethnic identity means to them, rather than youth who may be more likely to be exploring what their identity means to them.

It is important to note the direct effects of other factors in the regression models. Of note, females reported higher satisfaction with their families, and overseas-born Pacific peoples reported higher satisfaction with their health. These demographic differences warrant further investigation. In addition, it was observed that Cultural Efficacy (the extent to which Pacific peoples felt they were able to participate within Pacific cultural settings) was positively associated with family and health satisfaction. This is in line with previous research that shows a positive link between identity and wellbeing. Also of note, the results show that both ethnic identity and discrimination explain unique variance in familial wellbeing and health satisfaction, above and beyond the variance explained by the interaction.

Implications of Findings

Our results support the role of ethnic identity as part of a multi-faceted approach for achieving parity in health and wellbeing for Pacific peoples in NZ. Discriminatory experiences are a barrier to accessing and receiving healthcare. Thus it is imperative that steps are taken to ensure clinical settings are appropriate to the needs of diverse Pacific communities.[25]

While it is promising to see the protective properties of ethnic identity, attention must be also be paid to those for whom their perceptions of their ethnicity are not providing the same protection. Study one showed that for those that reported lower group membership evaluation (though their scores were still high overall) were more susceptible to discrimination's negative effects. This is not to suggest that those that report lower identity scores have some kind of identity or cultural deficit. Rather, this suggests we need to do more to understand how Pacific peoples engage with their identities and cultures. The dimensionality of these identity measures highlight that there is no uniform Pacific identity.

Strengths and Limitations

Each study uses cross-sectional data, so it is not possible to ascertain how discrimination will affect Pacific peoples health in the long-term. Furthermore, the measure of discrimination used is a single item measure, and does not account for the frequency of discriminatory experiences. However, the additional measure of perceived discrimination towards one's ethnic group means the analyses presented here help understand the unique effects of personal experiences of discrimination.

Each study has adult participants, and it is likely they have a greater understanding of what their ethnic identity means to them. Similar analyses should focus on Pacific youth, with particular focus on their ethnic and cultural identity development.

CONCLUSION

Multiple analyses across two independent studies provide evidence that strong ethnic that ethnic identity is a protective psychological resource for Pacific peoples. As nurturing and incorporating Pacific cultural practices or values into health service delivery and wider NZ society would be beneficial for positive health and wellbeing outcomes for Pacific peoples.

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Original Research **OPEN ACCESS**

Investigating principles that underly frameworks for Pacific health research using a co-design approach: learnings from a Tongan community-based project.

Veisinia PULU,[1] Jemaima TIATIA-SEATH,[2] Barry BORMAN,[1] Ridvan FIRESTONE[1]

ABSTRACT

The New Zealand Tongan peoples' worldview leans more towards a traditional and indigenous paradigm that encompasses the importance of family, spirituality or Christian beliefs and connection with their environment. These priorities align with core principles and values of co-design, and therefore, co-designed interventions will be better used and accepted in addressing health issues prevalent in the Tongan community. Co-design methods adapt to the cultural setting they are applied to, prioritizes the Tongan peoples' cultural values and worldviews and captures the needs of the Tongan community to inform the development of the intervention. It supports family members to stand with authority, as well as place the Tongan participants at the centre of the research by including families, employing culturally safe practices, addressing the broader determinants of health, and focusing on system issues rather than on individuals. The generation of discussion in co-design further aligns with the Pacific knowledge of systems, creation stories and oral stories which provide a culturally empowering way to generate discussion and insights from the Tongan community

Key words: Pacific peoples, Pacific research, diabetes, health disparities

INTRODUCTION

In Aotearoa New Zealand (NZ), the Pacific population is one of the fastest-growing ethnic groups. By 2026, Pacific peoples are projected to make up 10% of the general population,[1] in part, due to Pacific women experiencing higher fertility rates and teenage pregnancy rates compared to the general population.[2] The term Pacific refers to individuals whom self-identify with at least one of the ethnic groups originating from the Pacific Islands of Polynesia, Micronesia and Melanesia.[3] There are more than 40 diverse Pacific ethnic groups in Aotearoa NZ with various cultures, languages and histories.[4,5] However, the majority of NZ Pacific peoples identify with one or more of the following ethnic groups: Samoa, (48.7%), Cook Island (20.9%), Tonga (20.4%), Niue (8.1%), and Fiji (4.8%). Although Pacific peoples are very much established in to Aotearoa NZ society, they continue to maintain strong links with the Pacific Islands through family and village ties, culture, history, language and remittances.[6] According to Statistics New Zealand, [7] over 35.7% of the Pacific population are under the age of 15 years, compared to the 20.4% of the total population, thus they are described as a 'youthful' population. In addition, Pacific youth (15-24 years old) make up 19.2% of the Pacific population, compared to13.8% of the total population.[8]

Corresponding author: Vesinia Pulu
V.Pulu@massey.ac.nz
1. Centre for Public Health, Massey University, Wellington, New Zealand
2. School of Maori and Pacific Studies, University of Auckland, Auckland, NZ j.tiatia-seath@auckland.ac.nz
3. Centre for Public Health Research, Massey University, email: B.Borman@massey.ac.nz
4. Centre for Public Health Research, Massey University, email: R.T.Firestone@massey.ac.nz

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Pacific peoples have the highest burden of non-communicable diseases (NCDs) including cardiovascular diseases, respiratory diseases, diabetes and cancer compared to other ethnic groups in Aotearoa NZ.[5] They are diagnosed with NCDs at a younger age,[9] have longer periods of exposure to unhealthy lifestyles, and other health-related issues (e.g., lack of health service uptake), than their New Zealand European (NZE) counterparts. Pacific peoples also have the poorest health outcomes and reduced life expectancy compared to other ethnic groups.[10-12] Therefore, due to this health disparity it is important to identify culturally appropriate research approaches that may work well to address these health issues, particularly when working closely with Pacific communities and young people. The aim of this article is to describe an adapted co-design research methodology for use in a Pacific context, to address health concerns that are specifically relevant to a Tongan community.

Pacific Health Worldviews

Many Pacific peoples emphasize the needs of the collective group, rather than those of the individual, and view themselves within the context of their families and wider community. Most Pacific families consider the family and church, central to the Pacific wellbeing, as they are considered support structures which people may rely on for friendship, support and childcare.[13] This interdependent relationship for Pacific peoples demonstrates the strength of connectivity, and the welfare-wellbeing between the family unit, church and community.[13,14]

Pacific peoples have beliefs about individual and family health, community needs and, realities that differ from other Aotearoa New Zealanders.[3] For some Pacific peoples, good health is achieved where there is a positive and balanced relationship between cultural, spiritual, physical and environmental dimensions. Pacific peoples understanding of health, can be characterized by a holistic perspective, where healthy and strong families are the basis for the wellbeing of individuals and communities.[3,15,16] These beliefs influence their health choices and behaviours and therefore, it impacts upon health decision-making behaviours (e.g., avoiding doctors' visits and health interventions).[11,15] The collective strength and responsibility within Pacific families and communities asserts that the key to promoting a healthy lifestyle and effective health services is through working with families and communities.[17] The 'Pacific Health Action Plan' was developed to help achieve equitable health outcomes for Pacific peoples, with the objective of improving responsiveness to Pacific communities, contributing to best practice and services for Pacific people and their families; and working more collaboratively with government agencies, the wider health system and Pacific communities.[18]

Co-design principles, theory and practice

To date, more researchers are asserting the uptake of co-design methods by partnering with Pacific communities. The core principles of this approach include equity, understanding experiences, and prioritizing improving health or services (outcome-based).[19] Equity, in this context, refers to the partnership formed between researchers and participants. In public health research, researchers or health professionals primarily design all aspects of the research. However, with co-design there is a shift from participants being passive recipients of the research design to active participation with researchers or health professionals in the design of the proposed work.[20,21] The partnership formed between participants and researchers entails prioritizing relationships and community building at all phases of the research.

Furthermore, the co-design approach emphasizes the need for researchers to understand the experiences of participants which is key at the early stages of building trust, and respect between both parties; thus, there should be mutual understanding of the community in a social setting. A social setting in which participants' experiences are influenced by physical, social and cultural factors, community organization and individual behaviour.[22] Another core principle of co-design is prioritizing the improvement of services or the health of a target population. Co-design activities are outcomes-based which possess a pragmatic outcome, with clarity of vision and direction.[23,24] It also hones on developing practical real-world solutions to issues faced by families and communities.

The NZ Tongan population are at a high risk of developing prediabetes due to the high obesity prevalence amongst Tongans (60% for men and 78% for women).[25] There is limited research into the effectiveness of population-based approaches in limiting the prevalence of diabetes. An ethnic-specific research approach maybe more desirable due to the principles highlighted earlier. Furthermore, incorporating a co-design approach will also actively engage the Tongan community in all aspects of the research process and build upon existing community strengths. It will further enable the Tongan community to be equal partners in research activities, identify aspects of inquiry that is outside of Westernized research, build public health capacity in the Tongan community and empower them to find solutions to health issues. The aim of this paper is to describe and highlight the need to use a co-design approach as an important process of partnering with Pacific communities.

METHODS

There were two specific objectives from this project: a) to examine Tongan youths' perceptions and understanding of prediabetes and its risk on health and wellbeing, including identifying the barriers of access to lifestyle management programmes (phase one); b) to co-design a community-based intervention programme aimed at reducing the risk for prediabetes among Tongan youth (phase two).

In the co-design approach, we adapted Bratteteig's six steps of organisation:[21] 1) opportunity identification; 2) knowledge generation; 3) identification of needs and desires; 4) description of the health and wellbeing requirements; 5) envisaging the intervention programme; and 6) testing the programme. In phases one and two of the project, steps 1-5 took place across several interactive group meetings involving the community-based Tongan youth (n=7), aged 18-24 years old, and a group of Tongan adults aged 32-65 years old (n=9) who were also part of the church's health committee. Prior to commencing the first group meeting (phase one) consent forms were obtained. The adults (e.g., a parent, grandparent, aunt/uncle/or a guardian) and youth interactive group meetings were conducted separately to examine their awareness and understanding of prediabetes and how to manage this condition. The questions developed for phase one were used as a guide for the discussions (**Appendix 1**).

when there is a positive and balanced relationship between cultural, spiritual, physical

In phase two participants were involved in three activities to co-design a community-based intervention (steps1-3). The first activity (called 'Post it') involved generating ideas and knowledge. Participants were asked to write their thoughts on the post-it-notes and post it on each theme derived from phase one. The following activity (called 'Priority) focused on identifying the needs and desires of the participants. It involved thematizing and prioritizing the notes according to the different themes (identified from phase 1). The resulting priorities included: (1) lifestyle and education (from the adults' perspective) and (2) cultural and lifestyle (from a youth perspective), as important factors that the community perceived as necessary intervention considerations. For steps 4 and 5 of the co-design approach, the youth and adult groups were divided into two subgroups to focus on a particular theme, per group. Each subgroup discussed their theme and transformed their discussions into an actionable question. Another interactive activity (called 'Bus stop') was used to enable the participants to envision the intervention program using arts and crafts to model their discussions and ideas. Once the subgroups completed their model, the group collectively selected the best two ideas that were most aligned to the community's values and cultural protocol (see Appendix 2 for photos). Thereafter, a taskforce group was established, and it included representatives of the youth and family, a medical health doctor, a youth leader and a representative of the community church health community. The purpose of this group was to finalise the prototype intervention program (step 6), to identify intervention outcomes for the community programme and for the research project.

Using thematic analysis technique (26), the data obtained was coded, and compared until saturation of the themes were achieved, from across the interactive groups. Table 1 shows how the themes from steps 1-2 were used to identify the list of priority issues and questions of the co-design process (process 3). The first named author also undertook a process of participant validation by presenting the themes back to the participants. Before commencing step 3 (identification of needs and desires).

Ethical approval for all the phases of the study (SOA 19/34), Massey University, Human Ethics Committee, NZ.

Appendix 1: **Questions for phase one**

a) What do you know about prediabetes? Type 2 diabetes? Heart disease? (Deliver presentation on prediabetes and discuss what barriers for understanding and accessing help for this disease?)

b)Tell us how the programme could work for your community?

c)What processes need to be established for your community?

d)What would motivate you to attend this programme?

FINDINGS

Table 1 outlines the themes obtained from the initial interactive group meetings with the Tongan youth and adult groups. In summary, these themes were described as follows: *a) 'Knowledge about prediabetes'*, which refers to the participants' lack of knowledge and understanding regarding prediabetes; *b) 'Barriers to understanding and accessing help for* *prediabetes'* which refers to the factors that hinder participants from living a healthy lifestyle; *c) 'Motivations for attending an intervention program* which refers to ideas that will motivate participants to consistently attend an intervention program aimed at combating prediabetes; *d) 'Process that needs to be established in your community'* which refers to aspects in the community that help support participants live a healthy lifestyle. Of all the themes that were mentioned previously theme '(b)' was considered most important, given it provided an understanding of barriers that impact Tongan peoples' health. Both the youth and adults agreed that the following factors: lifestyle; cultural; income; and education were barriers to understanding and accessing help for prediabetes.

Table 1: Theme development from the interactive group meetings

*= themes that were prioritized by each group.

Themes	Family representatives (adults)	Youth
a. Knowledge about prediabetes	The family members understood some aspects of prediabetes. -Both family representatives and youth appear to have knowledge of prediabetes solely relating to increased levels of sugar rather than the risk factors that increase the risk of prediabetes such as family history, weight, diet, and inactivity.	The youth had some understanding of prediabetes.
b. Barriers to understanding and accessing help for prediabetes	Lifestyle factors (*) Cultural factors Education (*) Income	Lifestyle factors (*) Cultural factors (*) Education Income
c. Motivations for attending an intervention program	-To consider specific cultural values. For instance, including a physical activity that is appropriate for both men and women. - To include healthy cooking competitions where everyone can showcase healthy recipes and share it.	-The delivery of health messages should be interactive, interesting and motivating. -The physical activities should be varied and have some degree of competition -Inclusivity should be the main component of the intervention (Not just the youth but everyone in church)
d. Processes that needs to be established in your community	- There should be more health promotions happening in our Tongan communities. - Utilizing health professionals to deliver health messages in churches.	-The youth mentioned the structural factors in church and how it would impact the implementation of the intervention. An important question that was raised by the youth- "So many programs happening in church during the week. How are we going to fit the intervention program into the church schedule?"

The youth prioritized 'lifestyle and cultural' and the adults prioritized 'lifestyle and educational' factors as being important perspectives. The adults emphasized the impact of lifestyle factors relating to the Tongan peoples' food choices and lack of physical activity. For example, participant FM2 noted "*that people are aware of the consequences of diabetes, yet they choose to eat unhealthy foods*". The youth highlighted how food played a major role in the Tongan lifestyle. One of the youth (YP3) mentioned " *Like you have misinale (annual missionary offering) and all that stuff and it's bound to have like pigs and everything so like I think that having like the* *traditional like its supposed to be a big……supposed to be corn beef. Like its always been the lifestyle for Tongans*". Furthermore, the adults highlighted the importance of educating people regarding the risk factors, the impact of prediabetes, and how to prevent it. This was evident in participant FM4's discussion where he noted that "*most people often wait to reach the phase of diabetes and then think to live a healthy life. What we need is education to educate them about preventing diabetes*". On the other hand, the youth highlighted the impact of the church system on health. Considering that the church is central to the Tongan culture, the youth emphasized that the church obligations often take up their time; and therefore, they are unable to do physical activities.

DISCUSSION

The main findings of using a co-design approach to addressing prediabetes in a Tongan community relate to the main theme of 'barriers to understanding and accessing help for prediabetes', and this was evident for both the youth and adults. In co-design, the researcher's role involved facilitating the interactive group discussion as the participants shared their stories. This approach played an important role in understanding the participants' worldview and prioritizing their input. Furthermore, it allowed the use of culturally-centred methods which involved listening and attempting to understand each participant's reality as different but complementary to other Tongan youths (27, 28). Traditionally, the Pacific way is primarily oratory with verbal negotiations deep rooted in Pacific cultures (29). Subsequently, the interactive group discussion method selected in co-design ensured Tongan worldviews, values, belief systems, and ways of sharing knowledge were reflected. For instance, using Tongan metaphors and storytelling to foster expression, reflection and sharing. This method provided deeper insight into the Tongan peoples' lives and their aspirations as opposed to using traditional ethnographic methods which include in-depth interviews and observations. It also encouraged collaborative explorations and dialogue between the researcher and participants and enabled deeper, meaningful relationship to be formed (30).

With the co-design approach, the researcher prioritized the relationships and community building through collaborating, co-operating and co-learning with participants where mutual exchange of information and trust takes place. This two-way reciprocal process avoided the researcher imposing their own preconceived ideas on design sessions and enabled shared decision making in phase one of the research. Such a participatory approach emphasized the need for researchers to understand the experiences of participants. In this case the participants identified their health circumstances and their behavioural choices being influenced by income, culture, education and lifestyle factors. Both the youth and adult group highlighted the impact of lifestyle on healthy living and while the adult group further prioritized education, the youth prioritized cultural factors. This difference in prioritization of factors impacting health may explain the intergeneration views regarding the Tongan culture, particularly in regard to the role of the church. The church is central to the Tongan culture and is seen as a socially organized institution for the community, that provides spiritual sustenance and pastoral care. As the church becomes a centre for development and education for the Tongan people, especially for the youth, it is also a place where they can learn characteristics and behaviours intrinsic to Tongan values and beliefs (reference). Previous research highlighted the inability of Tongan churches to adapt to the duration, content and frequency of the activities to suit the New Zealand environment. For example, some critics noted that there should be fewer church activities during the week given that adult members have to work, and children have to focus on their education (reference). Moreover, the concept of church activities occupying lifestyle time was highlighted by the youth, yet this perspective is not shared with the adult group. The adult group viewed the church as an obligated institution that should not be questioned, and that fulfilling these obligations were regarded as blessings to their families. On the contrary, the youth viewed church activities as a time-filler and that attendance took up most of their time and prevent them from activities such as participating in physical activities. In general, both groups were aware of the benefits of physical exercise and its contribution to healthy living, yet the customs attached to the Tongan culture and the church environment does not necessarily promote healthy lifestyles, from a physical perspective.

The majority of Tongans value creating and maintaining good relationships within their family, friends and community networks and therefore prioritize positive social interactions. Utilizing a co-design approach ensured that the relationship established between both parties are grounded in principles of trust, mutual benefit, respect for diversity and the community's culture, and more importantly respecting the voices of the community (31-34) The use of co-design ensured a strong partnership between the community and the researcher, particularly through acknowledging Tongan worldviews and values, practising cultural protocols, involving Tongan people as co-researchers as well as valuing their input (6, 35). This creation of collaboration and co-ownership of outcomes can be of long-term benefit when it comes to sustaining a relationship, empowers participants and potentially ensure the success of the community-based intervention (not discussed as part of this paper). Throughout the interactive group discussion, the participants were able to experience their contributions and shared decision making, as a genuine process, particularly when their knowledge and perspectives were included as part of the design-thinking process. The participants made comparisons with the experiences and perspective of others, and their input provided strategies for progress particularly regarding their understanding of prediabetes and barriers to accessing lifestyle management programs (19, 36-38).

Co-design prioritizes the improvement of services or the health of a target population; therefore, the co-design activities are outcomes-based which possess a practical focus, with clarity of vision and direction (23, 24). The research project focused on developing a practical real-world solution to prediabetes, and therefore, prioritising health from a Tongan worldview as part of this research. Co-design also allowed for 'insider knowledge' to be tested and analysed between the different groups in this current study, enabling the proposed ideas for the intervention to consider different viewpoints (youth and adult groups), but keeping it pragmatic at the same time.

The transformation of ideas into specific actions, identifying improvements and how best to employ them formulates steps 5 and 6 of the co-design process, and although step 6 was not part of this paper per se, the processes learnt from the earlier steps involves systems development and promotes community capacity building with the goal of improving health outcomes for the community(24, 32, 34). The majority of the Tongans rely on the community as a support structure and work towards what is best for the collective (39), incorporating a co-design approach helps strengthen and empower Tongan communities to take control of their own futures by developing their own ideas, knowledge and skills in response to a particular health issue.

CONCLUSION

Co-design principles are placed well with Pacific health frameworks of research, as it gives importance to the needs and views of Pacific peoples. Involving Tongan people in all aspects of the current research, provides much deeper insight into their worldviews, culture, and values. As co-design prioritizes Tongan worldview, culture and values, it provides a greater understanding of Tongan peoples' situations, needs and ideas that contribute in conceptually developing and creating action health plans that may shape their future.

The processes, tools and methods employed in the co-design approach undertaken in the current study, enabled the Tongan people and health research on the basis of research being driven by end users and addressing needs voiced by the Pacific peoples and communities. Taken together, utilising co-design in Tongan communities will explore new approaches to inquiry underpinned by Tongan values, belief systems and ways of sharing knowledge and thus has a distinct contribution to knowledge and society.

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E le sauaina tatou tagata matutua: re-examining abuse through the cultural lens of the Fonofale model

Juliet BOON-NANAI,[1] Sandra THAGGARD,[2] El -Shadan TAUTOLO[3]

ABSTRACT

Introduction Cultural paradigms are emerging as the appropriate way to examine Samoan people's life experiences. This study employs the fonofale model to explore and examine the notion of abuse among Pacific elders, mainly from a Samoan lens.

Methods In framing this study, the talanoa approach was deemed culturally appropriate. Twelve Samoan *tagata matutua* (elderly people) were asked to *talanoa* (discuss) their experiences of what abuse means to them.

Findings These suggest that, initially, abuse of Samoan elders was contested. That is, it is not the *fa'asamoa* (Samoan way) or the *fa'akerisiano* (Christian way). However, as the talanoa gathered *mafana* (warmth) and *malie* (maintained healthy social relationships), most agreed that physical abuse was uncommon within an *aiga* (familial) context, but other forms as in spiritual abuse were apparent. Overall, the disruption of the *fa'asamoa* through the violation of relational *vā* concepts are noted and perceived as a form of abuse that counters the universally accepted notions of abuse.

Conclusion For these *tagata matutua,* six different forms of abuse were identified, with particular emphasis on cultural and spiritual abuse. Following the fonofale paradigm, which reflects a Samoan worldview, this article informs a perception of spiritual abuse from the Samoan elders' point of view. Their views have relevance to the wider Pacific context.

Key words: abuse, fa'asamoa, fonofale, spiritual, Talanoa, Samoan elderly

INTRODUCTION

Elder abuse is now a pervasive and global phenomenon.[1] There is a relative lack of conclusive research regarding elder abuse within the Samoan community. Samoans make up most of the Pacific population in Aotearoa New Zealand; they are the fifth largest ethnic group in the country and Samoan is the third most common language.[2] Samoan families, like many Pacific Island families, value and care for their elders.[3] Elderly people, known as *tagata matutua,* are esteemed in both the socio-cultural and spiritual context. They are sacred and, as such, abuse is not overtly considered conceivable. While much of the literature pertaining to abuse as a form of violence is focussed on women and children[4] as well as the physical, emotional, and sexual[5,6] abuse between intimate partners[7] perceptions of elder abuse among Samoan people residing in New Zealand are yet unexplored. Furthermore, older people's experiences of abuse, and the ways in which abuse impacts elders in the wider Pacific population are limiting.

Corresponding author: Juliet Boon-Nanai, juliet.nanai@aut.ac.nz

1. Equity Academic Pasifika, Auckland University of Technology, Auckland, New Zealand
2. Senior Lecturer, Nursing, School of Clinical Sciences, Faculty of Health and Environmental Sciences, Auckland University of Technology, New Zealand.
3. Associate Professor, and Director, Pacific Islands Families Study, Auckland University of Technology, New Zealand

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Elder abuse is an extensive and serious issue defined by the World Health Organisation (WHO)[8] as a "single or repeated act or lack of appropriate action occurring within any relationship where there is an expectation of trust, which causes harm or distress to an older person". Abuse of the older person can lead to severe physical injuries, financial misery, as well as to long-term psychological consequences through manifestations of mental health suffering.[9-12] Current Age Concern New Zealand statistics record one in ten people over 65 reporting abuse.[13] However, with many cases undisclosed, prevalence is extremely misattributed, with WHO reports indicating that only 4% of abuse is reported worldwide.[8]

In traditional cultures such as that of the Samoan people, where *fa'asamoa* (Samoan way) places great emphasis on faith and spiritual value (including the *fa'akerisiano* or the Christian way), spiritual abuse may have grave existential and psychological consequences. The WHO and other common definitions of elder abuse do not overtly mention spiritual abuse, but consider sexual, financial, psychological and physical abuse, as well as neglect both intentional or unintentional. Spiritual abuse (SA) has been broadly defined by Gray, LaBore and Carter[14] as, "actions that damage one's subjective experience and personal practice of the sacred, creating a severe disconnection with a higher power or other spiritual sources of meaning and resulting in harm to one's spiritual integrity, lack of access to spiritual resources to cope, and/or an inability to pursue spiritual growth" (p.3).

Research in this area is predominantly Eurocentric and primarily focused on spiritual abuse by church ministers or spiritual leaders within power positions.[15,16] Though conceptualised for American Indian cultures, and although characterisation will vary from culture to culture, Gray's definition is flexible and adapts well to the experiences of Samoan elders in this study where the elderly experience a severe relational disruption with the higher power or spiritual sources and with consequent harm to spiritual integrity, and disconnection through the inability to access spiritual resources to cope, therefore, leading to the inability to pursue spiritual growth. This may also have implications on elder neglect.

Definitions of elder neglect, too, are commonly centered around the failure of a caregiver to meet the needs of an older adult who is unable to meet those needs alone. Behaviours highlighted include denial of food, water, medication, medical treatment, therapy, nursing services, health aids, clothing and visitors. In research orientated toward indigenous American Indians, Gray and colleagues[14] highlight the importance of incorporating a definition of spiritual abuse which may aid in healing the historical trauma of colonisation, often perpetuated by acculturation and assimilation. Whether this is the case for the Samoan elderly is yet to be investigated. It is imperative to provide a Samoan perspective of the elderly person's role within New Zealand society in its traditional and contemporary context so as to understand how the participants' view of abuse is influenced in this study.

Samoan Elderly

Samoans address the old people or the elderly as *tagata matutua* and are perceived as mediators between the cosmos, people and the land. Traditionally, old people "often control useful knowledge and hold positions of political and economic power".[17] As a result, their status is regarded highly and is feared. *Tagata matutua* have a vital role in maintaining harmony within the communities as well as preserving and passing on cultural traditions and values to the younger generations. Tamasese and colleagues noticed how spirituality has a "significant role in maintaining elderly people's overall wellbeing".[18] Their identity and wellbeing are inherently related to family heritage, roles, connections, and responsibilities to their land, including being caregivers as well as custodians to genealogy and chiefly titles. Spirituality is central in this role, guiding them in such practices. In this regard, the *tagata matutua* were therefore perceived as 'sacred' figures who should be respectfully treated and not neglected or abused as expressed in this phrase *e lē sauāina tatou tagata matūtua*. Younger generations are expected to maintain this relational integrity through the *vā tapuia* (sacred spaces) concept. To be respectful you have to *tausi-le-vā*, that is to nurture and maintain this *vā fealoaloa'i* (respectful relations). To disrupt this relational covenant, one will be violating it, that is, *soli-le-vā*. One can restore this *vā* through *teu-le-vā* or restore the disrupted relations. To sustain this relational space, one has to care for the elderly through *fetausia'i* or servant leadership guided through mutual reciprocity, love *(alofa*), compassion and service (*tautua*).

Migration to New Zealand and other countries have posed challenges to this relational status of the Samoan elderly. They have become caregivers to their grandchildren. Cross-cultural studies conclude that loss of prestige and esteem by the elderly are the 'biproducts of urbanisation, industrialisation, and modernisation'.[17] Over time, their roles and intergenerational perspectives of the elderly as revered and sacred entities and even as cultural treasures have been misconstrued. The demands of children and grandchildren more assimilated to Western culture may leave elderly grandparents pressured to fulfil expected roles and are possibly exploited by their adult children.[19] With inadequate English comprehension and ability, Samoan elderly people in New Zealand have been treated as babysitters out of the financial necessity for adult children to save childcare costs and afford housing.[18] Therefore, Samoan perspectives of elderly and ageing in New Zealand conflict. Such views have impacted this *vā* as well as the spiritual relational domain that has influenced Samoan elderly views of abuse.

This study aims to further inform the definition of spiritual abuse, specifically from a Samoan worldview, by giving voice to the views of Samoan elders, and highlights any differences from the typical Eurocentric understanding of spiritual abuse.

METHODS

Fonofale Model as a Cultural Paradigm

A framework for understanding elder abuse must be culturally informed. The fonofale model was employed as a guiding framework to examine tagata matutua abuse within the Samoan worldview.[20] Pulotu-Endemann uses a traditional meeting (*fono*) house (*fale*) to portray the symbolic values underpinning Samoan values, beliefs, customs and world view. Drawing on his metaphorical representations, a Samoan is born into a *fale* that consists of the various *pou* (posts) conveying the spiritual, physical, emotional, sexual and other domains that facilitate Samoan well-being. Spirituality permeates all the physical landscapes and people and it is significantly broader than religion. Sometimes the two beliefs are conflated. In some ways, spirituality is inclusive or different from religion (*fa'akerisiano*).

On top of the *fale* is the thatched roof. The roof depicts the overall culture that shelters Samoans. The traditional foundation of the *fale* represents the basic unit of the *aiga* (family), and is indicative of the values embedded in the Samoan culture or *fa'asamoa*. Suaalii-Sauni, Wheeler[21] emphasises that "for the house to stand firm, its core structure must exist and hold together – from the foundation to the posts and roof" (p.27). This collective ideology of *aiga* in caring for elders is important. It reinforces the spiritual component as manifested in the nurturing social relations such as *tausi-le-vā*. If there are problems with one of the domains within the fonofale model, holistic well-being will be impacted. This impact is trampling or violating of the sacred spaces – *soli-le-vā*. For the purpose of this study, this means consideration of not only the biomedical condition and physical manifestations, but of other dimensions – including the socio-economic situation, cultural and spiritual beliefs, and aspirations regarding health issues – is imperative.

In order to explore what abuse means to the Samoan elderly, and in doing so, to identify any form of abuse witnessed within their *aiga* and/or communities, the talanoa methodological framework, introduced by Vaioleti[22] was employed. Grounded in phenomenology, with emphasis on the participants' lived experiences, talanoa has become multi-disciplinary and cross-cultural in its application, not only across the Pacific but also internationally within the wider social sciences and academic realm.

Participants

Twelve participants (6 females, 6 males, 58-87 years old) were recruited through purposive sampling who were included as part of a 50-person Pacific elderly cohort. They voluntarily agreed to engage in the larger Pacific Elderly Abuse Research Project between August and September 2019. All participants were Samoan-born, currently residing in West and South Auckland, New Zealand, still maintaining their cultural ties to the homeland. Except for a few, all held chiefly matai titles. Three of the respondents were currently caring for an elderly person.

Ethics and Anonymity

The Auckland University of Technology Ethics Committee provided approval for this project. (Reference 19/176 17 June 2019). Anonymity of the participants' responses are represented by their gender abbreviation and age (m, 63). Samoans regard their elderly people's knowledge as merit. Having a culture of oratory for many centuries, and acknowledging one's self in a discussion is regarded as a means of authenticating and validating knowledge.[23] All of the *tagata matutua* performed leadership roles within their families, communities, and the church, giving them life experiences that are to be valued. Samoan elders' views point to the importance of not being physically abused but how the next generation of adult children disrupt this meaning of respect, sacredness without reverence that can be addressed from a culturally and spiritually specific interpretation of abuse. *Talanoa (*discussion) with the twelve Samoan elders in the group were conducted within familiar community centres that were central to them.

Thematic analysis

Braun and Clarke[24] introduced a six-phase guide to the thematic analysis exercise which was adopted in this study. This approach to thematic analysis gives rise to the people's voices. Its findings provide the narratives evoked through the *talanoa,* giving meaning to the elders' social experiences. Patterns here reflected themes of cultural, spiritual, emotional and financial abuse.

DISCUSSION

All the participants initially declared that abuse was non-existent among their families, that is, "*e lē sauāina tatou tagata matutua*" (m,69). Participants argued that, *"due to our culture, we have to look after our elders"* (m, 69). Another participant concurred "*I agree with that. It's part of our culture. It was told to us by our parents."* (m, 63). With regards to the fonofale model, the *aiga* is the foundation and the basic unit of Samoan families. Such expressed views reflect *fetausia'i* or the reciprocal nurturing of serving between the *aiga* and the elderly is customary. Appreciation of this collective ideology of *aiga* in caring for the elders is reflected in many of the views that were comprehensively discussed. Often, this approach assists in the cultural dynamics because it is the *aiga* who makes decisions about who takes responsibility for the care of the *tagata matutua*.

These salient views perceived by the Samoan elderly participants were similar to that of communities where the collective ideology is important, as with Asian migrants, as well as Indians, and many Polynesian societies.[1,25,26] Notably, the fonofale model uses the concept of spirituality deliberately inclusive of pre-Christian values, beliefs and practices. Tamasese alluded to the importance of this spiritual understanding towards the mental well-being and quality of life of a Samoan elderly person. As one respondent succinctly put it, if "*Samoan families do not look after and care for their elderly people, they think that their sacrifice is not going up… these are the fundamental beliefs"* (m, 63), meaning the sacrifice to the cosmos (God). Parents who are often the elderly are viewed as a symbolic representation and connection with the spiritual realm. In return for their dedication, children will receive abundant blessings. This view is influenced by biblical scripture. Elders believe children are obligated because stipulations in the book of Exodus (Chapter 20, verse 12) is engrained through Sunday school or *aoga faifeau* (village pastor's school) that one must "honour your father and mother, so that you may live long in the land the Lord your god has given you". For Samoan elders, such a belief is synonymous with their cultural ones influenced the *vā* of respect, honour, and obedience. In this regard, elderly are considered as 'sacred' and treated with 'reverence' (*vā faaaloalo*). One participant considers that if this is the underlying view, then respecting elders is part of looking after them well and not abusing them.

Physical abuse of elders was strongly argued by the participants . A female participant began by stating that when she hears the word 'abuse', she only understands its physical connotations:

> *When I think about abuse, I think about punching, kicking, … so [elder] abuse is not the Samoan way because we do respect our elders but when I hear some of you, well, I guess it does happen in our culture but it's behind closed doors. Yes, I realise that there is the emotional and verbal abuse. I think, for the Samoan elderly, the emotional abuse is a big one. Not the physical or verbal but emotionally …* (f, 58).

While the WHO emphasise physical abuse as the most reported category of elder abuse because of the 'granny bashing' phenomenon in Western communities, the Samoan elders here countered this view.[27]

Another perceived view of abuse is the placing of elderly people in a rest home. The participants considered this as an act against *fa'asamoa*, and the spiritual values and beliefs encapsulated therein. According to one participant, abuse deprives an elderly person of their autonomy which leads to constraint and increased psychological deterioration. She clarified that she had not experienced it, but witnessed this form of abuse:

> *My understanding is that abuse takes away their [elderly] freedom, to uphold their values and opinions. For example, I've seen an elderly person who was a family member taken to the rest home. He had a bit of dementia. Because family members and extended family have abandoned him by not visiting, his memory quickly faded. He was staying with a palagi person and he lost that mother tongue [Samoan] language that he feels he needed. That mother tongue makes him not forget things. It would have helped if the family talked to him in his own language [to] make him feel good and feel valued* (f, 65).

Placing elderly in a rest home goes against the collective notion of *fetausia'i*. As mentioned earlier, the *aiga* has the obligation and responsibility of caring for elders. Apparently, this participant believed that placing an elderly in a rest home is mistreatment to exercise their independence to engage in cultural obligations. Although she had not experienced abuse in her home, she shared her observations from other members of their extended *aiga*, she heavily argued that the option of placing elders in a rest home is an act derived from conflicting held worldviews, values and beliefs between the Samoan elderly husband and his *palagi* (European) wife. According to her, this in the rest home, this elderly limited his abilities:

> *…to do things Samoan, like speaking Samoan, eating Samoan food, attending Samoan family gatherings… he was the head matai of his particular extended family. He could be closer to his Samoan family for his mental wellbeing and quality of living* (f, 65).

The example here suggests that not adhering to the fa'asamoa is considered abuse because it is potentially damaging cultural norms. This is because the elderly person is being withheld from conducting his *matai* duties. Such duties uphold the cultural domain of the fonofale model; the roof which is the overarching aspect of the holistic wellbeing of the Samoan person.

Abandoning elders in rest homes created much discussion because participants considered it a disrespectful act, against the *fa'asamoa* as well as *fa'akerisiano* (Christian) values. One participant likened opting to take the elderly person to a rest home as also a form of not upholding Christian beliefs:

> *It's like sinning. If we put our elders in a rest home; that's emotional abuse. I'm sure no elder wants to go and stay there. They want to be looked after by their children* (m, 69).

Disrespect was not a common feature of the Eurocentric literature. In a Chinese context, Tam and Neysmith[26] argue that "to categorize disrespect as psychological abuse or neglect misses its meaning and significance as a culturally specific form of abuse". Disrespect – of the individual elderly person, of their cultural role, and of their cultural and religious beliefs – is a powerful form of abuse because it is concealed within the cultural context, "where the value of elder respect lacks meaning equivalent to that in western society". In the Japanese context, Tomita[28] found that silence functioned as a form of abuse to suppress elderly people in a culture where free expression of emotion is unacceptable. While Japanese people may recognise disrespect as unacceptable, it remains invisible under the generic categories of elder abuse. Even though victims themselves may not articulate disrespectful acts as elder abuse, we surmise that they experience tremendous harm, given that disrespect means the rejection of cherished values by close family members.

The global literature identifies mistreatment as another form of abuse. Placing the elderly in a rest home may be considered mistreatment or neglect. Therefore, more research and discussions on such context-specific examples warrant recognition.

There were discussions on other forms of abuse, but participants highlighted the significance of what they perceived as spiritual abuse. The participants described not having access to Church:

> *Sometimes, I want to go to church, but no one takes me. Everybody has their own lives, and they don't think about me!"* (f, 70).

Another participant supported this view,

> *I went to Australia and I asked my cousins to look after my grandmother. I got a call from my cousin saying, "you'd better come; Grandma wants to go church". They argued, "no we don't have time to take her to church". That's abuse. I got on the phone and I said, "How dare you! I told you to look after her". Cousin replies "I don't have time. I went out last night and I'm tired". That, to me, is abuse",* (f, 58).

Two things are important here in a spiritual or *fa'akerisiano* (like a Christian) context; one is the relationship with God and the other is the act of worship. Boling[29] explains that as older people in the church mature, this relationship becomes a priority for them, they desire to make peace with God. They develop a spirit formation as they expect they will die soon and want to be ready for 'the crossing' to walk with God (p. 59). They want to go to church because they have been taught that through the practice of worship, such as hearing scripture readings from the Holy Bible and praying, they create the space and place to develop a sense of proximity before meeting their maker. While young people may not share the urgency of their faith, this aspect of spirituality is significant in adulthood. Attending church is a soul-searching experience and if family members do not help to ensure older people are assisted to church, it deprives elderly people of this journey. In effect, Lui and Schwenke[30] assert that if this happens, it will impact heavily on their holistic well-being, in particular, their spiritual and mental well-being. To demonstrate this the participants noted:

> *Abuse is not the Samoan way of life… I don't feel abused because I have a very*

> *good support system in place with my daughter. Our relationship sometimes go up and down, but she knows it's her place to look after us. We taught her those values and she has stuck to them. Values of respect for our elders. Humility: be humble in the presence of elders, lotoalofa – love and compassion, have faith, hope and love all the time. It is very important that we teach our kids the essence of spiritual life, so in this respect, they respect us. However, I know some older people are lonely.*

Being lonely and neglected occurs when children are not around to look after their elderly. This is an intergenerational conflict. The fonofale model also shows how time, environment, and context are dynamics that should be considered as social determinants of the context-specific analysis of abuse.

Caring for elders in New Zealand seem to be an obligation in nurturing the relational space or *tausi-le-va* and participants acknowledged that because of such neglect, they have witnessed some elders wanting to return to the homeland. For example:

> *Their kids leave them. I know some [elderly] want to return home to the islands because no one here wants to look after them. …* (f, 82).

Studies from the global literature identify neglect as another form of abuse with psychological and emotional consequences.[27] This above comment raises a problem solving solution, that the *aiga* collective can resolve *vā* relations amongst the generations, even over time as Ihara and Vakalahi suggested. [31,32]

Further exploration of such notions of abuse need to be clarified. This article argues that any definition of forms of abuse must be informed by the culture in which the abuse occurs. Discussions were focussed more on how the *fa'asamoa* and its values and beliefs are not practised when it comes to caring for the *tagata matutua*. Elder abuse is inextricably linked to specific cultural and spiritual elements because there are cultural variations that point to particular references in these areas.[33]

The Samoan worldview guided by the dimensions of the fonofale paradigm grounded the ontological importance of nurturing the *vā* (relationships). This nurturing is achieved by attempting to harmonise the balance between the spiritual, physical, emotional, cultural and intergenerational elements.[34] Because such are the epistemological underpinnings of these norms, as a result, abuse of the Samoan elderly was at first contested.[20] Biblical concerns to do with the care and respect for the elderly as a filial responsibility are also expressed in Jewish law with similarities in equating it with the *fa'asamoa* values, beliefs, customs and practices synergies presented in the participants' views here.[35]

For these Samoan elders, their belief was that their families should be looking after the parents or grandparents due to these philosophical or, as one participant said, 'fundamental' foundations. The relationships between these elements or domains involves the core values of *fa'aaloalo* (respect), *tautua* (service), *alofa* (love), and *fetausia'i* (reciprocity in the form of servant leadership).[36] Hence, the thought of putting their elders in a rest home was perceived as 'sinning' because it deviated from these core values. Equally abusive was the younger generation not making the effort for the elderly person to attend church. All twelve Samoan elders agreed with these views. The *fetausia'i* paradigm came through strongly. It is nuanced and theoretically related to the discourses alluding to the notions of elder abuse, neglect, disrespect and mistreatment.

CONCLUSION

The fonofale paradigm in this study afforded an awareness of the cultural and spiritual dimension within the Samoan *vā*, or relational framework, to allow an understanding of elder abuse*.* The elderly in this study drew on the *fa'asamoa* to explore and express whether the spiritual and cultural elements cherished by the *tagata matutua* are responded to by the younger generation. The findings highlight that elder abuse not only exists but is prevalent in the Samoan community and that there may be a need to redefine abuse using a cultural lens to inform health policies.

Elder abuse may be an associated emerging act of violence adding either to the deconstruction or the co-construction *talanoa* or dialogues of domestic violence and child abuse[1], which has potential significant adverse impacts on the health and quality of life of Samoan elderly and on Pacific people more broadly. This study has found that Samoan families, like other diasporic communities, are undergoing changes. Values in the traditional collective are impacted by the intergenerational values and priorities of children. However, it can be said that strengthening the *fa'asamoa* and *fa'akerisiano* within the families can deter elder abuse.

Conflicting Interests

The authors declare no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

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PHD PACIFIC HEALTH DIALOG

Original Research **OPEN ACCESS**

Lack of Native Hawaiian Neurologists and Disparities in Care for Native Hawaiians in Hawaiʻi

Maiya SMITH, Christina TSE, Nicholas FRACHER, Ryoko HIROI, William HARRIS, Selin KUTLU, Nicole ANZAI, Heather MIURA, Bryce CHANG, Douglas MILES

ABSTRACT

Introduction: In Hawaiʻi, there are 367,000 Native Hawaiian and Pacific Islanders. Native Hawaiians experience health disparities in a variety of conditions, including stroke, diabetes, and cancer. Ethnic minorities are underrepresented among physicians; this lack of physician-patient racial concordance may contribute to the disparities, as recent studies suggest that racial discordance resulted in poorer healthcare quality. This study aims to assess the current status of neurological health disparities in the Native Hawaiian population in Hawaiʻi, with a focus on identifying neurologist ethnic representation, neurological diseases, and healthcare-related challenges disproportionately affecting Native Hawaiians.

Methods: An anonymous survey on physician's attitudes and practice was emailed to all neurologists in the Hawaiʻi Neurological Society from February 2019 to June 2019.

Findings: Twenty-three full responses and one partial response was received. No participants self-identified as Native Hawaiian nor did they know of any Native Hawaiian neurologists in Hawaiʻi, yet all who completed the survey reported treating Native Hawaiians in their practice ($n = 23$), which identifies a gap in Native Hawaiian representation in the field of neurology in Hawaiʻi. In addition, majority of participants perceived that Native Hawaiians are disproportionately affected by neurological diseases and have difficulty accessing neurology services and obtaining quality care.

Conclusions: Future focus on creating opportunities to improve racially discordant physician-patient relationships and to increase Native Hawaiian representation in neurology may help narrow the gap in health disparities experienced by Native Hawaiians.

KEYWORDS: Native Hawaiian, Neurology, Racial Concordance, Health Disparities, Physician Shortage

INTRODUCTION

According to the United States Department Office of Minority Health, there are currently 1.5 million Native Hawaiian and Pacific Islanders living in the United States (US).[1] In Hawaiʻi alone, there are 367,000 Native Hawaiian and Pacific Islanders.[1] Native Hawaiians have the shortest life expectancy of any racial group and have significantly higher rates of many chronic, preventable diseases, such as diabetes, stroke, and heart disease.[1–4] These disparities may have to do with a long history of mistrust of Westernization by Native Hawaiians. Within 100 years of Captain James Cook's arrival to Hawaiʻi in 1778, 90% of the population passed away due to the introduction of new diseases.[5,6] As missionaries arrived in the 1800s, Western ideas were forced upon Hawaiian language and culture. In 1883, Americans overthrew the Hawaiian monarch, Queen Liliʻuokalani. To this day, some Native Hawaiians continue to oppose the recognition of the United States and argue that the overthrow violated international law. The cumulative effect of these historical traumas may be still influence Native Hawaiian interactions with Western healthcare today, and

Corresponding author: Maya Smith, maiyas22@hawaii.edu
University of Hawaiʻi at Manoa, John A. Burns School of Medicine, Honolulu, Hawaii, United States of America

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possibly play a role in Native Hawaiian healthcare disparities in Hawaiʻi.[7]

One way to ameliorate these health disparities could be to increase physician-patient racial concordance, defined as when a physician and patient are of the same race.[2-4] Studies have found that a physician's perception of a patient's race impacts the quality of care given.[8] Among some minorities, it has been shown that having physician-patient racial concordance can improve patient satisfaction, increase utilization of physician services, and possibly improve health outcomes.[2-4] However, as with other minorities, Native Hawaiians are often underrepresented among physicians. Although Native Hawaiians make up 18 to 22% of Hawaiʻi's population, only 4% of licensed physicians in Hawaiʻi are of Native Hawaiian ancestry.[9] Furthermore, a majority of these Native Hawaiian physicians tend to specialize in primary care, leaving other areas of specialization, such as neurology, particularly underrepresented. [10]

The prevalence of Native Hawaiian neurologists and attitudes toward Native Hawaiians by neurologists in the state of Hawaiʻi has not been reported to our knowledge. This study aims to assess the current status of neurological health disparities in the Native Hawaiian community living in Hawaiʻi, with a focus on identifying neurologist racial representation, neurological diseases, and health care-related challenges disproportionately affecting Native Hawaiians.

METHODS

Recruitment and Consent

An anonymous online survey was emailed to all 44 practicing neurologists in the Hawaiʻi Neurological Society (HNS), a professional organization for neurologists in the state of Hawaiʻi, at the time of data collection. A formal request for the email list and announcement of the study was made in-person by the authors at an HNS meeting, which was approved by the HNS board of directors. In addition, approval was granted by the University of Hawaiʻi Institutional review board (2018-00855) committee prior to conducting the survey.

A waiver of informed consent was obtained from all participants prior to conducting the online survey and was sent as an attachment in the email invitation. There was no payment or other form of incentive for participation. From February 2019 to June 2019, emails with a link to the survey were sent. Participation was voluntary.

No funding was provided for this research. All authors have full access to all of the data.

Measures

The Queen's Medical Center physician satisfaction survey measuring physician attitudes was adapted into a 26-question survey with permission from The Queen's Medical Center. The survey contained questions pertaining to physician background and training, perceptions of practicing in Hawaiʻi, and perception of disparities in access to and quality of neurology care for Native Hawaiians patients in Hawaiʻi. Demographic information was not asked in the survey with the concern of over identifying information from a small sample size by HNS board members. The anonymous online survey was hosted on REDCap, a Health Insurance Portability and Accountability Act compliant survey database.

Data Analysis

Microsoft Excel 2011 version 14.0.0 (Microsoft Corporation: Redmond, WA) was used to report descriptive statistics. Inferential statistics were not utilized due to the small number of participants.

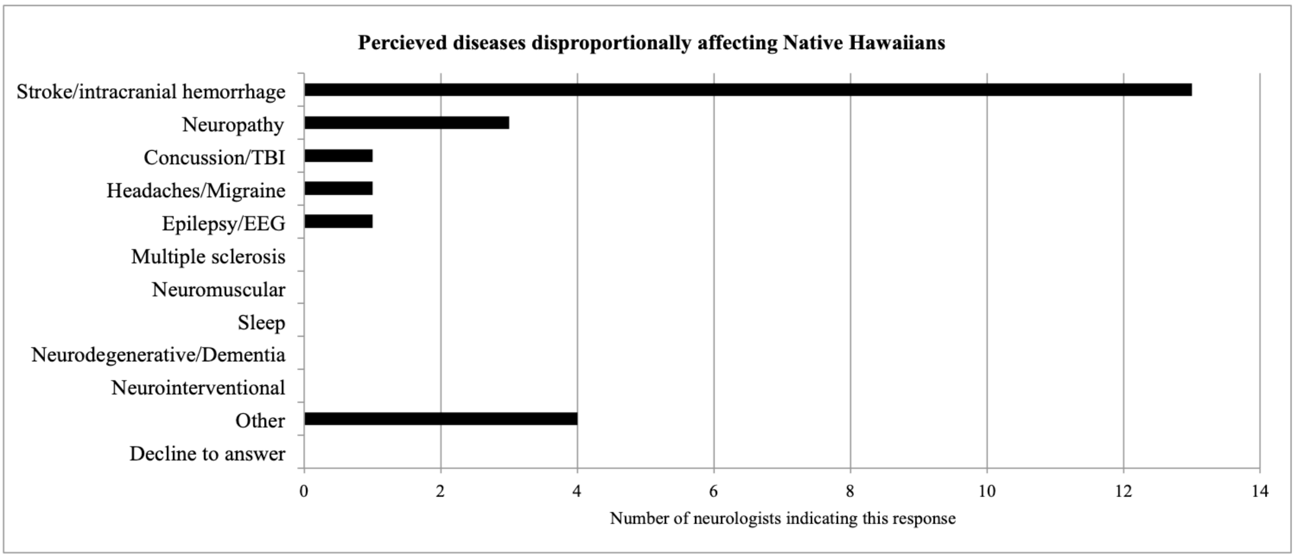
RESULTS

The survey received responses from 24 neurologists. Twenty-three completed the entire survey (52%) and 1 participant only partially completed the survey (2%). Participants reported an average of 14 years practicing in Hawaiʻi, ranging between 1.2 to 32 years ($n = 24$). Among participants ($n = 24$) only 25% ($n = 6$) were born and raised in Hawaiʻi and/or completed any part of their medical education in Hawaiʻi.

When asked about their ancestry and care of Native Hawaiian patients in their practice ($n = 23$), none of the participants who responded to the question were of Native Hawaiian descent or knew of any Native Hawaiian neurologists, but they all reported caring for Native Hawaiian patients. When asked if they perceived that, among the patients they treat, Native Hawaiians were disproportionately affected by certain diseases, a majority of participants agreed with the statement (61%, $n = 14$), specifying stroke and hemorrhage (57%, $n = 13$) (**Figure 1**).

Seventy-four percent of respondents ($n = 17$) perceived that Native Hawaiians have greater difficulty accessing or are less likely to seek out neurology services. The respondents also qualitatively reported lower health literacy and compliance among their Native Hawaiian patients.

Figure 1: Participants' responses to "among the patients you treat, do you feel that there are certain diseases that Native Hawaiians are disproportionately affected by?" (*n* = 23). Results were obtained by an anonymous survey to physician members of the Hawaiʻi Neurological Society. EEG = Electroencephalography; TBI = Traumatic Brain Injury.



One respondent noted that patients of Native Hawaiian descent have "[an] understanding of psychiatric disorders, however, the overall understanding of neurological disorders in this community [is] poor. I spend a lot of time educating." In addition, 39% (*n* = 9) of respondents indicated that they perceived special consideration is necessary when treating Native Hawaiian patients with three participants attributing this to access to care and cultural concerns, and two participants attributing this to health literacy.

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Respondents were also asked about various ways the John A. Burns School of Medicine (JABSOM) could alleviate Hawaiʻi's neurologist shortage (*n* = 23, 96%). Seventy-four percent (*n* = 17) recommended "neurology rotation for 3rd year medical students," 74% (*n* = 17) suggested "neurology residency program," 61% (*n* = 14) suggested "more opportunities to interact with practicing neurologists," 30% (*n* = 7) indicated "scholarship for medical students committed to neurology," and 17% (*n* = 4) recommended "more research opportunities in neurology."

DISCUSSION

It is a striking finding that none of the neurologists surveyed identified as Native Hawaiian or knew of any current Native Hawaiian neurologists, as there may be important implications for the Native Hawaiian population suffering disproportionately from stroke and other neurological disorders. [11,12] Namely, the fact that this survey found no Native Hawaiian neurologists in Hawaiʻi implies racial discordance of the physician-patient relationship. A study demonstrated racial concordance may be beneficial to Native Hawaiians, who are be hesitant to utilize Western medicine, and having a race concordant physician may encourage those of Native Hawaiian ancestry to better utilize physician services.[7,12] Racial concordance has been recognized in the literature to correlate with better patient satisfaction, improved health outcomes, and better utilization of physician services.[8,11,12] For example, African Americans who have a physician of the same race are more likely to express satisfaction and more likely to rate their physician as excellent.[13,14] Similar to African Americans, the benefits of race concordant care may be especially relevant in Hawaiʻi where many unique cultural practices associated with health and illness have been passed down generationally.[15] Therefore, it may be inferred that an increase in recruitment of Native Hawaiians into the field of medicine would help with greater race concordant relationships among Native Hawaiians and their physicians. In addition, prior research finds that physicians identifying as minorities were more likely to practice in underserved areas and treat a more diverse patient population, including patients in underrepresented and underserved ethnic groups, lower income and Medicaid patients, and patients with worse overall health statuses.[16] Thus, not only would recruiting more Native Hawaiians to medicine be beneficial for the Native Hawaiian populations in Hawai'i, but also to the greater underserved community. With more Native Hawaiians in medicine, it raises the likelihood of Native Hawaiians pursuing neurology. By having a Native Hawaiian neurologist in Hawaiʻi, it can improve the racial concordance between Native Hawaiians and neurologists, leading to better outcomes in their neurological disease.

JABSOM has taken several steps over the years to aid and encourage Native Hawaiian students to pursue a career in medicine with notable success. As of 2010, 118 actively practicing Native Hawaiian physicians were identified in Hawaiʻi, 96 of which were JABSOM graduates.[17] Despite this promising trend, these efforts have not led to any currently practicing Native Hawaiian neurologist in Hawaiʻi. The issue of low rates of medical students choosing to specialize in neurology is not unique to Hawaiʻi, or even the US at large.[18] This issue can be attributed to a perceived lack of effective treatment options, poor work-life balance, and/or lack of medical student engagement in neurology courses.[18] At the Boston University School of Medicine, faculty addressed these aforementioned issues through the creation of the Comprehensive Opportunities for Research and Teaching Experience (CORTEX) program, which offers students longitudinal contact with a neurology mentor as well as research and teaching opportunities throughout medical school.[19] A similar program implemented at JABSOM could benefit from culturally tailored longitudinal mentorship and integration of students into the local neurology community, in ways that integrate Native Hawaiian and Western values. For example, students could have the opportunity to work with neurologists who focus on Native Hawaiian research or work with neurologists who work with predominantly Native Hawaiian populations. Not only might this ameliorate some of the potential negative perceptions that many medical students may have of this field, but a program, like CORTEX, may also demonstrate to Native Hawaiian students their potential impact by directly exposing them to the neurological disparities faced by their own community.[18]

Fostering interest in neurology, especially among Native Hawaiian medical students, could also be encouraged through the implementation of mandatory neurology clerkships. A majority of the respondents recommended that JABSOM could help improve the neurologist shortage through a mandatory third-year neurology clerkship, creation of neurology residency, and/or facilitating greater interaction between neurologists and students. JABSOM is currently one of the few medical schools without a mandatory neurology clerkship and Hawaiʻi does not have a neurology residency. According to the AAMC (2018 - 2019), 83% of medical schools (*n* = 147) had a mandatory neurology clerkship.[20] As an initial first step, JABSOM started to offer an optional third-year neurology elective and fourth-year neurology intensive care unit elective in the 2020 to 2021 academic year and also instituted a mandatory two half days of neurology clinic for their third-year students. However, these changes may not be adequate in exposing students to neurology compared to other specialties who receive 4-weeks or more of exposure. By exposing more students to neurology, the school can facilitate greater exposure of the field to their Native Hawaiian students and students in general.

Even though the promotion of Native Hawaiian medical student enrollment and Native Hawaiian healthcare interest in neurology may eventually decrease Native Hawaiian disparities in neurology, establishing cultural competency programs that are available to the state's current pool of neurologists may improve their cultural sensitivity and subsequently their relationships with Native Hawaiian patients. The majority of physicians in the current study were not from Hawaiʻi and/or did not complete any of their training in the state. Respondents in this study also described challenges in communicating health information to their Native Hawaiian patients and spent a significant amount of time educating these patients about their neurological conditions. Multiple studies on cultural competency training have found that it has a beneficial effect not only on the attitudes, knowledge, and skills of physicians, but also on patient satisfaction.[21] Native Hawaiians themselves have expressed that medical students and other health professionals require cultural competency training.[22] As Hawaiʻi's only allopathic medical school, JABSOM has been actively working to integrate Native Hawaiian cultural competency into their curriculum. In 2003, the Department of Native Hawaiian Health at JABSOM was established and is the only medical school in the United States with a department solely dedicated to indigenous health. Since then, JABSOM students have been exposed to Native Hawaiian culture through cultural immersion opportunities; lessons on cultural historical trauma, indigenous healing, and communicating with Native Hawaiian patients; and traditional healing practice.[23] It may be of benefit to extend opportunities similar to the ones offered through JABSOM to currently practicing physicians, possibly in the form of a series of seminars on Hawaiian culture as it relates to healthcare.

CONCLUSIONS

The current study is the first, to our knowledge, to identify the lack of Native Hawaiian ancestry amongst currently practicing neurologists in Hawaiʻi and to discuss neurologists' attitudes and beliefs toward Native Hawaiian patients. The lack of racial concordance between neurologists and the Native Hawaiian patient population is concerning. Potential avenues to mitigate these effects include increasing cultural competency among currently practicing physicians, recruitment of Native Hawaiians into the field of neurology, increasing the mandatory third year neurology requirement at JABSOM, and creating a state neurology residency program.

A limitation of this research is the small sample size. However, a strength of this research is that it is the first to investigate Native Hawaiian prevalence and attitudes toward Native Hawaiians among a medical specialty. Further research may examine whether there are Native Hawaiian neurologists working elsewhere in the US, and factors that led them to practice neurology in their current location. Future studies may also investigate the number of Native Hawaiian physicians in other fields of medicine to identify potential lack of representation in other specialty areas or investigate reasons to what drew them to that specialty. Additionally, incorporation of Native Hawaiian focus groups would likely provide insight into specific Native Hawaiian healthcare needs and better learning of how physicians of non-Hawaiian backgrounds can be better prepared to address unique racial and cultural issues. Future directions as a result of this research include the formation of focus groups with Native Hawaiian medical students and physicians to identify the factors that contribute to their decision-making processes in choosing specialties. This information may yield greater insight into factors affecting Native Hawaiian representation in neurology.

Contributions:
Maiya Smith: contributed to study design and assisted with drafting and editing. All authors contributed in various forms including manuscript editing and approval.

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Availability of data and material: The data supporting the findings of this study is available on request from the corresponding author. The data is not publicly available due to privacy concerns among our small sample size of participants.

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Knowledge, Risk Perception, and Preventive Measures of COVID-19 among Medical and Nursing students in Samoa: A Cross-Sectional Analysis

Lawal O OLAYEMI, [1] Jyothi A ABRAHAM, [2] Vicky YEMOH, [3] Maatasesa SAMUELU-MATTHES, [4]

ABSTRACT

Objectives: There has been unprecedented spread and re-evolving of the SARS-COV-2 throughout the world with the emergence of new strains of the virus. This study investigated the knowledge, risk perception and preventive measures of COVID-19 among Medical and Nursing Students in Samoa.

Methods: This is a cross-sectional study conducted from August to October 2020 at the National University of Samoa (NUS). The study was conducted using an online self-administered questionnaire, which was distributed on specific social media and interactive online platforms such as Facebook, WhatsApp and Moodle groups of Medical and Nursing students. A total of 75 students participated in this study.

Results: About 88% of the study subjects were knowledgeable about COVID-19 and majority of them were females. 71% of the students were aware of early diagnosis of COVID-19. There was also a significant level ($p=0.003$) of association of COVID-19 in persons with underlying conditions and students' academic levels, depicting that a greater percentage (92%) of the participants' perceived adults above age 65 and individuals in the high-risk groups (diabetic, hypertensive and cancer patients) were more prone to COVID-19. Most of the students (95%) stated that observing basic safety precautions; sneezing and coughing into the elbow (86%), regular hand washing with soap and water (89%), observing personal hygiene and social distancing (84%) and frequent use of hand sanitizers (76%), could prevent the contraction of COVID-19.

Conclusion: Our findings suggested that medical and nursing students, who are future frontline healthcare workers in Samoa, showed a considerable level of knowledge, risk perception and preventive behaviour towards COVID-19. Additionally, updating the students' knowledge about the diagnosis and case management of COVID-19 is imperative when implementing proper preventive strategies to curtail the spread of the disease.

Key words: COVID-19; knowledge; Risk perception; preventive behaviour; Students; Samoa

INTRODUCTION

Human Coronaviruses are a large group of viruses that are rather common throughout the community. Coronaviruses (CoVs) belong to the order *Nidovirales* of the family *Coronaviridae*, which are positive-sense single stranded non-segmented RNA viruses. CoVs are divided based on their antigenicity into four groups: alpha-, beta-, gamma-, and delta CoVs.[1, 2] Alpha- and beta-CoVs infect humans and cause a wide variety of clinical sequelae ranging from common cold to croup, bronchiolitis, and pneumonia.[3, 4] Some CoVs, which were considered enzootic infections, have jumped across animal-human

Corresponding author: Lawal O Olayemi, Olayemi2002@yahoo.com

1. Senior Lecturer, School of Medicine, Faculty of Health Sciences, National University of Samoa, Samoa
2. Lecturer, School of Nursing, Faculty of Health Sciences, National University of Samoa, Samoa j.abraham@nus.edu.ws
3. Senior Lecturer, School of Medicine, Faculty of Health Sciences, National University of Samoa, Samoa v.yemoh@nus.edu.ws
4. Dean, Faculty of Health Sciences, National University of Samoa, Samoa m.samuelu-matthes@nus.edu.ws

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species barrier to become a zoonotic infection affecting humans. CoVs, such as the Severe Acute Respiratory Syndrome (SARS) and the Middle East Respiratory Syndrome (MERS), caused by SARS-CoV and MERS-CoV, consecutively, led to virulent infections in humans.[5, 6]

The year 2019 ended with a global panic in the form of an outbreak of a new strain of coronavirus called the Severe Acute Respiratory Syndrome Coronavirus Type 2 (SARS-CoV-2). On February 11, 2020, the World Health Organization (WHO) designated a new name for the epidemic disease caused by this virus – coronavirus disease 2019 (COVID-19). Evidence has shown that the virus for COVID-19 is transmitted through birds and mammals, with humans being particularly vulnerable to infection and transmission of the virus.[7] Epidemiological investigations have shown the incubation period of the SARS-CoV-2 to be between 1-14 days and the virus has also been found to be contagious in the asymptomatic patients.[8] Infection with COVID-19 is more prominent in the elderly people with underlying diseases[9, 10], where it clinically manifest in form of fever, cough, malaise and acute respiratory distress syndrome occurring in few patients which may eventually leads to death. However, in adults and children the disease is usually presented with mild flu-like illness.[11] The overall mortality rate of COVID-19 is 2% which is much lower than that of the Severe Acute Respiratory Syndrome (SARS) and Middle East Respiratory Syndrome (MERS). Increased respiratory transmission of the disease necessitates the practice of strict respiratory precautions for its prevention.[12] Medical staffs that are front liners are at increased risk of this contagious disease. Knowing that COVID-19 can probably be transmitted from non-symptomatic individuals, poses a multiplied risk of significant momentum.[13. 14, 15] This was elucidated in a study in Wuhan City by Wang *et al.* which reported transmission of SARS-CoV-2 to health professionals including medical students.[16] Chang *et al*. also indicated that a patient, who was scheduled to undergo surgery, had infected 14 health care workers even before the onset of symptoms.[17]

In addition, several studies have emerged assessing the virologic features and clinical effects of COVID-19;[18, 19] however, not enough studies have been carried out to focus on the understanding of knowledge, risk awareness and preventive behaviours for COVID-19 among health science students, who may become frontline healthcare workers, especially in the Pacific Island Countries and Territories (PICTs). In addition, knowledge is a prerequisite for establishing preventive beliefs, promoting positive attitudes and behaviours. Individuals' cognition, risk perception and preventive attitudes towards disease affect the effectiveness of their coping strategies and behaviours to a certain extent.[13] In case of the current pandemic, the knowledge and behaviour assessment of the public towards the disease is essential, especially due to the large amount of misconceptions and false information that are circulating on social media in regard to transmission of the disease and methods of acquisition.[20] This is of importance to healthcare professionals, service providers, medical and nursing students in preparing and providing quality care during pandemic events. Such assessments have proven useful as an important means in the education and raising awareness of best practice in previous viral outbreaks including SARS, MERS, and Ebola.[21, 22, 23]

In resource-limited settings, medical and nursing students may be the first individuals who have close contact with affected persons. Lack of proper related knowledge in this group can make them overestimate the situation, increase their stress and anxiety level and may interrupt the appropriateness of their medical judgments.[24] Due to the tourism and conservative culture of Samoa, it is highly susceptible to an outbreak of COVID-19 if strict public health regulations and prevention measures are not enforced.[25] Up until now, no similar study on this topic has been carried out in Samoa, being among the last few COVID-19 free countries worldwide.

METHODS

Study Design and location

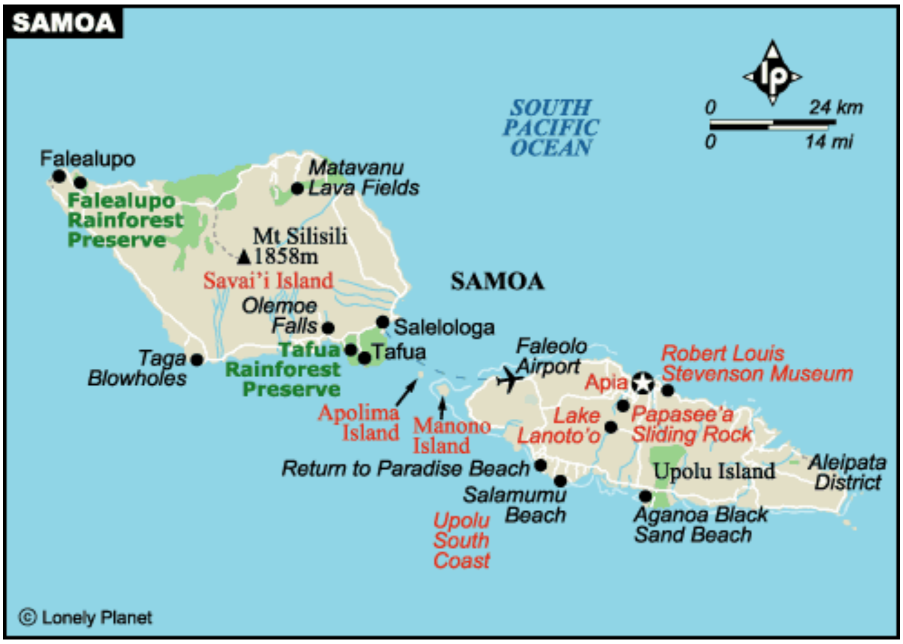
This was a quantitative cross-sectional study conducted from August to October 2020 at the NUS. The University's students' population is about 4,000 with a staff capacity of about 380. The participants included in this study were from the Faculty of Health Sciences including medical and nursing students, who could be potentially first responders to any future pandemic or disease outbreak in the country.

Demography of Samoa

Samoa, a Polynesian Island country in the Pacific Ocean consists of two main islands, which are Savai'i and Upolu. There are also two smaller inhabited islands, Manono and Apolima, and several small uninhabited islands including the Aleipata Islands (Nu'utele, Nu'ulua, Fanuatapu and Namua) (**Fig 1**). The capital city of Samoa is Apia. According to the World Bank population statistics in 2019, the population of Samoa was 197, 097 with males being 101, 781 and females 95, 316.[26]

Samoa's health system is made up of the public and private health sector. Primary and secondary healthcare are mainly based in the community and district hospitals, while the tertiary healthcare is provided in the referral-based hospital in Apia and overseas treatment scheme (New Zealand and India).[2]

Figure 1: Map of Samoa showing the different regions and districts
[Source: https://www.pinterest.com/pin/478226054154274446/]



METHODS

The study was conducted using Google form, an online self-administered questionnaire, which was distributed to specific social media and interactive online platforms such as Facebook, WhatsApp and Moodle groups of medical and nursing students.

Inclusion criteria

- Medical and nursing undergraduates
- any gender
- any nationality
- living in Samoa
- able to read and write
- has a Facebook, WhatsApp and Moodle account
- member of social media groups that were selected for the study

Exclusion criteria

- Not in the Faculty of Health sciences
- participants less than 18 years
- does not live in Samoa

Survey questionnaire

This was composed of an interface, which included three main items with a total number of forty-one questions. The questionnaire explained the aims and objectives of the study and informed consent statement was included to assure the participants of confidentiality. The questionnaire was structured in English and formatted into the Google forms, internet-based software, commonly used for data collection via personalized survey. It was preferred for its convenience, efficiency and high popularity, especially in the current scenario, where most educational institutions of the country were observing online teachings for students due to the imminent threat of COVID-19 and lock down situations. After questions were added into Google forms, a link for the same was generated and randomly distributed to the participants' social media groups.

The four main items in the questionnaire included:

Socio-demographic data such as gender, age group, academic level, residential village, religion, marital status, nationality, department and employment status.

Questions on knowledge included data on most important symptoms of COVID-19, level of awareness on diagnosis, knowledge on treatment and management of COVID-19 and geographical views on socio-biological factors of COVID-19.

Questions on risk perception included entities such as history of respiratory associated problems, perception about high risk groups (diabetes, hypertension, and cancer patient) and emotional states after diagnosis etc.

Questions on preventive measures included participants' behaviour towards acquisition of the infection such as hand washing, use of hand sanitizers, sneezing and coughing into the elbow, healthy eating, self-isolation, etc.

Data collection

The questionnaire link was distributed through social media groups. Thereafter, members who clicked on the link were directed to complete the survey. To reduce any missing information, the participants were requested to answer all questions.

Sample size calculation and Data analysis

The estimated sample size (n) was calculated using Kish formula[28] for sample size estimation at a 95% significance level and a margin of error below 5%. For this study, the representative sample size was 75. All captured data from the online survey were entered into Microsoft Excel and then imported into the Statistical Package for Social Sciences (SPSS) version 25. Data were analysed and the level of association was determined using the Chi-square test method. The categorical variables with their percentage frequencies were computed. The mean and standard deviation for the age groups were also analysed.

RESULTS

A total of 75 medical and nursing students responded to the survey questionnaire. The mean age was 24.7 years with the larger percentage (%) of participants falling between the age groups of 18 to 25 years. Among the participants, 20 (26.7%) were males and 55(73.3%) were females (**Table 1**). The majority of the participants were also females undergoing their bachelor's degree programs in the nursing and medicine departments. 40 (53.3%) of the female participants were employed and were involved in COVID-19 work-related trainings and awareness programs.

COVID-19 knowledge

The majority (88%) of the participants had heard about COVID-19 through social media. There is a high level (71%) of awareness on early diagnosis of COVID-19 among the participant (**Table 2**). When asked about symptoms of COVID-19, most of the students (85%) agreed that dry cough was a symptom of the disease. In contrast, a high number of the students (85%) stated that COVID-19 could not be treated. In addition, half of the participants agreed death could occur if COVID-19 was not well managed. Around 77% of the participants agreed on the effect of environmental factor (heat) in reducing the transmission of COVID-19, while 16% of the students thought otherwise. Study participants also differed in their knowledge of the effect of biological and geographical factors (56%), (32%) and (12%) on COVID-19. Based on the religious knowledge, a lower percentage (12%) of the participants agreed COVID-19 was a punishment from God.

Table 1: Demographic characteristics

Gender		
Characteristics	% (n =20) Males	% (n= 55) Females
Age group		
18 to 25 years	25.3 (19)	57.3 (43)
26 to 35 years	2.7 (2)	13.3 (10)
36-45 years	--	8.0 (6)
> 45 years	--	1.3 (1)
Academic level		
Foundation	1.3 (1)	--
Diploma	--	1.3 (1)
Bachelor	25.3 (19)	60.0 (45)
Postgraduate	--	9.3 (7)
Residential village		
Urban	22.7 (17)	29.3 (22)
Rural	2.7 (2)	40.0 (30)
Religion		
Christianity	26.7 (20)	70.7 (53)
Others	1.3 (1)	2.7 (2)
Marital status		
Single	25.3 (19)	52.0 (39)
Married	--	18.7 (14)
Others	--	1.3 (1)
Nationality		
Samoan	24.0 (18)	68.0 (51)
Others	--	5.3 (4)
Department		
Medicine	6.7 (5)	8.0 (6)
Nursing	18.7 (14)	64.0 (48)
Employment		
Employed	4.0 (3)	53.3 (40)
Not employed	20.0 (15)	34.7 (26)

Table 2: Levels of COVID-19 Knowledge, risk perception and preventive behaviour

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Level of Knowledge	Correct response Rate (%) Range 0 – 100%		
Items	**Yes**	**No**	**Maybe**
Where did you hear about covid-19? • Social media 66 (88%) • Friend 1 (1.3%) • University press 5(6.7%) • Family member 3(4%)			
Is early diagnosis possible?	71	26	3
Is coronavirus another name for covid-19?	65	23	12
Are you familiar with covid-19?	72	9	19
Dry cough is a symptom of covid19	85	15	0
Covid19 leads to death if not managed properly	49	16	35
Covid-19 can be treated	0	85	15
Covid19 is a disease that affects only the wealthy	73	24	3
Covid19 can be killed in hot environment	77	16	7
Covid19 does not respect geographical boundaries, ethnicity, age, religion and gender	56	32	12
Covid19 is a punishment from God for the sin of man	12	74	14
Level of Risk Perception			
Items	**Yes**	**No**	**Maybe**
Stress and genetic factors can be responsible for covid19	22	40	38
Covid19 affect more men compared to women	85	3	12
The elderly (>60yrs) are more susceptible to covid19 than young adults	72	28	0
Covid19 can make the victim feel isolated and different from the rest of the world	96	0	4
Individuals who have respiratory tract infections diabetes, hypertension cancer are more at getting risk of getting covid-19	92	5	3
Covid19 can cause feelings of sadness, worry scare and anger	77	14	9
Practicing preventive behaviours			
Items	**Yes**	**No**	**Maybe**
Avoid touching eyes, nose and ears to prevent covid19	93	7	0
Sneezing and coughing into the elbow can prevent covid19	86	0	14
Can covid-19 spread from person to person by direct contact	95	4	1
Washing hands frequently with soap and water can help to prevent a person from getting covid19	89	8	3
Avoid touching eyes, nose and ears to prevent covid19	93	7	0
Sneezing and coughing into the elbow can prevent covid19	84	0	16
Using hand sanitizer frequently can prevent covid19	76	15	9
Staying safe by visiting loved ones can prevent an individual from getting covid19	72	11	17
Going to the hospital if you are feeling feverish may save you from covid19	84	0	16
Observing personal hygiene and social distancing can prevent covid19	84	5	11
Eating a lot of veggies and fruits can increase your immunity against covid19	80	4	16
Isolating yourself for 2 weeks if you make contact with someone who has tested positive to covid-19 can help in preventing disease contraction	85	3	12

COVID-19 risk perception

Regarding the level of risk perception, 72% of the interviewees agreed that the elderly (> 60years) were more susceptible to COVID-19 and interestingly 85% of study participants indicated that coronavirus disease would have a greater effect on men compared to women. Perception about high risk groups (diabetes, hypertension and cancer patient) showed that a larger percentage (92%) of students thought that people with underlying conditions were more prone to contracting the disease. Furthermore, participants were indifferent about their perception on stress and genetic factors as being responsible for COVID-19 (Yes 22%, No 40%, Maybe 38%). Moreover, a high percentage of the subjects agreed that COVID-19 could result in feelings of isolation (96%), sadness, worry, scare and anger (77%).

COVID-19 preventive behaviour

While asked about preventive behaviours toward COVID-19, participants shared their agreement on avoiding touching of eyes, nose and ears (93%), sneezing and coughing into the elbow (86%), frequent washing of hands with soap and water (89%), observing personal hygiene and social distancing (84%) and frequent use of hand sanitizers (76%). Additionally, 95% of the interviewees stated by avoiding direct person-to-person contact could reduce the spread of COVID-19, 85% of study subjects agreed that personal isolation for 2 weeks could prevent coronavirus contraction if there was a contact with a confirmed or suspected COVID-19 case. Likewise, 80% of the participants agreed that eating more veggies and fruits could boost personal immunity against coronavirus disease and 84% participants stated that by visiting hospitals if unwell could save a person from COVID-19.

Association between level of knowledge, risk perception and preventive behaviour of COVID-19 among medical and nursing students in Samoa

We tested the association of students' COVID-19 knowledge, risk perception and preventive behaviour against major variables including age, gender, department, residential village, family status and academic level. There was a significant association between the students' knowledge about COVID-19 and their family status (p= 0.001*). There was also a significant association between the students' academic levels and their risk perception, especially having an underlying disease condition in contracting COVID-19 (p= 0.003*). Similarly, a significant relationship existed between preventive behaviour and students' academic level (p= 0.039*). The present study thus concludes that significant associations exist among the tested variables and students' level of knowledge, risk perception and preventive behaviour.

DISCUSSION

The imminent threat of COVID-19 to the survival of the global socio-economic space has continued to re-emerge, despite tremendous efforts and contributions by various government stakeholders. With ongoing possibility of vaccine containment measures, much is still needed to be done regarding inter and intra communities spread of the SARS-CoV-2. This could result in concerted collaborations and partnership amongst regional stakeholders in the Pacific Island Countries and Territories (PICTs) in keeping the coronavirus disease at bay through border control measures. There was great concern in Samoa of a positive case of COVID-19, which generated panic among the public and stigmatization of suspected cases of the disease due to the people's peculiar cultural beliefs and traditional way of living.[43] Additionally, significant fear of the impact of a vaccine preventable disease on an under vaccinated Samoan population was the result of a horrific recent measles experience, where 81 deaths and 5,675 cases of measles were reported from the epidemic in 2019.[29] However, to forestall a COVID-19 epidemic in Samoa, a great deal of awareness and prevention measures is imperative for healthcare professionals including student doctors and nurses, who are future frontline health workers. Hence, it is important to assess their knowledge about COVID and its causative agent, understanding their opinions on the risk factors and their preventive measures.

In this cross-sectional analytical study, we explored the knowledge, preventive behaviour and risk perception of nursing and medical students towards COVID-19 in Samoa. Based on our search, no current study on this topic among students had been carried out in Samoa or neighbouring pacific island nations. In April 2020, there was a surge in COVID-19 cases in New Zealand[25], hence, as a preparedness approach; we carried out this study to assess the level of awareness of medical and nursing students, since some of these students are currently working in the hospitals and community health centres, and are at high risk of infection transmission.

Table 3: Association between level of knowledge, risk perception and preventive behavior of COVID-19 among medical and nursing students in Samoa

	Age	**gender**	**department**	**residential village**	**family status**	**academic Level**
Level of knowledge						
1. COVID-19 can be treated.	x^2 10.450 p 0.577	x^2 1.904 p 0.753	x^2 8.182 p 0.085	x^2 1.815 p 0.770	x^2 12.279 p 0.139	x^2 15.181 p 0.232
2. COVID19 does not respect geographical boundaries, ethnicity, age, religion and gender	x^2 14.073 p 0.296	x^2 3.573 p 0.467	x^2 3.291 p 0.510	x^2 6.109 p 0.191	x^2 27.100 ***p 0.001**	x^2 10.976 p 0.531
3. COVID19 can be killed in hot environment	x^2 2.407 p 0.983	x^2 1.099 p 0.777	x^2 2.024 p 0.567	x^2 2.024 p 0.567	x^2 2.450 p 0.484	x^2 6.368 p 0.703
Risk perception						
1. COVID19 is a punishment from God for the sin of man	$x^2$17.429 p 0.134	x^2 5.232 p 0.264	x^2 10.177 ***p 0.029**	x^2 2.578 p 0.631	x^2 4.782 p 0.439	x^2 28.729 p 0.004
2. Individuals who have respiratory tract infections, diabetes, hypertension, cancer are more at risk of getting COVID-19.	x^2 4.198 p 0.898	x^2 2.596 p 0.458	x^2 1.413 p 0.703	x^2 4.198 p 0.241	x^2 3.259 p 0.776	x^2 6.984 ***p 0.003**
Preventive behavior						
1. Washing hands frequently with soap and water can help to prevent a person from getting COVID-19.	$x^2$13.166 p 0.155	x^2 1.854 p 0.603	x^2 2.644 p 0.450	x^2 5.641 p 0.130	x^2 13.904 p 0.126	x^2 13.166 p 0.135
2. Sneezing and coughing into the elbow can prevent COVID-19.	x^2 8.032 p 0.236	x^2 2.677 p 0.262	x^2 4.835 p 0.089	x^2 1.932 p 0.748	x^2 5.676 p 0.460	x^2 3.910 p 0.110
3. Using hand sanitizer frequently can prevent covid19	$x^2$13.926 p 0.731	x^2 7.924 p 0.244	x^2 3.233 p 0.779	x^2 19.952 p 0.068	x^2 14.845 p 0.900	x^2 5.341 ***p 0.039**

Key: x2= chi square value. P= p-value, *p-value < 0.05 is Significant

About 85% of participants had high level of knowledge related to COVID-19. The reason for this may be due to their access to available information from several media and literature. It is evident from this high response rate that the majority of students were aware of the early diagnosis and common symptoms of COVID-19. These findings acquiesces with previous studies, where there were high overall knowledge scores (60-98.7%) among medical and non-medical students towards coronavirus disease in Nepal[29], 74.5% among medical and nursing students in Egypt[30], 67.9% among health science students in Thailand,[31] 90% among Chinese medical students[32] and 79.6% among Iranian Medical students.[33] In contrast, 85% of participants were unaware about the availability treatment for COVID-19. This finding agreed with a study by Alzoubi *et al*[12.] which reported that 80% of the participants identified that there was unavailability of vaccines and treatment for COVID-19. This may be as a result of little information on therapeutic interventions. It could be suggested that current Food and Drug Administration (FDA) approved treatment modalities for COVID-19 under emergency use authorization need to be made available through Public Health social media platforms in Samoa. This would aid easy access to medical and nursing students.

In preparation for future pandemics, knowledge about epidemiologic triads for certain infectious diseases could also be published in Notifiable Disease Registry (NDR) and be accessible for students through the Samoa Public Health Department. Additionally, the Samoan government through its Ministry of Health is constantly promoting campaigns on epidemic preparedness via leveraging on available resources, capacity building; use of personal protective equipment (PPE) such as face masks and hand gloves; appropriate identification of isolation and quarantine facilities and strengthening communications to raise public awareness and counter rumours and misinformation.[25]

This study also reported high scores of risk perception, among elderly being more susceptible to coronavirus disease (72%). About 92% of students also identified that individuals having underlying conditions such as hypertension, cancer and diabetes were more vulnerable to contract COVID-19, owing to the fact that the PICTs including Samoa suffers from alarming rates of non-communicable diseases (NCDs)[34]. Majority (87%) of the participants in our study also opined that COVID-19 could result in emotional and psychological distress. These findings could be related to the incessant and stringent lockdown measures in neighbouring countries and feelings of being isolated from families and other members of the public once someone is infected with the disease.

There was a significant association between academic level of participants and preventive behaviours, ($p= 0.039$) but no significant association existed with other variables such as age, gender, department and family status. Most participants identified preventative measures towards the spread of COVID-19, such as avoiding direct person-to person contact (95%), frequent hand washing with soap and water (89%), regular use of hand sanitizers, having proper respiratory etiquettes (86%) and avoid touching facial orifices (93%). Similar outcomes were reported by Elhadi *et al*, where a high overall preventive behavioural score of 92.87% among medical students suggested that transmission of SARS-CoV-2 could be controlled successfully.[35] Outcomes of the current study are consistent with other previous studies, which showed that frontline healthcare workers had a high level of positive attitude towards prevention of COVID-19. [36, 37, 38]

Since findings of this study revealed an association between students' academic level with risk perception and preventive behaviour, this may imply a positive relationship among these factors. Yang *et al* revealed that an increase in risk perception led most students to adopt greater compliance with preventive practices, and suggested that the students who most feared the virus would most likely protect themselves.[39] Furthermore, a significant percentage (88%) of the students in this study had heard about COVID-19 through social media. This indicated the effect of social media on their attitudes towards preventing the disease. It also demonstrates that fear could mediate the relationship between social media exposure, individual risk perception, and preventive behaviours. This may suggest that social media exposure during an infectious disease outbreak could elicit self-relevant emotions and thus, increase individual risk perception and preventive behaviours[40].

Optimal nutrition and dietary nutrient intake could impact the immune system through gene expression, cell activation, and signalling molecules modification,[42] thereby promoting overall personal immunity. The nutritional statuses of individuals have been used as a measure of resilience towards a decline in health status. [41] This falls in tandem with our findings, where a larger percentage (80%) of the participants perceived that eating more veggies and fruits could boost immunity against coronavirus disease. About 84% of the students also perceived that individuals with underlying health conditions were more at risk of getting the virus. Therefore, it could be recommended that proper nutrition and healthy lifestyle could reduce the likelihood of being susceptible to COVID-19 and the possibility of an early recovery.

Limitations

This current study had some constraints. Firstly, due to the lockdown in the country, only online Google forms were used as the main means of data collection. Participation in this study could have been improved if additional data collection tools such as hard copy questionnaires were used. Secondly, our study only focused on medical and nursing students, which might have resulted in a selection bias.

Therefore, general views from other university students were not covered in this study. Lastly, in the questionnaire, the use of facemasks as a preventive measure was not included. However, as a health and safety precaution, face masks are currently recommended by the WHO globally in reducing the spread of SARS-CoV-2.

CONCLUSION

Our study has shown that there is significant level of knowledge, risk perception and preventive behaviour among medical and nursing students in Samoa towards the COVID-19 outbreak. However, it is pertinent for students and health professionals to choose wisely, when getting information from social media, and only use evidence-based public health websites. More emphasis should be put on updating the students' knowledge regarding the diagnosis and case management of COVID-19. Educational interventions for Samoa and PICTs should be tailored to include communities and healthcare workers, via accessible media and social networks.

Campaigns on healthy lifestyle programs should be promoted along with more COVID-19 awareness including health and safety practices. More studies should be conducted to look at the perceived levels of knowledge, attitude and risk of COVID-19 among frontline workers such as health professionals and hospitality personnel, who often are in close proximity to isolation and quarantine facilities. These could assist in decision making processes and coping strategies in preparing for future pandemics.

Abbreviations:

- **COVID-19:** Coronavirus disease 2019
- **CoVs**: Coronaviruses
- **FDA:** Food and drug administration
- **PICTs:** Pacific Island Countries and Territories
- **MERS:** Middle East respiratory syndrome virus
- **RT-PCR:** Reverse transcription polymerase chain reaction
- **SARS:** Severe acute respiratory syndrome
- **SARS-CoV-2:** Severe acute respiratory syndrome corona virus type 2

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Competing Interest

The authors declare that they have no competing interests.

Authors' contributions

LOO conceived the study and wrote the first draft together with JAA and VY. MSM supplied with useful resources. All authors made substantial contributions to the design, data acquisition, interpretation of data and tables, and took part in revising the manuscript for intellectual content. All the authors read and approved the final version to be published and are accountable for all aspects of the work.

Ethics Approval and Consent

The study was designed and conducted in accordance with the ethical principles established by the National University of Samoa Research Ethics Committee. Thus, ethical approval was obtained from the University Research and Ethics Committee.

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Original Research **OPEN ACCESS**

Non-operative management of adhesive intestinal obstruction in children, 2000-2012, at Waikato Hospital, New Zealand

Aaron OOI,[1] Udaya SAMARAKKODY,[2] Askar KUKKADY,[2] Stuart BROWN,[2] Jitoko K CAMA[2]

ABSTRACT

Introduction: Post-operative small bowel adhesions causing bowel obstruction is common in adults but is uncommon in the paediatric age group. The incidence of adhesive intestinal obstruction (AIO) requiring surgical intervention ranges between 2-8% in paediatric patients and majority would occur within the first two years after surgery.

Aim: To review our experience at a tertiary centre in children under 15years who were admitted with adhesive intestinal obstruction over a 12 year time period, 2000-2012, and to compare outcomes with other international reports

Methodology: This retrospective case series study of all paediatric surgical patients (aged between 1-15 years) admitted with adhesive intestinal obstruction to Waikato Hospital over a 12 year time period were identified by ICD-10-AM codes. Their demographic variables, information of previous surgery and the admissions details including particulars of management were tabulated.

Results: Out of 66 admissions, 10 were excluded and 56 admissions were analysed**.** 35 patients were successfully managed non-operatively and 21 patients proceeded for operative management (7 early and 14 late). Of the operative group, 3 underwent bowel resections (2 early and 1 late). There was no statistically significant difference between length of stay (LOS) among patients with non-operative and operative management. There was also no statistically significant difference between LOS among patients with early (≤24 hours) operative management and late (>24 hours) operative management. In assessing secondary aims, statistically significant differences in the time of presentation from initial surgery was noted for patients who underwent appendectomy who trended towards earlier presentation compared to other laparotomies.

Conclusion: This study demonstrated that there could still be a role of non-operative management of children with adhesive bowel obstruction but decision on further management should be clearly defined within 24hours to prevent development of complications.

Key words: intestinal obstruction, children, paediatric surgery, non-operative management

INTRODUCTION

Reports of 1.1% of patients under 16 years of age re-admitted to hospital after lower abdominal surgery are a direct consequence of adhesions, with 8.3% of patients re-admitted possibly related to adhesions over a 4 year follow up period.[2] Nevertheless, those adhesive intestinal obstruction in paediatric patients requiring surgical intervention has been reported to range between 2.2-8%, most of which occur within the first two years of surgery. [3,4]

The decision making as to the timing of operative management of any adhesive intestinal obstruction in children can be a daunting task for any paediatric surgeon. All surgeons would agree that one should proceed to the surgical intervention if there are clinical or radiological signs of bowel ischaemia. If there are no signs of bowel ischaemia, some surgeons

Corresponding author: Jitoko K Cama
Email: Jitoko.Cama@waikatodhb.health.nz
1. Paediatric Registrar, Paediatric Surgery Department, Waikato Hospital, Hamilton, New Zealand
2. Paediatric Surgeon, Paediatric Surgery Department, Waikato Hospital, Hamilton, New Zealand

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would advocate early operative management after the initial resuscitation to prevent bowel ischaemia but at the risk of causing more adhesions later on. Others have advocated the role of non-operative management as a safe option to prevent further adhesions. The success rate with non-operative management in adhesive bowel obstruction in children ranges between 16% to 48.6% without any increase in morbidity and mortality associated with delayed operative management.[5-7] This 12 year retrospective review was conducted in a tertiary centre at Waikato Hospital New Zealand to evaluate our experience with children under 15 years of age who are admitted with adhesive intestinal obstruction over a time period and comparing our results with other international reports.

METHODOLOGY

The medical records of all patients between one and fifteen years of age admitted under the Paediatric Surgical Department at Waikato Hospital between the first of January 2000 and 30th of June 2012 inclusive were reviewed retrospectively. Patients were identified based on the following ICD-10-AM codes: K565 – Intestinal adhesions [bands] with obstruction, K566 – Other and unspecified intestinal obstruction and K913 – Post-procedural intestinal obstruction. Of the patients identified, the diagnosis of adhesive intestinal obstruction was made on the basis of compatible clinical and radiologic findings in patients with a history of previous abdominal surgery, and where possible, confirmed on operative findings. Radiologic data were obtained from reports provided by specialist radiologists. Patients with an alternate primary diagnosis such as obstruction due to other causes or paralytic ileus were excluded from the study.

The following information was tabulated from patients' clinical notes: age at presentation with adhesive intestinal obstruction, ethnicity, gender, details of previous surgery (including age at surgery, date of surgery, type of initial surgery and indication, intraoperative and postoperative complications). Admission details were also collated including clinical presentation, type of radiological investigations requested and findings, aspects of conservative management (nil by mouth, intravenous fluid administration, nasogastric tube inserted for decompression and placed on free drainage/aspirates) and details of operative management (date and time of surgery, operative findings and rates of bowel resection). Patients were divided into three groups based on the type of management received; Non-operative management, early operative management (≤24 hours to surgery from time of presentation) and late operative management (>24 hours to surgery from time of presentation). Length of stay was used as a primary outcome measure to compare the differences in outcome between the aforementioned groups. Our study also set out to examine the difference in time to presentation from initial surgery between patients who underwent a previous appendicectomy compared to other operations.

In assessing the primary outcome of our study, comparison in the length of stay between the non-operative and operative groups, and the early and late operative group were calculated using the two sample Wilcoxon rank-sum (Mann-Whitney) test. Similarly, the time to presentation from time of initial surgery between the appendicectomy groups compared to other operations was also calculated with the same test.

RESULTS

A total of 66 admissions were identified which met our inclusion criteria with the diagnosis of adhesive intestinal obstruction over the 12-year period. Of these, 10 were excluded, nine due to failure in obtaining complete medical notes and one excluded as outcomes were unavailable as the patient was transferred to another tertiary centre. Ultimately, 54 patients were included in the study with 56 admissions, as 2 patients presented on two separate occasions (**Figure 1**). Twenty-eight (28, 50%) of the patients were male, with patients' ages ranging from 1 to 14 years of age (mean 8.2 years, standard deviation 4.0). Fifty two percent (52%) of patients identified as NZ European, with a further 36% being Maori, 8% Other European, 2% African and 2% Asian.

Cardinal symptoms of intestinal obstruction were seen in 93% who had abdominal pain and 91% with vomiting during their presentation. Less than half of the patients (41%) did not have abdominal distension and 36% of patients did not present with constipation. In our series, appendicectomy was the most common operation leading to adhesive intestinal obstruction, followed by exploratory laparotomy for gastric or intestinal perforations, Malone's Antegrade Continence Enema (MACE) procedures, Nissen fundoplication, gastroschisis repair and Ladd's procedure (**Table 1**). The ages at the time of the initial operation ranged from 2 days to 14 years of age (mean 6.0 years, standard deviation 4.6) and this correlates with the age group of children under the age of 15 years who are under the care of paediatric surgeons at Waikato Hospital. Based on the clinical assessments, 46 admissions (82%) proceeded with an abdominal x-ray as their initial investigation, of which 42 (91%) showed significant dilated bowel loops and air fluid levels suggestive of bowel obstruction. Of the total 56 admissions, 9 (11%) also had an additional USS most commonly done to exclude intussusception of which 7 (77%) proceeded to have a CT scan to exclude other causes such as intra-abdominal sepsis.

Table 1: Incidence of most common operations leading to AIO

Procedure	n	%
Appendicectomy	27	50.0
Laparotomy for gastric/intestinal perforation	6	11.1
MACE procedure	4	7.5
Nissen fundoplication	3	5.5
Gastroschisis repair	3	5.5
Ladd’s procedure	3	5.5
Diaphragmatic hernia repair	2	3.8
Other miscellaneous	6	11.1

All 56 admissions were initially managed non-operatively, with 21 admissions proceeding for operative management (**Figure 1**). All patients had a period of non-operative management which consisted of varying aspects of bowel rest; being placed nil by mouth, fluid resuscitation with intravenous fluids and insertion of a nasogastric tube for decompression. Operative management was required in 37% of our cases, of which 7 were in the early operative management group and 14 in the late operative management group, with a mean time to surgery of 13.4 and 70 hours respectively. Two out of these 7 (28.6%) patients in the early operative management group proceeded to immediate surgery within the first hour with both needing bowel resection. One patient in the late operative group underwent bowel resection which might be suggestive of late operative intervention as he was admitted for a few days prior to surgery, however this study was not designed to ascertain the exact reason.

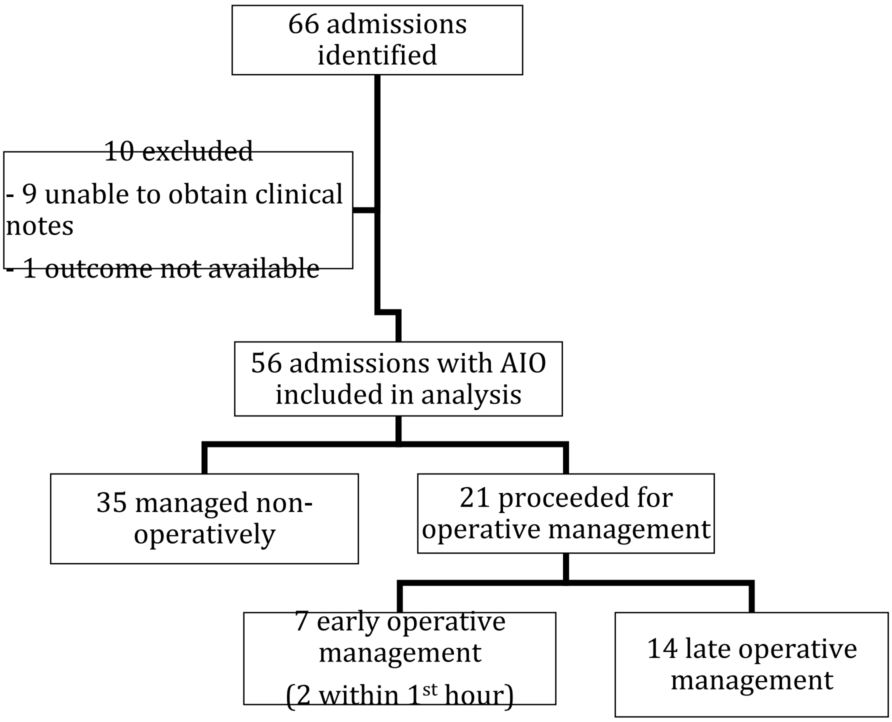
The mean and median LOS in the non-operative compared to the operative groups was 7.1 and 6.9, and 4.5 and 5 days respectively. A larger range of LOS was observed in the non-operative group (1-36 days versus 2-28 days in the operative group). However, there was no statistically significant difference in the LOS between patients undergoing non-operative compared to operative management (P value = 0.27). In comparing patients in the early and late operative group, a mean of 6.6 days and 5.1 days and a median of 5 and 4 days were found for both groups respectively (range 4-8 days and 2-28 days) but this was not statistically significant (P value = 0.87).

The time to presentation with adhesive intestinal obstruction from the time of initial surgery varied widely, from as early as one week to 14 years. A comparison of patients who underwent appendicectomy compared to other operations found a mean of 1.05 years and 3.87 years and median of 1 month and 2 years for both groups respectively. This trend towards earlier presentation with adhesive intestinal obstruction for patients who have had appendicectomy was observed to be statistically significant (P value = 0.001).

Table 2: Comparison of published studies of acute intestinal obstruction in children

Study	Year	n	No. of immediate operative mx	No. of non-operative management	Managed non-operatively, proceeded for operative mx	Total operative rate
Akgur et al	1991	230	81 (45%)	149 (55%)	39 (26% of 55%)	60%
Shieh et al	1995	71	13 (18%)	58 (82%)	23 (39% of 82%)	50.7%
Vijay et al	2005	74	5 (7%)	69 (93%)	33 (48% of 93%)	51%
Eeson et al	2009	165	32 (19%)	133 (81%)	107 (80% of 81%)	84%
Waikato Hospital	**2012**	**56**	**2 (3%)**	**35 (63%)**	**19 (38% of 100%)**	**37%**

Figure 1: Overview of management of patients with AIO



DISCUSSION

Adhesive intestinal obstruction continues to cause significant morbidity in the paediatric population following abdominal surgery, alongside significant health care costs. This is also seen in the era of laparoscopic surgery.[8] The time of onset of complications associated with adhesions varies widely, occurring as early as one week to several years following surgery and include abdominal pain, restriction of normal activities, time off school and the need for hospital readmissions and further surgery. [4,9,10]

Several studies have been published to date in examining potential outcome predictors to identify those whose clinical presentation are less likely to respond with non-operative management. Tachycardia and a younger age have been identified as likely factors associated with operative management across a number of studies.[5,6,11] The absence of leucocytosis and older age appeared to be associated with successful non-operative management. Other factors apart from the age at recent laparotomy, time elapsed since laparotomy, type of previous incision, duration of conservative trial and primary surgical diagnosis were also predictive criteria identified that correlated with the success of non-operative management.[7] The latter, in addition to age at presentation less than one year of age, also identified risk factors associated with high risk for operative management in other reports.[5-7] Nonetheless, consistent findings other than age at presentation or prospectively validated and sufficiently sensitive clinical predictors remain to be lacking, particularly in the paediatric population.

Despite advancements in surgical techniques, the aetiology of adhesive intestinal obstruction remains incompletely understood. Multiple factors have been implicated in the formation of post-surgical adhesions including infection, operative technique and traumatic factors.[12] Mechanical effects of pressure, excessive handling of the peritoneum and irritation of the peritoneal lining with blood and foreign materials have been found to be one of many several factors leading to adhesion formation, prompting meticulous attention to operative technique and tissue handling in the attempts to limit the extent of injury during surgery.[12] Although increasing numbers of studies have reported varying efficacy and safety of anti-adhesive technologies as an adjunct to reduce risk of post-operative adhesion formation in adults, limited literature exists to support its use in the paediatric population. [12,13]

Several studies have reported varying rates of adhesive intestinal obstruction according to type of initial surgery. Consistent with other studies done to date, appendicectomy served as a significant contributor to adhesive intestinal obstruction and appendicectomies are often the most frequently performed operations in the paediatric population, thereby likely posing a significant burden.[5,15] Although the reason for this is largely unknown, this may be attributable partly due to infections often being considered one of the most common triggers for adhesion formation, which may explain our finding of patients with appendicectomies tending to present earlier with adhesive intestinal obstruction compared to other operations noted in our cohort of patients. Despite this, a relatively low incidence of 0.31% of adhesion-related readmissions for appendicectomies have been reported, with inflamed and complicated appendicectomies having a higher risk of readmission of 0.36% as expected.[2] Surgeries noted to have an over representation of post-operative adhesive intestinal obstruction include Ladd's procedures, Nissen fundoplication, stoma formation and reversal, and repair of congenital abdominal wall defects, several of which were also noted in our study.[5,15] It is worth noting here that our centre currently perform the same type of surgeries as many other paediatric surgical centres with the exception of paediatric oncology.

The management of adhesive intestinal obstruction in the paediatric population continues to remain controversial, with current guidelines lacking and varying rates of successful resolution of symptoms with non-operative management in studies published in other literatures as shown in **Table 2**. Operative management, if indicated, is not without risks, having been associated with incidental bowel injury, blood loss, prolonged ileus and possibility of recurrence of adhesive intestinal obstruction, with multiple surgeries increasing the risk of further adhesion formation.[16] Vijay et al in a study of 74 admissions of adhesive intestinal obstruction in 2005 noted successful resolution of symptoms with conservative management alone in 52.2% of patients.[6] Similar findings of a total operative rate of 50.7% was found in a study by Shieh et al; 13 children required immediate surgery, with remaining 58 initially managed non-operatively with resolution of symptoms in 35 patients.[11] Akgur et al reported an operative rate of 60% in a study of 181 patients who presented with adhesive intestinal obstruction, with 39 (26.2%) episodes proceeding for operative management after a period of non-operative management in 149 cases.[7] In contrast, other authors have advocated for operative management based on findings showing high rates of surgery required in similar populations. This was demonstrated by Eeson et al, with a total laparotomy rate of 84% (107 out of 133 patients) requiring operative management after failure of non-operative management.[5]

Our study demonstrated a relatively lower total operative rate of 37% when compared to other similar studies, supporting our impression of a relatively significant role for non-operative management existing in paediatric patients presenting with adhesive intestinal obstruction. This may have been attributable to a number of factors, including surgeon preference and several acknowledged limitations in our study. Patient identification in our study was solely based on coding, raising the possibility of missed cases from patients who were incorrectly diagnosed or coded and the inability to identify patients managed without surgery that never presented to our tertiary centre. Documentation was also not available for a reasonable number of patients, contributing to our relatively small sample size in comparison to other studies published. Finally, we excluded infants less than one year of age due to the high likelihood of associated co-morbidities and often prolonged length of stay in NICU which may have skewed our results disproportionately for outcomes measured, but ultimately may have a lower threshold for operative management.

A limited number of studies have reviewed the various outcomes of non-operative versus operative management, which include the morbidity, mortality and rates of small bowel resection. Although Janik et al concluded that delays in operative management were associated with increased morbidity and mortality, several other recent studies have reported no difference with non-operative management.[5,6,17] The association between operative delay and the rate of small bowel resection has been previously studied by Lautz et al, who found similar adjusted odds of small bowel resection in the first and second day of admission, but increased in the third day.[18] Subsequently, they recommend consideration of operative management in patients who do not exhibit signs of improvement by the second day after admission, to avoid potentially increasing the risk of bowel loss.[18] The decision for surgery at 48 hours was also recommended in a study conducted by Feigin et al, where it was noted that strangulation did not occur in cases observed for 16 hours or less but rates increased the longer surgery was delayed.[15] Our current study adds a further outcome measure with regards to length of stay with no difference seen between those managed non-operatively and operatively, supporting consideration for non-operative management in the initial period if no immediate indications for surgery exist, particularly for the first 24 hours following presentation.

In order to assist with risk stratification for these patients on presentation, further prospective studies are required prior to the establishment of clear guidelines in the future. These include additional delineation of consistent clinical determinants that may help determine the need for operative management which is beyond the scope of this study. Evidence for timeframes in which to persist with non-operative management would also be further area of exploration. Ultimately, varied outcome measures on a larger multicentre scale would be required to be collectively studied prior to achieving a consensus in this challenging area of management.

CONCLUSION

We conclude that in children who present with adhesive intestinal obstruction, non-operative management should be considered in an attempt to reduce morbidity associated with surgery. Further studies are required in determining the ideal duration of non-operative management, with the advantages of non-operative management balanced against the risk of bowel resection in this population.

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Review **OPEN ACCESS**

Existing NCD Monitoring and Surveillance Systems and its adaptability to Fiji's context: A Systematic Review

Joshua LIGAIRI,[1] Donald WILSON,[1] Isimeli TUKANA, [2]

ABSTRACT

Introduction: The United Nations high-level meeting of the General Assembly on the Prevention and Control of Non-communicable Diseases passed a political declaration on Non-Communicable Diseases (NCD) prevention and control in 2011, emphasizing the great need for NCD surveillance including in Low-to-Middle-Income-Countries (LMICs).

Method: A review of literature was conducted and set for full text citations published in English dated 1 January, 2007 to 31 August 2019. MESH terms or key words were selected from the following groups of generic terms: the following words "Health surveillance systems" and "NCD monitoring and surveillance system". The literatures were tabulated according to the authors, date that was published and which journal, the title of the study, the surveillance design and their recommendations. The 13 articles that were identified, only one was conducted in a developing country while the rest were conducted in high income countries.

Results: 60% of the NCD surveillace system reviewed use passive surveillance, 30% uses passive assisted sentinel surveillance and 10% use passive assited spatial surveillance. Based on countries surveillance system there was an equal distribution on involvement in policy development (33%), behavioural risk associated aggregates (33%) and intergrated health information System (33%).Through intense review, passive assisted sentinel surveillance was mostly practiced and the use of spatial surveillace in this context for interregional comparisons of specified diseases.

Conclusion: There was less evidence on surveillance in LMIC but the following surveillance systems were identified as essential for Fiji's proposed NCD surveillance system. This study suggest that a probable surveillance system that can be adopted by Fiji is a passive assisted sentinel surveillance system enhanced with Spatial data. Further consultation and a feasibility study can be proposed as a way forward for this study findings.

Key Words: surveillance, population health, behavioural modification, non-communicable disease

INTRODUCTION

Non-communicable diseases (NCDs) are chronic conditions with rather slow progression and rarely completely curable. In 2016, 71 % of the global deaths were attributed to NCDs.[2] The increase of NCDs in low- and middle-income countries (LMICs) is accelerated by population ageing and is driven by rapid and unplanned urbanization and changing lifestyles. About 54 % of NCDs in LMICs and 46% of these deaths occur amongst people under the age of 70, compared to 28 % in high-income countries (HICs).[2]

Given their devastating health and socioeconomic effects, NCDs have gained increasing attention over the past decade in the international community. The UN High-Level Meeting of the General Assembly on the Prevention and Control of Non-communicable Diseases passed a Political Declaration on NCD prevention and control in 2011, emphasizing the need for NCD surveillance.[4]

Corresponding author: Joshua Ligairi, josualigairi@gmail.com

1. College of Medicine, Nursing and Health Science, Fiji National University
2. Ministry of Health and Medical Services, Fiji

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The goal of disease surveillance is to address a defined public health problem and to develop evidence-based measures to protect and promote population health.[5] It is defined as "the ongoing systematic collection, analysis and interpretation of health data essential to the planning, implementation, and evaluation of public health practice, closely integrated with timely dissemination of these data to those who need to know."[6] There are different types of surveillance designs and are noted as Passive surveillance which rely heavily on readily available data and sentinel surveillance that rely on data reported from sentinel sites or facility. Laboratory based surveillance rely on samples submitted for analysis and also act as sentinel sites. Then we have a periodic - population based survey or active surveillance that mostly focus on a one –off cross-sectional population surveys.

The WHO has assessed the current capacity for NCD surveillance as inadequate in several countries.[1] Evidence from HICs indicates that interventions for most NCDs can be effective and implemented at a rather low cost.[7] However, the long-term nature and complex disease aetiology of NCDs demand a comprehensive and long-term health-system mediated response. Essential to this goal is accurate and sequential data for planning and evaluation. Therefore, the WHO developed a global action plan for the prevention and control of NCDs, particularly cardiovascular diseases, cancers, chronic respiratory diseases and diabetes.[7] The action plan identifies six objectives, one of which is monitoring the trends and determinants of NCDs and evaluating progress in prevention and control. In order to attain these targets, the WHO suggests the following policy options: strengthen vital registration systems and cancer registries, integrate surveillance into national health information systems, undertake periodic risk factor surveillance, and strengthen technical and institutional surveillance capacities. [2, 7]

Against this background, the objective of this paper is to identify relevant literatures that highlight the possibility of establishing an NCD surveillance system (NCDSS) here in Fiji entailing strategies from other countries surveillance systems. The dynamics of the NCDSS shall be highlighted in this paper together with a proposed surveillance mechanism based on systems design and best practice.

METHODS

Desk-review was conducted together with on-line literature search using MESH generic terms: the following "Health surveillance systems" and "NCD monitoring and surveillance system". On-line literature search was narrowed from health surveillance systems to NCD monitoring and surveillance system where the search was further focused to good practice in health monitoring systems. These articles and studies identified were graded based on their objectives and designs whereas further analysis was conducted for good practice.

A systematic search was conducted and set for full text citations published in English between 1 January 2007 to 31st August 2019. The literature was tabulated by authors, date of publication, journal type, the title of the study, the surveillance design and their recommendations. Further analysis was conducted on the literature towards the country and its existing NCD surveillance design and what are some of the output of the countries adapted surveillance design. The following literature search design was followed through for information search (Figure 1)

Search Result

Of the 10 citations, six articles described or evaluated existing NCD surveillance systems and three supportive documents which are all peer reviewed articles entails the gaps and challenges identified on Surveillance system analysis of Best Practice. One of the articles provides information on how to link and adapt NCD surveillance system concepts from High Income Countries (HICs) to the LMICs.

RESULTS

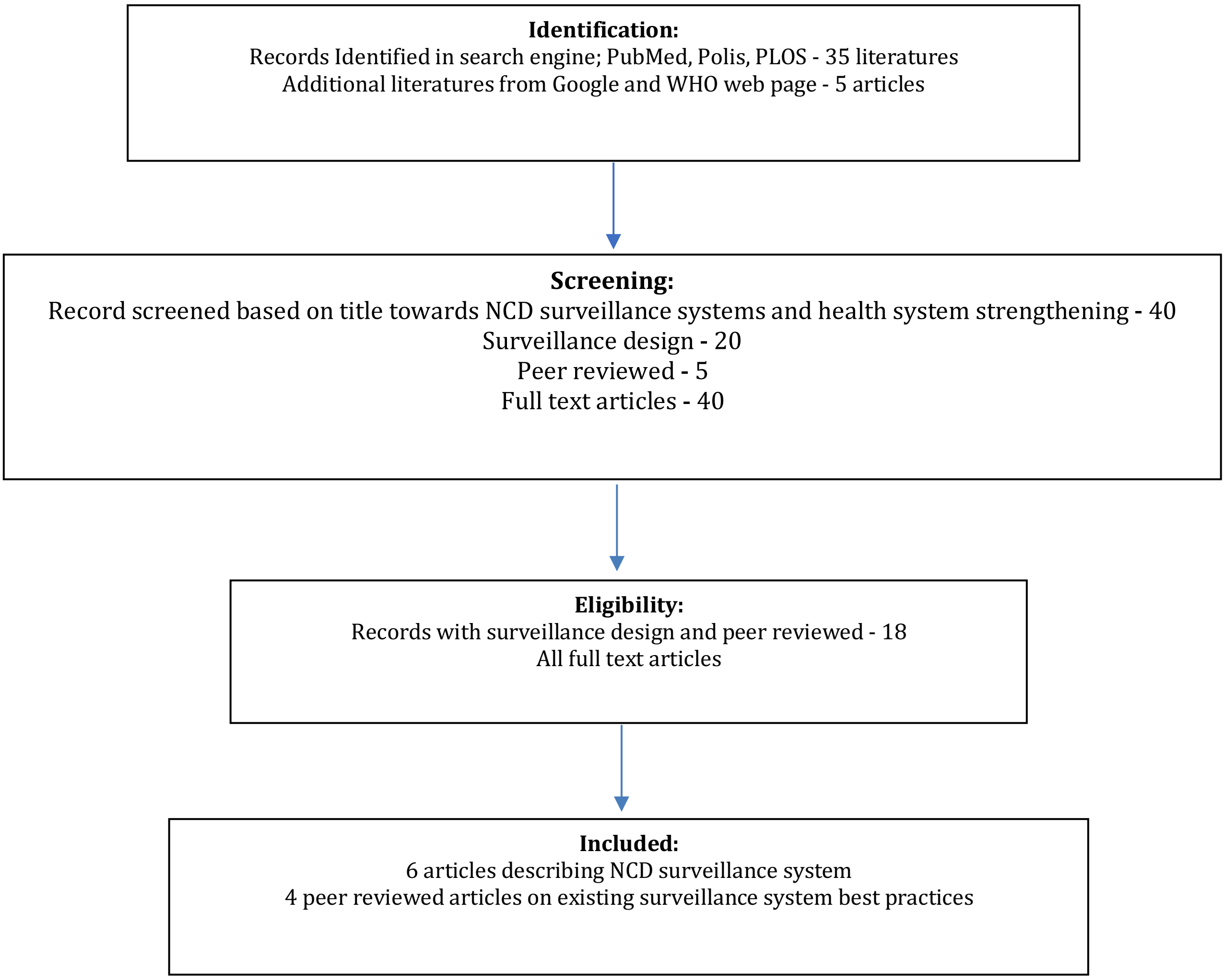
Of the 10 manuscripts obtained, only one was conducted in a LMICs while the rest were conducted in HICs.

Systems Design

Most of the surveillance systems designs (4 of the 6 assessed) were mixed systems whereas 60% of the surveillance systems understudy were Passive assisted Sentinel surveillance. One was a national survey using active surveillance design. The WHO [1, 9, 15-20] conducted questionnaire-based surveys among its member countries in 2000, 2005, 2010 and 2013 in order to assess the national capacity for NCD prevention and control. It was found that some progress – mainly in HICs – has been made in the last decade. More countries have developed strategies for combating NCDs and created the necessary infrastructure. However, the implementation process in many countries was assessed as inadequate and strategies often exist mainly on paper. More finding from WHO shows the HICs were 16 times more likely than LMICs to have population based NCD mortality data in their national health information system. However, the quality and completeness of data was not assessed in the survey. Authors[1,2,4,5] suggest, that major gaps exist in the accuracy, quality, standardisation of risk factor data, and reporting of NCD outcomes. Furthermore, data were often not linked to socioeconomic information and therefore did not facilitate the assessment of health disparities. Macfarlane[13] and Nolen *et al.* [14] also rated the quality of health data as inadequate in many LMICs. Macfarlane[13] identified costly duplications, inefficiencies and inconsistencies between reporting, storage and analysis of data as the main problems. Moreover, data were unreliable, unrepresentative, and often not analysed and disseminated in a timely manner.

The member states of the WHO South-East Asia office for example stated in their regional meeting in 2012, that health system and poor due to negligence of NCDs over a long time.[15]

Figure 1: PRISMA Flow-list diagram summarising the literature search process



Identification:
Records Identified in search engine; PubMed, Polis, PLOS - 35 literatures
Additional literatures from Google and WHO web page - 5 articles

Screening:
Record screened based on title towards NCD surveillance systems and health system strengthening - 40
Surveillance design - 20
Peer reviewed - 5
Full text articles - 40

Eligibility:
Records with surveillance design and peer reviewed - 18
All full text articles

Included:
6 articles describing NCD surveillance system
4 peer reviewed articles on existing surveillance system best practices

A comprehensive framework, robust mortality data and sufficient funding to effectively plan and implement NCD prevention and control programs are missing in most countries in the region.[16]

Therefore, the member states may need additional five years to establish robust surveillance systems and generate baseline data for targets of NCD monitoring due to the mentioned problems.[15]

Health Surveillance and Monitoring System and Analysis of Good Practice

There are countries that have their own health monitoring and surveillance system especially on NCD's. These countries were analysed and drafted as part of their best practice. These are the examples of the implementation of six country integrated monitoring systems, including the regular collection and evaluation of measured data, which play a crucial role in informing policy development.

Policy Development

Two countries surveillance system[4,6] fit in the scope of good practice through their involvement in the reformulation of food product through policies. Both surveillance systems collaborated more on the reformulation food product address food regulations on trans-fatty acid and salt intake. In both surveillance system, inter-sectorial collaboration was the main element of change in initiating the data to policy change.

Behavioural Risk Associated Aggregates

Addressing the behavioural risk components of the country surveillance system was practically being addressed in two ideal surveillance systems.[8,11] The Italian PASSI and the Vasterbotten Intervention program (VIP) focuses on community-based surveillance system whereas they monitor health behaviour and its associated risk. Furthermore, each system conduct inter region comparison which include spatial surveillance[8].

Integrated Health information system

An ideal information system is when multiple sources have a queue each on a central system that can integrate information and deliver an output that can generate reliable information for decision making. Two countries' surveillance[1, 9] profiles highlight the importance of interconnected health information system. Interoperability of this surveillance systems was the highlight of best practice using a unified identifier. The Malta Diabetes Information system captures screening, referral, treatment, drug therapy, admissions and discharge information for Diabetes. The Israel Online Electronic Health Record system sets the benchmark for remote and mainstream data reporting, data sharing and reporting based on best practice.

Various HICs have managed to design and customised their surveillance system to match the disease phenomenon and distribution they like to monitor and survey.

DISCUSSION

After reviewing the literature and going through the existing countries monitoring system it still remain a challenge as to whether Fiji has the capacity to have an NCD surveillance system.

Surveillance Systems Design

The current NCD surveillance system in Fiji is built within the Public Health Information System (PHIS) and the Patients Information System (PIS). The only NCD surveillance system in Fiji comes in the form of the NCD STEPS Survey which is conducted every 10 years. Birtwhistle suggest that it is possible to have Sentinel surveillance for NCD in primary health care but challenges in including risk factors and social determinants. According to WHO (2017), sentinel surveillance is used when high-quality data are needed about a particular disease that cannot be obtained through a passive system. Selected reporting units, with a high probability of seeing cases of the disease in question, good laboratory facilities and experienced well-qualified staff, identify and notify on certain diseases. Szeles *et al.* 2005, used a passive assisted sentinel surveillance system to study the distribution of cardiovascular diseases, diabetes and liver cirrhosis and shows that having sentinel stations at primary care level are feasible and sustainable, data provide important information for health policy and health service planning and regular contact to reporting units is important. Yiannakoulias *et al.* 2009 study asthma distribution using passive surveillance together with spatial surveillance using Geographic Information System (GIS). The study reveals spatial differences in the asthma prevalence in Alberta and suggests that spatial data in surveillance are important to inform policy makers about disease patterns; however availability of spatial data is a limiting factor in many countries especially in LMICs but would be an advantage if being adopted. Namusisi *et al.* 2011, conducted a pilot study on a passive assisted sentinel surveillance of NCDs with the main focus on Diabetes. He suggested that the use of hospital data is a valuable first step in setting up NCD surveillance systems, whereas risk factor data are important for disease prevention and intervention.

Surveillance Systems Best Practice

Summarising most of the countries monitoring and surveillance system (Table 2 annexed) it shows that the best surveillance system to be adopted for Fiji is a passive surveillance system that relies on readily collated data from primary health care facilities, hospital and with existing data sources. This was supported with the findings by FinRISK Study, 2014 that having continuous population survey will general result for policy action as shown on how their system was able to inflict change on food relation for food reformulation. Similar sentiments were eluded by Balissera S et al 2011 support the use of behavioural risk factors to address the burden of NCD in Italy through the Italian PASSI. Due to Fiji's geographical location and vast distribution of its population to these islands, the inclusion of a spatial surveillance system as an addition to its proposed passive surveillance system would be and added benefit. More, targeted interventions will be conducted if the GIS system is blended in with the passive surveillance system.

The proposed surveillance system for Fiji will be a Passive assisted Sentinel Surveillance enhanced with spatial surveillance. Based on literature, the passive assisted sentinel surveillance is appropriate for routine collection of data and a focused data collection mechanism based on the priority areas for reporting, Fiji have specialised health facilities like the health centre SOPD clinics and the Diabetes Hub centres who are the targeted sentinel sites for reporting on and of NCD of interest. Whereas in Fiji more discussions are centred in identifying what surveillance strategy is applicable to the small island nation where most of the gadgets and 'clinical toys' used in HICs are inaccessible to these South-seas health systems.

CONCLUSION

Diseases occurring in some of Fiji's communities in epidemic proportions somehow exceeding those rates found in affluent industrialised countries or High Incomed Countries (HICs). The frequency of alcohol and tobacco use and the number of cancers appear to be rising and are also becoming significant health problems. Unhealthy Diet increase consumption of carbonated drinks, high sodium intake, increased sugar intake, physical inactivity and cigarette smoking appear as the most significant factors involved in the development of these chronic non-communicable diseases. Therefore, with all of these risk factors and having a NCD related mortality at 80% of all deaths, it is about time for Fiji to have its own Non-Communicable Disease Surveillance System. A surveillance system that collate, analyse NCD and Behavioural Risk factors to inform policy makers in the Ministry of Health and medical services much sooner rather than relying on the WHO NCD Steps survey. This surveillance system should be able to produce a country yearly NCD status profile to assist the development and respond against Fiji 5 years NCD strategic plans. Fiji have resources and the existing reporting mechanism that can facilitate the need to develop its own Non-communicable disease surveillance system

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Annexes

Table 1.0: Summarises the study designs found suitable for this surveillance system design review (Kroll. M et al, 2015)

Author/Year	**Country**	**Surveillance Approach**	**Data source and reporting Unit**	**Disease under surveillance**	**Lesson learned**
Birtwhistle, 2009	Canada	Longitudinal study with passive and sentinel approach	General practitioners	HTN, DM, Depression, COPD, Osteoarthritis	Sentinel surveillance for NCD is possible for PHC but challenges in including risk factors and social determinants.
Saran et al, 2010	USA	Pilot study for a national surveillance system	Multiple secondary data sets	Chorionic kidney disease (CKD)	Six broad themes, several measures for CKD and several data sources were identified for a pilot phase; active surveillance methods might be Integrated in the future. Identification and acquisition of data sets and integration with other NCD surveillance systems were identified as some of the challenges.
Szeles *et al.* 2005	Hungary	Cross-sectional pilot study on a passive assisted sentinel surveillance system	General practitioners (n = 73) in four counties (Cohort size: 138,088)	Cardiovascular diseases, diabetes, liver cirrhosis, 4 malignant diseases	Sentinel stations at primary care level are feasible and sustainable, data provide important information for health policy and health service planning, regular contact to reporting units is important.
Yiannakoulias *et al.* 2009	Alberta, Canada	Study on passive surveillance using secondary data with special focus on spatial surveillance of NCDs using GIS	IPD hospital data, medical claims system (electronic public health insurance registry), hospital outpatient system	Asthma	The study reveals spatial differences in the asthma prevalence in Alberta. Disease distribution depends on case ascertainment algorithms and is aggravated through information inequity. Spatial data in surveillance are important to inform policy makers about disease patterns; however, availability of spatial data is a limiting factor in many countries.
Bollag, 2009	Switzerland	Longitudinal passive assisted sentinel surveillance system (Swiss Sentinel Surveillance Network, ongoing)	General practitioners, internists and paediatricians (total: 150–250 GPs)	Asthma, different communicable diseases	Sentinel surveillance on primary care level is a valid research instrument to analyse asthma incidence and seasonality. Denominator problems occurred since age and sex were only recorded for asthma cases, not all consultations.
Namusisi *et al.* 2011	Uganda	Pilot study on a passive assisted sentinel surveillance of NCDs	Regional referral hospital (n = 1) (1383 patient records)	Diabetes	Use of hospital data is a valuable first step in setting up NCD surveillance systems, risk factor data are important for disease prevention and intervention.

Table 2.0: summarise the analysis of good practice identified as essential to NCD control (Kroll M et al, 2015)

Country	**Program**	**Method**	**Analysis of Good Practice**
Denmark	Elimination of Trans-fatty acid in Food Products	Monitoring was conducted regularly (biennially) and the results were disaggregated by several characteristics (food groups, age and gender) and applied to policy. The regulation resulted in a decline in the number of products containing more than 2g of TFA from 26% in 2002 to 6% in 2013, showing that the elimination of TFA in food products is achievable through food reformulation	Introducing a regulation on TFA content in food products, monitoring its implementation and using the results to inform policy and practice on its impact, as done in Denmark, is a good example of how to address the alimentary risk factors for NCD.
Finland	Reduction of Salt-Intake	Finland has a long history of developing strategies for reducing salt intake. In 2008-2011, the Government developed regulations to decrease salt content in industry-produced foods, according to which, foods with high salt content had to be labelled "high-in-salt" to inform consumer choice. As a result of the regulations, industry has worked to reformulate products so that their salt levels are below the threshold requiring the "high-in-salt" warning. Since 1982, the salt intake in Finland has been monitored through the FINDIET survey.	The Finnish case is an example good practice in inter-sectoral collaboration and continuous population monitoring: baseline assessment followed by regular monitoring at 5-year intervals, and the integration of the monitoring systems involved (FINRISK) meets the criteria of good practice in health monitoring
Italy	Italian behavioural risk factor surveillance system (PASSI)	In 2007, Italy established PASSI, a surveillance system to monitor health behaviour and associated risk factors, PASSI (41) is an ongoing, multipurpose, community surveillance system. It is supported by the Ministry of Health, coordinated by the National Institute of Health (ISS) and run by the local health units and regional health authorities. Its main areas of investigation are: self-perceived health and quality of life; self-reported symptoms of depression; smoking habits and exposure to second-hand smoke; alcohol consumption; diet and nutritional status; physical activity; risk factors for CVD; cancer screening and vaccination campaigns (through participation in national preventive programmes); road safety; and domestic injuries.	PASSI meets several of the criteria of good practice: it provides ongoing data collection in a flexible, timely manner, allowing intraregional, region-to-region and region-to-nation comparison, and its regional-specific data, including sociodemographic information, offer a sound basis for developing and evaluating public health programmes, including those aimed at reducing social disparities by addressing health risks.

Malta	Diabetes Information System	Since Malta has no formal diabetes register, data pertaining to individuals registered for treatment free of charge were linked hospital-admissions data, the surgical-operations register, and laboratory biochemical data. Following this exercise, all identifiers other than year of birth and gender were dropped from the data set to anonymize the data. This linked data set makes it possible to estimate the incidence of diabetic complications and the indicators of quality of diabetes care as regards the extent and effectiveness of glucose and lipid monitoring in the diabetic population.	The secondary use of health-care data is passive, making it both affordable and sustainable. It is quite difficult for a health register to predict the high-resolution data required and keep up with the breadth of information demanded by health policy. Even if this were possible, it would be very resource intensive to maintain. Therefore, integrating disaggregated data from health registers with secondary health-care-associated data sets permits the same health registers to remain relevant to an ever-increasing, evidence-driven health-policy agenda.
Sweden	Vasterbotten Intervention Programme	In Sweden, mortality from CVD increased steadily in the 20th century; in the mid-1980s it was highest in the county of Västerbotten. Therefore, the Västerbotten Intervention Programme (VIP) was launched – a community programme with the aim of reducing morbidity and mortality from CVD and diabetes. A population-based strategy directed towards the public is combined with a strategy for reaching all middle-aged persons individually at ages 40, 50 and 60 years by inviting them to participate in systematic risk-factor screening and individual counselling about healthy lifestyle habits.	One of the main features of VIP is its ability to collect data on multiple NCD risk factors, making it a diverse surveillance system. It also includes information on the time trends of the collected data and allows data disaggregation by age, gender and socioeconomic features. Visualization of assessment output and data collection at the PHC level makes the system an example of good practice in this area. Lastly, its links with other registers and availability for scientific research make VIP a desirable NCD monitoring system.
Israel	Electronic Health Records for better NCD monitoring and Control	Israel is one of the global leaders in adopting innovative strategies to prevent and control NCD, especially in field of management of people with these diseases. Using online EHR data allows management to monitor the prevalence, incidence and control of most NCD in a precise and timely manner. Furthermore, the interoperability of the system and its user friendliness have enabled the early detection and prevention of complications and the continuity of health care, while containing costs related to the duplication of diagnostic and laboratory procedures.	This example shows the efficiency and cost-effectiveness of using clinical data en masse to ensure better NCD prevention and control. One of the important features of this multi-purpose monitoring system is its interoperability, which adds functionality, integration and real-time monitoring of the data and disaggregation of the indicators by socioeconomic status.

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Literature Review **OPEN ACCESS**

Examining the State of Health Research on Pacific Rainbow Communities in New Zealand: Literature Review

Patrick S THOMSEN, Sarah MCLEAN-ORSBORN, Hollyanna AINEA, Allyssa VERNER-PULA

ABSTRACT

Introduction: Pacific Rainbow/Queer Communities (PRCs) in New Zealand (NZ) have had scant attention paid to the specificities of their health and wellbeing needs in research. Recently, the Health Research Council of NZ funded its first Pacific-specific PRC project (The Manalagi Project) executed through the University of Auckland's Centre for Pacific Studies. This paper reports a literature review conducted to ascertain the current state of health research on PRCs, Rainbow/Queer and Pacific communities' health in NZ.

Methods: A scoping review was conducted where relevant public health database search engines were accessed, which included PubMed and Medline to explore both national and international health research pertaining to PRCs, Pacific communities and Rainbow/Queer communities. Additional Google searches were undertaken to identify more 'grey' material such as reports, websites, other relevant government sources, as well as non-profit organisation and educational resources not visible via scientific databases.

Findings/Outcome: The review identified published journal articles (n=20), books (n=1), reports (n=25) and theses (n=3) as well as other documents relevant to the study, such as websites and news articles pertaining to PRCs in NZ and abroad. It reveals a severe paucity of health research focused on PRCs domestically and internationally. Although more research is being conducted into the space of Pacific communities, as well as Rainbow/Queer communities, research that is PRC-focused is urgent and critical at this time.

Conclusion: Both Pacific and Rainbow/Queer communities in NZ are socially marginalised, thus experience a raft of health challenges represented by a racist and cisnormative heterosexist health system. This literature review reveals a lack of understanding around the nuances that exist when these experiences intersect and coalesce in the body and experience of PRC members. It has identified a significant gap in Pacific health research that exists in NZ and abroad that urge us to frame future research to also be intersectionally-informed to capture the unique needs and context of PRCs.

Key words: Pacific Health Research; Pacific Rainbow Health; Manalagi Project; Queer/Rainbow Health; MVPFAFF; LGBT

INTRODUCTION

Pacific peoples account for 8.2% of New Zealand's (NZ) national population and are the fastest growing ethnic group in the country.[1] Despite this, little is known regarding the shape and experiences of Pacific Rainbow Communities (PRC) with healthcare services in NZ. Currently, our [L]esbian [G]ay [B]isexual [T]akatāpui [T]ransgender [I]ntersex [Q]ueer [A]sexual+ (LGBTTIQA+) people are not accounted for in the Census. A further complication being that many

Corresponding author: Patrick S Thomsen
patrick.thomsen@auckland.ac.nz
Maori and Pacific Studies, Faculty of Arts, University of Auckland, New Zealand

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PRC members do not identify as LGBTTQIA+ as there are Pacific-specific non-normative gender and sexuality identities/framings that exist (see MVPFAFF).[2-4] Therefore, this literature review is designed to explore prior research that is attuned to PRCs experiences with NZ's healthcare system. It identifies the current state of Rainbow/Queer and Pacific health research in NZ, speaks to existing knowledge gaps on PRC health, ultimately suggesting the need for a more intersectional research approach into the health and wellbeing of PRCs in NZ.

METHODS

A scoping review[5] was undertaken to explore both national and international health research pertaining to PRCs. Relevant public health database search engines were accessed, which included PubMed and Medline in addition to Google Scholar and Jstor. Due to the paucity of research about PRCs, literature pertaining to non-Pacific Rainbow communities in general were also reviewed. Thus, international literature was included where there was a focus on comparative communities. The search terms for the review were Pacific health, Rainbow health, LGBTTIQA+ health and MVPFAFF health. Each relevant piece of literature was selected by title and abstract as depicted by the search engines, based on the inclusion of the key words: gender, sexuality or health care. Most of the relevant literature found and presented here was published between 2008 – 2020. Additional Google searches were undertaken to identify more 'grey' material such as reports, websites, other relevant government sources, as well as non-profit organisation and educational resources not visible via scientific databases. The scoping review entailed the identification of recurring themes and subthemes. These themes were used to structure this article including the identification of gaps and further areas of potential research. Literature that was reviewed for this paper include published journal articles (n=20), books (n=1), reports (n=26) and theses (n=3) as well as other documents relevant to the study, such as websites and news articles pertaining to PRCs in NZ and abroad.

Literature Review

Rainbow Health

Estimated to account for 6% to 15% of NZ's total population,[6] Rainbow communities in NZ do not form one conspicuous group, instead, are made up of individuals who come from diverse and varied ethnic, socio-economic, class, cultural and age backgrounds.[7] Contemporary research generally suggests that the effects of marginalisation and discrimination are inextricably linked to the overrepresentation of LGBTTQIA+ peoples in NZ with poorer health outcomes.[8]

Due to a raft of social stigmas, it is well documented that Rainbow/Queer peoples are more likely to experience adverse mental health disorders, higher rates of psychological and mental distress and more likely to engage in risk related behaviours compared to the general population.[8-10] Rainbow/Queer New Zealanders are 19% less likely to report being satisfied with life, while experiencing an increased likelihood of moderate to severe anxiety, depression and/or psychological distress; these concerns start at a young age with the Youth 12 survey reporting same-sex or both sex attracted students as three times more likely to experience symptoms of depression, self-harm, suicidal ideation and attempts as opposite attracted students.[11-12] The Youth19 survey shows similar findings for transgender and diverse gender students, reporting 57% of participants have experienced depressive symptoms and self-harmed, while one in five have attempted suicide. [13] The Counting Ourselves survey shows similar health outcomes from transgender and non-binary individuals in NZ, with 71% of participants reported as having experienced high or very high psychological distress in the immediately preceding four weeks, almost nine times higher than the general population. Alongside this, over the course of their lifetime, more than three quarters of transgender and non-binary individuals had seriously thought about attempting suicide, while more than a third had attempted, with 12% of those attempts coming in the previous year.[14-16]

An important factor identified is the lack of mental health services that adequately address issues specific to Rainbow/Queer populations. Instead, it has been found that mainstream services often perpetrate and reinforce heteronormative and homonegative attitudes and beliefs.[14,15,17] As relayed in research by Semp and Read, mental health services actively reproduce a culture of heteronormativity in many different, inadvertent ways.[18] These services unwittingly frame non-normative sexualities or genders as problematic, abnormal or inferior. This has led to a 'don't ask, don't tell' culture within mental health services in NZ toward Rainbow/Queer peoples, which initially aimed to remove assumptions about the sexuality of a patient but has had the side effect of replicating heteronormative and homonegative notions in mental health services.[17-18] This suggests then that mainstream providers do not understand how one's sexual and gender identity may impact their wider socialisation, how they are perceived within societal structures, the marginalisation they may face as a member of the Rainbow community and what burden this takes on their personal mental health.[17]

International scholarship suggests that this is a common experience for Rainbow/Queer communities outside NZ. Research from the Canada Psychiatric Association suggests that LGBTQ+ peoples are hesitant to engage with mental health services for fear of homophobia from healthcare providers, inadequacies in Queer identity healthcare knowledge and understanding, or being flat out refused care.[19] This reluctance also exists here in NZ, where there are no publicly funded Rainbow-specific mental healthcare services. As many Rainbow/Queer peoples feel their Rainbow/Queer identity is central to who they are as a person, the services they engage with must actively validate their identity.[20] However, the severe lack of explicitly Rainbow/Queer-friendly services has meant that Rainbow/Queer patients feel discouraged from seeking help, due to a number of factors, including anticipating having to justify their identity in the face of homophobic practitioners, expectations of being misunderstood and a lack of sensitivity toward Rainbow peoples' personal experience of sexuality and gender identity struggles, or the impacts of marginalisation from wider society.[17]

While accessibility to good quality healthcare remains a prevalent issue for LGBTQI+ peoples, healthcare professionals' cis-heteronormative attitudes further disempower Rainbow/Queer communities from addressing their health needs.[21] Multiple studies in NZ point out transgender and non-binary people are often uncomfortable disclosing their gender identity with their General Practitioner (GP), while also being more susceptible to inconsistent or disrespectful treatment from health professionals due to their gender identity; including the refusal to use preferred gender pronouns.[15,21,22] This also sits in line with international research where transgender peoples in America reported being more likely to face barriers and denials of equal treatment in the healthcare system.[23] As well as this, Youth 12 tells us that non-heterosexual students are less likely to utilise healthcare services, but more likely to experience difficulties when doing so in comparison to their heterosexual peers.[14] While the Youth 19 survey found that 55% of transgender and diverse gender participants were unable to access health care, and 31% of same-or multiple-sex attracted students were unable to access healthcare when they needed it.[13] This is a significant indicator of how cis-heteronormative attitudes in healthcare disadvantage Rainbow/Queer peoples, regardless of age and gender.

Due to limited funding and urban demands for gender affirming surgeries, Rainbow/Queer peoples embedded in rural areas of NZ are further marginalised from accessing appropriate healthcare services.[24] Within Rainbow communities, it is the transgender community who bears the brunt of these health inequities. Transgender patients are more likely to experience significant delays in accessing medical care, with many relaying their experience of waiting months for treatment, only to be told these services are not available to transgender people.[25] As well as this, limited availability, accessibility and high expense of gender affirming healthcare remains a prevalent barrier for Rainbow peoples wishing to pursue this treatment.[26-27] Limited funding and urban demands for these services further marginalises any Rainbow/Queer peoples who live rurally.[27-28] Limited practitioner understandings of gender affirming services and services available to Rainbow/Queer peoples, coupled with the racism inherent to the health system in NZ[29-31] suggests a bias toward the health and wellbeing needs of the cis-gendered Pākehā population.[32-34]

Pacific Health

Pacific peoples are NZ's most youthful, yet fastest growing population with a median age of 23.4 years, largely centred in highly urbanised areas including Auckland, Wellington, and Christchurch.[35] Although there is a large amount of literature that promotes the diversity of Pacific peoples in NZ, the current health system has not been successful in solving a myriad of issues that relate to poor health outcomes for its Pacific peoples.[36] Alongside Māori, data shows that Pacific peoples are more likely to have lower life expectancies compared to any other ethnic groups in NZ.[37] Based on data collected from the 2013 census, the Ministry of Health reported high diagnosis rates of non-communicable diseases, 10% of Pasifika peoples over the age of 15 were diagnosed with diabetes and were more likely to develop chronic illnesses as adults.[37] In terms of obesity, Pacific peoples have three times the average diagnosis rate in comparison to the general population.[38] Severe obesity rates for Pacific peoples reveal social inequities that indicate health interventions are not working for Pacific communities in this area.[36] Furthermore, Pacific peoples are more likely to develop unhealthy habits such as smoking, binge drinking, physical inactivity and substance abuse.[39]

The peripheral treatment of Pacific people in healthcare is directly associated with the monocultural and Western healthcare practices in NZ.[40] There is strong evidence that suggests determinants of Pacific health outcomes are complex and exist from a multitude of socioeconomic and cultural influences. These determinants include, but are not limited to, higher levels of deprivation, overcrowded housing, unemployment, cost, communication issues, transportation, lack of health literacy, and cultural stigma.[39,41] From a Pacific perspective, Pacific peoples have often felt a lack of personal connection with healthcare providers and services, who tend to be 'cold and calculative.'[42] This can start young, as demonstrated in the Youth 19 survey, which found that 25% of Pacific youth were likely to forgo access to health care when needed or wanted.[13] Indigenous Pacific health is promoted through social, physical, mental, environmental, and spiritual wellbeing; absence of one aspect, or 'pou' (pillar) will deteriorate the wellbeing of an individual.[43] Moreover, Pacific peoples value collectivity; healthcare systems in NZ focus on individuality and do not view health holistically, leading Pacific people to feel portrayed as 'consumers' in 'hostile' services that, by design is unable to enhance Pacific health and wellbeing in meaningful ways.[42,44,45] Thus, Pacific peoples are discouraged from seeking help and utilising healthcare services, leading to the deterioration of Pacific health.

'Te Rau Hinengaro: The New Zealand Mental Health Survey', NZ's most comprehensive national mental health epidemiological study found that Pacific people's poorer health status is not just limited to physical aspects of health, but that Pacific peoples experience a nearly 5% higher rate of adverse mental health (25%) in comparison to the rest of the general population (20.7%).[46,47] Furthermore, Pacific people most commonly reported lifetime mental disorders such as anxiety, depression and substance abuse disorders. Pacific females were more likely to experience an adverse mental disorder, whereas males had higher rates of substance use disorders.[48] In addition, Pacific peoples experience high rates of suicidal ideation, attempting suicide at three times the rate of the general population.[49]

These outcomes are often made worse by the widespread stigma that exists within Pacific communities toward mental illness. Research shows Pacific peoples are more likely to hold negative attitudes and beliefs towards those who suffer from mental illness and are less likely to interact with or show empathy towards those who suffer from mental health issues.[50] This creates a complex coalescence of marginalisation and internalised stigmatisation for communities burdened by a poor state of mental health and further encumbered by a culture that renders these issues invisible. As posited by Faalogo-Lilo, this stigma restricts people from addressing mental health issues, worried they may be perceived as weak, as a burden, or as having let their family down, due to Pacific beliefs that emphasise the importance of reliance on family to get through difficulties.[42] Furthermore, this stigma also exists in other locations where diasporic Pacific communities are embedded. Samoan Americans as an example, have communicated a belief that mental illness is not an acceptable subject to address in Samoan culture, labelling anyone who suffers from mental health issues, including their families, as 'cursed.'[51]

Despite high rates of suffering from severe mental health disorders, the Pacific community in NZ are also the least likely to access mental health services, and overall, Pacific peoples are 35% less likely to receive mental health treatment than the general population.[48] This is partially due to mainstream mental health services in NZ - much like physical healthcare services - not being attuned to the cultural specificity that allows Pacific peoples to be understood, as mainstream clinical approaches do not sit comfortably with Pacific community values and relational approaches to care.[51] This is due to a number of factors, including contrasting Western and Pacific value systems, which have led to differing framings of what mental health and mental illness look like between cultures.[42,52] In other words, community health issues are often perceived as either insider stigma, or outsider framing based on Eurocentric standards of health. It is likely that this will consistently manifest poor health outcomes, if these misconceptions and stigmas are not broken, addressed, and unpacked.[53]

Pacific Rainbow Health

Despite the dearth of studies on Pacific Rainbow Health in New Zealand health research, a handful of projects do acknowledge the intersecting identities of PRCs. Counting Ourselves found that transgender and non-binary Pacific people were at a higher risk of experiencing gender-based violence within the domestic sphere, at an increased risk of engaging in risk related behaviours, while also being more likely to be treated unfairly at a hotel, restaurant or theatre and avoid essential services like the bank or the doctor.[15] These findings although extremely insightful suffered from small Pacific sample size (4% of respondents were Pacific), where Pacific respondents had the highest dropout rate in the

Counting Ourselves survey. This pattern is also repeated in the Youth 12 survey where just 3.9% of Pacific participants identified as being attracted to the same or both sexes.[14-15] Ultimately, these surveys are unable to capture the depth and nuances of PRC worlds, let alone their experiences with healthcare. This lack of intersectionally-informed research risks health interventions being designed that miss the needs of important sections of Pacific communities.

There is strong evidence to suggest that geography of PRC peoples further impacts their engagement with mainstream healthcare providers. The overwhelming majority of both Rainbow/Queer and Pacific communities reside in, or are more likely to migrate to urban areas, with Auckland acting as the centrepoint for Rainbow/Queer and Pacific healthcare services.[27,28,35,60,61] However, the urban demand for healthcare services poses a variety of challenges for PRC peoples who live rurally. For example, if a Pacific trans person was living in rural Taranaki and needed treatment for gender affirming surgeries, they would need to travel to Auckland. To ensure these services are available throughout the country, more consideration should be taken on the geographical barriers to PRCs health and the consistency of healthcare services.[62]

It can be assumed through prior literature that it is likely that those who exist at the Rainbow-Pacific intersection are at an elevated risk of discrimination because of their double minority status. International studies confirm that this 'extra layer of marginalisation' strongly resonates with people of colour who identify Queer or Rainbow.[63-66] Within a Pacific context, stigma against PRCs is well-documented, but within Rainbow/Queer communities, Pacific voices are often overpowered by cisgendered, gay European men.[68] This doubled layer of marginalisation reflects a double marker of discrimination, for those who exist in both communities which are both consistently positioned as experiencing low health outcomes in comparison to the general population. This is a nuance that existing health research in NZ is not so attuned to.

DISCUSSION

This literature review reveals that very little research exists that focus specifically on the health and wellbeing of PRCs in NZ. As such, a more intersectional approach to health research will need to be taken to get a stronger gauge of the state of PRCs' health and wellbeing in NZ. Intersectionality was coined by Black feminist scholar, Kimberlee Crenshaw, to examine how the multidimensional, combinative factors of a person's many subsumed identity points may lead to unique forms of marginalisation in society that does not account for the point at which these stigmas meet.[54-57] Intersectionality is important in this context, as it teaches us to be attentive to the unique ways members of Rainbow communities *and* Pacific communities in NZ may experience multi-layered forms of marginalisation as a product of intersecting forms of stigma**.** Quite often, when literature explores the health and wellbeing of Pacific and Rainbow peoples, there is an urge to treat both populations as isolated communities, with both communities frequently described as being more likely to experience poor health, in comparison to the general population.[10,11,14,15,46,58] While this does allow investigators to provoke discussion on the needs of both communities, these conversations often overlook the unique contours of an experience that is both ethnically Pacific and Rainbow/Queer. To date, very little intersectionally-focused research has taken place in the health context in New Zealand. The latest being the Honour Project Aotearoa[15] and the newly HRC funded Manalagi Project.[59]

CONCLUSION

This paper shines a light on the lack of information on Queer and Rainbow Pacific health and wellbeing in NZ. The stigmatisation of PRC in NZ remains a prevalent issue for the NZ healthcare system. This literature review suggests that more health research needs to be positioned at the intersection of Pacific and Rainbow communities. The newly funded Manalagi Project by the Health Research Council will help to form a clearer picture of the needs of this often-neglected part of NZ's Pacific population.

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AUTHOR INVOLVEMENT:
The lead author led the shaping of the article, methods used, concept, data acquisition, analysis and interpretation. They give final approval and

agree to be accountable for all aspects of this work. SO did data collection, synthesis of data and helped analysis and interpretation. HA undertook large data collection activities, helped synthesis of data and provided analysis and interpretation support. AP undertook data collection, supported synthesis of data analysis and interpretation. All authors gave final approval and agreed to be accountable for all aspects of this work.

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Short Report **OPEN ACCESS**

Covid-19 and Palliative Care Delivery in Resource-Limited Settings: Healthcare Workers' Involvement

Lawal O OLAYEMI, [1] Jyothi A ABRAHAM, [2] Vicky YEMOH, [3] Kamoru A ADEDOKUN, [4] Maatasesa SAMUELU-MATTHES, [5]

ABSTRACT

As the global surge of the COVID-19 pandemic continues to rise, attention has been drawn to health implications and damaging effects caused by COVID-19 in patients with chronic conditions. Palliative care delivery in diseased patients and those with chronic conditions is imperative in mitigating unprecedented health outcomes. Though many health care workers in developed countries are implementing new strategies to address palliative care challenges in patients at risk of COVID-19, preventive measures and strategies are crucial in resource-limited settings, where palliative care is seen as a new concept. This report addresses the approach to palliative care delivery and changes that may arise from the coronavirus pandemic. It also looks at possible socio-behavioural entities, education, preventive measures and upscaling diagnostic capacity for COVID-19 in resource-limited settings. Harnessing these factors as guidance and delivery tools for healthcare workers in resource-limited settings could help to manage risks and benefits associated with providing optimal palliative care in this pandemic period.

Key words: COVID-19; palliative care; co-morbidities; chronic diseases; health care workers; resource-limited settings

INTRODUCTION

In January 30, 2020, the World Health Organization (WHO) declared the outbreak of the 2019 novel coronavirus disease (COVID-19) as a public health emergency of international concern (PHEIC) [1]. The SARS-CoV-2 disease (COVID-19) primarily manifests as a lung infection with symptoms ranging from those of a mild upper respiratory infection to severe pneumonia, acute respiratory distress syndrome, and death[2]. On-going conversations about COVID-19 and its impact on palliative care have raised concerns on the level of vulnerability of patients and caregivers in exposed situations. Despite the growing need for palliative care in most resource-constrained societies, a huge demand is still imminent for the urgent and continuous delivery of palliative care in non-communicable disease (NCD)-burdened communities. With the trepidation surrounding the current COVID-19 pandemic, there is a need for palliative care to be provided in creative ways that would remain consistent with the core on how it would be offered outside these unique circumstances[3]. More recent studies with consistent evidence have suggested that individuals with chronic non-communicable diseases such as heart disease, cancers, chronic kidney disease And those undergoing renal transplantation may be

Corresponding author: Lawal O Olayemi, Olayemi2002@yahoo.com

1. Senior Lecturer, School of Medicine, Faculty of Health Sciences, National University of Samoa, Samoa
2. Lecturer, School of Nursing, Faculty of Health Sciences, National University of Samoa, Samoa j.abraham@nus.edu.ws
3. Senior Lecturer, School of Medicine, Faculty of Health Sciences, National University of Samoa, Samoa v.yemoh@nus.edu.ws
4. Kamoru A. Adedokun MSc Research Scientist, Department of Oral Pathology, King Saud University Medical City, Riyadh, Saudi Arabia adeolokun@yahoo.com
5. Dean, Faculty of Health Sciences, National University of Samoa, Samoa m.samuelu-matthes@nus.edu.ws

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disproportionately affected with COVID-19 [4, 5, 6]. The level of mortality could increase if early interventions are not provided for those at an advanced stage of the disease.

According to the WHO, palliative care has been recognized as an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illnesses, through the prevention and relief of suffering utilizing early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual[7]. Different approaches to palliative care have contributed to the improvement in the quality of life of people dying with co-morbid non-communicable diseases and life-threatening infectious diseases[8]. High-income countries (HICs) may have effective palliative care interventions to respond to serious health-related sufferings. However, there is little access to pain relief or palliative care in resource-limited settings [9]. In the face of this current pandemic, palliative care meets new demands and needs (Table 1). This brings challenges to health care professionals, patients and other caregivers involved in palliative care delivery in these environments. In many countries, healthcare systems including governmental and non-governmental organizations are urgently re-establishing *de novo* practices that best suites patients, their families and caregivers needs. This paper aims to explore different approaches to palliative care delivery and to address the changes that may arise from the coronavirus pandemic.

Addressing Healthcare Workers' Role in Education, Prevention and Psychosocial support

Importance of Telehealth in controlling the spread of COVID-19

Unlike resource-limited settings, developed and high-income societies are less perturbed about the challenges of efficient education technologies and information systems. Moreover, tracking the medical history and records of patients with chronic diseases at end-of-life and those requiring palliative care may be less demanding due to the availability of sophisticated technologies. This has eased the burden and anxieties associated with loss of or shortage of patients' medical data and thus affecting overall healthcare outcomes. Additionally, achieving care goals and objectives is paramount despite accumulated phobias and anxieties amidst caregivers and patients. There is also the possibility of a disproportionate decrease or non-existent telemedicine and e-health in resource-limited settings, thereby obtaining quality palliative care may become problematic. These concerns could be addressed by enabling telemedicine or e-health to ease patients or caregivers' distress and to prevent hospitalizations[3]. Healthcare workers can provide telehealth services through devices such as computers, smartphones, and tablets[10]. Interaction between a care provider and a patient can still occur despite social distancing and stay-at-home orders, thus, eliminating the exposure risk inherent in an in-person clinic visit[11]. Telehealth can be used to monitor patients recovering from COVID-19 after their discharge from the hospital[12]. This may be made possible through institutionalizing user-friendly telehealth systems as part of routine patient care and clinical practice. This further stresses the urgent need for the provision of e-health services to patients in under-resourced settings, especially where limitations exist in bridging the patient's information from the community and district health care facilities to the main tertiary and referral hospital.

Addressing the role of Healthcare Workers in mitigating the spread of COVID-19 via video conferencing and electronic media:

In the inpatient setting, palliative care practitioners can effectively and creatively utilize telemedicine for patients with and without COVID-19 because personal protective equipment (PPE) may be limited and family/caregiver visitation may often be restricted. Patients with critical illness in the intensive care units may die, and families/caregivers are distressed as they grieve for their loved ones from a distance. For patients with COVID-19, clinical decline can be rapid, providing little time for families/caregivers to make difficult decisions. Communication during COVID-19 can be challenging since the outcome is uncertain but engaging family members through video calls enhances therapeutic presence[13]. Recent studies have shown how healthcare workers and organizations shifted their visits away from face-to-face visits to video conferencing and explained that patients often welcomed video visits in place of house calls when it was communicated that the decision was deliberate to maintain patient safety[14]. Healthcare workers and patients were also capable of building strong connections through video visits when available[14]. Video visits address two barriers: (i) they provide a form of face-to-face communication and (ii) they allow multiple healthcare workers to engage patients/ families and caregivers simultaneously, which can be a challenge in person. Additionally, Oseni et al[15] in 2020 highlights that education and

Table 1: Modified Palliative Care Pandemic Plan

Healthcare Workers	Resources	Settings	Structures
Recruit and train healthcare workers in emergency and palliative care expertise - Physicians - Nurse specialists	Adequate storage of medical equipment and test Kits.	Identify areas that can be converted into makeshift Intensive care units, isolation and quarantine spaces.	Generate a system to identify patients in need of specialist palliative care management
Provide focused education sessions to frontline staff for symptom management and end-of-life care for COVID-19 patients	Arrange test kits including Personal protective Equipment (PPEs) to deliver prompt and safe diagnostic techniques for long term management at facilities	Identify wards and non-clinical areas in all healthcare facilities that would be appropriate to accommodate large numbers of patients	Build a system for healthcare facility and community transfers to dedicated palliative care units and wards.
Involve allied healthcare workers to provide psychosocial support, grief and bereavement counselling. - Nursing assistants - Health attendants - Social workers - Spiritual care staff - Volunteers	Provide constant supply of water and electricity and ensure public awareness via Billboards, TV adverts and Radio Jingles, Print media	Maximize the use of identified palliative care unit, hospice, and ward beds.	Generate a system for consultation support telemedicine or user friendly video and mobile technology
	Provide locally produced hand sanitizers and face masks		Create comprehensive care plans for all patients admitted to health care facilities and age care homes
	Provide medical and emergency tents for admissions and treatment		Create tracking systems for all COVID-19 patients and those already recovered

Source: {Downar & Seccareccia. Palliating a pandemic: 'All patients must be cared for', Journal of Pain and Symptom Management. 2010; 39 (2), 291 – 295} copyright: *AAHPM 2010*

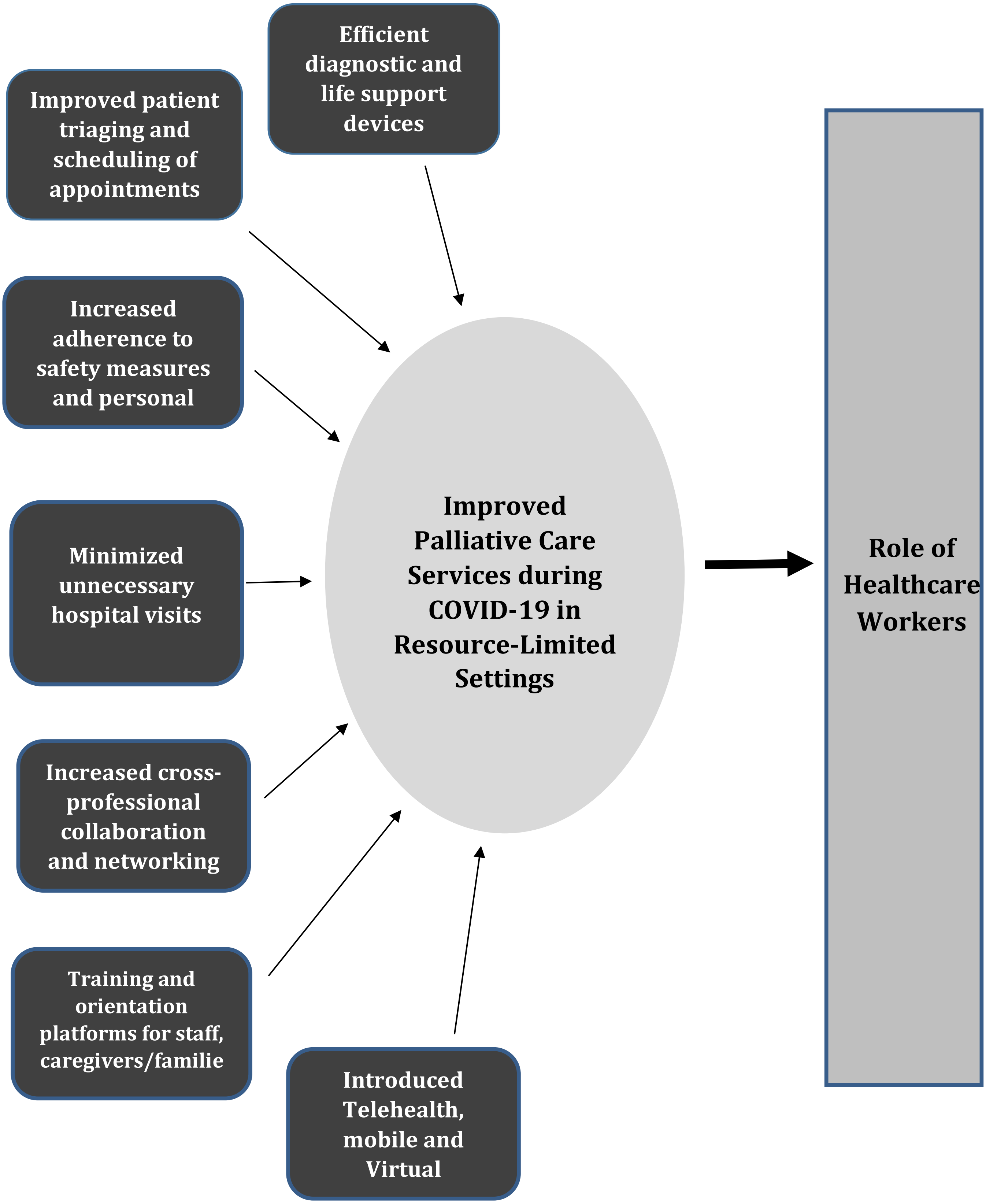

Figure 1: Conceptual framework for improving palliative care services during the period of COVID-19 in resource-limited settings. (Designed in Bio render)

enlightenment of the populace through health talks to patients presenting to out-patients clinics through electronic media have helped dispel rumours and provide accurate information on what should be done to prevent COVID-19 from spreading, and what to do if there is a suspected case[15]. Curtailing the transmission of COVID-19 via available means is imperative in stemming the tides of disease spread. These tools may allow continuous provision to early palliative care services, which are more necessary now (**Figure 1**).

Addressing the role of Healthcare Workers in psychosocial support in the period of COVID-19:

Patients, despite COVID-19 status, require advance care planning and may likely have conversations about their health conditions, with growing fears of limited medical resources and prolonged isolation. Families of patients with COVID-19 may face a significant psychological burden that is often magnified by family members themselves being in isolation or under financial strain, especially in resource-limited environments, where most people rely on daily earnings. This may affect both medical aspects and the psychosocial well-being of patients and their caregivers. Health workers need to have honest discussions with patients and their caregivers on plans to have the best care provided, but also prepare them for the worst that could happen[16]. Health care workers should also acknowledge the distress of this complex and unique situation for patients and their families, and be compassionate, respectful and empathetic[17]. There may be guilt over possibly transmitting the infection to their loved ones. The quality of the dying experience and lack of preparation for the death are both predictors of complicated grief. Healthcare workers should communicate with families regularly and where possible facilitate communication between patients and their families utilising virtual technology[16]. Healthcare workers themselves may be faced with different dilemmas in these unprecedented situations such as COVID-19 pandemic. Some healthcare workers currently caring for COVID-19 patients may be redeployed from their customary clinical environments, including those normally assigned to cardiac, cancer and renal disease care, to support heavily burdened clinical services[18]. Some staff may feel conflicted, being aware that their reassignment to support the obvious needs of COVID-19 patients might undermine the care of those whom they are normally responsible for. They may express some anxiety for being exposed to COVID-19 and this may increase the fears of healthcare workers working in these areas.

Addressing the need for improved COVID-19 life support medical equipment and diagnostic capacity:

Despite growing campaigns and demands for adequate publicly funded health systems, there is still lack of well-equipped state-of-the-art diagnostic health facilities for laboratory testing, public health disease control centres, and highly trained personnel to provide palliative care to patients exposed to COVID-19. Globally, COVID-19 testing has been seen to be a challenge, especially in countries that have less resources and capacity. Currently, only a few rapid immuno-diagnostic tests with high specificity and sensitivity are available and only in higher income settings[19]. Availability of sufficient diagnostic kits in resource-limited societies is low, as healthcare workers' capacity and their human resources to educate patients and their families are scarce to respond adequately to high caseloads. There is a need for targeted large-scale testing and this can only be achieved through a more rapid, accurate and affordable diagnostic testing approach and scaling up laboratory testing capacity. However, laboratory testing is not without challenges as resource-limited nations struggle with well- equipped laboratories and clinical laboratory professionals that can cater to its population[20]. This can contribute result to the diagnostic insufficiencies in these regions[20]. It further reinforces the need to develop laboratory capacity and its human resources in poorer countries to enable health workers to cater for diseased patients including those requiring palliative care.[21]

Furthermore, patients in hospital intensive care units often rely on lifesaving or support especially ventilators for patients, thereby making the patients and their families to become demoralized and worried. In difficult situations like these, healthcare workers may give subjective considerations to younger patients, infected healthcare workers with COVID-19 over older end-of-life care patients requiring ventilator support. Such decisions through unethical is based predominantly on the concept of distributive justice and this can as well cause moral distress to the healthcare workers[18]. Reallocation of ventilator support from critically ill patients will be distressing for healthcare workers, patients and their family/caregivers because, in regular conditions, the removal of ventilator support is only done when a family member approves[22]. Patients in these situations need continuous comprehensive palliative care to prolong their quality of lives. This calls for urgent action by respective stakeholders, in providing adequate and functionally efficient life support machines, to minimise the mortality rates in patients and those receiving palliative care.

CONCLUSION

In resource-limited settings, palliative care patients' with COVID-19 may have varying degrees of comorbidity scores and also produce a higher prevalence of symptoms and lower performance status with rapid health deterioration. Effective communication is very important between healthcare workers, patients/families and caregivers to adopt different care approaches at various levels, including primary and secondary forms of care. Consistent practice of educating patients and caregivers on preventive strategies towards COVID-19 via available technology such as telehealth, video and mobile devices should be incorporated in the delivery of palliative care. Progressive healthcare policies by policymakers and prompt interventions regarding diagnosis, laboratory confirmation of patients with COVID-19 and early referrals to palliative care are essential in reducing unforeseen resultant health outcomes. Cohesive and timely collaboration among healthcare workers, stakeholders and other institutions would assist in the quality delivery of palliative care, especially in areas with reduced human and material resources. These could assist in enhancing the confidence of patients, families and their caregivers. Healthcare workers should endeavour to provide optimum and cautious services as much as possible to improve the quality of health and provide end-of-life care with dignity. Further studies on the needs and psychological factors associated with patients/caregivers decision making should be carried out to measure and ascertain the acceptance level of care in patients during this pandemic season.

Abbreviations:
WHO: World Health Organization
PHEIC: Public Health Emergency of International Concern
NCD: Non-communicable diseases
HICs: High-Income Countries
PPE: Personal Protective Equipment

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Talanoa **OPEN ACCESS**

Manalagi Talanoa: A community-centred approach to research on the health and wellbeing of Pacific rainbow LGBTIQA+ MVPFAFF communities in Aotearoa, New Zealand

Patrick S THOMSEN, [1] Phylesha BROWN-ACTON, [2]

ABSTRACT

The Talanoa reported in this paper explores the way the Manalagi Project – recently funded by the Health Research Council of New Zealand – has been designed to empower the health and wellbeing of our Pacific Rainbow communities. Community-driven, co-designed and embedded, the Manalagi Project adopts a Pacific-centred holistic approach to wellbeing and research. Positioned at the beginning of its community consultation phase, this Talanoa between the two lead researchers, one who is an academic and the other a community practitioner, documents the genealogy of the project embedded in lived experiences and relationality through Talanoa. It speaks to the importance and timeliness of the project; the suitability of the research team; and intervenes in conversations around how we can activate Pacific research methodologies and praxis as a way to empower our communities to achieve their health and wellbeing aspirations. The findings from this Talanoa demonstrate the criticality in adopting intersectional approaches to understanding the differentiated and contextualised health and wellbeing needs of diverse Pacific communities.

Key words: Pasifika, rainbow community, Talanoa

INTRODUCTION

Announced in mid-2020, the Manalagi: Aotearoa Pacific LGBTIQA+ (Lesbian Gay Bisexual Transgender Intersex Queer/Questioning Asexual+) MVPFAFF+[1] (Māhu Vakasalewalewa Palopa Fa'afafine Akavaine Fakafifine Fakaleiti/Leiti) Health and Wellbeing Project is the first of its kind to be funded by the Health Research Council of New Zealand (HRC) as a Pacific health project.[2-3] Manalagi is a three-year project that involves a co-community designed survey, balanced with qualitative data gathered using the Talanoa methodology. It aims to capture a sample of 500-1000 survey respondents, with an additional sixty Talanoa to be conducted with individuals across New Zealand.[4] As lead researchers, we present this paper as a way to provide insights into the genealogy of the project, its conception, its design and its justification. This includes an outline as to why we believe Manalagi is needed, why now and why us specifically, as a way to unpack the potential of research to advance the health and wellbeing aspirations of our communities in which we are both embedded. This paper is structured using a brief thematic Talanoa that embeds interpretations around speech lifted directly from the in-person Talanoa centred in the paper as anchoring points for analyses and building important insights.[5]

Corresponding author: Patrick S Thomsen
patrick.thomsen@auckland.ac.nz
1. University of Auckland
2. F'INE Pasifika Aotearoa, Te Wānanga o Aotearoa.
phylesha@finepasifika.org.nz

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METHODS: TALANOA

Talanoa – the ongoing discussion in relational space – is an established Pacific methodology to maintain vā.[6-11] Talanoa as a research method can be described as a personal encounter where people story their issues, their realities and their aspirations.[12] It is guided by rules of relationship building and kinship, where participants actively probe, challenge and add their own opinion and stories to the discussion.[13-14] As Linda Tuhiwai-Smith notes, Indigenous knowledge takes a myriad of forms, including community storying and storytelling, which both recounts existing genealogies and produces new ones.[15] Our methodology was executed through a Talanoa between the principal investigator (PI), an academic based at the University of Auckland, with a key associate investigator who is a renowned community practitioner, activist and scholar in their own right. These two varied perspectives and standpoints bring together key elements of Pacific research that emphasises the need to connect research praxis with community embeddedness and knowledge.[5]

Both investigators are members of communities impacted by the Manalagi Project as a Sāmoan gay man and fakafifine, trans woman of Niuean heritage. The following thematic Talanoa argues that the Manalagi Project attempts to fill an essential gap that exists in our knowledge bank on the determinants of positive health and wellbeing outcomes for our communities. This relates to intersecting forms of stigma and discrimination that coalesce in not only the bodies of Pacific Rainbow LGBTIQA+ MVPFAFF+ communities, but can be traced through the narratives of the lead researchers, whose lived-experiences were crucial to the formation, design and potential success of the Manalagi Project.

CRITICALITY OF AN INTERSECTIONAL APPROACH TO PACIFIC RAINBOW HEALTH RESEARCH

> *"I think what's key in all settings, be it health, justice, education etc. - for our communities – is understanding how factors that impact access to services for us often first and foremost come down to trust. As a result of previously experiencing multiple forms of intersecting discrimination – whether based on sexuality, gender identity, gender expression, ethnicity, economic status etc. - affect the simple things for us. Even walking through a door at a medical centre to ask for help can be a difficult activity. Our past experiences teach us that people don't want to help us or automatically judge us from our appearance. Something as simple as the opening hours of clinics then becomes an issue. Some trans women I speak to do not want to go out during the day in public where their safety is at risk. Yet, we do not have any after-hours clinics in New Zealand anymore beside emergency rooms in hospitals."*

For trans communities, transphobia harms their ability to seek out appropriate healthcare, and when they do, very often gender-affirming services are either too expensive or not offered at all.[16] For Pacific trans women then, as an example, Kimberlé Crenshaw's articulation of intersectionality[17] compels us to examine how this experience could be even more fraught when transphobia, heterosexism and racism collide. In the Counting Ourselves survey, 67% of trans, non-binary LGBTIQA+ as respondents, reported feeling unsafe in public.[16] In this excerpt from our Talanoa, a quotidian experience of visiting a medical centre to ask for help is storied and complicated by varying levels of trust in healthcare service providers.

This suggests that for many in Pacific communities, the departure point in an experience with our health system begins in the relational. Parts of our communities are not likely to seek out healthcare treatment without trust in health services, which is well-documented in public health literature when it comes to marginalised groups.[18] Why intersectionality is helpful here is that it is attentive to suspicions of how experiencing discriminatory healthcare connects directly to notions of physical safety before cultural safety can even be discussed. This necessitates more nuance in speaking about the racialised and socioeconomic factors that impact health and wellbeing for our communities.

BROADENING OUR UNDERSTANDING OF ACCESS AND IMPACT FACTORS

> *"Many trans people don't want to go out in the middle of the day where they receive harsh, negative comments about being trans if they're not immediately passing. But if you are going to get a hip replacement, no matter what age you are, you get offered a taxi to go to your appointment, so that process is very anonymous. Whereas for a lot of trans people without access to their own transport, they have to use public transport. We know trans people are discriminated against in the workplace, (so are Pacific people) which makes it difficult for them to earn a meaningful income that will allow them to buy a reliable car. That means that it makes them more unlikely to want to go to the healthcare provider if they have to use a bus as you stand at a bus stop exposed to the whole world where you never know if someone's going to shout something horrible at you. I know many trans people that have to catch trains in particular who experience abuse and feel unsafe as it's a*

> *mode of transport where there's no one there to intervene. Relatedly, 8/10 clients I work with are going to get paid on a Wednesday, and then money's gone by Thursday because of bills, rent and food. So, if your appointment is on Friday, or the following Monday or Tuesday, you know in your head that you're not going to get to your appointment, because you're not going to get paid again until Wednesday."*

Through lived experience, a gap is identified that relates to how we understand access and interventions based on one's physical condition. A person who is likely to have mobility issues after a procedure such as hip surgery is recognised as needing assistance, yet the issue of safety for trans communities in particular is not well integrated. A cost-benefit analysis may need to be carried out on whether it could be more efficient to support trans communities' transportation assistance over the cost to the system that cancelled appointments carry and the opportunity cost of not intervening early into health issues Pacific trans communities may be facing. Further, quality of life is considered an important indicator of wellbeing and this shift in thinking has been reflected in the Wellbeing Budget adopted by the Ardern government.[19] The Manalagi Project will need to be attentive to understanding whether our communities can even get to a healthcare service, before we can even consider capturing what their experience with a healthcare provider is.

Broadening our understanding of access also plays out in the way we understand the impacts of employment discrimination. Counting Ourselves demonstrated that trans communities in New Zealand face harsh barriers when searching for work.[16] This is replicated for Pacific communities as well, where we know in New Zealand racism impacts health outcomes negatively for Māori and Pacific communities.[20-21] This excerpt demonstrates the intersectional criticality of this point, as limited means for many Manalagi impacted communities is already correlated with workplace discrimination. There is also a suspicion here that something as simple as timing when appointments are scheduled can impact the likelihood of members of our communities showing up to appointments.[22] When we take both factors into account, for Pacific, trans and other Manalagi impacted communities and individuals, the chances of receiving and accessing appropriate care that gives them the best opportunity for their health and wellbeing to thrive, becomes lower.

RELATIONALITY, CO-COMMUNITY EMBEDDEDNESS AND CO-DESIGN: IMPLEMENTING AN INTERSECTIONAL APPROACH TO PACIFIC RAINBOW RESEARCH

> *"What I love about Manalagi is that it speaks to pride and respecting the dignity of our communities. To the point of co-design, one thing that's unique about Manalagi is that it is led by members of our Manalagi impacted communities across the board from conception, design, consultation and implementation. This is vital. Surveys are often extractive; members of our communities are bringing our stories of trauma to bear on the design of this project. People trust us, you and I have genealogical connections to many people within Manalagi impacted communities. The fact you designed the proposal as exactly that: co-designed with a commitment to involve the community, placing them at the heart of the project, speaks volumes in not only the values that informs Manalagi, but its potential success for our communities. Our people will tell us if we're off the mark. They'll tell us because they know us. And it was my own long-standing connection with you and your family that got me excited about this project, knowing the energy and spirit your work brings to the mana of our communities meant I was willing to jump on-board."*

Pacific worldviews and research ethics emphasise the idea of relational connections as the foundational basis of not just social and kinship activities but also knowledge generation.[23] We argue through this excerpt that the concept of relationality must be understood in a meaningful and grounded way when conducting Pacific research. The idea of relationality, where individuals are positioned in a myriad of genealogical and social relationships as the foundation for notions of understanding the self as a relational being[24] has long been discussed by Pacific Studies scholars in a variety of critical ways and settings to illustrate the interconnectedness of Pacific communities, cultures and peoples.[25]

In the Manalagi context, there are two key routes in which these concepts are being enacted. The first speaks to involving communities in ways that acknowledge that our people live in relational realities that necessitate a broader examination of social determinants to health outcomes that incorporates this worldview. This means approaching community, identity, church and familial institutions as integral to wellbeing for Pacific communities[26] that may not be immediately apparent for Rainbow populations in general. The second is through activation of the research team who are positioned appropriately to be able to conduct the research. For the research team, mutual trust and respect between the community practitioner and an academic as PI, was based on relational connections established from within the communities Manalagi aims to serve.[27] This is important, we argue that no matter how well-intentioned, the optics of community legitimacy in research that seeks to understand experiences of the marginalised is crucial to the success of research that impacts our communities.

The Manalagi Project has two major forms of data gathering planned. Aside from the co-community designed survey, roughly a year-long individual Talanoa series will span the length of the country in attempting to capture the lived experiences of communities covered by Manalagi in qualitative form. Our lived experience teaches us that some of the stories that many members impacted by the work of the project will share, are likely to be laced with trauma. This increases the criticality of the positionality of the researchers in being entrusted with these stories and urges them to treat narratives as taonga connected to genealogies embodied in the spirit and mana of participants. This level of trust and legitimacy for the lead researchers can only be bestowed by the community and epistemologies of the academy are inadequate here to capture all the nuances that exist in this context.

COMPLICATING THE RAINBOW - MANALAGI'S MANA-FOCUSED APPROACH TO PACIFIC HEALTH RESEARCH IN NEW ZEALAND

> *"One of the hardest things with this project was actually finding a name for it. When I initially sent in the proposal, I just left in the Sāmoan word for rainbow, (nuanua) as a placeholder as I went through the process of searching for the right term. Finding an inclusive term that doesn't encourage different identity points to be in disharmony with each other was so difficult to negotiate. Some members of our community connect more to LGBTIQA+, some detest it. Some cannot stand the term queer. Some dislike the history of the rainbow being appropriated by the LGBT movement. I think for me it was important to try and find a term which took us away from those divisions as the starting point of the research. Rather, choosing to leverage what we're talking about here in reference to holistic views of health and wellbeing. That means focus should be on acknowledging everyone in our communities has intrinsic mana that is sanctioned from beyond this realm. It is sanctioned by the heavens, the lagi/langi/rangi and is embodied in all of us. This is a strength-based approach and I argue that we all have a responsibility to uphold the mana of all who are part of wider Pacific communities. This reframing is key to the research approach as it allows us to hold differences in respectful ways through the tensions that exist in relationality with each other. That's how I settled on Manalagi and I'm glad to know that as a concept, it's something that you could relate to and understood immediately when I explained it to you."*

Colloquially and crucially for health researchers, non-normative gender and sexualities that have coalesced under acronyms such as LGBTIQA+ and the Pacific-specific mnemonic MVPFAFF+[28] have come to be framed as an alphabet soup with a dizzying array of diversity within them.[29] Some argue that this alphabet soup can have the impact of reducing the legitimacy and practicality of claims to reform offered by many researchers who are embedded within this space.[30-31] For the Manalagi Project, this was clearly an important determining factor in not only design as a Pacific health and wellbeing project, but also in the way it was to be named. Naming practices in many different Pacific cultures are vital in illustrating the connection of individuals and organisations to wider genealogies within villages, communities and generations.[32] In this excerpt, we can see that the lead researchers leaned into Pacific concepts to overcome the gaps associated with an alphabet soup by creating a term that combined two Pan-Polynesian concepts, mana (spiritual authority) and lagi (Samoan spelling of the heavens and skies) to redirect the focus to holistic ideas of wellbeing tied to the spirit of individuals.

CONCLUSION: CHARTING OUR OWN RESEARCH COURSE FOR MANALAGI IMPACTED COMMUNITIES

> *"It's the sacred aspect in encouraging pride in ourselves for me. The pointing upwards, bringing the heavens into our horizon. It means this project is being guided by a vision. I love the fact that it is built in relation to the heavens and is connected to the stars because it draws in navigation, an important knowledge and technology of our ancestors. This is a journey, a path and builds forward momentum, it is inclusive.*

> *The rainbow has a different context in Pacific worlds. In Niue it's the symbol of our most revered and ancient god Tupua Tangaloa and Niueans believed that if you looked into the rainbow it would bring on bad omens. For Samoans, it's used as the symbol for the disability community and Hawai'i uses it as its symbol as the Rainbow State – there's a bit of history there that our uncritical use of the term means that we can't always bring each other together through this symbol. The Manalagi Project is about creating our own pathway through research that empowers our communities to be whoever they want to be."*

To conclude this brief thematic Talanoa, we wish to end with this excerpt that encapsulates the essence of the project. We are not foolhardy and green enough to claim that what we are doing is completely new. Data on Rainbow, LGBTIQA+ MVPFAFF and Pacific communities can be extracted tangentially from other studies, which have been mentioned here. Data can additionally be extracted from international studies including the UNAIDS Gap report in 2014 which focused on those being left behind in the global effort to end the public health threat of AIDS.[33] Comparative conclusions around access to health care were made by the Asia Pacific Transgender Network in 2017 which gathered data from 15 countries.[34] While useful, these studies are not embedded in the unique Aotearoa diasporic context, necessitating the need for a project like this. Furthermore, Manalagi is unique in that it asks crucially: when we place our communities at the centre of our work, what specific and contextual insights/nuances are there, and how can we best leverage this to improve the lives of Pacific communities?

What we know and have articulated here as researchers connects to the experiences and knowledges that exist within our communities, thus, we are not the first to speak of the criticality of a project such as this. What we *do* advance here is a commitment to finding better ways to do this research that centres the communities that are most impacted by the Manalagi Project's remit. Further, we are committed to helping our communities write, chart and build their own path. No one knows what they need more than the communities and individuals who create and sustain these spaces of relationality.

This final excerpt demonstrates the urgency of being able to map out what the Pacific-specific, Aotearoa-situated LGBTIQA+ MVPFAFF agenda and futurity may look like. The rainbow that shines over non-normative sexual and gender realities does not necessarily stretch to cover our Moana-Oceania region in ways that make contextual sense. Thus, our goal as researchers through the Manalagi Project, is also to create a scholarly infrastructure that shifts, centres and generates Pacific research for our communities that respects and enhances the mana of all, in pursuing optimal health and wellbeing outcomes for all Pacific peoples in Aotearoa.

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Address for correspondence:

submissions@pacifichealthdialog.co.nz

Pacific Health Dialog, 195L Main Highway, Ellerslie, Auckland. P.O. Box 11445, Ellerslie Auckland, 1542 NZ.

E: a.ekeroma@nus.edu.ws P:+685 7743450

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Associate Professor Rosalina Risale Richards Hessell, *PhD*
Co-Director, Senior Research Fellow, Cancer Society Social and Behavioral Research Unit. Associate Dean Pacific, Dunedin School of Medicine/Te Kura Whaiora o Ōtepoti. rose.richards@otago.ac.nz

Dr Kiki Maoate, *ONZM, FRACS*
Dr Kiki Maoate ONZM, FRACS is a Paediatric Surgeon and Paediatric Urologist based in Christchurch. He is currently the Chair of Pasifika Futures Ltd, the Whanau Ora Commissioning Agency for Pacific families and Chair of Pasifika Medical Association Ltd. He is Associate Dean Pacific Health University of Otago based in Christchurch. Dr Maoate is Clinical Director for the Pacific Island Project, Royal Australasian College of Surgeons. Kiki has served as a member of the New Zealand Health Research Council, Pacific Health Research Council and the University of Canterbury Council. He is an advisor to the Cook Islands Ministry of Health and provides advice and support across the Pacific region to clinicians. kiki@healthspecialists.co.nz

Associate Professor Faumuina Fa'afetai Sopoaga, *FNZCPHM, FRNZCGP, MPH, DPH*
Associate Dean (Pacific), Division of Health Sciences, University of Otago. Director of the Pacific Islands Research and Student Support Unit. tai.sopoaga@otago.ac.nz

Assistant Professor Maile Taualii, *BA, MPH, PhD*
Department of Public Health Sciences, Hawaiʻinuiākea School of Hawaiian Knowledge, University of Hawaii. mtaualii@hawaii.edu

Associate Professor El-Shadan Tautolo. *PhD*
Director of the Centre for Pacific Health at Auckland University of Technology and Head of the Pacific Island Family Study. dan.tautolo@aut.ac.nz

Dr Jemaima Tiatia-Seath *PhD*
Senior Lecturer of School and Head of Pacific Studies (Acting) Te Wānanga o Waipapa. School of Māori Studies and Pacific Studies. The University of Auckland. j.tiatia-seath@auckland.ac.nz

Associate Professor Vili Nosa *PhD*
Head of Pacific Health Section and Associate Professor from the University of Auckland. Member of the Pacific Health Research & Development Foundation Trust, Pacific Prostate Cancer Foundation Board. v.nosa@auckland.ac.nz

Associate Professor Donald Wilson
Head of School & Associate Professor Epidemiology & Biostatistics
School of Public Health & Primary Care, College of Medicine, Nursing & Health Sciences Fiji National University. donald.wilson@fnu.ac.fj

Journal Manager

Mrs Seini Jensen

Research Officer of the Pasifika Medical Association. Seini@pasifikafutures.co.nz