

Original Research

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

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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,

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Pacific youth (15-24 years old) make up 19.2% of the Pacific population, compared to 13.8% of the total population.⁸

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 (steps 1-3). 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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